Research Topics

Qualitative pain research: Capturing and integrating cultural, social and linguistic data

Edited by
Najmeh Khalili-Mahani, Richard Bruce Hovey and Dominik Mischkowski

Published in
Frontiers in Pain Research
Frontiers in Rehabilitation Sciences

ISSN 1664-8714
ISBN 978-2-83250-995-1
DOI 10.3389/978-2-83250-995-1

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

Qualitative pain research: Capturing and integrating cultural, social and linguistic data

Topic editors
Najmeh Khalili-Mahani — McGill Centre for Integrative Neuroscience, Montreal Neurological Institute, Canada
Richard Bruce Hovey — Faculty of Dental Medicine and Oral Health Sciences, Canada
Dominik Mischkowski — Ohio University, United States

Citation
Khalili-Mahani, N., Hovey, R. B., Mischkowski, D., eds. (2022). *Qualitative pain research: Capturing and integrating cultural, social and linguistic data*. Lausanne: Frontiers Media SA. doi: 10.3389/978-2-83250-995-1

Table of contents

frontiers | Frontiers in Pain Research

TYPE Editorial
PUBLISHED 24 November 2022
DOI 10.3389/fpain.2022.1082044

Editorial: Qualitative pain research: Capturing and integrating cultural, social and linguistic data

Najmeh Khalili-Mahani[1,2,3]*, Dominik Mischkowski[4]* and Richard B. Hovey[5]*

[1]McGill Centre for Integrative Neuroscience, Montreal Neurological Institute, Montreal, QC, Canada, [2]Culture and Mental Health Research Unit, Lady Davis Institute, Jewish General Hospital, Montreal, QC, Canada, [3]PERFORM Centre, Concordia University, Montreal, QC, Canada, [4]Department of Psychology, Ohio University, Athens, OH, United States, [5]Faculty of Dental Medicine and Oral Health Sciences, McGill University, Montreal, QC, Canada

KEYWORDS

qualitative research and analysis, pain research, patient–centered care, cultural medicine, indigenous methodology, phenomenology, hermeneutics, metaphors of illness

Editorial on the Research Topic
Qualitative pain research: Capturing and integrating cultural, social and linguistic data

OPEN ACCESS

EDITED AND REVIEWED BY
Marco L. Loggia,
Massachusetts General Hospital and Harvard Medical School, United States

*CORRESPONDENCE
Najmeh Khalili-Mahani
najmeh.khalilimahani@mcgill.ca
Dominik Mischkowski
mischkow@ohio.edu
Richard B. Hovey
richard.hovey@mcgill.ca

SPECIALTY SECTION
This article was submitted to Non-Pharmacological Treatment of Pain, a section of the journal Frontiers in Pain Research

RECEIVED 27 October 2022
ACCEPTED 07 November 2022
PUBLISHED 24 November 2022

CITATION
Khalili-Mahani N, Mischkowski D and Hovey RB (2022) Editorial: Qualitative pain research: Capturing and integrating cultural, social and linguistic data.
Front. Pain Res. 3:1082044.
doi: 10.3389/fpain.2022.1082044

In 2021, the International Association for the Study of Pain (IASP) added chronic pain to the WHO's International Classification of Disease (ICD-11) (1). Despite important progress in biomedical understandings of pain, major challenges remain to translate molecular and system medicine advances into clinical practice. According to the co-chairs of IASP's 2022 Global Year for Translating Knowledge to the Patient, such challenges include placebo effects, a persistent lack of molecular or clinical biomarkers of pain, and patient stratification for clinical trials (2). In addition, psychosocial and economic conditions interfere with access to medical pain management (2). Craig's Social Communication Model of Pain asserts that because humans must adapt to complex social environments, cognitive and social processes and contexts must be considered in understanding patients' own perceptions and behaviors in presence of pain (3). Kirmayer's Cultural Somatization model explains that because pain experience is mediated, elaborated and communicated through cultural models, it needs to be studied more thoroughly with appropriate qualitative methodologies and culturally grounded approaches (4, 5).

To date, the impact of qualitative research in healthcare remains limited (6), though qualitative research can improve care (7) by enriching clinical encounters (8) and patient-engagement in research (9, 10). It can also influence policy-making (11). There are both epistemological challenges [e.g., a reductionist view on replicability (7) and "quality" (12)] and institutional biases [e.g., funding (13)] that prevent the implementation of extensive qualitative research into clinical practices.

To address this shortcoming, we focused on Cultural, Social and Linguistic aspects of qualitative pain research in this special issue, building upon our own perspectives as both qualitative and quantitative pain researchers [e.g., (14–16)]. The following themes emerged within this collection:

Pain scales do not make sense for long term chronic pain treatment

Six articles in this Research Topic provide examples of how storytelling is essential to creating holistic patient-centered treatment programs.

Specifically, verbal and visual metaphors provide a strategy for pain communication. In *Lives Penciled In*, writing from a personal experience, Hovey et al. explain, "that health resists universal definition because it can only be interpreted, constituted, and reconstituted through specific professional, personal, promotional, educational, cultural, governmental, and communal lenses" and uses hermeneutics and the metaphor of "pencil" to draw the attention of healthcare providers to the fragility and brevity of healthcare encounters from the perspective of a cancer patient. Not only words, but drawings can help clinicians gain a more holistic view of how their patients progress over time. In *Portraying Improvement in the Management of Chronic Pain*, Nizza et al. examine the drawings of patients in a pain management program to illustrate their changing attitudes towards themselves and their pain over the course of six months.

Furthermore, two Indigenous studies in this collection illustrate that metaphors are culturally relevant. In *Clinical Strategies to Develop Connections, Promote Health and Address Pain From the Perspectives of Indigenous Youth, Elders, and Clinicians*, VanEvery et al. noted both intergenerational and intercultural differences in metaphors of pain, requiring sensitivity to not only historical and cultural backgrounds, but also literacy, linguistic abilities and inter- and intra-community connections when conducting research about the pain experience. In *A Window into Pain: American Indian Cancer Survivors' Drawings*, Hodge et al. assembled in 13 focus groups more than 130 adult American Indian cancer survivors and their caregivers living in urban and reservation communities in the Southwest USA. This research revealed the limitations of various standard pain scales as opposed to personal drawings of pain, suggesting that a mechanistic view of pain and cultural incongruity among patients and caregivers can lead to neglect and undertreatment of serious pain conditions.

Finally, storytelling constitutes an effective and preferred way of making sense of pain and sharing the pain experience with others. In *Beyond Pain Scales*, Miglio and Stanier concur that metaphors (verbal or visual) create a cognitive and emotional space for imagination and overcoming the limits of language, thus increasing collective understandings of chronic pain, and note that sharing the experience of pain through storytelling creates a sense of belonging and community. Furthermore, in *Toward a Digital Citizen Lab for Capturing Data About Alternative Ways of Self-Managing Chronic Pain*, Khalili-Mahani et al. report that the idea of creating a narrative-based participatory action is conceptually acceptable and desired by chronic pain patients. Indeed, Holowka's social-media research in *Mediating Pain: Navigating Endometriosis on Social Media* confirms the importance of collective sense-making and community-building in online support spaces, achieved through storytelling in social media by helping women to make their experience of endometriosis visible and describing its pain manifestations in their own terms.

Qualitative research needs to be sensitive to cultural differences

In addition to the two Indigenous studies listed above, two other mixed-methods studies in this collection emphasize the cultural underpinnings of qualitative research. In *Development of a Mixed Hypnosis and Music Intervention Program for the Management of Pain, Anxiety, and Wellbeing in End-of-Life Palliative Care*, Bissonnette et al. report concerns expressed by clinicians that metaphors or music might increase the emotional burden and increase a patient's level of distress. Examining the *Experiences of Community-Dwelling Older Adults with Chronic Low Back Pain in Hong Kong and Switzerland*, Schoeb et al. demonstrate that in addition to cross-country differences in availability and accessibility of healthcare, significant cultural differences in self-perceived roles within a family contribute to variations in seeking support and coping with chronic lower back pain. Thus, in an epistemological culture that is heavily dominated by quantitative research practices, to undertake qualitative studies may become challenging due to lack of familiarity with its paradigms. For example, despite showing interest in a participatory digital citizen lab for qualitative research (Khalili-Mahani et al.), and finding data retrieved from self-expression to be just as important as pain tracking, the concept of storytelling for reporting their pain remained foreign to respondents who lived with chronic pain.

Holistic and critical research frameworks enculture qualitative research

Several studies in this collection demonstrate that understanding cultural contexts is essential to providing good care and offer various theoretical and conceptual frameworks to capture the cultural dimensions of communicating pain.

In this collection, two holistic frameworks from Indigenous research methodologies were proposed. The LISTEN (*Language,* *Individual, Share, Teachable moments, Engage, and Navigate)* framework was guided by two pillars in Indigenous Epistemologies: 'Two-Eyed Seeing' and 'The Medicine Wheel' (VanEvery et al.). Both approaches provide the context for creating more culturally-grounded and safer practices for clinicians with the goal to manage pain and hurt more holistically. Consistent with this view, the Humanistic Nursing Theory acknowledges that "each person faces the end of life in a way that represents his or her unique life experience in the world", in order to provide culturally-sensitive care to cancer survivors (17).

The Affect Theory and Feminist Social Media Studies offer a critical framework to expose the legacy of discriminatory and gendered dismissal of pain in minorities and women [(18) in Holowka]. In this context, Miglio and Stanier suggest critical phenomenology as a framework to capture the socio-political dimensions which frame painful experiences, their expression, their lived significance, and their treatment. Furthermore, Khalili-Mahani et al. use the Transactional Theory of Stress and Coping to frame individual variations in adaptation to chronic pain. Nizza et al. offer that interpretative longitudinal phenomenological methods could map the dynamic trajectory of an individual's experience of pain treatment.

Conclusion

In conclusion, this Research Topic provides a glimpse into how cultural, linguistic, social and personal factors contribute to the authentic communication of the pain experience. The research studies featured in this collection offer different holistic and critical frameworks for qualitative research that can address current challenges in translational research through a community-based, patient-centered and encultured care plan.

Author contributions

All authors have made equal editorial contribution to the Research Topic. All authors contributed equally to the writing of the editorial and approved the submitted version.

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

1. Treede R-D, Rief W, Barke A, Aziz Q, Bennett MI, Benoliel R, et al. A classification of chronic pain for ICD-11. *Pain.* (2015) 156(6):1003–7. doi: 10.1097/j.pain.0000000000000160

2. Moaris C, Moyano J, Belton J, Moyo N. "Global inequities in pain treatment: how future research can address this better." International Association for the Study of Pain (IASP): IASP (2022). Available at: https://www.iasp-pain.org/resources/fact-sheets/global-inequities-in-pain-treatment-how-future-research-can-address-this-better/ (Acessed September 20, 2022).

3. Craig KD. The social communication model of pain. *Can Psychol.* (2009) 50 (1):22–32. doi: 10.1037/a0014772

4. Kirmayer LJ. Culture and the metaphoric mediation of pain. *Transcult Psychiatry.* (2008) 45(2):318–38. doi: 10.1177/1363461508089769

5. Kirmayer LJ. Culture, affect and somatization. *Transcult Psychiatr Res Rev.* (2016) 21(3):159–88. doi: 10.1177/136346158402100301

6. Richardson JC, Liddle J. Where does good quality qualitative health care research get published? *Prim Health Care Res Dev.* (2017) 18(05):515–21. doi: 10.1017/S1463423617000251

7. Leung L. Validity, reliability, and generalizability in qualitative research. *J Family Med Prim Care.* (2015) 4(3):324–7. doi: 10.4103/2249-4863.161306

8. Hovey RB. Enriching clinical encounters through qualitative research. *J Patient Exp.* (2022) 9:9. doi: 10.1177/23743735221077536

9. Rolfe DE, Ramsden VR, Banner D, Graham ID. Using qualitative health research methods to improve patient and public involvement and engagement in research. *Res Involv Engagem.* (2018) 4(1):49. doi: 10.1186/s40900-018-0129-8

10. Braun V, Clarke V. Novel insights into patients' life-worlds: the value of qualitative research. *Lancet Psychiatry.* (2019) 6(9):720–1. doi: 10.1016/S2215-0366(19)30296-2

11. Chafe R. The value of qualitative description in health services and policy research. *Healthc Policy.* (2017) 12(3):12–8.

12. Tutelman PR, Webster F. Qualitative research and pain: current controversies and future directions. *Can J Pain.* (2020) 4(3):1–5. doi: 10.1080/24740527.2020.1809201

13. Galdas P. Revisiting bias in qualitative research. *Int J Qual Methods.* (2017) 16(1):1–2. doi: 10.1177/1609406917748992

14. Khalili-Mahani N, Holowka E, Woods S, Khaled R, Roy M, Lashley M, et al. Play the pain: a digital strategy for play-oriented research and action. *Front Psychiatry.* (2021) 12:746477. doi: 10.3389/fpsyt.2021.746477

15. Hovey RB, Khayat VC, Feig E. Listening to and letting pain speak: poetic reflections. *Br J Pain.* (2018) 12(2):95–103. doi: 10.1177/2049463717741146

16. Mischkowski D, Palacios-Barrios EE, Banker L, Dildine TC, Atlas LY. Pain or nociception? Subjective experience mediates the effects of acute noxious heat on autonomic responses. *Pain.* (2017) 159(4):699–711. doi: 10.1097/j.pain.0000000000001132

17. Wu H-L, Volker DL. Humanistic nursing theory: application to hospice and palliative care. *J Adv Nurs.* (2012) 68(2):471–9. doi: 10.1111/j.1365-2648.2011.05770.x

18. Papacharissi Z. A networked self: identity, community and culture on social network sites. New York: Routledge (2011).

frontiers | Frontiers in Pain Research

ORIGINAL RESEARCH
published: 13 May 2022
doi: 10.3389/fpain.2022.857624

Clinical Strategies to Develop Connections, Promote Health and Address Pain From the Perspectives of Indigenous Youth, Elders, and Clinicians

Rachel VanEvery[1]*, *Margot Latimer*[2]* and *Angela Naveau*[3]*

[1] *Department of Health, Aging, and Society, McMaster University, Hamilton, ON, Canada,* [2] *Faculties of Health and Medicine, Dalhousie University, Centre for Pediatric Pain, IWK Health, Halifax, NS, Canada,* [3] *De dwa da dehs nye>s Aboriginal Health Centre, Hamilton, ON, Canada*

Edited by:
Najmeh Khalili-Mahani,
Montreal Neurological
Institute, Canada

Reviewed by:
Margaret Dunham,
Edinburgh Napier University,
United Kingdom
Anthony Herbert,
Queensland University of
Technology, Australia

***Correspondence:**
Rachel VanEvery
bomberrm@mcmaster.ca
Margot Latimer
mlatimer@dal.ca
Angela Naveau
ANaveau@dahac.ca

Specialty section:
This article was submitted to
Non-Pharmacological Treatment of
Pain,
a section of the journal
Frontiers in Pain Research

Received: *18 January 2022*
Accepted: *22 March 2022*
Published: *13 May 2022*

Citation:
VanEvery R, Latimer M and Naveau A
(2022) Clinical Strategies to Develop
Connections, Promote Health and
Address Pain From the Perspectives
of Indigenous Youth, Elders, and
Clinicians. Front. Pain Res. 3:857624.
doi: 10.3389/fpain.2022.857624

In this article we discuss findings from a community based, participatory action research study. The aim was to understand how Indigenous youth describe, experience, manage pain and hurt and how they seek care. A critical analysis guided by Two-Eyed Seeing and Medicine Wheel frameworks highlighted important clinical strategies for Indigenous youth to balance their health and reduce pain. This study is a partnership project with an Aboriginal Health Centre in Southern Ontario and the Canadian Institute of Health Research funded Aboriginal Children's Hurt and Healing Initiative (ACHH). The study gathered perspectives of Indigenous youth, Elders, and health clinicians using conversation sessions guided by a First Nations doctoral student and nurse researcher. Using the medicine wheel framework three main thematic areas emerged across the three groups and include (1) Predictors of Imbalance; (2) Indicators of Imbalance; and (3) Strategies to re-establish balance health in relation to pain. The main strategy includes considerations for clinicians using the acronym LISTEN (*Language, Individual, Share, Teachable moments, Engage, and Navigate*) approach that outlines strategies for clinicians that will be a safe guide to manage pain and hurt.

Keywords: Indigenous youth, clinical strategies, Two-Eyed Seeing, pain, hurt, community led research

INTRODUCTION

Understanding how Indigenous youth express hurt and pain in a clinical setting is critical for promoting a healthy life trajectory, including mental, emotional, spiritual, and physical wellbeing (1). Developing strategies to support Indigenous youth during this time is critical to healthy development and promoting positive experiences with health care providers. In particular, the impact of culturally safe and Indigenous-led health care has been demonstrated to improve health outcomes, integrate Western and Indigenous knowledge in care plans, and improve access and adherence (2). Indigenous Peoples in Canada experience high rates of physical pain compared to the non-Indigenous population, and the primary conditions for seeking health care relate to the following pain related symptoms; headaches, musculoskeletal, oral and ear that can profoundly impact children's growth and development (3, 4). The loss of Indigenous knowledge has disrupted Indigenous health systems, leaving few resources for youth to use to conceptualize pain and its associated health outcomes.

In 2016, approximately 26.8% of Indigenous Peoples in Canada were 14 years of age or younger, with the largest population living in the province of Ontario (5). There is a growing body of literature about the context of Indigenous children and youth's experience with pain, including a learned stoic expression of pain and hurt (1, 6–9) that may be impacting clinician's ability to accurately assess and subsequently manage that pain. Additionally, there are misunderstandings about the impact of historical trauma as a driver of pain and hurt that has led to persistent stereotypes. Two Eyed-Seeing approaches to clinical care and an indication of the importance of creating safe spaces to share pain have been identified as important considerations for health systems and clinicians (1, 4, 10). Creating safe health care spaces to engage Indigenous youth in meaningful hurt and pain conversations is an important way to promote health and mitigate the harmful impacts of intergenerational trauma. Indigenous people in Canada experience higher rates of adverse health outcomes and lower rates of specialist care referrals compounded by inequitable access to health care (4).

Untreated hurt and pain negatively influences participation, physical activity, academic performance, language and social development, sleep patterns, growth, behavior, mental health and substance use, therefore burdening future choices concerning their lives and health care utilization (11–16). In one study with First Nations people in Mi'kma'ki, participants identified the importance of considering who *family is to Indigenous People*, how *information* is exchanged between patient and clinician, building *relationships*, creating *safe spaces,* and considering *treatment* from both an Indigenous and western lens when supporting Indigenous people in the healthcare context (1). Recognizing the negative historical impact on Indigenous Peoples care seeking behaviors, lack of trust with the health care system and the reluctance to express themselves in terms of pain means prioritizing Indigenous youth and supporting them to navigate the healthcare system more effectively. Health clinicians can better support Indigenous youth to confidently express pain within clinical settings to meet their needs and address barriers for better health outcomes.

The negative effects of untreated pain can disrupt growth, sleep patterns, language development, social development, and mental health (17, 18). Youth with familial ties to Indian Residential Schools are at a higher risk of experiencing psychological pain and distress, suicidal thoughts, trauma, mental health issues, and physical pain (19–21). As a result of a long history of forced assimilation and colonization, significant inequalities exist for Indigenous youth. Therefore there is an important role for clinicians and Elders in the institutional health care system to improve health outcomes (22).

There is little evidence related to how urban Indigenous youth engage while in a clinical setting and describe pain and hurt as it relates to their health and overall wellbeing. The aim of this study is to mobilize Indigenous knowledge to improve the health care experiences for urban Indigenous youth. This study is an extension of the Canadian Institute of Health Research Chronic Pain Network (CPN) funded Aboriginal Children's Hurt and Healing (ACHH) Initiative, originating in Mi'kma'ki. This project, consistent with the original research conducted in Mi'kma'ki, is Indigenous community led, implemented with the knowledge interpreted and disseminated by community members with the process described in work by Sylliboy et al. (23). The larger study explored the expression of pain through art as well as healthcare utilization data with Indigenous children and youth in First Nations communities in Nova Scotia, New Brunswick and Prince Edward Island (1, 4, 10).

METHODS

Two-Eyed Seeing Approach

A Two-Eyed Seeing approach, coined by Mi'kmaw Elders Albert and Murdena Marshall, indicates both Indigenous and Western knowledge should be considered equally beneficial to co-create new learning's relevant to support the health and wellbeing of Indigenous peoples (24). Two-Eyed Seeing (TES) originates and mirrors how Indigenous people have evolved in their way of living in their ancestral territories, adapting to the evolving circumstances given the impacts of colonialism. TES considers the strengths and perspectives for every aspect of the research process (question development, engagement, methods, data gathering, interpretation and dissemination). The Two-eyed Seeing approach was utilized as a guiding principle to engage, gather, and interpret knowledge in this study. The first author (VanEvery) was the Research Coordinator in this study and contributed her lived experiences and Indigenous knowledge throughout the research process. She is Grand River Mohawk and has degrees in both nursing and public health. The second author (Latimer) is a settler Canadian with Scottish ancestry and has been working with Indigenous communities to mobilize community knowledge to improve health experiences. The third author (Naveau) is Anishnaabe Kwe, Bear Clan and a member of Mattagami First Nation in Northern Ontario. She began her journey with the Aboriginal Health Centre in 2004 and is dedicated to aligning Indigenous practices and ways of knowing and being to enhance the healthcare experiences and relationships for Indigenous people. Throughout the application of the Two-Eyed Seeing approach, data analysis was completed independently and then collectively by all authors. The authors met virtually over the period of several months, followed by an in-person visit where the ACHH team came together to discuss results and to clarify interpretation of the data, so that consensus could be reached. Using both Indigenous and Western perspectives, the data was interpreted to bridge both knowledge systems and to help clinicians understand how Indigenous youth express, share, and manage their pain.

Community Engagement

In keeping with the TES approach described by Sylliboy et al. (23) and to determine if the study goals would benefit and fit with the community expectations, a pre-study community engagement session took place with ACHH researchers and two health care providers, two Elders, two youth, as well as the Aboriginal Health Centre's privacy officer and a Nurse

Research Coordinator. This study employed a community based, participatory action research partnership with an Aboriginal Health Centre in Ontario and the ACHH Initiative research team following the Ownership, Control, Access, and Possession (OCAP) principles (25). The ACHH Initiative aims to work with communities, clinicians and universities to share knowledge that will improve Indigenous child and youth wellness by mobilizing Indigenous knowledge gathered and owned by community, into the health system.

This qualitative study sought to understand how Indigenous youth describe, experience, and manage pain and hurt and how they seek care. Youth, Elders, and health clinicians selected one-on-one interviews or small group conversation sessions and each session lasted approximately 1 hour. The research protocol received approval from an Indigenous Ethics Review Board and the partnering pediatric health care setting. A contract was signed by each of the two parties outlining the community ownership of the knowledge gathered and all decision-making was at the discretion of the community.

Setting and Sample

The setting of this study took place in two urban communities in Southern Ontario, Canada where both cities are located on the Iroquois Territory. There are several terms used to refer to Indigenous or Aboriginal people or in the US Native Americans. In this study we recognize Indigenous or Aboriginal people who in Canada, comprise of the First Nations, Inuit and Metis.

The Aboriginal Health Centre is available to self-identifying Indigenous peoples living in Hamilton, Ontario with an estimated population of 12,130 and Brantford with a population of 5,395 Indigenous people (26). The Aboriginal Health Centre serves to improve the wellness of Indigenous people and the Indigenous community by offering a blend of primary care and traditional healing services with respect to everyone's distinct cultural identity, values and beliefs. The Aboriginal Health Centre offers youth an Aboriginal Youth Mental Health Patient Navigator to ensure that the individualized needs of youths are addressed with appropriate and culturally safe support. This role has been crucial in helping youth reconnect within their communities; especially those involved in the Child Welfare system. This service aids in the development and guidance for youth to engage in a support system similar to a traditional family unit. The Aboriginal Health Centre also offers traditional healing guided by the principles of the Medicine Wheel to promote spiritual and emotional wellness. Registered patients have access to both traditional healers and Western medicine primary care clinicians. Traditional teachings are offered by Elders, knowledge keepers and medicine people. There is also access to cultural ceremonies and community events, workshops promoting cultural arts and ways of knowing and being, as well as one-on-one peer emotional support and hands on healing bodywork modalities.

There were three groups of participants: Elders, health clinicians and youth. Participants were recruited by the Nurse Research Coordinator engaging in convenience sampling, including by word of mouth and recruitment posters in local Indigenous centers and gathering spaces where potential participants frequent. Additionally, the Research Coordinator was invited to youth programming at the regional Indigenous Friendship Centre. Youth participants who met the following inclusion criteria were invited to participate: (1) self-identified Indigenous identity, (2) 13 years of age and older; and (3) living in Hamilton or Brantford. Elders/knowledge holders and health care clinicians were invited to participate if they had experience working with Indigenous youth in this area. They were recruited by email invitation, poster invites, and by word of mouth. The Research Coordinator contacted all eligible participants *via* telephone and/or email to further explain the study, confirm their eligibility and ensure all potential participants have an opportunity to ask any questions. All participants signed written consent forms and were provided with a gift card to thank them for their participation and contribution to this study. All consents and data from this study were locked in a cabinet at the Aboriginal Health Centre with copies kept confidential at the partnering ACHH Initiative space in Nova Scotia. The community ownership and storage of their own data was in keeping with ethical approach and consistent with the Ownership, Control, Access and Possession principles (OCAP) (25).

Data Collection and Analysis

Four sources of data were collected including: (1) Health Surveys, (2) Conversation Sessions, (3) Artwork, and (4) Child and Youth Health Centre electronic medical record (EMR) data between 2015 and 2019. This paper will share the main qualitative results from the conversation sessions with Elders, clinicians and youth. The four dimensions of the Medicine Wheel were used in the interpretation of the knowledge shared by these groups.

Medicine Wheel

Many Indigenous people live by the principles of the medicine wheel and it is integrally embedded in health beliefs representing the dimensions of health and healing. The circle represents the interconnectivity of all aspects of health. The Medicine Wheel is meant to convey wholeness and balance in a continuum, and the quadrants represent the 4 dimensions of well-being: physical, mental, emotional and spiritual (27, 28). The Medicine Wheel has no boundaries between the dimensions and is recognized by most Indigenous people in North America to represent the natural order or balance within the circle of life (29). The figure of the Medicine Wheel outlines each dimension and symbolizes balance, connectedness, wholeness and relationships. The dimensions of the Medicine wheel (emotional, spiritual, physical, mental) were used, as a proxy measure of the types of pain participants might be experiencing so were considered when analyzing the knowledge gathered in the conversation sessions. In related pain research (1), Indigenous study participants consistently responded that pain and hurt were experienced within the four dimensions of the Indigenous health perspective: mental, spiritual, physical, and emotional. Therefore, each dimension is used as a thematic area.

RESULTS

Demographics

In total, there were 33 participants in this study, 21 were youth (13-19 y/o), 6 Elders/ Knowledge holders and 6 clinicians (Nurses, Mental Health and Social workers) resulting in 33 conversation sessions. All Elders/ Knowledge holders self-identified as First Nation, no other demographic data was collected from these participants.

Conversation Sessions

Conversation sessions were held at the Indigenous Friendship Centre, where youth felt comfortable and safe and at a time that was convenient for the youth. Several questions were asked of the participants such as *"what does pain and hurt mean to you," "how do youth express their pain and hurt," "if a new doctor, nurse, or dentist was coming to work at the health centre and you had to tell them about how youth from your area express their hurt-what would you tell them."* Data analysis using the four dimensions of the Medicine Wheel and thematic coding strategies coincided collaboratively to describe *what pain and hurt means*. One Elder said "I buried my emotional pain, so it's just physical pain that I really react to, so that's what pain means to me, just physical pain." A clinician commented "If you go kind of based on the teachings it can also be spiritual pain where people have been deprived of their teachings" and yet another commented "hurt can be from like I said, bullying or shaming, just more emotional." One youth said "Pain means depression" and "feeling worthless like your nothing and feeling in a really low place." One youth described pain and hurt as both a physical experience such as scrape your knee, whereas emotional and mental pain as "something that's painful you don't want to deal with, you just wish it was over. It makes you kind of want to just die and be alone and stuff." She went on to say, "…feels like you're trapped there in that place of pain. It makes you just want to kill yourself and have it be over."

In response to the question *"how do youth express their pain and hurt,"* participants said, "Kids don't know their language so can't describe. Doctors use scale sometimes and you just feel dumb." One clinician said, "I see a lot of it being held within, and that is how a lot of them were raised to deal with it, to just keep it inside. Don't show it as weakness, and crying is weakness and all of that stuff. So, I think a lot of the emotional stuff they tend to try to not acknowledge it or deal with the pain the best they can."

There was a common theme that females were more open about expressing their emotional pain, for example a youth shared, "females hold it in and let out emotionally" but there were also general comments that they try not to cry- because one youth said, "younger siblings look up to me so I try to keep it together." There was an understanding that "Men don't show, women do, easier for women to express their feelings." Clinicians said youth express their pain and hurt through silence, isolation, acting out, get really moody or just pick on somebody else, perpetuate hurt toward others, and feel sorry for themselves. One Elder said "There's something missing, and that's why they go into addiction, why they have unhealthy behaviors, why they're taking medication, is because they're missing something in their life."

When considering the notion that health is a balance of the dimensions of the Medicine Wheel three main thematic areas informed by the conversation session content emerged across the three groups (Elders, youth and clinicians) and include: (24) predictors of health imbalance, (2) indicators of health imbalance and (3) Strategies to re-establish and/or maintain healthy balance.

1. *Predictors of Imbalance*: Circumstances that *predict imbalance of health* included access to resources such as safe surroundings, stable housing, family supports and financial stability. For example, one clinician said, "Poverty is a huge contributor to mental health" while another youth commented, "violence is second nature" and as is "homelessness."
2. *Indicators of Imbalance*: Quotes included content related to children and youth isolating themselves, bullying or being bullied, keeping the hurt inside, not attending school, hurting themselves, cutting, drinking, drugs, smoking, and engaging in risky behaviors. Youth commented "kids being bullies, and can't regulate emotions," "I just keep it to myself until something else comes up, another argument or maybe a bad thing that pops into my head, keeping it to myself until it explodes" with one clinician saying: "I see a lot of drug use and alcohol abuse to try to cope with those traumas and pain" and another said "times are different now because of technology too, and really seeing that kids are on technology all the time. And really try to say, you know, losing touch with that human one-to-one age, right?"
3. *Strategies to re-establish balance were conceptualized using the conversation content and represented with the acronym LISTEN*. The three groups suggested ways clinicians could improve clinical experiences for Indigenous youth. The LISTEN approach includes (a) Language; (b) Individual; (c) Share; (d) Teachable Moments; (e) Engage; and (f) Navigate.

Language

The conversation session content that represented youth's experiences of pain, resulted in a common theme of *language,* with three subthemes as key communication barriers. Participants described three strategies for youth to build a language with clinicians, including translating healthcare terminology, exploring health literacy, and being aware of cultural body language.

Translating Healthcare Terminology

Youth described the language of clinical assessments as unhelpful, frustrating, and numerical. One youth participant explained how clinicians can translate healthcare terminology to support her: "I'll go to the doctor and I'll describe pain and they'll be like, what does that mean? I'm like, I don't know exactly, that's just the way I describe it, and they should be more open to it." Another youth suggested: "Accepting your different vocabulary. I know personally I describe things very weird, or I don't know how to describe some things. It's a lot easier if they're helping you come up with a way of describing pain."

Elders and clinicians suggested translating healthcare terminology when working with youth as they have their own language and tools that they bring with them to the clinical setting. A clinician described the barriers of quantifying assessments with Indigenous patients as follows: "that number scale doesn't really work very well...it's more telling the story of why and what the thought is around it [pain]." Failing to translate medical terminology in lay terms resulted in pain left untreated and youth coping with symptoms on their own.

Exploring Health Literacy

Language was described by participants in respect to the health literacy of youth. Low health literacy was prohibitive for youth who prefer to discuss their health concerns as a result of social inequities. One youth described her frustrations:

How do you even tell your doctor, oh yeah, I'm sad because I'm poor. How do you say that? Even if you were to say something like, I feel like this is something that's contributing to my poor mental health, it's like, how is your doctor going to prescribe something to fix that?

Clinicians recognized how important it was to take the time to engage in the youth's social being and when they critically examined the use of their language they could provide better pain management. One clinician suggested sensitive communication strategies and a strengths-based approach to encourage youth to address their health concerns. Furthermore, when health literacy was explored avenues were created that allowed for clinical exploration of the social determinants of health, while also building language and empowering youth to feel heard.

Cultural Body Language

The three groups commented about varying cultural differences in body language and expression of pain. Clinicians shared their need to assess youth beyond physical pain and more holistically in terms of identifying cultural traits. A clinician shared her suggestions: "Pain is not always sadness. The pain is not always a facial feature. Pain is not always a gesture. And you have to really dig to uncover that piece, and how it's manifesting, and not just taken for face value." Elders discuss cultural body language of stoicism and silence as a cultural trait. However youth describe the same term as "bravery," "masking the pain" and inability to "express hurt and pain in words." Elders, clinicians and youth highlighted the importance of communication with youth by learning the local language, literacy and social skills of the urban Indigenous community as a way to establish balance.

Individual

Participants discussed balancing the unique needs of the Indigenous *individual* and role of the *institution*. The three groups shared how youth individually experience pain and hurt as a result of colonization, disconnection to culture, dysfunctional family, community, and historical trauma. One youth described her pain linking to childhood when asked, *what words do you use to describe pain or hurt to your doctor, nurse or dentist?*

I remember from such a young age, it was like I was always depressed and anxious. And I look back at photos when I was seven years old and I'm like, why was I fake smiling? Why did I need to fake-smile at the time, and also, why did I feel like I couldn't talk to somebody about why I didn't feel regular, why I was always angry, why I was always sad? In looking back, what I had to grow up with, those are natural emotions to have. But since I was hurting for so long, it's become pain, and it's pain that I still have to deal with.

Elders described how youth individually express pain as a result of a disruption of their culture, as well as how one is raised. An Elder described how she believed intergenerational trauma is linked to pain:

It is inherited like family pain and it's just never dealt with, so you just do the same thing, and that's where that term intergenerational trauma comes in, whereas you just don't deal with it and it's just always there, and everybody just kind of steps around it.

A clinician identified the role of the institution and optimism that pain is emerging in conversation so it can be dealt with sooner: "the recognition for it [pain] is a lot better than it ever used to be, because nobody really talked about it." The three groups shared helpful strategies including, "ask youth how they think the pain interferes with their social interactions or every day life," "keep that support open," "be nonjudgmental," "be compassionate," "take different approaches working with them such as using harm reduction techniques," "know the impact of colonization and institutionalization," "listen," "validate their perspectives," and "engage with respectful body language." The overall experience of pain as described by the three groups informed strategies that aid in individual healing and the important role of institutions in facilitating the process.

Share

Youth described mutual *sharing* of knowledge with clinicians as an opportunity for knowledge exchange and discussed their desire for a blend of Indigenous and Western practice when managing pain. Participants' recognized establishing clinical relationships by sharing information about one another provide comfort resulting in better health outcomes.

Sharing Knowledge About one Another

One youth shared how she faces challenges living in the city, yet despite this, recognized her role in achieving balance as an urban Indigenous youth: "Youth in the city must practice a certain type of wisdom to navigate living in the city and a connection with their culture." Youth discussed helpful pain management strategies, including, teachings, sharing circles, connecting with Elders, traditional medicine, herbs, cedar, praying with tobacco, sweat lodge, smudging*[1], art, drumming, singing, and dancing. Western remedies include

---

[1] Smudging is a tradition, common to many First Nations, which involves the burning of one or more medicines gathered from the earth. The four sacred medicines are tobacco, sage, cedar, and sweetgrass. The most common medicines used in a smudge are sweetgrass, sage, and cedar. There are many ways to perform a smudge and different variations exist. Smudging the whole being is meant to portray only the good part of our self through actions. Smudging allows people to stop, slow down, and become mindful and centred. This allows people to remember, connect, and be grounded in the event, task, or purpose at hand. Smudging also allows people to let go of negative feelings and thoughts. Letting go of things that inhibit a person from being balanced and focused comes from the feeling of being calm and safe while smudging (30).

physiotherapist, orthodontist, counseling, recreational activity, and pharmaceuticals.

Sharing Ways of Knowing

Clinicians faced their own challenges and experiences with navigating between Indigenous and Western practice. A clinician shared how she created a safe space as: "don't take the lead because then you empower them to help them make the decisions. I don't walk ahead, I don't walk behind, I walk with." Another clinician discussed sharing vs. suppressing pain as she described her experiences understanding Indigenous pain: "no wonder it hurts, or no wonder people are suffering, right? And how do you get at those strengths, and how do you get us to really honestly, truly practice from a Medicine Wheel perspective as opposed to falling into how we were trained." An Elder shared his perspective of pain as symbolizing water, whereas another Elder described sharing as, "when I deal with our people, I'm sharing about me too, because that's part of the relationship building. It's not just about what they're going to give. It's letting them know about you too."

Teachable Moments

The fourth theme that emerged was the importance for youth to re-establish balance by capitalizing on teachable moments and creating spaces for youth to teach clinicians as well. Clinicians described their role in teaching youth about resources to help connect with culture and recognized the importance of consulting traditional healers. One clinician said: "Introducing them to the traditional healing department. When it comes to a lot of the traditional medicines, I always make sure to let them know that that's not my expertise area, but certainly there's things that we can offer here." Another clinician described the importance of youth connecting with their culture:

They're disconnected from our teachings or to our way of being in that traditional sense, in that cultural sense, a way of being. There's that disconnect maybe from residential school, intergenerational trauma—Sixties Scoop, and so on and so forth, right? So, that all impacts a lot on how our families are today, that disconnect to all of that holistic piece. Because I know sometimes the families just don't know, because there's no one there to really teach them these aspects do matter, and it is important to your whole wellbeing.

Elders shared their concerns of Western medicine and the impact of youth misusing pharmaceutical medication. One Elder who worked at an Indigenous treatment centre shared her dilemma of choosing the right solution: "we cannot just give them medication because that's what they're asking for. And so, you have to teach them, to share that there's other ways of taking care of that health problem." Another Elder described pain as: "It's one of our most powerful teachers. That's the way I've been taught. Because if we've got pain, we're not listening to our body. We're not taking care of ourselves." Elders and clinicians recognized culture as treatment/therapy, however it is often disregarded and when found can be used as a health promoting tool to manage hurt and pain. Clinicians should offer teachable strategies from both an Indigenous and western perspective which may include, smudging, sweat lodge, going out for a walk/stairs, physical activity, nature and fresh air, mindfulness, water, medicine, and the environment.

Engage

The theme of engagement in the clinical setting was important as clinicians indicate they learn best from *listening* to their patients and using their own story in the way care is provided from a holistic perspective. One youth described the need for clinicians to share the clinical encounter with them and engage in pain conversations with an understanding of culture as she shared: "It's like the connection though. People need to feel like they mean something… it's the connection to their families, the connection to their communities, connection to the land." Youth shared engagement strategies such as "educating them to know that it's okay to feel this way, and that it's normal to feel this way," "encouraging them that we are the next generation, and that whatever we create and how we all work with each other now will benefit us all," "describe what you're feeling right now, you can change that," "be somebody in the world that can help how you're feeling right now," and "to be inspired, is what the youth need. They just need to be inspired."

Clinicians noted how youth state they don't feel heard, listened to or their concerns were not taken seriously. A clinician shared an engagement strategy may be offering the youth something to hold such as sweet grass or sage in the clinic. Another clinician discussed ways to engage in conversation with youth by initiating questions that will give them the power to direct the care they want to receive:

Asking them what they would like to see. Had they ever thought of these options? Give them options. Don't ask them, well, what do you want? What are the types of things you like to do? What works best for you? They may tell you. They may not. They may just sit there and listen for the first time. But if they come back, then you know you've done your job, right?

Elders recognized engagement as providing reassurance and supporting Indigenous youth with there own belongingness, hopes, dreams, goals, and desires:

You have this isolation from where you belong. So, I think there's intergenerational trauma, which I think that's definitely contributed too, as far as where colonialism has gone, but also just looking at it from a youth perspective, where they're really trying to figure out where they are, who they are, where they're going?

Experiences of poor engagement resulted in youth who reported that they do not feel listened to, are left wondering and do not have options to support them in how to cope with their painful experiences. Participants recognized that engaging in the historical, social and cultural components of pain facilitated feelings of confidence between youth and clinicians.

Navigate

Collectively, participants described how hard it is for youth to seek out help and the challenges they face to have their voices heard. This theme described the need for clinicians to help youth *navigate* and connect with relevant Indigenous and Western community services and resources. One youth described her frustration with a clinician offering a Western-based survey to assess her health concerns:

She was giving me these kind of surveys from one to 10, and it was just paper and it was basically telling me to list all of the reasons that I wanted to kill myself, and it was asking me how bad I wanted to kill myself, and all this stuff. It just wasn't helping.

This approach within clinical care was also raised by Elders, who discussed the importance of clinicians seeking out options that offer the appropriate support at the right time for youth, and the need for follow up appointments to reassess, build clinical trust and strengthen relationships. Clinicians recognized the importance of advocating for youth with other colleagues while supporting youth to navigate what is working and not working. Another clinician shared "I think from our positions, well what we're trying to do is direct them to, especially Aboriginal or Indigenous youth to connect with their culture, that there is counseling available. There are people that care, that kind of thing."

Ensuring that the individualized needs of youth are addressed with appropriate and culturally safe support were identified as being crucial in helping youth reconnect with their community and validate the important role of institutions. Furthermore, Indigenous navigation services aided in the development and guidance for youth to navigate a support system similar to a traditional family unit that would infuse cultural knowledge and ways of staying healthy using traditional practices. Youth identified that the positive ways they manage their pain is through songs, being in nature, smudging, spending time with Elders and being with others.

DISCUSSION: STRIVING FOR CONNECTIONS TO BALANCE HEALTH AND REDUCE PAIN

In this study 33 Elders, clinicians and youth identify consistent themes relating to the dimensions of hurt and pain and the practical ways for clinical intervention considering the Medicine Wheel and Two-Eyed Seeing lens. There is an underlying theme of the importance of connectedness, kinship and relationships for maintaining health. The Medicine Wheel guides the symbolic balance and interconnection between physical, spiritual, emotional and mental health. When considering the notion that health is a balance of the dimensions of the Medicine Wheel three main thematic areas emerged across the three groups and include (1) predictors of imbalance; (2) indicators of imbalance; and (3) strategies to re-establish balance. The main strategy includes the LISTEN (*Language, Individual, Share, Teachable moments, Engage, and Navigate*) approach that outlines cultural considerations and a safe guide for clinicians to assist with identifying and managing pain and hurt. The results further highlight that the concept of pain and hurt may be experienced and defined differently by Indigenous people which may explain why it remains underassessed and undertreated.

Findings from previous studies note pain is an unrecognized concept with no word directly translating to pain in First Nations languages (8, 31). The experience of pain has also been described using the dimensions of the Medicine Wheel and from a historical, community and family perspective consistent with the findings of the current research. For example, in research with First Nation communities in Mi'kma'ki (1) c*ultural* and *spiritual* pain were described as 'loss of language', cutting of hair, and centralization and relocation of communities. There was a sense of '*community* hurt' and hurt between people "you got hurt or someone hurt you" and these comments were similar by this study. The original study was conducted in rural First Nation communities and the current study was with urban participants highlighting that irrespective of place of residence; the experience, dimensions and scope of pain and hurt may be similar for urban and rural Indigenous youth. This study's findings are consistent with other research where clinicians identified the importance of connection and relationships in Indigenous youth for balancing wellness-such as share, exchange through teachable moments, engage and support for navigation. These findings are aligned with the FIRST principles which are clinician guidelines originating from a similar study with Indigenous children and youth in four First Nations communities in Mi'kma'ki. FIRST principles (1) support clinicians to understand who *family is*, how *information* is exchanged, the importance of building *relationships*, creating *safe spaces* and considering *treatment* from both an Indigenous and western lens when supporting Indigenous youth. In work related to creating humanizing health spaces for Indigenous People, Indigenous researcher Sylliboy and Hovey (32) share the idea that, nurturing positive relationships encourages trust with clinicians who are not familiar Indigenous People as there is a vulnerability for patients in these settings. Health clinicians need to find ways to learn, trust and care (32).

Culture is not a stationary concept, it is shaped by social construct, environment, relationships, beliefs, values and according to Matheson et al. (33) "rooted in ancestry (systems of knowledge), historical events (collective trauma), and evolving contexts (climate change, colonization, migration)" (p. 3). The dimensions of language related to culture, health, body language, expression and information exchange highlight the continuing importance of context of care. Previous research suggests that pain may be withheld to avoid attention and often seen as stoicism as a result of pain being viewed as a weakness in Indigenous cultures (6, 8). Clinicians are trained to use numerical or faces pain scales, however, only minimal research has been done to determine if these self-report pain scales are culturally appropriate for use with Indigenous youth (34, 35) and there is evidence that they are not helpful to First Nations youth (10) which was confirmed again in this research. Having language speakers with health care knowledge has been a recommendation to improve the navigation of the health care journey (1, 36, 37).

Striving to provide *individualized* care that holistically considers the strengths and unique needs of each individual without making assumptions about who they are or what they need is consistent with previous research (10). Similar to themes in the current study, Browne et al.'s (38) research with two urban Aboriginal Health Centres identified four key dimensions of equity-oriented health services including inequity-responsive care, culturally safe care, violence-informed care and contextually tailored or individual care. Individualizing care is a priority due to the evidence that Indigenous youth conceptualize, and experience pain differently compared to non-Indigenous youth consequently putting them at higher risk for poorer outcomes (1, 4). Providing youth with the opportunity to hold something that is culturally significant to them in the clinical setting is a tangible strategy easily implemented and step toward respectful practice and relationship building. Relationship building and meaningful engagement has been reported before as an essential component to the health journey of Indigenous people (39, 40).

Youth in this study reported accessing clinicians as a usual source of care to consult or receive medical advice and responded they felt comfortable seeking care yet there were some accepted practices in the mainstream system that may cause harm. There is a broader need for clinicians to take responsibility to educate themselves about Indigenous health, colonization and its impacts on health while reflecting on their own assumptions/biases and how these can perpetuate all dimensions of pain (emotional, spiritual, physical, mental). Evidence has shown that a connection to culture can buffer the predictors of imbalance and potentially reduce the experience related to the indicators of imbalance (1, 10, 33, 41). A large scoping review identified that culturally safe strategies can decolonize care by demonstrating awareness of colonialism, racism, and discrimination. The review identified strategies that build partnerships and share decision-making in the delivery of care all contribute to the philosophy of the LISTEN approach (42). A study by Jacklin et al. (37) with five Indigenous communities, reports that health care relationships are central to addressing the ongoing colonial dynamics in Indigenous health care and support the notion that they play a role in buffering past harms.

LIMITATIONS

One limitation of this study is the method used to collect data did not guarantee anonymity when participants selected conversation sessions vs. one-on-one interviews. This may have resulted in participants sharing perspectives to their personal agency of safety. Another limitation included the notion that engaging more communities could have provided a broader range of community member experiences. In addition, providing the participants an opportunity to speak in their own language would have potentially given more information about the role of language in the concept of pain.

CONCLUSION

The findings of this study have been interpreted by community members and health leaders, providing clinicians with the evidence to provide strengths-based clinical experiences and culturally safe care for Indigenous youth. The findings provide specific clinical implications to advance health clinicians knowledge and understanding to provide culturally safe care. Being culturally safe means knowing the history and the impact of that history on Indigenous People's health. Clinicians can consider those indicators of imbalance and how they can support indigenous people to re-gain balance using both Indigenous and Western ways of knowing and doing. Guided by the LISTEN approach clinicians can keep the idea of culturally safe care front of mind, and this approach can make healing feel achievable. The LISTEN approach will enrich cultural safety curriculum, integrate Indigenous Knowledge for clinicians, and promote the likelihood of healing.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because all data generated from this study belongs to the Community Health Centre as proxy owners for the study participants, as dictated by OCAP principles. Requests to access the datasets should be forwarded to ANaveau@dahac.ca.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by IWK Health Centre Research Ethics Board and Mi'kmaq Ethicswatch. The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

RV involved in design, data collection, data analysis, and writing of manuscript. ML and AN involved in design, data analysis, and writing of manuscript. All authors contributed to the article and approved the submitted version.

ACKNOWLEDGMENTS

The authors thank the youth, Elders, and clinicians for sharing their perspectives and acknowledge the contributions of the CIHR Chronic Pain Network funded Aboriginal Children Hurt and Healing Initiative, Aboriginal Health Centre and Indigenous Friendship Centre in Southern Ontario.

REFERENCES

1. Latimer M, Sylliboy J, Francis J, Amey S, Rudderham S, Finley GA, et al. Co-creating better health care experiences for First Nation Children and Youth: the FIRST approach emerges from Two-Eyed Seeing. *Pediatric Neonatal Pain*. (2020) 2:104–12. doi: 10.1002/pne2.12024
2. Allen L, Hatala A, Ljaz S, Courchene D, Bushie B. Indigenous-led health care partnerships in Canada. *CMAJ*. (2020) 192:E208–16. doi: 10.1503/cmaj.190728
3. Craig KD, Holmes C, Hudspith M, Moor G, Moosa-Mitha M, Varcoe C, Wallace B. (2020). Pain in persons who are marginalized by social conditions. *Pain*. 161:261–5. doi: 10.1097/j.pain.0000000000001719

4. Latimer M, Rudderham S, Lethbridge L, MacLeod E, Harman K, Sylliboy J, et al. Occurrence of and referral to specialists for pain related diagnoses in First Nations and non-First Nations children and youth. *CMAJ*. (2018) 190:E1434–1440. doi: 10.1503/cmaj.180198
5. Statistics Canada (2019). Aboriginal peoples in Canada: key results from the 2016 Census. Available online at: https://www150.statcan.gc.ca/n1/daily-quotidien/171025/dq171025a-eng.htm (accessed May 04, 2020).
6. Fenwick C. Assessing pain across the cultural gap: Central Australian Indigenous peoples' pain assessment. *Contemp Nurse*. (2006) 22:218–27. doi: 10.5172/conu.2006.22.2.218
7. Honeyman PT, Jacobs EA. Effects of culture on back pain in Australian Aboriginals. *Spine*. (1996) 21:841–3. doi: 10.1097/00007632-199604010-00013
8. Latimer M, Finley G, Rudderham S, Inglis S, Francis J, Young S, et al. Expression of pain among Mi'kmaq children in one Atlantic Canadian community: a qualitative study. *CMAJ Open*. (2014) 2:E133–8. doi: 10.9778/cmajo.20130086
9. Latimer M, Young S, Dell C, Finley GA. Aboriginal children and physical pain: what do we know? *J Aboriginal Health*. (2012) 9:7–14. doi: 10.18357/ijih91201212389
10. Latimer M, Sylliboy JR, MacLeod E, Rudderham S, Francis J, Hutt-MacLeod D, et al. Creating a safe space for First Nations youth to share their pain. *PAIN Rep*. (2018) 3:e682. doi: 10.1097/PR9.0000000000000682
11. Bidadi S, Nejadkazem M, Naderpur M. The relationship between chronic otitis media-induced hearing loss and the acquisition of social skills. *Otolaryngology*. (2008) 139:665–70. doi: 10.1016/j.otohns.2008.08.004
12. Casamassimo PS, Thikkurissy S, Edelstein BL, Maiorini E. Beyond the dmft: The human and economic cost of early childhood caries. *J Am Dental Assoc*. (2009) 140:650–7. doi: 10.14219/jada.archive.2009.0250
13. Cooper P, Kohler M, Blunden S. Sleep and academic performance in Indigenous Australian children from a remote community: an exploratory study. *J Paediatr Child Health*. (2012) 48:122–7. doi: 10.1111/j.1440-1754.2011.02059.x
14. Langan L, Sockalingam R, Caissie R, Corsten G. Occurrence of otitis media and hearing loss among First Nations elementary school children. *Can J Speech-Lang Pathol Audiol*. (2007) 31:178–85.
15. Lawrence HP, Binguis D, Douglas J, McKeown L, Switzer B, Figueiredo R, et al. Oral health inequalities between young Aboriginal and non-Aboriginal children living in Ontario, Canada. *Community Dent Oral Epidemiol*. (2009) 37:495–508. doi: 10.1111/j.1600-0528.2009.00497.x
16. Mathews L. Pain in children: neglected, unaddressed and mismanaged. *Indian J Palliat Care*. (2011) 17:S70–3. doi: 10.4103/0973-1075.76247
17. Mota N, Elias B, Tefft B, Medved M, Munro G, Sareen J. Correlates of suicidality: Investigation of a representative sample of Manitoba First Nation adolescents. *Am J Public Health*. (2012) 102:1353–61. doi: 10.2105/AJPH.2011.300385
18. Noel M, Chambers CT, McGrath P, Klein RM, Stewart SH. The influence of children's pain memories on subsequent pain experience. *Pain*. (2012) 153:1563–72. doi: 10.1016/j.pain.2012.02.020
19. Bombay A, Matheson K, Anisman H. The intergenerational effects of Indian residential schools: Implications for the concept of historical trauma. *Transcult Psychiatry*. (2014) 51:320–38. doi: 10.1177/1363461513503380
20. Walls ML, Huatala D, Hurley J. "Rebuilding our community": hearing silenced voice on Aboriginal youth suicide. *Transcult Psychiatry*. (2014) 51:47–72. doi: 10.1177/1363461513506458
21. First Nations Information Governance Centre. (2012). First *Nations Regional Health Survey [FNRHS] 2008/10*. (2012). National Report on Adults, Youth and Children Living in First Nations Communities. Available online at: https://fnigc.ca/sites/default/files/First_Nations_Regional_Health_Survey_2008-10_National_Report.pdf (accessed August 2020).
22. Goodman A, Fleming K, Markwick N, Morrison T, Lagimodiere L, Kerr T, Western Aboriginal Harm Reduction Society. They treated me like crap and I know it was because I was Native: the healthcare experiences of Aboriginal peoples living in Vancouver's inner city. *Soc Sci Med*. (2017) 178:87–94. doi: 10.1016/j.socscimed.2017.01.053
23. Sylliboy JR, Latimer M, Marshall A, MacLeod E. Communities take the lead: exploring indigenous health research practices through two-eyed seeing and kinship. *Int J Circum Health*. (2021) 80:1–11. doi: 10.1080/22323982.2021.1929755
24. Iwama M, Marshall M, Marshall A, Bartlett C. Two-eyed seeing and the language of healing in community-based research. *Can J Native Educ*. (2009) 32:3–23.
25. First Nations Information Governance Centre. *Ownership, Control, Access and Possession (OCAP^{TM}): The Path to First Nations Information Governance*. (2014). Available online at: https://fnigc.ca/sites/default/files/docs/ocap_path_to_fn_information_governance_en_final.pdf (accessed December 2020).
26. Statistics Canada. *Aboriginal Population Profile, 2016 Census*. (2018). Available online at: https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/abpopprof/search-recherche/lst/results-resultats.cfm?Lang=E (accessed May 04, 2020).
27. Doucette J, Bernard B, Simon M, Knockwood C. *The Medicine Wheel: Health Teachings and Health Research*. (2004). Available online at: http://www.integrativescience.ca/uploads/articles/2004June-Doucette-Bernard-Simon-Knockwood-Medicine-Wheel-Aboriginal-health-Integrative-Science.pdf (accessed June 18, 2021).
28. Fiedeldey-Van Dijk C, Rowan M, Dell C, Mushquash C, Hopkins C, Fornssler B, et al. Honoring Indigenous culture-as-intervention: development and validity of the Native Wellness Assessment^{TM}. *J Ethn Subst Abuse*. (2016) 16:181–218. doi: 10.1080/15332640.2015.1119774
29. Youngblood-Henderson J. "Ayukpachi: empowering aboriginal thought," in M. Battiste, editor. *Reclaiming Indigenous Voice and Vision*. Toronto, ON: UBC Press (2009). p. 248–78.
30. Smudging Protocols and Guidelines. *Indigenous Inclusion Directorate Manitoba Education and Training*. (2019). Available online at: https://www.edu.gov.mb.ca/iid/publications/pdf/smudging_guidelines.pdf (accessed February 2021).
31. Strong J, Nielsen M, Williams M, Huggins J, Sussex R. Quiet about pain experiences of Aboriginal people in two rural communities. *Aust J Rural Health*. (2015) 23:181–4. doi: 10.1111/ajr.12185
32. Sylliboy JR, Hovey RB. Humanizing Indigenous Peoples' engagement in health care. *CMAJ*. (2020) 192:190754. doi: 10.1503/cmaj.190754
33. Matheson K, Bombay A, Anisman H. Culture as an ingredient of personalized medicine. *J Psychiatry Neurosci*. (2018) 43:3–6. doi: 10.1503/jpn.170234
34. Ellis JA, Ootoova A, Blouin R, Rowley B, Taylor M, Decourtney C, et al. Establishing the psychometric properties and preferences for the northern pain scale. *Int J Circumpolar Health*. (2011) 70:274–85. doi: 10.3402/ijch.v70i3.17823
35. Jimenez N, Garroutte E, Kundu A, Morales L, Buchwald D. A review of the experience, epidemiology and management of pain among American Indian, Alaska Native and Aboriginal Canadian peoples. *J Pain*. (2011) 12:511–22. doi: 10.1016/j.jpain.2010.12.002
36. Health Council of Canada. *Empathy, Dignity and Respect: Creating Cultural Safety for Indigenous People in Urban Health Care*. (2012). Available online at: https://healthcouncilcanada.ca/files/Aboriginal_Report_EN_web_final.pdf
37. Jacklin KM, Henderson RI, Green ME, Walker LM, Calam B, Crowshoe LJ. Health care experiences of Indigenous people living with type 2 diabetes in Canada. *CMAJ*. (2017) 189:E106–12.
38. Browne AJ, Varcoe C, Lavoie J, Smye V, Wong ST, Krause M, et al. Enhancing health care equity with Indigenous populations: Evidence-based strategies from an ethnographic study. *BMC Health Serv Res*. (2016) 16:544. doi: 10.1186/s12913-016-1707-9
39. Crowshow LL, Henderson R, Jacklin K, Calam B, Walker L, Green ME. Educating for equity care framework: addressing social barriers of Indigenous patients with type 2 diabetes. *Can Family Phys*. (2019) 65:25–33.
40. Doane GH, Varcoe C. *How to Nurse: Relational Inquiry With Individuals and Families in Changing Health and Health Care Contexts*. Baltimore, MD: Wolters Kluwer Health/Lippincott Williams and Wilkins (2015).
41. Shepard SM, Delgado RH, Sherwood J, Paradies Y. The impact of Indigenous cultural identity and cultural engagement on violent offending. *BMC Public Health*. (2017) 18:50. doi: 10.1186/s12889-017-4603-2

42. Schill K, Caxaj S. Cultural safety strategies for rural Indigenous palliative care: a scoping review. *BMC Palliative Care*. (2019) 18:21. doi: 10.1186/s12904-019-0404-y

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 Pain Research

HYPOTHESIS AND THEORY
published: 24 May 2022
doi: 10.3389/fpain.2022.895443

Beyond Pain Scales: A Critical Phenomenology of the Expression of Pain

Nicole Miglio [1,2†] ***and Jessica Stanier*** [3*†]

[1] Philosophy Department, State University of Milan, Milan, Italy, [2] Women's and Gender Studies Department, University of Haifa, Haifa, Israel, [3] Wellcome Centre for Cultures and Environments of Health, Politics Department, College of Social Science and International Studies, University of Exeter, Exeter, United Kingdom

In this paper, we discuss the qualitative dimension of painful experiences by exploring the role of imagination and metaphorical association in the conceptualization and expression of pain. We employ an engaged critical-phenomenological approach to offer original analysis influenced by the perspectives of people in pain. The paper is organized into three parts. Part 1 reviews literature on the expression of pain, its communication, and its reception—attending in particular to the emphasis on verbalizing pain in healthcare contexts. We here discuss benefits and limitations of standard methods aimed at facilitating the meaningful expression of pain (such as "pain scales") from the perspectives of patients and practitioners, respectively. We suggest that these methods might be importantly complemented by facilitating creative expression of painful lived experiences with respect to personal lifeworlds. Part 2 deals with the role of imagination and metaphorical association in making sense of pain. We explore how imagination is a cognitive and affective mode of experiencing the world which plays a crucial role in determining how pain is experienced, as well as helping to make sense of pain figuratively in relation to the lifeworld. In Part 3, we draw from principles of engaged phenomenology to foreground case studies in which projects have been able facilitate the intersubjective expression of pain. These examples demonstrate the value of attending to the contours of painful lifeworlds in their specificity, affording both agency and accessibility in their communication, while remaining mindful of the complex power relations which govern perceived legitimacy and testimony relating to the transformation of pain. The overall paper aims to contribute to literature on qualitative pain research on both theoretical and practical levels. By exploring the expression of pain through phenomenology, we aim to enrich current debate on the qualitative experience of pain. We also seek to critically highlight the socio-political dimensions which frame painful experiences, their expression, their lived significance, and their treatment.

Keywords: phenomenology, pain, imagination, lived experience, lived body, critical phenomenology, expression, patient experience

OPEN ACCESS

Edited by:
Najmeh Khalili-Mahani,
Montreal Neurological
Institute, Canada

Reviewed by:
Margaret Dunham,
Edinburgh Napier University,
United Kingdom
Mathieu Roy,
McGill University, Canada

****Correspondence:***
Jessica Stanier
js708@exeter.ac.uk

[†]These authors have contributed equally to this work

Specialty section:
This article was submitted to Non-Pharmacological Treatment of Pain,
a section of the journal Frontiers in Pain Research

Received: *13 March 2022*
Accepted: *04 May 2022*
Published: *24 May 2022*

Citation:
Miglio N and Stanier J (2022) Beyond Pain Scales: A Critical Phenomenology of the Expression of Pain. Front. Pain Res. 3:895443.
doi: 10.3389/fpain.2022.895443

INTRODUCTION

For decades, the International Association for the Study of Pain (IASP) defined pain as "[a]n unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (1). In an article that has sparked much important debate, however, Cohen, Quintner, and van Rysewyk proposed an alternative definition of pain from that of the IASP (1). These authors drew on the phenomenological experience of pain—as a portent of a threatening future, as a corporeal experience, as a source of meaning, as a threat to existential integrity, and as involving an intersubjective perspective—in order to "embrace pain as a shared phenomenon" [(1), p. 6][1]. Their proposed alternative to the old IASP definition characterizes pain as "a mutually recognizable somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity" [(1), p. 6]. The IASP definition has since shifted away from the implication that those in pain are able to describe it, to be better inclusive of those who are unable to articulate pain, such as infants and animals ("An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" [(2)]).

This debate concerning the intersubjective status of pain has been welcomed, even by those who remain unconvinced by alternative definitions, as "an inspiration for broadening our approach to pain assessment" [(3), p. 3]. As phenomenologists, we are greatly heartened by how these considerations have enriched contemporary debate in the clinical sphere. Having previously argued that it crucially matters how pain is constituted in experience within an intersubjective (social and political) context, and that this affects the very painfulness of a given experience (4, 5) we also greet this discussion concerning the shared dimensions of painful experience with enthusiasm. It is similarly heartening to see the biopsychosocial model of pain gaining traction in research and practice as a means to recognize how intersecting biological, psychological, and social determinants all contribute to the overall experience of pain (6, 7) and that none of these determinants taken in isolation will sufficiently capture painful experience in its complexity. We feel that this promising discussion of pain and its intersubjective dimensions calls for sophisticated critical-phenomenological analysis specifically concerning the *creative expression* of pain, which is an integral part of any pain assessment and subsequent sense-making of pain[2,3]. This is especially pressing since people experiencing pain—particularly in its chronic forms—stand to benefit from potential theoretical insights put into practice [cf. (8)]. Indeed, disabled activists, scholars, and communities have long called for a reevaluation of the treatment of pain and the uncritical equivocation between pain and broader structures that sustain suffering [(9), p. 203]. Intersubjective sense-making may not amount to straightforward healing or alleviation of pain, but it nonetheless involves an important transformation of relations that affords control and agency to those experiencing pain.

As phenomenologists, we want to remain faithful to this lived experience of complex communicability, expressivity, and amelioration regarding pain and its treatment. Phenomenology is a rigorous philosophical approach that explores how objects of experience present themselves and how they become meaningful [(10), p. 9][4]. In this article, we draw especially from the critical-phenomenological approach, which "combines insights regarding embodied lived experience with analyses of socio-political structures and power relations which frame, inform, and shape that experience" [(11), p. 4]. We hope to introduce readers to key phenomenological concepts, alongside illustrative examples, with which to explore issues relating to the amelioration of painful experience. By attending to the role of imagination and metaphorical association in experiential constitution, from sensation to sociality, we offer a critical-phenomenological account that takes seriously the transformative potential of shared expression in this regard. Moreover, we draw from principles of engaged phenomenology to challenge "assumptions around narrativity and privileged articulacy," to remain "mindful of how experience is lived through constellations of relations with others," and to consider "the transformative potential of [people] sharing their experiences in meaningful ways, rather than merely assessing their 'utility' in academic terms" (12). The case studies in this article are, along these lines, intended to illustrate the various ways in which pain can be transformed through intersubjective expression, while also attending to the complex power relations which govern perceived legitimacy and testimony relating to discussion of pain.

ON THE EXPRESSION OF PAIN, ITS COMMUNICATION, AND ITS RECEPTION

> The sensations of my own body may be the only subject on which I am qualified to claim expertise. Sad and terrible, then, how little I know. "How do you feel?" the doctor asks, and I cannot answer. Not accurately. "Does this hurt?" he asks. Again, I'm not sure. "Do you have more or less pain than the last time I saw you?" Hard to say. I begin to lie to protect my reputation. I try to act certain [(13), p. 70].

---

[1] **Key definition: Intersubjectivity**
Intersubjectivity is the condition of being in the world alongside other subjects (i.e. other people). In the phenomenological tradition, the self is understood as intrinsically embodied and, by virtue of this embodiment, structurally related to other human beings—from basic interactions grounded in empathy to more complex social dimensions entailed by living together.

[2] **Key definition: Expression**.
Expression can be understood broadly as acts which convey some subjective meaning—often, but not always, communicating that meaning to others. Expressive modes include speech, gesture, bodily movement, musicality, the creation of art, and many other acts. The received meaning of any given expression can ambiguously deviate from its intended meaning, depending on the context of its reception. Nonetheless, perhaps especially in creative acts of poetry or artwork, this ambiguity can lend itself to the overall expressivity of the act.

[3] **Key definition: Sense-making**
In the context of phenomenology, sense-making is understood as the process by which individual and collective experiences become meaningful. While some aspects of sense-making take place on an unconscious level, being able to make sense of one's experiences consciously—in relation to objects, structures, and others in the world—enables one to act deliberately on the basis of lived experiences and to communicate it to others.

[4] **Key definition: Phenomenology**
Phenomenology is a philosophical tradition stemming from the work of German philosopher Edmund Husserl at the beginning of the 20th Century. It has developed into various different philosophical legacies, of which Existentialism and Hermeneutics are among the most prominent. While there are various internal philosophical debates within the phenomenological field, its various interpreters generally all maintain that the first-person perspective is primary in the production of knowledge. Lived experience is understood as integral to the sense-making processes of the self.

It is often felt by people experiencing pain that they are expected, as patients, to offer linguistically articulate expressions of pain with purported medical utility; while the amended IASP definition goes some way to separating description and experience of pain, verbal expression is still a key part of clinical evaluation (e.g., rating pain on a scale of 1–10). In some academic contexts, by contrast, pain is assumed to be ineffable, intrinsically private, and impossible to communicate [(14), p. 53]. Both of these approaches to pain problematically obscure a more complex reality—a matter that significantly motivated Cohen et al. (1) in the formulation of their alternative definition. The creative expression of pain has a long history, and contemporary patient groups and disability activists have been able to facilitate profound communicability through poetry, imagery, and all manner of communal artistic expression (see Part 3). It is very much possible—and often vitally important in relations of care—to receive another person's expression of pain, to understand something of its painful nature, and to demonstrate this understanding. We can accept this philosophically without requiring an identity of experience between the person in pain and their companion(s) [(9), p. 206; (4), p. 106]. We know intuitively when other people "get it". In this way, pain assessments are not merely instrumental means to understanding pain from a medical perspective; from a patient's perspective, this can be an important ethical interaction that can offer a sense of connection or alienation, depending on how the pain expressed has been received in this context.

Given that people are rarely offered other explicit opportunities to express their pain in the process of diagnosis and treatment, this encounter can take on additional and perhaps disproportionate significance. It is unclear that the assessment of pain can itself serve as a therapeutic intervention, and yet the responses of practitioners can here set the tone for how people relate to their pain moving forward. Without alternative avenues to explore shared understanding of pain, so much can depend upon this particular clinical encounter. This is not lost on practitioners, who are often acutely aware of how the multiple demands on the clinical encounter can compromise opportunities for compassionate care. As Disher (15) writes:

> It is concerning to imagine to what degree we may be failing to help our patients by assuring them that concerning feelings are "normal" or by being unable to understand the experience they are describing. It is not uncommon to have a sense that something is being missed, and one wonders if a phenomenological toolkit that could be quickly at hand could be used in these moments to support assessment, diagnosis, and treatment [(15), p. 1,097].

The experience of shared understanding can have a hugely significant impact on the experience of pain itself (16). This shared understanding is often made possible by enabling people in pain to explore the shape of their pain and its impact with respect to their life as a whole—this concerns how the phenomenon of pain presents in the context of a particular lifeworld, to use a phenomenological term [cf. (17)][5]. While the pain itself may linger, with no particular end in sight, a *transformation* of painful experience can be facilitated through meaningful intersubjective expression of pain, in which, as Hovey writes, "patients become people again" [(18), p. 12]. This can be the impetus for both attitudinal and material change in lifeworlds of people in pain. Painful sensations are put into relief by experiential circumstances which are not always inevitable but about which people can feel more or less hopeful depending on this perceived possibility of change:

> Do I trust in any healthcare provision to which I have access? How long do I anticipate this pain will continue as a result, and does that anticipation feel bearable? Does this pain feel shameful, and do I feel worthy of care? These aspects of the painful experience may, in fact, problematically intensify or normalize these very pain sensations, depending on the intersubjective social and political context within which I find myself [(4), p. 109].

Opportunities to discuss pain this broadly are rare in clinical encounters, which are primarily focussed on curing the physical body of its malady. However, without a detailed sense of how pain manifests in the lifeworld, medical consultation can feel frustratingly generic and detached for patients [(19), p. 3]. Especially in cases of chronic pain, individual painful circumstances shape and color the lifeworld and, in "attending to these complexities of painful experience and associated suffering, a radically different notion of care may emerge as appropriate for each person beyond unsympathetic and clinical elimination of pain altogether" [(4), p. 111]—it is, after all, not always possible for treatment to offer a straightforward "cure," and the unique significance of chronic pain for the patient must be taken seriously when exploring alternative treatment avenues. Ideally, treatment would respond specifically to the expression of pain for each individual in their particular situation.

So what is it like to have one's pain subject to the assessment of another? When I close my eyes, tense my body, and hold my breath when it hurts, try as I might not to flinch, what does this bodily expression tell you about my pain? What if I tell you it burns, or it feels sharp, or it aches? How can you know what this pain means to me? Given that painful sensations are only given directly in first-person experience, the attempt to gather up subjective pain into expression can feel particularly fraught. Indeed, as the IASP has come to recognize, not everyone experiencing pain is able to do this. Famously, in her seminal work *The Body in Pain*, Scarry argues that pain can "destroy language" [(14), p. 53]. Deep pain can indeed render linguistic expression, or even the attempt to conjure up words, void and impossible, such that a person in pain can but cry out in agony. It is interesting, however, that Scarry extrapolates

---

[5] **Key definition: Lifeworld.**
The lifeworld is the shared and communal world as experienced first-hand by the self in everyday life. Everyone has individual, perceptual, and social experiences that are foundational in the way they engage in the world thereafter. By emphasizing the importance of the lifeworld, phenomenology explores the experiential structures that underlie our immediate access to the world.

from the impossibility of linguistic expression to claim that pain "brings with it all the solitude of absolute privacy with none of its safety, all the self-exposure of the utterly public with none of its possibility for camaraderie or shared experience" [(14), p. 53]. Certainly, the urgency and aversiveness of painful experiences can underscore the fundamental separation between first and third person perspectives; it is precisely when we most need someone to understand our pain, to care that it hurts us, and to know how to cure it that others "can turn away in disbelief and disregard," since the pain *is* ultimately subjective [(4), p. 106]. To a certain extent, if someone tells you their pain is unbearable then you can but take their word for it (or choose to disbelieve); you cannot verify this claim with firsthand experiential evidence. However, we contend, unlike Scarry, that this appeal and desire for others to understand our pain actually discloses a very real possibility for the "camaraderie and shared experience" that she suggests pain might prevent.

Without discounting the plausibility of painful experiences in which people feel absolutely unreachable and inconsolable, we can, in fact, conceive of instances in which painful experiences are recognized and meaningfully understood by others without direct access to the painful sensations themselves. Such relations of empathy make it possible to offer care or cure, and these relations can develop between loved ones, between people who discover their respective pain bears resemblance, and importantly between patients and practitioners. Recognition that pain can indeed be shared in this intersubjective sense led Cohen, Quintner, and van Rysewyk to emphasize "mutual recognizability" in their alternative definition of pain [(1), p. 6]. They draw from Martin Buber's phenomenological analysis of first and third person perspectives, among other approaches, and conclude that the clinical encounter is, or should be,

> a legitimate (socially sanctioned) and safe communal space in which both parties can accept and negotiate the meanings of the experience, including the testing of boundaries, thereby creating a therapeutic relationship [(1), p. 5].

As much as practitioners might aspire to facilitate such a space, this description is very much idealistic; in reality, imbalances of power, intercultural barriers, competing demands on time, negative prior experiences, pressure on resources, and other such factors can color the clinical encounter and prevent the negotiation of meaning in therapeutic terms (4).

It is important to note, given that the clinical encounter can be fraught, that individuals *are*, of course, capable of self-reflexively altering their experience of pain outside of medical spaces. This is not, however, the same as expecting individuals to simply "get on with it" alone; those looking to ameliorate pain must recognize that external support structures play a key role. This much is already recognized by most biopsychosocial conceptualizations of pain (6, 7). Isolation, loneliness, and rumination have also been linked to the exacerbation of the painfulness of experiences. These magnify the undesirability of the experience, and feelings of helplessness are core components of catastrophic thinking that can diminish recovery in the "functioning" of pain patients (20, 21). Positive interventions are most often facilitated within a fretwork of social relations, which more or less explicitly encourage and make possible the individual transformation of painful experience [cf. (22)]. It is crucially important that conceptions of pain do not treat people as solely and individually responsible for making sense of their painful experiences, since the circumstances that have enabled one person to address their own pain may not be afforded to other people. The clinical encounter thus garners much of its significance in the analysis of painful experience from the fact that it is the *common* space in which one seeks a medical explanation and assistance that cannot be found elsewhere (23). This does not mean that the encounter will necessarily represent the beginning and end of a person's understanding of their own pain. The encounter is, however, framed by these specific concerns, and the expression of pain is understood by each party in this interaction accordingly. For a medical practitioner, a meaningful expression of pain might importantly reveal details pertinent to a diagnosis or relevant for signposting a patient to better support. For a patient, as illustrated by Biss's account quoted at the beginning of Part 1, it can be unclear which expression of pain will be recognized and accepted as valid by others. Most (in)famously, pain scales have highlighted verbalized expression as key to medical understanding of pain.

Medical tools to assist the expression of pain proliferated in the twentieth Century, especially in the West after the Second World War, including three key models of pain measurement: "psychophysics, multidimensional questionnaires using standardized descriptors, and scales which rate the intensity of pain" [(24), p. 15]. In 1939, Dallenbach listed 44 words in total to, respectively, describe "the temporal course of pain, its spatial distribution, fusions or integration with pleasure, affective coloring, and qualitative attributes" [(24), p. 16–17]. The McGill Pain Questionnaire was developed in 1975 by Melzack, in consultation with panels of students, patients, and doctors, to identify words to describe sensory, affective, and evaluative dimensions of pain and to rank these words according to pain intensity (25, 26). Gracely and Dubner (27) sought clinical utility and accuracy in their proposed five properties of an ideal verbal pain measure, as well as seeking the possibility of absolute valid comparison of pain across groups. From pain charts (28) to descriptive terms (25) and visual-linguistic scales (29), these developments helped medical practitioners and researchers to recognize the utility and importance of subjective reports of pain, as well as furnishing them with means to record something resembling a pain "measurement." Indeed, by the late 1990s, nursing literature began to refer to pain as "the fifth vital sign" (30). These notable and influential examples from twentieth century Western medicine, to mention just a few, illustrate how endeavors to facilitate the expression of pain have developed with respect to medical understanding.

While the medical profession now largely recognizes the importance of taking reports of pain into account, the communication of pain through scales and measures can be challenging for people experiencing the pain firsthand. Eula Biss (13) further describes the difficult process in her creative writing essay "The Pain Scale":

> Determining the intensity of my own pain is a blind calculation. On my first attempt, I assigned the value of ten to a theoretical experience—burning alive. Then I tried to determine what percentage of the pain of burning alive I was feeling.
> I chose thirty percent—three. Which seemed, at the time, quite substantial.
> Three. Mail remains unopened. Thoughts are rarely followed to their conclusions. Sitting still becomes unbearable after 1 h. Nausea sets in. Quiet desperation descends.
> "Three is nothing," my father tells me now. "Three is go home and take two aspirin."
> It would be helpful, I tell him, if that could be noted on the scale [(13), p. 72].

When the pain scale becomes the medium and vehicle for the expression of pain, "the questionnaire displaces the patient's own story, sidesteps the issue of pain's private meaning, and disrupts the potential for humane communication between patient and doctor" (31). The encounter *means* something crucially different to patients and practitioners, however much interpersonal relations of care mediate their communication, as Cohen et al. (1) might hope. As Padfield notes, "[b]y the time a patient ends up in a pain clinic there can be a wide gulf between the agendas of patient and clinician [...] and the significance it holds for them both. There is thus an urgency to find a means of crossing that gulf" [(32), p. 151].

Cohen et al. (1) do, however, offer a clue in their article as to how to realize a sense of intersubjective and mutual recognition of pain: "Through creative expression," they say, "differences of point of view can be resolved and new possibilities are allowed to emerge" [(1), p. 5]. *Creative expression* is here upheld as key to facilitating understanding of pain between the person in pain and potential practitioners who might bear witness. But why restrict such expression to the consulting room and to the remit of the medical profession? What extraordinary transformations of pain might be rendered possible if practitioners could *signpost* to creative outlets, or if people could creatively express their pain in communities where they already feel at home? And finally, given that creativity is here seen as integral to the processing of pain, how can we address inequalities that can preclude people in pain from expressing themselves freely? As critical phenomenologist Cressida J. Heyes observes:

> Ordinary life in the context of the pressures of postdisciplinary neoliberalism often feels compressed, demanding, teetering on the edge of possibility, utterly draining, yet also out-of-control, micromanaged by distant institutions and individuals. The response from even the most privileged individuals cannot always be to sit up, pay attention, work harder, work to change ourselves [... Sometimes] the only possibility of resistance (or even the only viable response) might be to detach from experience, to evade pain and fatigue, to slow down, and [...] to alter or even to lose consciousness [(33), p. 7].

For this reason, attempts to offer *generalizable* solutions or frameworks that might facilitate the expression of pain are unlikely to succeed in attending to the particular lifeworlds of people experiencing pain. General frameworks risk replicating social, political, and economic determinants of pain and will almost certainly limit the creative scope for people to explore their own painful experiences. A far more radical understanding of the role of imagination in the expression of pain can take us beyond the use of pain scales and toward a transformation of social and material conditions. To this end, we turn to critical phenomenology as an approach that "seeks not only to describe but also to repair the world" [(34), xiv].

PHENOMENOLOGY OF IMAGINATION AND EXPRESSION

Phenomenology, as a philosophical approach, explicitly concerns itself with understanding and explicating processes of embodied meaning development. Phenomenology thus offers a way to address and understand pain as it is lived through and comes to bear meaning—an aspect of experience that is often overlooked by pathological or clinical accounts which emphasize dimensions of pain which are broadly quantifiable (9). It is vitally important to acknowledge that individuals experience and respond to pain differently within the same cultural contexts, and that pain is therefore not straightforwardly determined by external structural factors only [though these factors manifestly and importantly matter, as evidenced by critical-phenomenological analysis: see (4)]. While people become familiar with their pain through shared intersubjective environments and norms, their experience of pain develops and accrues distinctively within the particular context of their individual lifeworlds, and thus pain is constituted and embodied differently according to personal context and circumstance.

Phenomenology is sometimes characterized as the neutral description of the world as it is perceived from the first-person perspective, free of presuppositions and normative judgment; the approach is therefore sometimes criticized for taking individual experiences too seriously and for abstracting structural considerations out of the picture [(35); cf (36)]. There is, however, a promising thread within the phenomenological tradition that acknowledges how reflecting on experience can actually *open up* possibilities for affecting change (12, 37–40). This conception of phenomenology makes explicit the fact that "the phenomenologist renews their understanding of certain phenomena in the world—at a particular time and in a particular place—through the activity of critical reflection, and this reflection generates a new orientation and world-view with respect to the lifeworld" (12)[6]. The process of taking a reflective stance toward lived experiences can enable their *transformation* and *renewal*—phenomenology can help to illuminate the significance of objects in experience, explore which aspects of their significance are structural or

---

[6] **Key definition: Critical phenomenology.**
This emerging theoretical and methodological approach investigates lived experiences by explicating the role of socio-cultural, political, economic, and historical dynamics. Although inherently diverse, critical-phenomenological approaches recognize that human experiences are shaped by factors like discriminatory practices, social injustice, and structural violence. By considering these elements of experience as "quasi-transcendental", critical phenomenology proposes a notion of the self that is neither neutral nor abstract.

contingent, and aid the expression of lived experience toward meaningful change [(40), p. 87]. This can be a particularly liberating avenue when some aspect of experience presents itself as especially urgent—perhaps, for example, during a painful experience.

The creative dimension underlying the transformation of sense is something that we hope to illuminate in this article, with a view to aiding practical understanding of imagination in the ameliorative expression of pain. Transforming how one understands and relates to one's pain—especially chronic pain—can have dramatic effects on everyday life. Having given an overview in Part 1 of the expression of pain in clinical assessment, we now delve into a phenomenological analysis of how imaginative expression enables people to make sense of their pain.

When experiencing pain, people are sometimes able to imaginatively shape their conception of their painful feelings to cope better with their impact (41–43). In this context, we argue that imagination should be conceived as a cognitive and affective strategy for transforming lived reality and making sense of personal experience. Traditional conceptions of imagination have, by contrast, upheld a distinction between body and mind, and have generally associated imagination solely with the "rational" side of the human being; as Irving (44) astutely points out, "it is curious [...] that the imagination is often seen as the faculty of fancy and a disengaged mind rather than as constitutive of bodily experience and practice" [(44), p. 298]. It is, indeed, strange to assume that imagination concerns only an abstract and disembodied "mind," since the range of imaginative possibilities garner their meaningful significance precisely *through* the embodied entanglement of emotion, biology, and lived experience. On this matter, phenomenology is an approach that explicitly recognizes the character of the body as both a material object and a living organism. Throughout canonical phenomenology, the physical and psychical components of the self are not conceived as separate ontological entities, but are instead considered integral to understanding the body as a whole (45–47).

For the purposes of this article, we are interested in the following two aspects of the expression of pain: (a) how the imaginative process incorporates the experience of pain; and (b) how the expression of pain may be facilitated through metaphorical association. To these ends, we hold that imagination should be understood in relation to the "as-structure" within associative experience. Imagination is, in this sense, can be understood as a particular form of "quasi" perception, as Summa, Fuchs, and Vanzago explain with the following example:

> If you try to imagine how it would be to meet a friend you haven't seen since your school time, you would somehow find yourself exploring that possibility: for instance, you would try to figure out how this person might look now after so many years, how s/he may have changed while still having some of the same bodily and/or expressive traits; also, you may imagine how it would feel like for you to have this person sitting nearby after so much time, etc. [(48), p. 6].

Imagination is thus better conceptualized as a form of "quasi" perception; in this example, my perception is overlaid *as if* my school friend were here now, even if I am fully aware that they are actually not here. The imaginative association is based on the as-structure, which Tengelyi similarly explores here, again from a phenomenological perspective:

> Wherever something is taken as something (this as that), i.e., wherever something is in reality complex, manifold, disparate and even, upon individual consideration, is of a different kind than another, counts, from a certain point of view, as the same as the other (as being identical with the other), we may witness the emergence and the fixation of sense, making sense approachable, available, and even graspable [(49), p. 80].

This mechanism based on the as-structure thus reveals how consciousness receives, associates, or constitutes something within experience as meaningful in a given way. For example, I experience this pain *as* normal or familiar, *as* located in my head, *as* something to which I can attend in various ways—and this happens below the level of deliberate consciousness. While I can actively imagine what it might be like for my school friend to be here now, there is a more passive sense in which prior association through the as-structure renders the whole experience as intelligible and recognizable at all. Sense-making is, in this way, a complex process that involves multiple evolving as-structures. Moreover, certain especially critical moments can shatter prior understanding (and its related *as-structures*), demanding new conceptions in order for lived experience to make sense anew. Experiences of pain can comprise this kind of transformative event. Indeed, experiences of pain viscerally demonstrate that imagination is rarely a straightforwardly neutral mental exercise, but instead importantly involves an affective dimension:

> [I]magining [...] involves something more like genuine rehearsal, "trying on" the point of view, trying to determine what it is like to inhabit it. It is something I may not be able to do if my heart is not in it. If we understood better why imagining [...] requires your heart to be in it, we would understand better what is being resisted when we resist [(50), p. 105].

We argue that imagination plays a crucial role in determining how the self makes sense of experiences of pain figuratively. Imagination is not only understood here as a cognitive tool, but also as a practical and situated way of dealing with painful experiences that is not always straightforwardly conscious. So what is special about imagination and why do we believe that focusing on imagination can inform pain treatment in a practical sense? First of all, it is crucial to bear in mind that pain is not a thing, a state, or a condition, but rather a "process that involves the whole person and whose complexity lies in the way it implicates all kinds of different biological structures and layers of meaning" [(51), p. 121]. Pain is therefore a phenomenon that cannot be categorized straightforwardly as a sensation or feeling, since it involves the totality of the human self (51, 52). The imaginative and figurative conception of pain can therefore be understood as an attempt to grasp this complex phenomenon through the as-structure. As Scarry points out, pain can be experienced *as if* it is caused by something coming from outside the body [(14), p. 12]. Ahmed (53) similarly grasps this aspect by pointing out that "we construct imaginary objects or weapons to take up" and with which to grasp experiences of pain [(53), p. 21]. We might imagine the intrusion of an external object into our bodily space and then seek to re-establish inner balance by addressing the implied cause of our pain. The absence of an actual object that causes the painful feeling is thus complemented by a metaphorical sense, and a related description, of some imagined material thing. In describing one's personal pain, it is not unusual to employ expressions such as "I feel pain *as if* there are needles on my skin" or "my stomach hurts *as if* it is burning". All these linguistic expressions should not be understood only as idiosyncratic means to express pain, but rather as potential modes of *communication* with others. As Geary (54) shows, metaphors are employed creatively in expressing states that are resistant to expression, and pain is an especially notable form of experience which challenges linguistic communication. Indeed, metaphor can express a non-verbal as-structure conceived prior to the intersubjective encounter, but only rendered communicable in that instant (i.e., "I realize now that my pain has always felt like needles on my skin, though it has only just occurred to me to express it like that to you.").

To explore this sense of the as-structure in another example, let us consider Ahmed's description of menstrual pain, in which she writes that,

> In the example of period pain [...], I also create an imagined object. The pain is too familiar—I have felt it so many times before. I remember each time, anew. So I know it is my period, and the knowledge affects how it feels: it affects the pain. In this instance, the blood becomes the "object" that pushes against me, which presses against me, and that I imagine myself to be pushing out, as if it were an alien within [(55), p. 27].

Again, Ahmed points out that we *shape* the object of our pain by individuating a part of our own body as the cause of the painful sensation. By means of our imagination, we individuate, separate, and give a new form to our self-understanding of our own body, e.g., the blood in the example above. The bodily part, felt *as if* it was an external object, is then objectified as something potentially or actually harmful. Leder describes a similar sense of "sensory intensification" in which the painful area of the body "suddenly speaks up" thus interrupting and overwhelming experience—a hyper-presence he calls "dys-appearance" (56). In pain, we can experience body parts in their materiality, as physical objects that we recognize as our own but over which we have little control. Pain thus paradoxically makes us recognize our bodies as physical entities, and accordingly enhances a sense of alienation from our own corporeality. In attempting to make sense of this experience, we can resort to imaginative construction. As Grüny (51) describes, linguistic expression is a way of making sense of this alienation:

> my abdominal pain feels as if I was being stabbed not just because this is my way of externalizing and objectifying a private experience, [...], but because I really do feel assaulted by an alien force that alienates part of my body, and I find myself nailed down without any way out [(51), p. 130].

These critical moments which give rise to the new formation of sense can be understood with reference to the as-structure. Alteration to the as-structure—when an experience previously received as "this" now makes sense also, or instead, as "that" —involves a breaking down of sedimented norms and expectations. This breakdown can also demand a revision of the relatively fixed narrative in which the original self-understanding was emplaced. Metaphor exemplifies the plasticity of the as-structure and its transformative potential; the creative reimagining of pain through metaphor makes possible new ways of being and relating. These considerations also lead us to recognize that painful experiences cannot be fully understood in quantitative terms. Although clinical practitioners sometimes need to grasp a patient's pain very quickly—calling for the use of a "pain scale" in some cases—in other circumstances (like chronic pain), the challenge is centered around managing pain through longer-term strategies in which the presence of personal pain is acknowledged and understood. In pursuit of this goal, the employment of imagination and metaphor offer potential both in a clinical context and for making sense of the broader lifeworld of the person in pain.

Practitioners might take up metaphorical language in order to make abstract medical knowledge accessible to patients (*practitioner to patient*); patients may want to express sensations, bodily feelings, and their psychical impact through metaphor to clinicians [*patient to practitioner,* see e.g., (57)] or to relate to others with similar experiences. This latter case (*patient to patient* or *person to person*) is of particular interest for the purposes of this article, because it captures the therapeutic potential of reaching an understanding with others in the mutual recognition of pain, as explored in Part 1. As Lakoff and Johnson explain in their seminal work *Metaphors we live by*, metaphor ought to be seen as "a matter of imaginative rationality" [(58), p. 325]. Metaphors make it possible to express and understand a given experience in terms of another through the as-structure by preserving coherence and mutual understanding. Far from being a mere rhetorical device, metaphor is not so much linked to language or intellect as with shared conceptual structures "including aspects of our sense experiences: color, shape, texture, sound, etc." [(58), p. 235]. That metaphorical language deals with human experience in a holistic sense is an aspect of pain expression that we consider to be salient. In these respects, as phenomenologists, it is our primary occupation to recognize "the situated experience of the subject, not only in terms of 'personhood' and abstract 'rights' but, also and above all, as embodied and situated" [(4), p. 112].

COLLECTIVELY MAKING SENSE OF PAINFUL EXPERIENCES

There is already widespread acknowledgment that imagination can be used to alter personal approaches to painful experiences. This kind of intervention effectively encourages the person in pain to find a way to express the pain to herself or perhaps to a practitioner who facilitates the intervention. Particularly in response to cases of chronic pain, pain without a known physical cause, or pain for which there is a long wait for treatment, practitioners have developed various frameworks and interventions through which patients are encouraged to renegotiate their attitude toward their pain to improve everyday life. Carel (8), for example, presents the idea of a phenomenological toolkit for patients—and, in fact, a whole facilitated workshop [cf. (15)]—as a means for people to attend to their relationship with their illness, to explore the ways it has changed their life, and to gain new understanding in light of these considerations.

The demonstrable benefits of these schemes are not in question here. As critical phenomenologists, however, we are interested in how shared understanding can facilitate transformation of painful experiences for the better—especially when the meaning is co-developed within a group dynamic of *shared power* to address marginalization. To this end, we are particularly curious about how endeavors *led by* people in pain have not only altered individual personal attitudes toward private pain, but also how they have transformed social relations in the medical contexts where they have taken place. These kinds of projects have the additional benefit, over more individualized approaches, of enabling horizontal cross-pollination of ideas across groups of patients, practitioners, communities, and others—developing networks of shared knowledge and more resilient means through which to transform the conditions which sustain or exacerbate painful experiences.

Approaches like this, which are able to foreground cultural contexts, importantly enable people experiencing pain to explore aspects of their intersubjective circumstances which exacerbate and sustain their painful experiences. As critical phenomenologists, we understand our experience "as emerging from structures of space, time, and embodiment; and always at the same time from contingent social and political structures that also constitute it" [(33), p. 134]; we therefore also understand cultural contexts as playing a crucial role in the constitution of painful experience and the lived possibility of its expression. The situated network of connections associated with a person in pain is highly pertinent to discussion of painful experience. From the perspective of someone experiencing pain, "[i]solation creates an additional layer of pain leading to depression, despondency, feelings of loss, purpose and value" [(18), p. 12]. As noted by Hodge, Itty, Samuel-Nakamura, and Cadogan, a pervasive sense that "we don't talk about it" (i.e., experiences of pain) can mean that "discussing such experiences can bring additional pain, suffering, and hardship to the family or community" [(59), p. 5]. This is a highly relevant consideration when it comes to addressing intersubjective contexts, which can serve to exacerbate or potentially ameliorate the lived significance of pain. Indeed, as Patsavas (9) notes, "when cultural discourses construct pain as the cause of feelings of devastation, they oversimplify complex cultural, historical, and political phenomena. More than that, they prevent us from examining the structural conditions that make experiences of chronic pain tragic" [(9), p. 204]—and these conditions are far from uniform across diverse contexts. Efforts which emphasize the specific meaning of painful experience for people in pain and which afford them agency in expression can, however, work toward mutual understanding and the transformation of painful experiences. When people experiencing pain are not simply framed as "patients" but instead as persons who have subjective interests, priorities, motivations, and capacities, holistic treatment of pain can facilitate and take seriously the importance of personal expression of pain with respect to their particular lifeworlds. Expression, in this context, must itself be imagined and regarded by people in pain *as* possible, *as* worthwhile, and *as* valued.

As we argued in Part 2, imagination plays a crucial role in the interpretation and reception of painful experiences. In this section, we explore some tangible examples that illustrate how people experiencing pain can find meaningful and transformative ways to share their perspectives (12). Shared endeavors enable participants to develop shared imaginaries through which they can make sense of their pain together. Painful experiences in these projects are not regarded as identical, nor are they presented as straightforwardly accessible to others. Nevertheless, projects like these proceed on the assumption that meaningful shared understanding of pain and its effects is worth pursuing—that coming together to understand painful experience is itself worthwhile and can affect change within contexts that "produce and sustain subjects in pain, as they are alternately marginalized, disbelieved, prioritized, or cared for" [(4), p. 102]. In this way, the conditions which shape experiences of pain can themselves be improved by those with firsthand knowledge of their effects. As phenomenologists, we are interested in how this important transformation of relations can afford control and agency to those experiencing pain, and specifically to those whose voices are otherwise marginalized. By introducing some key phenomenological concepts alongside illustrative examples, we hope to offer up a theoretical toolkit for pain researchers and clinicians with which to explore these issues. As such, we here review how different approaches can make it possible for individual experiences of pain to resonate through shared imaginaries and in the exploration of holistic treatment.

Pain Cards

Quantitative and qualitative analyses have shown that the use of imagery in medical consultations improves the perceived quality of the session and encourages a more collaborative atmosphere in the consulting room (60, 61). Linguist Elena Semino shows that pain cards—a set of laminated images representing aspects of pain—can encourage patients to volunteer descriptions of their experience without solicitation by the practitioner, affording them more agency over the discussion topic and over the pain itself (61, 62). The images on the cards are open to interpretation. For example, one photo depicts a person's mouth closed with a clothes peg, while some others show a rag doll struggling to navigate a human-sized world [(63), p. 50–51]. There are 52 cards in total, offering up a variety of metaphorical images with which to express one's pain. After choosing a card, patients explain why and how they made this decision; this gives them the opportunity to reflect on which aspects of their pain they want to openly discuss. *Topic control*, as Semino reports [(61), p. 274], is an aspect of the practitioner-patient interaction that indicates power relations. For the patient in consultation, pain cards are tools that grant them epistemic agency; this shift can adjust the balance in power relations and give the patient the opportunity to use visual depiction of their pain to enhance linguistic expression:

> The patient uses the image of the rag doll in the PAIN CARD as inspiration for describing herself via a simile ('when I'm completely like a rag doll'). The following explanation clarifies the basis of the similarity: there are times when the person is so exhausted that, like a rag doll, she cannot walk. [. . .] This patient uses a particular PAIN CARD as a springboard for a figurative description and a narrative that introduce three aspects of her life with chronic pain [(61), p. 281–282].

It is also significant that the use of pain cards does not so heavily rely on linguistic ability and instead relies on "visual imagination," whereas pain scales are often less accessibly "designed for people who find adjectives and adverbs useful for them" [(60), p. 27]. So with the use of pain cards, patients with a range of linguistic backgrounds and abilities can regain a sense of agency in clinical encounters and can find figurative means to express how they feel. Indeed, Padfield et al. (64) argue "that exploring meaning is an essential part of understanding pain better, and that images introduced into an encounter become catalysts for both meaning-making and change" [(64), p. 80]—offering a practical means to enact a translation and transformation of the as-structure we described in Part 2.

More than this, however, as these authors suggest, a more radical sense of agency and connection is made possible where patients have designed the pain cards themselves:

> [The pain cards] have been co-created with other pain patients and so could be seen as placing the bodies of other patients within the communication process. In another consultation for example, after using the cards, one patient says "At least I know I am not on my own" [(64), p. 78].

Though the authors only briefly remark on this mediated interaction between patients through the pain cards, the fact that other people in pain have created the figurative medium through which these interactions are facilitated is significant. No longer completely isolated, as Scarry (14) describes, in "all the solitude of absolute privacy with none of its safety, all the self-exposure of the utterly public with none of its possibility for camaraderie or shared experience" [(14), p. 53], the patient using pain cards is participating and reappropriating shared meaning in ways that can exceed the clinical encounter.

Connections

Indeed, political agency, communal engagement, and social awareness can emerge in many ways from such projects—not so much to attest a given state of affairs regarding pain, but rather to express a point of view and related feelings. The *Face2face* project powerfully illustrates this point [cf (65, 66)]. Facilitated by Zakrzewska and Padfield, the project was aimed at improving dialogue in the consulting room (using pain cards) and supporting people in pain in the creative depiction of their own pain. Participants were invited to collaborate on the co-creation of "pain portraits." Rather than "being an object on the other side of the lens" they used "objects, materials and the relations between them to evoke the internal abstract experience of pain, making it visible" and thus participants were "in charge of how [their pain] is seen by others" [(32), p. 155]. This resulted in the production of metaphorical images ranging from "exposed wires or rotting fruit" to more involved photographic experimentation [(32), p. 159]. The co-creation of pain portraits in this way made it possible for participants to regain some agency over their own pain and to challenge power dynamics in the medical setting. In fact, the process of creating a visual depiction of their pain not only helped participants to express their lived experience, but also initiated the renewal of sense-making with respect to their pain—a transformation of the as-structure. These types of interventions give people back the sense of control that long-term conditions can very often take away. Moreover, since these approaches do not treat participants as anonymous patients but instead respect the differences between people in pain and their individual situations, they can catalyze connection in something of a snowball effect. Aldous (63) participated in the *Face2face* project, for example, and describes how this "allowed me a chance to tell my story, to feel listened to and also to develop my own belief in my ability to identify triggers, reduce negative thoughts and improve my sleep" [(63), p. 52]. Consequently, as an occupational therapist, she was able to find ways to take up what she had learnt as a participant in her own practice with others:

> I have been able to harness my own experiences and have used considerable effort and have used considerable effort to help others through their problems through creative participatory arts projects across our town. [...] I returned to work as occupational therapist [sic] with the eating disorders charity. I continued to incorporate the use of imagery alongside the cognitive behavior therapy protocol for eating disorders as a way of encouraging my clients to discuss their relationships with food and emotional states. This proved to be very powerful and not dissimilar to the way in which the PAIN CARDS are used in consultation." [(63), p. 55].

Aldous' translation of her experience as a participant to her practice in her life and work more broadly exemplifies how people can share imaginative expression of pain across intersubjective contexts when health is conceived as part of networks of social relations. Agency and connection can be thus regarded as key aspects of how these alternative approaches to the expression of pain can transform the relations excluding or supporting people in pain.

Zines

It may be more appropriate, in some cases, for the imaginative exploration and expression of pain to take place more concretely outside medical contexts. In many ways, decentring the clinical encounter can liberate the expression of pain from discussions that seek to "treat" or "cure" pain, and instead open up more creative and intersubjective avenues. *Ache Magazine* exemplifies this spirit, spanning the space between zines and magazines.

Kirstie Millar, one of the editors, writes in the first issue about how *Ache* aims to bring together the voices of "self-identifying women and non-binary people,"

> to explore, question and articulate our experiences with illness and pain. No illness is identical, our identities and our bodies unique [sic]. But through our collective and shared experiences, we can shift the conversation and be heard [(67), p. 4].

As an independent publication run by volunteers, *Ache* circulates poetry, literature, fiction, and visual art through which contributors and readers can explore their lived experiences. Poems in this first issue include "The Art of Blacking Out" by Annie Dawid, [(67), p. 6–7], "Prayer to Migraine" by Helena Hinn [(67), p. 20], and "Quantifiable" by Mel Reeve. The project demonstrates how the expression of pain can mediate both personal interests and the social spaces afforded to these people.

Zines have been used as an "alternative" means of sense-making for decades, sometimes explicitly in opposition to the medical setting, largely due to the accessibility of both their production and circulation. The Do-It-Yourself (DIY) ethos behind zines underpins their political potential, as summarized by Duncombe in *Notes from Underground: Zines and the Politics of Underground Culture* (68): "make your own culture and stop consuming that which is made for you" [(68), p. 7]. Holtzman et al. (69) notes how creating zines is relatively simple and affordable, since "all that is needed by an individual with a desire to express her/himself is access to a photocopier" [(69), p. 49]. Zines are made by juxtaposition and assembly of existing pre-constituted material. Zine creators are, in this way, able to refract their personal experiences as part of a wide intersubjective context. As Radway points out, they should not be read as idiosyncratic expressions of individuality:

> I think zines should be read more for their radical generativity, for the way they combine and recombine rich repertoires of contradictory cultural fragments. They are experimental, multifarious performances, it seems to me, instantiations of multiple subject-positions [(70), p. 11].

Since zines are typically self-published, or published by small independent presses, they often circulate through localized networks and personal connections—through word-of-mouth and also, more recently, online. Access to zines is thus independent from institutional health settings, often deliberately so; zine production and dissemination instead relies on the self-organization of people who want to share their lived experiences in dialogical and creative ways. This can represent a powerful means for people to make sense of their experiences and make connections with others, sometimes in relation to experiences of illness and pain. Keyes, Peil, Williams, and Spiel, in their commentary on zines, note that,

> Devalued identities are particularly susceptible to trauma by way of living their everyday lives in a system that overemphasizes minds over bodies, masculinity over femininity, whiteness over any other race, able-bodies over bodies rendered as socially disabled, and the like [(71), p. 24].

They grasp these dynamics by focusing on three elements encompassed by zines which are absent in contemporary health-care systems: "(1) reimagined possibilities, (2) flexible frameworks for empowerment and (3) community support" [(71), p. 22]. Zines responding to this context are often designed for and by people who have been historically marginalized by and discriminated against in health-care settings, as a way to share their stories, to find recognition, and to gain a sense of agency over their experiences.

The creation and distribution of zines are a powerful means of addressing personal experiences within more structural issues as concise, readily and inexpensively made, and easy to share. Moreover, their visual design can be tailored to suit "a spectrum of learning styles," and can take into account additional accessibility requirements, such as the "translation into tactile imagery to complement expected Braille translations." [(71), p. 24]. Zines thus have the potential to broker meaningful connections, encouraging "both inspiration and empowerment of producers as well as readers" [(69), p. 49]. The equivocal and multifarious creative possibilities afforded by zines also offer a unique space in which to explore the contours of an altered lifeworld.

Community

Such explicitly arts-based projects may not be appropriate for everyone experiencing pain, however. At different times, and for different people, self-reflection on pain can be difficult and explicitly creative practices may not resonate. Where illness is associated with stigma, and when chronic pain is framed as a burden, people in pain may seek to avoid more direct or overt expression. Means of making sense of pain, in this context, may mean something altogether different. Researchers have explored the role of gendered social norms in experiencing and expressing pain, for example, revealing that men are less likely to seek social support and to share their painful experiences in certain socio-cultural contexts; gendered influences deeply impact how a person lives through and expresses their pain (72) and biases also affect pain assessment and treatment [e.g., (73, 74)]. The HOMEBASE project attends precisely to this context, as a "community-based project to reduce social isolation for men living with chronic pain" [(18), p. 13]. The project sets out "to offer every man suffering from chronic pain a community of care that extends beyond healthcare and into their communities to prevent social isolation and learn to live well with pain," according to their own intuitive sense of how best to do so [(18), p. 13]. The project importantly recognizes that its accessibility depends upon attending to the specific needs of these men, and how they may wish, or not wish, to communicate about their pain. Hovey, as both researcher and participant in the project, describes the sense in which these men prefer "talking sideways":

> Men working together and talking sideways seems to be a preferred way of doing things. We want to get men together working on things and not address it through sharing your emotions, but coming together, becoming acquainted with each other, getting to know each other, trusting each other, and talking sideways (75).

Taking a more overtly emotional or creative approach would have run contrary to the inclinations of group members in this instance. Learning to live well with pain has, in this community context, involved recognition that a direct approach to addressing painful experiences may in fact make the project less accessible to those it would most benefit. The HOMEBASE approach involves connecting a man newly diagnosed with chronic pain with a buddy whose experienced perspective could "help them navigate the complexity of the pain world" (76). The contrast between making sense of pain with others and doing so alone can be stark:

> When everything in our lives changes due to pain, when nothing is as it used to be (stuck in the liminal space) I feel exhausted, shattered, isolated and I do not know what to do anymore and I hide away from the world. Isolation creates an additional layer of pain leading to depression, despondency, feelings of loss, purpose and value [(18), p. 12].

In connecting with others through shared understanding of chronic pain, "there is transformation that occurs as patients become people again and are awakened by the multitude of challenges that lay ahead of them" [(18), p. 12]. The transformation that emerges here by no means replaces medical treatment of pain, but rather it is a transformation of lived sense. In this particular case, the as-structure is perhaps most importantly altered around perceptions of possibility:

> As I recall my own reflections during this process although my levels of pain did not change, however, all other aspects of my life improved and continue to do so. The transformative possibilities keep unfolding [(18), p. 14].

CONCLUSION

In this article, we have discussed how, while the clinical encounter is an event that can heavily influence the way people make sense of their pain, the process of making sense of chronic pain necessarily continues outside of and beyond medical settings. The clinical encounter is typically focussed on medical treatment, and therefore draws from expressive tools like pain scales which tend not to facilitate more holistic understanding and connection—this is, after all, not what they were designed to do. Appropriate means of expressing pain, as part of this sense-making process, thus vary accordingly.

We began Part 2 of this article with a quote from Biss's remarkable essay (13) on her experience of pain scales. As Jurecic (77) astutely commentates,

> Biss's essay suggests many reasons why the numerical pain scale is an inadequate gauge of experience. As a writer, she finds greater resonance in the metaphors of the Beaufort scale. The highest number on that scale, which represents hurricane-strength winds, is described in a single word: "devastation." When Biss was devastated by chronic pain, she recalls that she could ward off devastation by repeating and "secretly cherishing the phrase, "This too shall pass." She found solace not in numbers or faith, but in words, rhythm, and ritual.

We have here attempted to explore how imaginative expression—through means such as "words, rhythm, and ritual" —can be meaningfully employed to transform painful experiences beyond pain scales in medical settings. In particular, we have emphasized the significance of expression in *intersubjective* contexts. Through our critical-phenomenological understanding of imagination and expression, we sought to show that holistic treatment of pain must begin by enabling the person in pain to express themselves with respect to their particular lifeworld. Through an analysis of the as-structure, we summarized phenomenological insights that arise when taking the roles of creativity and imagination in painful expression seriously, as well as their transformative potential. We then explored examples illustrating how communities of people experiencing pain, as well as practitioners, can make such imaginative transformations possible by engaging with the material and relational conditions affecting painful lifeworlds.

The examples discussed in this article may not be suitable for all people experiencing pain. Indeed, the point of affording people the opportunity to meaningfully participate in these projects is that they are able to voice their own perspective; the project should be tailored to the priorities of those participating, and therefore a top-down, one-size-fits-all approach would precisely miss the point. Some people may still prefer to make sense of their own pain within the context of their existing lifeworld and connections. Given the lack of literature emphasizing the importance of imaginative expression within intersubjective contexts, however, we hope that our phenomenological contribution in this article will shed light on a potential avenue for those seeking structural solutions to the amelioration of pain.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary materials. Further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

NM wrote Part 2, JS wrote Part 1, and both authors together wrote Part 3, the Introduction, and the Conclusion. All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

FUNDING

This work was supported by the Israel Science Foundation [Grant No. 328/19], and the Wellcome Trust [Grant No. 203109/Z/16/Z].

REFERENCES

1. Cohen M, Quintner J, van Rysewyk S. Reconsidering the international association for the study of pain definition of pain. *Pain Rep.* (2018) 3:e634. doi: 10.1097/PR9.0000000000000634
2. International Association for the Study of Pain. *n.d. Terminology*. Available online at: https://www.iasp-pain.org/resources/terminology/ (accessed January 24, 2022).
3. Treede R. The International Association for the Study of Pain definition of pain: as valid in 2018 as in 1979, but in need of regularly updated footnotes. *Pain Rep*. (2018) 3:e643. doi: 10.1097/PR9.0000000000000643
4. Stanier J, Miglio N. Painful experience and constitution of the intersubjective self: a critical-phenomenological analysis. In: Ferrarello S, editor. *Phenomenology of Bioethics: Technoethics and Lived-Experience*. New York, NY: Springer (2021). p.101–14. doi: 10.1007/978-3-030-65613-3_8
5. Leder D. The phenomenology of healing: eight ways of dealing wth the ill and impaired body. *J Med Philos*. (2022) 47:137–54. doi: 10.1093/jmp/jhab038
6. Turk DC, Okifuji AO. Psychological factors in chronic pain: evolution and revolution. *J Consult Clin Psychol.* (2002) 70:678–90. doi: 10.1037/0022-006X.70.3.678
7. Hadjistavropoulos T, Craig KD, Duck, Cano A, Goubert L, Jackson PL, et al. A biopsychosocial formulation of pain communication. *Psychol Bull.* (2011) 137:910–39. doi: 10.1037/a0023876
8. Carel H. *Phenomenology of Illness*. Oxford: Oxford University Press (2016). doi: 10.1093/acprof:oso/9780199669653.001.0001
9. Patsavas A. Recovering a cripistemology of pain: Leaky bodies, connective tissue, and feeling discourse. *J Lit Cult Disabil Stud*. (2014) 8:203–18. doi: 10.3828/jlcds.2014.16
10. Zahavi, D. *Phenomenology: The Basics*. London: Routledge (2019). doi: 10.4324/9781315441603
11. Stanier J, Miglio N, Dolezal L. Pandemic Politics and Phenomenology - Editors' Introduction. *Puncta.* (2022) 5:1–12. doi: 10.5399/PJCP.v5i1.1
12. Stanier J. An introduction to engaged phenomenology. *J Br Soc Phenomenol.* forthcoming (2022).
13. Biss E. The pain scale. *Creat Nonfiction.* (2007) 32:65–84. Available online at: https://www.jstor.org/stable/44363570?seq=1
14. Scarry E. *The Body in Pain: The Making and Unmaking of the World*. Oxford: Oxford University Press (1987).
15. Disher T. Book review: phenomenology of illness by Havi Carel. *J Evaluation Clinical Prac.* (2017) 23:1096–8. doi: 10.1111/jep.12812
16. Boublil E. Compassion fatigue: assessing the psychological and moral boundaries of empathy. In: Ferrarello S, editor. *Phenomenology of Bioethics: Technoethics and Lived-Experience*. New York, NY: Springer (2021). p. 61–72. doi: 10.1007/978-3-030-65613-3_5
17. Dorfman E. History of the lifeworld: from Husserl To Merleau-Ponty. *Philos Today.* (2009) 53:294–303. doi: 10.5840/philtoday200953317
18. Hovey RB. The gift of pain with transformative possibilities. *Patient Exp.* (2018) 5:4:11–4. doi: 10.35680/2372-0247.1248
19. Hemingway A, Norton L, Aarts C. Principles of lifeworld led public health practice in the UK and Sweden: reducing health inequalities. *Nurs Res Pract.* (2015) 2015:124591. doi: 10.1155/2015/124591
20. Drahovzal DN, Stewart SH, Sullivan, MJ. Tendency to catastrophize somatic sensations: pain catastrophizing and anxiety sensitivity in predicting headache. *Cogn Behav Ther.* (2006) 35:226–35. doi: 10.1080/16506070600898397
21. Sullivan MJL, Martel MO, Tripp D, Savard A, Crombez G. The relation between catastrophizing and the communication of pain experience. *Pain*. (2006) 122:282–8. doi: 10.1016/j.pain.2006.02.001
22. Chambers C, Craig KD, Bennett SM. The impact of maternal behavior on children's pain experiences: an experimental analysis. *J Pediatr Psychol.* (2002) 27:293–301. doi: 10.1093/jpepsy/27.3.293
23. Rodemeyer L. I don't have the words. In: Mattens F, editor. *Meaning and Language: Phenomenological Perspectives*. Phaenomenologica. Dordrecht: Springer. (2008) 195–212. doi: 10.1007/978-1-4020-8331-0_10
24. Noble B, Clark D, Meldrum M, ten Have H, Seymour J, Winslow M, et al. The measurement of pain, 1945–2000. *J Pain Symptom Manage.* (2005) 29:14–21. doi: 10.1016/j.jpainsymman.2004.08.007
25. Melzack R. The McGill pain questionnaire: major properties and scoring methods. *Pain.* (1975) 1:277–99. doi: 10.1016/0304-3959(75)90044-5
26. Melzack R, Torgerson WS. On the language of pain. *Anethesiology.* (1971) 34:50–9. doi: 10.1097/00000542-197101000-00017
27. Gracely RH, Dubner R. Pain assessment in humans—a reply to Hall. *Pain.* (1981) 11:109–20. doi: 10.1016/0304-3959(81)90144-5
28. Hewer AJH, Keele CA, Keele KD, Nathan PW. A clinical method of assessing analgesics. *Lancet.* (1949) 1:431–5. doi: 10.1016/S0140-6736(49)90753-9
29. Jensen MP, Karoly P, Braver S. The measurement of clinical pain intensity: a comparison of six methods. *Pain.* (1986) 27:117–26. doi: 10.1016/0304-3959(86)90228-9
30. Joel LA. The fifth vital sign: pain. *Am J Nurs.* (1999) 99:9. doi: 10.1097/00000446-199902000-00002
31. Lee, C. *Ann Jurecic – Illness as Narrative*. (2015). Available online at: https://adogcalledpain.wordpress.com/2015/07/03/ann-jurecic-illness-as-narrative/ (accessed February 02, 2022).
32. Padfield D. The photograph as a mediating space in clinical and creative encounters. In: Padfield D, Zakrzewska JM, editors. *Encountering Pain: Hearing, Seeing, Speaking*. London: UCL Press (2021). p. 147–76. doi: 10.14324/111.9781787352636
33. Heyes, CJ. *Anaesthetics of Existence: Essays on Experience at the Edge*. Durham: Duke University Press (2020). doi: 10.1215/9781478009320
34. Weiss G, Murphy AV, Salamon G. Introduction: transformative descriptions. In: Weiss G, Murphy AV, Salamon G, editors. *50 Concepts for a Critical Phenomenology*. , Evanston: Northwestern University Press (2020). p. 8–9. doi: 10.2307/j.ctvmx3j22
35. Scott JW (1992) Experience. In: Butler J, Scott JW, editors. *Feminists Theorize the Political*. London: Routledge (1992). p. 22–40.
36. Stoller, S. Phenomenology and the poststructural critique of experience. *Int J Philos Stud.* (2009) 17:707–37. doi: 10.1080/09672550903301762
37. Welton D. Structure and Genesis in Husserl's Phenomenology. In: Elliston F, P McCormick P, editors. *Husserl: Expositions and Appraisals*. London: Notre Dame Press (1977). p. 54–69.
38. Toombs SK. The lived experience of disability. *Hum Stud.* (1995) 18:9–23. doi: 10.1007/BF01322837
39. Ahmed S. Queer phenomenology. *Orientations, Objects, Others*. Durham: Duke University Press. (2006).
40. Steinbock, AJ. *Limit-Phenomena and Phenomenology in Husserl*. Lanham: Rowman & Littlefield (2017).
41. Peerdeman KJ, van Laarhoven AM, Peters ML, Evers AWM. An integrative review of the influence of expectancies on pain. *Front Psychol.* (2016) 7:1270. doi: 10.3389/fpsyg.2016.01270
42. Peerdeman KJ, van Laarhoven AIM, Keij SM, Vase L, Rovers MM, Peters ML, et al. Relieving patients' pain with expectation interventions: a meta-analysis. *Pain.* (2016) 157:1179–91. doi: 10.1097/j.pain.0000000000000540
43. Peerdeman KJ, Geers AL, Della Porta D, Veldhuijzen DS, Kirsch I. Underpredicting pain: an experimental investigation into the benefits and risks. *Pain.* (2021) 162:2024–35. doi: 10.1097/j.pain.0000000000002199
44. Irving A. The color of pain. *Public Cult.* (2009) 21:293–319. doi: 10.1215/08992363-2008-030
45. Husserl E. *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy*. First book: general introduction to a pure phenomenology. Kluwer (1982). doi: 10.1007/978-94-009-7445-6
46. Merleau-Ponty M. *Phénoménologie de la Perception*. Paris: Gallimard (1945).
47. Beauvoir de S. *Le Deuxième Sexe I. Les faits et les mythes*. Paris: Gallimard (1949).
48. Summa M, Fuchs T, Vanzago L. *Imagination and Social Perspectives: Approaches From Phenomenology and Psychopathology*. New York, NY: Routledge (2018). doi: 10.4324/9781315411538
49. Tengelyi L. *The Wild Region in Life-history*. Evanston: Northwestern University Press (2004). doi: 10.2307/j.ctv47wftf
50. Moran R. The expression of feeling in imagination. *Philos Rev.* (1994) 103:75–106. doi: 10.2307/2185873
51. Grüny C. No way out: a Phenomenology of pain. In: Dahl E, Falke C, Eriksen TE, editors. *Phenomenology of the Broken Body*. New York, NY: Routledge (2019). p. 119–136. doi: 10.4324/9780429462542-8

52. Geniusas S. *The Phenomenology of Pain*. Athens: Ohio University Press (2020). doi: 10.2307/j.ctv224twdv
53. Ahmed S. The contingency of pain. *Parallax.* (2002) 8:17–34. doi: 10.1080/13534640110119597
54. Geary J. *I Is an Other: The Secret Life of Metaphor and How It Shapes the Way We See the World.* New York, NY: Harper Collins (2011).
55. Ahmed S. *The Cultural Politics of Emotion. 2nd Edn*. Edinburgh: Edinburgh University Press (2014).
56. Leder D. *The Absent Body*. Chicago: University of Chicago Press (1990).
57. Stewart M, Ryan SJ. Do metaphors have therapeutic value for people in pain? A systematic review. *Pain Rehabil J Physiother Pain Assoc.* (2020) 10–23. Available online at: https://research.brighton.ac.uk/en/publications/do-metaphors-have-therapeutic-value-for-people-in-pain-a-systemat
58. Lakoff G, Johnson M. *Metaphors We Live By.* Chicago: University of Chicago Press (1980).
59. Hodge FS, Itty TL, Samuel-Nakamura C, Cadogan M. We don't talk about it: cancer pain and American Indian survivors. *Cancers.* (2020) 12:1932. doi: 10.3390/cancers12071932
60. Padfield D, Fitzgerald M. Introduction II: What is pain? A neurobiological perspective In: Padfield D, Zakrzewska JM, editors. *Encountering Pain: Hearing, Seeing, Speaking*. London: UCL Press (2021). p.17–32.
61. Semino E (2021). Language and images in pain consultations. In: Padfield D, Zakrzewska JM, editors. *Encountering Pain: Hearing, Seeing, Speaking*. London: UCL Press (2021). p. 269–85.
62. Semino E. Descriptions of pain, metaphor, and embodied simulation. *Metaphor Symb.* (2010) 25:205–26. doi: 10.1080/10926488.2010.510926
63. Aldous L. Three testimonies from those living with pain. facial pain: managing facial pain through creativity. In: Padfield D, Zakrzewska JM, editors. *Encountering Pain: Hearing, Seeing, Speaking*. London: UCL Press. (2021) p. 46–56.
64. Padfield D, Omand H, Semino E, Williams ACC, Zakrzewska JM. Images as catalysts for meaning-making in medical pain encounters: a multidisciplinary analysis. *Med Humanit.* (2018) 44:74–81. doi: 10.1136/medhum-2017-011415
65. Picturing Health. *About*. (2020). Available online at: https://www.picturing-health.com/about (accessed January 24, 2022).
66. Picturing Health. *Media Education*. (2020). Available online at: https://www.picturing-health.com/about (accessed January 24, 2022).
67. Millar K, Reynolds-Grey R, Millar K. Ache Issue No. 1 (2018) Independently published.
68. Duncombe SR. *Notes From the Underground: Zines and the Politics of Underground Culture*. London: Verso Books (1997).
69. Holtzman B, Hughes C, Van Meter K. "Do it yourself… and the movement beyond capitalism." In: Graeber D, Biddle E, editors. *Constituent Imagination: Militant Investigations//Collective Theorization*. Oakland: AK Press. (2007). p. 44–61.
70. Radway J. *Girls, Zines, and the Miscellaneous Production of Subjectivity in an Age of Unceasing Circulation*. Speaker Series No. 18, Center for Interdisciplinary Studies of Writing and the Literacy & Rhetorical Studies Minor (2001).
71. Keyes O, Peil B, Williams RM, Spiel, K. Reimagining (Women's) Health: HCI, Gender and Essentialised Embodiment. *ACM Transactions on Computer-Human Interaction.* (2020) 27:1–42. doi: 10.1145/3404218
72. McClelland LE, McCubbin JA. Social influence and pain response in women and men. *J Behav Med.* (2008) 31:413–20. doi: 10.1007/s10865-008-9163-6
73. FitzGerald C, Hurst S. Implicit bias in healthcare professionals: a systematic review. *BMC Med Ethics.* (2017) 18:19. doi: 10.1186/s12910-017-0179-8
74. Samulowitz A, Gremyr I, Eriksson E, Hensing G. "Brave Men" and "Emotional Women": a theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain Res Manage.* (2018) 2018:6358624. doi: 10.1155/2018/6358624
75. Concordia University. *Homebase: A Community of Care for Men Enduring Pain and Isolation*. Available online at: https://www.concordia.ca/research/perform/about/blog/20171121-Homebase.html (accessed January 24, 2022).
76. McGill University Faculty of Dentistry. *Homebase an Initiative to Address Chronic Pain and Prevent Social Isolation Among Men.* (2016) Available online at: www.youtube.com/watch?v=B_aDp5yFZhs (accessed January 24, 2022).
77. Jurecic A. A literary pain scale. *Lancet.* (2018) 391:111. doi: 10.1016/S0140-6736(18)30022-9

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 Pain Research

ORIGINAL RESEARCH
published: 30 May 2022
doi: 10.3389/fpain.2022.889990

Mediating Pain: Navigating Endometriosis on Social Media

*Eileen Mary Holowka**

Department of Communication Studies, Concordia University, Montreal, QC, Canada

With the rise of social media, many people with endometriosis have turned to platforms such as Facebook and Instagram in the face of lacking care. This qualitative study focuses on why and how people with endometriosis use these platforms. Despite the risks of misinformation and conflict on social media, the results of this research show that many people with endometriosis find these spaces beneficial, particularly for information sharing, social support, representation, and advocacy practices around endometriosis. Using data collected from surveys and interviews, this study reveals that people with endometriosis often use social media to understand, experiment with, and navigate their symptoms and that these efforts deserve recognition by endometriosis researchers and practitioners. This article proposes that, in order to improve future patient-practitioner and patient-researcher relationships for endometriosis, we must understand, not dismiss, the social media practices of those with endometriosis. By understanding how and why patients turn to social media, clinicians and researchers can build toward more patient-oriented futures.

Keywords: endometriosis, social media, qualitative, chronic pain, information-sharing, patient communities, ethnography, meaning-making

OPEN ACCESS

Edited by:
Dominik Mischkowski,
Ohio University, United States

Reviewed by:
Hubert Van Griensven,
University of Hertfordshire,
United Kingdom
Margaret Dunham,
Edinburgh Napier University,
United Kingdom

Correspondence:
Eileen Mary Holowka
eileen.holowka@concordia.ca

Specialty section:
This article was submitted to
Non-Pharmacological Treatment of Pain,
a section of the journal
Frontiers in Pain Research

Received: *04 March 2022*
Accepted: *09 May 2022*
Published: *30 May 2022*

Citation:
Holowka EM (2022) Mediating Pain: Navigating Endometriosis on Social Media. Front. Pain Res. 3:889990.
doi: 10.3389/fpain.2022.889990

INTRODUCTION

Endometriosis is a chronic inflammatory condition that affects approximately 1 in 10 women and undetermined numbers of transgender, genderfluid, and non-binary people (1, 2). Endometriosis is defined by tissue that is similar to, but distinct from, the lining of the uterus growing outside the uterus and throughout the body. Primary symptoms include chronic pain, pain with sexual intercourse, fatigue, and infertility which can result in negative emotional impacts and an overall decreased quality of life (3–6). Although endometriosis has economic and societal costs similar to other chronic conditions, such as Rheumatoid Arthritis, Type 2 Diabetes, and Chron's disease, it receives disproportionately less funding (7, 8) and the worldwide average delay between start of symptoms and diagnosis is 7.5 years (9).

It is common for people living with endometriosis to experience dismissal and mistreatment associated with a long history of medical discrimination and sexism around chronic pain, particularly pain associated with gender and menstruation (10–13). The contemporary conception of endometriosis is, in the words of Redwine, "trapped by errant words of the past," and based on outdated conceptions of the disease and patient-blaming dating as far back as 400 BCE (11, 13, 14). Myth and misconceptions continue to haunt the representation of endometriosis today, where it is commonly referred to as "enigmatic" and "puzzling" by medical professionals and patients alike. Although communication about endometriosis has improved over the last 20 years, awareness of the disease, even in symptomatic individuals, is still lacking (15).

In the face of mistreatment, dismissal, long delays, isolation, and lacking resources, many people with endometriosis turn to the Internet and social media for answers and support (16, 17). In 2018, "what is endometriosis?" was the third most trending health-related question on Google and in each month of 2017 there were more than 400,000 Google searches of endometriosis in the United States alone (18, 19). Much of the literature on endometriosis and social media thus far has focused on information-seeking behaviors and the risks of misinformation (16, 17). While misinformation and information-seeking are important aspects of endometriosis-related social media use, there is more to the picture than just this. This article considers the variety of ways that a global, but predominantly North American, community of English-speaking people with endometriosis use social media and what these many practices communicate about their symptoms, desires, and healthcare needs. Although social media can have benefits, it is not an ideal place to navigate a chronic illness. Despite these challenges, many people with endometriosis continue to find value online. Rather than dismissing these social media practices, analyzing them in our research can help break the pattern of patient-blaming in endometriosis care and lead to more patient-oriented futures.

THEORETICAL FRAMEWORK

This research is necessarily multi-disciplinary. Just as proper endometriosis treatment relies on a multidisciplinary team that can address all aspects of the body and mind, research into endometriosis and social media requires not only a media studies perspective, but also a framework informed by affect theory and feminist disability studies. Online endometriosis spaces are complex and messy, full of conflicting information, heightened emotions, and variably moderated spaces. As social science scholar Kate Seear writes in her book on the disease, endometriosis is already "a disease exemplified by an unusually high degree of uncertainty, mess, and contestation" (20). Social media only further contributes and feeds off of this messiness. A multidisciplinary theoretical framework offers a suitably complex approach through which to consider the mess that emerges when patients go online to negotiate their care, as well as all the nuances and associated histories attached to those social media practices.

Social Media Studies and Affect Theory

Following recent turns in feminist social media studies, this research approaches the habitual practices of social media using affect theory (21, 22). Affect theory provides a way of understanding how people are drawn together online, how emotions circulate through digital spaces, and what those relationships, emotions, and practices produce (23). This approach also considers the ways in which everyday habits of social media use can provide people with methods of engaging in politics or putting themselves in conversations with others that may otherwise be inaccessible to them, such as people who are not able to "take to the streets" due to debilitating endometriosis (24–27).

Affect theory also provides a tool for conceptualizing what it means to live with chronic pain, which is one of the primary symptoms of endometriosis. Neuroscientific research shows that the sensation of pain can be experienced differently depending on how it is processed or understood psychologically (28–30). The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (31). The way pain comes to be felt in bodies is not just about physical damage or degeneration but is also dependent on the kinds of affects attached to that pain. This does not make the pain any less real, but only emphasizes how nuanced the experience of pain can be, particularly for people who have experienced chronic pain and are more susceptible to further pain through central sensitization syndrome (31).

Bridging the gap between the humanities and pain research, McCosker and Jackson use affect theory to explain how pain's meaning can shape how it is experienced (32, 33). Similarly, feminist scholar Ahmed uses neuroscience and affect theory to show how pain is felt and produced not only individually, but also socially (34). Although endometriosis does not always involve pain, chronic pain research is still useful for conceptualizing the way endometriosis's meaning can come to shape one's experience with it.

Feminist Disability Studies

Endometriosis has been largely absent from feminist disability studies thus far; however, it is still an important framework for understanding the ways that endometriosis gets embodied and understood (35). Disability studies takes a social-constructionist perspective to impairment and illness, considering how such concepts such as "disability" often frame individuals as flawed in opposition to a preconceived idea of normalcy (36). Endometriosis has similarly been constructed around the idea of individual flaws, as seen through discourses of hysteria and the 20th-century idea that endometriosis was a "career woman's disease" that occurred when women delayed childbirth to have careers (10, 11, 13). Endometriosis cannot be divorced from the histories and power structures that have come to establish how it is represented today and disability studies helps frame how these external forces can contribute to how it is experienced by patients (13, 20). Disability studies also privileges the stories and lived experiences of disabled, sick, and crip people as co-creators of knowledge (37–39). A feminist disability studies framework is useful for illuminating how the knowledge and meanings that people living with endometriosis produce on social media can shift how it is understood socially and even within research.

METHODOLOGY

Methods

Unlike big-data analyses which use algorithms and software to collect large amounts of data such as all the posts within a certain hashtag, this study used small data practices to focus on the intentions and personal experiences of those who live with endometriosis and use social media in relation to their disease. This article follows in the practice of other feminist media scholars who use qualitative methods such as digital ethnography to consider the individuals behind the big data (40, 41). It is particularly important to the author of this study, as not only researcher but also a fellow endometriosis patient working from a disability studies approach, that the experiences of these participants are at the forefront of this research. A qualitative ethnographic approach to this topic considers not only *what* people with endometriosis post on social media but *how* and *why* they do.

Participants and Approach

This research focuses on the platforms Facebook and Instagram as these are currently the predominant social media platforms used by those with endometriosis (16). This project was approved by the Research Ethics Board at Concordia University and all survey and interview respondents gave their consent to have their answers included in this research. The survey and interview questions as well as recruitment strategies were developed with mentorship from supervisors. To reach out to participants, a survey about endometriosis-related social media practices was shared on 5 popular private endometriosis Facebook groups with permissions from the group administrators. One-on-one interviews were then conducted with these administrators, 12 individuals who ran endometriosis-related Instagram pages, as well as those from the survey who had anomalous results, mainly two individuals whose answers were opposite to the rest of the results. Some of the interview participants were recruited using the snowball method. The interview participants ranged in age from late 20s to late 70s. Nineteen identified as women and three as non-binary or genderfluid. Eighteen of the participants lived in North America, while the others lived in Israel, South Africa, England, and Ireland. All participants were English-speaking and 7 of the 22 participants were visible minorities. All the survey participants were over 18, but no other demographic data was collected from them. All respondents identified as people living with endometriosis.

In total, the survey received 287 responses and 22 interviews were conducted. The survey took ∼20 min to complete and was composed of both multiple choice and short answer questions. The semi-structured interviews were conducted over zoom using pre-structured, open-ended questions and ranged from 30 to 60 min on average with one lasting over 2 h. The 24 interview questions and survey questions were very similar, although the interviews allowed for more elaboration and included 16 additional questions about group administration and Instagram for those it pertained to. Both the interview and survey focused on asking participants about their experiences with endometriosis symptoms, diagnosis, and treatment, what the disease means to them, and why and how they use social media. The full survey and interview questions are available on the author's website for those who wish to replicate the study: https://eileenmary.net/2021/05/03/interview-and-survey-questions/.

The survey results were compiled into a spreadsheet using Google Forms where the multiple-choice results could be analyzed in graphs and the longer answer questions could be coded and analyzed thematically in Dedoose. The interviews were transcribed and put into Dedoose and then coded based on themes that emerged, as well as the predominant social media practices that were identified in the survey results (**Figure 1**). These themes were identified through inductive coding while reviewing the interviews based on the most prominent and recurring topics. If multiple interviewees mentioned the word community, it would be coded as "community," but these excerpts could include differing feelings or representations of community. Multiple codes would be used per section if relevant. The total number of codes was 69, with the most discussed ones being: knowledge; connection; advocacy; reflections on social media; community, emotion, experiences and shared experiences; histories of hysteria and dismissal; labor; and doctor experiences (**Figure 1**).

A combination of *in vivo* coding and values coding was used (42). For the most part, participants' own words were used to determine the code names, although in the case of "histories of hysteria and dismissal," two codes were combined into one due to crossover. "Doctor experiences" refers broadly to the stories interviewees shared about various medical experiences. Many of these codes crossed over with the social media practices identified in the survey results, such as "connection," "knowledge," and "advocacy." The others, such as "labor" and "dismissal" feature in the findings and interpretations section in conversation with these broader practices.

Throughout every part of the surveys and interviews, the author was upfront about their own diagnosis with endometriosis with participants. They explained their positionality and personal investment in this research in both the calls for participation as well as before every interview. This bias was discussed upfront because, as Luka and Millette write, no research is immune from bias, whether quantitative or qualitative (40). Endometriosis research has a long history of bias toward certain voices and forms of knowledge-production, so it is particularly important to be transparent and make space for patient voices in current endometriosis research. Although limiting, this perspective was also essential to the research process, as many participants expressed feeling more comfortable sharing their answers with a researcher who understood the disease personally. The same participation might not be accessible to a researcher without endometriosis.

Due to this privileged position, measures were taken to maintain neutrality and facilitate feedback throughout the research process. Those whose survey answers differed from the majority of the responses were interviewed further to try and account for possible biased perspectives in the results, such as those who identified as less comfortable using social media. Throughout the research process, the publications born out of this research were shared with the interviewees as well as any survey respondents who provided their emails to encourage ongoing conversations and feedback. These public results have also been shared with the broader endometriosis social media network and endometriosis research networks to receive more feedback. The analysis of results was reviewed with the author's supervisor and compared to related research.

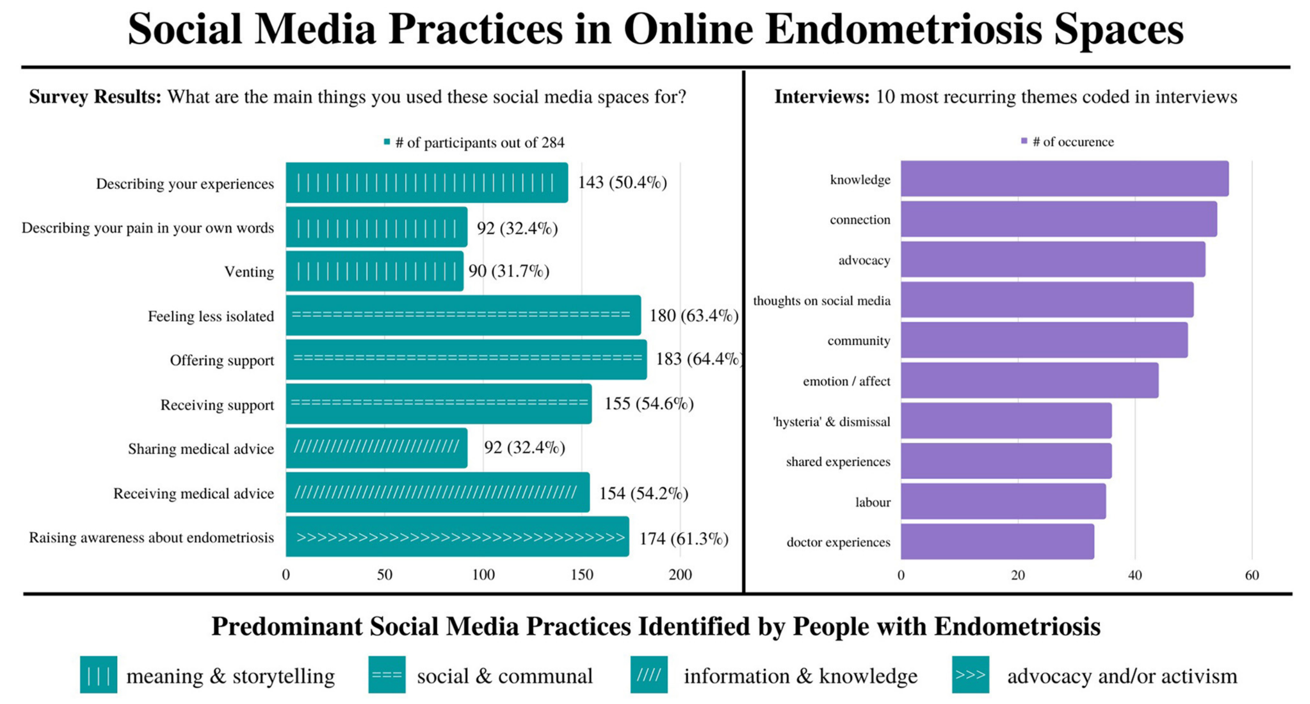


FIGURE 1 | A representation of the most common social media practices in endometriosis social media spaces based on survey results and including the most recurrent themes coded in interviews.

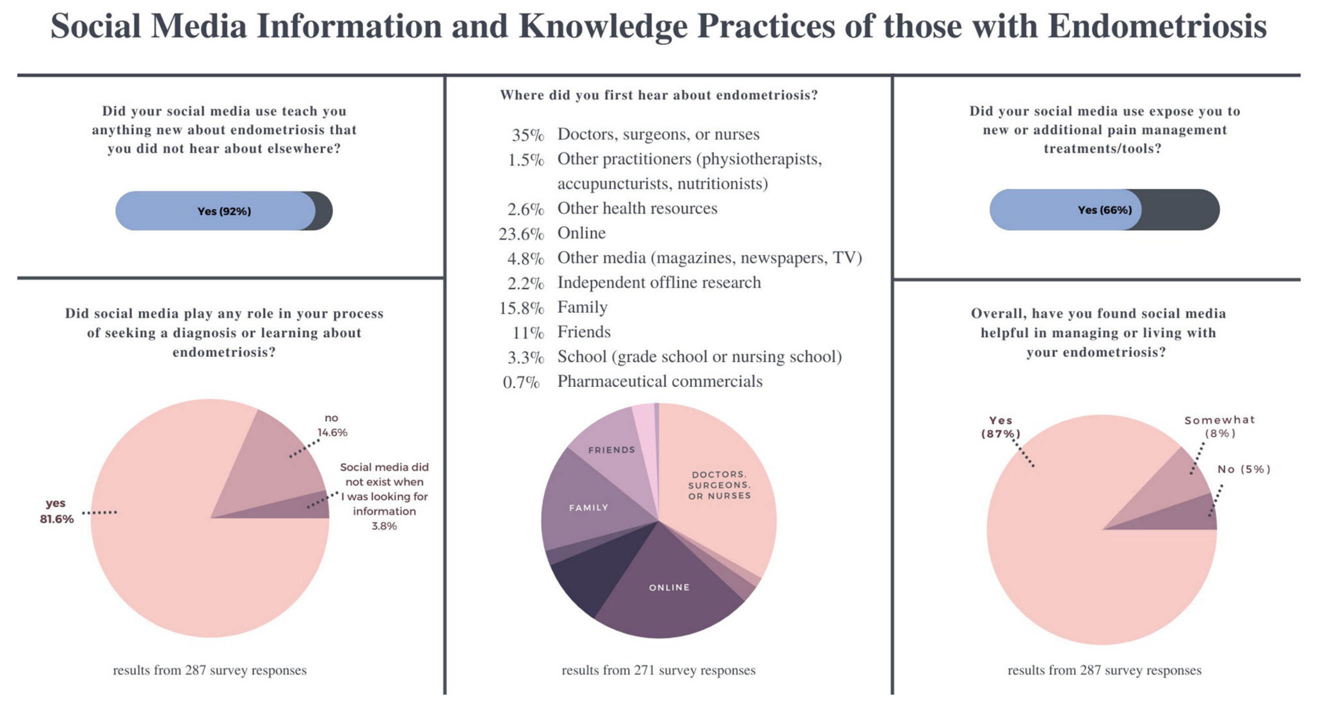


FIGURE 2 | Survey results showing how people with endometriosis use social media for information and knowledge practices and how these uses have influenced their life, diagnosis, and treatment options.

FINDINGS

The findings of this study have been organized based on what the survey results and interviews identified as the predominant practices people with endometriosis use on social media. These practices were then broken down into themes: meaning making and storytelling; social and communal; information and knowledge; and advocacy (**Figure 1**). These categories help frame what takes place in and what is produced on endometriosis social media spaces. Following the theoretical frameworks identified above, this research considers how everyday social media practices can help shape how endometriosis comes to be represented for and understood by both individuals and broader communities (43, 44). The number of survey respondents vary between results, as the participants were not required to answer every question.

Information and Knowledge Practices

When asked if social media played a role in their process of seeking a diagnosis or learning about endometriosis, 81.6% ($n = 235$) of respondents ($N = 287$) said yes, while 3.8% ($n = 11$) said that social media wasn't around when they were looking for information (**Figure 2**). Only 35% ($n = 95$) of respondents ($N = 271$) identified first hearing about endometriosis directly from a healthcare practitioner. 2.6% ($n = 7$) said they heard about it from other health resources, while 23.6% ($n = 64$) heard about it online from sources that may or may not have been health resources (**Figure 2**).

When asked if social media taught them anything new about endometriosis that they had not heard elsewhere, 92% ($n = 264$) of participants said yes. Sixty-six percentage ($n = 189$) said that social media exposed them to new or additional pain management treatments/tools and 85% said that social media had been helpful ($n = 250$) or somewhat helpful ($n = 22$) in managing or living with their endometriosis (**Figure 2**). This data is consistent with a number of recent studies which suggest that social media has opened up many new opportunities for information-sharing around chronic illnesses, particularly for people of marginalized genders or with stigmatized conditions (45–47). The potentials of social media for endometriosis have not been as extensively explored.

The average time between start of symptoms and diagnosis identified by my survey was 10 years—2.5 year higher than the average world estimate—suggesting that people social media use may be more common in those who have difficulty getting diagnosed. This theory is also supported by the results of the interviews, where a majority of participants identified turning to social media only after experiencing years of medical dismissal.

The benefit to Facebook and Instagram is that information is not only shared amongst many people, but that individuals can also save time by learning from one another's experiences. One interview participant described how this saved her time in her own treatment process.

> I wouldn't know [that pregnancy didn't treat endometriosis] if it wasn't for all these different Facebook groups, Instagram profiles [. . .] I think I had to see other people in different parts of that journey and what they were going through to really help myself make those decisions. [. . .] I skipped through a lot of that initial hair pulling frustration because I had people pointing me in the right direction.

Another participant described how she has seen social media empower people with endometriosis to ask for more from their practitioners:

> Women now have gone from maybe trusting their doctors implicitly to starting to question them and with the use of social media in particular [. . .] they are now able to go in and see themselves as equal to their medical team as well. They're able to negotiate a wee bit more and certainly in Ireland they're asking for referrals outside of the country because we don't have a lot of doctors who are able to help.

Survey respondents and interviewees both talked not only about their experiences being dismissed for their symptoms, but also for using social media for information. As one interviewee said:

> I did my own research and I know doctors hate when patients consult 'Dr. Google' but I wasn't getting any help anywhere but so I was just doing my best to put pieces together on my own.

The survey respondents and interviewees held differing opinions on which sources were the most reliable and, as one interviewee said: "what one person considers misinformation, another person considers accurate." Despite the misinformation and complexity of information-seeking on social media, the survey and interview results still showed that, overall, it was useful for many of the respondents.

Social and Communal Practices

Both the survey respondents and interviewees commonly expressed that online support groups and Instagram spaces made them "feel less alone." Seventy-eight percentage ($n = 223$) of participants ($N = 286$) said that participating in endometriosis social media spaces changed how they felt about or experienced their symptoms, with an additional 7% ($n = 20$) saying it "sort of" did (**Figure 3**). Forty-five percentage ($n = 129$) of participants ($N = 287$) said they had made connections with others through their endometriosis social media use. Those who did described feelings of community, connectedness, and friendship based on shared experiences:

> There's a, I would say unspoken but it's also spoken, bond that I think just happens. It happens with anyone with shared experience that involves being not only in so much pain, but dismissed, marginalized in our own ways. If you tell me you have endo, I know what that means and I don't care who you are, I'm here, what do you need?
>
> I feel like there is a really strong community, not here in Israel specifically, but around the world [. . .] because everyone experiences basically the same thing. At different levels, but people know what you mean.
>
> I've made some really good friends now in the last 6 months and there are people I check in with more online as opposed to real life because they get it and you can kind of message people and go

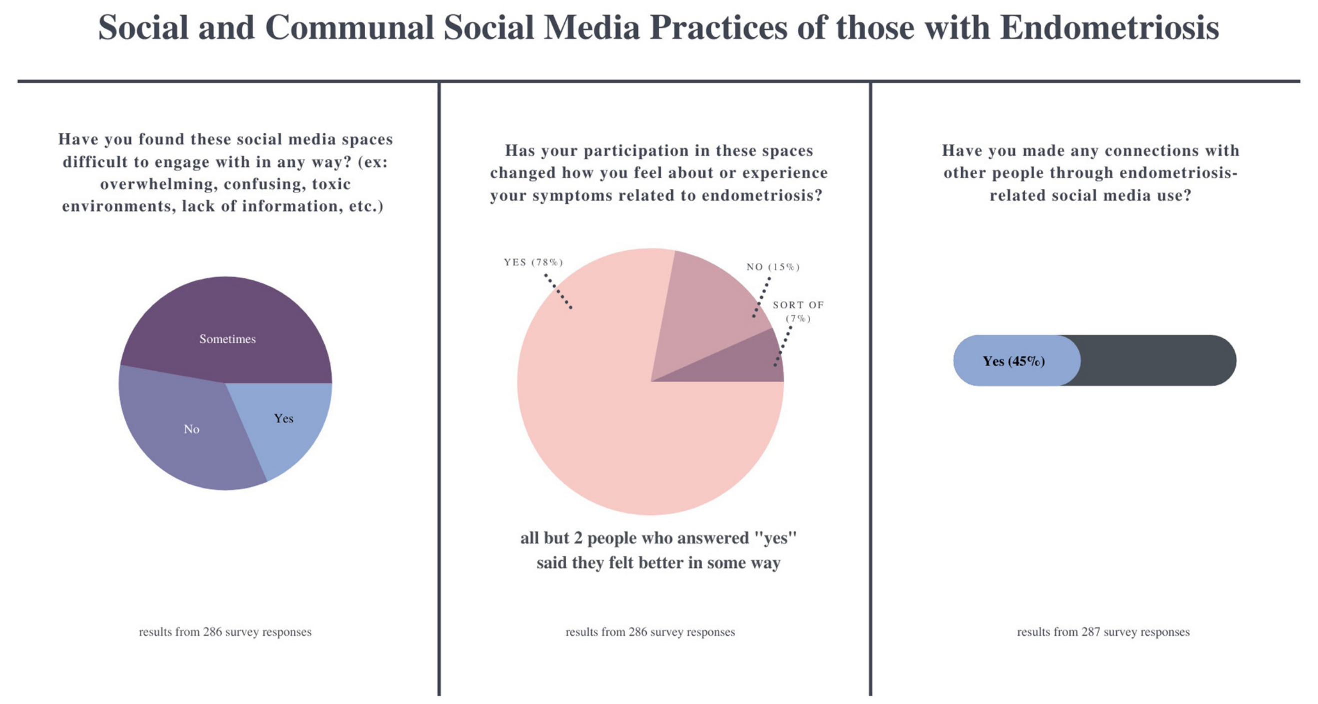


FIGURE 3 | Survey results illustrating the social and communal practices of people with endometriosis on social media.

> "I've had a really bad day" and you don't have to explain why [. . .] which is really lovely and I think that has really helped my mental health too, just knowing that if I need to talk to someone or if I need to vent about something generally people [will reach out].
>
> I have found support simply through the realization that there are many people who experience these symptoms than I thought, and that there is a valid explanation for the pain. It has been very validating to hear other people's experiences, particularly when it comes to being dismissed by medical professionals when seeking treatment.
>
> When you tell someone you have endometriosis and they tell you back, it's like we're already friends.

Many survey respondents specified that they only use social media for information, not connections. Others explained that they felt some connection with others but had not made any friendships or more substantial relationships. In the interviews, participants often used the words "community," "tribe," "sisterhood," or "brotherhood" to describe the experience of participating in online endometriosis spaces, despite also describing how the spaces can sometimes be unpleasant or unwelcoming, particularly for those from marginalized backgrounds such as visible minorities or those who do not identify as cisgender women (those assigned female as birth who live as women).

The survey and interview respondents were also transparent about the fact that online endometriosis spaces can be difficult to inhabit sometimes. When asked if they found endometriosis social media spaces to be difficult to engage with in any way (ex: overwhelming, confusing, toxic environments, lack of information, etc.) 47.2% ($n = 135$) survey participants said sometimes, while 18.5% ($n = 53$) said yes and 34.3% ($n = 98$) said no (**Figure 3**). The interviews highlighted these challenges:

> I think this is my first time saying it out loud, but [. . .] when I mentioned seeing sick people and all the suffering [. . .] I started to wonder if I was sick enough to be a part of this group. I do have a lot of good days; I do have days where my body is kind to me and I have peace on that day. [. . .] So I kind of have to learn to be kind not myself and say, "it's okay that you are okay." You don't have to be sick or unwell or in pain all the time to relate to other people in this space.
>
> I don't know, part of me doesn't want to be part of [many of the groups] because I don't see those spaces as safe places for non-binary or trans people and I think the communities need to be more actively focused on changing the language. And I don't think that's just the fault of cis-gendered women who have the disease, I think it's also the fault of the medical community in framing endo as a woman's disease.
>
> I've seen queer people post in those spaces about what needs to change to make those spaces safe for them and a lot of especially white, cisgender women being like "well, get out of this space then." Like really toxic, gross stuff.
>
> I didn't find anyone that was my color that was talking about it. And you know, within our community, we don't really discuss the health issues that we deal with [. . .] I really wanted to find [. . .] a community for other people that are African American just to see if we could compare notes.

> Because people have to self-advocate with endo so much, most people do a lot of research on it. [But] people are also constantly learning about endo for the first time [...] Because of this, I think there's often a clash in social media spaces because it seems that the well-researched folks get very annoyed when people who are just beginning their journey ask questions.

The perspectives of the respondents were often conflicting. For example, while one interview respondents said that there needs to be room for hard feelings in endometriosis social media spaces, another said that the emotional intensity of the spaces caused them to feel worse about their own condition:

> I feel like there needs to be a space for people to share the hard things because this is a hard thing we're going through. And there are no easy answers and feeling hopeless or frustrated or upset is like the natural human response to being in a situation that's awful.
>
> It came to a point that I needed to just put those pages on mute so that I could go to the page when I was feeling like I needed to find some information or just completely unfollow it because it wasn't good for my own mental space to just keep seeing how hard it is for people to live with this thing. So I had to kind of just separate myself from social media sometimes because it did become overwhelming and toxic.

Although some of the interview and survey participants found the social and communal aspects of social media to be very important and/or beneficial, this was not the case for all participants. While some found the social and communal aspects of endometriosis social media space difficult or overwhelming to engage in, others were just more interested in focusing on information and knowledge-sharing.

Meaning-Making, Storytelling, and Advocacy Practices

The other common practices on endometriosis social media spaces are meaning-making, storytelling, and advocacy practices. Beyond the value of information-sharing, education, and social supports, social media also offers a place where patients can make their endometriosis visible, describe it in their own terms, and even contribute to new cultural understandings of the disease (48). 50.4% ($n = 143$) of survey respondents ($N = 284$) described using social media to "describe their experiences," with 32.4% ($n = 92$) saying they used it to "describe their pain in their own words" and 31.7% ($n = 90$) using it for "venting." 61.3% ($n = 174$) said they use social media to raise awareness about endometriosis (**Figure 1**).

The interviewees described the different ways that storytelling, meaning-making, and representation on social media was useful to them:

> I'm a writer so being able to write things out [on social media] is very helpful and I also have memory problems sometimes so being able to go back and reread things and say I was in the worst pain fog when this conversation happened, like what were those tips and what was being shared and having a kind of record for that.
>
> If I was having a bad day, I could say to my boyfriend, just read my [Instagram] post from today because that's how I'm feeling and he would go, oh that makes sense. But now [...] I have so many people going "oh my god, it's so nice to know that I'm not alone in this" and "it's funny and you shouldn't be laughing but it's nice to laugh at it."
>
> So that account really started as just a diary for me, just to therapeutically be able to get it out and it wasn't even for connection at that point, it was just to get it off my chest, like this is what I'm dealing with, this is what my day-to-day is like. And then once I had surgery and I had more to share about my updates I had a lot of people asking questions and then it turned into more of an education resource.
>
> The day that I came out with my diagnosis I posted a picture, I'm sure you've seen it 100 times yourself with the surgery scars and the plasters over it. I posted a picture of that and explaining my story. Prior to my surgery I had posted about the fact that I was going into surgery to have a cyst removed and I thought I should tell you all because nobody speaks about this stuff so I'm telling you about it. [...] I can't count the number of times people have said to me: "I don't feel alone anymore. Thank you for sharing your story." And you know that's a virtual connection. That's someone would have made through something I would have spoken about.

One of the interviewees also described how online patient representations can also be useful for doctors, as well as for patients by capturing the qualitative aspects of pain which is the clinical pain scale does not account for. For example, in the interview she describes the experience of diaphragmatic endometriosis:

> Someone says 'I feel like I have an elephant sitting on my chest and I'm trying to blow up a flat balloon.' Maybe you don't know what it's like to have an elephant sit on your chest, but you know what it's like to blow up a flat balloon and how hard it is.

Some of the interview respondents also spoke about how social media inspired them to engage in advocacy and awareness raising:

> I'm a late comer to the endo community and jumping into the advocacy (it's not that I didn't have the condition, it's that we weren't really aware of that being something to be looked at) and I think part of that makes me mad because there are others like me, in my age group, that have gone decades that have struggled with the disease, really traumatic diseases, people that are isolated incidences, and it was always under the radar and I look at these people now and some of them, they had their whole life ahead of them and it just changed all that.
>
> And I mean when I did start speaking about [endometriosis online] I had no idea what to expect because I had never been an advocate for anything in my life before this time. So I didn't know what could have been coming but I think I got the best response because so many people could relate to me.
>
> At the beginning [when] I was starting [my Instagram] it was honestly it was mainly just for me. I mean I wanted to help

> other women and other people honestly but I was also like, I had no idea what's going on so I'm just going to start talking loudly and then hopefully someone will hear me and then I'll get help. I mean the reason I do it now, which I say over and over, is just so no woman thinks that they're alone in their pain. That's basically just the bottom line of why I do it now. Because I felt so alone and I felt no one knew what my pain was, no one understood my pain and I was, I want to be that person for someone else that does understand.

The way that participants understood and described their endometriosis both online and in the surveys and interviews was multiplicitous. In both the survey and interviews, participants were asked the open-ended question, "What does 'endometriosis' mean to you? Has this changed over time?" Some answered with clinical descriptions, some explained their symptoms, others were more metaphorical. While some answers focused on debilitating symptoms, others spoke of hope and growth. For some, endometriosis took on a kind of personality, described as "sadistic" or "controlling." For others, it was not only a disease, but a way of understanding the world, as shown by the answer "[endometriosis] has taught me access to care is unequal." One participant wrote, "[i]t's something that's forever a part of my life… but won't define it." Another said "it means losing out on my 'timeline' for my own life." The most persistent things that people talked about were pain, their lives, and the time endometriosis takes away from them. The most common words and themes that appeared in the answer to this question were symptoms ("fatigue," "pain," "cramps," "heavy [bleeding]," "nausea"); temporality ("time," "years," "always"); actors ("doctors," "medical,"); challenges ("struggle," "trying," "work"; "without," "help"); body parts ("organs," "endometrial"). In order to fully try and grasp the complexity of what endometriosis can mean to patients, all of these different aspects (individual, physical, structural, systemic) need to be considered. These nuance answers reflect the complex representations that are shared in endometriosis social media spaces every single day.

DISCUSSION

It is clear from looking at the varied social media practices of people with endometriosis that the illness cannot be easily summarized as just one thing. This complexity and nuance are part of what makes endometriosis social media spaces so significant. There are many different players at work on social media, and many differing viewpoints and experiences. Currently, social media offers a subjective, qualitative, and complex view of endometriosis that is rarely being represented clinically or even within research. Simply through posting and creating on social media, people with endometriosis are influencing how the illness gets talked about and challenging the simplistic ways that it has been addressed thus far with their experiences, connections, and information-sharing. In this section, the above findings will be explored by again breaking them down by practices:

Information and Knowledge Practices

The survey and interview results reveal a predominant communication and information gap between doctors and patients in the case of endometriosis. This trust gap has been something that has continually been acknowledged in research around stigmatized and gendered illnesses (49, 50). The kinds of information and knowledge produced in endometriosis social media spaces is not simple or straightforward and, as other scholars have explored, social media is rife with misinformation (16, 19).

Instead of becoming a further barrier to accessing care, with the right approach and support from practitioners, information-seeking and knowledge-sharing on social media could help improve time to diagnosis. A recent systematic review shows that seeking health information online can actually improve the patient-practitioner relationship when both parties talk about it openly and without judgment (51). These survey and interview results also suggest that if patients can access information from medical professionals sooner, they may not turn to social media for information as extensively.

The information-seeking practices of people with endometriosis on social media also show that patients value more than just scientific or medical knowledge. Shared experiences also play an important role and, although experiential knowledge tends to be considered less rigorous than biomedical knowledge, the survey results and interviews reveal that it is very valuable to many of those who live with endometriosis. In fact, by sharing their experiences online, people with endometriosis are helping create new forms of knowledge that others can draw on to understand their own experiences.

Social and Communal Practices

Research has shown that online support groups can be helpful for improving the overall wellbeing and quality of life for people with chronic illnesses through reducing isolation, improving feelings of support and community, and increasing patients' confidence interacting with their healthcare professionals (45, 52–54). However, online support groups and illness spaces can increase the risks of conflict, developing maladaptive coping strategies, or experiencing emotional overwhelm (17, 45, 52). These conflicting results were also reflected in the survey results and interviews of this study, where respondents expressed benefits but also challenges in connecting with others online.

Existing endometriosis research tends to be more accepting of using social media for support and community than information-seeking, however studies do not always acknowledge the complexities of these spaces (6, 16, 17, 55). The survey and interview responses show how conflicts that emerge in these online spaces often parallel the conflicts that exist in the societal and biomedical construction of endometriosis, such as longstanding prejudices, stigmas, and medical debates. The emotional toll of endometriosis, which is not always addressed clinically, also takes up space in these online communities and can drive the kinds of conversations these spaces produce. As feminist affect scholar Sara Ahmed writes, "emotions in their very intensity involve miscommunication, such that even when we have the same feeling, we don't necessarily have the same relationship to the feeling" (34). The contradiction of endometriosis spaces is that they both thrive off of shared experiences and shared feelings, but that these experiences inevitably contain differences, nuances, and conflicts.

Although, as the previous section showed, it is important not to dismiss the social media practices of people with endometriosis, it is also important that clinicians and researchers understand the full extent of these groups before referring their clients to them for emotional support. The social and communal aspects of online social media spaces reflect and exacerbate the conflicts and inequalities that already exist in endometriosis care. While social media can be beneficial, and while patients will continue to use these platforms if they don't have access to better alternatives, the complexities of these spaces should not be overlooked.

Meaning-Making, Storytelling, and Advocacy Practices

There has been extensive research and writing across disciplines on the challenges of communicating pain and illness, whether between a patient and practitioner or more broadly (56–59). Chronic pain and illnesses involve biological, psychological, cultural, and social factors that can make it difficult to assess quantitatively (60, 61). Despite the need for an interdisciplinary approach to pain, throughout Western medicine it is still common for many practitioners to use the "pain scale" in clinical practice, where patients are asked to label their pain on a scale quantitatively from 1 to 10. This tool has been critiqued for its subjectivity and, although other alternatives exist, they are not as commonly practiced (62, 63). Despite the prevalence of chronic pain and illnesses, people living with them are likely to experience disbelief and invalidation from their practitioners, which can cause isolation, depression, and emotional distress (64, 65).

Although endometriosis does not always involve chronic pain, it is one of the most common symptoms [experienced by at least 92% ($n = 261$) of my survey respondents], and research about pain communication provides a useful way for understanding how endometriosis gets represented, mediated, and recreated online. Elaine Scarry's formative work, *The Body in Pain*, is particularly useful for framing how pain's seeming unrepresentability can "unmake" an individual subject's world, while also "making" new worlds both despite and because of this unrepresentability. Pain's lack of referential content, its unfathomability, can destroy language, but this objectlessness also "gives rise to imagining" and new forms of meaning-making (57). For many endometriosis patients, the pain can be so severe that it renders a person unable to speak or move.

In contrast, the representation of endometriosis on social media is almost incessantly focused on *making that pain visible*. This visualization practice is sometimes done through language in Facebook posts or Instagram infographics, where pain is put into words and metaphors. It is also often represented visually online: sometimes through drawings; painting physical wounds on the outside of the body; or photography of a vulnerable moment, such as a person recovering from surgery or kneeled over in pain. The externally invisible, but full body, nature of the disease has also been represented through Instagram campaigns such as #IAmExtraNotRare or #ThisIsEndometriosis, where participants are asked to visually represent endometriosis on their body with graphics or by writing on their skin.

Social media also allows those who do not explore representational practices themselves to benefit through seeing other people's posts and potentially recognizing themselves in those shared experiences. Patient narratives, descriptors, or metaphors can also be useful for showing how people with endometriosis experience, feel, and understand their pain. For example, in a study by Stella Bullo and Jasmine Heath Hearn, 21 women described their endometriosis with metaphors that represented it as an external agent controlling their experiences, showing that they generally felt a helplessness and lack of control surrounding their disease (66). While patient representations are never perfect examples of endometriosis, the intense, affective, or fragmented metaphors that people use to describe their endometriosis can often reveal the emotional and physical toll of the disease better than the description itself. As Dolmage writes about disability storytelling and rhetoric, imperfect narratives like these have value—"meaning actually springs forth from gaps and flaws and mistakes" (67). The value of online endometriosis representations is not just about what is created, but about what the practice of representation itself reveals.

In this way, patients who post on social media create their own research networks of endometriosis outside of academic or medical institutions. But these networks can be complicated and unreliable. These storytelling practices have also been picked up by endometriosis organizations, pharmaceutical companies, and practitioners, who sometimes share patient narratives to add an impact to their own posts or sell products. As one interviewee describes, sharing personal stories gets her the "greatest engagement" on Instagram. While some may be sharing their stories for their own benefit, others may be using it as an advertising tactic. The online network of endometriosis stories is unregulated and the intentionality behind posts can be difficult to untangle for people just scrolling by.

The varied and sometimes contradictory meanings of endometriosis that survey and interview respondents shared speak louder when put in conversation with one another. The *social* nature of social media allows for some of endometriosis's complexities to be more thoroughly explored. Scholar Anthony McCosker draws together the social sciences and neuroscience to argue that pain cannot be defined by only one body. As he writes,

> The affective force of pain is located not simply within the perceiving subject, nor the object that 'initiates' sense perception, nor in the impulse striking out between cells in afferent synaptic chains coursing through the body, nor at the synaptic interference or within the nerve cells themselves at the site of a wound [...] Rather the affective force of pain lies in the complex interchange of any and all of these elements, along with others, through which bodies act upon one another and in relation to one another within an encounter (32).

Although pain and illness are always embodied individually, they are also structured through relations and cannot be divorced from the power structures that come to situate their meanings, feelings, and affective dimensions. Endometriosis comes to be felt through complex relations within ourselves, but it is even further constructed through social relations, the support of others, our experiences in medical institutions, our conceptions of ability and disability, our understandings of pain, our desire for productivity, and our media practices. Endometriosis, in all its relationalities, cannot be measured simply by numbers or even symptoms and to do so would be to do it a great disservice. Social media offers a glimpse of what a more complex representation of endometriosis might look at, but the people living with this disease deserve safer, more regulated spaces to explore this self-expression.

Implications

Endometriosis social media practices create an important, but messy, archive of the disease. This archive is built collectively through the narratives of many different people with the disease, practitioners, pharmaceutical companies, businesses, and more. The complexities of these crossovers only enhance the political density of these spaces and the potential resistance people with endometriosis engage in by participating. In a world where neither online or offline space are safe from healthcare inequalities, many with endometriosis are using social media to try and create an alternative.

As Gonzalez-Polledo writes of chronic pain communication on Tumblr, "in social media pain is reframed as a political issue as it is transformed from an individual, potentially disabling event that has the capacity to put life on hold to an inherently social, actionable, collective, *issue*" (59). Those living with endometriosis who engage collectively in these spaces "resist epistemic injustice and create inhabitable pain worlds" (59). By paying attention to the social media practices of those with endometriosis, we get not only "pain worlds," but *endometriosis* worlds, where the present and future of the disease can be reimagined. While this online engagement, and these endometriosis worlds, may not always change the dominant narrative, if we consider the long history of endometriosis—including the continued dismissal and mistreatment of patients and the influence of sexism, racism, and classism—even the sheer volume of patient voices on Facebook and Instagram is already an significant change. People with endometriosis have a place to connect, discuss, and learn from one another in ways that have never before been possible and this historical relevancy should not be underestimated.

It is important that practitioners and researchers going forward understand the amount of labor that people with endometriosis who use social media must conduct in order to access information, care, and support online, as well as raise awareness about the disease. Social media helps reveal the gaps in care for endometriosis patients and, although this article shows that it can be beneficial to some patients, it not a long-term solution. As Dusenbery writes in her book *Doing Harm*, "[w]hile some patients may *want* to be partners in their medical care, and the Internet has certainly made it easier for some patients to educate themselves, not all women have the vast resources require to become 'empowered patients.' And doing so should not be mandatory" (49). Understanding the realities that face so many people with endometriosis and why they might turn to social media can help practitioners and researchers have more productive conversations about patient social media use and patient-centered care.

Limitations and Recommendations for Future Research

The survey and interview participants for this research were recruited through social media so, although participants had varying degrees of usage, this study does not account for people with endometriosis who do not use social media at all. For a fuller picture of the role social media plays in the broader population of endometriosis patients, future research should recruit through other sources, such as patient groups and clinics. This study also focuses predominantly on English-speaking social media spaces with most participants coming from North America. Future research is needed to address this gap.

A broader method of analysis such as data-scraping could better inform on the wider range of post styles that appear in endometriosis spaces. This article is limited to self-reporting from survey respondents and interviewees who have endometriosis and therefore does not consider the many other people involved in online endometriosis spaces, such as clinicians, businesses, and caregivers. Due to the complexity and time-consuming nature of ethnographic research, this study was only able to cover a limited number of participants and the snowball method of recruitment for interviews could have resulted in more homogenous responses. Future researchers might consider using other qualitative methods such as focus groups to hear from a wider range of people. In particular, it would be beneficial to conduct focus groups with endometriosis patients so that they could workshop the interview questions and research methods before the research period using their lived experience. Future endometriosis research should do more to collaborate with patients as co-researchers/co-creators and, although this study aimed to emphasize patient voices, it would have benefited from having more patient collaborators contributing to and shaping the research process itself.

Ideally, future researchers in this area should also establish a larger and more interdisciplinary research group so that more data can be collected, and the results can be more thoroughly and complexly analyzed. A larger research team would not only help mitigate bias but could also be useful for addressing the accessibility needs that come up when researchers are themselves patients, as is the author of this article.

CONCLUSION

This research highlights the importance of not oversimplifying the experience of living with endometriosis. By looking at the social media practices of people with endometriosis, the disparities in care, histories of medical neglect, and complexities of life with chronic pain and illness are revealed. Significant archives of experience and patient-produced knowledge are available on social media, and these should not be dismissed or ignored. Although social media use comes with complexities and challenges, fully understanding why patients go online and what they use these spaces for can help practitioners and researchers better understand what people with endometriosis need from their care, such as validation and support, reductions to diagnosis, better access to accurate information, emotional support, and clearer representations of endometriosis in medicine and popular culture. This article is a first step toward validating and analyzing the social media practices of people with endometriosis so that future researchers and clinicians can use these findings toward shaping patient-centered futures.

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 Concordia University Human Research Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

FUNDING

The author's research was funded *via* the Joseph-Armand Bombardier Canada Graduate Scholarship (CGS) Doctoral Social Science and Humanities Research Council of Canada (SSHRC) Grant.

ACKNOWLEDGMENTS

Thank you to every person with endometriosis who has helped this research happen, whether by filling out the survey, doing an interview, or just offering your support. Thank you also to my PhD supervisor, Dr. Sandra Gabriele, and Dr. Najmeh Khalili-Mahani for encouraging my work.

REFERENCES

1. Shim JY, Laufer MR, Grimstad FW. Dysmenorrhea and endometriosis in transgender adolescents. *J Pediatr Adolesc Gynecol.* (2020) 33:524–8. doi: 10.1016/j.jpag.2020.06.001
2. Rogers PAW, D'Hooghe TM, Fazleabas A, Gargett CE, Giudice LC, Montgomery GW, et al. Priorities for endometriosis research. *Reprod Sci.* (2009) 16:335–46. doi: 10.1177/1933719108330568
3. Facchin F, Barbara G, Saita E, Mosconi P, Roberto A, Fedele L, et al. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol.* (2015) 36:135–41. doi: 10.3109/0167482X.2015.1074173
4. Warzecha D, Szymusik I, Wielgos M, Pietrzak B. The impact of endometriosis on the quality of life and the incidence of depression—a cohort study. *Int J Environ Res Public Health.* (2020) 17:3641. doi: 10.3390/ijerph17103641
5. Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Human Reproduction Update.* (2013) 19:625–39. doi: 10.1093/humupd/dmt027
6. Marinho MCP, Magalhaes TF, Fernandes LFC, Augusto KL, Brilhante AVM, Bezerra LRPS. Quality of life in women with endometriosis: an integrative review. *J Womens Health.* (2018) 27:399–408. doi: 10.1089/jwh.2017.6397
7. Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod.* (2012) 27:1292–9. doi: 10.1093/humrep/des073
8. Levy AR, Osenenko KM, Lozano-Ortega G, Sambrook R, Jeddi M, Bélisle S, et al. Economic burden of surgically confirmed endometriosis in Canada. *J Obstet Gynaecol Can.* (2011) 33:830–7. doi: 10.1016/S1701-2163(16)34986-6
9. Bullo S. Exploring disempowerment in women's accounts of endometriosis experiences. *Discourse Commun.* (2018) 12:569–86. doi: 10.1177/1750481318771430
10. Jones CE. Wandering wombs and "female troubles": the hysterical origins, symptoms, and treatments of endometriosis. *Womens Stud.* (2015) 44:1083–113. doi: 10.1080/00497878.2015.1078212
11. Guidone HC. The womb wanders not: enhancing endometriosis education in a culture of menstrual misinformation. In: Bobel C, Winkler IT, Fahs B, Hasson KA, Kissling EA, Roberts TA, editors. *The Palgrave Handbook of Critical Menstruation Studies*. Singapore: Palgrave Macmillan (2020). Available online at: http://www.ncbi.nlm.nih.gov/books/NBK565622/ (accessed March 30, 2021).
12. Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. Focus group study of endometriosis: struggle, loss and the medical merry-go-round. *Int J Nurs Pract.* (2003) 9:2–9. doi: 10.1046/j.1440-172X.2003.00396.x
13. Sanmiguel LM. *From "Career Woman's" Disease to "An Epidemic Ignored": Endometriosis in United States Culture Since 1948 (Dissertation)*. University of Illinois, Urbana (2000). Available online at: http://hdl.handle.net/2142/86621 (accessed February 4, 2022).
14. Redwine DB. *Googling Endometriosis: The Lost Centuries*. Scotts Valley, CA: Create Space Independent Publishing Platform (2012).
15. Shah DK, Moravek MB, Vahratian A, Dalton VK, Lebovic DI. Public perceptions of endometriosis: perspectives from both genders. *Acta Obstet Gynecol Scand.* (2010) 89:646–50. doi: 10.3109/00016341003657900
16. Sbaffi L, King K. Living with endometriosis: the role of the internet in suporting the diagnosis and treatment process. *J Consumer Health Internet.* (2020) 24:370–90. doi: 10.1080/15398285.2020.1816803
17. Shoebotham A, Coulson NS. Therapeutic affordances of online support group use in women with endometriosis. *J Med Internet Res.* (2016) 18:e109. doi: 10.2196/jmir.5548
18. Howard J. *10 Top Questions You Had for Dr. Google in 2018 CNN.* (2018). Available online at: https://www.cnn.com/2018/12/21/health/health-questions-2018-google-explainer/index.html (accessed February 24, 2022).
19. Hirsch M, Aggarwal S, Barker C, Davis CJ, Duffy JMN. Googling endometriosis: a systematic review of information available on the Internet. *Am J Obstet Gynecol.* (2017) 216:451–458.e1. doi: 10.1016/j.ajog.2016.11.1007
20. Seear K. *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics*. Burlington: Ashgate Publishing Limited (2014).
21. Papacharissi Z. *A Networked Self: Identity, Community and Culture on Social Network Sites*. New York: Routledge (2011).
22. Pybus J. Accumulating affect: social networks and their archives of feelings. In: *Networked Affect.* Cambridge: MIT Press (2015). p. 234–49.
23. Rentschler C. Affect. In: Gray J, Ouelette L, editors. *Keywords in Media Studies*. New York: New York UP (2017). p. 12–4.
24. Stewart K. *Ordinary Affects*. Durham: Duke UP (2007).
25. Wetherell MWM. *Affect And Emotion*. Los Angeles: Sage Publications (2012). 192 p.
26. Keller J. Making activism accessible: exploring girls' blogs as sites of contemporary feminist activism. In: Mitchell C, Rentschler C, editors. *The Politics of Place: Contemporary Paradigms for Research in Girlhood Studies*. Oxford: Berghahn Books (2014).
27. Chun WHK. *Updating to Remain the Same: Habitual New Media*. Cambridge: MIT Press (2016).

28. Melzack R. Pain and the neuromatrix in the brain. *J Dent Educ.* (2001) 65:1378–82. doi: 10.1002/j.0022-0337.2001.65.12.tb03497.x
29. Barbis J, Freedman M, Gehret J, Young G, Kamen L. A physiotherapeutic, biopsychosocial approach to the management of patients with peripheral neuropathic pain and complex regional pain syndrome. In: *Challenging Neuropathic Pain Syndromes: Evaluation and Evidence-Based Treatment*. St. Louis, MO: Elsevier (2018).
30. Edwards RR, Campbell C, Jamison RN, Wiech K. The neurobiological underpinnings of coping with pain. *Curr Dir Psychol Sci.* (2009) 18:237–41. doi: 10.1111/j.1467-8721.2009.01643.x
31. Maddern J, Grundy L, Castro J, Brierley SM. Pain in endometriosis. *Front Cell Neurosci.* (2020) 14:335. doi: 10.3389/fncel.2020.590823
32. McCosker A. Pain sense: nociception, affect and the visual encounter. *Transformations*. (2012) 1–12. Available online at: http://www.transformationsjournal.org/wp-content/uploads/2016/12/McCosker_Trans22.pdf
33. Jackson JE. Pain: pain and bodies. In: Mascia-Lees FE, editor. *A Companion to the Athropology of the Body and Embodiment*. Hoboken, NJ: Wiley-Blackwell (2011).
34. Ahmed S. *The Cultural Politics of Emotion*. Abingdon: Routledge (2013).
35. Jones CE. The pain of endo existence: toward a feminist disability studies reading of endometriosis. *Hypatia.* (2016) 31:554–71. doi: 10.1111/hypa.12248
36. Garland-Thomson R. Feminist disability studies. *Signs.* (2005) 30:1557–87. doi: 10.1086/423352
37. Lakshmi Piepzna-Samarasinha L. *Care Work: Dreaming Disability Justice*. Vancouver: Arsenal Pulp Press (2018).
38. Puar J. *The Right to Maim: Debility, Capacity, Disability*. Durham: Duke UP (2017).
39. Price M. The bodymind problem and the possibilities of pain. *Hypatia.* (2015) 30:268–84. doi: 10.1111/hypa.12127
40. Luka ME, Millette M. (Re)framing big data: activating situated knowledges and a feminist ethics of care in social media research. *Social Media + Society*. (2018) 4:205630511876829. doi: 10.1177/2056305118768297
41. Mendes K, Ringrose J, Keller J. *Digital Feminist Activism: Girls and Women Fight Back Against Rape Culture*. Oxford: Oxford UP (2019).
42. Saldana J. *The Coding Manual for Qualitative Researchers*. 3rd ed. Los Angeles: Sage Publications (2015). 366 p.
43. Humphreys L. *The Qualified Self: Social Media and the Accounting of Everyday Life*. Cambridge: MIT Press (2018).
44. Foucault M. Technologies of the self: lectures at university of Vermont in October 1982. In: *Technologies of the Self.* Amherst: University of Massachusets Press (1988). p. 16–49. Available online at: https://foucault.info/documents/foucault.technologiesOfSelf.en/ (accessed February 1, 2021).
45. Rains S. *Coping with Illness Digitally*. Cambridge: MIT Press (2018).
46. Kirschning S, von Kardorff E. The use of the Internet by women with breast cancer and men with prostate cancer-results of online research. *J Public Health.* (2008) 16:133–43. doi: 10.1007/s10389-007-0134-0
47. Lupton D, Maslen S. How women use digital technologies for health: qualitative interview and focus group study. *J Med Internet Res.* (2019) 21:e11481. doi: 10.2196/11481
48. Sendra A, Farré J. Communicating the experience of chronic pain through social media: patients' narrative practices on Instagram. *J Commun Healthcare.* (2020) 13:46–54. doi: 10.1080/17538068.2020.1752982
49. Dusenbery M. *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick*. New York: HarperOne (2017).
50. Cohen M, Quintner J, Buchanan D, Nielsen M, Guy L. Stigmatization of patients with chronic pain: the extinction of empathy. *Pain Med.* (2011) 12:1637–43. doi: 10.1111/j.1526-4637.2011.01264.x
51. Tan SSL, Goonawardene N. Internet health information seeking and the patient-physician relationship: a systematic review. *J Med Internet Res.* (2017) 19:e9. doi: 10.2196/jmir.5729
52. Parsons CS. Hystersisters: messages of social support in an online health support group for women. *J Commun Healthcare.* (2019) 12:121–33. doi: 10.1080/17538068.2019.1612211
53. Kim H. Enacted social support on social media and subjective well-being. *Int J Commun.* (2014) 8:21. Available online at: https://ijoc.org/index.php/ijoc/article/view/2243/1210
54. Patel R, Chang T, Greysen SR, Chopra V. Social media use in chronic disease: a systematic review and novel taxonomy. *Am J Med.* (2015) 128:1335–50. doi: 10.1016/j.amjmed.2015.06.015
55. Leonardi M, Horne AW, Vincent K, Sinclair J, Sherman KA, Ciccia D, et al. Self-management strategies to consider to combat endometriosis symptoms during the COVID-19 pandemic. *Human Reprod Open.* (2020) 2020:hoaa028. doi: 10.1093/hropen/hoaa028
56. Hadjistavropoulos T, Craig KD, Duck S, Cano A, Goubert L, Jackson PL, et al. A biopsychosocial formulation of pain communication. *Psychol Bull.* (2002) 137:910–39. doi: 10.1037/a0023876
57. Scarry E. *The Body in Pain: The Making and Unmaking of the World*. New York: Oxford UP (1985).
58. Käll LF. *Dimensions of Pain: Humanities and Social Science Perspectives*. London: Routledge (2012).
59. Gonzalez-Polledo E. Chronic media worlds: social media and the problem of pain communication on tumblr. *Social Media + Society.* (2016) 2:2056305116628887. doi: 10.1177/2056305116628887
60. Craig KD. Social communication model of pain. *Pain.* (2015) 156:1198–9. doi: 10.1097/j.pain.0000000000000185
61. Kirmayer LJ. Cultural competence and evidence-based practice in mental health: epistemic communities and the politics of pluralism. *Soc Sci Med.* (2012) 75:249–56. doi: 10.1016/j.socscimed.2012.03.018
62. Krebs EE, Carey TS, Weinberger M. Accuracy of the pain numeric rating scale as a screening test in primary care. *J Gen Intern Med.* (2007) 22:1453–8. doi: 10.1007/s11606-007-0321-2
63. Bullo S, Weckesser A. Addressing challenges in endometriosis pain communication between patients and doctors: the role of language. *Front Global Womens Health.* (2021) 2:88. doi: 10.3389/fgwh.2021.764693
64. De Ruddere L, Craig K. Understanding stigma and chronic pain: a state-of-the-art review. *Pain.* (2016) 157:1607–10. doi: 10.1097/j.pain.0000000000000512
65. Kleinman A. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Ann Arbor: The University of Michigan Press (1988).
66. Bullo S, Hearn JH. Parallel worlds and personified pain: a mixed-methods analysis of pain metaphor use by women with endometriosis. *Br J Health Psychol.* (2020) 26:e12472. doi: 10.1111/bjhp.12472
67. Dolmage JT. *Disability Rhetoric*. Syracuse: Syracuse UP (2014).

Conflict of Interest: The author declares 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 Pain Research

ORIGINAL RESEARCH
published: 22 June 2022
doi: 10.3389/fpain.2022.903724

Lives Penciled in, the Reality of Chronic Health Conditions and Trauma: Reflexivity, Health, and Shadowed Identities

Richard Bruce Hovey[1]*, *Veeresh Pavate*[1] *and Marie Vigouroux*[1,2]

[1] Faculty of Dental Medicine and Oral Health Sciences, McGill University, Montreal, Quebec, QC, Canada, [2] Department of Pediatric Anesthesia, Edwards Family Interdisciplinary Centre for Complex Pain, Montreal Children's Hospital, Montreal, QC, Canada

When living with chronic health conditions or experiences of trauma our lives can become perpetually penciled in. The use of the penciled-in metaphor means to arrange our time tentatively: a date, an appointment, a meeting, seeing a movie, or attending a class. In our technologically-driven world of electronic calendars where everything is entered electronically, the utility of the pencil and hand-written agendas have all but vanished. However, for the purpose of this article, the pencil provides a metaphoric common ground to learn about the totality of the disruption experienced by living with chronic health conditions and their residual trauma. The pencil is touchable, tangible and as a researcher and a person who lives with challenging health concerns, metaphors help me to create an understanding of the chaos of living a life in pain with cancer. This article is a person-centered account of the process of reflexive coping and self-processing of pain by a pain researcher and educator. This article focuses on the metaphor of penciled-in lives to provide a qualitative account of experiences of pain from chronic health issues and the trauma both physical and emotional it causes. This act of reflexivity becomes a personal examination of life. It reveals to me my beliefs, decisions, and practices before and during my hermeneutic journey and how these may have prejudiced my thinking and behaviors.

Keywords: chronic pain, cancer, thalassemia, posttraumatic stress disorder (PTSD), hermeneutics, metaphors

Edited by:
Mark Henry Pitcher,
National Center for Complementary and Integrative Health (NIH),
United States

Reviewed by:
Peter Pennefather,
gDial Inc, Canada
Matthew Herbert,
University of California, San Diego,
United States

Correspondence:
Richard Bruce Hovey
richard.hovey@mcgill.ca

Specialty section:
This article was submitted to Non-Pharmacological Treatment of Pain,
a section of the journal Frontiers in Pain Research

Received: *24 March 2022*
Accepted: *25 May 2022*
Published: *22 June 2022*

Citation:
Hovey RB, Pavate V and Vigouroux M (2022) Lives Penciled in, the Reality of Chronic Health Conditions and Trauma: Reflexivity, Health, and Shadowed Identities.
Front. Pain Res. 3:903724.
doi: 10.3389/fpain.2022.903724

ENIGMATIC RELATIONSHIP WITH HEALTH

As a person living with chronic pain and cancer, I learned that health resists universal definition because it can only be interpreted, constituted, and reconstituted through specific professional, personal, promotional, educational, cultural, governmental, and communal lenses. The components of health are complex, with multiple assessments and dimensions. For example, I can identify the usual suspects of health such as physical, occupational, spiritual, emotional, intellectual, social, sexual, mental health, and of course aging. However, during various stages of our life, we develop a sensibility (the ability of sense) of knowing when one's health is waning. We might say that we are not feeling right today, something is off; "I feel unwell." This awareness is based on how we feel when compared to how we typically navigate our worlds with anticipated expectations. Similarly, the expression of pain physically varies among people simply because they experience their health differently. When we attempt to diagnose illness, it is done as what is expected, or of concern based on biomedical test results. Therefore, although the possibility to diagnose with accuracy is a powerful resource of modern medicine. It is what saves many people with early detection. Living with pain and cancer means establishing a new self-determined sensibility of what personal health feels like. We still need to establish when our health shifts to illness, just differently (1).

There are challenges implicit in defining personal lived health precisely and adequately because health is an overarching conceptualization inherent within the human experience (2, 3). Health remains irreducible and resistant to the certainty of a purely positivistic objective definition (4–6). Health resides within us as reflective human beings. Nevertheless, this does not negate the value of discipline-specific definitions that provide direction, focus, and professional enculturation for healthcare practitioners, health promoters, and educators.

This metaphoric explication is of particular interest for people living with chronic pain and cancer where a recalibration of homeostasis is required. Since the new way of experiencing life means having a level of pain and uncertainty. The penciled-in metaphor offers a reflection on how pain and cancer have affected my life. This is just as they were as unique people before pain and cancer change my life. The way each person pencils in their life events, erases many, wears away the time of their life faded away helped by the tears that fall to view a shadowy reminder of oneself (7).

Metaphors as a Window Into Understanding

The word metaphor is a figure of speech by which a characteristic of one thing or topic is allocated to another. Greek word *meta* means over and across and *pherin*, to carry or bear. Together the Greek word *metapherin* means to transfer, carry over, change, alter, or use a word in an unusual way. This transfer of meaning is different but approximating it or comparable to help create an understanding of another topic or experience. The metaphor helps to consider that which is similar and that which is different while transferring meaning. In qualitative research, the metaphor becomes a technique to explore complex and sensitive human experiences such that they might become more apparent to the reader. The reader may not have had that experience and so finding a metaphoric common ground adds to the art of understanding at the heart of philosophical hermeneutics. For others who have had a similar experience such as loss and pain, it may help to validate their experiences and help them deepen their reflection on that with which they live (8).

Ricoeur writes, “If we can incorporate the surplus of meaning of metaphors into the domain of semantics, then we will be able to give the theory of verbal signification its greatest possible extension” (9). In other words, the metaphor invites reflection and can become a bridge to extend our understanding of something where words are not readily available to explain or interpret life challenges. The life penciled-in metaphor is my personal reflexivity moving from my internal thinking to being available to others for reflection and interpretation.

The metaphor provided below was adopted as a means to poetically illustrate the often unknown aspects of living with chronic pain, that of loss of choice, exhaustion, anxiety, depression, and trauma.

Reflective Metaphors

When I recall attending school as a much younger person, I remember having several freshly sharpened pencils readied for action on my desk in preparation for class to begin to take notes, doodle, and dream. I especially used them for drafting documents to be inked in or typed out later. I was not seeking pencil perfection. In a precomputerized world, the pencil provided a means to draft-write, draw, create, and offer thoughts with the option to erase and re-write over the old text. Our papers became shadowy imprints of what was written on the page, erased, and then written over, as new ideas toppled old, while there remained the remnants of the past writing, like a fading memory. The use of this metaphor is explicitly chosen to state that when I transitioned from acute to chronic pain, with a subsequent diagnosis of advanced metastasized prostate cancer, everything in my life changed, some quickly, others slowly. Much like the fragility of the act of erasing pencil marks from paper, there is the reflection of erasing my life expectations that take place. Living with chronic pain and cancer, I literately feel worn out, erased, folded, and creased as does the paper one works over and over, becoming exhausted and more fragile. My life as the written page metaphorically shrinks further and further into the shadows of my previous self, unless, beyond recovery; a healing narrative is all that is left (10). The fragility of health and identity become charcoaled and blurred.

The Fragility of Pencils

The lead within the pencil keeps the clarity of presentation through the applied tension and skillful pressure of the sharpened point onto the paper. Too much pressure on the pencil translates into a possible breaking point of the lead and tearing through the paper. As a person living with challenging health conditions, the transition from prepain to a pained life with cancer demanded changes. These changes were not by choice but provoked by the sheer desire to live well and find a new equilibrium and life. Too much stress and pressure from both internal (my sense of self) and external sources (demands of work and society) can disrupt this new sense of acquired equilibrium, sometimes to a breaking point of self, leading to a rupture through the paper. Without healing, when a cure is not possible, each metaphorical sharpening of the pencil shortens it and in a similar way, we eventually are left short of living a meaningful life. If the pain and cancer cannot be disrupted or arrested, we remain confined by our pain (11). “We notice how pain and the suffering it inflicts change in character when they are no longer accompanied by the certainty or the expectation that it can be eliminated” (4). The penciled-in metaphor illustrates that even though life is not always predictable or certain, we still can create possibilities through our choices as an altered sense of security even predictability. Much of this becomes erased and tattered over time while our pain dictates many of our losses and lack of choice.

One of my graduate students, Mr. Veeresh Pavate offers the following reflection about living with Thalassemia, not necessarily only physical pain but the pain of time and treatments.

> My agenda works on a 3-week schedule, and it is always penciled in advance. Being a person with thalassemia, a chronic inherited genetic health condition, I require timely blood transfusions. This allows me to accomplish my personal and my professional goals. As my body does not produce enough healthy red blood cells, it needs external assistance which means I have always led my life on a borrowed timeline. It entails the need for two units of blood transfusion every 3 weeks. This process takes 4–5 h on an outpatient basis at the hospital. Hence, as we keep writing with a pencil lead which not only becomes smaller with usage, the pencil needs to be re-sharpened to extend its life. That is the same feeling I feel every third week as I get tired and it becomes challenging to concentrate on my research work, the penciled-in date in my agenda approaching for my transfusion. After this date, I get the energy to continue on high octane for a couple of weeks and go through the 3-week cycle once again. This sort of hard-etched script is sometimes challenging for others in society to understand. The complex experience of having a chronic health condition and the trauma resulting from it is not easy for society to appreciate. In fact, my observation and life experiences have been that society has a preconceived (or already penciled in) image of people living with chronic health conditions: they cannot have the very same aspirations and ambitions as people with reasonably good health. When one experiences such things in life, one wishes that it was as easy as turning the pencil around to use the eraser to scrub away the experiences one has gone through. It is always a struggle to make others see us as people.

Pain and Cancer Experiences as Reflective Expressions

Every person living with chronic pain knows something of the profound inwardization involved in suffering and the endurance of pain (6). When we humanize our approach to qualitatively researching chronic pain, we carefully and sensitively begin to gain insight and understanding into another person's world with its substantial and oppressive magnitude of pain's effect. The complexity of life changes suddenly, profoundly with its effect on the whole person with its multidimensionality, "dragging us downward toward those dark demons, which our medical colleagues may if unable to find success with chronic pain describe in terms of hypochondria and depression" (4). If we listen carefully to others, we begin to learn how that chronic pain and cancer and the trauma they inflict, change the person's perspective of health (12, 13).

Continuing with the life penciled-in metaphor, one could say that, before living with chronic pain, the person used to pencil in only a few things at any given time, identifying them as uncertain. Life, for the most part, was lived with some certainty; where classes were scheduled, working hours printed out, going out to movies with friends, dinner with family, a next vacation destination, going for a walk, and feeling mostly well. This generalization illustrates the transition from a life with minor to then major disruptions; an existence of isolated pain and suffering to one where there are no longer only occurrences. Pain and cancer are now pervasive and persistent. As described by Ganadmer: "So powerfully does pain cause us to withdraw from all external experience of the world and turn us back upon ourselves" (4). We lose our sense of belonging in our own world and suffer in so many ways (14). It begins with physical pain but stretches perversely into all aspects of life. I am myself penciled into my own life. I ask myself: who am I now and who will I become?

Chronic pain ruthlessly changes a person's life. The intensity, duration, and perception of the pain dictate the degree of life that is lost, unlived, and forgotten. We fade away from who we thought we were, before chronic pain. The things that mattered to us begin to slip away over time with the pain. Jobs, school, friends, and all the other activities that we previously enjoyed without thought or concern now challenge us in ways never preconceived. Even if the pain is controlled over time, the loss of opportunity, personal goals, and a projected future of family and friends may change, fade away, or at best may be re-negotiated and perhaps partially returned (15).

Time Reflections

Researching chronic pain means researching the whole person, qualitatively and quantitatively. The whole person is complex and as such, the term chronic entails the time spent with the illness, expressed in months, years or decades. It refers to chronological or sequential time. To deepen the penciled-in metaphor, we offer a reflection on changing perceptions of time when dealing with chronic illness and its resulting trauma.

Chronos, one of the Greeks' conceptualizations of time, is the time when we engage directly with a structured time and place. It can be linked to the medical world, as primarily a quantitative concept (16–18). When we make an appointment with a medical expert, a counselor, or a physical therapist, for example, we arrive at a prearranged time, have medical tests, hear about diagnosis, discuss continuing or new treatment options, and then leave at the end of the appointment. Chronos is about preciseness, such as the exact dose of medicine, combinations, and our body's response. It is the marked time between medical visits, the time between taking medications and waiting for the effects and the unfortunate side effects, and the time in between finding pain and forgetting about it. These are moments in a time dominated by the promise of medicine, cure, and recovery where one anticipates the eradication of pain.

Regarding healthcare and its help with reducing the pain of the pained person Gadamer writes,

> This is something we know from contemporary medicine with its virtuosic capacity to "eliminate" pain, the source of the pain, the symptom, and sometimes even more than this. By means of its capacity to remove pain in this way modern medicine changed the role and importance within human life of certain illnesses, which can be so quickly dealt with today. One simply takes something for it and then it is gone (4).

Advancing the pencil metaphor, Chronos demands to pinpoint accuracy. The pencil needs to be at its sharpest to ensure that medical appointments are precisely scheduled, medications are accurately measured, with periods and commas not to be confused. For the person living with pain, being at their sharpest is challenging but necessary within Chronos time. But at what cost? Remembering the small pencil sharpeners, the continuous sharpening of the pencil which shortened the pencil each time, leaving an ever-present pile of shavings. This metaphor is transferable because too much of Chronos time for the person living with chronic pain translates into fatigue from being driven to meet expectations of self and others, a gradual sharpening. Regrettably, ending up put in a heap of our own, exhausted and possibly demoralized by the demands of Chronos. I have ended up in this metaphor pile there many times over the last decade while trying to keep up with the expectations dictated by my old life (10).

Kairos can be thought of as the length of time lived in-between Chronos time, which is far more extensive, where days, weeks, months, years, and tears can pass by without relief from our pain. The metaphoric pencil lead is allowed to dull here with wider marks on our paper of life. It eases the tension on the person and provides the time to reflect and create new passageways for life. This time becomes an experience in which there is the possibility of creating new meanings, ways of living, and healing of our souls. We experience time as Kairos, through the qualitative or hermeneutic time. For the person living with chronic pain, that experience is one of living in-between, which is the locus of hermeneutics, medical visits, treatments, and a life penciled in all the while punctuated by Chronos. For a more in-depth understanding of hermeneutics, please see the following references (4, 5, 15). Kairos time is where people living with chronic pain spend most of their lives; waiting, wondering, and hoping, while exhausted by the pain and trying to make sense or meaning from their experience. This unfolds while the unbridled Chronos is ticking away our lives. Returning to the pencil metaphor, this can be compared to the in-between: the point where the pencil is no longer sharp enough for Chronos but has much writing potential still left in the lead. This in-between time is where Kairos expands its potential into the creative possibility of writing poetry, prose, journaling, artistic doodling, sketching, or just dreaming of improving one's life. The sharpening of the pencil becomes a necessary annoyance that may disrupt the creative process, but we are still able to fall back into this hermeneutic experience. When a person cannot be cured, we can still help to heal them. Kairos is also where non-medicalized interactions may occur: pain support groups, alternative therapies, socializing within group activities, and perhaps even finding temporary peace. When not focused on a perpetually sharpened pencil, Kairos uses the whole of that lead until it really needs to be sharpened thereby extending the longevity of the pencil and, in other words, humanizing the realities of life for the person even if only for a short time.

Chronos vs. Kairos

The brevity of the healthcare encounter favors Chronos over Kairos. For example, take the Likert Scale to help assess pain. Each number from Chronos represents a perceived level of pain experienced by the person. However, it becomes obvious that a number only represents a minimalistic representation of the experience of health. The number from these scales can be thought of as a dam holding back the lived experiences of that person. Behind the number, the ever-increasing levels of water represent how all the dimensions of health are interwoven and affecting the whole person now. When I recall my transition from acute to chronic pain, the Likert Scale seemed to make more sense as I could recall being relatively pain-free. However, after close to a decade of chronic pain, the scale becomes less effective as a means of expressing my pain. My pain narrative is a much better way to express it. This kind of narrative needs practice, such that the patient and clinician become interpretative partners to cocreate a shared understanding of not only the perceived level of the pain, but what other dimensions of their health are influencing their health experiences. This co-creation can be facilitated by the use of metaphor.

When a person living with chronic pain offers a numeric answer from 1 to 10 out of 10, each Likert scale number (Chronos) is covering up Kairos, the collective manifestation of how all our dimensions of health are influencing our pain. As we move up the Likert scale, the energy to hold life together can become overwhelming. Time experienced in excessive pain cautions healthcare that the worse possible outcome is possible: suicide. The treatment of one health issue creates others as undesirable side effects: the lesser of two health-related outcomes. Treating the narrative beyond the chosen number becomes whole-person care. If a person living with pain can assemble a diverse community of healthcare providers who can help with each dimension of health, then one might find a new sense of wellbeing and life again.

Another of my graduate students, Ms. Marie Vigouroux explains her relationship with time and painful trauma.

> Somewhere along the line of living trauma and getting diagnosed with posttraumatic stress disorder, my relationship with time shifted greatly. I spent most days consciously and unconsciously avoiding situations that could cause more trauma, anxiously waiting for more trauma to happen. I put aside my big life plans, only letting life happen to me instead of actively taking part in creating the life I wanted for myself. I lived almost exclusively in Chronos, constantly anchoring myself to sharply written events in my agenda, unable to spend and invest time on my own healing. From an onlooker's perspective, I was functional: I held down a job, I maintained relationships, I cared for my pets. It is only when healthcare workers began interesting themselves in my experience of the time in-between that it became apparent to them that I had been living with posttraumatic stress.

Although my life remains still penciled in and tentatively lived, as the pandemic continues into 2022, we are left with the work of finding joy in life. This current article does not explore pain during a pandemic as it appears in other journal articles, but rather acknowledges pain as it manifests in many ways for many people.

We Cannot Overstep Our Own Shadow and Colored Pencils

Moving our thinking from the dullness of the charcoal pencil to colored pencils metaphorically offers people hope of exploring new and brighter options for their lives. A word of caution is that regardless as we explore time, it passes, and we get older with the disabling effects that are somewhat inevitable. The experience of pain in an aging body to me means not waiting until the pain is better, but learning to live it. Gadamer explains:

> An awareness of time—this is something momentous. For it does not signify merely an increase of knowledge, in the power of anticipation, but involves what is in fact a fundamentally different status altogether. It means the ability to forgo the gratification of the most immediate goal in favor of a long-term fixed purpose (4).

This means to keep seeking out new and different ways to experience the world with a fresh perspective, using new paper and colored pencils with which to re-story ourselves (19, 20). Remember: we cannot overstep our shadows because we always are reflectively everything that we are. Reflexivity reminds us to confront ourselves and our understanding of our life circumstances. This is a lifelong process that ebbs and flows, and we as humans are inherently reflective beings. A constant renewal becomes possible; who we were, who are, and who we can become with colored pencils to narrate a new self, coloring outside the lines means exploring new and meaningful life possibilities (21–23). Perhaps coloring outside of the metaphorical lines of our lives will mean something different to everyone; this is where its potential exists. The only thing I can be certain of is that my pain will be there with me as I continue as a work in progress.

CONCLUSION

The intention of the authors in writing this manuscript was to make the experience of chronic illness accessible to those researchers and clinicians who may never have experienced it. By hermeneutically exploring this experience through the penciled-in metaphor, the authors hope that people who have never experienced chronic illness will be able to better understand it. Humanizing the experience of chronic illness is necessary for its scholarship, and a provides a foundation upon which researchers can produce patient-centered research, and clinicians can provide patient-centered care.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

This study was reviewed and approved by the Institutional Review Board of McGill University. Written informed consent was obtained from all participants for their participation in this study.

AUTHOR CONTRIBUTIONS

RH conceptualized this manuscript. All authors contributed to the drafting and editing of the manuscript.

FUNDING

The authors wish to acknowledge the financial support of the Quebec Pain Research Network (QPRN) for the publication of this article.

REFERENCES

1. Khalili-Mahani N, Holowka E, Woods S, Khaled R, Roy M, Lashley M, et al. Play the pain: a digital strategy for play-oriented research and action. *Front Psychiatry*. (2021) 12:746477. doi: 10.3389/fpsyt.2021.746477
2. Pavate V. Thalassemia: with the "Red" in the bag amid COVID-19 reflections. *J Patient Exp.* (2020) 7:439–41. doi: 10.1177/2374373520951671
3. Vigouroux M. Over the rainbow: navigating the COVID-19 pandemic while living with PTSD. *J Patient Exp.* (2020) 7:293–4. doi: 10.1177/2374373520930456
4. Gadamer HG. *The Enigma of Health: The Art of Healing in a Scientific Age.* Stanford: Stanford University Press (1996).p. 180.
5. Davey N. *Unquiet Understanding: Gadamer's philosophical hermeneutics.* Albany, NY: State University of New York Press (2006) p. 291. (SUNY series in contemporary continental philosophy).
6. Hovey RB. Enriching clinical encounters through qualitative research. *J Patient Exp.* (2022) 9:237437352210775. doi: 10.1177/23743735221077536
7. Hovey R. *Assessment in health promotion: Deconstruction and metaphoric considerations in a nutshell*. In: Gilmore GD, editor. Needs and capacity assessment: Strategies for health education and health promotion. 4th ed. Sudbury, MA: Jones & Bartlett (2012) p. 333–44.
8. Metaphor. *Online Etymology Dictionary.* Available online at: https://www.etymonline.com/word/metaphor#etymonline_v_14710 (accessed on March 1, 2022)
9. Ricœur P. *Interpretation Theory: Discourse and the Surplus of Meaning. 8th print*. Fort Worth: Texas Christian University Press (1976).p. 107.
10. Kearney R. *Strangers, Gods, and Monsters: Interpreting Otherness*. London, New York: Routledge (2003). p. 294.
11. Richard H. Experiencing cancer during the COVID-19 pandemic: reflections and wagers. *ARS Med.* (2021) 16:19.
12. Orr AR. Work hours: a resident's reflection on time. *ARS Med.* (2020) 15:115–9.
13. Hovey RB, Amir N. The hermeneutics of suffering: researching trauma. *Int J Pers Centered Med.* (2013) 3:160–9. doi: 10.5750/ijpcm.v3i2.395
14. Hovey R, Pavate V, Vigouroux M, Amja K. A reconceptualization of the negative self-stereotyping of the patient-partner to the introduction of the patient perspective consultant. *Perm J.* (2020) 24. doi: 10.7812/TPP/20.006
15. Amja K, Vigouroux M, Pagé MG, Hovey RB. The experiences of people living with chronic pain during a pandemic: "crumbling dreams with uncertain futures". *Qual Health Res.* (2021) 17:104973232110148. doi: 10.1177/10497323211014858

16. Makridakis MK. *Creating Time: Using Creativity to Reinvent the Clock and Reclaim Your Life*. Novato, Calif: New World Library (2012). p. 267.
17. Smith JE, The Hegeler Institute. Time, times, and the “right time”, Chronos and Kairos. Monist. (1969) 53:1–13. doi: 10.5840/monist196953115
18. Hovey RB, Khayat VC, Feig E. Listening to and letting pain speak: poetic reflections. *Br J Pain.* (2018) 12:95–103. doi: 10.1177/2049463717741146
19. Hovey RB. The gift of pain with transformative possibilities. *Patient Exp J.* (2018) 5:11–4. doi: 10.35680/2372-0247.1248
20. Szwimer R, Widjaja M, Ingelmo P, Hovey RB, A phenomenological exploration of the personal implications of female adolescents living with chronic pain. *J Pediatr Health Care.* (2020) 34:470–7. doi: 10.1016/j.pedhc.2020.05.004
21. LaChapelle DL, Lavoie S, Boudreau A. The meaning and process of pain acceptance. perceptions of women living with arthritis and fibromyalgia. *Pain Res Manag.* (2008) 13:201–10. doi: 10.1155/2008/258542
22. Dahl J, Lundgren T. *Living Beyond Your Pain: Using Acceptance and Commitment Therapy To Ease Chronic Pain*. Oakland, CA: New Harbinger Publications (2006). p. 169.
23. Gardner T, Refshauge K, McAuley J, Hübscher M, Goodall S, Smith L. Goal setting practice in chronic low back pain. What is current practice and is it affected by beliefs and attitudes? *Physiother Theory Pract*. (2018) 34:795–805. doi: 10.1080/09593985.2018.1425785

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 Pain Research

ORIGINAL RESEARCH
published: 06 July 2022
doi: 10.3389/fpain.2022.926584

Development of a Mixed Hypnosis and Music Intervention Program for the Management of Pain, Anxiety, and Wellbeing in End-of-Life Palliative Care

Josiane Bissonnette[1,2], Stephica Pierre[3], Anh Thu Julia Duong[4], Anne-Marie Pinard[5,6], Pierre Rainville[7,8] and David Ogez[1,3,9]*

[1] Département d'anesthésiologie et de Médecine de la douleur, Université de Montréal, Montréal, QC, Canada, [2] Faculté de Musique, Université Laval, Laval, QC, Canada, [3] Département de psychologie, Université du Québec à Montréal, Montréal, QC, Canada, [4] Department of Medicine, McGill University, Montréal, QC, Canada, [5] Département d'anesthésiologie et de soins intensifs, Université Laval, Laval, QC, Canada, [6] Centre intégré de recherche en réadaptation et intégration sociale (CIRRIS), CIUSSS de la Capitale-Nationale, Québec, QC, Canada, [7] Département de stomatologie, Université de Montréal, Montréal, QC, Canada, [8] Centre de Recherche, Institut universitaire de gériatrie de Montréal (CRIUGM), Montréal, QC, Canada, [9] Centre de Recherche, Hôpital Maisonneuve-Rosemont (CR-HMR), Montréal, QC, Canada

Background: The palliative care people present needs that can be partially met by complementary intervention. Approaches based on the use of hypnosis and music are increasingly being studied and have shown potential benefits on pain, anxiety, and wellbeing for many populations including those in palliative care.

Objective: This study aims to present the initial process of creating and refining a hypnosis and music intervention program intended for persons in palliative care, with a panel of experts of diverse relevant backgrounds. It also aims to evaluate its feasibility, preliminary acceptability, and content.

Methods: To achieve the objectives, we followed ORBIT recommendations for the development and redesign of behavioral interventions (phase I a-b). Based on a meta-analysis, reference interventions were identified and then adapted to the target population. Twenty-two experts from different backgrounds were consulted to obtain their evaluation on the acceptability, feasibility, and content of the interventions.

Result: The various components of the program were deemed appropriate or very appropriate by over 80% of the experts. However, possible risks were raised related to some uncertainty about the reactions of individuals to the intervention. Several experts (32%) indicated potential adverse effects consisting of negative emotional experiences during the sessions. Modifications were proposed specifically to reduce or mitigate this risk. Over 90% of the experts considered that the revised program provides a safer and more appropriate intervention for palliative care persons.

Conclusion: A mixed intervention program with hypnosis and music has been developed and attained a high level of consensus by the experts. The proposed intervention is ready to be assessed for clinical efficacy in a pilot study (ORBIT Phase II).

Keywords: pain, anxiety, hypnosis, music, complementary intervention, intervention development, wellbeing, palliative care

Edited by:
Najmeh Khalili-Mahani,
Montreal Neurological Institute, Canada

Reviewed by:
Dominik Mischkowski,
Ohio University, United States
Maral Tajerian,
Queens College (CUNY), United States
Guylaine Vaillancourt,
Concordia University, Canada

****Correspondence:***
Josiane Bissonnette
josiane.bissonnette.1@ulaval.ca

Specialty section:
This article was submitted to Non-Pharmacological Treatment of Pain, a section of the journal Frontiers in Pain Research

Received: *22 April 2022*
Accepted: *15 June 2022*
Published: *06 July 2022*

Citation:
Bissonnette J, Pierre S, Duong ATJ, Pinard A-M, Rainville P and Ogez D (2022) Development of a Mixed Hypnosis and Music Intervention Program for the Management of Pain, Anxiety, and Wellbeing in End-of-Life Palliative Care. Front. Pain Res. 3:926584. doi: 10.3389/fpain.2022.926584

INTRODUCTION

The quality of life of patients in end-of-life palliative care is a fundamental issue for them and their families. It is at the heart of the comfort care provided at this stage of life (1). Fifty to seventy percent of cancer patients in England wish to die at home (2). Their choice to live these last moments in their residence meets an important need. However, this approach is demanding and refers to issues that people in palliative home care face on a daily basis. Palliative care mobile teams may be confronted with patient anxiety, pain and suffering as well as the presence of medication-related side effects (1, 3, 4). Other organizational challenges refer to difficulties in accessing resources and services at all times of the day (5).

To address the challenges related to the quality of end-of-life care, there is a variety of complementary non-pharmacological interventions (6). A complementary approach refers to "a non-mainstream approach used together with conventional medicine" (7). Among these proposals, interventions based on music and hypnosis are relevant.

Music intervention is an umbrella term referring to an intervention using music. Music medicine intervention is defined as "listening to pre-recorded music, offered by medical staff" (8). Music medicine differs from music therapy in that it does not focus on the therapeutic relationship between a provider and a patient (9). Several disciplines, including music therapy, community music, music education, daily use of music, and music medicine, may involve interrelationships between music, health, and wellbeing (10). The musical intervention developed here is part of the conceptual framework of music medicine and belongs to the category of complementary approaches, contrary to music therapy which is considered as a discipline. The musical approach we chose is based on previous studies demonstrating the superiority of self-selected or preferred music over standard selected music in improving pain and anxiety outcomes in a variety of settings (11–14). It also takes into consideration musical features to better accompany pre-recorded text (15).

Hypnotherapy is defined by The American Psychological Association Executive Committee, Division 30, as "the use of hypnosis in the treatment of a medical or psychological disorder or concern" and hypnosis as "a state of consciousness involving focused attention and reduced peripheral awareness characterized by an enhanced capacity for response to suggestion" (16). Music and hypnosis present little risk of side effects and can be self-administered at different times of the day and at different stages of the disease. They enhance the quality of life of different populations, acting on pain, anxiety, and wellbeing (8, 17–24).

A meta-analysis on hypnosis and music in a palliative care context observed a significant decrease in pain with an effect size of $d = -0.42$, $p = 0.003$ for randomized controlled trial studies ($k = 4$) (25). Analyses of the results of pre-post changes in hypnosis ($k = 3$), preferred music ($k = 3$), and music/hypnosis ($k = 2$) report an improvement in pain, anxiety, and wellbeing. Their acceptability and feasibility achieved a high level of satisfaction. These positive results should be interpreted with caution given the limited number of available studies testing music and hypnosis interventions developed with a rigorous protocol for people in palliative care. This justifies further development and testing of such interventions in various settings.

The Obesity-Related Behavioral Intervention Trials (ORBIT) model proposes four phases to develop a rigorous behavioral intervention program: design (phase Ia: define; phase Ib: refine); preliminary tests (phase II); test effectiveness (phase III); overall effectiveness (phase IV) (26).

The purpose of this study was to complete the design of a mixed hypnosis and music intervention program (ORBIT Phases Ia and Ib). Specifically, it aimed to assess the feasibility, preliminary acceptability, and content of the program for home-based palliative care patients, and to gather expert recommendations for improving the program for pilot testing.

METHODS

Development and Design of the First Version of the Mixed Intervention Program in Hypnosis and Music (ORBIT-Phase Ia)

The first stage of this project was to carry out the ORBIT-Phase Ia. It consists in defining the intervention program from the data of the literature and in developing the first version of a program.

Intervention Milestones

To establish the milestones of the intervention, we conducted a meta-analysis (25), we consulted papers on the effect of specific musical components and clinical reference literature on hypnosis.

We analyzed the strengths and weaknesses of selected interventions and identified flagship ones by assessing their feasibility and effect size. We retained three studies (20, 21, 23). Coelho and Gutgsell's interventions included, respectively, one and two intervention sessions; they had good feasibility and fidelity, and effect sizes for pain reduction are large ($d = -1.58$ and $d = -0.76$). Each session ranged in length from 13 to 20 min, with a high recruitment and low attrition rates. Both contain musical and hypnotic components. Coelho's intervention was accompanied by "relaxing music" and included an introduction, exercises of breathing and muscle relaxation, images of a comfortable place, and suggestions for wellbeing. This intervention was built according to the recommendations of the UK Medical Research Council (27). Gutgsell's intervention included preparation for the intervention, autogenic relaxation (breathing, relaxation), music at the same time as the patient explored a safe place, and a conclusion. The musical part contained various slow soft pieces and included improvisation in G myxolydian. Peng's music intervention consisted, first, of identifying the patient's musical preferences and, second, of playing the selected preferences. The acceptability and effect sizes of this intervention on pain ($d = -3.81$, $p < 0.001$) and anxiety ($d = -3.31$, $p < 0.001$) were very large (25).

To identify preferred musical characteristics in background music, we found a study that evaluated different musical components of musical frames accompanying pre-recorded spoken text. The results reported that musical accompaniments with a high degree of harmonic and melodic simplicity enabled a greater state of mindful state to be achieved during guided meditation with music (15).

To determine the content of the suggestions and metaphors, we consulted a clinical manual, frequently cited in scientific articles (28), as well as a script written and used in clinical practice by one of the authors (HYlaDO©, DO, psychologist and hypnotherapist)[1].

Intervention Development and Description

Based on the results of a meta-analysis (25), based on a clinical script (28)[1], and on studies on musical components (11–15), we developed the first version of a mixed intervention program that integrates hypnosis and music. In keeping with the principles of pragmatic studies and to foster respect for the individuality of patients according to the principles of person-centered care (29, 30), we offer three choices of interventions, which they can select according to their preferences: Hypnosis (H), Music (M), and Hypnosis with Music (HM). Inspired by Coelho et al.'s (20) and Gutgsell et al.'s (21) interventions, we determined that each intervention would consist of two sessions ranging from 15 to 30 min in length.

During the intervention setup, a health care provider is responsible for preparing the patient to receive the intervention in the best environmental and physical conditions possible. He/she may suggest taking a comfortable position, dim the lights, close or open the curtains, create a pleasant atmosphere, and try to reduce surrounding noise as much as possible. Then, he/she ensures that the patient is comfortable listening to the pre-recorded session.

All three interventions follow the same structure, with some variations (see **Table 1**). Intervention setup, introduction, induction, deepening, and emergence are similar for all the interventions. The main distinction between them (H, M and HM) lies in the transformation section. Instead of listening to metaphors, participants who chose an intervention with music (M or HM), listen to a piece of music that they enjoy. Background music also accompanies the music interventions.

The introduction presents the sequence of the session. The induction first involves the direction of the patient's attention on a fixed point, then for a moment, directs the attention toward respiration, "As you focus, you begin to direct your attention to your breathing, inhale and exhale at your own pace…". This is followed by suggestions of relaxation of the body "(…) as if the relaxation, in fact, goes down from the face to the lower body, a bit like a wave of relaxation (…) and maybe you can feel the heaviness of the body as well (…)." This section continues toward a 10-0 count where the patient is invited to deepen his/her state of wellbeing, and physical and psychological relaxation. In the interventions containing hypnosis (H, HM), patients are invited to experience and live a moment of wellbeing in a pleasant place.

The hypnosis intervention without music then narrates metaphors that are not present in the other two interventions. The "horse metaphor" tells the story of a child who rides a horse to his grandfather's house. One day, he gets completely lost and leaves the reins of his horse to return home. In this metaphor, it is suggested to trust one's body as the child trusts the horse. The metaphor of the island tells of a person's journey through different places to get to an island. He can choose a fast, but more laborious path or a slower path, and take his time. For its part, the reflection section of the second hypnosis session is designed to describe a moment when the individual looks at a reflection in the water and then realizes that it is their own. Finally, the "positive hand metaphor" consists of putting comfort, beautiful moments of his life, wellbeing, and a balm in a hand chosen by the patient. This positive hand is then placed on a less comfortable area of the patient and the feeling of wellbeing is transferred to the uncomfortable area and to the whole body.

The metaphors/techniques (safe place, positive hand, pain modulation) were selected from textbooks on clinical hypnosis according to the purpose of this program (to decrease pain, anxiety and improve wellbeing) (28). Other metaphors (horse and reflection) were defined by the hypnotherapist authors (JB, DO) for this project, taking into account the recommendations of hypnosis manuals (28)[1].

The two interventions with music (M and HM) involved a selection of preferred music by the patient and was inspired by Peng's study (23). The interventions with music also incorporate a soft musical background. Taking into consideration the results of Dvorak's study and some musical elements of Coelho's and Gutgsell's interventions, we created a musical framework in myxolydian with a simple melodic structure, taking care not to overload the listener (15, 20, 21). The tempo was undefined and very slow (fewer than 60 beats per minute), and the harmonic changes were relatively infrequent.

The recording of the text and music of each session was done by the first author (JB) and served as a prototype for the evaluation process. An intervention manual was created and includes the procedure to follow by health care providers for implementing the intervention. It also included the verbatim of each intervention session.

Evaluation Process of the Intervention Program (ORBIT Phase 1b)/Objective

Phase 1b involves evaluating the first version of the intervention described above and making the appropriate modifications to ensure acceptability, feasibility, and content validity from a diversity of perspectives.

Evaluators/Experts

We invited a group of experts from Quebec, also identified here as "evaluators," to critically review the first version of the intervention program. Experts are defined as "someone who possessed the relevant knowledge and experience and whose opinions are respected by fellow workers in the field" (31). To ensure a portrait of all the parties involved, we opted for a stratified voluntary sampling panel (32). The team of evaluators was composed of 22 individuals (questionnaire 1) and 20 individuals (questionnaire 2). It was composed of health service managers, hypnotherapists, nurses, physicians, music therapists, beneficiary attendant, family caregivers, social workers, speech

---

[1] Ogez D, Aubin M. *Pratiquer l'autohypnose dans la gestion de la douleur chronique. Hypnose et thérapies brèves.*

TABLE 1 | Structure of the MuzHyp© intervention program (version 1.0).

	Interventions				
	Hypnosis (2 sessions)	**Music (2 sessions)**		**Hypnosis and music (2 sessions)**	
Before the intervention (Health caregiver or beneficiary attendant)	Setting up of the intervention	Setting up of the intervention		Setting up of the intervention	
Pre-recorded sessions					
Introduction	Welcome and presentation of the intervention	Welcome and presentation of the intervention		Welcome and presentation of the intervention	
Induction	Respiration Relaxation	Respiration Relaxation	Soft background music in myxolydian	Respiration Relaxation	Soft background in myxolydian
Deepening	Counting	Counting		Counting	
Transformation	Pleasant place Metaphor 1 (horse) (session 1) Metaphor 2 (island) (session 1) Reflection (session 2) Positive hand exercise (session 2)	Music chosen by the patient		Pleasant place Music chosen by the patient	
Post-hypnotic suggestions	Post-hypnotic suggestions	N/A	Soft background in myxolydian	Post-hypnotic suggestions	Soft background in myxolydian
Emergence	Emergence with countdown	Emergence with countdown		Emergence with countdown	

therapist and psychologists. In the results section, participants' verbatim are identified by a code corresponding to them (see **Table 2**). They came from five different regions in the province of Quebec, Canada.

Two experts did not respond to the invitation to answer the second questionnaire. One expert mentioned that he had a busy schedule and did not have time to complete it. The evaluators included various age groups, with a majority (59%) between the ages of 34–49.

Ethics Committee Approval

The research project was approved by the Ethics Committee of the University of Montreal (# 2021-1243) and CISSS-Chaudière-Appalaches (CISSS-CA; # 2022-896). Each expert evaluator signed a consent form to participate in the project. No monetary compensation was provided.

Procedure

A validation process of the intervention protocol was conducted with the evaluators using the principles underlying the Delphi method.

Delphi method is a classical gold-standard approach for systematically collecting and aggregating the judgment of a group of experts on specific issues and problems to obtain a consensus of opinions (33, 34). It uses a series of questionnaires, each containing a summary of the responses and feedback from previous questionnaires. Delphi thereby offers experts the opportunity to modify or refine their responses at each stage. This method has the advantage of preserving the anonymity of the evaluators from each other, reducing potential biases associated with social acceptability, group dynamics and hierarchical status (social, professional or organizational), while allowing every evaluator to react to others' comments in the second iteration of the consultation. Finally, it allows individuals from different backgrounds to participate in the process, regardless of their respective availability.

The objective of the expert consultation was to validate and obtain consensus on (1) the feasibility and acceptability of the program and (2) the content of the intervention program.

Data Collection

The evaluators were asked to read the protocol and to listen to the recordings of the interventions. Considering the scope of the intervention program and to keep as many evaluators as possible by not overloading them, evaluators could choose one or more intervention(s) to evaluate between the following: hypnosis intervention ($n = 19$), music intervention ($n = 13$), and hypnosis and music intervention ($n = 14$). Those who wished to listen to the interventions with music could select the piece of their choice from a list or request a version containing their specific musical preference. Two rounds of questions were conducted to reach a consensus before making any changes to the interventions. The questionnaires were constructed by the first three authors (JB, SP, AD). After obtaining the responses to the first questionnaire, the results were summarized and presented to the experts in the second questionnaire. They were then asked to give their opinion on new suggestions and to re-evaluate their position on some of

TABLE 2 | Profile of evaluators.

Categories	Description of expertise in palliative care	*n* (%)
Gender (*n* = 22)		
Male		4 (18%)
Female		18 (82%)
Age (*n* = 22)		
18–34		3 (14%)
35–49		13 (59%)
50–64		2 (9%)
65 et +		4 (18%)
Region (*n* = 22)		
Québec		6 (27%)
Chaudière-Appalaches		10 (45%)
Laval		1 (5%)
Laurentides		1 (5%)
Mauricie		1 (5%)
Montréal		3 (14%)
Professions/competency[a]		
Health service manager (C1-C3)	Including coordination of at-home services	3
Hypnotherapist (HT1-HT6)	General practice[b]	6
Nurse (N1-N4)	N1-N4 Palliative care practice	5
Physicians (P1-P3)	Palliative care practice (P1-P2); Psychiatrist (P3)	3
Music therapist (MT1-MT2)	Palliative care practice (MT1). General practice (MT2)	2
Beneficiary attendant (BA)	General practice	1
Family caregiver (FC1-FC4)	Family caregiver for a person who has been or is currently in palliative care	4
Social worker (SW1-SW2)	Palliative care practice	2
Speech therapist (ST)	Other specialty	1
Psychologist (Psy1-Psy2)	General practice	2

[a] *Each evaluator may have more than one profession or skill, the percentages are therefore not calculated for this category.*

[b] *The term "general practice" is used to refer to practice that is not directed exclusively toward palliative care.*

TABLE 3 | Steps for conducting the evaluation process.

1. Send out emails through associations, social networks, health service organization, and professional contacts to recruit potential evaluators.
    - Interested evaluators are invited to respond to the announcement and leave their contact information.
2. Contact individually each potential evaluator to introduce the project and describe their role.
3. Send an email containing the intervention protocol and recordings to interested evaluators.
    - Ask the evaluator to get acquainted with the material before taking the next step.
4. Have evaluators complete the first questionnaire on Lime Survey online (link in an email with intervention protocol).
    - Have them sign the consent form.
    - Have them answer questions.
5. Summarize the answers from the first round.
    - Conduct quantitative descriptive analysis (using Excel file and tables).
    - Validate the categories of responses obtained with the QDA miner software.
    - Write the second questionnaire based on the responses obtained (suggestions and non-consensual items).
6. Have the evaluators complete the second questionnaire using Lime Survey.
7. Synthesize the quantitative and qualitative data.

the non-consensual items from the first questionnaire. The steps in the evaluation process are summarized in **Table 3**.

Measures

We first designed a customized questionnaire with a total of 27 questions: 5 questions about socio-demographic information (gender, age range, region, occupation), 8 questions on feasibility and preliminary acceptability of the interventions, 14 questions assessing the three interventions and their components. Each question was rated on an agreement likert scale (strongly agree, somewhat agree, somewhat disagree, strongly disagree, and "don't know"). One question was rated on a yes/no scale. We invited evaluators to provide comments for each question (see **Table 4**).

Based on the results of this first questionnaire, we developed a second questionnaire with 40 questions. Fifteen questions were addressed to all evaluators: six questions focused on the potential negative effects of interventions, two on the interpretation of the text, three on the language used, and four on the modalities of the intervention. Twenty-five questions focused on specific content and were primarily intended for hypnotherapists, although other reviewers could provide input if they wished. Evaluators could add their comments after each section.

Analyses

Questionnaire responses were analyzed quantitatively to assess program acceptability and feasibility. Unanswered and non-applicable ("I did not evaluate this intervention") questions were not counted to calculate response rates. In the literature, there is currently no consensus as to what percentage to use. Some authors interpret a percentage of 80–100% as a strong consensus (35). Based on this range of recommendations, the level of consensus for the first questionnaire was set at 80% agreement (strongly/somewhat agree or strongly/somewhat disagree). As a conservative measure, we considered in the calculations the answers "I don't know," as "strongly/somewhat disagree."

The comments collected from the evaluators were then compiled to extract their opinions. We performed an initial global reading of all answers in the first questionnaire to capture the full diversity of themes covered in the comments. We then divided the content into categories. To ensure that all comments were grouped according to the established themes, a content analysis was performed on these data using the QDA miner lite software (36). Two authors (SP and ATJD) validated the categories and content associated with each category. For the last step, we reread the content of each category several times to extract the overall meaning, before summarizing it. We also

TABLE 4 | Questionnaire 1.

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	I don't know	Blank
Preliminary program feasibility and acceptability						
1. Managing pain, anxiety, and increasing wellbeing in palliative home care patients are issues that warrant non-pharmacological intervention.	18 (82%) 100%	4 (18%)				
2. The intervention will have the desired effect on pain, anxiety, and wellbeing of patients.	8 (36%) 95%	13 (59%)			1 (5%)	
3. In your opinion, patients will be interested in participating in the intervention.	6 (27%) 95%	15 (68%)	1 (5%)			
4. The intervention program will fit well into the daily life of the consumers and will be easy to use.	11 (50%) 100%	11 (50%)				
5. With a short training session, the field workers will have the necessary skills to enable the implementation of the intervention.	14 (64%) 95%	7 (32%)	1 (5%)			
6. There will be good cooperation from staff and family caregivers in implementing the intervention. If no, please indicate the elements that will ensure the cooperation of the staff and caregivers.	9 (41%) 86%	10 (45%)	1 (5%)		2 (9%)	
7.What are the facilitators and barriers to implementing this program? Explain.	Comments only					
	No		Yes			
8.The intervention program may result in negative effects on patients.	15 (68%)		7 (32%)			

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	I don't know	I did not evaluate this intervention	Blank
General evaluation of interventions							
1. The hypnosis intervention is well-constructed and forms a coherent whole.	9 (50%) 94%	8 (44%)	1 (6%)			3	1
2. The music intervention is appropriate and coherent for the patients.	7 (58%) 92%	4 (33%)	1 (8%)			9	1
3. The hypnosis and music intervention as a whole is coherent and appropriate for the patients.	6 (46%) 100%	7 (54%)				8	1
4. Voice rate, timbre, pauses, and other sound parameters are appropriate.	12 (57%) 90%	7 (33%)	1 (5%)		1 (5%)		1
Assessment of intervention components							
1. The intervention's set-up by the on-site provider and its introduction are adequate and will promote the patient's adherence to the intervention.	11 (58%) 95%	7 (37%)			1 (5%)	3	
2. The "introduction," "induction," "safe place" and "deepening" sections are appropriate (vocabulary, content, etc.) and will be appreciated by palliative care patients aged 65 and over.	6 (32%) 84%	10 (53%)	1 (5%)		2 (11%)	3	
3. Metaphor 1 of the horse is adapted to patients (vocabulary, content).	10 (59%) 94%	6 (35%)		1 (6%)		3	2
4. Metaphor of Island is appropriate for consumers (vocabulary, content, etc.).	7 (47%) 87%	6 (40%)		1 (7%)	1 (7%)	4	3
5. Metaphor of "reflection" section of the second-guided imagery session is user-friendly (vocabulary, content).	8 (57%) 100%	6 (43%)				5	3
6. Metaphor of the positive hand technique is user-friendly.	6 (46%) 84%	5 (38%)	1 (8%)		1 (8%)	6	3

(Continued)

TABLE 4 | Continued

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	I don't know	I did not evaluate this intervention	Blank
7. The sections "post-hypnotic suggestion" and "emergence" are appropriate and adapted to the patients.	8 (42%) 63%	4 (21%)	3 (16%)		4 (21%)		3
Music intervention components							
1. Background music detracts from the effect of interventions with music		2 (14%)	4 (29%) 65%	5 (36%)	3 (21%)	5	3
2. Inserting preferred music detracts from the effect of the intervention			5 (33%) 93%	9 (60%)	1 (7%)	4	3
3. Text in the intervention "music" (induction, deepening, emergence, etc.) decreases the effect of the preferred music.		1 (7%)	3 (21%) 88%	8 (57%)	2 (14%)		3

The color blue corresponds to responses in favor of the initial intervention, taking into account the positive or negative wording of the question.

illustrated the content of the category by selecting one or a few comments representative of the opinions expressed.

For the second round, we first examined whether the non-consensual items in the first questionnaire received a sufficient level of agreement. We then analyzed the comments following the same procedure as for the first questionnaire.

RESULTS

Quantitative data with their qualitative content are presented in the following section for each of the questions asked. Results related to the preliminary feasibility and acceptability are presented first, followed by results related to the content of the interventions.

Preliminary Feasibility and Acceptability of the Intervention Program

The evaluators consensually rated the preliminary feasibility and acceptability of the program as adequate. Agreement was over 85% for all items except one concerning the risk that the intervention might cause negative effects among palliative care patients. Particular attention was paid to this aspect.

Relevance of the Program

According to experts, managing pain and anxiety and increasing the wellbeing of people in palliative care justifies the presence of a non-pharmacological intervention program. Indeed, several evaluators commented ($n = 6$) that pharmacological interventions alone are not effective in controlling pain and anxiety in people with palliative care. All physicians commented that polypharmacy issues warranted additional interventions.

Expected Effects of the Program

Almost all evaluators (95%) believed that the program would produce positive effects on pain, anxiety, and wellbeing. The interventions can bring help *"to relieve the body, to relax morally, to take a break to regain strength or to better control certain pains". (C2)* (Alphanumeric codes after the citations refer to the profession-competency of the evaluator, as described in **Table 2**).

Potential Interest of Patients

The evaluators (95%) believe that palliative care patients will be interested in taking part in the intervention. We received several suggestions for increasing patient interest and engagement: taking the time to clearly explain the project and demystify the intervention, clarifying the patients' expectations and reassuring them about their fears, involving the professionals who care for the patient in the process, and helping them with the process and application. Evaluators also reported that providing examples of positive experiences to patients could positively impact their interest in the program. Besides, they mentioned that adherence to the intervention may depend on the way the practitioner and family members present it, and their motivation to improve the care and quality of life of people in palliative care.

> *(. . .) I believe that if the staff adheres to the project, they become facilitators, since they are the ones who will "sell" the project to the patient. If the staff is convinced of the merits of the project, the patient will quickly be convinced. In a vulnerable situation, we quickly defer to the opinion of the person who is helping us. (N3)*

The attitude of staff and caregivers can actually help or hinder interest in the program.

> *In my opinion, the accompanying person must be empathetic, calm, and patient, in order to comfortably accompany people on their journey. (N2)*

However, the patients' condition is a factor that may work in favor or against the realization of the program. In the context of end-of-life, it was mentioned that some persons may change their minds due to a multitude of factors beyond their control. Attention and concentration skills may also be reduced and some patients with severe physical and cognitive impairments may not be able to participate in the interventions. An emergency or intense uncontrolled physical pain could prevent the person from being physically and mentally available for the content of the experience. These imponderables are part of the reality of people at the end of life.

Ease of Implementation of the Program

All evaluators agreed that the intervention program will be well-integrated into the daily lives of patients and that it will be easy to use. They emphasized the facility of implementing the intervention its flexibility, and the fact it could potentially be used independently by patients with no severe physical or cognitive impairments.

The technology aspects were also discussed. One evaluator mentioned that some patients may have hesitations to using technology to listen to interventions. Being forced to use headphones could also interfere with the intervention. As such, it was suggested that a small speaker could be used if necessary. Other evaluators (27%) gave positive comments about the ease and the flexibility in the use of the material. One mentioned that *"the pre-recorded treatment can be easily adapted to the beneficiary's schedule and will facilitate its implementation and the adherence of the palliative care patients" (N2).* Others mentioned "*It requires little equipment and preparation time ++" (BA),* and *"I can see it fitting in very well when patients feel they need a rest and quiet time" (N1).*

Some evaluators (22%) noted that the intervention length was considered too long, while others considered it was adequate. In response to our second questionnaire, experts indicated that the ideal length of the intervention would be 20 min (61% of respondents) and 25 min (72%).

Training

Most evaluators (95%) considered the short training offered to health care providers (nurses, social workers and beneficiary attendants) to be sufficient to facilitate the implementation of the intervention *"The process is quite simple, so it is easy to implement for the health care providers" (SW2).*

Conversely, other evaluators had a different opinion. On the one hand, one evaluator (4%) indicated that this training was not necessary for program implementation. On the other hand, two of them (9%) emphasized the need for more training to be able to respond to patients' hesitations and to develop interpersonal intervention and listening skills to support the potential emotions generated by the music and imagery.

> *How can we ensure that the workers on the site will have the training to accompany the person who expresses the emotions evoked by the music or imagery? (MT1)*

Cooperation of Staff and Caregivers in Implementing the Intervention

Most evaluators (89%) felt that the cooperation of staff and caregivers would be good. Adherence to the intervention, the quality of the caregivers' training (clear explanations, relevance), the support offered, and the time required of the caregivers are aspects that were raised as potentially influencing the cooperation of the staff.

> *The cooperation of the personnel always depends slightly on the time it takes and the adherence of a person in this type of intervention. Time can sometimes work against the professionals. For family caregivers, I believe that it will be easy to support the implementation of the intervention, except for the type of personality that is hesitant or does not believe in the approach. (N2)*

According to another evaluator, the most significant barrier may be overworked staff and their flexibility to change an already established routine. On the administrative side, one evaluator mentioned that strong commitment is important to facilitate the program implementation. They also note that limited financial issues could be a hurdle to program integration by delaying or preventing its completion.

The simplicity of program implementation may act as a facilitator for the program. Indeed, it was considered "*very clear, well described and easy to apply and pleasant to apply with a patient" (P2).* This implies possible benefits for health care providers (e.g., satisfaction) that may reinforce their engagement in the program.

Potential Negative Effects

Evaluators were asked if the intervention program could have negative effects on patients. One third of evaluators (32%) answered in the affirmative. Potential risks mentioned included:

- the pain could be increased when a feeling of heaviness is evoked in the induction part;
- the patient could have difficulty choosing a pleasant place, leading to a feeling of incompetence, a sense of failure or unhappiness;
- the music may evoke strong emotions;
- the images perceived could be different from those suggested which could create distress.

To reduce the risk of negative effects, we addressed these points in the second questionnaire.

Most of the evaluators (65%) agreed, in this second questionnaire, that adding alternative sensations, in addition to "heaviness" (e.g., the body could feel like it was floating), could decrease the risk that there would be an increase in pain associated with the word "heaviness." They also agreed (91%) that asking the patient to choose a pleasant place before the session and adding statements normalizing experiences in which they might not have visual, auditory, or other sensations might lower the risk of the patient experiencing a sense of failure.

To reduce the risk of unmanageable emotions related to listening to music, evaluators recommended that certain precautions be taken when selecting pieces. They suggested asking the patients to consciously choose a piece that generates a positive, pleasant, and wellbeing emotion in them and to make sure that this music does not refer to traumatic memories or too high negative emotional charges. Evaluators also proposed to verifying the musical content (lyrics, harmonic and melodic structure, mode, tempo, emotional content) of the chosen pieces. In the second questionnaire, the majority of evaluators (75%) indicated that these measures would significantly reduce the risk of uncontrollable negative emotions related to the chosen piece occurring during the intervention. Several evaluators (40%), however, expressed doubt that the intense emotions that could be generated by the music could be a negative element for the palliative care patients, as illustrated in the following remarks.

> *I agree that letting the client choose the music can only be helpful. However, I believe that grieving is also experiencing negative emotions at times, and experiencing this anger and sadness is actually helpful for the person. I don't think we should try to protect them from their own emotions, quite the contrary. We must be careful that our own fear of suffering does not taint this intervention. (N-H)*
> *I also believe that the so-called'negative' emotions that may surface are sometimes a necessary part of the process and can help release and reduce anxiety. These "negative" emotions are often more disturbing for those around them than for the person. (BA)*

Finally, one evaluator mentioned the possibility that images perceived by patients may be different from those suggested and that a patient may experience images of their death that could cause distress. This question was addressed and commented on by the evaluators in the second questionnaire:

> *(. . .) if a person is imagining their own death and it's causing them strong emotions, I think it's a good thing to release that. As long as the helper is comfortable with the emotions and just being present. (HT5)*

Despite the different opinions about the risks that music or images can generate strong emotion and distress, 70% of the evaluators agreed that a procedure for managing emotions would significantly decrease the likelihood that significant distress would persist beyond the session. One evaluator suggested that follow-up with an outside provider be offered, if necessary.

In summary, several suggestions were made and evaluated to decrease the risk of negative effects. When applying all the above measures, 90% of the evaluators disagreed that the intervention could have negative effects.

Other Considerations

Two evaluators (caregivers) noted that they fell asleep while listening to the intervention. In the second questionnaire, we asked what the best strategy would be to manage this type of situation. Ninety percent of the evaluators agreed that the time of naps should be checked so that the intervention would not take place at that time.

Evaluation of the Interventions

Program and content evaluations of each of the three interventions (H, M, and HM) showed that they were appropriately conceived and coherent. However, evaluators proposed several points of improvement for each of the components.

Setting Up the Intervention

In the first part of the protocol, we proposed a procedure for the intervener who will be on the site during the intervention sessions (i.e., at the home of the patient). It includes three steps: introduction to the intervention, preparation of the patient, and listening to the intervention. At the end of the intervention, the intervener concludes the session.

This protocol for the implementation of the intervention was evaluated as adequate and favorable to the patient's adherence to the intervention. It was considered *"simple and easy to carry out" (C1)* and the steps *"are well explained and clear" (FC1).*

Hypnosis Intervention

Evaluators positively rated the hypnosis intervention. A nurse hypnotherapist noted, "*Very nice script, very well structured and clear path. Lots of interesting material to experiment with it.*" Another evaluator noted it was *"easy and pleasant to listen to and led to greater relaxation. It is easy to follow the voice and see yourself in peaceful places where there is great well-being." (N1)*

A third nurse, however, indicated that she *"found it difficult not to have music in the hypnosis sessions, it brought me less into a deep relaxation" (N2).*

Suggestions related to language were offered. A speech therapist evaluator indicated that hypnosis interventions could be cognitively demanding for people in palliative care because of the number of verbal utterances. This person suggested limiting the number of utterances and encouraging simple sentences and silences. We addressed this point in the second round, and 92% of the evaluators agreed with his suggestion.

At last, more than 80% of evaluators rated all but one section of the script as appropriate for palliative care patients. The emergence section received <80% agreement. This was carefully considered. Comments to improve the content of interventions were given as detailed below.

Introduction

The introduction proposed that *"curiosity and openness allow you to discover new things, to be fascinated by what is going on, to keep a certain sparkle about life."* An evaluator suggested avoiding the term "sparkle about life," as well as the term "deep joy," *"which might bring a mixed or complex feeling" (P3).* Evaluators (73%) agreed with removing this phrase.

Induction and Deepening

In the induction phase, it was indicated to look at a fixed point without closing the eyes. Four evaluators (two family caregivers, a social worker and a nurse) indicated that this sentence generated a feeling of frustration in them. Not being able to keep their eyes open made them doubt their ability to fully experience the intervention. *"You wonder, for several minutes, if the experiment will be valid, if you miss this condition" (FC1).* It was therefore suggested that patients should not be asked to keep their eyes open. This suggestion was accepted by 75% of the evaluators in the second round.

In the induction, which contains elements of relaxation and release, a hypnotherapist indicated that it was important *"that the person can give himself/herself the right to be in pain."* It was suggested that "*there is dissociation between two parts of the self, one that has pain and one that does not, and that the first part be allowed to have pain in its own way while another can relax.*" The evaluators (70%) agreed with this sentence.

The original deepening included a 0–10 count. One evaluator indicated that it had too many words and that it was better to use a count to five only. This proposal was accepted by 91% of the evaluators.

Pleasant Place

In the intervention, patients are asked to imagine a pleasant place. The script took care to bring this pleasant place to live by directing attention experiences therapist to the different sensory modalities. It was mentioned that it would be appropriate to introduce different sensory modalities earlier on, to ensure that each individual feels concerned quickly, regardless of which sensory mode they prefer.

> *Using different sensory modes is fine. However, it's important to introduce the different modes at the beginning so that you don't lose too many people along the way (. . .) Doing smaller loops for each sensory mode could be helpful (instead of long loops). (HT4)*

Evaluators, including four hypnotherapists, agreed (64%) with this proposal.

Horse Metaphor

Nearly all evaluators (92%) indicated that the horse metaphor was appropriate for patients (vocabulary, content). In addition, evaluators indicated that the metaphor allowed for letting go and was beautiful.

> *It allows the patient to move towards letting go, to understand that sometimes letting go of the reins and letting go of your body, your intuition, letting go of life allows you to get to the right path. . . to let go of resistance and move towards trust. (N2)*

However, it was noted by a speech therapist and family caregiver, that the metaphor was a bit long and that it could be demanding for a person with cognitive limitations.

Island Metaphor

This metaphor was deemed appropriate for patients (vocabulary, content) by 87% of evaluators. However, the aim of the metaphor was rated as more or less clear.

> *I understand this metaphor less well. Either one chooses the quicker, but the more painful path (and at the same time, the person would be proud of himself), or one takes his time, and it is gentler to get to the Island. (HT5)*

Duration and Density of Interventions

In the first questionnaire, four evaluators, two physicians, and two hypnotherapists, indicated that the duration and density of the hypnosis intervention might be too high.

> *For the first session, it would be good not to put too many elements. Currently, the session is very busy, too dense. I suggest removing the island metaphor or removing the island metaphor and the horse metaphor. Maybe a little long, not much room for silence and pauses. (HT2)*

To reduce the length of a session, 44% agreed with removing the horse metaphor, and 63% agreed with removing the island metaphor.

Reflection

All evaluators indicated that the "reflection" section of the second-guided imagery session is appropriate (vocabulary, content). It was felt that this metaphor allowed the subjects to make sense of what they were experiencing and to see them taming their experience allowed them to *"regain confidence in their ability to be well and to regain the memory of a state of comfort and well-being (. . .) to appreciate themselves" (HT2)*, *"to make sense of what the subject is experiencing" (HT5)*, *"to appropriate peace and* serenity for *themselves" (SW2),* and *"to find them interesting and positive" (FC1).*

It was suggested that some kinesthetic elements be added to the "*reflection*" section so that it could be experienced more deeply.

Positive Hand

The evaluators (84%) rated the positive hand technique as adequate for patients. They indicated that the technique helped calm anxiety, feeling comfort and relief, and taking care of oneself. However, one evaluator noted that "*this technique is a bit longer and the description seems a bit more abstract, possibly more difficult to access for some patients in more concrete thinking (. . .)" (P1).*

To improve the technique, evaluators suggested giving more guidance when the light hand is placed on the part of the body that needs it, to better accompany this effect. It was proposed to connect the two parts, to create even more lightness so that the hand would start to float and then be strongly drawn to the part of the body that needs comfort. These suggestions were accepted by 78% of the evaluators (including 3 hypnotherapists).

Post-hypnotic Suggestions

Most of the evaluators (63%) felt that the post-hypnotic suggestions and emergence section were relevant. This percentage is lower than the 80% established for the first round. Therefore, we looked at this point conscientiously in the second round.

One of the post-hypnotic suggestions was to use a dimmer switch to manage pain levels. One evaluator suggested letting the person choose the part of the body where they wanted to put their switch and 70% agreed with this suggestion.

In the text, it was also written: "*The heart returns to a beat of normalcy*." This sentence alluding to normality was considered tricky by a family caregiver. The evaluators (91%) agreed that it would be better not use terms referring to normality.

In addition, two evaluators objected to the use of the word emergence in the subheadings of the scenario, thinking that patients would read it. This partly explains the low agreement rate in this section.

Music Intervention

Most evaluators (92%) felt that the music intervention was appropriate and consistent. They noted that the music intervention was *"easy to follow" (P2) "focused, relaxing,* *and easy to perform" (P1). "It allows for even more well-being" (SW2)* and is an "*important contribution and helps to relax" (N1).* It "*evokes positive emotions, gives energy, adds ideas" (FC4). "I love what the music brings to the experience!" (HT5).*

One evaluator (N-H), however, raised the possibility of a break between the rhythm of the spoken text and the music. The calm tone and script that leads to deep relaxation juxtapose with the "*jovial, inspiring*" music of pieces that may be chosen.

In the comments, it was suggested to remove the emergent section after the music. "*We don't need feedback after listening to a piece. Therefore, I propose that the intervention ends with the preferred music, without feedback from the voice" (HT4)*; Thirty-nine percent agreed with the proposal and 39% disagreed.

Contribution of Selected Music

More specifically, 93% of the evaluators judged positively the integration of music chosen by the patient him/herself. It allows the patient to be a stakeholder in his or her intervention, which "*will be a way of ensuring the patient's collaboration in this intervention" (FC1).*

Some evaluators also mentioned that hearing a song they knew was reassuring, that it "*brought back good memories" (BA).*

> *I'm all for favorite music, making the overall intervention more acceptable and enjoyable. I think it would help the patient do the procedure again more often. (P1)*

If the person does not have music in mind, it was suggested to *"add music choices that take them into a zone of memories and tenderness (e.g., Brahms's Lullaby, Goodnight) (...) that many grandmothers sang fondly to their children and grandchildren or other tunes from that time" (N1).*

Contribution of Background Music

In both the Music and the Hypnosis/Music interventions, background music was included during the phase of induction, deepening, post-hypnotic suggestions and emergence phases. We asked evaluators to comment on the following sentence: "*Background music detracts from the effect of interventions with music.*" Most of them (65%) disagreed with this sentence. This percentage is smaller than the targeted 80% agreement. Nevertheless, 10 evaluators gave comments, and these comments were positive about the musical background. The background music was rated as *"pleasant, relaxing and soothing" (P2), "It helps to wrap the person in softness" (FC4), "for me the music adds to the effect, the music carries me!" (HT5), "I like the background music. I wouldn't take it off" (P1).*

Hypnosis and Music Intervention

All the evaluators agreed with the following statement: "*The imagery and music intervention as a whole is coherent and appropriate for the patients.*" Background music and hypnosis *"complement each other well I think" (SW2). "I really like the combination of the two" (N-H),* it "*continues the effect of hypnosis. "The imagery and the music form an ensemble of great peace and well-being, that's how I experienced it" (N1).*

On the other hand, 88% of them disagreed with the statement "The text in the music intervention (induction, deepening, emergence, etc.) diminishes the effect of the preferred music," as indicated by this comment:

> *I find that the text allows us to better appreciate the music afterward (P1).*

Finally, given that the hypnosis and music intervention integrate components of the hypnosis intervention and of the music intervention, we consider that the suggestions made for each intervention separately may also apply to the combined intervention.

Interpretation of the Text

The way the text is delivered can influence how it is received. For this reason, we asked some questions related to the interpretation of the text, to make the necessary modifications. Most evaluators (90%) considered adequate the voice rate, timbre, pauses and other sound parameters. Nevertheless, some of them suggested more pauses and slower speech. This opinion was shared by 68% of them regarding the number of pauses and by 42% for the flow of the voice.

DISCUSSION

Program development research emphasizes the importance of the early stages of development prior to evaluation studies (37). As such, we defined the design of the MuzHyp$^{©}$ program and conducted a mixed-method study to refine the Program according to ORBIT-Phase Ia and Ib, respectively (26).

To meet those objectives, we conducted a consultation process that demonstrates the relevance, feasibility, and acceptability of the program and highlights the evaluators' recommendations for improvements.

Design

In accordance with ORBIT-phase 1a, we searched the literature for evidence-based procedures using hypnosis and/or music in the management of pain, anxiety, and wellbeing in palliative care patients. This design definition is an essential phase in the development of new programs, as behavioral science recommends improving existing procedures rather than creating new ones (37). Now that this protocol has been defined based on the identified studies, it was also important to define a program appropriate for a Quebec palliative care patient population. For this reason, in accordance with the ORBIT phase 1b model, we conducted a redesign study (26).

The evaluators consider that the intervention program meets a need in the palliative care population. They believe the implementation of the intervention to be simple, accessible, and requiring limited material, human and time resources. They assessed the content of each intervention as adequate, consistent, and appropriate for palliative care patients.

The expected effects of the interventions are positive and the need for non-pharmacological methods to manage pain, anxiety, and wellbeing was emphasized by the evaluators. These data are consistent with the issues raised about medication in palliative care (4).

According to the evaluators, participant interest is a key factor that may play a role in the effectiveness of interventions. In this regard, they raised several avenues to enhance their interest in participating in the intervention. This interest can also be promoted by the possibility of adapting the program according to the choice of intervention the patient wishes to experience (hypnosis, music, or music with hypnosis), their musical preferences, and the pleasant place they wish to explore. This flexibility respects the principles of person-centered medicine interventions (29). Besides, the ease of implementing a program was found to be a factor that could play a role in the acceptability of the intervention. The evaluators considered both the technology and the intervention program to be simple and flexible. The positive consensus reached on these issues by diverse actors, including caregivers, health care professionals and health service managers coordinating at-home palliative care setting is encouraging.

Redesign

In program development studies, it is essential to validate the design with patients or health professionals (38). In this project, we refined the intervention program considering the quantitative results of the consultation process as well as the comments of 22 evaluators from different professional fields with distinct socio-demographic characteristics.

Preliminary Feasibility and Acceptability

Training Manual and Cooperation of Health Care Providers

The evaluators identified several elements to support the cooperation of health care providers and family caregivers. The intervention should fit easily into their routine. The quality of training and the time required are also among the factors that can influence cooperation and the preliminary feasibility and acceptability of the intervention. Besides, caregivers are often faced with limited time resources and high levels of professional stress (39). It is therefore important not to overburden them with complex and time-consuming training and interventions.

Based on this feedback, we wrote an intervention manual, paying particular attention to the length of the training, the simplicity and the clarity of the intervention program description and the procedures to be followed. Considering the evaluators' recommendations, we also included the expected benefits and some positive testimonials, as well as recommendations to counter any hesitation and address patient concerns. Finally, in the intervention manual, we have added some basic recommendations on how to interact with palliative care patients in this program.

Duration/Density of the Sessions

The length of each session and its density were identified factors that can affect the feasibility of the program. The evaluators were sensitive to the importance of not tiring patients. For this reason, the maximum duration of the intervention was set at 25 min and the content of the interventions was reduced.

To reduce the density of the sessions, we removed the island metaphor. We also trimmed the text by reducing the number of words and favoring simple sentences.

Risk Reduction

The evaluators identified some potential risks of the interventions, including the risk of experiencing negative emotions. However, there was no consensus on this topic. Some of them considered that negative emotions, and images of one's own death are a normal process at this stage of life and that it would even be beneficial to experience them. Therefore, measures to minimize them would not necessarily be the most helpful for these individuals. Other evaluators, however, consider that too much negative emotion can lead to unwarranted distress. Considering that no negative effects have been found in studies of music or hypnosis in palliative care (25), we put some measures in place, while trusting the choices of palliative care people regarding the pleasant place and the musical pieces they wish to experience. As a preventive measure, during a preliminary meeting, we will ask the patients to identify a pleasant place and choose musical pieces that generate in them pleasant, positive emotions in addition to bringing them wellbeing. We will then verify that the pieces are not associated with painful or negative events, by asking them what it reminds them of and by checking if these pieces can generate a negative emotion in them. After the meeting, the first author will verify their content. If certain risks are identified, we will warn the interveners who will be on-site to be attentive to the participant's reactions, and plan additional meetings with qualified staff, to help him/her, if necessary. In order to work on risk reduction upstream, we have integrated some listening techniques to the care worker's manual that will be explained during the training.

Among the potentially negative effects identified, the evaluators noted the possibility of increasing the sensation of pain through the use of the word "heaviness." To reduce this risk, we added to the "heaviness" sensation, alternative sensations to be felt (e.g., lightness, looseness). It has been evaluated that this way of doing would allow the patient to choose the sensation he prefers and thus reduce the risk of increasing the pain.

To prevent participants from falling asleep, we take care not to give the intervention during their usual nap time. To encourage waking up if drowsy, we added three bell sounds at the end of the intervention. In case of falling asleep, it was decided to gently wake up the person 10 min after the end of the intervention.

Content

Following the various suggestions, we have removed the sentences referring to sparkles about life and normality. We also removed the sentence mentioning that patients should not close their eyes while staring at the dot. This was done to avoid showing doubt about their ability to experience the sessions properly.

Considering the probability that pain may persist despite the induction of a state of relaxation, we have added a sentence indicating that it is possible to feel less pleasant sensations while other areas of the body relax at their own pace. Then, to deepen the state of relaxation and letting go, we counted down to 5, instead of 10.

In response to the various suggestions related to the transformation section, we addressed the different sensory modes more quickly at the beginning of the "pleasant place" section. We slightly reduced the length of the horse metaphor, added kinesthetic elements to the reflection metaphor, and added guidelines to the positive hand metaphor to better accompany the hand as it lands on the body part that needs it. Finally, for the switch metaphor, we leave it up to the patient to place it where they wish.

In the comments, it was suggested that the emergence section be removed after the presentation of the chosen music. Since opinions were divergent on this point, we finally adopted the recommendations of music therapists who advocate keeping the emergence after the musical piece.

Finally, the contribution of background music reached a mixed level of consensus. Considering that all comments were contrary to the quantitative results, we suspect that the negative wording of the question might have misled some respondents. It is also possible to explain this result by the potential preference of some people to listen to the text alone, without musical background.

Internal and External Validity

We believe that the careful process of developing the intervention according to the ORBIT recommendations, the development of a manual to be used in the next phases of experimentation, and the presence of pre-recorded sessions will promote a good level of internal validity and reliability. The development of the study in collaboration with the host community, ensuring that the intervention is feasible and applicable “in the real world” will, in turn, promote the achievement of a certain level of external validity for future studies (ORBIT-Phase II). We think that the balance between external and internal validity in the development of the intervention program is an advantage both for future clinical implementation and for research.

Expected Outcome

This intervention program took care to consider some important issues related to the pain, anxiety, and wellbeing of patients in palliative care. It was inspired by those of Gutgsell et al. (21), Peng et al. (23), and Coelho et al. (40), which revealed positive effect sizes on pain, anxiety, and wellbeing. Given that the baseline interventions have been shown to be effective, we believe that MuzHyp© Program refined in this study also has the potential to achieve the desired effects on the palliative care population.

Limits and Strengths

We noted some limitations to consider in our study. First, a limitation could be the representativeness of the evaluators recruited. They are mostly 35–49 years old, female, and all come from the province of Quebec.

Second, the pre-recorded format of the intervention program can be both a limitation and a strength of the program. Unlike interventions where a therapist is present and can adapt in real time to the patient, the pre-recorded intervention is less flexible in terms of its content and possible variations. We may expect that face-to-face intervention with a therapist could potentially yield more important results and that in clinical terms, in-person interventions are recommended. Nevertheless, in a palliative care context where resources are limited and where individuals may have needs at different times of the day, having an accessible, easy-to-use tool can also contribute to its implementation, and increase member buy-in while complementing other services offered.

Finally, the development of a program, according to validated and well-defined standards as the ORBIT model, makes it possible to offer more targeted interventions. It also makes it possible to respect the time and material resources of both the receiving environments and the palliative care patients.

CONCLUSION

In conclusion, this program was assessed as feasible and acceptable, and its content was found to be adequate. The proposed amendments have contributed to increased feasibility and preliminary acceptability, including reducing the perception of potential adverse effects. We are confident that this standardized process has helped to improve the quality of the content offered. The next step will be to evaluate the feasibility, acceptability, and effectiveness of this program with patients in palliative care at home, in a pilot efficacy study. This research provides essential milestones for the successful development and integration of music and hypnosis as complementary approaches to personalized comfort care delivered at home.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. Those interested in the details of the intervention protocol may contact the first author directly.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee of University of Montreal -CERSE (# 2021-1243) and CISSS-Chaudières-Appalaches (# 2022-896). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JB, PR, and DO designed the protocol and secured funding to conduct the study. JB, SP, AD, and DO were involved in the design of the questionnaires. SP and AD participated in the validation of the categories and their content and A-MP, DO, and JB participated in the recruitment of evaluators. JB conducted the assessment process and the quantitative and qualitative analyses. JB wrote the report with PR and DO and all authors commented on or approved the final version of the manuscript.

FUNDING

This work was supported by Mitacs no. IT25481 in partnership with Recherche-Interventions Cétosia.

ACKNOWLEDGMENTS

We thank all expert evaluators who participated generously to the study and Melissa Leclerc and Stéphanie Roy who helped assemble a team of health professionals involved in palliative care to make this project possible. We would like to thank Dr. Huu Trâm Anh Nguyen for her financial contribution to the publication cost of this paper.

REFERENCES

1. Cohen SR, Mount BM. Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *J Palliat Care*. (1992) 8:40–5. doi: 10.1177/082585979200800310
2. Higginson IJ, Astin P, Imperial SD. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliat Med*. (1998) 12:353–63. doi: 10.1191/026921698672530176
3. Morris JN, Suissa S, Sherwood S, Wright SM, Greer D. Last days: a study of the quality of life of terminally ill cancer patients. *J Chronic Dis*. (1986) 39:47–62. doi: 10.1016/0021-9681(86)90106-2
4. Kallel N, Yangui I, Feki W, Ayedi H, Kammoun S. Place des opiacés dans le traitement de la dyspnée en soins palliatifs. *Méd Palliat*. (2020) 19:114–20. doi: 10.1016/j.medpal.2019.10.003
5. Hébert J, Ouellet N, Lessard L, Babineau L, Veillette A-M, Coutu M. *Conditions favorisant et limitant le maintien à domicile en soins palliatifs et de fin de vie sur le territoire du CISSS de Chaudière-Appalaches*. Québec: CISSS de Chaudière-Appalaches (2017).
6. Mansky PJ, Wallerstedt DB. Complementary medicine in palliative care and cancer symptom management. *Cancer J*. (2006) 12:425–31. doi: 10.1097/00130404-200609000-00011
7. NCCIH. *Complementary, Alternative, or Integrative Health: What's In a Name?* Available online at: https://www.nccih.nih.gov/health/complementary-alternativeor-integrative-health-whats-in-a-name (accessed May 28, 2022).
8. Bradt J, Dileo C, Magill L, Teague A. Music interventions for improving psychological and physical outcomes in cancer patients. *Cochrane Database Syst Rev*. (2016) 8:CD006911. doi: 10.1002/14651858.CD006911.pub3
9. Trondalen G, Bonde LO. Music therapy: models and interventions. In Raymond M, Gunter K, and Mitchell L. editors, *Music Health Wellbeing*. Oxford University Press (2012). pp. 40–62. Available online at: https://oxford-universitypressscholarship-com.acces.bibl.ulaval.ca/view/10.1093/acprof:oso/9780199586974.001.0001/acprof-9780199586974-chapter-004
10. MacDonald RA. Music, health, and well-being: a review. *Int J Qualit Stud Health Wellbeing*. (2013) 8:20635. doi: 10.3402/qhw.v8i0.20635
11. Lu G, Jia R, Liang D, Yu J, Wu Z, Chen C. Effects of music therapy on anxiety: a meta-analysis of randomized controlled trials. *Psychiatry Res*. (2021) 304:114137. doi: 10.1016/j.psychres.2021.114137
12. Mitchell LA, MacDonald RA. An experimental investigation of the effects of preferred and relaxing music listening on pain perception. *J Music Ther*. (2006) 43:295–316. doi: 10.1093/jmt/43.4.295
13. Bradt J, Dileo C, Potvin N. Music for stress and anxiety reduction in coronary heart disease patients. *Cochrane Database Syst Rev*. (2013) 2013:CD006577. doi: 10.1002/14651858.CD006577.pub3
14. Jafari H, Zeydi AE, Khani S, Esmaeili R, Soleimani A. The effects of listening to preferred music on pain intensity after open heart surgery. *Iran J Nurs Midwifery Res*. (2012) 17:1.
15. Dvorak AL, Hernandez-Ruiz E. Comparison of music stimuli to support mindfulness meditation. *Psychol Music*. (2021) 49:498–512. doi: 10.1177/0305735619878497
16. Elkins GR, Barabasz AF, Council JR, Spiegel D. Advancing research and practice: the revised APA Division 30 definition of hypnosis. *Am J Clin Hypnosis*. (2015) 57:378–85. doi: 10.1080/00029157.2015.1011465
17. Adachi T, Fujino H, Nakae A, Mashimo T, Sasaki1 J. A meta-analysis of hypnosis for chronic pain problems: a comparison between hypnosis, standard care, and other psychological interventions. *Int J Clin Exp Hypnosis*. (2014) 62:1–28. doi: 10.1080/00207144.2013.841471
18. Chen PY, Liu YM, Chen ML. The effect of hypnosis on anxiety in patients with cancer: a meta-analysis. *Worldviews Evid Based Nurs*. (2017) 14:223–36. doi: 10.1111/wvn.12215
19. Brugnoli MP, Pesce G, Pasin E, Basile MF, Tamburin S, Polati E. The role of clinical hypnosis and self-hypnosis to relief pain and anxiety in severe chronic diseases in palliative care: a 2-year long-term follow-up of treatment in a nonrandomized clinical trial. *Ann Palliat Med*. (2018) 7:17–31. doi: 10.21037/apm.2017.10.03
20. Coelho A, Parola V, Sandgren A, Fernandes O, Kolcaba K, Apóstolo J. The effects of guided imagery on comfort in palliative care. *J Hospice Palliat Nurs*. (2018) 20:392–9. doi: 10.1097/NJH.0000000000000460
21. Gutgsell KJ, Schluchter M, Margevicius S, Degolia PA, McLaughlin B, Harris M, et al. Music therapy reduces pain in palliative care patients: a randomized controlled trial. *J Pain Sympt Manag*. (2013) 45:822–31. doi: 10.1016/j.jpainsymman.2012.05.008
22. Liossi C, White P. Efficacy of clinical hypnosis in the enhancement of quality of life of terminally ill cancer patients. *Contemp Hypnosis*. (2001) 18:145–60. doi: 10.1002/ch.228
23. Peng CS, Baxter K, Lally KM. Music intervention as a tool in improving patient experience in palliative care. *Am J Hospice Palliat Med*. (2019) 36:45–9. doi: 10.1177/1049909118788643
24. Nakayama H, Kikuta F, Takeda H. A pilot study on effectiveness of music therapy in hospice in Japan. *J Music Ther*. (2009) 46:160–72. doi: 10.1093/jmt/46.2.160
25. Bissonnette J, Dumont E, Pinard A-M, Landry M, Rainville P, Ogez D. Hypnosis and music interventions for anxiety, pain, sleep and well-being in palliative care: systematic review and meta-analysis. *BMJ Support Palliat Care*. (2022) bmjspcare-2022–003551. doi: 10.1136/bmjspcare-2022-003551
26. Czajkowski SM, Powell LH, Adler N, Naar-King S, Reynolds KD, Hunter CM, et al. From ideas to efficacy: the ORBIT model for developing behavioral treatments for chronic diseases. *Health Psychol*. (2015) 34:971–82. doi: 10.1037/hea0000161
27. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. (2008) 337:a1655. doi: 10.1136/bmj.a1655
28. Hammond DC. *Handbook of Hypnotic Suggestions and Metaphors*. WW Norton & Company (1990).
29. Mezzich JE, Kirisci L, Salloum I, Trivedi J, Kar SK, Adams N, et al. Systematic conceptualization of person centered medicine and development and validation of a person-centered care index. *Int J Person Centered Med*. (2016) 6:13–22. doi: 10.5750/ijpcm.v6i4.610
30. Zhao J, Gao S, Wang J, Liu X, Hao Y. Differentiation between two healthcare concepts: person-centered and patient-centered care. *J Nurs*. (2016) 2352:0132. doi: 10.1016/j.ijnss.2016.08.009
31. de Villiers MR, de Villiers PJT, Kent AP. The Delphi technique in health sciences education research. *Med Teach*. (2005) 27:639–43. doi: 10.1080/13611260500069947
32. Patton M. Purposeful sampling. *Qualit Eval Res Methods*. (1990) 2:169–86.
33. Hohmann E, Cote MP, Brand JC. Research pearls: expert consensus based evidence using the delphi method. *Arthroscopy*. (2018) 34:3278–82. doi: 10.1016/j.arthro.2018.10.004
34. McPherson S, Reese C, Wendler MC. Methodology update: delphi studies. *Nurs Res*. (2018) 67:404–10. doi: 10.1097/NNR.0000000000000297
35. Booto Ekionea J-P, Bernard P, Plaisent M. Consensus par la méthode Delphi sur les concepts clés des capacités organisationnelles spécifiques de la gestion des connaissances. *Rech Qualit*. (2022) 29:168–92. doi: 10.7202/1085878ar
36. *Provalis Research, QDA Miner*. Montréal, QC, Canada (2021).
37. Ogez D, Péloquin K, Bertout L, Bourque C-J, Curnier D, Drouin S, et al. Psychosocial intervention programs for parents of children

with cancer: a systematic review and critical comparison of programs' models and development. *J Clin Psychol Med Settings*. (2019) 26:550–74. doi: 10.1007/s10880-019-09612-8

38. Ogez D, Bourque C-J, Péloquin K, Ribeiro R, Bertout L, Curnier D, et al. Definition and improvement of the concept and tools of a psychosocial intervention program for parents in pediatric oncology: a mixed-methods feasibility study conducted with parents and healthcare professionals. *Pilot Feasib Stud*. (2019) 5:20. doi: 10.1186/s40814-019-0407-8
39. Wilkins K. Work stress among health care providers. *Health Rep*. (2007) 18:82–003. Available online at: http://greylit.pbworks.com/f/Work%20Stress%20Among%20Health%20Care%20Providers.pdf
40. Coelho A, Parola V, Fernandes O, Querido A, Apóstolo J. Development of a guided imagery program for patients admitted to palliative care units. *J Nurs Ref*. (2018) 4:23–32. doi: 10.12707/RIV17082

Conflict of Interest: This article was completed as part of a Mitacs funded postdoctoral fellowship in partnership with Recherche-Interventions Cétosia, a company founded by JB. Conflict of interest controls are in place at the business incubator that supervises JB.

The remaining 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.

The handling editor NK-M declared a shared affiliation with the author AD at the time of review.

Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 15 August 2022
DOI 10.3389/fresc.2022.942822

Toward a digital citizen lab for capturing data about alternative ways of self-managing chronic pain: An attitudinal user study

Najmeh Khalili-Mahani[1,2,3,4]*, Sandra Woods[4,5], Eileen Mary Holowka[6], Amber Pahayahay[7] and Mathieu Roy[4,8]

[1]McGill Centre for Integrative Neuroscience, Montreal Neurological Institute, Montreal, QC, Canada, [2]Department of Design and Computation Arts, Faculty of Fine Arts, Concordia University, Montreal, QC, Canada, [3]PERFORM Centre, Concordia University, Montreal, QC, Canada, [4]Quebec Pain Research Network (QPRN), Sherbrooke, QC, Canada, [5]Patient Partner, Montreal, QC, Canada, [6]Department of Communication Studies, Faculty of Arts and Science, Concordia University, Montreal, QC, Canada, [7]School of Public Health and Health Systems, University of Waterloo, Waterloo, ON, Canada, [8]Department of Psychology, Faculty of Science, McGill University, Montreal, QC, Canada

EDITED BY
Susan Magasi,
University of Illinois at Chicago,
United States

REVIEWED BY
Patricia Welch Saleeby,
Bradley University, United States
Rachel Adler,
Northeastern Illinois University,
United States

*CORRESPONDENCE
Najmeh Khalili-Mahani
najmeh.khalilimahani@mcgill.ca

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 13 May 2022
ACCEPTED 13 July 2022
PUBLISHED 15 August 2022

CITATION
Khalili-Mahani N, Woods S, Holowka EM, Pahayahay A and Roy M (2022) Toward a digital citizen lab for capturing data about alternative ways of self-managing chronic pain: An attitudinal user study.
Front. Rehabilit. Sci. 3:942822.
doi: 10.3389/fresc.2022.942822

Background: Myriad psychosocial and cultural factors influence personal ways of coping with chronic pain (CP). Mobile health (mHealth) apps facilitate creation of citizen laboratories outside clinical frameworks. However, issues of safety, privacy and technostress must be addressed. This attitudinal user study aimed to assess whether persons with persistent pain (PwPP) would be open to sharing qualitative and quantitative data about their self-management of CP *via* mHealth platforms.

Methods: In March 2020, we invited PwPPs, their personal or medical caregivers, or those interested in the development of an app for researching alternative ways of self-managing CP to complete an anonymous survey. We formulated an attitudinal survey within the theoretical framework of stress to estimate whether the novelty, unpredictability, and risks of data-sharing *via* mHealth apps concerned users. Descriptive statistics (% Part/Group) were used to interpret the survey, and open comments were reflectively analyzed to identify emerging themes.

Results: Of 202 responses (June 2021), 127 identified as PwPPs (average age 43.86 ± 14.97; 100/127 female), and listed several primary and secondary CP diagnoses. In almost 90% of PwPPs, physical and emotional wellbeing were affected by CP. More than 90% of PwPPs used alternative therapies (acupuncture, homeopathy, massage therapy, etc.). Attitude toward mHealth apps were positive even though nearly half of PwPPs were unfamiliar with them. More than 72% of respondents were *open to using a health-related app as a research tool for data collection in real life situations.* Comprehensive data collection (especially about psychosocial factors) was the most important requirement. More respondents (especially medical professionals) were concerned about health hazards of misinformation communicated *via* health-related information and communication systems (maximum 80%) than about privacy (maximum 40%). Qualitative analyses revealed several promises and impediments to creation of data-sharing platforms for CP.

Conclusions: This study shows a general willingness among PwPPs to become partners in studying alternative pain management. Despite a generally positive attitude toward the concept of sharing complex personal data to advance research, heterogeneity of attitudes shaped by personal experiences must be considered. Our study underlines the need for any digital strategy for CP research to be person-centered and flexible.

KEYWORDS

chronic pain, data sharing, citizen science, attitudinal survey study, non-pharmacological pain treatment, mHealth, mixed-methods research, patient-oriented research

Introduction

Chronic pain (CP), experienced by at least 25% of the population in North America, continues to stymie biomedical models and pharmacological interventions (1, 2). In Canada (with a universal healthcare system), where this study took place, nearly 8 million people live with CP. Aligned with the World Health Organization, Canada recognizes CP as a disease, in and of itself, and diagnoses it as a condition in which "*pain continues for longer than 3 months, with no known cause; after injury has healed; and after the condition has been treated*." Conditions such as fibromyalgia, chronic pelvic pain, chronic musculoskeletal pain, and non-specific lower back pain are considered chronic primary pain, and post-surgical pain, rheumatoid arthritis or pain associated with cancer are considered chronic secondary pain (3).

The Canadian Pain Task Force report: June 2019 (4) emphasized the need for a Strategy for Patient-Oriented Research (SPOR), suggesting that "people living with chronic pain must be equal partners in research." Key action elements included viewing and managing pain as a public health issue with confounding biopsychosocial factors, in need of globally coordinated action; identifying efficient and effective assessment tools to inform correct pathways of care; person-centered and flexible care models reflective of individual needs and experiences; accessible pain education for the public and professionals, to minimize the risks of stigma and implicit biases; and finally, the creation of national data collection methodologies to reliably evaluate different types of interventions (pharmacological, physical, psychological and alternative).

Two years later, this Task Force's March 2021 report (5) called pain a national emergency. As in previous years, it proposed an action plan for equitable and collaborative action at political, medical, and community levels to address the social, psychological, and economic burdens of this debilitating health condition. Adding to the 2019 emphasis on patient-partnership in research, the new strategic research priorities shifted towards technology, in order to *"support research efforts to improve processes, technology and interventions in the area of digital technologies for health including e-health and virtual care."* One aim of accelerating research was said to be implementing a surveillance system to *"explore the potential of big data approaches that incorporate different data types from novel sources."*

Research that we present in this article is part of a larger project to develop a health-related information and communication (ICT) platform aiming to involve PwPPs in studying two important issues: first, the influence of cultural, psychosocial, and environmental context in which one experiences pain; second, a knowledgebase from individuals' personal experiences of coping with CP outside clinical frameworks (6). Throughout this paper, "alternative" refers to any methods that are not within the mainstream medical practice and not covered by standard insurance plans. We have conceptualized this framework as a potential digital citizen laboratory for coping with untreatable persistent pain through creative and self-expressive ways.

Background

A 2016 meta-analytical review of Citizen Science literature identified ecology, geography, and epidemiology as the three fields to benefit from massive data-collection (7). There is growing evidence to suggest that digital citizen laboratories for pain research are also likely to succeed. In a recent scoping review of more than 1200 clinical trials, we found a significant number of digital interventions used to conduct experimental quantitative pain research (8). In *Coping with Illness Digitally*, Stephan Rains illustrates the significance of different types of internet-based communication systems such as weblogs, and social networks in reinforcing connections; soliciting and providing social support; sharing experiences and seeking information; and even improving patient-provider relationships (9). Computerized clinical decision support systems have been long introduced (10), and applied in chronic pain management (11). With access to personal computers and the internet, it has become possible for pain patients to record and report the contextual variations in their daily experiences of pain digitally (12, 13); and to generate data about self-management techniques outside of clinical settings (14). Finally, it is expected that the accumulation of self-tracking data will make digital phenotyping easier (12, 15, 16). Data portals such as *PatientsLikeMe* aim to help individuals *"Find support from real people just like you and start taking charge of your health"*. As of April 2022, this portal enables 850,000 patients to conduct $N = 1$ self-trials (17), by empowering them to *"[...]compare treatments, symptoms & medication side effects. Track & monitor [their] own personal health data in real-time [...]"* while also creating a body of knowledge by exchanging personal experiences about symptoms and medications (18).

Mobile health applications (mHealth apps) have been widely researched and developed to facilitate personal pain management, and communication with healthcare providers. In a 2015 review "*There's an App for That Pain*," Lalloo listed nearly 300 pain apps for personal and research purposes (19) [a count that has reached 508 market-place apps by the end of 2021 (20)]. More recent apps such as *Manage My Pain* include features that help patients track their pain, function, and medication; respond to questionnaires; and make those reports and data available to clinicians who can remotely study clinically relevant trends and discover patterns using advanced analytics (21). While it was shown that *Manage My Pain* was effective in reducing anxiety and pain in the short term, the authors reported a need for improving the conditions to sustain user engagement. In fact, including users in designing mHealth apps for pain is often mentioned as the most important factor to make them useful in clinical practice and research (22).

In the context of the 2019 Task Force priorities, we proposed a Digital Strategy for Play Oriented Research and Action (DiSPORA) (6). In conditions as complex as chronic pain, where clinical interventions have not provided satisfactory relief, those affected by CP may try (*play* with) alternative choices for which sufficient clinical evidence is not available. Therefore, DiSPORA aimed to serve as a digital citizen laboratory to facilitate gathering large-scale qualitative data about self-experimentation and self-reporting of information that *users* deemed to be important as they played with various self-care options (23). This conceptual framework recognizes the need for adopting person-centered approaches to pain management and research (24). Given that alternative therapeutics are not accessible through or recommended by the standard healthcare systems, we aimed to develop a digital citizen lab to report on how one's experiences with non-pharmacological pain management impacts them.

Citizen science can be viewed as participatory action research that aims to democratize (25) and personalize healthcare research (26, 27). This requires participants to contribute knowledge from their lived experiences and contextual actions (28, 29). However, in a digital citizen lab, adding a layer of technology and algorithmic opacity to how data is generated, shared, and interpreted, may challenge the reciprocity and balance of power that is expected from participants. For this reason, user participation and acceptance is vital in the earliest steps of technology development (30).

Aims of the current study

This study aimed to assess whether the idea of an mHealth App to generate data from personal experiences, for advancing qualitative and participatory pain research, might be stressful to potential users. When technologies are first introduced, they cause what Brod (31) coined "technostress." Technostress results from creating functional or emotional overload, ambiguity about its benefits, physical or financial inaccessibility, and potential for invasiveness in one's life. It is plausible that introducing a technology that resembles a "public health surveillance system" for data generation would raise concerns about safety, privacy, and even equitable access to it.

The most obvious technostress (exacerbated by the digitization of healthcare since the onset of the COVID-19 pandemic) would be "surveillance creep;" i.e., when data collected for a specific purpose (e.g., traffic control) is later exploited for another use (e.g., facial recognition) (32). Another common source of technostress is caused by pressuring users to invest time and resources to learn and adopt them into their lives. A recent study in three Swiss psychiatric hospitals indicated that the introduction of digital technologies among healthcare professionals is causing them technostress (33).

The concept of studying pain in a qualitative and 'creative' framework that centers around communicating data on alternative ways of coping with pain might be just as stressful as the new technology itself. There has been a traditional tendency to dismiss alternative medicine as "quack science" (34, 35), despite the fact that the long-term efficacy of many pharmacological treatments for chronic pain is also debated (36–38). This bias seems to be stronger in physicians who are dismissive of the medically unexplained pain of their patients (39, 40). This attitude is gradually changing. According to a World Health Organization report, in 2019, 170 member states had acknowledged using complementary alternative medicine (41). Although the practice has been on the rise in the European and American nations, the adoption is reported to be markedly slower than in other nations.

Our motivation for creating a play-oriented digital citizen lab derives in part from these kinds of cultural and other biases that fail to account for the personal narratives of those who resort to non-pharmacological treatments. Accessibility and empowerment of patients can help overcome technostress and predict effective uptake of such technologies for mental e-health purposes (42). Within our proposed framework, we hope to foster a more democratic and participatory engagement with the psychosocial and cultural complexity of how pain is communicated and cared for. Thus, capturing the attitudes of target users of digital health interventions is an essential first step in addressing concerns about their effectiveness (43, 44).

Theoretical framework

In providing a perspective on the Law of Attrition (45), Eysenbach recommended that researchers develop a scientific framework to explain the reasons why a large proportion of eHealth solutions suffer high rates of drop-outs, discontinuation of use, or non-adoption. The challenge of attrition is also reported in mHealth apps for pain (22, 46, 47).

A suitable ecological and flexible framework for addressing this question is the Lazarus and Folkman's Transactional Theory of Stress and Coping (TTSC), which posits that when individuals are confronted with a novel experience, they recursively evaluate its relevance, beneficence, and risks against their existing resources, and would engage with or react to it based on their perceptual and adaptive strategies (e.g., cognitive or emotional, or avoidance and approach) (48). The Transactional Theory of Stress has been applied to the question of technostress when new digital technologies are introduced into the workplace (49–51) or, conversely, to examine whether ICTs can help alleviate stress (52–54).

Briefly, this model suggests that their primary appraisal (attitudes) towards the benefits or threats of a new challenge will determine whether a user would choose to approach or avoid it when it is first presented. In our case, those who have a strong negative attitude about the new technology are unlikely to participate in its development and testing. But, if there is an interest to consider the potential benefits, those who are ambivalent might try it and go on to develop a new attitude over time as they recursively examine the efforts needed to achieve gains (secondary appraisal). In this appraisal process, benefits are re-evaluated against the actual costs (psychological or material) of adopting the technology into their lives. Novelty, unpredictability, threat to self and sense of control (N.U.T.S) are predictors of stressful responses to new conditions (47, 48), particularly for chronic pain patients (55). If PwPPs do not have control over the use or refusal of a new technology that is introduced into their care, and this increases their uncertainty and threatens their self-care, they will experience 'technostress' (31, 56) and likely discontinue its use. What makes TTSC suitable for health related ICT design studies is its sensitivity to stress (as a psychobiological phenomenon)—an adaptive and dynamic process that is recursively informed by the active learning and decision-making of their users (primary and secondary appraisal) against the resources that they possess (physical, psychological and cognitive state). TTSC provides an empirical framework that accounts for (and allows experimental manipulation of) myriad factors that moderate one's physiological, psychological, and physical interactions with stressors (in our case, a chronic illness) and de-stressors (in our case, a self-research tool intended to empower and inform patients), which can be quantitatively measured (e.g., from stress hormones, electrophysiological brain responses, or autonomic responses). We have elsewhere elaborated on how this theoretical framework can be utilized to develop assistive ICTs (57), and have been testing the model in various studies in the relationship between ICT use and stress relief (58–60).

Methods

Study design

The current study sought to investigate the attitudes of potential stakeholders towards creation of a digital citizen laboratory for chronic pain. Our attitudinal methods aimed to develop an understanding of the overarching needs, beliefs, and general motivations of targeted users. Using simple but broad questions, we solicited opinions of would-be-users on the perceived appeal, quality, and/or usefulness of a design or any of its individual elements (61). As such, we formulated a short survey to capture the potential sources of N.U.T.S in our proposal by evaluating the degree of familiarity and general attitude of targeted stakeholders towards mHealth apps, in general, and personal data-sharing, in particular.

Sampling

With institutional ethics (REB) approval, we invited individuals (patients, caregivers, or healthcare professionals) who were *interested in helping to design an app for studying the creative ways of coping with pain* to join our study. A link to the study website offered explanations about the objective of the app, "*A Citizen's Laboratory for researching non-pharmacological treatments for chronic pain*," and invited participants to join our team efforts:

> *"We all have experienced pain, but our experiences are unique. We have unique ways of coping with pain too. Sometimes medications or physical therapies don't work. Sometimes meditation or cognitive therapies do work. Some of us might play. Some of us might pray. We want our unique ways of coping to be considered in research and care. This will guarantee that our healthcare systems will be inclusive and respectful of our specific needs. To become partners in research will help scientists design more targeted systems for personalized care or cure."*

The first step to join this partnership was an anonymous online survey (SurveyMonkey).

The invitation and link to the survey were sent to members of a mailing list of research participants of Concordia

University's PERFORM Centre, disseminated *via* the social media of researchers (Twitter, Facebook). The same link was shared across both the PwPP and bioethics/healthcare networks of our Patient Partner co-author (pain research groups, chronic pain patient associations, Facebook, Instagram, Twitter, her blog, and in conversations). Paper pamphlets were also distributed throughout the PERFORM Centre's athletic therapy unit. The survey was anonymous. Participants who wished to be involved in the next stage of the design were not identifiable from this survey, which was offered in both English and French (the official languages of Canada).

Survey questions

In general, we were interested in learning about the extent of familiarity of our target users with mHealth applications (Novelty), and their attitudes towards these in terms of projected benefits and risks associated with their use as a data-generation tool (Unpredictability, Threat to self, and Sense of Control).

We did not intend this to be a quantitative psychometric study, rather aimed to conduct a quasi-qualitative opinion survey by asking questions in a colloquial and conversational manner. We avoided jargon, acronyms, and other uncommon terms (such as eHealth, mHealth, Citizen Lab), and provided the flexibility to skip questions, to select more than one option (e.g., for type of pain, or reasons for participation), and allowed variable answer options (such as 'Maybe' or 'I don't know') in order to capture any ambivalence in responses, and to invite additional comments.

The categories of information for which we screened included:

- Reason for interest in the project (I have persistent pain; I am a caregiver to someone with persistent pain; I am a medical professional; I am a digital-health designer and researcher; I am a policy-maker; I am just curious).
- Demographics: age, gender, income, education, employment.
- Types of pain experienced by the PwPP, and the Impact of CP on different aspects of life (mobility, creativity, sociability, emotional wellbeing, hobbies, work, exercise).
- Current methods of coping with pain (medications, various therapies, distractions, activities), and interest in trying new techniques (mindfulness, hypnosis, virtual reality, different art therapies).
- Attitude towards alternative medicine (effectiveness, promise, safety).
- Access to mobile ICTs and usage.
- Attitude towards various forms of ICT (blogs, YouTube, official channels, social networks, apps, etc.) with regards to safety, privacy, and accuracy of health-related information exchange.
- Attitude towards mHealth applications, and their promise – if any—for research.
- Attitude towards data sharing (data types and data-collection system features).

In addition, we solicited comments on the following topics:

- Is there anything that you think would improve a pain-tracking app?
- To what extent do you agree with the following statements about pain evaluation:

- "Mood and anxiety questionnaires annoy me."
- "I can accurately score my pain experience with 1 to 10 numbers."
- "To keep track of psychosocial factors is important in understanding my pain."
- "To keep track of environmental factors like weather or pollution, is important in understanding my pain."
- "I prefer to use humor to describe my pain experience."
- "I prefer to use drama and story-telling to describe my pain experience."
- "I prefer scientific terminology to describe my pain experience."

These questions were developed as a result of feedback received during our two-day public drop-in event for PwPPs, during which we explored some of the challenges of documenting CP experience and creative ways to facilitate communication of pain as a qualitative and quantitative experience (59, 60).

Statistical analysis and reporting

All survey responses are presented as descriptive statistics (counts or percentage of part/group responses, plotted with bar and Likert charts, respectively. We used SPSS V.27 for MAC. Multivariable questions about the ICT repertoire under study are shown as radar plots of the response ratios, to provide a multidimensional overview of between-group and between-system differences in risk assessments.

All comments were reviewed, and if any provided additional information or insight they were included within Results.

Results

Participant characteristics

Of 202 survey responses received by June 2021, 128 identified as female, 32 as male; 0 as other; and 42 did not answer the question of gender. The sample was comprised of

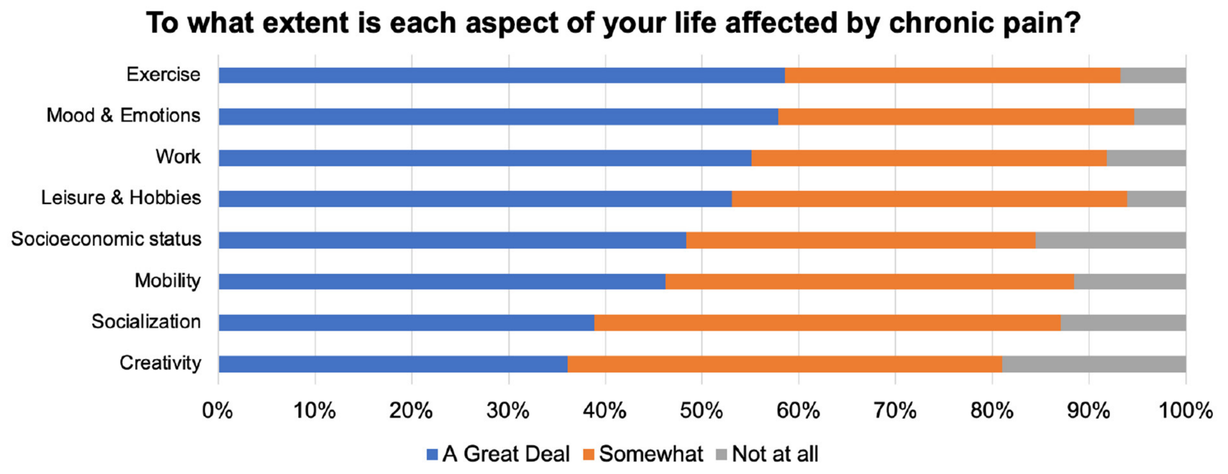


FIGURE 1
Impact of CP on different aspects of life ($n = 127$).

persons with persistent pain (PwPP) (100 female, 23 male, 4 not answered), caregivers (18 female, 4 male), Medical professionals such as nurses, doctors or healthcare workers (17 female, 4 male, 25 not answered) and others who were interested but were not in any of those categories (27 female, 8 male). Fifty respondents had indicted more than one reason for joining the study. For example, 20/46 Medical professionals were also PwPP; or 14/22 caregivers were also PwPP, etc. For this reason, we identified mutually exclusive groups based on first who was a PwPP ($n = 127$); next by who was a Medical professional but not PwPP ($n = 26$); the rest (who were neither Medical professionals nor PwPP) were classified under Other ($n = 49$).

The reported average age of PwPPs (43.86 ± 14.97) was close to the rest (42.11 ± 17.38). Nearly one third of PwPPs earned an income <$25,000 (CAD$). Fewer than 27% of PwPPs worked full-time; 9.8% were unemployed, 13% on disability leave, 10.6% retired, 13% students, and 13% indicated other situations (specified as maternity leave, student while working, retired and still working, self-employed, etc.).

Characteristics of PwPP and their coping strategies

Primary and secondary chronic pain were reported by our respondents. The most prevalent condition was Lower back pain ($n = 72$), followed by Headache ($n = 58$), Arthritis ($n = 35$), Fibromyalgia ($n = 33$), neurogenic pain ($n = 28$); post-trauma ($n = 22$), post-surgical ($n = 20$), unknown ($n = 18$), abdominal ($n = 18$); musculoskeletal ($n = 11$), Cancer ($n = 4$), endometriosis ($n = 3$), and ehlers-danlos syndrome ($n = 1$).

All aspects of life (primarily, exercise and physical activity) were impacted as a result of chronic pain (Figure 1). Consistently, among the various coping strategies that we listed, and those suggested by respondents in their comments, alternative physical therapies such as massage ($n = 47$), acupuncture ($n = 17$), homeopathy ($n = 8$), and chiropractic ($n = 6$) were cumulatively more frequently mentioned.

We listed a number of possible activities that PwPPs might use for pain coping, and asked them to add any that were missing. As can be seen in Figure 2A, various forms of complementary and alternative therapies were mentioned. We asked about attitudes towards several other alternative therapies that may be offered to PwPPs (Figure 2B) and found that in general there was a positive attitude towards trying interventions that were new to the respondents. Figure 2B also reveals that asking questions about a general method (e.g., mindfulness) may not be sufficient to capture nuances of the technique used. Here, it can be seen that although nearly 70% of respondents had experience with mindfulness, it was effective in only half of them.

Attitudes towards alternative medicine

Only 142/202 respondents offered comments on questions about attitudes towards alternative medicine. As Figure 3 illustrates, more than 75% of all three groups agreed that there is a need for more medical testing of alternative medicine to be accepted by doctors. Proportionately, fewer respondents believed it to be dangerous and more than 25% (including medical professionals) agreed that it was worthwhile trying it before seeing a doctors. Interestingly, more than 50% of respondents, especially medical professionals *Agreed* or *Strongly Agreed* that alternative medicine can reduce healthcare costs. We interpret these results as an indication of ambivalence and hope that further research in alternative medicine can

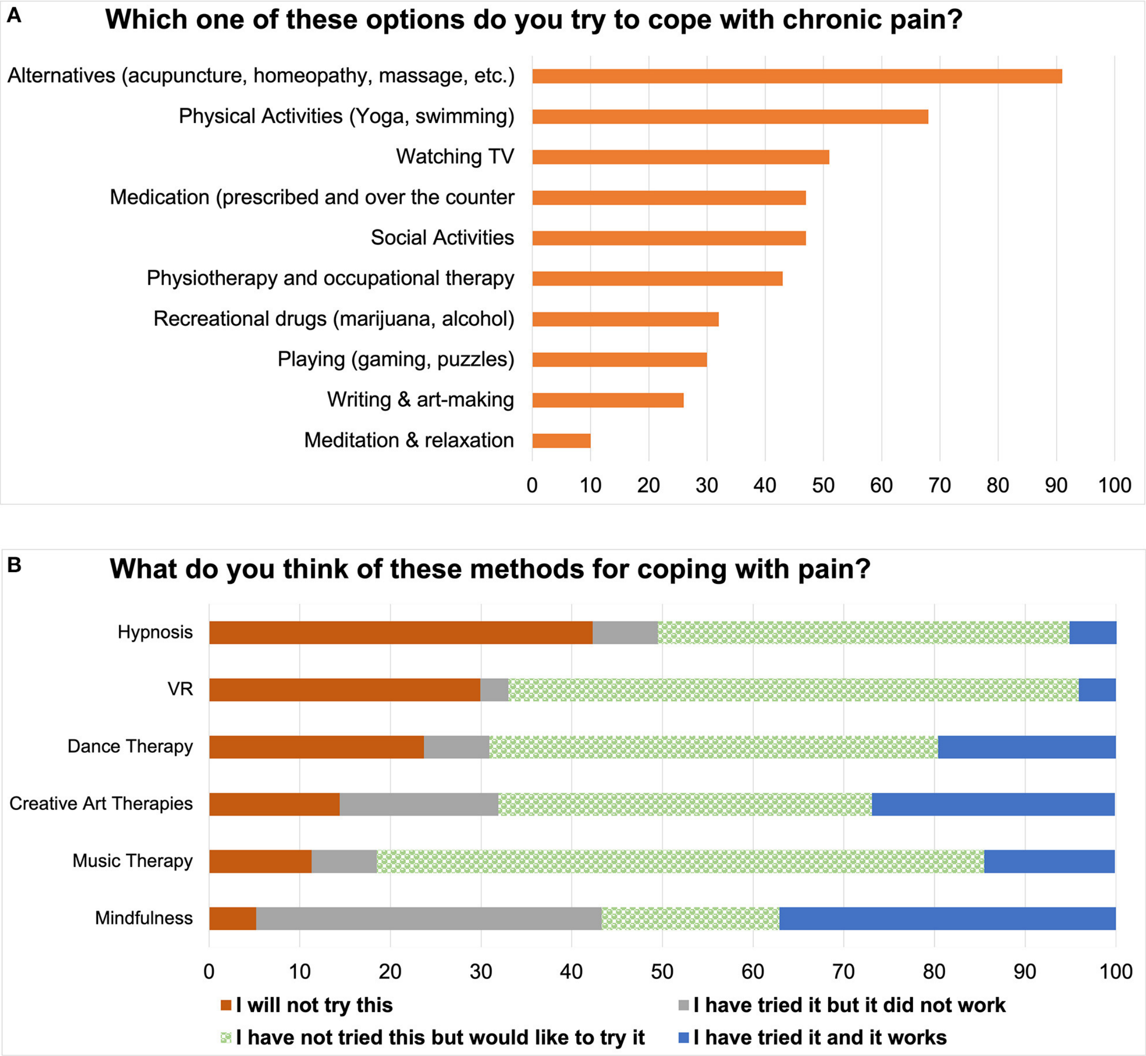


FIGURE 2
Coping strategies among PwPPs. **(A)** Common strategies; **(B)** Newer strategies.

produce beneficial results. The Kruskal-Wallis test did not reveal significant between-group differences but in two questions (that alternative medicine should be used for minor ailments ($p = 0.014$), and that alternative Medicine should be only used as a last resort ($p = 0.002$); with the Other group expressing a more positive attitude compared to medical professionals). Post-hoc comparison of attitudes among medical professionals who were also PwPPs *vs*. the rest did not reveal any differences.

General attitude towards using ICTs to cope with illness

Considering the affordances of coping with illness and pain digitally (9), we envisioned various types of ICTs that could facilitate knowledge generation and dissemination in a citizen science framework. As Figure 4 illustrates, professionally-maintained websites such as WebMD, PubMed and official forums were seen as the most trustworthy health information forums. Respondents did, however, express moderate concern about risks associated with flawed or incomplete information being communicated *via* YouTube, social media, blogs, and Wikipedia. Interestingly, there was significantly less concern about potential privacy violations on social media and digital apps than about hazards of inaccurate information. As can be seen from the radar plots in Figure 4, the responses of PwPPs and Medical professionals were remarkably similar (with medical professionals being overall more cautious). The Others were comparatively less concerned about safety hazards and privacy issues.

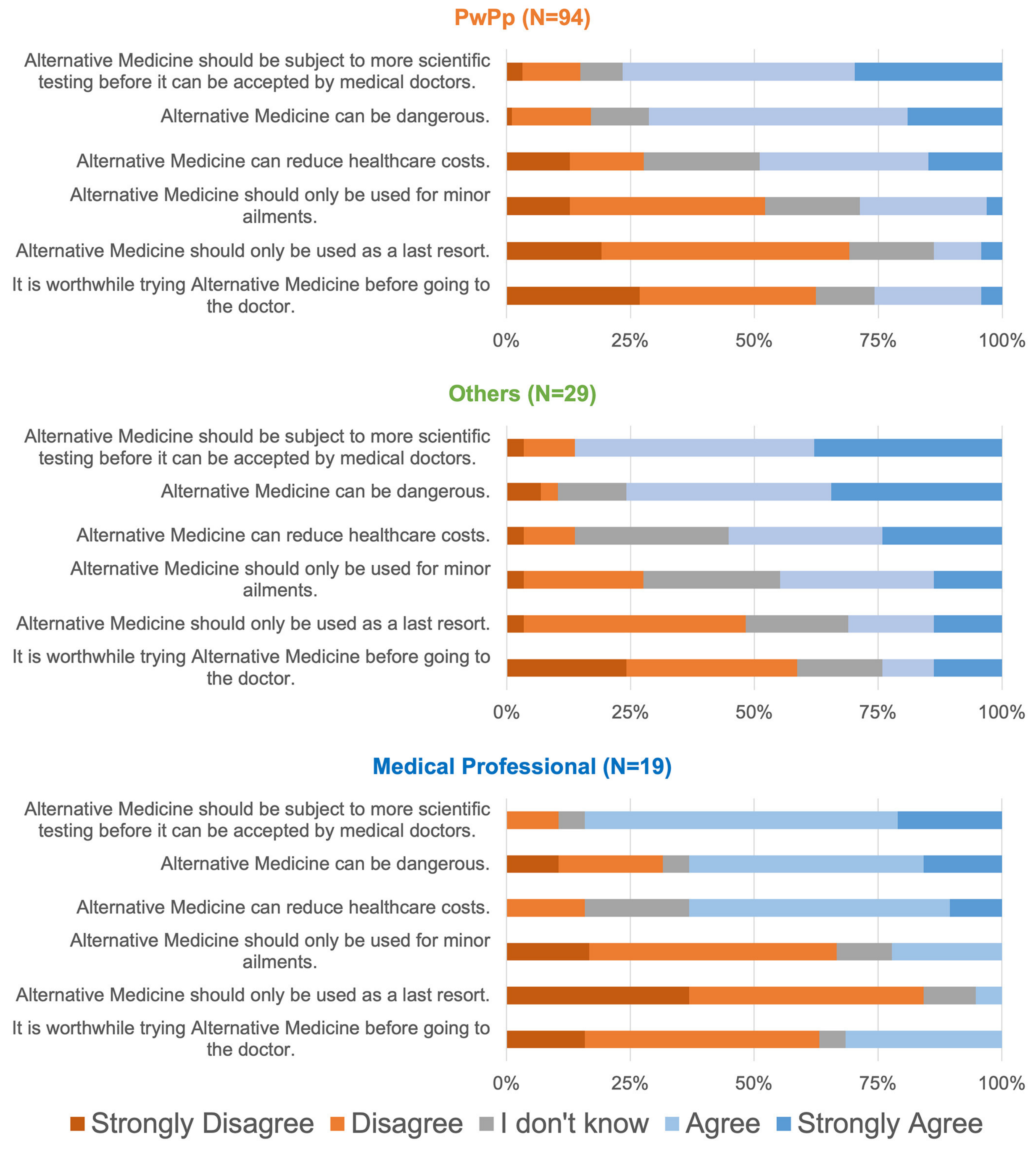


FIGURE 3
Attitudes towards alternative medicine.

Familiarity with mHealth

Despite high access to smartphones (92%) and tablets (67%) (which was comparable to Others and lower than Medical professionals), only 53% of PwPPs ($n = 57$) were familiar with digital self-tracking apps. As shown in Figure 5, Medical professionals were the least likely to be using mHealth apps. Compared to Others, the rate of mHealth app usage was lower among PwPPs and only a small number were familiar with pain tracking apps. In addition to the functions listed in Figure 5, respondents added apps for tracking; menstrual cycle ($n = 6$), weight-watching

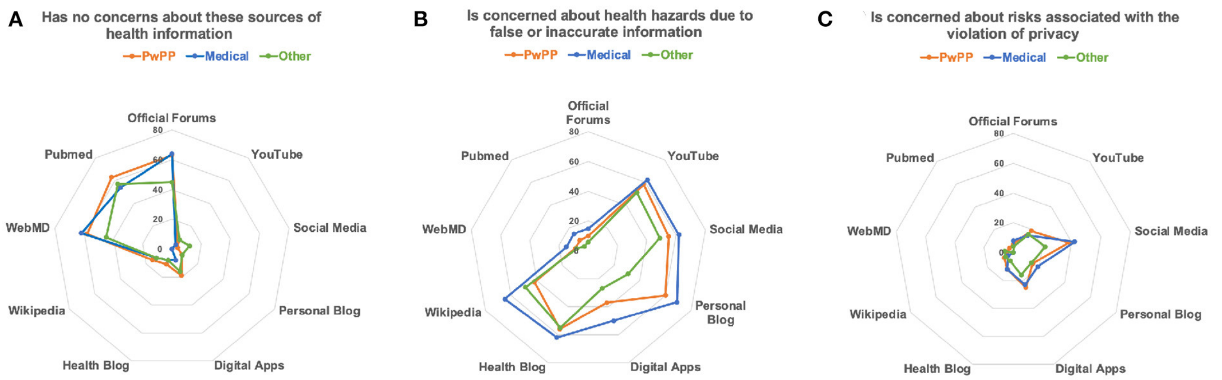


FIGURE 4
These radar diagrams illustrate differences in attitudes towards possible digital health information systems: **(A)** No concern; **(B)** Risks of wrong information; **(C)** Risk of violation of privacy. The radius of each point corresponds to the percentage of an affirmative responses within each group.

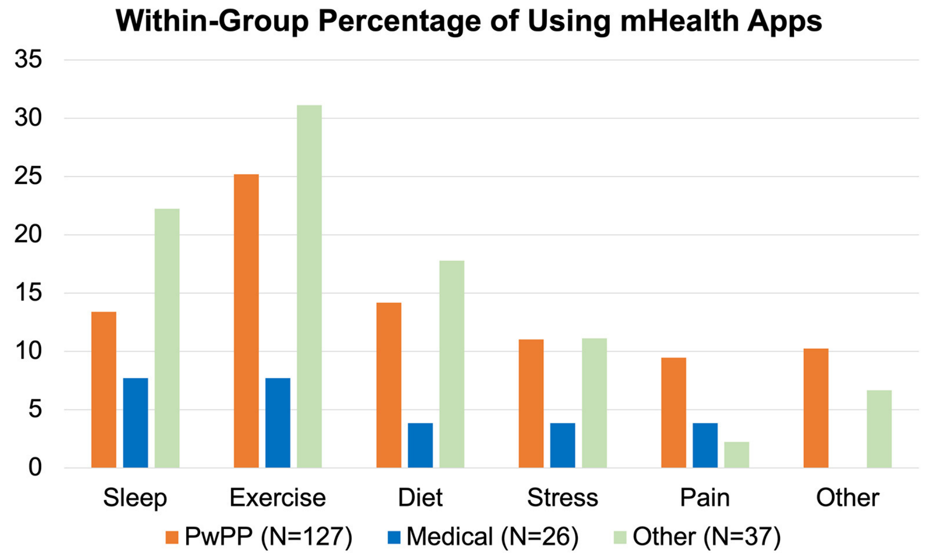


FIGURE 5
Percentage of mHealth App users within each respondent group. Medical and Other groups shown here are mutually exclusive from the PwPP category.

(n = 2), heart monitoring (n = 2), and mindfulness (n = 2).

Familiarity with pain tracking systems was also low. In response to *"Have you ever used a pain tracking and pain management app or computer program?"*, <20% (n = 21) of PwPPs responded "Yes." When asked about the frequency with which such systems were used, few indicated the use of pain tracking when pain symptoms flared up (n = 4) or to track physical activity (n = 2).

Neither access to technology nor digital literacy could explain these differences. Among the 107 PwPPs who replied to the question *"Please tell us how often you use a tablet or phone for each of the following activities?"* 98% indicated email and text messaging; 95% indicated surfing the net; 79% for pictures and videos; 77% for social media; 75% for news media; 45% for self-tracking apps; and 29% for playing digital games. Kruskal Wallis tests did not reveal any statistically significant difference between PwPPs, Medical professionals and Others in terms of their usage.

Appraisal of apps for self-tracking and management

Attitudes towards digital self-management of chronic conditions were generally positive. In response to the query *"Do you think apps can be useful to manage any of the*

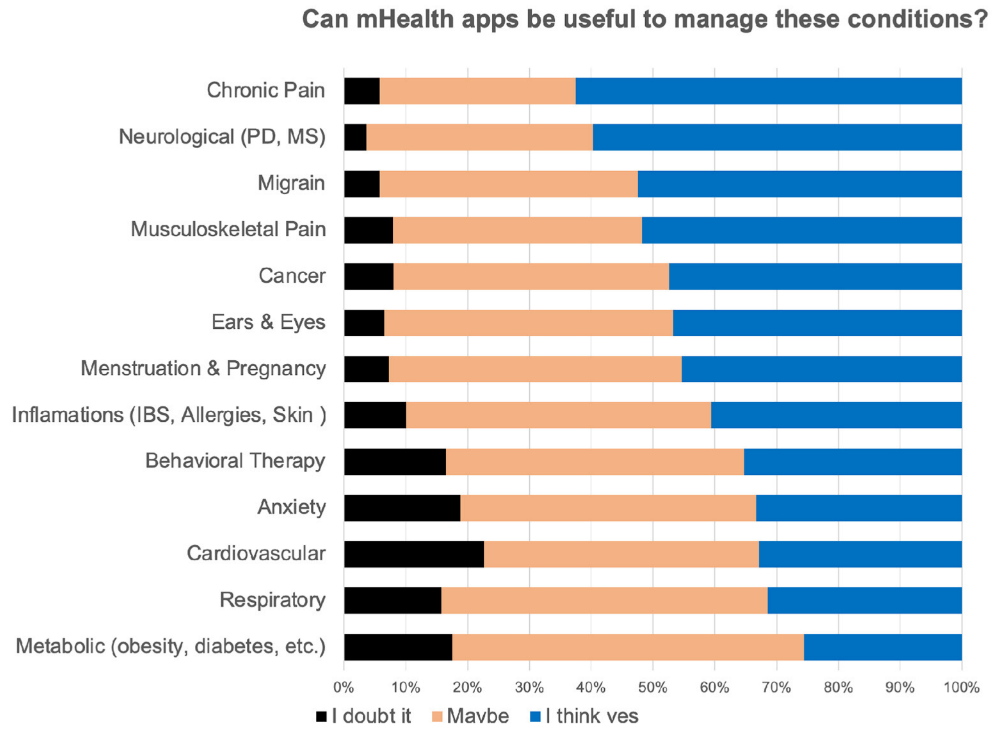


FIGURE 6
Beliefs about the usefulness of mHealth tracking apps for different chronic conditions.

following CHRONIC HEALTH CONDITIONS?", the majority (62%) selected the response: 'I think yes' for pain management. As can be seen in Figure 6, although certainty about effectiveness of such systems varied across conditions, the ratios of "I doubt it" responses were minimal across all chronic conditions. One surprising finding was that, similarly to cardiovascular and metabolic disorders, anxiety was not perceived as a condition to benefit from such systems.

Appraisal of apps for data generation and sharing

General attitudes towards data sharing *via* apps were positive. More than 72% of respondents answered "Yes" to the question *"Would you be open to using a health-related app as a research tool for data collection in real life situations?"*. Less than 2% responded "No," while 25.4% responded "Maybe." When asked: *"Do you believe that by using apps to collect your own data, you can help advance pain research?"*, 35% responded "Definitely yes", and 53% responded "Possibly." Less than 10% responded "I don't know", with only 3 responding "I don't think so." In response to the question: *"Would you be comfortable sharing your data collected in an app anonymously for specific health research purposes?"* 75% responded "Yes;" 13% replied "Maybe;" and only 7% selected "No."

We listed features common to self-tracking apps, and asked respondents to rate the importance of these (Figure 7A). The ability to share data with their doctors was the most important feature, followed by tracking of sleep. Those familiar with pain tracking apps also mentioned additional features such as receiving reminders ($n = 1$) or tips ($n = 2$), personalized predictive clues ($n = 5$), visual cues for pain recording ($n = 1$), and relaxing and pleasant experience ($n = 3$). When we asked respondents to rank the importance of features in a digital data collection system, comprehensive data collection scored the highest (Figure 7B).

Reflective analysis of comments

Excluding comments that offered specifics about type of pain and work status, we reviewed all comments about the usefulness of apps (19), data collection (11), improvement to features (23), reasons for using apps (11), concerns (6), and how best to express pain (12). We list themes that emerged from comments (all made by respondents who identified as female), that better

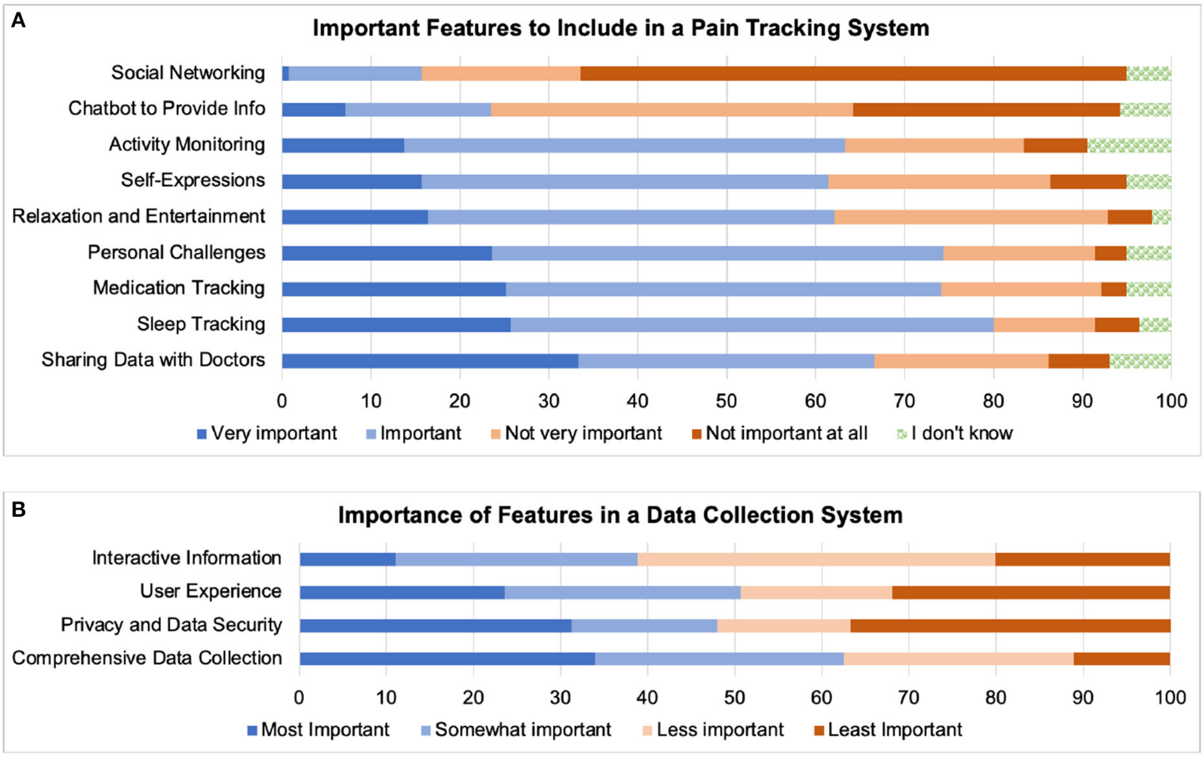


FIGURE 7
Desired features for **(A)** Pain tracking; **(B)** Data sharing.

illustrate which factors may motivate participation in our digital citizen lab, and which may contribute to technostress.

Positive appraisal 1: Contributing complex data

Commenting on the question of what motivated them to join the study, a 64-year old woman with lower back pain explained:

> *I developed chronic pain only about 2 years ago and have done a lot of personal research about how to reduce the pain through diet and exercise. I feel that I have hit a plateau and am looking at other alternative ways of discovering more about pain and its causes.*

In further elaborating on the question of the type of pain, she elaborated:

> *I cannot classify with absolute certainty the reason or source of the pain. I have been to see my doctor and had extensive blood work but nothing is conclusive. Other than the pain, especially in my lower back, neck and hips I am in very good health. I do not know if the pain is Psychogenic.*

This individual had access to Samsung Health app and monitored her exercise level but was not familiar enough with other features of the apps to answer the question: "how do you feel about existing apps in the market?"

> *It is hard for me to answer the questions as I have very little experience with health apps. I am however looking forward to participating fully in this research and learn to properly use your health app.*

In terms of data collection, she believed that tracking psychosocial factors, as well as environmental factors such as weather and pollutions was very important for understanding her pain, and was willing to contribute pain-tracking data (quantitative, narrative, expressive, psychometric):

> *Overall I am open to trying any of the above mentioned methods of pain tracking for my own benefit and the benefit of the research.*

She had a wide range of activities in which she engaged to cope with her pain, including:

> *Journaling, researching and using nutrition to discover pain sources, exchanging information with a group of friends who are as informed and curious as me, sharing my information and comparing with this group of friends, looking for alternatives, yoga, meditation.*

In explaining her response to the question: *Do you believe that by using apps to collect your own data, you can help advance pain research?*, she wrote:

> *I chose "possibly" because I do not want to have unrealistic expectations.*

Positive appraisal 2: Data aggregation towards personalization of care

Reviewing the 23 comments in response to *"What would you like to improve in your existing self-tracking apps?"* revealed interest in 'smarter apps' capable of data aggregation and algorithmic personalization of tips offered to users suffering complex neurogenic pains such as Fibromyalgia.

For example, a 53-year-old woman with neurogenic pain (rating her general health as very bad) who used apps for monitoring her irregular heartbeat wished for:

> *"Input for triggers and resolution tactics. What caused the pain and what helped mediate it."*

This respondent relied on meditation, massage therapy and recreational drugs, as well as art and literature to cope with her general poor health conditions.

One 34-year-old woman with Fibromyalgia, who rated her general health as very bad, and used a pain tracking app daily, wished for:

> *"aggregating data and making better correlations over time. For instance, my app says I feel more pain on slower days but doesn't see that I'm resting more because I have more pain. If I rest more one day and feel better the next it doesn't track that."*

A third woman (51-year-old) with Fibromyalgia and an unknown type of pain persisting after an accident (rating her General Health as 'okay'), with daily user of pain tracking apps wished for additional features:

> "tips or links to resources for point-of-need techniques such as meditation, soothing sounds, breathing exercises etc."

This respondent believed that the data collection could be successful depending on:

> *"how well planned and constructed the app is, and how rigorously analysed the resulting data is."*

Negative appraisal 1: Difficulty of access and use

Several comments of those who were familiar with mHealth indicated dissatisfaction with interfaces:

> *"I have not tried a great many, but I am easily overwhelmed by them."*

The added burden of technology was noted:

> *"It's hard to update an app when your [sic] in dying in pain".*

The numerousness of apps that have not been satisfactory, and their costs, were also mentioned:

> *"I have tried many apps for period tracking, exercise tracing, and sleep tracking, and I have found them all disappointing or annoying in some way. I don't know how to choose. I also don't want to pay monthly membership fees, but it's frustrating that the highest rated apps are all paywalled and the free ones are full of ads or not very good."*

Negative appraisal 2: Futility

To perceive a new technology as futile is an impediment to its exploration and adoption. We noted two types of negative appraisals, related to personal beneficence, and related to beliefs about feasibility.

An important example of negative appraisal was offered by a 36-year-old professional woman with facial chronic pain, who did not use any mHealth applications. She indicated that although she had created her own self-tracking computer program, she had stopped using it:

> *"I am not sure if it is a good thing to track pain. I stopped doing it because looking back over the months and years I could see that I had rarely had a pain free day, and that was very discouraging."* This respondent preferred to not focus on data-collection: *"One of the best strategies for me is to ignore it and get on with things. Thinking about it seems to make it worse."* She also felt that when one lives with untreated pain for a long time, then tracking it will not serve any purpose: " *I don't see the value* [of using apps] *in my own case because my issues is still not really diagnosed properly there doesn't seem to be much value in tracking it after already having one so for quite a while."*

Others cast doubt on the feasibility of making sense of, or analyzing, the type of data that could be collected in our proposed scheme.

In response to "Do you believe that by using apps to collect your own data, you can help advance pain research?" one 34-year-old woman (identified as an unemployed PwPP, without access to a smartphone or tablet) responded "I don't think so" and elaborated further:

> *"Chronic pain is so broad in how it is experienced. Unless the data collected is for a very specific experience/condition, I think it's likely just adding to the mountain of info that nobody seems to know how to climb."*

This respondent was one of ten (out of 123) who did not believe that they could accurately score their pain experience with 1–10 numbers. She was also among the minority of respondents who were annoyed by mood and anxiety questionnaires. She somewhat agreed about the importance of psychosocial factors, scientific terminology and use of humor to describe her pain experience. Instead, she considered tracking environmental factors as very important to understanding her pain (headache, lower back pain and joint pain). Nevertheless, in response to "*Would you be open to using a health-related app as a research tool for data collection in a real life situation*?," she replied "Maybe."

Concern about the validity of data generation was shared by a 61-year-old woman with a PhD in nursing. Similarly to the comments of the 34-year-old woman above, she did not believe that she could accurately score her pain experience with numbers. Although she was not a user of any mHealth apps, and was open to using them for health research, she thought that the possibility of the research succeeding depended on:

> "*whether the data collected and the intervention provided actually target* [one's] *chronic pain.*"

Negative appraisal 3: Ambiguity and intersubjectivity of pain

As Figure 8shows, when asked to evaluate statements about how to communicate their pain experience, a large majority was interested in psychosocial determinants of pain and more open to using scientific terminology or psychometric questionnaires.

Additional comments revealed a concern with data interpretation:

A 46-year-old woman who identified as PwPP who did not use any mHealth apps, commented on the transactional nature of pain communication:

> *" The description of pain and how a person feels changes with who they are interacting with. Some people may only be comfortable with humour for example so I stick with that when talking to them. Talking about chronic pain makes many people uncomfortable because they don't know how to react/what to say in response."*

Although this individual was not a user of mHealth apps, and strongly agreed with the statement:

> *"Health apps in the market are not properly tested by medical professionals."*

She believed that mHealth apps could help with all chronic conditions listed in the survey, and strongly agreed that by sharing her data she could advance pain research by helping others understand her better:

> *"I have Psoriatic Arthritis. My condition has been dismissed (to my face) by health professionals who do not understand my condition and pain levels. I think that advancements in pain research and management are very much needed. Pain is very complex and makes every aspect of life difficult- something most people rarely think about."*

Interestingly, a retired 78-year-old woman who identified as artist and poet (did not own a smartphone or tablet, and was not familiar with mHealth apps) commented on the novelty of both health apps and pain communication. In response to "Is there anything that you think would improve your pain tracking app?" she commented:

> *"I never knew there was such an app. I'd be tempted to buy a cell phone to try it out. Or maybe an Apple watch? Or maybe some other appliance?"*

When asked about different ways to capture one's pain experience, she commented:

> *"Truthfully, I never thought about expressing my pain to anybody much since it wears on anyone's patience to be overexposed to complaints."*

A 77-year-old female retired nurse who also identified as PwPP (owned both a smartphone and tablet, but did not use any mHealth apps) and preferred scientific terminology for description of her pain, commented that:

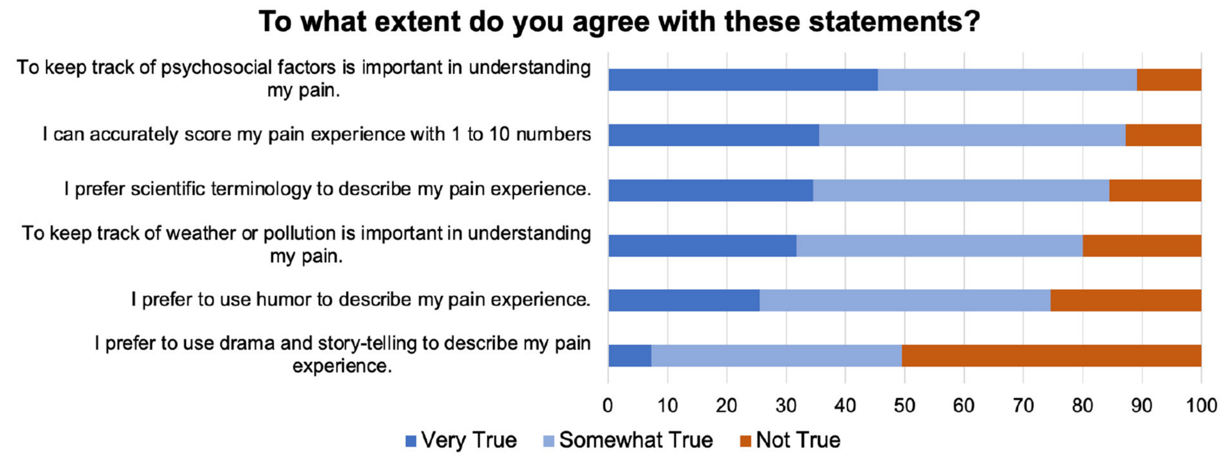


FIGURE 8
Questions asked about different ways of providing pain-related data to solicit comments from participants.

> *"I can find it difficult to quantify situations that are complex in a way that will fit a questionnaire."*

Discussion

Summary of findings

Within the theoretical framework of stress research (in recognition of the fact that innovative proposals such as DiSPORA—aiming to facilitate patient-partnership in research—may cause technostress), this quasi-qualitative attitudinal user study assessed the affordances of mHealth applications to create a digital citizen laboratory for person-centered research of alternative (non medical) pain management.

As expected, CP affected various aspects of PwPP's lives (Figure 1). The majority of PwPPs resorted to various alternative therapies such as acupuncture, massage, chiropractic, homeopathy mode than medications (Figure 2A). The majority of PwPPs in this study were also open to exploring more recent modalities (VR, mindfulness, art therapy), although efficacy of treatment (e.g., in mindfulness) varied among those who had tried them (Figure 2B). The majority of respondents (PwPPs, medical professionals and the rest) required more research to make alternative medicine acceptable to doctors. While the majority agreed that alternative medicine could be dangerous, nearly half of the respondents (especially 12/19 medical professionals who were not PwPPs) believed that alternative medicine could be saving healthcare costs (Figure 3).

Given the fact that since 2015 nearly 300 pain apps have been launched for personal and research purposes (19), we were surprised that despite having access to smartphones and tablet, and being digitally literate, only a small percentage of PwPPs were using such apps. Nevertheless, overall attitudes toward possible benefits of these apps were positive—especially for pain management.

Despite their novelty, more than 88% of respondents to our survey considered data collection through mHealth apps as *possibly* (53%) or *definitely beneficial* (35%). More than 70% of PwPPs were willing to participate in digital pain research, and were comfortable with sharing their anonymized data collected in an app. Although privacy was one of the more important requirements, the need for comprehensive data collection was ranked higher (Figure 7).

Reflective analysis of comments revealed three themes: (1) Positive appraisals were related to the affordances of mHealth apps for collecting complex personal data, and data aggregation towards personalized pain treatments. (2) Negative appraisals were about the futility of data collection about a condition that could not be cured and futility of collecting data that could not be meaningfully interpreted. (3)Technostress was associated with costs of acquiring such technologies, under experience, and understanding of the inner workings of the app and privacy.

New contributions to qualitative pain research

A framed-flexible approach

To the best of our knowledge, this is the first study to have approached the question of creating an mHealth app for citizen research into alternative means of coping with CP. In the first step of the recursive testing of appraisal, we chose an anonymous survey to provide an opportunity for candid appraisals. By inviting individuals to share ideas and knowledge for the creation of a hypothetical data-collection app aimed to break the typical hierarchy of subject-matter experts and participants, and sought to create a playful and welcoming atmosphere to encourage free self-expression.

To create a citizen lab for studying coping necessitates identifying users' activities (e.g., pain management strategies), motivations for engagement, and technological skills and attitudes (62, 63), as well as accounting for the fact that patients communicate their pain creatively (64–67). Addressing all of these factors in detail will have created an extensive list of questions that would normally be explored in a quantitative manner. However, an attitudinal research survey that was informed by conversations among our team (researchers, PwPPs and caregivers) helped us begin from a low-resolution but wide angled viewpoint that was informed by our team's own ambivalences: Is it *safe* and *acceptable* to create a mobile self-tracking app for communicating and documenting alternative self-care? Informed by previous user-centered studies (65–72), we asked questions about features that are known to be important to pain-tracking app users: ability to track pain accurately, to interact, to provide descriptive information about pain, and finally to distract from pain. This allowed us to ask whether there were concerns about these well-desired features (Figure 7).

One of the respondent's comments on the question listing different means of explaining their pain experience (scientific, humor, numeric scales, etc.) exemplifies the types of information that our study design sought to gather: Who has difficulty with expressing their chronic pain, and how do they cope with it?

> *"I've really never thought my own pain was severe enough to warrant attention or tracking. It exists, but it's not debilitating the vast majority of the time. I also think I have a fairly high pain tolerance—which is to say, I don't really know what objective number I would assign to pain because I feel able to handle it, even if it's severe. Also, less severe/sharp pain (such as my shoulder) is sometimes harder for me to cope with than a severe, acute pain. So, while I would objectively say that delivering a baby at home with no pain meds is very painful (I have done it three times), the shoulder pain is harder to cope with psychologically. I keep coming back to the shoulder because it's the least explained pain I've had for the longest period of time."*

We found that the strongest desire for data collection was expressed for sleep-tracking (something that should be done at the comfort of home and passively), and for sharing personal data with their doctors (something that requires active interactions and knowledge exchange). The fact that collecting comprehensive data was more important than ensuring privacy suggests the willingness of potential participants to be agents in capturing the complexity of their pain experiences, particularly psychosocial factors (Figure 8).

Barriers to digital citizen labs

Respondents to our call were interested and curious about alternative ways of coping with pain (Figure 2), even when acknowledging potential dangers and the fact that standard medical care should be the primary resource, and the need for more research and evidence (Figure 3). Nevertheless, more than half of participants, especially Medical professionals believed that alternative medicine could potentially save healthcare costs. This is consistent with the WHO report, that interest in traditional and complementary medicine is globally on the rise, but that resources and legal and ethical frameworks for research and implementation are lagging (41).

In addition, a lack of established health ICT frameworks and clear policies contributes to negative appraisals and technostress. It is not surprising that our participants found misinformation, privacy issues, and skepticism about interfaces, costs and algorithms to be areas of concern (73, 74).

To remedy, based on a scoping review of digital health science initiatives, Fu, Gray and Borda have suggested that participatory design of research data management systems would be an important step in overcoming hesitancy about the reliability and reproducibility of citizen health data collection initiatives (75). Hamilton et al.'s patient engagement research has identified that procedural requirements which ensure that data collection is consistent with the needs of both research and patients—and make it possible to do research at their own pace and with the ability to express their own views—are important to the design of citizen research practices (76).

Thomas, Scheller, and Schroder have recommended that an effective citizen laboratory for addressing complex questions (in our case, coping with chronic pain) must provide (1) a space for social encounters; (2) a framework for communicative practice; (3) a process to initiate social self-understanding; (4) and dynamics to engage in (counter-)public discourses (77). Our data suggest a foreseeable challenge in gaining trust about communication. As can be seen in Figure 7A, inclusion of a social networking feature in a pain tracking system was not at all important to the majority of respondents, and social media raised concerns about misinformation (Figure 4). It should be noted however, that our questions were too broad to tease apart the perceived benefits or risks of personal connections *via* ICTs and this issue needs to be more thoroughly examined in the future.

Beyond quantitative scales and towards innovative data collection

In a critical review of existing citizen science methodologies and approaches, Hidalgo et al. (78) have identified two dominant forms of citizen science. In the contributory model, scientists are the project designers and offer a technology to help citizens gather their data. In the co-creative and participatory model, citizens share their real-world problems and scientists are co-designers and facilitators of data tools that emerge from the real-world problems of citizen participants. There is a wealth of existing data on what users expect from pain-tracking apps, designed for therapeutic efficacy (64, 68–72). Our data suggests that the contributory model of citizen science is acceptable to our respondents. However, important work remains to be done to raise awareness about the critical role that patients can play in guiding the direction of research through communication of personal and shared experiences and complex needs (78).

An area that requires more precise research is alternative methods to pain communications (going beyond numeric pain scales). We had expected that, given the complexity of pain experience, self-expressive and metaphoric pain communication be important (64–67, 79). We found that although facilitating self-expression was just as important as physical activity tracking (Figure 7A), only half of participants were interested in performative approaches such as drama and storytelling (narrative reporting) for reporting their pain (Figure 8). We speculate that this might be due to negative connotations associated with the word "drama," that reflect the pervasive stigma of malingering (80) for women in particular, who represent the majority of our respondents. However, as several comments indicated, how one expresses and describes their pain is contextual and dependent on to whom the explanation is addressed. Therefore, while explaining pain in scientific terms or with numerical scales may simplify the challenges of intersubjectivity, welcoming alternative means of self-expression in pain research may be informative.

As one respondent commented:

> *"because I am not a scientist, I don't know how to express my pain in scientific terms."*

Additionally some were not comfortable 'burdening' others with their pain complaints. Future work should more closely examine the affordances of poetic and metaphorical self-expression in a digital citizen lab.

Limitations

The most important limitation of this study is the potential for sampling bias: our sampling method provided for self-selection (based on interest in joining a future participatory app design study). Thus, the respondents are not representative of the PwPP population. This self-selection resulted in a group of more than 73% female, educated, mostly English-speaking individuals (even though the study was also advertised in French) with high access to ICT. In reality, many PwPPs are in marginalized communities (2) without access to ICTs, and our study may not have reached them. For example, a recent rapid review of studies that examine the efficacy of mHealth qualities illustrates a great disparity in accounting for preferences of mHealth use in lower income countries (81).

Another potential bias is that most respondents reported lower back pain. Some estimates of the lifetime prevalence of chronic back pain "are as high as 84% in the adult population" (82). This disproportionate representation in our sample might be related to the fact that almost 60% (75/127) learned about our study from the PERFORM Centre's mailing list and had likely been involved in the other studies for treatment of the lower back pain (for which physical therapies exist) as opposed to migraine, for example. Future research should target a more diverse range of chronic pain conditions.

In this study, we chose not to employ any formally validated questionnaires, and instead allowed conversations with PwPPs (in an earlier public event) to guide the formulation of questions. As such, we can only provide descriptive statistics, with limited quantitative comparison across the sample. Recently published scales such as The Digital Stressor Instrument would be useful in conjunction with our survey, to obtain a more granular understanding of the ways in which digital stress may impact PwPPs (51).

Conclusion

This attitudinal user study showed that our survey respondents were interested in alternative therapies, and willing to share complex personal data, to advance pain research through data-analytics. The key finding of our study is that despite novelty and uncertainty about the outcomes of innovative health related ICT approaches, those with CP conditions and the medical professionals are open to researching CP in non-pharmacological and alternative frameworks. Although the primary appraisal of a digital citizen lab for exploring alternative ways of coping with and studying chronic pain is positive, heterogeneity in both positive and negative attitudes must be more carefully studied, and individual perspectives and experiences be considered in designing digital frameworks for citizen research. Specifically, respondents who commented about the study expressed doubts that computational algorithms would be successful in making meaningful inferences from the data, because pain is a complex experience and difficult to communicate and record. In future work, we need to reach those who did not have an opportunity or chose not to participate in our call. While a more representative sample, and more in-depth engagement is needed to plan DiSPORA, current results underline the necessity of clinically-framed, but flexibly person-centered and psychosocially-informed research and medical care for PwPPs.

Data availability statement

The dataset may contain personal and identifiable information requests to access the datasets should be directed to najmeh.khalili-mahani@concordia.ca.

Ethics statement

The studies involving human participants were reviewed and approved by Concordia University's Research Ethics Board. The patients/participants provided their written informed consent to participate in this study.

Author contributions

NK-M, SW, EH, AP, and MR: designed the study. NK-M, EH, and AP: conducted data collection and analysis. All authors contributed to the writing of the manuscript.

Funding

The funding for this study was provided by AUDACE-2019 grant from Fonds de recherche du Québec - Société et culture (FRQSC) to NK-M and MR.

Acknowledgments

The authors thank Réseau québécois de recherche sur la douleur (RQRD) for supporting open-access publication of this research. The authors would also like to thank Mr. Sriram Naryanan and Ms. Wendy Kunin for support to announce the study across the PERFORM Centre networks.

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

1. Thompson PM, Jahanshad N, Ching CRK, Salminen LE, Thomopoulos SI, Bright J, et al. ENIGMA and global neuroscience: a decade of large-scale studies of the brain in health and disease across more than 40 countries. *Transl Psychiatry.* (2020) 10:1–28. doi: 10.1016/j.biopsych.2020.02.167

2. Craig KD, Holmes C, Hudspith M, Moor G, Moosa-Mitha M, Varcoe C, et al. Pain in persons who are marginalized by social conditions. *Pain.* (2020) 161:261–5. doi: 10.1097/j.pain.0000000000001719

3. G.o. Canada. Chronic pain. In: *Health* (2021). Availabke onlilne at: https://www.canada.ca/en/public-health/services/diseases/chronic-pain.html#a1

4. Canadian Pain Task Force Report. Chronic Pain in Canada: Laying a Foundation for Action. Ottawa: Health Canada (2019).

5. Canadian Pain Task Force Report. An Action Plan for Pain in Canada, Government of Canada. Ottawa: Health Canada (2021).

6. Khalili-Mahani N, Holowka E, Woods S, Khaled R, Roy M, Lashley M, et al. Play the pain: a digital strategy for play-oriented research and action. *Front Psychiatry.* (2021) 12:746477. doi: 10.3389/fpsyt.2021.746477

7. Dorta-González P, Kullenberg C, Kasperowski D. What is citizen science?—A scientometric meta-analysis. *Plos ONE.* (2016) 11. doi: 10.1371/journal.pone.0147152

8. Khalili-Mahani N, Tran S. The bigger picture of digital interventions for pain, anxiety and stress: a systematic review of 1200+ controlled trials, digital human modeling and applications in health, safety, ergonomics and risk management. *Health, Operations Management, and Design.* Berlin, Germany, Springer. p. 67–78.

9. Rains SA. *Coping with Illness Digitally.* (2018). Cambridge: MIT Press.

10. Sutton RT, Pincock D, Baumgart DC, Sadowski DC, Fedorak RN, Kroeker KI, et al. An overview of clinical decision support systems: benefits, risks, and strategies for success. *NPJ Digital Med.* (2020) 3:1. doi: 10.1038/s41746-020-0221-y

11. Smith MY, DePue JD, Rini C. Computerized decision-support systems for chronic pain management in primary care. *Pain Med.* (2007) 8:S155–66. doi: 10.1111/j.1526-4637.2007.00278.x

12. Jibb LA, Khan JS, Seth P, Lalloo C, Mulrooney L, Nicholson K, et al. Electronic data capture vs. conventional data collection methods in clinical pain studies: systematic review and meta-analysis. *J Med Int Res.* (2020) 22:e16480. doi: 10.2196/16480

13. Lazaridou A, Elbaridi N, Edwards RR. *Chapter 5: Pain Assessment, Essentials of Pain Medicine.* (2018). St. Louis: Elsevier.

14. Thurnheer SE, Gravestock I, Pichierri G, Steurer J, Burgstaller JM. Benefits of mobile apps in pain management: systematic review. *JMIR mHealth uHealth.* (2018) 6:e11231. doi: 10.2196/11231

15. Insel TR. Digital phenotyping: technology for a new science of behavior. *JAMA.* (2017) 318:1215–6. doi: 10.1001/jama.2017.11295

16. Lee J, Mawla I, Kim J, Loggia ML, Ortiz A, Jung C, et al. Machine learning–based prediction of clinical pain using multimodal neuroimaging and autonomic metrics. *Pain.* (2018) 160:550–60. doi: 10.1097/j.pain.0000000000001417

17. Wicks P. Patient, study thyself. *BMC Med.* (2018) 16:217. doi: 10.1186/s12916-018-1216-2

18. Okun S, Wicks P. DigitalMe: a journey towards personalized health and thriving. *Biomed Eng Online.* (2018) 17:119. doi: 10.1186/s12938-018-0553-x

19. Lalloo C, Jibb LA, Rivera J, Agarwal A, Stinson JN. "There's a Pain App for That": review of patient-targeted smartphone applications for pain management. *Clin J Pain.* (2015) 31:557–63. doi: 10.1097/AJP.0000000000000171

20. MacPherson M, Bakker AM, Anderson K, Holtzman S. Do pain management apps use evidence-based psychological components? A systematic review of app content and quality. *Can J Pain.* (2022) 6:33–44. doi: 10.1080/24740527.2022.2030212

21. Bhatia A, Kara J, Janmohamed T, Prabhu A, Lebovic G, Katz J, et al. User engagement and clinical impact of the manage my pain app in patients with chronic pain: a real-world, multi-site trial. *JMIR mHealth uHealth.* (2021) 9:e26528. doi: 10.2196/26528

22. Ali SM, Lau WJ, McBeth J, Dixon WG, van der Veer SN. Digital manikins to self-report pain on a smartphone: a systematic review of mobile apps. *Eur J Pain.* (2020) 25:327–38. doi: 10.1002/ejp.1688

23. Bateson G. Steps to an ecology of mind; collected essays in anthropology, psychiatry, evolution, and epistemology (1972). San Francisco: Chandler Pub. Co..

24. Mintzberg H. Managing the myths of health care: bridging the separations between care, cure, control, and community (2017). Oakland, CA: Berrett-Koehler Publishers, Inc.

25. Tran VT, Riveros C, Péan C, Czarnobroda A, Ravaud P. Patients' perspective on how to improve the care of people with chronic conditions in France: a citizen science study within the ComPaRe e-cohort. *BMJ Qual Saf.* (2019) 28:875–86. doi: 10.1136/bmjqs-2018-008593

26. Wiggins A, Wilbanks J. The Rise of Citizen Science in Health and Biomedical Research. *Am J Bioethics.* (2019) 19:3–14. doi: 10.1080/15265161.2019.1619859

27. Walls TA, Forkus S, Coria A. Citizen health science. *Int J Popul Data Sci.* (2019) 4:1074. doi: 10.23889/ijpds.v4i1.1074

28. Fals-Borda O, Rahman MA. *Action and Knowledge: Breaking the Monopoly with Participatory Action Research.* (1991). New York, London: Apex Press; Intermediate Technology Publications. (1991).

29. Warriner DS, Bigelow M. *Critical Reflections on Research Methods: Power and Equity in Complex Multilingual Contexts, Multilingual Matters.* (2019). Bristol: Blue Ridge Summit.

30. Katapally TR. The *SMART* Framework: Integration of Citizen Science, Community-Based Participatory Research, and Systems Science for Population Health Science in the Digital Age. *JMIR mHealth uHealth.* (2019) 7:e14056. doi: 10.2196/14056

31. Brod C. *The Human Cost of the Computer Revolution.* (1984). Boston, MA: Addison-Wesley, Reading, Mass.

32. Calvo RA, Deterding S, Ryan RM. Health surveillance during covid-19 pandemic. *BMJ.* (2020). doi: 10.1136/bmj.m1373

33. Golz C, Peter KA, Müller TJ, Mutschler J, Zwakhalen SMG, Hahn S, et al. Technostress and digital competence among health professionals in swiss psychiatric hospitals: cross-sectional study. *JMIR Mental Health.* (2021) 8:e31408. doi: 10.2196/31408

34. Wadman M. Row over alternative medicine's status at NIH. *Nature.* (1997) 389:652–652. doi: 10.1038/39409

35. Joos S, Musselmann B, Szecsenyi J. Integration of complementary and alternative medicine into family practices in germany: results of a national survey. *Evidence-Based Complement Altern Med.* (2011) 2011:1–8. doi: 10.1093/ecam/nep019

36. Preuss CV, Kalava A, King KC. *Prescription of Controlled Substances: Benefits and Risks.* (2020). StatPearls, Treasure Island (FL).

37. Fenton JJ. The cost of satisfaction. *Arch Intern Med.* (2012) 172. doi: 10.1001/archinternmed.2011.1662

38. Jones W, Kurdyak P, Fischer B. Examining correlations between opioid dispensing and opioid-related hospitalizations in Canada, 2007–2016. *BMC Health Services Res.* (2020) 20:677. doi: 10.1186/s12913-020-05530-w

39. Hadjistavropoulos H, Williams A, Craig K. Psychological interventions: cognitive behavioral and stress management approaches. In: Lynch ME, Craig KD, Peng PWH, (Eds.) *Clinical Pain Management: A Practical Guide.* (2011). Chichester, West Sussex, England: Wiley-Blackwell; John Wiley and Sons, Ltd. p. 202.

40. Craig KD, Versloot J. *Psychosocial Perspectives on Chronic Pain, Clinical Pain Management.* (2010). Chichester, West Sussex: John Wiley and Sons, Ltd, p. 24–31.

41. World Health Organization. *WHO Global Report on Traditional and Complementary Medicine.* (2019). World Health Organization, Geneva.

42. Apolinario-Hagen JA, Tasseit S. Access to Psychotherapy in the Era of Web 2.0 – New Media, Old Inequalities? *Int J Health Prof.* (2015) 2:119–29. doi: 10.1515/ijhp-2015-0010

43. Waller R, Gilbody S. Barriers to the uptake of computerized cognitive behavioural therapy: a systematic review of the quantitative and qualitative evidence. *Psychol Med.* (2008) 39:705–12. doi: 10.1017/S0033291708004224

44. Musiat P, Goldstone P, Tarrier N. Understanding the acceptability of e-mental health—attitudes and expectations towards computerised self-help treatments for mental health problems. *BMC Psychiatry.* (2014) 14. doi: 10.1186/1471-244X-14-109

45. Eysenbach G. The law of attrition. *J Med Internet Res.* (2005) 7:e11. doi: 10.2196/jmir.7.1.e11

46. Zhao P, Yoo I, Lancey R, Varghese E. Mobile applications for pain management: an app analysis for clinical usage. *BMC Med Inform Decis Mak.* (2019) 19. doi: 10.1186/s12911-019-0827-7

47. Slepian PM, Peng M, Janmohamed T, Kotteeswaran Y, Manoo V, Blades AM, et al. Engagement with manage my pain mobile health application among patients at the transitional pain service. *Digital Health.* (2020) 6. doi: 10.1177/2055207620962297

48. Lazarus RS, Folkman S. *Stress, Appraisal, and Coping.* (1984). New York, NY: Springer Publishing Company.

49. Weinert C, Maier C, Laumer S, Weitzel T. How do users respond to technostress? An empirical analysis of proactive and reactive coping. In: *Proceedings of the 52nd Hawaii International Conference on System Sciences.* (2019).

50. Saleem F, Malik MI, Qureshi SS, Farid MF, Qamar S. Technostress and employee performance nexus during COVID-19: training and creative self-efficacy as moderators. *Front Psychol.* (2021) 12:595119. doi: 10.3389/fpsyg.2021.595119

51. Fischer T, Reuter M, Riedl R. The digital stressors scale: development and validation of a new survey instrument to measure digital stress perceptions in the workplace context. *Front Psychol.* (2021) 12. doi: 10.3389/fpsyg.2021.607598

52. Eden AL, Johnson BK, Reinecke L, Grady SM. Media for coping during COVID-19 social distancing: stress, anxiety, and psychological well-being. *Front Psychol.* (2020) 11:577639. doi: 10.3389/fpsyg.2020.577639

53. Khalili-Mahani N, Smyrnova A, Kakinami L. To each stress its own screen: a cross-sectional survey of the patterns of stress and various screen uses in relation to self-admitted screen addiction. *J Med Internet Res.* (2019) 21:e11485. doi: 10.2196/11485

54. Pahayahay A, Khalili-Mahani N. What media helps, what media hurts: a mixed methods survey study of coping with COVID-19 using the media repertoire framework and the appraisal theory of stress. *J Med Int Res.* (2020) 22:e20186. doi: 10.2196/20186

55. Pagé MG, Dassieu L, Develay E, Roy M, Vachon-Presseau E, Lupien S, et al. The stressful characteristics of pain that drive you nuts: a qualitative exploration of a stress model to understand the chronic pain experience. *Pain Med.* (2021) 22:1095–108. doi: 10.1093/pm/pnaa370

56. Weil MM, Rosen LD. *TechnoStress: Coping with Technology @work @home @play, J.* New York, NY: Wiley (1997).

57. Khalili-Mahani N, Schutter BD. Affective game planning for health applications: quantitative extension of gerontoludic design based on the appraisal theory of stress and coping. *JMIR Serious Games.* (2019) 7:e13303. doi: 10.2196/13303

58. Goodman-Vincent E, Roy M, Khalili-Mahani N. *Affective Game Planning for Playing the Pain, Extended Abstracts of the 2020 Annual Symposium on Computer-Human Interaction in Play.* (2020). p. 122–8.

59. Khalili-Mahani N, Assadi A, Li K, Mirgholami M, Rivard ME, Benali H, et al. Reflective and reflexive stress responses of older adults to three gaming experiences in relation to their cognitive abilities: mixed methods crossover study. *JMIR Mental Health.* (2020) 7:e12388. doi: 10.2196/12388

60. Assadi A, Elbaz S, Khalili-Mahani N. The belief in health benefits of digital play modulates physiological responses to games: a repeated-measures quantitative study of game stress in older adults playing different game genres, human aspects of IT for the aged population. *Supporting Everyday Life Activities*, 3–22. doi: 10.1007/978-3-030-78111-8_1

61. Doncaster P. *The UX Five-Second Rules: Guidelines for User Experience Design's Simplest Testing Technique, Morgan Kaufmann is an Imprint of Elsevier, Amsterdam.* (2014).

62. Cooper A, Reimann R, Cronin D, Cooper A. *About Face: The Essentials of Interaction Design.* (2014). Indianapolis, IN: John Wiley and Sons.

63. Wei Y, Zheng P, Deng H, Wang X, Li X, Fu H, et al. Design features for improving mobile health intervention user engagement: systematic review and thematic analysis. *J Med Internet Res.* (2020) 22:e21687. doi: 10.2196/preprints.21687

64. Vilardaga R, Davies PS, Vowles KE, Sullivan MD. Theoretical grounds of pain tracker self manager: an acceptance and commitment therapy digital intervention for patients with chronic pain. *J Context Behav Sci.* (2020) 15:172–80. doi: 10.1016/j.jcbs.2020.01.001

65. Hovey RB. Occasionally a patient. *J Patient Exp.* (2017) 5:63–4. doi: 10.1177/2374373517726074

66. Hovey RB, Amir N. The hermeneutics of suffering: researching trauma. *Int J Person Centered Med*. (2013) 3:160–9. doi: 10.5750/ijpcm.v3i2.395

67. Hovey RB, Khayat VC, Feig E. Listening to and letting pain speak: poetic reflections. *Br J Pain*. (2018) 12:95–103. doi: 10.1177/2049463717741146

68. Ledel Solem IK, Varsi C, Eide H, Kristjansdottir OB, Mirkovic J, Børøsund E, et al. Patients' needs and requirements for eHealth pain management interventions: qualitative study. *J Med Internet Res.* (2019) 21:e13205. doi: 10.2196/13205

69. Liu Y, Encelle B, Sehaba K. A user-centered approach to design a mobile application for chronic pain management. *Modell Measure Control C.* (2020) 81:24–9. doi: 10.18280/mmc_c.811-405

70. Lopes F, Rodrigues M, Silva AG. User-centered development of a mobile app for biopsychosocial pain assessment in adults: usability, reliability, and validity study. *JMIR mHealth uHealth.* (2021) 9. doi: 10.2196/25316

71. Jamison RN, Mei A, Ross EL. Longitudinal trial of a smartphone pain application for chronic pain patients: Predictors of compliance and satisfaction. *J Telemed Telecare.* (2016) 24:93–100. doi: 10.1177/1357633X16679049

72. Ledel Solem IK, Varsi C, Eide H, Kristjansdottir OB, Børøsund E, Schreurs KMG, et al. A user-centered approach to an evidence-based electronic health pain management intervention for people with chronic pain: design and development of EPIO. *J Med Internet Res.* (2020) 22:e15889. doi: 10.2196/15889

73. Murray E, Hekler EB, Andersson G, Collins LM, Doherty A, Hollis C, et al. Evaluating digital health interventions. *Am J Prev Med.* (2016) 51:843–51. doi: 10.1016/j.amepre.2016.06.008

74. Grande D, Luna Marti X, Feuerstein-Simon R, Merchant RM, Asch DA, Lewson A, et al. Health policy and privacy challenges associated with digital technology. *JAMA Network Open.* (2020) 3:e208285. doi: 10.1001/jamanetworkopen.2020.8285

75. Fu Y, Gray K, Borda A. Research data management in health and biomedical citizen science: practices and prospects. *JAMIA Open.* (2020) 3:113–25. doi: 10.1093/jamiaopen/ooz052

76. Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, et al. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. *Health Expect.* (2021) 24:863–79. doi: 10.1111/hex.13227

77. Thomas S, Scheller D, Schröder S. Co-creation in citizen social science: the research forum as a methodological foundation for communication and participation. *Human Soc Sci Commun.* (2021) 8. doi: 10.1057/s41599-021-00902-x

78. Senabre Hidalgo E, Perelló J, Becker F, Bonhoure I, Legris M, Cigarini A, et al. (2021). Participation and co-creation in citizen science. In: Vohland K, Land-Zandstra A, Ceccaroni L, Lemmens R, Perelló J, Ponti M, Samson R, Wagenknecht K, (Eds.), *The Science of Citizen Science.* New York, NY: Springer International Publishing, Cham. p. 199–218.

79. Kirmayer LJ. Culture and the metaphoric mediation of pain. *Transcult Psychiatry.* (2008) 45:318–38. doi: 10.1177/1363461508089769

80. Collier R. "Complainers, malingerers and drug-seekers"—the stigma of living with chronic pain. *Can Med Assoc J.* (2018) 190:E204–5. doi: 10.1503/cmaj.109-5553

81. Woulfe F, Fadahunsi KP, Smith S, Chirambo GB, Larsson E, Henn P, et al. Identification and evaluation of methodologies to assess the quality of mobile health apps in high-, low-, and middle-income countries: rapid review. *JMIR mHealth uHealth.* (2021) 9:e28384. doi: 10.2196/28384

82. Casiano VE, Sarwan G, Dydyk AM, Varacallo M. *Back Pain. [Up2021 Nov 13]. StatPearls [Internet].* (2021). Treasure Island (FL): StatPearls Publishing.

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 17 August 2022
DOI 10.3389/fresc.2022.920387

OPEN ACCESS

EDITED BY
Dominik Mischkowski,
Ohio University, United States

REVIEWED BY
Frane Grubišić,
Sisters of Charity Hospital, Croatia
Najmeh Khalili-Mahani,
McGill Centre for Integrative Neuroscience,
Montreal Neurological Institute, Canada

*CORRESPONDENCE
Veronika Schoeb
veronika.schoeb@hesav.ch

SPECIALTY SECTION
This article was submitted to Disability, Rehabilitation, and Inclusion, a section of the journal Frontiers in Rehabilitation Sciences

RECEIVED 26 April 2022
ACCEPTED 02 August 2022
PUBLISHED 17 August 2022

CITATION
Schoeb V, Misteli M, Kwan C, Wong CWY, Kan MMP, Opsommer E and Wong AYL (2022) Experiences of community-dwelling older adults with chronic low back pain in Hong Kong and Switzerland – A qualitative study.
Front. Rehabilit. Sci. 3:920387.
doi: 10.3389/fresc.2022.920387

Experiences of community-dwelling older adults with chronic low back pain in Hong Kong and Switzerland – A qualitative study

Veronika Schoeb[1]*, Marceau Misteli[1], Crystal Kwan[2], Chris W. Y. Wong[3], Mandy M. P. Kan[3], Emmanuelle Opsommer[1] and Arnold Y. L. Wong[3]

[1]School of Health Sciences (HESAV), University of Applied Sciences and Arts Western Switzerland (HES-SO), Lausanne, Switzerland, [2]Department of Applied Social Sciences, The Hong Kong Polytechnic University, Hung Hom, Hong Kong SAR, China, [3]Department of Rehabilitation Sciences, The Hong Kong Polytechnic University, Hung Hom, Hong Kong SAR, China

Introduction: The prevalence of chronic low back pain (LBP) increases with age and older adults are more vulnerable to develop chronic LBP. A recent Swiss study has shown that 78% of community-dwelling older adults aged ≥65 years experienced chronic LBP. Similarly, a study in Hong Kong found that approximately 30% of people aged above 60 years experienced chronic LBP. The aim of this collaborative research project was to illuminate older adults' experiences of living with chronic LBP and its implication on older adults' daily life in Western and Eastern cultures.

Methods: Twenty-five older people experiencing chronic LBP living in Switzerland or Hong Kong were recruited through health professionals or community centres. Using semi-structured interviews, participants shared their experiences regarding chronic LBP and its implications on their daily life. The interviews were recorded and transcribed "ad verbatim" in the original language. An inductive thematic analysis was used, using a qualitative data analysis software program (NVivo) and a shared code book in English. The Swiss and Hong Kong research teams engaged in collaborative analysis until a consensus was established, taking into consideration of cultural specificities. Ethical approval was obtained from the local ethic committees in both regions.

Results: Themes were related to negative perceptions/experiences: (1) interferences of daily function; (2) pessimistic attitudes toward their conditions/prognosis; and (3) self-perceived burden related to families. Conversely, four themes revealed attributes to social roles: (1) maintaining their roles in families; (2) experiencing supports from family and friends; (3) being content despite LBP; and (4) enjoying social activities. Cultural differences between Switzerland and Hong Kong were related to social circles and offers from the healthcare system, influencing individual experiences and perceptions.

Discussion: Although chronic LBP may negatively impact older adults, individual approaches as well as social and health system supports influence older adults' attitude toward their pain and self-management strategies.

Developing effective and culturally sensitive interventions for an elderly population with chronic LBP can be challenging but essential for the development of innovative healthcare services tailored to the population's needs. The methodological approach used for this research project establishes the framework for developing and evaluating complex interventions.

KEYWORDS

chronic low back pain, older adults, qualitative research, culture, healthcare services, community-dwelling

Introduction

The average human life expectancy of people aged 60 years or above is expected to increase continuously worldwide given the improved health care delivery and technologies (1). The United Nation has estimated that by 2050, of the multiple health issues, low back pain (LBP) will be the most prevailing health condition in older adults that leads to functional limitations and disability worldwide (2, 3). Several population-based studies (including Hong Kong) have estimated that the 1-year prevalence of LBP (regardless of chronicity) in community-dwelling older adults ranged from 13% to 50% (4, 5). Importantly, the prevalence of chronic LBP increases with age (6, 7) and older adults are more vulnerable to develop chronic LBP. Chronic LBP is defined as pain in or near the lumbosacral spine with or without leg pain that lasts for at least 3 months (8). A recent large-scale Swiss study has shown that up to 78% of community-dwelling older adults aged ≥65 years experienced chronic LBP (9), and that 17% of people from this age group have back pain several times a week, and another 17% several times a month (10). Similarly, a population-based study in Hong Kong found that approximately 30% of people aged above 60 years experienced chronic LBP (11). Older adults with chronic LBP experience problems in mobility, self-care, and emotions (9).

Multiple biopsychological factors have been attributed to the high prevalence of chronic LBP in older adults. Older adults are known to have high pain sensitivity because of age-related reduced brain activity responsible for endogenous (controlled by the central nervous system) pain modulation processing (12, 13), and lower pain thresholds (14, 15). The presence of comorbidities or spinal degeneration (e.g., lumbar spinal stenosis) in older adults may also worsen the physical function of patients with chronic LBP (16, 17), and reduce their treatment compliance (18). Compared to older adults without comorbidity, older adults with one or at least two comorbidities are 3 and 5 times more likely to have chronic LBP, respectively (14). Of various co-morbidities, psychological distress (e.g. depression and anxiety) is known to be an important risk factor for chronic LBP and LBP-related disability in community-dwelling older adults (19). Given the high prevalence of in older adults (20), and close association between depression and LBP, it is not uncommon to find older adults with chronic LBP and concomitant depression.

The high prevalence of comorbidities and frailty in older adults may result in very different perceptions and experiences of chronic LBP as compared to working-age adults (21). Older adults need to face multiple age-related physical and psychosocial challenges (e.g., deteriorated physical strength and mental capacity, comorbidity, the loss of loved ones, an altered social role, and financial constraints) that may compromise their LBP recovery and well-being (22). Additionally, chronic regional/widespread pain in older adults can increase their risk of psychological distress (23, 24) and social isolation, which in turn may compromise their health-related quality of life, and increases their risk of cardiovascular diseases and mortality (25). Furthermore, the chronic LBP experience in older adults may be modified by their way of living and social support (26). For instance, older adults residing alone may experience more pain and psychological challenges.

People living in Switzerland and Hong Kong have similar life expectancy: men's life expectancy at birth is 81.6 years in Switzerland and 82.1 years in Hong Kong, while women have a life expectancy of 85.4 years in Switzerland and 88.1 years in Hong Kong, making the top of the list of industrialised countries (27). While Switzerland has about a population size comparable to Hong Kong the two jurisdictions have different healthcare systems.

Switzerland's healthcare system is highly decentralised (28) as each of the 26 cantons has some power over key operations. The Swiss Federal Law on Compulsory Health Care (LAMal), however, requires all Swiss residents to buy private health insurance. The private health insurances are supervised by the state and the cantons, and provide coverage in case of sickness, accidents and maternity. Additional private insurance can be purchased to complement basic coverage (e.g. private hospitals, dental care) (28). While the quality of the Swiss healthcare system is high, it is one of the most expensive one in the world. As of the latest figures, Switzerland's health expenditure represented 11.3% as a fraction of gross domestic product (GDP) (29).

Hong Kong's healthcare system offers public hospital care comparable to the NHS (30), yet only requires 5.9% of Hong Kong's GDP (27). The Food and Health Bureau is responsible for resource allocation and healthcare policies, as well as supervising the Hospital Authority (HA) organised to serve the entire population with subsidised healthcare (31). A recent study investigating Hong Kong's longevity came to the conclusion that Hong Kong has the lowest cardiovascular mortality rate and few transport accidents due to low car ownership, low alcohol consumption and an excellent transport system (27). However, Hong Kong also has many high-quality private healthcare service providers in primary, secondary, and tertiary care settings to serve those who can pay for the medical expenses by themselves or paid by private health insurance.

Apart from the distinct healthcare systems, Western and Chinese cultures seem to deal differently with life challenges. In Western cultures, individualism is the social norm whereas "Chinese culture advocates collectivism" (32). Furthermore, Leung and Sung-Chan (32) argue that it is important for Chinese people to maintain a harmonious interpersonal relationship while simultaneously modify their attitude and behaviour to meet what is expected from them within their social system. This is in line with Leventhal et al.'s (33) perceptual-cognitive approach that explains how people vary in their representation of health and illness according to their socio-cultural background. According to Leventhal's theory, people with chronic pain make sense of their experience by drawing on their knowledge and beliefs (33). Representations and beliefs regarding illness and health are constructed within a social context, and therefore, it is interesting to know whether there are differences between older people with chronic LBP from Eastern and Western cultures.

Yet, as shown in this introduction living a long life does not necessarily mean living without chronic LBP. Given the complexity and adverse consequences of chronic LBP in older adults, it is essential for various stakeholders (e.g., allied health professionals or social workers) to gain an in-depth knowledge of the possible impacts of chronic LBP on older adults' daily life and overall experience of health. The findings can guide the development of more effective mono- or interprofessional pain management interventions for this largely heterogeneous group, as well as providing services adapted to the target population.

Against this background, the aim of this collaborative research project between Switzerland and Hong Kong was to illuminate older adults' experiences of living with chronic LBP and its implication on their daily lives in Western and Eastern cultures.

Methods

Participants and data collection

Twenty-five older adults experiencing chronic LBP living in Switzerland or Hong Kong were recruited through health professionals (GPs, physiotherapists), or community centres. To be eligible for the study, participants were required to be aged 65 years or above, and have LBP in or near the lumbosacral spine with or without leg pain for at least 3 months in the last 12 months (8). Using semi-structured interviews, participants shared their lived experiences regarding chronic LBP and its implications on their daily life (34). The interviews were recorded in the local language (French or German in Switzerland, Cantonese in Hong Kong) and transcribed "ad verbatim" in their entirety in the original language (35). By using a qualitative approach, participants can share their experiences regarding chronic LBP, and evaluate its implications on their daily life. Pilot interviews were conducted to control suitability of the overarching questions. An interview guide (Appendix) was used to ensure transparency and validity of the approach (36). Interviews lasted for approximately one hour. In qualitative studies, the questions of sampling and sample size are recurrent. Using a purposive sampling strategy is considered appropriate for an exploratory qualitative study, as the intention is not to have a representative sample but to get an in-depth understanding of a specific phenomenon from a variety of people who can talk about it (37). Given the exploratory nature of this study, the number of participants was limited to maximum of 15 in each country. According to a recent empirical study (38), recurrency of themes with each additional interview (also known as code saturation) was reached after nine interviews. However, the authors recommended to use between 16 and 24 interviews to reach meaning saturation.

Data analysis

An inductive thematic analysis was used using a shared coded book in English (39). The six steps described by Braun and Clarke (39) are as follows (p 87):

Step 1: Becoming familiar with the data (transcribing data, reading and rereading data, jotting down ideas),
Step 2: Generating initial codes (coding systematically across data set, collating data),
Step 3: Searching for themes (collating codes into themes, gathering data relevant to each theme),
Step 4: Reviewing themes (checking themes, generating thematic map),
Step 5: Defining themes (refining specifics of each theme and overall story of analysis, generate names of themes),

Step 6: Writing-up (selecting compelling extracts, final analysis, relating analysis back to research question and literature).

The particularity of this research team is that while English was the shared language, none of the interviews were conducted in English, but in French, German and Cantonese. Step 1 of the thematic analysis was done by each country team separately. Qualitative data analysis software program (NVivo, released in March 2020) was used for the coding and as mentioned above, the codebook was shared (Step 2). The Swiss and Hong Kong research teams discussed themes first separately (Step 3) before engaging in collaborative analysis until a consensus was established (Step 4), taking into consideration of cultural specificities. When defining themes (Step 5), country teams revisited the original data for confirmation. The write-up (Step 6) was done collaboratively, allowing for a final analytic step for theme construction. Thematic analysis across languages and cultural divides was an interesting endeavour and a methodological approach worth discussing about in an article later-on. Ethical approval was obtained from the respective local ethic committees in Switzerland (CER-VD No 2021-00241) and The Hong Kong Polytechnic University's Ethics Committee (No HSEARS20210128001).

Reflexivity was adopted throughout the study to ensure scientific rigor (36). Specifically, reflexivity is defined as a thoughtful and conscious process that includes continuous evaluation of subjective responses, interpersonal dynamics, and the research process itself (40). Additionally, a coding manual accessible to all members online was used throughout the data analysis to improve the transparency of the process and to help guide methodological steps.

Results

Table 1 summarises the characteristics of all participants ($n = 25$). Seven men and six women in Switzerland, and 12 women from Hong Kong (aged 68 to 92 years) participated in the study. The majority of participants (64%; $n = 16/25$) was married, while six participants (24%) were widowed, and three divorced ($n = 3$; 12%). Two participants from Hong Kong were excluded because one participant had acute back pain and the other participant was only 62 years old. Participants in Switzerland were recruited through physiotherapy and medical private practices, while participants in Hong Kong were recruited in Community Centres where people gathered to attend classes and talks, and to meet friends. The socio-economic status in Hong Kong is rather low as evidenced by the fact that half of the Hong Kong participants live in public housing and receive support from the Comprehensive Social Security Assistance Scheme (CSSA). These data are not relevant in Switzerland as public housing does not exist and all adults older than 65 years receive a social security subsidy.

Analysing the participants' professional backgrounds in the two regions, nearly half of the Swiss sample were white-collar workers (clerical, professional and managerial jobs) before retirement, whereas most participants in Hong Kong were blue-collar workers (cleaner, factory worker, hardware and grocery store workers) before retirement. Hiking, gardening, traveling and volunteering were the most common current leisure activities of Swiss participants, while doing exercises, walking/hiking and eating dim sum were the most frequent activities done by Hong Kong participants. Eating dim sum (going for a tea in an European setting) is an important social activity in Hong Kong. As the current study adopted convenience sampling, it happened that only female participants were recruited in Hong Kong while 50% of Swiss participants were men.

Despite different socioeconomic and cultural context, our analysis revealed some common themes but as hypothesized also some important differences.

The common themes were related to negative perceptions/experiences: (1) interferences of daily function (including sleep); (2) pessimistic attitudes toward their conditions/prognosis; and (3) self-perceived burden related to families and avoidance of talking about their pain with families.

Conversely, four themes revealed attributes to social roles: (1) maintaining their roles in families (e.g., housework); (2) experiencing supports from family and friends; (3) being content despite LBP; and (4) enjoying social activities. Cultural differences between Switzerland and Hong Kong were related to social support networks and opportunities/offers from the health and social system, influencing individual experiences.

Negative experiences

Interferences of daily function

Chronic LBP affected older adults' activities in daily life, since many of them reported difficulties in walking, sitting and prolonged standing. Some older adults had trouble in doing housework and/or carrying heavy objects, while others did not go out or drive any more.

> Sometimes I feel exhausted when I am doing housework, for example, when I stand for a long time. I need to do it for a while and sit for a while. (HK04_F_81)

> I can do this whole part of the house for you, including the dusting, all that, clean. But I can do it in half a day, I would say, because I'm a little bit… If you see something that's dirty, you go all the way, you finish your job. But now I

TABLE 1 Participants' characteristics.

Region	ID	Gender	Age	Civil status	Previous professions	Current occupations/leisure activities
Switzerland	S01_M_68	m	68	Divorced	Mechanic, technologist	Playing guitar, walking/hiking group
	S02_M_92	m	92	Widower	Carpenter	Retired
	S03_M_75	m	75	Married	Factory, construction worker, gardener	Traveling, gardening
	S04_F_70	f	70	Married	Housewife, kiosk owner	Playing board games, walking
	S05_M_72	m	72	Divorced	Field service (sales)	Riding motorbike, walking, breeding spiders
	S06_M_73	m	73	Married	Police ambulance driver	Retired
	S07_M_73	m	73	Married	Law, trade	Working as a lawyer, store managing, gardening
	S08_F_75	f	75	Married	Law	Taking care of grandchildren, travel
	S09_F_85	f	85	Married	Farmer, cook	Retired
	S10_F_69	f	69	Divorced	Secretary	Volunteering
	S11_F_74	f	74	Married	Employee (university degree)	Working as a translator, housing, traveling, taking care of grand-children
	S12_F_74	f	74	Married	Employee	Volunteering, teaching, hiking, taking care of grand children
	S13_M_78	m	78	Married	Employee, law, judge	Volunteering, skiing, walking, gardening
Hong Kong	HK01_F_83	f	83	Widow	Housewife	Going to elderly centre, eating dim sum with friends, travelling
	HK02_F_68	f	68	Married	Housewife	Doing housework, doing exercise, texting with friends (WhatsApp), travelling with friends, going to elderly centre
	HK03_F_75	f	75	Married	Travel agent	Going to gym, doing exercise, fitness class, yoga class, climbing, swimming, walking, church activities, watching "Youtube", texting with friends (WhatsApp)
	HK04_F_81	f	81	Married	Domestic helper	Doing exercise, going to elderly centre, eating dim sum with friends, visiting relatives, doing housework
	HK05_F_73	f	73	Widow	Clerk	Hiking, eating dim sum with friends, going to elderly centre, dancing, visiting elders, cycling machine
	HK06_F_75	f	75	Married	Factory worker	Walking, cycling, eating dim sum with friends, volunteer (visiting elders), taking grandchildren to school, going to elderly centre
	HK07_F_85	f	85	Widow	Housewife	Doing housework, walking, weaving/handicraft, eating dim sum with daughters, going to elderly centre
	HK08_F_80	f	80	Married	Tea seller/ factory worker	Volunteering (dancing class helper+ councillor's office + visiting elderly), doing exercise, eating dim sum, going to elderly centre, doing housework
	HK09_F_76	f	76	Married	Hardware business owner	Doing exercise, using smartphone, doing housework, browsing internet (Youtube), going to elderly centre, going to church and park
	HK10_F_72	f	72	Married	Cleaner	Doing exercise, doing housework, going to elderly centre, phonecall with friends, eating dim sum with children
	HK11_F_81	f	81	Widow	Grocery store worker	Doing housework, doing exercise, going to elderly centre and Po Leung Kuk, taking photos, walking in the park
	HK12_F_84	f	84	Widow	Accountant	Doing exercise in the park, reading books and newspaper, phonecall with friends

> can't. I do half, half a day, and the next day, another half day. (S12_F_74)

> Well, now, over time, for example, I told you I was singing in a big chorus. So, the fact of standing for a long time and carrying the score. And then to be carried away by the emotion, the music and everything that goes with it, it's starting to become difficult for me, but I haven't decided yet that I want to stop because of that, but sometimes I say to myself I'd rather have a lectern to put my score on it. (S13_M_78)

> I used to take the car, to have a drink at noon or 11am. Now I don't go out anymore. I hardly drive either. My wife and daughter tell me "You have to give your driver"s licence back, because you don't drive any more", I say well, we'll see, it's still up to me, for the moment. (S06_M_73)

Activities of daily living were not possible for participants in the same way as before or needed to be adjusted to the current possibilities and capacities. All participants realised that there were adaptations to be made, either to interrupt activities (HK04_F_81) as they were not able to do them without taking a rest, use more time to accomplish certain activities (S12_F_74) or use assistive devices to help overcome limitations (S13_M_78).

Pessimistic attitudes toward their conditions/ prognosis

Participants expressed that there was no cure for them, that the aging process would not allow them to be free of pain and that pain would actually stay with them "till the end of her life". It became also evident in our data, that worries were closely linked to back pain, independent of the participants' origin and cultural context.

> I am worried, because many people said it can't be cured. It's hard to cure it at my age. (HK10_F_72)

> I can do nothing. I feel … sometimes desperate because of the incurable condition. (HK03_F_73)

> I have always back pain, so that's what I am ending up being worried about. (S06_M_73)

Self-perceived burden related to families and avoidance of talking about their pain with families

Becoming a burden for family members was voiced as an important issue, in particular in Hong Kong. As illustrated in the following quotes, it even became existential.

> I am unhappy because I have done less housework … I once thought that it could be better if I died. Don't worry, I won't commit suicide. However, I think in this way, maybe it would be better if I die. I won't commit suicide because I don't have the courage to do it … I feel like I am giving them trouble. For example, when I tell them (family members) that I have LBP, they will just reply "Be careful and do more exercise!" They don't understand that it's useless to do more exercise … I am afraid of becoming a burden to them. If I can't walk anymore, they will need to assist me to go to the toilet. Many things will be affected, including my daily life. (HK06_F_75)

> My children seldom visit me because they are busy. They only make phone calls with me during holidays. They only come back to have dinner when it is my husband's birthday. They rarely visit us … I rarely chat with my family members. I don't want them to worry about me. Sometimes my daughter will find someone to take care of us [interviewee and her husband]. However, my home has little space. Hence, I don't want her to find someone … I seldom discuss my things with others. I don't want to increase their burden. Further, there's nothing they can do to help me. I rarely talk about this with my children. It's not necessary to talk about this. (HK04_F_81)

> Very interestingly, sometimes I feel helpless due to the intense pain. (HK03_F_75)

Family structure and respect for elders are inherent to the culture in Hong Kong. The importance of family is a core social value for Chinese, and is consistent with collectivism within this culture. Sung (41) argues that filial piety (responsibility, respect, sacrifice and family harmony) influences children's attitudes towards their elders. While one participant (HK06_F_75) saw herself as a burden, another participant (HK04_F_81) deplored that her children did not have time for her.

Social roles

Results revealed the importance of social roles for the older adults with chronic LBP. This theme had different aspects. While our participants indicated that they aimed to maintain their roles within their families, they also insisted on the fact that their families supported them, both psychologically or financially. In particular in the Hong Kong context, social roles were clearly described with children supporting their parents.

Maintaining their roles in families (e.g., housework)

It was considered a role of a spouse to take care of the partner and the children, as illustrated in the quotes from a Hong Kong and a Swiss culture.

> Now I need to take care of my old husband. I often use the wheelchair to bring him to the day care centre or wait for public transport. Sometimes when I bring him back with wheelchair, I will hold my lower back. (HK04_F_81)

> Well, there were times when I said to myself "Well, you've lived your whole life with pain", and I'm quite proud of myself for not having poisoned the life of my husband or my children, because I don't complain about it. (…) They didn't believe me when I was a child. So why am I still sharing the live with those I love. I have never made a misery. I put up with it, I've always put up with it. (S12_F_74)

Expectations about social roles were put forward in both regions. As mentioned in the introduction, Leventhal et al. (33) argue that representation of health and illness are shaped by the socio-cultural background. With regard to women's role in society, taking care of family members might be considered as a ubiquitous social role, independent of the cultural background.

Experiencing supports from family and friends

Family members and friends play an important role, either by helping in day-to-day activities, giving advice, or supporting the older adult financially.

> At that time my husband was still alive. He bought the cooking ingredients and cooked meals for us. I was in severe pain … My sons also give me money from time to time … My son told me I can live longer if I am careful. The most important thing is to stay healthy. (HK11_F_81)

> Three sons sent me to a hospital. I was sent to the hospital very early. Here is close to the Hong Kong Adventist Hospital in Tsuen Wan. Therefore, I received treatment there. My children brought me there. (H08_F_80)

> They just reminded me to be careful when I am eating and walking. (HK06_F_75)

> My friend also take care of me from time to time. My friend cooks meals for me. (HK12_F_84)

> My wife is here, if I have to put some of the cream on my back, well, she can do it. (S06_M_73)

A Swiss participant mentioned that some of his close friends actually did not know about his chronic pain.

> Many do not know that I have low back pain, many do not know. That is- I went this morning to a gathering [Apéro] at the lake with friends. Then I said that I have to go as I have an appointment with the physio this afternoon and an interview with question mark [pointing to interviewer, laughs]. "Ah what do you have with the back? Why do you need to go to the physio? Then I said: "another time" because I really had to go. But many do not know, as well people who are quite close to me, they do not know. (S05_M_72)

Maintaining social roles within family was considered important by participants. However, depending on the cultural context, some information regarding their health problem was not shared widely within the outer circle of family.

Being content despite LBP - coping

Participants, even though in pain and with limitation of activities, still felt rather optimistic and content. In addition, it was important for them to receive effective treatment for their back pain.

> I am an optimistic person. I have been optimistic since I was young. I don't feel sad … I won't be unhappy. I am satisfied. I have food and shelter. I won't ask for more … I am not worried about it. (HK07_F_85)

> I'm not worried. The most important thing is to receive effective treatment. It's great to receive treatment in Yan Chai Hospital, because it's not too expensive. (HK09_F_76)

> I've always had a good life, despite the pain. So it hasn't affected my morale. If it affects me, if it disturbs my morale, it's when I have other concerns, but not for my back. The back, I came into the world with it, so I'm going to leave with it. (S12_F_74)

> The body is part of the man, the human being. (…) Without body there is no psyche, it is part of it. The two-, it's the two elements, as we say the body and the soul. So, the body is what accompanies the soul, it's the two. I believe in the anima, in the soul, that means that when there are psychological problems, you perform physical activity, and you forget. And when you have physical pain, you try to escape through intellectualism, and then like that you find a balance. (S07_M_73)

Participants chose an active approach to improve the situation: as one participant considered herself a "hardworking individual" – as illustrated in the next quote – she will do her exercises (HK03_F_73) because she wanted to avoid surgery. Another participant would go for a walk even when tired (HK07_F_85).

> I think it was more related to my physical condition. I believe that I need to accept the fact and find methods to improve the situation. I am hardworking because I don't want to do the back surgery. I know I won't be able to do exercise after I return home today, that's why I already did the exercises before lunch. (HK03_F_73)

> I only feel tired. It's not a severe disease. It's fine if I take some rest. Nowadays I don't work anymore. When I feel tired I will go to sleep. When I wake up, I will take a walk if I am still tired. The back fatigue doesn't matter." (HK07_F_85)

It was also mentioned that the Swiss health insurance provided the services they needed to get better.

> Well, listen, except that… When we are insured, we are very well insured. But that's since the moment when we retire. Except for our doctor, we're very happy. We don't need anything else. We have our own medication. (S12_F_74)

The theme presented here reflects how participants adapted to the fact that they experienced LBP but they also gave meaning to other aspects of life or rely on quality healthcare services in order to get better.

Enjoying social activities

As most of the Hong Kong participants were interviewed at an elderly centre, some of them expressed their opinion on social activities, which tended to be positive.

> There were many "kaifongs" (街坊 ; neighbours). I went to Cantonese restaurant with them. (HK01_F_83)

> Now I am just a volunteer. For example, I am a helper in a dancing class. (HK08_F_80)

In Switzerland, social activities were also considered important, as some of the participants enjoyed traveling (S03_M_75) while others went hiking and ski touring.

> Well I go as well- we go out, we have the general ticket [*allowing for free train travel all around Switzerland*] and then we take often the train. The pain – it is little actually during the day, that I am limited. (S03_M_75)

> It depends on the time and the form of the crisis. Yes, that's it. And when I walk, I really like walking. But if I go for more than two and a half, three hours, then it really starts to pinch and pull down my leg. That's it. […] And in the end, I really enjoy walking and admiring the landscape. […]We walk in the snow, where the snow carries us. (S12_F_74)

> For example, I don't do downhill skiing anymore because it gives a lot of jolts in the lower back, among other things, and that doesn't suit me. I do ski touring still quite regularly when it's good, when there's snow. And since I belong to the Alpine Club. (S13_M_78)

Social activities helped older adults with chronic LBP to continue being part of a group, be it by volunteering (HK08_F_80), going to a restaurant (HK01_F_83), traveling (S03_M_75) or enjoying activities in nature (S12_F_74 and S13_M_78).

Discussion

The aim of this collaborative research project between Switzerland and Hong Kong was to illuminate older adults' experience of living with chronic LBP and to describe the implication of chronic pain on older adults' daily life in Western and Eastern cultures. The findings revealed a complex interaction between individual and social consequences of chronic LBP in an aging population. The following three subsections will summarise the study results: (1) adjustments and adaptations for activities of daily living; (2) social support and cultural influences; and (3) differences of healthcare systems in Hong Kong and Switzerland.

Adjustments and adaptations needed for activities of daily living when living with chronic LBP

While chronic LBP is known to adversely affect the well-being of patients, the types of responses and/or severity of distress/suffering experienced by different individuals vary considerably. Given that chronic pain is not purely a physical problem (42), the multidimensional interactions among biological, psychological, and social factors often result in differential experiences of individuals. Since older adults need to face various age-related physical and psychosocial changes (e.g., decreases in pain sensitivity or fitness (14, 43, 44), altered life goals and social roles, or reduced/terminated monthly income), these changes may affect the ability or experiences of older people in managing chronic LBP (45, 46). Similarly, the presence of chronic LBP in older adults may lead to fear avoidance behaviour, concerns about underlying severe pathology (47), reduced physical activity and deconditioning, or compromised social and family functioning (48, 49). Therefore, clinicians not only need to use age-specific assessment tools to comprehensively evaluate the condition of older people with LBP (50), but also need to educate these patients and/or their caregivers regarding the aetiology and trajectory of chronic LBP, as well as potential coping strategies.

Our study revealed that older adults with chronic LBP coped with their pain differently. While some people were pessimistic about their condition, others dealt with their pain positively. Although their differences may be attributed to individual personal traits, it may also be ascribed to their differential acceptance of living with chronic LBP (like other chronic diseases). Leventhal et al. (33) argue that illness representation and coping strategies are important to understand how people adapt to their physical problems. As socio-cultural background influences the way people with chronic pain live and manage their pain, it is important to uncover the underlying cultural beliefs and values. In order to facilitate older adults with chronic LBP to effectively cope with their pain and optimize their physical function, clinicians should educate these patients regarding the characteristics of chronic LBP (e.g., central pain amplification, psychological influences, and pain without biological value), provide proper self-management techniques, and manage their expectations (49, 51). For example, exercise is an evidence-based intervention for patients with chronic LBP (52–54) recommended by multiple clinical guidelines (55, 56). It is essential for older adults with chronic LBP to understand this important active approach in managing their pain. Other techniques, such as pacing and goal setting are useful strategies for the self-management of chronic pain (57). Given that chronic LBP is always associated with psychosocial issues, new cognitive behavioural therapy approach, namely acceptance and commitment therapy has been shown to be effective in improving clinical outcomes of older adults with chronic pain (58–61). This novel approach uses metaphors, experiential exercises, mindfulness practice, and cognitive defusion to help older adults accept the good and difficult feelings/emotion associated with pain in the journey of pursuing values-based action (e.g., a fulfilling family role). Through multimodal approaches, older adults with chronic

LBP can better manage their pain and associated psychological health.

Social support and cultural influences

Results revealed that maintaining social roles is important, which aligns with the findings from a systematic review of qualitative studies exploring patients' experiences of chronic LBP (62). Although the patients included in the review were not exclusively older adults (the age range was 17 to 84), the analysis revealed that relationships with family and friends was a key theme identified across all 27 studies. Specifically, friends and family provided emotional and tangible support, and helped to moderate "negative lower mood or even depression" (p. 292). At the same time, maintaining their social roles in the presence of chronic LBP related disruptions was identified as a problem and challenge that resulted in negative emotions such as guilt (e.g., feeling like a burden) and anger. The researchers also found that only one study highlighted the need to understand chronic LBP within the context of culture (e.g., cultural values in Iran that emphasize "duty to family" that contributed to the stress of the patients in juggling their LBP with their respective roles in the family).

The findings of the current study suggest that there is a need to take into consideration differences related to cultural aspects and society in order to help older adults with chronic LBP. In the Hong Kong context, co-residency of multiple generations is a common practice due to traditional cultural Confucian values (63) and financial reasons (e.g., Hong Kong has one of the least affordable housing markets in the world) (64). While this setting may provide good family supports, it may cause a lot of conflicts or confrontations if the needs of older adults are not met or the different generations have conflicting views on family roles and obligations (64, 65). For example, Holroyd (2003) found in her ethnographic study examining caregivers' perspectives toward chronically ill older adult members in Beijing and Hong Kong, that in both contexts, there was an emerging trend transitioning away from "Confucian-informed duty-centered family obligations to one in which obligations are now centered on relationships" (65), p. 316).

In Switzerland, the generation of the 65 + years old is still quite traditional, yet autonomous when it comes to their life choices. In particular, women maintain their tradition to take on the role of "guardian of family and extra-family relations" (66). Yet, the society is changing, with only 1% of households constituted with more than two generations, and 32% of older adults living alone (66). In the Swiss culture where self-determination is important, friends and a wider social circle can sometimes replace family relations. Therefore, differences regarding what is considered an acceptable social circle to discuss health issues (close family, friends, community) should be taken into consideration when designing interventions for older adults with chronic LBP.

Collectively, culture can play an influential role in shaping the experience of chronic LBP among older adults. Future research should examine the role of culture in shaping the chronic LBP experience, not only cross-culturally but also between generations.

Comparison between Swiss and Hong Kong healthcare systems

As mentioned above, differences between Switzerland and Hong Kong were related to social support networks but also to opportunities/offers from the health and social system, thereby impacting individual experiences with chronic LBP. As discussed in the introduction, the Swiss and Hong Kong healthcare systems are both of high quality; yet, access to services can become problematic in Hong Kong, but not in Switzerland.

More specifically, three quarter of the Swiss population between 65 and 74 years perceives their general health as good or very good, the best score in comparison with other European countries (67). Höpflinger argues that the health status of older people is closely associated with economic and socio-political factors and that the social and economic safety is related to the health of the aging population (67). The Swiss health care system (even though very expensive) allows for an excellent coverage of healthcare needs of the population.

Looking at the social security and health insurance schemes in both regions, it can be noted that there are remarkable differences. While Hong Kong's public healthcare system is quite efficient and cheap, yet with long waiting times, access to the Swiss healthcare system is unproblematic but can be very costly (e.g., out-of-pocket payment, co-payment, deductible, etc.). In particular, adults aged 80 years or older are in need of supplementary payments from the Old Age Insurance because they do not have sufficient funds to cover their healthcare costs (66). Financial hardship was part of the discourse in our study.

In sum, until now, multiple studies identifying factors that are related to or may modify chronic LBP outcomes in older adults have some limitations as they often used self-reported questionnaires to examine the influences of chronic LBP in older adults (68), without listening to the concerns or needs of older adults with chronic LBP (69). Although some qualitative studies have been conducted to investigate lived experiences of patients with chronic LBP (70–73), most of them did not focus on the experiences or needs of older adults. This qualitative study was able to shed light on consequences of chronic LBP for older adults allowing for a better understanding of their needs, and taking into consideration the contexts in which they live and receive health care services. While some qualitative studies have investigated the impacts of chronic LBP on various facets of life (e.g. coping strategies, social roles, attitudes towards treatments) in older adults (74, 75), often these studies investigated health issues in older adults residing in a specific setting, such as Nursing homes (68, 76) but not simultaneously in two different cultures. This qualitative research examined the distinct challenges, concerns or experiences faced by older adults with chronic LBP living alone or with family in the community setting, aiming to identify cross-cultural specificities in order to be able to better plan and implement adequate health and social service interventions. Given the growing trend of globalization and global mobility, it is not uncommon for people from different cultures to live in the same region or country. Clinicians should be aware of cultural differences (e.g., self-perceived roles in a family) in older adults, and provide proper medical services and psychosocial supports to older people with chronic LBP so as to enhance their abilities in self-managing chronic LBP.

The current results are crucial as they are the first step for developing and evaluating complex interventions according to the Medical Research Council's framework (77). Developing effective and culturally sensitive interventions for an older adult population experiencing chronic LBP can be challenging and, therefore, a systematic approach is required to propose an effective, feasible and person-centred intervention. The systematic methodological approach allows for the identification of important aspects crucial for successful interventions for older adults with chronic LBP.

Some limitations of this study should be noted. Participants enrolled in this study were selected through different gatekeepers: In Switzerland, medical and physiotherapy ambulatory practitioners were referring participants, while in Hong Kong community centres were the site of recruitment. These two different approaches are not comparable and might make comparison across the two regions more challenging. However, results indicate that there were common themes across regions despite different socio-economic status and professional background. A second challenge was related to the fact that the research team worked across languages and long distances, in particular, the pandemic did not allow for research teams to engage in face-to-face interactions as planned and had to resort to video-conferences, shared NVivo analyses and online documentation.

An interesting and noteworthy point of discussion from this cross-language study is related to translation. Our research team had several discussions regarding the role and implications of translation in our study, and in particular what paradigm we should adopt. On the one hand, for example, there is a common view in the literature that the translation process is technical and neutral, where the task simply involves exchanging words from one language to another, verbatim (78). On the other hand, there is the view that in cross-language research, the strive towards equivalence may not be ideal (79). There are words, phrases, socio-cultural idioms, and proverbs that exist in different languages that cannot be translated. Further, scholars like Temple (79) warned against "the linguistic imperialism central to the unquestioning use of English as a baseline language" (p. 847). Our team had numerous discussions and reflected on our own understandings and use of multiple languages. For example, it is noted here that our team is very unique in terms of (inter-) cultural competencies because one researcher is a Canadian Chinese, while another researcher is a Hong Kong-born Chinese who lived in North America for approximately six years. Therefore, the Hong Kong researchers are bilingual researchers who can communicate fluently in English. Meanwhile, on the Swiss team, one researcher speaks German, French and English, as well as has lived in the USA and Hong Kong for approximately seven years each. The other Swiss researcher is also trilingual (French, German, English) having lived in several European countries, therefore allowing for an in-depth understanding of languages and cultures. Our unique multi-cultural research team enabled the discussion of codes and concepts with ease.

The implication for other qualitative researchers who are interested in conducting cross-cultural studies is that they should collaborate with the right multi-lingual and (inter-cultural) collaborators in the countries of interest (especially for low-income countries where the English proficiency of local researchers may be relatively low). During our discussions, we came to the agreement that the paradigm suggested by Temple (79) should be adopted for our study. Overall, this experience prompted us to deeply reflect on the role and impacts of translation in future cross-language studies, and on strategies to enhance the translation process and to mitigate negative effects of it.

Conclusion

Although chronic LBP may negatively impact older adults in different aspects, individual approaches as well as social and health system supports influence older adults' attitude toward their pain and self-management strategies. Themes identified were related to negative perceptions/experiences: (1) interferences of daily function; (2) pessimistic attitudes toward their conditions/prognosis; and (3) self-perceived burden related to families. Conversely, four themes revealed attributes to social roles: (1) maintaining their roles in families; (2) experiencing supports from family and friends; (3) being content despite LBP; and (4) enjoying social activities. Developing effective and culturally sensitive interventions for an elderly population with chronic LBP can be challenging but is essential for the development of innovative healthcare services tailored to the population's needs. The methodological approach used for this research project establishes a framework for developing and evaluating complex interventions.

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 Cantonal Ethics Committee (CER-VD); Hong Kong Polytechnic University Ethics Committee. 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

VS, AYLW, EO and CK designed the study, performed data collection and analysis and reviewed and revised the manuscript. MM, CWYW, and MMPK implemented the study (data collection and analysis). All authors contributed to the article and approved the submitted version.

Funding

The study was funded by the Swiss Bilateral Science and Technology Programme with Asia (Bridging Grants BG 03-072020) supported by the State Secretariat of Education, Research and Innovation (SERI) Switzerland.

Acknowledgments

We would like to thank our collaborating institutions for recruitment and Fabienne Keller for her support during data collection and transcription.

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

1. Tse MM, Pun SP, Benzie IF. Pain relief strategies used by older people with chronic pain: an exploratory survey for planning patient-centred intervention. *J Clin Nurs*. (2005) 14(3):315–20. doi: 10.1111/j.1365-2702.2004.00976.x

2. Prince MJ, Wu F, Guo Y, Gutierrez Robledo LM, O'Donnell M, Sullivan R, et al. The burden of disease in older people and implications for health policy and practice. *Lancet*. (2015) 385(9967):549–62. doi: 10.1016/S0140-6736(14)61347-7

3. UN D. *World Population Ageing 2009*. New York: United Nations Publication (2010).

4. Leopoldino AA, Diz JB, Martins VT, Henschke N, Pereira LS, Dias RC, et al. Prevalence of low back pain in older Brazilians: a systematic review with meta-analysis. *Rev Bras Reumatol Engl Ed*. (2016) 56(3):258–69. doi: 10.1016/j.rbr.2016.01.004

5. Patel KV, Guralnik JM, Dansie EJ, Turk DC. Prevalence and impact of pain among older adults in the United States: findings from the 2011 national health and aging trends study. *Pain*. (2013) 154(12):2649–57. doi: 10.1016/j.pain.2013.07.029

6. Di Iorio A, Abate M, Guralnik JM, Bandinelli S, Cecchi F, Cherubini A, et al. From chronic low back pain to disability, a multifactorial mediated pathway: the InCHIANTI study. *Spine*. (2007) 32(26):E809–15. doi: 10.1097/BRS.0b013e31815cd422

7. Rudy TE, Weiner DK, Lieber SJ, Slaboda J, Boston JR. The impact of chronic low back pain on older adults: a comparative study of patients and controls. *Pain*. (2007) 131(3):293–301. doi: 10.1016/j.pain.2007.01.012

8. Andersson GB. Epidemiological features of chronic low-back pain. *Lancet*. (1999) 354(9178):581–5. doi: 10.1016/S0140-6736(99)01312-4

9. Ludwig C, Luthy C, Allaz AF, Herrmann FR, Cedraschi C. The impact of low back pain on health-related quality of life in old age: results from a survey of a large sample of Swiss elders living in the community. *Eur Spine J*. (2018) 27(5):1157–65. doi: 10.1007/s00586-017-5427-6

10. Rheumaliga. Rückenreport Schweiz; 2020. 2021.

11. Wong WS, Fielding R. Prevalence and characteristics of chronic pain in the general population of Hong Kong. *J Pain*. (2011) 12(2):236–45. doi: 10.1016/j.jpain.2010.07.004

12. Cole LJ, Farrell MJ, Gibson SJ, Egan GF. Age-related differences in pain sensitivity and regional brain activity evoked by noxious pressure. *Neurobiol Aging*. (2010) 31(3):494–503. doi: 10.1016/j.neurobiolaging.2008.04.012

13. Hackett J, Naugle KE, Naugle KM. The decline of endogenous pain modulation with aging: a meta-analysis of temporal summation and conditioned pain modulation. *J Pain*. (2020) 21(5-6):514–28. doi: 10.1016/j.jpain.2019.09.005

14. Lautenbacher S, Kunz M, Strate P, Nielsen J, Arendt-Nielsen L. Age effects on pain thresholds, temporal summation and spatial summation of heat and pressure pain. *Pain*. (2005) 115(3):410–8. doi: 10.1016/j.pain.2005.03.025

15. González-Roldán AM, Terrasa JL, Sitges C, van der Meulen M, Anton F, Montoya P. Age-related changes in pain perception are associated with altered functional connectivity during resting state. *Front Aging Neurosci*. (2020) 12:116. doi: 10.3389/fnagi.2020.00116

16. Stewart Williams J, Ng N, Peltzer K, Yawson A, Biritwum R, Maximova T, et al. Risk factors and disability associated with low back pain in older adults in low- and middle-income countries. Results from the WHO study on global AGEing and adult health (SAGE). *PLoS One*. (2015) 10(6):e0127880. doi: 10.1371/journal.pone.0127880

17. Wong CK, Mak RY, Kwok TS, Tsang JS, Leung MY, Funabashi M, et al. Prevalence, incidence, and factors associated with non-specific chronic low back pain in community-dwelling older adults aged 60 years and older: a systematic review and meta-analysis. *J Pain*. (2022) 23(4):509–34. doi: 10.1016/j.jpain.2021.07.012

18. Scherer M, Hansen H, Gensichen J, Mergenthal K, Riedel-Heller S, Weyerer S, et al. Association between multimorbidity patterns and chronic pain in elderly primary care patients: a cross-sectional observational study. *BMC Fam Pract*. (2016) 17:68. doi: 10.1186/s12875-016-0468-1

19. Meyer T, Cooper J, Raspe H. Disabling low back pain and depressive symptoms in the community-dwelling elderly: a prospective study. *Spine*. (2007) 32(21):2380–6. doi: 10.1097/BRS.0b013e3181557955

20. Volkert J, Schulz H, Härter M, Wlodarczyk O, Andreas S. The prevalence of mental disorders in older people in western countries - a meta-analysis. *Ageing Res Rev*. (2013) 12(1):339–53. doi: 10.1016/j.arr.2012.09.004

21. Collard RM, Boter H, Schoevers RA, Oude Voshaar RC. Prevalence of frailty in community-dwelling older persons: a systematic review. *J Am Geriatr Soc*. (2012) 60(8):1487–92. doi: 10.1111/j.1532-5415.2012.04054.x

22. Inouye SK, Studenski S, Tinetti ME, Kuchel GA. Geriatric syndromes: clinical, research, and policy implications of a core geriatric concept. *J Am Geriatr Soc*. (2007) 55(5):780–91. doi: 10.1111/j.1532-5415.2007.01156.x

23. Inoue S, Kobayashi F, Nishihara M, Arai YC, Ikemoto T, Kawai T, et al. Chronic pain in the Japanese community–prevalence, characteristics and impact on quality of life. *PLoS One*. (2015) 10(6):e0129262. doi: 10.1371/journal.pone.0129262

24. De Luca K, Wong A, Eklund A, Fernandez M, Byles JE, Parkinson L, et al. Multisite joint pain in older Australian women is associated with poorer psychosocial health and greater medication use. *Chiropr Man Therap*. (2019) 27(1):1–9. doi: 10.1186/s12998-018-0224-9

25. Wilkie R, Blagojevic-Bucknall M, Belcher J, Chew-Graham C, Lacey RJ, McBeth J. Widespread pain and depression are key modifiable risk factors associated with reduced social participation in older adults: a prospective cohort study in primary care. *Medicine*. (2016) 95(31):e4111. doi: 10.1097/MD.0000000000004111

26. Wong AYL, Forss KS, Jakobsson J, Schoeb V, Kumlien C, Borglin G. Older adult's experience of chronic low back pain and its implications on their daily life: study protocol of a systematic review of qualitative research. *Syst Rev*. (2018) 7(1):81. doi: 10.1186/s13643-018-0742-5

27. Ni MY, Canudas-Romo V, Shi J, Flores FP, Chow MS, Yao XI, et al. Understanding longevity in Hong Kong: a comparative study with long-living, high-income countries. *Lancet Public Health*. (2021) 6(12):e919–e31. doi: 10.1016/S2468-2667(21)00208-5

28. Tikkanen R, Osborn R, Mossialos E, Djordjevic A, Wharton G. *International profiles of health care systems*. New York, NY, USA: The Commonwealth Fund (2020).

29. Statistik B-Bf. Health Expenditures in OECD Countries, 2021. Available at: https://www.bfs.admin.ch/bfs/en/home/statistics/health/costs-financing.assetdetail.19524253.html

30. Schoeb V. Healthcare service in Hong Kong and its challenges. The role of health professionals within a social model of health. *China Perspect*. (2016) 2016(2016/4):51–8. doi: 10.4000/chinaperspectives.7118

31. Bureau FaH. Public Healthcare Services (2019). Available at: https://www.fhb.gov.hk/en/our_work/health/phs.html

32. Leung PW, Sung-Chan PP. Cultural values and choice of strategic move in therapy: a case of low back pain in a Chinese woman. *Clin Case Stud*. (2002) 1(4):342–52. doi: 10.1177/153465002236509

33. Leventhal H, Leventhal EA, Contrada RJ. Self-regulation, health, and behavior: a perceptual-cognitive approach. *Psychol Health*. (1998) 13(4):717–33. doi: 10.1080/08870449808407425

34. Mishler EG. *Research interviewing: Context and narrative*. Cambridge, MA, USA: Harvard university press (1991).

35. Bucholtz M. Variation in transcription. *Discourse Stud*. (2007) 9(6):784–808. doi: 10.1177/1461445607082580

36. Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: a review of the literature. *Health Technol Assess*. (1998) 2(16):iii–274. doi: 10.3310/hta2160

37. Campbell S, Greenwood M, Prior S, Shearer T, Walkem K, Young S, et al. Purposive sampling: complex or simple? Research case examples. *J Res Nurs*. (2020) 25(8):652–61. doi: 10.1177/1744987120927206

38. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? *Qual Health Res*. (2017) 27(4):591–608. doi: 10.1177/1049732316665344

39. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3(2):77–101. doi: 10.1191/1478088706qp063oa

40. Finlay L. "Outing" the researcher: the provenance, process, and practice of reflexivity. *Qual Health Res*. (2002) 12(4):531–45. doi: 10.1177/104973202129120052

41. Sung KT. An Asian perspective on aging east and west: filial piety and changing families. In: Bengtson VL, Kim KD, Myers G, Eun KS, editors. *Aging in East and West: Families, states, and the elderly*. New York, NY, USA: Springer Publishing Company (2000). p. 41–56.

42. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science*. (1977) 196(4286):129–36. doi: 10.1126/science.847460

43. Jacobs JM, Hammerman-Rozenberg R, Cohen A, Stessman J. Chronic back pain among the elderly: prevalence, associations, and predictors. *Spine*. (2006) 31(7):E203–E7. doi: 10.1097/01.brs.0000206367.57918.3c

44. Akiyama T, Chikuda H, Yasunaga H, Horiguchi H, Fushimi K, Saita K. Incidence and risk factors for mortality of vertebral osteomyelitis: a retrospective analysis using the Japanese diagnosis procedure combination database. *BMJ Open*. (2013) 3(3):e002412. doi: 10.1136/bmjopen-2012-002412

45. Ikeda T, Sugiyama K, Aida J, Tsuboya T, Watabiki N, Kondo K, et al. Socioeconomic inequalities in low back pain among older people: the JAGES cross-sectional study. *Int J Equity Health*. (2019) 18(1):1–11. doi: 10.1186/s12939-019-0918-1

46. Wong AY, Karppinen J, Samartzis D. Low back pain in older adults: risk factors, management options and future directions. *Scoliosis Spinal Disord*. (2017) 12(1):1–23. doi: 10.1186/s13013-016-0108-5

47. Hall A, Coombs D, Richmond H, Bursey K, Furlong B, Lawrence R, et al. What do the general public believe about the causes, prognosis and best management strategies for low back pain? A cross-sectional study. *BMC Public Health*. (2021) 21(1):1–7. doi: 10.1186/s12889-020-10013-y

48. Camacho-Soto A, Sowa GA, Perera S, Weiner DK. Fear avoidance beliefs predict disability in older adults with chronic low back pain. *PM&R*. (2012) 4(7):493–7. doi: 10.1016/j.pmrj.2012.01.017

49. Dueñas M, Ojeda B, Salazar A, Mico JA, Failde I. A review of chronic pain impact on patients, their social environment and the health care system. *J Pain Res*. (2016) 9:457. doi: 10.2147/JPR.S105892

50. Wong AY, Lauridsen HH, Samartzis D, Macedo L, Ferreira PH, Ferreira ML. Global consensus from clinicians regarding low back pain outcome indicators for older adults: pairwise wiki survey using crowdsourcing. *JMIR Rehabilitation Assist Technol*. (2019) 6(1):e11127. doi: 10.2196/11127

51. Katz J, Rosenbloom BN, Fashler S. Chronic pain, psychopathology, and DSM-5 somatic symptom disorder. *Can J Psychiatry*. (2015) 60(4):160–7. doi: 10.1177/070674371506000402

52. Hayden JA, Van Tulder MW, Tomlinson G. Systematic review: strategies for using exercise therapy to improve outcomes in chronic low back pain. *Ann Intern Med*. (2005) 142(9):776–85. doi: 10.7326/0003-4819-142-9-200505030-00014

53. Van Middelkoop M, Rubinstein SM, Verhagen AP, Ostelo RW, Koes BW, van Tulder MW. Exercise therapy for chronic nonspecific low-back pain. *Best Pract Res Clin Rheumatol*. (2010) 24(2):193–204. doi: 10.1016/j.berh.2010.01.002

54. Pinto SM, Boghra SB, Macedo LG, Zheng Y-P, Pang MY, Cheung JP, et al. Does motor control exercise restore normal morphology of lumbar Multifidus muscle in people with low back pain?–A systematic review. *J Pain Res*. (2021) 14:2543. doi: 10.2147/JPR.S314971

55. Wong J, Côté P, Sutton D, Randhawa K, Yu H, Varatharajan S, et al. Clinical practice guidelines for the noninvasive management of low back pain: a systematic review by the ontario protocol for traffic injury management (OPTIMa) collaboration. *Eur J Pain*. (2017) 21(2):201–16. doi: 10.1002/ejp.931

56. Qaseem A, Wilt TJ, McLean RM, Forciea MA, Physicians* CGCotACo. Noninvasive treatments for acute, subacute, and chronic low back pain: a clinical practice guideline from the American college of physicians. *Ann Intern Med*. (2017) 166(7):514–30. doi: 10.7326/M16-2367

57. Birkholtz M, Aylwin L, Harman RM. Activity pacing in chronic pain management: one aim, but which method? Part one: introduction and literature review. *Br J Occup Ther*. (2004) 67(10):447–52. doi: 10.1177/030802260406701005

58. Scott W, Daly A, Yu L, McCracken LM. Treatment of chronic pain for adults 65 and over: analyses of outcomes and changes in psychological flexibility

following interdisciplinary acceptance and commitment therapy (ACT). *Pain Med*. (2017) 18(2):252–64. doi: 10.1093/pm/pnw073

59. Alonso MA, López A, Losada A, González JL. Acceptance and commitment therapy and selective optimization with compensation for older people with chronic pain: a pilot study. *Psicol Conductual*. (2013) 21(1):59. doi: 10.1111/pme.12885

60. Wetherell JL, Petkus AJ, Alonso-Fernandez M, Bower ES, Steiner AR, Afari N. Age moderates response to acceptance and commitment therapy vs. Cognitive behavioral therapy for chronic pain. *Int J Geriatr Psychiatry*. (2016) 31(3):302–8. doi: 10.1002/gps.4330

61. Alonso-Fernández M, López-López A, Losada A, González JL, Wetherell JL. Acceptance and commitment therapy and selective optimization with compensation for institutionalized older people with chronic pain. *Pain Med*. (2016) 17(2):264–77.

62. Snelgrove S, Liossi C. Living with chronic low back pain: a metasynthesis of qualitative research. *Chronic Illn*. (2013) 9(4):283–301. doi: 10.1177/1742395313476901

63. Ko LS. Solidarity, ambivalence and multigenerational co-residence in Hong Kong. In: Arber S, Timonen V, editors. *Contemporary grandparenting: Changing family relationships in global contexts*. Bristol, YK: Policy Press (2012). p. 91–112.

64. Forrest R, Xian S. Accommodating discontent: youth, conflict and the housing question in Hong Kong. *Hous Stud*. (2018) 33(1):1–17. doi: 10.1080/02673037.2017.1342775

65. Holroyd EE. Chinese Family obligations toward chronically ill elderly members: comparing caregivers in Beijing and Hong Kong. *Qual Health Res*. (2003) 13(3):302–18. doi: 10.1177/1049732302250127

66. Höpflinger F, Hugentobler V, Spini D. *Habitat et vieillissement*. Seismo, Geneva, Switzerland: Seismo (2019).

67. Höpflinger F. Die neue Generation der 'jungen Alten'. Befindlichkeit und Werthaltungen in mitteleuropäischen Ländern. *Psychotherapie im Alter*. (2011) 8(2):155–66.

68. Tse MM, Lai C, Lui JY, Kwong E, Yeung SY. Frailty, pain and psychological variables among older adults living in Hong Kong nursing homes: can we do better to address multimorbidities? *J Psychiatr Ment Health Nurs*. (2016) 23 (5):303–11. doi: 10.1111/jpm.12303

69. Gold DT, Roberto KA. Correlates and consequences of chronic pain in older adults. *Geriatr Nurs*. (2000) 21(5):270–3. doi: 10.1067/mgn.2000.110838

70. Vroman K, Warner R, Chamberlain K. Now let me tell you in my own words: narratives of acute and chronic low back pain. *Disabil Rehabil*. (2009) 31 (12):976–87. doi: 10.1080/09638280802378017

71. Kawi J. Chronic low back pain patients' perceptions on self-management, self-management support, and functional ability. *Pain Manag Nurs*. (2014) 15 (1):258–64. doi: 10.1016/j.pmn.2012.09.003

72. Igwesi-Chidobe CN, Kitchen S, Sorinola IO, Godfrey EL. "A life of living death": the experiences of people living with chronic low back pain in rural Nigeria. *Disabil Rehabil*. (2017) 39(8):779–90. doi: 10.3109/09638288.2016.1161844

73. Toye F, Barker K. "Could I be imagining this?"–the dialectic struggles of people with persistent unexplained back pain. *Disabil Rehabil*. (2010) 32 (21):1722–32. doi: 10.3109/09638281003657857

74. Bailly F, Foltz V, Rozenberg S, Fautrel B, Gossec L. The impact of chronic low back pain is partly related to loss of social role: a qualitative study. *Joint Bone Spine*. (2015) 82(6):437–41. doi: 10.1016/j.jbspin.2015.02.019

75. Lyons KJ, Salsbury SA, Hondras MA, Jones ME, Andresen AA, Goertz CM. Perspectives of older adults on co-management of low back pain by doctors of chiropractic and family medicine physicians: a focus group study. *BMC Complement Altern Med*. (2013) 13:225. doi: 10.1186/1472-6882-13-225

76. Krueger AB, Stone AA. Assessment of pain: a community-based diary survey in the USA. *Lancet*. (2008) 371(9623):1519–25. doi: 10.1016/S0140-6736 (08)60656-X

77. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new medical research council guidance. *BMJ*. (2021) 374:n2061. doi: 10.1136/bmj.n2061

78. Sutrisno A, Nguyen NT, Tangen D. Incorporating translation in qualitative studies: two case studies in education. *Int J Qual Stud Educ*. (2014) 27 (10):1337–53. doi: 10.1080/09518398.2013.837211

79. Temple B. Crossed wires: interpreters, translators, and bilingual workers in cross-language research. *Qual Health Res*. (2002) 12(6):844–54. doi: 10.1177/104973230201200610

Appendix

Interview Guide

Pain experience

1. When you think about the last time you had back pain, can you tell me how it feels like?

Impact on daily life

2. Can you tell me about your experience of back pain and how it affects your life?
3. What are the experiences in living with chronic back pain?

> *For Yourself*
> *For Your friends and family*
> *For Your relationships with your healthcare providers (physician, nurse, therapists, …)*

4. What bothers you the most about your back pain?

Representation of health and illness

5. What do you think might cause your back pain?
6. What is in your opinion the evolution of your back pain?

Coping strategies

7. How do you manage your back pain?

Closing question

Is there anything you would like to tell us that we have not covered yet in this interview?

TYPE Original Research
PUBLISHED 20 September 2022
DOI 10.3389/fpain.2022.901271

Portraying improvement in the management of chronic pain: A multi-modal longitudinal interpretative phenomenological analysis study

Isabella E. Nizza[1], Jonathan A. Smith[1]* and Jamie A. Kirkham[2]

[1]Department of Psychological Sciences, Birkbeck University of London, London, United Kingdom,
[2]Kent Community Health NHS Trust, Ashford, United Kingdom

OPEN ACCESS

EDITED BY
Najmeh Khalili-Mahani,
Montreal Neurological
Institute, Canada

REVIEWED BY
Jasmine Hearn,
Manchester Metropolitan University,
United Kingdom
Joan Simons,
Independent Researcher, Milton
Keynes, United Kingdom

*CORRESPONDENCE
Jonathan A. Smith
ja.smith@bbk.ac.uk

SPECIALTY SECTION
This article was submitted to
Non-Pharmacological Treatment of
Pain,
a section of the journal
Frontiers in Pain Research

RECEIVED 21 March 2022
ACCEPTED 10 May 2022
PUBLISHED 20 September 2022

CITATION
Nizza IE, Smith JA and Kirkham JA
(2022) Portraying improvement in the
management of chronic pain: A
multi-modal longitudinal interpretative
phenomenological analysis study.
Front. Pain Res. 3:901271.
doi: 10.3389/fpain.2022.901271

Chronic pain is a common, profoundly disabling and complex condition whose effects on identity may explain the distress experienced by those affected by it. This paper concerns a study exploring how the relationship with pain and sense of self evolved following participation in a pain management program (PMP). Participants were interviewed at three timepoints: before attending a PMP, 1 month after the PMP and 6 months after the PMP. To facilitate a deep experiential description of pain and its effects, interviews were guided by participant-generated drawings of pain and Self. Interviews and drawings were analyzed longitudinally using interpretative phenomenological analysis. The evolving experience of participants was outlined through different trajectory types. Here we describe the upward and positive trajectory of three female participants who were able to regain control over their lives. From a state of psychological stress where pain was represented as an aggressive and oppressive presence, participants' drawings, their narratives and indeed their lives, changed for the best. Pain stopped being the main feature, they were able to integrate it into their lives, make important changes and find a new balance. The results demonstrate the idiosyncratic nature of chronic pain and offer a nuanced account of its links to the lifeworld of those living with it.

KEYWORDS

chronic pain, interpretative phenomenological analysis (IPA), longitudinal, visual methodologies, participant drawings, pain management program (PMP)

Introduction

Pain is diagnosed as chronic when it persists for more than 3 months in the absence of progressive disease (such as cancer) or structural abnormalities (1). Chronic pain (CP) is a major health concern in most Western countries. An American National Health Interview Survey found prevalence amongst adults of CP and high impact CP (which limits life and work activity) to be 20.4 and 8% respectively (2), while in the UK severely disabling pain has been estimated to affect between 10.4 and 14.3% of the adult population (3). Both studies indicate higher prevalence for women compared to men, and older adults compared to younger ones.

Qualitative literature has generated much insight into the profound and far-reaching impacts of CP on the lives of those affected: people are dramatically and intimately changed by their illness and have great difficulties in coming to terms with having CP (4). To support those with CP, most English national health trusts offer Pain Management Programs (PMPs), multidisciplinary interventions aimed at helping people to learn to live with their pain. Evidence on PMP efficacy is however weak, mostly for the wide range of study designs and outcome measures (5). Interestingly, the impact of CP on identity that clearly emerges from qualitative literature (4) is not directly reflected in how interventions are conceived, delivered and evaluated. This creates the question of what the effect of attending a PMP might be in terms of the existential impact that CP has on the life of those living with it.

CP as a health condition is particular because it is invisible, difficult to describe, impossible to assess objectively and profoundly idiosyncratic in its effects. Visual methods, increasingly used in qualitative research (6, 7), are particularly suited to investigate CP, because they enable the unexplainable experience of pain to be examined and conveyed more fully. Drawings, in particular, offer a direct path to revealing feelings and emotions (8); like metaphors, drawings can act as a 'safe bridge' to express painful feelings (9). Drawings of pain have revealed a complex imagery, with pain represented as an aggressive attacker (10) or an external malevolent object of torture (11), thus shedding additional light on the distressing descriptions of having CP provided through narratives alone. Such pain imagery vividly illustrates CP as an adversarial experience, characterized by a sense of impotence in which personal agency is lost to pain. In this study, drawings of pain were combined with drawings of Self to facilitate the expression of alternative narratives of participants' identities and personal worlds.

The medical definition of CP emphasizes its subjectivity and emotional impact (12), so a qualitative methodology, particularly a phenomenological and idiographic one such as Interpretative Phenomenological Analysis (IPA), is a very apt way of exploring the idiosyncratic aspects of the CP experience (13). If the aim is to understand change or the lack thereof, following an event such as PMP participation, a longitudinal design is the most appropriate (14). There is a small corpus of studies that have employed IPA longitudinally to explore changing CP experience after pharmacological treatment or an educational intervention (15, 16). Our study adopts a longitudinal design, to understand change after a PMP, by gathering data at three time points: before and after the PMP and 6 months after the PMP.

To summarize, this article presents results from a study where IPA interviews with drawings were analyzed longitudinally, to understand how pain and the sense of identity of participants with CP progressed after they participated in a PMP. The evolution of each participant's experience over the study's three time points was described as a trajectory, and three types of trajectories emerged from the overall study: an upward and positive trajectory, a negative and unchanging trajectory and a positive but complicated trajectory. This paper presents the detailed findings from the first upward and positive trajectory, by discussing the narratives and pain and Self drawings of three participants, Olga, Monica, and Jane, who showed a substantial and consistent improvement over time. The other trajectory groups are to be discussed in separate papers currently being prepared.

Materials and methods

Participants

Participants were 40–60-year-old women, unemployed and suffering from chronic pain for at least 2 years who had been referred to a National Health Service Community Chronic Pain Service (CCPS) in South-East England. Table 1 summarizes key details about participants. As you can see, although the data were gathered at equivalent timepoints, each participant arrived at the service with a long personal history of CP and the support they received was tailored to their needs. For instance, Olga attended tai-chi sessions and was referred relatively late to the PMP, while Monica received 1-to-1 psychological support.

Recruitment and data collection

Ethical approval for the study was granted by the NHS London-Stanmore Research Ethics Committee in 2015 (15/LO1872).

Participants were recruited during a pain education session that all people attend shortly after being referred to the service. Participants who expressed interest in the study during the session were given an information sheet, the opportunity to ask questions and were recontacted by the researcher a few days later to confirm participation. After a few months, and at the discretion of their care nurse, people can also be referred to a four-week-long non-residential PMP. Participants in this study were interviewed ∼2 weeks after attending their education session, 1 month after the end of their PMP and then again 6 months after the end of their PMP. Interviews were held in surgeries and lasted on average 78 min.

TABLE 1 Details about participants in the upward and positive trajectory group.

Pseudonym	Diagnosis	Age	Years with pain	Medication[a]	Non-medical treatments received from service[b]	Months between interviews 1 and 2	Months between interviews 1 and 3
Olga	Fibromyalgia and seronegative rheumatoid arthritis (RA)	55	20	RA medication	tai-chi	6	11
Monica	Fibromyalgia	40	30+	Opioid painkiller, antidepressant, paracetamol and treatment for hiatus hernia	psychology	3	8
Jane	Fibromyalgia, degenerated disks, depression	47	3	Opioid painkiller, anticonvulsant, antidepressant, paracetamol and supplements		4	8

[a] The contents of the Medication column are for the most part derived from the participants' clinical records at the end of the study.
[b] All participants also had regular personal appointments with a clinical nurse specialist and participated in the PMP.

At the start of the first interview, having signed the consent form and received reassurance that the artistic quality of drawings was not important, participants were left alone in a room for 15 minutes to create a drawing of their pain. They were given an A4 blank sheet of heavy paper and colored pencils, crayons and felt-tips, and were asked to "*draw a picture of what your pain feels like to you*". The researcher then returned to the room and asked them to "*draw a picture of yourself as you are now*", leaving them alone for 15 more minutes. When the drawings were complete, the semi-structured interview started. Focusing on one drawing at a time and starting with the pain drawing, participants were asked to describe their drawing, why it was drawn as it was and their thoughts looking at it; there were also questions on how the pain made them feel about themselves, how they thought others saw them and how they would have liked to feel.

When some participants became tearful, the interviewer gave them an opportunity to recover or the option to interrupt the interview, but all participants were happy to continue. At the end of the interview, there was also a debrief during which the researcher was able to verify how participants were feeling and answer any of their questions. No one expressed the need for further support.

The second and third interviews were similar, except that, in the second half, drawings from the earlier interviews were shown to encourage a reflection on change. All interviews were audio-recorded and transcribed verbatim. The interviewer (IEN) kept a reflexive journal and was clinically supervised by the third author (JK), a CP expert senior counseling psychologist.

Analysis

All participants were assigned pseudonyms and, when necessary, the drawings were anonymized by electronic editing. For each participant there were three pain drawings, three Self drawings and three interview transcripts to be analyzed. Data were analyzed inductively, idiographically and longitudinally, before comparing cross-case.

The analysis of each interview started with an analysis of the pain and Self drawings using the framework for visual analysis inspired by compositional analysis proposed by Boden and Eatough (6, 17). Then the interview transcript was analyzed to make notes and identify personal experiential themes, as suggested by the IPA method, linking the themes to the drawings (14, 18). Here particular attention was placed on prospective views (considerations that emerged from reviewing newly created drawings), and, in later interviews, retrospective views (considerations that emerged when comparing previous drawings with new ones). Finally, for the longitudinal analysis of each participant, the tables of personal experiential themes from the three timepoints and the drawings were considered as a gestalt to identify the participant's individual trajectory in the study. At the very end, the different individual trajectories were compared cross-case and grouped into three trajectory types: an upward and positive trajectory, a negative and unchanging trajectory and a positive but complicated trajectory.

In the next section, results from the upward and positive trajectory group are presented case-by-case. Each case develops chronologically, so that what happened to a participant at the first timepoint is discussed before discussing the second and the third timepoints. Within each timepoint, the focus is first on the pain drawing and then on the Self drawing. All the drawings from each participant are also presented in a single table figure, which contains one row per time point, and a pain and a Self-column, to enable horizontal comparisons between the pain and Self drawings from a given time point and vertical comparisons between the pain and Self drawings from different time points. Comparisons between participants are developed fully in the discussion.

Results

The upward and positive trajectory includes three participants who wholeheartedly embraced the change encouraged by the PMP and whose lives, in the following months, were transformed and normalized. Olga, Monica and Jane's stories and drawings share a consistent progress over time, although what constituted progress was different for each of them. As will become apparent reviewing their individual trajectories, they all started from a position in which the pain was represented as an aggressive and oppressive presence in their lives, and they appeared under great psychological stress in their initial Self drawings. Step-by-step, through attending the PMP, but not only, their drawings, their narratives and indeed their lives, improved. Pain stopped being the main feature of their lives, they were able to integrate it and find a new balance and sense of control. All women in this trajectory group embraced their time in the CCPS and their PMP attendance as a unique opportunity to make important life decisions, work on themselves and their situation and regain control over their life.

Olga's journey: From despondency to planning her future

Olga stayed the longest time within the study and was the only participant to successfully wean herself off opioids after having taken them for over 5 years. She illustrated her journey with two sets of surprisingly simple stick figures that evolved from her having overwhelming pain and extremely low mood, to having less pain and a strong sense of purpose in her life.

Time 1

Olga's first pain drawing (Figure 1, Pain T1) is a faceless stick figure on which the pain is described via metaphors: pokers in her joints, hammers on her knees, flames on her neck, toothache at the base of her spine, buckets of fizzy water at her feet. The variety of symptoms and the violence of some of the metaphors (e.g., flames and pokers) suggest a very aggressive pain. Olga had carefully chosen what to draw:

> I wanted it to be red, because it's angry and it hurts, and it's like somebody was pushing a hot poker or hot needles into my joints [Olga, T1]

Olga ascribed agency to the pain ("*it's angry and it hurts*") and imagined "*somebody*" pushing hot pokers into her joints. Her pain was not only strong, it was separate from her. In fact, Olga as a living person does not appear at all in her first pain drawing, because the figure has no face and no identifying features. The drawing is literally just about the pain. Pain seemed to have taken over Olga's body completely, with things being done to her body by an external force.

Olga had been tearful during her first interview and profoundly upset by the effects that pain was having on her life. She described the cloud above the stick figure's head as a constant overhanging "*heaviness*" and felt the pain isolated her from other people. It was clear that her physical pain was compounded by a low mood, possibly a form of depression, a diagnosis that would fit well with the sense of emptiness expressed by the figure's blank face.

Olga's first Self drawing (Figure 1, Self T1), with its large head and small stick figure body, illustrates in more detail the impact of pain on her mood. The face has a forlorn expression, with a downturned mouth and Olga's green sad eyes. As with pain, a large gray cloud hovers above the head. This is how Olga described her feelings:

> [tearful] I feel a bit angry [. . .] because I think why have I got all of these problems, you know? I'd like it to improve, I would really like to think I could improve on it, I don't want this, sometimes it kind of makes you feel, if this is it, if this is the best you're gonna feel, I don't want it to continue, if this is it for the next 20 years, do you really want the next 20 years? [Olga, T1]

This quote is rich and captures the depth of Olga's despair and the sense of hopelessness that her "*problems*" were evoking. The problems are listed as labels on the drawing, they include pain, but not only. Olga was physically "*inactive,*" for her pain and because she was overweight. She disliked her body ("*I'm big, so I try not to think about it*"*),* which is why it is out of proportion compared to the head and almost invisible, apart from having a "*stoop*" (the slight bend in the stick figure). Olga felt very self-conscious because her stoop caused a "*bad posture.*"

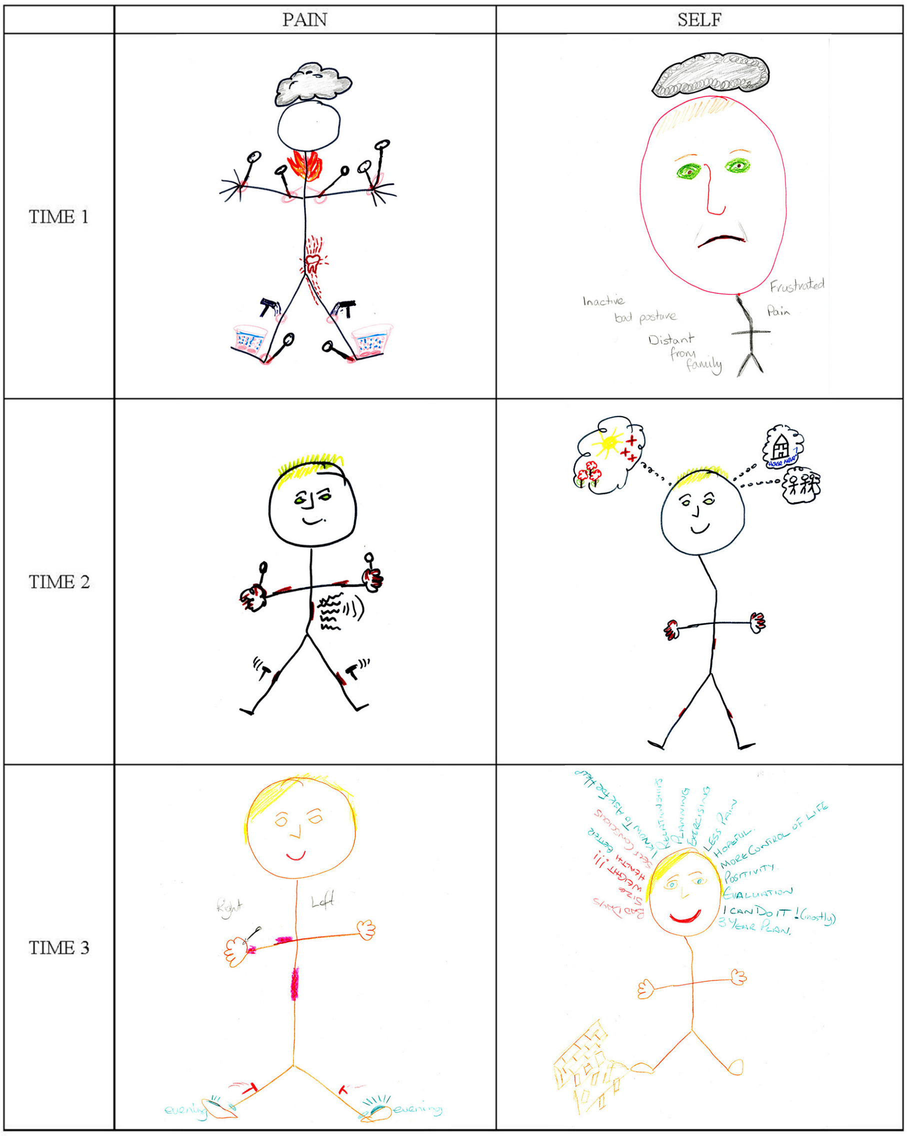


FIGURE 1
Olga's drawings of her pain and Self at Time 1 (T1), Time 2 (T2), and Time 3 (T3).

Her physical limitations affected her ability to engage with her loved ones, making her feel isolated and "*distant from family,*" and her overall situation made her "*frustrated*".

Going back to the quote, Olga felt that her current situation made for a life that was not worth living ("*if this is the best you're gonna feel, I don't want it to continue*"). However, her desire for something better ("*I would really like to think I could improve it*") felt tentative, she wanted to change, or rather, she wanted to "*think*" that she could change but did not entirely believe that this was possible. Her impulse for change was weak. She referred to her situation using pronouns such as "*this*" and "*it*", almost distancing herself from it, conveying a sense of impotence, as if her life were beyond her control.

At her first interview, Olga was suffering greatly both physically and psychologically: she was sad, in a body she disliked, feeling victimized by her pain and unable to react.

Time 2

By her second interview, which was 6 months after the first, Olga was feeling better. She had been referred to the PMP later than most and in the meantime her medication regime had been revised. Her second pain drawing (Figure 1, Pain T2) is, again, a stick figure with pain marks and, although it shares many similarities with the first (Figure 1, Pain T1), there are also important differences. Many metaphors are retained (notably, pokers and hammers), but some are omitted (e.g., no tooth and no flames), suggesting that the physical pain had diminished. Olga confirmed she was feeling better:

> I think my pain has definitely improved to what it was when I was here last time, which again, that straight away increases the quality of your life [Olga, T2]

Olga saw a link between her pain levels and her mood. Her second pain drawing reflected her improved mood because the stick figure had blonde hair (like Olga), a smiling face and no cloud above its head. The absence of a cloud was also indicative of greater mental clarity from taking less morphine. The inclusion of a recognizable smiling face, where previously there had only been emptiness, suggests that the balance had changed between Olga and her pain: previously pain had been the protagonist of the drawing, while this was a picture of her with pain. It was as if she had reconquered some of the space previously occupied by the pain and was affirming herself in relation to it.

When asked how she explained the change, Olga said:

> maybe coming off some of the pain killers, although you expect them to deal with all the pain but actually they don't always, do they? [...] now I understand that they can cause as much pain as they relieve and, yes, and just maybe not having my brain quite so foggy with the drugs and stuff, [...] when I did the PMP, it laid some of the fears for the future, so, ahm, I didn't realize how many different aids there were to help you with different things [Olga, T2]

Olga had experienced the detrimental effects of opioids, in terms both of mental fog and actual pain, a counter-intuitive effect of this type of medication difficult to believe. Participating in the PMP had also played a part, and, interestingly, the most important aspect for Olga had been learning about disability aids, such as kettle tippers. This detail speaks to the idiosyncratic nature of CP, whereby each sufferer is burdened by their own particular fears and concerns, but also illustrates how PMP participation can change participants' perspective about their future, as we shall see when discussing Olga's second Self drawing below.

Olga's second Self drawing (Figure 1, Self T2) is, again, a stick figure, but this time fairly proportionate and with hands and feet. The figure has Olga's blonde hair, green eyes and a happy smile. Above the head there is no dark cloud, but three thought bubbles which, from left to right, contain a shining sun with flowers and red crosses, a house with the text "*house move?*" and three other figures identified as Olga's family.

Although simple, Olga's drawings were always well thought-out. As previously, her Self drawing gives us insight into what was on her mind. Of the first bubble she said:

> this is my future, I feel like it's a little bit more rosy, I know that there's a little bit of help out there should I need it, and obviously the sun is shining [Olga, T2]

The bubble included roses because her future looked rosier to her; the red crosses (meaning first aid), were the "*little bit of help out there*" from the CCPS and the disability aids mentioned earlier; and the sun was shining because she felt hopeful about the future.

The second and third bubbles illustrate issues unrelated to health that Olga discussed during her interview: whether to relocate and other family matters. What was notable here was Olga's focus beyond the boundaries of her own bodily reality, her new-found closeness with family and her future-orientation.

The stick figure's body in Olga's second Self drawing (Figure 1, Self T2) has its hallmark stoop and is scattered with pain marks. Olga said that the pain marks showed how well she was feeling, despite the pain. She did not discuss the stoop but, for the first time, talked of possibly losing weight:

> I've got the motivation, because I know the quality of my life will improve, but I just can't, or I haven't at the moment clicked it the right place here [head] [Olga, T2]

Olga, who would be classed as obese, knew that her weight had an impact on the pain and on her overall quality of life, yet during her first interview she had only touched on the topic. This time she discussed needing a structured approach to dieting, but, despite feeling motivated, she was not psychologically ready to address the problem. There was a sense of purpose and self-awareness in Olga's words that seemed promising and boded well for the months to come.

Overall, at her second interview, Olga was feeling visibly better in herself. Her pain had reduced, and her mood had improved, she was smiling in both drawings, enjoying life and looking ahead.

Time 3

At the third interview 5 months later, Olga's situation was even better. Her third pain drawing (Figure 1, Pain T3) is quite like her previous one, but lighter, because drawn in pencil rather than felt-tip. The lightness of the drawing, especially the pain marks, was deliberate to show how the pain had changed:

> I definitely wanted that in pink, because I wanted it to be a lighter color than it was, not in red, because the red I feel is the real angry color [Olga, T3]

Since Olga's pain had changed in intensity, it required the use of milder colors; it had also changed in aggressiveness, so the red was no longer of the "*angry*" type but a milder pink. The figure, clearly identifiable as Olga, appeared larger, with a smile and lighter compared to previous ones, because instead of a black felt tip, she had used a softer skin-colored pencil mark to draw the outline, which gave the figure a "natural" look. This normalization reflected a change in Olga's narrative: her focus was no longer the pain but her weight-loss plans.

Looking across Olga's three pain drawings (Figure 1, Pain) it is interesting how they all present the same subject, and the subtle changes in tone and detail define a positive trajectory, over which the pain, from being a strong, depressing and depersonalizing presence, had reduced, allowing Olga to gently re-emerge and take center stage with a large smile, ready to live the rest of her life.

Olga's final Self drawing (Figure 1, Self T3) provides more detail on her plans. As always, it is a stick figure, this time drawn in brown and with a wide smile. Compared to previous Self drawings (Figure 1, Self T1 & T2), the figure has full hands and feet, the characteristic stoop is less accentuated, and it has no pain marks. To the left of the figure's foot there is a rough representation of a wall, with some bricks lying around. Above the head there is a halo of words. The words in red are negative things ("*bad day*", "*size*", "*weight!!!*", "*health*" and "*self-conscious*"), while the green words are positive things ("*better (for health)", "I know to ask for help",* etc.).

At her third interview, Olga was smiling like the figure in the drawing, feeling in control of her life and hopeful. She had successfully completely weaned herself off opioids and, with her husband, had devised a "*3-year plan*" to improve their wellbeing, which included losing weight. Olga was cautiously optimistic about succeeding in her intent, so she added "*(mostly)*" to the "*I can do it!*" statement in the drawing. Previously her motivation to lose weight had been lagging because she had not "*clicked in the right place,*" now she felt ready to tackle her weight loss project:

> I know I've gone on about my weight every time I've seen you but I really feel like I've got my head around it now, yes, I'm going to be able to make a difference to myself [Olga, T3]

Weight loss had hardly been prevalent in Olga's previous interviews, but in the last months it had probably been central to her thoughts and now it was her focus. In her drawing, three of the five red negative words in the figure's halo are weight-related ("*size*", "*weight*" and "*self-conscious*").

A notable (and new) aspect of her third Self drawing was the contrast between positive and negative elements. It was as if Olga had engaged in a battle with herself: the red words in her drawing were her opponents and those in green were her allies. Since there were more of the latter, she was optimistic about being successful.

The meaning of the crumbling wall in Olga's final Self drawing was more ambiguous. Initially she described it as "*the thing that stops me from doing things, the negativity in my life*". When comparing her new Self drawing to her previous ones, she explained the wall as being the diminished pain, explaining that she was "*not focusing on it as much*" and "*focusing on other things as well*", whereas before she had been "*completely enclosed*" by her pain. Now that she was no longer taking morphine and had less pain, the wall had crumbled, she was able to focus away from her pain, to "*hop over*" the wall and get on with her life. This was a pivotal moment:

> I am much better that than I was, I feel better in myself, my pain has improved, I feel like my life is sort of at a bit of a turning point really, I'm in control of what I do and what's happening to me, I can make it change [Olga, T3]

Summary

Olga's closing tone in this last quote feels miles away from the despair and impotency of her first interview. She was not only better, she felt in control and empowered to bring about the changes she needed in her life. Her overall trajectory, so powerfully illustrated in her simple pain and Self drawings, had been extremely positive. The pain that initially was controlling her life was dramatically reduced, her mood lifted and gradually she was able to re-engage with her life and embark on making important changes that would further improve her quality of life.

Monica's journey: From resistance to self-compassion

Monica's time in the study was a transformative journey of self-discovery. Her pain drawings evolved from pain being an aggressor to resist, to pain being a manageable challenge. In parallel, her Self drawings evolved from a precarious balance to a symbolic revelation of Monica's identity.

Time 1

Monica's first pain drawing is dense and slightly eerie (Figure 2, Pain T1). On the left it contains a gray cloud with a teddy bear-like face, and prominent vampire teeth; the rest is a dense pink fog interspersed with shapes: blue pins, yellow lightning, pink zigzag lines, small "*pop*" and "*pow*" explosions. There is a chilling contrast between the comic-book tone of the drawing and Monica's description of it:

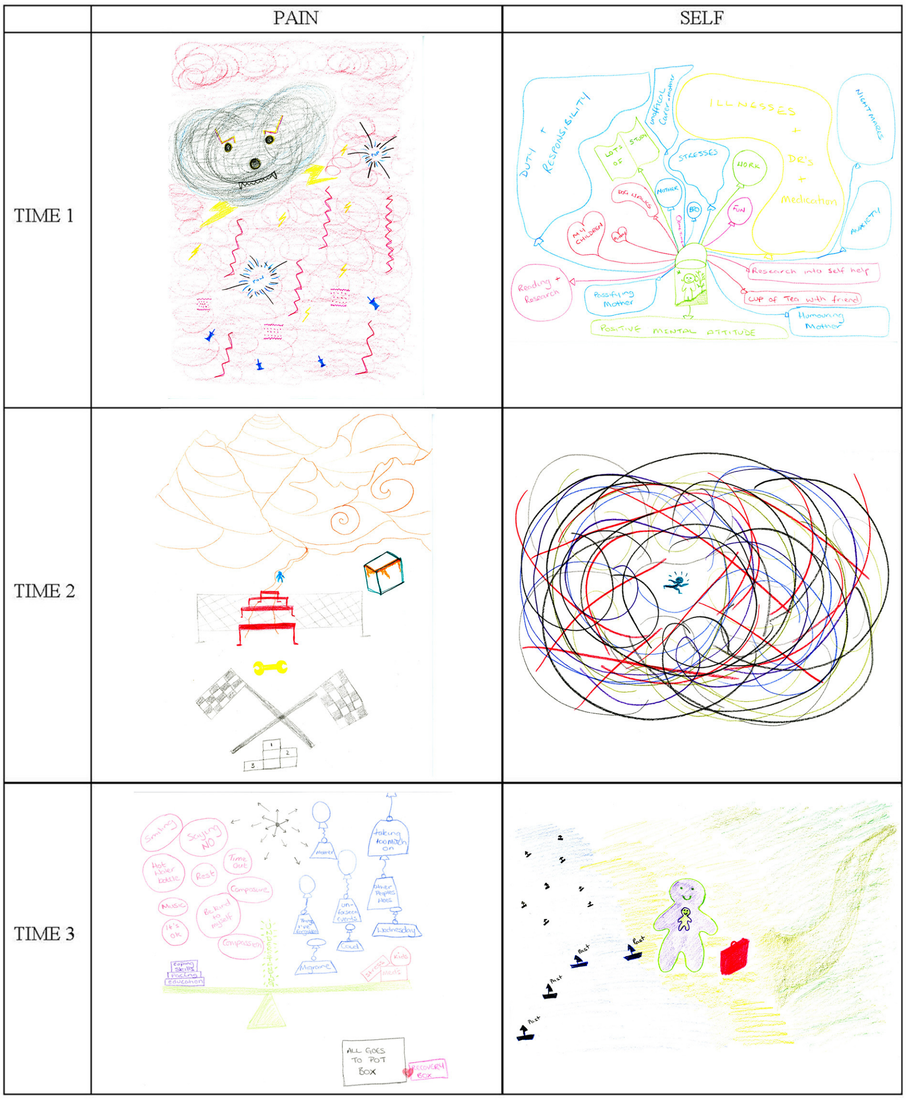


FIGURE 2
Monica's drawings of her pain and Self at Time 1 (T1), Time 2 (T2), and Time 3 (T3).

> some of the pain can feel cold and some of it can feel aggressive [...] it's like an aggressive being just sitting there waiting to... "What shall I do with you today?" [Monica, T1]

Along with the physical aspects of her pain (e.g., "*cold*"), Monica described the 'teddy bear' as aggressive, spiteful, agentic, and rather malevolent, intent on spoiling her life daily ("*What shall I do with you today?*"). Although some elements of the drawing seem playful, it conveys the sense of a pain which is widespread, complex, and aggressive.

During her first interview, it became apparent that Monica was not coping well. She was a single mother of two young children, caring for her mother, studying and working as a volunteer. With so many things going on, she was finding it difficult to focus on herself and her pain. Her first Self drawing (Figure 2, Self T1) is a dense and elaborate diagram of all the things she was juggling. Monica represented herself as a minute figure in a green basket attached to many balloons occupying the whole page above and beside her. The balloons are color-coded, with negative ones in blue (i.e., "*duty and responsibility*", "*stresses*", "*mother*", "*brother*", etc.) and positive ones in red (i.e., "*reading and research*", "*children*", "*puppy,*" etc.). Other important elements such as "*study*" and "*work*" are in green, while the largest balloon ("*illnesses + dr's + medication*") is yellow. The balloons appear constrained, oppressive for how they fill the space around the small figure and give the image a claustrophobic quality. Also, the blue and yellow balloons occupy in proportion considerably more space than the others, particularly the red ones which represent love and self-care.

The "*duty and responsibility*" balloon on the left is large because Monica spent most of her time taking care of her family ("*they're all my responsibility because they're hopeless*"). Four of the negative balloons concern her mother ("*mother*," "*unofficial carer-mother,*" "*pacifying mother*" and "*humoring mother*"), with whom Monica had a strained relationship. Monica spent little time looking after herself: in the drawing, her red "*me time*" balloon is so small that the label is written on the string. Having given herself entirely to others, Monica felt that there was none of her available to look after herself: "*I kind of need me more than anybody else does and I don't have time for me!*"

Could a simple lack of time explain why Monica wasn't taking care of herself? This quote offers insight on what was occurring at a deeper level:

> I should be allowed to go and be sick and get over it [laughs] in an ideal world. But I don't want to be like other people, I don't want to give in to it, because if I give in to it, I've lost my self, because if I do that, there won't be me, there will just be the illnesses and the pain and the yuck. [...] That balances out quite nicely, without me even realizing it [Monica, T1]

This quote captures the existential battle that Monica was fighting against her illness. She perceived her illness and her Self as two separate mutually exclusive entities. She knew that she should look after herself, yet she felt unable to do so because she was afraid that the illness would take over her life and that she as a person would cease to exist ("*if I give in to it, I've lost my self*"). Despite her "*ideal world*" claims, to stop her illness from winning the battle, Monica was not allowing herself to invest time and energy into caring for herself. Hers was an act of resistance.

Monica's drawing of her Self made perfect sense in these terms. Pain (yellow balloon) occupied a large amount of space in the picture, but it was almost invisible. She explained that she had drawn the illness and medication balloon in yellow because it was a color she "*really detested*", but, at the same time, it was a color that allowed her to pretend the balloon did not exist. She knew that the apparent "*empty space*" of the yellow balloon was just an illusion and that it could not really be filled by anything else. What she could do was fill the rest of the space with other things, so that the yellow balloon, however big, could not expand and occupy more space. Filling her day to the brim was Monica's way of keeping her illness at bay and resisting it.

It felt as if Monica were under constant threat of being annihilated by her illness. From the outside, her life appeared too full, but from Monica's perspective, all the elements were well balanced ("*that balances out quite nicely*"). Monica described her system of balloons as "*compartmentalization*" which she considered a successful strategy to keep a good psychological balance. The miniature idyllic environment surrounding the green figure at the bottom of the drawing was a symbol of her "*positive mental attitude,*" also part of her psychological survival toolkit.

At the start of the study, Monica was desperately resisting the attacks of pain toward her body and her very being. She was defending herself by filling her life so compactly that a psychological balance of sorts was achieved, although seen from the outside it appeared precarious and unsustainable.

Time 2

After attending the PMP, Monica was referred for individual psychological support within the service, where she had the opportunity to explore what was happening to her. Her second pain drawing (Figure 2, Pain T2) shows the results of her efforts to manage her pain. Pain is presented as an obstacle course, where every day is a race toward the finishing line:

> then you get down to here [...] and then you get all these hurdles put in front of you and so, "okay, right, okay, we'll get over some of these hurdles," [...] and then something happens and there's a spanner thrown in the works [Monica, T2]

The second-person voice in this quote suggests detachment and the expression "*you get all these hurdles put in front of you*" is passive, implying that Monica was still seeing the pain as an external entity exercising control over her.

Monica was still learning. Although her situation was far from ideal, she was dealing with the pain by staying focused on the present, confident that eventually she would be able to get down from the mountain and finally have a 'good day,' reaching the podium in her pain drawing.

Monica's second drawing of Self (Figure 2, Self T2) is the epitome of disruption, especially compared to her pain drawing (Figure 2, Pain T2) and her previous Self drawing (Figure 2, Self T1). It is a bundle of lines surrounding a tiny green figure on the run. The image is strong, colorful, and scary, but also playful in how the figure resembles Keith Haring's dynamic figurines. The day of her second interview, Monica was in a crisis because she was organizing her mother's relocation. She described the bundle as a "*hornet's nest*" and "*being in the middle of a tornado.*" Despite the catastrophic metaphors, Monica was confident that the situation would soon be resolved.

The PMP and counseling had improved Monica's ability to cope. Looking at her second Self drawing (Figure 2, Self T2), she said:

> I would have panicked about something like this before and I wouldn't have drawn it, because it shows that "Oh my God, you're insane!" No, I am not, what is going on here is that there is so much going on that this is the only way I can

> express it to you, but actually I am all right, I am not upset about it, I am not climbing the walls, this is just how it is [. . .] it [PMP] has given me an allowance to accept that that's okay [Monica, T2]

Monica had gained the understanding that not having everything under control could be normal and acceptable. She was not necessarily coping better with the chaos; she was interpreting her anxious response to chaos as within the range of "normality" and not as a sign of deteriorating mental health. By saying that previously she would not have allowed herself to create such a drawing, Monica was also shedding new light on her previous representation of her Self (Figure 2, Self T1). This second Self drawing (Figure 2, Self T2) felt much less constrained and disturbing than the first, the irony and freedom of the wild lines seemed energetic, healthy and refreshing in comparison to the oppressive concentration of balloons. Monica confirmed that despite being under pressure, she felt relaxed and accepting of her feelings. Listening to herself had been one of her main learning points from the PMP:

> It's listening to me and how I am actually feeling and not ignoring it, whereas before I have always ignored it and just carried on, but I am learning to listen [Monica, T2]

Previously too busy looking after others and resisting the pain, Monica was starting to "*listen*" to her needs and, occasionally, when her body would tell her to, she would stop. She had also started to change how she interacted with her mother, by saying no to some of her requests.

Although the pain still had a strong and limiting presence in Monica's life, her pain drawing reflected how she was learning to live with it. Her Self drawing showed the confusion of a challenging moment, but also her new-found ability to cope with chaos.

Time 3

Monica's third pain drawing (Figure 2, Pain T3) represents her new pain management equilibrium. It includes a large scale, with various elements balanced on either side: "*stress*", "*meds*" and "*kids*" on the right, the three constants in her life, kept into balance by "*coping skills*", "*pacing*" and "*education*", new skills from the PMP. Hovering on the right there are 'negative' blue weights hanging from balloons (e.g., her mother), to be balanced, on the left, with 'positive' pink bubbles of behaviors and attitudes, such as "*composure*" and "*compassion*". It is interesting to note how the negative weights on the right are external forces over which Monica had no control, while the positive bubbles on the left are resources through which Monica could exercise agency. Superficially, this drawing resembles Monica's first Self drawing (Figure 2, Self T1), with its numerous balloons. Yet here the components are tidier and less oppressive; there is plenty of white 'breathing' space around the scale and the sensation looking at it is indeed of balance.

Here is a practical example of how the balance was working for Monica:

> I did not sleep at all last night, I couldn't get comfortable, my brain wouldn't switch off, I wanted to take my legs off, so rather than doing what I'd normally do and get screwed up about it, I was listening to my relaxation music. It didn't work, I didn't sleep, but it did work because I wasn't stressed out, I was nice and relaxed. [. . .] Normally I'd have woken up [. . .] irritated, and strung out, and really tired, and really grotty and. . . and I'm not, and I've got a really busy day at work today, but I'm quite happy [. . .] So just a little bit of learning, a little bit of understanding and being <u>nice</u> to myself [laughs] has made it something to be dealt with, rather than something to fight against [Monica, T3]

This quote really brings the concept of self-management to life: faced with a difficult night of pain and restlessness, Monica turned to her tools ("*my relaxation music*"); although the tools did not eliminate her symptoms ("*it didn't work, I didn't sleep*"), her emotional response to the symptoms changed ("*but it did work because I wasn't stressed out*"); as a consequence, the downward spiral of increasing distress that a bad night could have triggered ("*irritated and strung out*") was not initiated, and in the morning Monica felt able to face her day with optimism ("*I am quite happy*"). With the tools and the "*understanding*" acquired through the CCPS and PMP, Monica had found a new way of living with her pain and complex life that felt balanced. Monica's relationship with her pain had changed substantially: pain had become "*something to be dealt with, rather than something to fight against.*"

Self-compassion ("*being <u>nice</u> to myself*") was a key component of Monica's ability to deal with the uncertainty of CP. The "*all goes to pot box*" on the bottom right of her third pain drawing (Figure 2, Pain T3) symbolizes Monica's awareness that, however well-balanced her new situation, there was always a risk of something disruptive occurring. For such cases, she had her pink "*recovery box,*" the ability to accept that not everything can always go to plan. When something went wrong in her day, Monica had learnt to stop and, most importantly, be "*very nice*" to herself.

Self-compassion was a new skill for Monica and her third drawing of Self (Figure 2, Self T3) sheds light on the underlying psychological transformation it entailed. At the center there are two figures, one inside the other like a Russian doll, standing next to a red suitcase. On the left there is a blue sea with small black boats, labeled "past" and on the right there is a path winding through pale green land. Monica explained that the two figures represented her: the outer figure was the person she presented to the world, while the inner figure was her "*Little Me*", her true Self:

> this is what carries me, really, I seem to exist inside me, I always have done, what's more important is how I feel inside as opposed to the person I wear [...] my Little Me gets hurt a lot, a lot of my life I disassociate how I feel from who I am, I have done it for a very, very long time. I've had a horrible little life. So I'm in there and this bit is what carries my Little Me, because the outside bit gets battered and bruised and abused and that's the bit that hurts [...] the little bit, it's the bit that gets protected inside and the little bit is happy at the moment [Monica, T3]

This is a complex quote, reflecting the understanding that Monica was developing during therapy. Her traumatic past, the extent of which had not been apparent up to that moment, became central to her representation and discussion of Self. Earlier abusive relationships had caused her to protect her most vulnerable Self from the world by enclosing it in a carapace-like external Self visible to others. Most of the time she had been playing a role for others, trying to live up to their standards and pushing herself beyond her own limits. Being "*nice*" to herself was part of the process of embracing her "*Little Me*" and giving it the love and care that it had never received before.

As part of her inner journey, Monica had reassessed the people in her life and cut many old toxic relationships ("*because of how they were, who they were, and how they made me feel*"), symbolized by the little black boats departing by sea in her Self drawing (Figure 2, Self T3). The red suitcase contained what was worth keeping. As part of her self-analysis, Monica had accepted that even negative experiences had taught her something and added to who she was today.

Monica's third interview felt like a breakthrough: she was making peace with a difficult past, that she had briefly mentioned but never represented in her Self images. Her early Self drawings had reflected her efforts to keep her complex emotional world in balance (Figure 2, Self T1) and, later, accepting that control was not always possible (Figure 2, Self T2). Her third drawing was, literally, a drawing of her Self (Figure 2, T3): with her fragilities, her difficult past, but also with a clear path into the future. It was a serene and spacious drawing that was promising. When reviewing the three drawings together, talking about the "*duty and responsibility*" balloon from her fist Self drawing (Figure 2, Self T1), Monica recognized that she had a choice ("*nobody's holding a gun to my head and making me do it, I have a choice in this*"). This view of responsibility as a choice was in sharp contrast with how Monica had described the support she gave her family, particularly her mother, during her first interview ("*they're all my responsibility because they're hopeless*"). In her second interview, she had described learning to say 'no' to her mother, now she felt empowered and recognized her agency in shaping her own life, including her family relationships.

Summary

Over the course of the study, from an external aggressive being, pain had been transformed into an integrated and manageable part of Monica's life. In parallel, Monica had embarked on a journey of self-discovery which brought her face to face with her own fragilities and from which she was emerging as an assertive woman determined to take care of herself.

Jane's journey: From dark oppression to serene normality[1]

Jane's journey was one of the most successful: from a very low and lonely place, in which pain was an oppressing presence, she was able to regain an overall sense of control and naturalness. Her pain drawings evolved to reflect the increasingly less important presence of pain in her life while, in parallel, how she depicted her life in her Self drawings changed from a dark arduous path to a lighter more natural one. Note that a more extensive analysis of Jane's pain trajectory, has already been published elsewhere (19).

Time 1

At the first timepoint, Jane drew her pain as a heavy one-ton weight hanging above the head of a small stick figure (Figure 3, Pain T1). The weight was disproportionate in comparison to the figure and the arrows suggest a downward movement, as if it might crush her, while she resists with flexed muscles. Jane described her pain as "*confining*" and "*crushing heavy.*" She equated the arrows projecting from the weight toward and around the stick figure's body to a cloak:

> Then when you're kind of cloaked in this sort of pain, you haven't got the energy [...] you're so focused on this [weight] [...] you're trapped in this sort of bubble of what you want to do, what you can do and what you actually feel like doing [Jane, T1]

The pain was enveloping Jane and keeping her trapped, attracting all her attention, forcing her look inwards, limiting her energy. There was a discrepancy between what she wanted to do, could do, and actually felt like doing, pointing to an effect of the pain on Jane's mood.

The sense of feeling overwhelmed is echoed in Jane's first Self drawing (Figure 3, Self T1). It includes two stick-figure

---

[1] A case study containing a more detailed analysis of Jane's pain drawings and with limited overlap with the current paper has already been published in: Nizza IE, Smith JA, Kirkham JA. 'Put the illness in a box': A longitudinal interpretative phenomenological analysis of changes in a sufferer's pictorial representations of pain following participation in a pain management programme. *British Journal of Pain*. 2018;12(3):163-70.

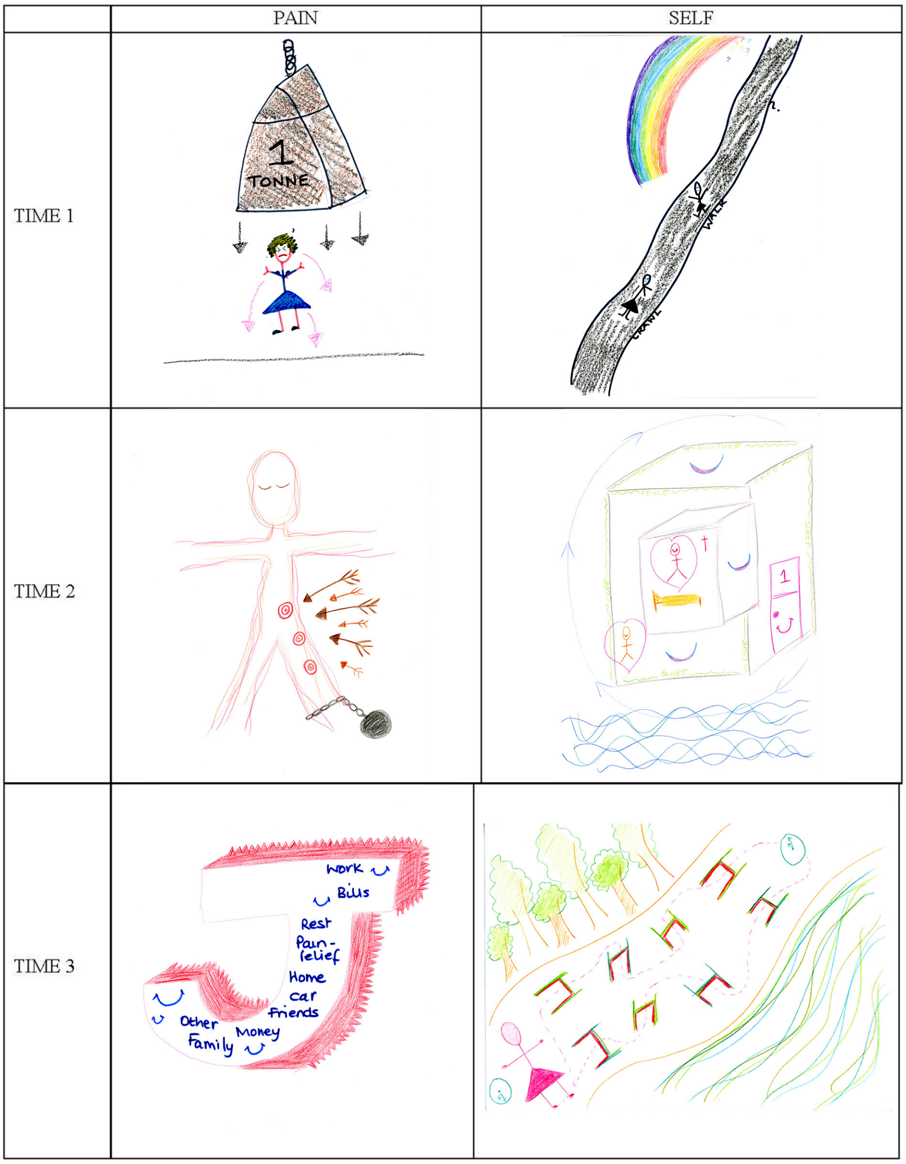


FIGURE 3
Jane's drawings of her pain and Self at Time 1 (T1), Time 2 (T2), and Time 3 (T3). Jane's pain drawings have already appeared in Nizza et al. (19) and are published with permission from Sage Publishing (c).

versions of her positioned on a long dark path that develops uphill across the page: the first figure is crawling, the second is walking, and further along the path there is an interrogation mark, questioning what lies ahead. A half rainbow hanging over the path ends somewhere beyond the page, as if hope had been interrupted:

> when you've got this pain all the time [pause] it's hard to be sort of optimistic [...] there are times when quite honestly I don't even want to know what is at the end of there [path], I'm not, I said to my GP actually, I want to see my son grow up, I want see him get married, have a career, I want to see him do all these things, but quite honestly, if I could fast forward through it all to the end, I would [...] just get to the end and just let me have a rest, just stop, enough [Jane, T1]

Jane's life with pain felt like a dark and difficult path, where she was finding it hard to look ahead and be hopeful. She had lost her desire to savor even her young son's major milestones, so she was prepared to zoom through them to reach "*the end*" and finally have some respite. Although she clarified that she was not suicidal, Jane felt the need to "*rest*" because living was a struggle for her.

Jane commented on the sense of loneliness in her Self drawing: *"there's no background to it, there is no [pause] no* *trees, no pictures of anybody else, just me, pain and an uncertain future."* Her sense of isolation was exacerbated by living with a partner who did not *"really understand"* her plight and feeling unable to effectively assert her own needs with him.

At the start of the study Jane was crushed, overwhelmed, and isolated by a pain that was preventing any form of *"normal"* life. She felt trapped in a dead-end situation: with a crippling tiredness, an unsatisfactory relationship, and an uncertain sense of her future.

Time 2

At the second timepoint, Jane drew her pain as an ethereal Christ-like figure with a ball and chain tied to its left ankle and some targets down its left leg (Figure 3, Pain T2). The impact of the pain appeared more limited compared to earlier: she said that the pain was "*direct in certain places*" and from there "*blurring everything else*," suggesting that, although still present, the pain was now localized and less overwhelming (e.g., no longer "*crushing,*" but "*blurring*"). It was as if the weight from her first pain drawing (Figure 3, Pain T1) had lifted from her head and was now simply tying her down.

She also described the body of the figure in her second pain drawing as "*bisected*": half linked to her painful past (with the pain marks and ball and chain), the other free half being her positive "*going forward side*":

> I've only done that on one side because of how my life is changed over the past few weeks [. . .] this half of my body is more positive [. . .] and that's the sort of going forward side [Jane, T2]

By her second interview, Jane's life had changed radically. During the PMP she had bonded with other CP sufferers, and this had given her the strength to leave her partner and move out of his home. She had also been offered a part-time job by a relative, which had the effect of "*reinforcing the positive side*" by making her feel supported by others.

When comparing her first and second pain drawings (Figure 3, Pain T1 & T2), Jane said, "*I've isolated the pain,*" and suggested that before she had "*allowed the pain to take over.*" In these expressions there is a marked shift in agency from the pain to Jane: where previously the control had been with the enveloping cloak of pain, now that the pain was more localized, the space it occupied seemed to have been reduced. Jane ascribed this shift to the PMP having provided her with tools through which she had been able to "*take ownership*" of the pain and "*put it in its place*". The result was a more balanced view of herself, reflected in the symmetrical posture of the figure in her second pain drawing. Although still in pain with half her body heavy from the ball and chain, this was counter-balanced by new resources, which allowed Jane to self-manage her pain and feel more empowered.

Breaking up from her partner had been a release for Jane. Her second drawing of her Self (Figure 3, Self T2) illustrates her new living situation: by the sea, in her own flat (outer cube), with her beloved son and in her own bedroom (inner cube):

> I just shut that door, that's my room, that's my space. [..] I am quite happy in my single bed and it's really lovely in there [. . .] I've got solitude, safe, sleep, love, quiet and care and calm, because they're the things that I want in life, they're the things that [. . .] I haven't had for quite a long time [. . .] I've kind of got to the end of my rainbow [Jane, T2]

The words listed by Jane in the quote appear along the perimeter of the external cube. Her home and bedroom were places where she could experience a tranquility and a security that had not been possible while she was living with her partner. By deciding to break up and live on her own, Jane had finally affirmed her own needs over the needs of others. This impetus had extended to her relationship with her son, who appeared in her Self drawing in a heart but outside the inner cube, because new understandings acquired during the PMP had redefined how she conceived her role as a mother:

> . . . it's okay to have, say, a bad day, it's okay to say I am going to bed, you know, tea is not happening tonight [. . .] I don't have to worry about, you know, well I am the mum here, I should be doing x, y, z. [Jane, T2]

It was as if at the PMP Jane had been given permission to behave and think of herself differently. Her previous beliefs about what her mother/partner role entailed had led to behaviors that were damaging Jane physically, for instance by forcing her, when having a "*bad day*", to stay up rather than go to bed. She took responsibility for her previous behaviors ("*I was making life harder for myself*") and was now recognizing her physical needs and acting accordingly.

The Self in Jane's second picture was a new version of her: free from her previous role constrictions, focused on her own needs and happy to the point of ecstasy. She described her new home as "*her sanctuary*" and dotted it with smiles and hearts. As Jane pointed out, the drawing contained the colors of the rainbow of which she had previously questioned the existence. The end of the rainbow had been reached. As the arrows around the cube in her second Self drawing showed, she had come "*full circle,*" finally coming home, both physically and metaphorically.

Jane's drawings of pain and Self at the second timepoint convey a new serenity and sense of control over her life. The role of pain was more contained than previously, and her Self drawing pointed to a newfound calmness and self-focus. The

PMP had stimulated her to make substantial changes and, more importantly, to achieve a new positive outlook.

Time 3

Five months later, at the third timepoint, Jane's life appeared to have stabilized. She drew her pain as a three-dimensional letter J, her initial, with its depth colored in red and spiky teeth in the background (Figure 3, Pain T3). By representing herself (the letter J) as a working front, with all the key words of a 'quasi-normal' life, Jane had been able to relegate the pain to the background:

> People can't see it, which is why I've done it behind me, it's there and it's sharp, and it is all over, but people, they don't see it, because I don't whinge and I don't moan about it [Jane, T3]

Jane felt able to live her life without making others aware of her pain, which she considered an achievement. The words she added to the front of the letter J provide insight into what was important to her at the time: there were names of family members (which have been blanked out in Figure 3), because the improvement of her pain and general wellbeing had been accompanied by a re-kindling of her family ties; there were words such as "*money*", "*car*", "*work*" and "*bills*" to emphasize a return to normality; but there were also "*rest*" and "*pain relief*" to indicate that, although not visible to others, pain was still an ongoing concern of hers.

Over the course of the study, Jane's pain had not ceased, but had been transformed from being an overwhelming presence, to being a part of her life that she felt control over and could conceal from others, within a routine of quasi-normality.

This new sense of normality also emerges from Jane's third Self drawing, which is a soft-colored representation of her "*path through life*" (Figure 3, Self T3). The drawing depicts a slightly uphill white path, with colorful obstacles, skirted on the left by a wood and on the right by the sea. A pink stick figure representing Jane stands at one end of the path, next to a clock. A dotted line weaves its way from her, through the obstacles, to another clock at the end of the path and back.

> I put the trees and the sea because they're ongoing, they never change and they keep going and going, so this is like the path through life and the two clocks are the beginning of the day and the end of the day, and these are hurdles, because whichever way I turn, every day, it's just hurdles, they're not insurmountable hurdles, they're hurdles nonetheless [Jane, T3]

Jane was describing her daily routine, weaving her way over hurdles, in an unchanging pleasant environment. Although this description may seem low-key, particularly compared to her blissfulness at T2, a regular alternation of small and large obstacles, within pleasant surroundings well-exemplifies the serenity that often underlies "normality". The obstacles Jane was facing were the ones she had listed in her third pain drawing (Figure 3, Pain T3): having to work, pay bills, manage a home, money, and so on. Considering that Jane had started her journey in the study on a dark path, to find her just 8 months later in control of her pain and working again almost full-time was astounding.

From being unemployed and financially dependent, Jane had become employed and running her own home. In her time off, she was also providing care for her sister's toddler:

> I can't say no, because there's nobody else she can ask [...] that was originally my day to just stop and do nothing [Jane, T3]

Was Jane's sense of sisterly obligation pushing her back into old behavior patterns, after having realized the importance of prioritizing her own needs at T2? Relationships of mutual support are fundamental building blocks of a "normal" life, so Jane's choice of helping her sister, despite adding to her hurdles, was another sign of regained naturalness and normality. What had changed was how Jane felt in control of her duties. When reviewing her third Self drawing alongside her previous ones (Figure 3, Self), she observed:

> there's no black on this picture at all, my road isn't black, they're all natural colors, that's life, isn't it? Green and blue. So that's, that's the way of life, that's natural, I know what I'm doing, I'm just stepping over my hurdles, not crawling on a black road anymore [Jane, T3]

The black path leading off the page to emptiness from T1 had been replaced at T3 by a "*natural*" white path. Her mood and outlook at T3 were normalized, and, more importantly, she was expressing a sense of control over her life ("*I know what I am doing*"): she was "*just*" stepping over her hurdles and owning her normality. The inner renegotiation of her roles, that had led to changes at T2, had been metabolized and she felt once again able to take care of others without damaging herself. It felt as if her previous caring Self was cautiously starting to emerge again.

Summary

Jane's pain and Self drawings show a very positive trajectory. At the start of the study her pain had been overwhelming and she had felt dispirited, with no sense of future. The PMP stimulated her to make important changes to her life as a result of which at T2 her pain appeared more contained, and she had acquired a home of her own and a new outlook that made her feel elated. By her third interview, she had settled down, was able to handle her pain in the background and was in control of her life again, facing the obstacles of "normality". There had been a substantial shift in power during the study: where previously the pain had controlled Jane's being, by the end she was able to assert herself over the pain and feel in control of herself and her life.

Discussion

There are many parallels between the journeys of Olga, Monica and Jane: their trajectories all included a successful transition from being oppressed by pain and depressive symptoms toward reclaiming agency from the pain and regaining some normalcy and control over their life. The trajectories are also consistently positive, so that there are visible improvements when comparing their drawings from T1 to T2 and from T2 to T3. The narratives reflect these improvements, also illuminating the idiosyncratic events that characterized the change within each of their lives.

At T1 all women in this trajectory group represented their pain as an oppressor having an overwhelming presence in their drawing: Monica was exposed to the whims of an evil being engulfed in a fog of pain; Olga was so oppressed that she was faceless, with only pain on her body and a heavy cloud over her mind; and Jane was a small figure crushed by a one-ton weight. Each of these drawings combines different pain metaphors of the types reported in literature. Monica's aggressive monster in a dense scattering of pain symbols includes metaphors of pain as an embodied attacker and as having physical properties, while Jane's resisting figure with its overhanging one-ton weight represents pain as an external, threatening, trapping and crushing entity (10, 11, 20, 21). By representing pain as an aggressive external agentic being, these drawings convey the disempowering psychological distress caused by pain and the sense of helplessness that Monica and Jane were experiencing at the time.

Olga's stick figure drawing, although apparently simpler and more literal in its description of pain symptoms, is more graphic than the others. It associates each type of pain to a specific implement attacking the body (pins and hammers) and illustrates pain in the lower back through the common experience of toothache (20), eliciting an almost physical recoiling response in a careful viewer. Olga's stick figure also has a blank face overhung by a dense cloud, suggesting a depersonalizing pain accompanied by depressive symptoms. Quantitative evidence has linked the use of particular pain metaphors to different types of distress, with pressure and weight pain metaphors associated to higher levels of depression and stress, and metaphors of physical damage caused by sharp objects linked to higher pain interference (22).

Each in its own way, the first pain drawings of women in this trajectory communicate a sense of being overwhelmed by an unbearable physical and psychological pain. This impact is complemented and further explained by the initial Self drawings, where Monica appeared suffocated by illness, duties and responsibilities and unable to care for herself, Olga had a desolate face and felt distant from family, and Jane drew herself as crawling on a steep dark path. The accompanying narratives spoke of depression, social isolation and hopelessness. Both Monica and Jane had a history of depression, while Olga was displaying depressive symptoms at the interview. During their first interview, both Olga and Jane questioned whether their current life was worth living. Instead, Monica was desperately resisting her pain trying to save her Self from it. The Self drawings thus illustrate the known correlations between CP and depression (23) and psychological distress more widely (24), which underly many CP treatment models (5). These Self drawings are also unique in that, to our knowledge, no other CP study has invited its participants to draw themselves to probe the existential impacts of having CP, although drawings of Self have been used to investigate other conditions, such as spinal-cord injury and dementia (25, 26). Together, the T1 pain and Self drawings illustrate how, at the start of the study, participants in this trajectory group were profoundly oppressed by their pain and afflicted by extremely low mood.

The PMP was a breakthrough moment for all participants and by T2 each of them had embarked on a new life course: Monica had started therapy to tackle her history of trauma and mental health difficulties; Olga was successfully weaning herself off opioids; and Jane had left an oppressive relationship, started to work again and moved into a new home. Accordingly, Monica's and Jane's Self drawings at Time 2 were very different from their earlier ones, with Jane's dream-like house and Monica's hornet's nest respectively representing a new ecstatic happiness and a new acceptance that life could be chaotic without this being a sign of deteriorating mental health. In contrast, Olga's second Self drawing was more subdued, but also relaxed for its concern with everyday family life.

At the same time, in the pain drawings, pain became less prominent: it was relegated to fewer body parts for Olga and to one leg for Jane, while Monica's external agentic pain was replaced by pain management strategies. A visible change had occurred for all three women and their second interviews shared a sense of relief from having broken free from previous constraints (i.e., Monica's fear of losing herself, Olga's obnubilation by morphine and Jane's toxic relationship). Each woman was expressing a new understanding of herself and her condition, starting to feel like herself again and daring to hope for the future.

The relatively short period between T1 and T2 was a turning point for these participants, with the PMP acting as a trigger leading to "changing perceptions, identities and understandings, and opening up the possibility of an alternative pathway for the future" (27). Indeed, the PMP and CCPS stimulated all three women to reconsider their life, break old patterns of behavior and challenge their own status quo. The cathartic quality of Monica's and Jane's Self drawings, particularly in comparison to their earlier drawings, conveys this sense of radical transformation. Olga's Self drawing is more proportionate and serene compared to her previous one, and illustrates her engagement with normal life.

Five months later, at T3, the progression toward normality appeared steady for all women. Pain drawings changed to give the pain even less space: Monica's pain was a careful balance of self-management strategies counterweighing life stressors; Olga's was a larger version of her smiling, with limited soft pink pain, in contrast to her previous bright red pain; Jane relegated her pain to the background, representing daily chores on the front of the J which represented her. The pain had not disappeared, but it was now manageable, and the drawings showed how: Monica's carefully balanced scale, Olga's light colors and smile and Jane's background pain with a front including "*pain relief*" and "*rest*". The accompanying Self drawings were images of serene normal lives, with a predominance of green, which appeared in Olga's words, Monica's plain and Jane's path. The form that normality took for each of them was different: for Olga it was making plans to tackle her ongoing obesity, for Monica it was clearing up her life and taking care of her "*Little Me*" and for Jane it was a life scattered with surmountable obstacles.

In response to their changing pain drawings, all three women talked of having taken back control from their pain, expressing a sense of agency and empowerment which had previously not been present in their narratives. They talked of finally feeling in control of their lives and able to take decisions as they had previously felt unable to do. Feeling empowered is considered an enabler for pain self management (28).

Another aspect that emerged for all women was the ability to focus on their own needs. It can be detected in Olga's "*I know to ask for help*" statement in her Self drawing and in her decision to finally lose weight, in Jane's inclusion of "*Rest*" and "*Pain relief*" in her pain drawing and in Monica's listing "*Rest*," "*Compassion*," and "*Be kind to myself*" among her self-management strategies in her pain drawing. All women were prioritizing their own wellbeing in a way that they had not done before. A useful construct to understand this change is self-compassion, which is receiving growing attention in CP, and includes being understanding toward oneself rather than self-critical (29). It is considered an adaptive process that can help reduce the impact of CP on the life of sufferers. Higher self-compassion is associated with lower depression, disability and pain-related fear, and greater pain acceptance, successful engagement in valued activities and use of pain coping strategies (30). Higher self-compassion has also been found to predict lower depressive symptoms at 6 and 12 months (31).

If we review Monica's trajectory through a self-compassion lens, we see how at T1 she had been entirely focused on looking after others and finding it difficult to look after herself. In her first Self drawing she appeared in a small green basket overwhelmed by balloons representing her burdens (her duties, her family, her illness). At T3, she drew herself as two Russian-doll figures on a serene green path, with the inner doll representing her "*Little Me*" whose happiness the outer one was protecting. Her focus had changed substantially: being nice to herself had become a priority and she was aware that it was up to her to prioritize her needs over the needs of others. Jane's decision to leave her partner was also dictated by a recognition that her own needs should take priority, as Olga's desire to lose weight stemmed from her wanting to finally take care of her body. We see here how self-compassion and regaining control are interlinked: being in control enables self-compassionate behaviors and the sense of self-compassion is empowering.

The PMP seemed to have been an empowering experience for these women: it stimulated in them a desire to take responsibility for their own wellbeing and gave them the tools to rethink their life with pain and take action toward managing it, each in her own way. The ACT psychological flexibility model (32) offers a useful framework to understand what may have happened. The model advocates for a shift from experiential avoidance to experiential acceptance, which, for CP, means acceptance of the physical and psychological experiences of pain. The reduced space occupied by the pain in their drawings over time and these participants' return to some "normality" is a testament to their ability to accept and incorporate pain and its consequences into their lives. Becoming psychologically flexible also entails a shift from being attached to one's concept of oneself and unable to act, to a more flexible view of oneself where, driven by actions in tune with one's personal values, a more vital life can be lived. The ability of participants in this group to challenge their view of themselves, reassess their lives and engage with what was important to them by taking concrete actions suggests a good degree of psychological flexibility. In a recent IPA study investigating perspectives on acceptance following an ACT-based PMP, participants spoke of acceptance as a journey encompassing enhanced self-efficacy, altered and flexible self-identity and openness to change (33), three experiences that resonate with what happened to participants in this trajectory group. Biguet, Nilsson Wikmar (34) talk of "acceptance as personal empowerment" (p. 1261), which they identify as the best possible outcome for CP sufferers, while Toye, Belton (35) see empowerment as a necessary step in the CP sufferer's journey toward healing. The sense of control over their pain developed by Olga, Monica and Jane over time, their growing sense of empowerment and the practical and psychological changes they underwent during the study suggest they were on a steady march on their path to healing.

The three women in this trajectory group started from a very low point and by the end were feeling much better in themselves and had made important changes to their lives. Meta-analytic evidence on PMP efficacy (36) points to group-based PMPs having significant effects on disability/function, pain intensity, psychological health, general health and quality of life, mainly with medium effect sizes. The women themselves attributed a role to the CCPS and PMP in their change processes. For Jane, understanding the multidimensionality of pain had been key: she compared pain to a large "*wall*" that needed to be dismantled "*brick by brick*". The CCPS had helped Jane reconceptualize CP into its different constituent components, which made changing the aspects of her life that needed to change more feasible. For Olga the CCPS helping her to come off morphine was a "*pivotal point*" and the PMP had shown her that she was "*not alone in this sort of spiral of painkillers and pain and feeling miserable and isolated,*" stimulating reflections on her future. For Monica, the PMP and the CCPS counseling had "*set the ball rolling*" in terms of her understanding of herself and her condition. Understanding the biopsychosocial nature of pain, being with similar others, and understanding oneself better are outcomes from PMP programs considered self-management enablers (28).

Causal conclusions are always problematic in research, particularly when phenomena occur in a complex environment, where multiple events, motives and meanings interact, yet a careful longitudinal analysis can reveal interesting details of how processes unfold (27). At least partly in response to the stimuli they received from the CCPS and the PMP, the women in this trajectory group had taken life-changing decisions which had made them feel better, reclaimed agency from their pain, expressed new feelings of self-compassion, gained a sense of control over their lives, and were able, by the end of the study, to live an almost 'normal' and serene life that would have been unthinkable at the start of the study.

The trajectories of all three women in this study confirm that CP is more than a biopsychosocial experience, it is a profoundly idiosyncratic one, where different aspects of the lifeworld of participants come into play, in a "relational and emergent process of sense-making through the lived body that is inseparable from the world that we shape and that shapes us" (37). Thanks to the level of detail inherent in a LIPA design, and the use of pain and Self drawings, the idiosyncratic sense-making of participants was contextualized within each person's particular set of circumstances.

From a methodological standpoint, this study confirms the value of using participant drawings alongside IPA interviews to obtain a more nuanced account of experience. Here, drawings of pain were accompanied by drawings of Self. The order in which drawings were produced may have influenced the imagery chosen by participants. It would be interesting in a future study to ask participants to draw themselves before drawing their pain.

This study offers readers an opportunity to immerse themselves in the experience of CP of three women who embraced PMP participation as a life-changing opportunity. The results offer a nuanced account of the interaction between the input participants received from the CP service and their responses, actions and sensemaking around CP and their life more widely. The study also offers an example of how CP constructs such as acceptance and self-compassion can be situated and illustrated in practice. Finally, although this was not the aim of this study, its results exemplify how IPA might be used longitudinally to understand the outcome of an intervention.

Data availability statement

The paper is self-sufficient we do not feel the need to make further data available. The raw data, although anonymized, includes sensitive material which is not suitable for general distribution.

Ethics statement

The study was reviewed and approved by London Stanmore Research Ethics Committee of the NHS Health Research Authority REC (15/LO/1872). The patients/participants provided their written informed consent to participate in this study.

Author contributions

IEN gathered the data and took the lead on analysis and writing. JAS and JAK contributed to the research at appropriate points. All authors contributed to design the study.

Funding

IEN received funding for the research by Birkbeck University of London through an Anniversary Scholarship.

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

1. Turk DC, Swanson KS. Evaluation of the patient in pain. In: Colvin LA, Fallon M, editors. *ABC of Pain*. Malden, MA: Wiley-Blackwell (2012). p. 11-5.

2. Dahlhamer J, Lucas J, Zelaya C, Nahin R, Mackey S, DeBar L, et al. Prevalence of chronic pain and high-impact chronic pain among adults - United States, 2016. *Morbid Mortal Wkly Rep.* (2018) 67:1001. doi: 10.15585/mmwr.mm6736a2

3. Fayaz A, Croft P, Langford RM, Donaldson LJ, Jones GT. Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. *BMJ Open.* (2016) 6:e010364. doi: 10.1136/bmjopen-2015-010364

4. Toye F, Seers K, Hannink E, Barker K. A mega-ethnography of eleven qualitative evidence syntheses exploring the experience of living with chronic non-malignant pain. *BMC Med Res Methodol.* (2017) 17:116. doi: 10.1186/s12874-017-0392-7

5. de C Williams AC, Fisher E, Hearn L, Eccleston C. Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database Syst Rev.* (2020) 8:CD007407. doi: 10.1002/14651858.CD007407.pub4

6. Rose G. *Visual Methodologies: An Introduction to Researching With Visual Materials. Thousand Oaks*, CA: Sage (2011).

7. Reavey P. Visual methods in psychology: Using and interpreting images in qualitative research. In: Reavey P, editor. *A Handbook of Visual Methods in Psychology*. 2nd ed. Abington: Routledge (2020). doi: 10.4324/9781351032063

8. Kearney KS, Hyle AE. Drawing out emotions: the use of participant-produced drawings in qualitative inquiry. *Qual Res.* (2004) 4:361–82. doi: 10.1177/1468794104047234

9. Shinebourne P, Smith JA. Images of addiction and recovery: an interpretative phenomenological analysis of the experience of addiction and recovery as expressed in visual images. *Drugs Educ Prev Policy.* (2011) 18:313–22. doi: 10.3109/09687637.2010.514621

10. Phillips J, Ogden J, Copland C. Using drawings of pain-related images to understand the experience of chronic pain: A qualitative study. *Br J Occup Ther.* (2015) 78:404–11. doi: 10.1177/0308022614562791

11. Kirkham JA, Smith JA, Havsteen-Franklin D. Painting pain: an interpretative phenomenological analysis of representations of living with chronic pain. *Health Psychol.* (2015) 34:398–406. doi: 10.1037/hea0000139

12. Raja SN, Carr DB, Cohen M, Finnerup NB, Flor H, Gibson S, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain.* (2020) 161:1976–82. doi: 10.1097/j.pain.0000000000001939

13. Smith JA, Osborn M. Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *Br J Pain.* (2015) 9:41–2. doi: 10.1177/2049463714541642

14. Farr J, Nizza IE. Longitudinal Interpretative Phenomenological Analysis (LIPA): a review of studies and methodological considerations. *Qual Res Psychol.* (2019) 16:199–217. doi: 10.1080/14780887.2018.1540677

15. Snelgrove S, Edwards S, Liossi C, A. longitudinal study of patients' experiences of chronic low back pain using interpretative phenomenological analysis: Changes and consistencies. *Psychol Health.* (2013) 28:121–38. doi: 10.1080/08870446.2011.630734

16. King R, Robinson V, Ryan CG, Martin DJ. An exploration of the extent and nature of reconceptualisation of pain following pain neurophysiology education: a qualitative study of experiences of people with chronic musculoskeletal pain. *Patient Educ Couns.* (2016) 99:1389–93. doi: 10.1016/j.pec.2016.03.008

17. Boden Z, Eatough V. Understanding more fully: a multimodal hermeneutic-phenomenological approach. *Qual Res Psychol.* (2013) 11:160–77. doi: 10.1080/14780887.2013.853854

18. Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis: theory, Method and Research. 2nd ed. London: Sage. (2022).

19. Nizza IE, Smith JA, Kirkham JA. "Put the illness in a box": a longitudinal interpretative phenomenological analysis of changes in a sufferer's pictorial representations of pain following participation in a pain management programme. *Br J Pain.* (2018) 12:163–70. doi: 10.1177/2049463717738804

20. Munday I, Newton-John T, Kneebone I. "Barbed wire wrapped around my feet": metaphor use in chronic pain. *Br J Health Psychol.* (2020) 25:814–30. doi: 10.1111/bjhp.12432

21. Bullo S, Hearn JH. Parallel worlds and personified pain: a mixed-methods analysis of pain metaphor use by women with endometriosis. *Br J Health Psychol.* (2021) 26:271–88. doi: 10.1111/bjhp.12472

22. Munday I, Kneebone I, Rogers K, Newton-John T. The language of pain: Is there a relationship between metaphor use and adjustment to chronic pain? *Pain Med.* (2021). doi: 10.1093/pm/pnaa467

23. Linton SJ, Bergbom S. Understanding the link between depression and pain. *Scand J Pain.* (2011) 2:47–54. doi: 10.1016/j.sjpain.2011.01.005

24. Toye F, Seers K, Allcock N, Briggs M, Carr E, Andrews J, et al. Patients' experiences of chronic non-malignant musculoskeletal pain: a qualitative systematic review. *Br J Gen Pract.* (2013) 63:E829–E41. doi: 10.3399/bjgp13X675412

25. Cross K, Kabel A, Lysack C. Images of self and spinal cord injury: exploring drawing as a visual method in disability research. *Vis Stud.* (2006) 21:183–93. doi: 10.1080/14725860600945044

26. Lev-Wiesel R, Hirshenzon-Segev E. Alzheimer's disease as reflected in self-figure drawings of diagnosed patients. *Arts Psychother.* (2003) 30:83–9. doi: 10.1016/S0197-4556(03)00022-4

27. Neale B. *The Craft of Qualitative Longitudinal Research: the Craft f Researching Lives Through Time*. London: Sage (2021).

28. Devan H, Hale L, Hempel D, Saipe B, Perry MA. What works and does not work in a self-management intervention for people with chronic pain? *Qual Syst Rev.* (2018) 98:381–97. doi: 10.1093/ptj/pzy029

29. Neff K. Self-compassion: an alternative conceptualization of a healthy attitude toward oneself. *Self Identity.* (2003) 2:85–101. doi: 10.1080/15298860309032

30. Edwards KA, Pielech M, Hickman J, Ashworth J, Sowden G, Vowles KE. The relation of self-compassion to functioning among adults with chronic pain. *Eur J Pain.* (2019) 23:1538–47. doi: 10.1002/ejp.1429

31. Carvalho SA, Trindade IA, Gillanders D, Pinto-Gouveia J, Castilho P. Self-compassion and depressive symptoms in chronic pain (CP): a 1-year longitudinal study. *Mindfulness.* (2020) 11:709–19. doi: 10.1007/s12671-019-01292-7

32. Hayes SC, Luoma JB, Bond FW, Masuda A, Lillis J. Acceptance and commitment therapy: model, processes and outcomes. *Behav Res Ther.* (2006) 44:1–25. doi: 10.1016/j.brat.2005.06.006

33. Casey M-B, Smart KM, Hearty C, Lowry D, Doody C. Acceptance of chronic pain. perspectives of individuals following an acceptance and commitment therapy pain management programme: an interpretative phenomenological analysis. *Physiother PractRes.* (2019) 40:9–19. doi: 10.3233/PPR-180120

34. Biguet G, Nilsson Wikmar L, Bullington J, Flink B, Löfgren M. Meanings of "acceptance" for patients with long-term pain when starting rehabilitation. *Disabil Rehabil.* (2016) 38:1257–67. doi: 10.3109/09638288.2015.1076529

35. Toye F, Belton J, Hannink E, Seers K, Barker K. A healing journey with chronic pain: a meta-ethnography synthesizing 195 qualitative studies. *Pain Med.* (2021) 22:1333–44. doi: 10.1093/pm/pnaa373

36. Romm MJ, Ahn S, Fiebert I, Cahalin LP. A meta-analysis of group-based pain management programs: Overall effect on quality of life and other chronic pain outcome measures, with an exploration into moderator variables that influence the efficacy of such interventions. *Pain Med.* (2021) 22:407–29. doi: 10.1093/pm/pnaa376

37. Stilwell P, Harman K. An enactive approach to pain: beyond the biopsychosocial model. *Phenomenol Cogn Sci.* (2019) 18:637–65. doi: 10.1007/s11097-019-09624-7

Frontiers in Pain Research

TYPE Original Research
PUBLISHED 21 October 2022
DOI 10.3389/fpain.2022.1031347

EDITED BY
Najmeh Khalili-Mahani,
Montreal Neurological Institute, Canada

REVIEWED BY
Margot Latimer,
Dalhousie University, Canada
Mark I. Johnson,
Leeds Beckett University, United Kingdom

*CORRESPONDENCE
Felicia S. Hodge
fhodge@sonnet.ucla.edu

SPECIALTY SECTION
This article was submitted to Non-Pharmacological Treatment of Pain, a section of the journal Frontiers in Pain Research

RECEIVED 29 August 2022
ACCEPTED 04 October 2022
PUBLISHED 21 October 2022

CITATION
Hodge FS, Line Itty T, Arbing RHA and Samuel-Nakamura C (2022) A window into pain: American Indian cancer survivors' drawings.
Front. Pain Res. 3:1031347.
doi: 10.3389/fpain.2022.1031347

A window into pain: American Indian cancer survivors' drawings

Felicia S. Hodge[1,2]*, Tracy Line Itty[1], Rachel H.A. Arbing[1] and Christine Samuel-Nakamura[1]

[1]School of Nursing, University of California Los Angeles, Los Angeles, CA, United States, [2]Fielding School of Public Health, University of California Los Angeles, Los Angeles, CA, United States

In order to explore the cultural constructs of pain, a series of focus groups were held among adult American Indian (AI) cancer survivors and their caregivers in the Southwest USA. Thirteen focus groups held at four sites (reservation, urban setting, hospital and clinic) elicited information on the barriers to cancer pain management. In response to facilitator questions about cancer pain and existing measurement scales, participants drew pictures to better explain their pain type (i.e., "pounding"), intensity (i.e., "spider web-like"), and other more abstract aspects of their pain episodes. Noting this novel outlet, subsequent groups were prompted for illustrations of pain. A total of 17 drawings were collected from focus group participants. We discuss seven of the drawings that best opened a window into the lived experience of pain, reflected through the eyes of cancer survivors. This study provides evidence that self-expression through color, imagery and written personal accounts provides more accurate depictions of pain for Southwest AI cancer survivors than pain scales alone. It is hypothesized that cultural modes of communication (i.e., storytelling) and intergenerational influences of artwork led to the depiction of pain in drawings. Suggestions for further exploration of the use of the pain drawings for pain assessment in healthcare settings are included.

KEYWORDS

pain, cancer, drawings, pictures, American Indian, pain assessment

Introduction

Chronic pain occurs as a major symptom of cancer and cancer treatment. Although pain is prevalent among most cancer survivors, effective treatment and management of cancer pain merits more attention (1, 2). Numerous studies have reported that minority groups, including American Indians (AIs), are more likely to have under-treated pain (3) and experience or encounter patient-related, provider-related, and pharmacy-related barriers to pain management (2). Barriers to cancer pain causing fragmented management can include language obstacles, high medication costs, health care system complexities, and difficulty in obtaining care and filling prescriptions (4). The experience of pain can vary based on sex, age, spiritual and cultural beliefs, and even the context in which pain is experienced.

The Centers for Disease Control and Prevention (CDC) report that American Indians and Alaska Natives (AI/AN) are more likely to be diagnosed with certain cancers compared to non-Hispanic Whites (5). Rates of lung, colorectal, liver, stomach, and kidney cancers are reported to be higher among AIs than non-Hispanic

Whites, particularly in the six regions where large numbers of AI/ANs reside (5). For instance, when AI/AN cancer rates per 100,000 people are compared against non-Hispanic Whites, liver cancer is twice as high (18.1 vs. 7.1) and cancers of the stomach (9.9 vs. 5.1) and kidney (29.8 vs. 16.5) are almost double. Reported rates per 100,000 people for AI/AN lung cancer (62.6 vs. 57.5) and colorectal cancer (50.7 vs. 36.0) also exceed rates for non-Hispanic Whites (6).

The treatment and management of cancer and cancer-related symptoms, such as cancer pain, is important for successful cancer care and quality of life. Good patient-provider communication is essential for proper diagnosis, assessment and treatment monitoring. Differing perception of pain etiology, pain experiences, and pain descriptors—particularly the context in which pain is experienced, affect successful communication between patient and provider. The experience of pain can vary widely, and the lack of good communication between patient and provider can result in limited or under-treated cancer-related pain. This paper reports on findings, specifically pain drawings, from focus groups held during the course of an intervention study on cancer pain management among Southwest AIs. The study sought to identify the types of cancer-related pain (burning, stabbing, throbbing, etc.), measures of pain, and the cultural constructs of pain. Initial focus groups gathered information on cancer pain experiences for the purposes of testing a cancer symptom management toolkit. Participants were asked to discuss their cancer-related pain experiences; however, they were initially reluctant to respond to the pain scales/figures, citing difficultly in placing numerical values to their pain. They commented that the Wong-Baker FACES® Pain Rating Scale (7) was "child-like" and appeared more "fearful" than painful. Several participants voluntarily decided that in order to best articulate the type of pain they experienced and its intensity, a drawing would be more appropriate rather than having to numerically rate or verbalize a reflection that was difficult to put into words. A group of survivors then submitted their drawings of their personal depiction of pain to the focus group facilitator for consideration in this study. The importance of imagery, as utilized in traditional native storytelling, was hypothesized to be a helpful framework for extrapolating meanings behind the drawings.

Materials and methods

This qualitative study was part of a NIH-supported randomized control trial (RCT) that tested a cancer symptom management intervention among Southwest AI cancer survivors. To better understand participants' cancer symptom experiences (both physical and non-physical), a series of focus groups were held a year prior to the development and implementation of the intervention. The resulting intervention consisted of a Cancer Symptom Management Toolkit that included an educational film and Talking Circles educational curriculum and materials for Southwest (SW) AI cancer patients, survivors and their families. This paper reports solely on the pain drawings collected during the Focus Group phase of the study.

Study population and recruitment

Thirteen focus groups conducted in three urban and two reservation communities recruited one hundred thirty-two ($N = 132$) adult cancer survivors, many accompanied by their caregiver. All participants were aged 18 years or older, living in a Southwest USA state, self-identified as AI, with a medically documented cancer diagnosis. The majority of participants were female (95 females and 37 males). Three focus groups were held at each of the three urban sites, and two focus groups each were held at two rural reservations located in the area. Seventeen participants ($n = 17$) from the final four focus groups drew their depiction of cancer pain on paper, which were then signed, dated and submitted to the focus group facilitator. The pain illustrations were drawn by 16 females and one male. No other additional demographic, cancer-type, or comorbidity data were collected on this subset of participants. The smaller sample size was considered adequate, considering the exploratory nature of the prompts, and enabled in-depth, case-by-case interpretation of each drawing (8).

Through a process of collaboration and agreement with rural and urban Indian health clinics, community centers, and reservation sites, adult AI cancer survivors were targeted for recruitment in the study. Recruitment lasted approximately two months and proceeded by way of word of mouth and recruitment flyers posted at community centers and clinic sites. The flyers provided information on the study, recruitment processes, and enrollment steps. Potential participants were informed of the focus group opportunity and were told if interested to sign up with the focus group moderator *via* a telephone call or in person at the clinic to reserve a space in the session. Contact individuals were accessible at the local sites and had information on the goal of the study, focus group sites and processes, recruitment and participant enrollment steps.

Description of focus groups

Tribal approvals to conduct the study were obtained prior to the implementation of the study. Institutional Review Board (IRB) approvals were also obtained from the research organization and from the local Indian Health Service that ensures the ethical conduct of research. Following recruitment and confirmation of eligibility, individuals were informed in person and in writing of the purpose of the study, that their participation was voluntary, and that they could withdraw at any time without any negative repercussions. Further, results of the study and publications were presented to tribal leaders and publications were approved prior to planned distribution, thus supporting the concept of community/tribal ownership of the research findings and publications. Consent forms were distributed, explained, and then signed and dated by participants prior to beginning the focus group. Each focus group was composed of 12–16 members. Groups ran for approximately one/one-half hours and were facilitated by a research moderator with an assistant to monitor the tape recorder and take any necessary notes. All moderators received training in focus-group implementation in AI populations. Particular attention in training was made to the cultural concept of pain (not to place personal values on the measure or identification of pain). Strict confidentiality was maintained for the duration of this project and participants were asked to use pseudonyms to protect their privacy. Focus group sessions were audiotaped and the tapes were transcribed verbatim to ensure accuracy and systematic analysis of the discussions. Refreshments were offered to participants, as is the custom at AI gatherings. Participants received a gift card for travel and other costs associated with participating in the sessions.

Storytelling methods (9) were employed in the focus group to facilitate a better understanding of the cancer pain experience. Participants took turns telling the story of their cancer diagnosis and cancer-related pain, the types of cancer-related pain they experienced (burning, stabbing, throbbing, etc.), measures of pain they used with providers, and the cultural constructs of pain they would like to share. Responses highlighted the pathways of communication among family, friends, and communities regarding the cancer diagnosis, revealing that they "don't talk about it." The stories moved on to methods of pain management (pharmaceutical, heat/cold, massage, etc.), cancer etiology beliefs, treatment protocols, and methods of self-care. Participants were asked to review and comment on the study project's educational materials and information as well. Participants were asked to provide their feedback on size, font, color, cultural appropriateness, helpfulness, and any gaps that they thought should be addressed. Facilitators provided access to colored pencils in case individuals wanted to make physical suggestions for any of the materials.

In response to facilitator questions about cancer pain and existing measurement scales, some participants spontaneously drew pictures to better explain their pain type, intensity, and other more abstract aspects of pain episodes and pain management. Noting this novel outlet, subsequent groups were prompted for illustrations of pain. Facilitators directed the focus groups that written annotations could also be included. Colored pencils were used by some participants to draw their depiction of cancer pain on paper, 17 of which were signed, dated and submitted to the focus group facilitator. Fifteen of the drawings also had the participants' description of what the drawing was meant to portray written on the backside of the paper drawing. Four illustrations that were collected from participants were drawn by caregivers, and 13 pain drawings were created by female cancer survivors, with 12 of these having accompanying annotations. The integrity of all drawings and descriptions was strictly maintained; as such, no additional descriptions or clarifications were added by facilitators or researchers.

Analysis of pain drawings

Items and groupings from the McGill Pain Questionnaire (MPQ) were used as a starting point to analyze the cancer-related pain drawings; this is a tool commonly used by the Indian Health Service as well as by healthcare providers worldwide (10). The MPQ is a self-reporting tool for pain measures among patients diagnosed with cancer and other chronic diseases. It measures both the quality and intensity of pain. Our analysis approach was to use the MPQ's four descriptors to categorize the pain drawings into four groupings:

Sensory: flickering/beating, jumping/shooting, pricking/lancinating, sharp/lacerating, pinching/crushing, tugging/wrenching, hot/searing, tingling/stinging, dull/heavy, tender/splitting
Affective: tiring/exhausting, sickening/suffocating, fearful/terrifying, punishing/killing, wretched/blinding
Evaluative: annoying/unbearable
Miscellaneous: spreading/piercing, tight/tearing, cold/freezing, nagging/torturing

Five researchers (an MD, two PhDs, and two MPH degreed researchers), two of which were AIs from the Southwest, two non-Hispanic Whites from eastern Canada, and one non-Hispanic White from the SW, ascribed each participant's depiction of their pain experience into one of the four groupings. The evaluators individually assessed each drawing using specific criteria set by the principal investigator. By continually reviewing and exploring the possible meaning of each drawing, overarching themes emerged that were mapped onto MPQ groupings (assigned with a primary, but also secondary designation, where applicable). Consensus was reached when an illustration was categorized into one or more groupings by the majority of evaluators. Although each grouping was initially mutually exclusive, two of the 13 drawings bridged pain categories so they were placed in each of the two descriptive groupings. Rigor was ensured throughout the process by using Shenton's strategies for ensuring trustworthiness (11), specifically cross-checking inferred meanings with AI researchers to demonstrate credibility, transferability, confirmability, and dependability. The process of analysis drew support from annotations by authors that were included with their drawings.

Guiding theory

Survivors' pain depictions in drawings and the individual explanations behind these pictures were also explored using tenets of humanistic theory. The theory asserts that, "each person responds differently to matters of self, others and the environment. Indeed, each person faces the end of life in a way that represents his or her unique life experience in the world" [(12) *p.* 472]. The theory recognizes that individuals are unique and exist in the current situation, but also have the capacity to interact with others to find meaning, and that each individual has the ability and freedom to respond to the current situation through self-reflection and interpret their experiences (13). The call-and-response of the provider towards the patient allows the meeting of unmet health-related needs of patients. These needs may include relevant assessment and interventions that promote wellbeing in the face of advanced disease. Further, the theory emphasizes the concept of community and its inclusiveness of family members, colleagues, and other health care providers in the lived-experience and meeting of health-related needs (13).

Results

Each drawing depicting a participating cancer survivor's experience with cancer-related pain was reviewed and placed into one or more of four groupings based upon MPQ categories. **Table 1** shows the frequency of the 13 survivors' drawings by pain category: sensory, affective, evaluative, and miscellaneous. **Table 2** displays frequency of evaluator's pain category assignment(s) for each illustration. Seven cancer survivors' drawings that depicted unique pain experiences are provided herein: three examples of sensory drawings, two examples of affective drawings, and two examples of miscellaneous drawings.

The sensory category held the largest number of drawings. Nine out of 13 drawings depicted sensory pain as flickering/beating, jumping/shooting, pricking/lancinating, sharp/lacerating, pinching/crushing, tugging/wrenching, hot/searing, tingling/stinging, dull/heavy, and/or tender/splitting. An example of one of the drawings in this category is displayed in **Figure 1**, where drawing #5 illustrates a hammer that is pounding and reports pain that "feels like constant hammering … Pound … Pound … Pound." The artist of this pain depiction chose to use a red colored pencil for the entire drawing to demonstrate the impact of the pain.

Many of the drawings included use of color to demonstrate the intensity of the pain, lines, and descriptors provided in writing on the back of the paper drawing for personal measurement. Use of such sensory descriptors as "pounding" and "screwdriver-inflicted" pain is visually strong and convey well how the pain must have felt to an observer of the picture. The etiology of cancer-related pain was identified by the comment: "The cancer and the knife (referencing surgery) were the cause of my pain." Drawing #7 (**Figure 2**) describes a "grayish part of my breast. The dark area in the middle of the picture is where they removed the cancer. Pain is like a screw that a Phillips screwdriver is screwing down to my inner breast. The other end is the sharp of a red knife that they removed the cancer. The red is for the slight blood during surgery." Interestingly, the end that this survivor explains as the sharp knife is bright red. The stem of the "screwdriver" is colorless and exaggeration is depicted using darker and lighter shades of black. The slight border around the picture has uneven edges and is a faint blue color.

TABLE 1 Frequency of pictures of pain by category.

Category	Frequency
Sensory	9
Affective	4
Evaluative	0
Miscellaneous	2[a]

[a] Also captured in the Affective category.

TABLE 2 Illustration assignment to pain category by rater frequency.

Picture #	Pain category:			
	Sensory	Affective	Evaluative	Miscellaneous
1	2	5	0	0
2	5	1	0	2
3	0	4	0	4
4	n/a	n/a	n/a	n/a
5	5	0	0	2
6	5	0	0	2
7	5	0	0	1
8	5	1	0	1
9	4	1	0	0
10	4	2	0	0
11	1	2	0	2
12	4	2	1	0
13	n/a	n/a	n/a	n/a
14	n/a	n/a	n/a	n/a
15	4	1	1	1
16	0	4	1	2
17	n/a	n/a	n/a	n/a

Reflects ratings from five evaluators.

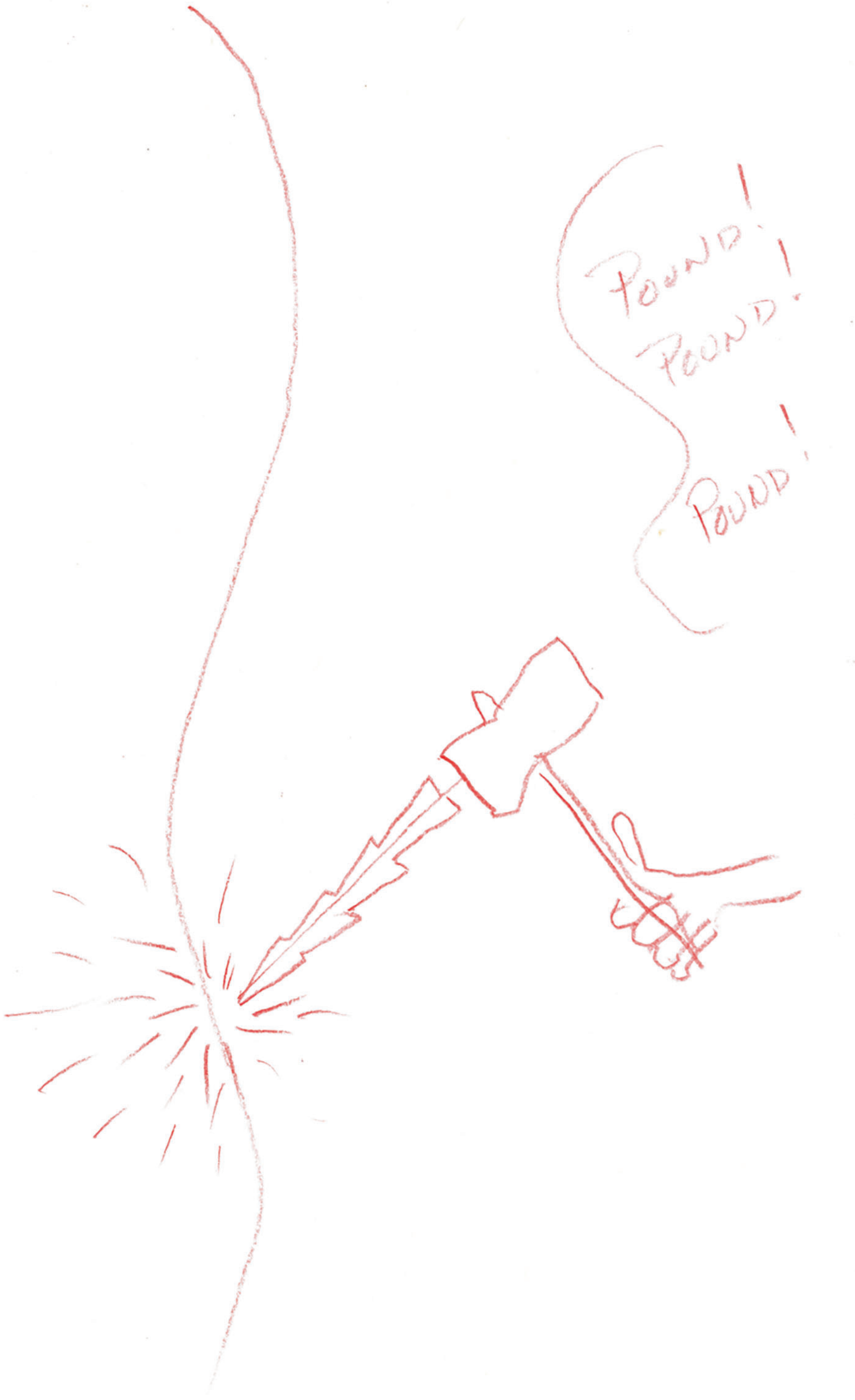


FIGURE 1
Pain as a red hammer.

FIGURE 2
Pain as a piercing screwdriver.

In another example of a sensory illustration, one survivor described their pain intensity (**Figure 3**), "The bottom is pain, but it is not a straight line. It has all these little branches along the way. The color is intense at the bottom but then it gets bigger and there is more to it at the top." The base of the branch in this drawing is a bold red color and the rest of the branch is very dark blue and green, almost looking black. At the end of each shoot off the branch, the artist included many whisks of color, mainly red, but also including green, blue and yellow, perhaps illustrating how pain can feel differently at different times and in different places.

The affective category was defined as pain experienced as tiring/exhausting, sickening/suffocating, fearful/terrifying, punishing/killing, or wretched/blinding. In drawing #1 (**Figure 4**), one cancer survivor describes the pain as "… many different types of angry monsters (that) were

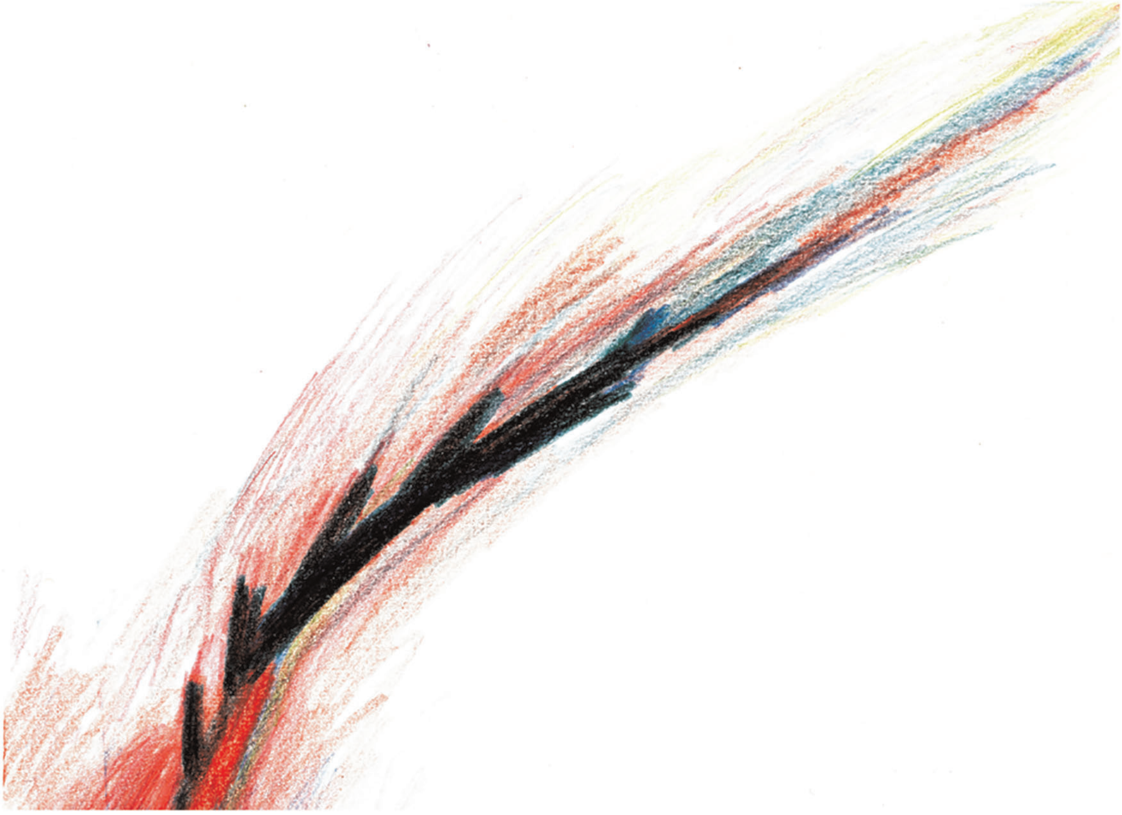


FIGURE 3
Pain as a multi-colored dark branch.

attacking me all over and in every direction." The cancer survivor drew small figures moving across the page in a menacing manner.

An additional drawing (#16, **Figure 5**) presents a picture of various scenes with notations highlighting the words "Fear," "Isolation," "denial of surious (serious)," and "Loss N grief of Friends." The terms "fear" and "pain" are outlined several times in bright colors such as red, green and yellow. Additionally, the survivor outlined the terms "isolation" and "thoughts of cancer" in darker colors including blue, black, and green. The survivor also notes that there are thoughts of cancer and pain, and also includes written-out words of emotions, symptoms, barriers to care and symptom management. This particular survivor chose to use various colors to portray their experience.

The evaluative category was for those drawings that depicted pain as annoying/unbearable. After a careful review of each of the drawings, the research team found no drawing that would be a good fit for the evaluative category.

Drawings #3 and #11 were placed in the category of "miscellaneous" (see **Figures 6**, **7**, respectively). Drawing #3 shows a dark drawing using a black pen, without any other color, and strong lines radiating out as a web or a maze. It depicts the intensity of pain and fear of reoccurrence. The cancer survivor wrote, "The pain is always there in the middle. It is all black and spreading out. I am always afraid that it will come back and this time it will get me. There is no escape from this blackness." This particular drawing was shared with the affective category, as it also described the cancer pain in the sensory term of "terrifying."

Picture #11 (**Figure 7**) was placed in the miscellaneous category (and shared with the Affective grouping). The descriptors of pain were largely measured by color, which was depicted in the cancer survivor's drawing in a series of colorful zigzag lines to "… give pain a color" … similar to stepping down stairs to "relieve you of pain." (If) black, (then) meditate until you get it down to white … down to a lot of purple." This drawing served to depict meditation as a means to reduce pain, to bring the color and thus the level of pain down.

Discussion

Limited research on the use of standardized assessment tools to evaluate pain intensity among AIs poses difficulty for

FIGURE 4
Pain as angry monsters.

nurses and other healthcare providers. Although there is no single method for pain measurement, there are some scales that have been shown to be valid measures of pain intensity in general populations and are commonly used: facial scales [FACES® (7)], the Visual Analog Scale (VAS), and the Numeric Rating Scale (NRS). The current study used the FACES scale to measure pain. Facial scales, such as the Wong-Baker FACES® Pain Rating Scale, consist of a spectrum of facial expressions that depict a level of distress and are arranged in hierarchical order (7). Often a numerical value is associated with each facial expression, however the facial scales were developed for children and the expressions are cartoonish. Other pain charts ask patients to identify the location of the pain by visual templates made up of drawings/outlines of the human body (14). Although pain scales such as those described above are commonly used and may be valid among the general population, focused pain assessment and measurement among AIs is limited.

This paper reports on Southwest AI cancer survivors' depiction of physical and non-physical (i.e., psychological, spiritual) pain experiences as illustrated through their drawings. While data on participant attitudes towards existing pain measurement scales was collected, once the pain drawings emerged this study's research interests shifted towards the implications of pain drawings for capturing the more holistic experience of pain that may be missed by mechanistic measurements of pain domains. As a part of a larger study, these focus groups conducted among AI cancer survivors found that experiences with cancer pain were often misunderstood and under-treated, indicating a need for a more comprehensive and culturally-sensitive method for pain assessment for this population. Ethnicity and cultural differences are of practical concern in treatment situations when patients and clinicians are of different ethnic backgrounds. Cultural differences can create boundaries between healthcare providers and patients and frustrate both

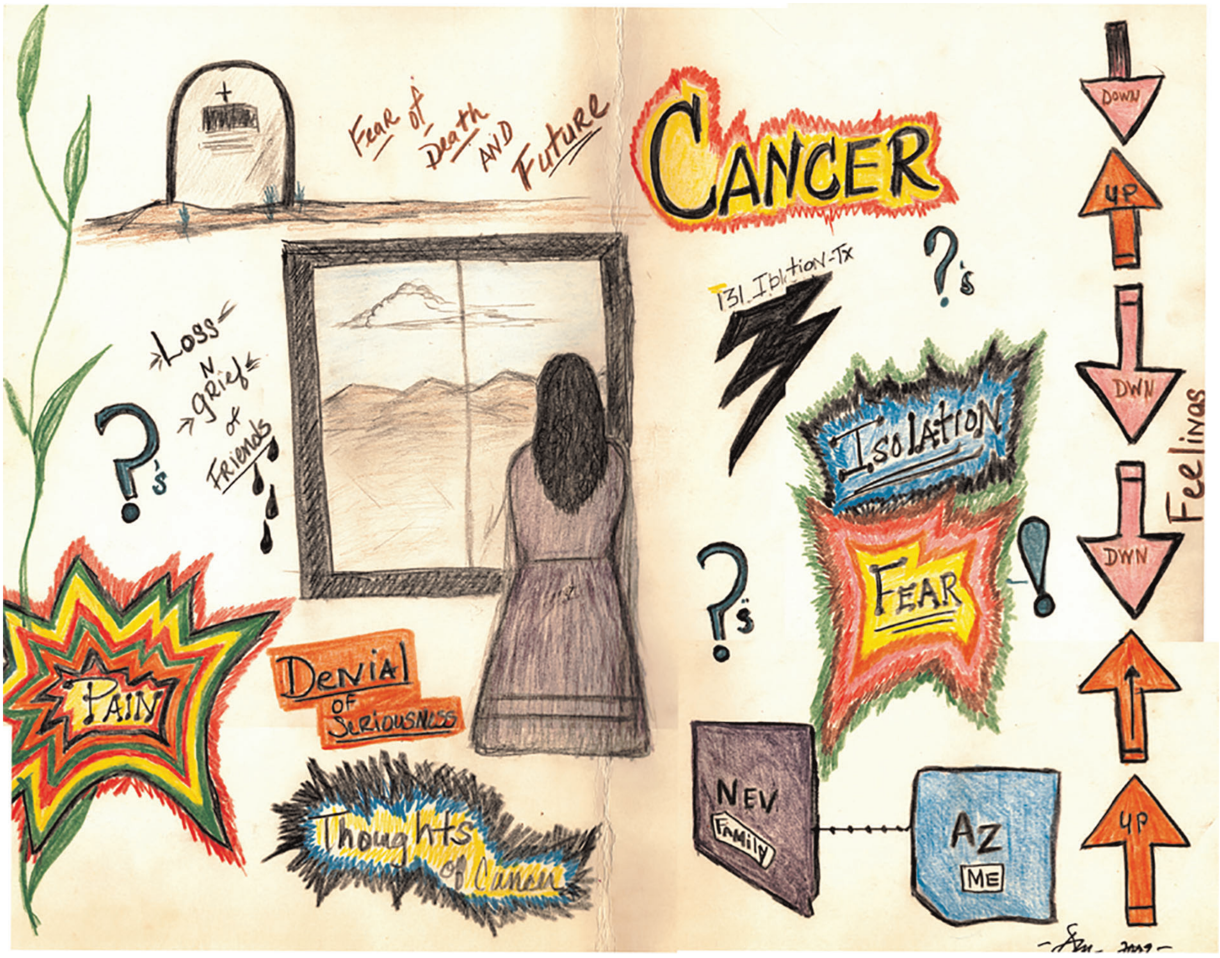


FIGURE 5
Pain caused by many factors.

(15). Under these circumstances, providers may be unable to respond appropriately to the personal needs of their patients and provide reassurance and effective treatment. Inadequate pain treatment may result from the lack of established relationships between patient and clinician, such as acute care settings, where implicit bias may have greater negative influences (3). Problems can occur if there are differences between provider and patient in medical views, beliefs, and social interactions (16). Thus, culture plays an important role in patient communications and provider perceptions of patient pain and other adverse symptoms (17, 18).

Efforts to explore cultural incongruities are reported in a study by Calvillo and Flaskerud (17). In a survey of 60 patients and 60 nurses, differences in Mexican-American and Anglo women's responses to cholecystectomy pain was examined. By comparing the nurses' attribution of pain to the patients' evaluation of the pain, the investigators found that the nurses assigned more pain to the Anglo-American patients than the Mexican-American patients, as well as evaluated their pain as less intense than the Anglo-American patients. The researchers concluded that the nurses' socio-cultural background influenced their perception of patient pain. Other studies have demonstrated effects of incongruent cultural backgrounds on nurses' perception of patient's experiences of pain, pain severity, and their interpretation of pain-relieving strategies (19). Orhan et al.'s systematic review (20) on chronic musculoskeletal pain across all populations, found differences among racial, ethnic or cultural groups with regards to their pain attitudes, perception of illness, self-efficacy, fear avoidance beliefs, and coping strategies for pain. In other studies, sex differences in pain drawings have been observed with women tending to ascribe pain to larger areas of the body (21, 22).

American Indians have a long history of recording their experiences and past histories through storytelling, oral accounts and through visual depiction. Storytelling has been reported as a form of education, entertainment, and as a means to record historical events (9, 23). The study

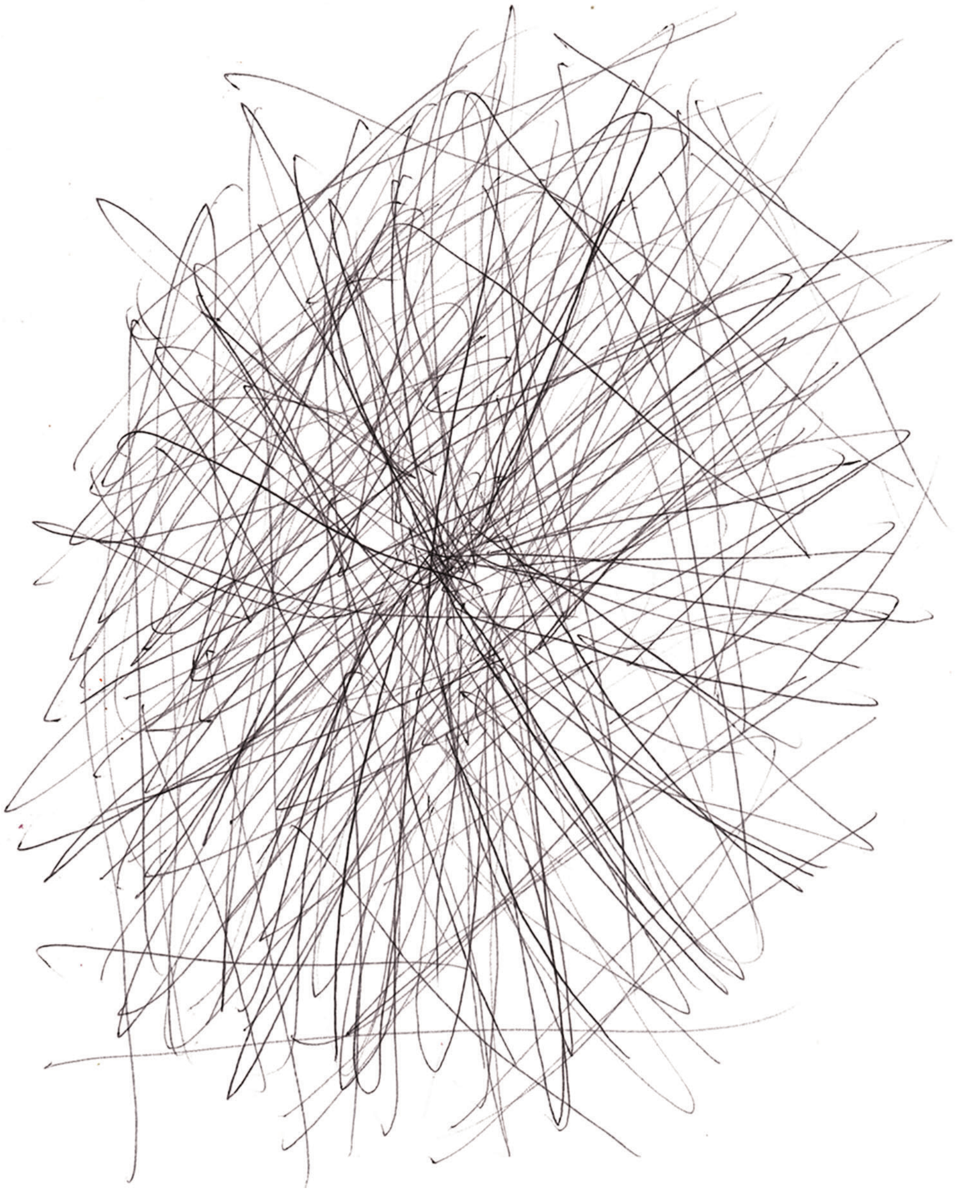


FIGURE 6
Pain as radiating black lines.

participants' illustration examples presented in this paper harkens back to the era of "ledger art" among AI groups, a style of visual history developed by AI warriors from the Northern and Southern Plains and from the Plateau and Great Basin of the United States (24). Using art to memorialize current events, such as cancer-related pain, is an important means to report and measure pain. This manuscript contributes to the understanding of how AI culture may affect provider-patient communication about pain experiences. In instances where AI cancer survivors express dissatisfaction with existing pain scales, holistic care may offer another option—be it blank paper to allow patients to visualize pain in a way that scales, numbers and words simply cannot do justice. Using holistic approaches such as those reported herein warrant further investigation.

Pain is a multi-dimensional feeling that can be interpreted in a two-dimensional format, as evidenced by the pain artwork created in AI cancer survivors taking part in this study. Their illustrations demonstrate not only pain severity and location, but aspects of the survivor's cultural identity and intergenerational traditions. Color has long been used in AI and Indigenous art for symbolic and spiritual purposes,

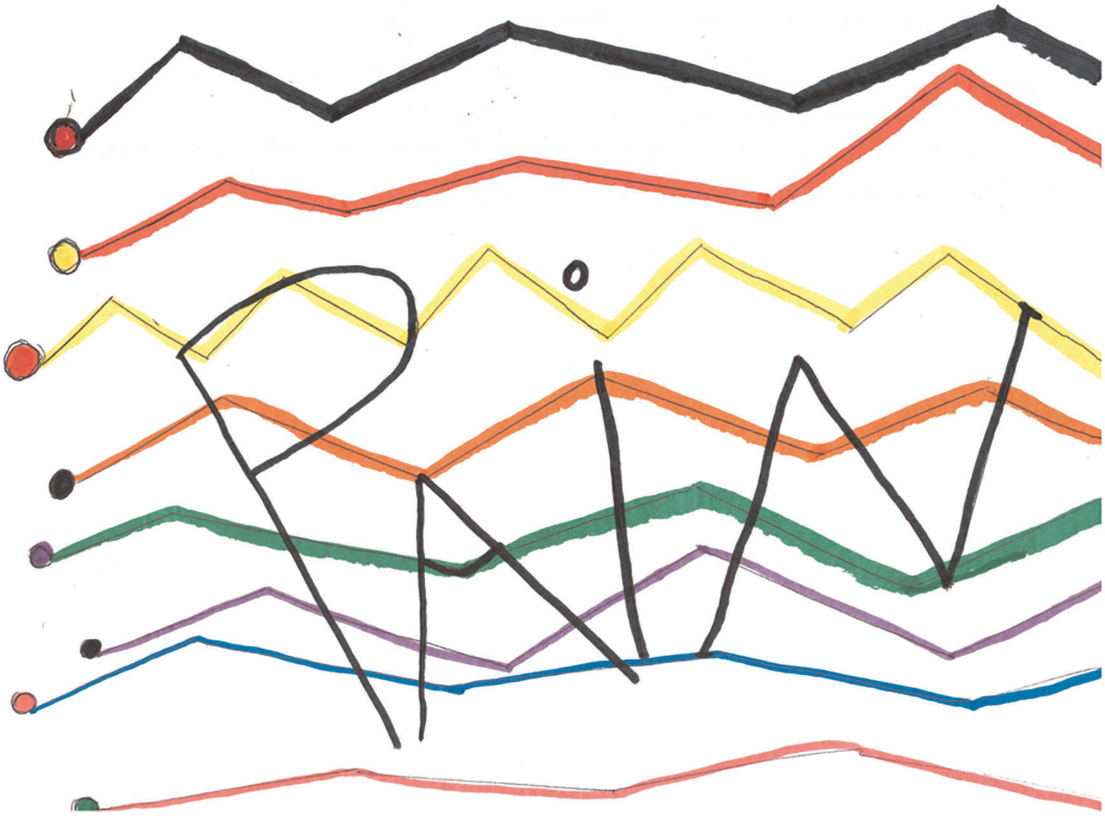


FIGURE 7
Pain as colored zigzag lines.

often with numerous meanings, varying by tribe and region (25–27). For example, for Navajo red may symbolize blood or fire, and yellow can mean fruition (25). Many of these meanings may have been in the minds of cancer survivors and their caregivers when creating their pictures of pain. For the purpose of this study, each participant's color choices were either self-explained in their annotation or inferred by the team of evaluators.

In this study, it is hypothesized that cultural ways of communication and intergenerational influences of artwork led to the depiction of pain in drawings. Each AI cancer survivor's drawing presented is a valid and culturally appropriate depiction of a survivor's pain experience. However, the drawings are based on an individual subjective experience and may not be accurately interpreted without a complimentary detailed description of the drawing that is considered in the context of the individual's situation. Other factors, such as differing cultural backgrounds of the patient and evaluator, must be considered in order to generate valid assessments. Further research is recommended to consider if pain drawings can be incorporated into a new scale or a representative measurement of cancer-related pain experience for individuals. Since the first step in treatment is the assessment of a patient's pain, research must explore the shortfalls of existing scales, particularly among racial/ethnic minorities. Studies targeting other populations used tablets to electronically capture pain drawings on a spatial body template which have shown to be a reliable measurement of acute pain (28). Another study has shown pain drawing on a digital body chart to be a valid measure of chronic neck pain (14), as well as shown promise in clinical assessment and treatment of acute pain (29). However, further investigation into new strategies for reimagining more-open-ended visual tools for pain assessment for the AI community and beyond is needed.

Implications for holistic clinical practice

This paper, guided by the concept of humanism, reinforces an individualized approach to therapy and care, thus it is important to assess preferred methods of communication among AIs. A humanistic approach understands that an individualized approach to assessment and therapy is needed in order to accurately measure and address pain intensity. For instance, among many AI tribes it is more common to think and express thoughts using traditional storytelling (30), and thus storytelling became an important method used in interpreting the focus group pain drawings, as well as in the larger study. Storytelling is a multidimensional, nonlinear, expression that uses events and relevant factors to help describe or explain emotions or experiences. Because the use of storytelling is the traditional form of communication in this community, it should be the duty of healthcare providers to pay closer attention to this cultural factor as it plays into assessment of pain among patients. American Indian patients' use of storytelling and art provide individual reflection and, in most cases, the former is the preferred method of conveying messages among AIs to others (23). Given this tradition, it would be sensible to assume that AI patients would find it more difficult to measure their pain by simply assigning their pain to one number on a scale, a single phrase of few words, or a facial expression, all of which assume linear thoughts and limited expression.

Better understanding the cancer pain experience adds depth and breadth to the holistic approach of patient care assessment and treatment. A humanistic approach to the assessment of pain in cancer patients can affect pain treatment regimens, and potentially patient satisfaction and outcomes. Enhancing culturally-competent communication with cancer survivors and healthcare providers facilitates and improves holistic clinical practice by utilizing the humanistic approach to care giving.

This study provides evidence that self-expression through color, imagery and written personal accounts offers more accurate depictions of pain for Southwest AI cancer survivors than pain scales alone. This qualitative and visual depiction of pain through art appears to better describe the apparent multidimensional aspects of pain, but would likely still need to be used in tandem with established quantitative pain level assessments. Still, the pain drawing technique could be practically applied in cancer care/healthcare settings in two important ways: (1) as groundwork for the development of an open-response, color-coded pain management index, and (2) as a therapeutic and cultural practice for healing, incorporating personal heritage/history documentation into the long-term cancer symptom management care plan. Pain drawings, such as those seen in this study, may be used to (31): differentiate between new experiences with pain from the old; help distinguish between nociceptive and neuropathic pain to improve treatment outcomes; aid in evaluating a patient's response to a given treatment or therapy; and divide patients into groupings by the area of the body that is painful or bothersome so, where appropriate, specialist support may be sought. Artwork therapies for pain (from cancer, as well as other diseases) (32) are being explored more frequently as routes for not only patient and survivors' expression, but also pain visualizations to help healthcare providers better understand patient pain experience (33) for guiding treatment.

Limitations of the study

There are some limitations to this study. For example, although the use of art for self-expression and for healing is a commonality shared across many tribes, regions, and cultures, the specific findings of the study may not be generalizable to AIs living outside of the Southwest United States. Reviewer bias is possible due to differing cultural lenses of the non-AI evaluators. Future studies might cross-check reviewer interpretation of pain drawings with participants to confirm intentions, although this is not always possible. Efforts to reduce bias included use of a clear and uniform evaluation structure and initial independent evaluator reviews of the pain drawings and annotations. Another limitation of the study was there was no control drawing. The role of demographics, cancer-type and severity, and comorbid conditions was not evaluated in this study. As such, this study may be seen as a pilot study in the assessment of individualized pain drawings for use in clinical practice.

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 University of California Los Angeles Institutional Review Board and Phoenix Area Indian Health Service. The patients/participants provided their written informed consent to participate in this study.

Author contributions

FH and TLI held focus groups with participants. FH and TLI wrote the original manuscript. FH, TLI, RA and CSN performed analyses. All authors contributed to manuscript editing, and approved the final submission. All authors contributed to the article and approved the submitted version.

Funding

This research was supported by a grant from the National Cancer Institute (NCI), National Institutes of Health (NIH), R01 CA115358.

Acknowledgments

We would like to express our gratitude to the cancer survivors and their caregivers for sharing their experiences. This manuscript's contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH/NCI or the Indian Health Service.

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

1. Adam R, Murchie P. Why are we not controlling cancer pain adequately in the community? *Br J Gen Pract*. (2014) 64(626):438–9. doi: 10.3399/bjgp14X681229

2. Reis-Pina P, Lawlor PG, Barbosa A. Adequacy of cancer-related pain management and predictors of undertreatment at referral to a pain clinic. *J Pain Res*. (2017) 10:2097–107. doi: 10.2147/JPR.S139715

3. Bonham VL. Race, ethnicity, and pain treatment: striving to understand the causes and solutions to the disparities in pain treatment. *J Law Med Ethics*. (2001) 29(1):52–68. doi: 10.1111/j.1748-720X.2001.tb00039.x

4. Kwon JH. Overcoming barriers in cancer pain management. *J Clin Oncol*. (2014) 32(16):1727–33. doi: 10.1200/JCO.2013.52.4827

5. CDC. Cancer in American Indians and Alaska Natives in the United States. Centers for Disease Control and Prevention. (2021) [cited 2022 Jan 19]. Available from: https://www.cdc.gov/cancer/dcpc/research/articles/cancer-AIAN-US.htm

6. U.S. Cancer Statistics Working Group. U.S. Cancer statistics data visualizations tool, based on 2020 submission data (1999–2018) [Internet]. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute (2021). Available from: www.cdc.gov/cancer/dataviz

7. Wong-Baker FACES® Pain Rating Scale. Wong-Baker FACES® Pain Rating Scale. Wong-Baker FACES Foundation. (2018) [cited 2021 Feb 23]. Available from: https://wongbakerfaces.org/

8. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol*. (2018) 18(1):148. doi: 10.1186/s12874-018-0594-7

9. Haozous EA, Eschiti V, Lauderdale J, Hill C, Amos C. Use of the talking circle for Comanche women's breast health education. *J Transcult Nurs*. (2010) 21 (4):377–85. doi: 10.1177/1043659609360847

10. Olisarova V, Tothova V, Cerveny M, Dvorakova V, Sadilek P. Pain assessment: benefits of using pain scales for surgical patients in South Bohemian Hospitals. *Healthcare (Basel)*. (2021) 9(2):171. doi: 10.3390/healthcare9020171

11. Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. *Educ Info*. (2004) 2(22):63–75. doi: 10.3233/EFI-2004-22201

12. Wu HL, Volker DL. Humanistic nursing theory: application to hospice and palliative care: humanistic nursing theory. *J Adv Nurs*. (2012) 68(2):471–9. doi: 10.1111/j.1365-2648.2011.05770.x

13. Paterson JG, Zderad LT. *Humanistic nursing*. New York, NY: John Wiley & Sons (1976).

14. Abichandani D, Barbero M, Cescon C, Gallace A, Punt D, Sanchis-Sanchez E, et al. Can people with chronic neck pain recognize their own digital pain drawing? *Pain Physician*. (2020) 23(2):E231–40.

15. Itty TL, Hodge FS, Martinez F. Shared and unshared barriers to cancer symptom management among urban and rural American Indians: barriers among American Indian cancer patients. *J Rural Health*. (2014) 30(2):206–13. doi: 10.1111/jrh.12045

16. Miner J, Biros MH, Trainor A, Hubbard D, Beltram M. Patient and physician perceptions as risk factors for oligoanalgesia: a prospective observational study of the relief of pain in the emergency department. *Acad Emerg Med*. (2006) 13(2):140–6. doi: 10.1197/j.aem.2005.08.008

17. Calvillo ER, Flaskerud JH. Review of literature on culture and pain of adults with focus on Mexican-Americans. *J Transcult Nurs*. (1991) 2(2):16–23. doi: 10.1177/104365969100200203

18. Pachter LM. Culture and clinical care. Folk illness beliefs and behaviors and their implications for health care delivery. *JAMA*. (1994) 271(9):690–4. doi: 10.1001/jama.1994.03510330068036

19. Fenwick C, Stevens J. Post operative pain experiences of central Australian aboriginal women. What do we understand? *Aust J Rural Health*. (2004) 12 (1):22–7. doi: 10.1111/j.1440-1584.2004.00541.x

20. Orhan C, Van Looveren E, Cagnie B, Mukhtar NB, Lenoir D, Meeus M. Are pain beliefs, cognitions, and behaviors influenced by race, ethnicity, and culture in patients with chronic musculoskeletal pain: a systematic review. *Pain Physician*. (2018) 21(6):541–58.

21. Toomingas A. Characteristics of pain drawings in the neck-shoulder region among the working population. *Int Arch Occup Environ Health*. (1999) 72 (2):98–106. doi: 10.1007/s004200050344

22. George SZ, Bialosky JE, Wittmer VT, Robinson ME. Sex differences in pain drawing area for individuals with chronic musculoskeletal pain. *J Orthop Sports Phys Ther*. (2007) 37(3):115–21. doi: 10.2519/jospt.2007.2399

23. Hodge FS, Pasqua A, Marquez CA, Geishirt-Cantrell B. Utilizing traditional storytelling to promote wellness in American Indian communities. *J Transcult Nurs*. (2002) 13(1):6–11. doi: 10.1177/104365960201300102

24. Powers WK. Drawing on cultural memory: self and other in native American ledger art [review of spirit beings and sun dancers: black hawk's vision of the Lakota world; arrow's elk society ledger; I will tell of my war story, by J. C. Berlo, M. Cowdrey, & S. M. Thompson]. *Am Anthropol*. (2002) 104 (2):663–6. doi: 10.1525/aa.2002.104.2.663

25. Gill SD. The color of Navajo ritual symbolism: an evaluation of methods. *J Anthropol Res*. (1975) 31(4):350–63. doi: 10.1086/jar.31.4.3629886

26. Warson E. Healing pathways: art therapy for American Indian cancer survivors. *J Cancer Educ*. (2012) 27(1 Suppl):S47–S56. doi: 10.1007/s13187-012-0324-5

27. Kaimal G, Arslanbek A. Indigenous and traditional visual artistic practices: implications for art therapy clinical practice and research. *Front Psychol*. (2020) 11:1320. doi: 10.3389/fpsyg.2020.01320

28. Barbero M, Moresi F, Leoni D, Gatti R, Egloff M, Falla D. Test-retest reliability of pain extent and pain location using a novel method for pain drawing analysis. *Eur J Pain*. (2015) 19(8):1129–38. doi: 10.1002/ejp.636

29. Shaballout N, Aloumar A, Neubert TA, Dusch M, Beissner F. Digital pain drawings can improve doctors' understanding of acute pain patients: survey and pain drawing analysis. *JMIR Mhealth Uhealth*. (2019) 7(1):e11412. doi: 10.2196/11412

30. Moody LE, Laurent M. Promoting health through the use of storytelling. *Health Educ*. (1984) 15(1):8–10, 12. doi: 10.1080/00970050.1984.10615710

31. Margoles MS. Letter to the editor. *Pain*. (1980) 8(1):115–7. doi: 10.1016/0304-3959(80)90094-9

32. Kim KS, Loring S, Kwekkeboom K. Use of art-making intervention for pain and quality of life among cancer patients: a systematic review. *J Holist Nurs*. (2018) 36(4):341–53. doi: 10.1177/0898010117726633

33. Kart SL. Art For Arachnoiditis. Art for Arachnoiditis. (2015) [cited 2021 Feb 24]. Available from: https://artforarachnoiditis.org/2015/05/

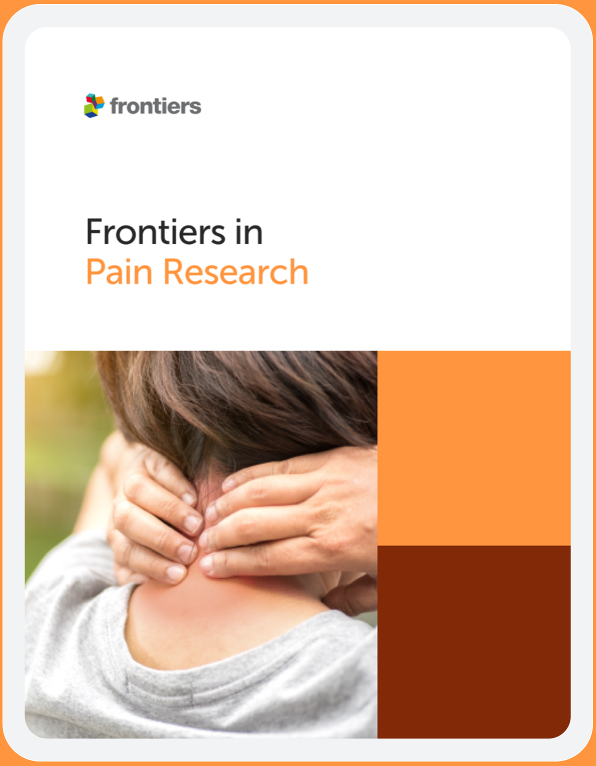
Frontiers in
Pain Research

Investigates new interventions for pain management

An exciting journal in its field, covering mechanisms, treatments, socioeconomics, diagnostics, preventative measures and pain management in a range of medical specialties such as rheumatology and orthopedics.

Discover the latest Research Topics

See more →



frontiers

Frontiers in
Pain Research

Frontiers

Avenue du Tribunal-Fédéral 34
1005 Lausanne, Switzerland
frontiersin.org

Contact us

+41 (0)21 510 17 00
frontiersin.org/about/contact