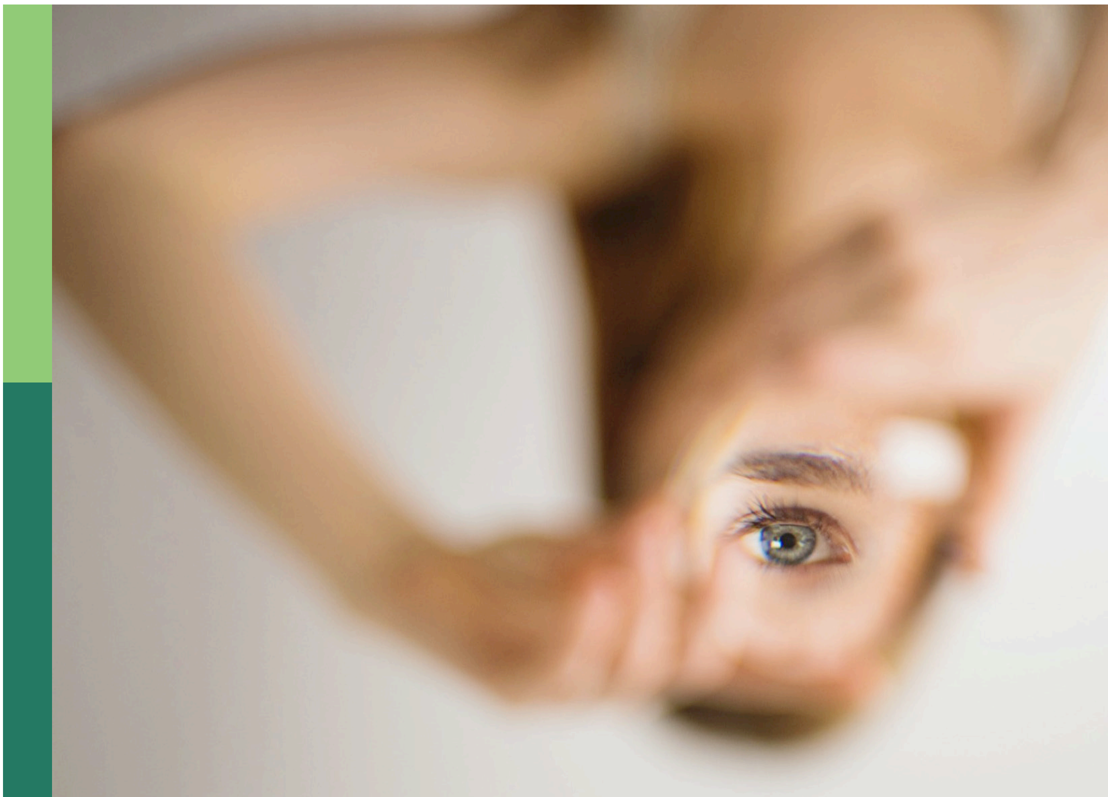
Research Topics

Facing cancer together: Current research and future perspectives on psychosocial, relational, and intervention approaches for couples

Edited by
Linda Charvoz, Aurélie Untas, Chiara Acquati and
Tanja Zimmermann

Published in
Frontiers in Psychology



ISSN 1664-8714
ISBN 978-2-8325-0334-8
DOI 10.3389/978-2-8325-0334-8

About Frontiers

Frontiers is more than just an open access publisher of scholarly articles: it is a pioneering approach to the world of academia, radically improving the way scholarly research is managed. The grand vision of Frontiers is a world where all people have an equal opportunity to seek, share and generate knowledge. Frontiers provides immediate and permanent online open access to all its publications, but this alone is not enough to realize our grand goals.

Frontiers journal series

The Frontiers journal series is a multi-tier and interdisciplinary set of open-access, online journals, promising a paradigm shift from the current review, selection and dissemination processes in academic publishing. All Frontiers journals are driven by researchers for researchers; therefore, they constitute a service to the scholarly community. At the same time, the *Frontiers journal series* operates on a revolutionary invention, the tiered publishing system, initially addressing specific communities of scholars, and gradually climbing up to broader public understanding, thus serving the interests of the lay society, too.

Dedication to quality

Each Frontiers article is a landmark of the highest quality, thanks to genuinely collaborative interactions between authors and review editors, who include some of the world's best academicians. Research must be certified by peers before entering a stream of knowledge that may eventually reach the public - and shape society; therefore, Frontiers only applies the most rigorous and unbiased reviews. Frontiers revolutionizes research publishing by freely delivering the most outstanding research, evaluated with no bias from both the academic and social point of view. By applying the most advanced information technologies, Frontiers is catapulting scholarly publishing into a new generation.

What are Frontiers Research Topics?

Frontiers Research Topics are very popular trademarks of the *Frontiers journals series*: they are collections of at least ten articles, all centered on a particular subject. With their unique mix of varied contributions from Original Research to Review Articles, Frontiers Research Topics unify the most influential researchers, the latest key findings and historical advances in a hot research area.

Find out more on how to host your own Frontiers Research Topic or contribute to one as an author by contacting the Frontiers editorial office: frontiersin.org/about/contact

Facing cancer together: Current research and future perspectives on psychosocial, relational, and intervention approaches for couples

Topic editors
Linda Charvoz — University of Applied Sciences and Arts of Western Switzerland, Switzerland
Aurélie Untas — Université Paris Cité, France
Chiara Acquati — University of Houston, United States
Tanja Zimmermann — Hannover Medical School, Germany

Citation
Charvoz, L., Untas, A., Acquati, C., Zimmermann, T., eds. (2023). *Facing cancer together: Current research and future perspectives on psychosocial, relational, and intervention approaches for couples*. Lausanne: Frontiers Media SA. doi: 10.3389/978-2-8325-0334-8

Table of contents

FACING CANCER TOGETHER: IMPACT OF CANCER ON MARITAL RELATIONSHIPS

FACING CANCER TOGETHER: INVESTIGATING THE RELATIONSHIP BETWEEN INDIVIDUAL FACTORS, CLOSE RELATIONSHIP PROCESSES, AND OUTCOMES AT THE INDIVIDUAL AND DYADIC LEVEL

FACING CANCER TOGETHER: SEXUAL ADJUSTMENT

FACING CANCER TOGETHER: MOVING TOWARDS DYADIC INTERVENTIONS

frontiers | Frontiers in Psychology

TYPE Editorial
PUBLISHED 14 July 2023
DOI 10.3389/fpsyg.2023.1238868

OPEN ACCESS

EDITED AND REVIEWED BY
Anja Mehnert-Theuerkauf,
University Hospital Leipzig, Germany

*CORRESPONDENCE
Linda Charvoz
✉ linda.charvoz@hetsl.ch

RECEIVED 12 June 2023
ACCEPTED 30 June 2023
PUBLISHED 14 July 2023

CITATION
Charvoz L, Acquati C, Untas A and Zimmermann T (2023) Editorial: Facing cancer together: current research and future perspectives on psychosocial, relational, and intervention approaches for couples.
Front. Psychol. 14:1238868.
doi: 10.3389/fpsyg.2023.1238868

Editorial: Facing cancer together: current research and future perspectives on psychosocial, relational, and intervention approaches for couples

Linda Charvoz[1]*, Chiara Acquati[2,3,4], Aurélie Untas[5] and Tanja Zimmermann[6]

[1]Faculty of Social Work (HETSL | HES-SO), University of Applied Sciences and Arts of Western Switzerland, Lausanne, Switzerland, [2]Graduate College of Social Work, University of Houston, Houston, TX, United States, [3]Department of Clinical Sciences, Tilman Fertitta Family College of Medicine, University of Houston, Houston, TX, United States, [4]Department of Health Disparities Research, The University of Texas MD Anderson Cancer Center, Houston, TX, United States, [5]Laboratoire de Psychopathologie et Processus de Santé, Université Paris Cité, Boulogne Billancourt, France, [6]Department of Psychosomatics and Psychotherapy, Hannover Medical School, Hanover, Germany

KEYWORDS

cancer, couples, relational factors, dyadic processes, individual and dyadic outcomes, prevention and intervention programs, dyadic measurement and research methods

Editorial on the Research Topic
Facing cancer together: current research and future perspectives on psychosocial, relational, and intervention approaches for couples

Theoretical background

An extensive number of studies has demonstrated that patients with cancer as well as intimate partners experience significant rates of psychological distress and that both need to be supported adjusting to the multiple types of burden associated with the disease (Kaye and Gracely, 1993; Heckel et al., 2015). Since then, cancer-related stress and coping have been regarded as interdependent processes (Bodenmann, 1997; Revenson et al., 2005). Cancer has been described as a "we-disease" (Kayser et al., 2007; Leuchtmann and Bodenmann, 2017) and couples coping with the illness has been conceptualized and investigated through several models, such as the Relationship-Focused Coping Model (Delongis and O'Brien, 1990; Coyne and Smith, 1991), the Systemic-Transactional Model (Bodenmann, 1997), the Communal Coping Model (Lyons et al., 1998), the Relational-Cultural Model (Kayser et al., 2007; Kayser and Acquati, 2019) and the Developmental-Contextual Coping Model (Berg and Upchurch, 2007). On the basis of these different models, programs reducing psychological distress and enhancing dyadic processes were developed (e.g., Kayser and Scott, 2008; Badr et al., 2015; Zimmermann, 2015).

Recent works have explored couples coping with cancer integrating different variables. For examples, studies displayed that various relational factors (e.g., attachment style, mutuality, etc.) and different close relationship processes (e.g., dyadic coping, communication, shared-decision making, etc.) have an impact on individual (e.g., physical and psychological health, quality of life) and dyadic (e.g., marital quality and satisfaction, sexual and reproductive health, etc.) outcomes (Kayser and Acquati, 2019; Meier et al., 2019; Bodschwinna et al., 2021).

This special Research Topic

Despite growing awareness and recognition of the psychosocial impact of cancer on close relationships, several gaps were identified in the extant literature. The present Research Topic was therefore aimed at addressing current aspects of limitations and to inform future directions.

The impact of certain relational factors and dyadic processes (e.g., authenticity, self-disclosure, etc.) on the quality of life and wellbeing of the patients, partners and couples remain to be determined. Furthermore, studies are needed to investigate the mechanisms (i.e., mediators and/or moderators) that regulate the associations between relational factors and/or dyadic processes affecting individual and/or dyadic outcomes. The modest effects reported by the prevention programs and/or clinical interventions developed to date suggest that more studies are needed to better understand for whom (e.g., which type of patients or of couples? which type of cancers?) and when these programs are beneficial. Additionally, factors associated with positive results, timing of the intervention, and the mechanism for therapeutic change should be considered. Many studies have focused on certain types of cancer (e.g., breast, lung, or prostate cancer) and couples (e.g., heterosexual couples, couples from elevated socioeconomic backgrounds). The aim of this issue is also to highlight studies conducted on different types of cancer, stages of the disease, and groups currently understudied and underserved. Additional studies are also needed to explore the experiences of patients and partners across the lifespan and the cancer care continuum.

This current Research Topic contains original articles and systematic reviews. It examines the psychosocial experience of couples facing cancer with the goal to highlight innovative methods and approaches, whether quantitative, qualitative, or a mixed-methods. This Research Topic begins with a systematic review, in which Fugmann et al. investigated the ***impact of cancer on marital dissolution***. The authors collected empirical evidence on the research questions whether a cancer diagnosis in general or the type of cancer affects the divorce rate. In addition, the methodological biases of the studies included in the review were discussed.

Three notable themes emerge throughout the 10 other contributions of this topic. One **first** central theme is the exploration of the *relationships between individual factors, close relationship processes, and individual and dyadic outcomes.* Through their qualitative study, Bodschwinna et al. developed a subtle understanding of the different types of coping (individual coping, dyadic coping and social support) used by couples facing hematological cancer. While the results reported differences between patients and partners with regard to coping and social support strategies, all of these results agreed that the different strategies were mainly focused on the wellbeing of the patient. Brosseau et al. explored through focus groups the individual and the close relationship factors obstructing and facilitating cancer-related dyadic efficacy, a predictor of positive individual and relational outcomes. Four main categories of influence could be highlighted including fluid facilitators and obstacles with respect to time and domain. The study of Lyons et al. investigated the potential moderating roles of two socio-demographic variables (age et sex) on the link between close relationship processes (active engagement and protective buffering) and depression in couples facing cancer. Their results confirmed the importance of the role of the close relationship processes on the level of depression reported by each of the partners, but also the importance of the role of the couples' sex and age. On the basis of individual (coping with cancer, body image) and relational (dyadic coping, relational closeness) factors, Saita et al. identified different dyadic profiles in couples facing breast cancer. These authors highlighted the differences in functioning between couples, with functional relationships (= both partners are coherent manner in terms of coping and facing cancer) reported lower rates of depression and anxiety.

A second theme developed in this topic is the ***sexual and intimacy adjustment*** in couples facing cancer. The purpose of the Stulz et al. study was to examine whether the congruence of dyadic coping within couples with a colon cancer improves emotional and sexual adjustment. In a longitudinal study, Rottmann et al. examined whether patient- and partner- characteristics (demographic and health characteristics, quality of life factors, cancer treatment) as well as relationship-related characteristics (emotional closeness, dyadic coping) were associated with sexual activity of couples facing breast cancer. Reese et al. explored the experiences of couples facing metastatic breast cancer as far as changes and concerns related to sexuality and intimacy were concerned, their efforts to cope with these concerns, information needs and intervention preferences.

A last contributing theme of this topic arose from the articles exploring and investigating *couple-based interventions*. Gorman et al. adapted a couple-based intervention to reduce reproductive and sexual distress by young and/or LGBTQ+ couples coping with breast or gynecologic cancer. The study of Fergus et al. aimed to evaluate the structure and content of an online psychological intervention for young couples facing breast cancer. The authors also examined the advantages and disadvantages of the program. The purpose of the systematic review of Hasdenteufel and Quintard was to propose an inventory of the experience of couples confronted with advanced cancer and to report the impact of psychosocial interventions focused on these dyads.

Future directions

Several considerations emerge from this Research Topic, and they are critical to inform future studies. It is now clear that our scientific investigation should expand its current focus to include the experience of couples with different backgrounds, in terms of age, socio-economic level, ethnicity, culture, family background, sexual orientation, type of cancer, stage of cancer (Reese et al.; Fergus et al.; Lyons et al.; Saita et al.; Stulz et al.). Indeed, despite our best efforts, this issue presents mostly results from samples of heterosexual, white, high socio-cultural patients or couples with early stage breast or colon cancer. Future research should further investigate couples coping processes over time. Associations among individual-, partner-, couple- related factors with relational and health outcomes should be further considered (Fugmann et al.; Hasdenteufel and Quintard). Methodologically, future studies would also benefit from analyzing real-life interactions in order to increase ecological validity (Bodschwinna et al.;

Rottmann et al.). Similarly, qualitative protocols would contribute to better understand each partner's representation of broader phenomena (e.g., end of life, expectations of partner, etc.) and therefore clarify how incongruence between partners' perception may influence their outcomes (Hasdenteufel and Quintard). In conclusion, these contributions all tend toward the same goal, namely to identify couples at greater risk and offer psychosocial care that is responsive to their needs and preferences (Fugmann et al.).

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

Badr, H., Smith, C. B., Goldstein, N. E., Gomez, J., and Redd, W. H. (2015). Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer* 121, 150–158. doi: 10.1002/cncr.29009

Berg, C. A., and Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol. Bull.* 133, 920. doi: 10.1037/0033-1336.920

Bodenmann, G. (1997). Dyadic coping-a systematic-transactional view of stress and coping among couples: theory and empirical findings. *Eur. Rev. Appl. Psychol.* 47, 137–140.

Bodschwinna, D., Ernst, J., Mehnert-Theuerkauf, A., Gündel, H., Weissflog, G., and Hönig, K. (2021). Dyadic coping and social support: various types of support in hematooncological patients and their spouses—Associations with psychological distress. *Psycho-Oncology* 30, 1041–1050. doi: 10.1002/pon.5631

Coyne, J. C., and Smith, D. A. (1991). Couples coping with a myocardial infarction: a contextual perspective on wives' distress. *J. Pers. Soc. Psychol.* 61, 404. doi: 10.1037/0022-3514.61.3.404

Delongis, A., and O'Brien, T. (1990). "An interpersonal framework for stress and coping: an application to the families of Alzheimer's patients," in *Stress and Coping In Later Life Families*, eds M. A. P. Stephens, J. H. Crowther, S. E. Hobfoll, and D. L. Tennenbaum (Washington, DC: Hemisphere), pp. 221–239.

Heckel, L., Fennell, K. M., Reynolds, J., Osborne, R. H., Chirgwin, J., Botti, M., et al. (2015). Unmet needs and depression among carers of people newly diagnosed with cancer. *Eur. J. Cancer* 51, 2049–2057. doi: 10.1016/j.ejca.06129

Kaye, J. M., and Gracely, E. J. (1993). Psychological distress in cancer patients and their spouses. *J. Cancer Edu.* 8, 47–52. doi: 10.1080/08858199309528207

Kayser, K., and Acquati, C. (2019). The influence of relational mutuality on dyadic coping among couples facing breast cancer. *J. Psychosoc. Oncol.* 37, 194–212. doi: 10.1080/07347332.2019.1566809

Kayser, K., and Scott, J.L. (2008). *Helping Couples Cope With Women's Cancers.* An Evidence-Based Approach for Pratitioners. New York: Springer New York.

Kayser, K., Watson, L. E., and Andrade, J. T. (2007). Cancer as a "we-disease": examining the process of coping from a relational perspective. *Fam. Sys. Health* 25, 404. doi: 10.1037/1091-7527.25.4.404

Leuchtmann, L., and Bodenmann, G. (2017). Interpersonal view on physical illnesses and mental disorders. *Swiss Arch. Neurol. Psychiatry Psychotherapy* 168, 170–174. doi: 10.4414/sanp.2017.00516

Lyons, R. F., Mickelson, K. D., Sullivan, M. J., and Coyne, J. C. (1998). Coping as a communal process. *J. Soc. Pers. Relat.* 15, 579–605. doi: 10.1177/0265407598155001

Meier, F., Cairo Notari, S., Bodenmann, G., Revenson, T. A., and Favez, N. (2019). We are in this together—Aren't we? Congruence of common dyadic coping and psychological distress of couples facing breast cancer. *Psycho-oncology* 28, 2374–2381. doi: 10.1002/pon.5238

Revenson, T. A., Kayser, K. E., and Bodenmann, G. E. (2005). *Couples Coping With* Stress: *Emerging Perspectives on Dyadic Coping*. Washington, DC: American Psychological Association.

Zimmermann, T. (2015). Intimate relationships affected by breast cancer: interventions for couples. *Breast Care.* 10, 102–108. doi: 10.1159/000381966

frontiers
in Psychology

SYSTEMATIC REVIEW
published: 09 March 2022
doi: 10.3389/fpsyg.2022.828656

A Systematic Review: The Effect of Cancer on the Divorce Rate

Dominik Fugmann[1]*, Martin Boeker[2], Steffen Holsteg[1], Nancy Steiner[1], Judith Prins[3] and André Karger[1]

[1] Medical Faculty, Clinical Institute of Psychosomatic Medicine and Psychotherapy, Heinrich-Heine-University-Düsseldorf, Düsseldorf, Germany, [2] University Medical Center Rechts der Isar, School of Medicine, Institute of Artificial Intelligence and Informatics in Medicine, Technical University of Munich, Munich, Germany, [3] Department of Medical Psychology, Radboud Institute of Health Sciences, Radboud University Medical Centre, Nijmegen, Netherlands

Introduction: Research on the impact of cancer on close relationships brings up conflicting results. This systematic review collects empirical evidence on the research questions whether a cancer diagnosis in general or the type of cancer affects the divorce rate.

Materials and Methods: This systematic review was conducted according to the guidelines of the Cochrane Collaboration and the PRISMA statement. The following electronic databases were searched: Web of Science, Ovid SP MEDLINE, PsycINFO, PsyINDEX, CINAHL, ERIC. Risk of bias assessment was performed with the preliminary risk of bias for exposures tool template (ROBINS-E tool). The grading of methodological quality was assessed with the Newcastle-Ottawa Scale.

Results: Of 13,929 identified records, 15 were included in the qualitative synthesis. In 263,616 cancer patients and 3.4 million healthy individuals, we found that cancer is associated with a slightly decreased divorce rate, except for cervical cancer, which seems to be associated with an increased divorce rate.

Discussion: According to this systematic review, cancer is associated with a tendency to a slightly decreased divorce rate. However, most of the included studies have methodologic weaknesses and an increased risk of bias. Further studies are needed.

Keywords: cancer, oncology, psycho-oncology, divorce, separation, marriage, couple, spouse

Edited by:
Chiara Acquati,
University of Houston, United States

Reviewed by:
Catarina Samorinha,
University of Sharjah, United Arab Emirates
Barbara Head,
University of Louisville, United States

***Correspondence:**
Dominik Fugmann
dominik.fugmann@med.uni-duesseldorf.de

Specialty section:
This article was submitted to Psycho-Oncology, a section of the journal Frontiers in Psychology

Received: *03 December 2021*
Accepted: *10 February 2022*
Published: *09 March 2022*

Citation:
Fugmann D, Boeker M, Holsteg S, Steiner N, Prins J and Karger A (2022) A Systematic Review: The Effect of Cancer on the Divorce Rate. Front. Psychol. 13:828656. doi: 10.3389/fpsyg.2022.828656

BACKGROUND

Divorce is a common occurrence around the world, with significant differences between countries. In 2019 there were 1.8 divorces in 1,000 residents in Germany (USA 2019: 2.7 divorces in 1,000 residents) (Centers for Disease Control and Prevention [CDC], 2021; Destatis Statistisches Bundesamt, 2021). A divorce can have harmful consequences: in addition to social and economic impacts, health can also be impaired (Amato, 2000; Sbarra et al., 2011; Sbarra, 2015; Leopold, 2018). A subgroup of divorced people shows significantly increased mortality as a result (Sbarra, 2015). For cancer patients, social and emotional support from close relationships are among the most protective factors (Aizer et al., 2013). In view of 18.1 million cancer diagnoses per year and an increasing tendency worldwide (International Agency for Research on Cancer [IARC], 2020), an effect of cancer on the divorce rate would be of considerable relevance.

Abbreviations: CI, confidence interval; HR, hazard ratio; NOS, Newcastle-Ottawa Quality Assessment Scale; OR, odds ratio; RR, risk ratio.

Cancer leads to distress in patients but also in their partners in dyadic relationships (Hodges et al., 2005; Hagedoorn et al., 2008). In literature there is evidence that distress increases within one year after diagnosis (Sjövall et al., 2009). The long-term effects of cancer on relationships are less clear (Manne and Badr, 2008; Regan et al., 2012). Furthermore, it is uncertain if there are detrimental effects on the quality of the relationship that can lead to a divorce due to a failure to cope. The literature is inconsistent in this regard: on the one hand, some studies report no higher risk of divorce after a cancer diagnosis of one spouse (Dorval et al., 1999; Joly et al., 2002; Carlsen et al., 2007). On the other hand, some studies provide evidence of a higher risk of divorce after a cancer diagnosis (Kirchhoff et al., 2012; Song et al., 2014).

In addition to known factors such as age at marriage or number of children (Heaton, 1990), the type of cancer could also have an influence on the risk of divorce. In a cohort study, 46,303 patients from the Danish cancer registry were compared to 221,028 matched patients from a Danish administrative registry: A higher divorce rate was only found in patients with cervical cancer (Carlsen et al., 2007). Keeping in mind that interdisciplinary cancer treatment is now organized in cancer type-specific centers, interventions that target unmet needs like maintaining the partnership could be easily implemented in clinical pathways. Targeted support in maintaining the partnership could be provided by all healthcare professionals in oncology, ranging from the provision of information to interventions to improve the quality of the relationship.

This systematic review collects empirical evidence on the research questions whether cancer in general or specific cancer types have an effect on the divorce rate.

In the literature a wide range of definitions of “marriage” and “divorce” can be found. Sometimes the category “divorced” includes both separated and divorced patients (Karraker and Latham, 2015), sometimes cohabitating couples are declared as married and moving into separate places of residence is declared a divorce (Carlsen et al., 2007; Dinh et al., 2018). Yet cohabitating couples separate more often than married couples (Bouchard, 2006). Accordingly, a systematic investigation of divorces following a cancer diagnosis could entail the risk of confounding because the groups compared can be composed differently, so that in the present systematic review only legally married couples and official divorces are considered in order to maximize internal validity.

MATERIALS AND METHODS

This systematic review was conducted following a protocol that was developed according to the guidelines of the Cochrane Collaboration and the PRISMA statement (Higgins and Green, 2011; Moher et al., 2015).

Objectives, Definitions, Inclusion, and Exclusion Criteria

The primary objective of this systematic review was to collect evidence in as a complete manner as possible, and to extract and synthesis it for changes in the divorce rate after a cancer diagnosis. The secondary objective was analyzing the collected evidence to determine whether diagnoses of different cancer types are associated with changes in the divorce rate.

In terms of the evidence, we only considered married couples for the review, which were defined as a couple relationship between two adults (aged $\geq$ 18 years), regardless of gender, who are officially married. We included cancer patients with solid or non-solid tumors of all organ systems, who were diagnosed during marriage. A diagnosis prior to marriage did not qualify for our review and such data was excluded. Healthy subjects or those with different types of cancer were studied as a comparison group while comparison groups with diseases other than cancer were excluded. The outcome examined in this review is the divorce rate. A divorce was defined as a certified separation of a former married couple. Studies which included the defined outcome but which were not necessarily restricted to this outcome were included: experimental and/or observational studies, randomized and non-randomized studies, prospective or retrospective cohort studies and descriptive studies. The following study types were excluded: qualitative studies, studies not presenting an outcome including commentaries, letters and editorials, studies not publicized in full-text and not-obtainable in full-text, studies only presenting marital status data within 6 months of the cancer diagnosis.

Search Strategy and Sources

A search strategy was developed to perform a wide search. Before the final search was performed, the Web of Science search strategy was reviewed by a PhD-level information scientist using PRESS: Peer review of Search Strategies model (McGowan et al., 2016).

A MESH term search while testing the search strategy did not yield any additional hits, so it was removed in the final search strategy. The search terms used are listed in **Supplementary Material**.

To ensure the relevance of the data, only studies released later than 1999 were considered. Only publications in English or German were considered due to the language abilities of the authors.

The following electronic databases were searched on 1st April 2020, a search update was carried out on 3rd June 2021. All studies were retrieved based on that search.

- Web of Science (Web of Science Core Collection, BIOSIS Citation Index, BIOSIS Previews, Current Contents Connect, Data Citation Index, Derwent Innovations Index, KCI-Korean Journal Database, MEDLINE, Russian Science Citation Index, SciELO Citation Index, Zoological Record)
- Ovid SP MEDLINE
- APA PsycINFO
- PsyINDEX
- CINAHL
- ERIC.

A complete sample search in Web of Science can be found in **Supplementary Material**.

To complete the search the following procedures were performed (hand search and cited-reference searches):

Reviewing the reference lists of the included publications, contacting experts in the examined field of psycho-oncology to gather information about other publications or not-yet published works (i.e., doctoral theses), performing a search for trial- and review registries, performing a citation search in Web of Science to find publications citing the publications included in the review and searching the local library catalog (Heinrich-Heine University Düsseldorf) for further publications.

Study Selection Criteria and Study Selection

Two authors (DF, SH or NS) independently categorized all discovered publications by title and abstract screening to determine whether these were to be included in, or excluded from, the review. If the classification remained unclear after abstract screening or the judgment was not unanimous, the full-text was obtained for a consensus-based decision of the two authors. All publications included at this point were obtained in full-text and reviewed by two authors (DF, SH or NS). Inclusion or exclusion of every publication was discussed by these authors. If no consensus could be achieved the publication in question was reviewed by another author (AK) who decided on inclusion and exclusion. We tracked all results in a Citavi Database (Citavi 6.3 2018). The selection process was recorded to create a PRISMA flow diagram (**Figure 1**).

Data Extraction Procedures

All publications remaining after this procedure were independently registered in a standardized data extraction form by two authors (DF, SH, or NS). Discrepancies were discussed by at least two authors to reach consensus. Only those parts of the studies dealing with divorce and meeting the inclusion criteria were extracted and evaluated. The following domains were assessed: Source, methods, participants, independent variable, outcome, data analysis, risk of bias, methodological quality, results. A detailed description of the data sheet is available in the **Supplementary Material**.

Risk of Bias Assessment

Two authors independently assessed the risk of bias and methodological quality in different domains (DF, SH). The overall risk of bias was graded as low, moderate, serious, or critical and the methodological quality was graded as low or high, in each case by two authors (DF, SH) independently. Discrepancies were discussed with another author (AK) to achieve consensus.

The risk of bias assessment of the interventional studies which were included was conducted according to the guidelines of the Cochrane Collaboration. Domains that were assessed are: Selection bias, performance bias, detection bias, attrition bias, reporting bias and other sources of bias.

The risk of bias for non-interventional studies was assessed with the preliminary risk of bias for exposures tool template (ROBINS-E tool) (Preliminary risk of bias for exposures tool template, 2020). The template is subdivided in "Preliminary considerations" and "Risk of bias assessment." Preliminary considerations in terms of confounding areas regarding the divorce rate assessed for this review were: socio-demographics, marriage details, socio-economic status and country. Preliminary considered co-exposures for this review were co-morbidity, a previous cancer diagnosis, advanced cancer at diagnosis and impairing cancer therapy. Criteria used to determine the accuracy of exposure measurement were security of source and detailed description of cancer diagnoses. Factors to consider when evaluating health outcome assessment were: definition of "married," definition of "divorce," contamination of the category "divorced," time between exposure and outcome assessed. Furthermore, study-specific confounding areas, co-exposures and criteria used to determine the accuracy of exposure measurement in the included studies were identified. The "Risk of bias assessment" includes the domains confounding, selection of participants, classification of exposures, departures from intended exposures, missing data, measurement of outcomes and selection of the reported result. The relative domain and finally the overall bias were graded in the categories low, moderate, serious, critical, and no information.

Assessment of Methodological Quality

The methodological quality of non-randomized studies was assessed with the Newcastle-Ottawa Quality Assessment Scale (NOS), which includes the domains selection, comparability, and exposure/outcome (Wells et al., 2020). For cross-sectional studies, an adapted version was used (Herzog et al., 2013). The overall rating scale goes from zero to nine stars for each study (ten stars for cross-sectional studies). The methodological quality was defined as low if the overall rating was six stars or lower, or if studies were rated with only one star in the domains "selection of cases and controls or cohorts" or "assessment of outcome," or if studies were rated with zero stars in any domain. The methodological quality of all other studies was defined as high.

Synthesis of Extracted Evidence

The data was analyzed and classified according to the identified primary and secondary outcomes. In systematic qualitative synthesis, evidence was summarized. A summary of the methodology and results of each of the studies included was provided in table form. If possible, the ratio of divorced cancer patients to divorced couples without a cancer diagnosis was calculated for each study group. If groups of studies had similar designs, cohorts, and outcomes and furthermore had low risk of bias and a high methodical quality, a standard test of heterogeneity was planned: In case of low heterogeneity (<25%), studies were set to be included in a meta-analysis.

RESULTS

The search yielded 13,929 publications, of which 15 finally met the inclusion criteria (**Figure 1**). One study was removed from the analysis because it could not be interpreted due to methodological weaknesses and a critical "risk of bias" rating (Cheng et al., 2018).

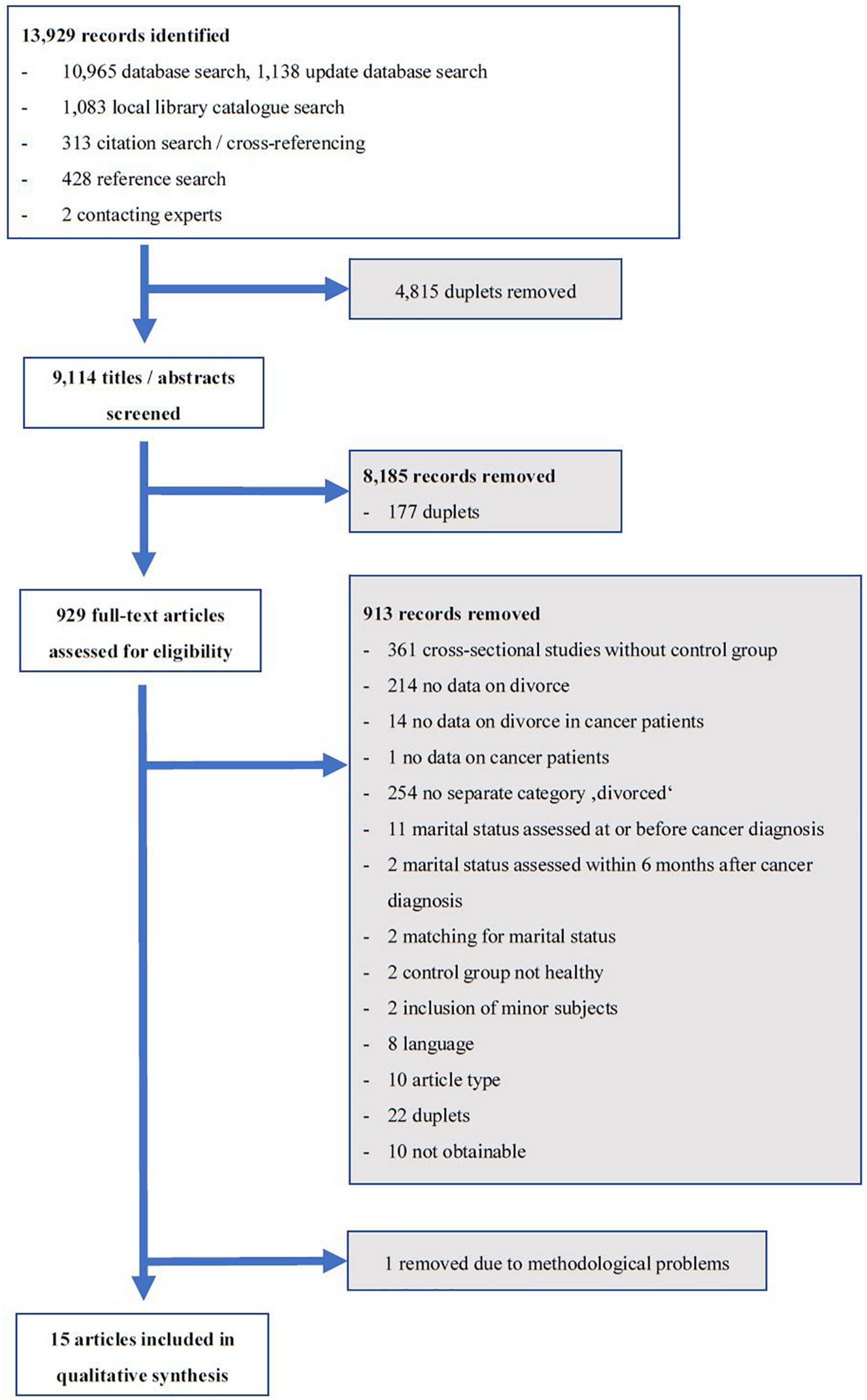


FIGURE 1 | PRISMA flow chart.

Due to the small number of studies and the heterogeneity of the study designs and the investigated groups, no meta-analysis could be performed.

The characteristics of the included studies are shown in **Table 1**, the corresponding rating of the methodological quality is illustrated in **Figure 2**.

General Cancer Diagnosis

Seven of the studies included present data on the primary question of whether cancer in general affects the divorce rate (**Table 2**).

Five very similar designed cross-sectional studies show marital status data on 739,599 subjects from the U.S. Surveillance, Epidemiology, and End Results database and compare two groups of patients with recent cancer diagnoses: Patients who already had a history of cancer before their recent second cancer diagnosis (*n* = 45,834) with those who have received their first cancer diagnosis ever (*n* = 736 304) (Saad et al., 2018; Al-Husseini et al., 2019a,b,c; Mohamed et al., 2020). In all five studies, the proportion of divorced patients in the previous cancer diagnosis group is marginally lower than in the comparison group with a ratio of divorce ranging from 0.87 to 0.96. Since all five studies primarily investigate other issues, the marital status data of the two groups was not adjusted in any way, so that a confounding must be assumed in several domains—the risk of bias was rated serious in all five studies. The methodological quality of the included parts of the studies is low (NOS 6/10 stars).

In a Norwegian registry study by Syse and Kravdal (2007) including 2.8 million subjects over an observation period of 27 years the odds ratio for divorce after a cancer diagnosis in already married subjects of 0.89 (95% CI 0.85–0.94) was calculated. The study was assessed with a low risk of bias and a high methodological quality (NOS 9/9 stars).

However, a cross-sectional study Kirchhoff et al. (2012) shows an increased risk ratio of 1.64 (95% CI 1.28–2.12) for divorce after a cancer diagnosis in one spouse. This study was conducted with 68,261 respondents, who were interviewed in 2009 in a telephone survey. The study was assessed with a moderate risk of bias and a high methodological quality (NOS 8/10 stars).

Cancer Type

Ten of the studies included provided data on the effect of specific cancer types on the divorce rate (**Table 3**).

Cervical Cancer

Two studies assessed divorce data on cervical cancer patients. Syse and Kravdal (2007) found an odds ratio for divorce after a cancer diagnosis of 1.36 (95% CI 1.26–1.47), Kirchhoff et al. (2012) found an increased risk of divorce after a cervical cancer diagnosis showing a risk ratio of 2.04 (95% CI 1.29–3.26).

Breast Cancer

Seven studies investigate breast cancer patients within the scope of the inclusion criteria of this systematic review:

In a German longitudinal, descriptive study Bischofberger et al. (2009) examined 108 patients for changes in their relationships one year after the initial diagnosis of breast cancer. During the observation period no divorce occurred. Information is lacking on many potentially confounding domains, so that the risk of bias was assessed as serious.

In a matched cohort study, Eaker et al. (2011) analyzed 4,761 breast cancer patients and 23,805 women matched by birth year and community. Time points were one year prior to the breast cancer patients' calendar year of diagnosis, at the time of diagnosis, after three, and after 5 years. The risk ratio for divorce for the breast cancer survivors, adjusted for educational level, was 0.95 (95% CI 0.87–1.05) three years after diagnosis and 1.00 (95% CI 0.90–1.10) five years after diagnosis. The risk of bias was graded moderate, the methodological quality high (NOS 8/9 stars).

A total of 3,225 early stage breast cancer patients were compared to 131,210 healthy people in a Finnish registry study by Laitala et al. (2015). There was no significant difference in the divorce rate over a 10-year observation period. Overall, the adjusted hazard ratio for divorce in breast cancer patients was 0.98 (95% CI 0.80–1.18). The study was assessed with a moderate risk of bias and a high methodological quality (NOS 9/9 stars).

Two similar designed studies investigated a peer counseling intervention, in which newly diagnosed breast cancer patients (cumulative *n* = 68) were accompanied by breast cancer survivors with completed therapy, who were on average 52.20 and 59.56 months away from diagnosis (cumulative *n* = 59) (Giese-Davis et al., 2006; Wittenberg et al., 2010): Only baseline data in this study included data on divorce, which was extracted and assessed. A lower proportion of divorced patients was found in the more experienced group, compared to the newly diagnosed patients (4.0 vs. 13.8 and 8.8 vs. 10.3%). Accordingly, the divorce ratio is low in both studies. Not least because of the unadjusted group differences, this study was assessed with a serious risk of bias and a low methodological quality (NOS 1/10 stars).

A subgroup analysis in the Norwegian registry study by Syse and Kravdal (2007) showed, that the odds ratio for divorce is slightly lower for breast cancer patients. A limiting factor is that in this calculation, contrary to the review inclusion criteria, some of the subjects were diagnosed with cancer before marriage (< 25%).

Only one Nigerian descriptive study presented a high divorce rate in breast cancer patients within a follow-up period of three years compared to national data that was not part of the study (Odigie et al., 2010; Ntoimo and Akokuwebe, 2014). However, only 86 female patients after mastectomy were examined, most of whom lived in polygamous marriages. The risk of bias was rated serious in this study.

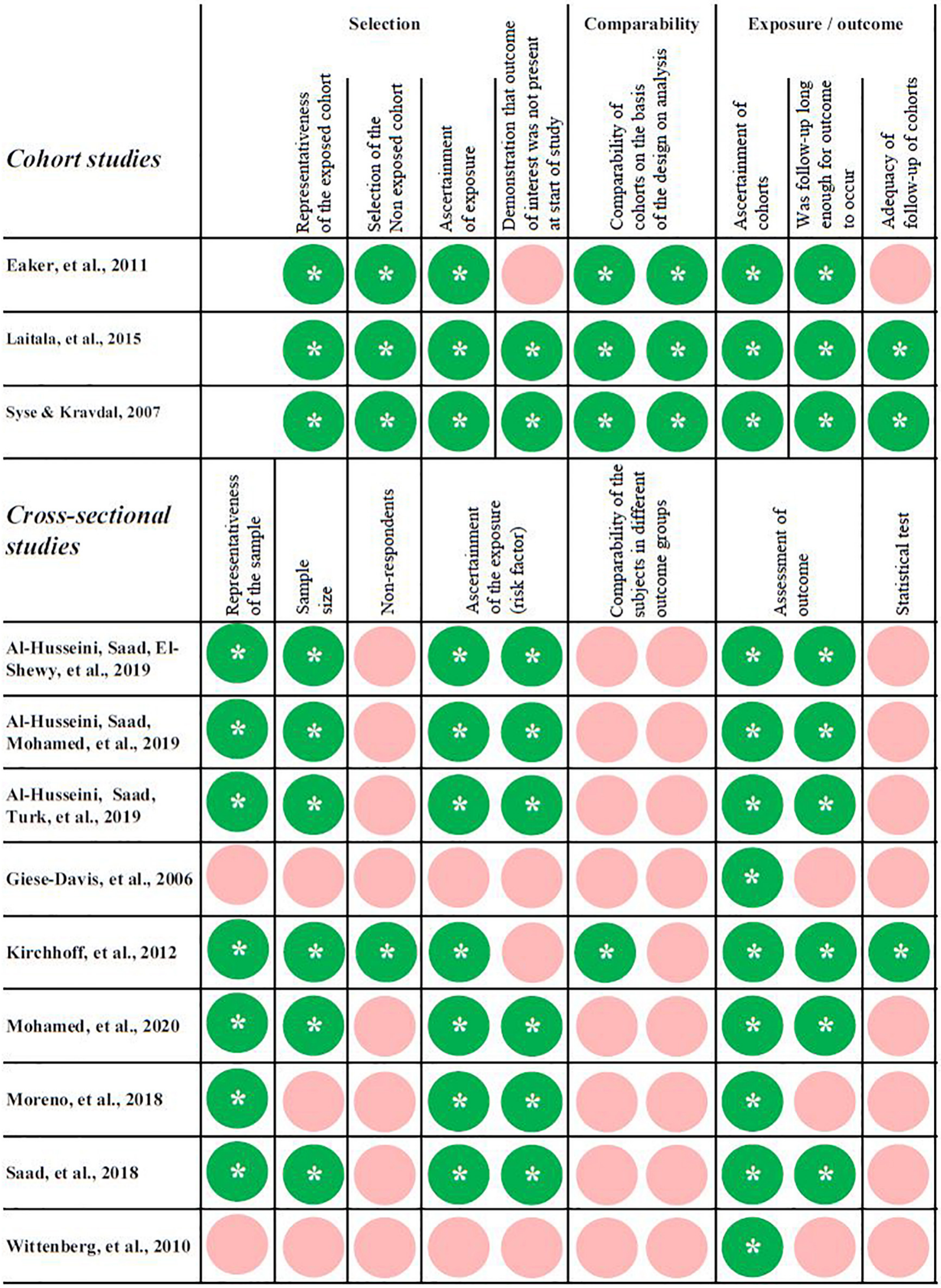
Hematologic Malignancies

Two studies provide divorce data on hematological malignancies:

Langer et al. (2010) examined 121 patients with hematological malignancies after hematopoietic stem cell transplantation, including patients with myelodysplastic syndrome (13.2%), which might not be considered as a malignancy. In a 5-year follow-up period the divorce rate was 7.3% (USA divorce rate 2008: 10.5%) (United States Census Bureau [USCB], 2020). The study was found to have a high risk of bias, partly because of an unclear proportion of subjects that was randomly assigned to an intervention to improve physical and cognitive limitations

TABLE 1 | Characteristics of the included studies.

Author	Study design	Period after cancer diagnosis	Groups/number of participants	Malignancies	Risk of bias
Al-Husseini et al. (2019a)	Cross Sectional	7 months—41 years	Cancer n = 2,980 Comparison n = 46,587	Prostate cancer 35%, breast cancer 14%, colorectal cancer 9%, urinary bladder cancer 6%, melanoma 6%, endometrial tumor 5%, non-Hodgkin 4%, lung and bronchial cancer 3%, kidney cancer 3%, others 15%	Serious
Al-Husseini et al. (2019b)	Cross sectional	7 months—40 years	Cancer n = 30,516 Comparison n = 497,697	Prostate cancer 31.3%, breast cancer 20.8%, urinary bladder cancer 7.5%, corpus and uterus cancer 6.6%, lung and bronchus cancer 5.4%, skin excluding basal and squamous cancer 4.0%, non-Hodgkin 3.7%, others 20.8%	Serious
Al-Husseini et al. (2019c)	Cross sectional	≤41 years	Cancer n = 4,774 Comparison n = 59,821	Prostate cancer 31%, breast cancer 18%, colorectal cancer 11%, urinary bladder cancer 6%, endometrial cancer 4%, lung cancer 4%, melanoma 4%, kidney cancer 3%, non-Hodgkin 3%, others 16%	Serious
Bischofberger et al. (2009)	Descriptive	1 year	Breast cancer n = 108	Primary invasive breast cancer	Serious
Eaker et al. (2011)	Cohort	3–5 years	Breast cancer n = 4,761 Comparison n = 23,805	Primary invasive breast cancer	Moderate
Giese-Davis et al. (2006)	Cross sectional	Not available	Experienced n = 25 Newly diagnosed n = 29	Breast cancer	Serious
Kirchhoff et al. (2012)	Cross sectional	2–21 years	Young adult cancer n = 1,198 Comparison n = 67,063	Cervical cancer 41.9%, melanoma 12.4%, ovarian cancer 7.9%, thyroid cancer 5.3%, breast cancer 5.2%, endometrial cancer 4.2%, testicular cancer 2.8%, hodgkin disease 2.8%, non-Hodgkin 2.2%, leukemia 1.3%, bone cancer 1.1%, brain tumor 1.0%, other 11.9%	Moderate
Laitala et al. (2015)	Cohort	≤17 years	Breast cancer n = 3,225 Comparison n = 131,210	Early staged breast cancer (T1–4N0–3M0)	Moderate
Langer et al. (2010)	Descriptive	5 years	Hematological malignancy n = 121	Chronic myeloid leukemia 35.5%, acute leukemia 18.2%, myelodysplasia 13.2%, lymphoma 11.6%, solid tumor 14.0%, other 7.5%	Serious
Mohamed et al. (2020)	Cross sectional	7 months—41 years	Cancer n = 6,127 Comparison n = 115,303	Breast 56%, colorectal 14% melanoma 5%, thyroid 4%, non-Hodgkin 4%, kidney and renal pelvis 2%, urinary bladder 2%, lung and bronchus 2%, others 11%	Moderate
Moreno et al. (2018)	Cross sectional	Not available	Breast cancer n = 128 Prostate cancer n = 90 Colorectal cancer n = 70	Breast cancer 44.4%, colorectal cancer 24.3%, prostate cancer 31.3%	Serious
Odigie et al. (2010)	Descriptive	3 years	Breast cancer n = 81	Breast cancer (stages II and III)	Serious
Saad et al. (2018)	Cross sectional	7 months—41 years.	Cumulative cancer group n = 1,437 Cumulative comparison group n = 16,896	Prostate cancer 25%/43%, colorectal cancer 11%/10%, breast cancer 8%/5%, lung & bronchus cancer 8%/5%, urinary bladder cancer 4%/9%, non-Hodgkin 2%/3%, kidney cancer 2%/2%, melanoma 2%/4%, endometrial cancer 2%/2%, others 36%/16%	Serious
Syse and Kravdal (2007)	Cohort	≤ 27 years	Cancer n = 216,584 Comparison n = approx. 2.6 million	*Men (person-years of observation):* no cancer 23.3 million, testicular cancer 40,321, skin cancer 90,196, renal/bladder cancer 94,137, colorectal cancer 97,944, head/neck cancer 45,850, Morbus Hodgkin 9,546, prostate cancer 155,580, brain cancer 8,488, non-Hodgkin 21,408, endocrine cancer 9,315, leukemia 20,561, lung cancer 28,247, other cancer 44,670 *Women:* no cancer 23.5 million, cervical cancer 90,931, other gyn. cancer 125,011, breast cancer 242,228, skin cancer 82,586, endocrine cancer 30,533, colorectal cancer 73,447, Hodgkin 6,733, brain cancer 6,754 Renal/bladder cancer 24,893, non-Hodgkin 15,636, leukemia 12,033 Head/neck cancer 10,203, lung cancer 8,146, other cancer 24,993	Low
Wittenberg et al. (2010)	Cross sectional	Not available	Experienced n = 34 Newly diagnosed n = 39	Breast cancer	Serious



Cohort studies	Selection				Comparability		Exposure / outcome		
	Representativeness of the exposed cohort	Selection of the Non exposed cohort	Ascertainment of exposure	Demonstration that outcome of interest was not present at start of study	Comparability of cohorts on the basis of the design on analysis		Ascertainment of cohorts	Was follow-up long enough for outcome to occur	Adequacy of follow-up of cohorts
Eaker, et al., 2011	*	*	*	○	*	*	*	*	○
Laitala, et al., 2015	*	*	*	*	*	*	*	*	*
Syse & Kravdal, 2007	*	*	*	*	*	*	*	*	*

Cross-sectional studies	Representativeness of the sample	Sample size	Non-respondents	Ascertainment of the exposure (risk factor)		Comparability of the subjects in different outcome groups		Assessment of outcome		Statistical test
Al-Husseini, Saad, El-Shewy, et al., 2019	*	*	○	*	*	○	○	*	*	○
Al-Husseini, Saad, Mohamed, et al., 2019	*	*	○	*	*	○	○	*	*	○
Al-Husseini, Saad, Turk, et al., 2019	*	*	○	*	*	○	○	*	*	○
Giese-Davis, et al., 2006	○	○	○	○	○	○	○	*	○	○
Kirchhoff, et al., 2012	*	*	*	*	○	*	○	*	*	*
Mohamed, et al., 2020	*	*	○	*	*	○	○	*	*	○
Moreno, et al., 2018	*	○	○	*	*	○	○	*	○	○
Saad, et al., 2018	*	*	○	*	*	○	○	*	*	○
Wittenberg, et al., 2010	○	○	○	○	○	○	○	*	○	○

FIGURE 2 | Rating of the methodological quality of the included cohort studies with the NOS (Wells et al., 2020). For the rating of the cross-sectional studies a modified version was used (Herzog et al., 2013). The overall rating scale goes from zero to nine stars (*) for each study (ten stars for cross-sectional studies).

and manage emotional and family changes associated with hematopoietic stem cell transplantation.

A reduced odds ratio for divorce for leukemia and non-Hodgkin's lymphomas was assessed by Syse and Kravdal (2007) only with respect to male patients. Again, a < 25% proportion of patients were diagnosed before marriage.

Colo-Rectal, Prostate, and Lung Cancer

In a cross-sectional study, data was divided into three groups: breast cancer (n = 128), prostate cancer (n = 90) and colorectal cancer (n = 70). There were no healthy controls (Moreno et al., 2018). The authors showed that the proportion of divorce was 14.8% for breast cancer patients, 7.7% for

TABLE 2 | Estimate effects of cancer diagnoses in general on the divorce rate.

Author	Proportion divorced	Effect type	Estimate of effect
Al-Husseini et al. (2019a)	Cancer group 7.7% Comparison group 8.0%	Ratio	0.96
Al-Husseini et al. (2019b)	Cancer group 6.2% Comparison group 7.1%	Ratio	0.87
Al-Husseini et al. (2019c)	Cancer group 8.6% Comparison group 9.5%	Ratio	0.91
Mohamed et al. (2020)	Cancer group 9.5% Comparison group 10.2%	Ratio	0.93
Saad et al. (2018)	Cancer group 10.9% Comparison group 11.7%	Ratio	0.93
Kirchhoff et al. (2012)	Cancer group 14.1% Comparison group 9.6% US population 2009 Census 10.5%	RR	1.64 (95% CI 1.28–2.12)
Syse and Kravdal (2007)	Not available	OR	0.89 (95% CI 0.85–0.94)

prostate cancer patients, and 18.5% for colorectal cancer patients. Since the groups were not adjusted and showed heterogeneity regarding socio-demographics, the risk of bias was assessed as serious and the methodological quality was assessed as low (NOS 4/10 stars).

Syse and Kravdal (2007) found a lower odds ratio of divorce in colorectal and prostate cancer patients compared to the healthy comparison group. A similar result was found in male but not female lung cancer patients.

DISCUSSION

Overall, according to six of the seven included studies on this question, there is evidence for a slightly decreased risk of divorce after a cancer diagnosis in general. The findings of Kirchhoff et al. (2012) differ from this conclusion, which is probably due to the following bias: a large proportion of patients in the cancer group suffered from cervical cancer, who were found to have a significantly increased risk ratio for divorce in the subgroup analysis. Furthermore, only young adult cancer survivors were examined: compared to older patients, younger patients more often are getting divorced after a cancer diagnosis (Syse and Kravdal, 2007). The fact that a cancer diagnosis does not increase the risk of divorce is supported by many studies, that apply a wider definition of separation in addition to official divorces (Dorval et al., 1999; Joly et al., 2002; Carlsen et al., 2007; Karraker and Latham, 2015).

Regarding the effect of a breast cancer diagnosis on the risk of divorce, most of the findings in the included studies are similar: a breast cancer diagnosis appears to have no or a decreasing effect on the risk for divorce. This finding is also consistent

TABLE 3 | Estimate effects of specific cancer types on the divorce rate.

Author	Proportion divorced	Effect type	Cancer type/estimate of effect
Kirchhoff et al. (2012)	Not available	RR	Cervical cancer 2.04 (95% CI 1.29–3.26)
Syse and Kravdal (2007)	Not available	OR	Men OR (95% CI):[b] Testicular cancer 1.05 (0.96–1.16) Skin cancer 0.96 (0.86–1.06) Renal/bladder cancer 0.88 (0.76–1.02) Colorectal cancer 0.80 (0.68–0.93) Head/neck cancer 1.00 (0.83–1.20) Morbus Hodgkin 1.02 (0.85–1.23) Prostate cancer 0.81 (0.67–0.98) Brain cancer 1.12 (0.92–1.37) Non–Hodgkin 0.80 (0.65–0.99) Endocrine cancer 1.01 (0.79–1.30) Leukemia 0.67 (0.50–0.89) Lung cancer 0.66 (0.49–0.88) Other cancer 0.83 (0.70–0.99) Women OR (95% CI):[b] Cervical cancer 1.36 (1.26–1.47) Other gyn. cancer 0.86 (0.78–0.96) Breast cancer 0.92 (0.85–0.99) Skin cancer 0.89 (0.80–0.98) Endocrine cancer 0.98 (0.85–1.12) Colorectal cancer 0.83 (0.69–0.99) Morbus Hodgkin 1.13 (0.91–1.40) Brain cancer 1.15 (0.92–1.44) Renal/bladder cancer 1.03 (0.80–1.32) Non-Hodgkin 0.80 (0.62–1.04) Leukemia 0.83 (0.59–1.17) Head/neck cancer 0.78 (0.53–1.15) Lung cancer 0.82 (0.54–1.24) Other cancer 0.82 (0.65–1.02)
Bischofberger et al. (2009)	Cancer group 0% *Divorce rate Germany 2009 2.3%*[a] *(Destatis Statistisches Bundesamt, 2021)*	None	Breast cancer Not calculable
Eaker et al. (2011)	1 year prior: both groups 17.4%. After 3 years: cancer group 18.7% comparison group 19.4% After 5 years: cancer group 19.1% comparison group 19.7%	RR	Breast cancer After 3 years: 0.95 (95% CI 0.87–1.05) After 5 years: 1.00 (95% CI 0.90–1.10)
Laitala et al. (2015)	Cancer group 9.7% Comparison group 14.4%	HR	Breast cancer 0.98 (95% CI 0.80–1.18)
Giese-Davis et al. (2006)	Cancer group 4.0% Comparison group 13.8%	Ratio	Breast cancer 0.29

(Continued)

TABLE 3 | (Continued)

Author	Proportion divorced	Effect type	Cancer type/estimate of effect
Wittenberg et al. (2010)	Cancer group 8.8% Comparison group 10.3%	Ratio	Breast cancer 0.85
Odigie et al. (2010)	After 3 years Cancer group 24.7% *Divorce rate Nigeria 2006 5.0%*[a] *(Ntoimo and Akokuwebe, 2014)*	Ratio	Breast cancer 4.94
Moreno et al. (2018)	Breast cancer 14.8% Prostate cancer 7.7% Colorectal cancer 18.5% *Divorce rate USA 2018 7.7%*[a] *(United States Census Bureau [USCB], 2020)*	Ratio	Breast cancer 1.92 Prostate cancer 1.00 Colorectal cancer 2.40
Langer et al. (2010)	After 5 years: Cancer group 7.3% *Divorce rate USA 2008 10.5%*[a] *(United States Census Bureau [USCB], 2020)*	Ratio	Hematological malignancy 0.70

[a] *Data not part of the study.* [b] *< 25% patients with a cancer diagnosis before marriage.*

with other studies in the field that have examined other types of separations besides official divorces (Dorval et al., 1999; Carlsen et al., 2007).

Remarkably, the risk ratio or the odds ratio of divorce for cervical carcinoma patients is increased in the included studies (Syse and Kravdal, 2007; Kirchhoff et al., 2012). This coincides with the findings of Carlsen et al. (2007), who found an increased risk of divorce in a subgroup analysis for cervical cancer patients. Yet, in this study, the definition of divorce also included moving to different places of residence. Young people in particular are affected by this diagnosis, but the divorce rate is elevated among older individuals, as well (Syse and Kravdal, 2007). It is conceivable that infertility plays a role in this context. However, Syse and Kravdal (2007) did not find any influence of fertility on the odds ratio of divorce after a cancer diagnosis in their analysis, but there is evidence for a negative correlation between infertility distress and relationship satisfaction, which Ussher and Perz (2019) show in a survey of 693 women and 185 men with a cancer diagnosis. This infertility distress is not only persistent long term, but it is also associated with a higher rate of mental health disorders and psychosocial distress (Logan et al., 2019), which is an additional burden for the affected couple. Beyond that, depending on its stage and therapy, a diagnosis of cervical cancer may be associated with long-term changes in sexuality such as a tighter and shorter vagina, dyspareunia, and sexual worries (Lammerink et al., 2012; Wiltink et al., 2020). The resulting changes in sexual relationships are also a central issue for male partners of cervical cancer patients (Oldertrøen Solli et al., 2019). In a cross-sectional study with 113 cervical cancer patients a connection between sexual satisfaction and marital adjustment, partially moderated by body image, was found (do Rosário Ramos Nunes Bacalhau et al., 2020). It is also possible that the group of cervical cancer patients is composed differently than groups suffering from other cancer types because the risk of developing the disease is associated with early sexual intercourse and the number of sexual partners (International Collaboration of Epidemiological Studies of Cervical Cancer, 2009).

Strengths and Limitations

Despite the large number of studies on the topic of separations or divorces after a cancer diagnosis, this is the first systematic review dedicated to this topic. The search strategy and inclusion criteria are very broad, including all countries and cultures, in order to fully reflect the current state of the literature. Thus, a very large number of studies could be found and screened in full-text. The focus on the outcome "divorce" instead of "separation" not only contributes to a high internal validity, but also allows a comparison of the results of the included studies with general divorce statistics.

However, as a result of this limitation exclusively to official divorces, only a few studies could be included. Some of these studies did not primarily investigate marital status in the context of cancer. Among other things, this has led to a more or less significant limitation of the methodological quality of these studies regarding divorce data. The significance of the present study is further diminished by the fact that no meta-analysis could be carried out because of the few and very heterogeneous studies included. Overall, the level of evidence provided by this systematic review is reduced due to the limitations mentioned. Further studies are needed to verify our results.

Time courses after a cancer diagnosis were not in scope of the present systematic review, although these proved to be quite relevant when reviewing the data: For example, Syse and Kravdal (2007) found an increased divorce rate within five years of a testicular cancer diagnosis, whereas the divorce rate is not increased after five years or overall.

What Happens Within the Partnership?

The outcome "divorce" is too general to differentiate between specific positive and negative effects of a cancer diagnosis on a partnership. A well-researched model showing how couples deal with stressors such as a cancer diagnosis is that of dyadic coping (Bodenmann, 1995): Positive coping mechanisms like providing or accepting support maintain or even improve the relationship functioning (Traa et al., 2015). Negative coping behavior such as hiding worries can contribute to increased distress in the partnership (Kayser et al., 2007; Badr et al., 2010; Traa et al., 2015). Thus, there may be subgroups that are heavily distressed by a cancer diagnosis due to failed coping and whose marriages break up in the further course of the disease (Stephens et al., 2016), but which, in regard of the divorce rate, are balanced by subgroups where positive effects of a cancer diagnosis have led to an improved quality of relationships.

We must be cautious to interpret a divorce always as negative. For some couples it could be part of a developmental process. The negative impact of a stressful relationship should not be underestimated. Also being alone and having no social support might have a greater influence on health-related issues than being divorced (Metsä-Simola and Martikainen, 2013). After being divorced there are some cancer patients who will engage after a short time in a new relationship.

Future research has to investigate more closely the longitudinal processes within relationships dealing with cancer and relate individual factors and the dyadic process to health-related outcomes. An important task of such research is to identify risk factors and subgroups of patients and their families who need specific psychosocial support.

CONCLUSION

Overall, we found evidence that cancer is associated with a slightly decreased divorce rate—an exception may be cervical carcinoma, which is associated with an increased divorce rate. The findings of the present study are limited by the heterogeneity and methodological weaknesses of most of the included studies. Thus, further research is needed, not only to validate the findings, but also to better understand the processes within the partnerships, with the aim of better adapting psychosocial support services to the vulnerable groups.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

AK, DF, and MB contributed to conception and design of the study. DF and MB conducted the protocol and the searches. DF, SH, and NS performed the screening. DF and SH performed the data extraction and rating. DF wrote the first draft of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

ACKNOWLEDGMENTS

We would like to thank Carla Fischer for her help in the preparation of the review and Kamila Leszek for her support in the evaluation of the studies.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.828656/full#supplementary-material

REFERENCES

Aizer, A. A., Chen, M. H., McCarthy, E. P., Mendu, M. L., Koo, S., Wilhite, T. J., et al. (2013). Marital status and survival in patients with cancer. *J. Clin. Oncol.* 31, 3869–3876. doi: 10.1200/JCO.2013.49.6489

Al-Husseini, M. J., Saad, A. M., El-Shewy, K. M., Nissan, N. E., Gad, M. M., Alzuabi, M. A., et al. (2019a). Prior malignancy impact on survival outcomes of glioblastoma multiforme; population-based study. *Int. J. Neurosci.* 129, 447–454. doi: 10.1080/00207454.2018.1538989

Al-Husseini, M. J., Saad, A. M., Mohamed, H. H., Alkhayat, M. A., Sonbol, M. B., and Abdel-Rahman, O. (2019b). Impact of prior malignancies on outcome of colorectal cancer; revisiting clinical trial eligibility criteria. *BMC Cancer* 19:863. doi: 10.1186/s12885-019-6074-6

Al-Husseini, M. J., Saad, A. M., Turk, T., Tabash, M. A., and Abdel-Rahman, O. (2019c). Impact of Prior Malignancy on Survival Outcomes of Stage IV Pancreatic Adenocarcinoma: SEER-Based Cohort. *J. Gastrointest. Cancer* 50, 794–800. doi: 10.1007/s12029-018-0158-4

Amato, P. R. (2000). The consequences of divorce for adults and children. *J. Marriage Fam.* 62, 1269–1287. doi: 10.1111/j.1741-3737.2000.01269.x

Badr, H., Carmack, C. L., Kashy, D. A., Cristofanilli, M., and Revenson, T. A. (2010). Dyadic coping in metastatic breast cancer. *Health Psychol.* 29, 169–180. doi: 10.1037/a0018165

Bischofberger, B., Mollova, M., Geyer, S., and Neises, M. (2009). [Changes in Partnership Relationships of Women After Breast Cancer Diagnosis]. *Geburtshilfe Frauenheilkund.* 69, 1091–1096. doi: 10.1055/s-0029-1240640

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping in couples. *Swiss J. Psychol.* 54, 34–49. doi: 10.1016/j.cpr.2008.10.004

Bouchard, G. (2006). Cohabitation versus marriage: the role of dyadic adjustment in relationship dissolution. *J. Divorce Remarriage* 46, 107–117.

Carlsen, K., Dalton, S. O., Frederiksen, K., Diderichsen, F., and Johansen, C. (2007). Are cancer survivors at an increased risk for divorce? A Danish cohort study. *Eur. J. Cancer* 43, 2093–2099. doi: 10.1016/j.ejca.2007.05.024

Centers for Disease Control and Prevention [CDC] (2021). *Marriage and Divorce, National Center for Health Statistics, USA*. Available Online at: https://www.cdc.gov/nchs/fastats/marriage-divorce.htm. (accessed December 3, 2021)

Cheng, A., Zeng, Y., Liu, X., Liu, S., Cheng, S., Kwok, C., et al. (2018). Cognitive challenges while at work and work output in breast cancer survivors employed in a rapidly evolving economy. *J. Cancer Surviv.* 12, 753–761. doi: 10.1007/s11764-018-0712-x

Destatis Statistisches Bundesamt (2021). *Ergebnis 12631-0001*. Available Online at: https://www-genesis.destatis.de/genesis/online?sequenz=tabelleErgebnis&selectionname=12631-0001 (accessed December 3, 2021)

Dinh, K. T., Aizer, A. A., Muralidhar, V., Mahal, B. A., Chen, Y. W., Beard, C. J., et al. (2018). Increased Vulnerability to Poorer Cancer-Specific Outcomes Following Recent Divorce. *Am. J. Med.* 131, 517–523. doi: 10.1016/j.amjmed.2017.11.039

do Rosário Ramos Nunes Bacalhau, M., Pedras, S., and da Graça Pereira Alves, M. (2020). Attachment style and body image as mediators between marital adjustment and sexual satisfaction in women with cervical cancer. *Support. Care Cancer* 28, 5813–5819. doi: 10.1007/s00520-020-05423-y

Dorval, M., Maunsell, E., Taylor-Brown, J., and Kilpatrick, M. (1999). Marital stability after breast cancer. *J. Natl. Cancer Inst.* 91, 54–59. doi: 10.1093/jnci/91.1.54

Eaker, S., Wigertz, A., Lambert, P. C., Bergkvist, L., Ahlgren, J., Lambe, M., et al. (2011). Breast cancer, sickness absence, income and marital status. A study on life situation 1 year prior diagnosis compared to 3 and 5 years after diagnosis. *PLoS One* 6:e18040. doi: 10.1371/journal.pone.0018040

Giese-Davis, J., Bliss-Isberg, C., Carson, K., Star, P., Donaghy, J., Cordova, M. J., et al. (2006). The effect of peer counseling on quality of life following diagnosis of breast cancer: an observational study. *Psychooncology* 15, 1014–1022. doi: 10.1002/pon.1037

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., and Coyne, J. C. (2008). Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychol. Bull.* 134, 1–30. doi: 10.1037/0033-2909.134.1.1

Heaton, T. B. (1990). Marital stability throughout the child-rearing years. *Demography* 27, 55–63.

Herzog, R., Álvarez-Pasquin, M. J., Díaz, C., Del Barrio, J. L., Estrada, J. M., and Gil, Á (2013). Are healthcare workers' intentions to vaccinate related to their knowledge, beliefs and attitudes? A systematic review. *BMC Public Health* 13:154. doi: 10.1186/1471-2458-13-154

Higgins, J. P. T., and Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. The Cochrane Collaboration*. Available Online at: http://handbook.cochrane.org (accessed March 4, 2020)

Hodges, L. J., Humphris, G. M., and Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc. Sci. Med.* 60, 1–12. doi: 10.1016/j.socscimed.2004.04.018

International Agency for Research on Cancer [IARC] (2020). *Cancer Today – IARC*. Available Online at: https://gco.iarc.fr/today/data/factsheets/cancers/39-All-cancers-fact-sheet.pdf (accessed October 1, 2020).

International Collaboration of Epidemiological Studies of Cervical Cancer (2009). Cervical carcinoma and sexual behavior: collaborative reanalysis of individual data on 15,461 women with cervical carcinoma and 29,164 women without cervical carcinoma from 21 epidemiological studies. *Cancer Epidemiol. Biomark. Prev.* 18, 1060–1069. doi: 10.1158/1055-9965.EPI-08-1186

Joly, F., Héron, J. F., Kalusinski, L., Bottet, P., Brune, D., Allouache, N., et al. (2002). Quality of life in long-term survivors of testicular cancer: a population-based case-control study. *J. Clin. Oncol.* 20, 73–80. doi: 10.1200/JCO.2002.20.1.73

Karraker, A., and Latham, K. (2015). In Sickness and in Health? Physical Illness as a Risk Factor for Marital Dissolution in Later Life. *J. Health Soc. Behav.* 56, 420–435. doi: 10.1177/0022146515596354

Kayser, K., Watson, L. E., and Andrade, J. T. (2007). Cancer as a "we-disease": examining the process of coping from a relational perspective. *Fam. Syst. Health* 25, 404–418. doi: 10.1037/1091-7527.25.4.404

Kirchhoff, A. C., Yi, J., Wright, J., Warner, E. L., and Smith, K. R. (2012). Marriage and divorce among young adult cancer survivors. *J. Cancer Surviv.* 6, 441–450. doi: 10.1007/s11764-012-0238-6

Laitala, V. S., Saarto, T., Einiö, E. K., Martikainen, P., and Silventoinen, K. (2015). Early-stage breast cancer is not associated with the risk of marital dissolution in a large prospective study of women. *Br. J. Cancer* 113, 543–547. doi: 10.1038/bjc.2015.216

Lammerink, E. A., de Bock, G. H., Pras, E., Reyners, A. K., and Mourits, M. J. (2012). Sexual functioning of cervical cancer survivors: a review with a female perspective. *Maturitas* 72, 296–304. doi: 10.1016/j.maturitas.2012.05.006

Langer, S. L., Yi, J. C., Storer, B. E., and Syrjala, K. L. (2010). Marital adjustment, satisfaction and dissolution among hematopoietic stem cell transplant patients and spouses: a prospective, five-year longitudinal investigation. *Psychooncology* 19, 190–200. doi: 10.1002/pon.1542

Leopold, T. (2018). Gender Differences in the Consequences of Divorce: a Study of Multiple Outcomes. *Demography* 55, 769–797. doi: 10.1007/s13524-018-0667-6

Logan, S., Perz, J., Ussher, J. M., Peate, M., and Anazodo, A. (2019). Systematic review of fertility-related psychological distress in cancer patients: informing on an improved model of care. *Psychooncology* 28, 22–30. doi: 10.1002/pon.4927

Manne, S., and Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer* 112, 2541–2555. doi: 10.1002/cncr.23450

McGowan, J., Sampson, M., Salzwedel, D. M., Cogo, E., Foerster, V., and Lefebvre, C. (2016). PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *J. Clin. Epidemiol.* 75, 40–46. doi: 10.1016/j.jclinepi.2016.01.021

Metsä-Simola, N., and Martikainen, P. (2013). The short-term and long-term effects of divorce on mortality risk in a large Finnish cohort, 1990-2003. *Popul. Stud.* 67, 97–110. doi: 10.1080/00324728.2012.746386

Mohamed, H. H., Ibrahim Sokkar, M., Afifi, A. M., Saad, A. M., Albarouki, S., and Al-Husseini, M. J. (2020). Does a history of malignancy impact the survival of a subsequent endometrial adenocarcinoma? Should clinical trials eligibility criteria be revisited? *J. Obstet. Gynaecol.* 40, 233–239. doi: 10.1080/01443615.2019.1621808

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., et al. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst. Rev.* 4:1. doi: 10.1186/2046-4053-4-1

Moreno, P. I., Ramirez, A. G., San Miguel-Majors, S. L., Fox, R. S., Castillo, L., Gallion, K. J., et al. (2018). Satisfaction with cancer care, self-efficacy, and health-related quality of life in Latino cancer survivors. *Cancer* 124, 1770–1779. doi: 10.1002/cncr.31263

Ntoimo, L. F. C., and Akokuwebe, M. E. (2014). Prevalence and Patterns of Marital Dissolution in Nigeria. *Nigerian J. Sociol. Anthropol.* 12, 1–15. doi: 10.36108/NJSA/4102/120210

Odigie, V. I., Tanaka, R., Yusufu, L. M., Gomna, A., Odigie, E. C., Dawotola, D. A., et al. (2010). Psychosocial effects of mastectomy on married African women in Northwestern Nigeria. *Psychooncology* 19, 893–897. doi: 10.1002/pon.1675

Oldertrøen Solli, K., de Boer, M., Nyheim Solbraekke, K., and Thoresen, L. (2019). Male partners' experiences of caregiving for women with cervical cancer-a qualitative study. *J. Clin. Nurs.* 28, 987–996. doi: 10.1111/jocn.14688

Preliminary risk of bias for exposures tool template (2020). *The ROBINS-E tool (Risk Of Bias In Non-randomized Studies - of Exposures)*. England: University of Bristol

Regan, T. W., Lambert, S. D., Girgis, A., Kelly, B., Kayser, K., and Turner, J. (2012). Do couple-based interventions make a difference for couples affected by cancer? A systematic review. *BMC Cancer* 12:279. doi: 10.1186/1471-2407-12-279

Saad, A. M., Al-Husseini, M. J., Elgebaly, A., Aboshady, O. A., Salahia, S., and Abdel-Rahman, O. (2018). Impact of prior malignancy on outcomes of stage IV esophageal carcinoma: SEER based study. *Expert Rev. Gastroenterol. Hepatol.* 12, 417–423. doi: 10.1080/17474124.2018.1426458

Sbarra, D. A. (2015). Divorce and health: current trends and future directions. *Psychosom. Med.* 77, 227–236. doi: 10.1097/PSY.0000000000000168

Sbarra, D. A., Law, R. W., and Portley, R. M. (2011). Divorce and Death: a Meta-Analysis and Research Agenda for Clinical, Social, and Health Psychology. *Perspect. Psychol. Sci.* 6, 454–474. doi: 10.1177/1745691611414724

Sjövall, K., Attner, B., Lithman, T., Noreen, D., Gunnars, B., Thomé, B., et al. (2009). Influence on the health of the partner affected by tumor disease in the wife or husband based on a population-based register study of cancer in Sweden. *J. Clin. Oncol.* 27, 4781–4786. doi: 10.1200/JCO.2008.21.6788

Song, H. Y., Kwon, J. A., Choi, J. W., Kim, S. J., and Park, E. C. (2014). Gender differences in marital disruption among patients with cancer: results from the Korean National Health and Nutrition Examination Survey (KNHANES). *Asian Pac. J. Cancer Prev. APJCP* 15, 6547–6552. doi: 10.7314/apjcp.2014.15.16.6547

Stephens, C., Westmaas, J. L., Kim, J., Cannady, R., and Stein, K. (2016). Gender differences in associations between cancer-related problems and relationship dissolution among cancer survivors. *J. Cancer Surviv.* 10, 865–873. doi: 10.1007/s11764-016-0532-9

Syse, A., and Kravdal, Ø (2007). Does cancer affect the divorce rate? *Demogr. Res.* 16, 469–492. doi: 10.4054/DemRes.2007.16.15

Traa, M. J., De Vries, J., Bodenmann, G., and Den Oudsten, B. L. (2015). Dyadic coping and relationship functioning in couples coping with cancer: a systematic review. *Br. J. Health Psychol.* 20, 85–114. doi: 10.1111/bjhp.12094

United States Census Bureau [USCB] (2020). *U.S. Marriage and Divorce Rates by State: 2008 & 2018*. Available Online at: https://www.census.gov/library/visualizations/interactive/marriage-divorce-rates-by-state.html (accessed November 30, 2021)

Ussher, J. M., and Perz, J. (2019). Infertility-related distress following cancer for women and men: a mixed method study. *Psychooncology* 28, 607–614. doi: 10.1002/pon.4990

Wells, G. A., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., et al. (2020). *The Newcastle Ottawa Scale (NOS) for assessing the quality of nonrandomized studies in meta-analysis*. Ottawa: The Ottawa Hospital Research Institute.

Wiltink, L. M., King, M., Müller, F., Sousa, M. S., Tang, M., Pendlebury, A., et al. (2020). A systematic review of the impact of contemporary treatment modalities for cervical cancer on women's self-reported health-related quality of life. *Support. Care Cancer* 28, 4627–4644. doi: 10.1007/s00520-020-05554-2

Wittenberg, L., Yutsis, M., Taylor, S., Giese-Davis, J., Bliss-Isberg, C., Star, P., et al. (2010). Marital status predicts change in distress and well-being in women newly diagnosed with breast cancer and their peer counselors. *Breast J.* 16, 481–489. doi: 10.1111/j.1524-4741.2010.00964.x

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

ORIGINAL RESEARCH
published: 19 May 2022
doi: 10.3389/fpsyg.2022.855638

Couples Coping With Hematological Cancer: Support Within and Outside the Couple – Findings From a Qualitative Analysis of Dyadic Interviews

Daniela Bodschwinna[1,2], Gregor Weissflog[3], Hartmut Döhner[2,4], Dietger Niederwieser[5], Anja Mehnert-Theuerkauf[3], Harald Gündel[1], Jochen Ernst[3], Ute Goerling[6]† and Klaus Hönig[1,2]†*

[1] Department of Psychosomatic Medicine and Psychotherapy, University Medical Center Ulm, Ulm, Germany, [2] Comprehensive Cancer Center Ulm, University Medical Center Ulm, Ulm, Germany, [3] Department of Medical Psychology and Medical Sociology, University of Leipzig Medical Center, Leipzig, Germany, [4] Department of Internal Medicine III, University Hospital of Ulm, Ulm, Germany, [5] Medical Clinic and Policlinic, Hematology, Cellular Therapy and Hemostaseology, Leipzig University Hospital, Leipzig, Germany, [6] Charité – Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Charité Comprehensive Cancer Center, Berlin, Germany

Edited by:
Linda Charvoz,
University of Applied Sciences and Arts of Western Switzerland, Switzerland

Reviewed by:
Kristopher Lamore,
Université de Lille, France
Emanuela Saita,
Catholic University of the Sacred Heart, Italy

****Correspondence:***
Daniela Bodschwinna
daniela.bodschwinna@uni-ulm.de

† These authors have contributed equally to this work and share senior authorship

Specialty section:
This article was submitted to Psycho-Oncology, a section of the journal Frontiers in Psychology

Received: *15 January 2022*
Accepted: *11 April 2022*
Published: *19 May 2022*

Citation:
Bodschwinna D, Weissflog G, Döhner H, Niederwieser D, Mehnert-Theuerkauf A, Gündel H, Ernst J, Goerling U and Hönig K (2022) Couples Coping With Hematological Cancer: Support Within and Outside the Couple – Findings From a Qualitative Analysis of Dyadic Interviews. Front. Psychol. 13:855638. doi: 10.3389/fpsyg.2022.855638

Objective: Cancer affects the patients as well as their partners. Couples use different strategies to cope with cancer and the associated burden: individual coping, dyadic coping, and support from the social network and from professional health care. The aim of this qualitative dyadic interviews is to gain a deeper and more differentiated understanding of the support system inside and outside of the couple.

Methods: Ten heterosexual couples (patients: seven men and three women) with different ages (patients: range = 22–75; spouses: range = 22–74), different hematological cancer (e.g., acute myeloid leukemia, non-Hodgkin's lymphoma) and cancer stages (initial diagnosis or relapse) participated in the study. Semi-structured dyadic interviews were conducted. Data of the verbatim transcripts were systematically coded and analyzed following structuring content analysis.

Results: Three main categories (individual coping, dyadic coping, and outside support) and ten subcategories about coping and support strategies in hematological cancer patients and their spouses could be identified. All couples described cohesion in relationship as an essential common dyadic coping strategy. Most strategies were focused on the patient's wellbeing. Furthermore, couples reported different common plans for the future: while some wanted to return to normality, others were reaching out for new goals.

Conclusion: Couples used various coping and support strategies, that differed in type and frequency between patients and spouses. Most of the strategies were perceived as beneficial, but some also triggered pressure. Overall, spouses seem to need more psychological support to improve their own wellbeing.

Keywords: hematological cancer, couple (spouses), dyadic interview, individual coping, dyadic coping, social support

INTRODUCTION

Hematological cancers include various heterogenous disease patterns that affect the hematopoietic system. Diseases like lymphoma, multiple myeloma and leukemia differ in treatment, progression, and forecast (Robert Koch Institute & Association of Population-Based Cancer Registries in Germany., 2021). Due to uncertainty about treatment effectiveness and cancer trajectory both patients and spouses suffer from psychological distress (Lambert et al., 2013; Kuba et al., 2019; Raphael et al., 2020). The couple faces new challenges (e.g., lack of knowledge about disease, financial burden), changing roles (e.g., single earner, family roles) and is concerned about their future together (Li et al., 2018; Serçe and Günüşen, 2021). In addition, highly aggressive treatments like high-dose chemotherapy, total body irradiation as well as treatment-related isolation of the patient in the case of stem cell transplantation leads to high burden in couples (Bishop et al., 2007; Beattie and Lebel, 2011).

Coping with cancer and its related burden can take place at different levels. Traditional models such as the transactional stress theory by Lazarus and Folkman (1984) focus on the individual centered view of stress management, in which coping efforts are described as an individual process. Over time dyadic approaches, in which couples respond to a shared stressor through a collaborative process, have gained increasing attention (Bodenmann, 1995). As cancer is a stressor that affects both patients and spouses as well as the close social network, coping and support efforts from all these parties should be considered (Bodenmann, 2005).

Individual coping, dyadic coping, and outside support are exceedingly important for couples facing cancer due to positive effects in adaption to the disease. Individual coping strategies such as reduction of negative mood, positive reappraisal or problem solving were generally associated with less psychological distress, fewer depression and anxiety symptoms (Brandão et al., 2017), higher quality of life, health and relationship satisfaction (Papp and Witt, 2010; Kvillemo and Bränström, 2014; Brandão et al., 2017). However, negative individual strategies like avoidance, denial, or resignation were related to higher psychological distress (Brandão et al., 2017). Dyadic coping strategies like open communication, positive and common dyadic coping were associated with improved relationship functioning and satisfaction, facilitation of couples' intimacy, higher relationship quality, and fewer depression symptoms (Papp and Witt, 2010; Regan et al., 2014; Rottmann et al., 2015; Traa et al., 2015; Pankrath et al., 2018; Meier et al., 2019; Lupinacci et al., 2021; Ştefănuţ et al., 2021). In contrast to the positive effects, higher use of negative coping forms (e.g., avoidant coping), higher level of interference in regular activities, and perception of dyadic support behavior were associated with depression and anxiety in oneself (Lambert et al., 2013; Regan et al., 2014; Rottmann et al., 2015; Bodschwinna et al., 2021). Social support like support from friends, family, or colleagues usually has a buffering effect on depression, anxiety, and distress (Hasson-Ohayon et al., 2010; Fong et al., 2017; Lotfi-Jam et al., 2019; Bodschwinna et al., 2021), with the limitation that this may only be true if the support is wanted (Vodermaier and Linden, 2019). Regarding professional support, interventions appear to be beneficial for patients, spouses and couples and future direction points toward online interventions (Badr and Krebs, 2013; Badr et al., 2019; Luo et al., 2020).

A recent study supports the assumption that different coping strategies occur simultaneously and are used depending on availability (Paschali et al., 2021). This is in line with Bodenmann's supplement of his sequential stress-coping-cascade model, which suggests that in continuous and cumulative stress situations people draw on different support simultaneously (Bodenmann, 1995, 2005). Furthermore, as individual and dyadic coping strategies are highly associated with each other (Papp and Witt, 2010; Paschali et al., 2021) it might be that combining specific forms of both strategies facilitate adaptation to cancer.

Despite the extensive quantitative research about coping with cancer, there have been fewer qualitative studies in this area. A recent interview study with hematological cancer patients and their family caregivers reported coping strategies like hiding emotions, thoughts and needs, a stronger dyadic relationship than in the past and changed roles within the dyad (Serçe and Günüşen, 2021). A systematic review of qualitative studies of men with prostate cancer identified coping strategies such as avoidance, employing positive focus, support seeking, retain pre-illness lifestyle and symptom management (Spendelow et al., 2018). However, less is known about the specific way in which different categories of coping strategies and support from outside of the couple are used by patients and their spouses as well as about the frequency with which they are used by each.

With the present interview study, we aim to explore how couples, in which one person is diagnosed with hematological cancer, cope individually and together with the disease and what coping and support strategies they use. Furthermore, we want to identify possible differences in coping behavior between the patient and partner. The deeper insights into specific types of coping and support strategies could improve the development of more detailed and tailored intervention programs for patients and their spouses suffering from cancer.

MATERIALS AND METHODS

Data of this qualitative study were collected as part of the project 'Dyadic coping in hematological patients over time' funded by the Deutsche José Carreras Leukämie-Stiftung between 2012 and 2015 (grant: DJCLS R 12/36). The corresponding multi-center longitudinal study examined a total of 330 couples at baseline and 217 couples at 6-month follow-up regarding their dyadic coping. Associations of dyadic coping with quality of life, relationship satisfaction, supportive care needs and psychological distress were investigated (Ernst et al., 2017; Weißflog et al., 2017; Pankrath et al., 2018; Bodschwinna et al., 2021). Since dyadic coping was a central aspect of the study, additional couple interviews were conducted to gain a deeper insight into the couples' coping and support network. Ethics approval was obtained from the Ethics Committees of the Medical Faculty of the University of Leipzig (No. 298-12-24092012) and the University of Ulm (No. 243/12) and carried out in accordance with the Declaration of Helsinki.

Participants and Procedures

Eligibility was based on the following criteria: Being a patient with hematologic cancer, living in partnership, age between 18 and 75 years, proficient in German. Both patients and partners were required to provide written informed consent prior to enrolment. The selection of couples for the interviews was made from a subsample of 100 couples early in the study process, who already finished the longitudinal survey. In order to reach a heterogeneous sample of couples with respect to age, gender, duration of relationship, type of hematological disease and total score of dyadic coping the maximum variation method was used (Moser and Korstjens, 2018). All couples were already made aware during participation in the longitudinal study that an interview request could be made afterward. Eligible couples for the interviews were contacted and informed about the procedure of the study via phone call and were invited to the clinic to a suitable appointment. In order to overcome challenging recruitment of couples (participation agreement of both), an expense allowance of 20€ per couple was provided. However, this did not significantly increase the willingness to participate.

Data Collection

At baseline assessment of the longitudinal study sociodemographic information including sex, age, employment, education, marital status, living together, duration of relationship and medical information including diagnosis, disease type, disease status, and time since diagnosis were collected via paper–pencil questionnaire. In addition, dyadic coping was assessed with the Dyadic Coping Inventory (DCI) (Bodenmann, 2008). With 37 items, different aspects of dyadic coping are recorded and an overall sum score (range: 35–175) can be calculated. A higher score reflects more reported dyadic coping.

We conducted semi structured face-to-face couple interviews by one interviewer each (GW and DL) in Leipzig and Ulm between May 2014 and April 2015. The interviews were performed using a guideline prepared by the study team. The guideline consists of three thematic areas with open-ended questions: introductory question about the disease and its course, a question about how the couple talks about cancer and questions about what kind of support and coping is experienced within and outside the couple. The interview aimed to go beyond standardized questionnaires to gain a deeper insight into the couples' coping system. A dyadic interview setting was used allowing participants to respond directly to each other's statements, leading to more dynamism and more relevance to everyday life during the interviews (Froschauer and Lueger, 2003). The interviews were conducted in an undisturbed atmosphere, mostly in a clinic office and once in the couple's home. All interviews were audio recorded, transcribed verbatim according to the predefined transcription rules and anonymized (Dresing et al., 2015).

Data Analyses

Sociodemographic and medical information were reported with basic descriptive statistics using IBM SPSS Statistics 26. Total score of dyadic coping was calculated using sum score of all items of the DCI (Bodenmann, 2008). The transcripts of the interviews were analyzed using MAXQDA version 2020. The structuring qualitative content analysis by Kuckartz (2018) was applied. First step of this analysis process included the initial work with the interviews, where important text passages were highlighted. Within the second step, main categories were developed deductively according to the basic theory. The third step included a first coding of all interviews using the main categories. In the fourth step all these passages were compiled per main category. Based on these collected text passages, subcategories were inductively formed in the fifth step. Since the subcategories of dyadic coping and outside support already exist theoretically, their configuration was not purely inductive. The remaining subcategories were formed inductively on basis of the interviews conducted. All these subcategories could be confirmed by the interviews. The resulting category system was discussed within the research team, adjusted twice through back-and-forth comparison with literature and interview content. Afterward an associated coding guide was developed with definitions, anchor examples of each subcategory and coding rules. The sixth step included coding of the entire material with this category system. Within the seventh and last step each subcategory was analyzed thematically and presented in summary (Kuckartz, 2018). The coding steps three and six were conducted by two researchers (DB and UG) independently. Inconsistent coding decisions were discussed by the coders to reach consensus. Interrater agreement was calculated with Kappa according to Brennan and Prediger (1981) and amounts $\kappa_n = 0.77$.

RESULTS

Sample Characteristics

Of 35 couples approached, 25 couples (71.4%) declined to participate, either by both partners or by one partner. The final sample comprised 10 heterosexual couples (seven male and three female patients). Since no substantial new information was obtained after the 10 interviews, data saturation could reasonably be assumed and re-recruitment was declined. The mean age in patients was 57.0 years (SD = 16.09, range = 22–75) and in partners 54.3 years (SD = 17.68, range = 22–74). The duration of relationship ranged between 2 and 52 years. Five patients had acute leukemia, three had non-Hodgkin lymphoma, and one each had multiple myeloma and chronic leukemia. The majority of patients were either in full remission ($N = 5$) or partial remission ($N = 2$) and time since diagnosis was less than 2 years for seven patients. The interviews lasted between 47 and 116 min. Sociodemographic and medical characteristics are given in **Table 1**. Structuring content analysis resulted into three main

TABLE 1 | Patient and spouse characteristics.

Characteristics		Patient		Spouse
		N		*N*
Sex	Male	7		3
	Female	3		7
Age mean (SD, range)		57.0 (16.1, 22–75)		54.3 (17.7, 22–74)
Employment	Pension/early retirement	7		4
	Employed	2		5
	Unemployed	1		1
Education	<10 years	2		1
	10 years	3		6
	>10 years (High school)	5		3
Total dyadic coping mean (SD, range)		131.8 (20.3, 89–155)		127.5 (15.1, 108–152)
			Couples	
			N	
Marital status	Married		8	
	Not married		2	
Living together	In same household		9	
	In separate households		1	
Duration of relationship – years, mean (SD, range)			24.4 (21.6, 2–52)	
		Patient		
		N		
Diagnosis	Acute leukemia	5		
	Chronic leukemia	1		
	Non-Hodgkin	3		
	Multiple myeloma	1		
Disease type	Initial diagnosis	8		
	Relapse	2		
Disease status	Full remission	5		
	Partial remission	2		
	Not assessable	3		
Time since diagnosis	≤2 years	7		
	3–5 years	2		
	>5 years	1		

categories: individual coping, dyadic coping, and outside support, each with several associated subcategories. **Table 2** shows the identified categories as well as the proportions of coping and support strategies used by patient and the spouse.

Individual Coping

Emotional Focused Strategies

Patients reported a variety of activities they undertook to improve their emotional wellbeing and relieve their stress, such as exercise, walking, reading books, playing games, watching movies, writing, practice rituals, meditation and relaxation techniques. In addition, some enjoyed trivia like trying to keep one's sense of humor or enjoyed motivational sayings. Acceptance of the disease and its consequences was perceived to promote serenity thus fostering calmness and relaxation. The spouses reported overall fewer strategies for improving their wellbeing. They also done some exercise, but indicated more emotional strategies such as rumination, distraction, crying or feelings of anger and helplessness while staying home alone during the hospitalization period of the patient.

Problem Focused Strategies

Among patients, problem focused strategies were characterized by seeking information about treatment and medicine and engaging in health-promoting activities. Moreover, prioritizing by importance to focus on what is most essential and being realistic overall were also mentioned as problem focused strategies. In contrast, some also wanted to cope with problem avoidance through suppression and downplaying. Some spouses

TABLE 2 | Patients' and spouses' quotes and frequency of categories identified.

Categories and subcategories	Number of interviews (*n* = 10)	Number of total text passages (*n* = 520)	Patients' text passages (*n* = 272)	Spouses' text passages (*n* = 248)	Representative quotes
Individual coping					
Emotional focused	10	79	56 (70.9%)	23 (29.1%)	"You have to do something. I can't sit around somewhere and lie and think about it and do nothing. I can't do that. So, I have to get out as much as I can. Even into the woods or whatever. I did wood, I did the horses. Everything I could do, I did. I did the garden, I planted hedges. So just those things." [P7]
Problem focused	10	72	44 (61.1%)	28 (38.9%)	"But I think I have started making lists right from the day of diagnosis: I have to resolve all this, and I have to do all this." [S3]
Positive reframing	9	60	31 (51.7%)	29 (48.3%)	"And the confidence that I have always shown. Just the diagnosis didn't cause hysteria in me, in any way. So, I'm not jumpy around and now I have to make a will and this and that. Nothing like that. It was simply: We can do it together! [. . .] That is a danger, but not the end. And that's actually what kept us going" [P9]
Dyadic coping					
Stress communication	8	40	30 (75.0%)	10 (25.0%)	"We have actually addressed everything, as said whether positive or negative." [P4] "Yes, we actually talked through all facets of the disease in our minds. Always together. As hard as it may be." [S4]
Supportive dyadic coping	9	41	7 (17.1%)	34 (82.9%)	"So, I was there every day. I went to work, then I went home and organized everything, cooked him something and then stayed as long as I could." [S1]
Delegated dyadic coping	7	16	0	16 (100%)	"I then took over that at home. Washing clothes, cleaning, and shopping and so on." [S6]
Negative dyadic coping	4	10	4 (40.0%)	6 (60.0%)	"So, he meant many things well. But I have also felt under pressure from time to time. And he didn't realize that. Because he had such stress and then he said: 'Do this, do that.' And it always had to be done immediately." [P10]
Common dyadic coping	10	110	38 (34.5%)	72 (65.5%)	"Of course, I would say that we got through it quite well and stuck together." [S3] -*cohesion* "It was important to me that everything is done at home as we are used to it, in this case. There was a bit of a handicap, but we have actually maintained the daily routine." [P9] – *return to normality* "But you should also turn to new things every now and then. We try to practice that now always?" [P6] – *new goals*
Outside support					
Social Support	10	50	42 (84.0%)	8 (16.0%)	"They [family and friends] can't help you either, but they can give you moral support. And they have supported. They came then. They always asked when we could visit [the patient] and they did, even if it was only for 10 min but at least they visited [the patient]." [S6]
Professional support	8	42	20 (47.6%)	22 (52.4%)	"But I'm glad when I have my doctor. Someone who understands me. Someone who says, yes, you have a hard time at the moment, but you can do it and you'll get out of it." [P5]

S = Spouse, P = Patient.

also searched for information, created lists for their tasks, planed the way back into everyday life, set boundaries and reduced extra work to have more time for themselves and the patient.

Positive Reframing

In all couples except one, patients and spouses reported different kinds of positive attitude and positive reframing. Positive reframing showed itself in hope and confidence, encouraging yourself, a new courage to live in patients and gratitude even for small advances. A wide variety of plans for the future reflected an optimistic outlook, both among patients and spouses.

Dyadic Coping

Stress Communication

While at the beginning of the disease there was a daily exchange about the disease and treatment, over time the disease fades into the background in communication. Some couples described an open communication, where they talked about everything, all facets of the disease, both positive and negative. Most of the stress communication, including fear and frustration, came from the patient, who reported that it is relaxing to have someone to communicate with. Spouses, on the other hand, who are often the first point of contact for any problems, reported that the patient's stress communication is very exhausting, but often this was the only way for the patient to relieve stress.

Supportive Dyadic Coping

Most supportive dyadic coping was provided by the spouses. One major part of this was simply being there for the patient including almost daily visits in hospital. Other spousal support includes instrumental, emotional and informational support, such as driving to appointments, physical closeness, providing distraction and encouragement, and gathering information about the disease and related issues. Not being alone and the presence of someone who is interested in the patients' sensitivities was perceived as very important by the patients, and for the spouses the feeling of being able to do something was also important. For their part, the patients were also concerned about their spouses and tried to support them again more over time.

Delegated Dyadic Coping

Only spouses reported temporarily taking over of certain tasks to relieve the patient's burden. This comprised instrumental support such as daily household tasks, childcare and organization of paperwork associated with the disease and sick leave, but also continuing of patients' leisure activities until they can take them over again. In addition, the spouses provided informational support by obtaining information from physicians or internet research. Patients appreciated this support as extremely helpful. One spouse reported the fear of being seen only as a caregiver and no longer as an equal partner.

Negative Dyadic Coping

Both patients and spouses indicated types of negative dyadic coping. Two patients reported individual situations in which the spouse does not take seriously their stress and alternative coping attempts. Moreover, some advice from spouses were perceived as triggering pressure by patients. Similarly, spouses reported conflict and feeling rejected when some of their support efforts were described as exaggerated and unhelpful by the patients. Mentioned examples of mutual negative dyadic coping were wordy disputes and not considering the other's point of view.

Common Dyadic Coping

Across couples, common dyadic coping was most frequently mentioned. Patients and spouses described multiple topics within common dyadic coping. The cohesion in the partnership, getting through the illness together and being there for each other were reported by all couples. These actions are associated with the deeper feeling of "we" and the strengthening of relationship. Some couples share that they show understanding of each other's feelings and regulate intense emotions together. There was also joint problem solving and joint decision-making regarding treatment and related areas (e.g., joint meal changes). Additionally, couples demarcate themselves together by taking distance from negative things and people or by relinquishing burdensome as well as time-consuming things. Moreover, while some couples reported that they try to live a normal everyday life again after the disease moved into the background, other couples used it as opportunity for new joint ventures, hobbies, and interests.

Outside Support

Social Support

Family and friends provided emotional support through visits and contact via telephone. They inquired about the patient's condition, while the partner tended to take a back seat. Partly the contact decreased over time, especially when they were afraid to talk about the disease. Exchange with other patients from the circle of friends was more open-minded and intensive. Family and friends also provided helpful instrumental support and friends with medical background helped with information and explanations. However, patients also felt pressured by some recommendations from friends. Various joint activities and spending time with friends and family provided joy and distraction for the couple. Only one spouse reported that a relative directly took care about the spouses' condition and advised a break. Another important factor was the support from the boss, who allowed to vary the working hours for the spouse to get more flexibility.

Professional Support

Both patients and spouses used professional offers for support services. Spouses emphasized the importance of supervision by a psychotherapist and the exchange with this neutral person. Patients perceived the assistance from social workers in making applications and referrals to other services as very helpful. Understanding and moral support from friendly, patient, and well-trained physicians and nurses, who treated the patient as a human being, was also reported by patients. Overall, many would recommend psychological support, especially for the partner. The wish for more proactive offers from the clinical side was expressed.

DISCUSSION

Coping and support strategies are key factors in improving wellbeing and adjustment in couples facing cancer. The purpose of this qualitative study was to go beyond quantitative data from prior questionnaire studies and to gain deeper insight into the specific strategies that are summarized in the theoretical categories. Compared to our previous quantitative studies (Ernst et al., 2017; Weißflog et al., 2017; Bodschwinna et al., 2021), we were able to confirm the main coping and support categories, as well as show similarities in the distribution of coping and support proportions between patient and partner. In addition, with the deeper insight new distinctions within these categories could be identified as well as the extensive scope of some categories. To our knowledge, this is the first study considering different coping and support strategies in cancer patients and their spouses using a dyadic interview setting.

Not only the frequency of individual coping strategies reported within a subcategory but also the type of strategy differed between patients and spouses. Regarding emotional strategies, patients focused on a variety of activities improving emotional wellbeing, while spouses reported more unfavorably strategies such as rumination or distraction. This is in line with previous research indicating that spouses commonly neglect their own need regarding wellbeing and are always with the patient in thought (Heynsbergh et al., 2019). Differences in problem focused strategies may be explained by role: patients reported more strategies which are directly associated with the diagnosis, while spouses focused more on tasks around and duties to path the way back to everyday life. The realistic approach of patients to the disease has already been reported as a strategy for advanced cancer patients (Walshe et al., 2017). The high level of positive reframing and future plans reported in both patients and spouses may be due to the fact that the majority of patients were in remission and therefore in a positive mood overall. On the other hand, this high level of positivity could be also due to patients' misunderstanding of their prognosis, which seems to be very common in palliative patients (Jacobsen et al., 2013). Positive reframing in our study was also expressed through gratitude and enjoyment of little things, which is a way of living in the now that has also proven important for patients with advanced cancer (Cottingham et al., 2018).

Open communication is essential for couples coping with cancer (Goldsmith and Miller, 2014; Li et al., 2018), but due to individual differences in couples, research should avoid the general and abstract concept of openness and move on to more differentiated descriptions (Goldsmith and Miller, 2014). As in previous dyadic studies, we found that communication within the dyad can change over cancer trajectory (Siminoff et al., 2020). Communicating stress in particular is positively related to better relationship quality, facilitates couples' intimacy and reduced distress (Badr et al., 2018; Lupinacci et al., 2021; Ştefănuţ et al., 2021). The relaxing effect of stress communication was also reported by patients in our study, while some spouses complained about how burdensome patients' stress communication was for them. To address these differences, couple-based interventions should change the generic notion of open communication into more individual approaches (Badr, 2017).

Because of the role-effect it is not surprising, that spouses provided more supportive dyadic coping than patients (Kroemeke et al., 2019). Spousal support was especially strong in the post-diagnosis period and during hospitalization (Antoine et al., 2013), while patients tried to reestablish support after recovery and return home (Kroemeke et al., 2019). Being there for the patient was a salient issue for the couple, helping both not to feel alone. Besides supportive behavior, spouses also took over tasks completely when the patients were unable to do so (Palmer Kelly et al., 2019). Thus, spouses may also worry about being perceived as caregivers only which may turn the relationship out of balance (Serçe and Günüşen, 2021).

The overall less reported negative dyadic coping may likely be due to a selection bias given that well-functioning couples might have been more willing to be interviewed. The fact that the interview was conducted jointly with both partners might additionally have reduced the chance to observe negative dyadic coping. Apart from this reasoning well-intentioned support from spouses can also cause negative acknowledgment from patients, if support does not match patient's needs (Palmer Kelly et al., 2019).

Within common dyadic coping, which was the most frequent coping strategy in our sample, cohesion in relationship was important in all couples and manifested in various manner. In addition to joint activities, it also seems to be essential to jointly distance oneself from negative and stressful things. Through all these experiences, couples achieve mutual growth, more intimacy and improvement in their relationship (Beattie and Lebel, 2011; Hasson-Ohayon et al., 2016; Lupinacci et al., 2021; Serçe and Günüşen, 2021). In addition, the couples could be divided into two groups: those who wanted to return to normality of the everyday life (Antoine et al., 2013) and those who wanted to discover new things together. This distinction in different future plans was also partially reflected in the individual coping strategies.

Like in our previous quantitative study as well as in other studies, spouses in the present sample reported less direct social support from friends and family compared with patients (Hasson-Ohayon et al., 2010; Bodschwinna et al., 2021). Nevertheless, instrumental social support for the patient can also be indirectly relieving for the spouse. Support from friends and family is perceived as helpful by most patients, while some recommendations cause patients to feel pressure. Therefore, it seems that social support should also meet the expectations or needs of patients in order to be beneficial (Reynolds and Perrin, 2004; Vodermaier and Linden, 2019). Over time social networks changed and received social support decreased for some of the participants, which can be due to burnout of support providers or because patients no longer needed outside support (Arora et al., 2007; Palmer Kelly et al., 2019).

Professional support is widely used in couples. Spouses in our sample were more likely to go to psychotherapist, while patients reported more instrumental help from social workers. More proactive support offers in general and psychological support for the spouses were desired, as perception of available support is low (Li et al., 2018; Heynsbergh et al., 2019).

STUDY STRENGTH AND LIMITATIONS

The combination of deductive and inductive categorization strategies is clearly the strength of the present qualitative study. This approach is well in line with previous research and theories, and additionally allows for more flexibility in identifying additional subcategories. Furthermore, the dyadic interview setting has the advantage to explore coping and support strategies of the couple with both partners together, since they also concern both of them. Some limitations of the study should be considered. Given that both partners had to agree to participate, there may be a selection bias in the sample toward couples who are in highly functional relationships and tend to communicate more openly. Furthermore, the high dropout rate is to be considered as a limitation. The reasons for this probably lie in the logistical challenge for the couples to appear together for an on-site appointment. Due to the large catchment area of the clinics, long distances often also had to be covered. Another limitation is, that the assumption of theoretical data saturation after 10 interviews did not follow the typical process. Initially, an unexpected high percentage of the couples approached declined to participate. Only subsequently re-recruitment was declined, as a review of the processed interviews revealed that no significant new information had been added in the most recent interviews. The ineffectiveness of the expense allowance may be due to the fact that a financial incentive is not a consideration for couples facing life-threatening cancer. Conducting the interview together may also have resulted in social desirability influencing the two partners' communication. While an effort was made to include heterogenous couples, some important variables were not considered. Therefore, our sample consisted mainly of patients in remission and the currently attenuated symptoms could account for the low proportion of negative coping strategies reported. Furthermore, generalization of our findings to other cancer types is not applicable, as this study was conducted only with hematological cancer patients and their partners.

CLINICAL IMPLICATION

Couples facing cancer use a variety of different coping and support strategies. In this context, patients and spouses differ in some of their used strategies and received support. Clinicians should keep track of the strategies used, intervene when they prove not to be useful, and recommend tailored improvement of the strategies. First, open communication should not be generally recommended, as stress communication has been shown to be both beneficial and burdensome (Badr, 2017). Furthermore, it should be highlighted, that we could identify two different types of future plans in couples: returning to normality and reaching out for new goals. These new insights could serve as a new direction for couple interventions by adding tools that help realizing the couples' individual plan for the future. Tailored support in couple-based online interventions could be a suitable implementation for this purpose (Luo et al., 2020). In addition, health care system should provide more proactive offers for psychosocial support for spouses, as their suffering still seems to be rather neglected. Emotional coping, in particular, should be improved in spouses, as they used very few strategies to relax and to improve their own wellbeing. Especially during the patients' hospitalization, clinicians should observe spouses' condition and recommend appropriate support services.

CONCLUSION

We identified various coping and support strategies regarding individual coping, dyadic coping, and outside support. Most of them were perceived as beneficial, but some triggered pressure. With qualitative research we were able to get a more detailed and deeper insight into the different strategies. For example, common dyadic coping showed various facets that a representation with a numerical value could not do justice to. We were also able to identify some differences in patient and spouse strategies that should be considered in couple intervention development. Further research in the area of coping and support strategies could gain even deeper insights by examining real-time interactions between patients and spouses (Lau et al., 2019).

DATA AVAILABILITY STATEMENT

Data are only available from the corresponding author on request, because of privacy or ethical restrictions.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committees of the Medical Faculty of the University of Leipzig (No. 298-12-24092012) and the University of Ulm (No. 243/12). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JE, GW, KH, and HG were responsible for funding and design of the study. AM-T, DN, and HD supervised design and conduction of the study in terms of psychological or hematological expertise. GW, JE, KH, and DB were responsible for recruiting participating couples and conducting the interviews. DB was responsible for the evaluation method and the development of the code system, performed the first coding of the interviews, supervised and contributed to the qualitative data analysis and interpretation, performed the quantitative analysis, and drafted the manuscript. UG was responsible for second coding of the interviews. All authors have read the manuscript critically and approved the final manuscript.

FUNDING

The study was funded by the Deutsche José Carreras Leukämie-Stiftung (grant no. DJCLS R 12/36).

ACKNOWLEDGMENTS

We thank Dirk Lang for conducting the interviews in Ulm and Tim Poessnecker for his support in qualitative research methods. We also would like to thank all the couples who participated in the interview study.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.855638/full#supplementary-material

REFERENCES

Antoine, P., Vanlemmens, L., Fournier, E., Trocmé, M., and Christophe, V. (2013). Young couples' experiences of breast cancer during hormone therapy: an interpretative phenomenological dyadic analysis. *Cancer Nurs.* 36, 213–220. doi: 10.1097/NCC.0b013e31826429a5

Arora, N. K., Finney Rutten, L. J., Gustafson, D. H., Moser, R., and Hawkins, R. P. (2007). Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psychooncology* 16, 474–486. doi: 10.1002/pon.1084

Badr, H. (2017). New frontiers in couple-based interventions in cancer care: refining the prescription for spousal communication. *Acta Oncol. (Madr).* 56, 139–145. doi: 10.1080/0284186X.2016.1266079

Badr, H., Bakhshaie, J., and Chhabria, K. (2019). Dyadic interventions for cancer survivors and caregivers: state of the science and new directions. *Semin. Oncol. Nurs.* 35, 337–341. doi: 10.1016/j.soncn.2019.06.004

Badr, H., Herbert, K., Bonnen, M. D., Asper, J. A., and Wagner, T. (2018). Dyadic coping in patients undergoing radiotherapy for head and neck cancer and their spouses. *Front. Psychol.* 9:1780. doi: 10.3389/fpsyg.2018.01780

Badr, H., and Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psychooncology* 22, 1688–1704. doi: 10.1002/pon.3200

Beattie, S., and Lebel, S. (2011). The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review. *Psychooncology* 20, 1137–1150. doi: 10.1002/pon.1962

Bishop, M. M., Beaumont, J. L., Hahn, E. A., Cella, D., Andrykowski, M. A., Brady, M. J., et al. (2007). Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *J. Clin. Oncol.* 25, 1403–1411. doi: 10.1200/JCO.2006.07.5705

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping in couples. *Swiss J. Psychol.* 54, 34–49. doi: 10.1016/j.cpr.2008.10.004

Bodenmann, G. (2005). "Dyadic coping and its significance for marital functioning," in *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping*, eds T. A. Revenson, K. Kayser, and G. Bodenmann (Washington, DC: American Psychological Association). 33–49. doi: 10.1080/10615806.2021.1912740

Bodenmann, G. (2008). *Dyadisches Coping Inventar: DCI Testmanual [Dyadic Coping Inventory: DCI test manual]*. Bern: Huber.

Bodschwinna, D., Ernst, J., Mehnert-Theuerkauf, A., Gündel, H., Weissflog, G., and Hönig, K. (2021). Dyadic coping and social support: various types of support in hematooncological patients and their spouses—associations with psychological distress. *Psychooncology* 30, 1041–1050. doi: 10.1002/pon.5631

Brandão, T., Schulz, M. S., and Matos, P. M. (2017). Psychological adjustment after breast cancer: a systematic review of longitudinal studies. *Psychooncology* 26, 917–926. doi: 10.1002/pon.4230

Brennan, R. L., and Prediger, D. J. (1981). Coefficient kappa: some uses, misuses, and alternatives. *Educ. Psychol. Meas.* 41, 687–699. doi: 10.1177/001316448104100307

Cottingham, A. H., Cripe, L. D., Rand, K. L., and Frankel, R. M. (2018). "My future is now": a qualitative study of persons living with advanced cancer. *Am. J. Hosp. Palliat. Med.* 35, 640–646. doi: 10.1177/1049909117734826

Dresing, T., Pehl, T., and Schmieder, C. (2015). Manual (on) Transcription - Handbook Interview, Transcription & Analysis: Instructions and Regulatory Systems for Qualitative Researchers. Audiotranskription.de. 92. Available online at: https://www.audiotranskription.de/wp-content/uploads/2020/11/manual-on-transcription.pdf (accessed February 28, 2022).

Ernst, J., Hinz, A., Niederwieser, D., Döhner, H., Hönig, K., Vogelhuber, M., et al. (2017). Dyadic coping of patients with hematologic malignancies and their partners and its relation to quality of life – a longitudinal study. *Leuk. Lymphoma* 58, 655–665. doi: 10.1080/10428194.2016.1194983

Fong, A. J., Scarapicchia, T. M. F., McDonough, M. H., Wrosch, C., and Sabiston, C. M. (2017). Changes in social support predict emotional well-being in breast cancer survivors. *Psychooncology* 26, 664–671. doi: 10.1002/pon.4064

Froschauer, U., and Lueger, M. (2003). *Das Qualitative Interview: Zur Praxis Interpretativer Analyse Sozialer Systeme [The Qualitative Interview: On the Practice of Interpretative Analysis of Social Systems]*. Wien: Facultas wuv utb.

Goldsmith, D. J., and Miller, G. A. (2014). Conceptualizing how couples talk about cancer. *Health Commun.* 29, 51–63. doi: 10.1080/10410236.2012.717215

Hasson-Ohayon, I., Goldzweig, G., Braun, M., and Galinsky, D. (2010). Women with advanced breast cancer and their spouses: diversity of support and psychological distress. *Psychooncology* 19, 1195–1204. doi: 10.1002/pon.1678

Hasson-Ohayon, I., Tuval-Mashiach, R., Goldzweig, G., Levi, R., Pizem, N., and Kaufman, B. (2016). The need for friendships and information: dimensions of social support and posttraumatic growth among women with breast cancer. *Palliat. Support. Care* 14, 387–392. doi: 10.1017/S1478951515001042

Heynsbergh, N., Botti, M., Heckel, L., and Livingston, P. M. (2019). Caring for the person with cancer and the role of digital technology in supporting carers. *Support. Care Cancer* 27, 2203–2209. doi: 10.1007/s00520-018-4503-8

Jacobsen, J., Thomas, J. D., and Jackson, V. A. (2013). Misunderstandings about prognosis: an approach for palliative care consultants when the patient does not seem to understand what was said. *J. Palliat. Med.* 16, 91–95. doi: 10.1089/jpm.2012.0142

Kroemeke, A., Knoll, N., and Sobczyk-Kruszelnicka, M. (2019). Dyadic support and affect in patient-caregiver dyads following hematopoietic stem-cell transplantation: a diary study. *J. Consult. Clin. Psychol.* 87, 541–550. doi: 10.1037/ccp0000398

Kuba, K., Esser, P., Mehnert, A., Hinz, A., and Johansen, C. (2019). Risk for depression and anxiety in long-term survivors of hematologic cancer. *Heal. Psychol.* 38, 187–195. doi: 10.1037/hea0000713.supp

Kuckartz, U. (2018). *Qualitative Inhaltsanalyse. Methoden, Praxis, Computerunterstützung [Qualitative Content Analysis. Methods, Practice, Computer Tools]*, 4th Edn. Weinheim, Basel: Beltz Juventa.

Kvillemo, P., and Bränström, R. (2014). Coping with breast cancer: a meta-analysis. *PLoS One* 9:e112733. doi: 10.1371/journal.pone.0112733

Lambert, S. D., Girgis, A., Lecathelinais, C., and Stacey, F. (2013). Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support. Care Cancer* 21, 75–85. doi: 10.1007/s00520-012-1495-7

Lau, K. K. H., Randall, A. K., Duran, N. D., and Tao, C. (2019). Examining the effects of couples' real-time stress and coping processes on interaction quality: language use as a mediator. *Front. Psychol.* 9:2598. doi: 10.3389/fpsyg.2018.02598

Lazarus, R. S., and Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.

Li, Q., Lin, Y., Chen, Y., and Loke, A. Y. (2018). Mutual support and challenges among chinese couples living with colorectal cancer: a qualitative study. *Cancer Nurs.* 41, E50–E60. doi: 10.1097/NCC.0000000000000553

Lotfi-Jam, K., Gough, K., Schofield, P., Aranda, S., and Jefford, M. (2019). A longitudinal study of four unique trajectories of psychological distress in cancer survivors after completing potentially curative treatment. *Acta Oncol. (Madr).* 58, 782–789. doi: 10.1080/0284186X.2018.1562209

Luo, X., Gao, L., Li, J., Lin, Y., Zhao, J., and Li, Q. (2020). A critical literature review of dyadic web-based interventions to support cancer patients and their caregivers, and directions for future research. *Psychooncology* 29, 38–48. doi: 10.1002/pon.5278

Lupinacci, L., Lamore, K., Seyeux, A. L., and Untas, A. (2021). Facilitators and obstacles to couples' intimacy after hematopoietic stem cell transplantation: a qualitative study. *J. Psychosoc. Oncol.* 6, 1–19. doi: 10.1080/07347332.2021.2004292

Meier, F., Cairo Notari, S., Bodenmann, G., Revenson, T. A., and Favez, N. (2019). We are in this together — aren't we? Congruence of common dyadic coping and psychological distress of couples facing breast cancer. *Psychooncology* 28, 2374–2381. doi: 10.1002/pon.5238

Moser, A., and Korstjens, I. (2018). Series: practical guidance to qualitative research. part 3: sampling, data collection and analysis. *Eur. J. Gen. Pract.* 24, 9–18. doi: 10.1080/13814788.2017.1375091

Palmer Kelly, E., Meara, A., Hyer, M., Payne, N., and Pawlik, T. M. (2019). Understanding the type of support offered within the caregiver, family, and spiritual/religious contexts of cancer patients. *J. Pain Symptom Manag.* 58, 56–64. doi: 10.1016/j.jpainsymman.2019.03.003

Pankrath, A. L., Weißflog, G., Mehnert, A., Niederwieser, D., Döhner, H., Hönig, K., et al. (2018). The relation between dyadic coping and relationship satisfaction in couples dealing with haematological cancer. *Eur. J. Cancer Care (Engl).* 27, 1–11. doi: 10.1111/ecc.12595

Papp, L. M., and Witt, N. L. (2010). Romatnic partners' individual coping strategies and dyadic coping: implications for relationship functioning. *J. Fam. Psychol.* 24, 551–559. doi: 10.1037/a0020836.Romantic

Paschali, A., Palli, A., Thomadakis, C., and Karademas, E. C. (2021). The interplay between individual and dyadic/common coping in female patients with cancer. *Eur. J. Psychol. Open* 80, 143–151. doi: 10.1024/2673-8627/a000012

Raphael, D., Frey, R., and Gott, M. (2020). Distress in post-treatment hematological cancer survivors: prevalence and predictors. *J. Psychosoc. Oncol.* 38, 328–342. doi: 10.1080/07347332.2019.1679320

Regan, T. W., Lambert, S. D., Kelly, B., McElduff, P., Girgis, A., Kayser, K., et al. (2014). Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. *Patient Educ. Couns.* 96, 120–127. doi: 10.1016/j.pec.2014.04.010

Reynolds, J. S., and Perrin, N. A. (2004). Mismatches in social support and psychosocial adjustment to breast cancer. *Heal. Psychol.* 23, 425–430. doi: 10.1037/0278-6133.23.4.425

Robert Koch Institute & Association of Population-Based Cancer Registries in Germany. (2021). *Krebs in Deutschland für 2017/2018.* Berlin. Available online at: https://www.krebsdaten.de/Krebs/DE/Content/Publikationen/Krebs_in_Deutschland/krebs_in_deutschland_node.html (accessed December 9, 2021)

Rottmann, N., Hansen, D. G., Larsen, P. V., Nicolaisen, A., Flyger, H., Johansen, C., et al. (2015). Dyadic coping within couples dealing with breast cancer: a longitudinal, population-based study. *Heal. Psychol.* 34, 486–495. doi: 10.1037/hea0000218

Serçe, Ö., and Günüşen, N. P. (2021). The interaction between hematological cancer patients and family caregivers and their life changes: a qualitative dyadic approach. *Cancer Nurs.* 44, E201–E208. doi: 10.1097/NCC.0000000000000800

Siminoff, L. A., Wilson-Genderson, M., Barta, S., and Thomson, M. D. (2020). Hematological cancer patient-caregiver dyadic communication: a longitudinal examination of cancer communication concordance. *Psychooncology* 29, 1571–1578. doi: 10.1002/pon.5458

Spendelow, J. S., Eli Joubert, H., Lee, H., and Fairhurst, B. R. (2018). Coping and adjustment in men with prostate cancer: a systematic review of qualitative studies. *J. Cancer Surviv.* 12, 155–168. doi: 10.1007/s11764-017-0654-8

Ştefănuţ, A. M., Vintilă, M., and Tudorel, O. I. (2021). The Relationship of dyadic coping with emotional functioning and quality of the relationship in couples facing cancer—a meta-analysis. *Front. Psychol.* 11:594015. doi: 10.3389/fpsyg.2020.594015

Traa, M. J., De Vries, J., Bodenmann, G., and Den Oudsten, B. L. (2015). Dyadic coping and relationship functioning in couples coping with cancer: a systematic review. *Br. J. Health Psychol.* 20, 85–114. doi: 10.1111/bjhp.12094

Vodermaier, A., and Linden, W. (2019). Social support buffers against anxiety and depressive symptoms in patients with cancer only if support is wanted: a large sample replication. *Support. Care Cancer* 27, 2345–2347. doi: 10.1007/s00520-019-04737-w

Walshe, C., Roberts, D., Appleton, L., Calman, L., Large, P., Lloyd-Williams, M., et al. (2017). Coping well with advanced cancer: a serial qualitative interview study with patients and family carers. *PLoS One* 12:e0169071. doi: 10.1371/journal.pone.0169071

Weißflog, G., Hönig, K., Gündel, H., Lang, D., Niederwieser, D., Döhner, H., et al. (2017). Associations between dyadic coping and supportive care needs: findings from a study with hematologic cancer patients and their partners. *Support. Care Cancer* 25, 1445–1454. doi: 10.1007/s00520-016-3541-3

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

TYPE Original Research
PUBLISHED 08 June 2023
DOI 10.3389/fpsyg.2023.949443

Check for updates

OPEN ACCESS

EDITED BY
Linda Charvoz,
University of Applied Sciences and Arts of Western Switzerland, Switzerland

REVIEWED BY
Jessica R. Gorman,
Oregon State University, United States
Chun Tao,
Mayo Clinic Arizona, United States

*CORRESPONDENCE
Danielle C. Brosseau
✉ danielle.brosseau@kingsu.ca

RECEIVED 20 May 2022
ACCEPTED 10 May 2023
PUBLISHED 08 June 2023

CITATION
Brosseau DC, Peláez S, Ananng B and Körner A (2023) Obstacles and facilitators of cancer-related dyadic efficacy experienced by couples coping with non-metastatic cancers. *Front. Psychol.* 14:949443.
doi: 10.3389/fpsyg.2023.949443

Obstacles and facilitators of cancer-related dyadic efficacy experienced by couples coping with non-metastatic cancers

Danielle C. Brosseau[1,2]*, Sandra Peláez[2,3], Bethsheba Ananng[2] and Annett Körner[2,4,5,6,7]

[1]Department of Psychology, The King's University, Edmonton, AB, Canada, [2]Department of Educational and Counselling Psychology, McGill University, Montreal, QC, Canada, [3]École de kinésiologie et des sciences de l'activité physique (EKSAP), Faculté de Médecine, Université de Montréal, Montreal, QC, Canada, [4]Lady Davis Institute, Jewish General Hospital, Montreal, QC, Canada, [5]Department of Oncology, McGill University, Montreal, QC, Canada, [6]Louise Granofsky Psychosocial Oncology Program, Segal Cancer Center, Montreal, QC, Canada, [7]Psychosocial Oncology Program, McGill University Health Centre, Montreal, QC, Canada

Introduction: Cancer-related dyadic efficacy is an individual's confidence to work together with a partner to conjointly manage the effects of cancer and its treatment. In other health contexts, higher levels of dyadic efficacy have been associated with fewer symptoms of psychological distress and higher ratings of relationship satisfaction. The aim of the current study was to explore patient and partner perspectives on what obstructs and facilitates cancer-related dyadic efficacy.

Methods: These aims were accomplished through a secondary analysis of data collected as a part of a collective qualitative case study. Participants (*N*=17 participants) were patients undergoing treatment or recently completed treatment (within 6 months) for a non-metastatic cancer and their partners. To enable in-depth discussions among participants, data was collected through five focus groups. Participants described obstacles and facilitators of dyadic efficacy as dimensions of a common influence. Consistent with these descriptions, reflexive thematic analysis was used to identify influences on cancer-related dyadic efficacy and their subsequent obstructive and facilitative dimensions.

Results: Four main categories of influence with the potential to obstruct or facilitate cancer-related dyadic efficacy were identified along with their subthemes: appraisals of the couple relationship (quality and togetherness), communication (pattern and interest in information), coping (strategy and evaluation), and responses to change (in tasks and roles and sex life). Eight obstructive and seven facilitative dimensions of these subthemes were described.

Discussion: This first analysis of obstacles and facilitators of couples' cancer-related dyadic efficacy capitalized on the experiential expertise of individuals with cancer and their partners. These thematic results are instructive for the design of dyadic efficacy-enhancing interventions for couples coping with cancer.

KEYWORDS

cancer, couples, dyadic efficacy, reflexive thematic analysis, focus groups, qualitative research methods, psychosocial

Introduction

In addition to the obvious physical effects, cancer and its subsequent treatment commonly affect the psychological, social, and spiritual well-being of the individual diagnosed and their family members (Stenberg et al., 2010; Carlson et al., 2011; Caruso et al., 2017; Bubis et al., 2018). Approximately 33 % of those diagnosed with cancer will also require support for a co-occurring mental health concern (Singer, 2018). The multiple effects of cancer on both the patient and their partner have led researchers to conceptualize cancer as a dyadic stressor (Bodenmann, 2005). An understanding of cancer as a dyadic stressor is also an important acknowledgement of the elevated levels of psychological distress that can be experienced by the individual diagnosed with cancer and his or her partner (Hagedoorn et al., 2008; Kuenzler et al., 2011; Moser et al., 2013).

Viewing the couple as the unit of analysis and accounting for the interactions that occur within the interdependent system of the couple provides advanced insight into couples' psychological distress and coping following a cancer diagnosis (Kayser et al., 2007; Badr et al., 2010; Traa et al., 2014; Regan et al., 2015; Jacobs et al., 2017). Looking outside of oncology, health researchers have applied a systemic approach to the study of efficacy expectations, examining what they termed, dyadic efficacy (Sterba et al., 2007, 2011). Dyadic efficacy extends from Albert Bandura's social cognitive theory, offering a dyadic counterpart to the individually-focused construct of self-efficacy (Bandura, 1977). Cancer-related dyadic efficacy is an individual's judgment of his or her confidence to conjointly manage the effects of cancer and its treatment together with a partner.

The interactions of patients' and partners' ways of coping with cancer influence each individual's psychological health and their relationship satisfaction (Berg and Upchurch, 2007; Berg et al., 2008; Badr et al., 2010; Rottmann et al., 2015). Dyadic efficacy represents a couples' appraisal of their joint coping capability and has the potential to be an important personal resource to identify and enhance among patients with cancer and their partners. In his early writings on self-efficacy, Bandura asserted that an individual's belief that he or she could complete a behavior (efficacy expectation) greatly influenced the probability that the individual would enact the behavior and would sustain the behavior in the face of obstacles (Bandura, 1977). Provided Bandura's assertions regarding self-efficacy extend to dyadic efficacy, patients' and partners' dyadic efficacy expectations may be a powerful tool for the propulsion and perseverance of beneficial joint coping actions. With these expectations in mind, it becomes essential to better understand what might impede or enhance cancer-related dyadic efficacy.

In the initial research on dyadic efficacy among couples managing one partner's rheumatoid arthritis, higher dyadic efficacy was associated with fewer depressive symptoms and higher ratings of relationship satisfaction and quality for both women with rheumatoid arthritis and their husbands (Sterba et al., 2007). Similarly, dyadic efficacy for smoking cessation was positively associated with relationship satisfaction and also predictive of support behaviors and dyadic coping (Sterba et al., 2011). Although no identification of facilitators or obstacles to dyadic efficacy were found, these associations between dyadic efficacy, psychological distress and relational factors may foreshadow the content of facilitative and obstructive influences on dyadic efficacy.

The present study

This study is part of a larger mixed-methods endeavor that, to our knowledge, was the first to examine dyadic efficacy in the cancer context (Brosseau et al., 2021, 2023). The primary data set used here was first collected to facilitate consultation with lay experts (individuals with cancer and their partners) regarding the conceptualization of cancer-related dyadic efficacy and the identification of content domains for assessment. In this foundational research, thematic analysis was used to describe three main qualities of cancer-related dyadic efficacy (it is multidimensional, consistent with established relational functioning and distinct from self-efficacy) and three main themes encompassing eight content domains that participants described to be essential for the assessment of cancer-related dyadic efficacy. These themes and domains reflected dyadic efficacy for managing: (a) illness intrusions related to the patients' physical experience, social life, couple life, the medical system, and ongoing responsibilities, (b) emotional responses of the patient and the partner, and (c) communication and care for children (Brosseau et al., 2023). Expanding on this initial work, the objective of the present study was to construct themes that reflected what facilitated or obstructed patients' and partners' cancer-related dyadic efficacy. The research question guiding the inquiry was: what helps or hinders couples' confidence to cope with cancer-related challenges together as a unit?

Materials and methods

Study design

This study presents the results of a secondary analysis of focus group data collected within the exploratory phase of the aforementioned scale development study (Brosseau et al., 2021). Long-Sutehall et al. (2010) recommend that researchers consider the appropriateness of secondary qualitative data analysis, including a consideration that the research questions are appropriate to the primary data. The impetus for this secondary data analysis emerged during thematic analyses of the primary data set. Participants' discussions of cancer-related dyadic efficacy and its measurement naturally extended into descriptions of what enhanced or hindered their confidence to manage cancer-related challenges together as a unit.

The process of eliciting participants' insights on cancer-related dyadic efficacy was guided by a collective qualitative case study design, which involved an in-depth analysis of multiple bounded systems (Stake, 2005). The boundaries set around the selection of cases are further detailed in the participants section below. Rooted in the social constructivist paradigm, knowledge was understood to be co–constructed through the dynamic interactions that occurred among the participants and the researchers (Stake, 1995; Gergen, 2009). With collective academic and clinical expertise in psychosocial oncology, psychology and qualitative research methods, the researchers were outsiders in relation to the participants in this study. As outsiders, the research team was cognizant of the need to continuously reflect on our own assumptions, carefully considering interpretations of the data that prioritized participants' voices.

Participants

Patients were eligible if they were currently receiving treatment or had recently completed treatment (within 6 months) for a non-metastatic cancer and were involved in a committed intimate relationship of at least 1 year (e.g., dating, common law, married). Partners of patients meeting these medical criteria were also invited to participate. All participants were (a) able to read and comprehend English, (b) 18 years of age or older, and (c) able to provide informed consent. The participation of complete dyads was sought but, to reduce barriers to participation, a patient or a partner was eligible to participate without the other member of the dyad. Patients diagnosed with metastatic disease were excluded in an effort to focus the discussion on confidence for managing the challenges of diagnosis and active treatment and to limit the heterogeneity of the sample.

Procedures

This study was approved by the research ethics committee of the Jewish General Hospital, Montréal, Canada (protocol #14–078). Convenience sampling was used to recruit eligible patients and partners. Recruitment was conducted through advertisement (paper and online) of the study at a large urban cancer centre and para-support programs in Montréal, Canada. In an effort to increase the diversity of the sample, referring health care providers (e.g., nurses, support staff) were encouraged to refer couples who reported ease working together to cope with cancer as well as those that reported great difficulty facing cancer-related challenges together as a unit.

Focus groups were chosen because this method facilitates the generation and refinement of ideas amongst participants and between participants and the researchers (Morgan, 1996). Based on recommendations in the literature, it was anticipated that conducting three to five focus groups would enable response consistency given the confined focus on cancer-related dyadic efficacy (Burrows and Kendall, 1997; Krueger and Casey, 2009). Small focus groups ($n = 5–7$ participants) were planned to aid the researchers' desire to elicit in-depth discussions among the participants at the couple and group level (Liamputtong, 2011). Beyond the bounds of each case, focus group composition was heterogeneous. The semi-structured focus groups ranged from 45–97 min ($\bar{X} = 75$ min). Focus groups began with an introduction and welcome from the researchers, followed by the completion of informed consent. Participants were then invited to introduce themselves and proceeded to complete and evaluate newly generated questionnaire items querying dyadic efficacy. This initial procedure was used for the broader scale development study. The researchers then facilitated a discussion of dyadic efficacy, informed by a topic guide that centered the discussion on patients' and partners' (a) descriptions of cancer-related dyadic efficacy, (b) perspectives on the types of challenges encountered, and (c) experiences coping with these cancer-related challenges together. For example, participants were asked about their conjoint coping efforts generally (In what ways do you and your partner work together to cope with cancer?) and more behaviorally (What tasks do you and your partner manage together as a part of coping with cancer?). Participants received a 20-dollar reimbursement for transportation or parking costs. Author DB led each group with the assistance of a co-moderator and a participant observer. Data collection using focus groups has been referred to as a process of listening in or eavesdropping (Barbour, 2007). DB adopted this stance to encourage participants' engagement with each other as they unraveled their own and each other's perspectives on dyadic efficacy. The co-moderator was minimally involved in querying participants' responses and primarily responsible for the organization of the group including recordings, timing, and note–taking (Krueger and Casey, 2009). Focus groups have been criticized for masking the effects of agreement or disagreement among group members in favour of the most dominant voices. The small size of the focus groups limited the potential for differing opinions to be masked because the facilitator was reasonably able to follow-up and inquire about the extent to which an idea resonated with the group more broadly.

Data analysis

All focus groups were audio-recorded and transcribed verbatim. Each transcript was examined by an independent second reviewer (a volunteer research assistant) and DB for consistency with the recording. With the exception of grammatical adjustments, the participant quotes presented in this report are verbatim (Poland, 2001). Data available for analysis included the data derived from the focus group transcripts, moderator and co-moderator notes and impressions. A reflexive thematic data analysis was conducted using Braun and Clarke's (2006, 2019) guidelines and included immersion in the data, generating initial codes, searching, reviewing and developing themes. An inductive approach to theme construction was used whereby the researchers sought to generate key themes that captured the diversity of what influenced participants' confidence to cope with cancer conjointly. MAXQDA (VERBI GmbH, Germany, version 11) was used to aid the analysis. DB familiarized herself with the data to the point of immersion through multiple readings of the transcripts and supplemental data with a focus on identifying what influenced participants' cancer-related dyadic efficacy. It became evident early in the immersion process that a given influence on dyadic efficacy did not act as a facilitator or an obstacle but that many influences on couples' confidence had facilitative or obstructive dimensions. In keeping with our data-driven approach, the focus of the coding process shifted to capture participants' descriptions of facilitative and obstructive dimensions of the same influence on dyadic efficacy. Journaling was used to denote potentially important codes, emerging theme ideas, and insights related to the similarities across influences. An initial list of what were later-termed subthemes was developed, discussed, and reviewed conjointly with SP. Using these identified subthemes, DB and SA independently coded each transcript, engaged in reflexive discussions regarding the meaning ascribed to a given coded segment, returned to the data, and redefined or expanded the subthemes to ensure they captured the essential aspects of the participants' descriptions. During theme construction, the researchers also reviewed and discussed similarities across themes which led to the construction of theme categories that functioned to group similar influences on dyadic efficacy together in meaningful clusters. Nowell et al. (2017) outline several strategies for enhancing the credibility of thematic analysis including the use of researcher triangulation. Researcher triangulation was used in this study during the development of the initial codes (DB and SP), throughout code development (DB and SA) and when reviewing the theme categories and their subthemes (DB, SA and SP).

Results

Participant characteristics

Participants ($N = 17$) included six patient–partner dyads, four patients and one partner who participated alone (see Table 1 for participant characteristics). Five focus groups were conducted with fewer participants then expected ($n = 2$–5 participants per group). Issues of coordinating participants' schedules, illness demands, and inclement weather limited the size of the focus groups and led to what Krueger and Casey (2009) termed, mini-focus groups. Reasons for participating alone included (a) their own or their partner's preference, (b) limited language abilities in English, or (c) work or childcare responsibilities. Both female ($n = 6$) and male ($n = 4$) individuals with cancer participated. Patients were on average 60 years old (range = 44–72 years), in relationships ranging from three to 48 years in duration ($\bar{X}$ = 22 years), and heterogeneous with respect to the type of cancer diagnosed. Partners were female ($n = 4$), male ($n = 2$) or non-binary ($n = 1$), an average of 51 years of age (range 25–72 years) and in relationships ranging from five to 48 years in duration ($\bar{X}$ = 26 years). Ten of the 11 distinct dyads represented heterosexual partnerships (one dyad included a female and a non-binary individual).

Obstacles and facilitators of cancer-related dyadic efficacy

Four main themes of influence and eight subthemes with the potential to facilitate or obstruct cancer-related dyadic efficacy were identified, namely cancer-related dyadic efficacy was influenced by: (a) appraisals couples made about the quality of their relationship and the meanings attributed to togetherness, (b) individual and dyadic communication patterns and preferences for cancer-related information, (c) coping strategies used and evaluations made about the chosen strategy, and (d) how changes to the division of everyday tasks and the couples' sex life were managed. The facilitative and obstructive dimensions of these factors are presented in Table 2 and described in the following paragraphs. To protect the anonymity of participants, all names used in this paper are pseudonyms.

A: Appraisals couples made about the quality of their relationship and the meanings attributed to togetherness

The confidence patients and partners had in their joint ability to manage adverse experiences associated with cancer and its treatment was influenced by appraisals of (a) the quality of the couple relationship and (b) togetherness.

TABLE 1 Patient and partner characteristics (N=17).

Dyad represented	Pseudonym	Role	Sex	Age range (years)	Relationship length (years)	Tumour site[a]	Stage of cancer[a]	Time since diagnosis[a]
1	Kelly	Patient	Female	40–49	8	Breast	1	6 months – 1 year
	Felix	Partner	Male	50–59	8			
2	Joanne	Patient	Female	50–59	11	Thyroid	2	Over 1 year
	Scott	Partner	Non-binary	30–39	11			
3	Luc	Patient	Male	60–69	38	Myeloma	1	Over 1 year
	Alice	Partner	Female	60–69	38			
4	Francis	Patient	Male	60–69	32	Palate	1	6 months – 1 year
	Ines	Partner	Female	50–59	32			
5	Gina	Patient	Female	70–79	48	Breast	1	Over 1 year
	Barry	Partner	Male	70–79	48			
6	Roy	Patient	Male	60–69	40	Multiple Myeloma	3	Over 1 year
	Fiona	Partner	Female	50–59	40			
7	Stephanie	Partner	Female	20–29	5	Lymphoma	Unknown	3–6 months
8	Louise	Patient	Female	40–49	12	Breast	3	Over 1 year
9	Tina	Patient	Female	50–59	12	Breast	1	6 months – 1 year
10	John	Patient	Male	70–79	3	Prostate	Unknown	Over 1 year
11	Sharon	Patient	Female	70–79	12	Multiple myeloma	Unknown	Over 1 year

[a] All medical data was self-reported by the study participant.

Medical data were not listed for partner participants with the following exception. Medical information corresponding to the patient was provided for the partner who participated alone.

TABLE 2 Influences that facilitate and obstruct patients' and partners' cancer-related dyadic efficacy.

Category	Subtheme	Facilitator	Obstacle
A. Appraisals couples made about the quality of their relationship and the meanings attributed to togetherness			
A1	Quality of the couple relationship	Stable couple relationship	Weak couple relationship
A2	Togetherness	Valued togetherness	Devalued togetherness
B. Individual and dyadic communication patterns and preferences for cancer-related information			
B1	Communication pattern	Congruent pattern	Incongruent pattern Lack of communication
B2	Interest in cancer-related information	Shared interest	Disinterest
C. Coping strategies used and evaluations made about the chosen strategy			
C1	Dominant coping strategy	–	Avoidant coping
C2	Evaluation of partner's coping strategies	Acceptance of partner's coping	Disapproval of partner's coping
D. How changes to the division of everyday tasks and the couples' sex life were managed			
D1	Tasks and roles	Flexibility	Lack of awareness
D2	Sex life	Patience	–

A1: Stable versus weak couple relationship

The functioning of the couple relationship prior to the cancer diagnosis was viewed as a "baseline" (Louise, woman with breast cancer) or "foundation" (Kelly, woman with breast cancer) for couples' confidence to respond to cancer-related challenges together. Appraisal of a stable or weak pre-existing relationship was presented as a facilitator or an obstacle to dyadic efficacy. While these participants did not overtly label their own relationship to be weak, they instead expressed doubts about whether those with a weak pre-existing relationship could withstand the stress a cancer diagnosis imposes on the couple relationship. This exemplary quote illustrates this idea:

> I find that if the relationship was weak, we wouldn't have made it. I mean the fact that we already had a stable foundation as a couple—we were respectful towards each other and we love each other unconditionally. When this [cancer] happened, there was no question just to love each other and to go through it together (Kelly, woman with breast cancer).

A2: Valued versus devalued togetherness

Dyadic efficacy was described as being enhanced or hindered by the appraisals patients and partners made which valued or devalued the experience of being together. Participants described togetherness with varying emphases on both symbolic and actual accounts of togetherness. Those with a more practical focus, gained confidence from facing challenges and approaching tasks together with their partner (e.g., doctor's appointments, treatments, leisure time). Roy and Fiona stated: "We always did everything together" (Roy, man with multiple myeloma); "Even when we are tired and we do not feel like talking—just sitting together on the couch and holding his hand was soothing for us" (Fiona, partner). The act of being present or simply being partnered was referred to as being beneficial, regardless of the specific behaviors or actions of the other person. As John (man with prostate cancer) described: "being aware of [my] partner's love" was itself sustaining. For some, like John, the meaning drawn from being together provided the very reason for enduring anticipated difficulties of cancer treatment and was very focused on a symbolic feeling of togetherness. For example:

> She helps me a lot, not because she did something. She helps me because I love her and the happiness I have because I love her. This helps me a lot during my treatments and still today (John, man with prostate cancer).

In contrast, dyadic efficacy was hindered when either a patient or a partner appraised togetherness as having little or no additional value for managing cancer-related challenges. For these participants, togetherness was described as unneeded, ineffective, or even a waste of time. This obstacle was well-captured in the following participant statement:

> He took me to my appointment, but I told him 'You know what, don't come with me. I'd rather you just go get a coffee'. I had to wrap my head around it first because if I don't do that, I'm not going to be able to cope. I knew it was going to be bad news. And I just said that if I had to worry about his emotions, then I'm not going to be able to deal with it. You know, if you cry, you cry for 5 minutes by yourself, but if you cry and you see someone else cry, it's just back and forth and it's never going to stop. So that's why to me, I kind of had to… let me get through my thing, take the shot. But if we had done it together, I think it would've been too hard for me (Sharon, woman with multiple myeloma).

Dyadic efficacy was also obstructed when participants believed that coping together would make their coping more difficult or add additional issues to be attended. Tina (woman with breast cancer) noted: "In treatment, I definitely did not want him there, because all he would do is run around, you know, being… feeling impotent and I'd have to take care of him." Likewise, when a participant felt that his or her experience could not be understood by his or her partner, togetherness was devalued. As Luc (man with myeloma) mentioned: "I would not put something on her that I knew she could not relate to."

For some couples, descriptions that devalued togetherness were expressed alongside events appraised to be manageable and only minimally threatening. In contrast, those that valued togetherness, drew strength from being together regardless of the perceived difficulty of the situation. Notably, those who devalued togetherness focused on very practical aspects of being together (i.e., attending appointments, leisure time) without addressing the more symbolic perspective.

B: Individual and dyadic communication patterns and preferences for cancer-related information

Cancer-related dyadic efficacy was influenced by patients' and partners' (a) communication patterns and (b) interest in cancer-related information.

B1: Congruent versus incongruent communication patterns and lack of communication

The extent to which communication preferences were evaluated by patients and partners to be congruent influenced confidence to jointly manage challenges. Acceptance of the communication pattern was more important than the extent to which a patient's or a partner's communication pattern was more open or restricted. For the purposes of this depiction, communication that was described as candid and vulnerable was labeled open, whereas communication that was described to have limits with respect to topics or depth was labeled restricted. Open communication facilitated dyadic efficacy when preferred by both members of the dyad. At times, open communication also included processing and discussing experiences, seeking clarity about their own experiences, requesting advice or seeking an alternative perspective. Kelly (woman with breast cancer), said this:

> We have this rule that we have to respect: we work together, if I'm not nice or something, he has to let me know. If I don't do well, he'll tell me, 'You know Kelly you're not doing too well today. You wouldn't do that on a normal day'.

The congruence of communication preferences between partners facilitated dyadic efficacy even when there was a dyadic preference for more restricted communication. Luc and Alice both felt satisfied with their restricted communication pattern that was largely limited to the discussion of practical issues: "I come home at night and it's not something that we talk about. We only talk about when we see the doctor and what we are going to do and what we should do" (Luc, man with myeloma). Dyadic efficacy was obstructed when the couple differed in their preferred communication pattern. Open communication was experienced as overwhelming and an additional challenge to contend with for individuals that preferred more restricted communication.

A lack of communication reflected the pattern of those who reported that cancer was "not something [they would] talk about" (Roy, man with multiple myeloma). Naturally, when one member of the dyad adopted a preference for this communication pattern, the other member reported feeling blocked in their ability to work together. Put simply: "you cannot manage symptoms together if he does not tell you that he's in pain" (Fiona, partner). Two main explanations were given when an individual expressed a lack of desire to talk about cancer: (a) to protect one's partner and/or (b) a history of keeping personal experiences to oneself. Participants who restricted their cancer-related communication in an effort to protect their partner, reported a belief that increased communication would burden their partner or increase their partner's fear or worry. Those who preferred or experienced a partner's lack of communication described the restriction as an obstacle to their ability to cope together with their partner due, in part, to increased isolation:

> I didn't want to talk to him about it because he's not interested and I don't want to scare him. There are things that I know that I would want to tell him but I can't so I sort of lock myself in the garage and I would cry by myself (Stephanie, partner).

Others shared that their tendency to keep thoughts, emotions and experiences to themselves was a long-time preference and cited little benefits to making their internal world known. Descriptions included a pattern of "keeping things to [myself]" (Louise, woman with multiple myeloma), "keeping things inside" (Roy, man with multiple myeloma), or simply "not sharing" (Fiona, partner). One couple described their experience of communication as follows: "When I ask him how he's feelings, he will not tell me. [He'll say,] 'I'm okay, I'm okay'" (Fiona, partner). Roy replied, "I've always been like that. I do not complain. If I get a pain, I do not complain. I never complain. Why complain? Your pain is alive anyways whether you complain or not" (Roy, man with multiple myeloma). Roy and Fiona's exchange is representative of the perspective of others who also saw little benefit to informing their partner about their symptoms or emotions. Fiona's exchange was littered with frustration which was a typical experience for those whose partner preferred not to talk about cancer.

B2: Shared interest versus disinterest in cancer-related information

Regardless of personal information-seeking styles, patients and partners who expressed a shared interest in cancer-related information increased confidence to process informational challenges together. For example, one couple described their approach to medical information as follows:

> She had been doing all the homework, she had been reading online (Barry, partner).
>
> [I went] from not knowing what a mastectomy is [partner laughs] to finding out the type of cancer and really researching it… I've never had any interest in that kind of thing and all of a sudden, I was very knowledgeable. I wanted to know what was going on. So, it's been good for me (Gina, woman with breast cancer).
>
> Yeah, it's been good for the both of us because we've been able to talk about it (Barry, partner).

Patients and partners reported that information about cancer became less intimidating and overwhelming when they were able to share it with their partner.

> He would not be the type to be able to go on the internet to get information. For him it was always about information overload so I fed him the information. So, in that respect it was good because then I kind of controlled my own treatments but we did it as a team in a sense that I always told him what was going on (Sharon, woman with multiple myeloma).

As described by Sharon, the process of sharing information as a team can involve independent tasks. Regardless of whether information was gleaned individually or together, a perception that one's partner participated in the flow of information at some level, be it through expressed interest, listening, processing, or gathering information, was said to increase confidence to deal with cancer-related information and decision-making together as a team.

On the contrary, a patient's or a partner's disinterest in cancer-related information was troublesome for dyadic efficacy.

> I think one thing for us that set the tone early on was I found that I had a very strong desire to know a lot of details about cancer and numbers and survival rates and all that kind of information and I blurted out one statistic to my husband one evening while we were talking, I told him this is the ten year survival rate for da da da da da and he just looked at me and said 'I don't want to know that at all…' No desire to know. I think for us as a couple, that set the stage as to what the communication was like with my husband around the cancer itself (Louise, woman with multiple myeloma).
>
> One partner also shared about the obstacle she encountered when her expressed desire to learn more about her partner's diagnosis was in opposition to his wishes stating, "I couldn't go behind his back and do it because it wasn't right. So, we just kind of muddled through" (Fiona, partner).

One member of the dyad's expressed disinterest in cancer-related information posed a perceived insurmountable obstacle for perceptions of capability to work together as a team to manage the vast amounts of information given and obtained following a cancer diagnosis.

C: Coping strategies used and evaluations made about the chosen strategy

Patients' and partners' (a) dominant coping strategy and (b) evaluation of partner's coping strategies influenced dyadic efficacy.

C1: Avoidant coping

While no dominant coping strategy that facilitated dyadic efficacy was identified in the data, coping that was focused on deviation of attention, or, as referred to by some participants, "not thinking about it [cancer]" (Luc, man with myeloma), was a substantial obstacle for dyadic efficacy. Coping characterized in this way was labeled avoidant coping for the purposes of this description. One partner recounted her struggle with a partner's avoidant coping as follows: "I find it so hard to see the positive side of it [cancer] and he does not see the negative or positive, he just does not even think about it so that's hard because we go through it so differently" (Stephanie, partner). Efforts to not think about cancer were enacted through the use of denial, distraction, or minimization. Some participants appraised these avoidant coping efforts to be working effectively. Regardless of their effectiveness at the individual level, patients and partners of individuals who coped by trying not to think about cancer felt severely impeded in their confidence to manage cancer-related challenges conjointly.

C2: Acceptance versus disapproval of partner's coping strategies

The way in which a patient or a partner evaluated the other's coping strategies helped or hindered dyadic efficacy. Acceptance of the other's coping behaviors was used to capture responses that ranged from suspending judgment to expressions of unconditional acceptance of the coping efforts made. Responses in between these extremes were also identified in which participants reported adapting to their partner's coping behaviors or learning to tolerate differences in coping. Acceptance was particularly facilitative of dyadic efficacy as these participants described efforts to accept their partner's coping behaviors even when these behaviors were different from their own coping preferences or what they believed to be best. Both those who reported a belief that their partner accepted their coping behaviors and those that expressed a conscious effort to accept their partner's current ways of coping noted benefits for increased confidence to cope with cancer together as a unit. As one patient noted: "I do not even know if he agreed with everything but he just… I felt loved and I felt supported, even though I was crazy" (Kelly, woman with breast cancer). Acceptance of a partner's coping efforts even extended to instances in which the coping strategies used were described to be less than ideal:

> My temper has been at its worst going through this. I have a bad temper to start with, and it's been so bad. I have yelled. I have screamed. I have thrown things. His patience with me during that has been nothing short of phenomenal (Joanne, woman with thyroid cancer).

Alternatively, patients' or partners' disapproval of the others' coping strategies impeded dyadic efficacy. Disapproval was used to encompass responses ranging from expressed worries and concerns to a patient's or a partner's explicit judgments of the other's coping behaviors. Expressions of disapproval were often accompanied by concern for one's partner and a desire to help the other cope more effectively. Despite these good intentions, the tendency to negatively evaluate a partners' coping efforts inhibited dyadic efficacy. Some participants described a process of fluctuating between disapproval and acceptance:

> He would say, 'It's just like I'm taking medication for a cold but it's stronger medication'. He couldn't understand why this was worse than anything else. He says, 'okay I'm sick but if I'm sick for something else, I'll just take pills and I'll be fine, same thing'. So, it got me frustrated because it's not the same thing, but then I had to sort of let go because what's the point, do I really want to try to convince him that it's an awful diagnosis? And that his prognosis wasn't good? Did I really have to rub it in and tell him remember, they told you it wasn't a good prognosis, do you know what that

> means? I mean at one point I just decided it wasn't necessary (Stephanie, partner).

Stephanie's ability to learn to let go and move toward acceptance of her partner's coping strategy provided an opportunity for dyadic efficacy to improve. These fluctuations between acting in ways that impeded or enhanced dyadic efficacy were common as patients and partners adapted to the cancer experience. Although this subtheme reflects patients' and partners' evaluations of individually focused coping efforts, it is the judgment of these coping efforts that influences dyadic efficacy. Those that felt accepted regardless of their adaptative or maladaptive coping behaviors expressed greater confidence to face cancer together as a couple.

D: How changes to the division of everyday tasks and the couples' sex life were managed

Cancer-related dyadic efficacy was influenced by a patient's or a partner's response to changes (a) in tasks and roles and (b) to the couples' sex life.

D1: Flexibility versus lack of awareness in response to changes in tasks and roles

The most common adjustments being negotiated related to tasks and roles around the home (e.g., day-to-day chores), childcare responsibilities, work schedules or a partner's transition to and from a caregiver role. The persistent influence of these changes in the everyday lives of the participants and their families heightened the importance of their successful navigation. The influence of changing tasks and roles also varied depending on how much change was required to the status quo of the couple.

Participants who perceived their partners to be flexible in response to changing roles and shifting needs for help expressed greater confidence to face these challenges together. Couples demonstrated flexibility in multiple ways. Although flexibility enhanced a patient's response to change, the emphasis on flexibility was largely placed on partners. A conventional response was the healthy partner taking on tasks typically completed by the individual with cancer. Partners took on additional tasks around the home, altered work schedules, provided extra care for children and, for some, took on basic caregiving tasks (e.g., washing, dressing). Allowing for independence was also a form of flexibility that was particularly appreciated and facilitative of efficacy in the male-patient female-partner dyads in our sample. Flexibility was further demonstrated when patients and partners decided together which tasks required external help from family, friends or professionals. For example:

> I think my biggest problem was lack of energy and tiredness. Fatigue was a big problem so I couldn't do anything. That was where again, you know I counted on my husband and my father-in-law to really take over and do everything that I normally do around the house (Louise, woman with multiple myeloma).

The response of each partner to their new role as a patient or caregiver was a key moment of change that influenced ongoing confidence to navigate the cancer experience together.

When a patient or a partner demonstrated a lack of awareness for change in the allocation of tasks or roles, dyadic efficacy was impeded and participants reported personal frustration and relational conflict when having to direct a partner's helping efforts or overtly ask for help. Sharon's experience exemplified this obstacle:

> Take the initiative. Because I do recognize that in every household one person will be responsible for these specific tasks and the other will be responsible for those tasks, right? However, when one of you is ill, the person who isn't is going to have to pick up the slack. I found that very frustrating. It's something as simple as a meal preparation. So, there was the stress of that and when you talk about it makes it sound like it's so petty but when you're actually going through it… it was so frustrating. To me that was big (Sharon, woman with multiple myeloma).

Participants who perceived reluctance in their partner's willingness or awareness of the need for shifting task and role responsibilities felt less able and ultimately less confident to cope with these ongoing responsibilities conjointly.

D2: Patience in response to changes in the couples' sex life

Patients and partners reported that responding to changes in their sex life was so integral to the couple relationship that successfully managing these changes generalized to their confidence to cope together with other cancer-related tasks and challenges. Cancer treatments, physical changes to the body, hormonal changes and the emotional toll of cancer were all noted to contribute to changes in the couple's sex life. Participants in our sample did not describe a specific response to change in their sex life that presented an obstacle for dyadic efficacy. Conversely, patience in response to sexual changes enhanced couples' dyadic efficacy. Changes to the couple's sex life were multiple and varied including changes in function (e.g., dryness), pain, reduced or enhanced desire due to emotional or hormonal alterations or increased insecurity due to bodily changes (e.g., weight loss or gain, hair loss, mastectomy). As one couple recounted:

> I didn't want to be touched anymore or seen by people. I didn't want to undress anymore. I felt like I was still grieving emotionally (Gina, woman with breast cancer)…. We worked it through together. We talked (Barry, partner).

Patience was beneficial when patients requested time to feel ready to re-engage in sexual intimacy which had commonly been slowed or stopped during active treatment. Responding with patience was also observed to be beneficial during sexual encounters when what was previously arousing for the patient had changed. Given the sensitive nature of changes to the sexual experience or changes to sexual body parts, patience created space for the couple to re-negotiate the ways they were typically sexual and explore other ways of enhancing intimacy. As Kelly (woman with breast cancer) stated: "sex has to be discussed between couples and it's so delicate to discuss it." Navigating changes to the couples' most intimate interactions was indeed delicate but those who were willing to work with the changes were rewarded in their increased efficacy to face these and other cancer-related challenges together as unit.

Facilitator and obstacle characteristics

Two essential elements should be noted in order to accurately understand the facilitators and obstacles to dyadic efficacy discussed here. Facilitators and obstacles were fluid with respect to time and domain. It would be inaccurate to classify participants' global experiences as either facilitative or obstructive of dyadic efficacy. Every participant in our sample described behaviors that would facilitate and others that would restrict dyadic efficacy. Patients and partners also described fluctuations in their facilitative or restrictive behaviors over time. Despite these fluctuations over time and between domains, it was evident that some patients and partners commonly embodied more facilitative dimensions than obstacles and vice versa.

Discussion

Placing dyadic efficacy in the broader research context, a perception of cancer as a shared stressor may form the very foundation on which cancer-related dyadic efficacy is built (Kayser et al., 2007). The theme outlined in this paper related to togetherness is akin to what others have discussed as 'we-ness' and may indicate that patients' and partners' sense of identity as a couple (shared or otherwise) influences their confidence to cope with cancer conjointly (Fergus and Reid, 2001; Kayser et al., 2007). Skerrett (2015) posited that a couples' sense of 'we-ness' fosters relational resilience. Our results suggest that enhanced cancer-related dyadic efficacy may be an additional dimension of resilience connected to couples' sense of togetherness or 'we-ness'. Participants in our sample also discussed a stable couple relationship as foundational for dyadic efficacy. The importance of patients' and partners' appraisal of the couple relationship was also consistent with previous research in which higher dyadic efficacy among couples coping with rheumatoid arthritis was associated with higher relationship functioning (Sterba et al., 2007). The facilitative or restrictive effects of relationship functioning on dyadic efficacy was also consistent with Bandura's theoretical assertion that efficacy expectations are influenced by past mastery (Bandura, 1977). Participants in our study who described higher levels of dyadic efficacy reported a history of successful conjoint coping. As an efficacy expectation, cancer-related dyadic efficacy represents patients' and partners' appraisal of their ability to cope conjointly. In a recent literature review, Chen and colleagues (2021) concluded that "dyadic processes, especially communication, were found to be significantly associated with dyadic outcomes for both members of a cancer couple" (p. 13). The results of the current study suggest that there may also be meaningful connections between couples' efficacy appraisals of their joint coping efforts (dyadic efficacy) and relational outcomes (i.e., relationship satisfaction).

Several obstacles to dyadic efficacy limited the couples' ability to share in the cancer experience together. Some of these behaviors were not only viewed as obstacles to higher levels of dyadic efficacy but as barriers that restricted the possibility for confidence in a shared response. Two obstacles, namely lack of communication and use of avoidant coping strategies, appeared detrimental to dyadic efficacy regardless of congruence with or acceptance by a partner. These obstacles share similarities or are consistent with previously identified constructs—lack of engagement, lack of emotional disclosure and avoidant coping—found to have a negative relational impact on couples coping with cancer and to make joint coping efforts less likely (Regan et al., 2015). Our results indicate that avoidant patterns exert similar restrictive effects on couples' perceptions of their capability to cope together (dyadic efficacy) as they do on couples' use of joint coping efforts (dyadic coping).

Attending to participants' descriptions of their individual behaviors as well as the interactions between patient and partner behaviors enabled the identification of obstacles and facilitators that occurred at the individual and the couple-level. Communication patterns and the management of cancer-related information became obstacles to dyadic efficacy when preferences diverged. Although participants discussed the benefits of open communication, these patterns were only beneficial for dyadic efficacy when understood in the context of within-dyad preferences. For example, the prescription for more open communication would not be facilitative of dyadic efficacy when one member of a dyad preferred to limit their communication about cancer to practical concerns. It would be beneficial to further explore how the influence of communication patterns on dyadic efficacy might diverge depending on the topic being discuss (e.g., practical matters compared to intimate concerns). Similarly, dyadic efficacy was obstructed when one member actively sought cancer-related information and the other chose to limit or avoid information about cancer. Badr (2017) has previously called for more nuanced advancement in couples' communication research that extends beyond a global recommendation for couples to enhance their open communication about cancer. Our results support this assertion and suggest that a within-dyad perspective is needed in order to accurately account for and make recommendations regarding couples' optimal communication patterns. In related research, early investigations of dyadic coping, social support and information-seeking focused on congruence and emphasized the importance of fit between a patient's and a partner's behaviors (Revenson, 2003; Barnoy et al., 2006; Regan et al., 2015). Broadly, similar or complimentary styles were associated with better psychological adjustment to cancer while divergent styles were associated with poorer adjustment. The importance of congruence in our sample was limited to patients' and partners' communication. Apart from avoidant coping, congruence of coping styles was not described to be influential for dyadic efficacy. Dyadic efficacy was enhanced when patients and partners allowed for and accepted similarities or differences in coping. Provided the couple perceived themselves to be coping together toward a shared goal, the congruence of their coping style was not believed to influence dyadic efficacy expectations.

Participants' descriptions of restricted communication due to an effort to protect their partner were consistent with protective buffering which has been defined as: "hiding one's concerns, denying one's worries, concealing discouraging information, preventing the patient from thinking about the cancer, and yielding in order to avoid disagreement" (Hagedoorn et al., 2000b, p. 275). Protective buffering has been well-examined among cancer patients and their partners with higher protective buffering behavior associated with increased psychological distress (Kuijer et al., 2000; Hagedoorn et al., 2000a; Manne et al., 2007) and poorer relationship satisfaction (Langer et al., 2009). Our results suggest that the detrimental effects of protective buffering may also extend to couples' cancer-related dyadic efficacy.

A couples' ability to negotiate role changes has long been a focus of clinical work in psychosocial oncology. Supporting these transitions is essential because a couples' ability to successfully navigate role changes following a cancer diagnosis has been associated with relationship satisfaction and patients' and partners' experience of psychological distress (Manne and Badr, 2008; Ussher et al., 2011). Research examining relational changes in practical (e.g., roles) or intimacy domains have commonly focused on couples' patterns of communication (e.g., Manne et al., 2010). In contrast, participants in the current study discussed the importance of flexibility and patience in response to changes in these types of domains. In addition to considering communication patterns, it may be beneficial to assess the extent to which patients' and partners' hold rigid perspectives on their roles and their ability to navigate change with patience.

Limitations and future research

The focus groups conducted in the present study were smaller than what has typically been recommended in the literature (Wilkinson et al., 2004). Factors including difficulties coordinating participants' schedules and no shows in response to poor weather and feeling ill reduced the anticipated size of the focus groups and led to what Krueger and Casey (2009) termed, mini-focus groups. Further, two focus groups included only one complete dyad and may be better referred to as an in-depth couple interview. Although the groups did not meet optimal size recommendations, the sample held sufficient "information power" (Malterud et al., 2016, p. 2) to generate meaningful themes within this new topic of study. As described by Malterud et al. (2016), higher information power lessons the demand on sample size. The information power of the current study was bolstered by the narrow study aim limited to dyadic efficacy influences and the rich quality of dialog that was facilitated within each of the mini-focus groups. Despite this, it bears repeating that our approach to this study was rooted in the social constructivist paradigm and we would be remiss to fail to acknowledge the ways in which additional themes may have been co–constructed through the additional interactions made possible within a larger focus group (Stake, 1995; Gergen, 2009). In addition to focus group size, future researchers might consider incorporating initial interviews with each individual or couple prior to focus group participation (Lambert and Loiselle, 2008). Given the conceptual complexity of the dyadic efficacy construct, participants may benefit from the opportunity to begin formulating their thoughts and opinions on the topic prior to engaging in the group dynamic.

The current study was limited by the constraints of the secondary analysis of data approach that was used. Participants were not asked directly about what influences their confidence to cope with cancer together. A more direct inquiry may have elicited additional descriptions that were not present in this data set. It would be beneficial to corroborate and refine the results presented here with a follow-up study that inquires directly about participants' perspectives on what enhances or impedes their confidence to cope with cancer conjointly. It may also be beneficial to limit the inclusion criteria to the participation of complete dyads. Our inclusion of patients or partners alone did not allow for a systematic consideration of intraindividual differences in dyadic efficacy within couples. Although the influence of communication patterns on dyadic efficacy was situated within the interactions of a couple, a more comprehensive focus on a dyadic level of analysis would be beneficial to include in a subsequent study on couples' cancer-related dyadic efficacy. The inclusion of complete dyads only would have enabled a more systematic consideration of similarities and difference between patients and partners in the other themes identified here (i.e., perspectives on togetherness). The decision to allow for individual participation was designed to reduce barriers to participation particularly for those with lower relationship satisfaction who may not actively pursue joint activities with their partner. The recruitment procedures used in the current study did not allow for the evaluation of this strategy. Future researchers should consider recruitment strategies that enable an evaluation of whether a more diverse sample is recruited when allowing for either couple or individual participation. With respect to diversity, the generalizability of the current study results was limited by a lack of racial, sexual and gender diversity that is common in close relationship research. Further research exploring cancer-related dyadic efficacy would benefit from actively working to recruit a more diverse sample or limiting the sample to an underrepresented group (i.e., same-sex partnerships; Williamson et al., 2022).

Conclusion

This first analysis of obstacles and facilitators to cancer-related dyadic efficacy capitalized on the experiential expertise of individuals with cancer and their partners. These couples provided a rich account of the ways in which their relationship appraisals, communication preferences, coping dynamics, and responses to change influenced their confidence to conjointly cope with the challenges of cancer and its treatment. These thematic results are also instructive for the design and testing of an efficacy-enhancing intervention for couples coping with cancer. Recently researchers have called for the need to identify and target relational processes important for supporting dyadic coping among couples faced with cancer (Regan et al., 2015). Cancer-related dyadic efficacy has the potential to be such a target as improved confidence to cope together is likely to encourage greater use of dyadic coping strategies.

Data availability statement

The datasets presented in this article are not readily available because consent for open data sharing was not included when participants provided informed consent. Requests for information should be directed to danielle.brosseau@kingsu.ca.

Ethics statement

This study involved human participants and was reviewed and approved by the research ethics Committee of the Jewish General Hospital, Montréal, Canada (protocol #14-078). The patients/

participants provided their written informed consent to participate in this study.

Author contributions

DB: conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, and writing-original draft. SP: formal analysis, methodology, supervision, writing-review and editing. BA: data curation and formal analysis. AK: supervision, resources, funding acquisition, formal analysis, writing-review and editing. All authors contributed to the article and approved the submitted version.

Funding

This research was supported by doctoral fellowships from the Psychosocial Oncology Research Training (PORT) program and the Fonds de Recherche du Québec-Santé (FRQS). The King's University research committee provided financial support for the open access publication fee.

Acknowledgments

A similar version of this paper appeared in DB's doctoral dissertation completed at McGill University (Brosseau, 2019).

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

Badr, H. J. (2017). New Frontiers in couple-based interventions in Cancer care: refining the prescription for spousal communication. *Acta Oncol.* 56, 139–145. doi: 10.1080/0284186X.2016.1266079

Badr, H. J., Carmack, C. L., Kashy, D. A., Cristofanilli, M., and Revenson, T. A. (2010). Dyadic coping in metastatic breast Cancer. *Health Psychol.* 29, 169–180. doi: 10.1037/a0018165

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychol. Rev.* 84, 191–215. doi: 10.1037/0033-295X.84.2.191

Barbour, R. (2007). *Doing focus groups*. London, England: Sage.

Barnoy, S., Bar-Tal, Y., and Zisser, B. (2006). Correspondence in informational coping styles: how important is it for Cancer patients and their spouses? *Personal. Individ. Differ.* 41, 105–115. doi: 10.1016/j.paid.2005.12.013

Berg, C. A., and Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol. Bull.* 133, 920–954. doi: 10.1037/0033-2909.133.6.920

Berg, C. A., Wiebe, D. J., Butner, J., Bloor, L., Bradstreet, C., Upchurch, R., et al. (2008). Collaborative coping and daily mood in couples dealing with prostate Cancer. *Psychol. Aging* 23, 505–516. doi: 10.1037/a0012687

Bodenmann, G. (2005). "Dyadic coping and its significance for marital functioning" in *Couples coping with stress: emerging perspectives on dyadic coping*. eds. K. Kayser, G. Bodenmann and T. A. Revenson (Washington, DC: American Psychological Association), 73–95.

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101. doi: 10.1191/1478088706qp063oa

Braun, V., and Clarke, V. (2019). Reflecting on reflexive thematic Analyis. *Qual. Res. Sport Exerc. Health* 11, 589–597. doi: 10.1080/2159676X.2019.1628806

Brosseau, D. C. (2019). *Furthering systemic inquiries into couples coping with Cancer through Adapatation and extension of a dyadic efficacy model [dissertation]*. Montreal, QC: McGill University.

Brosseau, D. C., Braeken, J., Carmack, C., Rosberger, Z., and Körner, A. (2021). We think we can: development of the dyadic efficacy scale for Cancer. *J. Psychosoc. Oncol. Res. Pract.* 3:4. doi: 10.1097/OR9.0000000000000066

Brosseau, D. C., Peláez, S., Ananng, B., and Körner, A. (2023). *Contextualizing measurement: establishing a construct and content Foundation for the Assessment of couples' confidence to cope with Cancer*. Manuscript under review.

Bubis, L. D., Davis, L., Mahar, A., Barbera, L., Li, Q., Moody, L., et al. (2018). Symptom burden in the first year after Cancer diagnosis: an analysis of patient-reported outcomes. *J. Clin. Oncol.* 36, 1103–1111. doi: 10.1200/JCO.2017.76.0876

Burrows, D., and Kendall, S. (1997). Focus groups: what are they and how can they be used in nursing and health care research? *Soc. Sci. Health* 3, 244–253.

Carlson, L. E., Waller, A., Groff, S. L., Giese-Davis, J., and Bultz, B. D. (2011). What Goes up does not always come down: patterns of distress, physical and psychosocial morbidity in people with Cancer over a one year period. *Psycho-Oncology* 22, 168–176. doi: 10.1002/pon.2068

Caruso, R., Nanni, M. G., Riba, M., Sabato, S., and Grassi, L. (2017). The burden of psychosocial morbidity related to Cancer: patient and family issues. *Int. Rev. Psychiatry* 29, 389–402. doi: 10.1080/09540261.2017.1288090

Fergus, K. D., and Reid, D. (2001). The Couple's mutual identity and reflexivity: a systemic-constructivist approach to the integration of persons and systems. *J. Psychother. Integr.* 11, 385–410. doi: 10.1023/A:1016658301629

Gergen, K. J. (2009). *Relational being: Beyond self and community*. NY: Oxford University Press.

Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T., and Sanderman, R. (2000a). Couples dealing with Cancer: role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology* 9, 232–242. doi: 10.1002/1099-1611(200005/06)9:3<232::AID-PON458>3.0.CO;2-J

Hagedoorn, M., Kuijer, R. G., Buunk, B. P., DeJong, G. M., Wobbes, T., and Sanderman, R. (2000b). Marital satisfaction in patients with Cancer: does support from intimate partners benefit those who need it the Most? *Health Psychol.* 19, 274–282. doi: 10.1037/0278-6133.19.3.274

Hagedoorn, M., Sanderman, R., and Bolks, H. N. (2008). Distress in couples coping with Cancer: a Meta-analysis and critical review of role and gender effects. *Psychol. Bull.* 134, 1–30. doi: 10.1037/0033-2909.134.1.1

Jacobs, J. M., Shaffer, K. M., Nipp, R. D., Fishbein, J. M., MacDonald, J., El-Jawahri, A., et al. (2017). Distress is interdependent in patients and caregivers with newly diagnosed incurable cancers. *Ann. Behav. Med.* 51, 519–531. doi: 10.1007/s12160-017-9875-3

Kayser, K., Watson, L. E., and Andrade, J. T. (2007). Cancer as a 'We-Disease': examining the process of coping from a relational perspective. *Fam. Syst. Health* 25, 404–418. doi: 10.1037/1091-7527.25.4.404

Krueger, R. A., and Casey, M. A. (2009). *Focus groups: A practical guide for applied research (4th)*. Los Angelas: Sage.

Kuenzler, A., Hodgkinson, K., Zindel, A., Bargetzi, M., and Znoj, H. J. (2011). Who cares, who bears, who benefits? Female spouses vicariously carry the burden after Cancer diagnosis. *Psychol. Health* 26, 337–352. doi: 10.1080/08870440903418877

Kuijer, R. G., Ybema, J. F., Buunk, B. P., DeJong, G. M., Thijs-Boer, F., and Sanderman, R. (2000). Active engagement, protective buffering, and overprotection: three ways of giving support by intimate Partners of Patients with Cancer. *J. Soc. Clin. Psychol.* 19, 256–275. doi: 10.1521/jscp.2000.19.2.256

Lambert, S., and Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *J. Adv. Nurs.* 62, 228–237. doi: 10.1111/j.1365-2648.2007.04559.x

Langer, S. L., Brown, J. D., and Syrjala, K. (2009). Intra- and inter-personal consequences of protective buffering among Cancer patients and caregivers. *Cancer* 115, 4311–4325. doi: 10.1002/cncr.24586

Liamputtong, P. (2011). *Focus group methodology: Principles and practices*. Los Angeles, CA: Sage.

Long-Sutehall, T., Sque, M., and Addington-Hall, J. (2010). Secondary analysis of qualitative data: a valuable method for exploring sensitive issues with an elusive population? *J. Res. Nurs.* 16, 335–344. doi: 10.1177/1744987110381553

Malterud, K., Siersma, V. D., and Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qual. Health Res.* 26, 1753–1760. doi: 10.1177/1049732315617444

Manne, S. L., and Badr, H. J. (2008). Intimacy and relationship processes in Couples' psychosocial adaptation to Cancer. *Cancer* 112, 2541–2555. doi: 10.1002/cncr.23450

Manne, S. L., Badr, H. J., Zaider, T., Nelson, C., and Kissane, D. (2010). Cancer-related communication, relationship intimacy, and psychological distress among couples coping with localized prostate Cancer. *J. Cancer Surviv.* 4, 74–85. doi: 10.1007/s11764-009-0109-y

Manne, S. L., Norton, T. R., Ostroff, J. S., Winkel, G., Fox, K., and Generosa, G. (2007). Protective buffering and psychological distress among couples coping with breast Cancer: the moderating role of relationship satisfaction. *J. Fam. Psychol.* 21, 380–388. doi: 10.1037/0893-3200.21.3.380

Morgan, D. L. (1996). Focus groups. *Annu. Rev. Sociol.* 22, 129–152. doi: 10.1146/annurev.soc.22.1.129

Moser, M. T., Künzler, A., Nussbeck, F., Bargetzi, M., and Znoj, H. J. (2013). Higher emotional distress in female Partners of Cancer Patients: prevalence and patient-partner interdependencies in a 3-year cohort. *Psycho-Oncology* 22, 2693–2701. doi: 10.1002/pon.3331

Nowell, L. S., Norris, J. M., White, D. E., and Moules, N. J. (2017). Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods* 16, 160940691773384–160940691773313. doi: 10.1177/1609406917733847

Poland, B. D. (2001). "Transcription quality" in *Handbook of interview research*. eds. J. F. Gubrium and J. A. Holstein (Thousand Oaks, CA: Sage).

Regan, T. W., Lambert, S., Kelly, B., Falconier, M., Kissane, D., and Levesque, J. V. (2015). Couples coping with Cancer: exploration of theoretical frameworks from dyadic studies. *Psycho-Oncology* 24, 1605–1617. doi: 10.1002/pon.3854

Revenson, T. A. (2003). "Scenes from a marriage: examining support, coping, and gender within the context of chronic illness" in *Social psychological foundations of health and illness*. eds. J. Suls and K. A. Wallston (Malden, MA, USA: Blackwell), 530–559.

Rottmann, N., Hansen, D. G., Larsen, P. V., Nicolaisen, A., Henrik, F., Christoffer, J., et al. (2015). Dyadic coping within couples dealing with breast cancer: a longitudinal, population-based study. *Health Psychol.* 34, 486–495. doi: 10.1037/hea0000218

Singer, S. (2018). "Psychosocial impact of Cancer" in *Psycho-oncology: Recent results in Cancer research*. eds. U. Goerling and A. Mehnert (Cham, Switzerland: Springer, Cham).

Skerrett, K. (2015). "Resilience in couples: a view of the landscape" in *Couple resilience: Emerging perspectives*. eds. K. Skerrett and K. Fergus (Dordetch, Netherlands: Springer), 3–22.

Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.

Stake, R. E. (2005). "Qualiative Case Studies" in *The SAGE handbook of qualitative research*. eds. N. K. Denzin and Y. S. Lincoln. *3rd Edn.* (Thousand Oaks, CA: Sage), 443–466.

Stenberg, U., Ruland, C., and Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with Cancer. *Psycho-Oncology* 19, 1013–1025. doi: 10.1002/pon.1670

Sterba, K. R., DeVellis, R. F., Lewis, M. A., Baucom, D. H., Jordan, J. M., and DeVellis, B. (2007). Developing and testing a measure of dyadic efficacy for married women with rheumatoid arthritis and their spouses. *Arthritis Rheum.* 57, 294–302. doi: 10.1002/art.22538

Sterba, K. R., Rabius, V., Carpenter, M. J., Villars, P., Wiatrek, D., and McAlister, A. (2011). Dyadic efficacy for smoking cessation: preliminary assessment of a new instrument. *Nicotine Tob. Res.* 13, 194–201. doi: 10.1093/ntr/ntq236

Traa, M. J., De Vries, J., Bodenmann, G., and Den Oudsten, B. L. (2014). Dyadic coping and relationship functioning in couples coping with Cancer: a systematic review. *Br. J. Health Psychol.* 20, 85–114. doi: 10.1111/bjhp.12094

Ussher, J. M., Wong, W. K. T., and Perz, J. (2011). A qualitative analysis of changes in relationship dynamics and roles between people with Cancer and their primary informal Carer. *Health* 15, 650–667. doi: 10.1177/1363459310367440

Wilkinson, S., Joffe, H., and Yardley, L. (2004). "Qualitative data collection: interviews and focus groups" in *Research methods for clinical and Health Psychology*. eds. D. Marks and L. Yardley (Thousand Oaks, CA: Sage), 39–55.

Williamson, H. C., Bornstein, J. X., Cantu, V., Ciftci, O., Farnish, K. A., and Schouweiler, M. T. (2022). How diverse are the samples used to study intimate relationships? A systematic review. *J. Soc. Pers. Relat.* 39, 1087–1109. doi: 10.1177/0265407521105384

frontiers in Psychology

ORIGINAL RESEARCH
published: 17 February 2022
doi: 10.3389/fpsyg.2022.816626

Active Engagement, Protective Buffering, and Depressive Symptoms in Young-Midlife Couples Surviving Cancer: The Roles of Age and Sex

Karen S. Lyons[1]*, *Jessica R. Gorman*[2], *Brandon S. Larkin*[3], *Grace Duncan*[1] *and Brandon Hayes-Lattin*[4]

[1]Connell School of Nursing, Boston College, Chestnut Hill, MA, United States, [2]School of Social and Behavioral Health Sciences, College of Public Health and Human Sciences, Oregon State University, Corvallis, OR, United States, [3]School of Nursing, Oregon Health & Science University, Portland, OR, United States, [4]School of Medicine, Oregon Health & Science University, Portland, OR, United States

OPEN ACCESS

Edited by:
Linda Charvoz,
University of Applied Sciences and Arts of Western Switzerland, Switzerland

Reviewed by:
Nina Rottmann,
University of Southern Denmark, Denmark
Dalnim Cho,
The University of Texas MD Anderson Cancer Center, United States

****Correspondence:***
Karen S. Lyons
karen.lyons@bc.edu

Specialty section:
This article was submitted to Psycho-Oncology, a section of the journal Frontiers in Psychology

Received: *16 November 2021*
Accepted: *24 January 2022*
Published: *17 February 2022*

Citation:
Lyons KS, Gorman JR, Larkin BS, Duncan G and Hayes-Lattin B (2022) Active Engagement, Protective Buffering, and Depressive Symptoms in Young-Midlife Couples Surviving Cancer: The Roles of Age and Sex. Front. Psychol. 13:816626. doi: 10.3389/fpsyg.2022.816626

Objective: Cancer researchers have found midlife couples to have poorer outcomes compared to older couples due to the off-time nature of the illness for them. It is unknown if young couples (aged 18–39), who are under-represented in cancer studies and overlooked for supportive programs, are at further risk. This study explored the moderating roles of survivor age and sex on the associations between active engagement and protective buffering and depressive symptoms in couples surviving cancer.

Methods: The exploratory study comprised 49 couples (aged 27–58) 1–3 years post-diagnosis. Multilevel modeling was used to explore the moderating roles of survivor age and sex, controlling for interdependent data.

Results: Approximately, 37% of survivors and 27% of partners met clinical criteria for further assessment of depression, with 50% of couples having at least one member meeting the criteria. Survivors and their partners did not significantly differ on depressive symptoms, active engagement, or protective buffering. Male survivors reported significantly higher levels of active engagement by their partners than female survivors and female survivors reported significantly higher levels of protective buffering by their partners than male survivors. We found some evidence to suggest that survivor age and sex may play moderating roles between active engagement and protective buffering and depressive symptoms. Older partners and female survivors appeared to experience more positive effects from engaging in positive dyadic behaviors than younger partners and male survivors.

Conclusion: Findings not only confirm the important role of dyadic behaviors for couples surviving cancer together, but also the important roles of survivor age and sex may play in whether such behaviors are associated with lower levels of depressive symptoms. Future research that examines these complex associations over time and across the adult life span in diverse populations is needed.

Keywords: dyadic coping, dyadic illness management, depression, communication, protective buffering, active engagement

INTRODUCTION

It is estimated that there will be over 22 million cancer survivors in the US by 2030 (American Cancer Society, 2021). A cancer diagnosis ripples throughout the family with couples surviving cancer facing uncertainty, disruption to family goals, and high levels of fear the cancer will recur (Champion et al., 2014; Kent et al., 2016; Shapiro, 2018; Lyons et al., 2022). In addition, partners typically face the strain of providing care and support, redistribution of roles, and household tasks, but also the possibility of losing the survivor. Both survivor and partner worry about the impact of the experience on their relationship, children they may have, and the course of the family trajectory and family goals (Corney et al., 2016; Collaço et al., 2019; Gorman et al., 2020). Although not all couples living with cancer report high psychological distress or depression, and some report the experience having a positive impact on their lives and relationship (Lyons et al., 2022), research has found that some cancer survivors and partners experience high levels of anxiety and depression, even years beyond treatment (Costanzo et al., 2009; Mitchell et al., 2013; Champion et al., 2014; Kim et al., 2016; Shapiro, 2018; Lee and Lyons, 2019). A meta-analysis of predominantly mid-late life survivors reported an 11.6% (95% CI 7.7–16.2%) prevalence of depression for survivors versus 10.2% (95% CI 8.0–12.6%) for healthy controls; prevalence for survivors and their partners was not statistically significant (Mitchell et al., 2013). Much less is known about young adult couples, who are often under-represented in studies and overlooked for supportive programs (Barnett et al., 2016; Smith et al., 2016; Hydeman et al., 2019; Gorman et al., 2020), despite incidence rates of cancer increasing in this age group (Howlader et al., 2019; Scott et al., 2020).

With strong evidence of the interdependent nature of health within couples and protective role of open communication (e.g., active engagement) and collaborative behaviors (e.g., shared activities; Berg and Upchurch, 2007; Kim et al., 2016; Lyons et al., 2016b, 2018; Shaffer et al., 2016; Winters-Stone et al., 2016; Langer et al., 2017; Lyons and Lee, 2018; Acquati and Kayser, 2019; Falconier and Kuhn, 2019; Lee and Lyons, 2019; Gorman et al., 2020; Lee et al., 2020; Streck et al., 2020; Wilson et al., 2020; Hornbuckle et al., 2021; Stefanut et al., 2021), it is especially important to focus on the couple as a unit to identify at-risk couples who may be less able to support one another. Numerous dyadic theories have contributed greatly to the dyadic science of illness over the past two decades (Bodenmann, 1997; Revenson et al., 2005; Berg and Upchurch, 2007; Regan et al., 2015; Traa et al., 2015; Badr and Acitelli, 2017; Falconier and Kuhn, 2019). In particular, many of these dyadic theories highlight the importance of support and collaboration within couples through positive dyadic coping (i.e., open communication, supportive behaviors, and a sense of "we-ness") and the need to focus on the couple as a unit (Acitelli and Badr, 2005). The current study was guided by the theory of dyadic illness management (TDIM; Lyons and Lee, 2018), which similarly moves beyond an individual perspective of illness to focus on the couple as the unit of focus. The overall goal of the theory is to optimize health within the couple by holding the health and needs of each member in balance and recognizing the heterogeneity that exists within groups and across couples.

The TDIM purports that how couples manage an illness like cancer influences the dyadic health of the couple. Integrating research on illness management, caregiving, and dyadic coping, the theory primarily focuses on the concept of dyadic management behaviors—a broad conceptualization of the collaborative verbal and non-verbal behaviors couples engage in to manage and cope with illness and survivor symptoms (i.e., communication, supportive behaviors, collaborative symptom and care management behaviors, and shared health activities; Lyons and Lee, 2018; Lyons et al., 2022). The theory also proposes the importance of shared dyadic appraisal and roles of contextual risk and protective factors at the individual (e.g., age and sex), dyadic, familial, and cultural levels in optimizing dyadic health.

Two examples of dyadic management behaviors are the relationship-focused strategies of active engagement and protective buffering (Coyne and Smith, 1991; Buunk et al., 1996). Active engagement represents open and supportive communication about the illness by one's partner, providing opportunities to share feelings, be listened to and validated. Thus, active engagement has been considered a type of positive dyadic coping behavior (Buunk et al., 1996; Hagedoorn et al., 2000; Falconier and Kuhn, 2019), as well as a positive dyadic illness management behavior (Lyons and Lee, 2018). Alternatively, protective buffering represents the partner's denial of or attempt to minimize illness concerns or worries, or avoidance of discussing the illness together. Thus, protective buffering has been considered a type of negative dyadic coping behavior (Buunk et al., 1996; Hagedoorn et al., 2000; Falconier and Kuhn, 2019) and negative dyadic illness management behavior (Lyons and Lee, 2018). More open and supportive communication (i.e., active engagement) has been consistently associated with more positive health in both survivors and partners (Traa et al., 2015; Lyons et al., 2016a; Acquati and Kayser, 2019; Falconier and Kuhn, 2019; Lee and Lyons, 2019; Meier et al., 2019; Streck et al., 2020; Dewan et al., 2021; Stefanut et al., 2021). However, the vast majority of studies on couples surviving cancer involves mid-late life couples and primarily breast or prostate cancer, where sex and role are often confounded. Thus, the link between active engagement and depressive symptoms by survivor age and sex is unclear, leading to one size fits all approaches (Chan et al., 2021). Furthermore, despite the term sounding positive, protective buffering has been found to be negatively associated with poor relationship outcomes, clinical-events, and depressive symptoms (Falconier et al., 2015; Lee and Lyons, 2019; Lyons et al., 2020, 2021). Given that men are sometimes more likely to "hold back" and avoid disclosures (Manne et al., 2004b, 2005, 2015), and some evidence that younger partners may engage more in protective buffering (Acquati and Kayser, 2019), exploring how these associations vary by survivor age or sex is also needed.

Transitions and experiences in life are interpreted with regard to timing in the life course (chronological, familial, and social) and the context in which they take place (Neugarten, 1979; Hareven, 1994; Berg and Upchurch, 2007). Adults do not expect to experience cancer or assume a care role for their partner in young adulthood or midlife. Although young-midlife couples may experience some commonality in the "off-time" nature of the illness, they do not share the same stage in the life span. Young adult couples (under 40) are more likely to be new to their adult roles, beginning careers and families, in shorter relationships, have less experience with collaborative coping skills and health behaviors, and are more susceptible to contextual factors, such as financial strain and illness (Berg and Upchurch, 2007; American Psychological Association, 2019; Hydeman et al., 2019). The long-term effects of cancer and implications for the young adult couple (e.g., fertility, disruptions to career and family goals, and changes in relationships) may be especially challenging (Barnett et al., 2016; Corney et al., 2016; Collaço et al., 2019; Hydeman et al., 2019).

Researchers have consistently found younger survivors and younger couples to have more negative outcomes compared with older survivors and older couples (Harden et al., 2006; Champion et al., 2014; Borstelmann et al., 2015; Rottmann et al., 2016; Lee and Lyons, 2019), but broad age ranges in studies make it difficult to purposely examine age risk when younger couples are often poorly represented. A notable exception includes a cross-sectional study of couples living with breast cancer that compared 35 young couples (aged 45 or younger) to 51 midlife couples (aged 46–66) within 3 months of diagnosis that found younger survivors had worse physical and mental health, greater negative impact of cancer and less social support than midlife survivors. Similarly, younger partners had worse mental health than midlife survivors (Acquati and Kayser, 2019). No differences in dyadic coping were found between age-groups for survivors, but younger partners had more negative dyadic coping than midlife partners (Acquati and Kayser, 2019). It is unknown if the theoretically purported benefits of positive dyadic behaviors, such as active engagement and low levels of protective buffering on depressive symptoms, vary by survivor age.

Similarly, cancer research has predominantly focused on breast and prostate cancer, where sex and role are often confounded (e.g., all survivors in the study are female), limiting the ability to fully understand the role of survivor sex in how couples experience and navigate cancer. Evidence suggests females, regardless of role, experience more negative outcomes than males (Hagedoorn et al., 2008; Falconier and Kuhn, 2019). Although female survivors have been found to engage in more positive dyadic behaviors, such as open communication and support (Acquati and Kayser, 2019), and to be more likely than males to collaborate and define themselves relationally (Kiecolt-Glaser and Newton, 2001; Berg and Upchurch, 2007), they may also be more vulnerable when such collaboration is absent (Kiecolt-Glaser and Newton, 2001; Berg and Upchurch, 2007; Lyons et al., 2018). Given the importance placed on collaborative dyadic behaviors (particularly behaviors, such as active engagement) as protective for couples experiencing cancer, more deliberate research on the role of survivor sex in couples across the life span is needed to address this gap.

Thus, the current study builds upon previous research and is guided by the TDIM to explore the moderating roles of survivor age and sex (i.e., individual contextual factors) on the associations between active engagement and protective buffering (i.e., dyadic illness management behaviors) and depressive symptoms of survivor and partner (i.e., dyadic health) in young-midlife couples 1 to 3 years after diagnosis.

MATERIALS AND METHODS

The current exploratory study recruited couples through the Oregon State Cancer Registry *via* targeted mailings. Per the cancer registry's protocol, letters describing the study were mailed by registry staff to survivors meeting initial eligibility criteria (i.e., diagnosis data, age, and zip code to optimize representation of both rural and urban-dwelling couples). A total of 700 letters were mailed with equal numbers sent to young survivors (aged 21–39 at diagnosis) and midlife survivors (aged 40–56 at diagnosis). Additionally, recruitment flyers were posted in an oncology clinic at Oregon Health and Science University (OHSU). All interested couples were screened for eligibility by research staff at OHSU. Eligibility criteria included that (1) the survivor had a primary diagnosis of invasive cancer in the preceding 18–36 months, (2) couples were co-residing at the time of diagnosis and recruitment, (3) couples were aged 21 to 56 years at diagnosis, (4) couples had the ability to read English, (5) couples had access to a telephone, and (6) couples were resident in Oregon. We selected the upper bound of 56 years of age to minimize inclusion of couples considering retirement at time of diagnosis. Couples were not required to be married and couples of any sexual orientation were eligible to participate.

A total of 160 survivors expressed interest in the study (158 from the targeted registry mailings—23% response rate—and two from the fliers posted in the oncology clinic). Thirty-three survivors (21%) were lost to follow-up and could not be reached for a screening phone call, even after several attempts. A total of 77 couples (48%), who were screened by phone, were eligible. The remaining 50 survivors (31%) were screened as ineligible because they did not have a partner (36%), were older than 56 at diagnosis (40%), did not meet diagnosis criteria/reason unknown (10%), could not read English (4%), the survivor had died (6%), or declined to participate (4%). The 77 eligible couples were mailed a packet containing separate surveys for survivor and partner and separate consent forms. Couples were asked to complete surveys independently and return them with signed consent forms in the provided stamped-addressed envelopes. A total of 49 couples (64%) returned surveys and signed consent forms for both survivor and partner. The study was approved by the Institutional Review Board at Oregon Health and Science University (e#15498).

Measures

All sociodemographic information and measures for both members of the couple were obtained through their respective mail surveys.

Depressive Symptoms

Depressive symptoms were measured with the Center for Epidemiological Studies Depression scale that has good internal consistency, sensitivity, specificity, and validity (Radloff, 1977; Beekman et al., 1997), including in couples with cancer (Lyons et al., 2014). Survivors and partners responded to 20 statements using a 0 (rarely or none) to 3 (most or all) scale (e.g., "I was bothered by things that do not usually bother me," "I felt depressed," and "I did not feel like eating/appetite was poor"). Scores were summed with higher scores indicating greater depressive symptomatology. A score of 16 or above indicates likely depression and the need for further assessment (Radloff, 1977). More recent research suggests a clinical cut-off score of 20 or above may have a more adequate trade-off of sensitivity and specificity for depression (Vilagut et al., 2016). Cronbach's alpha in the current study was 0.91 for survivors and 0.92 for partners.

Dyadic Illness Management Behaviors

Dyadic illness management behaviors are operationalized in two ways in the current study—active engagement and protective buffering. Active engagement and protective buffering were measured using the two subscales of the Dyadic Coping measure (Buunk et al., 1996; Hagedoorn et al., 2000). The active engagement subscale has five items that assess the extent to which the survivor and partner view each other's active involvement and support (e.g., "my partner tries to discuss cancer with me openly," "when something bothers me, my partner tries to discuss it with me," and "my partner is full of understanding towards me"). Participants respond to the five items using a Likert scale from 1 (never) to 5 (very often). Higher scores indicate higher levels of perceived active engagement by one's partner. The scale has exhibited strong internal consistency in studies of couples with cancer (Hagedoorn et al., 2000; Hinnen et al., 2007), including the current study (Cronbach's alpha for survivor = 0.89; Cronbach's alpha for partner = 0.81). The protective buffering subscale consists of six items that assess the extent to which the survivor and partner view each other's use of hiding concerns and denying worries (e.g., "my partner tries to hide his or her worries about me," "my partner just waves my worries aside," and "my partner tries to act like nothing is the matter"). Participants respond to six items using a Likert scale from 1 (never) to 5 (very often). Higher scores indicate higher levels of perceived protective buffering by one's partner. The scale has exhibited good internal consistency in studies of couples with cancer (Hinnen et al., 2007), including the current study (Cronbach's alpha for survivor = 0.77; Cronbach's alpha for partner = 0.65).

Analysis Plan

Descriptive statistics were used to characterize the sample (SPSS v26; IBM Corporation, Armonk, NY). Paired samples t-tests were used to compare survivor and partner depressive symptoms, active engagement and protective buffering due to the interdependent nature of the data. Multilevel modeling (Hierarchical Linear Modeling v8; Skokie, IL) was used to explore the moderating roles of survivor age and sex on the associations between active engagement and protective buffering and depressive symptoms at the level of the couple to control for interdependencies between survivor and partner data (Garcia et al., 2015). HLM uses full information maximum likelihood estimation, which estimates parameter values based on all existing data available to obtain unbiased estimates.

Two models were run to explore the moderating role of survivor age (as a continuous variable) on the association between each dyadic behavior (i.e., active engagement and protective buffering) and depressive symptoms. Each model included a moderated actor term that represented the interaction between survivor age and survivor report of the dyadic behavior (i.e., active engagement and protective buffering) and a moderated partner term that represented the interaction between survivor age and partner report of the dyadic behavior (i.e., active engagement and protective buffering; Garcia et al., 2015). A significant interaction effect was deemed evidence of moderation. Due to the small sample size, effect sizes $r = \sqrt{\frac{t^2}{\left(t^2 + df\right)}}$ were calculated and reported. Only results with medium ($r = 0.30$) or large ($r = 0.50$) effects were interpreted. Figures depict each variable's high (1 *SD* above the mean) and low (1 *SD* below the mean) values. A similar procedure was used to examine the moderating role of survivor sex on the association between each dyadic behavior (i.e., active engagement and protective buffering) and depressive symptoms. Variables were centered prior to creating interaction terms except for survivor sex, which was coded as 0 (male) and 1 (female).

Survivor age was treated as a continuous variable in moderation analyses due to significant disadvantages of dichotomizing data including significant loss of information, variability, statistical power (especially in small samples), and higher risk of false positive results (Altman and Royston, 2006). Thus, the role of age in moderation analyses is interpreted as the role of increasing/decreasing age (or being older or younger) across young-mid adulthood.

RESULTS

Sample Characteristics

Table 1 displays the sociodemographic and background characteristics for the sample of 49 couples. Survivors and partners were, on average, 43.5 (*SD* = 9.0) and 43.9 (*SD* = 9.7) years old, respectively, with 43% of the sample between the ages of 27 and 40. Survivors were predominantly female (69%), white (90%), non-Hispanic (88%), employed (61%), and had completed college. Average time since diagnosis was 2.26 (*SD* = 0.60) years. Partners were predominantly male (67%), white (82%), non-Hispanic (88%), employed (76%), and completed college (59%). Almost half of couples lived in designated rural areas. The small number of Hispanic couples (12%) was primarily rural dwelling and under 40 years of age.

TABLE 1 | Demographics and characteristics of survivors and partners ($n = 49$ couples).

Participant characteristics	Survivors M ± SD or *n* (%)	Partner M ± SD or *n* (%)	*t* statistic	Cohen's *d*	Correlation
Age (years)	43.5 ± 9.0	43.9 ± 9.7	−0.43		0.79***
Sex (% female)	34 (69%)	16 (33%)			
Race (% white)	44 (90%)	40 (82%)			
Ethnicity (% Hispanic)	6 (12%)	6 (12%)			
Education (% completed college)	36 (74%)	29 (59%)			
Employment (% employed)	30 (61%)	37 (76%)			
Residence (% rural location)	22 (45%)	–			
Length of co-residence (years)	16.6 ± 9.9	–			
Years since diagnosis	2.2 ± 0.6	–			
Depressive symptoms (0–60)	15.5 ± 11.3	12.6 ± 10.2	1.49	0.22	0.22
Active engagement (0–20)	13.4 ± 4.7	13.2 ± 3.8	0.26	0.04	0.30*
Protective buffering (0–24)	9.2 ± 4.9	7.5 ± 3.7	1.91	0.29	0.02

*Differences between survivors and partners were examined using paired t-tests. Correlations represent paired samples correlations between survivors and partners. *$p < 0.05$ and ***$p < 0.001$.*

Breast cancer was the most common diagnosis for survivors (20%), followed by cervical/ovarian (13%), colon (10%), and renal (10%).

Differences in Depressive Symptoms, Active Engagement, and Protective Buffering by Role, Survivor Age Group, and Survivor Sex

Table 1 includes comparisons by role (i.e., survivor versus partner) in depressive symptoms, active engagement, and protective buffering. On average, survivor depressive symptoms were 15.5 ($SD = 11.3$) with 37% of survivors at or above a score of 16 (clinical cut-off for further assessment). Partner depressive symptoms were, on average, 12.6 ($SD = 10.2$) with 27% of partners at or above a score of 16. Half of couples in the sample had at least one member meeting the clinical cut-off (17% of couples had both members). There were no significant differences found between survivors and partners on depressive symptoms, or in perceived active engagement and protective buffering. Depressive symptoms between survivors and partners were correlated at 0.22, indicating some covariation. Reports of active engagement were similarly correlated within couples. However, survivor and partner reports of protective buffering showed little to no correlation.

Table 2 includes comparisons by survivor age group (aged <40 versus aged 40 and older) in depressive symptoms, active engagement, and protective buffering. There were no significant differences in survivor or partner depressive symptoms, active engagement, or protective buffering behaviors by age group. Although not statistically significant, medium effects suggest younger survivors were more likely to report higher levels of active engagement by their partner (Cohen's $d = 0.50$) than midlife survivors; younger partners were more likely to report higher levels of active engagement by their survivor (Cohen's $d = 0.55$).

Table 3 includes comparisons by survivor sex in depressive symptoms, active engagement, and protective buffering. There were no significant differences in depressive symptoms by survivor sex for survivors or partners. Significant sex differences were found for survivor-reported active engagement and survivor-reported protective buffering. Male survivors ($p < 0.05$; Cohen's $d = 0.57$) reported significantly higher active engagement by their partner than female survivors. Female survivors ($p < 0.05$; Cohen's $d = -0.74$) reported significantly higher protective buffering by their partner than male survivors. No significant differences were found for partners.

Moderating Role of Survivor Age on the Associations Between Active Engagement and Protective Buffering and Depressive Symptoms

Table 4 includes the results of the moderation analysis using age as a continuous variable. One significant interaction was found. First, we found evidence of a moderated partner effect in that survivor age significantly moderated the association between the survivor's perception of protective buffering (in their partner) and partner depressive symptoms [$p < 0.5$; ES $(r) = 0.32$]. Older partners, whose survivors perceived them to engage in lower protective buffering, reported lower depressive symptoms. In contrast, younger partners, whose survivor perceived them to engage in lower protective buffering, reported higher depressive symptoms (**Figure 1A**). No significant moderation effects were found for survivor depressive symptoms.

Moderating Role of Survivor Sex on the Associations Between Active Engagement and Protective Buffering and Depressive Symptoms

Table 5 includes the results of the analysis exploring survivor sex as a moderator. Three significant interactions were found. First, we found evidence of a moderated actor effect in that survivor sex significantly moderated the association between survivor's report of protective buffering (by their partner) on survivor depressive symptoms [$p < 0.05$; ES $(r) = 0.39$]. Female survivors, who reported fewer depressive symptoms, were significantly more likely to report their partners engaging in low levels of protective buffering. Male survivors, who reported fewer depressive symptoms, were significantly more likely to report their partner engaging in high levels of protective buffering (**Figure 1B**).

Second, we found evidence of a moderated partner effect in that survivor sex significantly moderated the association

TABLE 2 | Comparison of depressive symptoms, active engagement, and protective buffering by survivor age group ($n = 49$ survivors).

Variable	Young SVRs (<40 years old) M ± SD	Midlife SVRs (> 40 years old) M ± SD	*t* statistic	Cohen's *d*
SVR depressive symptoms	13.4 ± 9.1	16.6 ± 12.2	−1.35	−0.29
Partner depressive symptoms	9.7 ± 10.4	13.9 ± 9.9	−1.35	−0.42
SVR active engagement	15.0 ± 3.6	12.7 ± 5.1	1.68	0.50
Partner active engagement	14.5 ± 3.8	12.5 ± 3.6	1.83	0.55
SVR protective buffering	8.7 ± 4.8	9.7 ± 5.0	−0.64	−0.19
Partner protective buffering	7.4 ± 4.1	7.2 ± 3.8	0.14	0.04

SVR, survivor.

TABLE 3 | Comparison of depressive symptoms, active engagement, and protective buffering by survivor sex ($n = 49$ survivors).

Variable	Female SVRs M ± SD	Male SVRs M ± SD	*t* statistic	Cohen's *d*
SVR depressive symptoms	16.3 ± 11.7	13.3 ± 9.8	−0.86	−0.27
Partner depressive symptoms	12.1 ± 7.8	13.4 ± 14.6	0.313	0.13
SVR active engagement	12.8 ± 5.3	14.4 ± 2.6	2.37*	0.57
Partner active engagement	12.9 ± 3.6	13.9 ± 4.3	0.85	0.27
SVR protective buffering	10.4 ± 5.1	6.9 ± 3.6	−2.37*	−0.74
Partner protective buffering	7.5 ± 3.6	6.8 ± 4.3	−0.60	−0.19

*SVR, survivor. *$p < 0.05$.*

between partner's report of protective buffering (by the survivor) on survivor depressive symptoms [$p < 0.05$; ES (r) = 0.31]. Female survivors, who reported fewer depressive symptoms, were significantly more likely to have partners, who perceived them (the survivor) as engaging less in protective buffering. Male survivors, who reported fewer depressive symptoms, were significantly more likely to have partners, who perceived them (the survivor) as engaging more in protective buffering (**Figure 1C**).

Third, we found evidence of another moderated partner effect in that survivor sex significantly moderated the association between survivor's report of active engagement (by their partner) on partner depressive symptoms [$p < 0.01$; ES (r) = 0.40]. The depressive symptoms reported by partners of female survivors (almost all men) had little to no association with how the female survivor perceived the active engagement of the partner. In contrast, partners of male survivors (almost all women) had more depressive symptoms when the male survivor reported them as engaging in more active engagement (**Figure 1D**).

DISCUSSION

This study set out to explore the moderating roles of survivor age and sex on the associations between active engagement and protective buffering and depressive symptoms among young-midlife couples 1 to 3 years after diagnosis. Although this study was limited by sample size, there are several noteworthy findings to inform future work. First, we found that over a third of survivors and a quarter of partners experienced high enough depressive symptomatology 1 to 3 years post-diagnosis to require further clinical assessment. We found no significant differences in level of depressive symptoms between survivors and partners or by survivor age group or sex. Within couples, we found that half of couples had at least one member (17% had both members) scoring above the clinical cut-off for further assessment. Second, although active engagement and protective buffering behaviors did not differ significantly between survivors and partners, we did find group differences by survivor sex. Male survivors reported significantly higher levels of active engagement by their partners than female survivors and female survivors reported significantly higher levels of protective buffering by their partners than male survivors. Finally, we found some evidence to suggest that survivor age and sex may play moderating roles between these behaviors and depressive symptoms. Older partners and female survivors appeared to experience more positive effects than younger partners and male survivors.

Consistent with previous research (Mitchell et al., 2013; Champion et al., 2014; Shapiro, 2018), this study found that some couples surviving cancer beyond the first year still experience depressive symptoms. In contrast to a study of 1,127 couples 3–8 years post-diagnosis that reported 18–27% of survivors with likely clinical depression requiring further assessment, our study (using similar clinical cut-offs) found 37% of survivors and 27% of partners requiring further assessment (Champion et al., 2014). Even using a more conservative cut-off of 20 that has been found to have a more adequate sensitivity-specificity balance for depression (Vilagut et al., 2016), our sample had 29% of survivors and 23% of partners meeting

TABLE 4 | Moderating role of survivor age on associations between active engagement and protective buffering and depressive symptoms ($n = 49$ couples).

Variables	Depressive symptoms			
	SVRs		Partners	
	B (SE)	ES (r)	B (SE)	ES (r)
Active engagement				
SVR age	0.18 (0.19)	0.14	0.11 (0.18)	0.09
SVR-reported active engagement	−0.28 (0.37)	0.12	0.21 (0.33)	0.10
Partner-reported active engagement	0.18 (0.19)	0.14	−0.08 (0.42)	0.03
SVR age*SVR-reported active engagement	−0.03 (0.04)	0.11	−0.02 (0.04)	0.08
SVR age*Partner-reported active engagement	0.05 (0.05)	0.17	−0.07 (0.04)	0.22
Protective buffering				
SVR age	0.20 (0.17)	0.19	0.06 (0.16)	0.06
SVR-reported protective buffering	0.56 (0.32)	0.27	0.24 (0.30)	0.02
Partner-reported protective buffering	0.34 (0.45)	0.12	0.74 (0.42)	0.28
SVR age*SVR-reported protective buffering	0.02 (0.04)	0.09	0.08 (0.04)*	0.32
SVR age*Partner-reported protective buffering	0.01 (0.05)	0.02	0.07 (0.04)	0.25

B, unstandardized coefficient; SVR, survivor. Survivor age was included as a continuous variable. Both survivor age and both dyadic management behavior variables were centered to create interaction terms. Higher scores on active engagement and protective buffering indicate higher levels of each behavior. Effect size $r = \sqrt{\frac{t^2}{\left(t^2 + df\right)}}$. *$^*p < 0.05$.*

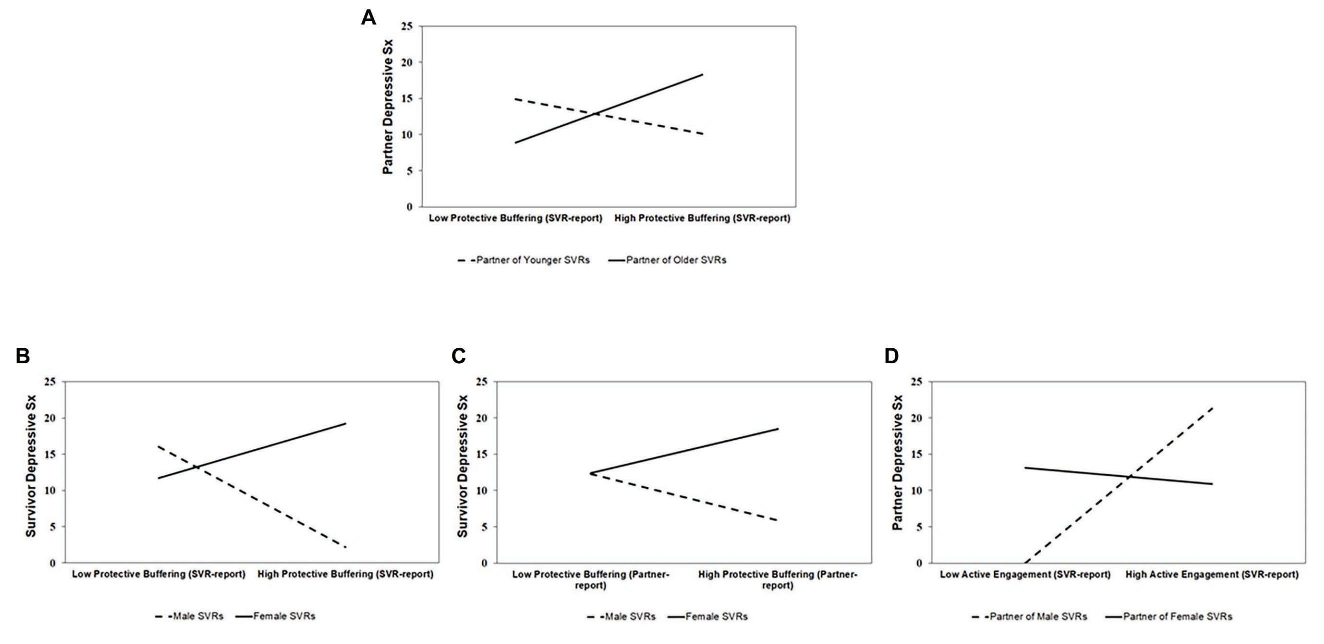


FIGURE 1 | The moderating effects of survivor age and sex on the associations between active engagement and protective buffering and depressive symptoms. Panel **(A)** shows the moderating role of survivor age on the association between survivor-reported protective buffering on partner depressive symptoms. Panels **(B–D)** show the moderating role of survivor sex on the association of survivor-reported protective buffering on survivor depressive symptoms, partner-reported protective buffering on survivor depressive symptoms, and survivor-reported active engagement on partner depressive symptoms, respectively. High and low values represent 1 SD above and below the mean on age, active engagement, and protective buffering. Sex was coded 0 (males) and 1 (females).

criteria. Moreover, 50% of our couples had one or both members meeting criteria. Unlike recent research on couples living with breast cancer, we did not find significant age-group differences (Acquati and Kayser, 2019) or survivor sex differences in depressive symptoms. As so little couple research in cancer has focused on cancers involving both sexes in young to mid-adulthood, replication of findings is needed before drawing strong conclusions about the lack of sex differences, though we acknowledge that 69% of survivors in our sample were female.

Despite the growing body of literature supporting the protective roles of open communication, supportive behaviors, and shared collaborative activities on the interdependent health

TABLE 5 | Moderating role of survivor sex on associations between active engagement and protective buffering and depressive symptoms ($n = 49$ couples).

Variables	**Depressive symptoms**			
	SVRs		**Partners**	
	B (SE)	**ES (r)**	**B (SE)**	**ES (r)**
Active engagement				
SVR sex	6.31 (4.12)	0.05	3.75 (3.62)	0.16
SVR-reported active engagement	1.65 (1.20)	0.21	2.78 (1.01)**	0.39
Partner-reported active engagement	0.23 (0.72)	0.05	−0.44 (0.62)	0.11
SVR sex*SVR-reported active engagement	−2.07 (1.26)	0.25	−3.01 (1.07)**	0.40
SVR sex*Partner-reported active engagement	−0.25 (0.91)	0.04	0.60 (0.79)	0.01
Protective buffering				
SVR sex	6.36 (3.70)	0.27	−2.13 (3.88)	0.09
SVR-reported protective buffering	−1.40 (0.75)	0.29	0.24 (0.83)	0.05
Partner-reported protective buffering	−0.83 (0.60)	0.22	0.92 (0.71)	0.21
SVR sex*SVR-reported protective buffering	2.16 (0.83)*	0.39	−0.08 (0.91)	0.01
SVR sex*Partner-reported protective buffering	1.63 (0.80)*	0.31	−0.86 (0.91)	0.15

B, unstandardized coefficient; SVR, survivor. Survivor sex was coded 0 (male) and 1 (female). Both dyadic management behavior variables were centered to create interaction terms. Higher scores on active engagement and protective buffering indicate higher levels of each behavior. Effect size $r = \sqrt{\frac{t^2}{\left(t^2 + df\right)}}$. *$^*p < 0.05$ and $^{**}p < 0.01$.*

of the dyad (Berg and Upchurch, 2007; Berg et al., 2008; Falconier et al., 2015; Regan et al., 2015; Traa et al., 2015; Shaffer et al., 2016; Lyons and Lee, 2018; Streck et al., 2020; Stefanut et al., 2021), few studies have explicitly examined whether such beneficial effects vary by survivor age or sex. Our findings suggest that the beneficial effects of such behaviors may not be universal.

Specifically, older partners (i.e., as age increased) experienced lower depressive symptoms when the survivor reported them as engaging in less protective buffering. Thus, partners, in our sample, more likely to be older (i.e., in midlife) than younger, benefitted from low levels of protective buffering. Yet, younger partners did not appear to benefit similarly in the current sample. Younger couples tend to be newer to their relationships with one another (as was true in our study) and may be less experienced in these types of positive communication skills and supportive behaviors than older couples (Berg and Upchurch, 2007), with recent evidence that younger partners engage in significantly higher levels of negative dyadic behaviors than midlife partners (Acquati and Kayser, 2019). The off-time nature of the cancer experience and unexpected role of care partner may be particularly challenging for younger-aged partners, who may be unsure of how to emotionally support the survivor over time and the appropriateness of balancing their own needs.

Relatedly, the social cognitive processing theory (Lepore and Revenson, 2007) purports that our psychological health is influenced by our ability to process and discuss traumatic events, such as a cancer diagnosis, with those who are closest to us. When attempts to discuss or communicate openly about the experience with one's partner or family member is perceived to be met with unsupportive responses or social constraints, the person attempting to share can be hindered in their ability to cognitively process the experience, leading to intrusive thoughts and cognitive avoidance, and ultimately higher depressive symptoms (Lepore and Revenson, 2007; Cohee et al., 2017). Several items on the protective buffering measure are similar to those on measures of social constraint by one's partner (e.g., "my partner tries to hide worries about me," "my partner tries to act as if nothing is the matter," "my partner just waves my worries aside," and "my partner does everything to prevent me from thinking about my cancer"). Thus, when young survivors in the current sample reported high levels of what could be considered social constraint behaviors by their partners, partners reported low levels of depressive symptoms. It is possible that younger partners are experiencing some benefit from not engaging in open communication and discussion about the cancer experience either because they see their supportive role as one of protection through denial and distraction (Manne et al., 2004a, 2005, 2015; Lepore and Revenson, 2007), because they lack skills and confidence to openly communicate, or such supportive and open communication about their partner's cancer may be too emotionally draining for them (Ernst et al., 2017; Crangle et al., 2020; Reblin et al., 2020). It is also possible they perceived social constraints from the survivor. All of which highlight the complexity of communication and support within couples experiencing illness and need for couple-based interventions to facilitate these skills of sharing and reciprocal disclosure, particularly for those in care partner and supportive roles, who often feel guilty about expressing their own needs and challenges (Spillers et al., 2008; Yeung et al., 2018).

However, given the cross-sectional nature of the study, it is also possible that younger partners with high levels of depressive symptoms were more likely to be perceived by the younger survivor as engaging in less protective buffering. Younger couples may not want or be unsure of how to openly discuss due to their earlier stage in life and early stage of the relationship, and may be more prone to want to move on and avoid discussion or believe this is the positive thing to do (Pistrang and Barker, 2005). Clearly, much more research is needed to untangle these effects and how they unfold for the younger couple over time.

Similarly, we found differential effects by survivor sex. Female survivors, who reported few depressive symptoms, were either significantly more likely to report their partners engaging in lower levels of protective buffering or were more likely to have partners who perceived them (the survivor) as engaging less in protective buffering. The same beneficial effect was not observed for male survivors. This raises the potential of how male survivors are interpreting the meaning and value of protective buffering behaviors (by themselves and their partners) and whether we are detecting engendered effects about the relational nature of women's identities versus the social expectations of masculinity that may drive patterns of distraction and denial/avoidance by men in illness contexts (Manne et al., 2005, 2015; Pistrang and Barker, 2005; Badr and Carmack Taylor, 2006; Mahalik and Dagirmanjian, 2019). Men, across races, ethnicities, and the adult life span, have been found to seek help for mental health and depression less than women (Addis and Mahalik, 2003). Indeed, recent research suggested that husbands of women with breast cancer, who highly endorsed masculine strength, experienced significantly higher levels of guilt when they did seek help and those husbands who engaged in protective buffering experienced significantly less guilt (Yeung et al., 2018).

Finally, partners of male survivors (all women but one) reported higher levels of depressive symptoms when the survivor perceived them to be engaged in high levels of active engagement. It is unclear if this indicates that partners experiencing higher levels of depressive symptoms were prompted to engage in more open communication to deal with what they were experiencing and as a way to process and seek support rather than the engagement in open communication leading to depressive symptoms. Though social cognitive processing theory would suggest that if those active engagement behaviors, by the predominantly female partners in the study, were met with social constraint, they could lead to poor mental health over time (Lepore and Revenson, 2007).

It is unfortunately not possible to untangle the full story behind the effects observed in the current study, nor tease apart what may well be an intersection of age and sex in how styles of communication and ability to openly communicate, receive the communication and reciprocally disclose are interpreted and used. Social constraints arise not only from the environment and social context present, but are also strongly driven by the interpretation of the person disclosing (Lepore and Revenson, 2007), which may not be readily understood by the person hearing that disclosure. Although much of the work around couple communication in cancer and other illnesses has focused on the survivor's disclosures and the supportive/unsupportive behaviors and responses of their partner, a more balanced approach to the transactions within couples and partner's disclosures may lead to a more shared understanding of the positive ways to communicate and support, promote reciprocal disclosures, empathetic listening, and perspective-taking by both. In addition to the potential roles of age and sex in dyadic behaviors, the family care literature highlights some of the misplaced assumptions and guilt care partners can feel in voicing their own needs and challenges, particularly for male and younger partners (Spillers et al., 2008; Yeung et al., 2018). This guilt and perceived role expectations to remain positive and focus solely on the needs of their partner with illness may hinder the couple from achieving healthy, long-term communication, and mutually supportive skills and strategies. Research has consistently found that care partners also experience negative outcomes and poor health as in the current study (Kent et al., 2016; Kim et al., 2016; Shaffer et al., 2016), sometimes at significantly higher levels than the person with illness (Lee and Lyons, 2019).

Limitations

There are several important limitations to the current work. First, the sample is small and cross-sectional. This not only prevents us from drawing any conclusions about directionality of associations (though theory strongly guided our research questions), but we are underpowered to adequately test moderation and draw strong conclusions from our findings. We tried to ameliorate the small sample by focusing only on those results with medium-large effect sizes and using age as a continuous variable in the moderation analyses (Altman and Royston, 2006), but call for replication of our results in larger, more diverse samples. Second, our homogeneous sample also lacked racial diversity and included only one same-sex couple preventing us from examining these associations within groups of couples. Thus, it is possible that in larger, more diverse samples or samples focused solely on couples under-represented in couple research, we may uncover other contexts where the benefits of dyadic behaviors are not present or are unclear. Finally, we did not limit our sample to a certain type of cancer or group of cancers as we deliberately wanted to explore survivor sex separate from role (i.e., survivor versus partner). We acknowledge the heterogeneity that this introduces, but given that our guiding theory purports to be relevant for most illness contexts, we believe this inclusive criterion has provided salient information. Finally, we did not include a measure of collaborative illness management in the study so cannot compare the more non-verbal ways couples collaborate and support one another in the context of illness.

Strengths and Implications

Despite these limitations, this population-based study contributes to the field of dyadic science in cancer in several ways. First, our results question the universal benefits of more open communication and the potentially salient roles of survivor age and sex. It is our hope that these results will guide future directions for more deliberate research to examine these processes within larger samples over time in more nuanced ways. Moreover, to truly examine the role of age in dyadic processes and behaviors, samples should purposely include couples across the entire adult life span (Acquati and Kayser, 2019). Second, we believe our inclusion of more than one cancer increases the generalizability of our findings and prompts further work to tease apart the intersectionality of sex, age, and role. Third, our purposeful focus and recruitment of couples under the age of 40 1–3 years post-diagnosis from both rural and urban areas adds to the emerging body of research on the ongoing challenges and experiences of these overlooked couples. Finally, our findings highlight the ongoing emotional strain experienced by some young and midlife couples surviving cancer after the first year of diagnosis.

We see several implications from this work. Examining the roles of sex and age within diverse groups of couples is needed to understand how dyadic processes hold up in different cultures and contexts across the life span. Moreover, the role of family around the couple is often neglected from the dyadic science of illness, yet the family context and family relationships can play important (albeit different) roles for couples across the life span and in different cultures (Carter et al., 2010; Jeong et al., 2018; Bonds Johnson et al., 2021). We have found familial support to be an important factor for dyadic outcomes in much of our research (Lyons and Lee, 2018; Lyons et al., 2021, 2022). Combining dyadic theories of health and illness with more specific theories of social cognitive processing and communication may lead to more balanced and nuanced ways to design couple-based interventions that not only facilitate communication skills and non-verbal collaboration, but also acknowledge the challenges for care partners, the readiness to share and listen within the couple, and times when other supporters beyond the couple may be beneficial. Furthermore, supportive and open communication is just one way that couples collaborate and manage cancer together. The TDIM purports that dyadic illness management behaviors comprise of not just open communication, but also supportive behaviors to survivor and care partner, shared health behaviors, and collaborative illness and care management behaviors (Lyons and Lee, 2018; Lyons et al., 2022). Thus, multicomponent couple-based interventions and approaches may be optimal and provide maximum tailoring to the specific needs and challenges of couples.

Clearly, one size does not fit all couples and challenges around communication and support may change with the cancer trajectory, stage of cancer, place in the life span, stage of the relationship, the sex of both survivor and partner, and their role in the relationship. Younger couples may be particularly in need of interventions to learn to cope with stress compared to older couples who may have already weathered challenges together. Similarly, some men (particularly in partner roles) may benefit from more nuanced approaches to open communication that acknowledge the role of more traditional masculine identities and potential lack of skill and experience with disclosure and open communication. Research that delves deeper into the ways couples communicate and collaborate and identifies couples who are most vulnerable and unable to support one another is needed. Recent longitudinal work examining communication and relationship outcomes using ecological momentary assessment is a noteworthy example (Langer et al., 2018). The dyadic science of illness and health has led to important and relevant theories and knowledge and directly informed effective couple-based interventions (Li and Loke, 2014; Winters-Stone et al., 2016; Langer et al., 2018; Hornbuckle et al., 2021; Reese et al., 2021). This study not only supports that work but prompts further exploration of when, why, and for whom these processes do not lead to beneficial outcomes.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Institutional Review Board at Oregon Health and Science University (e#15498). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

KL and BH-L contributed to the conceptualization and design of the study. JG contributed to the conceptualization of the study. BL contributed to the data management and preliminary analysis. GD contributed to the preliminary analysis. KL wrote the first draft of the manuscript. KL and JG wrote sections of the manuscript. All authors contributed to the manuscript revision, read, and approved the submitted version.

FUNDING

This work was generously supported by the Betty Gray Foundation, Oregon.

ACKNOWLEDGMENTS

The authors are sincerely grateful to the couples who participated and for the support of the staff at the Oregon State Cancer Registry (OSCaR). We are also grateful to Susan Rosenkranz, Wafaa Bin Ali, and Mashael Dewan for their roles in recruitment and data collection.

REFERENCES

Acitelli, L. K., and Badr, H. J. (2005). "My illness or our illness? attending to the relationship when one partner is ill," in *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping*. eds. T. A. Revenson, K. Kayser and G. Bodenmann (Washington, DC: American Psychological Association), 121–136.

Acquati, C., and Kayser, K. (2019). Dyadic coping across the lifespan: A comparison between younger and middle-aged couples with breast cancer. *Front. Psychol.* 10:404. doi: 10.3389/fpsyg.2019.00404

Addis, M. E., and Mahalik, J. R. (2003). Men, masculinity, and the contexts of help-seeking. *Am. Psychol.* 58, 5–14. doi: 10.1037/0003-066X.58.1.5

Altman, D. G., and Royston, P. (2006). The cost of dichotomising continuous variables. *Br. Med. J.* 332:1080. doi: 10.1136/bmj.332.7549.1080

American Cancer Society (2021). *Cancer Treatment and Survivorship Facts and Figures 2019–2021*. Atlanta: American Cancer Society.

American Psychological Association (2019). Stress in America: Stress and Current Events (Online). Available at: https://www.apa.org/news/press/releases/stress/2019/stress-america-2019.pdf (Accessed January 20, 2020).

Badr, H., and Acitelli, L. K. (2017). Re-thinking dyadic coping in the context of chronic illness. *Curr. Opin. Psychol.* 13, 44–48. doi: 10.1016/j.copsyc.2016.03.001

Badr, H., and Carmack Taylor, C. L. (2006). Social constraints and spousal communication in lung cancer. *Psycho-Oncology* 15, 673–683. doi: 10.1002/pon.996

Barnett, M., Mcdonnell, G., Derosa, A., Schuler, T., Philip, E., Peterson, L., et al. (2016). Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *J. Cancer Surviv.* 10, 814–831. doi: 10.1007/s11764-016-0527-6

Beekman, A. T. F., Deeg, D. J. H., Van Limbeek, J., Braam, A. W., De Vries, M. Z., and Van Tilburg, W. (1997). Criterion validity of the Center for Epidemiological Studies Depression Scale (CES-D): results from a community-based sample of older subjects in the Netherlands. *Psychol. Med.* 27, 231–235. doi: 10.1017/S0033291796003510

Berg, C. A., and Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol. Bull.* 133, 920–954. doi: 10.1037/0033-2909.133.6.920

Berg, C. A., Wiebe, D. J., Butner, J., Bloor, L., Bradstreet, C., Upchurch, R., et al. (2008). Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychol. Aging* 23, 505–516. doi: 10.1037/a0012687

Bodenmann, G. (1997). Dyadic coping - a systematic-transactional view of stress and coping among couples: theory and empirical findings. *Eur. Rev. Appl. Psychol.* 47, 137–140.

Bonds Johnson, K., Brewster, G. S., Cicero, E., Hepburn, K., Clevenger, C. K., Daniel, G., et al. (2021). Promoting caregiver mastery in black American dementia caregivers. *Gerontologist*. doi: 10.1093/geront/gnab147, [Epub Ahead of Print].

Borstelmann, N. A., Rosenberg, S. M., Ruddy, K. J., Tamimi, R. M., Gelber, S., Schapira, L., et al. (2015). Partner support and anxiety in young women with breast cancer. *Psycho-Oncology* 24, 1679–1685. doi: 10.1002/pon.3780

Buunk, B. P., Berkhuysen, M. A., Sanderman, R., Nieuwland, W., and Ranchor, A. V. (1996). Actieve betrokkenheid, beschermend bufferen en overbescherming: Meetinstrumenten voor de role van de partner bij hartrevalidatie [The role of the partner in heart disease: active engagement, protective buffering, and overprotection]. *Gedrag. Gezondheid.* 24, 304–313.

Carter, J. H., Lyons, K. S., Stewart, B. J., Archbold, P. G., and Scobee, R. (2010). Does age make a difference in caregiver strain? Comparison of young versus older caregivers in early-stage Parkinson's disease. *Mov. Disord.* 25, 724–730. doi: 10.1002/mds.22888

Champion, V. L., Wagner, L. I., Monahan, P. O., Daggy, J., Smith, L., Cohee, A., et al. (2014). Comparison of younger and older breast cancer survivors and age matched controls on specific and overall quality of life. *Cancer* 120, 2237–2246. doi: 10.1002/cncr.28737

Chan, R. J., Nekhlyudov, L., Duijts, S. F. A., Hudson, S. V., Jones, J. M., Keogh, J., et al. (2021). Future research in cancer survivorship. *J. Cancer Surv.* 15, 659–667. doi: 10.1007/s11764-021-01102-x

Cohee, A. A., Adams, R. N., Fife, B. L., Von Ah, D. M., Monahan, P. O., Zoppi, K. A., et al. (2017). The relationship between depressive symptoms and social cognitive processing in partners of long-term breast cancer survivors. *Oncol. Nurs. Forum* 44, 44–51. doi: 10.1188/17.ONF.44-51

Collaço, N., Wagland, R., Alexis, O., Gavin, A., Glaser, A., and Watson, E. K. (2019). The challenges on the family unit faced by younger couples affected by prostate cancer: A qualitative study. *Psycho-Oncology* 28, 329–335. doi: 10.1002/pon.4944

Corney, R., Puthussery, S., and Swinglehurst, J. (2016). Couple relationships in families with dependent children after a diagnosis of maternal breast cancer in the United Kingdom: perspectives from mothers and fathers. *J. Psychosoc. Oncol.* 34, 413–431. doi: 10.1080/07347332.2016.1199080

Costanzo, E. S., Ryff, C. D., and Singer, B. H. (2009). Psychosocial adjustment among cancer survivors: findings from a national survey of health and well-being. *Health Psychol.* 28, 147–156. doi: 10.1037/a0013221

Coyne, J. C., and Smith, D. A. (1991). Couples coping with a myocardial infarction: A contextual perspective on wives' distress. *J. Pers. Soc. Psychol.* 61, 404–412. doi: 10.1037/0022-3514.61.3.404

Crangle, C. J., Torbit, L. A., Ferguson, S. E., and Har, T. L. (2020). Dyadic coping mediates the effects of attachment on quality of life among couples facing ovarian cancer. *J. Behav. Med.* 43, 564–575. doi: 10.1007/s10865-019-00096-3

Dewan, M. F., Gorman, J. R., Hayes-Lattin, B., and Lyons, K. S. (2021). Open communication and physical intimacy in young-midlife couples surviving cancer. *Oncol. Nurs. Forum* 48, 669–679. doi: 10.1188/21.onf.669-679

Ernst, J., Hinz, A., Niederwieser, D., Döhner, H., Hönig, K., Vogelhuber, M., et al. (2017). Dyadic coping of patients with hematologic malignancies and their partners and its relation to quality of life – a longitudinal study. *Leuk. Lymphoma* 58, 655–665. doi: 10.1080/10428194.2016.1194983

Falconier, M. K., Jackson, J. B., Hilpert, P., and Bodenmann, G. (2015). Dyadic coping and relationship satisfaction: a meta-analysis. *Clin. Psychol. Rev.* 42, 28–46. doi: 10.1016/j.cpr.2015.07.002

Falconier, M. K., and Kuhn, R. (2019). Dyadic coping in couples: A conceptual integration and a review of the empirical literature. *Front. Psychol.* 10:571. doi: 10.3389/fpsyg.2019.00571

Garcia, R. L., Kenny, D. A., and Ledermann, T. (2015). Moderation in the actor–partner interdependence model. *Pers. Relationship* 22, 8–29. doi: 10.1111/pere.12060

Gorman, J. R., Smith, E., Drizin, J. H., Lyons, K. S., and Harvey, S. M. (2020). Navigating sexual health in cancer survivorship: A dyadic perspective. *Support. Care Cancer* 28, 5429–5439. doi: 10.1007/s00520-020-05396-y

Hagedoorn, M., Kuijer, R. G., Wobbes, T., and Sanderman, R. (2000). Marital satisfaction in patients with cancer: does support from intimate partners benefit those who need it the most? *Health Psychol.* 19, 274–282. doi: 10.1037/0278-6133.19.3.274

Hagedoorn, M., Sanderman, R., Coyne, J. C., Bolks, H. N., and Tuinstra, J. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychol. Bull.* 134, 1–30. doi: 10.1037/0033-2909.134.1.1

Harden, J. K., Northouse, L., and Mood, D. (2006). Qualitative analysis of couples' experience with prostate cancer by age cohort. *Cancer Nurs.* 29, 367–377. doi: 10.1097/00002820-200609000-00004

Hareven, T. K. (1994). Aging and generational relations: A historical and life course perspective. *Annu. Rev. Sociol.* 20, 437–461. doi: 10.1146/annurev.so.20.080194.002253

Hinnen, C., Hagedoorn, M., Sanderman, R., and Ranchor, A. V. (2007). The role of distress, neuroticism and time since diagnosis in explaining support behaviors in partners of women with breast cancer: results of a longitudinal analysis. *Psycho-Oncology* 16, 913–919. doi: 10.1002/pon.1153

Hornbuckle, L. M., Rauer, A., Winters-Stone, K. M., Springer, C., Jones, C. S., and Toth, L. P. (2021). Better together? A pilot study of romantic partner influence on exercise adherence and cardiometabolic risk in African-American couples. *J. Racial Ethn. Health Dis.* 8, 1492–1504. doi: 10.1007/s40615-020-00912-6

Howlader, N., Noone, A. M., Krapcho, M., Miller, D., Brest, A., Yu, M., et al. (2019). SEER Cancer Statistics Review, 1975–2016 Based on November 2018 SEER Data Submission (Online). Bethesda, MD: National Cancer Institute. Available at: https://seer.cancer.gov/archive/csr/1975_2016/ (Accessed August 2021).

Hydeman, J. A., Uwazurike, O. C., Adeyemi, E. I., and Beaupin, L. K. (2019). Survivorship needs of adolescent and young adult cancer survivors: a concept mapping analysis. *J. Cancer Surviv.* 13, 34–42. doi: 10.1007/s11764-018-0725-5

Jeong, A., Shin, D., Park, J. H., and Park, K. (2018). What we talk about when we talk about caregiving: The distribution of roles in cancer patient caregiving in a family-oriented culture. *Cancer Res. Treat.* 51, 141–149. doi: 10.4143/crt.2017.557

Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. S., Shelburne, N., et al. (2016). Caring for caregiver and patients: research and clinical priorities for informal cancer caregiving. *Cancer* 122, 1987–1995. doi: 10.1002/cncr.29939

Kiecolt-Glaser, J. K., and Newton, T. L. (2001). Marriage and health: his and hers. *Psychol. Bull.* 127, 472–503. doi: 10.1037/0033-2909.127.4.472

Kim, H. J., Sun, V., Raz, D. J., Williams, A. C., Fujinami, R., Reckamp, K., et al. (2016). The impact of lung cancer surgery on quality of life trajectories in patients and family caregivers. *Lung Cancer* 101, 35–39. doi: 10.1016/j.lungcan.2016.08.011

Langer, S., Lehane, C., and Yi, J. (2017). Patient and caregiver adjustment to hematopoietic stem cell transplantation: a systematic review of dyad-based studies. *Curr. Hematol. Malig. Rep.* 12, 324–334. doi: 10.1007/s11899-017-0391-0

Langer, S. L., Romano, J. M., Todd, M., Strauman, T. J., Keefe, F. J., Syrjala, K. L., et al. (2018). Links between communication and relationship satisfaction among patients with cancer and their spouses: results of a fourteen-day smartphone-based ecological momentary assessment study. *Front. Psychol.* 9:1843. doi: 10.3389/fpsyg.2018.01843

Lee, C. S., and Lyons, K. S. (2019). Patterns, relevance and predictors of dyadic mental health over time in lung cancer. *Psycho. Oncology* 28, 1721–1727. doi: 10.1002/pon.5153

Lee, C. S., Sethares, K., Thompson, J. H., Faulkner, K. M., Aarons, E., and Lyons, K. S. (2020). Patterns of heart failure dyadic illness management: The important role of gender. *J. Cardiovasc. Nurs.* 35, 416–422. doi: 10.1097/JCN.0000000000000695

Lepore, S. J., and Revenson, T. A. (2007). Social constraints on disclosure and adjustment to cancer. *Soc. Personal. Psychol. Compass* 1, 313–333. doi: 10.1111/j.1751-9004.2007.00013.x

Li, Q., and Loke, A. Y. (2014). A systematic review of spousal couple-based intervention studies for couples coping with cancer: direction for the development of interventions. *Psycho-Oncology* 23, 731–739. doi: 10.1002/pon.3535

Lyons, K. S., Bennett, J. A., Nail, L. M., Fromme, E. K., Dieckmann, N., and Sayer, A. G. (2014). The role of patient pain and physical function on depressive symptoms in couples with lung cancer: A longitudinal dyadic analysis. *J. Fam. Psychol.* 28, 692–700. doi: 10.1037/fam0000017

Lyons, K. S., Flatley, C., Gorman, J. R., Hanan, D. M., and Hayes-Lattin, B. (2022). Challenges experienced and resources identified by young to midlife couples 1–3 years post-cancer diagnosis. *Psycho-Oncology* 31, 116–121. doi: 10.1002/pon.5788

Lyons, K. S., Hiatt, S., Gelow, J. M., Auld, J., Mudd, J. O., Chien, C. V., et al. (2018). Depressive symptoms in couples living with heart failure: The role of congruent engagement in heart failure management. *Aging Ment. Health* 22, 1585–1591. doi: 10.1080/13607863.2017.1381945

Lyons, K. S., Hutton-Johnson, S., and Lee, C. S. (2021). The role of symptom appraisal, concealment and social support in optimizing dyadic mental health in heart failure. *Aging Ment. Health* 25, 734–741. doi: 10.1080/13607863.2020.1711866

Lyons, K. S., and Lee, C. S. (2018). The theory of dyadic illness management. *J. Fam. Nurs.* 24, 8–28. doi: 10.1177/1074840717745669

Lyons, K. S., Miller, L. M., and Mccarthy, M. J. (2016a). The roles of dyadic appraisal and dyadic coping in couples with lung cancer. *J. Fam. Nurs.* 22, 493–514. doi: 10.1177/1074840716675976

Lyons, K. S., Sadowski, T., and Lee, C. S. (2020). The role of concealment and relationship quality on patient hospitalizations, care strain and depressive symptoms in heart failure dyads. *Eur. J. Cardiovasc. Nurs.* 19, 118–124. doi: 10.1177/1474515119863791

Lyons, K. S., Winters-Stone, K. M., Bennett, J. A., and Beer, T. M. (2016b). The effects of partnered exercise on physical intimacy in couples coping with prostate cancer. *Health Psychol.* 35, 509–513. doi: 10.1037/hea0000287

Mahalik, J. R., and Dagirmanjian, F. R. (2019). Working-class men's constructions of help-seeking when feeling depressed or sad. *Am. J. Mens Health* 13:155798831985005. doi: 10.1177/1557988319850052

Manne, S. L., Kissane, D., Zaider, T., Kashy, D., Lee, D., Heckman, C., et al. (2015). Holding back, intimacy, and psychological and relationship outcomes among couples coping with prostate cancer. *J. Fam. Psychol.* 29, 708–719. doi: 10.1037/fam0000096

Manne, S., Ostroff, J., Rini, C., Fox, K., Goldstein, L., and Grana, G. (2004a). The interpersonal process model of intimacy: The role of self-disclosure, partner disclosure, and partner responsiveness in interactions between breast cancer patients and their partners. *J. Fam. Psychol.* 18, 589–599. doi: 10.1037/0893-3200.18.4.589

Manne, S., Ostroff, J., Sherman, M., Heyman, R. E., Ross, S., and Fox, K. (2004b). Couples' support-related communication, psychological distress, and relationship satisfaction among women with early stage breast cancer. *J. Consult. Clin. Psychol.* 72, 660–670. doi: 10.1037/0022-006X.72.4.660

Manne, S., Ostroff, J., Winkel, G., Grana, G., and Fox, K. (2005). Partner unsupportive responses, avoidant coping, and distress among women with early stage breast cancer: patient and partner perspectives. *Health Psychol.* 24, 635–641. doi: 10.1037/0278-6133.24.6.635

Meier, F., Cairo Notari, S., Bodenmann, G., Revenson, T. A., and Favez, N. (2019). We are in this together - Aren't we congruence of common dyadic coping and psychological distress of couples facing breast cancer. *Psycho. Oncol.* 28, 2374–2381. doi: 10.1002/pon.5238

Mitchell, A. J., Ferguson, D. W., Gill, J., Paul, J., and Symonds, P. (2013). Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol.* 14, 721–732. doi: 10.1016/S1470-2045(13)70244-4

Neugarten, B. L. (1979). Time, age, and the life cycle. *Am. J. Psychiatr.* 136, 887–894. doi: 10.1176/ajp.136.7.887

Pistrang, N., and Barker, C. (2005). "How partbers talk in times of stress: A process analysis approach," in *Couples Coping With Stress: Emerging Perspectives on Dyadic Coping*. eds. T. A. Revenson, K. Kayser and G. Bodenmann (Washington, DC: American Psychological Association), 97–119.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Appl. Psychol. Meas.* 1, 385–401. doi: 10.1177/014662167700100306

Reblin, M., Otto, A. K., Ketcher, D., Vadaparampil, S. T., Ellington, L., and Heyman, R. E. (2020). In-home conversations of couples with advanced cancer: support has its costs. *Psycho. Oncol.* 29, 1280–1287. doi: 10.1002/pon.5416

Reese, J. B., Sorice, K., Pollard, W., Handorf, E., Beach, M. C., Daly, M. B., et al. (2021). Efficacy of a multimedia intervention in enhancing breast cancer patients' clinical communication about sexual health: results of a randomized controlled trial. *Psycho. Oncol.* 30, 681–690. doi: 10.1002/pon.5613

Regan, T. W., Lambert, S. D., Kelly, B., Falconier, M., Kissane, D., and Levesque, J. V. (2015). Couples coping with cancer: exploration of theoretical frameworks from dyadic studies. *Psycho-Oncology* 24, 1605–1617. doi: 10.1002/pon.3854

Revenson, T. A., Kayser, K., and Bodenmann, G. (eds.) (2005). *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping*. Washington, DC: American Psychological Association.

Rottmann, N., Hansen, D. G., Hagedoorn, M., Larsen, P. V., Nicolaisen, A., Bidstrup, P. E., et al. (2016). Depressive symptom trajectories in women affected by breast cancer and their male partners: a nationwide prospective cohort study. *J. Cancer Surviv.* 10, 915–926. doi: 10.1007/s11764-016-0538-3

Scott, A. R., Stooltzfus, K. C., Tchelebi, L. T., Trifiletti, D. M., Lehrer, E. J., Rao, P., et al. (2020). Trends in cancer incidence in US adolescents and young adults, 1973-2015. *JAMA Net. Open* 3:e2027738. doi: 10.1001/jamanetworkopen.2020.27738

Shaffer, K. M., Kim, Y., and Carver, C. S. (2016). Physical and mental health trajectories of cancer patients and caregivers across the year post-diagnosis: a dyadic investigation. *Psychol. Health* 31, 655–674. doi: 10.1080/08870446.2015.1131826

Shapiro, C. L. (2018). Cancer survivorship. *N. Engl. J. Med.* 379, 2438–2450. doi: 10.1056/NEJMra1712502

Smith, A. W., Seibel, N. L., Lewis, D. R., and Al, E. (2016). Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future. *Cancer* 122, 988–999. doi: 10.1002/cncr.29870

Spillers, R. L., Wellisch, D. K., Kim, Y., Matthews, B. A., and Baker, F. (2008). Family caregivers and guilt in the context of cancer care. *Psychosomatics* 49, 511–519. doi: 10.1176/appi.psy.49.6.511

Stefanut, A. M., Vintila, M., and Tudorel, O. I. (2021). The relationship of dyadic coping with emotional functioning and quality of the relationship in couples facing cancer - A meta-analysis. *Front. Psychol.* 11:594015. doi: 10.3389/fpsyg.2020.594015

Streck, B. P., Wardell, D. W., Lobiondo-Wood, G., and Beauchamp, J. E. S. (2020). Interdependence of physical and psychological morbidity among patients with cancer and family caregivers: review of the literature. *Psycho-Oncology* 29, 974–989. doi: 10.1002/pon.5382

Traa, M. J., De Vries, J., Bodenmann, G., and Den Oudsten, B. L. (2015). Dyadic coping and relationship functioning in couples coping with cancer: a systematic review. *Br. Psychol. Soc.* 20, 85–114. doi: 10.1111/bjhp.12094

Vilagut, G., Forero, C. G., Barbaglia, G., and Alonso, J. (2016). Screening for depression in the general population with the Center for Epidemiologic Studies Depression (CES-D): A systematic review with meta-analysis. *PLoS One* 11:e0155431. doi: 10.1371/journal.pone.0155431

Wilson, S. J., Pengb, J., Andridgeb, R., Jaremkac, L. M., Fagundesd, C. P., Malarkeye, W. B., et al. (2020). For better and worse? The roles of closeness, marital behavior, and age in spouses' cardio metabolic similarity. *Psychoneuroendocrinology* 120:104777. doi: 10.1016/j.psyneuen.2020.104777

Winters-Stone, K. M., Lyons, K. S., Dobek, J., Dieckmann, N. F., Bennett, J. A., Nail, L., et al. (2016). Benefits of partnered strength training for prostate cancer survivors and spouses: results from a randomized controlled trial of the exercising together project. *J. Cancer Surviv.* 10, 633–644. doi: 10.1007/s11764-015-0509-0

Yeung, N. C. Y., Zhang, Y., Ji, L., Lu, G., and Lu, Q. (2018). Guilt among husband caregivers of Chinese women with breast cancer: The roles of male gender-role norm, caregiving burden and coping processes. *Eur. J. Cancer Care* 27:e12872. doi: 10.1111/ecc.12872

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers
in Psychology

BRIEF RESEARCH REPORT
published: 23 March 2022
doi: 10.3389/fpsyg.2022.869905

Edited by:
Marialaura Di Tella,
University of Turin, Italy

Reviewed by:
Adelina Mihaela Ştefănuţ,
West University of Timişoara,
Romania
Mona Vintilă,
West University of Timişoara,
Romania

***Correspondence:**
Denise Vagnini
denise.vagnini@unicatt.it

†ORCID:
Emanuela Saita
orcid.org/0000-0003-0790-2819
Giulia Ferraris
orcid.org/0000-0003-0957-0918
Chiara Acquati
orcid.org/0000-0002-6232-5834
Sara Molgora
orcid.org/0000-0002-2517-2373
Antonia Sorge
orcid.org/0000-0002-2372-594X
Francesco Valenti
orcid.org/0000-0001-8134-3774
Massimo Maria Grassi
orcid.org/0000-0001-5903-1205
Denise Vagnini
orcid.org/0000-0002-3796-7202

Specialty section:
This article was submitted to
Psycho-Oncology,
a section of the journal
Frontiers in Psychology

Received: 05 February 2022
Accepted: 28 February 2022
Published: 23 March 2022

Citation:
Saita E, Ferraris G, Acquati C,
Molgora S, Sorge A, Valenti F,
Grassi MM and Vagnini D (2022)
Dyadic Profiles of Couples Coping
With Body Image Concerns After
Breast Cancer: Preliminary Results
of a Cluster Analysis.
Front. Psychol. 13:869905.
doi: 10.3389/fpsyg.2022.869905

Dyadic Profiles of Couples Coping With Body Image Concerns After Breast Cancer: Preliminary Results of a Cluster Analysis

Emanuela Saita[1†], Giulia Ferraris[2†], Chiara Acquati[3,4,5†], Sara Molgora[1†], Antonia Sorge[1†], Francesco Valenti[6†], Massimo Maria Grassi[6†] and Denise Vagnini[1†]*

[1] Department of Psychology, Catholic University of Sacred Heart, Milan, Italy, [2] Department of Health Psychology, University Medical Center Groningen, University of Groningen, Groningen, Netherlands, [3] Graduate College of Social Work, University of Houston, Houston, TX, United States, [4] Department of Clinical Sciences, College of Medicine, University of Houston, Houston, TX, United States, [5] Department of Health Disparities Research, The UT MD Anderson Cancer Center, Houston, TX, United States, [6] Breast Unit, Humanitas Gavazzeni Clinical Institute, Bergamo, Italy

Breast cancer treatments have multiple adverse effects, including concerns about body appearance and function that are experienced by most patients. Altered body image negatively affects mental health, social, and relationship functioning. While the relationship with a partner is critical for patients' psychological wellbeing and partners can promote positive body image, limited research has investigated individual and relational factors affecting the experience of both. This cross-sectional study aimed at (1) exploring rates of body image concerns among breast cancer patients, and (2) identifying dyadic profiles among participating dyads. Couples composed by patients who had undergone surgery and their romantic partners ($n = 32$) were recruited from the Breast Unit of a hospital in northern Italy. Both partners completed measures of personality characteristics (BFQ-2), psychological distress (HADS), coping flexibility (PACT), dyadic coping (DCQ), and closeness (IOS). Body image (BIS) and adjustment to cancer (Mini-MAC) measures were completed by patients only. K-mean cluster analyses identified 2-cluster solution among patients and partners, respectively. "Active patients" (cluster-1) reported low rates of body image concerns ($p < 0.001$), anxious preoccupation, negative dyadic coping, and self-oriented stress communication ($p < 0.05$), compared to "worried patients" (cluster-2). "Comfortable partners" (cluster-1) reported lower anxiety and depression ($p < 0.001$), self-oriented negative dyadic coping and closeness ($p < 0.05$) than "uncomfortable partners" (cluster-2). Three different dyadic profiles emerged: *functional*, *dysfunctional*, and *ambivalent*. Significant variations ($p < 0.05$) by anxiety, depression, and delegating dyadic coping existed. Results indicate there are groups of couples at greater risk for impaired psychological distress and body image concerns, which should be addressed in the context of dyadic psychosocial interventions.

Keywords: body image, breast cancer, couples, emotional wellbeing, relationship functioning

INTRODUCTION

A breast cancer (BC) diagnosis is an unexpected and destabilizing event that can have a potentially negative impact on quality of life over time (Zimmermann et al., 2010). Among the long-term negative consequences of the disease and its treatments (i.e., surgery, neoadjuvant/adjuvant therapies) impaired physical functioning, femininity, and sexual health have been extensively documented. Impacts in these areas may also produce a negative body image, which is defined as perceptions, thoughts, or emotions about one's physical appearance (Cash, 2004; Fobair et al., 2006; Lindwall and Bergbom, 2009; Falk Dahl et al., 2010). Between 17–33% of BC patients and 15–30% of long-term survivors report some degree of body image concerns due to irreversible (e.g., scarring/amputations) or temporary (e.g., hair loss, weight, and hormonal fluctuations) changes in appearance (Begovic-Juhant et al., 2012; McKean et al., 2013; Fingeret et al., 2014).

Body image concerns have been linked to compromised psychological functioning (e.g., mood disturbances and severe depressive symptoms) especially among patients who undergone invasive treatments (Moreira and Canavarro, 2010; Morales-Sánchez et al., 2021). Previous studies have primarily focused on body image as an aspect of individuals' psychosocial adjustment (Rowland and Metcalfe, 2014) or as a predictor of anxiety and depression (Falk Dahl et al., 2010), and have considered the effects of surgery (Fingeret et al., 2013) and age (Rosenberg et al., 2013; Leigh et al., 2019). Women undergoing more radical surgery approaches reported significantly worse adaptation, and younger women report greater distress for this domain of quality of life (Acquati and Kayser, 2019; Davis et al., 2020). Personality characteristics also influence the psychosocial adjustment to cancer, with different levels of flexibility associated with specific personality traits. For example, extraversion and conscientiousness predicted more problem-solving and cognitive restructuring, compared to neuroticism (Connor-Smith and Flachsbart, 2007). Similarly, personality traits correlated with relationship functioning, highlighting that couples characterized by higher levels of neuroticism experienced lower levels of marital satisfaction. On the contrary, couples reporting high conscientiousness were more satisfied (Sayehmiri et al., 2020). In addition, the quality of patients' relationship with a partner is also a crucial factor facing cancer (Zimmermann et al., 2010; Shrout et al., 2020). Empirical evidence linked supportive and satisfactory relationships with positive body image in the immediate post-operative period (2–6 weeks), as well as 1 year later (Brandão et al., 2017; Cairo Notari et al., 2017; Saita et al., 2018).

However, research on couple-level factors, such as dyadic coping and relationship satisfaction, is scarce. Due to the interdependence that exists among patients and partners, both can be profoundly affected by the cancer experience (Kayser et al., 2007; Zimmermann, 2015). Couples experienced several changes to their previous roles within the dyad, with marital adjustment contributing to patient's physical, mental, and sexual functioning. Moreover, relationship characteristics have been linked to the level of burden experienced (Keesing et al., 2016; Brandão et al., 2017). Dyadic coping behaviors may be particularly salient for patients' body image, since women's self-image is established, in part, within the context of their intimate relationships (Scott et al., 2004). For instance, the Michelangelo Phenomenon (which refers to how our self-image is constructed according to how our partner sees us, in the same way Michelangelo saw the sculpture hidden in the stone) contributes to illustrate the influence of partners' responses on patients' body image (Drigotas et al., 1999). Recent studies have documented that partners' empathic responses moderated the association between patients' body image concerns and depressive symptoms after surgery, while partners' disgusting responses were correlated with patients' self-reported feelings of disgust (Fang et al., 2015; Azlan et al., 2017).

These emerging results confirm that, in addition to the above-mentioned individual variables, the quality of close relationships and the interaction between partners might protect couples from negative outcomes both at the individual and relational level (Manne and Badr, 2010; Saita et al., 2015; Kayser and Acquati, 2019). Patients and partners mutually influence each other in their stress and coping process, confirming that the experience of cancer is influenced by the patients' interpersonal context (Hagedoorn et al., 2008). For instance, the ability to display relational mutuality promotes adaptive dyadic coping behaviors (Acquati and Kayser, 2019; Kayser and Acquati, 2019). Therefore, coping with cancer-related body image concerns should be regarded as a dyadic affair, and investigated as a stressor regarding both partners.

The aim of the study is to (1) explore rates of body image concerns among BC patients 1 week after surgery, and (2) identify dyadic profiles of couples according to individual and relational variables. We assumed a relational perspective, guided by the *Systemic-Transactional Model of Dyadic Coping* (STM) by Bodenmann (1995). This model assumes that the mechanism of stress and coping is a social process of interdependence between two partners. A threatening event affects both individuals' psychological wellbeing and the couple as a unit. Stress is conceived as a we-stress, and the disease is represented as a we-disease (Kayser et al., 2007). A good dyadic functioning consists in responding to the problem of both by providing mutual support, with the aim of re-establishing the homeostatic balance of the dyad (Bodenmann, 1995, 1997, 2005). Therefore, in this study it was hypothesized that:

(1) Patient's self-reported body image perceptions is one of the pivotal variables characterizing dyadic profiles.
(2) Both individual and relational factors influence the psychosocial experience of patients and partners, and they contribute in profiling couples facing BC.
(3) Dyadic profiles will distinguish between functioning vs. burdened couples.

METHODS

Procedure and Participants

A cross-sectional survey of 32 couples composed by BC patients and their partners ($N = 64$) was conducted in 2018–2019.

Subsequently, data collection was interrupted due to COVID-19 pandemic. In addition, considering the effects of the pandemic on cancer patients and caregivers' psychosocial wellbeing (Dhada et al., 2021; Ludwigson et al., 2022), couples recruited after the first lockdown were considered intrinsically different and therefore were not included in the present contribution.

Participants were recruited from the Breast Unit of a Hospital located in Northern Italy using a convenience, non-probabilistic sampling approach. They were invited to participate in the research study by the medical staff (e.g., surgeons or nurses) the day after the surgery or during the patients' follow-up visit (1 week later). The same day, interested participants met with trained members of the research team and psycho-oncologists to complete printed copies of the survey. Patients were eligible to participate if they: (1) were $\geq$ 18 years, (2) had received a diagnosis of BC within the previous 6 weeks, (3) had surgery (i.e., quadrantectomy or mastectomy), (4) were in a romantic relationship with a partner available to participate, and (5) were Italian speaking. Eligible partners: (1) had to be $\geq$ 18 and (2) Italian speaking. Exclusion criteria for both comprised having a declared serious mental illness or dementia symptoms. Couples provided informed consent before survey completion. Participants provided socio-demographic information (e.g., sex, age, marital status, and rural/urban location), while clinical information about surgery (i.e., quadrantectomy or mastectomy) was obtained medical records. Data were anonymized through an alphanumeric code, identical for members of the dyad to match partners. All procedures were approved by the Ethics Committee of the participating institutions.

Measures

Individual Variables

Body Image

The Italian version of Body Image Scale (BIS) was used ($\alpha = 0.93$) (Hopwood et al., 2001; Cheli et al., 2016). It consists of a 10-item questionnaire assessing diverse dimensions of body image in cancer patients after surgery, or treatment (example item: Have you felt less physically attractive as a result of your disease or treatment?). Items are scored on a 4-point Likert response scale (from 0 = not at all to 3 = very much) and the final score range 0–30, with higher scores corresponding to more perceived body image concerns. The literature does not provide intermediate cut-offs for the interpretation of clinical aspects. For this reason, total scores were organized in three categories according to previous studies conducted by the team of investigators (e.g., Saita et al., 2018): "good body image" (0–10), "composite body image" (11–20), and "impaired body image" (21–30).

Coping With Cancer

The Mental Adjustment to Cancer (Mini-MAC) (Watson et al., 1988; Grassi et al., 2005) is a 29-item questionnaire ($0.78 < \alpha < 0.93$). Respondents rate on a 4-point Likert scale (from 1 = completely disagree; to 4 = completely agree) the prevailing coping style used to cope with cancer: Fighting Spirit (example item: I am determined to beat this disease); Hopeless/Helplessness (example item: I feel like giving up); Anxious Preoccupation (example item: I feel very angry about what has happened to me); Fatalism (example item: At the moment I take one day at a time); and (5) Avoidance (example item: I distract myself when thoughts about my illness come into my head).

Personality Traits

The Italian version of the Big Five Questionnaire (BFQ-2) Short Form ($0.60 < \alpha < 0.90$) (Caprara et al., 1993) presents fifteen personality characteristics (e.g., effusive; unselfish; creative), ranging on a 7-points Likert scale (from 1 = it does not describe me at all; to 7 = it describes me perfectly). It was administered to define five dimensions of personality: extraversion; agreeableness; conscientiousness; openness; and neuroticism.

Coping Flexibility

The Italian version of Perceived Ability to Cope with Trauma (PACT) Scale (Bonanno and Pat-Horenczyk, 2011; Saita et al., 2017), consisting of 20 items scored on a 7-step Likert scale (from 1 = not capable at all; to 7 = extremely capable), was used to assess the perceived ability of processing the trauma (Trauma Focus Subscale $\alpha = 0.91$; example item: I reflect on the meaning of the event), and moving beyond the trauma (Forward Focus Subscale $\alpha = 0.79$; example item: I remind myself that things will get better). The Flexibility score, which indicates the ability to modify coping strategies depending on the environment/social context, is obtained by combining the sum and the discrepancy score.

Psychological Distress

The Italian version of the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983; Costantini et al., 1999) evaluated distress, anxiety, and depression. It contains two 7-item Likert scales ranged 0–3 measuring respectively anxiety (HADS-A $0.68 < \alpha < 0.93$; example item: Worrying thoughts go through my mind), and depression (HADS-D $0.67 < \alpha < 0.90$; example item: I feel as if I am slowed down). The total score of both subscales range 0–21. The cut-off of $\geq$ 11 defines the presence of psychological morbidity with "abnormal" level of mood disturbances, while scores of 8–10 are indicative of a "borderline" level, and 0–7 scores characterize "normal" profiles.

Relational Variables

Dyadic Coping

The Italian version of the Dyadic Coping Questionnaire (DCQ) (Bodenmann, 2005; Donato et al., 2009) is a 37-item measure assessing different dyadic coping styles ($0.72 < \alpha < 0.81$). Items are scored on a 5-point Liked scale ranging from 1 (very rarely) to 5 (very often). Example of items are: We try to manage the problem together and find concrete solutions; When I am too busy, my partner helps me out; When he/she is stressed I avoid him/her. The inventory includes the following subscales: common dyadic coping, supportive, delegating, and negative. In addition, DCQ includes subscales for stress communication, and two single items concerning satisfaction with and efficiency of dyadic coping. Except for the two single items and common dyadic coping, all subscales measure the respondents' own behavior (self-measured) and the respondents' perception of their partner's behavior (other-measured).

Interpersonal Closeness

The Inclusion of the Other in the Self Scale (IOS) (Aron et al., 1992), a single item on a 7-point Likert scale (from 1 = absence of closeness, to 7 = extreme closeness), was used to measure the degree of closeness, or intersubjectivity with the partner. It is composed of seven Euler-Venn diagrams; the first set of each diagram represents the Self while the second represents the significant Other (i.e., the romantic partner). The width of the intersection between the two sets indicates the degree of proximity within the couple. From a graphic point of view, the amplitude of diagrams' intersection increases linearly: the first pair shows an absence of perceived closeness, while the seventh shows an almost total overlap.

Data Analysis

Data were analyzed using IBM SPSS Statistical Software version 27.0 (IBM Corp., 2020). Participants (n = 32 patients, n = 32 partners) completed the background information sheet with socio-demographic data and the survey with psychological measures. All metric variables were assessed to verify normal distribution for asymmetry and kurtosis (George and Mallery, 2010). Missing values analysis (MVA) showed no missing data. Descriptive statistics (i.e., frequency, mean, and SD) and t-test ($p < 0.05$) for independent samples were performed to present psychological variables by role (patients vs. partners). Then, two separated *k-mean cluster analyses* were conducted on patients and partners' subsamples to identify groups characterized by high between-clusters homogeneity, and high between-clusters distance (Hair and Black, 2000; Henry et al., 2005). All the individual and relational variables assessed in the study were included. Given the exploratory nature of the study, different groupings were tested. Each cluster was then labeled based on participants' prevailing psychological characteristics. Output tables demonstrated the belonging of each statistical unit (i.e., each subject) to the separately extracted clusters. Then, each couple was examined to identify whether (1) partners belonged to a cluster of greater individual and relational wellbeing; (2) both partners belonged to a cluster of impaired individual and relational wellbeing; and (3) one partner belonged to a cluster of greater wellbeing and the other to a cluster of more impaired wellbeing. Descriptive analysis of the resulting dyadic profiles was performed. Finally, individual and relational variables were included as dependent variables in a univariate one-way analysis of variance (ANOVA), with Bonferroni correction in *post hoc* tests, to investigate dissimilarities between couples' profiles.

RESULTS

Participants' demographics and patients' clinical characteristics are summarized in **Table 1**.

Table 2 presents descriptive statistics and t-test comparisons.

TABLE 1 | Participants' demographics and clinical characteristics.

Sociodemographic and clinical variables	Patients (n = 32)	Partners (n = 32)
Sex		
Females	32 (100%)	0
Males	0	32 (100%)
Living situation		
Cohabitation	32 (100%)	32 (100%)
Age M ± SD (range)	60.19 ± 10.72 (35–75)	61.09 ± 10.73 (35–77)
Surgery		
Conservative surgery	21 (65.6%)	NA[a]
Mastectomy	11 (34.4%)	NA[a]
Body Image		
Positive body image (BIS score 0–10)	26 (81.3%)	NA[a]
Composite body image score (BIS score 11–20)	4 (12.5%)	NA[a]
Impaired body image (BIS score 21–30)	2 (6.2%)	NA[a]

[a] *NA, not applicable.*

Cluster Analysis

Results of the cluster analysis supported our first hypothesis regarding variables affecting healthy vs. impaired functioning of patients and partners when coping with cancer. A 2-cluster solution was selected to discriminate among patients with statistically significant mean score variation by body image, anxious preoccupation, negative dyadic coping, and stress communication. Not all the variables were meaningful for the clusters, and significant F tests are summarized in **Table 3**. The first cluster (n = 24; 75%) included patients who experienced positive body image after surgery ($M_{BIS} = 3$), low levels of anxious preoccupation ($M_{Mini-MAC} = 2.04$), low levels of negative dyadic coping strategies, either self-($M_{DCQ} = 1.4$) and other-reported ($M_{DCQ} = 1.5$), and lower stress communication rates self-related than patients in cluster two ($M_{DCQ} = 3.19$). According to these individual/relational variables, cluster 1 was labeled as: "*Active patients*," indicating patients who actively adopt individual/relational resources, functional coping styles, and report elevated mood and self-rated wellbeing. The second cluster included patients (n = 8; 25%) with high levels of body image concerns ($M_{BIS} = 17$) and anxious preoccupation ($M_{Mini-MAC} = 2.63$), high levels of negative dyadic coping strategies about themselves ($M_{DCQ} = 1.9$) and the partner ($M_{DCQ} = 2.0$), and a greater use of stress communication within the couple ($M_{DCQ} = 3.94$). Patients' cluster 2 was labeled "*Worried patients*," indicating patients who fear the effects of therapies on their body appearance and show intense concerns facing individually the stressor, talking about it intensely within the couple, but without perceiving a functional dyadic coping in the partnership. No significant differences were detected for other variables considered.

Then, the K-mean cluster analysis on partners' scores resulted in a 2-cluster solution. Similarly, not all the variables were significantly different among the partners; significant F tests are summarized in **Table 4**. Partners in cluster 1 (n = 25; 78.1%) were characterized by anxiety ($M_{HADS-A} = 5$) and depression ($M_{HADS-D} = 2$) below of the clinical cut-offs (≥ 11), low scores on self-related negative dyadic coping style ($M_{DCQ} = 1.6$) and interpersonal closeness ($M_{IOS} = 6$), which

TABLE 2 | Descriptive statistics of individual and relational measures by role (patients vs. partners).

	Patients (n = 32)	Partners (n = 32)	Range	T-test	
Individual measures	**M ± SD**	**M ± SD**	**Likert scale**	**t (df)**	**Sig.**
Extraversion (BFQ-2)	4.60 ± 1.21	4.86 ± 1.08	1–7	−0.98 (62)	$p = 0.367$
Agreeableness (BFQ-2)	6.32 ± 0.65	5.56 ± 0.94		3.680 (62)	$p = 0.0001$**
Conscientiousness (BFQ-2)	5.55 ± 1.02	5.41 ± 1.10		0.509 (62)	$p = 0.612$
Openness (BFQ-2)	2.31 ± 1.01	3.25 ± 1.41		−3.104 (62)	$p = 0.003$*
Neuroticism (BFQ-2)	4.54 ± 1.20	5.09 ± 1.10		−1.935 (62)	$p = 0.58$
Forward focus (PACT)	5.64 ± 0.84	5.16 ± 0.75	1–7	2.385 (62)	$p = 0.020$*
Trauma focus (PACT)	4.92 ± 0.77	4.88 ± 0.95	1–7	0.205 (62)	$p = 0.838$
Flexibility (PACT)	0.84 ± 0.06	0.84 ± 0.05	0–1	−0.229 (62)	$p = 0.820$
Anxiety (HADS-A)	7.66 ± 4.95	6.47 ± 3.51	0–3	1.106 (62)	$p = 0.273$
Depression (HADS-D)	4.95 ± 2.65	3.87 ± 3.34	0–3	0.497 (62)	$p = 0.621$
Body Image (BIS)	6.47 ± 7.31	NA[a]	0–3	NA[a]	NA[a]
Fighting spirit (Mini-MAC)	2.94 ± 0.63	NA[a]	1–4	NA[a]	NA[a]
Helplessness-hopelessness (Mini-MAC)	1.67 ± 0.52	NA[a]		NA[a]	NA[a]
Fatalism (Mini-MAC)	2.66 ± 0.81	NA[a]		NA[a]	NA[a]
Anxious preoccupation (Mini-MAC)	2.19 ± 2.64	NA[a]		NA[a]	NA[a]
Avoidance (Mini-MAC)	2.39 ± 0.99	NA[a]		NA[a]	NA[a]
Relational measures					
Supportive dyadic coping_self (DCQ)	3.72 ± 0.70	3.5 ± 0.73	1–5	1.242 (62)	$p = 0.219$
Supportive dyadic coping_other (DCQ)	3.62 ± 0.82	3.63 ± 0.83		−0.30 (62)	$p = 0.976$
Delegating dyadic coping_self (DCQ)	3.00 ± 1.07	3.56 ± 0.82		−2.349 (62)	$p = 0.022$*
Delegating dyadic coping_other (DCQ)	3.35 ± 1.00	3.01 ± 0.89		1.442 (62)	$p = 0.154$
Common dyadic coping (DCQ)	3.74 ± 0.85	3.57 ± 0.72		0.879 (62)	$p = 0.383$
Negative dyadic coping_self (DCQ)	1.48 ± 0.46	1.73 ± 0.65		−1.811 (62)	$p = 0.075$
Negative dyadic coping_other (DCQ)	1.60 ± 0.65	1.63 ± 0.66		−0.227 (62)	$p = 0.821$
Stress communication_self (DCQ)	3.37 ± 0.86	2.78 ± 0.80		2,910 (62)	$p = 0.007$*
Stress communication_other (DCQ)	2.61 ± 1.01	3.50 ± 0.65		−4.134 (62)	$p = 0.0001$**
Coping evaluation (DCQ)	4.04 ± 0.90	3.75 ± 0.79		1.399 (62)	$p = 0.167$
Closeness (IOS)	5.56 ± 1.70	5.78 ± 1.28	1–7	−0.580 (62)	$p = 0.564$

*$p < 0.05$.
**$p < 0.001$.
[a]NA, not applicable.

TABLE 3 | Cluster Analysis on patients' subsample: ANOVA.

Measures	Cluster mean square	df	Error mean square	df	F	Sig.
Body Image (BIS)	1239.844	1	13.871	30	89.385	$p = 0.0001$**
Anxious Preoccupation (Mini-MAC)	2.078	1	0.346	30	6.001	$p = 0.020$*
Negative dyadic coping_self (DCQ)	1.450	1	0.175	30	8.275	$p = 0.007$*
Negative dyadic coping_other (DCQ)	1.707	1	0.380	30	4.486	$p = 0.043$*
Stress Communication_self (DCQ)	3.375	1	0.654	30	5.159	$p = 0.030$*

*$p < 0.05$ (two-tailed).
**$p < 0.001$ (two-tailed).

enable them to maintain a sense of differentiation between the self and the other. This cluster was labeled as: "*Comfortable partners*," indicating partners who demonstrate confidence in their role as caregivers. This was exemplified by stable mood and the ability to meet the needs of the dyad while maintaining a functional sense of differentiation from patients. Partners in cluster 2 (n = 7; 21.9%), showed "abnormal" levels of anxiety ($M_{HADS-A} = 11$), and "borderline" levels of depression ($M_{HADS-D} = 9$), elevated self-related negative dyadic coping ($M_{DCQ} = 2.2$), and inability to differentiate oneself from the partner ($M_{IOS} = 7$). Partners' cluster two was labeled as "*Uncomfortable partners*," indicating partners struggling to adjust the tasks and emotional responsibilities required by the caregiving function. Partners in this group showed a clearly compromised mood, poor ability to engage in functional dyadic coping strategies, and the inability of differentiating their experiences from the patients'. No significant differences were registered for the remaining measures.

TABLE 4 | Cluster Analysis on partners' subsample: ANOVA.

Measures	Cluster mean square	df	Error mean square	df	F	Sig.
Closeness (IOS)	7.800	1	1.456	30	89.385	$p = 0.028$*
Negative dyadic coping_self (DCQ)	1.687	1	0.382	30	4.413	$p = 0.044$*
Depression (HADS-D)	222.403	1	4.170	30	53.335	$p = 0.0001$**
Anxiety (HADS-A)	220.414	1	5.385	30	40.930	$p = 0.0001$**

*$p < 0.05$ (two-tailed).
**$p < 0.001$ (two-tailed).

Dyadic Profiles

Three dyadic profiles emerged from this analysis: (1) *functional relationships* (n = 19 couples; 59.4%), with both partners belonging to cluster 1; (2) *dysfunctional relationships* (n = 2 couples; 6.2%), in which both partners reported impaired individual and relational wellbeing (cluster 2); and (3) *ambivalent relationships* (n = 11 couples; 34.4%) where each partner belonged to two different clusters. This result confirmed our hypothesis regarding couples' functioning. However, it also revealed that there are groups of dyads characterized by lack of congruence in terms of coping and functioning in the cancer aftermath, as evidenced by stressful, incoherent, and oppositional responses. Statistically significant differences were reported for partner-perceived delegating dyadic coping (DCQ) [$F_{(2,61)} = 4.838$, $p = 0.011$], anxiety (HADS-A) [$F_{(2,61)} = 5.049$, $p = 0.009$], and depression (HADS-D) [$F_{(2,61)} = 5.961$, $p = 0.004$]. *Post hoc* tests with Bonferroni correction indicated that couples in functional relationships engaged more often in delegating strategies (M = 3.197; SD = 0.97), as compared to couples characterized by dysfunctional relationships (M = 1.89; SD = 1.18). Functional couples scored low on anxiety (M = 5.74; SD = 3.71) compared to ambivalent couples (M = 8.91; SD = 4.75), while they reported the lowest depression score (M = 3.13; SD = 2.17) when compared to both dysfunctional (M = 7.0; SD = 2.16) and ambivalent couples (M = 5.14; SD = 3.70).

DISCUSSION

The present contribution explored rates of body image concerns among BC patients and identified resulting dyadic profiles of couples facing the disease in the immediate post-operative period. Most patients experienced low levels of body image concerns, as anticipated by previous literature linking conservative surgery to better physical adjustment (Fingeret et al., 2013). Furthermore, patients were in their 60s and confirmed previous studies (e.g., Rosenberg et al., 2013; Champion et al., 2014; Leigh et al., 2019) that found lower concerns in older patients.

Despite the small sample size, the cluster analysis revealed two different clusters for patients (*active vs. worried*), and partners (*comfortable vs. uncomfortable*). Cluster 1 included individuals with better psychosocial and relational wellbeing. Women had low or absent body image concerns, compared to cluster two. Findings confirm the crucial role of body image, individual coping strategies (e.g., anxious preoccupation), stress communication, and negative dyadic coping in delineating different patterns of patients' wellbeing. In line with theories that consider body image as structured by perceptive, emotional, and relational dimensions (White, 2000; Cash, 2004; Fingeret et al., 2014), patients and partners reported an overall elevated wellbeing. It is possible that patients reporting body image concerns also faced more challenges coping with the illness and perceived their partners to engage more often in negative dyadic behaviors. Further research is needed to investigate how the association between individual/relational variables and body image concerns evolves over time. Moreover, relational variables such as stress communication and negative dyadic coping may contribute to inform women's physical and psychological adjustment. Similarly, partners significantly differed in their level of depression, anxiety, negative dyadic coping (self-perception), and interpersonal closeness. Facing breast cancer can create different configurations of emotional and relationship exchange among partners. In line with the existing literature (Maliski et al., 2002), common and positive dyadic coping strategies contributed to higher emotional and relational outcomes.

Three different dyadic profiles were identified (*functional, dysfunctional, and ambivalent relationships)*. It is important to note that anxiety, depression, and delegating dyadic coping significantly varied between couples. Several possible factors may contribute to the differences recorded between profiles. First, when women have low or absent levels of body image concerns and the partners rate their emotional and psychological wellbeing in a similar manner, they may be less anxious and depressed. Second, positive dyadic coping (i.e., delegated) characterized couples better adjusted to the illness. When couples are committed to mutual support, they feel they can rely on their partner's resources and they are more engaged to achieve common goals; an ability which leads to the perception of greater effectiveness to cope and overcome the stressful event (Brandão et al., 2017). Finally, delegated dyadic coping involves efforts to help the partner reducing stress by taking over some tasks and responsibilities (Keesing et al., 2016; Falconier and Kuhn, 2019). According to the *Systemic-Transactional Model of Dyadic Coping* (Bodenmann, 1995), positive dyadic coping strategies benefit both partners' psychological and relationship functioning. Overall, our results are consistent with previous studies examining short and long-term consequences of cancer, especially in relation to marital satisfaction (Hagedoorn et al., 2008; Dekel et al., 2014). In the last 30 years, the application of a dyadic framework has identified variables able to increase wellbeing and satisfaction, since cancer has negative implications for both (Scott et al., 2004; Stanton et al., 2007; Kim et al., 2016;

Saita et al., 2016). Several studies have illustrated the significant association between self-reported dyadic coping and partner's outcomes, and the importance of the congruence between partners' coping strategies (Kayser et al., 2007).

Some limitations should be discussed. First, to answer the research question, and unable to recruit further dyads for the above-mentioned reasons, we used the k-mean cluster analysis with a limited sample size (Dagan and Hagedoorn, 2014). This could affect the generalization of results to other groups. A more properly powered sample is needed to investigate the different profiles of couples dealing with breast cancer. Second, the decision to collect data from a single institution might affect external validity of the findings. Future research is needed to recruit larger and more representative samples. Third, patients varied in terms of cancer stage, type of surgery, and age. It would therefore be appropriate to investigate whether these variables influence participants' wellbeing and stratify samples accordingly. Despite these limitations, the implementation of a relational approach allowed the research team to describe the psychological experience of both couple's members and to explore dyadic profiles of relationship functioning 1 week after surgery. Future studies should investigate the role of relational variables on body image concerns among diverse cancer types and sexual minority survivors. It is recommended to add a qualitative exploratory phase to better understand couples' experiences. It would also be relevant to examine the role of underlying interpersonal processes, as younger couples are characterized by unique psychosocial issues (Kayser and Acquati, 2019). Finally, we recommend exploring the role of individual and relational characteristics in the context of other diseases (e.g., Riazuelo, 2021; Weitkamp et al., 2021).

CONCLUSION

Present results can help health care teams develop dyadic psychosocial interventions openly addressing body image concerns, in order to improve the quality of life and wellbeing of couples facing BC. By gaining an in-depth understanding of the mechanisms that inform behavior at the individual and couple level, it will be possible to assist researchers and clinicians in the field. Our findings, albeit preliminary, further confirm that the presence of a supportive partner contributes to women's outcomes and that the interaction between partners can affect their relational wellbeing. For couples most at risk, such as those in the dysfunctional and ambivalent clusters, clinicians should focus on improving communication and dyadic coping skills to manage cancer-related stress.

AUTHOR'S NOTE

An earlier version of this work was presented at the 20th World Congress of the International Psycho-Oncology Society, November 2018, Hong Kong, with the title *Dyadic Profiles of Couples Coping with Breast Cancer: Results of a Cluster Analysis of Body Image Concerns.*

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethic Commission for Psychology Research (CERPS), Department of Psychology, Catholic University of Sacred Heart of Milan. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

ES and CA contributed to the conception, design, and methodology of the study and wrote and revised sections of the manuscript. GF and DV contributed to the data collection, performed statistical analysis, and wrote and revised the first draft of the manuscript. SM and AS contributed to the methodology and wrote and revised sections of the manuscript. FV and MG contributed to the data collection, the organization of database, and the revision of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

REFERENCES

Acquati, C., and Kayser, K. (2019). Dyadic Coping Across the Lifespan: A Comparison Between Younger and Middle-Aged Couples With Breast Cancer. *Front. Psychol.* 10:404. doi: 10.3389/fpsyg.2019.00404

Aron, A., Aron, E. N., and Smollan, D. (1992). Inclusion of Other in the Self Scale and the structure of interpersonal closeness. *J. Personal. Soc. Psychol.* 63, 596–612. doi: 10.1037/0022-3514.63.4.596

Azlan, H. A., Overton, P. G., Simpson, J., and Powell, P. A. (2017). Effect of Partners' Disgust Responses on Psychological Wellbeing in Cancer Patients. *J. Clin. Psychol. Med. Settings* 24, 355–364. doi: 10.1007/s10880-017-9521-z

Begovic-Juhant, A., Chmielewski, A., Iwuagwu, S., and Chapman, L. A. (2012). Impact of Body Image on Depression and Quality of Life Among Women with Breast Cancer. *J. Psychosoc. Oncol.* 30, 446–460. doi: 10.1080/07347332.2012.684856

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping incouples. *Swiss J. Psychol.* 54, 34–49.

Bodenmann, G. (1997). Dyadic coping: a systemic-transactional view of stress and coping among couples: theory and empirical findings. *Eur. Rev. Appl. Psychol.* 47, 137–141. doi: 10.1037/11031-007

Bodenmann, G. (2005). "Dyadic coping and its significance for marital functioning," in *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping*, eds T. A. Revenson, K. Kayser, and G. Bodenmann (Washington: American Psychological Association), 33–49. doi: 10.1080/10615806.2021.1912740

Bonanno, G. A., and Pat-Horenczyk, R. (2011). Coping flexibility and trauma: The Perceived Ability to Cope with Trauma (PACT) Scale. *Psychol. Trauma* 3, 117–129. doi: 10.1037/a0020921

Brandão, T., Pedro, J., Nunes, N., Martins, M. V., Costa, M. E., and Matos, P. M. (2017). Marital adjustment in the context of female breast cancer: A systematic review. *Psycho-Oncology* 26, 2019–2029. doi: 10.1002/pon.4432

Cairo Notari, S., Notari, L., Favez, N., Delaloye, J. F., and Ghisletta, P. (2017). The protective effect of a satisfying romantic relationship on women's body image after breast cancer: a longitudinal study. *Psycho-Oncology* 26, 836–842. doi: 10.1002/pon.4238

Caprara, G. V., Barbaranelli, C., Borgogni, L., and Perugini, M. (1993). The "big five questionnaire": A new questionnaire to assess the five factor model. *Personal. Individ. Differ.* 15, 281–288. doi: 10.1016/0191-8869(93)90218-R

Cash, T. F. (2004). Body image: past, present, and future. *Body Image* 1, 1–5. doi: 10.1016/S1740-1445(03)00011-1

Champion, V. L., Wagner, L. I., Monahan, P. O., Daggy, J., Smith, L., Cohee, A., et al. (2014). Comparison of younger and older breast cancer survivors and age-matched controls on specific and overall quality of life domains. *Cancer* 120, 2237–2246. doi: 10.1002/cncr.28737

Cheli, S., Agostini, A., Herd-Smith, A., Caligiani, L., Martella, F., and Fioretto, L. (2016). The Italian Version of Body Image Scale. Reliability and Sensitivity in a Sample of Breast Cancer Patients. *Psicoterapia Cogn. Comportament.* 22, 65-79 doi: 10.1037/t56642-000

Connor-Smith, J. K., and Flachsbart, C. (2007). Relations between personality and coping: A meta-analysis. *J. Personal. Soc. Psychol.* 93, 1080–1107. doi: 10.1037/0022-3514.93.6.1080

Costantini, M., Musso, M., Viterbori, P., Bonci, F., Del Mastro, L., Garrone, O., et al. (1999). Detecting psychological distress in cancer patients: validity of the Italian version of the Hospital Anxiety and Depression Scale. *Support. Care Cancer* 7, 121–127. doi: 10.1007/s005200050241

Dagan, M., and Hagedoorn, M. (2014). Response rates in studies of couples coping with cancer: A systematic review. *Health Psychol.* 33, 845–852. doi: 10.1037/hea0000013

Davis, C., Tami, P., Ramsay, D., Melanson, L., MacLean, L., Nersesian, S., et al. (2020). Body image in older breast cancer survivors: a systematic review. *Psycho-Oncology* 29, 823–832. doi: 10.1002/pon.5359

Dekel, R., Vilchinsky, N., Liberman, G., Leibowitz, M., Khaskia, A., and Mosseri, M. (2014). Marital satisfaction and depression among couples following men's acute coronary syndrome: Testing dyadic dynamics in a longitudinal design. *Br. J. Health Psychol.* 19, 347–362. doi: 10.1111/bjhp.12042

Dhada, S., Stewart, D., Cheema, E., Hadi, M. A., and Paudyal, V. (2021). Cancer Services During the COVID-19 Pandemic: Systematic Review of Patient's and Caregiver's Experiences. *Cancer Manage. Res* 13, 5875–5887. doi: 10.2147/CMAR.S318115

Donato, S., Iafrate, R., Barni, D., Bertoni, A., Bodenmann, G., and Gagliardi, S. (2009). Measuring dyadic coping: The factorial structure of bodenmann's "dyadic coping questionnaire" in an Italian sample. *TPM Test. Psychometrics Methodol. Appl. Psychol.* 16, 25–47.

Drigotas, S. M., Rusbult, C. E., Wieselquist, J., and Whitton, S. W. (1999). Close partner as sculptor of the ideal self: Behavioral affirmation and the Michelangelo phenomenon. *J. Personal. Soc. Psychol.* 77, 293–323. doi: 10.1037/0022-3514.77.2.293

Falconier, M. K., and Kuhn, R. (2019). Dyadic coping in couples: A conceptual integration and a review of the empirical literature. *Front. Psychol.* 10:571. doi: 10.3389/fpsyg.2019.00571

Falk Dahl, C. A., Reinertsen, K. V., Nesvold, I.-L., Fosså, S. D., and Dahl, A. A. (2010). A study of body image in long-term breast cancer survivors. *Cancer* 116, 3549–3557. doi: 10.1002/cncr.25251

Fang, S. Y., Chang, H. T., and Shu, B. C. (2015). The moderating effect of perceived partner empathy on body image and depression among breast cancer survivors. *Psycho-Oncology* 24, 1815–1822. doi: 10.1002/pon.3868

Fingeret, M. C., Nipomnick, S. W., Crosby, M. A., and Reece, G. P. (2013). Developing a theoretical framework to illustrate associations among patient satisfaction, body image and quality of life for women undergoing breast reconstruction. *Cancer Treat. Rev.* 39, 673–681. doi: 10.1016/j.ctrv.2012.12.010

Fingeret, M. C., Teo, I., and Epner, D. E. (2014). Managing body image difficulties of adult cancer patients: Lessons from available research. *Cancer* 120, 633–641. doi: 10.1002/cncr.28469

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., and Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology* 15, 579–594. doi: 10.1002/pon.991

George, D., and Mallery, P. (2010). *SPSS for Windows Step by Step: A Simple Guide and Reference Fourth Edition*. Boston, MA: Bost Pearson Educ Inc.

Grassi, L., Buda, P., Cavana, L., Annunziata, M. A., Torta, R., and Varetto, A. (2005). Styles of coping with cancer: The Italian version of the Mini-Mental Adjustment to Cancer (Mini-MAC) scale. *Psycho-Oncology* 14, 115–124. doi: 10.1002/pon.826

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., and Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychol. Bull.* 134, 1–30. doi: 10.1037/0033-2909.134.1.1

Hair, J. F., and Black, W. C. (2000). "Cluster analysis," in *Reading and Understanding Multivariate Statistics*, eds L. G. Grimm and P. R. Yarnold (Washington: American Psychological Association), 115–145.

Henry, D. B., Tolan, P. H., and Gorman-Smith, D. (2005). Cluster analysis in family psychology research. *J. Fam. Psychol.* 19, 121–132. doi: 10.1037/0893-3200.19.1.121

Hopwood, P., Fletcher, I., Lee, A., and Al Ghazal, S. (2001). A body image scale for use with cancer patients. *Eur. J. Cancer* 37, 189–197. doi: 10.1016/S0959-8049(00)00353-1

Kayser, K., and Acquati, C. (2019). The influence of relational mutuality on dyadic coping among couples facing breast cancer. *J. Psychosoc. Oncol.* 37, 194–212. doi: 10.1080/07347332.2019.1566809

Kayser, K., Watson, L. E., and Andrade, J. T. (2007). Cancer as a "we-disease&quot: Examining the process of coping from a relational perspective. *Families Systems Health* 25, 404–418. doi: 10.1037/1091-7527.25.4.404

Keesing, S., Rosenwax, L., and McNamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. *BMC Women's Health* 16:57. doi: 10.1186/s12905-016-0337-z

Kim, Y., Shaffer, K. M., Carver, C. S., and Cannady, R. S. (2016). Quality of life of family caregivers 8 years after a relative's cancer diagnosis: follow-up of the National Quality of Life Survey for Caregivers. *Psycho-Oncology* 25, 266–274. doi: 10.1002/pon.3843

Leigh, E. K., Chipman, M., Stephenson, J., Robinson, K., Giandinoto, J. A., and Trisno, R. (2019). Recovery in early stage breast cancer—An Australian longitudinal study. *Int. J. Nurs. Pract.* 25, e12747. doi: 10.1111/ijn.12747

Lindwall, L., and Bergbom, I. (2009). The altered body after breast cancer surgery. *Int. J. Q. Stud. Health Well Being* 4, 280–287. doi: 10.3109/17482620903106645

Ludwigson, A., Huynh, V., Myers, S., Hampanda, K., Christian, N., Ahrendt, G., et al. (2022). Patient Perceptions of Changes in Breast Cancer Care and Well-Being During COVID-19: A Mixed Methods Study. *Annal. Surg. Oncol.* 29, 1649–1657. doi: 10.1245/s10434-021-11209-1

Maliski, S. L., Heilemann, M. S. V., and McCorkle, R. (2002). From "death sentence" to "good cancer": Couples' transformation of a prostate cancer diagnosis. *Nurs. Res.* 51, 391–397. doi: 10.1097/00006199-200211000-00007

Manne, S., and Badr, H. (2010). Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho-Oncology* 19, 941–954. doi: 10.1002/pon.1645

McKean, L. N., Newman, E. F., and Adair, P. (2013). Feeling like me again: a grounded theory of the role of breast reconstruction surgery in self-image. *Eur. J. Cancer Care* 22, 493–502. doi: 10.1111/ecc.12055

Morales-Sánchez, L., Luque-Ribelles, V., Gil-Olarte, P., Ruiz-González, P., and Guil, R. (2021). Enhancing Self-Esteem and Body Image of Breast Cancer Women through Interventions: A Systematic Review. *Int. J. Environ. Res. Public Health* 18:1640. doi: 10.3390/ijerph18041640

Moreira, H., and Canavarro, M. C. (2010). A longitudinal study about the body image and psychosocial adjustment of breast cancer patients during the course of the disease. *Eur. J. Oncol. Nurs.* 14, 263–270. doi: 10.1016/j.ejon.2010.04.001

Riazuelo, H. (2021). Couples coping with the serious illness of one of the partners. *Front. Psychol.* 12:638938. doi: 10.3389/fpsyg.2021.638938

Rosenberg, S. M., Tamimi, R. M., Gelber, S., Ruddy, K. J., Kereakoglow, S., Borges, V. F., et al. (2013). Body image in recently diagnosed young women with early breast cancer. *Psycho-Oncology* 22, 1849–1855. doi: 10.1002/pon.3221

Rowland, E., and Metcalfe, A. (2014). A systematic review of men's experiences of their partner's mastectomy: Coping with altered bodies. *Psycho-Oncology* 23, 963–974. doi: 10.1002/pon.3556

Saita, E., Acquati, C., Fenaroli, V., Zuliani, C., and Bonanno, G. A. (2017). A Confirmatory factor analysis of the perceived ability to cope with trauma (PACT) scale. *Test. Psychomet. Methodol. Appl. Psychol.* 24, 255–258.

Saita, E., Acquati, C., and Kayser, K. (2015). Coping with early stage breast cancer: examining the influence of personality traits and interpersonal closeness. *Front. Psychol.* 6:88. doi: 10.3389/fpsyg.2015.00088

Saita, E., Acquati, C., and Molgora, S. (2016). Promoting Patient and Caregiver Engagement to Care in Cancer. *Front. Psychol.* 7:1660. doi: 10.3389/fpsyg.2016.01660

Saita, E., Ferraris, G., Molgora, S., Fenaroli, V., and Grassi, M. (2018). Body image in women with breast cancer. a research within a relational perspective. *Ricerche Psicol.* 41, 729–743. doi: 10.3280/RIP2018-004011

Sayehmiri, K., Kareem, K. I., Abdi, K., Dalvand, S., and Gheshlagh, R. G. (2020). The relationship between personality traits and marital satisfaction: a systematic review and meta-analysis. *BMC Psychol.* 8:15. doi: 10.1186/s40359-020-0383-z

Scott, J. L., Halford, W. K., and Ward, B. G. (2004). United We Stand? *J. Consult. Clin. Psychol.* 72, 1122–1135. doi: 10.1037/0022-006X.72.6.1122

Shrout, M. R., Renna, M. E., Madison, A. A., Alfano, C. M., Povoski, S. P., Lipari, A. M., et al. (2020). Relationship satisfaction predicts lower stress and inflammation in breast cancer survivors: A longitudinal study of within-person and between-person effects. *Psychoneuroendocrinology* 118, 104708. doi: 10.1016/j.psyneuen.2020.104708

Stanton, A. L., Revenson, T. A., and Tennen, H. (2007). Health Psychology: Psychological Adjustment to Chronic Disease. *Annu. Rev. Psychol.* 58, 565–592. doi: 10.1146/annurev.psych.58.110405.085615

Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C., and Robertson, B. (1988). Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychol. Med.* 18, 203–209. doi: 10.1017/S0033291700002026

Weitkamp, K., Feger, F., Landolt, S. A., Roth, M., and Bodenmann, G. (2021). Dyadic Coping in Couples Facing Chronic Physical Illness: A Systematic Review. *Front. Psychol.* 12:722740. doi: 10.3389/fpsyg.2021.722740

White, C. A. (2000). Body image dimensions and cancer: a heuristic cognitive behavioural model. *Psycho-Oncology* 9, 183–192. doi: 10.1002/1099-1611(200005/06)9:3<183::AID-PON446<3.0.CO;2-L

Zigmond, A. S., and Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scand.* 67, 361–370. doi: 10.1111/j.1600-0447.1983.tb09716.x

Zimmermann, T. (2015). Intimate Relationships Affected by Breast Cancer: Interventions for Couples. *Breast Care* 10, 102–108. doi: 10.1159/000381966

Zimmermann, T., Scott, J. L., and Heinrichs, N. (2010). Individual and dyadic predictors of body image in women with breast cancer. *Psycho-Oncology* 19, 1061–1068. doi: 10.1002/pon.1660

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

ORIGINAL RESEARCH
published: 09 May 2022
doi: 10.3389/fpsyg.2022.802603

Emotional and Sexual Adaptation to Colon Cancer: Perceptual Congruence of Dyadic Coping Among Couples

Alexandra Stulz[1,2], Nicolas Favez[3] and Cécile Flahault[2]*

[1] Department of Oncology, Hôpital Saint-Joseph, Paris, France, [2] Department of Laboratoire de Psychopathologie et Processus de Santé, Université Paris Cité, Paris, France, [3] Department of Unité de Psychologie Clinique des Relations Interpersonnelles, Université de Genève, Geneva, Switzerland

Context: Colon cancer is the 3rd most common cancer in the world. The diagnosis leads the patient and his relatives into a process of mourning for their health and previous life. The literature highlights the impact of the disease on couples. Cancer can either alter or strengthen the relationship. The disease will directly or indirectly affect both partners. Such impact starts with the diagnosis and lasts long after treatments. No study has analyzed both emotional and sexual interactions between partners throughout the illness so far.

Objective: This research aims to identify and describe whether congruence within couples tends to improve emotional and sexual adjustment.

Method: Thirteen couples took part in this research by answering a set of questionnaires investigating, in particular, dyadic coping strategies, marital and sexual satisfaction. Non-parametric analyses were performed on the quantitative data.

Results: Emotional satisfaction is good among the couples in our study. There are important similarities in partners' emotional adjustment. Patients who are most satisfied with their couple typically have a partner who is also satisfied. This was an expected result based on the literature. Overall, sexual satisfaction is described as average, which is either related to a low frequency of sexual intercourse, or a gap between the ideal and actual frequency of intercourse. In terms of dyadic coping, similarities within couples tend to improve emotional and sexual adjustment. Couples in which communication about stress between the patient and their partner is congruent tend to report good marital satisfaction. We found the same results for delegated coping of both the patient and the partner, and for negative coping of the partner. Sexual adjustment is linked to a similar perception within the couple of a common dyadic coping.

Conclusion: Emotional and sexual adjustment is largely linked to the quality of the partner's support. The congruence of couple support strategies has been identified as an important factor in emotional satisfaction. In addition, the more couples implement joint stress management, the better their sexual satisfaction.

Keywords: colon cancer, couple, congruence, dyadic coping, emotional and sexual satisfaction

Edited by:
Tanja Zimmermann,
Hannover Medical School, Germany

Reviewed by:
Susan Koranyi,
University Hospital Leipzig, Germany
Federica Vallone,
University of Naples Federico II, Italy

****Correspondence:***
Alexandra Stulz
alexandra.stulz@hotmail.fr

Specialty section:
This article was submitted to
Psycho-Oncology,
a section of the journal
Frontiers in Psychology

Received: *26 October 2021*
Accepted: *17 March 2022*
Published: *09 May 2022*

Citation:
Stulz A, Favez N and Flahault C (2022) Emotional and Sexual Adaptation to Colon Cancer: Perceptual Congruence of Dyadic Coping Among Couples. Front. Psychol. 13:802603. doi: 10.3389/fpsyg.2022.802603

INTRODUCTION

Context

Institutions focusing on cancer epidemiology report a particularly high incidence of colon cancer (INCa, 2017). The most recent data show that colorectal cancer was the 3rd (respectively 2nd) most diagnosed cancer in men (respectively women), in 2016.

Physical and Psychological Impacts

Colon cancer as well as its treatments can have significant physical repercussions: abdominal pain; transit disorder; anemia; rectorrhagia; fatigue; weight loss, loss of appetite, nausea, and vomiting; bowel obstruction or perforation (American Cancer Society, 2013).

In addition, the experience of cancer is subjective and characterized by psychological upheaval (Baillet and Pelicier, 1998; Reich et al., 2008; Dolléans, 2010). The diagnosis of cancer is often associated with intense emotional shock, incomprehension or a feeling of injustice (Baillet and Pelicier, 1998; Wisard, 2008). Cancer conveys an image of death, of emaciated bodies, of suffering (Reich et al., 2008; Altmeyer and Pinault, 2009); patients talk about their fear of dying, fear of suffering and physical mutilation. They also mention their worries about losing their place in their personal and intimate life, and their place in society (Wisard, 2008; Dolléans, 2010).

More specifically, in the case of colon cancer, the symbolism of the affected area has psychological repercussions on patients (Dolléans, 2010). Indeed, colon cancer refers to the notion of stool, fecal matter, which is taboo in our society (Altmeyer and Pinault, 2009). Patients may feel a sense of shame associated with the location of their disease and the need to discuss bowel movements in detail with healthcare teams. There are also concerns related to cleanliness, loss of sphincter control, or a fear of disgust that this might produce in others. Furthermore, treatments can be experienced as an intrusion into the body, a brutal and violent aggression (Altmeyer and Pinault, 2009). The body is most often damaged by the treatments, both in the short and long term, which can lead to psychological distress (Reich et al., 2008), a feeling of depersonalization, a loss of control over oneself and one's identity, isolation, shame, and anger (Altmeyer and Pinault, 2009).

The impact of both the disease and the treatment reaches beyond the individual patient. The onset of cancer within a family causes both emotional and functional upheavals (Carlson et al., 2000; Sevaux, 2006; Razavi et al., 2008; Revenson and DeLongis, 2011). Spouses are often the primary "caregivers," very commonly cited as the most important source of support by patients (Baider et al., 1996; Pitceathly and Maguire, 2003; Stuhlfauth et al., 2018). The relationship between a patient and their partner is complex and differs from the supportive relationships held with family and friends. Partners have a supportive role in the healing process, sharing in the daily routine (Lory, 2010).

Spouses may experience significant existential stress knowing their partner is ill. The diagnosis of cancer, let alone the mere use of this term, awakens anxieties about death, uncertainty, suffering, loss, and separation (Reynaert et al., 2006; Proia-Lelouey and Lemoignie, 2012). As a key source of support for patients, they are also the most affected by the disease (Razavi et al., 2008). The literature highlights the frequent presence of psychological distress and anxiety in partners, sexual dysfunction and/or decreased libido, loss of mobility and decreased leisure activities, or difficulties in marital communication and romantic relationships (Libert et al., 2006; Braun et al., 2007).

Cancer and the Interdependence of Partners: A «We-Disease»

The psychological and relational adjustment of couples is increasingly studied in the field of cancer. Research focuses on patient and partner distress, support, cohesion, relational satisfaction, and communication within couples (Acitelli and Badr, 2005; Kayser et al., 2018), most often in the context of breast or prostate cancer (Proia-Lelouey and Lemoignie, 2012). However, the majority of studies still focuses on patients and partners independently, omitting the relational consequences for the couple as a system (Acitelli and Badr, 2005). Here we wish to focus on the dyadic dimension and congruence within couples in adjusting to illness.

Interdependence can be defined as the mutual influence of two partners, acting as a unit rather than as two independent individuals (Kayser and Scott, 2008). The couple as an interpersonal and interdependent system can contribute to individual wellbeing, improve the effectiveness of adjustment, create a safe environment where partners can talk to each other, express their needs, recognize each other's strengths, change the meaning of the illness and allow for effective coping strategies to be implemented. Conversely, the relationship can participate in the development or maintenance of psychological suffering when difficulties arise and persist, both at the individual or couple level (Bodenmann, 2005; Kayser et al., 2007; Kayser and Scott, 2008; Drabe et al., 2015; Feeney and Collins, 2015).

When faced with illness, two distinct patterns of reaction by couples have been described (Acitelli and Badr, 2005; Kayser et al., 2007; Kayser and Scott, 2008):

- "mutual reactivity": the illness is experienced as a common stressor, affecting both partners. This type of pattern allows for individual and couple developments, strengthens the relationship, increases intimacy;
- "avoidance–indifference": the illness is perceived as an individual stress, referring only to what is experienced by each partner separately, not taking into account the experience of the other. This type of pattern brings little evolution to the couple, it can, however, bring personal evolution.

In general, couples who perceive illness as a "couple experience" report better individual and dyadic adjustment to illness and greater relationship satisfaction than those who perceive illness as an individual stressor (Acitelli and Badr, 2005; Ahmad et al., 2017).

Congruence Within Couples

Partner interdependence raises the question of congruence in partner responses to adjustment to cancer. This field of research was developed in the 1980s and focuses on the effects of congruence on the emotional adjustment of patients and partners, mostly in breast cancer (Kraemer et al., 2011; Meier and Cho, 2019). A few studies have subsequently applied the concept of congruence to marital satisfaction (Badr, 2004; Norton and Manne, 2007; Meier and Cho, 2019). These works assess how similarities in the perception and/or coping mechanisms put in place by partners affect their individual and relational adjustment (Iafrate et al., 2012; Falconier and Kuhn, 2019).

Congruence can be assessed by looking at the degree to which partners agree on how they cope as a couple or "perceptual congruence of dyadic coping." It is an assessment of the recognition of each partner's efforts, measured at the couple level (Meier and Cho, 2019).

A look at the current literature tells us that the congruence effect between partners depends on the variables studied (Falconier and Kuhn, 2019). For example, couples reporting high congruence in their "perceived dyadic adjustment" showed greater marital satisfaction with no effect on individual distress (Iafrate et al., 2012). Badr (2004) adds that congruence can be helpful depending on the type of coping strategy implemented: couples who are more congruent in active engagement and more complementary in protective and avoidance behaviors report greater marital satisfaction.

Results in the field of cancer are heterogeneous and have never been applied to colorectal cancer. Moreover, the evaluation of congruence only concerns individual adjustment or marital satisfaction, without looking at sexual adjustment. Our study thus proposes to pay attention to the congruence in the emotional and sexual adjustment of couples where one of the members has colon cancer.

Objectives

This research aims to identify and describe congruence within couples that may impact emotional and sexual adjustment.

In order to meet our objective, we defined specific research questions touching upon the following aspects:

- RQ1: Marital and sexual satisfaction of couples in our sample. This research question is exploratory; we wish to observe partner satisfactions. However, we expect to observe rather high levels of satisfaction within the couples, which we will discuss more specifically in the Section "Discussion."
- RQ2: Intra-couple correlations of marital and sexual satisfaction to observe congruence between partners. We expect partners to exhibit a high degree of similarity in marital and sexual satisfaction.
- RQ3: Correlation between congruence of dyadic coping strategies and marital and sexual satisfaction. We expect a positive correlation between congruence and satisfaction: the more partners report congruence, the more satisfied they are with their marital and sexual life.

MATERIALS AND METHODS

Methods

This research is a quantitative, cross-sectional study of couples in which one of the partners has colon cancer.

The recruitment of patients and their partners took place in the oncology department of the Groupe Hospitalier Paris Saint Joseph. Participation in this study was open to all patients (men and women) diagnosed with colon cancer, during chemotherapy or in remission.

Patients meeting all study inclusion criteria (**Table 1**) were identified within the oncology or digestive surgery department. Identification was performed routinely between March 1, 2019 and March 31, 2020. Patients were then offered participation in the research *via* physical mail sent to their home and telephone contact. After oral acceptance of participation, all the necessary documents for the study were sent to the patients (information documents, consent, and questionnaires). Through them, the study was proposed to their partner.

Materials

Sociodemographic and Medical Questionnaire

We created a socio-demographic questionnaire including information on gender, role (patient or partner), age, marital status, number of children, socio-professional status. Information about psychological and/or sexological monitoring was also collected. We also obtained relevant medical information for this study from the patients' medical records (treatments, dates).

Dyadic Coping Questionnaire

Bodenmann (2008) Dyadic Coping Inventory (DCI) assesses dyadic coping within couples. This tool measures the degree

TABLE 1 | Inclusion criteria.

Patients	
Inclusion criteria	***Non-inclusion criteria***
Patient with colon cancer	Being unable to answer the questions (e.g., cognitive impairment)
Patient who has been in a relationship for more than 2 years	Presence of a psychiatric disorder modifying the relationship to reality or impairing participation in the study
Patient over 18 years old and able to read French	
Patient who has given free and informed consent	
Partners	
Inclusion criteria	***Non-inclusion criteria***
Partner over 18 years of age and able to read French	Cancer in treatment or in remission
Partner has given free and informed consent	Inability to answer questions (e.g., cognitive impairment) Presence of a psychiatric disorder that modifies the relationship to reality or hinders participation in the study.

of support and help provided and perceived by each spouse during a stressful event. Specifically, it assesses communication around stress, positive dyadic coping (including supportive, delegative, and shared coping), negative dyadic coping, and perceived effectiveness of couple stress management. This scale also includes an assessment of marital satisfaction. The scale has been used in many previous studies, it has good psychometric qualities in its French version (α between 0.64 and 0.89–only the negative dyadic coping subscales have lower α at 0.50 and 0.53, which we take into account in our analysis) (Ledermann et al., 2010). In our sample, α's ranged from 0.75 to 0.93, with the negative dyadic coping scales exhibiting higher values than expected (0.62 and 0.76, respectively, for patients and their partners).

Sexual Functioning Questionnaire

We chose the Derogatis Sexual Functioning Inventory (DSFI) by Derogatis and Melisaratos (1979), translated into French by Gauthier and Garceau (1982). This questionnaire is divided into 10 subscales: Information, Recent Experiences, Drive, Attitudes, Psychological Symptoms, Emotions, Role Definition, Fantasy, Body Image, and Sexual Satisfaction (overall score). The subscales can be used separately. For our study, we used only the Recent Experiences, Sexual Satisfaction, and Global Sexual Satisfaction Index scales. The tool has good psychometric qualities in its original version with α's ranging from 0.60 to 0.97 (Géonet et al., 2017). In our study, the α's range from 0.60 to 0.78.

TABLE 2 | Descriptive data.

	Full sample (*N* = 26)		**Patients (*N* = 13)**		**Partners (*N* = 13)**		***p***
Age (mean [*sd*])	56,50 [*13,89*]		56,08 [*13,91*]		56,92 [*14,41*]		*ns*
	N	**%**	***N***	**%**	***N***	**%**	
Couple Status							/
Cohabitation	6	8,0	/		/		
Married/Partnered	20	92,0					
Duration (mean)	26,62						
Children							/
Yes	17	65,4	/		/		
Number	2,75						
Level of study							*ns*
No diploma	1	3,8	1		0		
BEPC, CAP, BEP, or equivalent	6	23,1	3		3		
High school diploma or équivalent	1	3,8	0		1		
High school diploma +2	3	11,5	1		2		
Bachelor's degree and more	15	57,7	8		7		
Professional status							0,039
In activity	11	42,3	3		8		
Leave of absence from work	5	19,2	5		0		
Looking for a job/not working	1	3,8	0		1		
Retired	9	34,6	5		4		

Statistical Analysis

Non-parametric analyses were performed on the quantitative data. In order to respond to RQ1, descriptive analysis (mean, standard deviation) was conducted on marital and sexual satisfaction of couples; in order to respond to RQ2, Spearman correlations were performed between each partner's marital and sexual satisfaction within the same couple. Finally, in order to respond to RQ3, we first created a congruence score for each couple (delta between the patient's and partner's score). This score was then correlated with marital and sexual satisfaction.

Ethical and Deontological Aspects

The study involving human participants was reviewed and approved by the Conseil d'évaluation éthique pour les recherches en santé (CERES) on September 13, 2016. The delay between the committee's approval and the actual start of our research (March 2020) was linked to the organization of doctoral work and the setting up of hospital partnerships.

We informed the participants of the anonymity of the data provided, as well as of their right to refuse or withdraw from the study, without any consequence on their medical monitoring.

RESULTS

Descriptive Data

All 13 couples in our study were 56 years old on average (min: 33, max: 80, sd: 13.89). They had been in a relationship for 27 years (min: 4, max: 47, sd: 14.92) and had on average 2.75 children per couple. Ten couples were married or in a civil union, while 3 were cohabiting. Finally, the vast majority of couples lived together, with only one couple living separately (the patient's spouse was working abroad) (**Table 2**).

A comparison between patients and partners indicates that they differ only in professional status, partners being significantly more active than patients.

Finally, all the patients were diagnosed at stage 3 (62%) or 4 (38%), and about half of our sample was undergoing treatment

TABLE 3 | Medical data.

	Patients (*N* = 13)	
	N	**%**
Cancer stage (TNM)		
3	8	61,5
4	5	38,5
Treatment status		
In process of chemotherapy	6	46,2
In remission	7	53,8
Treatments		
Surgery	12	92,3
Chemotherapy	13	100
Radiotherapy	1	7,7
Stoma	1	7,7
Time since diagnosis	1,977 year [*sd: 1,51*]	

(46.2%). All of them received chemotherapy, 12 of them also underwent surgery and only one received radiotherapy (**Table 3**).

RQ1: Descriptive Analysis of Marital and Sexual Satisfaction of Couples

Couples described themselves as quite satisfied with their relationship ($M = 4$, sd = 1.2, on a Lickert scale of up to 5). Just over three-quarters of the participants reported being very or extremely happy. About 10% reported being somewhat or extremely unhappy.

Since the disease, half of the participants report having sex less than once a month, with almost 20% never having sex. It is interesting to note that the actual frequency of intercourse is significantly correlated with sexual satisfaction ($r = 0.588$, $p < 0.05$): the less frequent the intercourse, the less satisfied they are. The degree of difference between actual and desired frequency of intercourse is strongly correlated with sexual satisfaction ($r = -0.519$, $p < 0.005$): the greater the difference between actual and desired, the less satisfied the partners are with their sexuality (**Table 4**).

Perceptive Congruence Between Partners: Analysis of the Correlation Between Partner Data

RQ2: Congruence of Marital and Sexual Satisfaction

There was a strong positive and significant correlation between the marital satisfaction scores of the patients and their partners ($r = 0.617$, $p < 0.05$): the more positively the patients evaluated their marital relationship, the more positively their partner evaluated it. There was also a positive and significant correlation between the sexual satisfaction scores of patients and their partners ($r = 0.638$, $p < 0.05$): the more patients evaluated their sexuality in a positive way, the better the evaluation by partners of their own sexuality (**Table 5**). When there are differences between partners, patients always report slightly more satisfaction with their sexuality than spouses.

TABLE 4 | Correlation between the variables of the DSFI (couples).

		1	2	3	4
1. Actual frequency of sexual intercourse	Correlation coefficient	1,000	,422*	−,456*	,588**
	Sig. (2-tailed)	.	,032	,019	,002
2. Ideal frequency of intercourse	Correlation coefficient		1,000	,596**	−,002
	Sig. (2-tailed)		.	,001	,992
3. Differences between actual and ideal frequency	Correlation coefficient			1,000	−,519**
	Sig. (2-tailed)			.	,007
4. Sexual satisfaction	Correlation coefficient				1,000
	Sig. (2-tailed)				.

***Correlation is significant at the 0.01 level (2-tailed).*
**Correlation is significant at the 0.05 level (2-tailed).*

TABLE 5 | Patient-partner correlation of marital satisfaction/sexual satisfaction.

	Patients	
Partner	**Marital satisfaction**	**Sexual satisfaction**
Marital satisfaction	,617*	/
Sig. (2-tailed)	,025	
Sexual satisfaction	/	,638*
Sig. (2-tailed)		,019

**Correlation is significant at the 0.05 level (2-tailed).*

TABLE 6 | Correlation between delta of dyadic coping strategies and adjustment variables.

		Marital satisfaction	Sexual satisfaction
Delta perception of patient communication	Correlation coefficient	−,452*	−,220
	Sig. (2-tailed)	,048	,280
Delta perception of partner communication	Correlation coefficient	−,576**	,027
	Sig. (2-tailed)	,002	,895
Delta perception of patient's supportive coping	Correlation coefficient	−,377	−,339
	Sig. (2-tailed)	,058	,090
Delta perception of partner's supportive coping	Correlation coefficient	−,341	−,160
	Sig. (2-tailed)	,088	,436
Delta perception of patient's negative coping	Correlation coefficient	−,387	−,202
	Sig. (2-tailed)	,051	,323
Delta perception of partner's negative coping	Correlation coefficient	−,582**	−,044
	Sig. (2-tailed)	,002	,832
Delta perception of patient's delegated coping	Correlation coefficient	−,413*	−,278
	Sig. (2-tailed)	,036	,170
Delta perception of partner's delegated coping	Correlation coefficient	−,473*	−,267
	Sig. (2-tailed)	,015	,188
Delta common dyadic coping	Correlation coefficient	−,220	−,417*
	Sig. (2-tailed)	,280	,034
Delta dyadic coping assessment	Correlation coefficient	−,321	−,170
	Sig. (2-tailed)	,109	,406
Delta total perceived dyadic coping	Correlation coefficient	−,173	−,090
	Sig. (2-tailed)	,399	,663

***Correlation is significant at the 0.01 level (2-tailed).*
**Correlation is significant at the 0.05 level (2-tailed).*

RQ3: Dyadic Coping and Marital and Sexual Satisfaction

Dyadic coping variables require preliminary work to facilitate the analysis of similarities.

- Communication around stress, supportive, negative, and delegated dyadic coping subscales:
    - Patients and partners rated both their own and their spouse's coping
    - We chose to create a variable assessing the similarity of perception by partners (e.g., the difference between patient and spouse scores on patient communication)
- Common dyadic coping subscales, coping effectiveness assessment, and total dyadic coping:
    - Patients and partners rated only their own perception
    - We created a simple variable to measure the difference between patient and partner scores.

The degree of similarity between what one partner does and their spouse's perception of it (e.g., how I communicate and what my partner perceives of my communication) is related to marital satisfaction for several of the dyadic coping subscales. Indeed, there are negative and significant correlations with patient ($r = -0.452, p < 0.05$) and partner ($r = -0.576, p < 0.01$) communication perceptions, partner negative coping perceptions ($r = -0.582, p < 0.01$), and patient ($r = -0.413, p < 0.05$) and partner ($r = -0.473, p < 0.05$) delegated coping perceptions. Two trends were identified for all other perceptions (cf. **Table 6**).

Finally, sexual satisfaction was only negatively and significantly correlated with the gap in joint dyadic coping assessed by partners ($r = -0.417, p < 0.05$). This means that the more the two partners of the same couple differ in their implementation of common strategies, the less satisfied they are with their sexuality. No other correlation was significant (**Table 6**).

DISCUSSION

Colon cancer is one of the most frequently diagnosed cancers in the world, for which screening and treatment currently allow a longer survival. However, all of the treatments available today lead to a significant alteration in the quality of life of both patients and partners. The couple will experience the onset of the disease, often modifying its functioning. These global repercussions will persist for several years. We felt it was necessary to look at the emotional and sexual experiences of these couples affected by colon cancer.

Couples (RQ1)

In our sample, couples described themselves as happy or very happy in their relationship. We expected couples to describe themselves as happy, as studies of couples often have a selection bias: happy couples are more likely to participate. However, sexual satisfaction is described as average in couples, due to the low frequency of sexual intercourse and a significant gap with the ideal frequency of intercourse. This alteration in sexual satisfaction is a common consequence of cancer and related treatments, and is recognized as one of the most persistent impacts after treatment (Traa et al., 2012).

Congruence

Congruence in the emotional and sexual adjustment of couples in which one member has colon cancer has never been evaluated in the literature.

Emotional Adjustment and Marital Satisfaction (RQ2)

We have seen that there are important similarities between partners within couples. Thus, the partners of patients who are most satisfied with their relationship also tend to be satisfied themselves. This result was expected, due to the couple-focused theme of our research and the enrollment of partners through patients. Two couples still rated their marital satisfaction very negatively, with a strong similarity as well.

In other words:

> *"When I am satisfied with our relationship as a couple, you are too.*
> *If I'm not, neither are you."*

Sexual Adjustment (RQ2)

Although there is a correlation between the sexual satisfaction of patients and partners, highlighting similarities between the partners, differences still exist. When there are differences between partners, patients always declare themselves slightly more satisfied with their sexuality than spouses. It can probably be explained by different expectations between patients and partners on sexuality (Almont et al., 2019): patients tend to put sexuality on hold at the time of diagnosis and during treatment, in relation with the shock of the diagnosis, the death anxiety, and the implementation of treatments altering quality of life. Putting sexual issues on hold seems easier for patients–who are focused on treatment–than for their partners.

In other words:

> *"When I am satisfied with my sexuality, you tend to be too"*

Dyadic Coping (RQ3)

Similarities within couples in dyadic coping tend to facilitate marital and sexual adjustments.

Thus, when patient and partner communication is well perceived by both members of the couple, they are more satisfied with their marital relationship. More broadly, our results emphasize the amount and need of communication within couples (Badr, 2004; Barnoy et al., 2006). A couple in which one partner reports a great deal of illness-related communication while the other does not perceive it will tend to do worse from a relationship standpoint, due to the latter's difficulty to adjust to the needs of their partner.

On the other hand, when patients and partners perceive the partner's negative coping strategies in the same way, then marital satisfaction is better. These results are interesting, as negative coping strategies are usually associated with lower marital satisfaction in the literature. This would mean that the similarity of perception in couples regarding these strategies actually promotes better marital adjustment. Congruence could thus provide benefits, even when identified on negative strategies (Bodenmann et al., 2011).

Finally, the correct perception of delegated coping strategies by patients and partners is related to the good marital satisfaction of both partners. In other words, if the patient asks for help and perceives that his or her partner is providing it, marital satisfaction is better. Similarly, if the partner is supportive and the partner perceives that he or she is supportive, then marital satisfaction is higher.

Congruence of support strategies in the couple has been identified as an important factor in marital satisfaction in several studies of different types of cancer, including colorectal cancer (Barnoy et al., 2006; Norton and Manne, 2007; Meier and Cho, 2019). For women followed for breast cancer (Ben-Zur et al., 2001), it is primarily in the area of supportive coping (including emotional support) that congruence plays a positive role on affective adjustment in patients. Bodenmann et al. (2011) also emphasize that congruence in supportive coping is related to marital satisfaction; they, however, mention that congruence between partners is less predictive of marital satisfaction than initial coping strategies. In our sample of couples, congruence in supportive coping strategies was not found, suggesting that the effect of supportive behavior is more efficient than the perception of congruence within couples in couples' emotional adjustment.

Taken together, these correlations tell us that similarities in partners' perceptions of dyadic communication and coping strategies promote marital satisfaction. In other words, "the more my partner and I perceive the same thing about each other's behavior, the more likely we are to be satisfied with our relationship."

Lastly, sexual adjustment is linked to a similar perception of a common dyadic coping within the couple. Common dyadic coping strategies are all the behaviors and cognitions of the couple, in order to manage the stress of the illness. These strategies emphasize the commitment of both partners to the relationship. Thus, the more couples implement joint stress management, the more sexually satisfied they are.

Limits

There are limitations to this work that we would like to discuss. First of all, the inclusion of patients as soon as they are diagnosed with cancer remains laborious, be it for medical clinical trials or psychosocial studies. The shock of diagnosis, death anxiety, pre-treatment anxiety and uncertainty about the future probably limit these inclusions. Moreover, recruitment of couples is not easy. Dyadic studies often face a low participation rate of couples who, when they do participate, generally report very good marital satisfaction (Manne et al., 2004; Segrestan-Crouzet, 2010; Hagedoorn et al., 2011).

In addition, there is a selection effect here that should be noted, as partners are recruited through patients. We are aware that this leads to the recruitment of couples who are mostly satisfied with their relationship. Nonetheless, it remains clinically relevant to try and identify factors that favor a good adjustment of couples to the disease.

Finally, the topic of sexuality is an additional barrier, being a taboo in itself. Indeed, talking about sexuality remains difficult, for both patients and caregivers (Annerstedt and Glasdam, 2019; Traumer et al., 2019). The number of couples included in our research is therefore limited. This makes it difficult to generalize our results to all colon cancer patients and their partners. This also reduces the statistical power, limits the choice of our analyses and therefore requires attention in the interpretation of the results.

In addition, the questionnaires used in our study do not include questions about life events that patients and partners may be going through outside the disease. As our study recruited patients several years after diagnosis, it is possible that other life events may have influenced our results.

CONCLUSION

The originality of this study was to focus on couples and to analyze their emotional and sexual adjustment during and after treatment.

Stress management within couples is an important variable in the adjustment of patients and partners (Untas et al., 2009). First, communication between partners regarding individual needs and attention to each other is quite high and frequent. It has positive effects especially when it is congruent and corresponds to each other's needs. The majority of couples use positive behaviors, favoring joint management of the disease and treatments. Negative behaviors are rarely used, and remain associated with an alteration in emotional and sexual adjustment. All of these results are also found in the literature regarding overall emotional adjustment, particularly in breast cancer (Segrestan-Crouzet, 2010; Stulz et al., 2014). In addition, we note a link between patient and partner adjustment, and strong similarities within couples on many variables. Congruence within couples tends to promote emotional and sexual adjustment, so couples tending to react in similar ways seem to do better than couples reacting in very divergent ways to the disease. These findings are clinically interesting, but remain to be confirmed, especially as the literature continues to emphasize the superiority of coping strategies *per se* over perceived congruence as a predictor of couples' affective adjustment (Bodenmann et al., 2011; Regan et al., 2015).

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The study involving human participants was reviewed and approved by the Conseil d'évaluation éthique pour les recherches en santé (CERES) on September 13, 2016. Written informed consent to participate in this study was provided by both the patient and the spouse.

AUTHOR CONTRIBUTIONS

AS contributed to conception and design of the study and the acquisition, analysis, or interpretation of data for the work, drafted the work, organized the database, performed the statistical analysis, wrote the first draft of the manuscript, and wrote sections of the manuscript. NF and CF revised the work critically for important intellectual content. All authors contributed to manuscript revision, read, and approved the submitted version.

REFERENCES

Acitelli, L. K., and Badr, H. J. (2005). “My illness or our illness? Attending to the relationship when one partner is ill,” in *Couples coping with stress: Emerging perspectives on dyadic coping*, eds T. A. Revenson, K. Kayser, and G. Bodenmann (Washington, DC: American Psychological Association), 121–136. doi: 10.1037/11031-006

Ahmad, S., Fergus, K., Shatokhina, K., and Gardner, S. (2017). The closer ’We’ are, the stronger ’I’ am: the impact of couple identity on cancer coping self-efficacy. *J. Behav. Med.* 40, 403–413

Almont, T., Farsi, F., Krakowski, I., ElOsta, R., Bondil, P., and Huyghe, E. (2019). Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. *Supp. Care Cancer* 27, 887–894. doi: 10.1007/s00520-018-4376-x

Altmeyer, A., and Pinault, P. (2009). *Prise en charge psychosociale Cancer du côlon et du rectum*. Strasbourg: Réseau Oncolie.

American Cancer Society (2013). *Colorectal Cancer*. Atlanta, GA: American Cancer Society.

Annerstedt, C. F., and Glasdam, S. (2019). Nurses’ attitudes towards support for and communication about sexual health-A qualitative study from the perspectives of oncological nurses. *J. Clin. Nurs.* 28, 3556–3566. doi: 10.1111/jocn.14949

Badr, H. (2004). Coping in marital dyads: a contextual perspective on the role of gender and health. *Pers. Relationsh.* 11, 197–211. doi: 10.1111/j.1475-6811.2004.00078.x

Baider, L., Kaufman, B., Peretz, T., Manor, O., Ever-Hadani, P., and Kaplan De-Nour. (1996). “A. Mutuality of fate: adaptation and psychological distress in cancer patients and their partners,” in *Cancer and the family*, eds L. Baider, C. L. Cooper, and A. KaplanDe-nour (New York, NY: Wiley), 173–187.

Baillet, F., and Pelicier, N. (1998). L’annonce diagnostique. Impact psychologique et aspects pratiques. *L’Encéphale* 24, 35–41.

Barnoy, S., Bar-Tal, Y., and Zisser, B. (2006). Correspondence in informational coping styles: How important is it for cancer patients and their spouses? *Pers. Ind. Diff.* 41, 105–115. doi: 10.1016/j.paid.2005.12.013

Ben-Zur, H., Gilbar, O., and Lev, S. (2001). Coping with breast cancer: Patient, spouse, and dyad models. *Psychoso. Med.* 63, 32–39. doi: 10.1097/00006842-200101000-00004

Bodenmann, G. (2005). “Dyadic coping and its significant for marital functioning” in T. A. Revenson, K. Kayser, and G. Bodenmann (Eds.), *Couples coping with stress: Emerging perspectives on dyadic coping*. Washington, DC: American Psychological Association. 33–50. doi: 10.1016/j.cpr.2008.10.004

Bodenmann, G. (2008). Dyadic coping and the significance of this concept for prevention and therapy. *Zeitschrift für Gesundheitspsychologie* 16, 108–111. doi: 10.1026/0943-8149.16.3.108

Bodenmann, G., Meuwly, N., and Kayser, K. (2011). Two conceptualizations of dyadic coping and their potential for predicting relationship quality and individual well-being: a comparison. *Eur. Psychol.* 16, 255–266. doi: 10.1027/1016-9040/a000068

Braun, M., Mikulincer, M., Rydall, A., Walsh, A., and Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *J. Clin. Oncol.* 25, 4829–4834. doi: 10.1200/JCO.2006.10.0909

Carlson, L. E., Bultz, B. D., Speca, M., and St-Pierre, M. (2000). Partners of cancer patients. *J. Psychosoc. Oncol.* 18, 39–63. doi: 10.1300/J077v18n03_03

Derogatis, L. R., and Melisaratos, N. (1979). The DSFI: a multidimensional measure of sexual functioning. *J. Sex Marit. Ther.* 5, 244–281. doi: 10.1080/00926237908403732

Dolléans, M.-C. (2010). Les répercussions psychologiques du cancer du côlon. *Soins* 743, 48–49.

Drabe, N., Klaghofer, R., Weidt, S., Zwahlen, D., Büchi, S., and Jenewein, J. (2015). Mutual associations between patients’ and partners’ depression and quality of life with respect to relationship quality, physical complaints, and sense of coherence in couples coping with cancer. *Psycho. Oncol.* 24, 442–450. doi: 10.1002/pon.3662

Falconier, M. K., and Kuhn, R. (2019). Dyadic coping in couples: a conceptual integration and a review of the empirical literature. *Front. Psychol.* 10:571. doi: 10.3389/fpsyg.2019.00571

Feeney, B. C., and Collins, N. L. (2015). A new look at social support: a theoretical perspective on thriving through relationships. *Pers. Soc. Psychol. Rev.* 19, 113–147. doi: 10.1177/1088868314544222

Gauthier, P., and Garceau, L. (1982). *L’inventaire du Fonctionnement Sexuel de Derogatis* [Texte inédit].

Géonet, M., De Sutter, P., and Zech, E. (2017). Quelles mesures pour évaluer la baisse du désir sexuel chez la femme? *Sexol. Eur. J. Sexol. Sexual Health* 26, 103–109. doi: 10.1016/j.sexol.2016.06.005

Hagedoorn, M., Dagan, M., Puterman, E., Hoff, C., Meijerink, W. J., Delongis, A., et al. (2011). Relationship satisfaction in couples confronted with colorectal cancer: the interplay of past and current spousal support. *J. Behav. Med.* 34, 288–297. doi: 10.1007/s10865-010-9311-7

Iafrate, R., Bertoni, A., Margola, D., Cigoli, V., and Acitelli, L. K. (2012). The link between perceptual congruence and couple relationship satisfaction in dyadic coping. *Eur. Psychol.* 17, 73–82. doi: 10.1027/1016-9040/a000069

INCa (2017). *Les cancers en France en* 2016, L’essentiel des faits et des chiffres, Boulogne-Billancourt. Bethesda: INCa

Kayser, K., Acquati, C., Reese, J. B., Mark, K., Wittmann, D., and Karam, E. (2018). A systematic review of dyadic studies examining relationship quality in couples facing colorectal cancer together. *Psychooncology* 27, 13–21. doi: 10.1002/pon.4339

Kayser, K., and Scott, J. L. (2008). “Why working with couples?” in *Helping Couples Cope with Women’s Cancers*, eds K. Kayser and J. L. Scott (New York, NY: Springer), 35–51. doi: 10.1007/978-0-387-74803-0_2

Kayser, K., Watson, L. E., and Andrade, J. T. (2007). Cancer as a “We-Disease”: Examining the process of coping from a relational perspective. *Famil. Syst. Health* 25, 404–418. doi: 10.1037/1091-7527.25.4.404

Kraemer, L. M., Stanton, A. L., Meyerowitz, B. E., Rowland, J. H., and Ganz, P. A. (2011). A longitudinal examination of couples’ coping strategies as predictors of adjustment to breast cancer. *J. Fam. Psychol.* 25, 963–972. doi: 10.1037/a0025551

Ledermann, T., Bodenmann, G., Gagliardi, S., Charvoz, L., Verardi, S., Rossier, J., et al. (2010). Psychometrics of the dyadic coping inventory in three language groups. *Swiss J. Psychol.* 69, 201–212. doi: 10.1024/1421-0185/a000024

Libert, Y., Merckaert, I., Étienne, A., and Farvacques, C. (2006). Les besoins psychosociaux et le soutien apporté aux patients atteints d’un cancer: une étude nationale belge. *Oncologie* 8, 465–476. doi: 10.1007/s10269-006-0439-6

Lory, J.-L. (2010). *Etude ethnologique des malades du cancer en milieu hospitalier. Opus 2, L’entourage : la maladie en partage*. Paris: Press’Publica.

Manne, S., Ostroff, J., Winkel, G., Goldstein, L., Fox, K., and Grana, G. (2004). Posttraumatic growth after breast cancer: patient, partner, and couple perspectives. *Psychoso. Med.* 66, 442–454. doi: 10.1097/01.psy.0000127689.38525.7d

Meier, L. L., and Cho, E. (2019). Work stressors and partner social undermining: comparing negative affect and psychological detachment as mechanisms. *J. Occup. Health Psychol.* 24, 359–372. doi: 10.1037/ocp0000120

Norton, T. R., and Manne, S. L. (2007). Support concordance among couples coping with cancer: relationship, individual, and situational factors. *J. Soc. Pers. Relationsh.* 24, 675–692. doi: 10.1177/0265407507081454

Pitceathly, C., and Maguire, P. (2003). The psychological impact of cancer on patients’ partners and other key relatives: a review. *Eur. J. Cancer* 39, 1517–1524. doi: 10.1016/s0959-8049(03)00309-5

Proia-Lelouey, N., and Lemoignie, S. (2012). Couples face au cancer. *Dialogue* 197, 69–79. doi: 10.3917/dia.197.0069

Razavi, D., Brédart, A., Delvaux, N., Dumoulin, C., and Libert, Y. (2008). "Réactions familiale," in *Précis de Psycho-Oncologie*, eds D. Razavi and N. Delvaux (Issy les Moulineaux: Elsevier Masson).

Regan, T. W., Lambert, S. D., Kelly, B., Falconier, M., Kissane, D., and Levesque, J. V. (2015). Couples coping with cancer: exploration of theoretical frameworks from dyadic studies. *Psycho-Oncol.* 24, 1605–1617. doi: 10.1002/pon.3854

Reich, M., Vennin, P., and Belkacémi, Y. (2008). L'annonce du diagnostic de cancer : l'acte qui doit sceller le pacte de confiance médecin-malade. *Bulletin du cancer* 95, 841–847.

Revenson, T. A., and DeLongis, A. (2011). "Couples Coping with Chronic Illness," in *The Oxford Handobook of Stres, Health, and Coping*, ed. S. Sarason (Oxford: University Press), 101–123.

Reynaert, Ch, Libert, Y., Jacques, D., Godenir, F., and Zdanowicz, N. (2006). Cancer et dynamique de couple. *Louvain Med.* 125, S1–S14.

Segrestan-Crouzet, C. (2010). *Evolution et Différences Dans L'ajustement des Couples au Cancer du Sein: Rôle des Facteurs Psychosociaux et Influence Réciproque des Deux Membres de la Dyade*. Doctoral theses. Available online at: http://www.theses.fr/2010BOR21729

Sevaux, M. A. (2006). Etre proche, une place difficile à trouver. *Revue Francophone de Psycho-Oncologie* 4, 230–233. doi: 10.1007/s10332-006-0146-y

Stuhlfauth, S., Melby, L., and Hellesø, R. (2018). Everyday life after colon cancer: the visible and invisible challenges. *Cancer Nurs.* 41, E48–E57. doi: 10.1097/NCC.0000000000000506

Stulz, A., Boinon, D., Dauchy, S., Delaloge, S., and Brédart, A. (2014). Ajustement psychologique des couples confrontés à un cancer du sein : perceptions des comportements de soutien du conjoint. *Bulletin du Cancer* 101, 690–697. doi: 10.1684/bdc.2014.1951

Traa, M. J., De Vries, J., Roukema, J. A., and DenOudsten, B. L. (2012). Sexual (dys)function and the quality of sexual life un patients with colorectal cancer: a systematic review. *Ann. Oncol.* 23, 19–27. doi: 10.1093/annonc/mdr133

Traumer, L., Jacobsen, M. H., and Laursen, B. S. (2019). Patients' experiences of sexuality as a taboo subject in the Danish healthcare system: a qualitative interview study. *Scand. J. Caring Sci.* 33, 57–66. doi: 10.1111/scs.12600

Untas, A., Quintard, B., Koleck, M., Borteyrou, X., and Azencot, A. (2009). Impact de la gestion dyadique du stress sur l'ajustement à une reconstruction mammaire différée après cancer. *Ann. Médico-Psychologique* 167, 134–141. doi: 10.1016/j.amp.2006.11.004

Wisard, M. (2008). Cancer et sexualité masculine. *Revue médicale Suisse* 4, 2610–2623.

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

ORIGINAL RESEARCH
published: 07 April 2022
doi: 10.3389/fpsyg.2022.828422

Sexual Activity in Couples Dealing With Breast Cancer. A Cohort Study of Associations With Patient, Partner and Relationship-Related Factors

Nina Rottmann[1,2,3], Pia Veldt Larsen[4], Christoffer Johansen[5,6], Mariët Hagedoorn[7], Susanne Oksbjerg Dalton[6,8,9] and Dorte Gilså Hansen[2]*

[1]Department of Psychology, University of Southern Denmark, Odense, Denmark, [2]Research Unit of General Practice, Department of Public Health, University of Southern Denmark, Odense, Denmark, [3]REHPA, The Danish Knowledge Center for Rehabilitation and Palliative Care, University Hospital Odense and Department of Clinical Research, University of Southern Denmark, Nyborg, Denmark, [4]Mental Health Services in the Region of Southern Denmark, Vejle, Denmark, [5]Oncology Department, Finsen Center, Rigshospitalet, University of Copenhagen, Copenhagen, Denmark, [6]Survivorship and Inequality in Cancer, Danish Cancer Society Research Center, Copenhagen, Denmark, [7]Health Sciences/Health Psychology, University Medical Center Groningen, University of Groningen, Groningen, Netherlands, [8]Department of Clinical Oncology and Palliative Care, Zealand University Hospital, Næstved, Denmark, [9]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark

Edited by:
Tanja Zimmermann,
Hannover Medical School, Germany

Reviewed by:
Andrea B Horn,
University of Zurich, Switzerland
Caroline Rometsch,
Klinik für Psychosomatische Medizin und Psychotherapie, LVR Krankenhaus Essen, Germany

****Correspondence:***
Nina Rottmann
nrottmann@health.sdu.dk

Specialty section:
This article was submitted to Psycho-Oncology, a section of the journal Frontiers in Psychology

Received: *03 December 2021*
Accepted: *15 March 2022*
Published: *07 April 2022*

Citation:
Rottmann N, Larsen PV, Johansen C, Hagedoorn M, Dalton SO and Hansen DG (2022) Sexual Activity in Couples Dealing With Breast Cancer. A Cohort Study of Associations With Patient, Partner and Relationship-Related Factors.
Front. Psychol. 13:828422.
doi: 10.3389/fpsyg.2022.828422

Objective: Breast cancer may profoundly affect a couple's sex life. The present study examines whether patient-, partner- and relationship-related characteristics are associated with sexual activity of couples following breast cancer diagnosis in the treatment phase and over time.

Methods: Women with breast cancer and their male cohabiting partners participated in a longitudinal study in Denmark. Logistic regression was used to examine associations of patient-, partner- and relationship-related characteristics at baseline ($\leq$4 months following surgery) with couples' sexual activity at baseline, 5 and 12 months later. The longitudinal analyses were stratified for couples' sexual activity status at baseline.

Results: A total of 722, 533 and 471 couples were included in the analyses at baseline, 5- and 12-months follow-up, respectively. Older age, depressive symptoms and lower vitality of patients were associated with lower odds of couples' sexual activity at baseline; chemotherapy treatment and older age of patients were associated with lower odds at 5-months follow-up in couples who were not sexually active at baseline. Higher ratings of emotional closeness, affectionate behavior and satisfaction with dyadic coping were associated with higher odds for sexual activity at baseline and over time in couples who were sexually active at baseline.

Conclusion: Sexual counseling during cancer treatment and rehabilitation should include a couple perspective. Relationship-related variables may be a protective factor for remaining sexually active after breast cancer diagnosis. Interventions could focus on strengthening these factors. Health professionals also need to consider the patients' breast cancer treatment, vitality, and emotional distress in counselling on sexuality.

Keywords: breast cancer, sexual activity, couples, patient, partner, relationship, cohort study

INTRODUCTION

According to the WHO sexuality is "a central aspect of being human throughout life" (World Health Organization, 2006, p. 5), and sexual activity has been found associated with greater enjoyment in life (Smith et al., 2019). For many cancer patients, including women with breast cancer, sexuality is a significant aspect of quality of life (Flynn et al., 2011; Bober and Varela, 2012). Yet, patients and their partners may experience changes to their sexual life after breast cancer diagnosis: The different changes that diagnosis and treatment of a potentially life-threatening illness may bring about, such as side or late effects of treatment, psychological distress and changed social roles can affect a couple's sexual relationship (Fletcher et al., 2010; Ussher et al., 2012; Keesing et al., 2016). Couples may renegotiate their sexuality, and while some can experience a strengthened sexual relationship, others might less frequently engage in sexual activity or even cease to be sexually active. The literature on sexual activity following cancer is inconsistent, with some studies reporting decreases in sexual activity following cancer diagnosis (Ussher et al., 2012; Male et al., 2016), while others report sexual activity levels that are comparable to cancer-free controls (Jackson et al., 2016).

Sexuality within couples is a dyadic issue, and qualitative research among couples dealing with breast cancer has pointed out difficulties in resuming sexual activity for both patients and partners (Loaring et al., 2015; Keesing et al., 2016). Factors related to the patient, the partner and their experience of the couple relationship are likely to be relevant for couples' sexual activity.

Previous studies have examined whether breast cancer treatment, emotional distress after breast cancer diagnosis (here defined as depressive symptoms) and other possible side or late effects of breast cancer treatment are associated with sexual activity among partnered breast cancer survivors. Treatment with chemotherapy has been found associated with sexual inactivity in some (Avis et al., 2018), but not all studies (Fobair et al., 2006), and several studies found no significant associations between sexual inactivity and other treatment modalities (Fobair et al., 2006; Marino et al., 2017; Avis et al., 2018). Findings suggest that depressive symptoms (Marino et al., 2017; Avis et al., 2018), self-image problems, such as not feeling attractive (Marino et al., 2017; Avis et al., 2018), and lack of vitality (Fobair et al., 2006) are associated with sexual inactivity. Cancer survivors have also reported pain as one of several reasons for decreases in sexual frequency (Ussher et al., 2015); among women with breast cancer, pain in the arm, breast and shoulder area is frequent (Gartner et al., 2009) and might impact sexual activity. Further, older age has been associated with sexual inactivity among women with breast cancer (Avis et al., 2018) and in the general population (Kleinstäuber, 2017), as have other medical or chronic conditions (Kleinstäuber, 2017).

It is likely that partners' emotional distress after breast cancer diagnosis, their potential physical health problems and age also affect couples' sexual activity (Kleinstäuber, 2017). In line with this, breast cancer survivors have reported physical problems of the partner as one of several reasons for sexual inactivity (Meyerowitz et al., 1999), and women who perceived their partner to fear sexual intercourse were found to be less likely to be sexually active (Brédart et al., 2011). However, these studies measured partner-related variables indirectly through the patients' ratings and did not include the partners themselves. Thus, studies are needed that also include the partners' perspective.

The role of relationship factors in couples' sexual activity following breast cancer has been examined sparsely and primarily from the patients' perspective. While emotional closeness to one's partner was not associated with sexual activity in one study (Marino et al., 2017), breast cancer survivors' feelings of emotional separation in the couple relationship were negatively associated with their sexual activity in another study (Brédart et al., 2011). Behavioral aspects in the relationship may also play a role for sexual activity. Findings from the broader literature on sexual health point towards the relevance of touching and physical closeness. However, only few studies have assessed such associations (Kleinstäuber, 2017); yet, studies point to the general importance of affectionate touch in relationships for both psychological, relational and physical wellbeing (Jakubiak and Feeney, 2017; Debrot et al., 2020). Finally, couples' perceptions of how they deal with stress as a couple, more specifically, their satisfaction with their dyadic coping, may influence sexual activity (Bodenmann et al., 2010).

To be able to provide sexual counselling and support to couples during cancer treatment and rehabilitation it is central to understand what characterizes couples who are sexually active versus inactive after breast cancer diagnosis. However, studies that not only include the patients' but also the partners' perspective and that examine the role of relationship-related factors are sparse. Furthermore, previous research in this area has often been cross-sectional (Meyerowitz et al., 1999; Fobair et al., 2006; Brédart et al., 2011; Marino et al., 2017) and only few studies have used a longitudinal design (Avis et al., 2018). As challenges can occur in different phases throughout the cancer trajectory, a longitudinal perspective is important though. We need to know whether we early on in the cancer trajectory can identify factors that predict couples' sexual activity at a later time point, when they transition through the often challenging re-entry phase, in which they may have to create a new normal and deal with the changes the breast cancer has brought about, to the early survivorship phase (Stanton et al., 2005).

The present study aims at contributing to filling these research gaps. Using an epidemiological approach and including information from both patients and partners within couples in a longitudinal design, this study will examine factors related to couples' sexual activity, assessed as a couple-based outcome, while adjusting for a set of possible confounders (age, chemotherapy treatment and type of breast cancer surgery). We wish to identify potential risk or protective factors with respect to couples' sexual activity that clinicians should pay attention to when they meet a couple, a patient or partner in a clinical setting. To our knowledge this is the first study on factors associated with couples' sexual activity after breast cancer that has a longitudinal design and systematically includes the partner.

The overall aim of the present longitudinal study is to examine whether patient-, partner- and relationship-related characteristics are associated with sexual activity of couples following breast cancer diagnosis in the treatment phase and over time. Firstly, we examine whether individual characteristics of patients and partners and their experience of the couple-relationship in the treatment phase (Time1, T1) are associated with couples' sexual activity at T1. Secondly, we examine whether individual characteristics of patients and partners and their experience of the couple-relationship in the treatment phase (T1) are associated with couples' sexual activity at the re-entry phase (Time 2, T2) and the early survivorship phase (Time 3, T3), stratified on sexual activity at T1.

MATERIALS AND METHODS

The present study is based on data from the Danish Couples and Breast Cancer Cohort (DCBCC; Terp et al., 2015), a nationwide, population-based cohort of couples dealing with breast cancer in Denmark. It includes self-report data from both patients and partners and data from Danish nationwide registries.

Procedure and Participants

Between July 2011 and August 2012, all women newly diagnosed with breast cancer who were cohabiting with a male partner in Denmark were eligible to participate. Specifically, couples were eligible if the patient was female, aged ≥18 years, residing in Denmark, had had surgery for primary invasive breast cancer no more than 4 months before study invitation, and was cohabiting with a male partner aged ≥18 years.

Couples received questionnaires at baseline (≤4 months following surgery; T1), and 5 months (T2) and 12 months (T3) later, which assessed their individual wellbeing and relationship aspects. Demographic and health-related data were obtained from nationwide administrative, health- and disease-specific registries. The study procedure has been described in detail elsewhere (Terp et al., 2015).

In the present study, we used self-report data on couples' sexual activity at baseline, T2 and T3. All other included data were assessed at baseline. We excluded couples with missing information on sexual activity at baseline.

The study was reported to the Danish Data Protection Agency *via* the University of Southern Denmark (file number SDU 10.143). The project was also notified to The Regional Scientific Ethical Committee for Southern Denmark, which assessed that the project fell outside the scope of projects to be approved by an Ethical Committee in Denmark (ID: S-20110103).

Measurements

Unless otherwise specified all measures were obtained for both patients and partners.

Sexual Activity

Sexual activity was assessed using one item from the Patient-Reported Outcomes Measurement Information System (PROMIS)® Sexual Function and Satisfaction measure (SexFS) version 1.0 (Flynn et al., 2013): *'In the past 30 days, when you have had sexual activity, how satisfying has it been?'*. Response options ranged from 1= *not at all* to 5= *very* and included the option 0= *have not been sexually active in the past 30 days.* A respondent was categorized as sexually active if she/he chose one of the response options *not at all* to *very* (satisfying) on the sexual satisfaction item. A respondent was categorized as not sexually active if she/he reported that she/he had not been sexually active in the past 30 days. Patients' and partners' scores were then combined in a couple score: Couples were considered as not sexually active, if one partner or both had been categorized as not sexually active in the past 30 days. Couples were scored as active if both partners had been categorized as sexually active in the past 30 days.

Depressive Symptoms

Depressive symptoms were measured using the Danish version of the Center for Epidemiologic Studies-Depression Scale (CES-D), a 20-item validated scale assessing depressive symptoms in the last week (Radloff, 1977; Hann et al., 1999). Higher scores indicate more symptoms (score range: 0–60). In the present study, Cronbach's alpha was 0.9 for patients and partners in our sample.

Pain

Patients' pain in the arm, breast or shoulder area was assessed with a single item inspired by the item format of the Breast Cancer Prevention Trial Eight Symptom Scale (BESS; Cella et al., 2008). Patients were asked to report to which degree they had been bothered by pain in the arm, breast, or shoulder area in the past 4 weeks on a five-point scale with response options ranging from *0 = not at all* to 4 = *extremely*.

Vitality

Patients' vitality was measured by the four-item vitality subscale of the SF-36® Health Survey (version 1) with 6-point rating scales (Bjørner et al., 1997, 1998; Ware and Gandek, 1998). The scale score ranges from 0 to 100 with higher scores indicating higher vitality. The scale has previously been used as an indicator of fatigue (Brown et al., 2011). Cronbach's alpha was 0.87.

Body Image

Patients indicated body image symptoms on the 10-item Body Image Scale (Hopwood et al., 2001). Items have four response options ranging from *0 = not at all* to *3 = very much*. The total score ranges from 0–30 with higher scores indicating greater body image disturbance. Cronbach's alpha was 0.87.

Emotional Closeness

Emotional closeness was measured by one item on how close participants felt to their partner during the past 30 days [inspired by Manne et al. (2004)]. Response options ranged from *1 = not at all* to *5 = very*, thus higher scores represent a higher degree of emotional closeness.

Affectionate Behavior

Affectionate behavior was measured with two items from the PROMIS® SexFS version 1.0 item pool on sexual activities: one item on the frequency of holding and hugging romantically, and one on the frequency of kissing romantically, with another person in the past 30 days (Flynn et al., 2013). We replaced 'another person' by 'your partner'. The response options for both items included *1 = have not done in the past 30 days; 2 = once a week or less; 3 = once every few days; 4 = once a day;* and *5 = more than once a day*. As the two items were highly correlated within patients ($r = 0.76$) and partners ($r = 0.79$), mean scores were computed as a single score for affectionate behavior (range 1–5).

Satisfaction With Dyadic Coping

Satisfaction with dyadic coping was assessed with the Evaluation of dyadic coping-subscale of the Dyadic Coping Inventory (DCI; Bodenmann, 2008). Respondents rate their satisfaction with the couple's dyadic coping in times of stress on two items with five response options each (*1 = very rarely; 5 = very often*). A score is computed by summing the two items (scale range: 2–10). The two items were highly correlated: $r = 0.91$ within both patients and partners.

Demographic and Health-Related Information

We obtained information on age at time of study invitation through the Danish Civil Registration System (Pedersen, 2011) and information on breast cancer treatment through the database of the Danish Breast Cancer Cooperative Group (Moller et al., 2008). Relationship length was self-reported by the patient at T1. Based on data from the Danish National Patient Register, covering all hospitalizations since 1977 and outpatient visits since 1995 (Lynge et al., 2011), we calculated the Charlson Comorbidity Index (CCI; Charlson et al., 1987) as a measure of patient comorbidity and partner morbidity. The CCI includes 19 different conditions, such as myocardial infarction, chronic pulmonary disease, and diabetes. Patients' breast cancer diagnosis was not included in the CCI.

Statistical Analyses

Descriptive Statistics

We calculated percentages or mean values with standard deviations (SD) for sample characteristics. The Pearson correlations within couples were calculated for the relationship-related variables satisfaction with dyadic coping, emotional closeness and affectionate behavior that were rated by both patients and partners. The agreement between patient and partner on ratings of sexual activity was evaluated using Cohen's kappa and % of agreement.

Inferential Statistics

To examine the association between couples' demographic, health-, quality of life- and relationship-related characteristics at baseline and their sexual activity at baseline, T2 and T3, respectively, we used logistic regression. Odds ratios (ORs) of continuous covariates are presented per scale unit as well as per sample standard deviation (SD) of the given covariate. All regression analyses were adjusted for age, type of surgery and chemotherapy. The longitudinal analyses, which included couples' sexual activity at T2 and T3 as outcome, were stratified on couples' sexual activity at baseline in separate models. Further, for all relationship-related variables with ratings by both partners, sensitivity analyses were conducted with additional adjustment for the respective partner's score. For all models, assumptions on linearity of continuous covariates were assessed using deviance residual plots. Due to indications that the linearity assumption on affectionate behavior was not satisfied at T1, the variable was dichotomized in all analyses. Based on the content of the response options a score of <3 was defined as infrequent and a score of ≥3 as frequent affectionate behavior.

Because of the large number of analyses only results at a significance level of $p < 0.01$ are described and discussed.

RESULTS

Study Sample

A total of 2,254 couples were eligible for the DCBCC study, and 792 (35%) participated. The present study was based on the 722 couples (response rate: 32%), in whom information on sexual activity status at baseline (T1) was available for both patients and partners. Of these 722 couples, 533 (response rate: 24%) and 471 (response rate: 21%) also gave information on the study outcome at T2 and T3, respectively. Thus, of the 722 responders at T1, 74% had data available at T2, and 65% had data at T3.

At T1, non-responding couples ($n = 70$, 9%) were about a decade older (mean age patients: 67 vs. 57 years; partners: 70 vs. 59 years), fewer patients in non-responding couples had received chemotherapy (29% vs. 53%), and more partners had one or more comorbidities (53% vs. 35%). At T2 and T3, the characteristics of non-responders and responders were similar (data not shown).

The 722 couples in the present analysis were on average in their late fifties (see **Table 1**) and had been together for an average of 28.6 years (SD = 14.6). One quarter of the women (26%) had received a mastectomy, and half of them (53%) were allocated to chemotherapy treatment.

A total of 59, 61 and 62% were sexually active at T1, T2 and T3, respectively. For most couples, sexual activity status did not change from T1 to T2 and from T1 to T3. From T1 to T2, 11% of couples changed from being not sexually active to being active, while 7% changed from being sexually active to not active. A similar pattern was observed from T1 to T3 (see **Table 2**).

The agreement between patient and partner on sexual activity was high at all three timepoints (all % of agreement >83%), although kappa values were only moderate (all kappa ≥0.59). Patients' and partners' ratings of the relationship-related variables were moderately to strongly correlated: satisfaction with dyadic coping, $r = 0.37$; emotional closeness, $r = 0.45$; affectionate behavior, $r = 0.64$.

Associations With Sexual Activity at Baseline

At baseline, older age and depressive symptoms of patients were significantly associated with lower adjusted odds for couples being sexually active (**Table 3**). The odds increased significantly with higher ratings of patient vitality and with higher ratings of all three relationship variables: satisfaction with dyadic coping, emotional closeness and affectionate behavior of both patients and partners.

TABLE 1 | Baseline patient and partner characteristics of 722 couples, stratified on couple sexual activity.

	Total	Not sexually active at baseline	Sexually active at baseline
Total, *n* (%)	722	293 (41%)	429 (59%)
PATIENT			
Demographic and health characteristics			
Age in years, mean (SD)	57.1 (10.4)	59.5 (10.3)	55.5 (10.3)
Charlson Comorbidity Index, *n* (%)			
No comorbidity (0)	520 (72)	201 (69)	319 (74)
Comorbidity (≥1)	202 (28)	92 (31)	110 (26)
Breast cancer treatment			
Type of surgery, *n* (%)			
Mastectomy	186 (26)	73 (25)	113 (26)
Lumpectomy	536 (74)	220 (75)	316 (74)
Allocated to chemotherapy, *n* (%)			
No	339 (47)	153 (52)	186 (43)
Yes	383 (53)	140 (48)	243 (57)
Allocated to endocrine treatment, *n* (%)			
No	200 (28)	85 (29)	115 (27)
Yes	522 (72)	208 (71)	314 (73)
Quality of life-related factors			
Depressive symptoms, mean (SD)[a]	12.0 (9.0)	13.3 (9.3)	11.0 (8.7)
Pain in arm, breast or shoulder area, mean (SD)[b]	0.9 (0.9)	0.9 (1.0)	0.9 (0.9)
Vitality, mean (SD)[c]	52.9 (22.3)	48.7 (21.8)	55.8 (22.3)
Body image, mean (SD)[d]	8.2 (6.0)	8.0 (6.1)	8.4 (6.0)
Relationship-related factors			
Satisfaction with dyadic coping, mean (SD)[e]	7.9 (1.9)	7.5 (2.2)	8.2 (1.7)
Emotional closeness, mean (SD)[f]	4.4 (0.8)	4.2 (0.9)	4.6 (0.7)
Affectionate behavior, *n* (%)[g]			
Infrequent (<3)	173 (24)	105 (36)	68 (16)
Frequent (≥3)	545 (76)	185 (64)	360 (84)
PARTNER			
Demographic and health characteristics			
Age, mean (SD)	59.1 (10.9)	61.7 (10.5)	57.3 (10.8)
Charlson Comorbidity Index, *n* (%)			
No comorbidity (0)	468 (65)	175 (60)	293 (68)
Comorbidity (≥1)	254 (35)	118 (40)	136 (32)
Quality of life-related factors			
Depressive symptoms, mean (SD)[h]	8.8 (8.3)	9.6 (9.1)	8.3 (7.6)
Relationship-related factors			
Satisfaction with dyadic coping, mean (SD)[i]	7.9 (1.9)	7.6 (2.1)	8.1 (1.7)
Emotional closeness, mean (SD)[j]	4.5 (0.8)	4.3 (1.0)	4.6 (0.6)
Affectionate behavior, *n* (%)[k]			
Infrequent (<3)	173 (24)	110 (38)	63 (15)
Frequent (≥3)	546 (76)	182 (63)	364 (85)

SD, Standard deviation. [a] *3 missing values (0.4%).*

[b] *4 missing values (0.6%).*

[c] *1 missing value (0.1%).*

[d] *4 missing values (0.6%).*

[e] *19 missing values (2.6%).*

[f] *3 missing values (0.4%).*

[g] *4 missing values (0.6%).*

[h] *2 missing values (0.3%).*

[i] *25 missing values (3.5%).*

[j] *1 missing value (0.1%).*

[k] *3 missing values (0.4%).*

Associations With Sexual Activity at Follow-Up

Couples Who Were Not Sexually Active at Baseline

Patients' older age and chemotherapy treatment were significantly associated with lower odds for couples being sexually active at T2 (**Table 4**). No significant associations were found between couples' baseline characteristics and their sexual activity at T3 (**Table 5**).

Couples Who Were Sexually Active at Baseline

Patients' perception of emotional closeness and affectionate behavior, and partners' perception of emotional closeness, affectionate behavior and satisfaction with dyadic coping were significantly associated with higher odds for couples' sexual activity at T2 (**Table 4**). Patients' perception of affectionate behavior and partners' perception of affectionate behavior, satisfaction with dyadic coping and emotional closeness were significantly associated with higher odds for sexual activity at T3 (**Table 5**).

TABLE 2 | Couple sexual activity over time from baseline to T2 and T3, respectively.

From T1 to T2			From T1 to T3		
N **=533 couples**			***N*** **=471 couples**		
Sexual activity status			**Sexual activity status**		
T1	**T2**	***n*** **(%)**[a]	**T1**	**T3**	***n*** **(%)**
Not active	Not active	154 (29)	Not active	Not active	124 (26)
Not active	Active	56 (11)	Not active	Active	57 (12)
Active	Not active	36 (7)	Active	Not active	24 (5)
Active	Active	287 (54)	Active	Active	266 (57)

T1, Time 1, ≤4 months following surgery for breast cancer; T2, Time 2, 5 months; T3, Time 3, 12 months later. [a]Percentages do not add up to 100 due to rounding.

Sensitivity Analyses of Relationship-Related Variables

Sensitivity analyses on the associations between sexual activity and patients' and partners' perceptions of the relationship-related variables with additional adjustment for the respective other partner's score showed similar results to the main analyses, although with some changes in the significance level (**Supplementary Tables A–C**). When adjusted for the respective other partner's score, all baseline associations between patients' and partners' relationship experience and sexual activity remained significant (**Supplementary Table A**). In couples who were sexually active at baseline, patients' perception of affectionate behavior and partners' perception of satisfaction with dyadic coping were significantly associated with higher odds for sexual activity at T2 (**Supplementary Table B**); no significant associations were present in the sensitivity analyses concerning T3 (**Supplementary Table C**).

DISCUSSION

Summary of Main Results

In this large, longitudinal study with 1-year follow-up, roughly 60% of couples were sexually active in the first year after a

TABLE 3 | Associations between patient and partner characteristics and sexual activity at baseline.

	OR$_{\text{crude}}$	**OR$_{\text{adj}}$ (95%-CI)**[a]	**OR$_{\text{SDadj}}$ (95%-CI)**[a]
PATIENT			
Demographic and health characteristics			
Age (per year)	0.96***	0.96 (0.94, 0.98)***	0.65 (0.53, 0.81)***
Charlson Comorbidity Index (ref. no comorbidity (0)): comorbidity (≥1)	0.75	0.85 (0.61, 1.19)	0.85 (0.61, 1.19)
Breast cancer treatment			
Type of surgery (ref. mastectomy): lumpectomy	0.93	1.01 (0.71, 1.43)	1.01 (0.71, 1.43)
Allocated to chemotherapy (ref. no): yes	1.43*	0.86 (0.59, 1.25)	0.86 (0.59, 1.25)
Allocated to endocrine treatment (ref. no): yes	1.12	1.13 (0.80, 1.58)	1.13 (0.80, 1.58)
Quality of life-related factors			
Depressive symptoms[b]	0.97**	0.96 (0.95, 0.98)***	0.69 (0.63, 0.83)***
Pain in arm, breast or shoulder area[b]	0.94	0.91 (0.77, 1.07)	0.92 (0.79, 1.06)
Vitality[b]	1.01***	1.02 (1.01, 1.03)***	1.55 (1.25, 1.93)***
Body image[b]	1.01	0.99 (0.96, 1.01)	0.94 (0.78, 1.06)
Relationship-related factors			
Satisfaction with dyadic coping[b]	1.19***	1.22 (1.12, 1.32)***	1.46 (1.24, 1.69)***
Emotional closeness[b]	1.75***	1.92 (1.56, 2.35)***	1.69 (1.43, 1.98)***
Affectionate behavior [ref. infrequent (<3)]: frequent (≥3)	3.00***	3.16 (2.19, 4.55)***	3.16 (2.19, 4.55)***
PARTNER			
Demographic and health characteristics			
Age (per year)	0.96***	0.97 (0.94, 1.01)	0.72 (0.51, 1.11)
Charlson Comorbidity Index [ref. no comorbidity (0)]: comorbidity (≥1)	0.69*	0.82 (0.60, 1.13)	0.82 (0.60, 1.13)
Quality of life-related factors			
Depressive symptoms[b]	0.98*	0.98 (0.96, 0.99)*	0.85 (0.71, 0.92)*
Relationship-related factors			
Satisfaction with dyadic coping[b]	1.13**	1.17 (1.07, 1.27)***	1.35 (1.14, 1.57)***
Emotional closeness[b]	1.69***	1.93 (1.56, 2.38)***	1.69 (1.43, 2.00)***
Affectionate behavior [ref. infrequent (<3)]: frequent (≥3)	3.49***	3.76 (2.60, 5.43)***	3.76 (2.60, 5.43)***

OR, Odds Ratio; OR$_{SD}$, Odds Ratio measured in units of sample SD for continuous covariates; ref., reference category.

[a]Adjusted for patient age, type of surgery and chemotherapy.

[b]Per scale unit (resp. SD) increase.

**$p<0.05$; **$p<0.01$ ***$p<0.001$.*

TABLE 4 | Associations between patient and partner characteristics and sexual activity at time T2, stratified on baseline sexual activity.

	Associations with sexual activity at T2 (*n* = 533 couples)					
	Couples not sexually active at T1			Couples sexually active at T1		
	n = 210			*n* = 323		
	OR_{crude}	OR_{adj} (95%-CI)[a]	OR_{SDadj} (95%-CI)[a]	OR_{crude}	OR_{adj} (95%-CI)[a]	OR_{SDadj} (95%-CI)[a]
PATIENT						
Demographic and health characteristics						
Age (per year)	0.97	0.93 (0.89, 0.97)**	0.47 (0.30, 0.73)**	1.02	1.02 (0.97, 1.06)	1.23 (0.73, 1.82)
Charlson Comorbidity Index [ref. no comorbidity (0)]: comorbidity (≥1)	0.43*	0.43 (0.20, 0.93)*	0.43 (0.20, 0.93)*	1.00	0.99 (0.44, 2.24)	0.99 (0.44, 2.24)
Breast cancer treatment						
Type of surgery (ref. mastectomy): lumpectomy	1.01	1.04 (0.49, 2.24)	1.04 (0.49, 2.24)	1.34	1.19 (0.54, 2.60)	1.19 (0.54, 2.60)
Allocated to chemotherapy (ref. no): yes	0.58	0.24 (0.10, 0.56)**	0.24 (0.10, 0.56)**	0.65	0.82 (0.33, 2.03)	0.82 (0.33, 2.03)
Allocated to endocrine treatment (ref. no): yes	1.50	1.84 (0.86, 3.93)	1.84 (0.86, 3.93)	1.57	1.63 (0.78, 3.43)	1.63 (0.78, 3.43)
Quality of life-related factors						
Depressive symptoms[b]	1.00	1.00 (0.96, 1.04)	1.00 (0.68, 1.44)	1.00	1.01 (0.96, 1.05)	1.09 (0.70, 1.53)
Pain in arm, breast or shoulder area[b]	0.96	0.86 (0.61, 1.22)	0.86 (0.61, 1.22)	0.90	0.92 (0.63, 1.34)	0.93 (0.66, 1.30)
Vitality[b]	1.00	1.01 (0.99, 1.02)	1.24 (0.80, 1.54)	1.00	0.99 (0.98, 1.01)	0.80 (0.64, 1.25)
Body image[b]	0.98	0.94 (0.88, 1.01)	0.69 (0.46, 1.06)	0.98	1.00 (0.94, 1.06)	1.00 (0.69, 1.42)
Relationship-related factors						
Satisfaction with dyadic coping[b]	1.14	1.20 (1.01, 1.42)*	1.49 (1.02, 2.16)*	1.28*	1.28 (1.04, 1.58)*	1.52 (1.07, 2.18)*
Emotional closeness[b]	1.07	1.20 (0.82, 1.74)	1.18 (0.84, 1.65)	2.01**	2.05 (1.31, 3.21)**	1.65 (1.21, 2.26)**
Affectionate behavior [ref. infrequent (<3)]: frequent (≥3)	1.62	1.85 (0.90, 3.80)	1.85 (0.90, 3.80)	6.48***	6.93 (3.19, 15.09)***	6.93 (3.19, 15.09)***
PARTNER						
Demographic and health characteristics						
Age (per year)	0.98	1.04 (0.96, 1.11)	1.51 (0.65, 2.99)	1.03	1.04 (0.96, 1.14)	1.53 (0.64, 4.12)
Charlson Comorbidity Index [ref. no comorbidity (0)]: comorbidity (≥1)	0.40**	0.46 (0.22, 0.92)*	0.46 (0.22, 0.92)*	3.12*	3.02 (1.11, 8.20)*	3.02 (1.11, 8.20)*
Quality of life-related factors						
Depressive symptoms[b]	0.98	0.98 (0.94, 1.02)	0.98 (0.94, 1.02)	0.97	0.98 (0.93, 1.02)	0.86 (0.58, 1.16)
Relationship-related factors						
Satisfaction with dyadic coping[b]	1.11	1.14 (0.97, 1.34)	1.32 (0.94, 1.85)	1.39***	1.38 (1.16, 1.65)***	1.73 (1.29, 2.34)***
Emotional closeness[b]	1.45	1.59 (1.04, 2.43)*	1.59 (1.04, 2.43)*	1.93**	1.91 (1.20, 3.06)**	1.47 (1.12, 1.96)**
Affectionate behavior [ref. infrequent (<3)]: frequent (≥3)	2.05*	2.38 (1.17, 4.84)*	2.38 (1.17, 4.84)*	3.69**	3.92 (1.77, 8.69)**	3.92 (1.77, 8.69)**

Odds ratios are shown with 95% confidence intervals (CI). OR, Odds Ratio; OR_{SD}, Odds Ratio measured in units of sample SD for continuous covariates; ref., reference category;

[a]Adjusted for patient age, type of surgery and chemotherapy.

[b]Per scale unit (resp. SD) increase.

$^*p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

diagnosis of female breast cancer. At baseline, couples were more likely to be sexually active, if patients and partners felt emotionally close to each other, showed affectionate behavior, or were satisfied with their way of dealing with stress as a couple. These relationship characteristics also predicted sexual activity at follow-up, but only in the group of couples who were sexually active at baseline. Older age and symptoms of depression or low vitality of patients were associated with lower odds for couples being sexually active at baseline. Treatment with chemotherapy was found to influence sexual activity at 5 months follow-up, and only among couples who were sexually inactive at baseline. Thus, individual patient-related and relationship-related characteristics played a role, with the relationship variables being most consistently associated with couples' sexual activity.

Relationship-Related Variables

Our results point towards the importance of patients' and partners' experience of emotional closeness for couples' sexual activity. This is in line with findings of Brédart et al. (2011) and with the relationship intimacy model of couple adaptation to cancer, positing that emotional intimacy is central for the experience of relationship well-being in general (Manne and Badr, 2008). In a study by Marino et al. (2017) women's ratings of emotional closeness to the partner were not related to sexual activity, and most women felt close to their partners. However, the sample consisted of female cancer survivors, who were seen in a specialty clinic for menopause symptoms after cancer. Perhaps personal, partly symptom-related, factors, rather than partner-related factors were central in this specific sub-population,

TABLE 5 | Associations between patient and partner characteristics and sexual activity at time T3, stratified on baseline sexual activity.

	Associations with sexual activity at T3 (*n* = 471 couples)					
	Couples not sexually active at time T1			Couples sexually active at time T1		
	n = 181			*n* = 290		
	OR_{crude}	OR_{adj} (95%-CI)[a]	OR_{SDadj} (95%-CI)[a]	OR_{crude}	OR_{adj} (95%-CI)[a]	OR_{SDadj} (95%-CI)[a]
PATIENT						
Demographic and health characteristics						
Age (per year)	0.99	0.98 (0.94, 1.03)	0.81 (0.53, 1.36)	1.00	1.00 (0.95, 1.05)	1.00 (0.59, 1.65)
Charlson Comorbidity Index [ref. no comorbidity (0)]: comorbidity (≥1)	0.61	0.62 (0.30, 1.25)	0.62 (0.30, 1.25)	0.75	0.74 (0.29, 1.92)	0.74 (0.29, 1.92)
Breast cancer treatment						
Type of surgery (ref. mastectomy): lumpectomy	1.36	1.37 (0.65, 2.92)	1.37 (0.65, 2.92)	0.80	0.77 (0.27, 2.19)	0.77 (0.27, 2.19)
Allocated to chemotherapy (ref. no): yes	1.08	0.91 (0.42,2.00)	0.91 (0.42,2.00)	0.88	0.85 (0.30, 2.45)	0.85 (0.30, 2.45)
Allocated to endocrine treatment (ref. no): yes	0.61	0.61 (0.30, 1.23)	0.61 (0.30, 1.23)	1.82	1.85 (0.78, 4.37)	1.85 (0.78, 4.37)
Quality of life-related factors						
Depressive symptoms[b]	0.99	0.99 (0.95, 1.02)	0.91 (0.62, 1.20)	0.98	0.98 (0.93, 1.02)	0.84 (0.53,1.19)
Pain in arm, breast or shoulder area[b]	0.82	0.83 (0.58, 1.18)	0.83 (0.58, 1.18)	0.95	0.94 (0.59, 1.50)	0.95 (0.62, 1.44)
Vitality[b]	1.01	1.01 (0.99, 1.02)	1.24 (0.80, 1.54)	1.00	1.00 (0.98, 1.02)	1.00 (0.64, 1.56)
Body image[b]	1.00	1.00 (0.94, 1.07)	1.00 (0.69, 1.51)	0.98	0.98 (0.91, 1.06)	0.89 (0.57, 1.42)
Relationship-related factors						
Satisfaction with dyadic coping[b]	1.03	1.04 (0.89, 1.21)	1.09 (0.77, 1.52)	1.32*	1.38 (1.06, 1.80)*	1.73 (1.10, 2.72)*
Emotional closeness[b]	1.12	1.14 (0.80, 1.63)	1.13 (0.82, 1.55)	1.53	1.59 (0.96, 2.65)	1.38 (0.97, 1.98)
Affectionate behavior [ref. infrequent (<3)]: frequent (≥3)	1.47	1.42 (0.70, 2.87)	1.42 (0.70, 2.87)	4.69**	4.90 (2.00. 12.02)**	4.90 (2.00. 12.02)**
PARTNER						
Demographic and health characteristics						
Age (per year)	0.99	1.01 (0.95, 1.09)	1.11 (0.58, 2.47)	1.00	0.99 (0.89, 1.09)	0.90 (0.28, 2.54)
Charlson Comorbidity Index [ref. no comorbidity (0)]: comorbidity (≥1)	0.69	0.71 (0.36, 1.38)	0.71 (0.36, 1.38)	1.48	1.51 (0.56, 4.05)	1.51 (0.56, 4.05)
Quality of life-related factors						
Depressive symptoms[b]	0.98	0.98 (0.95, 1.02)	0.83 (0.63, 1.20)	1.02	1.02 (0.96, 1.08)	1.16 (0.73, 1.79)
Relationship-related factors						
Satisfaction with dyadic coping[b]	1.14	1.15 (0.98, 1.36)	1.34 (0.96, 1.91)	1.37**	1.36 (1.11, 1.67)**	1.69 (1.19, 2.39)**
Emotional closeness[b]	1.27	1.30 (0.88, 1.91)	1.30 (0.88, 1.91)	2.08**	2.11 (1.26, 3.52)**	1.57 (1.15, 2.13)**
Affectionate behavior [ref. infrequent (<3)]: frequent (≥3)	1.98*	2.04 (1.03, 4.06)*	2.04 (1.03, 4.06)*	4.37**	4.39 (1.74, 11.04)**	4.39 (1.74, 11.04)**

Odds ratios are shown with 95% confidence intervals (CI). OR, Odds Ratio; OR_{SD}, Odds Ratio measured in units of sample SD for continuous covariates; ref., reference category

[a] *Adjusted for patient age, type of surgery and chemotherapy.*

[b] *Per scale unit (resp. SD) increase.*

$^*p < 0.05$; $^{**}p < 0.01$.

such as being bothered by weight change and not being able to feel like a woman (Marino et al., 2017).

Furthermore, our findings draw attention to additional dimensions of the relationship to consider among couples dealing with breast cancer. Firstly, both patients' and partners' reports of affectionate behavior, i.e., kissing and hugging or holding in the couple, were associated with higher odds for sexual activity both at baseline and over time. Of the three relationship-related variables in the present study this rating of behavior is potentially most closely related to the behavioral outcome sexual activity, and couples agree rather strongly on the occurrence of this type of behavior in their relationship (within-couple correlation $r = 0.68$). Previous research has shown that affectionate behavior also is associated with other sexual health indicators, such as satisfaction with sex life (Fisher et al., 2015; Rottmann et al., 2017). However, there is also a relatively large subgroup of couples at baseline that report frequent affectionate behavior but no sexual activity. It is possible that health-related sexual dysfunction may limit their sexual activity, either in relation to breast cancer or in relation to other health- and aging-related issues. Perhaps, for some of these couples, affectionate behavior may be enough. We do not know whether they miss being sexually active or are happy with the situation as it is. This group could be interesting to examine further in future studies.

Secondly, patients' and partners' satisfaction with their dyadic coping, i.e., their overall evaluation of how they deal with stress as a couple, was positively associated with sexual activity. This is in line with results of a previous study among university students that also suggested an association between dyadic coping and sexual activity (Bodenmann et al., 2010). High scores on dyadic coping satisfaction may be an indicator of a well-functioning relationship (Falconier et al., 2015). Satisfaction with dyadic coping may also indicate lower stress levels, as the couple is coping well, and this can positively affect sexual activity (Bodenmann et al., 2010).

The baseline findings for the relationship-related variables may underscore the relevance of a positive relationship experience for a couple to engage in sexual activity, which has also been shown in studies based on the general population (Kleinstäuber, 2017). However, the cross-sectional observational design does not allow for conclusions on causality, and the associations are possibly bidirectional. One could, e.g., hypothesize that sexual activity may enhance feelings of emotional closeness in a couple or can be used as a way of dyadic coping with stress.

Importantly, the longitudinal findings differ depending on whether couples are sexually active at baseline or not: The relationship-related variables predict couples' sexual activity over time, but only in couples who are sexually active at baseline. Thus, feeling emotionally close to one's partner, showing affectionate behavior and satisfaction with dyadic coping at baseline seem to be protective factors for keeping up sexual activity, but do not contribute to couples taking up sexual activity. Perhaps not the baseline factors *per se*, but changes in these factors are associated with resumption of sexual activity. For example, emotional closeness or satisfaction with dyadic coping may increase in some couples as they go through the cancer trajectory together, which could result in resumption of sexual activity. This could be examined further in future studies.

Furthermore, although the results of our sensitivity analyses do not change the overall conclusions, they indicate that patients' and partners' unique perceptions of the relationship constructs may contribute differently to sexual activity. The analyses suggest that the patient's rating of affectionate behavior and the partner's rating of satisfaction with dyadic coping may be particularly important for the couple's sexual activity at T2. These processes within couples could be explored in future research, e.g., using a Dyadic Score Model (Iida et al., 2018), which could examine the contribution that the dyadic level of the relationship-related variables or differences in patients' and partners' scores make in predicting the outcome. In-depth knowledge of such processes would be helpful for health professionals such as sexologists or psychologists, who work in-depth with couples.

Individual Patient and Partner Characteristics

Of the quality of life-related variables patients' depressive symptoms and lower levels of vitality seemed to affect couples' sexual activity at baseline, which is in line with previous research (Fobair et al., 2006; Marino et al., 2017; Avis et al., 2018), whereas partners' depressive symptoms were not associated with couples' sexual activity. Potentially, the patients' emotional distress is more important for couples' sexual activity several months after diagnosis. This could be further examined in future studies. Interestingly, patients' body image and pain in the arm, breast or shoulder area were not related to couples' sexual activity. This might partly be explained by the low levels of body image concerns and pain in our sample.

Our study confirms findings suggesting that age is a relevant factor impacting sexual activity after breast cancer diagnosis (Avis et al., 2018). In our study, patients' older age was associated with lower odds of sexual activity both at baseline and at 5 months-follow up in the subgroup of couples who were not sexually active at baseline.

Among the treatment-related variables, treatment with chemotherapy was negatively associated with sexual activity at 5 months follow-up among couples who were sexually inactive at baseline, which confirms findings from an earlier study among breast cancer survivors recruited within 8 months of cancer diagnosis (Avis et al., 2018). In our study, the side effects of chemotherapy might still have been present at 5 months follow-up, and patients and partners may have been in the process of adjusting to the experience of chemotherapy, although patients usually have completed chemotherapy at this timepoint. The lack of significant associations between treatment-related variables and sexual activity at baseline may be due to heterogeneity in the timing of treatment and questionnaire completion in the sample. The baseline questionnaire was mailed to patients within 4 months after surgery, where patients may have been in different treatment phases, e.g., with some only being about to initiate chemotherapy treatment. In line with previous research, type of surgery and endocrine treatment were not associated with sexual activity (Fobair et al., 2006; Marino et al., 2017; Avis et al., 2018).

Comorbidity of patients and partners was not significantly associated with couples' sexual activity, although previous research has shown that the presence of medical or chronic conditions is related to less sexual activity (Kleinstäuber, 2017). This difference may potentially be explained by the broad measure we used. Our calculation of the Charlson index is based on registration of diagnoses in relation to hospital visits. It does not include functional impairment or the subjective experience of an illness, which may be more likely to impact sexual activity.

Sexual Activity in the Study Sample

In the present study, 59, 61 and 62% of couples were sexually active at ≤4 months after diagnosis (T1), and 5 (T2) and 12 months (T3) later, respectively. In approximately 17% of couples, sexual activity status changed from T1 to T2 and from T1 to T3.

Sexual activity was measured using a subjective approach, which did not further define sexual activity. This approach allows respondents to include the aspects that are personally important and meaningful to them. We assessed sexual activity at the couple level, which has the advantage of including both the patient's and the partner's perspective. Only couples in whom both the patient and the partner reported sexual activity were categorized as sexually active, which was a rather conservative approach. However, the within-couple agreement was high, and our rates of sexual activity of roughly 60% are on par with other studies of partnered women dealing with breast cancer who reported on sexual activity in the past month: In a study of younger women aged 22–50, who were primarily 2–7 months after diagnosis, 67% reported sexual activity (Fobair et al., 2006). In a study of women with a mean age of 54 years, 52, 59 and 61% reported sexual activity within the first 8 months of diagnosis, and 6 and 18 months later, respectively (Avis et al., 2018).

The rates of sexual activity in our study are lower than what has been found in the Danish population, where only 11% of persons in a relationship reported that they had not had sex with a partner during the past year (Frisch et al., 2019). However, these data from the general population are based on a sample of 15–89-year old persons and, in general, rates of sexual activity decline with older age (Frisch et al., 2019). A study of middle-aged women (mean age 56 years) found, e.g., that 71% had been sexually active in the past year (Addis et al., 2006). In a study of men who were cohabiting with a partner, approximately 75% of the 61–70 year old and almost 50% of men older than 70 reported sexual activity (Beutel et al., 2018).

Study Strengths and Limitations

The present study has several strengths. To our knowledge it is the first large, longitudinal study examining sexual activity after breast cancer that systematically includes both the patients' and the partners' perspective. Eligible couples were identified through nationwide population-based registries. Couples were followed throughout the first year after diagnosis of breast cancer. A broad range of variables was assessed including demographic and health-related, quality of life-related and relationship-related variables, and the study combines self-report data with information from nationwide Danish registries. By using clinical information on breast cancer treatment and other health-related information from nationwide registries, which were established independently of the study, recall and selection bias were avoided with respect to the measurement of these variables. Furthermore, to address issues of multiple testing we only concluded on results that were significant at the 0.01 level.

The study also has several limitations. The relatively low response rates of 32, 24 and 21% at T1, T2 and T3, respectively, might have introduced non-response bias. However, it is challenging to recruit couples into studies (Dagan and Hagedoorn, 2014), and our population-based design permitted us to compare participants with non-participants. We have previously shown that participation in the DCBCC was reduced by lower socioeconomic status, older age and partner morbidity (Terp et al., 2015). This pattern is in line with findings from previous studies on participation in research among cancer patients and their partners (Geller et al., 2011; Christie et al., 2013). In the present study, non-responding couples, i.e., those who did not provide information on sexual activity status, were older and more partners had morbidity. Perhaps non-response is related to the fact that sexuality often is perceived as a sensitive topic, which may be particularly true for elderly people. Possibly, some found these questions to be less relevant at older age, which would be in line with the finding of declining sexual activity at older age (Frisch et al., 2019). However, we do not know if our results can be generalized to populations with more diverse sociodemographic profiles.

We did not assess couples' sexual activity status prior to diagnosis and can thus not examine the impact of breast cancer diagnosis on their sexual activity, but due to the longitudinal design it was possible to examine change and factors affecting sexual activity in the first year after diagnosis. The subjective assessment of sexual activity does not provide insight into respondents' concrete understanding of sexual activity. We believe that respondents were primed to think about sexual activity with the partner and not solitary sexual activity, as the question on sexual activity was posed in the last part of a couple-based survey after a range of measures with focus on the couple relationship; however, we cannot be certain about this. Further, some respondents might include affectionate behavior such as kissing or hugging in their understanding of sexual activity. In a recent population-based survey of sex in Denmark, sex was defined as vaginal intercourse, oral sex, anal sex or hand sex (Frisch et al., 2019). Although this does not represent participants' subjective understanding, we believe most people would spontaneously think of these behaviors when answering questions on their sexual activity in a questionnaire. The assessment of sexual activity can be considered a proxy measure, as it was assessed through one response option on an item assessing satisfaction with sex life.

Furthermore, several of the variables in the questionnaire were measured by single items only. However, the brevity of the measures permitted us to include measurements of a broader range of different constructs.

The use of global, retrospective self-report measures may induce recall bias and may not be optimal to examine how behavior changes and develops in real life settings. Future studies could apply ecological momentary assessments, which allow the study of microprocesses that influence behavior in real-world contexts and maximize ecological validity (Shiffman et al., 2008). However, while the present study does not study microprocesses within couples, it contributes with knowledge on risk or protective factors at a more global level.

Finally, the data were collected approximately 10 years ago and may not mirror recent advances in breast cancer treatment. Nevertheless, a recent review of reviews suggests that breast cancer treatment and its side effects, such as pain and fatigue, as well as psychological issues still affect patients' quality of life, and that issues related to sexual function need more attention (Mokhatri-Hesari and Montazeri, 2020).

Clinical Implications

The results of the present study suggest that relationship variables are important for couples' sexual activity. Thus, a couple perspective should be included in sexual counseling during cancer treatment and rehabilitation. The findings point towards concrete aspects of the couple relationship that clinicians can work with in sexual counselling of patients, partners, and couples. These include working with couples on retaining emotional closeness in the relationship; encouraging couples to use affectionate behavior in their everyday, such as kissing, hugging, and holding each other; and teaching them skills to effectively deal with stress as a couple if needed.

Furthermore, our findings indicate that clinicians should address patients' emotional distress and fatigue in relation to sexual activity, as well as the role of age and chemotherapy treatment especially during encounters with couples who are not sexually active.

Sexuality or sexual side effects in relation to cancer are not always addressed during oncology treatment (Flynn et al., 2012), and couples may have unmet sexual information and support needs (Gilbert et al., 2016). According to our results, information and counseling about sexuality should already be placed in the treatment phase, as several factors assessed in the first months after diagnosis affected sexual activity throughout the first year after cancer diagnosis. However, we believe it is important to take couples' individual preferences for timing into account.

One step towards a couple-based approach in sexual counseling is to include the patients' partner in consultations. In previous research most women diagnosed with breast cancer described a conversation with a professional together with their partner as preferred method of communication about sexuality and intimacy (Den Ouden et al., 2019). Couple-based psychosexual interventions have shown promising results among couples dealing with breast cancer (Carroll et al., 2016), and our findings contribute to consolidate the knowledge base of such interventions.

Conclusions and Perspectives

In conclusion, this study indicates that not only the patients' but also the partners' experience of an affectionate, emotionally close relationship with satisfying dyadic coping is associated with couples' sexual activity in the first months after breast cancer diagnosis and over time in the re-entry and early survivorship phases. Older age and chemotherapy treatment of patients reduce the odds of couples taking up sexual activity. Patients' emotional distress and fatigue was associated with lower odds for sexual activity in the first months after diagnosis.

Future research should focus on couples who are currently not sexually active but wish to take up sexual activity. The present study has identified risk factors that may hinder couples in taking up sexual activity over time, but more knowledge on understanding modifiable factors would be important. Furthermore, sexual activity may not be equally important for all couples, and other subjective dimensions, such as satisfaction with sexual life or intimacy among those who are not sexually active, should also be considered.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because we are according to the EU and Danish data protection legislation not allowed to submit the data or give access to the data used for the analyses. Data from the Danish National Patient Register and the Civil Registration System are available from the Danish Health Data Authority[1] for researchers who meet the criteria for access to confidential data. Data from the clinical database Danish Breast Cancer Cooperative Group[2] are available for researchers who meet the criteria for access to these confidential data. Requests to access the datasets should be directed to NR, nrottmann@health.sdu.dk.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

NR, DGH, CJ, and MH contributed to the study design. PVL analyzed the data. NR wrote the first draft of the manuscript. All authors critically revised the manuscript, read and approved the submitted version.

FUNDING

The study was funded by the Danish Cancer Society.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.828422/full#supplementary-material

---

[1] https://sundhedsdatastyrelsen.dk/da/english

[2] http://www.dbcg.dk/

REFERENCES

Addis, I. B., Van Den Eeden, S. K., Wassel-Fyr, C. L., Vittinghoff, E., Brown, J. S., Thom, D. H., et al. (2006). Sexual activity and function in middle-aged and older women. *Obstet. Gynecol.* 107, 755–764. doi: 10.1097/01.AOG.0000202398.27428.e2

Avis, N. E., Johnson, A., Canzona, M. R., and Levine, B. J. (2018). Sexual functioning among early post-treatment breast cancer survivors. *Support. Care Cancer* 26, 2605–2613. doi: 10.1007/s00520-018-4098-0

Beutel, M. E., Burghardt, J., Tibubos, A. N., Klein, E. M., Schmutzer, G., and Brähler, E. (2018). Declining sexual activity and desire in men—findings from representative German surveys, 2005 and 2016. *J. Sex. Med.* 15, 750–756. doi: 10.1016/j.jsxm.2018.03.010

Bjørner, J. B., Damsgaard, M. T., Watt, T., Bech, P., Rasmussen, N. K., Kristensen, T. S., et al. (1997). Dansk manual til SF-36. Et spørgeskema om helbredsstatus. Copenhagen: Lif.

Bjørner, J. B., Thunedborg, K., Kristensen, T. S., Modvig, J., and Bech, P. (1998). The Danish SF-36 health survey: translation and preliminary validity studies. *J. Clin. Epidemiol.* 51, 991–999. doi: 10.1016/s0895-4356(98)00091-2

Bober, S. L., and Varela, V. S. (2012). Sexuality in adult cancer survivors: challenges and intervention. *J. Clin. Oncol.* 30, 3712–3719. doi: 10.1200/jco.2012.41.7915

Bodenmann, G. (2008). *Dyadisches Coping Inventar (DCI): Testmanual [Dyadic Coping Inventory: Test Manual]*. Bern, Switzerland: Huber Screw Press.

Bodenmann, G., Atkins, D. C., Schar, M., and Poffet, V. (2010). The association between daily stress and sexual activity. *J. Fam. Psychol.* 24, 271–279. doi: 10.1037/a0019365

Brédart, A., Dolbeault, S., Savignoni, A., Besancenet, C., This, P., Giami, A., et al. (2011). Prevalence and associated factors of sexual problems after early-stage breast cancer treatment: results of a French exploratory survey. *Psychooncology* 20, 841–850. doi: 10.1002/pon.1789

Brown, L. F., Kroenke, K., Theobald, D. E., and Wu, J. (2011). Comparison of SF-36 vitality scale and fatigue symptom inventory in assessing cancer-related fatigue. *Support. Care Cancer* 19, 1255–1259. doi: 10.1007/s00520-011-1148-2

Carroll, A. J., Baron, S. R., and Carroll, R. A. (2016). Couple-based treatment for sexual problems following breast cancer: a review and synthesis of the literature. *Support. Care Cancer* 24, 3651–3659. doi: 10.1007/s00520-016-3218-y

Cella, D., Land, S. R., Chang, C. H., Day, R., Costantino, J. P., Wolmark, N., et al. (2008). Symptom measurement in the breast cancer prevention trial (BCPT) (P-1): psychometric properties of a new measure of symptoms for midlife women. *Breast Cancer Res. Treat.* 109, 515–526. doi: 10.1007/s10549-007-9682-9

Charlson, M. E., Pompei, P., Ales, K. L., and Mackenzie, C. R. (1987). A new method of classifying prognostic co-morbidity in longitudinal studies - development and validation. *J. Chronic Dis.* 40, 373–383. doi: 10.1016/0021-9681(87)90171-8

Christie, K. M., Meyerowitz, B. E., Stanton, A. L., Rowland, J. H., and Ganz, P. A. (2013). Characteristics of breast cancer survivors that predict partners' participation in research. *Ann. Behav. Med.* 46, 107–113. doi: 10.1007/s12160-013-9477-7

Dagan, M., and Hagedoorn, M. (2014). Response rates in studies of couples coping with cancer: a systematic review. *Health Psychol. Open* 33, 845–852. doi: 10.1037/hea0000013

Debrot, A., Stellar, J. E., MacDonald, G., Keltner, D., and Impett, E. A. (2020). Is touch in romantic relationships universally beneficial for psychological well-being? The role of attachment avoidance. *Personal. Soc. Psychol. Bull.* 47, 1495–1509. doi: 10.1177/0146167220977709

Den Ouden, M. E. M., Pelgrum-Keurhorst, M. N., Uitdehaag, M. J., and De Vocht, H. M. (2019). Intimacy and sexuality in women with breast cancer: professional guidance needed. *Breast Cancer* 26, 326–332. doi: 10.1007/s12282-018-0927-8

Falconier, M. K., Jackson, J. B., Hilpert, P., and Bodenmann, G. (2015). Dyadic coping and relationship satisfaction: A meta-analysis. *Clin. Psychol. Rev.* 42, 28–46. doi: 10.1007/s10549-007-9682-9

Fisher, W. A., Donahue, K. L., Long, J. S., Heiman, J. R., Rosen, R. C., and Sand, M. S. (2015). Individual and partner correlates of sexual satisfaction and relationship happiness in midlife couples: dyadic analysis of the international survey of relationships. *Arch. Sex. Behav.* 44, 1609–1620. doi: 10.1007/s10508-014-0426-8

Fletcher, K. A., Lewis, F. M., and Haberman, M. R. (2010). Cancer-related concerns of spouses of women with breast cancer. *Psychooncology* 19, 1094–1101. doi: 10.1002/pon.1665

Flynn, K. E., Jeffery, D. D., Keefe, F. J., Porter, L. S., Shelby, R. A., Fawzy, M. R., et al. (2011). Sexual functioning along the cancer continuum: focus group results from the patient-reported outcomes measurement information system (PROMIS(R)). *Psychooncology* 20, 378–386. doi: 10.1002/pon.1738

Flynn, K. E., Lin, L., Cyranowski, J. M., Reeve, B. B., Reese, J. B., Jeffery, D. D., et al. (2013). Development of the NIH PROMIS (R) sexual function and satisfaction measures in patients with cancer. *J. Sexual Med.* 10, 43–52. doi: 10.1111/j.1743-6109.2012.02995.x

Flynn, K. E., Reese, J. B., Jeffery, D. D., Abernethy, A. P., Lin, L., Shelby, R. A., et al. (2012). Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology* 21, 594–601. doi: 10.1002/pon.1947

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., and Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psychooncology* 15, 579–594. doi: 10.1002/pon.991

Frisch, M., Moseholm, E., Andersson, M., Andresen, J.B., and Graugaard, C. (2019). *Sex in Denmark Key Findings From Project SEXUS 2017–2018*. Statens: Serum Institute and Aalborg University.

Gartner, R., Jensen, M. B., Nielsen, J., Ewertz, M., Kroman, N., and Kehlet, H. (2009). Prevalence of and factors associated with persistent pain following breast cancer surgery. *JAMA* 302, 1985–1992. doi: 10.1001/jama.2009.1568

Geller, B. M., Mace, J., Vacek, P., Johnson, A., Lamer, C., and Cranmer, D. (2011). Are cancer survivors willing to participate in research? *J. Community Health* 36, 772–778. doi: 10.1007/s10900-011-9374-6

Gilbert, E., Perz, J., and Ussher, J. M. (2016). Talking about sex with health professionals: the experience of people with cancer and their partners. *Eur. J. Cancer Care* 25, 280–293. doi: 10.1111/ecc.12216

Hann, D., Winter, K., and Jacobsen, P. (1999). Measurement of depressive symptoms in cancer patients: evaluation of the Center for Epidemiological Studies Depression Scale (CES-D). *J. Psychosom. Res.* 46, 437–443. doi: 10.1016/s0022-3999(99)00004-5

Hopwood, P., Fletcher, I., Lee, A., and Al Ghazal, S. (2001). A body image scale for use with cancer patients. *Eur. J. Cancer* 37, 189–197. doi: 10.1016/S0959-8049(00)00353-1

Iida, M., Seidman, G., and Shrout, P. E. (2018). Models of interdependent individuals versus dyadic processes in relationship research. *J. Soc. Pers. Relat.* 35, 59–88. doi: 10.1177/0265407517725407

Jackson, S. E., Wardle, J., Steptoe, A., and Fisher, A. (2016). Sexuality after a cancer diagnosis: a population-based study. *Cancer* 122, 3883–3891. doi: 10.1002/cncr.30263

Jakubiak, B. K., and Feeney, B. C. (2017). Affectionate touch to promote relational, psychological, and physical well-being in adulthood: a theoretical model and review of the research. *Personal. Soc. Psychol. Rev.* 21, 228–252. doi: 10.1177/1088868316650307

Keesing, S., Rosenwax, L., and McNamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. *BMC Womens Health* 16:57. doi: 10.1186/s12905-016-0337-z

Kleinstäuber, M. (2017). Factors associated with sexual health and well being in older adulthood. *Curr. Opin. Psychiatry* 30, 358–368. doi: 10.1097/yco.0000000000000354

Loaring, J. M., Larkin, M., Shaw, R., and Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: the experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychol.* 34, 426–436. doi: 10.1037/hea0000195

Lynge, E., Sandegaard, J. L., and Rebolj, M. (2011). The Danish National Patient Register. *Scand. J. Public Health* 39, 30–33. doi: 10.1177/1403494811401482

Male, D. A., Fergus, K. D., and Cullen, K. (2016). Sexual identity after breast cancer: sexuality, body image, and relationship repercussions. *Curr. Opin. Support. Palliat. Care* 10, 66–74. doi: 10.1097/spc.0000000000000184

Manne, S., and Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer* 112, 2541–2555. doi: 10.1002/cncr.23450

Manne, S., Ostroff, J., Rini, C., Fox, K., Goldstein, L., and Grana, G. (2004). The interpersonal process model of intimacy: The role of self-disclosure, partner disclosure, and partner responsiveness in interactions between breast cancer patients and their partners. *J. Fam. Psychol.* 18, 589–599. doi: 10.1037/0893-3200.18.4.589

Marino, J. L., Saunders, C. M., and Hickey, M. (2017). Sexual inactivity in partnered female cancer survivors. *Maturitas* 105, 89–94. doi: 10.1016/j.maturitas.2017.04.020

Meyerowitz, B. E., Desmond, K. A., Rowland, J. H., Wyatt, G. E., and Ganz, P. A. (1999). Sexuality following breast cancer. *J. Sex Marital Ther.* 25, 237–250. doi: 10.1080/00926239908403998

Mokhatri-Hesari, P., and Montazeri, A. (2020). Health-related quality of life in breast cancer patients: review of reviews from 2008 to 2018. *Health Qual. Life Outcomes* 18:338. doi: 10.1186/s12955-020-01591-x

Moller, S., Jensen, M. B., Ejlertsen, B., Bjerre, K. D., Larsen, M., Hansen, H. B., et al. (2008). The clinical database and the treatment guidelines of the Danish breast cancer cooperative group (DBCG); its 30-years experience and future promise. *Acta Oncol.* 47, 506–524. doi: 10.1080/02841860802059259

Pedersen, C. B. (2011). The Danish civil registration system. *Scand. J. Pub. Health* 39, 22–25. doi: 10.1177/1403494810387965

Radloff, L. S. (1977). The CES-D scale: a self-report depression scale for research in the general population. *Appl. Psychol. Meas.* 1, 385–401. doi: 10.1177/014662167700100306

Rottmann, N., Hansen, D. G., de Pont Christensen, R., Hagedoorn, M., Frisch, M., Nicolaisen, A., et al. (2017). Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study. *Acta Oncol.* 56, 212–219. doi: 10.1080/0284186X.2016.1266086

Shiffman, S., Stone, A. A., and Hufford, M. R. (2008). Ecological momentary assessment. *Annu. Rev. Clin. Psychol.* 4, 1–32. doi: 10.1146/annurev.clinpsy.3.022806.091415

Smith, L., Yang, L., Veronese, N., Soysal, P., Stubbs, B., and Jackson, S. E. (2019). Sexual activity is associated with greater enjoyment of life in older adults. *Sexual Med.* 7, 11–18. doi: 10.1016/j.esxm.2018.11.001

Stanton, A. L., Ganz, P. A., Rowland, J. H., Meyerowitz, B. E., Krupnick, J. L., and Sears, S. R. (2005). Promoting adjustment after treatment for cancer. *Cancer* 104, 2608–2613. doi: 10.1002/cncr.21246

Terp, H., Rottmann, N., Larsen, P. V., Hagedoorn, M., Flyger, H., Kroman, N., et al. (2015). Participation in questionnaire studies among couples affected by breast cancer. *Support. Care Cancer* 23, 1907–1916. doi: 10.1007/s00520-014-2554-z

Ussher, J. M., Perz, J., and Gilbert, E. (2012). Changes to sexual well-being and intimacy after breast cancer. *Cancer Nurs.* 35, 456–465. doi: 10.1097/NCC.0b013e3182395401

Ussher, J. M., Perz, J., and Gilbert, E.The Australian Cancer and Sexuality Study Team (2015). Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. *BMC Cancer* 15:268. doi: 10.1186/s12885-015-1243-8

Ware, J. E., and Gandek, B. (1998). Overview of the SF-36 health survey and the international quality of life assessment (IQOLA) project. *J. Clin. Epidemiol.* 51, 903–912. doi: 10.1016/S0895-4356(98)00081-X

World Health Organization (2006). *Defining Sexual Health. Report of a Technical Consultation on Sexual Health, 28–31 January 2002, Geneva*. Geneva: World Health Organization.

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

ORIGINAL RESEARCH
published: 06 April 2022
doi: 10.3389/fpsyg.2022.864893

Coping With Changes to Sex and Intimacy After a Diagnosis of Metastatic Breast Cancer: Results From a Qualitative Investigation With Patients and Partners

Jennifer Barsky Reese[1]*, Lauren A. Zimmaro[1], Sarah McIlhenny[1], Kristen Sorice[1], Laura S. Porter[2], Alexandra K. Zaleta[3], Mary B. Daly[4], Beth Cribb[5] and Jessica R. Gorman[6]

[1]Cancer Prevention and Control Program, Fox Chase Cancer Center, Philadelphia, PA, United States, [2]Department of Psychiatry & Behavioral Sciences, Duke University Medical Center, Durham, NC, United States, [3]Research and Training Institute, Cancer Support Community, Philadelphia, PA, United States, [4]Department of Clinical Genetics, Fox Chase Cancer Center, Philadelphia, PA, United States, [5]Cancer Support Community of Greater Philadelphia, Philadelphia, PA, United States, [6]College of Public Health and Human Sciences, Oregon State University, Corvallis, OR, United States

Edited by:
Auréliev Untas,
Université de Paris, France

Reviewed by:
Kristopher Lamore,
Université de Lille, France
Anne Brédart,
Institut Curie, France

***Correspondence:**
Jennifer Barsky Reese
Jennifer.Reese@fccc.edu

Specialty section:
This article was submitted to
Psycho-Oncology,
a section of the journal
Frontiers in Psychology

Received: 29 January 2022
Accepted: 18 March 2022
Published: 06 April 2022

Citation:
Reese JB, Zimmaro LA, McIlhenny S, Sorice K, Porter LS, Zaleta AK, Daly MB, Cribb B and Gorman JR (2022) Coping With Changes to Sex and Intimacy After a Diagnosis of Metastatic Breast Cancer: Results From a Qualitative Investigation With Patients and Partners.
Front. Psychol. 13:864893.
doi: 10.3389/fpsyg.2022.864893

Objective: Prior research examining sexual and intimacy concerns among metastatic breast cancer (MBC) patients and their intimate partners is limited. In this qualitative study, we explored MBC patients' and partners' experiences of sexual and intimacy-related changes and concerns, coping efforts, and information needs and intervention preferences, with a focus on identifying how the context of MBC shapes these experiences.

Methods: We conducted 3 focus groups with partnered patients with MBC [$N = 12$; M age = 50.2; 92% White; 8% Black] and 6 interviews with intimate partners [M age = 47.3; 83% White; 17% Black]. Participants were recruited through the Fox Chase Cancer Center Tumor Registry and the Cancer Support Community. Qualitative data were analyzed using the Framework Method and Dedoose software.

Results: Qualitative analyses revealed several key themes reflecting ways in which MBC shapes experiences of sex/intimacy: (1) the heavy disease/treatment burden leads to significant, long-term sexual concerns (e.g., loss of interest and vaginal dryness/discomfort) and consequent heightened emotional distress for both patients (e.g., guilt around not being able to engage in intercourse) and partners (e.g., guilt around pressuring the patient to engage in sexual activity despite pain/discomfort); (2) viewing the relationship as having "an expiration date" (due to expected earlier mortality) influences patients' and partners' concerns related to sex/intimacy and complicates coping efforts; and (3) information needs extend beyond managing sexual side effects to include emotional aspects of intimacy and the added strain of the life-limiting nature of the disease on the relationship. The heightened severity of sexual concerns faced by patients with MBC, compounded by the terminal nature of the disease, may place patients and partners at risk for significant adverse emotional and interpersonal consequences.

Conclusion: Findings suggest unique ways in which sex and intimate relationships change after a diagnosis of metastatic breast cancer from both patients' and partners' perspectives. Consideration of the substantial physical and emotional burden of MBC and the broader context of the relationship and intimacy overall is important when developing a sexuality-focused intervention in this population. Addressing sexual concerns is a critical part of cancer care with important implications for patients' health and quality of life.

Keywords: metastatic breast cancer, couples therapy, interventions, qualitative research, sexuality

INTRODUCTION

With treatments continually improving for metastatic breast cancer (MBC), nearly one-third of women with this diagnosis can expect 5-year survival (Siegel et al., 2020). In light of these data, and clinical survivorship guidelines that apply to those living with chronic cancers (i.e., metastatic disease; National Comprehensive Cancer Network, 2021), there are growing calls to address cancer-related symptoms and side effects for patients with metastatic disease, including in their sexual function and intimate relationships (Di Lascio and Pagani, 2017; Langbaum and Smith, 2019). Contrary to common beliefs about patients with advanced cancer (e.g., that sex is not a priority), data suggest that patients with MBC report significant sexual concerns, wish to maintain physical intimacy in their relationships, and would like support in coping with treatment-related sexual concerns (Andersen, 2009; McClelland et al., 2015; McClelland, 2016; Reese et al., 2016).

Sexual concerns are reported by 50 to 80% of patients with a diagnosis of MBC (Reese et al., 2010b; Gambardella et al., 2018). Common sexual problems related to breast cancer treatments include those that are physical, including vaginal dryness and discomfort (Burwell et al., 2006; Alder et al., 2008), motivational/emotional, including decreased sexual interest (Fobair et al., 2006; Ochsenkuhn et al., 2011), and interpersonal in nature, including avoidance of sexual activity (Gilbert et al., 2010; Bredart et al., 2011; Loaring et al., 2015). Other common concerns include post-surgery breast changes that can influence body image and sexual activity, such as the loss of the breasts (Djohan et al., 2010; Otterburn et al., 2010). Because breast cancer-related sexual problems can be persistent (Raggio et al., 2014), it is critical to develop efficacious interventions to address these concerns.

In light of the lifespan limitations associated with having a terminal disease and the heightened physical and emotional symptom burden associated with metastatic disease and its treatments (Vilhauer, 2008; Mosher and DuHamel, 2012; Mosher et al., 2013), and prior research suggesting that women with MBC voice unique psychosocial impacts of their disease relative to those with early stage disease (Vilhauer, 2011), it seems likely that patients with MBC could have unique experiences related to the effects of their cancer on sex and intimacy. Yet, relatively few studies have examined changes to sex and intimacy after a diagnosis of MBC (Drageset et al., 2021), limiting our understanding of the sexual and intimacy-related concerns and experiences of this population (Silverman and Rabow, 2018). In addition, because partners of women with breast cancer also report sexual, relationship, and psychological problems associated with the cancer (Zahlis and Lewis, 2010; Milbury and Badr, 2012; Zimmermann, 2015), and because women generally involve their partners in coping with sexual concerns (Reese et al., 2016), it is essential to understand partners' perspectives within this research. Yet, the bulk of the research examining sexual issues for women with advanced (e.g., recurrent) or metastatic breast cancer has included only patients (Andersen et al., 2007; Andersen, 2009; McClelland et al., 2015; McClelland, 2016), and these studies have been critical in identifying key issues in women's experiences in the context of MBC, they have not shed light on partners' perspectives on the same types of experiences. Alternatively, studies of psychosocial issues in MBC that have included partners, while highly informative, did not examine sexual issues (Badr et al., 2010; Milbury and Badr, 2012). Finally, of the psychosocial interventions aimed at addressing sexual concerns in patients with breast cancer, nearly all have excluded those with MBC (Schover et al., 2013; Candy et al., 2016; Hummel et al., 2017b; Reese et al., 2019, 2020b; Sopfe et al., 2021), making it difficult to know whether these interventions would apply to or be effective for patients living with MBC. In sum, there is a gap in information that could inform interventions addressing sexual concerns in this population, including how MBC patients and partners experience and cope with such concerns, as well as information needs and intervention preferences.

The objective of this study was thus to characterize the experiences of sexual and intimacy-related changes and concerns for patients and intimate partners facing an MBC diagnosis through a qualitative investigation with an eye toward intervention development for this population. The following primary research questions guided the present investigation: (1) What are the sexual and intimacy-related changes (i.e., physical, emotional, and relational) and concerns for patients with MBC and partners of patients with MBC?; (2) What are patients' and partners' experiences of coping with these concerns?; and (3) What are patients and partners' information needs and intervention preferences? For all three questions, we were particularly interested in understanding how the context of metastatic disease may have shaped patients' and partners' experiences. We include both the terms "sexual" and "intimacy" in our aims and methods because we recognize that patients' experiences of physical intimacy may or may not include sexual activity, *per se*, and aim for inclusivity and breadth in our investigation. For our purposes, we define intimacy as an interpersonal process involving mutual sharing and understanding and feelings of closeness, warmth, and affection, with both physical and emotional aspects (Reese et al., 2012).

MATERIALS AND METHODS

Setting and Participant Eligibility

The study protocol and procedures were reviewed and approved by the Institutional Review Board at Fox Chase Cancer Center (Protocol #20–1,039). The consolidated criteria for reporting qualitative research (COREQ) checklist was followed in reporting the methods and findings of this study (Tong et al., 2007). Participants completed online consent prior to the focus group or interview. Women aged 18 years or older were eligible if they (a) had a diagnosis of metastatic breast cancer (i.e., Stage IV), (b) had a romantic partner, and (c) were willing to have their participation in the qualitative study audio-recorded. Partners of women meeting these criteria were also eligible to participate. There were no limitations in eligibility based on gender identity, sexual orientation, or marital status. Exclusion criteria included the inability to read or speak English, or having a poor functional status (i.e., capable of only limited self-care or being completely disabled, as determined by an Eastern Cooperative Oncology Group (ECOG) performance score > 2; Oken et al., 1982) or being medically unable to participate as judged by a physician, medical record, or self-report.

Recruitment

In an attempt to diversify our sample, we recruited through both convenience methods (i.e., mailings to pre-screened patients identified using the Fox Chase Tumor Registry) and community-based stakeholder engagement methods (i.e., email, social media, and online community posts) in partnership with the Cancer Support Community, a national non-profit advocacy organization, and Cancer Support Community of Greater Philadelphia. A trained research assistant conducted eligibility screening privately over the phone with patients who were interested in participating. Interested patients were asked for permission to contact their partners about participation and for their contact information. Partners for whom this information was provided were then contacted and screened privately over the phone. If a potential participant screened as eligible, the research assistant discussed the study details and confidentiality and provided the opportunity for the potential participant to ask any questions and to enroll if interested. Participants who agreed to enroll then provided written consent and filled out an availability form to help facilitate scheduling. Participants received $40 in gift cards for their participation. Participants had no personal knowledge of the interviewers (JBR, LZ) or members of the research team prior to or during data collection that could potentially bias data.

Data Collection

Data were collected in February–April 2021. All patient participants ($N = 12$) participated in one of three 90-min focus groups. Focus groups were selected because the shared nature of the conversations can often elicit deep discussion of issues, even for sensitive topics like sexuality; we have used this format in other qualitative studies on a similar topic in breast cancer (Reese et al., 2016, 2017). In past studies with a similar focus by our team (Reese et al., 2016), three focus groups provided sufficient information; we planned the number of focus groups based on this prior experience, with the understanding that if thematic saturation were not achieved we could conduct more. Partners were recruited for individual interviews ($N = 6$, 60- to 75-min interviews each) once it was determined that scheduling and recruitment challenges would render the focus group format unfeasible for study partners. All other aspects of the qualitative interviewing process were similar across the focus group and individual interview formats; no repeat interviews were carried out; All focus groups and interviews were conducted virtually using password protected Zoom meetings and led by female licensed psychologists who had at least severe years of clinical and research experience conducting qualitative research in cancer settings (JBR, LZ). Privacy of participants was ascertained at the start of every focus group/interview. All participants reported being in private settings at home, with no non-participants present. The PI (JBR) led all patient focus groups, with a co-author (LZ) acting as note-taker; either JBR or LZ led the partner interviews using the same standardized, structured interview guide, described in the next paragraph.

All focus groups and interviews used a semi-structured format following a pre-specified guide, which was designed to facilitate examination of the research questions. The same qualitative guide was used for patients and for partners. Development of the qualitative guide was informed both by conceptual models, including biopsychosocial models of sexual concerns in cancer (Bober and Sanchez Varela, 2012) and of coping with sexual concerns after cancer (Reese et al., 2010a), and by prior qualitative research conducted by our study team with a similar focus (e.g., Reese et al., 2016; Gorman et al., 2020; See **Table 1** for examples of questions). The qualitative guide was thoroughly reviewed for appropriateness and completeness by the study team.

All interviews began with the interviewer introducing herself (i.e., her role within Fox Chase Cancer Center and within the research project), reviewing the study purpose, and clarifying any participant questions. To facilitate rapport and transition the participants into a discussion of potentially more sensitive sexual concerns, the qualitative guide opened with a general relationship question, and from there, questions were broken into two main parts: (1) Sexual and Intimacy-Related Changes and Coping Efforts, and (2) Information Needs and Intervention Preferences. To encourage open communication of potentially sensitive topics, patients and partners were interviewed separately. Demographic data (i.e., age, race/ethnicity, education, employment status, and relationship duration) were obtained through online self-report questionnaires at the time of consent. Clinical data (i.e., diagnosis as either recurrent or as initial

TABLE 1 | Focus group guide.

Part 1: Sexual and intimacy-related changes and coping efforts	
1	[We know that the experience of metastatic breast cancer can affect women's relationships with their partners in many ways]. How would you say your [your partner's] breast cancer diagnosis and treatment has affected your relationship with your partner?
2	How about effects on your intimate relationship with your partner, meaning specifically your physical or sexual relationship with your partner? [Prompt for: sexual scripts changing, loss of sexual/intimate activities, roles changing toward caregiver/patient]
3	Many women report changes in their sexual enjoyment, interest, performance, or in their feelings about their body or their appearance. What have you noticed about how the breast cancer diagnosis or treatments have affected you [your partner] in these kinds of ways?
4	For women with recurrent disease: Some of you [your partners] may have recurrent disease, that is, you were [your partner was] diagnosed earlier and the cancer went away, and then it came back. I'm curious as to what you notice about how the experience is different this time versus previously in terms of its effects on your sex life or your intimate relationship?
5	Thinking about everything we have been talking about—including physical, emotional, and treatment effects on intimacy and sexuality—which of these changes have you found most challenging to deal with? Most bothersome?
6	Have you discussed these issues with your partner?
7	If discussed, when you and your partner have talked about these issues, how have these conversations gone?
8	Can you think of a time that you and your partner managed (or coped with) some of the physical or emotional challenges in your sexual relationship?
9	What kinds of things have you tried to help manage or cope with some of these challenges? How helpful were these in coping with these challenges?
10	Is there anything else that you can think of that would help you better manage (or cope with) some of these challenges?
11	How important is finding ways of coping with these challenges to you? To your relationship?
Part 2: Information needs and intervention preferences	
1	Thinking about everything we have just discussed, if we were to offer a program designed to address sexual and intimacy issues, what would you most hope to gain from this kind of program? What kind of information would you most want included?
2	If you were offered a program for you and your partner to help address sexual and intimacy issues like the ones you have mentioned today, what concerns would you have about participating?
3	What would make it easier for you to participate?
4	What concerns do you think your partner would have in participating in a program like this? What might help address these concerns?
5	What else would you like us to consider or have in mind as we put together this program? Anything that might make it likely you and your partner would participate?

metastatic diagnosis and length of time since diagnosis) were obtained through coding transcripts and corroborated with patients' charts when possible.

Data Preparation

All focus group and interview discussions were audio-recorded and transcribed verbatim using the Zoom audio transcription feature. This feature functioned by automatically transcribing verbatim the audio of each recorded meeting and providing a text file that was divided into timestamped sections for each portion of recorded audio. These text files were then downloaded to a secure server and de-identified for any identifying information by one of the interviewers (LZ). The de-identified verbatim transcription was then checked and edited for accuracy by a research assistant through cross-referencing with the original audio recording and field notes taken during the interviews. Any sections of audio or transcribed text that were unclear were double-checked and clarified by one of the interviewers (LZ, JBR). Participants were not provided a copy of the interview transcripts.

Data Analysis

Data were then analyzed following the steps outlined in the framework method (Gale et al., 2013, 2014), with regular meetings with the qualitative research expert on the study team (JG). The framework method is a systematic and pragmatic approach well suited to meet the objectives of the current investigation (Gale et al., 2013, 2014). The framework method provides a flexible, stepped approach to qualitative data management and guided our deductive (i.e., initial codes were developed based on the research questions) and inductive approach to analysis (i.e., codes were added to and modified as analysis progressed and ideas emerged from the data; Gale et al., 2013). The defining feature of the framework method is the matrix output, which is used to summarize and organize the qualitative data to facilitate analysis. In the matrix, the data are summarized according to transcripts and codes, which provides a structure for the data that allows for analysis by case (individual transcript) and code, and for comparison both within and across cases.

One of the lead coders (JBR) has substantial experience in conducting qualitative analysis using the framework method (Reese et al., 2016, 2017) as well as significant research and clinical knowledge on breast cancer and sexual wellbeing; all other coders completed training prior to embarking on coding. Training included readings and discussions on implementing the framework method and coding, including how to apply codes reliably, review of the codebook, and practice coding. At all stages in the coding process, discussions were held between coders to identify issues arising during the coding process and resolve any discrepancies in coding and uncertainties in applying codes or around code definitions.

Data from patients and partners were analyzed separately by four coders (JBR, LZ, KS, SM), and proceeded in several steps. First, two lead coders (JBR, LZ), constructed a coding book with definitions based on the research questions, the interview guide, and a close read of the first patient transcript, as described in the framework method. Because the same interview guide was used for both patients and partners, capturing their unique perspectives on the same issues, the codes were also the same with a few exceptions (e.g., a code called "infoneeds_patient" referred to partners' perceptions of the patients' information needs related to a sexuality intervention and only applied to partner transcripts.) The information gained directly from patients about this topic was more detailed and thus necessitated coding using more codes related to different areas of need. Second, once the codebook was finalized, two independent, trained coders (KS, SM) autonomously applied codes to the transcripts. Coders engaged in frequent discussion and reflection to discuss any emergent differences in coding application with the PI and, when needed, the qualitative expert (JG) until consensus was reached (Bradley et al., 2007). Finally, once codes were finalized, we then imported the data and coding into Dedoose to facilitate analysis and identification of themes. Specifically, we used the data from the code matrix in Dedoose to examine overlap of codes both within and across transcripts and compare codes across patients and partners for differences. Reviewing the data in the matrix is a key part of the framework method that leads to the identification of patterns within the data and thus themes. In identifying patterns, particular attention was paid to the most common codes and those that were farthest reaching (i.e., linked with a greater number of other codes), as this suggests important patterns in the data. From this examination, we derived key themes and subthemes that represented the qualitative data characterizing the experiences and coping efforts of patients and partners. In this step, relevance to the research questions, importance to participants, and novelty from a research perspective (e.g., distinctiveness from data observed in early stage breast cancer patients and partners) were strongly weighed. Regarding inter-rater agreement, for focus groups, the inter-rater agreement was high (92%) after reviewing data from one group, and as such further inter-rater agreement tests were deemed not necessary. All partner transcripts were double-coded and average inter-rater agreement was high (87%).

TABLE 2 | Patient and partner characteristics.

Variable	Patients	Partners
	Mean (SD or range)	**Mean (SD)**
Age	50.2 years(11.2)	47.3 years(8.1)
Time since patient's diagnosis	4.7 years (1 month-11 years)	n/a
	N (%)	N (%)
Race*		
White	11(91.7%)	5(83.3%)
Black/African American	1(8.3%)	1(16.7%)
Education		
Bachelor's degree or higher	10(84%)	4(67%)
Some college/associate's degree	2(16%)	2(33%)
Employment		
Full-time	4(33%)	5(83%)
Part-time/self-employed	2(17%)	1(17%)
Retired	3(25%)	0(0%)
Full-time disability	3(25%)	0(0%)
Length of relationship**		
≤10 years	2(17%)	3(50%)
13–15 years	3(25%)	1(17%)
≥20 years	7(58%)	2(33%)
Metastatic diagnosis status		
Recurrent disease	5(42%)	n/a
New diagnosis	7(58%)	n/a

**All participants identified as having non-Hispanic ethnicity.*

***All participants reported being married (vs. cohabitating) and having a household income of greater than $35,000.*

RESULTS

Recruitment Data and Sample Characteristics

Patients

Twenty-one patients screened as eligible and were approached for participation; of these, 16 consented to the study (76%). Four patients who completed consent did not end up participating in the focus groups (3 were lost to follow-up during scheduling, and 1 reported discomfort in discussing her relationship). The total patient sample therefore included 12 women, 8 of whom were recruited through FCCC, with the remainder recruited through the community-based recruitment methods. Patient characteristics are provided in **Table 2**.

Partners

Six partners participated in study interviews; 1 consented but was lost to follow-up when attempting to schedule for the interview and 9 partners who the recruiter attempted to recruit opted out. In 5 cases, this occurred when the patient indicated that the partner would not be interested and so no further attempts were made to enroll the partner, and in 4 cases, this occurred when the patient indicated that she had spoken to the partner and the partner refused. Reasons for partner refusal included not being interested ($n = 4$), privacy/topic is sensitive or embarrassing ($n = 3$), or scheduling issues ($n = 2$). Partner characteristics are provided in **Table 2**.

Results of Qualitative Analysis

Overview of Qualitative Findings

Five themes emerged from the analysis: (1) Patients' Experiences of and Reactions to Sexual and Intimacy Changes and Concerns; (2) Partners' Experiences and Roles; (3) Context of a Life-Limiting Illness; (4) Coping with MBC-Related Sexual Concerns; and (5) Information Needs and Intervention Preferences. Main themes, theme descriptions, corresponding subthemes, and illustrative quotes are shown in **Table 3** (for themes 1 to 3) and **Table 4** (for themes 4 and 5). For the purposes of verbatim quotations, we have provided fictive names for each of the participants. In this study, we defined saturation as when little additional information was gained from subsequent transcripts and used thematic coverage of higher-order groupings (themes) across transcripts in determining this (Hennink and Kaiser, 2022). Complete thematic coverage was achieved for the focus group data, offering support for achieving

TABLE 3 | Part 1: Qualitative themes 1–3 and illustrative quotes: patients' and partners' experiences of sex and intimacy after MBC diagnosis.

Main themes and subthemes	Illustrative quotes corresponding to themes
Theme 1: Patients' Experiences of Sexual and Intimacy Concerns after Diagnosis of Metastatic Breast Cancer (MBC)— Significant disease burden amplifies sexual changes and challenges	
MBC-related sexual changes and concerns: Cumulative treatments and disease can amplify the severity and complexity of sexual problems, also may complicate responsiveness or ability to benefit from common treatment strategies	…all happened, you know a chemo-induced menopause and I had surgery, then, you know, ovaries out, double mastectomy. I said, like, really quick—at 45, I was saying, "well I'm one operation away from being a man" (Gloria, age 57). –
Patients' emotional reactions to sexual changes: Emotional reactions to the sexual problems often include guilt and pressure, which can further exacerbate distress	…There are ways of being close without the intercourse, you know, without the goal…but again, I think it's the, you know, you want to be a good partner and so it's—I think a lot of that is, you know, the guilt part of it (Rose, age 67). –
Combined effects of chronic physical and emotional sexual changes: Combination of the persistent and often severe physical and emotional sexual concerns take a significant toll on patients and the relationship by wearing down hope and positive expectations, in snowball-like effect	It never goes away, you know, I mean it's always like a mountain that you are trying to climb and find, you know, ways to, you know, overcome those obstacles (Kim, age 51). –
Theme 2: Partners' Experiences and Roles— Partners' experiences of sexual changes, emotional responses, and perceived impact of sexual changes play key role in shaping outcomes for the patient and the relationship	
Awareness of MBC-related sexual changes: Partners and patients describe a range of experiences and levels of awareness for partners of the changes in their sexual relationship, including the patients' problems, their own sexual problems, and changes in the intimacy in their relationship	My husband thinks that'll work – see, and I think you guys have same [issue] that I do. Men do not feel what we feel so they think that we are moist and we are not. And so I'm trying to say to him, "no it hurts" and he's like, "I do not know what you are talking about. It's not dry" and I'm saying; "yes, it really is dry" (Donna, age 39). –
Partners' emotional reactions to patients' cancer-related sexual changes and concerns: Partners describe substantial emotional effects of the patients' sexual problems, including guilt at wanting to engage in sexual activity even when painful or not enjoyable for the patient	…the times that we have, you know, been—been intimate, it's like…she's not enjoying it [chuckle] and…I'm like, she's doing it for my benefit, you know, and I feel bad that…like, that I'm making her do this…she's, like, dry...and like, she's tried different things, but, like, you know, it hurts... (Paul, age 43). –
Partners' roles in coping with sexual changes and concerns: Partners' experiences and emotional responses impact the intimacy in the relationship and on patients' adjustment to their sexual problems (e.g., not wanting to cause pain leads to pulling back from intimacy whereas openness and patients in the partner can enhance the intimacy)	…I've found that when we have run into those periods in our relationship, then my husband kind of pulls back too, you know, for a while. And—and does not want to pressure me and does not want to initiate because he does not want to make me feel bad, you know. So, then—then that span of time grows and grows where nothing is—is happening (Kim, age 51). –
Theme 3: Context of a Life-Limiting Illness: Viewing the Future through the Lens of a Relationship with an "Expiration Date"— Living with life-limiting disease shapes the experience of sexual and intimacy changes, and responses to these changes	
Viewing the relationship as time-limited: The awareness of the life-limiting nature of the disease leads to changes in conceptualizing the relationship in general as a context for the intimacy	And now that I'm, like, deteriorating even further…it's hard for him to watch this happen and it's hard for me to watch him watch it happen…because, you know, we always thought we would, you know, retire together someday. It really seems unlikely that I'll—I will get to a retirement age—ever, you know (Gloria, age 57). –
Emotional consequences of life-limiting context for relationship: There is a range of emotional responses and effects on intimacy, which for some couples included feeling closer, and for others, included additional stress changes in the definition of intimacy	…all these different stressors, you know, being able to provide financially, long term health insurance for me, you know, all these different factors play into just the additional stress on the relationship that did not exist before. And taking intimacy just even out of the equation (Kim, age 51). –
Balancing life as normal with coping with MBC: Patients and partners described a difficult balance between acknowledging the life-limiting nature of the disease versus living life as normal	Like, I always say, like, I'm—talk about it when it needs to be talked about but, like, especially, like, family-wise, like, with the kids and stuff, but then I sort of just put it on a shelf and it's there. It's always there and it can be taken down and looked at and talked about, but it does not need to be every day, and so we just sort of go on living as much as possible (Patricia, age 45). –

saturation. Coverage was high for partners as well, with only theme 3 appearing in fewer than all partner transcripts. With only 6 transcripts, full thematic coverage was not achieved for partners, but information obtained was robust (Malterud et al., 2016).

Patients' Experiences of and Reactions to Sexual and Intimacy Changes and Concerns (Theme 1)

MBC-Related Sexual Changes and Concerns

Within this theme, patients described a range of sexual concerns (e.g., physical, emotional/motivational, and relational), and they

TABLE 4 | Part 2: Qualitative themes 4–5 and illustrative quotes: coping with MBC-related sexual changes, information needs, and intervention preferences.

Main themes and subthemes	Illustrative quotes corresponding to themes
Theme 4: Coping with MBC-related Sexual Concerns—	
Coping efforts differed, seeming to bifurcate into effective and ineffective strategies; the stakes seem higher for poor coping given that the symptoms are worse	
Effective approaches to coping with sexual concerns: Couples who coped well and enjoyed intimacy despite sexual changes and limitations tended to approach the situation rather than avoid, tended to be flexible in their attitudes and behaviors toward sex and intimacy, acceptance without resignation, and open attitudes	It can be can be fun, you know, we can lube each other up. [laughter] So it's, I do not know, I only see it as a positive honestly. I do not think there's anything negative about it. (Robert, age 46) –
Ineffective approaches to coping with sexual concerns: Couples whose coping was less effective tended to employ cognitive and behavioral strategies that were often more rigid, or that suffered through the pain with a sense of duty or hopelessness, and that avoided the situation	And yes, it [sex] is very painful. Some days are better than others, you know even just trying to find different lubricants or different things that will help. Trying to find different methods and it's very trying and taxing and sometimes I find myself just saying okay I'm going to do it regardless...Let us just hurry up and get through it…I'm sitting there like Jesus, help me, this is excruciatingly painful. But sometimes I just think, you know, what am I supposed to do? (Donna, age 39) –
Role of communication in coping with sexual concerns: Communication about sexual issues differed among couples; for some, communication was a way to connect and share changing needs or offer support, whereas for other couples, communication was strained initially and suffered further with MBC, and included significant avoidance and discomfort regarding discussing sex and intimacy	Our communication is very open, we talked about every aspect of it. He's very supportive. Like I said, he's a really good sport and he's got a really good sense of humor so it all helps...Just to know that he is as supportive, as he is and just to know that he loves me no matter what [is helpful]. (Michelle, age 62) –
Theme 5: Information Needs and Intervention Preferences—	
Patients and partners reported needs for information on a range of issues and coping strategies, including the importance of addressing emotional aspects of intimacy and the relationship	
Specific information needs: Patients and partners commonly expressed a need for information on the effects of their treatments on their sexual function and intimacy, as well as for information on strategies to cope with their distressing sexual problems; some patients, however, who had lived for many years with sexual problems they felt were intractable, wondered at the potential usefulness of such information as they had tried a number of strategies that did not help	So I did not realize how much it was going to affect me until it started to just become very painful during intercourse. And my- the nurse did say to get the lubricant and I cannot use any estrogen and all of that stuff so that was a help. But I-I did not realize if I was supposed to be using it every day. (Brenda, age 46) –
Beyond information: emotional needs: A number of patients talked about the need for an intervention to address emotional issues and to normalize the sexual problems; for some patients, who had addressed their sexual issues, they felt they could benefit from help in addressing their fear of the other shoe dropping	I mean a program in that respect I think has to go even deeper than just sexual relations because there's so many other psychological aspects to it that layer onto your ability to have that sexual relationship. Just because he's-he has his own physical issues because of the psychological pressures, you know that he puts on himself… (Kim, age 51) –
Motivation for participation in sexual concerns intervention: Motivations differed, with some patients saying that the program would be worthwhile, and others reporting a lack of interest in participating in a program to address sexual intimacy, but the reasons diverged, ranging from a sense of pointlessness since the sexual problem was not perceived as addressable, to not prioritizing their issues, to not needing it since they had addressed it on their own, some said they thought their partners would not want to participate or might be more likely to discuss sexual issues with the physician than with a counselor	I do not think I have an issue to where I need to speak with a counselor or a specialist to talk about it or cope with it. Because I feel like I've been coping with it every day, and I've been coping with it for seven years. So, unless it was beneficial to where you guys had information that will really help me turn the situation around...I will feel like you know we are discussing it, but it's really nothing that we can do about it. (Donna, age 39) –

noted how the cumulative treatments they had received due to their advanced disease seemed to amplify the severity and complexity of their sexual problems and/or complicate their responsiveness to or ability to benefit from common treatment strategies. For instance, one woman described how, because she was "neutropenic all the time," when she would engage in sexual intercourse with her husband, she would experience infections, saying, "you are in the hospital with sepsis. I'm way beyond, like, dilators and lubricants" (Gloria, age 57). The same patient spoke about how the extensive nature of her surgeries and treatments contributed to changes in her view of herself as a woman, saying, "Sometimes I'll say something like, well … you know … chemo-induced menopause and I had surgery, then, you know, ovaries out, double mastectomy. I said—at 45, I was saying, 'well I'm one operation away from being a man'" (Gloria, age 57). Another patient reported that "because of it being breast cancer, I could not take any hormones or estrogen or anything, so it threw me in a full-blown menopause with no help from anything and the situation went from bad to worse. You know, even now it's [intercourse is] painful" (Donna, age 39). Loss of desire was also a significant problem, with one patient commenting on a total loss of desire for sex, saying, "For me, I'm just not like interested in, like, intimacy at all. I do not have like any urges or desire, like I could just be fine without it" (Joyce, age 33). Partners also commented on patients' sexual concerns, including on the impact it had on the intimacy in their relationship. For example, one partner commented, "we have never been like a holding hand kind of couple … but, like, I feel like maybe I'd say we like would cuddle less because that usually like that comes before after or both, so I feel like there's less there's definitely less physical contact between us than before" (Paul, age 43).

Patients' Emotional Reactions to Sexual Changes

The severity of the sexual problems experienced by many of the patients tended to be linked to substantial emotional reactions. For instance, the decreased ability to engage in sexual intimacy with their partners led to feelings of pressure and guilt, which served further to exacerbate patients' distress about the sexual difficulties. Patients spoke of how their desire to be "a good partner" could bring with it pressure to engage in sexual activity and then guilt when the sexual experience does not go as planned (see quote in **Table 3**, Theme 1.b., Rose, age 67). In another example, one patient, who indicated that sexual intimacy with her husband was dictated by her faith beliefs, described the pressure she feels in needing to have sex with her husband despite pain, stating that "I just feel like it's my job as his wife [to engage in intercourse despite pain] … and that coincides with my faith …" (Joyce, age 33); at a different point in the group, this patient also described guilt at not being able to engage in sexual intercourse despite this pressure, saying, "Sometimes I feel really bad … like, it's not his fault I cannot do this [engage in intercourse]." Another patient noted that her inability to engage in sexual intercourse, compared to prior to cancer, caused emotional distress, saying that "… you are thinking, this is not how our sex life was going to be, you know, should be for such a young individual … so I put a lot of pressure on myself to perform, I guess, if you will" (Kim, age 51).

Combined Effects of Chronic Physical and Emotional Sexual Changes

This subtheme describes how the combination of the often severe, chronic physical sexual problems with the emotional reactions to these problems in the previous two subthemes takes a cumulative toll on patients and the relationship by compromising hope and positive expectations in a snowball-like effect. For instance, one patient noted that coping with sexual issues after metastatic breast cancer felt like a never-ending set of obstacles that was difficult to overcome (Kim, age 51; see **Table 2**, Theme 1.c); this same patient commented on the ups and downs she experienced in coping with these issues, stating that "it kind of went through peaks and valleys over the years since we have been dealing with it for so long." When asked about the kinds of information she might benefit from, one patient commented on how the chronicity of her sexual problems made her skeptical that any information might help, saying, "I feel like I've been coping with it every day and I've been coping with it for 7 years. So, unless it was beneficial to where you guys had information that will really help me turn the situation around. I … feel like you know we are discussing it, but it's really nothing that we can do about it [the sexual problem]" (Donna, age 39). One partner also described feelings of frustration and futility associated with attempting to engage in sexual intimacy in between treatments (when the patient might feel better physically) and expressed desperation his wife felt. Specifically, the partner commented, "Yeah, just so much going on and different periods, especially, but even the in between periods like, [there's] not quite enough time to say things are back to normal. I do not know … between surgeries … when she is almost healed or things like that … here comes another surgery or here comes radiation … She's even mentioned, like, 'hey, maybe I can take some pain pills, and then we can go at it' and I do not know if she was joking but that's just a bad idea" (Raymond, age 42).

Partners' Experiences and Roles (Theme 2)

Awareness of MBC-Related Sexual Changes

Both partners and patients described a range of experiences for partners in their sexual relationship, including partners' own sexual difficulties (e.g., loss of interest in sex) as well as different levels of awareness of the patients' sexual problems. Partners described their personal experiences with these sexual changes, their emotional responses, and the perceived impact of sexual changes on outcomes for the patient and the relationship. For instance, one partner commented on how his wife's decreased sex drive had impacted his own, saying, "I feel like I do not have as much of, maybe, as a sex drive, as I used to either … it used to be like we'd go through, like those ruts and it'd be like we'd both be going like 'We got to do that more often' [laughter] you know … whereas it's like now it happens and … I do not think it's like 'oh wow, got to do that again like tomorrow.' It's just less of a drive there … if that makes sense" (Paul, age 43). One patient commented on how the changes in their intimate relationship had impacted her husband's sexual function, saying, "he has his own physical issues because of the psychological pressures, you know, that he puts on himself" (Kim, age 51). Occasionally, patients and partners commented on different levels of awareness partners had of the patients' sexual changes, with one patient pointing out her husband's lack of awareness of changes in her vaginal lubrication during sex (see quote, **Table 3**, Theme 2.a., Donna, age 39), and one partner noting an awareness of his wife's loss of libido, stating, "it's obvious when there's interest and no interest and you are just doing it just to do it" (James, age 51).

Partners' Emotional Reactions to Patients' Cancer-Related Sexual Changes and Concerns

As with patients, partners also experienced emotional effects of patients' sexual concerns and the changes in their intimate relationships, including guilt at wanting to engage in sexual activity even if it was uncomfortable for the patient (see quote in **Table 3**, Theme 2.a., Paul, age 43). Patients at times recognized partners' conflicting feelings about engaging in sexual activity when not enjoyable for the patient. For instance, one patient stated, "So it's just it's a struggle, it really is … I mean, it's stressful for him too because, obviously, he does not want me to be in pain. That's not enjoyable" (Brenda, age 46). Another partner spoke of the cumulative effects of the patient's pain during sexual activity combined with the pressure he felt to engage in sexual activity despite these problems, stating that "… it got—it got to a point recently where it [sex] wasn't fun anymore … It's that moment where … you got this time and you want to make the most of it … and it's no longer fun and it's stressful. That's not a good spot to be in" (James, age 51).

Partners' Roles in Coping With Sexual Changes and Concerns

When it came to coping, patients and partners described divergent ways of partners' coping, with some participants describing avoidant behavioral reactions that tended to be less successful (i.e., led to ineffective solutions and did not improve outcomes) and others commenting on more approach-oriented reactions that tended to be more successful (i.e., led to effective solutions and better outcomes). For instance, as shown in **Table 3**, Theme 2.c, one patient (Kim, age 51) described how her husband tends to avoid initiating sexual intimacy because he does not want to pressure her, leading to an extended length of time in which no sexual contact is. In a similar vein, one partner described how neither he nor his wife takes the initiative to start sexual contact, leaving them without sexual activity, saying, "we do occasionally … snuggle … or spoon … you are thinking one thing and she's thinking another thing, and you are on two different tracks and one veers this way and one veers that way, and then the moment is gone and it's like alright goodnight" (James, age 51). By contrast, another patient observed, "my husband is very, like, patient and understanding. And it's made us intimate in other ways, because I always used to think, like, sex was, like, intimacy but I'm learning that is not the case" (Mary, age 39). In a similar vein, one patient commented on how her husband's positive view of her body helped her cope somewhat with her own negative thoughts about her body, saying, "he thinks I'm the sexiest thing that walked this earth … and I'm like, you know, it really helps my confidence because of the fact that he thinks that I'm beautiful and I'm sexy that I'm like, wow. I do not know what you see but okay" (Donna, age 39).

Context of a Life-Limiting Illness (Theme 3)

Viewing the Relationship as Time-Limited

This subtheme describes how the experience of living with a life-limiting disease shaped the experience of sexual and intimacy changes, and responses to these changes. First, patients tended to speak openly about how having metastatic disease reshaped how they viewed their relationship in general—which could serve as a backdrop for sex and intimacy—and their expectations for the relationship in the context of the life-limiting nature of their diagnosis. For instance, one woman described this sentiment by saying, "… you should not, I guess, view your relationship as having an expiration date" (Kim, age 51). Other patients concurred, including one woman who spoke about having to adjust to the idea that she may not live long enough to retire with her husband (quote shown in **Table 3**, Theme 3.a., Gloria, age 57). One partner described it similarly, stating, "When you get together with someone, you do not think about – oh, how's this going to end, but when it says, "Oh, I have stage IV cancer … you see it – it's like, real" (Thomas, age 62). Although the quotes in this and the other subthemes within Theme 3 are not specifically related to the sexual effects of the cancer, they help characterize the relationship context in which patients and partners are experiencing and coping with these sexual concerns, and we thus choose to include them.

Emotional Consequences of Life-Limiting Context for Relationship

This change in context to a time-limited relationship tended to come along with emotional and psychological impacts on the relationship. For instance, one patient commented on how difficult it was for her partner to adjust to their changed future, saying, "It's hard for him [my husband] to watch this happen … we always thought that we would retire together someday" (Gloria, age 57). When asked about what should be included in an educational program addressing intimacy, the same patient who described her relationship as having an expiration date stated, "I mean a program, in that respect, I think, has to go even deeper than just sexual relations because there's so many other psychological aspects to it that layer onto your ability to have that sexual relationship" (Kim, age 51). However, while some patients described stress on the relationship (see quote in **Table 3**, Theme 3.b.), other emotional responses were more positive or shifted over time. For instance, one woman acknowledged, "it's been very stressful at times, but I think in—in the beginning, it brought us closer, to be honest with you, just because we were going through this together" (Brenda, age 46).

Balancing Life as Normal With Coping With Metastatic Cancer

The last subtheme within Theme 3 describes the challenges of trying to balance acknowledging the life-limiting nature of MBC while also wanting to live life as normally as possible. For instance, one patient described acknowledging that the terminal nature of her cancer is ever-present but that she chooses when to discuss it so that she can live a normal life without thinking of the issue constantly (**Table 3**, Theme 3.c., Patricia, age 45). One partner noted, "it's just sometimes inconceivable the way your mind sometimes runs away on you and you got to kind of reel it back in quick" (James, age 51), illustrating his approach to coping with the constant presence of this diagnosis by "reeling back in" the negative thoughts. Another patient described using humor with her husband to attempt to strike this balance between an awareness of her terminal diagnosis, and experiencing life as normal: "we'll be sitting at the kitchen table having something eat. … and I'll say something like you know "the year after I die … one year after, I'm coming back and this kitchen better be spotless [laughter]" (Gloria, age 57).

Coping With MBC-Related Sexual Concerns (Theme 4)

Effective Approaches to Coping With Sexual Concerns

Couples who seemed to cope well and enjoy intimacy in their relationships despite the considerable sexual challenges tended to approach (rather than avoid) intimacy with a sense of openness, flexibility, and acceptance (without resignation). This often involved shifting toward a more inclusive definition of intimacy and toward non-intercourse sexual activity. For example, one patient shared, "My husband is awesome [chuckle] … he really tries. He brings home new toys and different things—like, anything that you can think about to help me. He's like, you know, 'I do not want it to be one sided. I do not want to just be enjoying it by myself. I want you to enjoy yourself also. So whatever I can do, you know. Let us see if this works or how about we talk to your doctor about this' …" (Donna, age 39). This open attitude and collaboration between patient and partner was viewed as critical by this couple for finding effective approaches. Another patient acknowledged the importance of "removing that psychological pressure so that you can kind of regain maybe that emotional intimacy between one another, where you can then start building those blocks toward, you know, the sexual relationship again" (Kim, age 51), illustrating the importance of addressing the emotional piece in order to regain physical intimacy. Another patient talked about how her physical intimacy had shifted from intercourse to other activities, saying, "And we do communicate and we do, you know—for me—I hate to say this, but, like, he rubs my head and to me that feels as good anything [laughter]. So, you know, there are ways of being close without the intercourse, you know, without the goal" (Rose, age 67).

Ineffective Approaches to Coping With Sexual Concerns

While some participants spoke of finding effective strategies for coping, others cited strategies that proved ineffective in that they left them without physical intimacy in their relationships. For instance, one patient, described earlier as having a religious faith proscribing sexual activity within marriage, noted, "I feel bad, like, it's not his fault that I cannot do this..so I do offer, you know, oral sex or something like that, but it's not also a preference …" (Joyce, age 33). Another patient described tolerating painful sex because the effort required to find sexual aids was "trying and taxing" (**Table 4**, Theme 4.b, Donna, age 39).

Role of Communication in Coping With Sexual Concerns

A key factor of both effective and ineffective coping strategies was often communication. For some participants, communication was a helpful way to connect and share changing needs or offer support. For instance, the patient whose partner helped her find sexual aids described open communication that facilitated success and intimacy in the process, stating, "We're very open. Anything that we need to discuss and talk about, we do not shy away from it" (Donna, age 39). Additionally, one partner who described a resilient attitude toward sexual problems explained how he used communication to diffuse the effect of sexual problems within the relationship, saying, "I tell her all the time, I say 'if this happens, it happens … if it does not, do not think that that's the defining moment of our relationship'" (Thomas, age 62). For others, communication was strained and included significant avoidance and discomfort regarding discussing sex and intimacy. For instance, one partner commented on the role of communication in avoidance of sexual activity, saying, "Yeah, like, I did not feel like, 'hey, now's the time, let us go, and she did not say, 'I need it – give it to me,' so it just did not happen (Raymond, age 42). Avoiding talking about the sexual relationship sometimes went along with the ineffective coping strategies described previously. For instance, one patient stated, "we do not talk about, like, it hurting ever, you know what I mean? I've explained it to him that it hurts, but now I just endure it, so um, yeah … That's a choice of me, like, not deciding to tell him about it …" (Joyce, age 33).

Information Needs and Intervention Preferences (Theme 5)

Specific Information Needs

Patients and partners reported informational needs for a range of issues and coping strategies, including emotional aspects of intimacy and the relationship, effects of their treatments on their sexual function and intimacy, and strategies to cope with distress related to sexual problems. For instance, one partner wished he had received "basics of 'here's some things when you are on hormonal therapy that may be helpful during intimacy'" (Robert, age 46). Another partner who had lamented a loss of sex drive for his wife and himself stated that he would like "information on how she could get that drive back … and if there's something I can do to help with that process …" (Paul, age 43). When asked what he most hoped to gain from an educational program, he explained, "a way for us to be more intimate and, I guess, for us and for her to want to be intimate, you know, like … to get that kind of connection back that we had … we still love each other, and we still like being around each other, so … I think it's more about, like, maybe getting back to that sex drive that's missing that way" (Paul, age 43).

Beyond Information: Emotional Needs

In addition to information about physical sexual side effects, some patients and partners discussed the importance of an intervention that could address emotional concerns pertaining to the sexual changes and more broadly, related to the relationship (see quote in **Table 4**, Theme 5.b., Kim, age 51). For instance, one partner commented on the importance of learning how to manage change in expectations for intimacy in light of the patient's sexual function changes, saying, "I think it takes a little bit of willingness on everybody's part to say, 'although this is not exactly what we would like this to be, this is what it is, let us make—let us make this fun and it's certainly better than not having any intimacy at all … So managing, or you know, maybe you could have [a] part on managing your expectations" (Thomas, age 62). Several patients commented that hearing other women in the focus group discuss their sexual concerns was helpful to them because it let them know their experiences were common, thus normalizing the experience. For instance, one woman said, "So this, for me, is very educational and helpful because I'm not the only person going through this. There's lots of other people going through this and to me, this was very helpful for myself" (Brenda, age 46).

Motivation for Participation in Sexual Concerns Intervention

Many of the patients and partners described interest in learning new tools and strategies for coping with sexual concerns through the intervention, including learning specific information about sexual issues and ways for coping effectively. For instance, one patient commented, "If you guys are giving us tips on other ways to be intimate … That would be interesting" (Donna, age 39). Alternatively, some patients and partners described having already coped satisfactorily with sexual changes, such that an intervention would not be beneficial, as with one partner who stated, "I feel like we are pretty comfortable with where we are at with everything. I do not—I do not know, I mean, it sounds good …" (Robert, age 46). By contrast, others felt that their sexual concerns were so intractable as to be beyond hope. The chronicity of these issues seemed to play a role in these perceptions and lack of expectations for usefulness of interventions. For example, one patient said she would consider participating in a sexuality-focused intervention "to help someone else more than myself, because I almost feel like I'm a lost cause it's—it's I almost feel like it's no hope at this point for me and it's just I'm—I'm in this situation, or predicament and I just have to deal with the cards that have been dealt me" (Donna, age 39). Similarly, one partner stated, "So, I mean, I've been doing this for six years and she's been keeping on top of it … for someone new, that [educational program] might be just the thing … we also have worked on our own selves … We've been continuing to grow through this so I do not know whether we need it anymore, but I'll participate in whatever you present" (Thomas, age 62).

DISCUSSION

Overall, results of this qualitative investigation in patients with metastatic breast cancer (MBC) shed light on unique aspects of the experience of sexual concerns in this population, while also contributing to our understanding of both patients' and partners' perspectives on a changed view of the relationship itself in the context of a life-limiting diagnosis. In general, the types of issues patients and partners described were similar in nature to what has been reported in the literature for women with non-metastatic breast cancer (e.g., Rosenberg et al., 2014). However, the substantial disease and treatment burden associated with MBC seemed to heighten the acuity of the sexual problems that women with MBC experienced and potentially further compromise the effectiveness of coping options. For instance, some patients with MBC spoke of vaginal dryness so severe that engaging in sexual intercourse could cause a potentially dangerous infection as the vaginal tissue would likely tear during the activity; others spoke of having tried numerous sexual or vaginal aids without relief such that they had lost hope in ever engaging in comfortable sex. The heightened severity of these concerns seemed to increase the risk for considerable adverse emotional and interpersonal consequences for patients (e.g., guilt over not being able to engage in intercourse) and partners alike (e.g., guilt in pressuring the patient to engage in sexual activity despite pain/discomfort). In sum, while these findings echo the emotional consequences of sexual concerns seen for patients with breast cancer generally, they also suggest that these experiences may be especially pronounced for some women facing metastatic disease.

This study provided novel findings on MBC partners' perspectives of cancer-related sexual changes and concerns, with the role of partners being especially notable in discussions of coping with the sexual concerns. For example, partners' involvement helped to determine the directions and effectiveness of strategies patients described in coping with sexual concerns, including whether to approach or avoid the sexual issues in the relationship. For instance, partners' openness to find solutions for vaginal symptoms that were interfering with sex seemed to help allay patients' negative feelings associated with their sexual concerns while also leading to creative solutions. By contrast, partners who seemed to cope by avoiding discussing the topic or by withdrawing from physical intimacy inadvertently perpetuated a lack of intimacy and feelings of disconnection between the couple. In sum, these findings are consistent with those of prior studies demonstrating the important role of the partner in BC-related sexual concerns (Ganz et al., 2002; Fobair and Spiegel, 2009).

With these findings in mind, a couple-based intervention approach seems well suited to addressing sexual concerns because it addresses partners' coping and the interpersonal context of such concerns. Indeed, prior studies provide convincing evidence for couple-based interventions in addressing women's sexual concerns after cancer (Taylor et al., 2011). However, it is also worth noting that sexual health interventions delivered to women on their own also have demonstrated efficacy (Hummel et al., 2017b; Bober et al., 2018). Given that recruiting partners to a couples' only intervention study can add to the challenges inherent in recruiting to these studies (Regan et al., 2013), there is value in considering multiple types of interventions depending on patients' and partners' needs and preferences. Moreover, findings from our study suggest that patients and partners who have experienced perceived failure in trying to address their sexual problems may doubt the potential benefits or effectiveness of a proposed intervention. A belief such as this (that sexual problems are beyond hope), could pose further challenges to researchers and others interested in offering interventions to patients and partners in this population, while also suggesting that earlier intervention—given before such feelings of hopelessness and futility can pervade—may have the best chance for uptake and possibly effectiveness in this population.

Novel findings from this study include ways that the life-threatening nature of MBC seemed to shape patients' and partners' perspectives on the relationship. Most strikingly, some patients openly described their relationship in terms that indicated an endpoint (i.e., "as having an expiration date"). In the same vein, some patients acknowledged competing needs for confronting the reality of the diagnosis with still maintaining normalcy in the relationship. These ideas echo those found in prior research that suggest that the stress of the life-limiting diagnosis itself can influence women's intimate relationships and sexuality through stress and emotional distress (Vilhauer, 2008), above and beyond physical side effects. Further, although the quotes supporting these ideas were often not specifically related to sexual concerns, they are relevant to the focus of the present investigation because (a) they help us understand the context in which patients and partners are experiencing and coping with these sexual concerns (i.e., the partnered relationship), and (b) they have implications for interventions and clinical practice.

A major implication of these findings is the importance of addressing the broader context of survivors' and partners' emotional and interpersonal needs during discussions of sexual concerns related to the cancer. Researchers aiming to design an intervention addressing sexual concerns in this population could consider building off prior interventions that have aimed to help women and partners cope with the diagnosis of advanced breast cancer (e.g., Northouse et al., 2005). Specifically, researchers could consider including information on managing feelings and expectations about the relationship in the context of the metastatic diagnosis alongside information on common sexual problems and coping strategies. Similarly, clinical discussions of cancer-related sexual changes could also allow for discussions of changes in expectations or priorities around sex and intimacy within the relationship. For example, when raising the issue clinically, clinicians could acknowledge this context explicitly (e.g., "I know that you have a lot to handle right now, and this may not be top of your mind, but sexual concerns can come up for many women who have this diagnosis"). The broader context should most likely be acknowledged throughout an intervention or clinical process (e.g., therapy) as patients' and partners' thoughts and feelings on the subject may change over time. Overall, these findings are consistent with prior research demonstrating a range of types of changes experienced in the relationships of women with metastatic breast cancer (Valente et al., 2021) and highlight the importance of considering the context of the metastatic diagnosis and the changed overall relationship when addressing sexual concerns for partnered women with MBC.

Clinical Implications

In addition to implications for intervention development, this study has several important clinical implications. First, when inquiring about sexual concerns, clinicians may benefit from awareness of the severity of the common sexual concerns in the context of the heavy disease and treatment burden. Having appropriate referrals is important when treating patients who are experiencing severe or intractable sexual problems, or significant emotional concerns or relationship distress alongside sexual concerns. In addition, educating clinicians to broach the topic of sexual health could normalize the conversation in clinical settings, decrease perceived stigma associated with discussing sexual issues, and hopefully facilitate productive dialogue between clinicians and their patients in the future (Bober et al., 2016; Reese et al., 2017). Second, given the important role of partners in coping with sexual concerns, clinicians should ideally provide partners with information about potential sexual side effects along with the patients and, if it aligns with patients' wishes, should include partners in discussions of sexual concerns. Including the partner in such discussions is also consistent with clinical guidelines for discussing sexual health and function after cancer (Carter et al., 2017). Our findings suggest that including partners in discussions of sexual concerns, when desired by the patient, could help alleviate some burden from patients by confirming that the sexual concerns are common and related to the treatments, while also setting a stage for joint coping efforts. Finally, many of the participants who described coping effectively displayed signs of coping flexibility, a concept that can be useful in guiding coping efforts with cancer-related sexual concerns (Reese et al., 2010a). This concept involves making shifts in thoughts and behaviors related to how sexual activity and function are defined and enacted within the relationship. Clinicians working with patients after cancer might be encouraged to notice potentially rigid or inflexible beliefs when discussing breast cancer-related sexual issues (e.g., "I do not want to use artificial lubricant during sex because that feels weird"). They could then validate the perspective while encouraging greater flexibility (e.g., "I can understand how this might feel different from what you are used to, but it could be worth a shot, as they are safe from a cancer standpoint and many women and their partners find them very helpful in getting back to sexual activity. What are your thoughts about that?"). Clinicians could also encourage a sense of openness and curiosity toward new coping strategies, such as using a vibrator during sex, spending more time in non-intercourse sexual activities, pursuing pelvic floor physical therapy, or other strategies that patients and partners may not have previously considered but that could prove helpful. With that said, we acknowledge that there are significant barriers to open patient-provider communication about breast cancer-related sexual health concerns (McClelland et al., 2015; Reese et al., 2017). Many clinicians could thus benefit from obtaining further training to feel comfortable enough to raise such discussions effectively with their patients.

Limitations

There are several important limitations to this research study to acknowledge. First, although we made efforts to recruit using both site-based and community-based methods in the hopes of recruiting a more diverse sample, the sample was ultimately limited in its racial and ethnic diversity as well as sexual orientation and gender identity. Some research suggests that the types of sexual concerns and information needs that breast cancer patients report tend to be similar across racial and ethnic backgrounds (Reese et al., 2020a), although some differences in experiences and preferences regarding communication about sexual issues have been found (Anderson et al., 2021). Nevertheless, more research is needed specifically examining sexual health and communication in women with breast cancer of diverse backgrounds and identities, especially those with MBC. Second, the fact that women had to be partnered in order to participate may limit generalizability of findings to women with MBC who experience sexual concerns but are unpartnered, and may also contributed to limitations in diversity. Third, the sample size was small, particularly for partners. Indeed, although we had initially hoped to obtain similar participation from patients and partners in the study, challenges in recruiting partners compromised our ability to meet the initial objective, leading to more limited participation by partners in the study, with most partners who opted not to participate ending up not participating after their partners (i.e., the patients) refused on their behalf. As well, several partners who refused study screening reported discomfort in discussing issues of sex and intimacy. Indeed, the challenge in recruiting partners to couple-based studies, which generally requires the agreement of both patients and partners, has been reported in studies in breast and other cancers (Fredman et al., 2009; Reese et al., 2018); this is especially true for late-stage disease (Regan et al., 2013). Further, when recruitment of partners to breast cancer studies is optional, sample sizes of partners tend to be smaller than those of patients in the same studies (Giese-Davis et al., 2000; Hummel et al., 2017a). Thematic coverage in our patient data supported the notion that saturation was achieved; reaching saturation with a small number of focus groups can be possible in less heterogeneous samples, as ours is (Hennink and Kaiser, 2022). Although complete thematic saturation was not achieved for partners, we observed substantial overlap in the perspectives across partners as well as complementary findings when compared to patients' own perspectives, lending support for the robustness and important contributions of the data obtained from partners. Finally, the sample was too small to explore how clinical factors like length of treatment for metastatic disease, length of time since diagnosis, status of having recurrent versus primary metastatic diagnosis, or location of metastasis might impact findings. Future studies on intimacy using larger sample sizes of partners of patients with metastatic breast cancer could add to the findings of the present investigation.

Conclusion

Findings from the present investigation contribute to our understanding of challenges to sex and intimate relationships for patients living with MBC. An important finding is that the often-heightened severity of sexual concerns for patients with MBC, compounded by the terminal nature of the disease, may place patients and partners at risk for potentially significant adverse emotional and interpersonal consequences. Results suggest that when developing interventions, researchers should consider acknowledging and potentially addressing the range of emotional responses to sexual concerns, helping patients and partners navigate changes in their intimate relationships, and equipping both patients and partners with skills for coping with these changes amidst the considerable physical and emotional burden of MBC. Addressing unmet sexual health and intimacy needs is a fundamental part of whole-person cancer care that has important implications for the wellbeing and quality of life of patients with MBC and of their partners.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because of the sensitive nature of the qualitative data in order protect patient confidentiality. Requests to access the datasets should be directed to jennifer.reese@fccc.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Fox Chase Cancer Center Institutional Review Board. The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JR, LZ, AZ, LP, MD, and JG contributed to conception and design of the study. JR, LZ, SM, KS, LP, AZ, and BC contributed to resources acquisition and data collection. JR, LZ, SM, KS, and JG conducted analyses. JR wrote the first draft of the manuscript. LZ contributed significantly to a revised next draft. All authors contributed to the article and approved the submitted version.

FUNDING

This study was funded in part by 134607-RSG-029-01-CPPB from the American Cancer Society to JR, PhD and P30 CA006927 funded by the National Cancer Institute of the National Institutes of Health. The funding agencies had no role in the conduct of this study.

ACKNOWLEDGMENTS

We would like to thank Whitney Pollard, BA and Folashade Adekunle, MA for their time and efforts toward recruitment for this study.

REFERENCES

Alder, J., Zanetti, R., Wight, E., Urech, C., Fink, N., and Bitzer, J. (2008). Sexual dysfunction after premenopausal stage I and II breast cancer: do androgens play a role? *J. Sex. Med.* 5, 1898–1906. doi: 10.1111/j.1743-6109.2008.00893.x

Andersen, B. L. (2009). In sickness and in health: maintaining intimacy after breast cancer recurrence. *Cancer J.* 15, 70–73. doi: 10.1097/PPO.0b013e318198c742

Andersen, B. L., Carpenter, K. M., Yang, H. C., and Shapiro, C. L. (2007). Sexual well-being among partnered women with breast cancer recurrence. *J. Clin. Oncol.* 25, 3151–3157. doi: 10.1200/jco.2006.09.6958

Anderson, J. N., Graff, J. C., Krukowski, R. A., Schwartzberg, L., Vidal, G. A., Waters, T. M., et al. (2021). "nobody will tell you. You've got to ask!": an examination of patient-provider communication needs and preferences among black and white women with early-stage breast cancer. *Health Commun.* 36, 1331–1342. doi: 10.1080/10410236.2020.1751383

Badr, H., Carmack, C. L., Kashy, D. A., Cristofanilli, M., and Revenson, T. A. (2010). Dyadic coping in metastatic breast cancer. *Health Psychol.* 29, 169–180. doi: 10.1037/a0018165

Bober, S. L., Recklitis, C. J., Michaud, A. L., and Wright, A. A. (2018). Improvement in sexual function after ovarian cancer: effects of sexual therapy and rehabilitation after treatment for ovarian cancer. *Cancer* 124, 176–182. doi: 10.1002/cncr.30976

Bober, S. L., Reese, J. B., Barbera, L., Bradford, A., Carpenter, K. M., Goldfarb, S., et al. (2016). How to ask and what to do: a guide for clinical inquiry and intervention regarding female sexual health after cancer. *Curr. Opin. Support. Palliat. Care* 10, 44–54. doi: 10.1097/spc.0000000000000186

Bober, S. L., and Sanchez Varela, V. (2012). Sexuality in adult cancer survivors: challenges and intervention. *J. Clin. Oncol.* 30, 3712–3719. doi: 10.1200/jco.2012.41.7915

Bradley, E. H., Curry, L. A., and Devers, K. J. (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv. Res.* 42, 1758–1772. doi: 10.1111/j.1475-6773.2006.00684.x

Bredart, A., Dolbeault, S., Savignoni, A., Besancenet, C., This, P., Giami, A., et al. (2011). Prevalence and associated factors of sexual problems after early-stage breast cancer treatment: results of a French exploratory survey. *Psycho-Oncology* 20, 841–850. doi: 10.1002/pon.1789

Burwell, S. R., Case, L. D., Kaelin, C., and Avis, N. E. (2006). Sexual problems in younger women After breast cancer surgery. *J. Clin. Oncol.* 24, 2815–2821. doi: 10.1200/jco.2005.04.2499

Candy, B., Jones, L., Vickerstaff, V., Tookman, A., and King, M. (2016). Interventions for sexual dysfunction following treatments for cancer in women. *Cochrane Database Syst. Rev.* 2:CD005540. doi: 10.1002/14651858.CD005540.pub3

Carter, J., Lacchetti, C., Andersen, B. L., Barton, D. L., Bolte, S., Damast, S., et al. (2017). Interventions to address sexual problems in people With cancer: American society of clinical oncology clinical practice guideline adaptation of Cancer Care Ontario guideline. *J. Clin. Oncol.* 36, 492–511. doi: 10.1200/jco.2017.75.8995

Di Lascio, S., and Pagani, O. (2017). Is it time to address survivorship in advanced breast cancer? A review article. *Breast* 31, 167–172. doi: 10.1016/j.breast.2016.10.022

Djohan, R., Gage, E., Gatherwright, J., Pavri, S., Firouz, J., Bernard, S., et al. (2010). Patient satisfaction following nipple-sparing mastectomy and immediate breast reconstruction: an 8-year outcome study. *Plast. Reconstr. Surg.* 125, 818–829. doi: 10.1097/PRS.0b013e3181ccdaa4

Drageset, S., Austrheim, G., and Ellingsen, S. (2021). Quality of life of women living with metastatic breast cancer and receiving palliative care: a systematic review. *Health Care Women Int.* 42, 1044–1065. doi: 10.1080/07399332.2021.1876063

Fobair, P., and Spiegel, D. (2009). Concerns about sexuality after breast cancer. *Cancer J.* 15, 19–26. doi: 10.1097/PPO.0b013e31819587bb

Fobair, P., Stewart, S. L., Chang, S. B., D'Onofrio, C., Banks, P. J., and Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology* 15, 579–594. doi: 10.1002/Pon.991

Fredman, S. J., Baucom, D. H., Gremore, T. M., Castellani, A. M., Kallman, T. A., Porter, L. S., et al. (2009). Quantifying the recruitment challenges with couple-based interventions for cancer: applications to early-stage breast cancer. *Psycho-Oncology* 18, 667–673. doi: 10.1002/pon.1477

Gale, N. K., Heath, G., Cameron, E., Rashid, S., and Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med. Res. Methodol.* 13:117. doi: 10.1186/1471-2288-13-117

Gale, N. K., Shapiro, J., McLeod, H. S., Redwood, S., and Hewison, A. (2014). Patients-people-place: developing a framework for researching organizational culture during health service redesign and change. *Implement. Sci.* 9:106. doi: 10.1186/s13012-014-0106-z

Gambardella, A., Esposito, D., Accardo, G., Taddeo, M., Letizia, A., Tagliafierro, R., et al. (2018). Sexual function and sex hormones in breast cancer patients. *Endocrine* 60, 510–515. doi: 10.1007/s12020-017-1470-7

Ganz, P. A., Desmond, K. A., Leedham, B., Rowland, J. H., Meyerowitz, B. E., and Belin, T. R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. *J. Natl. Cancer Inst.* 94, 39–49. doi: 10.1093/jnci/94.1.39

Giese-Davis, J., Hermanson, K., Koopman, C., Weibel, D., and Spiegel, D. (2000). Quality of couples' relationship and adjustment to metastatic breast cancer. *J. Fam. Psychol.* 14, 251–266. doi: 10.1037/0893-3200.14.2.251

Gilbert, E., Ussher, J. M., and Perz, J. (2010). Sexuality after breast cancer: a review. *Maturitas* 66, 397–407. doi: 10.1016/j.maturitas.2010.03.027

Gorman, J. R., Smith, E., Drizin, J. H., Lyons, K. S., and Harvey, S. M. (2020). Navigating sexual health in cancer survivorship: a dyadic perspective. *Support. Care Cancer* 28, 5429–5439. doi: 10.1007/s00520-020-05396-y

Hennink, M., and Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: a systematic review of empirical tests. *Soc. Sci. Med.* 292:114523. doi: 10.1016/j.socscimed.2021.114523

Hummel, S. B., Hahn, D. E. E., van Lankveld, J. J. D. M., Oldenburg, H. S. A., Broomans, E., and Aaronson, N. K. (2017a). Factors associated With specific diagnostic and statistical manual of mental disorders, fourth edition sexual dysfunctions in breast cancer survivors: a study of patients and their partners. *J. Sex. Med.* 14, 1248–1259. doi: 10.1016/j.jsxm.2017.08.004

Hummel, S. B., van Lankveld, J. J., Oldenburg, H. S., Hahn, D. E., Kieffer, J. M., Gerritsma, M. A., et al. (2017b). Efficacy of internet-based cognitive behavioral therapy in improving sexual functioning of breast cancer survivors: results of a randomized controlled trial. *J. Clin. Oncol.* 35, 1328–1340. doi: 10.1200/jco.2016.69.6021

Langbaum, T., and Smith, T. J. (2019). Time to study metastatic-cancer survivorship. *N. Engl. J. Med.* 380, 1300–1302. doi: 10.1056/NEJMp1901103

Loaring, J. M., Larkin, M., Shaw, R., and Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: the experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychol.* 34, 426–436. doi: 10.1037/hea0000195

Malterud, K., Siersma, V. D., and Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qual. Health Res.* 26, 1753–1760. doi: 10.1177/1049732315617444

McClelland, S. I. (2016). "I wish I'd known": patients' suggestions for supporting sexual quality of life after diagnosis with metastatic breast cancer. *Sex. Relatsh. Ther.* 31, 414–431. doi: 10.1080/14681994.2015.1093615

McClelland, S. I., Holland, K. J., and Griggs, J. J. (2015). Vaginal dryness and Beyond: the sexual health needs of women diagnosed with metastatic breast cancer. *J. Sex Res.* 52, 604–616. doi: 10.1080/00224499.2014.928663

Milbury, K., and Badr, H. (2012). Sexual problems, communication patterns, and depressive symptoms in couples coping with metastatic breast cancer. *Psycho-Oncology* 22, 814–822. doi: 10.1002/pon.3079

Mosher, C. E., and DuHamel, K. N. (2012). An examination of distress, sleep, and fatigue in metastatic breast cancer patients. *Psycho-Oncology* 21, 100–107. doi: 10.1002/pon.1873

Mosher, C. E., Johnson, C., Dickler, M., Norton, L., Massie, M. J., and DuHamel, K. (2013). Living with metastatic breast cancer: a qualitative analysis of physical, psychological, and social Sequelae. *Breast J.* 19, 285–292. doi: 10.1111/tbj.12107

National Comprehensive Cancer Network (2021). NCCN clinical practice guidelines in oncology (NCCN Guidelines): survivorship, (version 3.2021).

Northouse, L., Kershaw, T., Mood, D., and Schafenacker, A. (2005). Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psychooncology* 14, 478–491. doi: 10.1002/pon.871

Ochsenkuhn, R., Hermelink, K., Clayton, A. H., von Schonfeldt, V., Gallwas, J., Ditsch, N., et al. (2011). Menopausal status in breast cancer patients with past chemotherapy determines long-term hypoactive sexual desire disorder. *J. Sex. Med.* 8, 1486–1494. doi: 10.1111/j.1743-6109.2011.02220.x

Oken, M. M., Creech, R. H., Tormey, D. C., Horton, J., Davis, T. E., McFadden, E. T., et al. (1982). Toxicity and response criteria of the eastern cooperative oncology group. *Am. J. Clin. Oncol.* 5, 649–656. doi: 10.1097/00000421-198212000-00014

Otterburn, D. M., Sikora, K. E., and Losken, A. (2010). An outcome evaluation following postmastectomy nipple reconstruction using the C-V flap technique. *Ann. Plast. Surg.* 64, 574–578. doi: 10.1097/SAP.0b013e3181c01290

Raggio, G. A., Butryn, M. L., Arigo, D., Mikorski, R., and Palmer, S. C. (2014). Prevalence and correlates of sexual morbidity in long-term breast cancer survivors. *Psychol. Health* 29, 632–650. doi: 10.1080/08870446.2013.879136

Reese, J. B., Beach, M. C., Smith, K. C., Bantug, E. T., Casale, K. E., Porter, L. S., et al. (2017). Effective patient-provider communication about sexual concerns in breast cancer: a qualitative study. *Support. Care Cancer* 25, 3199–3207. doi: 10.1007/s00520-017-3729-1

Reese, J. B., Keefe, F. J., Somers, T. J., and Abernethy, A. P. (2010a). Coping with sexual concerns after cancer: the use of flexible coping. *Support Care Cancer* 18, 785–800. doi: 10.1007/s00520-010-0819-8

Reese, J. B., Porter, L. S., Casale, K. E., Bantug, E. T., Bober, S. L., Schwartz, S. C., et al. (2016). Adapting a couple-based intimacy enhancement intervention to breast cancer: a developmental study. *Health Psychol.* 35, 1085–1096. doi: 10.1037/hea0000413

Reese, J. B., Porter, L. S., Somers, T. J., and Keefe, F. J. (2012). Pilot feasibility study of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. *J. Sex Marital Ther.* 38, 402–417. doi: 10.1080/0092623x.2011.606886

Reese, J. B., Shelby, R. A., Keefe, F. J., Porter, L. S., and Abernethy, A. P. (2010b). Sexual concerns in cancer patients: a comparison of GI and breast cancer patients. *Support. Care Cancer* 18, 1179–1189. doi: 10.1007/s00520-009-0738-8

Reese, J. B., Smith, K. C., Handorf, E., Sorice, K., Bober, S. L., Bantug, E. T., et al. (2019). A randomized pilot trial of a couple-based telephone intervention addressing sexual concerns for breast cancer survivors. *J. Psychosoc. Oncol.* 37, 242–263. doi: 10.1080/07347332.2018.1510869

Reese, J. B., Sorice, K. A., Oppenheimer, N. M., Smith, K. C., Bober, S. L., Bantug, E. T., et al. (2018). Why do breast cancer survivors decline a couple-based intimacy enhancement intervention trial? *Transl. Behav. Med.* 10, 435–440. doi: 10.1093/tbm/iby129

Reese, J. B., Sorice, K. A., Pollard, W., Zimmaro, L. A., Beach, M. C., Handorf, E., et al. (2020a). Understanding sexual help-seeking for women with breast cancer: what distinguishes women who seek help from those who do not? *J. Sex. Med.* 17, 1729–1739. doi: 10.1016/j.jsxm.2020.06.004

Reese, J. B., Zimmaro, L. A., Lepore, S. J., Sorice, K. A., Handorf, E., Daly, M. B., et al. (2020b). Evaluating a couple-based intervention addressing sexual concerns for breast cancer survivors: study protocol for a randomized controlled trial. *Trials* 21:173. doi: 10.1186/s13063-019-3975-2

Regan, T., Lambert, S. D., and Kelly, B. (2013). Uptake and attrition in couple-based interventions for cancer: perspectives from the literature. *Psychooncology* 22, 2639–2647. doi: 10.1002/pon.3342

Rosenberg, S. M., Tamimi, R. M., Gelber, S., Ruddy, K. J., Bober, S. L., Kereakoglow, S., et al. (2014). Treatment-related amenorrhea and sexual functioning in young breast cancer survivors. *Cancer* 120, 2264–2271. doi: 10.1002/cncr.28738

Schover, L. R., Yuan, Y., Fellman, B. M., Odensky, E., Lewis, P. E., and Martinetti, P. (2013). Efficacy trial of an internet-based intervention for cancer-related female sexual dysfunction. *J. Natl. Compr. Cancer Netw.* 11, 1389–1397. doi: 10.6004/jnccn.2013.0162

Siegel, R. L., Miller, K. D., and Jemal, A. (2020). Cancer statistics, 2020. *Cancer J. Clinic.* 70, 7–30. doi: 10.3322/caac.21590

Silverman, M. R., and Rabow, M. W. (2018). Sexual health in young women with metastatic breast cancer: The state of the science. *J. Clin. Oncol.* 36:223. doi: 10.1200/JCO.2018.36.34_suppl.223

Sopfe, J., Pettigrew, J., Afghahi, A., Appiah, L. C., and Coons, H. L. (2021). Interventions to improve sexual health in women living with and surviving cancer: review and recommendations. *Cancers* 13:3153. doi: 10.3390/cancers13133153

Taylor, S., Harley, C., Ziegler, L., Brown, J., and Velikova, G. (2011). Interventions for sexual problems following treatment for breast cancer: a systematic review. *Breast Cancer Res. Treat.* 130, 711–724. doi: 10.1007/s10549-011-1722-9

Tong, A., Sainsbury, P., and Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int. J. Qual. Health Care* 19, 349–357. doi: 10.1093/intqhc/mzm042

Valente, M., Chirico, I., Ottoboni, G., and Chattat, R. (2021). Relationship dynamics among couples dealing with breast cancer: a systematic review. *Int. J. Environ. Res. Public Health* 18. doi: 10.3390/ijerph18147288

Vilhauer, R. P. (2008). A qualitative study of the experiences of women with metastatic breast cancer. *Palliat. Support. Care* 6, 249–258. doi: 10.1017/s1478951508000382

Vilhauer, R. P. (2011). 'Them' and 'us': the experiences of women with metastatic disease in mixed-stage versus stage-specific breast cancer support groups. *Psychol. Health* 26, 781–797. doi: 10.1080/08870446.2010.496853

Zahlis, E. H., and Lewis, F. M. (2010). Coming to grips with breast cancer: the Spouse's experience with his wife's first six months. *J. Psychosoc. Oncol.* 28, 79–97. doi: 10.1080/07347330903438974

Zimmermann, T. (2015). Intimate relationships affected by breast cancer: interventions for couples. *Breast Care* 10, 102–108. doi: 10.1159/000381966

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers in Psychology

ORIGINAL RESEARCH
published: 04 February 2022
doi: 10.3389/fpsyg.2022.813548

Adapting a Theory-Informed Intervention to Help Young Adult Couples Cope With Reproductive and Sexual Concerns After Cancer

Jessica R. Gorman[1]*, *Karen S. Lyons*[2], *Jennifer Barsky Reese*[3], *Chiara Acquati*[4,5,6], *Ellie Smith*[1], *Julia H. Drizin*[1], *John M. Salsman*[7,8], *Lisa M. Flexner*[9], *Brandon Hayes-Lattin*[10] *and S. Marie Harvey*[1]

[1]*School of Social and Behavioral Health Sciences, College of Public Health and Human Sciences, Oregon State University, Corvallis, OR, United States,* [2]*Connell School of Nursing, Boston College, Chestnut Hill, MA, United States,* [3]*Cancer Prevention and Control Program, Fox Chase Cancer Center, Philadelphia, PA, United States,* [4]*Graduate College of Social Work, University of Houston, Houston, TX, United States,* [5]*Department of Clinical Sciences, College of Medicine, University of Houston, Houston, TX, United States,* [6]*Department of Health Disparities Research, The UT MD Anderson Cancer Center, Houston, TX, United States,* [7]*Department of Social Sciences and Health Policy, Wake Forest School of Medicine, Winston-Salem, NC, United States,* [8]*Wake Forest Baptist Comprehensive Cancer Center, Winston-Salem, NC, United States,* [9]*Doctor of Physical Therapy Program, Oregon State University, Bend, OR, United States,* [10]*School of Medicine, OHSU Knight Cancer Institute, Oregon Health and Sciences University, Portland, OR, United States*

Edited by:
Andreas Dinkel,
Technical University of Munich,
Germany

Reviewed by:
Scott Siegel,
Christiana Care Health System,
United States
Ting Guan,
University of North Carolina at Chapel Hill, United States

***Correspondence:**
Jessica R. Gorman
jessica.gorman@oregonstate.edu

Specialty section:
This article was submitted to Psycho-Oncology,
a section of the journal
Frontiers in Psychology

Received: 11 November 2021
Accepted: 10 January 2022
Published: 04 February 2022

Citation:
Gorman JR, Lyons KS, Reese JB, Acquati C, Smith E, Drizin JH, Salsman JM, Flexner LM, Hayes-Lattin B and Harvey SM (2022) Adapting a Theory-Informed Intervention to Help Young Adult Couples Cope With Reproductive and Sexual Concerns After Cancer.
Front. Psychol. 13:813548.
doi: 10.3389/fpsyg.2022.813548

Objective: Most young adults diagnosed with breast or gynecologic cancers experience adverse reproductive or sexual health (RSH) outcomes due to cancer and its treatment. However, evidence-based interventions that specifically address the RSH concerns of young adult and/or LGBTQ+ survivor couples are lacking. Our goal is to develop a feasible and acceptable couple-based intervention to reduce reproductive and sexual distress experience by young adult breast and gynecologic cancer survivor couples with diverse backgrounds.

Methods: We systematically adapted an empirically supported, theoretically grounded couple-based intervention to address the RSH concerns of young couples coping with breast or gynecologic cancer through integration of stakeholder perspectives. We interviewed 11 couples (22 individuals) with a history of breast or gynecologic cancer to review and pretest intervention materials. Three of these couples were invited to review and comment on intervention modifications. Content experts in RSH and dyadic coping, clinicians, and community advisors (one heterosexual couple and one LGBTQ+ couple, both with cancer history) participated throughout the adaptation process.

Results: Findings confirmed the need for an online, couple-based intervention to support young couples experiencing RSH concerns after breast or gynecologic cancer. Qualitative themes suggested intervention preferences for: (1) A highly flexible intervention that can be tailored to couples' specific RSH concerns; (2) Active steps to help members of a dyad "get on the same page" in their relationship and family building plans; (3) A specific focus on raising partners' awareness about how cancer can affect body image and physical intimacy; and (4) Accessible, evidence-based information about RSH for both partners. These results, along with feedback from stakeholders, informed adaptation and finalization of the intervention content and format. The resulting virtual intervention, *Opening the Conversation*, includes five weekly sessions offering training to couples in communication and dyadic coping skills for addressing RSH concerns.

Conclusion: The systematic adaptation process yielded a theory-informed intervention for young adult couples facing breast and gynecological cancers, which will be evaluated in a randomized controlled trial. The long-term goal is to implement and disseminate *Opening the Conversation* broadly to reach young adult couples with diverse backgrounds who are experiencing RSH concerns in cancer survivorship.

Keywords: young adult, cancer, sexual health, reproductive health, survivorship, sexual and gender minorities, qualitative, adaptation

INTRODUCTION

Young adult survivors of breast and gynecologic cancer (defined as those diagnosed between the ages of 18 and 39) face several unique challenges, including abrupt and often unexpected changes to their life plans and intimate relationships (Gorman et al., 2011, 2012, 2020). Younger survivors are at greater risk of psychological distress, as compared to those diagnosed at older ages (Arndt et al., 2004; Bidstrup et al., 2015; Acquati and Kayser, 2019). At least half of young survivors experience negative effects of cancer and cancer treatment on their reproductive and sexual health (RSH; Fobair et al., 2006; Wettergren et al., 2017; Jing et al., 2019). Adverse late effects of cancer on RSH include infertility, worry about personal health after pregnancy, concerns about potential risks to a future child's health, hot flashes, poor body image, sexual pain, low sexual desire, concerns about disclosure to new partners, and related issues (Walshe et al., 2006; Karabulut and Erci, 2009; Carter et al., 2010; Grover et al., 2012; Robinson et al., 2014; Schover et al., 2014; Bradford et al., 2015; Wettergren et al., 2017). RSH concerns are among the most distressing aspects of life after cancer for young survivors and their partners, and when left unaddressed, often lead to poorer mental health and quality of life (Carter et al., 2010; Levin et al., 2010; Vaz et al., 2011; Canada and Schover, 2012; Robertson et al., 2016; Ljungman et al., 2018; Patterson et al., 2020). Despite the common and distressing nature of RSH concerns for many young adult survivor couples, these concerns are generally not adequately addressed by their healthcare providers (Gorman et al., 2021). Furthermore, there are no evidence-based interventions designed to help both young adult survivors and their partners reduce cancer-related reproductive and sexual distress. Therefore, development of age-specific interventions that support couples experiencing RSH concerns is essential.

There are several important considerations when developing an RSH intervention for young adult survivor couples. First, it is important to acknowledge that RSH concerns can be challenging to articulate because they encompass a variety of interwoven aspects (e.g., problems with sexual function alongside the desire for a biological child) and evolve over time along with the relationship, health status, and other life circumstances. Second, available approaches emphasize specialist care, such as sex therapists or fertility specialists, and are limited in scope, often focusing only on the survivor's experience and neglecting support for partners. Third, these services are not widely available, particularly in rural areas, and access to care remains a barrier. Additionally, where psychosocial interventions are available, additional barriers to participation include time and travel requirements (Fredman et al., 2009; Regan et al., 2012). Finally, most interventions have been developed for heterosexual couples and have overlooked the needs and preferences of LGBTQ+ couples, who experience inequities in care and have significant unmet survivorship care needs (Boehmer et al., 2013; Hulbert-Williams et al., 2017; Seay et al., 2018). Although there is insufficient research on the RSH concerns of LGBTQ+ cancer survivors and partners, emerging literature points to a long-term impact on relationships and sexual intimacy, psychological distress, and the need for support for both partners (Kamen et al., 2015; Brown and McElroy, 2018; Kent et al., 2019). Additionally, there may be differences in the RSH experiences and needs of LGBTQ+ couples, but relationship factors influencing sexual satisfaction appear similar across groups and include sexual communication (Henderson et al., 2009; Fleishman et al., 2020).

Cancer is characterized as a "we-disease," where couples navigate the experience together as a unit (Kayser et al., 2007; Lyons and Lee, 2018). Effective communication and dyadic coping, which encompasses the range of actions by one or both partners to cope with stressors and individual/joint strategies to assist the other partner with managing stressful situations or events, are important for psychosocial adjustment and relationship functioning for couples facing cancer (Regan et al., 2012; Badr and Krebs, 2013; Traa et al., 2015; Kayser et al., 2018; Acquati and Kayser, 2019). Although limited research on couple communication about reproductive concerns after cancer exists, evidence to date suggests that couple communication about fertility is important and beneficial to coping with these concerns, but it is sometimes avoided because of fears about partner discomfort, relationship problems, lack of understanding, and related concerns about the way infertility could impact the relationship (Hawkey et al., 2021a,b). There is also some evidence that couples with fertility concerns experience fear of abandonment and relationship difficulties (Dryden et al., 2014; Lehmann et al., 2018), suggesting that engaging both partners is important.

Couple communication is increasingly recognized as an important predictor of relationship functioning, sexual health, and both patient and caregiver outcomes (Badr, 2017; Otto et al., 2021). In general, engaging both partners is important because couples who communicate effectively and engage in joint coping efforts have more positive relationship and mental health outcomes (Manne et al., 2006, 2015; Badr et al., 2008; Lyons et al., 2014, 2016). Conversely, when partners withdraw, engage in protective buffering, or hold back, poorer outcomes have been documented (Manne et al., 2006, 2015; Badr et al., 2008; Manne and Badr, 2008). With regard to sexual health, partners' active engagement in coping with patients' cancer-related sexual concerns is important because (a) sexual concerns are often experienced in the context of partnered sexual activity (Ganz et al., 2002; Fobair and Spiegel, 2009), (b) partners commonly report sexual health concerns (Loaring et al., 2015; Hummel et al., 2017a), and (c) survivors tend to want their partners involved in this process (Reese et al., 2016). Indeed, the most effective approaches to addressing sexual health and reducing sexual distress after cancer have systematically engaged partners (Schover et al., 2013; Carroll et al., 2016; Hummel et al., 2017b). In sum, it follows that couple-based interventions to improve dyadic coping strategies and effective communication represent a promising strategy for improving the relationship functioning of couples coping with the long-term effects of cancer on their relationship and that these approaches may be effective for reducing RSH-related distress across the cancer continuum (Scott and Kayser, 2009; Hawkey et al., 2021a).

Evidence indicates that psychosocial interventions enhance dyadic coping and communication in the context of cancer (Badr and Krebs, 2013; Traa et al., 2015; Li et al., 2020) and that they may be most effective for improving sexual health and quality of life when incorporating elements of psychoeducation, skills training, and couple-counseling (Li et al., 2020). One such intervention, *Side by Side*, provides training for individual and relationship skills specific to breast and gynecologic cancer survivor couples' experience. It focuses heavily on sharing thoughts and feelings and couple communication about cancer-related issues. The intervention was designed for delivery *via* four in-person sessions of 2 h each. In a randomized controlled trial involving 72 heterosexual German couples (age 25–80 years, median age 52 years) who were married or in a committed relationship, those in the active condition reported less avoidance in dealing with cancer, more posttraumatic growth, better communication quality, and better dyadic coping than those in an attention control condition (Heinrichs et al., 2012).

Side by Side is grounded in methods of cognitive behavioral therapy (Epstein and Baucom, 2002) and Bodenmann's conceptualization of dyadic coping (Bodenmann and Shantinath, 2004; Bodenmann et al., 2006; Heinrichs et al., 2012). It was originally based on CanCOPE (Scott et al., 2004) and was previously modified in a pilot trial (Zimmermann et al., 2006). Following Bodenmann's Systemic Transactional Model (STM), one partner's stress appraisal influences and it is influenced by the other partner and the relationship (Bodenmann, 1995, 1997; Bodenmann et al., 2016). Following this theory, dyadic coping mitigates the negative impact of stress on a couple's relationship (Bodenmann, 1997, 2008; Bodenmann and Shantinath, 2004). Dyadic coping involves cognitive (e.g., stress appraisal), emotional (e.g., shared emotions), and behavioral processes (e.g., active listening and problem solving) where both members of the couple participate as equal partners. To enhance dyadic coping, *Side by Side* incorporates training and practice in Bodenmann's three-phase method (Bodenmann, 2007). The three-phase method helps partners to: (1) communicate their stress to their partner, (2) meet the specific needs of the stressed partner, and (3) improve their ability to cope together with the stress. Following the STM, stressors can include daily life stressors or more severe stressors, such as those resulting from illness (Bodenmann, 2007; Bodenmann et al., 2016). The present study extends application of the theory to stressors related to cancer's impact on RSH in young adult couples, which can range in form and severity.

In the present study, we describe the systematic adaptation and tailoring of *Side by Side* for young adult couples with breast or gynecologic cancers, who are 6 months to 5 year post-diagnosis, and with any sexual orientation or gender identity, to help them communicate about and cope with RSH concerns. The primary outcomes are sexual and reproductive distress. The intervention format was also adapted for videoconference delivery. Our overarching goal was to optimize acceptability and feasibility while retaining core components (i.e., intervention practices linked to theory-driven mechanisms of change). Our specific goals for the adaptation process were to increase fit/relevance, elicit and address the primary RSH-related concerns for both survivors and partners, and increase LGBTQ+ inclusivity. This work was completed in preparation for the intervention's efficacy testing *via* randomized controlled trial (NCT04806724).

MATERIALS AND METHODS

We adapted the intervention following the assessment, decision, adaptation, production, topical experts, integration, training, and testing (ADAPT-ITT) framework's systematic process (McKleroy et al., 2006; Wingood and DiClemente, 2008), including integration of target audience and other stakeholder perspectives (**Figure 1**). ADAPT-ITT has evolved over years of work by the CDC and others in the context of HIV, has resulted in successful and cost-effective intervention adaptations, and follows commonly recognized steps in the adaptation process (Wingood and DiClemente, 2008; Latham et al., 2010; Escoffery et al., 2019). Importantly, systematic adaptation facilitates intervention fit for a specific audience and setting while retaining core components of the intervention, which is essential for future implementation and dissemination (Escoffery et al., 2019).

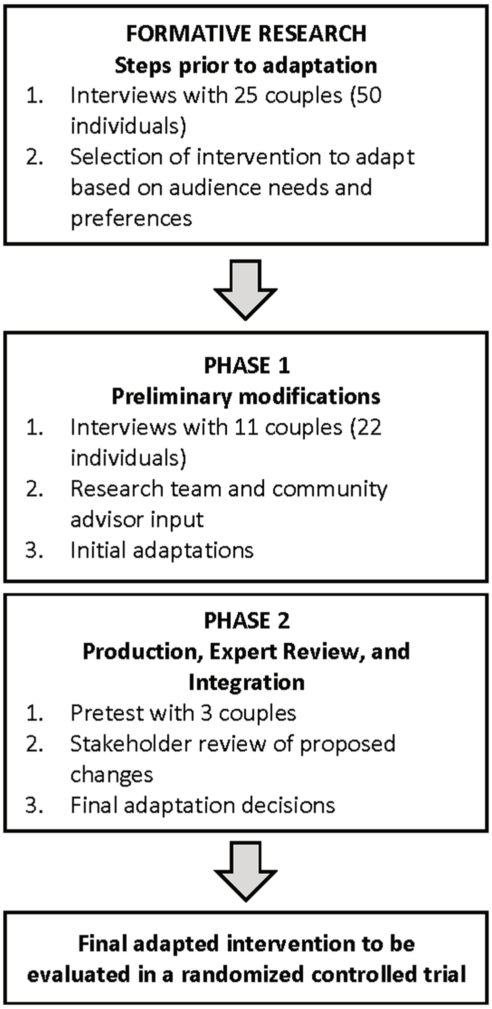


FIGURE 1 | Summary of intervention adaptation process. Formative research results are published elsewhere.

Formative research conducted prior to the present study involved individual interviews with 25 young adult survivor dyads (50 individuals) to assess psychosocial supportive needs and to identify an intervention strategy that would meet that need (Gorman et al., 2020). Importantly, couples reported that maintaining open communication was central to preserving strong relationship functioning through cancer and expressed preferences for a couple-focused intervention strategy providing support for both partners that was delivered in an online/virtual format (Gorman et al., 2020). This formative research was guided by the theory of dyadic illness management, which posits that the way couples experience cancer is influenced by each partner's appraisal and management of its impact and that this ultimately affects the health of both partners (dyadic health; Lyons and Lee, 2018). Our findings revealed that couples experience a wide range of RSH concerns and that these vary according to contextual factors, such as current life circumstances. Results also highlighted the promise of intervention strategies facilitating "togetherness," mutual support, and collaborative management of RSH concerns after cancer to support dyadic health, further building upon the theoretical foundation for the adapted intervention (Gorman et al., 2020). Based on our results, and a review of the literature validating substantial need for intervention focused on RSH for this population (Stabile et al., 2017; Logan et al., 2018, 2019; Jing et al., 2019), we consulted with the intervention developers and selected *Side by Side* for adaptation. This dyadic intervention was selected based on a combination of factors suggesting fit for the audience and evidence for potential impact, including alignment with needs and preferences identified in our formative research, targeted focus on communication and coping skills, grounding in theory and evidence-based practice, specificity for breast and gynecologic cancer survivors, and demonstrated effectiveness for improving relationship and psychosocial outcomes (Epstein and Baucom, 2002; Bodenmann et al., 2006; Heinrichs et al., 2012).

A stakeholder panel was assembled that included content experts in RSH concerns after cancer, dyadic interventions, dyadic coping behaviors and illness management after cancer, AYA survivorship, AYA oncology, oncology social work, and four community advisors, one heterosexual couple, and one LGBTQ+ couple, both with a cancer history and representing diversity in sexual orientation as well as trans/cisgender identity. We purposefully invited stakeholders representing diverse perspectives who were familiar with or identified as members of the intended audience for the intervention. We also sought stakeholders with medical care roles as well as social/psychological care roles. There were not specific inclusion or exclusion criteria.

The study protocol was approved by the Oregon State University Institutional Review Board. All study participants completed oral informed consent procedures.

Phase 1: Administration-Preliminary Adaptation and Feasibility Assessment

The purpose of this step was to consult with the intended audience to determine factors that would support RSH communication after cancer and to review *Side by Side* intervention materials with the goal of eliciting stakeholders' perspectives on content adaptation. We used purposive sampling to represent and reflect the diversity of perspectives in the intended audience and to document potential variations and common patterns (e.g., needs and preferences) that cut across cases to inform intervention adaptations that meet diverse needs (Palinkas et al., 2015). Eligibility criteria for cancer survivors were: breast/gynecologic cancer diagnosis between the ages of 18 and 39 years, current age under 45 years, cancer diagnosis 6 months–5 years prior, cancer stage 1–4, moderate or higher reproductive concerns in one domain of the Reproductive Concerns After Cancer scale (Gorman et al., 2014), ability to participate in a Zoom interview, a committed partner who is willing to participate, English speaking, and high speed Internet access. Inclusion criteria for partners were: age 18 or older, English speaking, ability to participate in a Zoom interview, and high speed Internet access.

Data Collection

Trained team members conducted individual semi-structured interviews *via* Zoom (audio only) with each partner separately. Interviews were completed between August 2020 and January 2021. The semi-structured format provided an opportunity to explore ideas and clarify concepts throughout the interview (24). Participants were provided with a bulleted summary of *Side by Side* intervention content/activities and sample participant handouts prior to the interview. Interviews were approximately 1 h in duration and were audio recorded and professionally transcribed. The interviewer first asked questions about demographics, cancer history, and reproductive history. Interview questions covered the following domains: general relationship (e.g., "How would you describe your relationship with your partner?"), communication about sexual health (e.g., "How do you keep your communication open about sexual health?" and "How did you talk about sex before your/your partners' cancer diagnosis?"), communication about reproductive health (e.g., "How has your/your partner's experience with cancer affected how you talk about fertility or having children?" and "How often do you talk to your partner about fertility or having children?"), preferred aspects of the intervention (e.g., "Thinking about what would help you and your partner, what are the most important issues or skills that you think the program should focus on?"), intervention content to address RSH specifically, while reviewing the *Side by Side* materials provided (e.g., "What kinds of resources and information would you like to see included in the program to help you to better manage your reproductive or sexual health after cancer?"), and intervention preferences related to feasibility and acceptability (e.g., "How much time per week could you imagine yourself being able to commit to this program?", "Please describe the person you would feel most comfortable leading the weekly sessions" and "What are your thoughts on having this program delivered online, by videoconference (for example, Zoom) where a counselor would connect privately with you and your partner in your home?").

Analysis

Transcripts were imported, organized, and coded in QSR NVivo 12 software. Interviews were analyzed utilizing a structural coding approach (Saldaña, 2015). The initial codebook was developed based on interview guide domains. Then, two members of the research team completed initial coding of survivor and partner interviews separately to determine the final codebook. Once a codebook was developed, we moved to structured coding, where we identified the most relevant and common codes and applied them to the transcripts. Next, researchers employed thematic analysis to identify themes and patterns in the data that informed intervention adaptations (Braun and Clarke, 2006). Researchers met frequently during the coding process to discuss findings and employed memo-taking to increase reliability of results. Results were compared between survivors and partners to identify potential differences in responses or preferences and then summarized and subsequently reviewed by members of the research team. The team also consulted with the community advisors who reviewed materials and gave feedback on planned adaptations during this phase. The research team came to consensus on final themes and decisions about adaptations.

Phase 2: Production, Expert Review, and Integration-Development of the Final Adapted Intervention

The research team first translated feedback obtained in the prior step to inform modifications to the intervention content and format. Adaptations focused on improving relevance to the target population, addressing the RSH-related concerns of survivors and their partners, aligning with intended audience expressed needs, and modifications for a virtual intervention setting. To develop new educational content focused on RSH concerns, the team conducted a review of the literature to identify potential adverse effects of cancer on RSH (e.g., changes in fertility and sexual function) and recommended strategies to address those concerns (e.g., discussion with a fertility specialist and use of vaginal health aids). Adaptation decisions were agreed upon by five team members after each round of revisions. The team took care to maintain all intervention practices linked to theory-driven mechanisms of change (e.g., speaker/listener skills, Bodenmann's three-phase-method training and practice, and coping self-talk). After making these modifications, three couples of diverse sexual/gender orientations were invited back to review and comment on the resulting participant materials.

Data Collection

Couples received a copy of the revised and new participant handouts and a bulleted summary of the weekly intervention topics/activities to review prior to their interview. Couple interviews were conducted together *via* Zoom, following a semi-structured interview guide. Interviews were approximately 60–90 min in duration and were audio recorded. Participants were first asked questions about each of the five sessions (e.g., "Was there anything you did not understand?," "What aspects do you think would be most helpful to you?," "Are there aspects of the handouts that we should change related to reproductive or sexual health?," and "What other suggestions do you have for improving the materials?"). This was followed by a series of questions about the overall intervention, including general comments about the flow of the intervention/sessions, things they particularly liked or disliked, aspects they would include or change, and ways we could bring the program to the attention of couples who might benefit.

Analysis

Interviewers documented responses and reviewed transcripts to categorize recommendations, which were reviewed and discussed by the research team to inform further adaptations. Similar to structural coding procedures, interviewers developed categories for recommended changes based on interview guide questions (Saldaña, 2015). Responses related to potential adaptations were listed and categorized. The few that did not align with the scope of research or were not feasible were not implemented (e.g., adding elements focused on diet and exercise).

To obtain an assessment of consensus on adaptation decisions, the resulting revised materials were then disseminated to all stakeholders, including community advisors, who were asked to provide feedback *via* an online survey. Prior to completing the survey, stakeholders were asked to review the participant handouts and modifications to the interventionist manual focusing on content related to RSH. The research team made final modifications based on this feedback. Intervention adaptations were tracked and summarized (Wiltsey Stirman et al., 2019).

RESULTS

Phase 1: Administration-Preliminary Adaptation and Feasibility Assessment

In this first phase, 11 couples participated (22 individuals) in separate qualitative interviews. This included eight breast cancer and three gynecologic survivors (two ovarian and one cervical), one survivor who identified a gay/lesbian, one survivor who identified as bisexual, and one partner who identified as gay/lesbian. Survivors ranged from ages 29 to 40 years ($M = 35.2$ years) and were diagnosed between 6 months and 6 years ago ($M = 3.0$ years since diagnosis). Partners were ages 25–42 years ($M = 34.6$ years). Relationship duration varied from 1 to 22 years ($M = 10.2$ years; **Table 1**).

The following themes emerged after Phase 1 interviews, suggesting intervention preferences for: (1) A highly flexible intervention that can be tailored to couples' specific RSH concerns; (2) Active steps to help members of a dyad "get on the same page" in their relationship and family building plans; (3) A specific focus on raising partners' awareness about how cancer can affect body image and physical intimacy; and (4) Accessible, evidence-based information about RSH for both partners. Results did not reveal any differences between the intervention preferences of survivors or their partners. **Table 2** demonstrates how themes informed intervention adaptations.

Theme 1. A Highly Flexible Intervention That Can Be Tailored to Couples'-Specific RSH Concerns

Couples described a desire for an intervention that can "meet them where they are," as opposed to one-size-fits-all approach, as it relates to their specific RSH concerns. One survivor explained, "So that would be my biggest comment; to design these programs or this program and sessions in a way that does not try to get all the cancer patients in the same pot, but differentiate between where, what kind of stage they are in and what kind of life stage and cancer stage they are in, I would say." One way couples noted that this could be achieved is spending time in the first session getting to know the couple including their history with cancer, relationship duration, and stage of family building goals [e.g., already have child(ren) or not]. For example, one survivor described, "For me, I think what you'll find is that every couple is kind of different. And every couple obviously is going to bring different things to the table. I mean, you are going to have couples that it's their fifth kid, and they are in their later years, they were not planning on having any more, or you are going to have couples that did not get any kids."

TABLE 1 | Participant characteristics.

	Cancer Survivors (*N* = 11) *n* (%)	Partners (*N* = 11) *n* (%)
Demographic Characteristics		
Current Age, yrs[a]	35.2 (3.7)	34.6 (5.7)
Race		
Asian	1 (9)	1 (9)
Native Hawaiian/Pacific Islander	0 (0)	1 (9)
White	10 (91)	9 (82)
Hispanic/Latinx	0 (0)	0 (0)
Gender		
Man	0 (0)	10 (91)
Woman	11 (100)	1 (9)
Sexual Orientation		
Bisexual	1 (9)	0 (0)
Gay/Lesbian	1 (9)	1 (9)
Heterosexual	9 (82)	10 (91)
Married	9 (82)	9 (82)
Relationship duration, yrs[a]	10.2 (5.5)	10.4 (4.6)
College graduate	10 (91)	8 (73)
Employed	8 (73)	9 (82)
Cancer Characteristics		
Type		
Breast	8 (73)	–
Cervical	1 (9)	–
Ovarian	2 (18)	–
Stage at diagnosis		
1	4 (36)	–
2	4 (36)	–
3	3 (28)	–
Age at diagnosis, yrs[a]	32.2 (3.0)	–
<35 years old	9 (81.8)	–
≥35 years old	2 (18.2)	–
Time since diagnosis, yrs[a]	3.0 (2.0)	–
Reproductive Characteristics		
1+ live births	4 (36)	–
Seen fertility specialist	5 (45)	4 (36)
Currently pregnant	1 (9)	0 (0)
Currently trying for pregnancy	0 (0)	0 (0)
Wants a/another baby	9 (82)	6 (55)
Sexually active	11 (100)	11 (100)
Uses contraception	5 (45)	4 (36)
Biological children important	5 (45)	6 (55)
Interested in adoption	5 (45)	5 (45)
Time since diagnosis, yrs[a]	2.5 (2.3)	**–**

[a] *Mean (standard deviation).*

TABLE 2 | Translation of qualitative results to intervention adaptation.

Theme	Illustrative Quotes	Adaptations
Theme 1. A highly flexible intervention that can be tailored to couples' specific RSH concerns	"So I think the counselor getting that picture could really illuminate the type of discussions that are going to be happening between that couple. I think that again, the counselor should explicitly get a picture of, from each person, what their goals are as far as their own fertility, like do they want kids, blah, blah, blah, like how important. That should be something that's explicitly included." "Maybe my one feedback would be, it's going to take a lot of sessions, maybe like two or three, just to really understand the patient. My story is really long and complicated. It's not just I had cancer. It's like the whole story that gets you there, I think helps develop an understanding for where someone is at." "I think maybe an important thing that could be included is an explicit inclusion of the counselor or whoever is running the session, they should get a picture of what the prognosis for that couple's diagnosis, just so that they can understand, "Okay this is like game over for fertility," or in my case it was like there's a 10% chance that you are going to lose fertility."	• Discussion about couples' history, needs, and specific RSH concerns • Flexible prompts for RSH discussion topics across sessions • New session 5 to allow them to practice supportive communication with RSH topic of choice • Diverse range of RSH topics in new educational material
Theme 2. Active steps to help members of a dyad "get on the same page" in their relationship and family building plans	"The emphasis on the communication, I think is so important. I think I take our communication for granted, because I think it's really, really strong. I think that's the most important thing, is being able to communicate things that, I mean it is difficult to tell your partner, 'I do not want to talk about this right now. It's nothing you did.' Or, 'I do want to talk about this. Are you available?'" "So, finding a common ground to be together and support each other on is, I think, important. I think this event can make it difficult to see that or get there, and potentially having a program or an outside third party to bring that around could be good." "And understanding my partner's different than me, and the support that they need, and the support that I need. And I think being able to come to a common ground and understanding of one another and the needs of each other is huge."	• Opportunity for fertility/family building focused supportive communication practice in session and at home • Educational material to support shared understanding
Theme 3. A specific focus on raising partners' awareness about how cancer can affect body image and physical intimacy	"I think the physical intimacy, especially for men, I feel like that's such a big part of it. The conversations and stuff, I think, are really important, but I also think that there is something to be said for that kind of physical connection. Again, whether it's holding hands and going for a walk or something where it's a physical connection because you do kind of feel… It's super easy to feel just like a cancer patient and not like a human on some levels. I think that that… I know, especially in the beginning, my husband was like, 'Can I touch you? Are you okay? I do not know what to do.' And so it's like establishing those here's what my boundaries are and encouraging that, I think would be really helpful, too." "I think that kind of emotional… talking about the self-esteem and changes to the body and how a partner can support the person going through cancer and struggling with that." "Some of the things that I've mentioned, like how to navigate intimacy when you are dealing with physical changes to your body because of cancer treatment, how to have the discussions about fertility preservation, and then adjusting your life plans based on the reality of your cancer. Also, talking about birth control, that's part of the conversation about, how can sex be pleasurable and rewarding for both parties after so much change…"	• Exercise to promote shared understanding of perspectives on emotional and physical intimacy • Educational material to support shared understanding • Home practice focused on intimacy building activities
Theme 4. Accessible, evidence-based information about RSH for both partners	"I would say the most practical stuff you can give is the best. Like, 'Here's what happens to fertility and here are these… there's this information about how these things are normal and how there are lots of support groups out there.'" "My friend also had her hysterectomy. And she's like, 'Oh, yeah, I went on Amazon, and I bought myself a vibrator.' And it was like, way better than just this dilator that's like this hard piece of plastic that you shove up inside you. And I was like, 'Oh, God, I wish I would have known that.' So maybe those types of resources." "And I think it would just be nice to have at your fingertips some of those programs and aids and organizations that… All in one place. Because I just think it's all so scattered. And again, what you do not know, you do not know. And so I think having a centralized database or information base would be really good to have."	• Educational material on RSH topics with bulleted evidence-based information, options to consider, and tips for partners • Trusted resource list of online resources on a range of RSH topics • Tips for healthcare provider communication/ patient advocacy • Glossary of terms

Theme 2. Active Steps to Help Members of a Dyad "Get on the Same Page" in Their Relationship and Family Building Plans

Couples explained a desire for the intervention to help them align their goals and priorities regarding their family building plans and intimate relationship. For example, several survivors noted that couples may not feel comfortable sharing intimate information with each other, especially in front of an interventionist, and that it is important to include an opportunity to hear both survivors' and partners' perspectives. One survivor noted this would be facilitated well by the interventionist during the session, "I just feel like I'm always trying to explain myself and I do not always do a great job of fully explaining, and so to have a very detailed professional person explaining what is going on makes a lot more sense." Couples noted how this should be followed by learning "skills" to not only manage these difficult conversations but take active steps forward in their relationship. For example, one survivor described, "I think maybe, especially as things come up, let us say a fertility conversation comes up or something like that, kind of like a 'next steps', like a 'where to go from here,' because now we have got the foundation to be able to have these conversations, but like a 'now what' would be helpful."

Theme 3. A Specific Focus on Raising Partners' Awareness About How Cancer Can Affect Body Image and Physical Intimacy

Couples emphasized the importance of including activities and elements focused on helping the partner without cancer to understand physical body changes experienced after cancer and how those might impact their intimacy. For example, one survivor explained her thoughts and feelings in this way:

"I think what would be most important to me is particularly the physical changes… The physical changes that affect self-esteem and self-worth as a woman, if you will. It is not something that a man can necessarily always super relate to… I think that having conversations around and encouraging conversations around like, hey, it is okay that you feel this way. I still love you regardless. Kind of talking about more of the emotional impact of the cancer treatments as they change you physically."

Survivors noted that the program should include skills for "how a partner can support their person going through cancer and struggling with that [body image]," as they also describe their challenges with body image, for example, feeling "ugly and sick and undesirable." Several partners described a desire for skills around listening and processing difficult conversations. Survivors expressed a need to build their confidence through skill building, in addition to having conversations. One survivor stated, "I think it is expanding up this "ways to express tenderness and closeness" part… It needs to be more than just a conversation… there needs to be daily activities and strategies and exercises around being romantic again."

Theme 4. Accessible, Evidence-Based Information About RSH for Both Partners

A leading request from couples was to include educational materials for both partners about how cancer can affect RSH. Couples reported a "huge lack of information for the patients and for their partners about anything" related to RSH after cancer. In addition to information provided during the intervention, couples desired "somewhere you can go back and find more information or more resources" once completing the intervention for sustained engagement and learning opportunities. As one survivor said as:

"If there were bullet points and checklists, those are things that if they boiled down some takeaways where if you have completed the program and you want to go back to it and were able to just go through bullet points and it would refresh you on various things."

Couples wanted information and resources to be accessible, reliable, and educational, such as links to videos of other survivors sharing their experiences. They identified several types of information they would like to see included, such as how to manage health insurance related to family building needs, the range of emotional and physical changes couples experience after cancer, fertility preservation options, statistics on cancer treatment's impacts on fertility, legalities of fertility preservation, and alternative family building options outside of biological parenthood. They also described the importance of gaining skills during the sessions that they could take home with them to continue having conversations after the intervention ended. One survivor said, "I think you need to add a whole session on the end that it is like a counselor facilitated discussion to get the conversation started between the two partners about intimacy and fertility. So that door is opened, and then they can go home and finish the conversation or continue to talk about it." Thus, accessible RSH information was perceived as important for increasing shared knowledge and continued engagement and sustainment of behavior change after the intervention ended.

Phase 2: Production, Expert Review, and Integration-Development of The Final Adapted Intervention

This phase informed development of the final adapted intervention. **Table 3** summarizes intervention modifications across both phases. After changes from Phase 1 were integrated, the stakeholder panel reviewed and made minor additional edits based on prior expertise with dyadic intervention. Then, three couples were invited back to review and comment on the materials. Participants included one heterosexual, one bisexual, and one lesbian couple and both breast and gynecologic cancer survivors. Survivors ranged in age from 34 to 38 years old ($M = 36.3$ years) and were diagnosed between 6 months and 5 year prior ($M = 2.5$ years since diagnosis). Partners were between 25 and 39 years old ($M = 32.7$ years). Relationship duration for these couples ranged from 6 to 8 years ($M = 7.3$ years). Feedback from community advisors affirmed the changes made during Phase 1 and provided more specific feedback to further improve inclusivity for LGBTQ+ survivors (e.g., editing language to avoid any assumptions about sexual orientation or gender identity), adding minor elements (e.g., new medical terms to the glossary), and modifying design (e.g., more closely aligning the look of new and original handouts). The stakeholder panel supported the implementation of all proposed changes and provided additional minor edits to materials (e.g., wording recommendations to improve comprehension and identifying spelling errors).

Modifications were made to increase fit/relevance, address the primary RSH-related concerns for both survivors and partners, and increase LGBTQ+ inclusivity, with the goal of optimizing feasibility and acceptability of *Opening the Conversation*. Key modifications included adding educational material for both partners to review and discuss focused on a range of RSH-related concerns (e.g., contraception, pelvic health, fertility, family building, and sexual health). When creating materials, the team considered participants' desires for "digestible" information, but also of "hard data," statistics, and potential solutions or next steps. Other key modifications focused on integrating opportunities to focus on RSH topics across all sessions in addition to adding a fifth session to provide an opportunity for couples to use skills learned during the intervention to focus on an RSH topic of their choice. New handout material included tips on a variety of topics that couples indicated a desire for, including patient advocacy, communicating with healthcare providers about RSH, tips specific to partners, use of lubricants and moisturizer, and LGBTQ+ specific resources. We also developed a trusted online multimedia resources list. Some original *Side by Side* content was removed, such as aspects focused on cancer's immediate impact on their lives, to increase fit for the intended audience (younger age, 6-months to 5-years post-diagnosis). All fidelity/core elements (e.g., training in speaker/listener skills and three-phase method) were retained (**Table 3**).

The resulting intervention, *Opening the Conversation*, includes five weekly modules (1.5 h each) to be delivered *via* videoconference by a masters-level trained interventionist and organized around the following topics: (1) Understanding the impacts of cancer and ways to support one another; (2) Building coping and communication skills for both partners; (3) Practicing coping skills individually and together; (4) Sustaining a strong relationship after cancer: Emotional and physical intimacy; and (5) Sustaining a strong relationship after cancer: Reproductive health, family building, and relationship goals. To avoid a "one size fits all" approach, all participants receive RSH educational materials covering a wide range of topics and are encouraged to review and select those that are most relevant. Additionally, each session contains flexible discussion prompts, which allow

TABLE 3 | Summary of major intervention adaptions across phases.

Phase	Type of Modification	What was modified?
Initial adaptations based on Phase 1 interview results, research team expertise, and consultation with community advisors	Context	*Format/setting* • Videoconference delivery *Audience* • Young adult couples
	Content	*Tailoring* • Inclusive language for LGBTQ+ couples *New content* • Evidence-based information about RSH after cancer • Reproductive health discussion/exercises • Sexual health and body image discussion/exercises • Patient advocacy and patient-provider communication • Specific to partner/caregiver • Specific to LGBTQ+ couples • Discussion of options and action steps for RSH • Trusted resources • Glossary of terms *Removing content* • Focus on immediate post-cancer timeframe *Tweaking/Refining* • Reorganized session content • Content on mindfulness • Language for comprehension and usability • Visual look of materials
Adaptations based on Phase 2 pretest	Content	*Tweaking/Refining* • Specific to LGBTQ+ couples • Emphasize flexibility to address RSH concerns • More focus on partner perspectives • Handout clarity, relevance, comprehension, and visual elements
Adaptations based on Phase 2 stakeholder review	Content	*Tweaking/Refining* • Add glossary terms • Handout clarity, relevance, comprehension, and visual elements • Session flow

couples to select discussion topics relevant to their unique situation and RSH concerns.

DISCUSSION AND CONCLUSION

The iterative, systematic adaptation process yielded a theoretically grounded intervention, *Opening the Conversation*, which, if determined to be efficacious, could fill a critical gap in supportive care for young breast/gynecologic cancer survivors and their partners (Keesing et al., 2016; Gorman et al., 2021; Hawkey et al., 2021b) who are experiencing RSH concerns. Feedback at multiple time points and from diverse stakeholders guided decisions about intervention modifications. In sum, the results provided essential guidance for development of an inclusive, flexible psychosocial intervention for young couples facing a range of different RSH concerns after cancer that includes education and skill building opportunities to improve dyadic coping and communication.

Prior research has demonstrated the utility of dyadic interventions for enhancing relationship functioning after cancer (Manne and Badr, 2008), with emerging data also suggesting benefits for couples experiencing reproductive (Lehmann et al., 2019; Hawkey et al., 2021b) and sexual distress (Badr and Taylor, 2009; Reese et al., 2014; Perz et al., 2014; Reese et al., 2019; Gorman et al., 2020). A novel aspect of *Opening the Conversation* is the focus on both reproductive and sexual concerns, which couples often experience in tandem (Luk and Loke, 2019; Hawkey et al., 2021b). This represents a promising approach to supporting couples experiencing one or more RSH concern after cancer. Indeed, couples in this study stressed the importance of an intervention that would be flexible in the sense that it could be tailored to address their current RSH needs and concerns. Because RSH concerns and needs change over time (Gorman et al., 2021), couples can continue to benefit from knowledge and skills gained to address new issues as they arise. Based on our results, the flexibility to tailor to specific RSH concerns and inclusion of a broad range of RSH concerns are essential to help couples understand and address their RSH concerns as a unit.

An important finding in this study was that couples described the value of a chance to "name out loud" their RSH concerns but also wished to go beyond "opening the conversation" to build their skills and decide on "action steps" together. They specifically discussed this in two primary contexts. First, they talked about a wish to align their goals and priorities regarding family building. In other research, couples have also reported the benefits of open communication about fertility, along with several challenges including avoidance of discussion for fear of upsetting their partner (Benyamini et al., 2009; Hawkey et al., 2021a). *Opening the Conversation* provides an important opportunity for couples to share their perspectives and improve upon supportive communication to manage fertility-related concerns as a team. Similarly, most couples felt that discussions about sexual health and body image could be difficult to navigate and wished for knowledge and skills to help them do this. Numerous studies have demonstrated the challenges faced by couples in addressing sexual concerns after cancer (Hawkins et al., 2009; Gilbert et al., 2011; Robinson et al., 2014; Ussher et al., 2014; Dobinson et al., 2015; Loaring et al., 2015). Our results indicate that young couples desire and would benefit from intervention strategies that facilitate effective communication to enhance mutual understanding and management of sexual health challenges together. Overall, results suggest that improving the quality of communication for couples facing RSH concerns is an essential aspect of the intervention.

One particularly novel aspect of this study is that we centered LGBTQ+ identifying couples' perspectives during the adaptation process, which informed inclusion of new materials (e.g., online resources and educational information) as well as use of inclusive language and content across sessions. LGBTQ+ survivors and their partners have significant unmet survivorship care needs specific to sexual health (Seay et al., 2018) where partners are in need of support, and the impact of cancer on relationships can be devastating (Brown and McElroy, 2018). LGBTQ+ individuals also often do not feel welcome in clinic/support group settings and experience poorer satisfaction with care than heterosexual survivors (Jabson and Kamen, 2016); therefore, an intervention that is able to reach them remotely, outside of a clinical setting, may be especially valuable. Further, LGBTQ+ couples face specific and unique RSH needs that may not be encompassed in current interventions (Brown and McElroy, 2018; Damaskos et al., 2018; Boehmer et al., 2020). Therefore, *Opening the Conversation* aims to provide inclusive informational resources as well as the flexibility to focus on couples' unique RSH needs.

Participants emphasized that it was essential to provide education and support for both partners as part of the adapted intervention, noting a distinct lack of support for those partners without a cancer history. Research demonstrates that partners of cancer survivors experience unique needs that often remain unaddressed by cancer support services, and existing interventions for partners are rarely implemented in practice (Northouse et al., 2012). In formative research with the intended audience, couples also stressed the need for partner-specific resources, such as support groups, informational resources, and skill building to support survivors (Gorman et al., 2020). Survivors and their partners indicated a specific need for practical/problem-oriented support, such as transportation to appointments, involvement of partners during appointments, and emotional support, which is exemplified by the development of skills to comfort the survivor during difficult decisions and ability to express physical intimacy (e.g., gentle touch and hugs; Gorman et al., 2020). Therefore, intervention modifications included the addition of resources and educational information for both partners and underscored the importance of both partners reviewing and discussing materials together.

Strengths of the study included triangulation of decisions across multiple stakeholder perspectives to make adaptation decisions, purposeful inclusion of LGBTQ+ perspectives, and an iterative, systematic process of intervention adaptation with the goal of optimizing feasibility and acceptability. While we could not achieve data saturation with the small number of LGBTQ+ participants, we gained critical insight on the needs and preferences of this population from survivors and partners, including from community advisors at multiple time points. The emphasis on inclusion is important given the current lack of supportive care resources for LGBTQ+ survivors, partners, and couples (Hill and Holborn, 2015; Brown and McElroy, 2018; Kamen et al., 2019). Another limitation is the specific focus on breast and gynecologic cancer survivors; young couples with other types of cancer also experience RSH concerns (Karabulut and Erci, 2009; Schover et al., 2014; Ljungman et al., 2019). Finally, although we sought broad inclusion of stakeholders and cancer survivor couples throughout the adaptation process, the sample is small and mostly identified as White and college educated. Because adaptations reflect the experiences and perspectives of our sample of participants and stakeholders, adaptations may not generalize to a broader audience of young survivor couples. If this intervention proves effective, future research could adapt the intervention further to meet the needs of other audiences.

Addressing the RSH concerns of young adult breast and gynecologic cancer survivors and their partners is essential, and supportive care interventions are scarce. This study yielded a novel and inclusive dyadic coping and communication intervention that can be tailored to help couples communicate about and cope with their current RSH concerns. Education and skills gained are expected to support couples in addressing new concerns that may arise after the conclusion of the intervention. *Opening the Conversation* will be evaluated in a randomized controlled trial, with the long-term goal of broad implementation and dissemination as part of a comprehensive, coordinated survivorship care strategy for young adult couples with diverse backgrounds who are experiencing RSH concerns. In the intervention proves effective, future research will to explore implementation strategies in cancer care settings.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because of the sensitive nature of the research and confidentiality concerns; participants did not consent to data sharing. Requests to access the datasets should be directed to JG, Jessica.Gorman@oregonstate.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Oregon State University Institutional Review Board. The patients/participants provided their verbal informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JG, KL, JR, SH, and CA: conceptualization. JG: methodology, writing—original, and funding acquisition. LF, KL, JR, CA, JS, and BH-L: validation. JG, ES, and JD: formal analysis and investigation. JG, KL, JR, CA, ES, JD, JS, LF, BH-L, and SH: writing—reviewing and editing. BH-L and JS: supervision. All authors contributed to the article and approved the submitted version.

FUNDING

This study was funded by the American Cancer Society (RSG-19-123-01-CPPB).

ACKNOWLEDGMENTS

We wish to thank the cancer survivors, partners, and other stakeholders who contributed to the adaptation of this intervention. We are also grateful to Tammy Winfield for her assistance with data collection and formatting/editing intervention materials. Finally, we wish to thank Dr. Nina Heinrichs and Dr. Tanja Zimmermann for supporting our team's adaptation of Side by Side.

REFERENCES

Acquati, C., and Kayser, K. (2019). Dyadic coping Across the lifespan: A comparison Between younger and middle-aged couples With breast cancer. *Front. Psychol.* 10:404. doi: 10.3389/fpsyg.2019.00404

Arndt, V., Merx, H., Sturmer, T., Stegmaier, C., Ziegler, H., and Brenner, H. (2004). Age-specific detriments to quality of life among breast cancer patients one year after diagnosis. *Eur. J. Cancer* 40, 673–680. doi: 10.1016/j.ejca.2003.12.007

Badr, H. (2017). New frontiers in couple-based interventions in cancer care: refining the prescription for spousal communication. *Acta Oncol.* 56, 139–145. doi: 10.1080/0284186X.2016.1266079

Badr, H., Acitelli, L. K., and Taylor, C. L. (2008). Does talking about their relationship affect couples' marital and psychological adjustment to lung cancer? *J. Cancer Surviv.* 2, 53–64. doi: 10.1007/s11764-008-0044-3

Badr, H., and Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psychooncology* 22, 1688–1704. doi: 10.1002/pon.3200

Badr, H., and Taylor, C. L. (2009). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psychooncology* 18, 735–746. doi: 10.1002/pon.1449

Benyamini, Y., Gozlan, M., and Kokia, E. (2009). Women's and men's perceptions of infertility and their associations with psychological adjustment: a dyadic approach. *Br. J. Health Psychol.* 14, 1–16. doi: 10.1348/135910708X279288

Bidstrup, P. E., Christensen, J., Mertz, B. G., Rottmann, N., Dalton, S. O., and Johansen, C. (2015). Trajectories of distress, anxiety, and depression among women with breast cancer: looking beyond the mean. *Acta Oncol.* 54, 789–796. doi: 10.3109/0284186X.2014.1002571

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping in couples. *Swiss J. Psychol.* 54, 34–49.

Bodenmann, G. (1997). Dyadic coping: A systemic-transactional view of stress and coping among couples: theory and empirical findings. *Eur. Rev. Appl. Psychol.* 47, 137–141.

Bodenmann, G. (2007). "Dyadic coping and the 3-phase-method in working with couples" in *Innovations in Clinical Practice: Focus on Group and Family Therapy*. ed. L. Vandecreek (Sarasota: Professional Resources Press), 235–252.

Bodenmann, G. (2008). Dyadic coping and the significance of this concept for prevention and therapy. *Zeitschrift Gesundheitspsychol.* 16, 108–111. doi: 10.1026/0943-8149.16.3.108

Bodenmann, G., Pihet, S., and Kayser, K. (2006). The relationship between dyadic coping and marital quality: a 2-year longitudinal study. *J. Fam. Psychol.* 20, 485–493. doi: 10.1037/0893-3200.20.3.485

Bodenmann, G., Randall, A. K., and Falconier, M. K. (2016). *Coping in Couples: The Systemic Transactional Model (STM), In Couples Coping with Stress: A Cross-Cultural Perspective*. New York: Routledge/Taylor & Francis Group, 5–22.

Bodenmann, G., and Shantinath, S. D. (2004). The couples coping enhancement training (CCET): A new approach to prevention of marital distress based upon stress and coping. *Fam. Relat.* 53, 477–484. doi: 10.1111/j.0197-6664.2004.00056.x

Boehmer, U., Glickman, M., Winter, M., and Clark, M. A. (2013). Long-term breast cancer survivors' symptoms and morbidity: differences by sexual orientation? *J. Cancer Surviv.* 7, 203–210. doi: 10.1007/s11764-012-0260-8

Boehmer, U., Stokes, J. E., Bazzi, A. R., and Clark, M. A. (2020). Dyadic quality of life among heterosexual and sexual minority breast cancer survivors and their caregivers. *Support. Care Cancer* 28, 2769–2778. doi: 10.1007/s00520-019-05148-7

Bradford, A., Fellman, B., Urbauer, D., Gallegos, J., Meaders, K., Tung, C., et al. (2015). Assessment of sexual activity and dysfunction in medically underserved women with gynecologic cancers. *Gynecol. Oncol.* 139, 134–140. doi: 10.1016/j.ygyno.2015.08.019

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101. doi: 10.1191/1478088706qp063oa

Brown, M. T., and Mcelroy, J. A. (2018). Unmet support needs of sexual and gender minority breast cancer survivors. *Support. Care Cancer* 26, 1189–1196. doi: 10.1007/s00520-017-3941-z

Canada, A. L., and Schover, L. R. (2012). The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psychooncology* 21, 134–143. doi: 10.1002/pon.1875

Carroll, A. J., Baron, S. R., and Carroll, R. A. (2016). Couple-based treatment for sexual problems following breast cancer: A review and synthesis of the literature. *Support. Care Cancer* 24, 3651–3659. doi: 10.1007/s00520-016-3218-y

Carter, J., Chi, D. S., Brown, C. L., Abu-Rustum, N. R., Sonoda, Y., Aghajanian, C., et al. (2010). Cancer-related infertility in survivorship. *Int. J. Gynecol. Cancer* 20, 2–8. doi: 10.1111/IGC.0b013e3181bf7d3f

Damaskos, P., Amaya, B., Gordon, R., and Walters, C. B. (2018). Intersectionality and the LGBT cancer patient. *Semin. Oncol. Nurs.* 34, 30–36. doi: 10.1016/j.soncn.2017.11.004

Dobinson, K. A., Hoyt, M. A., Seidler, Z. E., Beaumont, A. L., Hullmann, S. E., and Lawsin, C. R. (2015). A grounded theory investigation into the psychosexual unmet needs of adolescent and young adult cancer survivors. *J. Adolesc. Young Adult Oncol.* 5, 135–145. doi: 10.1089/jayao.2015.0022

Dryden, A., Ussher, J. M., and Perz, J. (2014). Young women's construction of their post-cancer fertility. *Psychol. Health* 29, 1341–1360. doi: 10.1080/08870446.2014.932790

Epstein, N. B., and Baucom, D. H. (2002). *Enhanced Cognitive-Behavioral Therapy for Couples: A Contextual Approach*. Washington, DC: American Psychological Association.

Escoffery, C., Lebow-Skelley, E., Udelson, H., Boing, E. A., Wood, R., Fernandez, M. E., et al. (2019). A scoping study of frameworks for adapting public health evidence-based interventions. *Transl. Behav. Med.* 9, 1–10. doi: 10.1093/tbm/ibx067

Fleishman, J. M., Crane, B., and Koch, P. B. (2020). Correlates and predictors of sexual satisfaction for older adults in same-sex relationships. *J. Homosex.* 67, 1974–1998. doi: 10.1080/00918369.2019.1618647

Fobair, P., and Spiegel, D. (2009). Concerns about sexuality after breast cancer. *Cancer J.* 15, 19–26. doi: 10.1097/PPO.0b013e31819587bb

Fobair, P., Stewart, S. L., Chang, S. B., D'onofrio, C., Banks, P. J., and Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psychooncology* 15, 579–594. doi: 10.1002/pon.991

Fredman, S. J., Baucom, D. H., Gremore, T. M., Castellani, A. M., Kallman, T. A., Porter, L. S., et al. (2009). Quantifying the recruitment challenges with couple-based interventions for cancer: applications to early-stage breast cancer. *Psychooncology* 18, 667–673. doi: 10.1002/pon.1477

Ganz, P. A., Desmond, K. A., Leedham, B., Rowland, J. H., Meyerowitz, B. E., and Belin, T. R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. *J. Natl. Cancer Inst.* 94, 39–49. doi: 10.1093/jnci/94.1.39

Gilbert, E., Ussher, J. M., and Perz, J. (2011). Sexuality after gynaecological cancer: a review of the material, intrapsychic, and discursive aspects of treatment on women's sexual-wellbeing. *Maturitas* 70, 42–57. doi: 10.1016/j.maturitas.2011.06.013

Gorman, J. R., Bailey, S., Pierce, J. P., and Su, H. I. (2012). How do you feel about fertility and parenthood? The voices of young female cancer survivors. *J. Cancer Surviv.* 6, 200–209. doi: 10.1007/s11764-011-0211-9

Gorman, J. R., Drizin, J. H., Smith, E., Flores-Sanchez, Y., and Harvey, S. M. (2021). Patient-centered communication to address young adult breast cancer Survivors' reproductive and sexual health concerns. *Health Commun.* 36, 1743–1758. doi: 10.1080/10410236.2020.1794550

Gorman, J. R., Smith, E., Drizin, J. H., Lyons, K. S., and Harvey, S. M. (2020). Navigating sexual health in cancer survivorship: a dyadic perspective. *Support. Care Cancer* 28, 5429–5439. doi: 10.1007/s00520-020-05396-y

Gorman, J. R., Su, H. I., Pierce, J. P., Roberts, S. C., Dominick, S. A., and Malcarne, V. L. (2014). A multidimensional scale to measure the reproductive concerns of young adult female cancer survivors. *J. Cancer Surviv.* 8, 218–228. doi: 10.1007/s11764-013-0333-3

Gorman, J. R., Usita, P. M., Madlensky, L., and Pierce, J. P. (2011). Young breast cancer survivors: their perspectives on treatment decisions and fertility concerns. *Cancer Nurs.* 34, 32–40. doi: 10.1097/NCC.0b013e3181e4528d

Grover, S., Hill-Kayser, C. E., Vachani, C., Hampshire, M. K., Dilullo, G. A., and Metz, J. M. (2012). Patient reported late effects of gynecological cancer treatment. *Gynecol. Oncol.* 124, 399–403. doi: 10.1016/j.ygyno.2011.11.034

Hawkey, A., Ussher, J. M., Perz, J., and Parton, C. (2021a). Talking but not always understanding: couple communication about infertility concerns after cancer. *BMC Public Health* 21:161. doi: 10.1186/s12889-021-10188-y

Hawkey, A. J., Ussher, J. M., Perz, J., Parton, C., Patterson, P., Bateson, D., et al. (2021b). The impact of cancer-related fertility concerns on current and future couple relationships: people with cancer and partner perspectives. *Eur. J. Cancer Care* 30:e13348. doi: 10.1111/ecc.13348

Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M., and Sundquist, K. (2009). Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. *Cancer Nurs.* 32, 271–280. doi: 10.1097/NCC.0b013e31819b5a93

Heinrichs, N., Zimmermann, T., Huber, B., Herschbach, P., Russell, D. W., and Baucom, D. H. (2012). Cancer distress reduction with a couple-based skills training: a randomized controlled trial. *Ann. Behav. Med.* 43, 239–252. doi: 10.1007/s12160-011-9314-9

Henderson, A. W., Lehavot, K., and Simoni, J. M. (2009). Ecological models of sexual satisfaction among lesbian/bisexual and heterosexual women. *Arch. Sex. Behav.* 38, 50–65. doi: 10.1007/s10508-008-9384-3

Hill, G., and Holborn, C. (2015). Sexual minority experiences of cancer care: A systematic review. *J. Cancer Policy* 6, 11–22. doi: 10.1016/j.jcpo.2015.08.005

Hulbert-Williams, N. J., Plumpton, C. O., Flowers, P., Mchugh, R., Neal, R. D., Semlyen, J., et al. (2017). The cancer care experiences of gay, lesbian and bisexual patients: A secondary analysis of data from the UK cancer patient experience survey. *Eur. J. Cancer Care* 26:e12670. doi: 10.1111/ecc.12670

Hummel, S. B., Hahn, D. E. E., Van Lankveld, J., Oldenburg, H. S. A., Broomans, E., and Aaronson, N. K. (2017a). Factors associated With specific diagnostic and statistical manual of mental disorders, fourth edition sexual dysfunctions in breast cancer survivors: A study of patients and their partners. *J. Sex. Med.* 14, 1248–1259. doi: 10.1016/j.jsxm.2017.08.004

Hummel, S. B., Van Lankveld, J. J. D. M., Oldenburg, H. S. A., Hahn, D. E. E., Kieffer, J. M., Gerritsma, M. A., et al. (2017b). Efficacy of internet-based cognitive behavioral therapy in improving sexual functioning of breast cancer survivors: results of a randomized controlled trial. *J. Clin. Oncol.* 35, 1328–1340. doi: 10.1200/JCO.2016.69.6021

Jabson, J. M., and Kamen, C. S. (2016). Sexual minority cancer survivors' satisfaction with care. *J. Psychosoc. Oncol.* 34, 28–38. doi: 10.1080/07347332.2015.1118717

Jing, L., Zhang, C., Li, W., Jin, F., and Wang, A. (2019). Incidence and severity of sexual dysfunction among women with breast cancer: a meta-analysis based on female sexual function index. *Support. Care Cancer* 27, 1171–1180. doi: 10.1007/s00520-019-04667-7

Kamen, C. S., Alpert, A., Margolies, L., Griggs, J. J., Darbes, L., Smith-Stoner, M., et al. (2019). "treat us with dignity": a qualitative study of the experiences and recommendations of lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients with cancer. *Support. Care Cancer* 27, 2525–2532. doi: 10.1007/s00520-018-4535-0

Kamen, C., Mustian, K. M., Dozier, A., Bowen, D. J., and Li, Y. (2015). Disparities in psychological distress impacting lesbian, gay, bisexual and transgender cancer survivors. *Psychooncology* 24, 1384–1391. doi: 10.1002/pon.3746

Karabulut, N., and Erci, B. (2009). Sexual desire and satisfaction in sexual life affecting factors in breast cancer survivors after mastectomy. *J. Psychosoc. Oncol.* 27, 332–343. doi: 10.1080/07347330902979101

Kayser, K., Acquati, C., Reese, J. B., Mark, K., Wittmann, D., and Karam, E. (2018). A systematic review of dyadic studies examining relationship quality in couples facing colorectal cancer together. *Psychooncology* 27, 13–21. doi: 10.1002/pon.4339

Kayser, K., Watson, L. E., and Adnrade, J. T. (2007). Cancer as a "we-disease": examining the process of coping from a relational perspective. *Fam. Syst. Health* 25, 404–418. doi: 10.1037/1091-7527.25.4.404

Keesing, S., Rosenwax, L., and Mcnamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. *BMC Womens Health* 16:57. doi: 10.1186/s12905-016-0337-z

Kent, E. E., Wheldon, C. W., Smith, A. W., Srinivasan, S., and Geiger, A. M. (2019). Care delivery, patient experiences, and health outcomes among sexual and gender minority patients with cancer and survivors: A scoping review. *Cancer* 125, 4371–4379. doi: 10.1002/cncr.32388

Latham, T. P., Sales, J. M., Boyce, L. S., Renfro, T. L., Wingood, G. M., Diclemente, R. J., et al. (2010). Application of ADAPT-ITT: adapting an evidence-based HIV prevention intervention for incarcerated African American adolescent females. *Health Promot. Pract.* 11, 53S–60S. doi: 10.1177/1524839910361433

Lehmann, V., Ferrante, A. C., Winning, A. M., and Gerhardt, C. A. (2019). The perceived impact of infertility on romantic relationships and singlehood among adult survivors of childhood cancer. *Psychooncology* 28, 622–628. doi: 10.1002/pon.4999

Lehmann, V., Nahata, L., Ferrante, A. C., Hansen-Moore, J. A., Yeager, N. D., Klosky, J. L., et al. (2018). Fertility-related perceptions and impact on romantic relationships among adult survivors of childhood cancer. *J. Adolesc. Young Adult Oncol.* 7, 409–414. doi: 10.1089/jayao.2017.0121

Levin, A. O., Carpenter, K. M., Fowler, J. M., Brothers, B. M., Andersen, B. L., and Maxwell, G. L. (2010). Sexual morbidity associated with poorer psychological adjustment among gynecological cancer survivors. *Int. J. Gynecol. Cancer* 20, 461–470. doi: 10.1111/IGC.0b013e3181d24ce0

Li, M., Chan, C. W. H., Chow, K. M., Xiao, J., and Choi, K. C. (2020). A systematic review and meta-analysis of couple-based intervention on sexuality and the quality of life of cancer patients and their partners. *Support. Care Cancer* 28, 1607–1630. doi: 10.1007/s00520-019-05215-z

Ljungman, L., Ahlgren, J., Petersson, L. M., Flynn, K. E., Weinfurt, K., Gorman, J. R., et al. (2018). Sexual dysfunction and reproductive concerns in young women with breast cancer: type, prevalence, and predictors of problems. *Psychooncology* 27, 2770–2777. doi: 10.1002/pon.4886

Ljungman, L., Eriksson, L. E., Flynn, K. E., Gorman, J. R., Stahl, O., Weinfurt, K., et al. (2019). Sexual dysfunction and reproductive concerns in young men diagnosed with testicular cancer: an observational study. *J. Sex. Med.* 16, 1049–1059. doi: 10.1016/j.jsxm.2019.05.005

Loaring, J. M., Larkin, M., Shaw, R., and Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: the experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychol.* 34, 426–436. doi: 10.1037/hea0000195

Logan, S., Perz, J., Ussher, J. M., Peate, M., and Anazodo, A. (2018). A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age. *Psychooncology* 27, 401–409. doi: 10.1002/pon.4502

Logan, S., Perz, J., Ussher, J. M., Peate, M., and Anazodo, A. (2019). Systematic review of fertility-related psychological distress in cancer patients: informing on an improved model of care. *Psychooncology* 28, 22–30. doi: 10.1002/pon.4927

Luk, B. H. K., and Loke, A. Y. (2019). Sexual satisfaction, intimacy and relationship of couples undergoing infertility treatment. *J. Reprod. Infant Psychol.* 37, 108–122. doi: 10.1080/02646838.2018.1529407

Lyons, K. S., and Lee, C. S. (2018). The theory of dyadic illness management. *J. Fam. Nurs.* 24, 8–28. doi: 10.1177/1074840717745669

Lyons, K. S., Lee, C. S., Bennett, J. A., Nail, L. M., Fromme, E. K., Hiatt, S. O., et al. (2014). Symptom incongruence trajectories in lung cancer dyads. *J. Pain Symptom Manag.* 48, 1031–1040. doi: 10.1016/j.jpainsymman.2014.02.004

Lyons, K. S., Miller, L. M., and Mccarthy, M. J. (2016). The roles of dyadic appraisal and dyadic coping in couples with lung cancer. *J. Fam. Nurs.* 22, 493–514. doi: 10.1177/1074840716675976

Manne, S., and Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer* 112, 2541–2555. doi: 10.1002/cncr.23450

Manne, S. L., Kissane, D., Zaider, T., Kashy, D., Lee, D., Heckman, C., et al. (2015). Holding back, intimacy, and psychological and relationship outcomes among couples coping with prostate cancer. *J. Fam. Psychol.* 29, 708–719. doi: 10.1037/fam0000096

Manne, S. L., Ostroff, J. S., Norton, T. R., Fox, K., Goldstein, L., and Grana, G. (2006). Cancer-related relationship communication in couples coping with early stage breast cancer. *Psychooncology* 15, 234–247. doi: 10.1002/pon.941

Mckleroy, V. S., Galbraith, J. S., Cummings, B., Jones, P., Harshbarger, C., Collins, C., et al. (2006). Adapting evidence-based behavioral interventions for new settings and target populations. *AIDS Educ. Prev.* 18, 59–73. doi: 10.1521/aeap.2006.18.supp.59

Northouse, L., Williams, A. L., Given, B., and Mccorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *J. Clin. Oncol.* 30, 1227–1234. doi: 10.1200/JCO.2011.39.5798

Otto, A. K., Ketcher, D., Heyman, R. E., Vadaparampil, S. T., Ellington, L., and Reblin, M. (2021). Communication between advanced cancer patients and their family caregivers: relationship with caregiver burden and preparedness for caregiving. *Health Commun.* 36, 714–721. doi: 10.1080/10410236.2020.1712039

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., and Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Admin. Pol. Ment. Health* 42, 533–544. doi: 10.1007/s10488-013-0528-y

Patterson, P., Perz, J., Tindle, R., Mcdonald, F. E. J., and Ussher, J. M. (2020). Infertility after cancer: how the need to be a parent, fertility-related social concern, and acceptance of illness influence quality of life. *Cancer Nurs.* 44, E244–E251. doi: 10.1097/ncc.0000000000000811

Perz, J., Ussher, J. M., Gilbert, E., and Australian, C.Sexuality Study, T (2014). Feeling well and talking about sex: psycho-social predictors of sexual functioning after cancer. *BMC Cancer* 14:228. doi: 10.1186/1471-2407-14-228

Reese, J. B., Porter, L. S., Regan, K. R., Keefe, F. J., Azad, N. S., Diaz, L. A. Jr., et al. (2014). A randomized pilot trial of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. *Psycho-Oncology* 23, 1005–1013. doi: 10.1002/pon.3508

Reese, J. B., Porter, L. S., Casale, K. E., Bantug, E. T., Bober, S. L., Schwartz, S. C., et al. (2016). Adapting a couple-based intimacy enhancement intervention to breast cancer: A developmental study. *Health Psychol.* 35, 1085–1096. doi: 10.1037/hea0000413

Reese, J. B., Smith, K. C., Handorf, E., Sorice, K., Bober, S. L., Bantug, E. T., et al. (2019). A randomized pilot trial of a couple-based intervention addressing sexual concerns for breast cancer survivors. *J. Psychosoc. Oncol.* 37, 242–263. doi: 10.1080/07347332.2018.1510869

Regan, T. W., Lambert, S. D., Girgis, A., Kelly, B., Kayser, K., and Turner, J. (2012). Do couple-based interventions make a difference for couples affected by cancer? A systematic review. *BMC Cancer* 12:279. doi: 10.1186/1471-2407-12-279

Robertson, E. G., Sansom-Daly, U. M., Wakefield, C. E., Ellis, S. J., Mcgill, B. C., Doolan, E. L., et al. (2016). Sexual and romantic relationships: experiences of adolescent and young adult cancer survivors. *J. Adolesc. Young Adult Oncol.* 5, 286–291. doi: 10.1089/jayao.2015.0061

Robinson, L., Miedema, B., and Easley, J. (2014). Young adult cancer survivors and the challenges of intimacy. *J. Psychosoc. Oncol.* 32, 447–462. doi: 10.1080/07347332.2014.917138

Saldaña, J. (2015). *The Coding Manual for Qualitative Researchers*. London: SAGE Publications

Schover, L. R., Van Der Kaaij, M., Van Dorst, E., Creutzberg, C., Huyghe, E., and Kiserud, C. E. (2014). Sexual dysfunction and infertility as late effects of cancer treatment. *EJC Suppl.* 12, 41–53. doi: 10.1016/j.ejcsup.2014.03.004

Schover, L. R., Yuan, Y., Fellman, B. M., Odensky, E., Lewis, P. E., and Martinetti, P. (2013). Efficacy trial of an internet-based intervention for cancer-related female sexual dysfunction. *J. Natl. Compr. Cancer Netw.* 11, 1389–1397. doi: 10.6004/jnccn.2013.0162

Scott, J. L., Halford, W. K., and Ward, B. G. (2004). United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. *J. Consult. Clin. Psychol.* 72, 1122–1135. doi: 10.1037/0022-006X.72.6.1122

Scott, J. L., and Kayser, K. (2009). A review of couple-based interventions for enhancing women's sexual adjustment and body image after cancer. *Cancer J.* 15, 48–56. doi: 10.1097/PPO.0b013e31819585df

Seay, J., Mitteldorf, D., Yankie, A., Pirl, W. F., Kobetz, E., and Schlumbrecht, M. (2018). Survivorship care needs among LGBT cancer survivors. *J. Psychosoc. Oncol.* 36, 393–405. doi: 10.1080/07347332.2018.1447528

Stabile, C., Goldfarb, S., Baser, R. E., Goldfrank, D. J., Abu-Rustum, N. R., Barakat, R. R., et al. (2017). Sexual health needs and educational intervention preferences for women with cancer. *Breast Cancer Res. Treat.* 165, 77–84. doi: 10.1007/s10549-017-4305-6

Traa, M. J., De Vries, J., Bodenmann, G., and Den Oudsten, B. L. (2015). Dyadic coping and relationship functioning in couples coping with cancer: a systematic review. *Br. J. Health Psychol.* 20, 85–114. doi: 10.1111/bjhp.12094

Ussher, J. M., Perz, J., and Gilbert, E. (2014). Women's sexuality after cancer: A qualitative analysis of sexual changes and renegotiation. *Women Ther.* 37, 205–221. doi: 10.1080/02703149.2014.897547

Vaz, A. F., Pinto-Neto, A. M., Conde, D. M., Costa-Paiva, L., Morais, S. S., Pedro, A. O., et al. (2011). Quality of life and menopausal and sexual symptoms in gynecologic cancer survivors: a cohort study. *Menopause* 18, 662–669. doi: 10.1097/gme.0b013e3181ffde7f

Walshe, J. M., Denduluri, N., and Swain, S. M. (2006). Amenorrhea in premenopausal women after adjuvant chemotherapy for breast cancer. *J. Clin. Oncol.* 24, 5769–5779. doi: 10.1200/JCO.2006.07.2793

Wettergren, L., Kent, E. E., Mitchell, S. A., Zebrack, B., Lynch, C. F., Rubenstein, M. B., et al. (2017). Cancer negatively impacts on sexual function in adolescents and young adults: The AYA HOPE study. *Psychooncology* 26, 1632–1639. doi: 10.1002/pon.4181

Wiltsey Stirman, S., Baumann, A. A., and Miller, C. J. (2019). The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions. *Implement. Sci.* 14:58. doi: 10.1186/s13012-019-0898-y

Wingood, G. M., and Diclemente, R. J. (2008). The ADAPT-ITT model: a novel method of adapting evidence-based HIV interventions. *J. Acquir. Immune Defic. Syndr.* 47, S40–S46. doi: 10.1097/QAI.0b013e3181605df1

Zimmermann, T., Heinrichs, N., and Scott, J. L. (2006). CanCOPE "Schritt für Schritt": die Effektivität eines partnerschaftlichen Unterstützungsprogramms bei frauen mit Brust- oder gynäkologischen Krebserkrankungen. [CanCOPE 'Step by Step': The effectiveness of a couple-based intervention program for women with breast or gynecological cancer]. *Verhaltenstherapie* 16, 247–255. doi: 10.1159/000096122

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

ORIGINAL RESEARCH
published: 16 June 2022
doi: 10.3389/fpsyg.2022.862555

Treatment Satisfaction With Couplelinks Online Intervention to Promote Dyadic Coping in Young Couples Affected by Breast Cancer

Karen Fergus[1,2]*, Adina Tanen[3], Saunia Ahmad[2,4], Sandra Gardner[5,6], Ellen Warner[2], Deborah McLeod[7], Joanne Stephen[8], Wendy Carter[9] and Amanda Periera[1]

[1] Psychosocial Oncology Lab, Department of Psychology, York University, Toronto, ON, Canada, [2] Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, ON, Canada, [3] School of Medicine, University of Toronto, Toronto, ON, Canada, [4] Toronto Psychology Clinic, Toronto, ON, Canada, [5] Rotman Research Institute, Baycrest Health Sciences, Toronto, ON, Canada, [6] Division of Biostatistics, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada, [7] School of Nursing, Dalhousie University, Halifax, NS, Canada, [8] Clinical Neurosciences, Alberta Health Services, Calgary, AB, Canada, [9] Toronto Academic Pain Institute, Women's College Hospital, Toronto, ON, Canada

Edited by:
Linda Charvoz,
University of Applied Sciences and Arts of Western Switzerland,
Switzerland

Reviewed by:
Ute Goerling,
Charité – Universitätsmedizin Berlin,
Germany
Jochen Ernst,
University Hospital Leipzig, Germany

***Correspondence:**
Karen Fergus
kfergus@yorku.ca;
karen.fergus@sunnybrook.ca

Specialty section:
This article was submitted to
Psycho-Oncology,
a section of the journal
Frontiers in Psychology

Received: 26 January 2022
Accepted: 17 March 2022
Published: 16 June 2022

Citation:
Fergus K, Tanen A, Ahmad S, Gardner S, Warner E, McLeod D, Stephen J, Carter W and Periera A (2022) Treatment Satisfaction With Couplelinks Online Intervention to Promote Dyadic Coping in Young Couples Affected by Breast Cancer.
Front. Psychol. 13:862555.
doi: 10.3389/fpsyg.2022.862555

Background: This study evaluated participant satisfaction with "Couplelinks," an online psychological intervention designed for younger couples coping with breast cancer. The program included six experiential learning exercises (plus one optional module), psychoeducational information, and support from a personal mental health professional.

Objective: The primary objectives were to examine participants' perceptions of: the online intervention's structure and content; the value of including a professional facilitator; and benefits and drawbacks of the program.

Methods: A treatment satisfaction questionnaire comprised of Likert indices and open-ended questions pertaining to treatment satisfaction was completed by 26 patients and 27 male partners (N = 53) approximately 1–2 weeks following the intervention which occurred in the context of a randomized controlled trial. Descriptive statistics were used to summarize satisfaction ratings and generalized linear models with fixed effect for gender were used to test for differences in male-female outcomes. A thematic analysis was undertaken in order to understand, organize and summarize the qualitative textual feedback.

Results: Participants reported an overall satisfaction rating of 4.3 out of 5 (SD = 0.54) with patient satisfaction ratings being higher than that of male partners' (p = 0.01). The majority of participants considered the facilitator's role to be necessary 4.6 (SD = 0.60), and found the program to be convenient 4.1 (SD = 0.81) despite some participants struggling to keep up with the modules. Subjective data revealed participants valued the convenience and flexibility of the online intervention and appreciated the program's involvement of both partners. Participants also reported that including a professional facilitator humanized the intervention, served as motivation to progress through the program, facilitated insight into their relationship, and was reassuring. Experiential gains noted by participants included that the program: helped couples to open channels of communication; prompted them to designate quality time for one another; evoked feelings of unity and togetherness; and inspired new insight in the relationship.

Conclusion: Such feedback supports the feasibility and acceptability of the Couplelinks program while offering directions for improvement of online couple-based interventions in cancer.

Keywords: breast cancer, couples, intervention, online, dyadic coping, psychosocial, satisfaction, young

INTRODUCTION

Women diagnosed with breast cancer (BC) during their childbearing years tend to face challenges that make accessing traditional psychosocial supports particularly burdensome because they are often juggling myriad family and employment-related responsibilities alongside invasive and taxing treatments (Gould et al., 2006). The quality of life and psychological wellbeing of women with BC under age 50 tend to be poorer than that of older woman (Reis, 2007), ascribable to the unique frustrations and challenges they face because of their younger age (Ali and Warner, 2013; Acquati and Kayser, 2019). Moreover, BC diagnosed early in life tends to be more aggressive and have a worse prognosis (Stamatakos et al., 2011), and yet, young women report having more difficulty accessing relevant information about BC than do older women (Gould et al., 2006). In one large-scale longitudinal study of women who were diagnosed with BC prior to the age of 50 and assessed at 5- and 10-years post-diagnosis, BC survivors reported diminished quality of life including reduced physical wellbeing and sexual activity (Bloom et al., 2012)—a finding consistent with other studies of younger couples and BC (Walsh et al., 2005; Fiszer et al., 2014).

Although it is the woman who is directly affected by the life-threatening diagnosis and burden of treatment, the challenges and psychological distress associated with the illness also extend to her partner. Male partners of patients with BC tend to experience reduced psychological wellbeing, lower quality of life, and lower sexual engagement compared to pre-diagnosis (Fletcher et al., 2010; Badr and Krebs, 2013). They are also often preoccupied by many anxieties such as the cancer's potential return, the emotional wellbeing of their children, how to behave in a supportive role, and how to be helpful in a practical way (Fletcher et al., 2010). As well, male partners often neglect their own self-care by putting their own needs on hold while supporting their wives' needs during cancer treatment, and keeping home life in order (Hilton et al., 2000).

BC also generates challenges that are psychologically distressing to both partners concurrently. For example, due to the more common need for gonadotoxic chemotherapy when treating younger BC patients, potential infertility is a distressing fear for many young couples who have not started or completed their families (Stamatakos et al., 2011). Sexual dysfunction post BC treatment is another source of anxiety and tension within the relationship (Hilton et al., 2000; Stamatakos et al., 2011). Given the numerous challenges faced by younger couples undergoing cancer treatment or coping with its after-effects, support programs specifically designed to address their psychological needs as individuals and an intimate dyad are essential.

Dyadic Coping and Adjustment to Cancer

Dyadic coping ability is associated with improved couple adjustment to BC and reductions in the individual psychological distress of each partner (Berg and Upchurch, 2007; Heinrichs et al., 2012; Kayser et al., 2017). Couples who employ dyadic coping strategies demonstrate greater reductions in BC-related fears, less avoidance in dealing with the cancer, and more posttraumatic growth (Heinrichs et al., 2012). Greater levels of "we-ness" are also positively associated with a woman's confidence in dealing with BC-related stressors, contributing to an easier adjustment to cancer (Ahmad et al., 2017). Research also demonstrates that the more dyadic coping skills couples utilize, the greater reductions in psychological distress the BC patient and her partner will experience (Rottmann et al., 2015). Improving relationship quality and facilitating feelings of support and intimacy through dyadic coping is therefore an important goal of interventions for couples affected by BC.

Online Interventions for Couples

The development and evaluation of online interventions as a flexible and accommodative alternative to traditional, in-person therapy in cancer care has been a burgeoning area of research. Further support for the feasibility of online modalities in cancer care comes from a review by Yoon (2013) that found online interventions to yield a high rate of satisfaction among cancer patients and their caregivers. According to Yoon, the perceived benefits of online interventions included the flexibility of using the intervention on one's own time, its ability to foster communication about delicate, cancer-related topics, and its efficient transfer of scientifically vetted information.

In regard to couples in particular, Doss et al. (2016) successfully translated an in-person therapy program for heterosexual couples into an 8-h online program called OurRelationship.com. The participating couples in this large-scale study reported significant improvements in relationship satisfaction (Cohen's $d = 0.69$), relationship quality ($d = 0.57$), and relationship confidence ($d = 0.47$), and individual functioning 12 months post-treatment (Doss et al., 2019). The online intervention was significantly less costly than the in-person version of the treatment rendering it appropriate for couples with limited income. The couples who participated in OurRelationship.com reported satisfaction nearly equivalent to that reported after high-quality in-person therapy, supporting the feasibility and promise of couple-based interventions administered through an online modality.

In a recent review of online interventions for couples affected by cancer, Vanstone and Fergus (2020) identified areas of growth in the field over the last decade as well as future potential. Strides have been made, for example, in relation to virtual support programs for intimate dyads coping with prostate cancer. Schover et al. (2012) investigated the efficacy and perceived benefits of an online intervention for heterosexual couples affected by prostate cancer. In a randomized controlled trial, men diagnosed with prostate cancer and their female partners received CAREss sexual counseling face-to-face or through an online modality. Results demonstrated that the online version of CAREss produced equally significant gains in the men's sexual function and satisfaction as the face-to-face intervention. Two studies of real-time, couple-based interventions delivered via video-conference platforms, one for couples coping with advanced gastrointestinal cancer (Porter et al., 2017), and the other for couples wishing to improve their sexual intimacy after BC (Cullen and Fergus, 2021) showed promise in terms of their feasibility and acceptability to participants. The intervention by Porter et al. (2017), as a pilot randomized controlled trial, also provided preliminary evidence for efficacy in terms of improved relationship satisfaction outcomes based on small to moderate between-group effect sizes for patients (Cohen's d = 0.30) and partners (d = 0.34), and between-group effect sizes for patients on communication around affect (d = -0.35) and problem-solving (d = -0.50) with lower scores signifying improvement.

Adding to the literature on the benefits of remotely delivered couple-based interventions in general, and in relation to cancer specifically, are findings from a randomized controlled trial of the Couplelinks intervention to support younger couples affected by BC (Fergus et al., 2021). The greater burden posed by BC to younger couples, combined with the known benefits of online modalities including greater flexibility, accessibility and convenience (Korp, 2006; Paul et al., 2013; Badr et al., 2015; Kruse et al., 2017) inspired the development of "Couplelinks." Couplelinks is an asynchronously delivered, professionally facilitated web-based program entailing a series of dyadic exercises and with opportunities for relationship reflection that partners undertake together with the aim of improving their mutual understanding, support, and ability to communicate constructively around the impacts of BC on each partner and the relationship (described further below). In the RCT, couples from across Canada were randomized to treatment or waitlist control conditions. The analysis, based on 31 couples in the treatment group and 36 couples in the waitlist group, showed modest improvements in positive dyadic coping (Cohen's d = 0.24) and perceived ability to cope as a couple with BC (d = 0.23), but effects were not maintained at 3-month follow-up and no effect was seen on overall relationship adjustment or satisfaction (Fergus et al., 2021).

Current Study

The purpose of the present study was to evaluate participant satisfaction with Couplelinks based on their quantitative and qualitative responses to a non-standardized Treatment Satisfaction Questionnaire (TSQ) administered approximately 1–2 weeks after program completion. The primary research objectives were to understand participant perceptions of: (1) the online intervention's structure and content; (2) the professional facilitation component; and (3) the ways in which the program did and/or did not benefit them.

MATERIALS AND METHODS

Procedures

The study upon which this analysis was based received ethics approval by the following institutions: Sunnybrook Health Sciences Centre and York University in Ontario (ID# 300-209); QEII Health Sciences Centre in Nova Scotia (ID# 2010-357); the British Columbia Cancer Agency (ID# H10-00300); and Cancer Care Manitoba (ID# 2013-017).

The current study is based on an analysis of feedback collected from 53 participants representing 30 couples who completed the Couplelinks program as part of an RCT (Fergus et al., 2021; 23 dyads and seven individual partners). Couples were eligible for participation in the RCT provided that (1) they were in a committed (i.e., married, cohabitating, engaged, or dating for at least 6 months) heterosexual relationship, (2) the female partner was 50 years or younger and had a diagnosis of invasive, non-metastatic breast carcinoma within the previous 36 months, (3) both partners were fluent in English, and (4) they had access to a reliable Internet connection. Couples were excluded from participation if they were currently in couple counseling or if they intended to partake in couple counseling over the course of the study period. Additional exclusion criteria included mental illness that could hinder either partner's progress through the program such as severe depression, psychotic disorders, or substance abuse. The presence of interpersonal violence or abuse in the relationship also excluded couples from participating in the study. The inclusion/exclusion criteria were assessed over the phone via a detailed screening interview protocol at the time of initial contact with all participating patients and partners individually.

Couples were actively recruited for the RCT by health care providers at collaborating institutions in Ontario, Nova Scotia, Manitoba, and British Columbia. In addition, flyers were displayed in hospitals and cancer agencies, announcements were made during hospital meetings and in BC support groups, and links to the informational webpage of Couplelinks were posted on social media and on other online BC resources. The recruitment and treatment period spanned 5 years from 2010 to 2015. A total of 75 couples were randomized to treatment (n = 39) and waitlist control (n = 36) groups. Participants were informed of their randomization outcome after baseline measures had been completed. Seven couples dropped out of the treatment arm (three withdrew before beginning the program, and an additional four dropped out during the program). One additional couple was omitted from the analysis as they neglected to read the facilitator's asynchronously delivered feedback, and thus were considered to not have experienced an integral component of the treatment.

Couplelinks Online Intervention

Conceptual Underpinnings

"Couplelinks" as an online relationship enhancement program for young couples coping with BC, was designed to help partners improve their communication, communal support, self-other knowledge and mutual perspective-taking vis-à-vis the illness and their relationship in general (Fergus et al., 2014, 2015). The intervention, entailing a series of sequentially delivered dyadic exercises (described further below), is rooted conceptually in systemic-constructivist metatheory (Fergus and Reid, 2001; Reid and Ahmad, 2015) which emphasizes couple intersubjectivity and reflexivity (i.e., building upon partners' implicit understandings of self and other, and their capacity to conjointly reflect upon relationship dynamics so as to improve these). The overarching goal of Couplelinks is to help partners strengthen their mutual bond and sense of "we-ness" in reference to the shared stressor of BC, and to function more effectively as a team (Fergus and Reid, 2001; Fergus, 2015). In a marital therapy context, strengthening we-ness mediated improvements in relationship adjustment (Reid et al., 2006; Ahmad and Reid, 2016). While Couplelinks, as a professionally facilitated but primarily self-guided program, is distinct from couple counseling, the exercises were nonetheless intended to facilitate relationship reflection in a way that is conducive to fostering we-ness and to tackling BC as a collective challenge (Bodenmann, 2005). Assuming a team-based approach to dealing with BC-related stressors has consistently been shown to allow for better adjustment to cancer and reductions in individual psychological distress (see Brandão et al., 2014).

Program Description

The first iteration of the program was developed by the authors and pilot tested from 2008 to 2010 (Fergus et al., 2014), and then assessed in the context of a Canada-wide RCT from 2010 to 2015. Its purpose is to enhance relationship functioning, feelings of closeness, support and adjustment to cancer, by guiding couples through six experiential exercises or "Dyadic Learning Modules" (DLMs) that are intended to strengthen the couple's listening skills, emotional and physical intimacy, and positive affect in the relationship, as well as to promote perspective- taking and the ability to engage in open, constructive communication about cancer (see **Supplementary Material 1** for list of DLMs). Each module focuses on a theme fundamental to relationships such as "Creating Connection," or "Facing Cancer as a Unified Front" and contains a related experiential exercise the couple must complete for homework, such as creating a visual representation of their experience with cancer. Couples in the program also have the option to complete an additional DLM focused on building concrete communication skills should they and their facilitator agree that would be helpful. Upon completion of each module, couples provide feedback and a written reflection on the experience. Couples are given a timeframe of approximately 8-weeks to complete all six modules. In addition to the six modules, there are psychoeducational articles and video clips relevant to young couples and BC. For example, a video clip shows a younger couple speaking about their experiences with BC, exposing Couplelinks participants to another couple in their shoes as a way of reducing feelings of difference and isolation; written materials focused on issues relevant to younger BC patients such as premature menopause or communicating with children about cancer.

Professional Facilitation Component

A personal professional facilitator adds a level of individualization to the standard curriculum of the Couplelinks program. The facilitator provides individual support, guidance, and instruction about the program's aims, principles and strategies used. The facilitators use a private online space on the Couplelinks website called the "Dialogue Room" to communicate asynchronously with their designated couple via text over the course of the program. A notification is sent to the facilitator upon the couple's completion of each module along with their feedback and reflections. Feedback is then sent by the facilitator *to* the couple and access to the next module is granted. Each couple receives a phone call from their facilitator after the completion of the second and fourth modules, and has the option of scheduling additional phone conversations as needed (for more detailed description of the intervention see Carter et al., 2015; Fergus et al., 2015; Ianakieva et al., 2016).

Materials

To evaluate the perceived satisfaction of couples with the Couplelinks program, their responses and feedback were collected through the following:

Treatment Satisfaction Questionnaire

After completing the intervention, each partner was asked to complete a Treatment Satisfaction Questionnaire (TSQ). The TSQ guides participants to rate their degree of satisfaction with the program overall, the program's convenience, and the quality of the professional facilitation on a five-point Likert scale. To obtain written, more in-depth understanding of the program's perceived value, limitations and benefits, open-ended questions were included such as, "What did you like best about the program?" and "What did you like least about the program?" In the final sections of the TSQ, participants used both Likert scales and open-ended questions to provide specific feedback on the value of the psychoeducational articles and videos. For the last item, there is a space to provide "any additional comments" regarding the overall program (see **Supplementary Material 2** for the TSQ).

Data Analysis

Quantitative

Descriptive statistics such as means and standard deviations (SD) were used to summarize the quantitative data obtained from the Likert scales on the TSQ. Generalized linear models with a random intercept for couples to adjust for the within couple correlation using a variance component correlation structure were developed. A fixed effect for gender was entered into the model to test for differences in mean outcome scores.

Effect sizes for the difference in outcome scores (females-male) were calculated as model estimated value divided by the pooled standard deviation. The data analysis was conducted using SAS/STAT software version 15.2 and the SAS System for Windows version 9.4.

Qualitative

For the data obtained from the open-ended questions in the TSQ, Braun and Clarke's (2006) procedure for thematic analysis was used. The first and second authors (KF and AT) took the lead on the qualitative analysis. First, the data were repeatedly read to gain familiarity with the depth and scope of its content. Second, recurring themes across participant responses pertaining to the research objectives were systematically identified and collated into meaningful categories in an "open-coding" fashion (Glaser and Strauss, 1967). The analysts met regularly to review codes and discuss their interrelationships. As this analysis was more descriptive than interpretative, achieving consensus was fairly straightforward. Rare differences of opinion were resolved through discussion until a consensus had been reached. Patterns across the dataset were derived inductively from the data themselves rather than from preconceptions based on prior research or theory. Third, the categories were sorted and combined to create meaningful overarching themes. Finally, the prescribed themes were reviewed, revised, and organized into a coherent framework. To ensure quality thematic analysis, themes were generated on the basis of a thorough, inclusive, comprehensive and equally weighted view of the entire dataset rather than from a few vivid data extracts (Braun and Clarke, 2006). Themes were identified at a manifest (vs. latent) level rather than looking interpretively beyond what participants had written (Graneheim and Lundman, 2004).

RESULTS

Participant Characteristics

Demographics of the participants and couples are summarized in **Tables 1**, **2**, respectively. A total of 53 participants completed the questionnaire (23 patient-caregiver pairs, and seven individual partners ($n = 3$ women and $n = 4$ men) representing 30 couples in total).[1] The 26 participating women were an average age of 38.9 years old (*SD* = 5.48). There were no age restrictions for the 27 males, although they were on average 40.8 years old (*SD* = 6.35). Eighty-one percent of the couples were married, 15% were cohabitating, and 4% were living apart. On average, couples had been together for 13.8 years (*SD* = 7.46). At the time of participation, most women were receiving follow-up care (54%), although a sizable portion were undergoing active treatment (31%), or had just finished active treatment (8%). Only two women (8%) were recently diagnosed. Forty-six percent of women had Stage I BC, 19% had Stage II, and 35% had Stage III. The majority of participants (83%) were White and most had completed university or college (86%).

TABLE 1 | Individual Participant Characteristics (*N* = 53 participants).

	Female (*N = 26*)				Male (*N = 27*)			
	M	***SD***	***n***	**%**	***M***	***SD***	***n***	**%**
Age	38.92	5.48			40.81	6.35		
Race								
Caucasian			21	80.77			23	85.19
Asian			3	11.54			1	3.70
Other			2	7.69			3	11.11
Highest level of education								
High-school			1	3.85			3	11.11
College			10	38.26			10	37.04
University			12	46.15			13	48.15
Post-graduate			3	11.54			1	3.70
Age at diagnosis	37.50	5.40						
Stage								
Stage 1			12	46.15				
Stage 2			5	19.23				
Stage 3			9	34.62				
Treatment period								
Recently diagnosed			2	7.69				
Active treatment			8	30.77				
Just completing treatment			2	7.69				
Follow-up			14	53.85				

TABLE 2 | Couple characteristics (*N* = 30).

	M	***SD***	***n***	**%**
Marital status				
Dating/Engaged			1	3.85
Common-law			4	15.38
Married			21	80.77
Length of relationship	13.88	7.46		
Length of marriage	10.90	6.91		

Quantitative Results

In terms of the Likert indices on the TSQ, participants reported a satisfaction rating of 4.3 out of 5 (*SD* = 0.54) on average, and all but two (both males) indicated that that they would recommend the program to a friend in similar circumstances. In terms of the professional facilitation component, the vast majority of participants agreed or strongly agreed that the facilitator role was necessary (*M* = 4.7, *SD* = 0.60), that the level of interaction with the facilitator was sufficient (*M* = 4.4, *SD* = 0.86), and that the facilitator's feedback was important (*M* = 4.6, *SD* = 0.60). Participants found the program was generally convenient to use

---

[1] Both partners completed the TSQ independently and in some instances, only one member of the couple completed it. Although efforts were made to encourage non-completers to provide their feedback, these were ultimately not successful and the research team felt it was important to not ask too much of participants who had already given a lot to the project, and who would also be completing a lengthy follow-up test battery at a later date. Moreover, the TSQ was originally administered as a separate online survey but later became integrated with the full post-treatment test battery. Thus once this integration occurred, TSQ completion rates improved. In the case of one couple, neither partner completed the TSQ and thus of the 31 couples comprising the treatment condition for the RCT, 30 are represented in this evaluation.

(*M* = 4.09, *SD* = 0.81). Male and female participants differed only on the overall satisfaction variable with females' satisfaction ratings being significantly higher (*p* = 0.01, **Table 3**), with a medium effect size = 0.57.

Qualitative Results

The qualitative analysis of the TSQ identified 432 meaningful units, which were collated into 30 codes and 14 overarching themes. The themes and corresponding codes were organized by the research objective that it addressed. Six themes emerged from the analysis of participants' perceptions of the online intervention's structure and content. Four themes emerged from the analysis of participants' perceptions of including an online facilitator in the program. Five themes spoke to the experiential gains participants felt they took away from the program (see **Table 4**). Direct quotes written by participants on the TSQ were identified by their gender and participant ID. Quantitative data in support of each research objective were incorporated into the qualitative descriptions of the results.

Program Structure

Curriculum

Each couple was expected to complete the program's standard curriculum consisting of six Dyadic Learning Modules (DLMs), while reviewing the psychoeducational articles and videos was left to each participant's discretion. The majority of the participants' comments revealed favorable evaluations of the DLMs such as couples repeatedly reporting on the value of the "the variety of activities," (F13) or "the role playing" (M16) involved in some of the modules. One participant commented, "I found something useful in all the exercises" (M4) and another wrote, "All aspects were very valuable." (F23) However, not every couple was able to derive maximal benefit from the modules or see their value. The most illustrative example of individual factors shaping couples' evaluations was the dichotomous responses regarding the enjoyment of the "Facing Cancer as a Unified Front" module. In this module, each couple was tasked with using their creativity to build a graphic representation of their illness on the webpage. While a number of participants wrote explicitly about the value of this module, couples who did not perceive themselves as "artistic" wrote that it was challenging and unenjoyable. As one female participant wrote, "The exercise where we did the drawing was outside my comfort zone—I do not like that sort of thing." (F16)

TABLE 3 | Outcomes by gender (*N* = 53).

	Female (*n* = 26)		Male (*n* = 27)			
Variable	***Mean***	***SD***	***Mean***	***SD***	***p*-value***	***ES*****
Program satisfaction	4.46	0.51	4.15	0.53	0.01	0.57
Program convenience	4.15	0.83	4.04	0.81	0.45	0.15
Facilitator feedback important	4.58	0.70	4.48	0.70	0.62	0.11
Facilitator amount of interaction sufficient	4.35	0.98	4.37	0.74	0.83	–0.06
Facilitator role necessary	4.58	0.64	4.67	0.55	0.59	–0.13

**Generalized linear model with a random intercept for couples to adjust for within couple correlation.*

***Effect size was calculated as the model estimated mean difference divided by the pooled SD.*

TABLE 4 | Themes and codes from analysis of the Couplelinks treatment satisfaction questionnaire.

Themes	Codes
Program structure	
Curriculum	▪ Activity-based learning (e.g., exercises) ▪ Psychosocial materials (e.g., videos, articles)
Involvement of both partners	▪ Inclusion of the male partner ▪ Support for the male partner
Time allotted	▪ Insufficient time to complete all modules ▪ Sufficient time to complete all modules
Self/couple- guided	▪ Easy to progress through program ▪ Difficult to stay on task
Convenient and flexible	▪ Accommodating of each couple's schedule ▪ Flexibility of online education
Desire for in-person contact	▪ Face-to-face sessions ▪ Privacy concerns with online self-disclosure
Professional facilitation	
Humanized the intervention	▪ Skilled feedback ▪ Participant-facilitator connection
Motivated couples to progress through program	▪ Instruction clarification ▪ Accountability ▪ Encouragement
Facilitated insight into relationship	▪ Skilled reflection by facilitator ▪ Helped develop novel insight
Offered reassurance	▪ Affirmation ("on the right tract") ▪ Validation and confidence
Experiential gains	
Opening channels of communication	▪ Opportunity for important conversations ▪ Communication skill improvement
Carving out time for each other	▪ Opportunity to focus on relationship ▪ Quality time and fun
A sense of togetherness	▪ Couples feel "in this" together ▪ Closeness
Gaining insight into the relationship	▪ New or different perspective ▪ Identified areas of improvement ▪ "There really wasn't anything shockingly new"

In terms of the written psychoeducational materials, slightly more than half of participants reported to have read these, and of those that read the articles, the majority indicated they valued them. Over half of participants also watched the psychoeducational videos and the majority of these individuals found them to contain valuable information. As one participant wrote:

> The videos provided additional guided support with the various phases of the program. No one really understands how you feel, the fears you have or how cancer has affected your relationship until they've been through it. I found that I could relate to many aspects of the. . . videos. (F17)

However, one psychoeducational video was met with constructive feedback by one couple. Reflecting on the value of the videos, one female conveyed how she could not relate to the couple in one video clip:

> They [couple in video] seem to have faced an early stage cancer, since they say they were always clear that they would

> be okay after the treatment. I could not relate with that case because our main concern was always whether I would survive or not. Treatment side effects were always a minor thing compared to the fear of dying and [names of couple in the video] were apparently in a different situation, where the worst part of the journey is associated with the treatment, side effects. (F22)

Involvement of Both Partners

The Couplelinks program importantly provides male partners with the opportunity to receive psychosocial support, addressing each couple as a *dyad*, instead of just the single partner alone: "It was the first "cancer" activity that actively involved both of us." (29F) Positive responses regarding the inclusion of the male partner in the program suggest that couples perceive psychological support in cancer care to be more readily available to the identified patient, the woman with BC. As one participant stated: "By participating in a program that involved us as protagonists, it highlighted how important our relationship is and how much care and attention we need to give in order to feel happy with each other." (F20)

Time Allotted

Couples were asked to complete the Couplelinks program within approximately 8 weeks by reviewing the psychoeducational materials, and completing the experiential dyadic exercises on weekly basis. Feedback was split among participants regarding the time allotted for completion. Participants reported either needing "more time" (M4, F7, F30), feeling "pressure" (M3, M25) or "pressed for time to complete by the deadline" (F30) ($n = 13$) *or* that the timeframe was "totally doable" (F15), "appropriate" (M28), and "reasonable" (M19) ($n = 8$). One participant wrote, "It was very difficult to make the time to complete the modules within the allocated time" (26F) which contrasted with another participant who wrote, "I was given more than enough time to complete each module." (12F)

Self/Couple-Guided

The Couplelinks program was designed and structured to function as an asynchronously delivered, self-managed intervention. The ability to decide when to complete the modules was viewed as a benefit for some couples, and a drawback for others. Some participants wrote about the challenge of "finding the time" (M8) to fit the weekly exercises into their schedules ($n = 14$), while other participants reported that the program's flexibility allowed for it to be easily incorporated into their week ($n = 4$). As well, while most participants wrote about the benefits of the program's convenience and of doing the intervention at their "own pace," (F10) some wrote about how it was perhaps a little *too* flexible ($n = 5$). For these participants, the lack of structure was a challenge and made it harder to complete the weekly exercises. As one female participant explained:

> It was a little too convenient and I found that despite our ability to do it when we had time, that almost gave us an excuse when we were too busy. For me personally, I need something a bit more structured, and we could have done better if my husband and I scheduled the time between us and kept to the schedule. (16F)

Although feedback regarding the Couplelinks program's design and structure was mostly split between participants, there were also contradictions observed sometimes within a single participant. The same female participant (16F) continued:

> The flexibility. I loved that and hated it too. I'm sort of like a child that needs to be reminded from time to time, and I really appreciated the support from the moderators. Everyone has been very kind and I felt like they were really on my (our) side.

Convenient and Flexible

The primary benefit identified regarding the virtual nature of the intervention was its accommodative nature ($n = 22$). Participants appreciated the freedom to complete the program and exercises at home on one's "own terms." (9M) Accessing the intervention online, and at their own pace, was perceived as an advantage over scheduled appointments or "driving into the city." (6F) As one participant put it, "We never felt pressured, and found being able to go online at our own leisure was very convenient." (10M) For young couples with busy schedules, juggling early careers or childcare, the flexibility also made psychological intervention more feasible, when it otherwise might not have been possible: "The phone call check in's were scheduled for a time that was best for [husband's name] and I, which meant evenings due to his work schedule." (11F)

Desire for In-Person Contact

While many participants stated that they benefited from the convenient and accommodative nature of the online program, the most commonly reported limitation was the absence of in-person contact ($n = 9$). Some participants claimed they were simply a "face-to-face kind of person" (5F) and preferred to communicate with others through in-person contact. One man wrote: "[I did not like] that it was almost entirely online. But my own bias is for more face-to-face (or on the phone)." (M29) As well, disclosing personal information through an online modality instead of face-to-face was evidently disconcerting for certain participants. One participant felt "awkward" (5F) talking on the phone to the professional facilitator. Another participant felt "raw" and "expos[ed]" (16F) revealing personal information through the online modality without the immediate feedback or validation received in in-person counseling.

Professional Facilitation

Participant feedback revealed that while couples generally appreciated the online, and standard, components of the intervention, they saw particular value in the facilitator's contributions to their participation in the program and the way that the facilitator tailored their feedback on the modules to the unique couple and their needs:

> "Even though having such a program in an online mode has several advantages, especially for introverted people who may feel a bit uncomfortable and for whom it would be difficult

> to open and share in front of a third party, it is key to have someone following the process." (F22)

Humanized the Intervention

The vast majority of the participants "strongly agreed" or "agreed" that the professional facilitator's role was necessary and that their feedback was important to their successful utilization of the program. The facilitator allowed participants to feel they "weren't alone doing some online program" (18F) and ensured a smooth progression through the generic aspects of the program.

Motivated Couples to Progress Through Program

Another primary benefit identified regarding the professional facilitator was that he or she served as a motivator and helped couples "stay on track" (M16) (*n* = 19). The facilitator importantly pushed the couples to keep pace and meet their deadlines, as one participant wrote, "if we were left on our own without someone there pushing us a little bit, we may not have completed the course." (5M) Participants appreciated having an "encouraging, instructive" (19M) facilitator to help clarify instructions, ensure the exercises were done correctly, who offered guidance when they were "experiencing difficulties" (24M) and ensured they "got the most out of each activity." (24F)

Facilitated Insight Into Relationship

The facilitator's "invaluable feedback" (11F) helped couples make headway in the program (*n* = 16). Many participants appreciated the facilitators' skillful reflections on their progress through each module considering these to be a "major benefit" (17F) of the program. The personalized feedback and support "put a voice and thoughts" (1M) to problems, helped couples "reflect on things," (5F) identify areas for improvement, and afforded them new directions to consider. According to one participant, the facilitator helped "to reframe, interpret, elaborate, redirect, [and] refer."(21M)

Offered Reassurance

The feedback also importantly served as a source of affirmation and validation, giving couples the confidence to proceed through the program (*n* = 8). One participant wrote, "I often wondered if my responses to some of the questions were clearly understood, [and] his feedback helped reassure me." (4F) Another participant wrote, "The feedback was such a great validation to know that we were on the right track and doing well." (11F)

Experiential Gains

A positive evaluation of the Couplelinks program ran through the majority of the couples' feedback. Thematic analysis of responses revealed four experiential gains participants felt they took away from the program: (a) opening channels of communication; (b) carving out time for each other; (c) gaining insight into their relationship; (d) evoking a sense of togetherness, while a few participants felt; (e) "there wasn't anything shockingly new" in reference to possible gains from the program.

Opening Channels of Communication

Many participants reported that the intervention facilitated a sense of openness within their relationship (*n* = 19). The DLMs and experiential exercises facilitated "open" (4F) (*n* = 10) discussions between partners, "without requiring someone to initiate a "we need to talk" situation" (19M) which could seem more ominous. The exercises encouraged, and enabled, couples to "share their experiences and emotions openly" (7M) and presented an "excuse" (4F) or opportunity for participants to be "more open, and straightforward" (22F) with their partners. The Couplelinks program guided couples through "difficult dialogue" (23F) and for one couple, opened "doors that were closed many years ago" (22M), evoking important conversations that they might not otherwise have had. As one participant commented: it was "helpful to have something to force us to communicate." (23F)

Some couples reported a distinct change and improvement in their method of communication as a result of the program (*n* = 5). For example, one female participant shared a concrete way in which she and her partner's communication ameliorated: "I learned there were hidden feelings deep inside of me, even though I was being positive and optimistic. It's okay to feel down and express how I feel to my husband" (27F). The program helped couples "enhance" (11F) their communication skills, and acquire "better" (26F) or "new ways to communicate," (6M), and "got [them] to talk in a different way." (5F) One patient summed this up by saying that, "the program provided several tools that we can use in the future in talking about our feelings [and] concerns." (19F)

The Couplelinks program helped couples recognize the value of bringing effective and open communication into their relationship (*n* = 10), even "as awkward as the communication might be." (21F) In one participant's written feedback, she reflected, "It's important for us to keep talking to each other and making time for each other" (18F), and another participant wrote that the program helped him realize that, "Taking time to listen and talk is key to keeping a healthy marriage.″ (1M)

Carving Out Time for Each Other

Participation in the program provided couples with a set time to spend together each week, "like a date," as one woman (19F) put it. One participant commented: "It [was] a way to sort of nurture our relationship after a period of not paying attention to our relationship at all... next to no intimacy, no dates -you know- for a long period of time." (19F) Many wrote about enjoying "dedicated time" (29M) with their partner (*n* = 6), and as one participant articulated, "Having a project that was just about the two of us. No kids involved, no work involved... just the two of us." (21F) One participant expressed the gratitude she felt to have the opportunity to spend quality time alone with her partner as "there are also issues of body image and sexuality associated with BC." (26F)

Partaking in the program also allowed for couples to set specific time aside for focusing on their relationship (*n* = 11). Many couples appreciated that Couplelinks granted them the opportunity to "sit down and breathe" (25M) or take pause "even in busy times" (28F) to explore or think about their relationship (*n* = 11). As a female participant wrote, "[It was a] good reason to make time to talk about us." (F18)

A related benefit that was reported described how participation in the program allowed couples the opportunity to pay special attention to the physical aspect of their relationship. The evaluation of the pilot version of Couplelinks revealed that couples wanted a module aimed to help them reconnect physically and re-engage in sexuality after treatment (Fergus et al., 2014). Thus the RCT protocol included a "Getting Physical" DLM (Fergus et al., 2015) and dedicating time for intimacy contributed to this theme as mentioned by this participant:

> "I most liked an opportunity for [name of husband] and I to focus on our sexual relationship. It's something that had been an issue for us before the program and then cancer treatment only made it that much more difficult. The exercise on reconnecting physically was very helpful for us and helped give us a framework to kick-start the physical side of relationship again." (21F)

A Sense of Togetherness

Participating in the Couplelinks program helped couples recognize, as one participant put it, that they are "in this together" (16F) (n = 15). The DLMs the couples completed together, as a team, allowed participants to remember that they are "coping with BC as a couple" (13M) vs. as individuals. By facilitating the "opportunity to connect," (28M) Couplelinks allowed couples to "deepen" (F11) their relationships, bringing partners closer together (n = 7). As one participant wrote: "... [Couplelinks] made us be together, closer to each other in many levels." (22F)

Gaining Insight Into the Relationship

Couples made reference to how completing the program's exercises and modules enabled them to view their relationship from a "new and different perspective." (M6) As one participant wrote about her husband: "The program allowed me to see him in a new light, it made him more human to me." (16F) This change of perspective also allowed for the discovery of new realizations about the nature of participants' relationships. For example, one woman recognized, "My husband and I need to have projects and things to do together, alone without our sons." (22F)

This enhanced relationship awareness also allowed participants to identify areas in their relationship in need of improvement (n = 18). A female participant wrote: "The program has "showed me" to slow down and be more responsive/considerate and patient with him," (16F) while her husband learned: "[The program] helped me realize that I have a lot of work to do to make our relationship work. I need to express myself more and I need to be more attentive/aware of what my spouse is going through." (16M) Another female participant came to identify, "We need to pay more attention to connecting physically and taking an emotional chance with each other in order to do that." (6F)

While gaining new insight allowed some participants to identify areas in their relationship in need of improvement, others found affirmation of their mutual bond by, for example, seeing "how strong (our) relationship is." (9M) Another participant wrote, "I learned that [wife's name] and I have a very strong relationship and that I'm proud of how hard we work at it." (15M)

Another type of learning gained by the couples was reportedly a "great set of tools and strategies to help for managing relationship 'stuff' (29M)." The strategies learned were "useful and practical" (25F) and, as one participant wrote, "identified 'problems/topics' and helped you develop techniques to address them." (17F) Some participants made specific reference to acquiring a framework with which to think about and discuss the relationship as one participant noted, "One concept we still talk about is "Turning Toward and Away" from one another." (5M)

"There really wasn't anything shockingly new." 13F While most participants wrote about the many tools, strategies, and insights learned, some participants reported that they did not get "a lot out of it" (15F) (n = 5). As one participant put it, "Except for the physical exercise, the rest of the components didn't really share anything new for me." (21F)

The most common reason reported among couples that expressed a lack of novel learning from the program was due to a perception of an already strong relationship. For example, a female participant wrote:

> I, personally, didn't find most of [the DLMs] helpful, but that, I think, is reflective of the fact that we already think about and talk about the things that were prompted in the modules, so there wasn't anything new, really. (21M)

Some couples who felt they were in particularly high-functioning relationships perceived to have not benefited from the stock components of the program as much as other couples. The same female participant cited above wrote, "My husband and I found that it mostly just reinforced that we have a very good and supportive relationship. But I can see how it would be very valuable for couples who were struggling." (21F)

DISCUSSION

The current study examined participant feedback on an online psychological intervention designed to help young couples cope with BC through the use of dyadic coping strategies, psychoeducation, and weekly experiential learning exercises. Participants unanimously saw the benefit in the convenience and flexibility of the program, and appreciated the intervention's involvement of both partners. Including a professional facilitator in the online intervention was well received among participants as they humanized the intervention, served as motivation to progress through the program, facilitated insight into their relationship, and offered reassurance. The analysis revealed numerous experiential gains that participants felt they took away from the program. Couplelinks helped to: (1) open channels of communication, (2) designate quality time for couples to spend together each week, (3) evoke feelings of unity and togetherness, and (4) inspire new insight in the relationship.

Among young couples affected by BC specifically, the cost effectiveness and flexibility of self-managed interventions provide further value over face-to-face therapy sessions (Hilton et al., 2000; Gould et al., 2006). The Couplelinks program, which targets the couple as a unit specifically, also corroborates past research demonstrating the important effects of psychosocial interventions that focus on improving relationship quality in adjusting to the psychological and physical effects of cancer (Brandão et al., 2014; Ahmad et al., 2017; Kayser et al., 2017). The generally positive evaluations in the current analysis provide evidence that participants perceive self-guided couple-based psychosocial programs to be beneficial and valuable in their experience managing and coping with BC. Below we discuss findings from this study in the context of the Couplelinks RCT outcomes, and how these tie in with literature on the importance of professional online facilitation. We also consider the subset of couples who found the program banal.

Discrepancies Between Subjective and Objective Indicators of Benefit

It is interesting to consider overall favorable treatment satisfaction findings relative to the RCT outcomes which demonstrated short term improvement in positive dyadic coping but no between group differences in marital adjustment or relationship satisfaction—and given that participants in the current sample represented 30 of the 31 couples randomized to the treatment arm of the RCT (Fergus et al., 2021). Specifically, experiential gains of improved communication, greater closeness, and increased insight into the relationship, should, in theory, be reflected in improvements on standardized instruments such as the Revised Dyadic Adjustment Scale (RDAS). In hindsight, it is possible that the RDAS, as one of the selected primary outcome measures, lacked sensitivity to the change processes being targeted by the intervention. For example, the relationship satisfaction subscale is comprised of items to do with marital conflict and instability—aspects of intimate relationships which were deliberately *not* targeted by Couplelinks with its relationship enhancement, strengths-based (rather than conflict resolution) focus.

Moreover, the Dyadic Coping Inventory, a measure that was evidently more sensitive to the changes provoked by Couplelinks, showed these changes were not maintained at follow-up (Fergus et al., 2021). In this regard, it is important to bear in mind that the TSQ was completed soon after completing the program when any treatment gains would have been most salient for participants. Disparities in outcomes at different data collection time-points raise questions about the situation specificity of programs like Couplelinks that aid couples in enhancing their bond while participating in the intervention but which diminish over time as "everyday life" takes over and couples are less inclined to make their relationship the focus of their attention (one of the main tasks of Couplelinks). A useful analogy here is of a garden that needs tending. The plants and flowers may not be so far gone as to be failing, but the florae are overgrown and unruly, borders are less crisp, and weeds may have begun to proliferate. Thus the benefits of Couplelinks as a relationship enhancement intervention may well be, almost by definition, temporary. This consideration raises intriguing questions around the value of "booster" modules, and more broadly the importance of "relationship tending" in the maintenance of couple bonds.

Professional Facilitation as Integral to Web-Based Couple Interventions

While the couples' subjective accounts regarding the structure and content of the program were mixed (e.g., time allotted per module), feedback on their experience receiving the professional facilitator's individualized support and guidance was consistently viewed as an asset and integral to their satisfaction and successful completion of the program. Past research on self-managed interventions demonstrates the benefits of incorporating a coach or therapist in the program (e.g., Larson et al., 2007), a finding corroborated in the series of investigations of the population-based online intervention, OurRelationship.com (Doss et al., 2013, 2016; Roddy et al., 2016). An early iteration of this program (Doss et al., 2013) illustrates how increasing a program's scope or mass-influence may limit the impact and effectiveness it can have on single individuals. To maximize the program's reach, adoption, implementation and maintenance among a nationally representative sample, OurRelationship.com was kept brief and initially did not include professional facilitators. A facilitator was added to later iterations of the intervention and investigators found that, importantly, the professional facilitation enabled couples to gain maximal benefit from the program (Roddy et al., 2016). The presence of a facilitator reduced dropout rates due to increased feelings of accountability to complete each of the program's activities. This finding, too, is consistent with the current analysis; many couples reported they would not have completed the Couplelinks program without having the facilitator helping them "stay on track" (7F) and progress through the program.

Ceiling Effects With Relationship Enhancement Programs

A notable weakness of the Couplelinks curriculum is illustrated by the subset of couples that reported that they did not "learn anything shockingly new." A commonly reported reason for this was that they felt their relationship was already strong and functional (e.g., "I know for us [Couplelinks] wasn't overly challenging. But that's partially because we are just who we are. Like we do openly talk and discuss things frequently. We're very like-minded." (9F)) While this can suggest that the Couplelinks program may be less effective for couples who embark on the program with a higher level or quality of relationship functioning, other couples were *both* well-adjusted *and* able to benefit from the program's content. Indeed, a primary goal of the Couplelinks program was relationship enhancement, and many functional couples did in fact experience novel learning. This disparity may be due to the fact that the subset of couples who perceived themselves to be well-adjusted and did not report achieving insight through the program viewed the stock curriculum as an affirmation of their relationship strengths (e.g., "It definitely seemed that it was just showing us what we already knew about each other" (9M)). It may have been that these couples already perceived themselves to possess the relationship skills taught in the DLM, or that they were unable to incorporate new learning into a relationship they already saw as strong. This finding highlights both the limitations of interventions with pre-determined content designed for mass administration, as well as the added value of professional facilitation which allows for additional tailoring and personalization to couples whose feelings of affirmation prevent them from acquiring new skills and learning.

Limitations and Future Directions

One limitation of the current analysis is the absence of couple-derived feedback in which partners are addressed together and able to build from one another's reflections about the program in a co-constructed fashion. Given the intervention is focused on developing "we-ness," dyadic as well as individual-based evaluations of the program would have been appropriate and likely would have added to the understanding achieved through individual evaluations. An additional consideration is that the sample (N = 53) did not include all 62 participants from the RCT treatment arm (n = 31 couples). Thus there is the possibility that the present findings were biased toward more favorable impressions of the intervention. Having said that, the fact that there was representation from 30 of the 31 RCT couples in the present sample, with more males than females participating (and it was the male participants who were comparatively less satisfied with the program according to the outcome X gender analysis with this sample), lends confidence to the validity of our findings.

Another sample-related limitation is that this treatment satisfaction analysis was limited to the RCT participants, which was comprised of mainly White couples with post-secondary education inclined to volunteer for novel interventions such as Couplelinks. This result points to a potential self-selection bias or that needing to have Internet and computer access may have posed a barrier to couples of lower socioeconomic status. Moreover, all couples were heterosexual. Future research is needed in order to determine if same sex couples and patients or partners of more diverse ethnicities and educational backgrounds would have the same evaluations. Lastly, the subset of participants who indicated face-to-face counseling would have been preferred should not be overlooked. This finding stands as an indication that traditional counseling should still be available for those who prefer it over a self-directed program, and who have the resources to access it.

CONCLUSION

The current study uncovered the perceived benefits and limitations of an online intervention for young couples coping with BC, as well as examined the experience of those using it. The current analysis demonstrates the perceived value of an online, predominantly self-managed, couple-based psychological intervention with personalized support and guidance for young couples with BC. The reported benefits provide support that couples view online interventions to be viable, flexible, accommodative and an unencumbered alternative to traditional face-to-face couple counseling. Findings from the current study support the feasibility and acceptability of the Couplelinks program for couples coping with BC while offering directions for improvement of online couple-based intervention in cancer care.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because participants did not provide consent to share the information in a publicly accessible database. Questions regarding the datasets should be directed to KF, karen.fergus@sunnybrook.ca.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Sunnybrook Health Sciences Centre and York University in Ontario (ID# 300-209); QEII Health Sciences Centre in Nova Scotia (ID# 2010-357); British Columbia Cancer Agency (ID# H10-00300); and Cancer Care Manitoba (ID# 2013-017). The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

KF: conceptualization, formal analysis, funding acquisition, investigation, methodology, project administration, resources, supervision, visualization, writing original draft, and review and editing. AT: methodology, data curation, formal analysis, writing original draft, and review and editing. SA: conceptualization, data curation, formal analysis, investigation, methodology, project administration, supervision, visualization, and review and editing. SG: conceptualization, data curation, formal analysis, funding acquisition, methodology, supervision, visualization, writing original draft, and review and editing. EW: conceptualization, funding acquisition, investigation, methodology, resources, and writing–review and editing. DM and JS: conceptualization, funding acquisition, investigation, methodology, resources, and writing-review. WC: conceptualization, investigation, methodology, and writing-review. AP: data curation, investigation, methodology, and project administration. All authors contributed to the article and approved the submitted version.

FUNDING

This study was funded by the Canadian Breast Cancer Network which is comprised of funding from the Canadian Cancer Society Research Institute, Canadian Institutes of Health Research, and Canadian Breast Cancer Foundation.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.862555/full#supplementary-material

REFERENCES

Acquati, C., and Kayser, K. (2019). Dyadic coping across the lifespan: a comparison between younger and middle-aged couples with breast cancer. *Front. Psychol.* 10:404. doi: 10.3389/fpsyg.2019.00404

Ahmad, S., Fergus, K., Shatokhina, K., and Gardner, S. (2017). The closer 'We' are, the stronger 'I' am: the impact of couple identity on cancer coping self-efficacy. *J. Behav. Med.* 40, 403–413. doi: 10.1007/s10865-016-9803-1

Ahmad, S., and Reid, D. (2016). Enhancing the relationship adjustment of south asian canadian couples using a systemic-constructivist approach to couple therapy. *J. Marital Fam. Ther.* 42, 615–629. doi: 10.1111/jmft.12161

Ali, A., and Warner, E. (2013). pynk : BC program for young women. *Curr. Oncol.* 20, e34–e39.

Badr, H., Carmack, C. L., and Diefenbach, M. A. (2015). Psychosocial interventions for patients and caregivers in the age of new communication technologies: opportunities and challenges in cancer care. *J. Health Commun.* 20, 328–342. doi: 10.1080/10810730.2014.965369

Badr, H., and Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psychooncology* 22, 1688–1704. doi: 10.1002/pon.3200

Berg, C. A., and Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol. Bull.* 133, 920–954. doi: 10.1037/0033-2909.133.6.920

Bloom, J. R., Stewart, S. L., Oakley-Girvan, I., Banks, P. J., and Shema, S. (2012). Quality of life of younger breast cancer survivors: persistence of problems and sense of well-being. *Psychooncology* 21, 655–665. doi: 10.1002/pon.1965

Bodenmann, G. (2005). "Dyadic coping and its significance for marital functioning," in *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping; Couples Coping with Stress: Emerging Perspectives on Dyadic Coping*, eds T. A. Revenson, K. Kayser, and G. Bodenmann (Washington, DC: American Psychological Association), 33–49. doi: 10.1037/11031-002

Brandão, T., Schulz, M. S., and Matos, P. M. (2014). Psychological intervention with couples coping with BC: a systematic review. *Psychol. Health* 29, 491–516. doi: 10.1080/08870446.2013.859257

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101. doi: 10.1191/1478088706qp063oa

Carter, W., Fergus, K. D., Ahmad, S., McLeod, D., and Stephen, J. (2015). Defining the role of the online therapeutic facilitator: principles and guidelines developed for Couplelinks, an online support program for couples affected by breast cancer. *J. Med. Internet Res. Cancer* 1, 1–13. doi: 10.2196/cancer.3887

Cullen, K. A., and Fergus, K. D. (2021). Acceptability of an online relational intimacy and sexual enhancement (iRISE) intervention after breast cancer. *J. Marital Fam. Ther.* 47, 515–532. doi: 10.1111/jmft.12516

Doss, B. D., Benson, L. A., Georgia, E. J., and Christensen, A. (2013). Translation of integrative behavioral couple therapy to a web-based intervention. *Fam. Process* 52, 139–153. doi: 10.1111/famp.12020

Doss, B. D., Cicila, L. N., Georgia, E. J., Roddy, M. K., Nowlan, K. M., Benson, L. A., et al. (2016). A randomized controlled trial of the web-based our relationship program: effects on relationship and individual functioning. *J. Consult. Clin. Psychol.* 84, 285–296. doi: 10.1037/ccp0000063

Doss, B. D., Roddy, M. K., Nowlan, K. M., Rothman, K., and Christensen, A. (2019). Maintenance of gains in relationship and individual functioning following the online our relationship program. *Behav. Ther.* 50, 73–86. doi: 10.1016/j.beth.2018.03.011

Fergus, K., Ahmad, S., Gardner, S., Ianakieva, I., McLeod, D., Stephen, J., et al. (2021). Couplelinks online intervention for young couples facing BC: a randomised controlled trial. *Psychooncology* 31, 512–520. doi: 10.1002/pon.5836

Fergus, K., Ahmad, S., McLeod, D. L., Stephen, J., Gardner, S., Pereira, A., et al. (2015). Couplelinks- an online intervention for young women with BC and their male partners: study protocol for a randomized controlled trial. *BioMed. Central* 16:33. doi: 10.1186/s13063-014-0534-8

Fergus, K. D. (2015). "Theoretical and methodological underpinnings of resilience in couples: locating the "We," in *Couple Resilience: Emerging Perspectives*, eds K. Skerrett and K. Fergus (Berlin: Springer SBM), doi: 10.1007/978-94-017-9909-6_2

Fergus, K. D., McLeod, D., Carter, W., Warner, E., Gardner, S. L., Granek, L., et al. (2014). Development and pilot testing of an online intervention to support young couples' coping and adjustment to BC. *Eur. J. Cancer Care* 23, 481–492. doi: 10.1111/ecc.12162

Fergus, K. D., and Reid, D. W. (2001). The couple's mutual identity and reflexivity: a systemic-constructivist approach to the integration of persons and systems. *J. Psychother. Integr.* 11, 385–410. doi: 10.1023/A:1016658301629

Fiszer, C., Dolbeault, S., Sultan, S., and Brédart, A. (2014). Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psychooncology* 23, 361–374. doi: 10.1002/pon.3432

Fletcher, K. A., Lewis, F. M., and Haberman, M. R. (2010). Cancer-related concerns of spouses of women with BC. *Psychooncology* 19, 1094–1101. doi: 10.1002/pon.1665

Glaser, B. G., and Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago, IL: Aldine.

Gould, J., Grassau, P., Manthorne, J., Gray, R. E., and Fitch, M. I. (2006). 'Nothing fit me': nationwide consultations with young women with BC. *Health Expect.* 9, 158–173. doi: 10.1111/j.1369-7625.2006.00383.x

Graneheim, U. H., and Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ. Today* 24, 105–112. doi: 10.1016/j.nedt.2003.10.001

Heinrichs, N., Zimmermann, T., Huber, B., Herschbach, P., Russell, D. W., and Baucom, D. H. (2012). Cancer distress reduction with a couple-based skills training: a randomized controlled trial. *Ann. Behav. Med.* 43, 239–252. doi: 10.1007/s12160-011-9314-9

Hilton, B. A., Crawford, J. A., and Tarko, M. A. (2000). Men's perspectives on individual and family coping with their wives' breast cancer and chemotherapy. *West. J. Nurs. Res.* 22, 438–459. doi: 10.1177/01939450022044511

Ianakieva, I., Fergus, K., Ahmad, S., Pos, E., and Pereira, A. (2016). A model of engagement promotion in a professionally facilitated online intervention for couples affected by breast cancer. *J. Marit. Fam. Ther.* 42, 701–715. doi: 10.1111/jmft.12172

Kayser, K., Acquati, C., Reese, J. B., Mark, K., Wittmann, D., and Karam, E. (2017). A systematic review of dyadic studies examining relationship quality in couples facing colorectal cancer together. *Psychooncology* 27, 13–21. doi: 10.1002/pon.4339

Korp, P. (2006). Health on the internet: implications for health promotion. *Health Educ. Res.* 21, 78–86. doi: 10.1093/her/cyh043

Kruse, C. S., Krowski, N., Rodriguez, B., Tran, L., Vela, J., and Brooks, M. (2017). Telehealth and patient satisfaction: a systematic review and narrative analysis. *BMJ Open* 7:e016242. doi: 10.1136/BMJOPEN-2017-016242

Larson, J. H., Vatter, R. S., Galbraith, R. C., Holman, T. B., and Stahmann, R. F. (2007). The relationship evaluation (RELATE) with therapist assisted interpretation: short- term effects on premarital relationships. *J. Marital Fam. Ther.* 33, 364–374. doi: 10.1111/j.1752-0606.2007.00036.x

Paul, C. L., Carey, M. L., Sanson-Fisher, R. W., Houlcroft, L. E., and Turon, H. E. (2013). The impact of web-based approaches on psychosocial health in chronic physical and mental health conditions. *Health Educ. Res.* 28, 450–471. doi: 10.1093/her/cyt053

Porter, L. S., Keefe, F. J., Baucom, D. H., Olsen, M., Zafar, S. Y., and Uronis, H. (2017). A randomized pilot trial of a videoconference couples communication intervention for advanced GI cancer. *Psychooncology* 26, 1027–1035. doi: 10.1002/pon.4121

Reid, D. W., and Ahmad, S. (2015). "Identification with the relationship as essential to marital resilience: theory, application and evidence," in *Couple Resilience Across the Lifespan: Emerging Perspectives*, eds K. Skerrett and K. Fergus (Netherlands: Springer SBM), 139–161. doi: 10.1007/978-94-017-9909-6_8

Reid, D. W., Dalton, E. J., Laderoute, K., Doell, F. K., and Nguyen, T. (2006). Therapeutically induced changes in couple identity: the role of we-ness and interpersonal processing in relationship satisfaction. *Genet. Soc. Gen. Psychol. Monogr.* 132, 241–283. doi: 10.3200/mono.132.3.241-288

Reis, V. A. (2007). *Young Women with BC: A Meta-Analysis of Age Differences Across Quality of Life Domains (Order No. AAI3237767).* Los Angeles, CA: University of Southern California. (accessed on January 20, 2022).

Roddy, M. K., Nowlan, K. M., and Doss, B. D. (2016). A randomized controlled trial of coach contact during a brief online intervention for distressed couples. *Fam. Process* 56, 835–851. doi: 10.1111/famp.12262

Rottmann, N., Hansen, D. G., Larsen, P. V., Nicolaisen, A., Flyger, H., Johansen, C., et al. (2015). Dyadic coping within couples dealing with BC: a longitudinal, population-based study. *Health Psychol.* 34, 486–495. doi: 10.1037/hea0000218

Schover, L. R., Canada, A. L., Yuan, Y., Sui, D., Neese, L., Jenkins, R., et al. (2012). A randomized trial of Internet-based versus traditional sexual counseling for couples after localized prostate cancer treatment. *Cancer* 118, 500–509. doi: 10.1002/cncr.26308

Stamatakos, M., Stefanaki, C., Xiromeritis, K., Pavlerou, N., and Kontzoglou, K. (2011). BC in the reproductive age. The new plague or just myth? *Surg. Oncol.* 20, 169–174. doi: 10.1016/j.suronc.2011.05.004

Vanstone, R., and Fergus, K. D. (2020). Online couple interventions in cancer. *Curr. Opin. Support. Palliat. Care* 14, 67–73. doi: 10.1097/SPC.0000000000000476

Walsh, S. R., Manuel, J. C., and Avis, N. E. (2005). The impact of breast cancer on younger women's relationships with their partner and children. *Fam. Syst. Health* 23, 80–93. doi: 10.1037/1091-7527.23.1.80

Yoon, H. (2013). How do cancer patients and caregivers perceive web-based interventions? A qualitative study. *West. J. Nurs. Res.* 35, 1228–1229. doi: 10.1177/0193945913487172

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

frontiers | Frontiers in Psychology

SYSTEMATIC REVIEW
published: 08 June 2022
doi: 10.3389/fpsyg.2022.827947

Dyadic Experiences and Psychosocial Management of Couples Facing Advanced Cancer: A Systematic Review of the Literature

Marie Hasdenteufel and Bruno Quintard*

LabPsy – Laboratoire de psychologie de l'université de Bordeaux, Unité de recherche EA 4139, Bordeaux, France

Edited by:
Chiara Acquati,
University of Houston, United States

Reviewed by:
Suzie Xu Wang,
Leeds Beckett University,
United Kingdom
Ute Goerling,
Charité Universitätsmedizin
Berlin, Germany

***Correspondence:**
Marie Hasdenteufel
marie.hasdenteufel@u-bordeaux.fr
orcid.org/0000-0002-2172-0440

Specialty section:
This article was submitted to
Psycho-Oncology,
a section of the journal
Frontiers in Psychology

Received: *02 December 2021*
Accepted: *21 March 2022*
Published: *08 June 2022*

Citation:
Hasdenteufel M and Quintard B (2022) Dyadic Experiences and Psychosocial Management of Couples Facing Advanced Cancer: A Systematic Review of the Literature. Front. Psychol. 13:827947. doi: 10.3389/fpsyg.2022.827947

Background: Cancer diagnosis and treatment represent a real upheaval both for the patient and for his or her life partner. Adjustment to cancer has been widely studied at the individual level, however, there is little in the literature about the experiences of the couple as an entity. This is especially true with regard to a population facing advanced cancer. This systematic review aimed to make an inventory of 1) the current knowledge relating to the experience of the patient-partner dyad when confronted with advanced cancer, and 2) the psychosocial interventions specifically centered on this dyad.

Method: This review was conducted using the Cochrane methodology. The eligibility criteria for the literature review were: one of the members of the dyad being treated for advanced cancer, dyad composed of the patient and his/her life partner. Databases from PubMed, PsycArticle, PsycInfo, Psychology and Behavioral Sciences Collection and Scopus were investigated. A thematic content analysis on the basis of admitted articles made it possible to respond to each of our research objectives.

Results: Three hundred eighty-nine citations were found. Twenty were admitted to the systematic review of the literature. It highlighted the following experiences of the advanced cancer patient-life partner dyad: uncertainty about the future, disjointed time, intrusion into the couple's intimacy, attachment style and caregiving within the couple, couple's adjustment to cancer symptomatology, the couple's supportive care needs, role changes, nature of communication within the couple, anticipation of the coming death, and the meanings and beliefs around death. This review also describes the range of couple therapies used in the context of advanced cancer: emotionally focused-couple therapy, existential therapy, art therapy, support therapy and couple communication and intimacy promotion. These therapies seem to have individual beneficial effects for both the patient and his or her life partner as well as improving marital functioning.

Conclusions: These results clearly highlight that consideration of the couple and communication within the couple during care are fundamental to dyadic adjustment to advanced cancer. Further studies (qualitative and quantitative) are needed to better understand the couple's experience in order to adapt the management of the couple facing advanced cancer.

Keywords: advanced cancer, couple, couple's experience, couple therapy, end-of-life

BACKGROUND

Cancer diagnosis and treatment represent a real upheaval, both for the patient and for those around him or her (Nijboer et al., 1998; Carlson et al., 2000; Kayser et al., 2007; Mangione, 2017). It generates multiple repercussions of a psychological, physical, social and existential nature (Janda et al., 2007; Hagedoorn et al., 2008; Northouse and McCorkle, 2015). Faced with cancer and these repercussions which act as stressors, cancer patients and their family members adopt diverse individual strategies to cope (to modify the situation or to modify their reactions to make it more bearable) (Lazarus Folkman, 1984). While many studies have been carried out using this approach and focusing on the experience of the cancer patient, few studies have explored the experience of the couple, as an entity, and its adjustment to the disease (Untas et al., 2012).

Many studies showed that the wellbeing of caregivers and their loved ones with cancer are closely linked; this is particularly true when the primary caregiver is the spouse (Northouse, 1989; Baider et al., 1996; Northouse et al., 1998; Hodges et al., 2005). Both members of a couple have a mutual impact on each other's quality of life, psychological health and adaptation to their respective roles (Northouse et al., 1998; Kim et al., 2008). Cancer diagnosis and treatment then appear as stressors for the couple (Maughan et al., 2002; Dankoski and Pais, 2007).

Stress and its management would be then an interactive phenomenon between the two partners of a couple, the signs of stress of one triggering management reactions in the other (Bodenmann, 1995). Concept of dyadic coping was thus introduced and it corresponds to the set of efforts of one or both partners intended to manage stressful events, as well as the tensions experienced by one (individual stress) or by both partners (dyadic stress) (Bodenmann, 1995). It includes management strategies for maintaining or restoring the structural, functional, behavioral, emotional and social balance of the dyadic system as well as the balance of each partner (Bodenmann, 1995). If this is a first way of conceiving the dyad, we can even go further in its apprehension by taking into account the disease, the family, medical and social contexts, while specifying the relations between the patient and his/her life partner (that is to say taking into account the patient, the life partner and their relationship); each entity (patient, relative, dyad) with its own characteristics in terms of history, transactional variables and criteria (Berg and Upchurch, 2007; Untas et al., 2012). Finally, 3 concepts are fundamental to understanding the dyad (and fit perfectly into the conception presented above): "communication," "reciprocal influence," and "patient-caregiver congruence"[1] (Manne and Badr, 2008; Fletcher et al., 2012; Li and Loke, 2014). Indeed, in the context of cancer, a satisfactory communication between couples is linked to less distress and better marital adjustment (Li and Loke, 2014). Multiple interactions within dyads correlate with a sense of wellbeing and dyadic adjustment (Li and Loke, 2014). And congruence in dyads is linked to better individual health-related quality of life outcomes and relationship satisfaction (Li and Loke, 2014). For example, symptoms related to cancer affect the communication and interaction within a couple (Li and Loke, 2014).

If the symptoms linked to cancer appear as predominant mediating factors in the adaptation of the dyad to cancer, they are all the more present when the patient is in the palliative phase of the disease; which may suggest that the adaptation of the couple is all the more complicated. The palliative phase of the disease can be assimilated to what is called "advanced cancer" which is defined as follows: "cancer that is unlikely to be cured or controlled with treatment; it may have spread from where it first started to nearby tissue, lymph nodes, or distant parts of the body [...]" (NIH, 2011). What is more, as well as the symptomatic which worsens, the palliative phase resounds with the anticipation of the fatal outcome, which generates an intense distress for the couple (Delvaux, 2006). In addition, there are communication difficulties, difficulties relating to physical and emotional care and emotional difficulties linked, particularly in the way to feelings of separation and loss (Delvaux, 2006).

If at the individual level, we know that the palliative cancer phase exacerbates these difficulties (Weitzner et al., 1999), it is legitimate to think that at a dyadic level it is the same thing. However, there is very little evidence in this specific area of dyadic end-of-life experience. von Heymann et al. (2017) wrote that "the application of the concept of dyadic adaptation at the end of life is relatively new and the role of dyadic adaptation at very advanced stages of the disease is not clear" (von Heymann et al., 2017). It is therefore essential to take an interest in the dyadic adaptation of the patient and his/her life partner in this last phase of the life. Thus, the objectives of this systematic review of the literature were: 1) to explore the literature on the dyadic experience of the patient and his/her life partner when confronted with advanced cancer; and 2) to highlight the main psychosocial interventions

---

[1] Communication:"a transactional process in which individuals create, share, and regulate meaning."
Reciprocal influence: "the effect the two members of a dyad have on each other."
Caregiver patient congruence: "the concept of congruence synthesizes individual data into a dyad variable, related to agreement, concordance, and their opposite, disparity" (Fletcher et al., 2012).

offered to the patient-life partner dyad in the context of advanced cancer and what their effects are.

METHOD

Eligibility Criteria

To establish our search strategy, we relied on the PICOTS criteria (Population, Intervention, Comparison, Time, Setting) to break down the evaluation question into different concepts that we used to build the research strategy:

- Population: All studies on adult patients (>18 years old) with a diagnosis of advanced cancer ("stage III" and "stage IV" or "terminal cancer") and their life partner (spouse, partner, husband, wife, civil union), with no limitations regarding time since diagnosis or cancer location were included. Couples could be either homosexual or heterosexual.
- Intervention: Studies relating both to (1) the couple's experience and (2) psychosocial interventions intended for the couple, in the context of advanced cancer, were included.
- Comparison: In view of the difficulty accessing the population studied, the absence of a control group was not an exclusion criterion.
- Outcomes: Studies relating to the quality of life, psychosocial aspects and symptoms were included and any studies reporting results which related to the structural, functional, behavioral, emotional and social balance of the dyadic system.
- Temporality: We did not place any time restrictions.
- Setting: The study population is accompanied by care services (ambulatory or complete) or an oncologist.

We are aware that with such broad search criteria many documents could be found (editorials, letter to the editor, open forum, news, summary articles, original articles). We wanted to make our own selection of the types of documents to integrate according to the number of results found. We made this choice with regard to the research context (end of life) in which we operate. We know that this is a context where it is difficult to conduct analytical studies.

Source Information and Search Strategy

We queried the following electronic databases: PubMed, PsycArticle, PsycInfo, Psychology and Behavioral Sciences Collection and Scopus, with no limitation for publication date or language. The search was last updated on 31 October 2021. While the search strategies were the same for each database, they were adapted to the way the database works. The search strategy with thesaurus was as follows: "Couple" AND "palliative care" (**Appendix**). According to the database thesaurus, there could have been nuances in some key terms (e.g., for the expression "palliative treatment"). The search strategy without thesaurus was: "Couple" AND "palliative care" OR "end of life care" OR "terminal care" OR "dying." Without the thesaurus, a search strategy was carried out with descriptor "Keyword" and "Subject." All of these strategies were used in each database. This search strategy was validated by a librarian.

Study Screening and Selection

All search results were merged into an Excel spreadsheet. Duplicates were excluded. The title and abstract of each of the articles were reviewed and those who did not meet the eligibility criteria were excluded. The process of excluding articles on the basis of title and abstract was carried out in an independent double rating, by MH and BQ on 10 references, in order to reinforce the interrater validity of this review. In case of doubt, the full texts were read. Full texts were studied for all remaining studies. Those who did not meet the eligibility criteria were excluded. The process of excluding articles on the basis of reading the full texts, was carried out in independent double rating, by MH and BQ on 10 references in order to reinforce the interrater validity of this review. For accepted articles, a characteristic table of studies was completed. We completed our search strategy by studying the bibliographies of the included studies.

Then, for each study, a distinction was made as to whether it met objective 1 (dyadic experience of the patient and his/her life partner when confronted with advanced cancer) or objective 2 (psychosocial interventions offered to the patient-life partner dyad in the context of an advanced cancer and their impact). Finally, a thematic content analysis of each study was conducted separately by two psychology researchers (BQ and MH) who then compared their results in order to identify the main themes mentioned in the literature, related to each of the two research objectives. This thematic content analysis was conducted according to the methodology proposed by Paill and Mucchielli (2021).We chose thematic content analysis because it is no longer just a question of identifying themes, but also of checking whether they are recurrent from one material to another and how they overlap, join, contradict each other, complement each other (Paill and Mucchielli, 2021).

Critical Evaluation of Study Quality

The Critical Appraisal Toolkit was developed by a team from the Public Health Agency of Canada and a Cochrane reviewer with methodological expertise to appraise analytical studies, descriptive studies and reviews of literature (Public Health Agency of Canada, 2014). This toolkit was originally designed to evaluate evidence in the field of infection prevention and has been applied to other areas. This toolkit addresses the following points for analytic studies: participants, internal validity, confounding control, ethics, analyses, and applicability. For descriptive studies, the following points are evaluated: the participants, the sources and methods of collection, the instruments used, the ethics and the analyses. Moreover, the toolkit for descriptive analyses proposes criteria to try to understand the quality of a case report; which in our field of study seems very relevant. Finally, the Critical Appraisal Toolkit classifies the quality of studies as high (no impediment to the ability to draw a conclusion about the clear association between the exposure and the outcome under study), medium (probability that there is an association between the exposure and the outcome under study) or low (association between exposure and outcome under study is compromised). This tool therefore gives us the opportunity to assess the quality of the study but also the strength of the study design and the directness of the evidence.

This methodological quality appraisal of the included studies was performed independently by two researchers (BQ and MH). When discrepancies appeared, oral discussion of the manuscripts was performed for consensus.

RESULTS

Selection and Description of Studies

A total of 389 citations were found through this search strategy, including 301 through PsycINFO, PsycArticle, Psychology and Behavioral Sciences Collection, 71 through PubMed and 17 through Scopus (**Figure 1**). After excluding duplicates ($n = 40$), 349 records were screened (titles and abstracts), which led to the exclusion of 293 studies (object of study, population). Thus, 56 full-text articles were assessed, of which 38 were excluded, leaving 18 studies. Two additional references, found in the bibliography of the articles, were included, which finally corresponded to 20 studies admitted to the review. Ten studies met our first objective and 10 studies met our second objective.

Themes Identified in the Literature on the Dyadic Experiences of the Patient and His/Her Life Partner When Confronted With Advanced Cancer

Of the 20 studies admitted in our review, 10 met our first objective (to describe the adjustment of the patient-life partner dyad for advanced cancer):we identified 1 book chapter, 1 clinical correspondence, 1 case study, 1 review of the literature (2007), 3 qualitative studies and 3 quantitative studies (2 descriptive-cross-sectional, 1 descriptive longitudinal). Most of the studies were conducted in North America (2 in the United States, 3 in Canada). The other studies were conducted in Switzerland ($N = 1$), the United Kingdom ($N = 1$), France ($N = 1$), Belgium ($N = 1$) and Germany ($N = 1$). At least 779 couples were studied. Patients had an average age of 63.08 years. Caregivers had an average age of 60.27 years. The results of these studies are summarized in **Table 1**.

The results of the quality assessment are summarized in **Table 2**. Very high inter-rater agreement was obtained. Two studies were "high quality." Four studies were "moderate quality" due to missing information concerning ethics, tools whose validity and reliability have not been demonstrated but whose validity can be believed in the light of the questions asked and the expertise of researchers, analyses that cannot demonstrate the effect with certainty, or non-random sampling. Finally, four studies (1 case study and 3 reviews) were characterized as having "low quality": the reviews because they were narrative reviews; the case report because the quality (particularly at the level of the analysis) was not high. While for six of these studies, the quality is "good" to "moderate," the research plan remains is "low" because of the design of the study (descriptive study).

Couples in which one partner had been diagnosed with advanced and terminal cancer report both their individual (intra-personal) and shared (dyadic) experiences (Gardner, 2008). While most of the time the discourses of patients and their spouses agreed, there may be some discrepancies (e.g., death, beliefs, etc.) (Gardner, 2008). The systematic analysis of the issues faced by these couples could be grouped into ten main themes which are summarized as follows: uncertainty about the future, disjointed time, intrusion into the couple's intimacy, attachment style and caregiving within the couple, couple's adjustment to cancer symptomatology, the couple's supportive care needs, role changes within the couple, nature of communication in the couple, anticipation of the coming death, and the meanings and beliefs around death.

Uncertainty About the Future

One of the most common concerns described by patients and spouses was the struggle to deal with the uncertainty and ambiguity surrounding the patient's health status and future (and thus the partner's own future) (Gardner, 2008; Weißflog et al., 2017). This concern could weigh on the relationship (Gardner, 2008).

A Disjointed Time

Faced with serious illness, time-sharing no longer took the same signification (Reny, 2020a). The patient and their partner found themselves in a time that could no longer be joined (Reny, 2020a). The crisis caused by the disease generated a feeling of rupture (Reny, 2020a). Nothing was the same as before (Reny, 2020a).

Intrusion Into the Couple's Intimacy

Changes in relationships were related, among other things, to treatment (Drabe et al., 2016). Indeed, illness and treatment intruded into the realm of the couple just as they burst into the body of the patient (Reny, 2020a). Complicity, intimacy and being together were harder to achieve (Reny, 2020a). Intimacy is the deepest thing in ourselves, the most secret, it is above all what we do not share, or only if we decide, with those who we choose (Reny, 2020a). The intimate refers to the hidden, to the personal, to what cannot be seen in the eyes of all (Reny, 2020a). Therefore, the intimate is not reduced to the sexual (Reny, 2020a). Both intimacy and sexuality, are damaged by illness and care. The myth of cancer contagion and fear of pain can drive the couple away from sexuality (Cort et al., 2004). Irrespective of whether the cancer site involved the sexual organs, sexual self-esteem and functioning can be impaired (Cort et al., 2004). Sexual problems often arise from interpersonal problems to which both partners contribute (Cort et al., 2004). In some cases, the diagnosis of cancer could allow couples to re-examine their relationship and move forward in a positive way (Cort et al., 2004). The reverse is also true (Cort et al., 2004).

Depending on the functioning of the couple, the defenses against the intrusion of the disease and treatment, can be more or less extreme (Reny, 2020a). Some couples will need to fight against the disease by being in complete fusion, to "become one" in the face of the intrusion of the disease and the treatment associated with it (Reny, 2020a). While others will, on the contrary, be in a distancing mode to protect themselves from too much anxiety (Reny, 2020a). The regulation of proximity/distance within the couple appears to be a fundamental issue for the couple (Drabe et al., 2016).

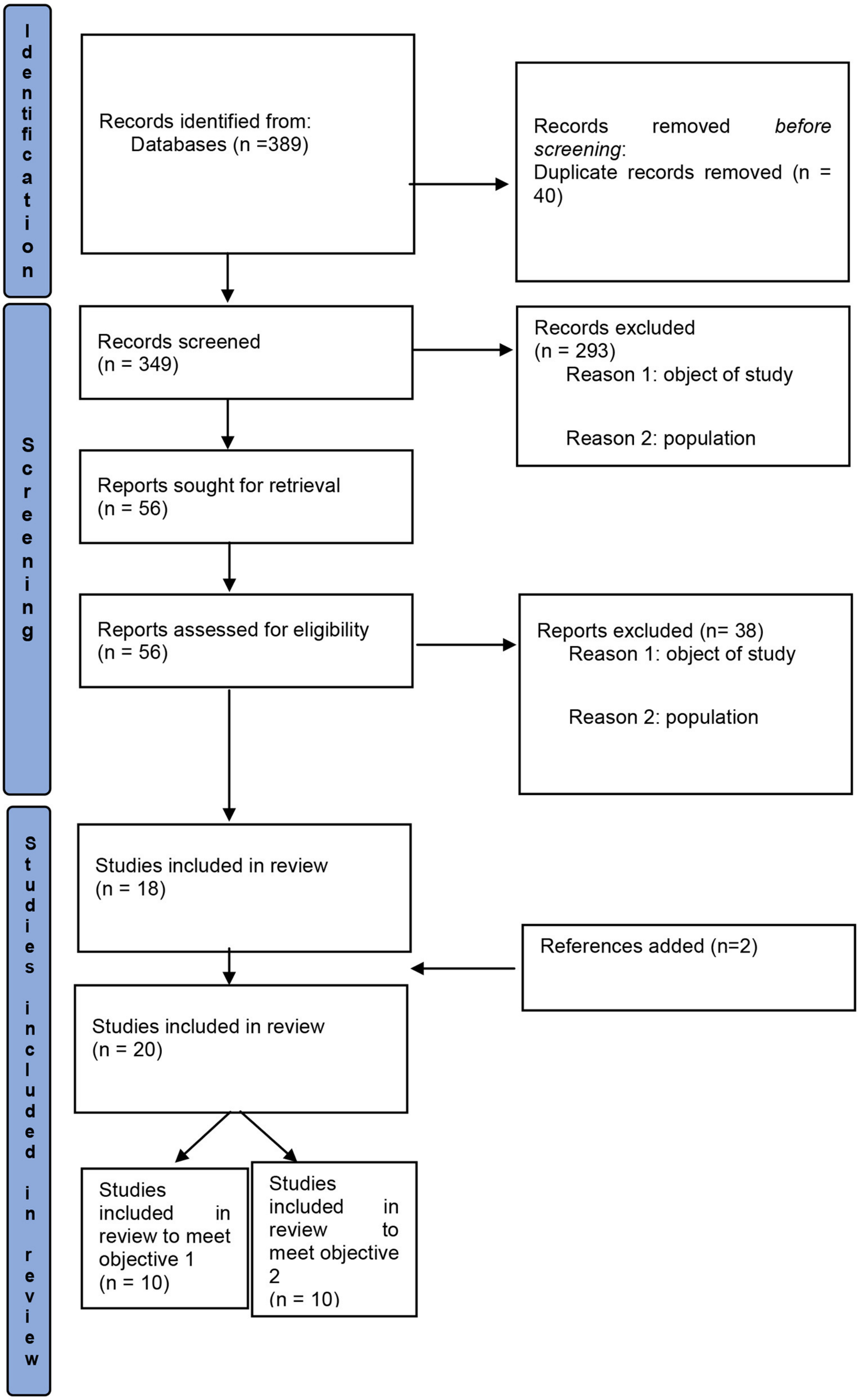


FIGURE 1 | Flowchart of the study selection process.

TABLE 1 | Descriptive table of experience of patient-life partner dyad faced with advanced cancer.

References	Aim	Population	Instruments	Data analyses	Results
Opsomer et al. (2019)	To explore how couples cope with nutrition-related issues in advanced cancer	7 couples Patients: - women 57.14% - age 67.6 y - advanced cancer (multisite) Caregivers: - women 42.86% - age: NA	Semi-structured interviews (patient and his or her partner were interviewed concurrently)	Qualitative Analysis Guide of Leuven (QUAGOL)	Overarching coping strategies: to maintain routines and normality in daily life; to create new routines or a new normality. Disclosure of nutrition-related problems: overt communication, presenting the problem the way it appears; overt communication of problem together with its solution or how to deal with it; hiding problem from the partner and disclosing it during the interview; exposing problem because it is too obvious to hide. Couple-coping pathways: practical oriented (action of partner: adapting food; taking over daily tasks; searching for a practical solution; making it easy for the patient) (reaction of the patient: accepting help; not accepting help); emotion oriented (action of partner: emphasizing the severity, confirming empathically, insisting) (reaction of the patient: confirming the words of the partner, toning down the words of partner, contradicting the word of partner); distance oriented (action of partner: withdrawing, not responding) (reaction of partner: coping individually)
Gardner (2008)	To explore patterns of relationships, support and communication in married couples or couples where one partner is diagnosed with advanced and terminal cancer	35 couples Patient: - women 29% -age 66 y - advanced cancer (multisite) Caregiver: - women 71.43% - age 65 y	Semi-structured interviews (each patient and partner caregiver met face-to-face with an interviewer, first together and then for separate interviews)	Grounded theory analytic methods	Individual and dyadic processes: existence of individual and dyadic discourses, where patient and partner respondents moved fluidly and repeatedly between individual and dyadic frames of reference. Living with uncertainty: most common concerns that patients and caregivers described was the struggle to deal with the uncertainty and ambiguity surrounding the patient's medical condition and future. Illness and dying trajectories: awareness of death pervaded the responses of study participants and its interrelated themes of uncertainty about the future. Search for shared meanings: despite differences in personal awareness and acceptance about death, some couples seemed to be working toward a shared understanding, narrative, or philosophical approach related to the patient's illness trajectory and ultimate prognosis.
Weißflog et al. (2017)	To evaluate the levels of dyadic coping and supportive care needs and their concurrent associations	330 couples Patients: - women 36.7% - age 57 y -advanced cancer (hematologic) Caregiver: - women 63% - age 56 y	Dyadic coping inventory (DCI) Supportive care needs survey-short form German version (SCNS-SF-34-G)	Actor-partner interdependence models (APIM)	Perception of partners' delegated dyadic coping was higher. Higher perceptions of partners' negative dyadic coping were associated with higher supportive care needs for both patients and partners. Higher perceptions of patients' own stress communication and supportive care need, but only for the patients.

(Continued)

TABLE 1 | Continued

References	Aim	Population	Instruments	Data analyses	Results
Mah et al. (2020)	To evaluate a moderated mediation model in which perceived couple communication mediates the relationship between attachment security and death preparation in individuals with advanced cancer and in which gender and age moderate these relationships.	Participants -women 55.4% -age 58.10 y	Quality of Life at the End of Life Cancer Scale (QUAL-EC) Experiences in Close Relationships Scale (ECR). Couple Communication Scale Patient Health Questionnaire (longitudinal data: baseline, 3 and 6 months)	Mediation and moderated mediation	Couple communication mediated the relationship of attachment security to preparation for end of life and life completion Anxiety and Gender effects on baseline couple communication: indicated that women with greater attachment anxiety reported worse communication than their male counterparts. Couple-communication, gender and age effects on baseline preparation for end of life: suggested that women showed better preparation with better couple communication. Younger patients reported less preparation than older patients, especially with poorer communication, but their preparation increased with better communication, especially in younger men.
Braun et al. (2012)	To examine associations between caregiving styles and caregivers' and patients' attachment orientations among couples facing advanced cancer.	110 couples Patients: - women NA - age 61.7y Advanced cancer (lung cancer gastrointestinal) Caregivers: - women 76.9% - age 59.8 y	Experiences in Close Relationships inventory (ECR) Caregiving Questionnaire Demand Subscale from the Caregiving Burden Scale	Hierarchical regressions	Caregivers reported high levels of proximate and sensitive caregiving and moderate levels of controlling and compulsive caregiving. Both caregiving proximity and sensitive caregiving were negatively associated with caregivers' avoidant attachment. Controlling caregiving was positively related to caregivers' avoidant and anxious attachment orientations. Compulsive caregiving was positively associated with caregiving demand and caregivers' attachment anxiety. Compulsive caregiving was positively associated with patients' attachment avoidance and negatively associated with patients' attachment anxiety.
Reny (2020a)	To examine how the couple is accompanied when faced with the end of life	Patient: - women: 25% - age: NA - advanced cancer (multisite) Caregiver: - women: 75% - age: NA	Case study		Time-sharing no longer took the same signification. Achievements such as complicity, intimacy, being together were called into question. Complete fusion of couple VS phenomenon of distancing. The roles of each become different. Patients and spouses report actively hiding negative emotions and grief from their counterparts to avoid worry about each other. Talking to each other, understanding each other becomes more complex. The disease breaks a part of illusion: soon the couple will no longer be.

(Continued)

TABLE 1 | Continued

References	Aim	Population	Instruments	Data analyses	Results
McLean and Jones (2007)	To provide an overview of the impact of cancer on the couple,	End of life cancer	Review		Major depressive syndromes, anxiety, and role adjustment problems: patients and their spouses (increases as death approaches). Similarities in terms of distress response between patients and their spouses. Factors could explain distress: patient's condition (demographic, and psychological factors, social support and resources), level of marital satisfaction, quality of family functioning, difficulties in the ease of couples communicating cancer-related concerns, high conflict, low expressiveness, low cohesion (and the other hand: high levels of support, cohesion, expressiveness, and low conflict, positive emotional environment could help). Secure marital bond: attachment insecurities and behaviors are adequately addressed within the relationship (and the other hand: with insecure marital bond, attachment insecurities and behaviors may be expressed in maladaptive patterns of interaction that maintain separation distress). Attachment and caregiving styles are closely linked: secure attachment is linked to highly responsive care while, insecure attachment is linked to a low level of responsive care. Unresolved issues (with emotions, such as anger, sadness and longing, shame, and fear) in the marital relationship can either pose as a significant threat to the attachment bond, or an opportunity for further growth and development. Patients facing end of life express concerns regarding their spouses and families + the desire to strengthen relationships (these concerns can often exceed disease-related concerns). Patients and spouses may seek increased avoidance, or proximity and closeness to each other.
Drabe et al. (2016)	To gain a deeper understanding about couples' relationship changes over time after one partner is diagnosed with an incurable advanced melanoma.	8 couples	Semi structured interviews (longitudinal data: baseline, 6 months)	Qualitative content analysis	Baseline: relationship changes reported in terms of caring, closeness/distance regulation, and communication patterns. 6 months: relationship changes reported in terms of caring, distance/closeness regulation, greater appreciation of the relationship and limitations in terms of planning. 50% of patients and partners: hiding their negative emotions and sorrows from their counterparts to spare them worry.

(Continued)

TABLE 1 | Continued

References	Aim	Population	Instruments	Data analyses	Results
Iwasaki et al. (2018)	To discuss the existential questions of patients and their partner facing the end of life	Advanced cancer	Clinical correspondence		Patients are concerned about the future of their family members, especially their spouses. End-of-life discussions often remain practical in nature (pain relief, funeral arrangements, distribution of belongings, etc.). Scaffolding for communication about "what about you after I'm gone¿' can be important. Discussing a spouse's future intimate relationships and happiness could ease deep concern and existential distress in dying patients; it helps the surviving partner to feel less distressed if such opportunity arises Having the agreement or permission of a dying patient may reduce the possible negative consequences associated with a new romantic relationship if it is continued. Such a conversation may reduce existential distress, increase peace of mind and bring the dying patient to a state of relief.
Cort et al. (2004)	To describe the sexual and intimacy needs of the couple when one partner has a terminal illness	Advanced cancer	Chapter of book		The myth of cancer contagiousness and fear of pain can drive the couple away from sexuality. Sexual problems often arise from interpersonal problems to which both partners contribute. Diagnosis of cancer could allow couples to re-examine their relationship and move forward in a positive way (reverse is also true).

TABLE 2 | Quality assessment of the included studies of dyadic experiences of the patient and his/her life partner when confronted with advanced cancer.

References	**Type of studies**	**Research question**	**Particip-ants**	**Sources and methods**	**Tools**	**Ethics**	**Analyses**	**Study plan strength**	**Quality of study**	**Directness of evidence**
Opsomer et al. (2019)	Descriptive	✓	—	✓	—	✓	⊗	Low	Moderate	Direct
Gardner (2008)	Descriptive	✓	—	✓	—	⊗	—	Low	Moderate	Direct
Weißflog et al. (2017)	Descriptive	✓	—	✓	✓	✓	✓	Low	High	Direct
Mah et al. (2020)	Descriptive	✓	—	✓	✓	✓	—	Low	Moderate	Direct
Braun et al. (2012)	Descriptive	✓	—	✓	✓	⊗	✓	Low	High	Direct
Drabe et al. (2016)	Descriptive	✓	—	✓	—	✓	—	Low	Moderate	Direct

References	**Type of studies**	**Participants (case report)**	**Quality (case report)**	**Conclusion**
Reny (2020a)	Descriptive (case report)	✓	⊗	This case study suggests lines of thought relating to the phenomenon under study. It is necessary to carry out more robust studies in order to have a sufficient level of proof to validate the hypotheses put forward.

References	**Type of studies**	**Research question**	**Included Studies and Critical Appraisal**	**Conclusion**
Iwasaki et al. (2018)	Review	—	⊗	This review suggests lines of thought relating to the phenomenon under study. It is necessary to carry out more robust studies in order to have a sufficient level of proof to validate the hypotheses put forward.
Cort et al. (2004)	Review	—	⊗	
McLean and Jones (2007)	Review	✓	⊗	

✓*: strong/high*
—*: moderate/medium*
⊗*: weak/low*

Attachment Style and Caregiving Within the Couple

The regulation of proximity/distance can be explained, among other things, by the type of attachment between partners. Several studies have worked on the type of caregiving[2] according to attachment style (McLean and Jones, 2007; Braun et al., 2012). Research has shown that attachment and caregiving styles are closely related and predictive of marital satisfaction. Avoidant attachment of spouses was negatively correlated with proximal and sensitive care (Braun et al., 2012). Anxious attachment of spouses and demand for care were positively associated with compulsive care (Braun et al., 2012). Avoidant and anxious attachment of spouses was positively correlated with controlling care (Braun et al., 2012). Finally, compulsive care provided by the caregiver was positively associated with avoidant attachment of patients and negatively associated with anxious attachment of patients (Braun et al., 2012). Another study showed that secure attachment was correlated with highly reactive care (a composite of proximity, sensitivity, and cooperation) and insecure attachment with reactive care (McLean and Jones, 2007).

Couple Adjustment to Cancer-Related Nutrition Issues

Daily life as a couple was also seriously threatened by nutrition-related problems and only one study addresses this issue. Opsomer et al. (2019) report that in their attempt to cope with nutrition issues threatening their health, couples seem to adopt three different couple coping paths: practice-oriented, emotionally-oriented, or distance-oriented. Each consists of an action of the partner followed by a reaction of the patient. The practice-oriented path is characterized by the partner trying to offer practical help (e.g., by adapting the patient's diet or taking care of daily tasks), followed by the reaction of the patient who has often accepted the proposed help. In the emotion-driven journey, the partner's action is communicative, emphasizing the severity of symptoms, making empathetic responses, or insisting that the patient eats. Such a communicative action is usually followed by a communicative reaction on the part of the patient: it confirms the partner's words, attenuates them or contradicts them. For the distance-oriented pathway, the partner withdraws or does not take any action. Therefore, the patient must cope alone.

Couple Adjustment and Supportive Care Needs

Levels of dyadic adaptation appear to be related to supportive care needs (Weißflog et al., 2017). High perceptions of partners' negative dyadic coping were associated with high support care need for both patients and partners (Weißflog et al., 2017). The same was true for patients' own stress communication and support care need, but only for the patients (Weißflog et al., 2017).

Roles Changes Within the Couple

Treatment and illness generate an asymmetry between the ill partner and the one who is (assumed to be) healthy (Reny, 2020a). Faced with illness, couple dynamics change; roles change and the weight of guilt, even debt can be experienced (Cort et al., 2004; Reny, 2020a). While communication (e.g., open, empathetic, on existential questions, on fears and the changing perception of time, on the concrete modalities of the end of life, but also reflecting back on married life) within the couple promotes adaptation to changes in roles, it also appears to be a key element in the adoption of more adaptive coping strategies, and in the satisfaction and the quality of the conjugal relationship (McLean and Jones, 2007).

Communication Within the Couple

Communication is central to the intimate relationships. Following the diagnosis of advanced cancer, communicational patterns within the couple change (Drabe et al., 2016). Patients and spouses report actively hiding negative emotions and grief from their counterparts to avoid worrying each other (Cort et al., 2004; Drabe et al., 2016; Reny, 2020a). Talking to each other, understanding each other becomes more complex (Reny, 2020a). Difficulty communicating about cancer problems can lead to emotional insecurity, distress and relationship instability (McLean and Jones, 2007). Conversely, a good level of communication contributes to the proper functioning of the couple (as well as a high level of support and cohesion and less conflict), which will in turn reduce the level of distress, anxiety and depression (McLean and Jones, 2007).

It turns out that end-of-life communication is essentially focused on the practical dimension (e.g., pain relief, funeral arrangements, distribution of personal belongings, etc.) (Iwasaki et al., 2018). However, one study demonstrates that discussion between patient and spouse about the surviving spouse's romantic future would help reduce the negative consequences associated with a new romantic relationship in which the surviving spouse may become involved (Iwasaki et al., 2018). Such a conversation can reduce existential distress, increase peace of mind, and bring relief to the dying patient (Iwasaki et al., 2018). Finally, another study highlights that open couple communication mediates the relationship between attachment security and end-of-life preparation (Mah et al., 2020). Specifically, the interaction between anxious attachment and gender influences communication within the couple: women with anxious attachment reported worse dyadic communication than their male counterparts. In addition, Mah et al. (2020) showed that couple communication, gender and age influence preparation for the end of life. Partners of women showed better preparation than partners of men for the end of life (in connection with better couple communication). In the same study, younger patients reported less end-of-life preparation than older patients (related to poor couple communication), but their end-of-life preparation increases with better couple communication, especially in younger men.

---

[2] Caregiving proximity – comfort with physical closeness during support provision; Sensitive caregiving – attuned responsiveness to partner's signals and needs; Controlling caregiving – a domineering style of caregiving, which lacks sufficient respect for partner's own problem-solving and decision making processes; Compulsive caregiving – a tendency to be over involved and over-protective, often being overwhelmed by extreme identification with partner's problems (Braun et al., 2012; McLean and Jones, 2007).

Anticipation of Upcoming Death

Couples are not prepared to anticipate the death of the other (Reny, 2020a). The couple is defined as the union of two people by means of a "love bond marked by an avowed or undeclared intention to last" (Reny, 2020a). The possibility of the death of the other impacts this primary intention of the couple (Reny, 2020a). The disease breaks a part of the illusion: soon the couple will no longer be (Reny, 2020a). It is a moment of doubt about the value that the other can bring us and about the value we can also give (Reny, 2020a). While death consciousness is a central concern for the patient and his/her spouse, it can be denied and distanced from couple discussions (Gardner, 2008). For many patients, the subject of death is closely linked to concrete concerns about the wellbeing of their partners, children and grandchildren (Gardner, 2008). For caregivers, the problem of the future without the loved one is essential (Gardner, 2008). Despite differences in personal awareness and acceptance of death, some couples are working toward a common understanding, narrative or philosophical approach of the future, related to the trajectory of the patient's disease and ultimate prognosis (Gardner, 2008). A new layout is necessary, a new way of being together is worked (Reny, 2020a).

The Meanings and Beliefs Around Death

While spouses share personal and shared beliefs about health and disease in relation to cancer, the most common is the importance of maintaining a positive or optimistic attitude (Gardner, 2008). Many considered positive thinking as a method of control in the face of an uncertain course and prognosis of the disease (Gardner, 2008). Patients and spouses talked about working together to maintain a positive approach and value mutual optimism (Gardner, 2008). Many participants relied on faith to make sense of their situation (Gardner, 2008). For couples with differing beliefs, lack of shared meaning sometimes interfered with mutual support (Gardner, 2008).

To summarize, advanced cancer and the care it requires have an impact on both the individual and the couple. As reported in the selected studies in the field, the couple facing death is confronted with a multitude of questions and changes related to the future, time, intimacy, roles, nutrition, confrontation with death and communication. Communication, supportive care needs, the need for dyadic optimism, the type of caregiving are all ways in which the couple deals with these issues and changes. For these reasons offering couple therapy in this difficult time can lead to a reduction in psychosocial distress and may actually offer an opportunity for relational growth during the later stage of life (Murillo and Holland, 2004; Hodges et al., 2005). We will discuss types of interventions in the following section.

Impact of Dyadic Psychosocial Interventions on the Couple's Experience of Advanced Cancer

Of the 20 studies included in this review, 10 met our second objective (to describe couple-centered interventions dealing with advanced cancer): 5 case studies, 2 qualitative studies, 3 quantitative studies (2 descriptive-cross-sectional and 1 experimental with a randomized controlled trial). Most studies were conducted in America (3 = USA, 4 = Canada). The other studies were conducted in the United Kingdom ($N = 1$), Switzerland ($N = 1$) and France ($N = 1$). At least 69 couples were studied. Patients had an average age of 61.28 years. Caregivers had an average age of 55.59 years. We detailed the methodology and results of each of the included studies in a comparative table (**Table 3**). Five categories based on the type of intervention emerged: emotionally focused-couple therapy, existential therapy, art therapy, support therapy, and couples' communication and intimacy promotion. They are presented below.

The results of the quality assessment are summarized in **Table 4**. Very high inter-rater agreement was obtained. Two studies were characterized as "high quality"(of which one case report that used the most robust methodology possible). Four studies were defined as having a "moderate quality" with regard to a multitude of criteria (ethics, tools, analyzes, power and effect size, comparability, information bias, etc.). Finally, four studies (case reports) were characterized as having a "low quality" because the quality, particularly at the level of the analysis, was not high. Although for 6 of these studies, the quality is "high" to "moderate," the research plan remains is predominantly "low" because of the design of the study (non-comparative before-and-after study, descriptive study). Only 1 study was a randomized controlled trial.

Emotionally Focused-Couple Therapy

Two studies used emotionally focused-couple therapy (modified for advanced cancer population) (McLean and Hales, 2010; McLean et al., 2013). This therapy aims to facilitate marital relationships by changing habitual and distressing patterns of interaction, to increase mutual understanding and emotional engagement, and to strengthen the marital bond. Couples benefited from 8 sessions. There was an improvement in marital functioning and the patients perceived their partners' behavior as more empathetic.

Existential Therapy

Two studies explored existential therapy (Lantz and Ahern, 1998; Wagner et al., 2016). This therapy aims to increase meaning in life and sense of transcendence, determine wishes and hopes, and help patients and their partners communicate more openly about death and dying. With the intervention, the loss of meaning and the issues generating the loss of meaning were reduced (Lantz and Ahern, 1998). In addition, there was a decrease in anxiety and depression among caregivers, and an increase in feelings of peace about the illness and perceptions of coping ability (secondary assessments) (Wagner et al., 2006).For patients, threat assessment decreased (Wagner et al., 2006). A third study used an intervention echoing existential therapy as it related to an intervention with conversations centered on hope and suffering (Benzein and Saveman, 2008). With this intervention couples felt that they engaged themselves in a trustful relationship, and that it was a healing experience. They had opportunity to unburden themselves. It was a way of learning and finding new strategies for managing daily life.

TABLE 3 | Descriptive table of interventions focused on the patient-life partner dyad faced with advanced cancer.

References	Disease	Intervention	Population	Instruments	Data analyses	Significant results	Non-significant results
Mohr et al. (2003)	Metastatic cancer	8 sessions of 50/60 min. 1/week. Reduction of distress in the couple, improving communication, and increasing intimacy to the degree that these are goals of the couple. Facilitate change of meaning (beliefs, goals, values). Increase intimacy, emotional support, reciprocity. Facilitate discussion of death and dying. Facilitate discussion about children.	6 couples Patients: - women 66.7% - age 49.3 y Caregivers: - women 33.3% - age 50.1 y	Death anxiety and worrying Depression: Beck Depression Inventory-II (BDI-II) Quality of life: global QOL Relationship quality: Positive relationship and negative relationship Social support: Perceived Spousal Support Scale (positive support and negative support). Caregiver burden: Zarit Caregiver Burden	Effect sizes	Patients: Decreased distress about dying Improved positive relationship Partners: Decreased frequency of worry about dying	Patients: Worry about dying Depression Quality of life Relationship Negative Positive support Negative support Partners: Distress about dying Depression Quality of life Caregiver Burden Relationship positive Relationship Negative Positive support Negative support
McWilliams (2004)	Terminal breast cancer	Psychotherapy based in attachment theory aimed at increasing intimacy	1 couple: 1 female patient aged 83 y, male caregiver aged 81 y	Case study		Psychological growth and preparation for future bereavement. To trust each other more and to trust that they could continue to grow as a couple even though their time was limited.	

(Continued)

TABLE 3 | Continued

References	Disease	Intervention	Population	Instruments	Data analyses	Significant results	Non-significant results
Mowll et al. (2015)	Advanced cancer	PDI–CI intervention (to improve communication around end-of-life issues for couples where one has advanced cancer) 1 session of 1 h.	9 couples: Patients: - women 55% - age 64 y Caregivers: - women 44.4% - age 64 y	Semi-structured interviews	Thematic analysis	The intervention allowed the men to speak. Men and women in couples expressed that the structure of the PDI-CI is particularly useful for men to discuss issues. The intervention helped lift the veil on the feelings of each other. A number of couples reported that the intervention highlighted areas of difference between them, which then made it easier to clarify communication at that time or afterwards. The intervention facilitated changes in behavior toward others. A couple said that discussing the PDI-CI questions made the patient recognize her deteriorating health and accept more help from her husband. A patient from another couple noticed changes in the way her husband looked after her. The importance of the intervention to help prepare for the end of life was also emphasized. The intervention validated an already functional mode of communication. A number of couples felt that the intervention improved their already good communications, which aroused positive feelings. Through the intervention, more than half of the participating couples expressed that they could return to see the psychologist.	
Benzein and Saveman (2008)	Multisite cancer	Conversations about hope and suffering 3 sessions every 2 weeks	6 couples Patients: - women 83.3% - age 52–84 years	Semi-structured interviews	Thematic analysis	Couples feel that they were part of a trustful relationship, and that it was a healing experience. Opportunity to unburden themselves. Way of learning and finding new strategies for managing daily life.	

(Continued)

TABLE 3 | Continued

References	Disease	Intervention	Population	Instruments	Data analyses	Significant results	Non-significant results
Lantz and Ahern (1998)	Advanced cancer	Existential psychotherapy (re-collection)		Case study		To reduce the meaninglessness and the symptoms and problems around meaningless that often develop around the time of the death of a family member. To help the couple facing death to remember, find, discover, confirm, and honor meanings that have been reaffirmed and deposited in the eternity of the past.	
Wagner et al. (2016)	Various forms of cancer	Existential psychotherapy: to increase meaning in life and sense of transcendence, determine wishes and hopes, and help patients and their partners communicate more openly about death and dying. 4 sessions of 60 min.	12 couples Patients: - women 63.4% - age 59.1 y Caregivers: - women 54.4% - age 59.6 y	Anxiety and Depression: the Hospital Anxiety and Depression Scale (HADS) Meaning: Meaning/Peace subscale of the Functional Assessment of Chronic Illness Therapy Spiritual Well-Being scale (FACIT-Sp) Appraisals: Cognitive Appraisals of Health scale (CAHS) Transcendence: The Missoula Vitas Quality of Life Index (M-VITAS) Interview (assess satisfaction of intervention)	Descriptive statistics and paired samples *t*-tests. Thematic analysis.	Partners: Decreased anxiety and depression Secondary Appraisals;Increased peace with Illness Patients: Decreased threat appraisals	Partners: Meaning/Peace Threat appraisals Harm/Loss Appraisals Challenge Appraisals Patients: Anxiety and depression Meaning/Peace Harm/Loss Appraisals Challenge Appraisals Secondary Appraisals Peace with Illness Transcendence
Reny (2020b)		Support		Case study		Allows "emotional discharge." Means of recirculating the word within the couple. Allows (through the support and mediation offered) that the privacy of the subject and the couple is heard and recognized in the face of the invasion of hospital and caregivers within the couple. Opportunity to mourn the couple before the illness. A new arrangement is necessary, a new way of being together is being worked on. Preventively: promotes transmission and support for future bereavement for the loved one.	

(Continued)

TABLE 3 | Continued

References	Disease	Intervention	Population	Instruments	Data analyses	Significant results	Non-significant results
McLean and Nissim (2007)	Metastatic ovarian cancer	Emotionally focused couple therapy (modified for the advanced cancer population). To facilitate marital relationships by changing habitual and distressing patterns of interaction, to increase mutual understanding and emotional engagement, and to strengthen the marital bond. 8 sessions.	Patient: - women:100% - age: 60 Caregiver: - women: 0% - age:30 years	Case study		Breakthrough in their distress pattern and an internal shift in consciousness that allowed them to respond more effectively, sharing more primary feelings than secondary defensive reactions. They both experienced a new sense of control in their ability to defuse a painful cycle. More support, empathy and love evident in their interactions. Need for multidisciplinary support was more than necessary in view of the increasingly important physical symptoms over time generating intense distress	
McLean et al. (2013)	Metastatic cancer	Emotionally focused couple therapy (modified for the advanced cancer population). To facilitate marital relationships by changing habitual and distressing patterns of interaction, to increase mutual understanding and emotional engagement, and to strengthen the marital bond. 8 sessions of 60 min. 1/week.	42 couples (22 Intervention Group; 20 Control Group) Patient IG: - women:29% - age:51.83 y Caregivers IG: - women: 24% - age: 48.82 y Patient CGs: - women: 26% - age: 49.45 y Caregiver CGs: - women: 21% - age:50.89	Marital functioning: Revised Dyadic Adjustment Scale Depression: Beck Depression Inventory-II (BDI-II) Hopelessness: Beck Hopelessness Scale (BHS) Empathic caregiving (patient): Relationship-Focused Coping Scale(RFCS) Caregiver burden (caregiver): Two subscales (Demand/Difficulty) of the Caregiver Burden Scale	Descriptive and inferential statistics (ANCOVAs)	Improved marital functioning Improved patient's perspective of caregiver's empathic behavior	Depression Hopelessness Caregiver burden time Caregiver burden difficulty

(Continued)

TABLE 3 | Continued

References	Disease	Intervention	Population	Instruments	Data analyses	Significant results	Non-significant results
Clements-Cortes (2011)	Multisite cancer	Music therapy	2 couples Patient - women: 50% - age: 77 y Caregivers - -women: 50%	Semi-structured interviews were conducted with participants and coparticipants	Thematic analysis	The results indicate that examining life, signing songs and creating musical gifts were central to each participant's process. Love was the central feeling that had to be conveyed by all participants to help them complete their relationships. Grief were part of the experiences of all participants. The sub-themes of strength/hope, denial, fear/pain, and knowledge can be linked to it. People who are going through their last weeks and days often express intense gratitude for their lives and for the people they have known. Each participant grew in their understanding of the importance of engaging in the completion of the relationship with the key people in their life. All of the participants also used their last weeks and days to live instead of waiting to die. They were open to growth, learning and the possibility of transformation. Strength / hope animates couples facing the end of life, just like courage and strength. Inherent in accepting your diagnosis of terminal cancer is the awareness to say goodbye to family and friends, and ultimately to life as the person knows it. Although it was difficult for the participants to say goodbye verbally, their actions show that they were doing just that.	

TABLE 4 | Quality assessment of the included studies of dyadic interventions of the patient and his/her life partner when confronted with advanced cancer.

References	Type of studies	Research question	Participants	Sources and methods	Tools	Ethics	Analyses	Participants (case report)	Quality (case report)	Study plan strength	Quality of study	Directness of evidence
Mowll et al. (2015)	Descriptive	✓	✗	✓	—	✗	—			Low	Moderate	Direct
Benzein and Saveman (2008)	Descriptive	✓	—	✓	—	✓	—			Low	Moderate	Direct

References	Type of studies	Participants (case report)	Quality (case report)	Conclusion
Lantz and Ahern (1998)	Descriptive (case report)	✓	✗	This case report suggests lines of thought relating to the phenomenon under study. It is necessary to carry out more robust studies in order to have a sufficient level of proof to validate the hypotheses put forward.
McWilliams (2004)	Descriptive (case report)	✓	✗	
Reny (2020b)	Descriptive (case report)	✓	✗	
McLean and Nissim (2007)	Descriptive (case report)	✓	✗	
Clements-Cortes (2011)	Descriptive (case report)	✓	✓	

References	Type of studies	Research question	Participants	Selection bias	Misclassification bias	Information bias	Tools	Storage and monitoring	Comparability	Confounding variables	Ethics	Analyses	Power and size effect	Generalization	Feasibility	Study plan strength	Quality of study	Directness of evidence
Mohr et al. (2003)	Analytique (ENCAA)	✓	✓	✓	✓	✗	✓	✗	✗	✗	✗	✓	✗	—	✓	Low	Moderate	Direct
Wagner et al. (2016)	Analytique (ENCAA)	✓	—	✗	✓	✗	✓	✓	✗	✗	✓	✓	✗	—	✓	Low	Moderate	Direct
McLean et al. (2013)	Analytique (ECR)	✓	✓	✓	✓	✓	✓	—	✓	✓	✓	✓	✓	✓	✓	High	High	Direct

✓*: strong/high*

—*: moderate/medium*

✗*: weak/low*

Art Therapy

Only one intervention involving art (in the broad sense) as a mediator was identified (Clements-Cortes, 2011). This was an intervention focused on music therapy. The results of this study indicated that examining life, signing songs, and creating musical gifts were at the heart of each participant's process. Grief, strength/hope, courage, but also gratitude and developmental growth were among the experiences of all participants. While all participants used their last weeks and days to live instead of waiting to die, they also invested this space in order to say goodbye to their loved one (often through their musical actions rather than verbally). Finally, love was the central feeling that had to be conveyed by all participants to help them complete their relationship.

Support Therapy

Similarly, only one support-oriented intervention was identified. Support for the couple promotes ”emotional discharge“ (Reny, 2020b). This is a means of re-circulating speech within the couple. What is more, through support and mediation work (between caregivers and couples), the intimacy of the subject and the couple can be heard and recognized by the caregiver. Finally, this is a space where "the couple they were before the critical illness" can be mourned. This can lead to a new functioning of the couple and a new way of being together.

Communication and Intimacy Promotion

Finally, three studies tested the effect of couple therapies whose objectives are common to most forms of couples therapy (e.g., to promote communication and intimacy) without being linked to a particular current (Mohr et al., 2003; McWilliams, 2004; Mowll et al., 2015). These studies showed that the interventional support promoted communication in men, lifted the veil on the feelings of each other, clarified the divergences within the couple favoring subsequently communication and changes in behavior toward the other (including preparation for the end of life) (Mowll et al., 2015). For the patient, these therapies tend to decrease distress with regard to death and increase the perception of the positive aspects of the relationship (Mohr et al., 2003). Among spouses, there is a decrease in worries about death (Mohr et al., 2003). With these couple interventions, psychological growth is observed in both the patient and his/her partner. Patients and spouses trust each other more and have confidence in their ability to continue to grow as a couple even if their time is limited (McWilliams, 2004). This type of intervention can also make it possible to value a communication that is already functional within the couple (Mowll et al., 2015).

Finally, several studies conclude by stipulating that participating in couple therapy during the illness makes it possible to create a link with the psychologist (McWilliams, 2004; Mowll et al., 2015; Reny, 2020b). In this sense, it is often accepted that couple interventions can help with the transition to bereavement follow-up once the loved one is gone (McWilliams, 2004; Mowll et al., 2015; Reny, 2020b).

By way of summary, we can say that the interventions offered to the couple confronted with advanced cancer improve marital functioning (cohesion, satisfaction, consensus, trustful in relationship, developmental growth, new functioning) (McWilliams, 2004; Benzein and Saveman, 2008; McLean and Hales, 2010; Clements-Cortes, 2011; McLean et al., 2013; Reny, 2020b), help to learn and find new strategies to manage daily life (Benzein and Saveman, 2008), to unburden themselves (Benzein and Saveman, 2008) and to reduce the loss of meaning (Lantz and Ahern, 1998). For patients, the intervention can be a space to say goodbye (Clements-Cortes, 2011). What's more, it improves the perception of patients (with regard to the relationship and the partners) (Mohr et al., 2003; McLean and Hales, 2010; McLean et al., 2013). Finally, it reduces distress (Mohr et al., 2003; Wagner et al., 2016). For spouses, the intervention has the effect of reducing anxiety, depression and worries about death (Mohr et al., 2003; Wagner et al., 2016) and increasing feelings of peace about the illness and perceptions of coping ability (Wagner et al., 2006).

DISCUSSION

The two objectives of this systematic review of the literature were (1) to explore scientific actual knowledge about the dyadic experience of the patient and his/her life partner when they are confronted with advanced cancer; (2)to highlight the impact of psychosocial interventions that are offered to the couples in the context of an advanced cancer.

Faced with often uncertain and ambiguous circumstances, cancer patients and their partners describe the individual and dyadic processes in which they have engaged as they approach the end of life (Gardner, 2008). Changes in the relationship were mainly focused on care, proximity/distance regulation, and modes of communication (Drabe et al., 2016). Communication appears to be an essential factor for both individual and dyadic adjustment (Cort et al., 2004; McLean and Jones, 2007; Drabe et al., 2016; Iwasaki et al., 2018; Mah et al., 2020; Reny, 2020a). Moreover, through better couple communication, attachment security supports preparation for death in cancer (Mah et al., 2020). Patient and spouse attachment styles contribute to spouse caregiving patterns (McLean and Jones, 2007; Braun et al., 2012). Indeed, the insecure attachment style and the resulting ”request-withdrawal“ and ”avoidance-chase“ couple interaction patterns are potential sources of distress (Braun et al., 2012). In addition, stress communication between partners and negative dyadic coping behaviors are correlated with high supportive care needs (Weißflog et al., 2017). Finally, dyadic adaptation has also been studied from the perspective of nutrition-related problems in advanced cancer: it is a dynamic and interactive process that relies on different adaptation pathways (Opsomer et al., 2019).

These results, particularly those related to communication, are consistent with the results found among the cancer population (Li and Loke, 2014). Our results suggest that for the population facing advanced cancer, psychotherapeutic interventions should be oriented toward a target population (e.g., young people, people with anxiety or insecure attachment, etc.) and focus on certain topics as applicable (e.g., communication, intimacy, adaptive behavior, problems specific to advanced cancer, etc.).

However, based on the critical analysis of the integrated studies, these results are based on limited evidence (low quality research plan and heterogeneous quality of study).Our results (and our avenues for reflection) should therefore be taken into consideration (as there are no others), but with a critical eye. They allow us to think about the relationship between the couple and advanced cancer, without asserting that a conclusion proposed in a study is a general truth. This is all the more true since there is a great diversity in the ways of apprehending the experience of the couple facing advanced cancer (relationship to food, communication, intimacy, temporality, etc.).This diversity, although very enriching, is confronted with the lack of existing studies, which means that there is little or no possibility of comparing the results of our studies (except for communication).

The interventions identified in our review focus on certain areas of interest identified above (e.g., communication, intimacy). All interventions identified have common general objectives: the promotion of communication and intimacy within the couple. Couple therapy, as a complement to end-of-life care, generates a relationship of trust between the couple and the therapist (which already appears to be a beneficial experience from the perspective of the dyad), gives couples the opportunity to express their concerns together, to identify differences in understanding, and to learn to find new strategies to manage daily life (Benzein and Saveman, 2008; Mowll et al., 2015; Reny, 2020b). It reduces the "meaning vacuum" and improves marital functioning. It also improves patient experiences (e.g., significant decrease in patients' distress at the thought of dying, perception of the threat) and that of partners (e.g., significant decrease in the frequency of partners' worries about the death of their partner, anxiety, depression, significant increase in peace with regard to illness, and perception of coping ability) (Lantz and Ahern, 1998; Mohr et al., 2003; McLean and Jones, 2007; Benzein and Saveman, 2008; McLean and Hales, 2010; McLean et al., 2013; Reny, 2020b). Finally, couple therapy has the potential to mitigate a catastrophic end of life and therefore a complicated marital bereavement, and it is also an easier transition to the accompaniment of the partner during the time of mourning, once the loved one is gone (McLean and Jones, 2007; McLean and Hales, 2010; Mowll et al., 2015; Reny, 2020b). We note that if the objectives remain the same, several models of interventions are proposed: existential, humanistic/systemic, psychodynamic and cognitive-behavioral. This is consistent with the 4 major models of psychotherapeutic interventions that are recognized as being able to be proposed in palliative care (Van Lander et al., 2015).

Based on the critical analysis of the integrated studies, these results can be said to be based on limited evidence (low quality research plan and heterogeneous quality of study). Our results must therefore be interpreted with caution. Normally, it cannot be used as the basis for a practical recommendation unless no other source of evidence is available; which is the case here. Consequently, we could develop clinical recommendations, but we will not do so and will only propose avenues for reflection. There is an obvious observation: using a robust methodology (and therefore obtaining evidence) in the context of the end of life is a real challenge. This raises the following question: should we focus on the level of evidence and exclude from review certain leads proposed by poor quality studies or should we lower our requirements regarding the level of evidence and adopt an inclusive approach? (We made the choice to reduce our level of requirements with regard to the field of study in which we are enrolled: that of the end of life).

Through these results, one can see that communication is an axis that has been widely studied by descriptive and interventional research. This is consistent with all models of dyadic adjustment that consider communication as a fundamental element (Manne and Badr, 2008; Fletcher et al., 2012). In a literature review that focuses on cancer, it was found that better communication between couples was linked to less distress and better marital adjustment (Li and Loke, 2014), which we find in our results on the couple facing advanced cancer. Communication could also be an element underlying the two other fundamental dimensions to the apprehension of the dyad: "reciprocal influence" and "congruence" (Fletcher et al., 2012; Li and Loke, 2014). These dimensions illustrating the concept of "reciprocal influence" (e.g., attachment style—-caregiving, nutrition-related problems, mutual optimism/positive approach) and "congruence" (e.g., almost total congruence on all the problems that the couple encounters in the face of advanced cancer, incongruence on beliefs and fears and subjective concerns related to death) are much less studied in an advanced cancer population than in the overall cancer population. In general, for the cancer population, concordance in dyads was linked to better individual outcomes and relationship satisfaction (Li and Loke, 2014). In the only study that evokes congruence within our population, this seems to be true: having divergent beliefs within the couple could interfere with mutual support (Gardner, 2008). These dimensions can very well be integrated into the systemic and transactional model of dyads (Untas et al., 2012). Integrating these elements into this model opens up the field of possibilities both in the clinic and in research.

Finally, the notion of temporality included in the model of Untas et al. (2012) is fundamental. While the temporality and trajectory of the disease are still largely underestimated in research on family care in oncology, we approach them essentially from a biological perspective based on pathological and radiological results (stage I-IV, early stage VS advanced stage). While this perspective is useful for defining groups for comparison in cross-sectional research, the evidence on disease stage in relation to the caregiving stress process is mixed (Fletcher et al., 2012). Future studies may show more definitive relationships between the stage of the disease and the stress process and researchers may also find that other ways to conceptualize the trajectory of cancer would be more fruitful. Indeed, we could conceptualize the trajectory of cancer in terms of phases that reflect the daily experiences of patients and family caregivers ("critical moments," "nodal points in the trajectory of the disease," etc.) and thus consider periods of transition.

Despite the methodological robustness (linked to the Cochrane methodology) that guided this systematic exploration of the literature, some limitations should be highlighted. While we followed the recommendations of Cochrane, the selected studies include various risks of bias due to their design: selection bias, response bias, social desirability bias, absence of psychometric data on certain questionnaires used, small sample size, non-generalizable results, variables not considered, correlational effects and not causality, little diversity, high attrition rate, use of established tools and criteria that are not necessarily those recognized at the present time current. In addition, from one study to another, we observe significant differences (e.g., theoretical bases, methodologies and various protocols) which leads to difficulties in comparing our results.

CONCLUSION

A relatively small number of articles were eligible for inclusion in this review, demonstrating the lack of evidence on the experiences of patients and life partners facing advanced cancer, but also the lack of evidence on the effectiveness of couple interventions. This observation limits the current clinical perspectives in terms of solid management of these dyads and conversely, it offers a multitude of research perspectives.

This literature review reveals that consideration (both psychological and physical) of the couple within the care appears fundamental. What is more, communication within the patient-life partner dyad is an essential axis of work. While many other variables appear important in the couple's dyadic adjustment to advanced cancer, there is very little evidence on the couple facing advanced cancer, though we know how severely the couple unit is impacted by cancer (Dankoski and Pais, 2007; Hagedoorn et al., 2008).

Descriptive and analytic studies are needed to advance research in this area. Indeed, longitudinal studies may, for example, be relevant to follow couples prospectively and assess the effect of the course of the disease on the couple (e.g., interactional patterns, emotional responses, dyadic adjustment strategies etc.). It could also provide elements of response relating to the apprehension of the trajectory of the disease by each partner of the dyad and from an interactional point of view. Also, qualitative protocols would allow a better understanding of the phenomena studied, in particular the representations that each partner has of the illness, the end of life, the post-death, etc. and the possible conflicts or difficulties resulting from a representational incongruence between them both. That is why, an openness to the concepts of ”reciprocal influence“ and ”congruence“ seems fundamental in order to open up our research perspectives in this field. Finally, experimental studies are needed (e.g., randomized controlled trials) to scientifically test the impact of specific dyadic therapies for couples facing advanced cancer and at the end of life. These research approaches would enable greater understanding of the complexity of the issues surrounding the dyadic experience of couples facing advanced cancer and allow effective psychosocial interventions to be proposed that are as close as possible to the realities of individual and dyadic experiences.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

MH and BQ participated in the overall research and writing of the article. Both authors contributed to the article and approved the submitted version.

ACKNOWLEDGMENTS

We would like to thank Pippa McKelvie-Sebileau for proofreading the article.

REFERENCES

Baider, L., Kaufman, B., Peretz, T., and Manor, O. (1996). “Mutuality of fate: Adaptation and psychological distress in cancer patients and their partners,” in *Cancer and the family* (John Wiley & Sons).

Berg, C. A., and Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol. Bull.* 133, 920–954. doi: 10.1037/0033-2909.133.6.920

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping in couples. *Swiss J. Psychol.* 54, 34–49.

Braun, M., Hales, S., Gilad, L., Mikulicer, M., Rydall, A., and Rodin, G. (2012). Caregiving styles and attachment orientations in couples facing advanced cancer: Caregiving style and attachment orientations in couples facing cancer. *Psychooncology* 21, 935–943. doi: 10.1002/pon.1988

Carlson, L. E., Bultz, B. D., Speca, M., and Pierre, M. (2000). Partners of cancer patients: I. Impact, adjustment, and coping across the illness trajectory. *J. Psychosoc. Oncol.* 18, 39–63. doi: 10.1300/J077v18n02_03

Clements-Cortes, A. (2011). Portraits of music therapy in facilitating relationship completion at the end of life. *Music Med.* 3, 31–39. doi: 10.1177/1943862110388181

Cort, E., Monroe, B., and Oliviere, D. (2004). Couples in palliative care. *Sex. Relationship Therapy* 19, 337–354. doi: 10.1080/14681990410001715454

Dankoski, M. E., and Pais, S. (2007). What's love got to do with it? *J. Couple Relationship Therapy* 6, 31–43. doi: 10.1300/J398v06n01_04

Delvaux, N. (2006). L'expérience du cancer pour les familles. *Cahiers critiques de thérapie familiale et de pratiques de réseaux* 36, 81. doi: 10.3917/ctf.036.101

Drabe, N., Jenewein, J., Weidt, S., Engeli, L., Meier, C., Büchi, S., et al. (2016). When cancer cannot be cured: A qualitative study on relationship changes in couples facing advanced melanoma. *Palliat. Support. Care* 14, 652–663. doi: 10.1017/S1478951516000055

Fletcher, B. S., Miaskowski, C., Given, B., and Schumacher, K. (2012). The cancer family caregiving experience: An updated and expanded conceptual model. *Eur. J. Oncol. Nurs.* 16, 387–398. doi: 10.1016/j.ejon.2011.09.001

Gardner, D. S. (2008). Cancer in a dyadic context: older couples' negotiation of ambiguity and search for meaning at the end of life. *J. Soc. Work End Life Palliat. Care* 4, 135–159. doi: 10.1080/15524250802353959

Benzein, E. G., and Saveman, B. I. (2008). Health-promoting conversations about hope and suffering with couples in palliative care. *Int. J. Pallait. Nurs.* 14, 439–445. doi: 10.12968/ijpn.2008.14.9.31124

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., and Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychol. Bull.* 134, 1–30. doi: 10.1037/0033-2909.134.1.1

Hodges, L. J., Humphris, G. M., and Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc. Sci. Med.* 60, 1–12. doi: 10.1016/j.socscimed.2004.04.018

Iwasaki, M., Di Bianca, M. S., and Nicholas, D. R. (2018). A forbidden topic at the end of life: "What about you after I'm gone?" *Psychooncology* 27, 2665–2667. doi: 10.1002/pon.4772

Janda, M., Steginga, S., Langbecker, D., Dunn, J., Walker, D., and Eakin, E. (2007). Quality of life among patients with a brain tumor and their carers. *J. Psychosom. Res.* 63, 617–623. doi: 10.1016/j.jpsychores.2007.06.018

Kayser, K., Watson, L. E., and Andrade, J. T. (2007). Cancer as a "we-disease": Examining the process of coping from a relational perspective. *Famil. Syst. Health* 25, 404–418. doi: 10.1037/1091-7527.25.4.404

Kim, Y., Kashy, D., Wellisch, D., S., Cannady, R., Kaw, C., et al. (2008). Quality of life of couples dealing with cancer: dyadic and individual adjustment among breast and prostate cancer survivors and their spousal caregivers. *Ann. Behav. Med.* 35, 230–238. doi: 10.1007/s12160-008-9026-y

Lantz, J., and Ahern, R. (1998). Re-collection in existential psychotherapy with couples and families dealing with death. *Contemp. Family Therapy* 20, 47–57.

Lazarus and Folkman (1984). *Stress, Appraisal, and Coping*. Available online at: https://books.google.fr/books/about/Stress_Appraisal_and_Coping.html?id=i-ySQQuUpr8C&redir_esc=y

Li, Q., and Loke, A. Y. (2014). A literature review on the mutual impact of the spousal caregiver-cancer patients dyads: 'communication', 'reciprocal influence', and 'caregiver-patient congruence'. *Eur. J. Oncol. Nurs.* 18, 58–65. doi: 10.1016/j.ejon.2013.09.003

Mah, K., Shapiro, G. K., Hales, S., Rydall, A., Malfitano, C., An, E., et al. (2020). The impact of attachment security on death preparation in advanced cancer: The role of couple communication. *Psychooncology* 29, 833–840. doi: 10.1002/pon.5354

Mangione, J. (2017). Le couple face à la maladie grave. *Jusqua la mort accompagner la vie* 129, 29–34. doi: 10.3917/jalmalv.129.0029

Manne, S., and Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer* 112, 2541–2555. doi: 10.1002/cncr.23450

Maughan, K., Heyman, B., and Matthews, M. (2002). In the shadow of risk: How men cope with a partner's gynaecological cancer. *Int. J. Nursing Stud.* 39, 27–34. doi: 10.1016/S0020-7489(01)00004-9

McLean, L. M., and Hales, S. (2010). Childhood trauma, attachment style, and a couple's experience of terminal cancer: Case study. *Palliative Support. Care* 8, 227–233. doi: 10.1017/S1478951509990976

McLean, L. M., and Jones, J. M. (2007). A review of distress and its management in couples facing end-of-life cancer. *Psychooncology* 16, 603–616. doi: 10.1002/pon.1196

McLean, L. M., and Nissim, R. (2007). Marital therapy for couples facing advanced cancer: case review. *Palliat. Support. Care.* 5, 303–313. doi: 10.1017/s1478951507000466

McLean, L. M., Walton, T., Rodin, G., Esplen, M. J., and Jones, J. M. (2013). A couple-based intervention for patients and caregivers facing end-stage cancer: Outcomes of a randomized controlled trial: Couples facing terminal cancer: randomized controlled trial. *Psychooncology* 22, 28–38. doi: 10.1002/pon.2046

McWilliams, A. E. (2004). Couple psychotherapy from an attachment theory perspective: A case study approach to challenging the dual nihilism of being an older person and someone with a terminal illness. *Eur. J. Cancer Care* 13, 464–472. doi: 10.1111/j.1365-2354.2004.00547.x

Mohr, D. C., Moran, P. J., Kohn, C., Hart, S., Armstrong, K., Dias, R., et al. (2003). Couples therapy at end of life. *Psychooncology* 12, 620–627. doi: 10.1002/pon.746

Mowll, J., Lobb, E. A., Lane, L., Lacey, J., Chochinov, H. M., Kelly, B., et al. (2015). A preliminary study to develop an intervention to facilitate communication between couples in advanced cancer. *Palliative Support. Care* 13, 1381–1390. doi: 10.1017/S1478951514001333

Murillo, M., and Holland, J. C. (2004). Clinical practice guidelines for the management of psychosocial distress at the end of life. *Palliat. Support. Care* 2, 65–77. doi: 10.1017/s1478951504040088

NIH (2011). *Definition of advanced cancer—NCI Dictionary of Cancer Terms—National Cancer Institute* (nciglobal, ncienterprise) [NciAppModulePage]. Available online at: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/advanced-cancer

Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. J., and Van Den Bos, G. A. M. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psychooncology* 7, 3–13. doi: 10.1002/(SICI)1099-1611(199801/02)7:1<3::AID-PON320>3.0.CO;2-5

Northouse, L. (1989). A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncol. Nurs. Forum* 16, 511–516.

Northouse, L. L., and McCorkle, R. (2015). *Spouse Caregivers of Cancer Patients. Psycho-Oncology, 3rd ed*. Oxford: Oxford University Press.

Northouse, L. L., Templin, T., Mood, D., and Oberst, M. (1998). Couples' adjustment to breast cancer and benign breast disease: A longitudinal analysis. *Psychooncology* 7, 37–48. doi: 10.1002/(SICI)1099-1611(199801/02)7:1<37::AID-PON314>3.0.CO;2-#

Opsomer, S., Joossens, S., De Wit, C., Lauwerier, E., and Pype, P. (2019). Couples coping with nutrition-related problems in advanced cancer: A qualitative study in primary care. *Eur. J. Oncol. Nursing* 38, 76–84. doi: 10.1016/j.ejon.2018.12.006

Paill,é, P., and Mucchielli, A. (2021). *L'analyse Qualitative en Sciences Humaines et Sociales*. Armand Colin. Available online at: https://www-cairn-info.docelec.u-bordeaux.fr/l-analyse-qualitative-en-sciences-humaines-9782200624019.htm

Public Health Agency of Canada (2014). *Infection Prevention and Control Guidelines: Critical Appraisal Tool Kit*.

Reny, J. (2020a). L'intimité du couple à l'épreuve de la fin de vie: Que reste-t-il de nos amours? *Dialogue* 229, 65–80. doi: 10.3917/dia.229.0065

Reny, J. (2020b). Le soutien aux proches: Un dispositif favorable à la communication dans le couple. *Médecine Palliative* 19, 100–104. doi: 10.1016/j.medpal.2020.02.005

Untas, A., Koleck, M., Rascle, N., and Bruchon-Schweitzer, M. (2012). Du modèle transactionnel à une approche dyadique en psychologie de la santé. *Psychologie de la santé* 57, 97–110. doi: 10.1016/j.psfr.2012.03.004

Van Lander, A., Aubry, R., and Bacqué, M.-F. (2015). *Apports de la psychologie clinique aux soins palliatifs*. Éditions Érès.

von Heymann, A., Puggaard, L., Nissen, K., Benthien, K., Bidstrup, P., Coyne, J., et al. (2017). Dyadic psychological intervention for patients with cancer and caregivers in home-based specialized palliative care: The Domus model. *Palliat. Support. Care* 16, 189–197. doi: 10.1017/S1478951517000141

Wagner, C. D., Bigatti, S. M., and Storniolo, A. M. (2006). Quality of life of husbands of women with breast cancer. *Psychooncology* 15, 109–120. doi: 10.1002/pon.928

Wagner, C. D., Johns, S., Brown, L. F., Hanna, N., and Bigatti, S. M. (2016). acceptability and feasibility of a meaning-based intervention for patients with advanced cancer and their spouses: a pilot study. *Am. J. Hospice Palliative Med.* 33, 546–554. doi: 10.1177/1049909115575709

Weißflog, G., Hönig, K., Gündel, H., Lang, D., Niederwieser, D., Döhner, H., et al. (2017). Associations between dyadic coping and supportive care needs: Findings from a study with hematologic cancer patients and their partners. *Support. Care Cancer* 25, 1445–1454. doi: 10.1007/s00520-016-3541-3

Weitzner, M. A., McMillan, S. C., and Jacobsen, P. B. (1999). Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *J. Pain Symptom Manage.* 17, 418–428. doi: 10.1016/s0885-3924(99)00014-7

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

APPENDIX

For each database we used the thesaurus when available (structured directory of terms for content analysis and document classification). In the table below, you will find the terms that are covered by the thesaurus keywords. The "+" equals other integrated terms not expanded.

	"Couple"	**"Palliative care"**
PubMed	Family Characteristics Couples Therapy	Palliative care Hospice and Palliative Care Nursing Palliative Medicine
PsycArticle	Interpersonal relationships Same sex Couples cohabitation + Dating violence Dyads Family + Online dating Romance Significant others Social dating Spouses +	Health care services Assisted suicide Euthanasia Advance directives Death and dying + Health care delivery + Hospice Life sustaining treatment + Long term care Pain management Symptoms based treatment Terminally ill patients End of life care
PsycInfo	Interpersonal relationship Same sex couples Cohabitation Dating violence Dyads Family + Online dating Romance Significant others Social dating Spouses +	Health care services Assisted suicide Euthanasia Advance directives Death and dying + Health care delivery + Hospice Life sustaining treatment Long term care Pain management Symptoms based treatment Terminally ill patients End of life care
Behavorial Sciences Collection	Interpersonal relations Academic couples African american couples Architect couples Criminal couples Gay couples Infidelity (couples) Interethnic couples Intergenerational couples Interracial couples Lgbtq+ couples Life partners Married people Older couples Royal couples Unmarried couples Conjoint therapy Couples in art Couples in literature Couples in motion pictures Couples on television Crimes against couples Dating (social customs) Dyadic communication Dyads Primary groups (social groups) Relationship status Sexual partners Heterosexual couples	Therapeutics Brompton cocktail Hospice care Palliative medicine Palliation (medical care) Palliative treatment