ACTIVE AND HEALTHY AGEING: A MULTIFOCAL NOVEL TREND TO INCREASE RESILIENCE IN ELDERLY

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ACTIVE AND HEALTHY AGEING: A MULTIFOCAL NOVEL TREND TO INCREASE RESILIENCE IN ELDERLY

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SYSTEMATIC REVIEW
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Fostering the Resilience of People With Dementia: A Narrative Literature Review

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Background: Resilience is a process through which people use resources to adapt to adversity. Interventions aiming to support resilience in people with dementia have been developed. However, the optimal content, structure and impact of these interventions is unclear. This literature review explores the factors through which interventions foster resilience in people with dementia and examines their efficacy.

Methods: Eight databases were searched systematically, for literature published from 2000 to 2019. Following the removal of duplicate articles, the titles and abstracts of 6,749 articles were screened. Articles were selected if they: reported empirical studies in English; focused on resilience; involved people with dementia and psychosocial interventions. The full text of 53 articles were examined and three studies, reported in six papers, were included in the final review. Data were systematically extracted, and two authors critiqued the studies using the Critical Appraisal Skills Programme check lists. The studies were examined to determine how resilience was defined and operationalized and their findings were synthesized using the theoretical resilience framework.

Results: Five interventions aiming to foster resilience were identified: Dementia Advisors; Peer Support Network Services; Visual Arts Enrichment Activities; Memory Makers; and Early-Stage and Beyond Community Activities. All studies defined resilience as a process and most involved people with mild dementia who had family carers. The interventions impacted resilience by reducing the adversity of stigma and social isolation; increasing personal and social resources, providing stigma-free space and reciprocal support. Interventions empowered people with dementia, increasing their self-esteem and self-worth. Resilience can be fostered both during, and after interventions. However, the efficacy of interventions could not be determined because the research designs utilized did not measure efficacy.

Conclusions: Interventions need facilitators to ensure they are strength-based, person-centered and they enable reciprocal social interactions. Future research needs to develop interventions that aim to foster the resilience of people with dementia who lack family carers and/or have more advanced dementia through meaningful activities that are identified by people with dementia as important to their resilience. Robust methodologies, including randomized controlled trials should be used to measure effectiveness and explore the impact of interventions regarding the: interplay between individual and community resources; the importance of reciprocity; and temporal aspects of resilience.

Keywords: dementia, Alzheimer's, resilience, systematic review, aging, interventions

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INTRODUCTION

Dementia is a chronic progressive syndrome, which currently affects 50 million people worldwide (1). Having dementia can negatively impact the person's cognitive functioning, memory, thinking, orientation, language, and emotional control (1). Dementia can cause anxiety (2), and it may be linked to depression (3). Every year, as more people live into old age, there are 10 million people newly diagnosed with dementia (1). Consequently, it is increasingly important to develop strategies that facilitate and support people with dementia to remain independent and functioning well for as long as possible (4).

Resilience is important for people with dementia (5) because it can help with the challenges of living with the condition (6, 7). Resilience has been defined as a dynamic "process of effectively negotiating, adapting to, or managing significant sources of stress or trauma" [(8), p. 2]. Resilience has also been described in terms of a resilience framework (9) which draws upon the ecological systems theory (10). This framework regards resilience as occurring within a complex interacting multi-layered system, in the presence of a significant adversity, which can be acute or chronic in nature (8, 11). A person's response to adversity is facilitated by use of, and access to, resources that can be internal and/or external to the individual in their environment. There are a range of possible resilience outcomes, from vulnerability to flourishing (12). Outcomes of resilience can include maintaining normal development or competence in the presence of mental or physical health difficulties (9). Therefore, resilience can be present when a person with a chronic disease adapts to the condition and demonstrates processes that include acknowledging the condition, gaining a sense of control over it and integrating it into their life and lifestyle (13).

In the context of dementia, resilience is complex and multifaceted (4). It involves the use of resources to negotiate living with the challenges of dementia (14) and the compensatory practices of other people who are close to the individual with dementia (significant others), who act as a resource to support the person, as the dementia progresses (4). Resilience in dementia is strongly related to being socially connected with other people (15) and the participation of individual people with dementia in purposeful activity (16). Harris (17) applied the theoretical framework of resilience using in-depth case study methodology and the qualitative interviewing of people with dementia ($n =$ 2) who were "doing okay" and managing to live well with their dementia. Harris (17) found that positive adaptation in dementia involved overcoming negative influences and having assets and protective factors that outweighed the risks and vulnerabilities experienced by individuals with dementia. They identified that in dementia assets included: having effective coping strategies; acceptance of the dementia diagnosis; accepting changes to life and the need to accept help from available support networks; a positive attitude; and productivity. Whereas, protective factors included: positive relationships with other people that supported personhood (18); and having positive role models. Other researchers have also emphasized the importance of acceptance (19) and of having positive thoughts and feelings (20). In addition, resilience in dementia has been characterized as a process of continual adjustment through which people with dementia learn to live with progressive limitations in their lives (21, 22).

Core outcome sets (23) for resilience in dementia have not yet been established but there has been a small amount of research focusing on outcome measures. Stoner et al. (24, 25) developed and validated with people with dementia ($n = 126$), the Positive Psychology Outcome Measure (PPOM) which measures capacity for resilience, and hope. PPOM has to our knowledge yet to be utilized in research, but Stoner et al. (25) found that PPOM may assist with the future development of asset–based approaches and interventions for dementia. From this literature, and that described above, it can be determined that the capacity of people with dementia for resilience can be improved through the presence of protective factors and that outcomes for resilience in dementia include: having capacity for resilience and protective factors; having the ability to cope effectively and recover from stress; having the ability to adjust and adapt attitudes and behavior to respond positively to dementia; and the ability to accept the challenges and limitations of life with dementia.

Psychosocial interventions aiming to support resilience in people with dementia need to be informed by factors that support and limit resilience (4). However, to date no published literature has examined the existing evidence concerning the content, structure and impact of interventions that aim to support resilience in people with dementia. This narrative literature review aims to explore the evidence concerning interventions that aim to foster resilience in people with dementia: to identify and examine how the concept of resilience is defined and operationalized in these investigations, the efficacy of interventions and the factors through which they impact resilience.

The objectives of this research were to:

- Identify and describe the psychosocial interventions designed to foster the resilience of people with dementia.
- Describe how the interventions were perceived and experienced by people with dementia.
- Critically appraise the methodologies used to design and investigate the interventions.
- Apply the empirical findings of the studies reviewed to the resilience process and framework.
- Describe the efficacy and impact of the interventions on the resilience process of people with dementia.
- Examine the factors that impacted the effectiveness of the interventions.

METHODS

Search Strategy

A comprehensive and systematic search of the literature published from 2000 to 2019 was conducted with the guidance of an expert librarian. Eight databases: Scopus, Web of science, EBSCO-CINAHL, Ageline, PsycINFO, Cochrane, OpenGrey, and Proquest were utilized. Abstracts and titles were searched using keywords, MeSH terms and subject headings (**Table 1**), which were selected as they corresponded to the

TABLE 1 | Search terms.

Population	Phenomenon of interest	
Dementi* OR Alzheimer's Disease OR Alzheimer* OR Lewy body OR (Korsakoff OR Creutzfeldt-Jakob) N2 (disease OR syndrome) OR "Creuzfeldt-Jakob Disease" OR Frontotemporal dementia OR Huntington's Disease (Mixed OR Vascular) N2 dementia OR Parkinson's Disease	Resilien* OR Adapt* OR "Bounce back" OR accept* OR Cop* OR Adjust* OR "protective factors"	Intervention* OR Improve* OR enhance* OR increase* OR therap* OR promot* OR foster* OR program* OR support* OR treat* OR educ* OR mang* OR method* OR approach* OR strategy*

All possible endings of this word were included in the search.

key characteristics of resilience in dementia that have been described above. An example of the search strategy outcomes is provided in Appendix i (**Supplementary Material**). In addition, the references of relevant papers were hand searched and their citations were examined using Google Scholar.

Inclusion and Exclusion Criteria

Papers were screened for eligibility by SW, the lead author. To be included, items needed to report empirical studies that involved people with dementia with any type of dementia of any severity. Studies also needed to involve non-pharmacological psychosocial interventions that addressed resilience or where this was named as an outcome measure. Interventions were defined as any physical, cognitive or social activities that aimed to maintain or improve "functioning, interpersonal relationships and well-being in people with dementia" (26). All comparators to the interventions were included: treatment as usual, no-treatment control, comparison with other interventions, usual treatment/care as were all design methods. Studies were excluded if they involved non-psychological interpretations of resilience, such as resilience in relation to the physical health or the geographical environment, and if they involved people with mild cognitive impairment or involved pharmacological interventions. They were also excluded if the studies used proxy terms for resilience such as self-efficacy, sense of coherence, hardiness, or quality of life. This ensured that the review focused on interventions which explicitly aimed to foster resilience.

Data Extraction and Quality Assessment

Data from the selected papers were extracted systematically, by SW, using an extraction form relevant to the research objectives. This form captured the key features of the included studies (**Table 2**). As critical appraisal of studies has been strongly recommended when performing narrative reviews (33–35), the methodological strengths and limitations of the studies were assessed independently by two reviewers (SW, ÁT) using the Critical Appraisal Skills Programme (CASP-uk.net) qualitative checklist. The CASP checklist is a widely used tool for qualitative evidence synthesis and is recommended by World Health Organization guidelines (36). No study was excluded as a result of this quality assessment.

REVIEW FINDINGS

The PRISMA diagram in **Figure 1** summarizes the selection and screening process (37). The initial search identified 6,977 items. After removing duplicates, the abstract and titles of 6,749 items were screened according to the inclusion and exclusion criteria. Three additional papers were identified through hand searching the reference lists of relevant studies. This resulted in 53 studies being retained for full-text review, against the inclusion criteria. The final review included six papers that reported five interventions (27–32).

An overview of the studies and the interventions is provided below. Enough detail is provided in this overview to enable readers to make sense of studies' context and findings (33), as has been strongly recommended in narrative literature reviews (34, 35). Following the overview, this review then focuses on how the concept of resilience was defined and operationalized within the included studies. After this, the findings of the studies are interpreted in relation to the resilience framework (9).

Overview of the Studies and the Interventions for Resilience

Dementia Advisors and Peer Support Network Services

Clarke et al. (27, 28) conducted a study which evaluated a national programme in the UK that aimed to compare the influence of dementia advisers (DA's) and peer support network (PSN) services on the well-being and resilience of people with dementia and their family carers, living in a community setting. The DA's provided information and an ongoing point of contact for service users. They aimed to provide information about dementia and signpost other services, such as social groups, legal or financial supports. The PSN provided emotional and social support to people with dementia and carers through Alzheimer Society support groups and dementia cafes. Both DA's and PSN facilitators were lay health workers, and many were volunteers (28). At the time of the Clarke et al.'s evaluation, the interventions had been operating for 10 years at 40 demonstrations sites.

Clarke et al. used a mixed methods design which emphasized qualitative methodology (28). An organizational survey was conducted along with case studies of some demonstration sites ($n = 8$). People with dementia were interviewed, at their convenience, alone or with their family carers 1–3 times. These semi-structured interviews lasted up to 2 h. At the time of interview, quantitative questionnaires were also administered. These included the adult social care outcomes toolkit (ASCOT) (38) which collected data on unmet needs and the DEMQoL (39), that recorded health related quality of life. In addition, staff and stakeholders ($n = 82$) were interviewed. Participants were recruited through key staff working at the chosen demonstration

TABLE 2 | Key features of the studies.

Study ID Country Overall design	Aim	Intervention name Target Population Facilitators	Intervention description	Context delivered, duration, frequency	Study design and methods	Study population	Results	Conclusion
Clarke et al. (27, 28) UK	To compare the influence of DA and PSN services to identify ways they contribute to well-being and resilience of people with dementia and family carers	1. DA 2. PSN People with dementia and Carers/Families Lay Health Workers	1. Signpost to other services and ongoing support. Lay Health Worker 2. Psychosocial Support in Alzheimer Society support groups and dementia cafes.	Community Ongoing	Mixed Methods Qualitative semi-structured Interviews Thematic analysis Well-being and QoL surveys using ASCOT and DEMQoL. Statistically analyzed.	People with dementia ($n = 47$) Early Dementia, family carers ($n = 54$), staff and stakeholders ($n = 82$).	Themes -Addressing the needs of the individual and community -Promoting independence. -Control and choice. -Getting a life back.	Public health models of healthcare provision. Should be used to promote resilience.
Newman et al. (29) and Windle et al. (30) UK	To evaluate the impact of visual arts enrichment activities on opportunities for resilience.	Visual arts enrichment activities people with dementia. Artists trained about dementia	Creative individual and collective activities	Care Home Weekly, 2 h for 3 months	Mixed Methods (only Qualitative data focused on resilience) Interviews baseline, post-intervention, and 3 months follow up with People with dementia, relatives, and Carers. Sessions Videoed Facilitator Structured notes.	People with dementia ($n = 48$) in care homes ($n = 4$) aged 70 to 99, CDR scale—$n = 6$ was 0.5 questionable; $n = 18$ 1 mild; $n = 8$ 2 moderate; $n = 16$ 3 severe, care staff, family ($n = 37$)	Supported resilience through creative expression, increased communication, improved self-esteem and relationships with significant others.	Resilience can be supported by visual arts enrichment activities. The concept of respondent habitus may be useful.
Matchar et al. (31) USA	(Not explicitly stated)	Early-Stage and Beyond Community Post Memory Makers People with dementia and Family Carers Four Masters level Social Workers trained by Alzheimer's Association Early-Stage Group Facilitators Manual.	1. Lunch gatherings 2. Museum tours, activities, lunch 3. Support groups 4. Workshop for partners 5. Carer support groups 6. Lecture series for carers 7. Concerts, movies, education	Community 1. Monthly 2. Monthly 3. Monthly 4. 4 monthly every 1–2 years 5. Monthly 6. Quarterly 7. Random	Observational and Descriptively reported rather than using specific outcome measures.	Graduates from 16 Memory Makers support programme groups Family units ($n = 1{,}799$) with people early dementia ($n = 166$; aged 49–93) and their care givers ($n = 178$).	Resilience fostered through acceptance, disclosure, significant others, sense of purpose, routines, and familiar environments and memory aids, showing up/value of a support group, faith.	Resilience is of critical importance to people with dementia regarding acceptance of diagnosis and adaptation to it and there is limited work completed to date as to how resilience can be strengthened.
Matchar and Gwyther (32) USA	To explore the impact on resilience of an Alzheimer education and support group	Memory Makers program Structured Educational support group People with dementia and Family Carers 2 Masters level Social Workers trained by Alzheimer's Association Early-Stage Group Facilitators Manual.	Structured Educational support group; with carer-people with dementia 5–12 dyads. 75 min of discussion separately and then dyads together on different topics weekly.	Community 3 h weekly, for 8 weeks	Observational Descriptive Evidence from 4 groups. Open-ended evaluation surveys were emailed after intervention. Anecdotes from these combined with facilitator observations	People with early dementia and care partner dyads ($n = 35$) spouse 86% adult daughter 14%	People with dementia expressed gratitude for care partner, perceived small victories sustained their resilience. Groups shared coping strategies, expressed hope, humor, living the best lives they could, reciprocal caring.	Resilience benefits from sense of belonging to peer group.

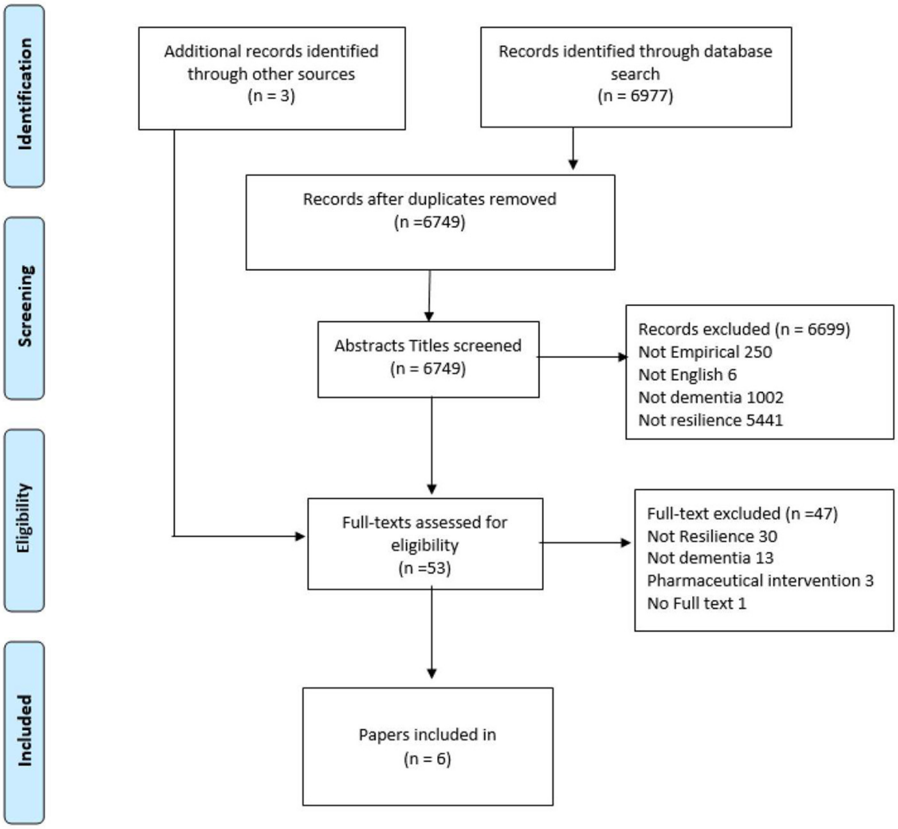

FIGURE 1 | Prisma flow diagram describing the identification, screening, eligibility, and inclusion criteria of the studies identified under the scope of this review.

sites and a sampling matrix was used to select a range of staff and stakeholders who had accessed the services. Participants included family carers ($n = 54$) and people with dementia ($n = 47$), the majority of whom were aged 65–85 years and had early stage (mild) dementia. The quantitative data were analyzed using SPSS, to ascertain statistical representation of frequency and modal responses for each respondent and all people with dementia as a group. All the interview data was uploaded into NVIVO and descriptive content analysis was conducted on 25 of the interview transcripts from which the research team developed a coding framework which was used to analyse the remaining data into themes.

Clarke et al. identified three themes: addressing the needs of individual and communities; promoting choice, control and independence; and getting a life back. The findings included in the first theme revealed that both interventions operated through identifying and responding to the needs of their users. The DA and PSN were informed and shaped by the needs and expressed desires of the people with dementia and their carers. The carers wished to remain well and both the carer and person with dementia wished that the stigma surrounding dementia could be reduced. The data also revealed that the PSN and DA's responded to the needs of the people with dementia by providing a wider range of services than those offered by traditional providers, including for example, gardening clubs and music groups. Also, the PSN and DA facilitators raised awareness about dementia with the wider public through providing training and information. This was illustrated by a carer who said:

> '*I think people need a lot more training on it [dementia], because it's something that is not to be frightened of.*' (Beth, daughter of couple who had accessed DA service) [(28), p. 389].

The second theme, incorporated findings concerning how the services promoted independence, through providing information directly and through signposting access to further support. As one care partner stated:

> '*It [the PSN] allows him to feel independent, and it allows me to be myself, or more myself.*' (Nancy, care partner from PSN site) [(28), p. 390].

The third theme illustrated how the PSN and DA service users considered that they had been enabled to establish a new, improved life with dementia. Self-esteem and self-worth were increased, and participants commented that they had been able to replace the social life and activities that they had lost due to dementia. One participant said:

> *'It's [the PSN] been the best thing that's happened to me for a few years now. I've been going to an art class for Alzheimer's and meeting people. It's fantastic because we can all talk to each other.'* (Lillian, person with dementia who had accessed PSN site) [(28), p. 391].

Visual Arts Enrichment Activities

The second study included in this review was conducted between 2013 and 2017 in the UK (29). This study aimed to evaluate the impact of visual arts enrichment activities (VAEA) on opportunities for the resilience of people with dementia. This study was part of a wider mixed methods study on dementia and imagination (30) that prioritized qualitative methodology. Papers reporting on the wider study were excluded from this review because they did not focus on resilience.

During the VAEA intervention, experienced participatory artists who had received training in dementia, used a person-centered approach to organize activities around the interests, abilities and energy of people with dementia ($n = 48$), aged 70–99 years, living in care homes ($n = 4$). The Clinical Dementia Rating scale (40) was used to rate the severity of participants' dementia. This found that the participants' dementia was borderline normal ($n = 6$), mild ($n = 18$), moderate ($n = 8$) and severe ($n = 16$).

The VAEA sessions lasted 2 h and were held weekly, for 3 months. The VAEA aimed to engage the senses of the participants in activities that could be, for example, individual collage painting or collective, film making, sculpture, or poetry. Participants also visited a contemporary arts center and a celebratory event was held that included their family and carers. Data was captured at 3 time points: baseline, when the activity sessions finished and 3 months after their cessation. Data was collected from people with dementia ($n = 3$) and family carers ($n = 3$) who were interviewed separately and the participatory artists ($n = 2$) who completed structured notes after each session. In addition, sessions were videoed, and recordings were observed to verify the study's findings. The data was analyzed in NVIVO, where multiple readings were used to identify emergent codes which were collated into themes.

This study found that the resilience of people with moderate and advanced dementia can be supported through VAEA. Newman et al. (29) found that VAEA provided a platform which facilitated creative expression; increased communication and self-esteem and that the intervention enhanced the relationships between participants with dementia, their carers and relatives. For example, collectively creating a poem relied upon participants expressing their emotional responses to their individual memories, of being at the sea. The first four lines of this poem were:

The Cruel Sea

> *The beautiful sea goddess*
> *Godiva Pearl*
> *Beautiful ruffles*
> *The ripples* [Poem Created by participants, (29), p. 8]

Creating the poem was facilitated by participants being of similar age and possessing compatible attitudes. Newman et al. (29) argue that in order to produce this adaptive response, participants drew on both personal and collective resources. These resources were cognitive, emotional, imaginative, and aspects of their social selves, including being able to perceive and interpret the thoughts and feelings of others in the group.

Participants were more resilient during the activity than they would have been without it. Newman et al. (29) describes how one person with dementia who was usually solitary and uncommunicative, was poised and passionate when painting. And, as a result of group singing, her interactions with others were observed to increase and be more socially engaging. Newman et al. (29) suggested that the VAEA increased her selfhood and therefore supported her resilience. A carer reported:

> *'It really did feel quite different to me all of the activities were bringing everybody together. . . .She was really connecting with other people as well in the group as well. Her whole body language seemed to be different.'* [Care home Director, (29), p. 11].

Self-esteem of participants was also increased, through participants' mastery of the activity and their success being praised by other people. However, self-esteem could also be undermined if a person was not able to accomplish the task or participate within the group and if the person's attention was drawn to their lack of ability and they became frustrated. Yet, when this occurred, participants demonstrated their ability to adapt because they still found the sessions enjoyable and wanted to participate in them. One man was able to participate, despite his communication difficulties, because he had developed a good relationship with the facilitators. It was argued that his resilience was supported through the social context of the VAEA.

Researchers also found that VAEA supported resilience through promoting personhood. VAEA enabled people to attain their potential without being inhibited by the assumptions other people made about their capabilities. In addition, VAEA increased the knowledge of carers and family members about the capabilities of people with dementia. One care home director said:

> *'I loved hearing people read and was surprised how confident the readers were. I suppose I'd underestimated how capable people with dementia are and had assumed they would find this difficult. You underestimate people don't you, you think 'Oh they're not going to do that'.* [Care home director, (29), p. 13].

Improving the knowledge of significant others of the individuals' personhood meant VAEA had the potential to increase resilience in a sustained way in future interactions. This potential was also increased through VAEA giving residents, carers and relatives, an opportunity to celebrate and enjoy the activities together, in an atmosphere of positive equal relationships:

> *'It just felt like any social occasion/party-friends enjoying themselves, no distinction between those who were experiencing dementia and carers, family and friends.'* [Care home director, (29), p. 13].

Memory Makers

The fourth intervention, "Memory Makers," started in the USA in 2012 and was investigated in a study that aimed to explore its impact on resilience, using an observational descriptive study design (31, 32). This community-based intervention recruited people with dementia from memory clinics, medical practices and the Alzheimer's Association. To participate, people with dementia needed to be: in the early stage of their disease; aware of their diagnosis; able to discuss their feelings and experiences about dementia; have no behavioral psychiatric medical difficulties that would cause them to disrupt the group; have transport to the group and a care partner who was able to attend the majority of sessions. Participants included people with dementia ($n = 35$), aged 56–93 and family carers ($n = 35$).

"Memory Makers" provided structured education about dementia and psychosocial support in a group setting for people with dementia and their family carers. The groups were facilitated by master's educated social workers (two per group) who were trained with information from the Alzheimer's Association early stage group facilitators manual. Memory Maker sessions lasted 3 h and were conducted weekly for 8 weeks. During each session, people with dementia and carers ($n = 12$ dyads) were separated into two groups for 75 min, where they discussed different topics related to living with dementia. After this time, the groups joined. On the final session, the participants wrote a communal poem about their group bonding which aimed to capture the spirit of their resilience.

Data for the study was collected from consecutive groups ($n = 4$), at the end of each group of sessions, via an emailed online evaluation survey. This recorded perceived outcomes anecdotally. This study's findings, which will be described after the fifth intervention is introduced, were also derived from the facilitators' observations. Details as to how data analysis was conducted is not provided by the authors.

Early-Stage and Beyond Community Activities

The fifth intervention was the Early-Stage and Beyond Community Activities (ESBCA) (31). This involved a range of activities (see **Table 2**) for people with dementia and family carers who were graduates from the Memory Maker program. ESBCA aimed to build resilience by developing community support. ESBCA was facilitated by trained social workers (31). Data was collected from family units ($n = 1{,}799$), that included people with dementia ($n = 166$), aged 49–93 years, and family carers ($n = 178$). The authors do not provide details as to how data was collected or analyzed.

The impact on resilience of the Memory Makers programme (32) and the ESBCA (31) will now be discussed together because the interventions involved similar participants and the findings of their investigations concur with one another. Matchar et al. (31) describes themes that were derived separately from people with dementia and their family carers. Here however, in keeping with the aims of this review only the themes identified for people with dementia will be reported. The eight themes identified were: acceptance; disclosure; significant others; sense of purpose; faith; routines, familiar environments, and memory aids; showing up/the value of a support group. The theme of acceptance relates to evidence in which participants described that they were resigned to having dementia, living with limitations and that they accepted this with a determination to make the best of life. One gentleman with dementia said:

> *'There's no changing it [having dementia]. I'm just rolling with it.....I want to find some strategy to best function...'* [Person with dementia, (31), p. 273].

Participants also identified that disclosure to others about their dementia was important to them as a source of support. This allowed them to continue with activities that they enjoyed. For example, one lady continued playing golf as her friends kept score for her. The second theme recognized that the support of significant others was crucial to people with dementia. Participants also highlighted the importance of having a sense of purpose and taking opportunities to stay engaged and socially active. Several participants adapted their activities to accommodate the dementia. Sometimes adaptation to continue activities occurred facilitated by friendships developed through Memory Makers. This happened when one person who could no longer drive was facilitated to continue with voluntary work, delivering donated food, because a Memory Maker friend, who also had dementia, drove them.

The theme, routines, familiar environments, and memory aids, revealed the ways in which participants benefitted from sharing strategies with one another. Doing so increased their knowledge and independence about managing daily life with dementia. Such strategies included keeping objects in the same place, keeping to the same routine including using the same shops or recreational facilities. The final theme illustrated clearly the beneficial impact of the Memory Makers group. Members valued attending the group. One person said it gave her "*renewed meaning*" in life [Person with dementia, Matchar et al. (31), p. 274]. Matchar et al. (31, 32) also reported that participants thoroughly enjoyed the "bubbly ambience" of Memory Maker, and ESBCA which were filled with fun, humor and laughter. One participant said:

> *'It's like a party....Everyone's laughing, and everyone is happy'* [Participant with Dementia, (31), p. 274].

The atmosphere of the groups meant that participants could relax, be themselves, focus on their strengths rather than losses (32), in an environment which was free from stigma and one in which they felt safe to make mistakes (32). In the activities offered by both these interventions, participants were treated with "*acceptance, kindness, and respect*" and the study authors argue that this helped participants to build and maintain their resilience (31). One participant illustrated these findings saying:

> *'Everyone in the group 'got it' and that was a very liberating experience......I felt less like complaining and more inclined towards positive planning and living one day at a time'* [Person with dementia, (32), p. 174].

Being a member of the group provided participants with a sense of belonging. One participant said they had gained a new family, and this empowered them as individuals. The power of the group and the bonds created within them was captured in a poem that participants created:

> *'You are not alone.*
> *I felt the group was a life saver*
> *It brought a life, empowering us all'* [(32), p. 173].

Key features of the studies and interventions are summarized in **Table 2**.

Having provided an overview description of the studies, this paper now focuses on how the concept of resilience was defined and operationalized during the investigations.

DEFINITION AND OPERATIONALIZATION OF RESILIENCE

To address the aims of this review to fully examine and integrate the findings of the studies it is important to establish how resilience was defined and operationalized. This is because historically resilience has been defined in different ways (8). Newman et al. (29) and Matchar et al. (31, 32) state that they defined resilience as a dynamic process that encompasses positive adaptation in the presence of adversity. Although a definition of resilience is not expressly stated by Clarke et al. (28), the study's design supports the supposition that resilience was defined as a process. This is because resilience is reported to be an outcome of the DA and PSN interventions, and yet quantitative outcome measures of well-being and quality of life are used in the study, rather than scales that aim to measure the psychological capacity for resilience.

The studies identified in this review were informed by different research paradigms and theoretical backgrounds including, social constructivism and social disability (28); the ecological theory of human development and the ecological framework of resilience (29); and the social context perspective (31, 32). Newman et al. (29) explicitly stated that the ecological view of resilience underpins their investigation, but all the studies included in this review appear to endorse the view that the resilience of people with dementia is impacted by resources that are accessed at individual, social and community level (8). This supposition is supported because the interventions target both people with dementia and their family carers and the wider community.

Because resilience has been operationalized in this way it is appropriate to apply the resilience framework (9) to the studies' findings to facilitate a more in depth examination as to how the interventions impacted the resilience of people with dementia. This is relevant because resilience can potentially be supported through: reducing the adversity and via improving the provision or access to resources. In applying the framework in this review, community level resources that support resilience are defined as being people in direct contact with people with dementia (significant others) and societal level resources are defined as referring to people outside immediate contact with individual service users.

The results of applying the framework to the included studies are discussed below and summarized in **Table 3**.

THE IMPACT OF THE FIVE INTERVENTIONS ON THE RESILIENCE OF PEOPLE WITH DEMENTIA

DA and PSN Services (27, 28)

The DA and PSN services supported resilience by helping to identify the adversity and needs of people with dementia. This included identifying participants' needs and desires to have a wide range of activities to help them stay well. The adversity experienced by individuals through the stigma of dementia was also combated through DA facilitators providing education to groups of people (other than the participants) about dementia and the needs of people with dementia.

The interventions enabled access to resources that occurred at individual, community and societal levels. Individual resources included the activities that were applicable to people's individual strengths, needs and desires. Indeed, access to these was supported through the participants' increased independence and sense of control. One participant referred to how the services empowered her make choices with her partner:

> *'It gave us the confidence to move in the directions we wanted to move in'* (Jilly, care partner who had accessed DA service) [(27), p. 392].

At community level, the interventions impacted the resilience of the people with dementia through providing support to their carer and through providing participants with access to social peer support. Lillian, a participant with dementia said of the PNS:

> *'It's fantastic because we can all talk to each other'* [(27), p. 391].

Having access to resources appeared to impact the outcomes of resilience. The theme, "getting a life back" speaks to participants having achieved a "new normal" and improved quality of life. One of the participants said:

> '*We've sort of got back some normality now. He's got quite a week of things happening most days.*' (Carer) [(27), p. 391].

Memory Maker and ESBCA (31, 32)

The Memory Maker and ESBCA, did not use a specific tool to identify the needs of the people with dementia as part of the investigation. Never-the-less, it can be extrapolated from the study's data, that participants were experiencing adversity particularly regarding social isolation as a result of the dementia and stigma.

The interventions provided participants with time with others who shared their experiences as people with dementia and family carers. Having time to bond as a group was a resource for individuals and the community through which resilience could be supported and sustained (31).

TABLE 3 | The impact of interventions applied to the Resilience Process (8) and Framework (9).

	Adversity	Resources	Outcomes for individuals diagnosed
PSN and DA Services Clarke et al. (27, 28)	Identified and address a wide range of needs.	**Individual** - Provided resources relevant to strengths and desires of individuals. e.g., people wanted to keep well, wide range of services, and purposeful activities - Supported access to resources, through empowering participation, choice, independence, control. **Community** - Social contact with peers - Supported significant others. **Societal** Education for others in society and advocated on behalf of people with dementia.	- Increase QoL, independence. - Achieved a "new normal" living with dementia. - Recommenced social life and purposeful activities. - Improved self-esteem, self-worth, improved self-identity, confidence to disclose dementia to others.
Memory Maker and ESBCA Matcher et al. (31, 32)	Identified Stigma Reduced Social Isolation	**Individual** - Access to information about successfully living with dementia **Community** - Opportunities to support and receive support from others - Social contact with peers. - Opportunities for social life and environment without stigma.	- Improved independence, positivity, communication. - Adapted purposeful activities. - Empowered to seek further help through disclosure. - Reframed dementia normalizing existence.
VAEA Newman et al. (29)	Variable cognitive and communication difficulties, Stigma Excessive Disability	Access to group and individual creative activities Access to context which supports personhood. Access to and use of interplay of individual and social resources.	Did better than expected. Increased communication, self- esteem Improved relationships with others.

The outcomes of these interventions for resilience, were improved communication between people with dementia and care partner dyads (32), increased capacity for empowerment, independence, and positivity going forward into the future. The data also suggested a more global outcome, that group membership helped move individuals toward a more normal life with dementia, which included being themselves and having a social life with friendships that reduced social isolation. In this regard, their lives with dementia were normalized and the dementia was reframed as being part of their lives. The findings further revealed that participants had more confidence to disclose their dementia to other people (31). This suggests that not only do these outcomes have the potential to be sustained within this community of participants, but outcomes could potentially develop as a result of individuals seeking and benefiting from the support of others outside this immediate peer group community. However, evidence that this occurred is not provided by Matchar et al. (31, 32).

VAEA (29)

In terms of reducing adversities, the VAEA intervention highlighted that participants had cognitive and communication difficulties, that were more severe than those experienced by participants in the other studies. The severity of difficulties was variable both in and between individuals (29). Newman et al. (29) also identified that the beliefs and actions of carers and relatives, regarding the person with dementia's capabilities, impacted how adversity was experienced by people with dementia. Newman et al. (29) found that seeing people with dementia involved in VAEA increased their awareness. This could potentially change the behavior of carers and relatives resulting in them acting in way that supported resilience and did not cause excessive disability. However, no evidence of this change was reported by the study.

In contrast to the other studies, Newman et al. (29) argue that participating in the VAEA increased access to resources but these resources could not be separated into distinct individual and community categories. Instead, resources were used in a complex interplay which was enabled by VAEA. VAEA had no visible impact on resilience through wider societal issues but the impact was through individual, and community issues as described above.

VAEA resulted in people doing better than would otherwise be expected and this can be regarded as an outcome of resilience, during the intervention. In addition, their communication and interaction with others increased in quality and their self-esteem improved.

The findings of this review are now discussed in relation to the wider literature and then recommendations for future research are proposed.

DISCUSSION

The studies reported the perceptions and experiences of people with dementia and the findings reveal that the interventions were well-received by participants who engaged with them voluntarily. Many people with dementia reported the interventions to be beneficial and their views concurred with the observations and opinions of significant others (27, 28, 31, 32). Newman et al. (29) reported the experiences of people with dementia using the intervention as being beneficial to their resilience but did so using the observations and verbal reports of significant others, rather than directly from people with dementia. This raises questions about the challenges involved in assessing the resilience of people with moderate and advanced dementia. As dementia progresses it is important to find ways to accurately capture the perspectives of people with dementia about their resilience. Not to do so is potentially problematic because the perspectives of people with dementia and carers can differ regarding perceptions of quality of life (41) and what makes activities meaningful (42).

One of the benefits of the interventions, was that they empowered people with dementia to disclose their diagnosis to other people (27, 28, 32). Disclosure of dementia diagnosis to friends and family is beneficial (43) and it is logical that informing significant others may be a gateway to the person gaining support from significant others. This finding was less pertinent in the study population living in residential care, but it is notable that involvement with VAEA also improved communication with other people (29). The latter could improve the possibility of compensatory support which may increase the resilience of people with dementia (4).

It is noticeable that only the study reporting VAEA described any weakness or disadvantages to the interventions. VAEA was reported as enjoyable despite some people with dementia experiencing frustration, if they were unable to master certain activities.

The results of this review reveal that most studies to date have focused on people with dementia who are "doing okay" (44). Participants with dementia who were recruited for Memory Makers and ESBCA were relatively well-supported, and those accessing PSN and DA services had the capacity to reach out to the services and engage with them. Although participants involved with VAEA all had significant vulnerabilities, only people without severe communication difficulties were involved in the study. Clarke et al. (28) acknowledges that not accessing people with dementia who did not use the service, was a limitation of their investigation. In addition, except for some participants, involved with VAEA, most participants had early stage dementia. Therefore, the findings of the community-based studies reflect the impact of the interventions on the resilience of people with dementia who have a relatively high ability to access and use resources to support their resilience. This is a situation common to other studies conducted regarding resilience in people with dementia where participants were deemed to be "doing okay" (15, 44), living with people who were supportive and willing to participate in research (22, 45, 46), had contact with support groups (16, 47, 48), and were in receipt of support services (19). However, Harris (44) investigated the resilience of people with dementia including some who were not "doing okay" ($n = 5$). Therefore, it is possible to examine the resilience with people with dementia who are adapting less well to the challenges of living with dementia. Accessing and recruiting participants who are in the most need can be challenging (49). It may take more time to convince gatekeepers that such individuals would be able to participate and to gain participants' consent (50). It may also be challenging to convince funders that recruitment time and study duration in the context of dementia research may need to be extended to facilitate the inclusion of individuals who are in most need.

This review identified that a small number of studies have examined interventions that aimed to support the resilience of people with dementia, who live in both community and residential care settings. The studies were undertaken within the last decade and three of the papers reporting their evaluations were published in 2018. This suggests that the investigation of interventions to support resilience in dementia is a relatively recent and developing field of research and practice. This novelty is reflected in the research designs used to evaluate the interventions. The assessment of the studies methodological strengths and weaknesses during this review found that all the studies produced valuable results in terms of their contribution to knowledge and regarding the aims of this review. However, only Clarke et al. (27, 28) and Newman et al. (29, 30) rated highly in terms of methodological quality. This result was obtained by the two reviewers whose independent assessments, which initially revealed a high degree of consensus, achieved full consensus following discussion (Appendix ii in **Supplementary Material**).

The research designs of all the studies do not seek to measure change in well-being but instead seek to describe how the services were used and experienced by people with dementia and to identify what stakeholders perceived their impact to be. Matchar et al. (31, 32) and Newman et al. (29) focused on describing details of the perceived process and outcomes of the interventions. Their investigations infer that outcomes are as a result of the interventions, and there was no attempt to isolate variables and measure change. Newman et al. (29) did obtain data at multiple time points in relation to participation in VAEA, including data obtained 3 months after the intervention, but their findings concerning potential changes in well-being beyond the VAEA sessions were not reported. Without alternative study designs providing control group comparisons, it is impossible to ascertain effectiveness and whether participation was beneficial due to the components of each intervention per say, or due to them being offered in the absence of another viable activity. Therefore, it cannot be determined to what degree the social component of the group interventions were important. Never-the-less, it should be noted that the varied interventions examined here all supported resilience through socially related characteristics namely, their positive impact on stigma, social contact, and social support.

The stigma associated with dementia was highlighted as an adversity in that it contributed to excessive disability (29) and social isolation (28, 31, 32). This concurs with findings elsewhere, that the actions of other people in applying negative stereotypes increase the difficulties of living with dementia (43). It is therefore significant that the interventions reduced these adversities through providing stigma free, psychosocially safe platforms (29) in which people were free from the fear of potential embarrassment (43, 51).

Social contact and support from other people are also important for resilience (5, 15, 22), as is the quality of the relationships that people with dementia have with other people (52). It appears that the quality of relationships within all the group interventions were improved because they involved people who shared the experience of living with dementia. The interventions provided the opportunity for participants to interact and belong to a peer group and this was hugely valued by participants (28, 29, 31, 32). Belonging to a peer group is known to positively impact resilience in dementia (16, 19, 53) by empowering people, providing opportunities to share practical information strategies to increase their repertoire of adaptive coping strategies (54) and enhancing positivity, which is important for resilience (15, 55).

The quality of relationships between people with dementia and the interventions' facilitators were also important to the success of the interventions. It is notable that all the interventions involved facilitators who played key roles conducting and creating both the content of the interventions and their processes. The artists created the VAEA intervention, enabled participation and ameliorated the impact on self-esteem for individuals who were not able to master the activity (29). The lay health advisors of the DA intervention had ongoing in-depth interactions with service users throughout their journeys with dementia and they shaped the service in response to needs (27, 28). In order to be effective, these facilitators had direct personal knowledge of dementia and intimate knowledge of communities (27) and had training in dementia care as social workers (31) or as researchers (29). This reveals that successful resilience building interventions requires skilled facilitation. In addition, as dementia progresses the way facilitators facilitate interventions is likely to differ and require additional skills.

The interventions also impact resilience through being supportive of the personhood (56) of individuals with dementia, by providing them with meaningful activities (29, 31). Meaningful activities are likely to contribute to the increased self-worth and self-esteem that resulted from the interventions (27–29). Indeed, the activities may support resilience through providing a sense of continuity in identity (55, 57) which can be balanced against the changing perceptions of identity that occur due to the dementia. Successfully managing this balance is important for resilience in dementia (53, 58). The proposition that the interventions may support this important "task" of resilience in dementia is supported by participants in the studies who said the interventions helped them adjust to dementia, to reframe and normalize living with the condition (27, 31, 32).

Another characteristic of the interventions is that they were strength-based in that they built upon the assets and resources that people with dementia already possessed. The interventions required participants to have and use personal and social skills in order to participate. For example, the group interventions required communication and cooperation skills and when participating in the VAEA interventions, participants used aspects of their personal and shared cultural, previous and present identities (29). This implies that people with dementia did not just receive the interventions, but they contributed of themselves, to the intervention and to other group members. Indeed, because their participation involved reciprocity, questions can be raised as to how the positive impact on the resilience of individuals might be increased through the interventions providing opportunities to contribute to communal resilience. People with dementia want to give support to others and contribute (16, 59, 60) and doing so provides them with opportunities for increased self-worth through reinforcing positive self-identity (43). It appears that when the interventions impacted as resources to support resilience, the lines between individual and community resources are blurred regarding reciprocity. Lines between these resource categories were also blurred because two out of three interventions aimed to support the resilience of both people with dementia and family carers. Indeed, carers can be regarded as a community support for people with dementia and family carers with greater well-being may have greater capacity to support the resilience of the people with dementia. It is also noteworthy that Newman et al. (29) identified there was interplay between individual and community resources during VAEA.

The findings of the review revealed that resilience can be fostered "in the moment" during an intervention and/or sustained after the intervention has finished. "In the moment" increased adaptation was highlighted during VAEA, whereas the community-based interventions placed greater emphasis on supporting resilience with the goal of attaining sustainable outcomes (31), through increased independence and on-going well-being (27, 28). However, fostering of resilience "in the moment" was implied during all the interventions through the reports of humor, joy, and release reported by participants. These positive emotions equate to what have been described as "good moments" (61) of happiness. It appears logical that interventions that create opportunities for small moments of happiness are likely to increase positivity and hope which are very important for resilience in people with dementia (16, 19, 21).

The studies in this review provide some evidence that the effects of interventions on resilience can be sustained. Some people with dementia reported and recalled the effects of the interventions when data was obtained (27, 28) and after they had occurred (32) and effects of ESBCA were on-going (31). On-going sustained effect was not highlighted in the findings of VAEA, but the potential for this exists if carers were to act differently due to improvements in relationships and increased awareness concerning the capabilities of people with dementia. Potential for sustained effect on resilience also exists regarding the other interventions due to their empowerment effects and the potential for increased support from other people due to disclosure.

IMPLICATIONS FOR FUTURE RESEARCH

Applying the resilience process (8) and framework (9) to the interventions discussed in this review, facilitated in-depth understanding as to how these interventions impacted resilience of people with dementia. Therefore, it would be useful for future research to include a resilience perspective using the framework. Doing so would be particularly beneficial to investigations concerning interventions that aim to support people with dementia in any purposeful activity. This is because purposeful activity, chosen by a person (57, 62) and compatible with their tacit norms (63), is important to the resilience of people with dementia (48, 55, 57, 63, 64). For example, spirituality can be an important resource for the resilience of many people with dementia (5, 19, 48, 51, 59, 65–67). But to date interventions targeting spirituality have not, to our knowledge, focused on resilience even through spirituality based interventions have been found to impact well-being (68–70). Applying the resilience process when examining such interventions may increase understanding of how they impact well-being.

This review also found that although supporting resilience was beneficial to people with dementia, only a limited number of interventions have been developed and these have been assessed predominantly with people in early dementia in community settings who are currently "doing okay." Future research should focus on interventions that have the potential to support resilience through facilitating communication opportunities for people with more advanced dementia to interact with other people (58, 71, 72). Indeed, touchscreen technology has been found to enhance personhood of people with dementia (73) and robotic technologies can positively impact quality of life (74, 75) and improve mood (76). The potential of these interventions to support resilience could be investigated. Indeed, focusing on people with moderate dementia and those not "doing okay" might reveal the need to target different areas and develop different strategies to support their resilience.

This review highlights gaps in current knowledge concerning how interventions support the resilience of people with dementia and their carers differently, similarly, and jointly. This warrants further investigation, as joint interventions may not suit all dyads and could even harm the resilience of either party. Furthermore, if it is found that the resilience of people with dementia can be enhanced by interventions that also support family carers, then the potential for interventions that jointly target the resilience of people with dementia and professional carers should be investigated in residential care settings.

The findings of this review suggest that resilience can be supported "in the moment" and/or sustained after interventions. This suggests that resilience in relation to time needs further examination. Further investigation is also warranted concerning the interplay between individual and community resources (29), particularly regarding reciprocity and how reciprocity can be used in interventions to support resilience in people with dementia.

It is difficult assess the impact of interventions that occur in clinical environments (77), particularly when investigating them in the context of dementia, which is a progressive disease and where the symptoms of the disease and the adversity caused vary within and between individuals (29). Therefore, in order to potentially influence policy and practice, future research ideally needs to use methodologies that elucidate changes that occur both during and as a result of interventions. Furthermore, tools such as Dementia Care Mapping (78) and the Observational measurement of Engagement (79), may be needed to accurately capture behavioral responses to stimuli and measure changes in resilience. In addition, because the resilience of individuals is impacted by significant others, it is important that future investigations examine the social context into which interventions are introduced and their impact on resilience in the light of this.

LIMITATIONS

This review has limitations and its findings should be considered in the light of these. The search was limited to items published in English and in order to focus on resilience, it excluded proxy terms for resilience. Therefore, intervention investigations reported in different languages and those that explored alternative well-being outcomes, which may have impacted resilience, were omitted. In addition, the search process and data extraction were conducted by one reviewer therefore some relevant articles might have been erroneously excluded. However, the review utilized a theoretically informed systematic approach and the included studies were subjected to in-depth analysis applying resilience theoretical constructs.

SUMMARY

This review used a systematic approach to identify and examine research that investigated psychosocial interventions that aimed to support the resilience of people with dementia. The findings revealed a variety of interventions conducted in both residential care and community living settings. The interventions were found to impact all the components of the resilience process (8) and sometimes there was interplay between the individual and social resource components of resilience. The findings reveal that interventions can support resilience, both during and after the intervention sessions, although evidence of their effectiveness is limited because studies are descriptive and do not measure change. This review found there is a need for further research in this developing field. However, interventions that successfully build resilience in people with dementia need skilled facilitators to ensure that they are supportive of personhood and that they enable reciprocal social interactions to occur. It is also important that interventions are provided within a stigma-free context.

AUTHOR CONTRIBUTIONS

SW conceived, planned, and conducted all aspects of the review including writing the manuscript. ÁT conducted critical appraisal of the included papers, reviewed the drafts, and the final paper. DC provided guidance, critically reviewed drafts, and the final paper.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fmed.2020.00045/full#supplementary-material

REFERENCES

1. World Health Organization. *Dementia Factsheet.* (2019). Available online at: https://www.who.int/news-room/fact-sheets/detail/dementia (accessed March 4, 2019).
2. Porter VR, Buxton WG, Fairbanks LA, Strickland T, O'Connor SM, Rosenberg-Thompson S, et al. Frequency and characteristics of anxiety among patients with Alzheimer's disease and related dementias. *J Neuropsychiatry Clin Neurosci.* (2003) 15:180–6. doi: 10.1176/jnp.15.2.180
3. Ganguli M. Depression, cognitive impairment and dementia: why should clinicians care about the web of causation? *Indian J Psychiatry.* (2009) 51:S29–34.
4. Clare L, Kinsella GJ, Logsdon R, Whitlatch C, Zarit SH. Building resilience in mild cognitive impairment and early-stage dementia: innovative approaches to intervention and outcome evaluation. In: Resnick B, Gwyther L, Roberto K, editors. *Resilience in Aging.* New York, NY: Springer (2011). p. 245–60. doi: 10.1007/978-1-4419-0232-0_16
5. Harris PB, Keady J. Wisdom, resilience and successful aging: changing public discourses on living with dementia. *Dementia.* (2008) 7:5–8. doi: 10.1177/1471301207085364
6. Angus J, Bowen-Osborne S. A self-narrative of life-long disability: a reflection on resilience and living with dementia. *Dementia.* (2014) 13:147–59. doi: 10.1177/1471301212455121
7. Harris P. Is resilience a key to living a meaningful life with dementia? Factors that contribute to the resilience process in early stage dementia. In: *The 63th Annual Scientific Meeting of the Gerontological Society of America*. New Orleans, LA (2010).
8. Windle G. What is resilience? A review and concept analysis. *Rev Clin Gerontol.* (2011) 21:152–69. doi: 10.1017/S0959259810000420
9. Windle G, Bennett KM. Caring relationships: how to promote resilience in challenging times. In: Ungar M, editor. *The Social Ecology of Resilience: A Handbook of Theory and Practice.* New York, NY: Springer (2012). p. 219–31. doi: 10.1007/978-1-4614-0586-3_18
10. Bronfenbrenner U. Ecological models of human development. *Int Encyclopedia Educ*. (1994) 3:37–43.
11. Gillespie BM, Chaboyer W, Wallis M. Development of a theoretically derived model of resilience through concept analysis. *Contemp Nurse*. (2007) 25:124–35. doi: 10.5172/conu.2007.25.1-2.124
12. Windle G. The contribution of resilience to healthy ageing. *Perspect Public Health.* (2012) 132:159–60. doi: 10.1177/1757913912449572
13. Garcia-Dia MJ, Dinapoli JM, Garcia-Ona L, Jakubowski R, O'Flaherty D. Concept analysis: resilience. *Arch Psychiatr Nurs.* (2013) 27:264–70. doi: 10.1016/j.apnu.2013.07.003
14. Bailey C, Clarke C, Gibb C, Haining S, Wilkinson H, Tiplady S. Risky and resilient life with dementia: review of and reflections on the literature. *Health Risk Soc*. (2013) 15:390–401. doi: 10.1080/13698575.2013.821460
15. Bailey GH. *"This is my life and I'm going to live it": a grounded theory approach to conceptualising resilience in people with mild to moderate dementia* (Doctoral dissertation). The University of Edinburgh, Edinburgh, Scotland (2017).
16. Casey D, Murphy K. People with dementia's perceptions of resilience and the factors that strengthen resilience. In: *Gerontological Society of America 2014 Annual Scientific Meeting*. Washington, DC (2014).
17. Harris, PB. Another wrinkle in the debate about successful aging: the undervalued concept of resilience and the lived experience of dementia. *Int J Aging Hum Dev.* (2008) 67:43–61. doi: 10.2190/AG.67.1.c
18. Kitwood TM. *Dementia Reconsidered: The Person Comes First*. Buckingham. Open University Press (1997).
19. Pipon-Young FE, Lee KM, Jones F, Guss R. I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study. *Dementia Int J Soc Res Pract.* (2012) 11:597–616. doi: 10.1177/1471301211421087
20. Preston L, Marshall A, Bucks RS. Investigating the ways that older people cope with dementia: a qualitative study. *Aging Ment Health.* (2007) 11:131–43. doi: 10.1080/13607860600844572
21. Werezak L, Stewart N. Learning to live with early dementia. *Can J Nurs Res.* (2009) 41:366–84.
22. Van Dijkhuizen M, Clare L, Pearce A. Striving for connection: appraisal and coping among women with early-stage Alzheimer's disease. *Dementia*. (2006) 5:73–94. doi: 10.1177/1471301206059756
23. Williamson PR, Altman DG, Blazeby, JM. Developing core outcome sets for clinical trials: issues to consider. *Trials*. (2012) 13:132. doi: 10.1186/1745-6215-13-132
24. Stoner CR, Orrell M, Long M, Csipke E, Spector, A. The development and preliminary psychometric properties of two positive psychology outcome measures for people with dementia: the PPOM and the EID-Q. *BMC Geriatr*. (2017) 17: 72. doi: 10.1186/s12877-017-0468-6
25. Stoner CR, Orrell M, Spector A. The Positive Psychology Outcome Measure (PPOM) for people with dementia: psychometric properties and factor structure. *Arch Gerontol Geriatr*. (2018) 76:182–7. doi: 10.1016/j.archger.2018.03.001
26. Moniz-Cook E, Vernooij-Dassen M, Woods R, Orrell M, Interdem Network. Psychosocial interventions in dementia care research: the INTERDEM manifesto. *Aging Ment Health*. (2011) 15:283–90. doi: 10.1080/13607863.2010.543665
27. Clarke C, Keyes S, Wilkinson H, Alesjuk J, Wilcockson J, Robinson L, et al. *Healthbridge: The National Evaluation of Peer Support Networks and Dementia Advisers in Implementation of the National Dementia Strategy for England*. (Ref: 025/058). Department of Health Policy Research Programme Project (2013).
28. Clarke C, Keyes S, Wilkinson H, Alesjuk J, Wilcockson J, Robinson L, et al. 'I just want to get on with my life': a mixed-methods study of active management of quality of life in living with dementia. *Ageing Soc*. (2018) 38:378–402. doi: 10.1017/S0144686X16001069
29. Newman A, Goulding A, Davenport B, Windle G. The role of the visual arts in the resilience of people living with dementia in care homes. *Ageing Soc.* (2018) 39:2465–82. doi: 10.1017/S0144686X18000594
30. Windle G, Newman A, Burholt V, Woods B, O'Brien D, Baber M, et al. Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ*. (2016) 6:e011634. doi: 10.1136/bmjopen2016-011634
31. Matchar BG, Gwyther LP, Galik E, Resnick B. Building resilience in persons with early-stage dementia and their family carers. In: Resnick B, Gwyther L, Roberto K, editors. *Resilience in Aging*. New York, NY: Springer (2018). p. 261–79. doi: 10.1007/978-3-030-04555-5_14
32. Matchar BG, Gwyther LP. Resilience in early-stage dementia. *Top Geriatr Rehabil.* (2014) 30:170–5. doi: 10.1097/TGR.0000000000000020

33. Baumieister R, Leary M. Writing narrative literature reviews. *Rev Gen Psychol.* (1997) 1:311–20. doi: 10.1037/1089-2680.1.3.311
34. Green B, Johnson C, Adams A. Writing narrative literature reviews for peer reviewed journals: secrets of the trade. *J Chiropr Med.* (2006) 5:101–14. doi: 10.1016/S0899-3467(07)60142-6
35. Ferrari R. Writing narrative style literature reviews. *Med Writ.* (2015) 24:230–5. doi: 10.1179/2047480615Z.000000000329
36. Noyes J, Booth A, Flemming K, Garside R, Hardent A, Lewins S, et al. Cochrane qualitative and implementation methods group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *J Clin Epidemiol.* (2018) 97:49–58. doi: 10.1016/j.jclinepi.2017.06.020
37. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med.* (2009) 151:264–9. doi: 10.7326/0003-4819-151-4-200908180-00135
38. Office of National Statistics. *Measuring Outcomes for Public Service Users (MOPSU) Project*. Final Report. London: Office of National Statistics (2010).
39. Banerjee SS, Smith SC, Lamping DL, Harwood RH, Foley BB, Smith PP, et al. Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *J Neurol Neurosurg Psychiatry.* (2006) 77:146–8. doi: 10.1136/jnnp.2005.072983
40. Hughes CP, Berg L, Danziger, W, Coben LA, Martin RL. A new clinical scale for the staging of dementia. *Br J Psychiatry*. (1982) 140: 566–72. doi: 10.1192/bjp.140.6.566
41. Spector A, Orrell M. Quality of life (QoL) in dementia: a comparison of the perceptions of people with dementia and care staff in residential homes. *Alzheimer Dis Assoc Disord.* (2006) 20:160–5. doi: 10.1097/00002093-200607000-00007
42. Harmer BJ, Orrell M. What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging Ment Health.* (2008) 12:548–58. doi: 10.1080/13607860802343019
43. Sabat SR. *Alzheimer's Disease and Dementia: What Everyone Needs to Know.* New York, NY: Oxford University Press (2018).
44. Harris PB. Resilience and living well with dementia. In: Clarke C, Wolverson E, editors. *Positive Psychology Approaches to Dementia.* London: Kingsley (2016). p. 133–51.45.
45. Sørensen L, Waldorff F, Waldemar G. Coping with mild Alzheimer's disease. *Dementia*. (2008) 7:287–99. doi: 10.1177/1471301208093285
46. Pearce A, Clare L, Pistrang N. Managing sense of self: coping in the early stages of Alzheimer's disease. *Dementia*. (2002) 1:173–92. doi: 10.1177/147130120200100205
47. Ditta G. *Resilience and Wellbeing in People Living With Dementia in Relation to Perceived Attitudes in Their Communities.* Alzheimer Scotland (2015).
48. Beard RL, Knauss J, Moyer D. Managing disability and enjoying life: how we reframe dementia through personal narratives. *J Aging Stud.* (2009) 23:227–35. doi: 10.1016/j.jaging.2008.01.002
49. Watson JL, Ryan L, Silverberg N, Cahan V, Bernard MA. Obstacles and opportunities in Alzheimer's clinical trial recruitment. *Health Aff.* (2014) 33:574–9. doi: 10.1377/hlthaff.2013.1314
50. Beuscher L, Grando VT. Challenges in conducting qualitative research with individuals with dementia. *Res Gerontol Nurs.* (2009) 2:6–11. doi: 10.3928/19404921-20090101-04
51. Bryden C. A spiritual journey into the I-Thou relationship: a personal reflection on living with dementia. *J Relig Spiritual Aging.* (2016) 28:7–14. doi: 10.1080/15528030.2015.1047294
52. Donnellan WJ, Bennett KM, Soulsby LK. What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging Ment Health.* (2015) 19:932–9. doi: 10.1080/13607863.2014.977771
53. McDermott O, Charlesworth G, Hogervorst E, Stoner C, Moniz-Cook E, Spector A, et al. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health*. (2019) 23:393–403. doi: 10.1080/13607863.2017.1423031
54. Stocker KB. *Personal experience of coping with brain disease: neglected are of research* (Doctoral dissertation). University of Massachusetts, Boston, MA, United States (2001).
55. Schmidt T. *Resilience in dementia: Perspectives of those living with dementia* (Master's thesis). University of Alberta, Edmonton, AB, Canada (2014).
56. Kitwood T, Bredin K. Towards a theory of dementia care: personhood and well-being. *Ageing Soc.* (1992) 12:269–87. doi: 10.1017/S0144686X0000502X
57. Smith D, Smith D. Our journey with Alzheimer's disease. *N Z J Occup Ther*. (2012) 59:5.
58. Astell AJ, Savundranayagam MY, Kelson E, Purves B, Phinney A. Fostering resilience in dementia through narratives: contributions of multimedia technologies. In: Resnick B, Gwyther L, Roberto K, editors. *Resilience in Aging.* New York, NY: Springer (2018). p. 245–60. doi: 10.1007/978-3-030-04555 5_13
59. Bryden C. *Dancing With Dementia: My Story of Living Positively With Dementia*. London: Jessica Kingsley Publishers (2005).
60. Suwa S, Otani S, Tsujimura M, Nogawa K, Shiya Y. The diary of a nonagenarian-centenarian woman with dementia: memory loss, life changes, and community care in Japan. *Int J Nurs Pract.* (2018) 24:e12655. doi: 10.1111/ijn.12655
61. Sabat SR. Existential phenomenology and the quality of life of carers and are recipients: a case study. *Dementia*. (2009) 8:163–6. doi: 10.1177/1471301209103247
62. Friedell M. Awareness: a personal memoir on the declining quality of life in Alzheimer's. *Dementia.* (2002) 1:359–66. doi: 10.1177/147130120200100307
63. Cerderall Y,Torres S, Åberg AC. Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging Ment Health*. (2015) 19:679–88. doi: 10.1080/13607863.2014.962004
64. Olsson A, Lampic C, Skovdahl K, Engstrom M. Persons with early-stage dementia reflect on being outdoors: a repeated interview study. *Aging Ment Health*. (2013) 17:793–800. doi: 10.1080/13607863.2013.801065
65. Beuscher LM. *Exploring the role of spirituality in coping with early stage Alzheimer's disease* (Doctoral dissertation). University of Arkansas for Medical Sciences, Little Rock, AR, United States (2007).
66. Agli O, Bailly N, Martinent G. Spirituality, quality of life, and depression in older people with dementia. *J Relig Spirituality Aging*. (2018) 30:268–78. doi: 10.1080/15528030.2018.1452832
67. Ramsey JL, Blieszner R. *Spiritual Resiliency and Aging: Hope, Relationality, and the Creative Self*. New York, NY: Routledge (2016). doi: 10.4324/9781315230979
68. McGee JS, Myers D. Sacred relationships, strengthened by community, can help people with mild or early-stage Alzheimer's. *Generations*. (2014) 38:61–7.
69. Wu LF, Koo M. Randomized controlled trial of a six-week spiritual reminiscence intervention on hope, life satisfaction, and spiritual well-being in elderly with mild and moderate dementia. *Int J Geriatr Psychiatry*. (2016) 31:120–7. doi: 10.1002/gps.4300
70. Mackinley E. Resistance, resilience, and change: the person and dementia. *J Relig Spirituality Aging*. (2012) 24:80–92. doi: 10.1080/15528030.2012.633048
71. Subramaniam P, Woods B, Whitaker C. Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. *Aging Ment Health*. (2014) 18:363–75. doi: 10.1080/13607863.2013.837144
72. Subramaniam P, Woods B. Digital life storybooks for people with dementia living in care homes: an evaluation. *Clin Interv Aging*. (2016) 11:1263–76. doi: 10.2147/CIA.S111097
73. Evans SB, Bray J, Evans SC. The iPad project: introducing iPads into care homes in the UK to support digital inclusion. *Gerontechnology.* (2017) 16:91–100. doi: 10.4017/gt.2017.16.2.004.00
74. Barrett E, Burke M, Whelan S, Santorelli A, Oliveira BL, Cavallo F, et al. Evaluation of a companion robot for individuals with dementia: quantitative findings of the MARIO project in an Irish residential care setting. *J Gerontol Nurs.* (2019) 45:36–45. doi: 10.3928/00989134-20190531-01
75. Moyle W, Jones C, Cooke M, O' Dwyer S, Sung B, Drummond S. Social robots helping people with dementia: assessing efficacy of social robots in the nursing home environment. In: *Proceedings of the 6th International Conference on Human System Interactions (HSI).* Sopot: IEEE (2013). p. 608–13. doi: 10.1109/HSI.2013.6577887

76. Lane GW, Noronha D, Rivera A, Craig K, Yee C, Mills B, et al. Effectiveness of a social robot "Paro," in a VA long-term care setting. *Psychol Serv*. (2016) 13:292–9. doi: 10.1037/ser0000080
77. Craig P, Dieppe P, Macintyre S, Michie S, Nazarath I, Petticrew M. Medical research council: developing and evaluating complex interventions: new guidance. *BMJ*. (2008) 337:a1655. doi: 10.1136/bmj.a1655
78. Bradford UO. *DCM 8 User's Manual*. Bradford: School of Dementia Studies; University of Bradford (2016).
79. Cohen-Mansfield J, Dakheel-Ali M, Marx MS. Engagement in persons with dementia: the concept and its measurement. *Am J Geriatr Psychiatry*. (2009) 17:299–307. doi: 10.1097/JGP.0b013e31818f3a52

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Shared Experiences of Resilience Amongst Couples Where One Partner Is Living With Dementia—A Grounded Theory Study

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Resilience is a concept which may help explain how older people are able to live well with dementia. Existing resilience research in dementia focuses on the caregiver and relatively little is known about how dyads (person with dementia and care partner) experience resilience. Using constructivist grounded theory, this qualitative study aimed to develop a theory of shared resilience amongst couples where one partner is living with dementia. Interviews were conducted with 12 dyads ($n = 24$) to explore their shared understanding of resilience, what helps to develop and maintain their resilience and how resilience shapes their relationship and mutual well-being. Findings indicate that resilience was experienced as continuing with a "normal" life as a couple notwithstanding the impact of dementia. This is in contrast to models of resilience which emphasize bouncing back or flourishing in the face of adversity. Instead, couples described a shared resilience that enabled them to maintain their couplehood, a sense of togetherness and reciprocity in their relationship, which in turn provided a further source of resilience. Findings emphasize the importance of dyadic research in developing a clearer understanding of the experience of living well with dementia. Interventions aimed at building resilience should engage dyads to consider how the couple's shared resilience can be maintained and enhanced.

Keywords: resilience, dementia, couplehood, qualitative, well-being

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INTRODUCTION

Resilience is a concept that may help explain why some people are able to continue to live meaningful lives despite facing adversities associated with dementia (1). Narratives of resilience promote a strength-based approach to dementia that moves beyond dominant discourses of loss and deficit (2). Such an approach furthers our understanding of what it means to live well with dementia (1) and as such is a vital way to empower people living with dementia (PLwD).

Lepore and Revenson (3) outlined three dimensions from which the construct of resilience can be understood: "resistant resilience," remaining strong in the face of adversity; "recovery resilience," bouncing back to previous functioning after facing adversity; and finally, "reconfiguration resilience," going through a period of growth after adversity. This final form of resilience is separate to post-traumatic growth although research often fails to distinguish between them (4).

To date, the majority of research into resilience in dementia has focused on caregivers, with findings indicating that resilience can increase both physical and mental well-being by reducing anxiety, depression and by fostering coping (5). High levels of caregiver resilience benefit PLwD by reducing rates of care recipient institutionalization and even death (6). To date, little research has directly explored resilience with PLwD, possibly due to an assumption that PLwD cannot live well (7) and/or may not be able to sustain or develop resilience. However, two recent qualitative studies shed more light on the potential dimensions of resilience in living with dementia. Williamson and Paslawski (8) interviewed seven people with dementia who described resilience as process of maintenance, the ability to adapt what they did to keep life as normal as possible after diagnosis. Clarke and Bailey (9) highlight the importance of a sense of belonging in a social and physical space in enabling resilience for people with dementia.

An important way to further our understanding of resilience in dementia is to take a dyadic approach. This is important given that dementia affects both members of a couple individually while also potentially influencing their couplehood. Couplehood has been defined as a mutual sense of togetherness and reciprocity in the dyad, which provides insight into how couples live together with the challenges that dementia brings (10). Wadham et al. (11) suggest that a shared sense of resilience in couples may enable them to achieve and maintain a sense of couplehood.

A significant barrier to furthering our understanding of resilience with respect to living with dementia is that there remain few theoretical frameworks from which research can be based. At present, within dementia, definitions of resilience vary widely and include: adjusting to adversity, a personal attribute, well-being and inner strength, level of burden and sufficient social support (12). Proposed definitions of resilience vary between professionals and caregivers, with caregivers focusing more on social support and the relationship with PLwD, whilst professionals prioritize maintaining quality of life and coping (13). Whilst prominent frameworks of resilience exist [for example (14)] and have been cited in relation to caregivers within the dementia literature [for example (15)], they are not specific to dementia and do not incorporate relational factors.

Given the need for a theoretical framework of resilience in dementia, particularly in relation to the perspective of PLwD and the dyad, this study aimed to generate a theory of shared resilience using a constructivist grounded theory approach. This study therefore aimed to explore what resilience means in the context of couplehood in dementia, how dyads experience a shared sense of resilience, how they develop and maintain resilience and how this impacts upon their relationship.

METHODS

Design

This qualitative study used Charmaz's approach to constructivist grounded theory (16) to guide sampling, data collection, and data analysis. Grounded theory is a research method intended to develop a theoretical explanation of a social phenomenon that is "grounded in" naturalistic data.

TABLE 1 | Participant inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
One member of the dyad to be living with dementia and aged over 65 years. The other member of the dyad to be over 18, a spouse or partner of the person with dementia and to self-identify as their caregiver. The dyad is living together within the community, as moving to residential care can significantly change roles and the relationship (20). Both participants have capacity to give consent to involvement in the study.	Dyads with a diagnosis of young onset dementia (YOD). Research indicates that the experiences of people with YOD may differ from people diagnosed in later life (18). People who had received their diagnosis <3 months previously. Research (19) indicates that it takes around 3 months to adjust to a diagnosis and this study was focused on the experience of living with dementia rather than that of receiving a diagnosis.

Sample

Within constructivist grounded theory there are no agreed standard sample sizes; the aim of the data collection being to reach data saturation—when further collection of data will not lead to additional information related to the research question (16). Guest et al. (17) suggest this can be achieved with between 6 and 12 interviews. In accordance with grounded theory, initially purposeful sampling was used to select people who were likely to have had a broad range of experiences but who considered themselves to be resilient. Subsequent participants were selected using theoretical sampling, whereby initial data analysis informed subsequent decisions regarding what data would be collected next and from whom. Participants were recruited from across Yorkshire (UK) via a local NHS Foundation Trust, memory cafés run by the Alzheimer's Society and the Join Dementia Research database. **Table 1** provides an overview of the inclusion and exclusion criteria for the research.

Twelve dyads took part in total. Ten males and two females were diagnosed with dementia, with a range of diagnoses: mixed (n = 5), Alzheimer's Dementia (n = 4), Vascular Dementia (n = 1), Lewy Body Dementia (n = 1), and unknown subtype (n = 1). Participants received their diagnosis between 3 months and 6 years ago (mean = 2.9 years). The age of PLwD ranged from 67 to 89 (mean = 75.3). Of the caregivers taking part in the research, 10 were female and 2 were male, ranging in age from 53 to 87 (mean = 72.3). Eleven of the dyads interviewed were married, ranging from 22 to 66 years (mean = 46.2 years); 1 dyad was unmarried, but had been in a relationship for 10 years. All participants interviewed were White British. **Table 2** describes characteristics and pseudonyms of the participants.

Ethics and Consent

The London—Riverside Research Ethics Committee and the UK Health Research Authority (Approval No. 17/LO/1121) granted

TABLE 2 | Participant characteristics.

Dyad surname pseudonym	Years together	Time since diagnosis
Jones	49	2 years
Davies	28	1 year
Roberts	51	1 year
Brown	66	6 years
Smith	52	5 years
Evans	24	2 years
Williams	10	3 years
Thompson	50	3 years
Green	59	3 years
Taylor	22	3 months
Wood	60	2 years
Edwards	47	6 years

ethical approval prior to commencing the study. Each dyad was provided with verbal and written information about the study prior to gaining consent. An assessment of capacity to give informed consent was made by the lead researcher (LC), assessed by ensuring both members of the dyad were able to understand and retain information about the study, weigh up the information in order to make a decision about participating in the study and then communicate this decision to the researcher. Both members of the dyad were asked to complete written consent forms. One dyad who expressed interest were excluded because one member was unable to provide informed consent to take part.

Data Collection

All dyads were interviewed by choice in their home once. Each dyad completed a demographic questionnaire. The interviews then commenced, with the researcher interviewing the dyad together, allowing an opportunity for shared meanings to be developed and new knowledge to be generated between the dyad (21). Dyads were asked about their understanding of resilience, what had helped to develop and maintain their resilience as a couple and what impact their resilience had had on their relationship and shared well-being. Consistent with a grounded theory approach, theoretical sampling was used to help clarify and address gaps in any emergent theory (16). This centered on adding and adapting interview questions over the course of data collection on the basis of initial coding and constant comparative analysis. Both members of each dyad participated in the interviews; however, participation was not always even as PLwD led some interviews, whilst in others it was their partner who led. Interviews ranged in length from 37 to 75 min (mean = 56 min). Dyads were invited to provide further information following the interviews via email or telephone, with one dyad responding. In accordance with Charmaz (22), saturation was reached as further data collection did not give further detail to the categories or theory. Consideration of data saturation, time constraints, and management of data therefore determined the sample size of 12 dyads.

Analysis

Each interview was transcribed verbatim prior to the next interview, allowing for constant comparative analysis. Analysis of data was carried out referring to recommendations made by Charmaz (16). Coding of the transcripts began with initial coding, in which data was coded line by line and key quotes and ideas were identified and highlighted within the margin of the transcriptions. We then categorized the initial codes that were most frequently mentioned and also most meaningful, using focused coding to analyze larger sections of data. Focused codes were then used for theoretical coding in which the categories developed by focused coding were compared, developing overarching themes in which interrelationships between them were conceptualized and mapped, forming an emergent theory of shared resilience. This was an iterative process; we revisited earlier codes, comparing these repeatedly to emerging overarching themes. We also consulted previous research and literature examining resilience for similarities and differences and to see how similar findings had been categorized and grouped in order to aid the development of the theory. Quotes from participants were integrated into the narrative of our findings, selected to illustrate and represent the experiences of participants and the emergent theory (23).

RESULTS

Four main themes emerged from the data: Understanding Resilience, Shared Resilience, Developing Resilience, and Resources—Support and Stability. Each theme is described with illustrative quotes from interviews and an emergent theory is then presented to describe the development and maintenance of shared resilience.

Understanding Resilience

Participants initially struggled to define resilience, with one caregiver stating "I don't know really, what exactly does resilience mean?" (Mrs. Smith—caregiver), whilst Mr. Taylor described it as "the 'in' word that's come from somewhere" (Mr. Taylor—PLwD). Difficulties defining the term appeared to stem in part from the construct being so deeply embedded in participants' everyday lives. The majority of couples framed resilience as the importance of being able to continue living the life they had before the dementia, both individually and together. For example, Mr. Smith described resilience as "maintaining what I've been used to doing, all be it not as well" (Mr. Smith—PLwD). For couples, feeling resilient related to continuing activities together. Continuing their shared activities, confirmed for them that they were coping, able to "just lead a normal life" (Mr. Jones—PLwD) and "keeping a hold on, the sort of life that we used to have, the values of that life, erm and not letting dementia win" (Mrs. Evans—caregiver). As such, ideas of resilience and well-being were often enmeshed for couples -"I'd assumed that we're, we are talking about our happiness as a couple, cos I think, we're saying we've got plenty of resilience, if we hadn't we wouldn't be very happy" (Mrs. Evans—caregiver).

Resilience was therefore a process of maintenance and continuity of a shared life, but this required active effort and agency. Couples described adopting two positions in their attitude and approach to living with dementia, one was the decision to remain positive and the second was a decision to fight. Remaining positive was not necessarily shared by both partners but instead tended to be "held" by one partner for the benefit of the other, with one caregiver stating "I'm a great believer in looking on the bright side of things" (Mrs. Brown—caregiver). A sense of humor was frequently referred to by couples as helping maintain a positive outlook; "there's always been a sense of humor" (Mr. Williams—PLwD). The decision to fight the dementia was always shared between the couple; Mrs. Roberts describes their approach to "fighting against it (dementia), fighting against what it's making him into sort of thing, and making our lives" (Mrs. Roberts—caregiver).

Shared Resilience

A theme of shared resilience and a resilient togetherness dominated all the interviews; "there is an absolute determination that dementia is not going to come between us" (Mrs. Evans—caregiver). Couples described how they had grown closer since the dementia, with one caregiver stating that they "are now more of a couple than two individuals getting on with life" (Mrs. Roberts—caregiver), whilst another caregiver spoke about how since dementia the couple "live more harmoniously than we did before" (Mr. Edwards—caregiver).

Couples described how their relationship and sense of togetherness enabled them to develop and maintain resilience, but also how their resilience improved the quality of their relationship, enabling them to continue living the same kind of life; "resilience is trying to strengthen our relationship if possible and it's something that I've been doing… so that we can continue to live together through this diagnosis" (Mr. Edwards—caregiver).

For some couples, time spent in the relationship was important for the development of their shared resilience, with a caregiver stating "we've been together nearly 50 years, would I feel like this if I'd only been together 7,8,10?" (Mrs. Jones—caregiver). For others it was more about the quality of relationship they felt they had; the Williams who had been in a relationship for 10 years, the shortest amount of time in comparison to the other couples interviewed, disagreed, stating, "we're comfortable, if we'd have been for 50 years we couldn't be more comfortable with each other" (Ms. Williams—caregiver).

An important factor in the maintenance of shared resilience was demonstrating and sharing acts of love, with a caregiver stating "when things get a bit rough we give each other a kiss, it's amazing how er how that helps" (Mrs. Evans—caregiver). Another caregiver mentioned that she appreciated her husband buying her flowers every week, despite his age, dementia, and arthritis. A further way in which shared resilience was maintained was by talking together about the dementia, talking through and solving the problems they faced. However, discussion about the dementia had to be limited, with one participant living with dementia stating that they "don't talk about it every day" (Mrs. Edwards—PLwD). Not talking about dementia every day allowed priorities to be given to other things in their life. Couples spoke of actively shifting the perspective on dementia and relegating it to the background in terms of their values, priorities and goals, ensuring that "Alzheimer's is something that is a shadow" (Mr. Edwards—caregiver).

For both members of the couple, retaining a sense of independence was important in providing respite and an opportunity for both to recharge their batteries. For PLwD it was important that their diagnosis did not negatively impact on their partner, with one person saying "I don't hold her back from doing things" (Mr. Brown—PLwD). By doing this it was hoped that their relationship would be able to continue in the same positive way, as Mr. Taylor explained not doing so "would destroy her anyway and destroy our relationship" (Mr. Taylor—PLwD).

Developing Resilience

When seeking to explore where resilience came from, responses varied widely both within and between couples. Some felt their resilience was part of who they were as individuals and therefore a personality trait not affected by dementia, with one person stating "if you're that way inclined I think it goes straight through your life" (Mr. Green—PLwD). Others felt that their resilience developed due to previous experiences, particularly adversities they faced during childhood, "I think the start of your life" (Mrs. Wood—PLwD). Participants also described how shared, difficult experiences since being a couple had developed their shared resilience and been important in developing the fighting approach that couples described as important in facing adversities associated with dementia; "we've had to face up to problems in life like that and that's the approach" (Mr. Wood—caregiver).

The development of resilience (both individual and shared) was experienced as a continual process, growing over time with age; "maybe it's just something that we've learnt as we've gone on… I think it probably has grown over the years" (Mrs. Taylor—caregiver). It was also a direct result of living with dementia "as a result of the diagnosis and that increased dependence on each of us erm, I think that has strengthened the relationship and provided that resilience" (Mr. Edwards—caregiver).

Some couples stated that, over the years, they have not always been resilient, with their resilience varying depending on "what you've got to cope with erm, as to whether then you can be resilient enough to cope with it" (Mr. Taylor—PLwD). It was important for couples to accept that "you can't be strong all of the time" (Mrs. Green—caregiver), and that "sometimes you just feel knocked down and vulnerable, and I think you've just got to accept that" (Mrs. Green—caregiver).

Resources—Support and Stability

Resources relates to the external supports that contribute to a couple's resilience in living with dementia. The support of others was imperative to be able maintain resilience, as a caregiver stated "you need people, you need family or someone who cares" (Ms. Williams—caregiver). People providing support included family (talking about their daughter); "she's been very supportive because she comes round and you know she makes sure that we're alright and everything" (Mr. Roberts—PLwD), friends; "I can't express enough about friends, you need… you must have a decent base of friends" (Mr. Smith—PLwD), neighbors; "the neighbors are very good, and if anything was wrong they're here" (Mrs. Brown—caregiver) and even pets; "I'd be totally lost without my dogs, I couldn't be without one" (Mrs. Thompson—caregiver). However, couples highlighted the importance of also not becoming too reliant on others, with one caregiver stating "you just rely on each other and you just get on with it, don't you, you don't rely on anybody else" (Mrs. Davies—caregiver).

Couples also valued the support of professionals in the maintenance of resilience. This included healthcare professionals from whom couples valued consistency and collaboration, which Mr. Evans stated was beneficial as "consequently I think there isn't anything that we experience we wouldn't tell him [GP] is there?" (Mr. Evans—PLwD). Other couples sought support from dementia support groups, enabling PLwD in the dyad to meet other people, learn about dementia, whilst also providing a routine for the couple and a different perspective on life with dementia. However, dementia support groups were not attended by all, as one caregiver stated it was "people just moaning" (Mrs. Taylor—caregiver), and also PLwD reportedly worrying that it showed what the future might hold for them; "he doesn't want to go, because there will be people there with advanced dementia" (Mrs. Davies—caregiver).

Financial stability was helpful for couples to manage dementia, enabling them to afford to make adaptations to their homes in order to maintain a similar kind of life as before and go on holidays to give themselves a break. Having financial stability also provided couples with peace of mind that should the PLwD need to go into a care home, they would be able to afford one which felt like home. For other couples, the benefits of finances were less about affording the luxuries and more about affording the basics to continue the life they enjoyed, with a caregiver stating "if I was cold or uncomfortable or hungry all the time I'd be in a bad temper" (Ms. Williams—caregiver).

Emergent Theory

For couples living with dementia, resilience is a process of maintenance, related to the ability to adapt together in order to continue to live a good shared life. Couples utilized two perspectives to remain resilient; a positive outlook and fighting the dementia. Their sense of couplehood served as evidence to them of their resilience but was also recognized as contributing to their resilience. Shared resilience enabled each partner to maintain and develop their individual resilience, whilst the development and maintenance of individual resilience in turn helped develop and grow their shared resilience. As such shared resilience was equally valued by and valuable for both partners. This reciprocal process resulted in the continual development of resilience throughout the couples' lives together, which continued through the journey with dementia. Shared resilience ebbed and flowed depending on the amount the couple had to cope with on a day-to-day basis and the support they received. Shared resilience therefore was dynamic and continued to develop over time, enabling couples to continue living well despite the challenges of dementia.

DISCUSSION

A key aim of the study was to develop an understanding of what resilience meant to couples living with dementia. However, perhaps understandably, couples often found resilience difficult to define. This is consistent with previous research that has asked caregivers of PLwD about resilience (24). Yet despite the difficulties defining resilience, all couples were able to talk about what it meant to them and how it was experienced, describing resilience fundamentally as their ability to continue living a normal life together. This "everyday resilience" diverges from more prominent definitions of resilience as recovering, bouncing back (3) or flourishing (25). Findings from our study concur with the idea that resilience is an "ordinary magic" (26), in which people adapt and change to cope with the everyday difficulties they face. This is consistent with the findings that in later life (14) and in dementia (8), resilience is a process of continuity and perceived maintenance of functioning, with people adapting how they do things, not what they do.

A central finding from this study is the importance of the relationship in maintaining and developing shared resilience whilst living with dementia. When couples considered their shared sense of resilience, they intuitively drew upon their sense of couplehood and the shared strategies they used to continue to lead what they considered to be a "normal life." This emphasizes the importance of dyadic research in developing a clearer understanding of the experience of resilience. Ideas of family resilience, in which the relationship of the family is vital for the development of a shared sense of resilience between its members (27), and relational resilience are not new. Indeed, the value of shared resilience has been recognized in other chronic illnesses (28). Furthering this dyadic research in dementia is essential to learn more about reciprocity in relationships and its role in supporting living well.

Couples took two different perspectives in order to maintain a normal life in the face of dementia: positivity and fighting. This reflects Clare's (29) finding that people adjust to early stage dementia by developing a "fighting spirit," in which they face the threats of dementia head on, alongside "holding on" and compensating, trying to preserve their sense of self. Whilst Clare's (29) study focused on individuals in the early stage of Alzheimer's dementia, our findings capture the experiences of dyads in both the early and mid-stages of dementia. This suggests that the perspectives of positivity and fighting the dementia can be maintained along the journey of dementia as symptoms progress, but also can be held together as a couple. Within the current study most couples utilized both perspectives flexibly in order to maintain a normal life. However, older couples and those who had been living with dementia for longer tended to focus on remaining positive (i.e., using humor) rather than maintaining a fighting spirit, possibly due to it becoming harder to "fight" dementia as it progresses. In addition to this, it may be that remaining positive becomes an important way to experience positive emotions whilst also preserving a sense of mutuality in relationships (i.e., staying positive together) as dementia progresses.

The finding that resilience is dynamic and develops over time resonates with perspectives which define resilience as a cyclical process as opposed to a trait which people either do or do not possess (30). This has also been demonstrated in resilience research with caregivers in dementia (24). Our emergent theory therefore presents the development and maintenance of shared and individual resilience as a cyclical process, something which Windle and Bennett's (14) framework has been criticized for lacking in relation to caregivers in dementia (24). Despite this critique, the resources enabling shared resilience identified within this study could be divided into individual, community, and society resources, the taxonomy Windle and Bennett (14) outline within their framework. Findings from this study therefore provide evidence that couples living with dementia may utilize similar resources to remain resilient as caregivers of older adults.

This is an exploratory study, informing emergent theory. However we may consider some tentative suggestions for clinical practice at this early stage. The integration into practice of the consistent and specific assessment of resilience to inform and guide well-targeted plans for intervention is the next logical step. Asking couples what they value in their shared life together, what has got them through difficult times in terms of their shared experiences and capabilities may lead to the identification of asserts and resources that can serve as the foundation for clinical intervention. It is important to talk with dyads about the "ordinary magic" of resilience to avoid the "tyranny of the positives" (31) and any mandating of what a good life with dementia looks like. Couples should expect resilience to ebb and flow and a shared life review may help couples to recognize this lifelong pattern of resilience. Clinicians should not overlook the value of small actions to promote resilience; demonstrating acts of love, planning for financial stability and getting affairs in order and knowing what support is available when needed and finding time alone.

LIMITATIONS

A strength of this research lies in its dyadic approach; taking both perspectives into account provides a better understanding of the changes and processes taking place within relationships as dementia progresses. Interviewing dyads together generates a comprehensive insight into the dyadic interplay but it also raises challenges in relation to social desirability of responses and openness in front of the other partner. As such, a key procedural issue is managing the conversation during data collection so as to ensure that both members of the dyad are equally heard. It might be expected that one member of the couple, usually the carer, might dominate the conversation and talk for the person with dementia. This may have been the case historically or it might be the result of a carer becoming accustomed to answering on behalf of the person living with dementia.

These issues reflect the influence of relationship factors and dynamics on how dyads respond to and talk about their experiences of dementia. Prior relationship quality in dementia impacts on emerging relationship style as dementia progresses; dyads able to maintain high levels of mutuality [positive, reciprocal interactions; see (32)] in their relationship do so by focusing on continuation of roles and preservation of identity and/or through a deliberate focus on reciprocation. In contrast, for dyads (couples) with low prior relationship quality, the style of the caring relationship might be based on detachment and/or a sense of duty, which is likely to be associated with lowered well-being for both members [see (33)]. Similarly, couples' efforts to nurture their sense of togetherness and resilience in dementia run in parallel with how they negotiate changes in role and power, preserve identity, and maintain empathic attunement [see (11)].

In recognition of these issues, efforts were made during interviewing to ensure questions were directed toward and opened to both members of the dyad, and whilst in some interviews carers did more of the talking, this was certainly not always the case. At the same time, prior and current relationship dynamics were not directly investigated. This leaves open the possibility that the way couples described their experiences of shared resilience was influenced by long-standing relationship quality and/or shifts in role, power, and empathy. Key differences between couples/dyads in these areas and the impact of these differences on experiences of shared resilience should be the focus of further research.

In order to reach saturation we purposively sampled volunteer participants. However, it could be argued that a limitation of the study was the lack of diversity amongst participants. According to the social graces model (34), diversity is a multi-faceted concept that includes gender, geography, race, ethnicity, and sexual orientation. When considering gender, the majority of caregivers involved in the current study were female, whilst the majority of PLwD were male. Research has found there are gender differences in the experience of providing care for PLwD (35) and future research could therefore aim to recruit gender balanced samples. Couples in this study were also recruited from a small regional area of the UK, with all of the participants identifying as White British. Furthermore, participants were not asked about the perceived impact of their ethnicity or geography. As such, the generalizability of our findings and emergent theory may be limited. Finally, in relation to sexual orientation, each of the couples interviewed were in heterosexual relationships. McParland and Camic (36) found evidence that dementia is experienced differently by same sex couples. As such, future research should also include same sex partnerships or aim to expand our understanding of how differences in experiences according to sexual orientation are experienced.

In addition to limitations relating to diversity, this research only offers an insight into shared resilience within romantic relationships. There are a number of other caregiving relationships in which shared resilience may be developed and maintained, such as parental and sibling relationships or friendships. Future research could therefore consider how different types of care relationships may foster shared resilience in dementia.

During the interviews, couples reflected on whether, as they continue through the journey of dementia, their resilience will change. Resilience research could therefore benefit from either being longitudinal to understand how a shared sense of resilience might change over time or include couples who have been living with dementia for longer.

CONCLUSIONS

Living well has been a rhetoric in dementia care for some time; we need to develop our understanding of how people live well and what strengths they draw up. Key to this is recognizing that people do not flourish in isolation and that couples will have shared strengths and resources. This study is important in its dyadic focus to enable further insight into our understanding of resilience and living well with dementia. In contrast to models of resilience which emphasize bouncing back or flourishing in the face of adversity, the couples in this study described resilience as continuing with a "normal" life notwithstanding the impact of dementia. Couples described a shared resilience, which enabled them to maintain their couplehood—that is their shared sense of togetherness and the reciprocity in their relationship. This sense of couplehood in turn provided another source of resilience. Our findings emphasize the value of dyadic research and interventions in developing our understating of living well with dementia and how we can support couples to maintain and enhance their resilience.

DATA AVAILABILITY STATEMENT

The raw datasets will not be made publicly available due to ethical constraints. Requests can be made and taken under consideration by contacting EW, e.wolverson@hull.ac.uk.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the London—Riverside Research Ethics Committee and the Health and Research Authority (Approval No. 17/LO/1121). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

LC, EW, and CC designed the study collaboratively. LC collected the data and led the data analysis, with EW and CC helping in refining and developing themes. LC drafted the initial manuscript. EW and CC revised and edited the manuscript to help prepare for submission.

REFERENCES

1. Harris PB. Resilience and living well with dementia. In: Clarke C, Wolverson E, editors. *Positive Psychol Approach Dementia.* London: Kingsley (2016). p. 133–51.
2. Windle G. What is resilience? A review and concept analysis. *Rev Clin Gerontol.* (2011) 21:152–69. doi: 10.1017/S0959259810000420
3. Lepore S, Revenson T. Relationships between posttraumatic growth and resilience: Recovery, resistance, and reconfiguration. In: Calhoun LG, Tedeschi RG, editors. *Handbook of Posttraumatic Growth.* New York, NY: Routledge (2014). p. 38–60.
4. Westphal M, Bonanno GA. Posttraumatic growth and resilience to trauma: different sides of the same coin or different coins? *Appl Psychol.* (2007) 56:417–27. doi: 10.1111/j.1464-0597.2007.00298.x
5. Fernández-Lansac V, López MC, Cáceres R, Rodríguez-Poyo M. Resilience in caregivers of patients with dementia: a preliminary study. *Revista espanola de geriatria y gerontologia.* (2012) 47:102–9. doi: 10.1016/j.regg.2011.11.004
6. Gaugler JE, Kane RL, Newcomer R. Resilience and transitions from dementia caregiving. *J Gerontol Ser B Psychol Sci Soc Sci.* (2007) 62:P38–44. doi: 10.1093/geronb/62.1.P38
7. Harris PB. Another wrinkle in the debate about successful aging: the undervalued concept of resilience and the lived experience of dementia. *Int J Aging Hum Dev.* (2008) 67:43–61. doi: 10.2190/AG.67.1.c
8. Williamson T, Paslawski T. Resilience in dementia: perspectives of those living with dementia. *Can J Speech Lang Pathol Audiol.* (2016) 40:1–15. Available online at: https://cjslpa.ca/files/2016_CJSLPA_Vol_40/No_01/CJSLPA_Vol_40_No_1_2016_Williamson_Paslawski_1-15.pdf
9. Clarke CL, Bailey C. Narrative citizenship, resilience and inclusion with dementia: on the inside or on the outside of physical and social places. *Dementia.* (2016) 15:434–52. doi: 10.1177/1471301216639736
10. Hellström I, Nolan M, Lundh U. 'We do things together' A case study of 'couplehood'in dementia. *Dementia.* (2005) 4:7–22. doi: 10.1177/1471301205049188
11. Wadham O, Simpson J, Rust J, Murray CD. Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. *Aging Mental Health.* (2016) 20:463–73. doi: 10.1080/13607863.2015.1023769
12. Dias, R., Santos RL, de Sousa MFB, Nogueira MML, Torres B, Belfort T, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. *Trends Psychiatry Psychother.* (2015) 37:12–19. doi: 10.1590/2237-6089-2014-0032
13. Joling KJ, Windle G, Dröes RM, Huisman M, Hertogh CMPM, Woods RT. What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination. *Aging Ment Health.* (2017) 21:509–17. doi: 10.1080/13607863.2015.1124836
14. Windle G, Bennett KM. Caring relationships: how to promote resilience in challenging times. In: Ungar M, editor. *The Social Ecology of Resilience.* New York, NY: Springer (2012) 219–31. doi: 10.1007/978-1-4614-0586-3_18
15. Donnellan WJ, Bennett KM, Soulsby LK. What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging Mental Health.* (2015) 19:932–9. doi: 10.1080/13607863.2014.977771
16. Charmaz K. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage (2006).
17. Guest, G., Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods.* (2006) 18:59–82. doi: 10.1177/1525822X05279903
18. Clemerson G, Walsh S, Isaac C. Towards living well with young onset dementia: an exploration of coping from the perspective of those diagnosed. *Dementia.* (2014) 13:451–66. doi: 10.1177/1471301212474149
19. Vernooij-Dassen, M., Derksen E, Scheltens P, Moniz-Cook E, et al. Receiving a diagnosis of dementia: the experience over time. *Dementia.* (2006) 5:397–410. doi: 10.1177/1471301206067114
20. Graneheim UH, Johansson A, Lindgren BM. Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights from a meta-ethnographic study. *Scandinav J Caring Sci.* (2014) 28:215–24. doi: 10.1111/scs.12046
21. Seymour J, Dix G, Eardley T. *Joint Accounts: Methodology and Practice in Research Interviews with Couples*. York: Social Policy Research Unit, University of York (1995).
22. Charmaz K. *Constructing Grounded Theory*. London: Sage (2014).
23. Anderson C. Presenting and evaluating qualitative research. *Am J Pharmac Educ.* (2010) 74:141. doi: 10.5688/aj7408141
24. O'Dwyer S, Moyle W, Taylor T, Creese J, Zimmer-Gembeck M. In their own words: how family carers of people with dementia understand resilience. *Behav Sci.* (2017) 7:57. doi: 10.3390/bs7030057
25. Bekhet AK, Avery JS. Resilience from the perspectives of caregivers of persons with dementia. *Archiv Psychiatr Nurs.* (2018) 32:19–23. doi: 10.1016/j.apnu.2017.09.008
26. Masten AS. Ordinary magic: resilience processes in development. *Am Psychol.* (2001) 56:227–38. doi: 10.1037/0003-066X.56.3.227

27. Walsh F. Family resilience: a collaborative approach in response to stressful life challenges. In: Southwick SM, B. Litz BT, Charney D, Friedman MJ, editors. *Resilience and Mental Health: Challenges Across the Lifespan*. Cambridge: Cambridge University Press (2011). p. 149–61. doi: 10.1017/CBO9780511994791.012
28. Lim JW, Shon EJ, Paek M, Daly B. The dyadic effects of coping and resilience on psychological distress for cancer survivor couples. *Suppor Care Cancer*. (2014) 22:3209–17. doi: 10.1007/s00520-014-2334-9
29. Clare L. We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Aging Mental Health*. (2002) 6:139–48. doi: 10.1080/13607860220126826
30. Jacelon CS. The trait and process of resilience. *J Adv Nurs*. (1997) 25:123–9. doi: 10.1046/j.1365-2648.1997.1997025123.x
31. Held BS. The tyranny of the positive attitude in America: observation and speculation. *J Clin Psychol*. (2002) 58:965–91. doi: 10.1002/jclp.10093
32. Ball V, Snow AL, Steele AB, Morgan RO, Davila JA, Wilson N, et al. Quality of relationships as a predictor of psychosocial functioning in patients with dementia. *J Geriatr Psychiatry Neurol*. (2010) 23:109–14. doi: 10.1177/0891988710363709
33. Ablitt A, Jones GV, Muers J. Living with dementia: a systematic review of the influence of relationship factors. *Aging Mental Health*. (2009) 13:497–511. doi: 10.1080/13607860902774436
34. Burnham J. Developments in Social GRRRAAACCEEESSS: visible–invisible and voiced–unvoiced 1. *Culture and Reflexivity in Systemic Psychotherapy*. London: Routledge (2018). p. 139–60. doi: 10.4324/9780429473463-7
35. Pinquart M, Sörensen S. Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *J Gerontol Ser B Psychol Sci Soc Sci*. (2006) 61:P33–45. doi: 10.1093/geronb/61.1.P33
36. McParland J, Camic PM. How do lesbian and gay people experience dementia? *Dementia*. (2018) 17:452–77. doi: 10.1177/1471301216648471

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Effect of Capacity to Undertake Instrumental Activities of Daily Living on Entry to Aged Residential Care in Older People With Heart Failure

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Background: Heart failure is a common condition in older people with complex medical needs. A key factor in resilience after heart failure is the capacity to perform the instrumental activities of daily living (IADLs). Knowing the association between capacity to perform IADLs and entry into aged residential care will help health professionals plan interventions that will allow older people to remain independent longer.

Methods: We analyzed the association between the capacity to perform eight IADLs and entry into ARC. Participants included New Zealanders aged ≥65 years with a diagnosis of heart failure, and who had an InterRAI 9.1 Home Care assessment between July 2012 and June 2018. A multivariable competing risks regression model for entry to ARC with death as the competing risks was used to establish sub-hazard ratios (SHR) for IADL capacity. Co-variates included demographic variables, co-morbidities, living arrangements, cognitive performance, depression, timed walk, alcohol use, smoking, activities of daily living, recent hospitalization and history of falls.

Results: There were 13,220 participants with heart failure who were followed for a median 1.69 (0.70–3.17) years. There were 3,177 (24.0%) participants who entered aged residential care and 5,714 (43.2%) who died without having first entered residential care. Overall capacity to perform specific IADLs was "very poor" for housework (85.5%), shopping (68.0%), stairs (61.7%), meal preparation (53.0%), and transportation (52.2%). In the multivariable model, compared to adequate capacity (the reference) poorer capacity for managing finance, managing medications, meal preparation and transport were all associated with increased risk of entering aged residential care, with SHR from 1.05 to 1.18. Overall, the IADL capacity explained ∼10% of the risk of entering aged residential care.

Conclusion : Capacity to perform IADL is a key factor in maintaining resilience in older people with heart failure. Capacity to manage finances, transport and medications, prepare meals, and transport oneself with minimal supervision could reduce the risk of entry into aged residential care. Developing early interventions and support for people with poor capacity to perform their IADL may help reduce admission into aged residential care.

Keywords: heart failure, instrumental activities of daily living (IADL), aged residential care, older people, InterRAI, resilience

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INTRODUCTION

Heart failure is a common condition affecting ∼38 million people worldwide (1). It is most common in adults more than 60 years in age. The prevalence of heart failure is increasing (2, 3) with an estimated 5–10 new diagnoses per 1,000 persons per year (4).

Heart failure has serious impacts on older people including high rates of hospitalization. Generally, the prognosis for heart failure patients is poor with many individuals having reduced life expectancy compared to those without heart failure (4). After a heart failure exacerbation, the 30-day mortality is ∼10–20% (4). A heart failure event may be the trigger for some older people to enter aged residential care facilities (ARC) because they are or believe they are unable to manage at home. However, there may be other factors contributing to the decision to enter ARC. ARC is costly, the daily cost per resident can range from $148.33 to $162.30 (NZD) (5). As of 2013, there were 31,899 people living in ARC facilities in New Zealand (6).

The New Zealand interRAI-Home Care (HC) is a comprehensive clinical assessment used to assess community-dwelling older adults to help provide tailored home care services. It captures diagnoses of heart failure and provides a unique opportunity to investigate factors that may be associated with entry to ARC. Extensive training is given to interRAI assessors to ensure that all assessments are undertaken with the same standard of quality (7). As well as providing information useful for individually tailored care plans for older people, the interRAI data can be used for larger scale research.

Instrumental Activities of Daily Living (IADL) are self-care activities that often require more complex interactions than Activities of Daily Living (ADL) (8). For example, ADLs include bathing, personal hygiene, and bed mobility, whereas IADLs are more complex items such as managing medications, phone use, and meal preparation. IADLs are key factors in resilience of older people. A key factor contributing to resilience after heart failure is the capacity to perform the instrumental activities of daily living (IADLs). Knowing the association between capacity to perform IADLs and entry into aged residential care (ARC) would help health professionals plan interventions that allow older people to remain at home longer. The aim of this study was to identify within older people with heart failure any associations between capacity to perform IADLs and entry to ARC.

MATERIALS AND METHODS

Design

This was a prospective observational study of routinely collected health data.

Participants

Participants consisted of individuals aged 65 years and older who underwent an interRAI-HC assessment between 1 July 2012 and 30 June 2018 and who had received a diagnosis of heart failure in the interRAI. All participants consented for their data to be used for research purposes. The interRAI-HC assessment is compulsory for all older people wanting to receive publicly funded health care services, including funding to stay in aged residential care. Exclusion criteria included death or entry into ARC within 30 days of assessment, living in a non-home setting at the time of assessment, and any repeat assessments. **Figure 1** details the participant selection criteria. Each participant had a minimum follow-up of 30 days, and the study period ending was 30 July 2018.

Data Collection

Anyone who receives healthcare in New Zealand is assigned a unique identification number known as their national health index number (NHI) number (9). Encrypted NHI numbers were used to link interRAI-HC assessments with mortality and ARC entry data. New Zealand's Technical Advisory Services provided interRAI-HC records of all individuals who consented for their data to be used for research and planning purposes. ARC admission dates were provided by The Ministry of Health using its Contracted Care Payment System database. The interRAI database only contains publicly funded ARC residents which is ∼90% of all ARC residents in New Zealand. The other 10% are privately funded individuals who may or may not have completed an interRAI-HC assessment before entering ARC. Mortality information was provided by The National Mortality Collection Register.

In section G of the interRAI-HC 9.1 assessment tool there are two types of IADL assessment. The first is for self-performance of routine activities during the previous 3 days and the second is for capacity based on presumed ability to carry out the activity as independently as possible. For this analysis we have chosen to use the capacity scores only to avoid the issue of large amounts of missing data due to no activity taking place in the previous 3 days. There are seven IADL activities, namely; meal preparation, ordinary housework, managing finances, managing medications, phone use, managing a full flight of stairs, shopping performance, and managing transportation. Functional status for each IADL is graded on a scale: Independent, Setup help only, Supervision (oversight/cuing), Limited assistance (help on some occasions), Extensive assistance (help throughout the task but performs ≥50% of the task on own), Maximal assistance (help throughout the task but performs <50% of the task on own), and Total dependence. To avoid overfitting or spurious results due to smaller numbers in any grade, for the competing risks model we grouped Independent and Setup help only as "Adequate"; Supervision and Limited Assistance, as "Poor"; and Extensive Assistance, Maximal Assistance, and Total dependence as "Very Poor."

Statistical Analysis

Descriptive information of variables of interest were reported. For categorical variables data are presented as *n* (%); for normally distributed quantitative variables as mean and standard deviation; and for non-normally distributed variables as median and the lower quartile-upper quartile range. Correlations are Spearman r.

A multivariable competing-risks regression model was used to assess the association between IADLs and ARC entry. A

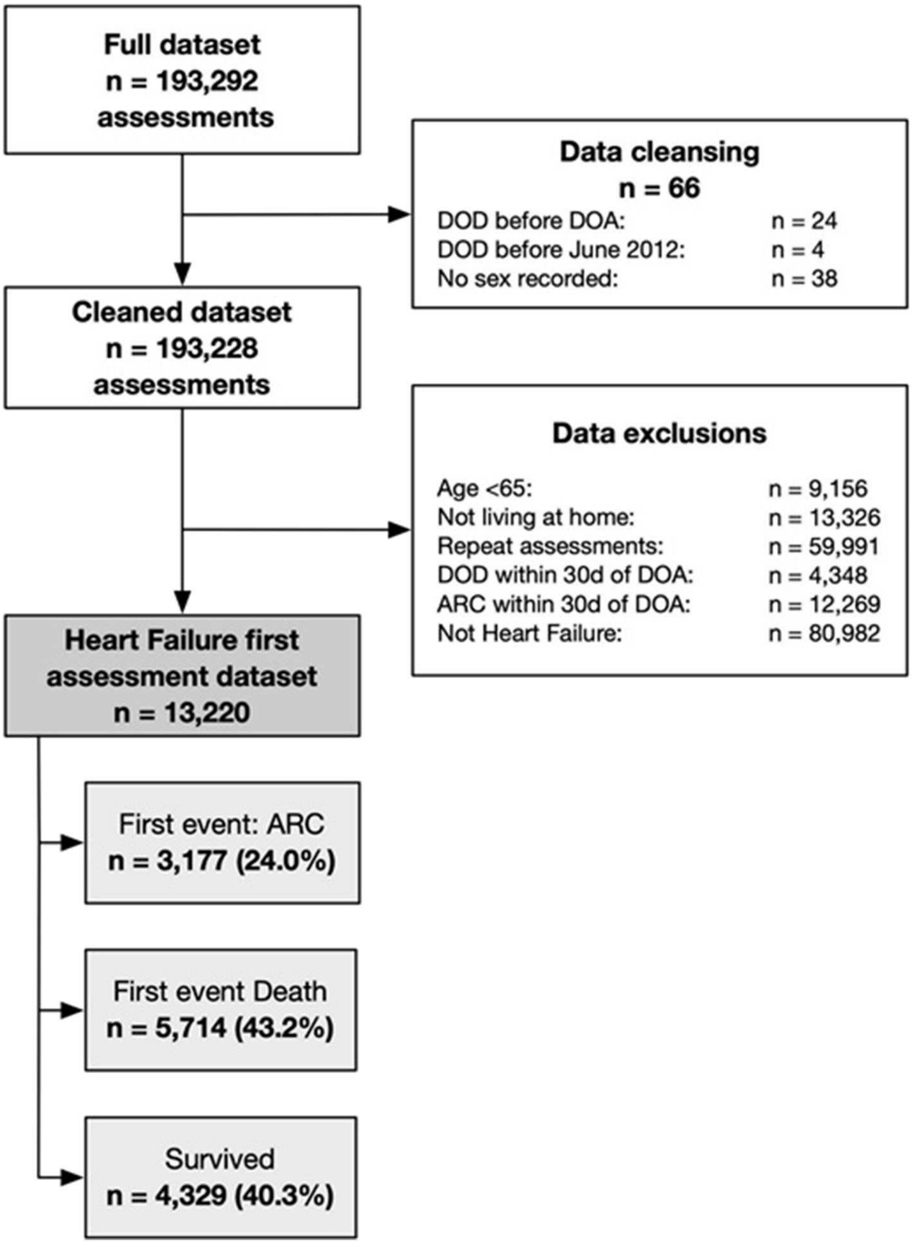


FIGURE 1 | Participant selection criteria.

competing risk model was required to account for the substantial number of people who die before they may otherwise have entered ARC. This makes death a competing risk. The effects of variables on the likelihood of participants entering ARC were reported as sub distribution proportional hazard ratios (SHR). The Fine-Gray method was used to calculate SHRs with the *cmprsk* package in R (10). A SHR >1 indicates an increased risk of entering ARC relative to the reference (e.g., SHR of 1.5 indicates a 50% increase in risk), whereas a SHR <1 indicates a decreased risk (e.g., SHR of 0.67 indicates a 1/0.67 = 1.5 or 50% decrease in risk).

To assess the relative importance of each variable, we calculated the percentage contribution of variable to the model. We used the chi-square statistic minus the number of degrees of freedom for that variable relative to the chi-square minus the number of degrees of freedom for all the model; we present these graphically (11).

The STROBE guidelines (www.strobe-statement.org) were used to guide this report. All calculations were performed in R version 3.5.2 (12). Ethics approval was obtained from the Ministry of Health, Health and Disability Ethics Committee (14/STH/140/AM07).

TABLE 1 | Demographics and IADL frequencies and Sub Hazard Ratios (SHR) for entry to ARC from multivariable competing risks models.

	Survive (*n* = 4,329)	**ARC** (*n* = 3,177)	**Death** (*n* = 5,714)	**Multivariable SHR for ARC**
Age				
Mean (SD)	81.1 (7.47)	84.5 (6.68)	83.7 (7.30)	1.02 (1.01 to 1.02)
Sex				
Female	2,633 (60.8%)	1,949 (61.3%)	2,937 (51.4%)	1 Reference
Male	1,696 (39.2%)	1,228 (38.7%)	2,777 (48.6%)	0.85 (0.76 to 0.93)
IADL Meal Preparation Capacity				
Adequate	1,762 (40.7%)	858 (27.0%)	1,438 (25.2%)	1 Reference
Poor	748 (17.3%)	579 (18.2%)	829 (14.5%)	1.18 (1.06 to 1.29)
Very poor	1,819 (42.0%)	1,740 (54.8%)	3,447 (60.3%)	1.05 (0.94 to 1.16)
IADL Housework Capacity				
Adequate	250 (5.8%)	117 (3.7%)	184 (3.2%)	1 Reference
Poor	549 (12.7%)	328 (10.3%)	494 (8.6%)	0.96 (0.75 to 1.17)
Very poor	3,530 (81.5%)	2,732 (86.0%)	5,036 (88.1%)	0.97 (0.78 to 1.16)
IADL Finance Capacity				
Adequate	2,440 (56.4%)	1,193 (37.6%)	2,390 (41.8%)	1 Reference
Poor	674 (15.6%)	575 (18.1%)	879 (15.4%)	1.17 (1.06 to 1.28)
Very poor	1,215 (28.1%)	1,409 (44.4%)	2,445 (42.8%)	1.15 (1.04 to 1.26)
IADL Managing medications Capacity				
Adequate	2,635 (60.9%)	1,437 (45.2%)	2,807 (49.1%)	1 Reference
Poor	804 (18.6%)	775 (24.4%)	1,230 (21.5%)	1.14 (1.04 to 1.25)
Very poor	890 (20.6%)	965 (30.4%)	1,677 (29.3%)	1.16 (1.05 to 1.28)
IADL Phone use Capacity				
Adequate	3,739 (86.4%)	2,495 (78.5%)	4,426 (77.5%)	1 Reference
Poor	231 (5.3%)	231 (7.3%)	467 (8.2%)	0.83 (0.69 to 0.98)
Very poor	359 (8.3%)	451 (14.2%)	821 (14.4%)	1 (0.87 to 1.14)
IADL Stairs Capacity				
Adequate	1,198 (27.7%)	687 (21.6%)	1,064 (18.6%)	1 Reference
Poor	722 (16.7%)	545 (17.2%)	853 (14.9%)	1.06 (0.94 to 1.17)
Very poor	2,409 (55.6%)	1,945 (61.2%)	3,797 (66.5%)	1.06 (0.96 to 1.15)
IADL Shopping Capacity				
Adequate	1,306 (30.2%)	545 (17.2%)	898 (15.7%)	1 Reference
Poor	561 (13.0%)	364 (11.5%)	562 (9.8%)	1.07 (0.93 to 1.21)
Very poor	2,462 (56.9%)	2,268 (71.4%)	4,254 (74.4%)	1.08 (0.96 to 1.21)
IADL Transportation Capacity				
Adequate	2,013 (46.5%)	957 (30.1%)	1,708 (29.9%)	1 Reference
Poor	521 (12.0%)	441 (13.9%)	638 (11.2%)	1.18 (1.06 to 1.31)
Very poor	1,795 (41.5%)	1,779 (56.0%)	3,368 (58.9%)	1.04 (0.93 to 1.14)

RESULTS

There were 13,220 participants with heart failure of whom the first event was entry into ARC for 3,177 (24.0%) and death for 5,714 (43.2%), and 4,329 (40.3%) survived until the end of the study period without entering ARC (**Figure 1**). Participants were followed for a median 1.69 [interquartile range: 0.70–3.17, maximum: 5.85)] years.

More females (56.9%) than males were assessed (**Table 1**). The mean (SD) age was 83.1 years (7.3 years). The population comprised 10.0% Māori, 3.0% Pacific peoples and 84.4% New Zealand Europeans. At the time of assessment, a little under half the participants (48.7%) were living alone. Hospitalization in the previous 90 days was common (44.3%), as was Dyspnea (72.7%), some Fatigue (80.3%), Coronary Heart Disease (CHD: 53.6%), Chronic Obstructive Pulmonary Disease (COPD: 26.8%) and Diabetes Mellitus (DM: 26.3%). A full table of the variables of interest can be found in **Table S1**.

When all IADL participant capacities are considered (in all participant categories: Survive, ARC, Death), the most independent was phone use and least housework (**Figure 2**). The overall capacity for housework was *very poor* for 85.5% of the participants. Also, *very poor* were capacity for shopping (68.0%), stairs (61.7%), meal preparation (53.0%), and transportation

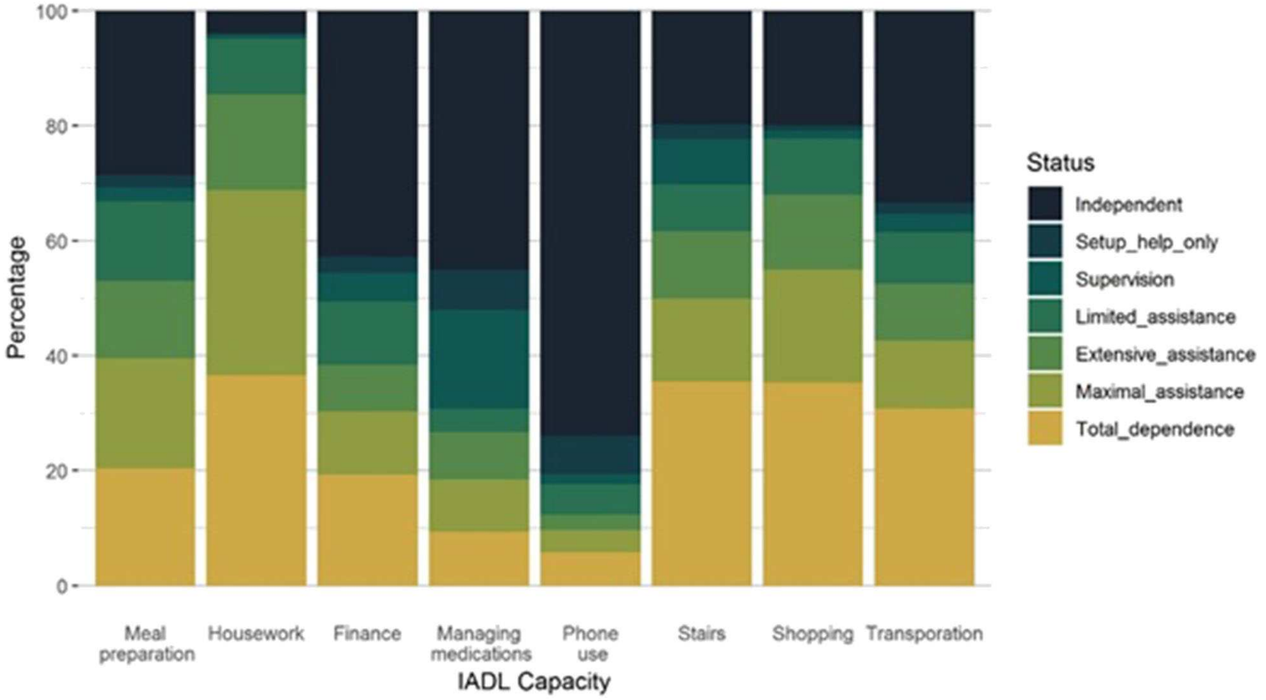
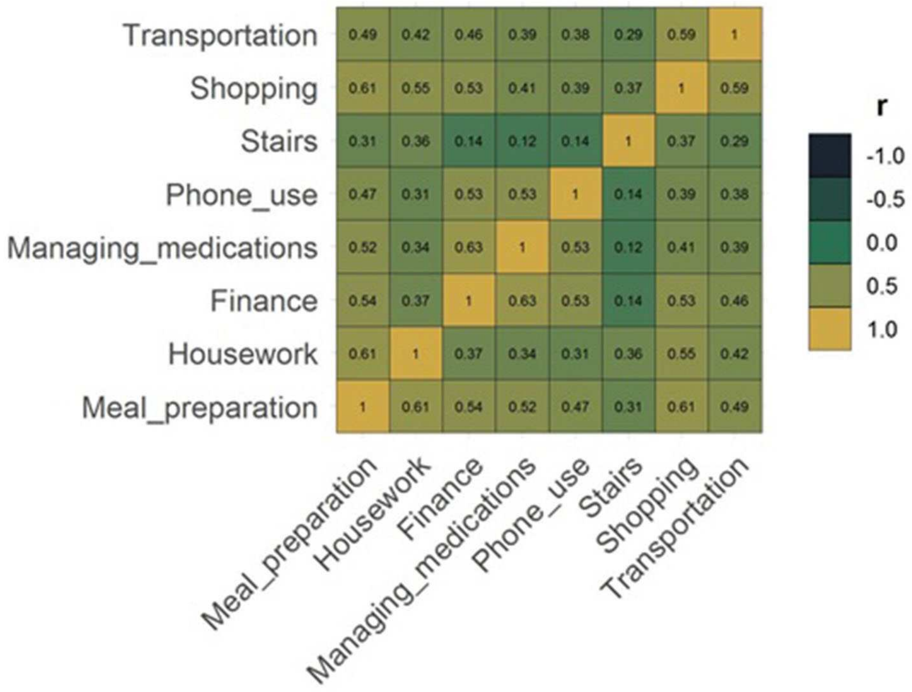


FIGURE 2 | IADL capacity and independence level frequencies.



	Meal_preparation	Housework	Finance	Managing_medications	Phone_use	Stairs	Shopping	Transportation
Transportation	0.49	0.42	0.46	0.39	0.38	0.29	0.59	1
Shopping	0.61	0.55	0.53	0.41	0.39	0.37	1	0.59
Stairs	0.31	0.36	0.14	0.12	0.14	1	0.37	0.29
Phone_use	0.47	0.31	0.53	0.53	1	0.14	0.39	0.38
Managing_medications	0.52	0.34	0.63	1	0.53	0.12	0.41	0.39
Finance	0.54	0.37	1	0.63	0.53	0.14	0.53	0.46
Housework	0.61	1	0.37	0.34	0.31	0.36	0.55	0.42
Meal_preparation	1	0.61	0.54	0.52	0.47	0.31	0.61	0.49

FIGURE 3 | Correlation matrix between different IADLs.

(52.2%). The capacity was *adequate* for phone use for 80.6% and for managing medications for 52.0% of participants (**Table 1**). Many of the IADLs were moderately correlated with each other, except for the capacity to use stairs which was only weakly correlated with the other IADLs (**Figure 3**). The strongest correlations were between transportation and shopping, shopping and meal preparation, and meal preparation and housework.

In the multivariable model for entry to ARC, compared to *adequate* capacity (the reference) poorer capacity for managing finance, managing medications, meal preparation and transport were all associated with increased risk of entering ARC (**Table 1**). The point estimates of the SHR were greatest for poor meal predation preparation capacity and poor transportation capacity indicating an 18% increased risk. These increased risks were slightly greater than those in the multivariable model for a recent fall (12% increased risk for fall within previous 30 days; **Table S1**) or depression (13% increased risk for depression indicated on the Depression Rating Scale; **Table S1**). The IADL increase in risk were less than for decreased cognitive performance which ranged from a 26% increased risk for minimal loss of cognitive performance on the Cognitive Performance Scale to 118% for severe loss of cognitive performance (**Table S1**). Each IADL contributed independently between 0 and 3% of the overall risk of entering ARC and combined ∼10% of the overall risk (**Figure 4**).

DISCUSSION

This study confirmed that capacity to perform instrumental activities of daily living is associated with entry into ARC. After accounting for multiple confounding factors, and compared to *adequate* capacity (the reference), poorer capacity for managing finance, managing medications, meal preparation and transport were all associated with increased risk of entering ARC. Each IADL contributed independently between 0 and 3% of the overall risk of entering ARC.

Instrumental Activities of Daily Living and Entry Into Aged Residential Care

While all IADLs were associated with entry into ARC, managing finances and managing medications contributed more highly to ARC entry than several other variables. Both difficulty managing finances and medications are associated with cognitive impairment (13–15), which can also lead to entry into ARC (16, 17). Additionally, poor medication management has been previously reported associated with entry into ARC (18). Medication management is particularly important as a mismanagement of medications could lead to an overdose or missing a needed dose of medication could lead to adverse health effects. HF patients have a high medication load and so mismanagement of medications carries a particularly high risk.

The IADL with the second highest contribution to ARC entry was meal preparation. When an individual has problems with meal preparation, they may be less likely to eat enough food each day. This can lead to health issues such as malnutrition and severe weight loss. Anyone having issues with meal preparation may be more likely to enter ARC where their meals will be prepared for them.

While our primary interest was ARC entry and death was treated as a competing risk, we note that for all participants IADL capacity was poorer in those who died compared to those who survived without entry to ARC. Very poor IADL (meal preparation, stair use, transportation) capacity was higher in those who died than those who entered ARC.

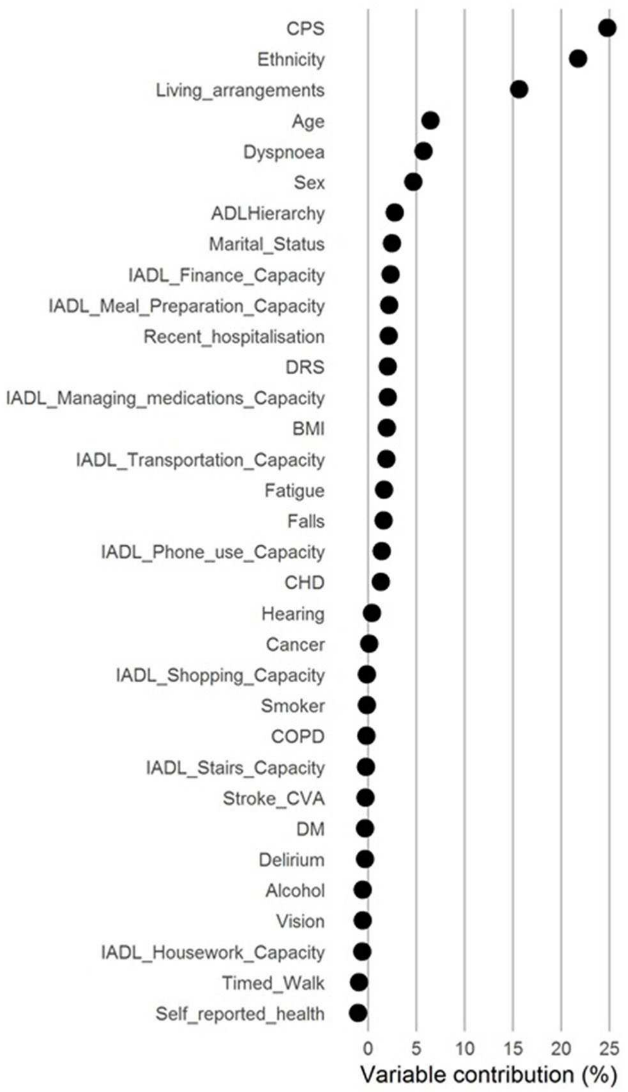


FIGURE 4 | Variable percentage contribution to the regression model.

Limitations With the InterRAI

This research was based on a large national database of comprehensive clinical assessments, the data was linked with other health outcomes allowing for extensive adjustment of confounders and more accurate health information. However, there are some limitations. The ARC database does not include everyone who entered ARC, rather only those who receive publicly funded care. Approximately, 10% of people living in ARC will not be recorded and any fundamental differences between this 10 and the 90%

receiving publicly funded care is unknown. There may have been some loss of follow up information if people leave New Zealand, when this happens there are no ARC entry or mortality records for that individual. To avoid double counting individuals only first homecare assessments were used, however, this means any later assessments where the individual might have more complex health needs were not considered.

This study was completed using information from a New Zealand population of people over the age of 65 years with complex health care needs who were being considered for homecare services. The findings, therefore, may not be generalizable to a healthier population of people nor for an international audience. Nevertheless, the results could be used to inform studies in these populations.

CONCLUSION

With the growing aging population, it is important to understand resilience and drivers of entry into residential care. Capacity to perform IADLs is a key factor for those with HF. Interventions and services that assist with the management of IADLs, especially finances and medications may delay entry into aged residential care.

DATA AVAILABILITY STATEMENT

The datasets generated for this study will not be made publicly available. The data is held by Technical Advisory Services in New Zealand who do not allow for the distribution and sharing of the data. Anyone who wishes to gain a copy of the dataset must apply to Technical Advisory Services.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Health and Disability Ethics Committee 14/STH/140/AM07. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

HJ conceived the study and its design, acquired the funding, oversaw the study, contributed to interpreting the data and writing the paper, and approved the manuscript for submission. RA-N contributed to data analysis and writing the paper. JP led the data analysis and its interpretation. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fmed.2020.00386/full#supplementary-material

REFERENCES

1. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet.* (2012) 380:2163–96. doi: 10.1016/S0140-6736(12)61729-2
2. Riddell T. Heart failure hospitalisations and deaths in New Zealand: patterns by deprivation and ethnicity. *N Z Med J.* (2005) 118:U1254.
3. McMurray JJ, Stewart S. Epidemiology, aetiology, and prognosis of heart failure. *Heart.* (2000) 83:596–602. doi: 10.1136/heart.83.5.596
4. Mosterd A, Hoes AW. Clinical epidemiology of heart failure. *Heart.* (2007) 93:1137–46. doi: 10.1136/hrt.2003.025270
5. Grant Thornton NZ Ltd. *Aged Residential Care Service Review Steering Group. Aged Residential Care Service Review.* Auckland: Grant Thornton NZ Ltd (2010). Available online at: http://nzaca.org.nz/publication/documents/ARSCR.pdf
6. Statistics New Zealand. *Living Outside the Norm: An Analysis of People Living in Temporary and Communal Dwellings Census.* Wellington: Statistics New Zealand (2013). Retrieved from: http://m.stats.govt.nz/~/media/Statistics/Census/2013%20Census/profile-and-summary-reports/living-outside-norm/living-outside-the-norm.pdf (accessed September 19, 2019).
7. Schluter PJ, Ahuriri-Driscoll A, Anderson TJ, Beere P, Brown J, Dalrymple-Alford J, et al. Comprehensive clinical assessment of home-based older persons within New Zealand: an epidemiological profile of a national cross-section. *Aust N Z J Public Health.* (2016) 40:349–55. doi: 10.1111/1753-6405.12525
8. Roley S, DeLany JV, Barrows C, Honaker D, Sava D, Talley V. Occupational therapy practice framework: domain and process. *Am J Occup Ther.* (2008) 62:625–83. doi: 10.5014/ajot.2014.682006
9. Ministry of Health. *National Health Index Overview.* Wellington: Ministry of Health (2018). Available online at: https://www.health.govt.nz/our-work/health-identity/national-health-index/national-health-index-overview (accessed September 19, 2019).
10. Fine JP, Gray RJ. A proportional hazards model for the subdistribution of a competing risk. *J Am Stat Assoc.* (1999) 94:496–509. doi: 10.1080/01621459.1999.10474144
11. Harrell FE Jr. *Regression Modeling Strategies: With Applications to Linear Models, Logistic and Ordinal Regression, and Survival Analysis.* New York, NY: Springer (2015). doi: 10.1007/978-3-319-19425-7
12. R Core Team. *R: A Language and Environment for Statistical Computing.* Vienna: R Foundation for Statistical Computing (2013).
13. Okonkwo OC, Wadley VG, Griffith HR, Ball K, Marson DC. Cognitive correlates of financial abilities in mild cognitive impairment. *J Am Geriatr Soc.* (2006) 54:1745–50. doi: 10.1111/j.1532-5415.2006.00916.x
14. Edelberg HK, Shallenberger E, Wei JY. Medication management capacity in highly functioning community-living older adults: detection of early deficits. *J Am Geriatr Soc.* (1999) 47:592–6. doi: 10.1111/j.1532-5415.1999.tb02574.x
15. Jekel K, Damian M, Wattmo C, Hausner L, Bullock R, Connelly PJ, et al. Mild cognitive impairment and deficits in instrumental activities

of daily living: a systematic review. *Alzheimers Res Ther*. (2015) 7:17. doi: 10.1186/s13195-015-0099-0

16. Kendig H, Browning C, Pedlow R, Wells Y, Thomas S. Health, social and lifestyle factors in entry to residential aged care: an Australian longitudinal analysis. *Age Ageing*. (2010) 39:342–9. doi: 10.1093/ageing/afq016
17. Weatherall M, Slow T, Wiltshire K. Risk factors for entry into residential care after a support-needs assessment. *N Z Med J*. (2004) 117:U1075.
18. Lieto JM, Schmidt KS. Reduced ability to self-administer medication is associated with assisted living placement in a continuing care retirement community. *J Am Med Dir Assoc*. (2005) 6:246–9. doi: 10.1016/j.jamda.2005.04.002

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.

ORIGINAL RESEARCH
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The Application of the Concept of Resilience in Aging Research and Older Adult Care: A Focus Group Study

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Introduction: Research incorporating resilience, a concept featuring a positive outcome despite some type of stressor, has the potential to identify possibilities for promotion of the well-being of older people. This study aims to gain insight into the value and potential applications of resilience in both research and care practice from the perspective of researchers and care professionals. Specifically, the value of two scientific approaches, the *a priori* (i.e., based on *a priori* definition of a stressor and outcome) and dynamical systems approaches (i.e., based on mathematically modeled patterns in the real-time response to perturbations), was explored.

Methods: Focus groups were performed to explore the thoughts of academic researchers from different disciplines in the fields of aging and care and care professionals on the application of the concept of resilience, including the *a priori* and dynamical systems approaches. Analysis of these focus groups was based on the framework method.

Results: Five focus groups were held with a total of nine researchers from different disciplines (e.g., epidemiology, sociology) and 15 older adult care professionals from different professions (e.g., elderly care physician, physiotherapist). The participants described resilience as a concept with value for both aging research and care through its positive connotation and comprehensiveness. Continued research was thought to play an important role in clearing up some of the existing ambiguity surrounding resilience. The importance of resilience in the context of both high- and low-intensity stressors was underscored. The *a priori* and dynamical systems approaches were considered to have their specific advantages and disadvantages on both conceptual and feasibility levels. Therefore, the use of both approaches, side by side and in combination, was suggested.

Conclusion: This qualitative exploration among researchers and care professionals confirms that the concept of resilience, including the *a priori* and dynamical systems approaches, is valuable. However, more work is necessary before can be delivered

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on the potential of resilience in aging research and older adult care practice. Greater conceptual and operational clarity can be achieved through more qualitative studies on the concept that take the perspective of older people into account and through empirical studies that work with both approaches simultaneously and/or in combination.

Keywords: resilience, older adult care, aging, focus group, research approach

INTRODUCTION

As a consequence of increasing longevity, there is an increasing interest in promoting the quality of life or well-being in older age (1). Research incorporating the concept of resilience, which refers to situations characterized by a positive or better-than-expected outcome (response) to some form of adversity (stressor), may have the potential to improve older adult care policy and practice (2, 3). The idea behind most resilience research is that there are traits or resources that play a role in achieving the positive outcome (2, 4). It has been suggested that gaining insight into these factors can help to promote quality of life in this population (2, 3).

However, there is a lack of consensus about what resilience is and how it should be investigated in empirical research (2, 5–7). Recent reviews highlight that there are various theoretical approaches to operationalizing resilience (2, 6). The applicability of empirical results in elderly care practice may depend on the chosen approach. Two of the currently most commonly used, distinctive approaches in research in older persons are the *a priori* approach (4) and the dynamical systems approach (8). The *a priori* approach has also been called the definition-driven or researcher-driven approach (2, 6). In this approach, researchers define the two essential components of resilience, the stressor and an outcome (doing better than expected given exposure to that stressor), *a priori* for the specific situation of interest (4, 6). A study subject's resilience is inferred based on this definition. For example, Kok et al. (9) utilized this approach in a study of resilience in older adults with a low social economic status. The stressor was defined as having had a low socioeconomic position throughout life. The positive outcome was an above-average score on a successful aging index, which encompassed trajectories of physical, mental, and social functioning in old age based on cohort data. A number of participants who met these criteria were interviewed about their life. Subsequently, grounded theory analysis was employed to identify themes on how the subjects handled the stressors they encountered throughout their life. The *a priori* approach has also been applied in various other empirical studies in older persons (10–12).

The underlying assumption of the dynamical systems approach is that a person's reactions to daily hassles, perturbations, or stressors (so-called "microrecoveries") give an impression of a person's overall capacity to recover. These microrecoveries can be captured by monitoring a person in real time (8, 13, 14). Many types of data can theoretically be monitored within this approach as long as the data can realistically be measured repeatedly over time, for instance, with ecologic momentary assessments. The time frame in which the data within this approach is collected varies greatly, depending on the time scale in which meaningful change takes place. This can, for example, be within minutes in the case of a physiological or physical parameter, such as postural balance, to months in the case of a mood or well-being parameter. Determining the correct time frame to measure a specific parameter is essential to the dynamical systems approach (8, 13, 15, 16). This data can subsequently be plotted over time, and specific mathematically modeled patterns are characterized as resilient. Gijzel et al. (8), for example, apply this approach in a study in older long-term-care facility residents using daily self-reported health data measured over 100 days. They observe three data patterns that are indicative of resilience, so-called dynamical indicators of resilience (DIORs): low variance, low temporal autocorrelation, and low cross-correlation. For example, self-reported physical health of someone with high resilience will fluctuate less (low variance) than in someone with a low level of resilience (8). A shorter time to return to equilibrium following disruptions (low temporal autocorrelation) is also indicative of resilience. A resilient person will recover more quickly from a disruption in self-reported physical health. Finally, low cross-correlation entails that, in resilient individuals, disruptions in one system do not necessarily lead to disruptions in other systems. For example, when resilient individuals experience a disruption in their physical health, this does not necessarily lead to a disruption in mental health (8).

The two approaches that we describe here both operationalize resilience but do so in different ways. For this study, we were interested in exploring the opportunities and barriers for application of these two approaches in research and older adult care practice. The aim of this study was to gain insight into the value and potential applications of the concept of resilience in both research and care practice from the perspective of researchers from different academic disciplines and care professionals. We feel that exploring the perspectives of these stakeholders, who typically are not included in discussions on the concept of resilience, may lead to novel insights relevant for older adult care. We primarily explored this for the *a priori* and the dynamical systems approaches to resilience.

MATERIALS AND METHODS

Study Design

A qualitative study involving focus group interviews was performed to explore views and thoughts on the relevance, applicability, and possible applications of the concept of resilience in older persons in general and the *a priori* and dynamical systems approaches in particular, for both research and care practice.

Participants

We were interested in the applications in science and practice as both are of great importance to improving the care of older people. Therefore, focus groups were held with two groups of stakeholders: (1) academic researchers involved in different disciplines within aging and care research and (2) care professionals within different professions in the care of older people. Purposive sampling among the network of the research group was employed to ensure the recruitment of participants across different fields of expertise, institutions, and professions throughout the Netherlands. Possible participants were sent an email requesting their participation and/or their help in recruiting among colleagues. Experienced older adult care professionals currently employed at a health care organization or hospital in the region of Amsterdam and researchers with different specializations (e.g., sociology, epidemiology, movement sciences, geriatric rehabilitation) within aging and care of older people affiliated to a Dutch university were invited to participate. These researchers were not specialized in resilience and had not worked with the two approaches described here previously. Within the care professional group, we invited both professionals who work with older persons living in the community and those living in long-term-care facilities. Professionals, ranging from district nurses to physiotherapists to medical specialists in the hospital setting, were approached.

Data Collection

The focus group methodology was chosen because it allows for efficient data collection and provided the opportunity for group discussion allowing participants to build on each other's thoughts and compare experiences. We found this of particular value for this conceptual and relatively abstract topic.

Four initial focus groups of ∼90 min each were held, two with researchers and two with older adult care professionals. The focus groups were led by two different moderators with some background knowledge on the approaches (FS for focus groups 1 and 3; MS for focus groups 2 and 4). Prior to each focus group, participants were asked to watch a brief video providing a general introduction on the background of the concept of resilience in science and the two approaches. At the start of each focus group, a researcher (MA) gave an introductory presentation about resilience with a particular focus on the specifics of the two approaches. The content of this presentation was comparable to the description of the approaches in the introduction of this article (see **Supplementary Materials** for a translated example). MA and MH prepared the introductory video and presentation. MA remained present during the discussions to both observe and assist the moderator.

The topic guide for these focus groups addressed: current recognition or uses of resilience in clinical and research practice, potential advantages and disadvantages, and possible research and older adult care applications of resilience. Both the *a priori* and dynamical systems approaches of resilience were explored. The topic guide and introduction were refined after each focus group, following the principles of research as an iterative and reflexive process (17).

Finally, a fifth focus group of ∼60 min was held with a combination of participants of the previous focus groups consisting of both researchers and care professionals, moderated by FS. Again a variation in profession and area of expertise was sought. During this focus group, preliminary results from the first four focus groups were presented to the participants, and the participants were asked to reflect on and react to these results. Thus, this final focus group functioned as respondent validation or a "member check" for the preliminary results (17).

The focus groups were conducted in Amsterdam and Utrecht, the Netherlands, from January until March 2019. Subsequently, audio recordings of each focus group session were transcribed verbatim.

Analysis

The transcripts were anonymized before being analyzed in the computer-assisted qualitative data analysis software ATLAS.ti. Analysis was based on the framework method for the analysis of qualitative data in multidisciplinary health research (18). An "*in vivo*" coding strategy (17) was applied to reflect the terminology used by the participants. Two focus groups were independently coded by two researchers trained in qualitative research (MA, AM). The resulting codes were discussed and organized during face-to-face research meetings until agreement on a working analytical framework was reached. This working analytical framework was subsequently applied to the coding of the other three focus groups by one researcher (MA). Addition of codes and changes to the analytical framework were made in agreement with a second researcher (AM). The interpretation of the data and patterns emerging from the data were discussed within a group of four researchers (MA, AM, CH, and MH).

A combined thematic analysis approach was undertaken: Themes were both inductively established from participant accounts and were guided by our main research questions: What are the views and thoughts of experts on (the applicability of) resilience in older persons? What are possible advantages and disadvantages of the *a priori* and dynamical systems approaches? What are possible applications of resilience and the two approaches in research and practice? The complete analytical framework including all codes is available upon request.

Ethical Review

Each participant gave written informed consent prior to participating in the focus groups. The medical ethics review committee of VU University Medical Center assessed the study protocol and concluded that, according to Dutch legislation, it was exempt from their approval; reference number 2018.527.

This report was composed in accordance with the consolidated criteria for reporting qualitative research (COREQ) (19).

RESULTS

Twenty-four participants, nine researchers, and 15 care professionals participated in the first four focus groups.

TABLE 1 | Research disciplines and professions represented by the focus group participants in no particular order.

Focus group 1: care professionals	Focus group 2: researchers	Focus group 3: researchers	Focus group 4: care professionals	Focus group 5: care professionals & researchers
2 clinical psychologists	2 care of older people & welfare	1 epidemiology	4 elderly care physicians	1 clinical psychologist
1 district nurse	1 care of older people	1 geriatric rehabilitation	1 clinical psychologist	1 elderly care physicians
1 elderly care physician	1 (medical) humanities	1 (medical) humanities	1 internist-geriatric medicine	1 occupational therapist
1 nurse practitioner		1 movement sciences	1 occupational therapist	1 researcher epidemiology
1 physiotherapist		1 sociology	1 physiotherapist	1 researcher geriatric rehabilitation
1 senior advisor				1 researcher (medical) humanities

Table 1 provides an overview of the research disciplines and older adult care professions represented by the focus group participants. The six participants of the final member check focus group agreed with the preliminary results as presented in this focus group and were able to elaborate on the preliminary themes. As the input from the researchers and care professionals showed a high level of agreement, their input was analyzed collectively.

Three main themes were identified in the analysis: the concept of resilience in older persons, the *a priori* and dynamical systems approaches, and the application of resilience in research and older adult care practice. Within each theme, several subthemes were identified (**Table 2**), which are presented below and are substantiated by verbatim quotes.

TABLE 2 | Overview of identified themes and subthemes.

The concept of resilience in older persons
Interpretation of resilience
Added value of resilience
Finiteness of resilience
The *a priori* and dynamical systems approaches
Recognition/comprehensibility/intuitiveness
Stressor
Judgment
Feasibility
Use of both the *a priori* and the dynamical systems approaches
Application of resilience in research and older adult care practice
Application of resilience in research
Application of resilience in care practice

The Concept of Resilience in Older Persons

Interpretation of Resilience

There were many different interpretations of what resilience entails and its most important components or contributing factors.

Recovery, resistance, acceptance, anticipation, compensation, self-management, and reflection were all described by the participants to play a role in resilience. Resistance and recovery were mentioned as aspects of resilience in the introductory presentation. Resistance to the occurrence of (the negative effects of) a stressor and recovery from those effects were subsequently acknowledged by participants to be essential to resilience (research). Essential to the recovery aspect of resilience is the level of recovery that is expected in the context of resilience. Participants felt that different stable states, e.g., levels of functioning, can be achieved in the recovery process. It is not always necessary or even advantageous to remain at or return to the same state as prior to the stressor. Participants described that a new state can be indicative of resilience as long as it remains stable over time. Acceptance can play an important role in this type of resilience: being successful in a different state, e.g., a lower level of functioning, than before. In short, dealing with stressors requires adaptability, and this adaptability was described to be an important aspect of resilience.

> "Of course it is also possible that you stay at that level, and that you remain stable and simply continue. That's fine of course. You don't have to come back to exactly where you were because that is not always the most ideal situation." (researcher 9, fg3)

In discussions on the resistance aspect of resilience, anticipation was described to play an important role. Indeed, it was suggested that the exposure to a stressor or the negative effects of this exposure could be avoided by thinking and acting proactively. Participants also believed that anticipation was closely related to compensation for losses, such as loss of independence, at this age. This anticipation was described to encompass two aspects: reflection and action/organization. Different specific examples of anticipation in the context of aging were given, including building a social support system, proactively making changes in the home or moving to a single-story house, training different skills, and remaining interested in the environment.

> "Yes, and there, this implies in a practical sense that you organize it, but also that you are already preparing in your mind for what [...] That things may get worse and how that would be for you, and yes, of course this can make you all depressed, but it can also help you cope with it later on, but well, how do you measure that? And there may be many more aspects to this anticipation. Of

> course there are people who will, uh, start training really intensely to prevent them from, uh, deteriorating, in all areas." (researcher 6, fg5)

Personality and coping style were described as important sources of resilience. For many participants, social support, the social network, and especially reciprocal relationships, were additionally highly important to resilience on a contextual level.

> "I may have a really good example of that. Of someone who, uh. . . , I teach fall prevention classes these days. [. . .] And this lady, she was always at home by herself, and no social contacts either. And she joined this group, and it was a very nice and warm group. And she says, now I have twelve new friends. She applies for all kinds of classes at once, and she goes from a to b. And all the people who didn't treat her well, because they walked all over her, she ditched them. And she sort of created a whole new life, which increased her quality of life." (care professional 6, fg1)

Examples of other contributing factors mentioned during the focus groups were previous experience with dealing with stressors, level of physical activity, and level of education.

Added Value of Resilience

Although resilience was repeatedly described by the participants to be similar to other related concepts, such as coping, frailty/physical reserve capacity and self-management, most agreed that resilience is of added value compared to these other concepts through its comprehensiveness and positive connotation. Resilience was described as more comprehensive than other constructs by not only including individual characteristics, such as personality and coping strategies, but also incorporating characteristics related to time and context.

> "[. . .] I see resilience much more as sort of a systems approach: what it is that makes. . . and then you do justice to the situation, and to that social network, and that context, and that moment in time. And that, I feel, makes it more complete than, uh, those coping strategies." (researcher 4, fg 2)

In contrast to concepts such as frailty, resilience was reported to have a positive connotation as it focuses on recovery/the opportunity for a positive outcome in light of stressors and not on the negativity of the stressor itself. It also incorporates the potential of improvement through, e.g., interventions. Finally, resilience was described to have a holistic nature, implying more than just overcoming a single challenge.

> "But the resilience model is of course nice and abstract, just like positive health, but that it allows you to, uh, create a thinking model in which it makes sense that you go a little further than just treating the disease. That you also help someone toward a positive health to increase his resilience so he doesn't get sick again as quickly and you have to do all kinds of things again." (care professional 11, fg5)

Finiteness of Resilience

Another recurring theme within the discussions of the concept of resilience was its finiteness. The idea that resilience has limits was brought up in all focus groups; however, different interpretations of this finiteness were given. It was described in relation to increasing age, imminent death, and a high number or intensity of stressors. Loss of meaningfulness, self-management, physical condition, and motivation were all thought to play a role in this finiteness. Older persons were described as being able to sense this end of resilience. Participants believed that, in some cases, it reflected a type of withdrawal from life.

> "More like what you say, flexibility diminishes, which literally means you lose your resilience. An older person, yes in the beginning, I imagine, the line goes like this [indicating a stable line], and at some point it starts to fluctuate a lot more because this flexibility is gone." (care professional 15, fg4)

Participants also discussed whether resilience really ends or if resilience may actually take on a different form in some situations. This tied in with the expected level of recovery as described above: One does not always have to remain in the same state, e.g., the same level of functioning, to be resilient. For example, actively coping with challenges may turn into acceptance of one's decline and end of life, and this may be indicative of resilience as well. Thus, some participants feel that, in this situation, resilience does not end, as it were, but takes a different form.

> "Of course, there are other ways to go forward then. It doesn't have to be like it was every time before, uh, that you think, oh I will get back to a certain level, uh, but then move forward again on a different level." (care professional 5, fg5)

> [. . . .] "Yes, that has more to do with the aspect of giving meaning to life, that a person, even in a new role in which his ability or willingness to do things independently is decreased [. . .], can still find happiness." (care professional 11, fg5)

The *a priori* and Dynamical Systems Approaches

Table 3 provides an overview of advantages and disadvantages of the *a priori* and dynamical systems approaches as described by the participants. Below, we give a more extensive description of the participants' considerations regarding these two approaches.

Recognition/Comprehensibility/Intuitiveness

The *a priori* approach was seen to be intuitive and easy to understand. Furthermore, especially care professional participants saw a clearer translation to practice as compared to the dynamical systems approach because there is a strong connotation of possibilities for intervention. At first glance, the dynamical systems approach was more difficult to understand; it was considered to be more abstract compared to the *a priori* approach.

Additionally, some participants described that the resilient patterns within the complex dynamical systems approach do

TABLE 3 | Overview of advantages and disadvantages of the *a priori* and dynamical systems approach as seen by researchers and care professionals.

	Advantages	**Disadvantages**
a priori approach	• Recognizable, easy to understand and translate to intervention • Feasible, possible with existing data	• Less flexible, stressor pre-determined • More judgmental • Only incorporates reaction to one stressor • Emphasizes limitations • Too broad, anything can be encorporated
Dynamical systems approach	• Studies disturbances in daily life • Flexibility in timescales • Incorporates resistance and recovery • Patterns feel less judgmental • Innovative • Nuanced • Organic • Includes resignation	• Difficult to understand /abstract • Circumstances & stressor unknown • Intensive data collection

not correspond with their own interpretation of resilience. Specifically, the "low-variance" pattern was counterintuitive. A "dip" after a more intense stressor, which would imply high variance in the data, was actually seen as healthy by most participants. Therefore, rapid recovery from such a dip, characterized by low temporal autocorrelation in the data, was felt to be more in line with resilience than not having these "dips" altogether.

> "That you can actually say that the degree of recovery [...] say, the time it takes for you to climb back up, actually says more about your resilience than remaining stable on a straight line." [in response to resilient patterns in the complex dynamical systems approach] (researcher 7, fg3)

The low-variance pattern also did not reflect thoughts on a healthy balance between variability and stability: complete stability and too much variability both were seen as disadvantageous to resilience by participants. In other words, a certain amount of baseline variance is important for many types of parameters. For example, in the case of balance parameters, complete stiffness is undesirable; a healthy person constantly shifts to determine their position in space.

> "What we also see, for example with balance, is that if you indeed lack variation or are too stiff, uh, you know. We always think that limited variation is good, but you also need to be able to explore your limits and have some variability to also be able to resist... so I think that an overly rigid line is not good either." (researcher 9, fg3)

Stressor

Stressors were seen to be an important part of the concept of resilience. According to the participants, consideration of stressors is what differentiates the concept of resilience from functioning in general. Two different types of stressors were recognized: a high- and a low-intensity stressor. A high-intensity stressor may include loss (e.g., of a partner), disease, amputation, or past trauma. It is in the nature of *a priori* approaches that this type of stressor is clearly defined as the context in which resilience takes place. This may be part of the reason that this approach was more recognizable for many participants. However, the definition of the stressor was also seen as a disadvantage; it makes this approach less flexible.

> "Then I recognize what you are saying. The *a priori* [approach] is of course a bit, it is defined a little more sharply and is therefore less flexible, yes and resilience is basically about flexibility, I think." (researcher 2, fg2)

As described above, both resistance (to the occurrence of and/or negative effects of a stressor) and recovery were seen as important aspects of resilience. Participants agreed that the recovery aspect of resilience can be studied using both approaches. However, resistance to the occurrence of a stressor can only be studied with the dynamical systems approach, precisely because the stressor is not defined. Thus, resistance to stressors is incorporated in the low-variance pattern of resilience. In other words, avoidance of stressors leads to a more stable pattern. This opportunity to incorporate resistance was described as an advantage of the dynamical systems approach.

> "What I see here in the dynamical systems approach, more than in the *a priori* one I think, is that it comprises two factors. Namely what you had in your definition, ability to resist and recover. Uh, this also is. Here you also see when there is no adversity, you don't measure that. But that is the ability to resist that that this adversity affects you or occurs at all. And then I am thinking from the uh, physical, uh, perspective, for example balance. [...] If I disrupt a person's balance, then we very often look at how can someone recover. But the question how well can a person actually withstand such a disruption of balance. That is far more important. But that is not what you measure, because that has not taken place." (researcher 9, fg3)

Throughout the day, there are constantly small natural perturbations that require an individual to adapt. According to several participants, resilience is not only portrayed in response to high-intensity stressors, but also in the reaction to these low-intensity stressors or disturbances in daily life. Therefore, these participants felt that an advantage of the dynamical systems approach is that it studies these disturbances in daily life.

> "What I like about it is uh, what is actually also my starting point in my own research. Is that uh, uh, I think it is good to start not only from adversity and then how people adapt. But that there is actually always something to adapt to. That is a little more compatible with, with the dynamical systems approach." (researcher 8, fg3)

Judgment

In the *a priori* approach, the desired outcome after exposure to a stressor is defined *a priori*, and in the dynamical systems approach, the resilient patterns are described as a mathematical characteristic of a system. As a result of this, the dynamical systems approach felt less judgmental to participants than the *a priori* approach.

> "I really, I really like to be able to explain how things go the way they go. And that you can say that there are patterns people can fit into. That that can also be reassuring to people. So if you can explain they are not different from others, which is often how they feel." (care professional 6, fg1)

Feasibility for Research

The *a priori* approach can be applied retrospectively with existing (cohort) data, making it a relatively feasible approach for research. The dynamical systems approach, on the other hand, requires specific collection of data at many different time points, which was seen as more cumbersome by participants.

Use of Both the *a priori* and Dynamical Systems Approaches

In short, both approaches were recognized to have their own value by the participants. As a consequence, an interest in using both approaches to study resilience was expressed in all focus groups. These two approaches may be employed in different situations. For example: many participants felt both types (high and low intensity) of stressors to be important, but the resilience that is portrayed in reaction to these stressors may be different. In other words, resilience in the context of these two different stressors may represent different types of resilience. Therefore, the different approaches may be used to study resilience in reaction to different types of stressors.

> "Because for different types you also need different approaches, different solutions, etc. And I think the same will prove to be true for resilience." (researcher 1, fg2)

According to participants, another way to utilize both approaches is by combining (aspects of) them. For instance, by applying the dynamical systems approach around the time of a high-intensity stressor or measuring them both within one individual at the same time.

Application of Resilience in Research and Older Adult Care Practice

Application of Resilience in Research

Participants described different considerations for the application of resilience in research.

The fact that there is no clear definition of resilience was reported to complicate research. Future research on the concept of resilience may help resolve some of this ambiguity.

> "Yes, and then especially, that is the beauty of it, that it is being studied to make sure, or to prevent that it becomes one of those catch-all terms, but rather to put more flesh on it." (researcher 3, fg 2)

Furthermore, it was put forward that resilience may be so person-specific that it may be impossible to generalize resilience to populations.

> "Or it varies so much from person to person that in the end you can't really say anything about it. That is also a possibility, I think, but well..." (researcher 7, fg5)

A preference for longitudinal data collected specifically for resilience research as opposed to the use of existing data was expressed.

A recommendation was to do justice to the subjective nature of resilience in resilience research. Three different aspects of this subjectivity in resilience (research) were described. First, the perspective of the subjects themselves is important for both the discussion of what a stressor is and what a resilient response is in the context of resilience. Second, on an individual level, the meaning that someone attaches to certain aspects or activities in their life are of importance to the role of these aspects in achieving resilience. Last, it was suggested that the quest to clarify the use of the approaches in studies would benefit from input of (representatives of) the subjects themselves.

> "But then I would also want to know, what are people themselves saying about it. Actually that question we have [discussed] here before. What are people saying about how they function, about how they deal with adversity." (researcher 7, fg3)

The participants were specifically asked to think about data that can be used within the dynamical systems approach. Self-rated health and balance measures and measurement using wearables were given as examples in the introduction of the focus groups. The participants themselves suggested quality-of-life data, gait pattern, well-being data (experience sampling), registration data in general practice, mood measurement, positive health data, sleep patterns, and voice patterns (volume, speed, and/ or intonation).

Participants described several considerations concerning the application of the dynamical systems approach. There is a necessity of repeated measurement data. Therefore, the data should be relatively easy and quick to collect with little burden to the participant. Repeated measurements may lead to learning effects. Cognitive data, for example, may, therefore, be difficult to collect. Implicit measurement can help to prevent this and other types of bias. Ambulant monitoring of behavior (with wearables) was recognized as a good way to apply implicit measurement.

Tying in with the holistic character of resilience, multifactorial data should be considered within the dynamical systems approach. Although, this applies for all resilience research, it was stressed for the dynamical systems approach in particular. This importance is also implied by the inclusion of the resilience pattern of low cross-correlation (low correlation between patterns across different systems, e.g., mental and physical health) within this approach. Determining resilience using one data type may give a distorted view. Other functional systems that are not captured by the data may either compensate for or disrupt the resilience portrayed by this one data type. In one focus group, the different domains within the positive health concept described by Huber et al. (20) were seen as ideally suited to function as a guideline for this combination of data.

Application of Resilience in Care Practice

Aspects of resilience and, specifically, the description of resilience within the *a priori* approach were recognized in care practice, particularly within the geriatric rehabilitation setting. In this setting, everyone is recovering from some sort of high-intensity stressor.

Intervention and clinical decision making were seen as two important applications of resilience in practice. Knowledge of the factors that play a role in resilience can be used to map someone's strengths and weaknesses. This can, in turn, give direction to intervention or justification for clinical decision making.

> "Well, what I think we were just saying, that you, this, that this is part of what you could include in, uh, diagnostics and drawing up a treatment plan. So mapping it out. So I think that is where it starts, and the question is whether this is always something we can influence, but it starts with mapping." (care professional 14, fg4)

Thus, there is a keen interest in factors that play a role in resilience. With knowledge of these factors, care professionals can influence them to improve resilience. Relative weaknesses can be improved on by specific interventions. For example, social support can be improved by advising participation in social activities. On the other hand, strengths, such as optimism, can be called upon by care professionals in the recovery process. This type of influencing of resilience is currently being applied in daily practice by, for example, psychologists, physiotherapists, and occupational therapists but often quite implicitly. This could be done more explicitly; for example, resilience assessment can play a specific role in the development of personal treatment plans in accordance with the principles of personalized medicine.

> "Not very consciously, I think, but I think sometimes with people you do … if you think about it a little, then you know like, these are resilient [persons] in my opinion. And when I think of the *a priori*, I can also see why that is. So whether [this person] is optimistic, or [they] have always been very active physically, for example. If you think about it like that, then they are there. But I don't think we are always aware of it." (care professional 9, fg4)

> "My background is of course one of medical training. So then the logical places to start are, uh, start with exercise, start with nutrition. These are measures of resilience I think I can influence. Increasing your social network is also something we recommend, uh, activities, day center. Uh, uh, that kind of thing, yes." (care professional 10, fg4)

Besides using resilience to give direction to the use of existing interventions, resilience research may also lead to the development of specific interventions to improve resilience.

At the basis of resilience interventions is the discussion on if resilience can be influenced. Most participants agree that resilience can be influenced both by individuals themselves and by interventions or treatment. This potential to influence resilience may be limited by different factors, such as age and total number of stressors. However, as described earlier, resilience is also seen as something finite by some. Thus, at a certain point resilience ends and with it the possibility to influence it.

Knowledge of a person's resilience can also inform clinical decisions that are not necessarily meant to improve resilience. Assessing someone's resilience can help predict a subject's course over time, thereby informing clinical decision making, for example, in the context of starting cancer treatment or performing an operation and triage for rehabilitation.

> "I immediately start thinking about treatment goals. […] We are asked frequently in the policlinic and the clinic whether we think an individual is still able to undergo an, uh, aortic valve replacement, or to get chemotherapy or not, or to undergo surgery. To think about how far you take medical treatments. Well, in that case you naturally do a full examination of a person. But, I also think that you consciously try to determine: is this person able to handle this, and perhaps subconsciously that means: is a person resilient enough." (care professional 10, fg4).

DISCUSSION

Academic researchers and care professionals believe the concept of resilience to be valuable for aging research and older adult care and are positive about both the *a priori* approach and dynamical systems approach. Resilience is seen as being similar to other concepts, such as frailty. However, its specific value is believed to lie in its positive connotation through the implication of the possibility for recovery. Furthermore, participants felt that the concept does justice to the whole person and incorporates time and context. However, there is still a lot of ambiguity surrounding resilience. During the focus group discussions, this was evident from the large amount of different associations resilience evoked among the participants. Examples of different associations that were evoked were adaptation to new states and resistance to stressors through anticipation and acceptance. In contrast with the interest in anticipation in some focus groups, the incorporation of a stressor was also seen as essential and distinguishing to the concept of resilience. The participants further described that continued research, such as the current study, can help clear up some of the existing ambiguity. The importance of resilience in the context of both high- and low-intensity stressors was underscored. The *a priori* and the dynamical systems approaches were described to each have their specific advantages and disadvantages on a conceptual and a feasibility level. The application of these two approaches was expected to yield different but valuable types of information.

Contrary to expectations, no real differences or contrasts were found between the viewpoints of the researchers and care professionals. Both groups of stakeholders had very comparable ideas about the application of resilience and the two approaches; therefore, their input was analyzed collectively.

Participants described the dynamical systems approach to feel less judgmental than the *a priori* approach. However, although this was not discussed during the focus groups, it can be argued that the dynamical systems approach also incorporates a norm through the patterns that are considered to be resilient. In other words, the normative aspect may be hidden within the mathematical model.

Comparison With Existing Literature

In a reflection of the scientific literature, the concept of resilience itself and its aspects were the subject of much discussion during the focus groups.

Many of the aspects of resilience highlighted by the participants during the focus groups were similar to discussions surrounding resilience in the scientific literature. For example, the importance of the social and broader context of a person, and especially the level of social support they experience, to their resilience is often emphasized in both empirical and conceptual literature on resilience in older persons (5).

The participants pointed to the need to involve older persons themselves in the discussion of what resilience is and how it should be applied or investigated. The importance of the inclusion of this stakeholder group when conceptualizing resilience was also described by literature reviews (5). Indeed, a Delphi study of features of resilience of informal caregivers of persons with dementia demonstrates that the perspective of caregivers themselves on the features of resilience differ considerably from that of professional experts (21).

Aspects of resilience are already routinely applied in the care of older people. Often this is done implicitly, but participants saw opportunities to work more explicitly with resilience. The most important opportunities for the contribution of resilience as described by the participants were improvement of resilience through intervention, clinical decision making, and triage for rehabilitation. A recent review of the dynamical systems approach and clinical practice argues for a more explicit exploration of resilience in geriatric medicine. Although resilience is often implicitly assessed as part of the clinical management of older persons, the review suggests that this clinical management can be improved by the explicit use of the dynamical systems approach of resilience (14).

The participants touched upon the related concept of "positive health" as described by Huber et al. (20). Positive health is conceptualized as "the ability to adapt and to self-manage in the face of social, physical and emotional challenges." The six dimensions within the concept of positive health, namely bodily functions, mental functions and perception, spiritual/existential dimension, quality of life, social and societal participation, and daily functioning, are suggested to also be useful in guiding multifactorial resilience research.

Additionally, the participants suggested combinations of the two approaches. A recent article portrays a first example of a combination of the approaches as suggested by the participants during the focus groups (22). This study applied both the *a priori* and the dynamical systems approach at the same time surrounding a high-impact stressor.

The interest in and thoughts of the participants on the finiteness of resilience and the importance of anticipation in resilience in older adults have not been extensively described in the literature. Participants associated resilience with anticipation of stressors through reflection and taking measures to prevent them or their effects. In general, within the scientific literature, a stressor is seen as essential to the portrayal of resilience (3). Although avoidance of a stressor has been mentioned to be an aspect of resilience (23), others specifically argue against this (24, 25).

Strengths and Limitations

This study has several strengths. It is, to our knowledge, the first qualitative study on the applicability and application of different approaches of resilience. This study provides an initial glimpse into what the value of resilience and the *a priori* and dynamical systems approaches in particular can be to aging research and older adult care practice according to experts working in these fields. Also, the study includes the input of participants from many different backgrounds. Experienced academic researchers in different disciplines within aging and care and experienced older adult care professionals from different professions took part in the focus groups. This allowed for a broad and in-depth exploration of the implications of resilience for both research and care practice.

This study also presents some limitations. First, by design, it fails to present a comprehensive inventory of all potential applications of resilience in both research and care practice for older people. Instead, the qualitative exploration yields several illustrative examples of (potential) applications and allows experts to reflect on them and the added value for care practice. Second, participants made several associations between resilience and related concepts (e.g., frailty, coping) and extensively discussed how these related to each other. Subsequently, in the coding process, it appeared difficult to make a clear-cut distinction between interpretations, similar concepts, factors, aspects, components, responses, and outcomes of resilience. As a result, an *in vivo* coding strategy was applied to stay as close as possible to the phrasing used by the participants. Third, the introduction presentation, although prepared with attention to objectivity, might have influenced the discussions in the focus groups (e.g., terminology used by participants).

Conclusion and Future Research

The participants of the focus groups described both the concept of resilience and specifically the *a priori* and dynamical systems approaches to be of value for aging research and older adult care practice. However, the current ambiguity surrounding the concept and application was both recognized by the participants and evidenced by the large amount of different associations that the participants had with resilience. Therefore, much work is to be done before it can be delivered on the full potential of resilience in aging research and older adult care settings. Greater conceptual and operational clarity can be achieved through more qualitative studies, such as the current study; older persons themselves, in particular, should be included in the discussion. The specific value of the approaches can be explored further through empirical studies that work with both approaches side by side and combine them in different ways.

DATA AVAILABILITY STATEMENT

Because of the nature of the data (focus group transcripts) these cannot be fully anonymized. The complete codebook including all codes will be available upon request.

AUTHOR CONTRIBUTIONS

MA, KJ, CH, and MH developed the project. MA and MH developed the topic list and introductory presentation and video for the focus groups. MS and FS facilitated the focus groups as a moderator. MA and AM performed initial coding, data analysis, and drafted the manuscript. All authors contributed to the finalization of the manuscript.

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SUPPLEMENTARY MATERIAL

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REFERENCES

1. Cosco TD, Howse K, Brayne C. Healthy ageing, resilience and wellbeing. *Epidemiol Psychiatr Sci.* (2017) 26:579–83. doi: 10.1017/S2045796017000324
2. Cosco TD, Kok A, Wister A, Howse K. Conceptualising and operationalising resilience in older adults. *Health Psychol Behav Med.* (2019) 7:90–104. doi: 10.1080/21642850.2019.1593845
3. Windle G. What is resilience? A review and concept analysis. *Rev Clin Gerontol.* (2011) 21:152–69. doi: 10.1017/S0959259810000420
4. Huisman M, Klokgieters SS, Beekman ATF. Successful ageing, depression and resilience research; a call for *a priori* approaches to investigations of resilience. *Epidemiol Psychiatr Sci.* (2017) 26:574–8. doi: 10.1017/S2045796017000348
5. van Kessel G. The ability of older people to overcome adversity: a review of the resilience concept. *Geriatr Nurs.* (2013) 34:122–7. doi: 10.1016/j.gerinurse.2012.12.011
6. Cosco TD, Kaushal A, Hardy R, Richards M, Kuh D, Stafford M. Operationalising resilience in longitudinal studies: a systematic review of methodological approaches. *J Epidemiol Community Health.* (2017) 71:98–104. doi: 10.1136/jech-2015-206980
7. Aburn G, Gott M, Hoare K. What is resilience? An integrative review of the empirical literature. *J Adv Nurs.* (2016) 72:980–1000. doi: 10.1111/jan.12888
8. Gijzel SMW, van de Leemput IA, Scheffer M, Roppolo M, Olde Rikkert MGM, Melis RJF. Dynamical resilience indicators in time series of self-rated health correspond to frailty levels in older adults. *J Gerontol A Biol Sci Med Sci.* (2017) 72:991–6. doi: 10.1093/gerona/glx065
9. Kok AAL, van Nes F, Deeg DJH, Widdershoven G, Huisman M. "Tough times have become good times": resilience in older adults with a low socioeconomic position. *Gerontologist*. (2018) 58:843–52. doi: 10.1093/geront/gny007
10. Infurna FJ, Luthar SS. The multidimensional nature of resilience to spousal loss. *J Pers Soc Psychol.* (2017) 112:926–47. doi: 10.1037/pspp0000095
11. Hildon Z, Montgomery SM, Blane D, Wiggins RD, Netuveli G. Examining resilience of quality of life in the face of health-related and psychosocial adversity at older ages: what is "right" about the way we age? *Gerontologist.* (2010) 50:36–47. doi: 10.1093/geront/gnp067
12. Netuveli G, Wiggins RD, Montgomery SM, Hildon Z, Blane D. Mental health and resilience at older ages: bouncing back after adversity in the British household panel survey. *J Epidemiol Community Health.* (2008) 62:987–91. doi: 10.1136/jech.2007.069138
13. Montpetit MA, Bergeman CS, deboeck PR, Tiberio SS, Boker SM. Resilience-as-process: negative affect, stress, and coupled dynamical systems. *Psychol Aging.* (2010) 25:631–40. doi: 10.1037/a0019268
14. Gijzel SMW, Whitson HE, van de Leemput IA, Scheffer M, van Asselt D, Rector JL, et al. Resilience in clinical care: getting a grip on the recovery potential of older adults. *J Am Geriatr Soc.* (2019) 67:16149. doi: 10.1111/jgs.16149
15. Gijzel SMW, van de Leemput IA, Scheffer M, van Bon GEA, Weerdesteyn V, Eijsvogels TMH, et al. Dynamical indicators of resilience in postural balance time series are related to successful aging in high-functioning older adults. *J Gerontol A Biol Sci Med Sci*. (2018) 74:1119–26. doi: 10.1093/gerona/gly170
16. Varadhan R, Seplaki CL, Xue QL, Bandeen-Roche K, Fried LP. Stimulus-response paradigm for characterizing the loss of resilience in homeostatic regulation associated with frailty. *Mech Ageing Dev.* (2008) 129:666–70. doi: 10.1016/j.mad.2008.09.013
17. Green J, Thorogood N. *Qualitative Methods for Health Research*. 4th ed. London; Los Angeles: Sage publications Ltd (2018).
18. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol.* (2013) 13:117. doi: 10.1186/1471-2288-13-117
19. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Quality Health Care.* (2007) 19:349–57. doi: 10.1093/intqhc/mzm042
20. Huber M, van Vliet M, Giezenberg M, Winkens B, Heerkens Y, Dagnelie PC, et al. Towards a 'patient-centred' operationalisation of the new dynamic concept of health: a mixed methods study. *BMJ Open.* (2016) 6:e010091. doi: 10.1136/bmjopen-2015-010091
21. Joling KJ, Windle G, Droes RM, Huisman M, Hertogh C, Woods RT. What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination. *Aging Ment Health.* (2017) 21:509–17. doi: 10.1080/13607863.2015.1124836
22. Gijzel SMW, Rector J, van Meulen FB, van der Loeff RS, van de Leemput IA, Scheffer M, et al. Measurement of dynamical resilience indicators improves the prediction of recovery following hospitalization in older adults. *J Am Med Directors Assoc.* (2019) 21:525–30.e4. doi: 10.1016/j.jamda.2019.10.011

23. Rosowsky E. *Resilience and Personality Disorders in Older Age*. KS Appelberg, University of Florida, United States. E-mail: sappelberg@pathology.ufl.edu. New York, NY: Springer (2011). p. 31–50. doi: 10.1007/978-1-4419-0232-0_3
24. Ryff CD, Singer B, Love GD, Essex MJ, Lomranz J, Lomranz J. *Resilience in Adulthood and Later Life: Defining Features and Dynamic Processes*. New York, NY, US DB - psyh DP - EBSCOhost: Plenum Press (1998). p. 69–96. doi: 10.1007/978-1-4899-0098-2_4
25. Pruchno R, Heid AR, Genderson MW. Resilience and successful aging: aligning complementary constructs using a life course approach. *Psychol Inquiry*. (2015) 26:200–7. doi: 10.1080/1047840X.2015.1010422

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Care Professionals Manage the Future, Frail Older Persons the Past. Explaining Why Frailty Management in Primary Care Doesn't Always Work

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Frailty management focuses on optimizing the physical and psychological functioning of older people with frail health through early risk identification and intervention in primary care. Such care programs demand a joint effort by primary care professionals and older persons, one in which professionals are expected to promote or facilitate self-management practices and older persons are expected to adhere to the professional advice. It is known that patients and professionals hold different perspectives on frailty, but we know little about how this may affect their cooperation in frailty management. In this article, we therefore study how different perspectives of older persons and their primary care professionals play a role frailty management in practice. Nine cases of frailty management were reconstructed through semi-structured interviews with older persons, their family doctor and practice nurse. Drawing from literature on managing complex problems, we analyzed how "factual" and "normative" orientations played a role in their perspectives. We observe that the perspectives of care professionals and older persons on frailty management were substantially different. Both actors "manage" frailty, but they focus on different aspects of frailty and interestingly, care professionals' rationale is future-oriented whereas older person's rationale past-oriented. Primary care professionals employed practices to manage the medical and social factors of frailty in order to prevent future loss. Older persons employed practices to deal with the psychological, emotional and social aspects of the different types of loss they already experienced, in order to reconcile with loss from the past in the present. These findings raise fundamental questions regarding the different perceptions of and priorities around not only care for frail older people in general, but also implied professional-patient relations and the value of a risk-management approach to care for older people with frail health. The distinction between these perspectives could help care professionals to better respond to older patients' preferences and it could empower older persons to voice preferences and priorities that might not fit within the proposed care program.

Keywords: frail older persons, frailty management, professional-patient cooperation, emergency department visits, primary care, dealing with loss, double management challenge, case studies

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INTRODUCTION

A growing number of community-dwelling older people with disabilities and chronic disease experience acute health incidents such as falls, COPD problems and heart failure. This leads to Emergency Department (ED) overcrowding in hospitals (1, 2). In the Netherlands, for example, of the 800,000 ED visits made by older people in 2016, 500,000 could have been prevented according to the Dutch National Institute of Health and Environment (3). Without policy changes, the number of ED visits from older people is expected to grow by 40%—from 800,000 in 2015 to 1,100,000 in 2040 (4).

In the primary-care sector, health risk management is seen as a promising policy response to this cascade of ED visits (5, 6). Specifically, older persons' "frailty" should be "managed" in order to prevent further deterioration, lowering emergency department utilization and chances of hospital readmissions. Scholars have introduced the concept of "frailty" to indicate a status of extreme vulnerability to different types of risks with negative health-related outcomes. Frailty management programs in primary care focus on optimizing the physical and psychological functioning of older people with frail health through early risk identification and intervention. Examples of care programs that can be typified as frailty management are "proactive care" (7, 8), "preventive care" (9), "reablement" (10), and "screening for frailty" (5). Such frailty management programs demand a joint effort by care professionals and older persons, one in which care professionals are expected to promote or facilitate physical activity, a healthy lifestyle and meaningful and pleasurable activities, and older persons are expected to make health optimizing decisions, to adjust their lifestyles and to comply with medication therapy.

Research on the success of frailty management programs shows mixed results (11). Some authors claim that preventive home visit interventions have not been proven effective (12–14), whilst other studies report positive outcomes (7, 15). Healthcare programs that focus on a single disease are more likely to be effective than programs that focus on complex, heterogeneous conditions such as frailty (16). The effectiveness of frailty management programs relates to the intrinsic motivation of frail older people to participate in these programs (17) and to their self-rated health and level of comorbidity (18). Thus, older people with complex health issues, a lower self-rated health and low intrinsic motivation are less likely to benefit from frailty management programs. To better understand why we see this pattern, we need in-depth insight into the lived experiences of frailty management by older persons with frail health and their care professionals.

In this article, we therefore study frailty management as a social process in which care professionals and older people both play a role and have their own perspectives regarding its implementation. By reconstructing the narratives of nine acute health incidents from three different perspectives—i.e., that of older persons who experienced the incident, and that of their family doctors and practice nurse—we have been able to analyze (1) which (different) practices were used to (attempt to) manage frailty, (2) the underlying rationale of these practices, and (3) how these different perspectives could influence the joint effort required by frailty management. Our study contributes to the extant literature by broadening the debate on frailty management by showing how different, coexisting perspectives on frailty management manifest in practice and why we cannot assume that these perspectives can be integrated into a shared perspective of patient and professional. Before discussing our empirics, we first discuss how and why studying frailty management from different perspectives sheds new light on the extant literature.

DIFFERENT PERSPECTIVES ON FRAILTY MANAGEMENT PRACTICES

Frailty is a complex health problem that is difficult to manage for four reasons. First, because the risk factors that contribute to an older person's frailty can be clinical, functional, behavioral, biological, psychological, emotional and/or social, a broad range of expertise is needed to identify potentially relevant risks (19, 20). Second, because risk factors are often obscure (21) and older persons do not tend to perceive themselves as "frail" (22), they are unlikely to identify when they are at risk themselves. Third, because it is difficult to predict how different risks will interact, it is also difficult to predict how (a combination of) risk factors will develop (23). And fourth, because older people with frail health can suddenly and quickly deteriorate (24) and frailty can fluctuate (25), it is to a certain extent unpredictable.

Scholars have drawn attention to the difference between "medical" and "lay" understandings of frailty and chronic disease management, the former focusing on biomedical risks and the latter on the social consequences of health risks (20, 22, 23, 26). Older persons with frail health and their care professionals have different ideas about frailty, including what constitutes an appropriate care response and what should be prioritized when making care-related decisions (27). The biomedical perspective on frailty remains dominant in chronic disease management programs. Therefore, it is argued that different perspectives on frailty should be acknowledged in care programs (22, 28, 29). Current literature on frailty management deals with these different perspectives by proposing a holistic care program, i.e., by integrating the divergent perspectives of older persons and their care professionals (28, 30, 31). Also, it is thought that the development of a measurable, holistic understanding of frailty should be the highest priority on the frailty research agenda (5, 6). However, different perspectives on frailty cannot easily be integrated in one holistic perspective precisely *because* they are different.

Factual and Normative Dimensions of Perspectives

The integration of different perspectives on frailty management is intricate due to "factual" and "normative" dimensions of an individual's perspective toward a highly complex problem (32). Perspectives can be understood as a set of ideas about which "facts" need to be known to understand the problem and about what should be done to deal with the problem, the "normative" dimension. These two dimensions are interrelated:

a specific factual belief leads to a corresponding normative rationale, and a specific normative orientation influences a person's ideas on which facts are relevant to understand a problem. For example, a doctor may interpret a patient's frailty as a medical problem and propose a medical solution—e.g., a new drug therapy—while an older person may see frailty as a consequence of loneliness and propose a social solution—e.g., chatting with neighbors. This example does *not* show that one person is right and the other is wrong; it shows that their perspectives are *different*. While these are two very different solutions to frailty, both are factually correct justifications in and of themselves: they both solve the problem as it was defined (32). The strategy's justification thus is correct from the individual's own perspective, but does not necessarily comprise or align with the normative preference of the other individual involved in frailty management. This means that we cannot just assume that the integration of two perspectives will produce satisfying results for both care professionals and older persons. Precisely because their preferences are different, the integration of both perspectives is problematic. It is, then, more likely that one preference will "overrule" the other when deciding which intervention to execute.

The different perspectives of older persons with frail health and care professionals may affect the efficacy of the joint effort needed to manage frailty in practice. Effective management of complex problems requires clarity on the factual and normative dimension (33). However, literature shows that frailty management is characterized by very diverse factual and normative understandings. Factually, it is difficult to pin down someone's frail health status and thus normatively, it cannot easily be claimed what will be the best care response. To better understand how frailty management programs work in practice, we must acknowledge that it is a social process in which the different factual and normative orientations of care professionals and older persons toward frailty management may collide. The next step, then, is to characterize the perspectives of care professionals vs. older persons with frail health by identifying which factual and normative orientations they hold. This theoretical lens helps to gain specific insight into how different perspectives might influence the effectiveness of cooperation between professional and older patient.

METHOD

Research Design

A qualitative method fit this study's purpose to better understand the practice of frailty management from the different perspectives of older people and their care professionals, as it allows researchers to interpret people's actions and experiences in terms of the meaning that respondents give them (34). Our study consists of a series of nine in-depth case studies of frail older persons and their care professionals. Case studies are comprehensive examinations of single examples. We used two purposive sampling strategies for case selection, to ensure the sample is relevant to the research question posed. First, one general practice was selected as an *exemplary case,* which means that this practice's care program for frail older persons exemplifies the general trend in primary care toward proactive frailty management. Second, the incident-cases were selected as *critical cases*, which means that these cases show specific characteristics that permit a logical inference about the phenomenon of interest (35, 36). The critical criteria were: (1) the older patient should be in frail health; (2) the older person should have recently experienced an acute health incident; (3) the older person should be involved in a frailty management program; and (4) the care professionals should be experienced with frailty management. These four characteristics create a critical situation: while frailty was "managed," older persons still experienced an acute health incident. Each case consisted of narrative reconstructions of the acute health incident and frailty management practices as experienced by the older persons who experienced the acute health incident, their family doctor and their practice nurses.

Research Setting

One general practice, located in a large city in the Netherlands and responsible for the proactive primary care of older people with frail health, participated in our study. The aim of the practice's care was to either maintain or improve the older people's functioning and to prevent avoidable or undesirable acute health incidents.

Respondents

The first author interviewed nine older patients with frail health, their family doctor and two practice nurses (POH in Dutch). The practice nurses hold a Bachelor degree in nursing and are specialized in elderly care. After an exploratory conversation with the family doctor about the study, the doctor and practice nurses recruited older persons within their care practice for interviews. They searched through their patient files for older persons with frail health who had experienced an acute health incident within the past year. Patients' frail health was determined on the basis of clinical judgment of the family doctor, which is considered to be an accurate frailty instrument (37). They also assessed whether it was psychologically permissible (38) to approach them for this study. Eleven patients were found eligible. They invited the patients either during their routine home visits or by telephone. Older persons who were interested in participating received an informational leaflet about the study. Then, once a patient had read the leaflet and agreed to be contacted for participation, the practice nurse gave the first author the patient's telephone number. The first author phoned the eleven older persons to arrange the interviews. Two patients had told the practice nurse they would participate but ended up changing their minds as they lacked the motivation for a 1 h-interview.

Procedure

Data was collected in July, August and September of 2017. The first author interviewed the older people at their homes and the care professionals at their general practice. Before every interview, informed consent was discussed. Interview duration ranged from 60 to 105 min. During the interviews with the older persons, respondents' perspectives on (1) the lead up to the incident, (2) the incident itself and (3) the aftermath were discussed, as well as were (4) their experiences with care, ownership of care decisions, quality of life, their living situations and their daily lives. We used the topics of the validated Patient Assessment Integrated Elderly Care (PAIEC) (39) for the fourth part of the interviews. This assessment covers three themes: patient activation and contextual information; goal setting and problem solving; and coordination and follow-up. At this time, permission was also requested to discuss the incident (prior to the interviews) with the respondents' family doctor and practice nurse. While interviewing the care professionals, respondents were similarly asked about their perspectives on and experiences with frailty management vis-à-vis their patients' incidents, including (1) the lead up, (2) the incidents themselves, and (3) the aftermath, as well as about (4) their general ideas on frailty management and each older person's quality of life and ownership in care decisions. The fourth part of the interview was based upon the PAIEC. As we wanted to understand the lived experiences of our respondents, the topics were addressed in a semi-structured way. The respondents were asked to explain their thoughts about the topics and give examples. In these examples, respondents raised other topics that they found relevant in the light of the interview. The interview guides are included in the **Supplementary Material**. All interviews were audio recorded with permission, transcribed verbatim and made anonymous.

Data Analysis

We used a narrative analysis strategy. Narratives are stories that people tell about events they have experienced and their evaluative impressions of these experiences (35, 40). Analyzing these narratives enables researchers to interpret people's rationale for their actions. Narrative analysis was done by the first author in two ways: thematically and structurally (40). Thematic analysis meant that she analyzed the content of the interviews by focusing both on "what" was said by respondents and on recurrent topics. Structural analysis implied that the first author looked at "how" respondents told their stories by focusing on narrative structures. The first author's first round of analysis in MAXQDA resulted in clusters of open and axial codes on both themes and narrative structure. The thematic-narrative focus led to the identification of respondents' (different) frailty management practices. The older persons felt uncomfortable with the PAIEC-questions in the interviews, explaining the interviewer that these questions did not make sense to them. In their explanations, older persons emphasized other ways of coping with their frailty. This response showed that the older persons did not experience the proactive, planned approach of frailty management programs as making sense in their lives. These responses informed us to look beyond the proactive paradigm and pay close attention to how the respondents prioritized different matters in managing their frailty on a daily basis. The structural-narrative focus identified different orientations of time in the respondents' stories.

Credibility is established by (1) ensuring that the research is carried out according to the principles of good practice, and (2) checking whether the researchers have understood the respondents correctly, so-called member validation [(34), p. 384]. To ensure the credibility of the first author's interpretations, the transcripts were divided among three other researchers (second author, third author and fourth researcher) who each analyzed three cases. Together, the four researchers then discussed and compared their interpretations of the themes and narrative structures they had identified between the nine cases and the relations between them. Next, the first author selectively coded the identified thematic and narrative codes using the theoretical concepts of "factual dimension" and "normative dimension" to characterize the different perspectives on frailty management. Saturation was reached on eight of the nine cases based on the richness of the data and an overall sense of recurrent themes (41). At this point, new cases did no longer suggest new dimensions to the findings, nor was contrary evidence found for the developed theoretical insights (34). As a last analytical step, the first author brought the perspectives "into dialogue" (35): she looked for (dis)continuities, identified tensions between them and reasoned how these perspectives may relate and interconnect, both within and between the cases. Through the iterative process of open, axial and theoretical coding, as well as through revision and discussion, we sought to be rigorous in our analysis. As a form of member validation, the second aspect of credibility, a summary of the findings in the form of a popular article was sent to every participant in the study, the first author discussed the results in a focus group with representatives from a frail older people network of the city, and the first author presented the results to family doctors and practice nurses from other practices working in the same city within in the field of proactive care for older persons with frail health.

Ethical Considerations

The study was cleared by the Medical Ethical Review Committee of the VUmc Medical Center Amsterdam.

FINDINGS

In total, nine community-dwelling, frail older persons within an age range of 79–94 years (mean: 86.8; SD: 5.57), one family doctor and two practice nurses were interviewed to reflect on the nine different cases of acute health incidents that had led

TABLE 1 | Overview of the nine acute health incident cases.

	Overview cases acute health incidents	Interviewed respondents
Case 1	Fall incident	Older person 1, family doctor, practice nurse 1
Case 2	COPD suffocation incident	Older person 2, family doctor, practice nurse 1
Case 3	Fall incident	Older person 3, family doctor, practice nurse 2
Case 4	Fall incident	Older person 4, family doctor, practice nurse 2
Case 5	Fall incident	Older person 5, family doctor, practice nurse 1
Case 6	Fall incident	Older person 6, family doctor, practice nurse 2
Case 7	Fall incident	Older person 7, family doctor, practice nurse 1
Case 8	Fall incident	Older person 8, family doctor, practice nurse 1
Case 9	High blood pressure and fall incident	Older person 9, family doctor, practice nurse 1

TABLE 2 | Characteristics older persons with frail health in cases.

	Numbers
Age	75–79 ($n = 1$)
	80–84 ($n = 3$)
	85–89 ($n = 1$)
	90–94 ($n = 4$)
Sex	Male ($n = 2$)
	Female ($n = 7$)
Marital status	Married ($n = 2$)
	Widowed ($n = 7$)
Living situation	Living alone, apartment ($n = 5$)
	Living alone, senior's apartment ($n = 2$)
	Living with partner, apartment ($n = 1$)
	Living with partner, townhouse ($n = 1$)

each older person to an ED visit (see **Tables 1**, **2**). Narrative reconstructions from these three different perspectives showed how frailty management was experienced in very different ways. Below, we first describe the care professionals' perspectives on the frailty management practices used in the lead up to the acute health incidents. Second, we describe the older person's perspectives on the same matters. Third and lastly, we discuss how these perspectives interact in practice.

Care Professionals' Frailty Management Practices: Case Management

The interviews with care professionals reflected a narrative of case management. When care professionals were asked to reflect on an acute health incident, they responded by talking about the frailty management practices they had used prior to the incident: summarizing symptoms, collecting information from different sources and estimating the effects of this information. In other words, care professionals' frailty management practices involved *making a case*. Older persons with frail health were seen as "cases" with an eye on the future: what could happen in the future and what should be done today to prevent adverse outcomes? Care professionals used a staccato and distanced speaking style, referring to patients as "it"—a case—and also to care providers who execute a care plan as "it"—a mechanism for managing a(n aspect of the) patient's frailty: "There is a senior care plan *in it* [in the "case"], and they come once a week, also to—well you could say—to talk to him, that is it. But *it* [the "care plan"] showers him as well" (practice nurse, case 1). This style could underscore the idea that care professionals see their patients' frailty as a collection of different aspects that need to be checked and managed.

To manage their cases, the care professionals described to employ different practices. We extracted four "case management strategies" from the data: *proactive monitoring*, *proactive planning*, *multidisciplinary collaboration* and *tightening of the strings*. These strategies can be interpreted as mechanisms for frailty management in their case management narrative. First, *proactive monitoring* is an important task of practice nurses: "She also has someone who visits her at home for her COPD now, so we're monitoring everything now" (practice nurse, case 2). As seen in our study, practice nurses generally visited their older patients with frail health once every 3 months to screen them for frailty risk factors:

> There are a number of things we do can objectively: is there a possible urinary tract infection? We check for that. Is there something odd with their blood pressure? Is there something with, well, we also check for diabetes at the diabetics check. We look at their general sense of dizziness too, if they're walking strangely or also when people suddenly lose weight (practice nurse, case 4).

Second, *proactive planning* is described by the care professionals as the following step in their frailty management efforts. Instead of only being responsive to older people's care needs, care professionals set proactive goals for the improvement of their patient's current, frail situation — to make them stronger, healthier and/or more resilient. The following quote shows a description of proactive planning practice, narrated in an abstract, case management style:

> Then we make a few plans or goals and then we first go tackle those, and then eh—look, and then we want *him* [patient is seen as a "case"] to *come back* next time [the case will come back on the agenda of the next multidisciplinary consultation], like, what have we achieved at that point? (practice nurse, case 1).

Third, the care professionals stressed the importance of *multidisciplinary collaboration* for frailty management, because it enables them to generate an understanding of the high complexity of someone's frailty through the use of different opinions and knowledge. "I must say, the physical therapist is doing so much with people, such good work. Strengthening their muscles, reducing their risk of falling, providing insight into their own movement" (practice nurse, case 4).

> We look indeed at the different opinions [of other care professionals, in multidisciplinary consultation], with each other, like hmm, like okay, we need to look at this as well. Who is this person [patient], what does that [social] system look like—eh, the family doctor knows that exactly, he has known [this patient] for a very long time of course (practice nurse, case 1).

Fourth, in response to an acute health incident, care professionals described to *tighten the strings* and controlling for possible contributing factors:

> It turned out, I think, that it [ED admission] was necessary, you could say. So whether we had seen it [the incident] coming, I don't know. It was a mix of a lot of things. [. . .] Later it turned out that she also had a form of, I thought COPD or something, and that plus the fact that her inhaler wasn't compatible with what she used before. So when she was here [at the general practice], we took steps to improve that (practice nurse, case 2).

These responses show how the interviewed care professionals' "factual orientation" sees frailty as a collection of medical and

TABLE 3 | Care professional perspective.

Case management practices	Examples	Factual orientation	Normative orientation
Proactive monitoring	Blood pressure screenings, weigh-ins, the timely detection of ailments.	Medical and social facts that construct frailty need to be identified and measured.	Future oriented: preventing future loss.
Proactive planning	Making a care plan with future goals, e.g., improving muscle strength, lowering blood pressure.	Medical and social facts that construct frailty need to be predicted and translated a step-wise plan to respond to future risks.	Future oriented: preventing future loss.
Multidisciplinary collaboration	Organizing multidisciplinary consultations, sharing information and tasks.	Facts from a wide variety of disciplines that construct frailty need to be detected, identified and acted upon.	Future oriented: ensuring a holistic approach to be able to prevent future loss.
Tightening the strings	Changing medications, increasing check-up frequency, including care professionals from different disciplines.	Medical and social facts that construct frailty need to be controlled.	Future oriented: preventing future loss.

social risk "facts" that needed to be identified, measured, step-wise addressed and controlled. This factual understanding of frailty is related to a "normative orientation" on preventing future loss. Care professionals employ these structured, planned practices because future incidents need to be prevented and, should they still happen, at least professionals need to ensure they cannot be blamed: they have done everything possible within the limits of their knowledge and capacity. All in all, in terms of frailty management, these findings can be summarized as a perspective of future-oriented case management (**Table 3**).

Older Persons' Frailty Management Practices: Dealing With Loss

The interviews with older persons with frail health reveal a narrative of dealing with loss. When the older persons were asked to reflect on their own acute health incidents and its lead up, each responded hesitantly. During the interviews, the older persons reported having little recollection of the specifics surrounding the lead-up to the incident and thus limited potential explanations as to why it happened. To them it "just happened" and they felt unable to identify clear signals or causes, whether before the incident or in retrospect:

> Before I knew it I was lying on the floor! I came out of the mall and then, actually, I wanted to close my jacket. Yes and then, whether I got dizzy I can't remember either. But then I… I don't know! (…) You can't prevent it because there I was, lying there. So unexpectedly (older person, case 8).

When the older persons were asked about their thoughts on preventing future incidents, including a care plan and its goals, they responded with sighs, silence or awkwardness. The majority of the older persons vocalized not finding it useful to think about such concerns. As they explained why, they turned the topic of conversation to loss: when you have already experienced a lot of loss in life, you lose your belief in the usefulness of prevention and try to avoid thinking about new potential losses in the future. They expressed that the experience of preparing for future risk felt alienating, confrontational and sometimes painful. As such, the interviewed older persons perceived their frailty as a state of loss: "Setting goals? That's something for young people, but at my age…" (older person, case 5).

Instead of making plans for future deterioration, the interviewed older persons focused on reconciling past loss in the present. We identified four ways they dealt with these feelings of loss: *by accepting ailments as a part of daily life*, *by putting their own situation in perspective*, *by living day to day and trying to keep doing what they had done before,* and *by grieving their losses*. First, because the older persons had lost many of their physical capacities and were confronted with ailments and pain on a daily basis, *accepting ailments as a part of daily life* was experienced as key to "living a little":

> I already had pain of course. I still had pain and, and I didn't know what [it was]. (…) You could say yes, if you're older you should think about—but my husband is also older, what are you supposed to think about [in terms of prevention]? Yes, you can think about all sorts of things, but I still want to live a little. (…) Should you then—once you've passed uh, 70 or something, or when you're getting close to 80—keep on thinking about what could go wrong? Should I already start organizing in-home nursing care? No! (older person, case 4).
>
> And that one [doctor] said, "Well, it is quite possible that you broke something, but I can't see that now. But if it all gets worse, then you'll have to go to the hospital in an ambulance." I say, "Okay, I'll see what happens then." (…) I couldn't care less. I'll see what happens again the next day (older person, case 7).

Second, the older persons with frail health frequently *put their own situations in perspective* by comparing themselves to others who were worse off and by downsizing their own problems. They compared themselves with other older people who faced (combinations of) dementia, cancer, disability, depression, and loneliness, but also to younger people (e.g., their children) who they perceived as vulnerable.

> I was never sick—well, I had that [cancer] radiation. But I was lucky. I had a friend. I stood with him at the hospital desk to register and he… He came out of the elevator. He stood next to me. After 2 months he was already gone. And I hear this a lot from acquaintances and friends (older person, case 9).

TABLE 4 | Older person perspective.

Dealing-with-loss practices	Examples	Factual orientation	Normative orientation
Accepting ailments as a part of daily life	Ignoring pain or ailments; avoiding thinking about future health goals.	Medical facts that construct frailty need to be ignored, e.g., deliberately ignoring potential signs of physical loss.	Past-and-present oriented: reconciling with loss of physical capacities from the past in the present.
Putting their own situation in perspective	Comparing self to others who are worse off (e.g., sister with dementia, daughter in poor health, late friends).	Social and emotional facts need to be placed in perspective, e.g., toning down their own daily experience of loss.	Past-and-present: reconciling with all types of loss, e.g., physical capacities, social network, living situation.
Living day by day and trying to continue doing what they used to do	Not using a walker; providing informal care to partner; cooking despite becoming blind.	Medical and social facts that construct frailty need to be valued considered in relation to identity threats.	Past-and-present-oriented: maintaining their identities and lifestyles as built in the past; maintaining a feeling of self and purpose in life.
Grieving	Reminiscing about lost loved ones, lost social relations, meaningful activities that are no longer possible, e.g., traveling, reading, ice skating.	Social and emotional facts that construct frailty need explicit acknowledgment and attention, e.g., on one's daily experience with loss.	Past-and-present-oriented: being attentive to present grief caused by past loss.

Third, all respondents stressed the importance of *trying to keep doing what they had done before*. Thinking about everything that could go wrong in the future felt, as they reported, like it took attention away from what they were still able to do—which would threaten not only their sense of identity, but also their quality of and purpose in life.

> When I go out with my friend we walk too far and I'm aware of that. But I don't want to ruin it so I just keep on walking. But then the next day it does hurt for a while. (...) I could do anything, back when I was healthy. [silence] Yes, age of course plays a role. I get tired. And I'm not used to that. I mean, eh, I've been playing tennis from my 25th until my 85th. I used to live in an area where we went ice skating during the winter. And then you received a medal—I skated 600 km. So I mean, I'm strong. I've never had anything and then suddenly... (...) You slip into it. And that is tough. You have to accept it. That's difficult (older person, case 9).

For some respondents, *trying to keep doing what they had done before* meant not letting themselves slip into a depression. One older person told the interviewer about the great loss of her two children and husband, for which her (ongoing) coping mechanism was "just staying put": "In the short time that I have left, I'll just stay put. I'll never do anything crazy, absolutely not. And you never know when it's time, and yes—I have had the longest time" (older person, case 3).

Lastly, respondents told stories about the role of *grief* in their daily lives. They described grieving their lost loved ones (partners, family, friends and children), their physical capacities (walking, traveling, housekeeping, sports, knitting, gardening, concert going, etc.), their memory (forgetting their medicine, finances, administration, or even who is visiting), their personal property (the house in which their children grew up, material items with emotional value, e.g., records, encyclopedias, furniture, cars, their garden) and their purpose in life (their job, hobbies, ability to help others, travel,

> I don't dare say it. [Laughs nervously, then silence.] For me, life has no use anymore. [...] If you look at my activities: embroidery, painting over there [points at a painting in the living room], making cards and knitting piles of sweaters and cardigans and whatever they all wear. All those things have become impossible. I get up at 8 am, then I go sit here and eat my yogurt and well... Well, it's not 10 am yet... And in a while, you [the interviewer] will be gone and then I'll go to the square. And then I'll walk across the square, hop by the pharmacy to drop off a prescription for my neighbor. Well, that's about it. And then I'll sit here again. And back in the day, it was reading and socializing and you name it... Everything you did, it's no longer possible. And... All your friends pass away (older person, case 6).

Such responses show how the interviewed older persons' "factual orientation" sees frailty as loss of medical, social and emotional "facts" that needs to be ignored, toned down, protected and acknowledged. This factual understanding of frailty is grounded in a "normative orientation" of reconciling with loss from the past in the present. The older persons viewed the ignorance, downplaying, protection and acknowledgment of loss as the most relevant understanding of frailty because it shifts their attention to their normative priority: reconciling with loss and maintaining their identities and lifestyles from the past in the present. All in all, these findings can be summarized as a past-and-present oriented dealing-with-loss type of frailty management (**Table 4**).

Care Professionals' and Patients' Perspectives "in Dialogue": Dilemmas in Normative Preferences

The existence of these two frailty management perspectives shows how managing (an interpretation of) frailty is different for care professionals vs. older persons themselves. To understand the tension between these two perspectives, we put these perspective "into dialogue" (35): identifying (dis)continuities and tensions between the perspectives, and reasoning how these perspectives can relate and interconnect. When we compare

Tables 3, **4**, we see that both tried to get a grip on reality through sense making (of the patient's frail health situation), but also that both told different narratives in order to do so. Whereas, care professionals were focused on controlling frailty by checking as many frailty risk-factor "boxes" as possible—with an initial focus on physical well-being and a normative preference for the prevention of future loss—older persons predominantly tried to shift their attention away from their complex health issues while concentrating on the psychological, emotional and social challenges of being frail and displaying a normative preference for reconciling with past loss.

These differences indicate different priorities, but do not imply that care professionals and older persons do not acknowledge and honor each other's perspectives in practice. In fact, care professionals showed a conspicuous understanding of and empathy for their older patients' initial discomfort to, e.g., adapting their lifestyles or accepting a care intervention for preventative reasons. In response to this discomfort, care professionals adapted their implementation of an intervention to "the older person's own pace," and emphasized that older persons should feel in charge of their own lives. Likewise, the interviewed older persons showed respect for their care professionals' risk-minimizing orientation by, e.g., being extra careful to take medication following a procedure, or "not doing stupid things" such as washing windows on a ladder.

This process—of acknowledging and honoring the other's perspective—worked out well for both parties as long as it did not (directly) interfere with their own normative preferences. Tensions arose both when the older persons felt that their practices for reconciling past losses were threatened by their care professionals' attempts to minimize risk factors and when care professionals felt that their older patient's lifestyle choices posed a threat to their aim of risk management. In two cases (4, 6), the older patients were determined to continue cooking their own meals—because they enjoyed it and stopping would imply a loss of identity and independence. A practice nurse explained how she had suggested that one of her older patients switch from a gas stove to an electric one, but the patient "was not open to it," which worried her:

> Why not go for peace of mind? I find it scary. And that's the tricky part, because it's a trade-off people make for themselves; between doing what you've always done because you know that on autopilot and therefore it feels safe. That's the choice she's made in this case' (practice nurse, case 6).

Another example concerns physical therapy. The interviewed care professionals believed in the effect of preventive physical therapy to reduce the risk of falling. One older respondent, who did intensive physical therapy as part of her revalidation after a fall, enjoyed the exercises but quit when she moved back home because she felt unable to combine weekly sessions with the informal care she provided for her husband (case 8). She prioritized what she was used to doing—taking care of her husband—over managing potential future risks.

Lastly, it could be argued that these tensions show how frailty management may entail a *loss dilemma* for older people. When they do not cooperate with their care professionals' practices, the older persons inherently accept risks of acute health incidents in the future. When they do cooperate, however, their care professionals' practices may interfere with their own attempts to reconcile with their losses from the past. Both outcomes result, then—when the older person values both risk management *and* dealing with loss—in a new loss.

DISCUSSION

While scholars currently see the development of a measurable, holistic understanding of frailty management (5, 6), and by extension its preventive ability to reduce ED-visits (1, 2), as the most relevant step toward improving care for older patients with frail health, our study shows how the difficulty of frailty management in practice is not solved by solely generating more knowledge on frailty as a (bodily) phenomenon. Our study shows the importance of the social aspect of the frailty management process and the roles and attitudes of care professionals and older adults herein. A deeper understanding of this social process helps to understand why frailty management does not always work and could contribute to frailty management in practice. In an effort to widen the scope of what frailty management entails, we contribute to the extant literature by addressing fundamental issues about (1) different, co-existing perspectives on frailty management, (2) implied patient-doctor relations concerning health risk management, and (3) the desirability of using frailty management as a form of risk management in all cases.

First, we have demonstrated how frailty management involves two disparate perspectives: the future-oriented, case-management perspective of care professionals and the past-and-present oriented, dealing-with-loss perspective of older patients. Because each follows its own factual and normative understanding of frailty management (32, 33), the incongruity of these perspectives does not disappear in the face of cooperative frailty management. Consequently, their co-existence influences how frailty is actually managed in practice. Both deal in their own way with the older person's frail health status but prioritize things differently. This knowledge could inform the gap in the literature on why frailty management programs are less likely to work for older persons with lower self-rated health (18), complex health issues (16) and low intrinsic motivation to participate in these programs (17): older people with frail health who experienced an acute health incident see their uncertain future as something that is less relevant to focus on than their past and present, and thus do not cooperate with a future-oriented care program. Our study shows that it is relevant to look at the *content* of the intrinsic motivation of older people with frail health—what intrinsically motivates them in dealing with their frail health—instead the extent to which they are motivated to participate in a frailty management program. While previous scholars have also indicated a difference in perspective between care professionals and older persons (20, 22, 26, 28–30), they did not structurally characterize these differences on factual and normative orientations toward frailty, or analyze the consequences of different orientations for cooperation between professional and patient in practice. Our results show how professionals' and patients' perspectives are not "just" different, they also seem related to their positions. Care professionals are in a position to manage cases and are responsible for providing good care: they look to the future. Older persons have experienced severe loss and are aware that they are in the last phase of their lives: they focus on the past. In Western societies, people are generally expected to reason in a future-oriented way regarding their health but, for some people, living an enjoyable life today is more pragmatic than investing in a "mythical" future health (42). Our study shows how this is specifically relevant to older people with frail health, whose future by itself could literally be a myth.

Second, our findings seem to exemplify Foucauldian thought on risk-management practices in healthcare. In this research tradition, the term "case management" is used for clinical practices that use individualistic and epidemiological data sources to govern individuals who are deemed threatening or disruptive to the social order. Through various discourse, strategies and practices, distinctions are made between those (1) with greater or lesser risk of illness, (2) who are more or less utilizable or productive, and (3) who are more or less able to be coached toward the health standards set by clinical experts (43, 44). In our case, overcrowded EDs could be understood as a Foucauldian threat, which calls for case management practices that force patients to become "docile bodies" who manage themselves in line with specific policies (43). Our findings show, however, how this view neglects human agency and the possibility of self-management that is not governed by a clinical logic. Indeed, while patients are usually regarded as passive, recipient actors in care relations (45), our study shows how the lived experience of "managed" older persons is richer than that of being a mere "docile body." Older persons were willing to cooperate with care professionals and their practices as long as doing so did not interfere with their normative, past-focused preferences. When case management interventions did threaten older persons' priorities, they showed self-managing capacities according one's own personal preferences—especially when case management practices were experienced as a potential new loss, e.g., refusing to use a walker in order to maintain an able-bodied identity.

Third, given our observation that older people prioritized dealing with loss over managing future risks, our findings question the desirability of a future-oriented risk management perspective in all cases. Today's primary care programs for older people with frail health strongly steer toward proactively optimizing health (8, 10, 46). These programs have potential to create positive outcomes—when patients are intrinsically motivated and share a future-oriented perspective—but we should not assume that it matches with all patients' priorities and preferences. Care programs often try to motivate chronic patients for risk-avoiding self-management by sharing information on health risks (23), but our results suggest that it is unlikely that more risk knowledge will make older persons' shift from focusing on loss toward prioritizing future care goals. Instead, frailty management is a dialogue in which care professionals and older people need to acknowledge the other's different understandings of autonomy and self-management to deal with frailty. When this difference in perspective is not acknowledged and voiced, the risk could arise that the older person's perspective is missed or the older person does not work along with the frailty management program—which can be overt (telling the professional to disagree) but also covert (agreeing to use a walker but not using it practice). Also, the distinction between a future-oriented care perspective and past-oriented loss perspective could help older persons in making sense of the rationale of a proposed care intervention and why they could feel uncomfortable with it. This could empower older persons with frail health to voice preferences and priorities that might not fit within the care approach as proposed by care professionals.

A care approach that does not focus on health optimization is palliative care. Family doctors' awareness of palliative care needs often arises gradually and relatively late in disease trajectories of their oldest patients. The key point for family doctors to start with a palliative trajectory is the diagnosis of a life-threatening illness (47). This key point complicates the integration of a palliative trajectory in frailty management because frailty is not an acute threat. Older people's frail health rather develops on a subthreshold level and fluctuates in severity (21, 25). As a consequence, we cannot speak of a relatively strict demarcation between the preventive and palliative phase of frail elderly care. The family doctor is, therefore, dependent on the older patient to determine this transition from preventive to palliative per individual case. This underlines our argument that frailty management benefits from a dialogue between professional and patient in which different perspectives are acknowledged.

Our study also has important implications for future research: it underscores the usefulness of investigating and honoring different perspectives when it comes to the embodiment of frailty management. In the future, scholars may want to test to what extent this perspective can be generalized to a broader population of older persons with frail health. Also, it would be interesting to explore how care for older people with frail health may be organized according to various factual and normative orientations instead of just one. The challenge is not to "solve" frailty's factual and normative diversity—since this is, in fact, inherent to the concept of "frailty" itself—the challenge is to find ways to build health programs that are attentive to these two dimensions and to the lived experiences of the actors involved; e.g., programs in which care professionals are still future-oriented and able to manage cases, but with a different care goal. Instead of targeting to reducing health risks, professionals could direct their case management practices toward achieving the highest possible quality of (geriatric) life as defined by the older persons themselves. Such a switch in focus could still allow care professionals to manage cases while better accommodating for an older person's need to deal with loss.

Strengths and Limitations

Thanks to the design of our research—i.e., zooming in on nine different cases of acute health incidents according to three different actors—the strength of this study is the depth with which we have been able to depict the lived experiences, practices and underlying factual and normative orientations of participants. Health incidents are often analyzed by identifying the root cause and addressing it as a single issue or by examining the healthcare system and imagining how the weaknesses found in the procedures and services may have led to the undesirable outcome (48). Neither approach, however, allows for the coexistence of different perspectives on the healthcare problem. Our identification and analysis of two competing perspectives does allow for different, coexisting "diagnoses" of frailty management, which provides a new analytical perspective on the root of healthcare problems. While incident analyses tend to focus on single events, our study of a series of cases provided insight into the structural themes that help explain the observed practices (48). Next, since patients are rarely interviewed after incidents, the patients' perspectives provided an exclusive look into the experienced healthcare system (38). The qualitative methodology chosen allowed for the identification of the topic of loss. This topic was not included in the topic list but was recurrently addressed by the older persons themselves.

A limitation of the study is the fact that we only included professionals and patients within one general practice. The inclusion of more practices could have offered a different practice of frailty management. Though, the selected general practice is an exemplary case because it has worked for years with a proactive care program for frail older adults, which is in line with the general trend toward proactive frailty management in primary care. The fact that all patients had the same family doctor and one of the two practice nurses is a selection bias of the study. The older persons could have responded in certain ways because they receive care from these specific professionals and because they live in a specific area. As we only included patients from this general practice who had experienced an incident within the past year and were willing to participate, we could only select a relatively small number of participants. Due to the older persons' frailty, their perspectives were apt to be different on a better or worse day. Nonetheless, as we found similar patterns among the nine cases, we expect that the characteristics identified in respondents' perspectives are representative of their general state of mind. Moreover, our choice to select participants based on an incident history and to structure the interviews around these events could invoke the belief that frailty management itself is unproductive, because the incident they experienced had not been prevented. The quality of care practitioners' responses could have been influenced by an impulse to defend their frailty management practices and avoid blame for the incidents. Lastly, seven out of nine acute health incidents concerned a fall. This can be explained by the fact that community-dwelling older people with frail health are highly likely to experience a future fall (49), so it is a common acute health incident for this specific patient population. Different acute health incidents may have led to different results, although the 2 other incident cases did not deviate from the fall-cases.

Due to the two chosen purposive sampling strategies, our study offers starting points for further theory development. Because we found future vs. past-and-present perspectives in this exemplary case, these perspectives could also be relevant for other general practices working with similar care programs. We studied a general practice experienced with proactive, preventive care for older persons with frail health, so it could be the case that general practices without an explicit focus on future goals also have a group of patients with a past-and-present perspective. Because we selected on critical cases, we knew that the selected older persons did not just live with the threat of future problems; they had already experienced at least one serious health incident. As the selected older persons—with very frail health—showed autonomy in determining their own health priorities and shifting their attention away from frailty managing practices, it could imply that older adults who are in better health are able to show as much if not more autonomy in deciding whether or not to cooperate with frailty management practices.

CONCLUSION

In this article, we have studied the different perspectives of care professionals and frail older persons on frailty management after a recent acute health incident, why a difference in perspectives exists and how this difference influences cooperation between professional and patient in frailty management programs. We observe that perspectives of primary care professionals and older persons with frail health are fundamentally different. Healthcare professionals focus on the future through case management practices, while older persons with frail health avoid to look in the future and prioritize practices to deal with loss from the past. Our findings may explain why frailty management does not always work: older people with frail health who experienced an acute health incident view future risk management practices as less relevant than reconciling with loss from their past in the present and thus do not cooperate with frailty management programs. While holistic conceptualizations of frailty are often seen as a solution to different perspectives on frailty, we demonstrate that in practice different perspectives are not integrated: they coexist. Cooperation between care professional and patient can be enhanced by approaching it as a dialogue in which both perspectives are acknowledged as meaningful and valuable. Acknowledging both perspectives creates space for a past-and-present orientations to frailty management next to a future-oriented perspective. This way, care professionals could respond better to older person's needs and older persons with frail health could feel empowered to voice preferences that might not fit within the proposed care program.

DATA AVAILABILITY STATEMENT

The datasets generated for this study will not be made publicly available because of the privacy of the respondents. Requests to access the datasets should be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Medical Ethical Review Committee of the VU

Medical Center Amsterdam. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

YL: conceptualization, software, formal analysis, methodology, investigation, writing—original draft and project administration. DB: writing—review & editing and supervision. HH: methodology, writing—review & editing, supervision, project administration, and funding acquisition. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fmed.2020.00489/full#supplementary-material

REFERENCES

1. Street M, Mohebbi M, Berry D, Cross A, Considine J. Influences on emergency department length of stay for older people. *Europ J Emerg Med.* (2018) 25:242–9. doi: 10.1097/MEJ.0000000000000452
2. Legramante JM, Morciano L, Lucaroni F, Gilardi F, Caredda E, Pesaresi A, et al. Frequent use of emergency departments by the elderly population when continuing care is not well established. *PLoS ONE.* (2016) 11:e016593. doi: 10.1371/journal.pone.0165939
3. RIVM [National Institute for Public Health, the Environment]. (2019). Gebruik Acute Zorg. Avaialble online at: https://www.volksgezondheidenzorg.info/onderwerp/acute-zorg/cijfers-context/gebruik-acute-zorg#!node-gebruik-seh-naar-leeftijd (accessed October 21, 2019).
4. Kiers B. Acute ouderenzorg moet radicaal anders. *Zorgvisie*. (2018). Available online at: https://www.zorgvisie.nl/ouderenzorg-moet-radicaal-anders/?tid=TIDP218220XCA66E1113D4F4E5D84F2A90287BB152CYI4&utm_medium=email&utm_source=20181019%20zorgvisie%20nieuwsbrief%20-%20dagelijks&utm_campaign=NB_Zorgvisie (accessed March 29, 2019).
5. Gwyther H, Shaw R, Jaime Dauden E-A, D'Avanzo B, Kurpas D, et al. Understanding frailty: a qualitative study of European healthcare policy-makers' approaches to frailty screening and management. *BMJ Open.* (2018) 8:e018653. doi: 10.1136/bmjopen-2017-018653
6. Cesari M, Prince M, Thiyagarajan JA, De Carvalho IA, Bernabei R, Chan P, et al. Frailty: an emerging public health priority. *J Am Med Dir Assoc.* (2016) 17:188–92. doi: 10.1016/j.jamda.2015.12.016
7. Bleijenberg N, Ten Dam VH, Steunenberg B, Drubbel I, Numans ME, De Wit NJ, et al. Exploring the expectations, needs and experiences of general practitioners and nurses towards a proactive and structured care programme for frail older patients: a mixed-methods study. *J Adv Nurs.* (2013) 69:2262–73. doi: 10.1111/jan.12110
8. Hoogendijk EO, Van Der Horst HE, Van De Ven PM, Twisk JWR, Deeg DJH, Frijters DHM, et al. Effectiveness of a geriatric care model for frail older adults in primary care: results from a stepped wedge cluster randomized trial. *Eur J Intern Med.* (2016) 28:43–51. doi: 10.1016/j.ejim.2015.10.023
9. Liimatta H, Lampela P, Laitinen-Parkkonen P, Pitkala KH. Effects of preventive home visits on older people's use and costs of health care services: a systematic review. *Eur Geriatr Med.* (2016) 7:571–80. doi: 10.1016/j.eurger.2016.08.006
10. Aspinal F, Glasby J, Rostgaard T, Tuntland H, Westendorp RGJ. New horizons: reablement - supporting older people towards independence. *Age Ageing.* (2016) 45:574–8. doi: 10.1093/ageing/afw094
11. King AI, Boyd ML, Dagley L, Raphael DL. Implementation of a gerontology nurse specialist role in primary health care: health professional older adult perspectives. *J Clin Nurs*. (2018) 27:807–18. doi: 10.1111/jocn.14110
12. Bouman A, Van Rossum E, Nelemans P, Kempen GI, Knipschild P. Effects of intensive home visiting programs for older people with poor health status: a systematic review. *BMC Health Serv Res.* (2008) 8:1–11. doi: 10.1186/1472-6963-8-74
13. Mayo-Wilson E, Grant S, Burton J, Parsons A, Underhill K, Montgomery P. Preventive home visits for mortality, morbidity, and institutionalization in older adults: a systematic review and meta-analysis. *PLoS ONE.* (2014) 9:e89257. doi: 10.1371/journal.pone.0089257
14. Suijker JJ, Van Rijn M, Buurman BM, Ter Riet G, Van Charante EPM, De Rooij SE. Effects of nurse-led multifactorial care to prevent disability in community-living older people: cluster randomized trial. *PLoS ONE*. (2016) 11–7:e0158714. doi: 10.1371/journal.pone.0158714
15. Swan M, Ferguson S, Chang A, Larson E, Smaldone A. Quality of primary care by advanced practice nurses: a systematic review. *Int J Q Health Care.* (2015) 27:396–404. doi: 10.1093/intqhc/mzv054
16. Parker S, Fuller J. Are nurses well placed as care co-ordinators in primary care and what is needed to develop their role: a rapid review? *Health Soc Care Community.* (2016) 24:113–22. doi: 10.1111/hsc.12194
17. Van Hooft SM, Been-Dahmen JM, Ista E, Van Staa A, Boeije HR. A realist review: what do nurse-led self-management interventions achieve for outpatients with a chronic condition? *J Adv Nurs*. (2017) 73:1255–71. doi: 10.1111/jan.13189
18. Bleijenberg N, Imhof L, Mahrer-Imhof R, Wallhagen MI, de Wit NJ, Schuurmans MJ. Patient characteristics associated with a successful response to nurse-led care programs targeting the oldest-old: a comparison of two RCTs. *World Evid Based Nurs*. (2017) 14:210–22. doi: 10.1111/wvn.12235
19. Dent E, Kowal P, Hoogendijk EO. Frailty measurement in research and clinical practice: a review. *Eur J Intern Med.* (2016) 31:3–10. doi: 10.1016/j.ejim.2016.03.007
20. Van Campen C. *(red.)*. Kwetsbare Ouderen. Den Haag: Sociaal en Cultureel Planbureau (2011).
21. Fried LP, Ferrucci L, Darer J, Williamson JD, Anderson G. Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *J Gerontol Series A Biol Sci Med Sci.* (2004) 59:M255–63. doi: 10.1093/gerona/59.3.M255
22. Nicholson C, Gordon AL, Tinker A. Changing the way 'we' view and talk about frailty. *Age Ageing.* (2017) 46:349–51. doi: 10.1093/ageing/afw224
23. Morden A, Jinks C, Ong BN. Rethinking risk and self-management for chronic illness. *Soc Theory Health.* (2012) 10:78–99. doi: 10.1057/sth.2011.20
24. Boult C, Wieland GD. Comprehensive primary care for older patients with multiple chronic conditions: 'nobody rushes you through.' *JAMA*. (2010) 304:1936–43. doi: 10.1001/jama.2010.1623

25. Stolz E, Mayerl H, Freidl W. Fluctuations in frailty among older adults. *Age Ageing.* (2019) 48:547–52. doi: 10.1093/ageing/afz040
26. Manthorpe J, Harris J, Stevens M, Moriarty J. 'We're effectively becoming immigration officers': social care managers' experiences of the risk work of employing migrant care workers. *Health Risk Soc*. (2018) 20:113–25. doi: 10.1080/13698575.2018.1432758
27. D'Avanzo B, Shaw R, Riva S, Apostolo J, Bobrowicz-Campos E, Kurpas D, et al. Stakeholders' views and experiences of care and interventions for addressing frailty and pre-frailty: a meta-synthesis of qualitative evidence. *PLoS ONE.* (2017) 12:e0180127. doi: 10.1371/journal.pone.0180127
28. Coker JF, Martin ME, Simpson RM, Lafortune L. Frailty: an in-depth qualitative study exploring the views of community care staff. *BMC Geriatr.* (2019) 19:1–12. doi: 10.1186/s12877-019-1069-3
29. Kendall M, Carduff E, Lloyd A, Kimbell B, Cavers D, Buckingham S, et al. Different experiences and goals in different advanced diseases: comparing serial interviews with patients with cancer, organ failure, or frailty and their family and professional carers. *J Pain Symptom Manage.* (2015) 50:216–24. doi: 10.1016/j.jpainsymman.2015.02.017
30. Wiles J, Miskelly P, Stewart O, Kerse N, Rolleston A, Gott M. Challenged but not threatened: managing health in advanced age. *Soc Sci Med.* (2018) 227:104–10. doi: 10.1016/j.socscimed.2018.06.018
31. Skilbeck JK, Arthur A, Seymour J. (2018). Making sense of frailty: an ethnographic study of the experience of older people living with complex health problems. *Int J Older People Nurs*. (2018) 13:e12172. doi: 10.1111/opn.12172
32. Bannink DBD, Trommel W. Intelligent modes of imperfect governance. *Policy Soc.* (2019) 38:198–217. doi: 10.1080/14494035.2019.1572576
33. Bannink DBD. Localized crafting management tools responding to a double mangement challenge. In: Bannink DBD, Bosselaar JH, Trommel WA. editors. *Crafting Local Welfare Landscapes.* The Hague: Eleven International Publishers (2013). p. 79–94.
34. Bryman A. *Social Research Methods.* Oxford: Oxford University Press (2016).
35. Flyvbjerg B. *Making Social Science Matter: Why Social Inquiry Fails and How It Can Succeed Again*. Oxford: Oxford University Press. (2001) doi: 10.1017/CBO9780511810503
36. Ruddin LP. You can generalize stupid! Social scientists, Bent Flyvbjerg, and case study methodology. *Q Inquiry.* (2006) 12:797–812. doi: 10.1177/1077800406288622
37. Hoogendijk EO, Van der Horst HE, Deeg DJH, Frijters DHM, et al. The identification of frail older adults in primary care: comparing the accuracy of five simple instruments. *Age Ageing.* (2013) 42:262–5. doi: 10.1093/ageing/afs163
38. Peerally MF, Carr S, Waring J, Dixon-Woods M. The problem with root cause analysis. *BMJ Qual Saf.* (2017) 26:417–22. doi: 10.1136/bmjqs-2016-005511
39. Uittenbroek RJ, Reijneveld SA, Stewart RE, Spoorenberg SL, Kremer HP, Wynia K. Development and psychometric evaluation of a measure to evaluate the quality of integrated care: the Patient Assessment of Integrated Elderly Care. *Health Expect.* (2016) 19:962–72. doi: 10.1111/hex.12391
40. Riessman CK. "Narrative analysis." In: Kelly N, Horrocks C, Milnes K, Roberts B, Robinson D, editors. *Narrative, Memory and Everyday Life*. Huddersfield: University of Huddersfield Press. (2005). p. 1–7.
41. Silverman D. *Doing Qualitative Research*. *Third ed*. Sage (2010).
42. MacKay K. Reflections on responsibility and the prospect of a long life. *Public Health Ethics.* (2019) 12:130–2. doi: 10.1093/phe/phz010
43. Foucault M. *Discipline and Punish. The Birth of the Prison.* New York, NY: Pantheon Books (1977).
44. Lupton D. Risk. Second ed. New York, NY: Routledge (2013). doi: 10.4324/9780203070161
45. Fine M, Glendinning C. Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency.' *Ageing Soc.* (2005) 25:601–21. doi: 10.1017/S0144686X05003600
46. Fried LP. Interventions for human frailty: physical activity as a model. *Cold Spring Harb Perspect Med.* (2016) 6:1–14. doi: 10.1101/cshperspect.a025916
47. Claessen SJ, Francke AL, Engels Y, Deliens L. How do GPs identify a need for palliative care in their patients? An interview study. *BMC Family Practice.* (2013) 14:1–7. doi: 10.1186/1471-2296-14-42
48. Vincent C. Analysis of clinical incidents: a window on the system not a search for root causes. *Quality Safety Health Care.* (2004) 13:242–3. doi: 10.1136/qshc.2004.010454
49. Kojima G. Frailty as a predictor of future falls among community-dwelling older people: a systematic review and meta-analysis. *J Am Med Dir Assoc.* (2015) 16:1027–33. doi: 10.1016/j.jamda.2015.06.018

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The Influence of Life Experiences on the Development of Resilience in Older People With Co-morbid Health Problems

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Background: Co-morbidity is a major late-life challenge with poor outcomes, yet many older people are resilient. We consider an ecopsychosocial framework of resilience to investigate this disparity. This theorises that sources of resilience may be personal, social and structural. We explored older people's responses and reactions to significant life experiences, to understand resilience development for managing later life health challenges.

Methods: We applied a two-stage, cross-sectional mixed-methods design to the Cognitive Function and Ageing Studies Wales (CFAS Wales). Participants' defined quantitatively as resilient (high level of well-being despite co-morbidity) were identified in the wave 1 dataset. A sub-sample of the resilient participants aged 65+ were randomly selected for semi-structured interviews ($N = 20$). Qualitative thematic analyses were both inductive and deductive.

Results: The analyses revealed four primary life experiences reflecting different developmental trajectories. "Early years as formative" and "work and employment as formative" occurred at normative developmental stages in the life-course. In contrast non-normative life events such as loss, bereavement, illness of self, and others underpinned the themes of "adverse events and experiences" and "caring experiences." Four potential mechanisms for resilience were central to these life experiences, reflecting reactions, actions, and development: "character and self-identity;" "approach to life and insight;" "meaningful relationships and belonging."

Conclusions: This work contributes further theoretical insights into the ecopsychosocial resilience framework. It highlights the process of interdependence between the individual and the wider environment, suggesting how the availability and accessibility of resources and human agency (protective factors), can influence, and be influenced by, the timing of significant events and experiences. In doing so, it corroborates international healthy ageing policy which recognises resilience as important for a public health response to support older people to adjust to changes and losses experienced in later life. It highlights the importance of current and future policies and services for supporting the

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management of adverse events earlier in the life-course, and recommends that policies and services take a "long view" on population health and well-being and consider the whole life-course, in addition to specific points in the ageing process.

Keywords: resilience, health, life course, adverse events, co-morbidites, healthy ageing

INTRODUCTION

In developed nations there has been an "epidemiologic transition," reflecting the decline of infectious and acute diseases and a growth in chronic and degenerative diseases and co-morbidity (1). Comorbidity is associated with mortality, reduced quality of life and functional status, and increased use of health care (2–4). Older adults with increasing numbers of chronic conditions experience declines in life satisfaction (5). Declines in life satisfaction are associated with the prevalence of fair/poor general health and increases in disability, physical distress, mental distress, activity limitation, depressive symptoms, anxiety symptoms, sleep insufficiency, and pain (6).

Yet many older people with health problems do not necessarily see chronic conditions as an adversity or as a barrier to a good older age. These discrepancies between actual and perceived health are indicative of resilience in older age [e.g., (7)]. "Resilience" explains how some people have a good, or better than expected, outcome in the face of significant challenges. However, definitions of resilience vary. In response to the requirement for concept clarification a review and concept analysis of over 270 resilience research papers across the lifespan, synthesised with stakeholder perspectives, developed a working definition of resilience as "*the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life-course, the experience of resilience will vary*" (8). This recognises that resilience is more than just an aspect of personality and has multiple sources.

International healthy ageing policy recognises resilience as important for a public health response that supports older people to navigate and adapt to changes and losses experienced in later life (9, 10). Despite this international interest, reviews conclude that far less is known about resilience in later life compared to childhood resilience [e.g., (11, 12)]. Quantitative research demonstrates the importance of resilience for well-being when living with ill-health (13), reducing the impact of a new chronic condition on disability (14), adjustment to multiple chronic conditions (15), and moderating the impact of daily stress on negative emotions (16). However, this does not reveal *how* resilience may have developed as these models are constrained by prior theoretical assumptions or limited data and, therefore, are unable to discover new processes (17). Several qualitative studies have explored resilience in older age [e.g., (18–20)], but, these studies have not focussed specifically on samples with ill-health. Moreover, little is known about the extent to which determinants of resilience earlier in the life course may influence later life challenges, especially when faced with a common adversity, particularly ill-health (12).

Longitudinal research on resilient children indicates that despite being born and raised in "high risk" circumstances (e.g., poverty, significant difficulties in their home environment) one third of these children went on to be competent, confident and caring adults (21). Some early life experiences might have contributed to success later, including opportunities to utilise diverse sources of support. Seery et al. (22) also found that the experience of some lifetime adversity predicted better mental health and well-being outcomes. This suggests that an adverse experience early in life rather than have a negative, sensitizing effect (perhaps due to pervasive deprivation and adversity), could have a strengthening "steeling" effect in relation to the response to adversity or stress in later life (23). Cumulative Inequality Theory (24) provides some explanation, recognising that personal trajectories are shaped by the accumulation of risk, available resources, perceived trajectories and human agency (2009, p. 334). The availability and accessibility of resources and human agency (protective factors), can influence, and be influenced by, the timing of significant events and experiences. Thus, the life course perspective represents a formal theoretical context within which the development of resilience can be embedded, as it reflects lifelong as well as age-specific challenges and resource opportunities.

Recognising that older age is shaped by prior experiences (25), we address the gaps in knowledge about resilience in later life. We apply a two-stage mixed methods design, first identifying a sub-sample of older people defined quantitatively as resilient (high level of well-being despite comorbidity) in order to explore the life experiences that may have enabled this resilience. We recognize that identifying and measuring resilience is a source of debate. A number of resilience measurement scales exist, although most measure factors that facilitate a resilient outcome, focusing mainly on psychological aspects (12). Contemporary research acknowledges that a quantitative evaluation of resilience should take into account two common components of resilience; the adversity, and the outcome of interest often referred to as "positive adaptation" (26). A key requirement is the adversity could ordinarily increase the risk of a poor outcome. The adversity could be biological, psychological, economic, or social (8). For example Joling et al. (27) operationalised dementia caregiver resilience as high levels of psychological well-being despite different types of high caregiving demands. Hildon et al. (28) operationalised resilience in older age as better-than-average quality of life in the face of significant adversity, such as ill-health, stress, changing life circumstances, being worse off financially, and experiencing a negative or difficult event such as bereavement.

As previously outlined, comorbidity is associated with a number of poor outcomes, and is particularly pertinent given it is increasing likely to occur as people age (9). Hence comorbidity is the adversity chosen for this study. The second stage then qualitatively explores the participants' responses to significant life experiences as the context for the development of resilience. We draw on an ecopsychosocial resilience framework to understand experiences [**Figure 1**, adapted from (29)]. This recognises that resilience arises from the relationship between the individual and the environment around them, supporting people to deal with the health and social disadvantages they potentially face.

METHODS

Participants

Data and participants are from the Cognitive Function and Ageing Studies Wales (CFAS Wales). This is a population-based study investigating change in health, well-being and cognitive function in community dwelling older people (including a proportion in care facilities) aged 65 years and over living in urban and rural areas of Wales. Participants were randomly sampled from general practice lists between 2011 and 2013, with equal numbers drawn from the age groups 65–74 and 75 and above ($N = 3{,}593$). Participants were interviewed in their own homes by a trained researcher. The response rate was 46%. Ethical approval was granted by North Wales Research Ethics Committee West. Participants first took part in main CFAS Wales interviews during 2011–2013, administered using assisted computer direct data entry.

This paper applies a cross-sectional mixed-methods design in two stages. First, we identified participants defined as resilient in the CFAS Wales wave 1 dataset. A systematic review of methodological approaches for measuring resilience found that "positive adaptation" had mainly been operationalised as the absence of psychiatric distress (e.g., no depression; no anxiety) in the face of an adversity, and no studies specifically measured positive mental adaptation and well-being, an important outcome in older age (26). Following the conclusions of Cosco et al., we operationalised resilience in this first step as a high level of well-being (a good outcome, as indicated by high life satisfaction) despite a significant adversity (two or more health problems). This identified potential participants, and a sub-sample were then selected for interview from those defined as resilient.

Measures

High well-being was assessed with the Satisfaction with Life Scale (30). Five questions ascertain global cognitive judgments of satisfaction with one's life. Individual responses range from "1" (strongly disagree) to "7" (strongly agree). The final scale ranges between 1 (low satisfaction/extremely dissatisfied) and 35 (highly satisfied). Scores of 25 or more indicate high well-being.

Health problems were defined from the methodology of Brayne et al. (31). We identified participants who had experienced two or more of the following conditions: stroke, heart attack, angina, high blood pressure, diabetes, vascular disease, asthma, chronic bronchitis, arthritis, sight difficulties, and hearing difficulties that interfere with daily living, TIA, Parkinson's Disease, or epilepsy.

Participants were required to be cognitively capable of a discussion and were included in the sampling frame if their mini-mental status score (MMSE) >21. Scores range from 0 to 30, with higher scores indicative of better cognitive functioning (32). Demographic data were collected on age (years), gender (male/female), care setting (living in a care home/not living in care home), marital status (a dichotomous variable representing whether or not participants were married/cohabiting), education (years).

Interview

A topic guide contained questions to encourage the participant to think about key events over their life. It was designed to capture unique experiences without explicitly referring to the theme of resilience in the interview. To mitigate against elements of deception around the nature of the interview, at the outset the interviewer clarified with the participant why they had been selected for this study. An early draft was discussed with the research team, refined and piloted (see **Supplementary File 1**). The semi-structured interviews took place during 2012–2013, in the homes of the participants at a time of their convenience. Participants understood they did not have to disclose details of past trauma and distressing experiences unless they wished to. The interviews were in English or Welsh, depending on preference. All interviews were audio-recorded. The semi-structured interviews were professionally transcribed, and then anonymised by a member of the CFAS Wales research team. Welsh interviews were transcribed in the original language and subsequently professionally translated into English. CFAS Wales study had a detailed data management plan and this was adhered to at all times.

Data Analysis

We used a two-stage hybrid method for our qualitative analysis. First, we used the approach of IPA (Interpretive Phenomenological Analysis) to examine personal lived experience in detail, inductively interpreting how participants made sense and navigated their significant life experiences, rather than examining experience through a lens prescribed by pre-existing theoretical preconceptions (33). Each member of the team coded in detail the same two interviews, to establish a common view and to ensure agreement. The authors discussed the analysis on several occasions. Once all the interviews had been analysed individually, a thematic approach identified common themes, and further refinement made through discussions between all team members. We also independently read six interviews and produced summaries which were then compared with fully analysed interviews and discussed by the team. Finally, we synthesised the themes to identify significant life experiences and resilience resources.

RESULTS

Thirty-eight people were identified using random sampling, 20 interviews, lasting ∼1 h, were undertaken. Participants' average

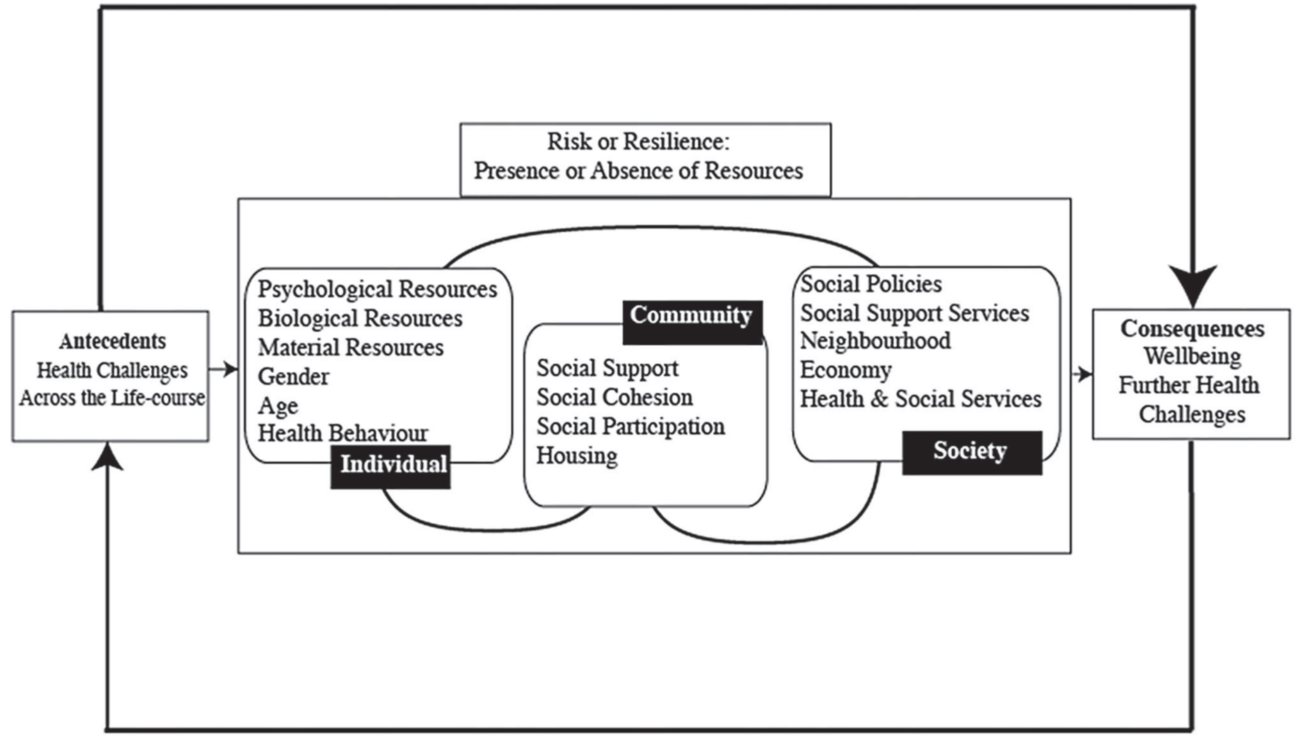


FIGURE 1 | Resilience framework.

age was 77 years (*SD* = 7 years), 12 were female, 10 were married, six widowed, two divorced, and two had remarried following a divorce. The average life satisfaction score was 29.15 (*SD* = 2.39), higher than the mean of the total sample (*M* = 26.84, *SD* = 5.23). The average number of health problems was 4 (*SD* = 2.0). More specifically, the number of conditions reported across the participants were angina = 4, diabetes = 9, Parkinson's Disease = 1, stroke = 3, epilepsy = 2, chronic bronchitis = 3, asthma = 2, arthritis = 14, hearing difficulties = 9, eyesight difficulties = 6, high blood pressure = 8.

There was a negative correlation between higher reports of health problems and lower life satisfaction for the total sample r (3,387) = −0.19, p = 0.001. This remained significant for those with two or more health problems r (2,222) = −0.16, p = 0.001, but not for those with one or no health problems r (1,165) = −0.04, p = 0.12.

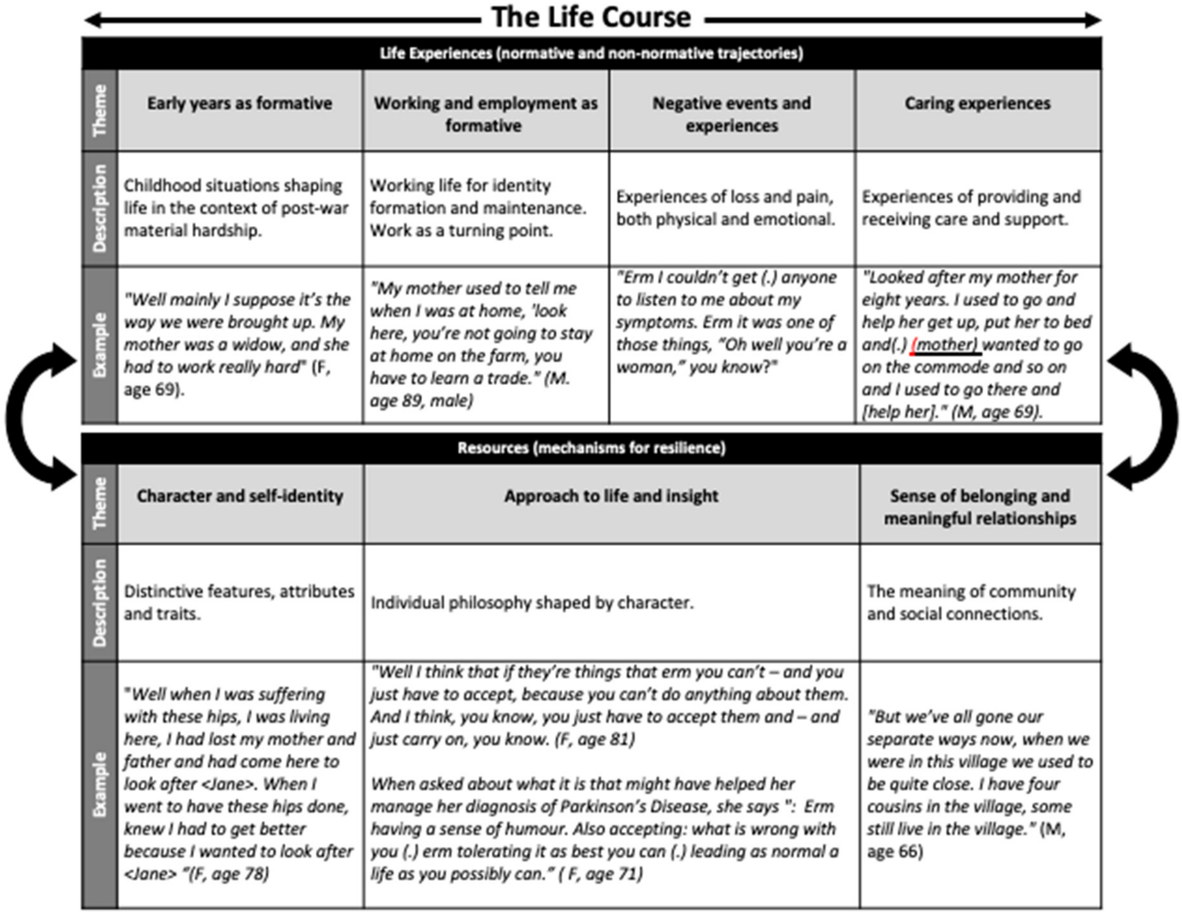
The analysis suggested four events representing both normative and non-normative experiences, (i.e., they occurred within or outside an expected developmental trajectory). These are: *"early years as formative;" "work and employment as formative;" "adverse events and experiences;"* and *"caring experiences."* Central to these experiences were the participant's accounts of their reactions and subsequent actions, how they understood and managed the experience, which we define as: "*character and self-identity;" "approach to life and insight*;" and "*sense of belonging and meaningful relationships.*" These themes reflect an interplay between their development and application in the context of the life experiences, which can be described as resources, or mechanisms for resilience (see **Figure 2**). We illustrate each theme with examples, but the experiences and mechanisms for resilience are often inter-dependent and the interpretation synthesises these two elements to make sense of the narratives.

Life Experiences

Early Years as Formative: "I'll Start With My Childhood, Because I Think That Explains a Lot"

Participants described childhood situations which shaped their subsequent lives, often in the context of material hardship from World War II and the early post-war years. The childhood perception of a family member making sacrifices was common. These experiences had a strong impact on identity development and strategies for dealing with subsequent challenges. When reflecting on her life and how she had managed her mother's manic depression, her father's Alzheimer's disease, her divorce and her own health problems (diabetes, arthritis, high blood pressure and eyesight difficulties affecting daily living), one participant remarked:

> *"I look back on the past and think, "Well how did—what did mum and dad do?"… I just feel that you just have to take whatever comes and hits you. And, just get on with it really, because there are other people relying on you.… you just [(sighs)] you know, I've always been erm (.) what is it? Half—you know, is it half—half-full. (F, age 69).*



The Life Course

Life Experiences (normative and non-normative trajectories)

Theme	Early years as formative	Working and employment as formative	Negative events and experiences	Caring experiences
Description	Childhood situations shaping life in the context of post-war material hardship.	Working life for identity formation and maintenance. Work as a turning point.	Experiences of loss and pain, both physical and emotional.	Experiences of providing and receiving care and support.
Example	*"Well mainly I suppose it's the way we were brought up. My mother was a widow, and she had to work really hard"* (F, age 69).	*"My mother used to tell me when I was at home, 'look here, you're not going to stay at home on the farm, you have to learn a trade." (M. age 89, male)*	*"Erm I couldn't get (.) anyone to listen to me about my symptoms. Erm it was one of those things, "Oh well you're a woman," you know?"*	*"Looked after my mother for eight years. I used to go and help her get up, put her to bed and(.) (mother) wanted to go on the commode and so on and I used to go there and [help her]." (M, age 69).*

Resources (mechanisms for resilience)

Theme	Character and self-identity	Approach to life and insight	Sense of belonging and meaningful relationships
Description	Distinctive features, attributes and traits.	Individual philosophy shaped by character.	The meaning of community and social connections.
Example	*"Well when I was suffering with these hips, I was living here, I had lost my mother and father and had come here to look after <Jane>. When I went to have these hips done, knew I had to get better because I wanted to look after <Jane> "(F, age 78)*	*"Well I think that if they're things that erm you can't – and you just have to accept, because you can't do anything about them. And I think, you know, you just have to accept them and – and just carry on, you know. (F, age 81)* *When asked about what it is that might have helped her manage her diagnosis of Parkinson's Disease, she says ": Erm having a sense of humour. Also accepting: what is wrong with you (.) erm tolerating it as best you can (.) leading as normal a life as you possibly can." (F, age 71)*	*"But we've all gone our separate ways now, when we were in this village we used to be quite close. I have four cousins in the village, some still live in the village."* (M, age 66)

FIGURE 2 | Life course experiences and mechanisms for resilience.

This illustrates the importance of role models for learning and adaptation. Early experiences of helping their parents was important for several people and facilitated independence and a sense of family responsibility:

> *My brother, he was 2 years younger than me, we were both young boys, and we use to go and help. My father worked on the farm next to where we lived, and he use to go around with a milk cart in those days, horse. ….. He use to get up at six o clock in the morning to deliver the milk and we helped him …. In a way it taught us a great deal, it was training, to prepare us for work. (M, age 89).*

School experiences were strong influences. Some participants described school as a happy time, but others described learning to tolerate difficulties in school, an important characteristic for managing future challenges. For Welsh speaking children, communication in school was particularly challenging, when many subjects were taught in English.

> *I learnt the things, but I didn't know how to pronounce the words properly* (F, age 75).

Despite this, she achieved in subjects not requiring the use of English, reflecting an early capacity to negotiate a complex situation for the self as a source of resilience. She indicates how these early experiences and negotiations have facilitated her subsequent approach to life despite her ill-health (diabetes, asthma, arthritis and high blood pressure):

> "*Nothing has left its mark on me for long.*"

Participants' early environments, although challenging, provided experiences for learning and the development of character, a resilience mechanism.

Working and Employment as Formative: "I Wanted to Do Something With My Life"

This theme occurred across all of the lifespan and was an important influence on identity formation and maintenance. For most, entering work was a turning point, influencing their future. One participant, who described herself as not "*very good at school,*" went on to further training and then ran her own small shop from late teens to retirement. Work was important in defining her character and approach to life. When discussing how she managed the loss of her husband and her own ill-health and disability (diabetes, arthritis, hearing difficulties affecting daily living), she remarked:

> *"I suppose it's because I've always had to stand on my own two feet you know? Like having a business from an early age … you just do have to stand on your own two feet and get round everything and get on with it. You know, there is nobody to fall back on."* (F, age 72).

Often work was a source of pride, pleasure and enjoyment, and later on for keeping busy and maintaining continuity. One participant, still farming in older age despite his health problems (stroke and arthritis), captures this, saying:

> *"I think it would be quite dangerous to stop (.) I'm sure I'd be quite lost if I moved to a bungalow with no problems. Because I'm used to problems at work all the… Something goes wrong here every day, there's always something to do and paperwork—I'd miss that" (M, age 89).*

Some participants were unable to enter their chosen profession demonstrated their ability to compromise and accept their situation.

> *"Well I wanted to be a nurse, but mum was so poorly so there was more than enough work for me at home"* (F, age 84).

Others describe long hours in apprenticeships, factories or farms, yet needing to be valued *"I haven't come to do cheap labour, I've got to get on,"* (M, age 85). This early determination, to maximise a situation, along with compromise and acceptance reflect the development a strong sense of self and character, all important for managing sources of stress in later life. This participant reflects on the influence of his father's death on his young life:

> *"I was young- determined to do something with my life—perhaps my life would have been completely different had my father been alive."*

The determination fostered in early life continues into later life and how he managed his diabetes (he also reported eyesight and hearing difficulties affecting daily living):

> *"but I was determined to know how to do it, perhaps I'm not a doctor or a nurse but I've learnt about diabetes. It hasn't stopped me, I went to hospital for a week at the beginning and I had to learn how to inject myself."*

There are other examples where learning from experiences in earlier years has enabled participants to manage later challenges. For example, this participant found out early in life that keeping busy was helpful throughout her life:

> "*Having plenty of work to do so you have to think of other people not yourself"* (F, age 75).

Another participant spoke at length about how her earlier experiences of being self-employed helped her become the woman she now was.

Adverse Events and Experiences: "I Don't See It as an Illness, I See It as a Challenge"

Experiences of loss and pain, both physical and emotional, resonate in the narratives. *"Things haven't been hunky-dory all the time, there have been problems."* (M, age 70). Non-normative family bereavements occurred in many participants' childhoods and multiple losses were extremely painful. Determination resonates. This participant, living with arthritis and the effects of a stroke, who experienced the loss of four boys from his family, remarked:

> *"Well I don't know, as one says,.. make the best of a bad situation, when you're determined"* (M, age 89).

This highlights how adaptive strategies that draw on personal resolve influence the experience's meaning and interpretation.

The significance of an early major event resonates with another participant, whose mother died of Tubercolosis, and who also contracted the disease herself and was hospitalised as a child for 2 years. She describes her emotional response to the loss:

> "*When me mum died I thought, "Right, nothing worse than this can happen." And then you get into yourself and think, you know, "It's my time now," and get on with it."* (F, age 74).

There is a realisation that this was the worst thing that could happen to her, and "life goes on" negating the impact of subsequent major events.

Many participants described the limitations brought about by their illnesses which affected them primarily in their older age. In the face of disabling arthritis, one participant remarks:

> *"I want to walk and that's it, or try to walk. You've got pain after but I know what it is. I know what the pain is, it's arthritis and that, and there's nothing you can do about it." So why should I waste my life worrying about that?"* (F, age 74).

One participant, who had been told in early adulthood she would be unable to have any more children, and who had significant mobility issues through arthritis in older age remarked:

> *"Well I think the thing is you just have to accept things. And if you can't accept things, you're no good to anyone are you?"* (F, age 81).

Being determined, yet able to accept, are aspects of character which have developed and prevailed across the life course. Although there are experiences of loss and pain, character development is prominent. Those early experiences are important in positively re-framing illness in later life.

Participants discussed the ups and downs of their life history. For example, this participant reports she did not cope well with a diagnosis because it impacted on her work, which found rewarding:

> *"Well I didn't cope with it in the beginning because I was working, <I worked> with the Social Services. And erm, that was what started off as Homecare obviously, and I did over 30 years service with that. Erm, and I really enjoyed my work."* (F age 69).

She reported feeling envious of friend whose health problem was resolvable whilst hers was not. These emotions hindered, for a while, her resilience:

> *"And a friend of mine now, she just had her hip done, and me being a bit jealous about that, because she's alright now. I mean I go into hospital and I'll come out exactly the same way practically."*

This final example, demonstrates how on occasion, one event contributes, in this case the death of her mother and her own hospitalization, both to the dynamic nature of resilience:

> *"No I never used to worry about anything; no I'd have enough worries when I was 10, so it doesn't bother me anymore. Nothing bothers—nothing bothers—when you lose somebody like that you're not worried about anything."* (F age 74).

Caring Experiences: "It Didn't Feel Like Work, You See, It Was the Natural Thing to Do"

This theme reflects the experiences of providing care and support to others, but also receiving care and support from families, friends and professional services. This was often initiated in childhood, with participants caring for a sick parent.

> *"And you know there was no electric lights, nothing was in them days, so I used to go down with me candle. She wanted a drink of tea which I had to make and her cream crackers. And I was thinking, "I don't mind doing this because I'll have one as well." [(Laughs)] I always remember that. Nothing was too much to do at that age." (F, age 74).*

Although a child, she highlights a positive interpretation of an adverse situation, suggesting it provided something of value to the self. When discussing later life in the face of health and mobility restrictions she demonstrates this ability to re-interpret an adverse situation, *"I look forward to getting up every morning and I look forward to going to me bed at night, read me papers, watch me telly and that's it, that's my happiness."* Developing the ability to identify value in less than desirable situations is an important aspect of resilience.

Giving care also enabled the focus to move away from participants' own problems. In early adulthood, in the face of her own grief at her mother's death another participant describes how she thought her father needed more help "*and in doing so you know, I dealt with the situation*" (F, age 71). This sense of purpose was a way of coping with her own loss. Family support is reciprocated across the generations, with older parents supporting their younger family members when experiencing earlier difficulties and can be interpreted as family resilience. This participant illustrates this from young adulthood:

> *I got married when I was twenty four, I had a daughter when I was 25, then I had two other children close to each other, and then my brother died when my children were quite young..... I was 9 years older than him, so I used to look after him a lot I suppose. (F, age 75)*

And later:

> *("[Nephew]'s grandmother brought him up, his father suffered a stroke the same time, so [Nephew] used to come over to us. So that's why we've done so much with [Nephew], he didn't have any other family, so we've helped poor [Nephew]"*

Throughout she describes a long history of family caregiving, but only towards the end of the interview does she express regret that she did not become a nurse.

Resources (Mechanisms for Resilience)

Character and Self-Identity: "That's How It Was, We Were Determined"

Participants described their reactions to experiences and how they felt they dealt with them, particularly when faced with significant challenges. Tolerance and acceptance were common, suggesting that well-being was maintained in the face of challenges, particularly in later life, drawing on these characteristics. This woman remarks, when describing her hard working life in her teenage years, *"you got on with it and that was it, that's life*" (F, age 78). Later, when talking about her rheumatoid arthritis and osteoporosis she says:

> *"I didn't ask for it to come, you can't take it away so I've just got to adapt to it. I can't do things that I would like to do, I just can't do it but I'm not sitting worrying about it. They tell me when I first was diagnosed with it they told me to walk about as walking gets oxygen into you bones. Well I've walked but it's not happening like it should and I can't do anything about it so it's there and I just have to live with it."*

This draws attention to the continuity of aspects of character such as tolerance and acceptance despite challenges.

Determination, as already noted, is explicitly referenced across life-course experiences. This is illustrated by this participant: *"I dunno now, as I say, it just always been drilled into me, you just gotta do it and get on with it. ... just determination." (F, age 72).* As she retired, she also lost her husband, yet notes *"I don't know, I suppose I just got on again really (.) just pick yourself up and carry on?"*

Despite their own difficulties, comparisons with others enables participants to provide a different perspective "*Always somebody worse off. But I remember saying that to the consultant and he said, 'Yes, but it doesn't help you, does it?' I said, 'It helps my mind.'" (F, age 69, with chronic bronchitis, arthritis and hearing difficulties affecting daily living).* This attribute enables a re-appraisal of the situation, again underpinning continuity. There is an intrinsic need to either maintain or restore equilibrium, to preserve the self.

Participants displayed several characteristics which appeared to facilitate successful psychological adjustment. This draws attention to a recognition of knowing that life will contain events that could be considered less than desirable, and a need to draw on the self to turn this into something that can be managed and avoid or reduce the impact.

Approach to Life "You Have to Look on the Bright Side of Life, That's What I Think"

The characteristics inferred from the participants' narratives were important in understanding how they dealt with their concerns and reactions to events over the life-course. This approach to life involved their understanding their situations, and actively managing them. Focusing on the present—*"just not think about anything—just live for today and not think about tomorrow"* (F, age 74)—reflects an important perspective for managing the self when faced with very difficult ill-health. This also reflects a temporal aspect, a focus on the present-time in later life, which is further articulated "*you have to deal with things, if you don't, then you make life miserable for the children, don't you. And this and the other, you have to cope with things as they happen* (F, age 75). Not worrying too much and having a positive outlook featured as an important perspective when faced with challenges "*Hard work doesn't kill anyone. It's worry that kills people."* (M, age 85).

Keeping active and occupied was seen as important. In discussing his brother in law's death 1 year after retiring, one participant describes his understanding of this early death:

> *"He stopped working you see, he stopped doing what he used to do, it's unwise for anyone who's used to working to stop like that. It's better if you look for something to do, it doesn't matter what, even if you do voluntarily without any pay"* (M, age 89 living with arthritis and the effects of a stroke).

The awareness that change at this transition point potentially represents a detrimental break in continuity is important for strategies to keep mentally and physically active. The role of activity and occupation, despite ill-health was also important for remaining socially engaged *"well if you stay at home, you'll only get depressed*" (F, age 75, living with diabetes, asthma and arthritis). Religion was important for many participants both for staying socially connected and providing meaning for life events. In discussing his mother's death, one participant notes *"Other people came to offer their sympathy and so on but there was something that was part of me that helped me. I can't explain, it was my belief that helped me most."* (M, age 66, living with diabetes, epilepsy, chronic bronchitis, and hearing difficulties affecting daily living

An ability to "keep going" was observed by one participant in early life, who noted:

> "*My mother developed arthritis quite badly soon after (Participant's brother died) and she couldn't move. That shook us all but then you have to carry on when you have three children, you just had to, there wasn't any choice."*

This earlier observation was reflected when talking about her own health difficulties (she was living with diabetes, arthritis, asthma, high blood pressure, and also reported Polymyalgia Rheumatica):

> *"I'm better than I've been for a while, I can move better, much better than I used to. One of my friends for example, she doesn't see anyone all day long where she lives, so she's [decided] to move to a home. I don't understand [her], I'll keep going until I can't cope any more, for example, if I couldn't move, but while I can move I'm staying here, I'm staying put. [(laugh)]"*

Meaningful Relationships and Belonging "'Cause He Looked After Us, We Looked After Him"

Participants discussed their connections with friends and family, set in the contexts of the broader importance of attachments to the home and the locality for feelings of cohesion. For all participants, despite experiences of loss and hardship, family attachments are important: relationships between parents, siblings, children and spouses are an important resource for support. In describing the family's response to the early death of her young nephew, one participant captures this, saying *"well I don't know, I don't know how we got through it. We supported each other"* (F, age 78). Participants described family as important in times of crises. Family responsibility, having family members to look after, experiences of having been looked after as a child all motivated ongoing reciprocal exchanges of support.

Broader friendships in the community were also an important resource for emotional support and sharing problems *"as you get older, it's good to have someone your own age that you can talk things over with*" (F, age 78). Others had friends and neighbours who they felt would provide practical support if they needed it, as one participant notes,

> *"I got the bug 1 day and I didn't go out, and they noticed that my car hadn't moved from here, and they phoned to ask, 'are you alright?' 'yes'. So they would help you, I fell and hurt myself once, and [Friend] came over to ask 'what do you want?'"* (F, age 75).

As with family relationships, reciprocity was part of friendships, facilitating ongoing exchanges. The same participant describes how her neighbours call on her for help.

> *"They turned to me the other day, one of the girls was ill and (neighbour) came here, can you come over, isn't well."*

However, "*there isn't much of a community now."* (M, age 70) reflects the changing nature of local life that resonated in older age.

A sense of belonging through connections to communities, meaningful relationships within and between friends and family within these communities and beyond, provides an important resource for support at times of need, but also through providing support to others, enables reciprocal exchanges to continue to feel valued and needed, facilitating individuals to be resilient in the face of chronic health conditions.

DISCUSSION

We explored how life experiences influenced the development of resilience, by interrogating narratives of significant events or stressful experiences in the life-course and how these were managed, to understand the meaning of those experiences. The study focuses on the experiences of resilient older adults, as indicated by high life satisfaction despite facing adversity (in this study co-morbid health conditions). The results yield important insights from a life-course perspective to understand resilience. Fundamentally, we suggest that later life resilience is determined by both normative and non-normative experiences that influence the development of resources, which we term "resilience mechanisms." Two of these mechanisms can be seen as individual factors of the ecopsychosocial model: character and self-identity; and approaches to life and insight. The other two mechanisms reflect both community and societal resources: a sense of belonging and meaningful relations. In turn, these mechanisms potentially determine the impact of subsequent challenges, illustrating resilience as a dynamic process, and contesting perspectives which argue that resilience is inherent in the "self." Collectively our findings provide support for the ecopsychosocial resilience framework, as participants drew on personal, social and structural aspects, highlighting the interrelationships between the individual and their wider environment.

Elsewhere, gerontologists interested in resilience in later life share similar thinking around the conceptualisation of resilience, contributing to the advancement of theory. For example, Wiles et al. (19) qualitatively explore resilience in older people in New Zealand. They found that internal, or personal characteristics of resilience such as positive attitude or purpose in life were deeply embedded in social and environmental contexts that could underpin or undermine resilience. They argue that "*resilience should be seen as a contextualised process which can be both individual and environmental*" (p. 416). Wild et al. (34) examined the utility of the concept of resilience for critical gerontology. They suggested some key principles for its use, notably that individual resilience should be situated within other levels of resilience such as neighbourhood, community and society, recognising the interdependence between the different levels of older people's lives. In Canada, Wister et al. (35) reviewed and synthesised the literature to suggest a life-course model of multi-morbidity resilience which represents a set of risk or protective traits, resources and processes that occur over the life-course to promote resilience. Taken together, gerontologists are developing the evidence base for resilience in later life to be defined as a process of interdependence between the individual and the wider environment where aspects of the environment can enable the personal strengths to adapt and manage. This complements resilience research undertaken with children and adolescents [e.g., (36–38)].

Although all our participants experienced adverse events, none disclosed any information about serious maltreatment in childhood. This does not necessarily mean this did not happen to the participants, but we allowed people to tell us what was important to them and did not explicitly ask about serious adverse childhood experiences. This is an important consideration, as significant, persistent maltreatment in childhood may lower the ability to be resilient compared to life events [see (23), for discussion]. However, positive, normative experiences in later life, such as marriage, employment, and family relationships (as noted in our study) are suggested as "turning points" by others, countering the effects of significant early adversities such as maltreatment [e.g., (39)]. Nevertheless, it would appear from our exploration that the participants' experiences of life events were to some extent time-limited adverse experiences, such as childhood bereavement. Whilst they did not prevail over long periods of time, the long-term consequences are known to be detrimental to the mental health of adults (40). Still, rather than letting those experiences influence their lives adversely, they utilised those experiences to build their characters, allowing them to reframe their later life illnesses positively. The early deprivation experienced by some participants did not prevail across the life span, as participants drew on, and developed, their characters to take advantage of employment opportunities, for example.

Similarly, participants drew strength from their caring experiences to foster later life resilience. Not only did those experiences develop character, sense of purpose and skills but they also encouraged connectedness and reciprocity with family, friends, and neighbours, which persisted into later life, either concerning long-standing relationships but also developing new ones. These experiences may have enabled the strengthening or "steeling" effects suggested by Rutter (23), and provide further support for the conclusion of Seery et al. that, "*in moderation, whatever does not kill us may indeed make us stronger*" [(22), p. 1,025]. More broadly, considering this in the context of Cumulative Inequality Theory (24) the availability of resources and human agency, described here as resilience mechanisms, may have modified any potential negative outcome posed by the risks from adversity, such as health difficulties.

Implications for Policy and Practice

This dynamic nature of resilience as highlighted in our research is acknowledged by the World Health Organisation as a target for public health policy and important for Healthy Ageing (9). As more longitudinal studies of resilience emerge which consider the life-course perspective, the challenge will be for policy makers and practitioners who currently focus on discrete areas of development (e.g., geriatrics, pediatrics) to take the "long view" on population health and well-being and work together to develop a life-course approach to support healthy development.

Of course, it will always be important to focus on specific phases of development. Therefore, not only should a long view forward be taken by policy makers but also a long view backward, when working with older people. This long view backward could consider not only individual experiences but also the historical and cultural context which formed the experiences and characters of older people. By drawing on successful past personal and community experiences of overcoming challenge, one may be able to provide older people with the tools, often already existent, to face and overcome challenges of ageing.

The World Health Organisation's European Strategy for Child and Adolescent Health (41) recommends adopting a life-course approach to support development, acknowledging that health, and illness in adulthood are embedded in health and experiences in previous stages of the life-course. In our study, "early years as formative" and "work employment as formative" had a strong impact on the participants' development. The findings suggest the environment gives opportunities for the individual's learning and the development of the distinctive features, attributes and traits of their character. This work can begin in childhood, as noted by others, and can continue throughout adulthood [e.g., (21–23)]. Also important is providing opportunities for people to reflect on their own development and in times of stress draw on both their personal strengths and on the strengths in their communities. As the ecopsychosocial resilience framework suggests, it is the collective and collaborative impact of these factors which promote resilience.

A suggestion from this study could be that utilising this framework in both policy and in practice within a life-course perspective will enable societies to both support those resilient people to remain resilient but also to identify areas for action to facilitate resilience in those who are not yet resilient or who are vulnerable. These policies and practices need to be implemented at the individual, community and societal levels. Our data suggests specific areas of policy. For example, enhancing social support from families and communities, fostering social cohesion, and strong neighbourhoods could promote resilience (42). Where informal social support is not available, polices are required to ensure that more formal or statutory social support is in place.

Other aspects of intervention might focus on the individual, primarily drawing on psychological therapies. Indeed, there is a growing global interest in resilience-building interventions, as captured in systematic reviews. Macedo et al. (43) concluded that despite evidence to suggest that resilience promotion interventions were effective, the interpretations were hindered by the poor methodological quality of available studies. Moreover, no interventions were targeted at older people, and all were psychological interventions. Whilst Leppin et al. (44) included some patients with chronic conditions in their review, many of the included studies used a wide array of conceptualisations in relation to intervention application. There was some evidence to suggest the interventions were effective, but the authors indicate the studies were poorly specified and lacked theoretical clarity. None specifically targeted older people. Another systematic review of randomised controlled trials (RCTs) or controlled trials assessing the efficacy of programmes designed to develop, enhance or improve resilience in adults showed that interventions using mindfulness or CBT techniques appeared to enhance measures of individual resilience. Unfortunately, no descriptions of the study samples are included, so it is not possible to ascertain if any of these programmes included, or specifically targeted, older people (45). Despite the potential, resilience interventions have yet to be developed and tested with older people specifically and have not yet translated into models of service delivery for older people.

Strengths and Limitations

The mixed methods approach to resilience is unique. To date most research on resilience has either taken a quantitative approach or a qualitative approach. In this study we have identified, quantitatively, a sample of older people who have high levels of life satisfaction despite experiencing health comorbidities, following the approaches of others for operationalising resilience in cohort data [e.g., (26–28)]. These participants can be defined as resilient. This approach was only possible because this study is embedded within a large-scale cohort study.

Quantitative research has shown resilience is important for maintaining well-being in the face of chronic illness (13), reducing the impact of a chronic condition on disability (14) and adjustment to multiple chronic conditions (15). Our research adds qualitative insights into how older people may develop the resilience measured quantitatively in these previous studies. Qualitative research can provide context and can contribute new theoretical understandings to the study of resilience in later life (17), and the meaning of experiences (23). Thus, some important factors may be missing or lacking in sufficient detail in quantitative studies to understand the nuances which underpin resilience and its mechanisms. The current study goes some way to address those deficits. In turn, it provides further insights for future quantitative models to test, thereby making a major contribution to resilience research.

We thought carefully about the design of the qualitative aspects, using a transparent and consistent approach to research design and conduct, derived from a framework for excellence in qualitative research (46). Notable in our research was the attention to detail in the process of coding and interpreting themes, involving considerable discussion between the authors of the meaning and interpretation of the participant's narratives. Participants' were not explicitly asked about resilience. Interpreting how they made sense and navigated their significant life experiences was the challenge of the analysis.

There are two limitations in our design. First, it is retrospective, and one could argue that our participants are looking back through "rose-tinted glasses." However, there are two counter arguments to that. By using a life-course perspective in a time-unlimited interview we are giving participants the opportunity to reflect on their lives, and our experience elsewhere suggests that positive response sets are less likely in those situations (47). In addition, our focus is on resilience in later life, and therefore, one should not dismiss the positive self-reflections on past life, because that may indeed be a mechanism for later life resilience. Second, our study focuses on those who are resilient, and we do not have a non-resilient comparison group. Thus, we are not able to say for certain whether our themes and mechanisms would be present for those non-resilient participants. Other work has found differences between resilient and non-resilient participants at all levels of the ecopsychosocial framework (18, 48) and further work could usefully explore the extent to which our findings replicate in other groups of older people, and identify the unique aspects that enable resilience. An optimal research design could follow people over the whole life course to see how life experiences help develop resilience, and how in turn resilience is useful for managing chronic conditions. Unfortunately this was not possible for this study. However, future research could expand on this work to look at the life-course events of both resilient and non-resilient participants with chronic conditions to see how these may differ. The focus of our study was the development of resilience and we chose co-morbid heath difficulties as the contextual adversity. Future studies could select different adversities pertinent to older age (e.g., the onset of cognitive impairment) or consider a different approach in the data collection such as more explicit questioning around illness experiences.

We are also unable to say whether their hardships were objectively normative or non-normative. Given the age of our cohort, many people who were born at this time would have experienced similar levels of hardship in the war and post-war years. One might argue that our participants had experienced enough stability to provide the foundations for resilience. To address this question, we would need to examine the life-course of non-resilient participants.

CONCLUSION

Our work is important for its contribution to four areas: method; theory; knowledge; and application. The study has a distinctive mixed-methods approach with a strong sampling approach. Uniquely, we drew our qualitative sample from a large panel dataset, using classical sampling methods. Our sample comprised older people who had high levels of life satisfaction despite facing significant health challenges. In addition, the interview was novel in two ways. First, the interview followed a life course perspective, whilst second, avoiding explicit questions about resilience. Thus, our findings reflect non-primed responses. The study provides an important contribution to the theory of resilience and the development of resilience. It demonstrates the importance of resources at individual, community, and societal levels to the development of resilience across the lifespan. Our findings highlight the importance of both normative life events such as early years and work, and non-normative events such as adverse life experiences (e.g., bereavements), and caring experiences, on the development of resilience for older people. The results also provide insight into the mechanisms which facilitate resilience. Collectively, these findings demonstrate how the availability and access to the resources interact with the timing of significant life events and experiences to facilitate (and one could argue, hinder) resilience. Finally, the implications of our work provide some early indication that it is not only important to take a forward view when thinking about service provision and ageing well, but also a long backward view. Understanding the life experiences of older people is essential if we are to provide appropriately tailored services and resources for older people that they consider appropriate and are willing to use.

DATA AVAILABILITY STATEMENT

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by North Wales Research Ethics Committee West. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

GW and KB were CFAS Wales co-investigators. GW designed the qualitative sub-study, developed the topic guide, oversaw the data collection, and led the writing of the manuscript. KB contributed to the writing, editing of the early drafts, and manuscript. CM contributed to quantitative data collection, oversaw the qualitative data management, and contributed to the writing of the final manuscript. All authors developed the coding system, undertook data analysis, and interpretation.

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SUPPLEMENTARY MATERIAL

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REFERENCES

1. World Health Organisation. *Global Health.* (2011). Available online at: http://www.who.int/ageing/publications/global_health.pdf (accessed September 7, 2020).
2. Carstensen J, Andersson D, André M, Engström S, Magnusson H, Borgquist LA. How does comorbidity influence healthcare costs? A population-based cross-sectional study of depression, back pain and osteoarthritis. *BMJ Open.* (2012) 2:e000809. doi: 10.1136/bmjopen-2011-000809

3. Incalzi RA, Capparella O, Gemma A, Landi F, Bruno E, Di Meo F, et al. The interaction between age and comorbidity contributes to predicting the mortality of geriatric patients in the acute-care hospital. *J Internal Med.* (1997) 242:291–8. doi: 10.1046/j.1365-2796.1997.00132.x
4. Mulrow CD, Gerety MB, Cornell JE, Lawrence VA, Kanten DN. The relationship between disease and function and perceived health in very frail elders. *J Am Geriatr Soc.* (1994) 42:374–80. doi: 10.1111/j.1532-5415.1994.tb07484.x
5. Friiedman EM, Ryff CD. Living well with medical comorbidities: a biopsychosocial perspective. *J Gerontol.* (2012) 67:535–44. doi: 10.1093/geronb/gbr152
6. Strine TW, Chapman DP, Balluz LS, Moriarty DG, Mokdad AH. The associations between life satisfaction and health-related quality of life, chronic illness, and health behaviors among U.S. community-dwelling adults. *J Commun Health.* (2008) 33:40–50. doi: 10.1007/s10900-007-9066-4
7. Ryff CD, Singer B. Understanding healthy aging: key components and their integration. In: VL Bengston, D Gans, NM Pulney, M Silverstein, editors. *Handbook of Theories of Aging.* 2nd ed. New York, NY: Springer Publishing Co. (2009). p. 117–44.
8. Windle G. What is resilience? a review and concept analysis. *Rev Clin Gerontol.* (2011) 21:151–69. doi: 10.1017/S0959259810000420
9. World Health Organisation. *World Report on Ageing and Health.* (2015). Available online at: http://www.who.int/ageing/publications/world-report-2015/en/ (accessed September 7, 2020).
10. World Health Organisation. *Global Strategy and Action Plan on Ageing and Health.* Geneva: World Health Organization. (2017).
11. Bennett KM. *Emotional and Personal Resilience Through Life. Future of an Ageing Population: Evidence Review*. London: Foresight, Government Office for Science. (2015). Available online at: https://www.gov.uk/government/publications/future-of-ageing-emotional-and-personal-resilience (accessed September 7, 2020).
12. Windle G, Bennett K, Noyes J. A methodological review of resilience measurement scales. *Health Qual Life Outcomes.* (2011) 9:8. doi: 10.1186/1477-7525-9-8
13. Windle G, Woods B, Markland DA. Living with ill-health in older age: the role of a resilient personality. *J Happiness Stud.* (2009) 11:763–77. doi: 10.1007/s10902-009-9172-3
14. Manning L, Carr DC, Kail BL. Do higher levels of resilience buffer the deleterious impact of chronic illness on disability in later life? *Gerontologist.* (2014) 56:514–24. doi: 10.1093/geront/gnu068
15. Jason KJ, Carr DC, Washington TR, Hilliard TS, Mingo CA. Multiple chronic conditions, resilience, and workforce transitions in later life: a socio-ecological model. *Gerontologist.* (2015) 57:269–81. doi: 10.1093/geront/gnv101
16. Ong AD, Bergeman CS, Bisconti TL, Wallace KA. Psychological resilience, positive emotions, and successful adaptation to stress in later life. *J Personal Soc Psychol.* (2006) 91:730–49. doi: 10.1037/0022-3514.91.4.730
17. Ungar M. Qualitative contributions to resilience research. *Qualitative Social Work*. (2003) 2:85–102. doi: 10.1177/1473325003002001123
18. Donnellan WJ, Bennett KM, Soulsby LK. What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging Mental Health.* (2014) 10:932–9. doi: 10.1080/13607863.2014.977771
19. Wiles J, Wild K, Kerse N, Allen R. Resilience from the point of view of older people: 'There's still life beyond a funny knee'. *Soc Sci Med.* (2012) 74:416–24. doi: 10.1016/j.socscimed.2011.11.005
20. Ottman G, Maragoudaki M. Fostering resilience in later life: a narrative approach involving people facing disabling circumstances, carers and members of minority groups. *Ageing Soc.* (2015) 35:1–29. doi: 10.1017/S0144686X14000828
21. Werner EE, Smith RS. *Journeys From Childhood to Midlife: Risk, Resilience, and Recovery*. Ithaca, NY: Cornell University Press. (2001).
22. Seery MD, Holman EA, Silver RC. Whatever does not kill us: cumulative lifetime adversity, vulnerability, and resilience. *J Personal Soc Psychol.* (2010) 99:1025–41. doi: 10.1037/a0021344
23. Rutter M. Resilience as a dynamic concept. *Dev Psychopathol.* (2012) 24:335–44. doi: 10.1017/S0954579412000028
24. Ferraro KF, Shippee TP. Aging and cumulative inequality: how does inequality get under the skin?. *Gerontologist*. (2009) 49:333–43. doi: 10.1093/geront/gnp034
25. Elder G. Time, human agency, and social change: perspectives on the life course. *Soc Psychol Quarterly*. (1994) 57:4–15. doi: 10.2307/2786971
26. Cosco TD, Kaushal A, Hardy R, et al. Operationalising resilience in longitudinal studies: a systematic review of methodological approaches. *J Epidemiol Commun Health.* (2017) 71:98–104. doi: 10.1136/jech-2015-206980
27. Joling KJ, Windle G, Dröes RM, Meiland F, van Hout H, MacNeil Vroomen J, et al. Factors of resilience in informal caregivers of people with dementia from integrative international data-analysis. *Dementia Geriatric Cognitive Disord.* (2016) 42:198–214. doi: 10.1159/000449131
28. Hildon Z, Smith G, Netuveli G, Blane D. Understanding adversity and resilience at older ages. *Sociol Health Illness*. (2008). 30:726–40. doi: 10.1111/j.1467-9566.2008.01087.x
29. Windle G, Bennett KM. Caring relationships: how to promote resilience in challenging times. In: M Ungar, editor. *The Social Ecologies of Resilience. A Handbook of Theory and Practice.* New York, NY: Springer. (2011). p. 219–31. doi: 10.1007/978-1-4614-0586-3_18
30. Diener E, Emmons R, Larsen J, Griffin S. The satisfaction with life scale. *J Personal Assessment.* (1985) 49:71–5. doi: 10.1207/s15327752jpa4901_13
31. Brayne C, Mathews FE, McGee M, Jagger C. Health and ill-health in the older population in England and Wales. *Age Ageing.* (2001) 30:53–62. doi: 10.1093/ageing/30.1.53
32. Folstein MF, Folstein SE, McHugh PR. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res.* (1975) 5:89–98. doi: 10.1037/t07757-000
33. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage. (2009).
34. Wild K, Wiles J, Allen R. Resilience: thoughts on the value of the concept of critical gerontology. *Ageing Soc.* (2013) 33:137–58. doi: 10.1017/S0144686X11001073
35. Wister AV, Coatta KL, Schuurman N, Lear SA, Rosin M, MacKey D. A lifecourse model of multimorbidity resilience: theoretical and research developments. *Int J Aging Human Dev.* (2016) 82:290–313. doi: 10.1177/0091415016641686
36. Hart A, Gagnon E, Eryigit-Madzwamuse S, Cameron J, Aranda K, Rathbone A, et al. Uniting resilience research and practice with an inequalities approach. *SAGE Open.* (2016) 1–13. doi: 10.1177/2158244016682477
37. Luthar S, Cichetti D, Becker B. The construct of resilience: a critical evaluation and guidelines for future work. *Child Dev.* (2000) 71:543–62. doi: 10.1111/1467-8624.00164
38. Ungar M, Ghazinour M, Richter J. Annual research review : what is resilience within the social ecology of human development? *J Child Psychol Psychiatr.* (2013) 54:348–66. doi: 10.1111/jcpp.12025
39. Masten AS, Burt KB, Roisman GI, Obradovic J, Long JD, Tellegen A. Resources and resilience in the transition to adulthood: continuity and change. *Dev Psychopathol.* (2004) 6:1071–94. doi: 10.1017/S0954579404040143
40. Høeg BL, Appel CW, von Heymann-Horan AB, Frederiksen K, Johansen C, Bøge P, et al. Maladaptive coping in adults who have experienced early parental loss and grief counseling. *J Health Psychol.* (2016) 22:1851–61. doi: 10.1177/1359105316638550
41. World Health Organisation. *Investing in Children: The European Child and Adolescent Health Strategy 2015–2020*. (2014). Available online at: https://www.euro.who.int/en/health-topics/Life-stages/child-and-adolescent-health/policy/investing-in-children-the-european-child-and-adolescent-health-strategy-20152020 (accessed September 7, 2020).
42. Cosco T, Hardy R, Howe L, Richards M. Early-life adversity, later-life mental health, and resilience resources: a longitudinal population based birth cohort analysis. *Int Psychogeriatr.* (2018) 31:1249–58. doi: 10.1017/S1041610218001795
43. Macedo T, Wilheim L, Gonçalves R, Coutinho ESF, Vilete L, Figueira I, et al. Building resilience for future adversity: a systematic review of interventions in non-clinical samples of adults. *BMC Psychiatry*. (2014) 14:227. doi: 10.1186/s12888-014-0227-6
44. Leppin AL, Bora PR, Tilburt JC, Gionfriddo MR, Zeballos-Palacios C, Dulohery MM, et al. The efficacy of resiliency training programs: a systematic review and meta-analysis of randomized trials. *PLoS ONE.* (2014) 9:e111420. doi: 10.1371/journal.pone.0111420
45. Joyce S, Shand F, Tighe J, Laurent SJ, Bryant RA, Harvey SB. Road to resilience: a systematic review and meta-analysis of resilience

training programmes and interventions. *BMJ Open*. (2018) 8:e017858. doi: 10.1136/bmjopen-2017-017858

46. Tong A, Sainsbury P, Craig JC. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. (2007) 19:349–57. doi: 10.1093/intqhc/mzm042
47. Bennett KM, Hughes GM, Smith PT. Psychological response to later life widowhood: coping and the effects of gender. *Omega J Death Dying*. (2005) 51:33–52. doi: 10.2190/9JPJ-1FM1-37NX-2DEC
48. Bennett KM, Reyes-Rodriguez MF, Altamar P, Soulsby LK. Resilience amongst older Colombians living in poverty: an ecological approach. *J Cross-cultural Gerontol*. (2016) 31:385–407. doi: 10.1007/s10823-016-9303-3

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Strategy for Deployment of Integrated Healthy Aging Regions Based Upon an Evidence-Based Regional Ecosystem—The Styria Model

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In 2013, the European Commission founded the platform European Innovation Partnership on Active and Healthy Aging as a communication and innovation network in this domain. The goal of the current study was the development of an integrated regional ecosystem for active and healthy aging for the region of Styria via a step-by-step co-creation process. A mixed model approach was used to establish an ecosystem for active and healthy aging, which includes macro-, meso- and micro-level stakeholders in the province of Styria, Austria. Based on the results, eight recommendations for the deployment of a healthy aging region were developed. The visibility and accessibility of healthy aging products and services were evaluated as key factors for innovation in active and healthy aging in the region. Health professionals were identified as major drivers of innovation related to active and healthy aging in Styria. The study presented in this article assessed the capacities for healthy aging in the Styria region and identified the need to improve communication pathways between all levels of the public health system and market.

Keywords: active and healthy aging, reference site, ecosystem, deployment, health services and products

INTRODUCTION

Longevity is one of the main achievements of modern societies. Currently, almost one quarter of the European population is 60 years and older (1). The European Union has launched numerous initiatives to adapt to changes in the social, medical and economic needs driven by this demographic shift. A special emphasis has been placed on prolonging "active and healthy life-years" across Europe (2).

In this context, in 2013 (3) the European Union (EU) launched the European Innovation Partnership on Active and Healthy Aging (EIP/AHA) with a major goal of encouraging a broad partner and stakeholder engagement. Several calls for individual partner and regional commitments have been launched. To date, the EU has awarded 77 European regions the status of "reference sites for active and healthy aging" (4), which are coordinated and deployed under the umbrella of the Reference Site Collaborative Network (RSCN) (5). Reference Sites (RS) are "ecosystems which comprise various players (including regional and/or local government authorities, cities, hospitals/care organizations, industry, SMEs and/or start-ups, research and innovation organizations including universities and civil society), that jointly implement a comprehensive, innovation-based approach to active and healthy aging, and can give evidence and concrete illustrations of the impact of such approaches on the ground" (5, 6).

However, to date no recommendations for healthy aging regions (HARs) have been issued that describe the structured and evidence-based development and process of establishing and sustaining regional ecosystems based upon the model provided by the RSCN. A pilot study presented in this publication addresses this issue and describes the co-creation process of an ecosystem for active and healthy aging, including an indicator system for further monitoring of the awarded reference site Styria in southeastern Austria, Europe. The region concerned has about 1.24 million inhabitants with 20.1% of the population aged over 65 years. The population density varies from 24 inhabitants/km² in the rural northern area to 260 inhabitants/km² in the urban central area. Gross value added is structured in 1.9% of agriculture and forestry (primary sector), 33.2% industry, energy and construction (secondary sector), and 64.9% services (tertiary sector). The Styrian research and development rate amounts to 5.14%, which is the highest quota of Austria (7). The project presented in this publication was funded by the Styrian government following the award of the region as HAR by the European Commission in 2013.

METHODS

To achieve a comprehensive state of the art in active and healthy aging ecosystems, the authors of this publication selected a mixed model approach. The goal of this integrative procedure was to ensure a rigorous scientific research in the field of the development of an active and healthy aging ecosystem and to detect capacities, strengths and communication processes within micro-, meso- and macro-level of the ecosystem. First, evidence on ecosystem building was gathered from the international scientific literature, which was subsequently used to kick-off a regional co-creation process to establish an integrated ecosystem for active and healthy aging in the province of Styria. The entire process is explained in detail in the following Method Section and outlined in **Figure 1**.

As **Figure 1** indicates, the process included three integrative steps: a comprehensive international literature review and a review of regional databases (applying identical key words); a qualitative research, including data collection via workshops and interviews; and a consensus-building process for the regional ecosystem, including recommendations for future capacity building.

Comprehensive Literature Review of Pre-existing Data on Development of Ecosystems for Active and Healthy Aging Regions

A comprehensive literature review of the databases Medline (via Pubmed), Cochrane Database of Systematic Reviews and ScienceDirect was conducted using the search terms "healthy aging," "aging-related diseases," "frailty," "frailty prevention," and "reference site" (**Figure 1**). Furthermore, a hands-on search of grey literature was performed using the same search terms. Only articles published in English and German languages were considered for further evaluation, regardless of the year of publication. In addition, publications addressing sustainable outcome parameters and key indicators for monitoring a healthy aging reference site were included in the analysis.

All relevant information from the literature search was analyzed using the STROBE-Statement (STrengthening the Reporting of OBservational studies in Epidemiology) (8) and assessed for relevance according to the search terms described. This initial methodological step was conducted within a timeframe of 2 months.

Comprehensive Online-Review of Active and Healthy Aging Activities on Regional Level Addressing the Region of Styria, Austria

National and regional databases of ministries, chambers and cluster organizations were screened to identify stakeholders, companies, and organizations using the search terms in English and German language in accordance to those used in the international literature review. A pre-feasibility study aimed at clarifying the structural complexity of the regional ecosystem and subsequently explaining possible relations and communication pathways for a regional stakeholder analysis. It was performed using an online tool to create a power/interest matrix (9). Individual and organizational strengths and activities addressing active and healthy aging were analyzed by rating the organizations in terms of their influence and importance within the region on a scale from 1 to 10 and their commitment to active and healthy aging on a scale from −5 to 5 (10). Answers from five regional stakeholders participating in this pre-feasibility work were weighted and transferred into one file to provide a first overview of stakeholders within the region.

Based upon the results of pre-feasibility study, an interview questionnaire was developed for face to face interviews with local experts in the field of active and healthy aging. In this interview template the following discriminators were applied according to the various levels of integrative neighborhood (11) and regional stakeholders: (1) readiness of political stakeholders and organizational structures at meso- and macro-levels to deliver services and products supporting active and healthy aging of Styrian citizens; (2) potential for innovation within the entire innovation cycle (12); (3) scalability at the international level; (4) evidence for triple win; and (5) proof of concept for deployment

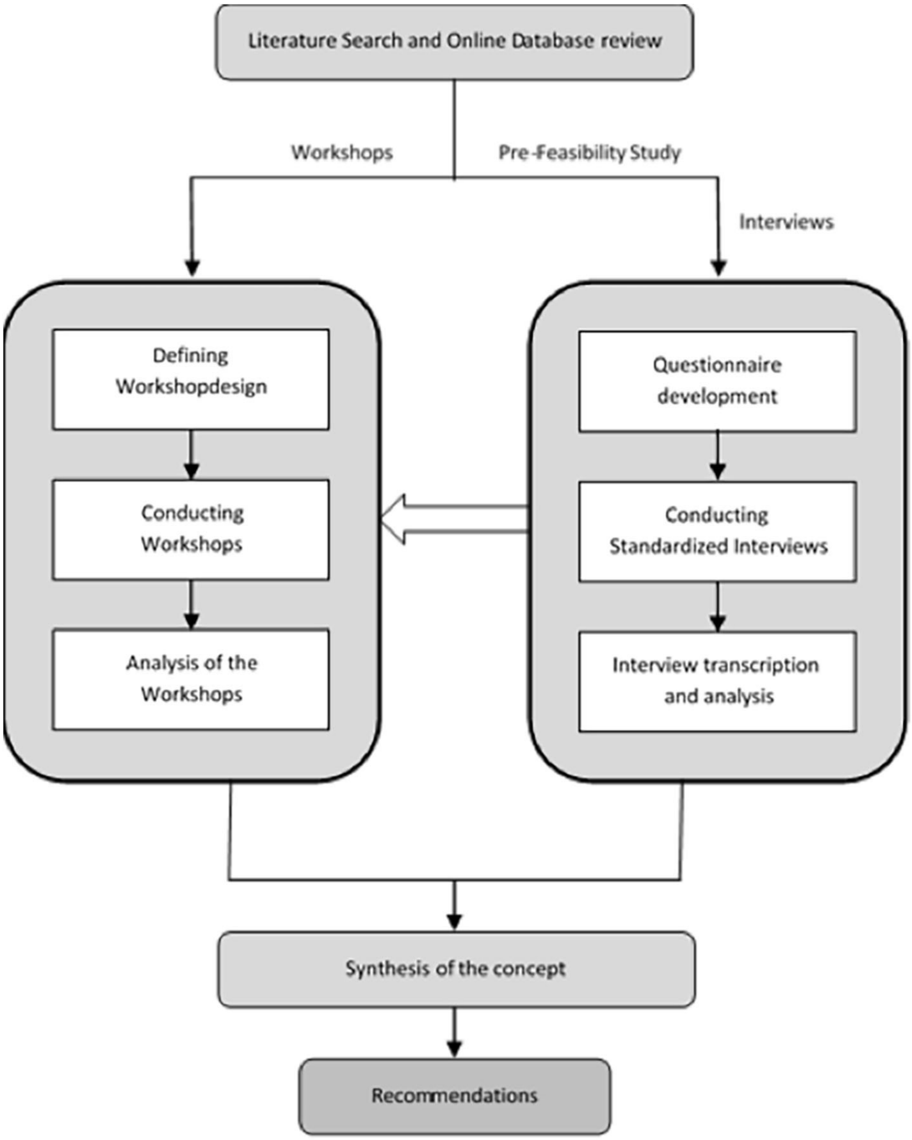

FIGURE 1 | The method to develop an integrated ecosystem for active and healthy aging in the reference site Styria.

and innovation. Altogether, this step required time resources of 2 months.

Selection of Experts

National and regional databases of ministries, chambers and cluster organizations were screened to identify relevant stakeholders within the content analysis described before. A list of regional stakeholders as potential interview partners and workshop participants was produced. Out of this list, the invited experts were selected using a random generator.

Expert Interviews

The semi-structured interviews were conducted, transcribed and analyzed according to a standardized protocol. Information from the transcripts of the interviews was categorized and summarized in inductive steps. The experts received the questionnaire prior to the interview. All interview partners were informed about anonymity and data privacy and gave their consent to the interviews. Each interview was divided into four sections based on the results of the stakeholder analysis and the level of an integrative region (micro-, meso- or macro-level). Potential contributions, barriers and the role of industrial partners were discussed. One of the key aspects in this section was how the various levels of stakeholders should communicate and how the recipients of healthy aging services and products should be informed. Further, the participants were asked how and where they would start with regard to the implementation of healthy aging actions. Interviews were conducted by one investigator (MB) within a timeframe of 3 months.

Expert Workshops

Five interdisciplinary standardized workshops with representatives of regional stakeholders were conducted over 3 months. Groups were formed in a way that ensured heterogeneous distribution of stakeholders within the working groups. All workshops focused on the strengths and capacities that had been discussed during the regional reviews (see Comprehensive literature review of pre-existing data on development of ecosystems for active and healthy aging regions and Comprehensive online-review of active and healthy aging activities on regional level addressing the region of Styria, Austria and **Figure 1**) using the method of participatory learning and a standardized approach (13). The goal was to obtain consensual results during the integrative group discussions, which were set up as interdisciplinary thinking corners and thematically aligned with the focus areas identified in the pre-feasibility study. Results for the working groups were summarized and transcribed according to the method of Philip Mayring (14).

Data Analysis

All stakeholder interviews (as described in Expert interviews) were transcribed according to a standardized protocol and adjusted using dialect and filler words since the data were translated from German to English. Translation and summarization were accomplished by two researchers independently via a qualitative analysis approach proposed by Mayring (14). The categories of transcripts were analyzed, abstracted and summarized accordingly. To increase the intra-coder agreement, the inductive analysis was repeated by the same investigator at the end of the qualitative work, increasing the validity of the summaries.

The results were transferred to the workshops and the focus was narrowed using the discriminators that were applied in the first online phase of the consultation as part of the stakeholder analysis (see Comprehensive online-review of active and healthy aging activities on regional level addressing the region of Styria, Austria), i.e., readiness of political stakeholders and organizational structures on meso- and macro-levels to deliver services and products supporting active and healthy aging of Styrian citizens, potential for innovation, including the entire innovation cycle, scalability at the international level. Feedback from the participants was subsequently grouped and another inductive analysis was performed following the workshops to increase the validity of the summaries.

Based upon the methodology applied during the expert interviews and workshops, precise recommendations on how to strategically deploy the reference site in future political actions were developed. For this purpose, the main results of the literature research, expert interviews and focus group discussions were outlined and concrete recommendations were developed (**Table 1**). The emphasis was put on how well the framework for action for the reference site Styria matched the criteria launched by the reference site collaborative network (RSCN) (5, 6). This final conclusive methodological step was conducted over 4 months.

RESULTS

Results of the Literature Review

Overall, 11 articles were identified based on the search terms used. After screening and analyzing the reports using the STROBE-statement, data from 6 relevant publications were extracted for further use in the analysis process during the literature review (8). The remaining publications ($n = 5$) were excluded from this analysis due to missing description of the methodology used in the report. Sustainable outcome parameters and key indicators detected for the search terms used (also see Comprehensive literature review of pre-existing data on development of ecosystems for active and healthy aging regions) were as follows: (1) quality of life (11, 15); (2) self-reported health (15, 16); and (3) frailty in the older population (17); (4) the need for enforced communication (17) between all stakeholder groups; and (5) the importance of considering a very specific and individual situation regarding health, social and economic aspects (18, 19).

Results of Regional Online Analysis of Active and Healthy Aging Stakeholders

The initial data base search (online-review) revealed 63 institutes, companies and organizations which could be attributed to the topic of active and healthy aging and were subsequently structured and clustered at the various public health levels in the ecosystem (macro- and meso-levels). As shown in **Figure 2**, all stakeholders were categorized by the core team based on their role in the entire ecosystem and their proximity to the recipients of services and technologies. **Figure 3** shows the direct communication pathway between health professionals and allied health professionals and their clients. In contrast, research organizations, such as universities and research companies that develop supportive assistance and technologies, have a more distant relation to end-users and citizens. To complete the list of relevant stakeholders, databases, and business directories of regional organizations for healthy aging services and products were analyzed, yielding additional 198 hits. The organizations identified include health and social services ($n = 18$), self-aid groups ($n = 20$), tourism and leisure providers ($n = 3$), local suppliers and mobility ($n = 7$), education and further qualification ($n = 9$), food supplement and pharma ($n = 9$), suppliers and services in the field of human technology ($n = 65$), education and research and development ($n = 22$), healthcare ($n = 63$), providers of related technologies ($n = 26$), representation of interests ($n = 19$).

Results of Pre-feasibility Study of Stakeholders in the Future Ecosystem on Active and Healthy Aging

Research organizations, governmental organizations, associations and clusters are strongly committed to healthy aging and the Styrian EIP/AHA reference site. Data privacy organizations have a high influence in this field with respect to assisting technologies (7, 5/10). At the same time, data

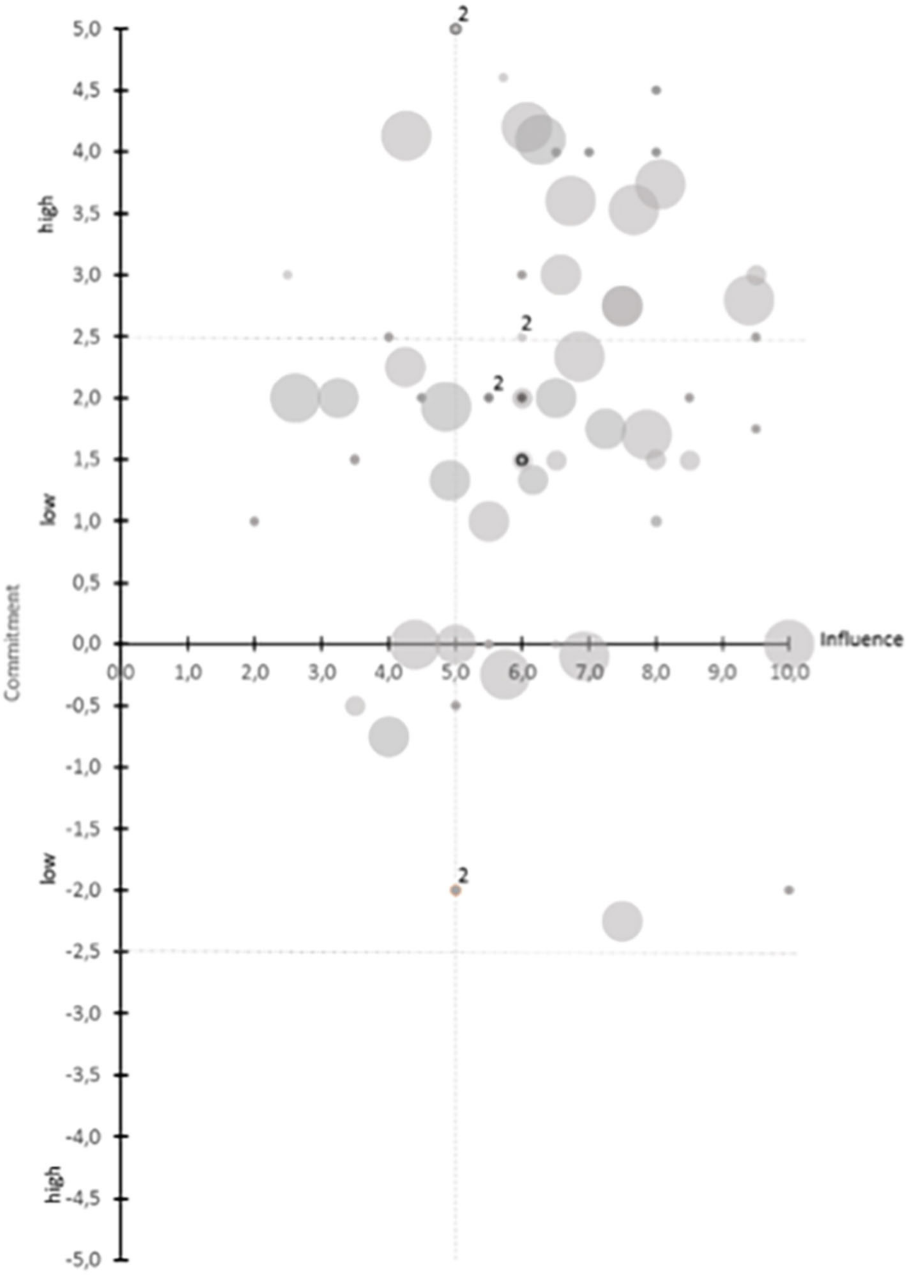

FIGURE 2 | Results from the power/interest matrix (9) analysis condensed from feedbacks from 5 experts from the study core group of the current project. As may be seen from the figure, the method allowed analysis of individual commitments of different regional stakeholders and their effective influence on the development of an active and healthy aging region (HAR). This approach also allows to construct a taxonomy of regional stakeholders as primary "framework" of an ecosystem toward a HAR, not considering communication pathways at this point of the process management.

privacy aspects are considered a challenge to the development and implementation. In 14 ratings, all five experts provide their rating. In 35 of 63 ratings, one of the experts provided a rating for the organizations with activities in the field of healthy aging. Overall, within the Styrian EIP/AHA Reference Site the commitment to healthy aging activities is high (**Figure 2**).

Results of Expert Interviews

Based upon results of the pre-feasibility study, 30 questions were included in the questionnaire for the expert interviews (data not shown).

Overall, 10 (5 male and 5 female) interview partners were invited and agreed to participate. One of the key messages conveyed during the interviews by the experts was a common

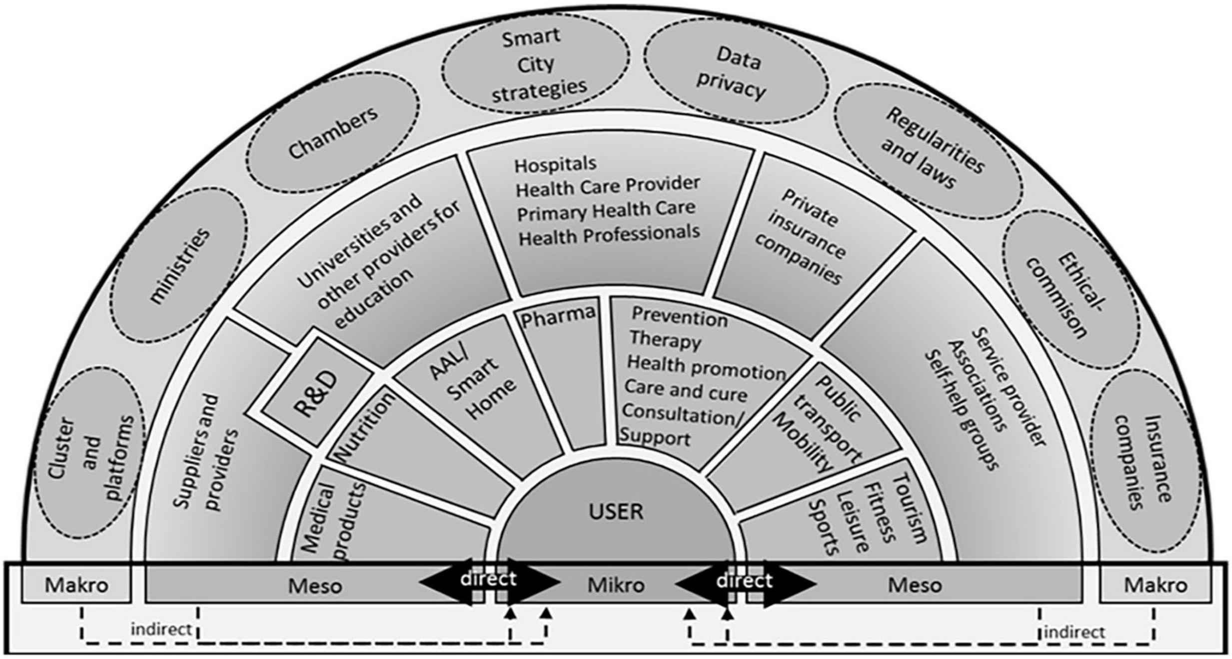

FIGURE 3 | Humans, institutions and legal bodies and their position in the active and healthy aging ecosystem Styria according to results from the study presented in the current publication. In a mixed-model approach it was possible to condense information on regional structure and processes with evidence gathered during a literature search and feedback collected in face to face interviews and workshops with regional experts and stakeholders.

understanding of healthy aging in Styria as one of the main strengths of the region. Furthermore, a high number of organizations active in this field represents a decisive regional strength. In addition, the experts described a requirement for improving visibility, transparency and communication related to the active and healthy aging reference site. There is a need to connect the stakeholders and to create collaborative initiatives in the region following a common strategy for active and healthy aging, focusing on structuring communication between the stakeholders (see **Table 1** that summarizes all information from the three information sources). The key results shown in **Table 1** represent prioritized spheres of activity, which were considered in at least two out of the three information sources (**Table 1**).

To support interaction leading to an integrated active and healthy aging ecosystem, the recipients of the services and technologies as well as the GPs, health professionals and formal and informal caregivers must be informed about the decisions and projects that directly concern them. Furthermore, including healthy aging aspects into the domains of housing, leisure time, mobility, and public transport was described to have high importance. Experts from research organizations would like to have evidence of the effectiveness and efficiency of assistive technologies for older people.

Results of Workshops

Thirty three experts (16 male/17 female) agreed to participate in the workshops. Their professional background was as follows: health and social care professional, nursing professional, social services professional, a sociologist, medical doctors, managers, technicians, scientists, engineers, nurses, physiotherapists, an occupational therapist, a research manager, a health manager, public health experts, representatives of insurance companies, members of the Styrian chamber of commerce, the Styrian government, a business development professional, and a health economics expert.

The workshops narrowed the fields of strengths in the province of Styria. Following the workshops and based upon the clustering of capacities, the authors aligned the results along the ecosystem (**Figure 3**).

As shown in the **Figure 3**, in the ecosystem a direct connection and communication exist between the providing companies and organizations and the citizens concerned. Other organizations at the meso-level of the AHA regional ecosystem have an indirect connection with the target population. This structure indicated a "follower's role" of these institutions and services in the deployment of services and products for citizens. The same indirect link is observed for organizations at the macro-level, implying a lack of information transfer with regard to population needs and demands. For example, actions in the field of Research and Development (R&D), such as innovative solutions and products for AHA, were not visible to the recipients at the time of the project.

Based upon a structure provided by the RSCN, the experts in the focus groups clustered all activities detected in the ecosystem and identified major areas of strength: activities related to the prevention and early diagnosis

TABLE 1 | Recommendation for action toward an integrated ecosystem for AHA in Styria.

Recommendation	Mentioned in scientific literature	Mentioned in interviews with experts	Mentioned in workshops with experts
1. Further expanding of the visibility of the references site on micro-, meso-, and macrolevel	X	X	X
2. Proof of effectiveness of AAL-solutions and assistive technologies	-	X	X
3. Development of an integrated healthy aging strategy	-	X	X
4. Demand oriented development of innovative products and services for healthy aging	X	X	X
5. Intensify the coordination tasks in the reference site	-	X	X
6. Development of relevant regionally available training offers for health professionals	-	X	X
7. Implementation of proposed measures by the experts to achieve the identified goals of the reference site (key performance indicators—KPIs)	-	X	X
8. Integration of healthy aging actions in health tourism and leisure activities	-	X	X

Eight recommendations for action to foster a sustainable ecosystem for AHA in Styria. Only two of the recommendations have been discussed in scientific literature so far: visibility of the ecosystem for AHA in the region and support of product development for the market within the ecosystem. The remaining six recommendations elaborated reflect regional requirements.

of diseases, activities addressing environmental factors supporting active and healthy aging and, finally, care services and products.

Recommendations for an Integrated Ecosystem for Active and Healthy Aging in Styria (AHA Styria)

Figure 3 depicts the structure and stakeholders involved in the ecosystem for active and healthy aging Styria (AHA Styria).

As shown in **Figure 3**, the ecosystem around citizens defined as "end-users" groups the stakeholders in the region according to their impact and support for Styrian citizens with regard to a healthy lifestyle and social integration. The meso-level includes the provision of preventive offers, mobility, nutrition, pharma and leisure offers, which are well developed in the region of Styria. Such direct citizen's empowerment reflects the regional capacities and culture and demonstrates that the proposed method is suitable for aligning the integrated AHA ecosystem with the local strengths.

The methodology used also allowed to analyze the communication pathways and rank the obtained information, resulting in precise recommendations for future developments in Styria.

Benchmarking the regional recommendations based upon the results of the interviews and workshops suggests that only two of the eight recommendations are reflected in the scientific literature: the visibility of AHA ecosystem in the region and the support of product development for the market within the ecosystem. The remaining six recommendations concern regional requirements and are as follows: a proof of effectiveness of AAL solutions and assistive technologies, the development of an integrative and politically binding integrated healthy aging strategy, coordination in the region, training offers for professionals involved in AHA, the development of regionally applicable key performance indicators (KPI) to measure the success of AHA actions and the integration of the topic of AHA into leisure activities and health tourism. **Table 1** summarizes the action recommendations.

DISCUSSION AND STRENGTHS AND LIMITATIONS OF THE WORK

This work provides a methodology for developing integrated AHA ecosystems in the context of reference sites of EIP/AHA. To achieve this objective a mixed model approach (20) was used. By combining evidence from the international scientific literature with AHA regional capacities and stakeholder input, a structured co-creation process was established, which was led by academic institutions (21). It resulted in a set of recommendations (**Table 1**) on how to specifically address the needs of end-users or citizens with regard to AHA. The approach also allowed identifying regional strengths and capacities in the field of AHA. The inclusion of communication pathways made it possible to detect communication gaps and create a taxonomy within the regional AHA support systems and offers.

The first important finding of the work presented is the fact that evidence in literature on the topic of system development in the context of AHA reference sites is scarce. This is not surprising given the innovation factor of this construct launched for the first time by the EC in 2013. A lot of evidence is presented on micro-level for interventions and solutions supporting individual AHA. However, transfer of this knowledge and experience into daily practice of European citizens is still unstructured, often happens by fortune and systems are not systematically developed toward the aim of AHA. Despite the involvement of academia in AHA, the process of co-creation on system level is still not well established in the context of the EIP/AHA partnership. This fact makes the current project pioneering work which promotes integrated system development at the regional level.

The main objective of this work was to place stakeholders and citizens in the center and actively engage them in the process in order to generate ideas that reflect the status quo in our reference site (**Figure 1**). A web-based search of all regional stakeholders possibly involved in the system actions toward AHA offered an opportunity to learn more about them and to get to know them before inviting them to interviews and workshops. This approach to the development of markets (22) and community health services (23) has been proven effective in the literature. In their work on health promotion in systems, Naaldenberg et al. (24) describe health and well-being as the result of a series of complex processes during which an individual interacts with other people and the environment. The authors argue that health promotion and active and healthy aging are "not a straightforward technical process but a complicated and diffuse social process in which stakeholders have to work together and share information, ideas and decisions." Our major contribution presented in this paper is the development of combined methodologies that take into account social interaction at many levels, introducing power/interest analysis as well as workshops and structured interviews. Using this bottom-up approach, it was possible to gain comprehensive insights into the regional system supporting health and AHA.

Our work also offers a broad view on the topic of AHA and allows further understanding of developments needed within health, care and social systems regionally. Aging is not related to health or illnesses exclusively. The ability to live independently and autonomously, making individual decisions, and planning leisure time plays a key role with regard to HARs. A principal goal of health promotion is to instigate changes at the individual level as well as in the social and physical environments, driving the entire system forward rather than fixing one component. Culture, sports and social integration are also aspects of an HAR that need to be considered. Health and social care, health services, self-health management, and senior tourism require ready models. **Figure 3** shows the results of our project confirming this theory. Not only is the Styria region rich in natural resources for health and tourism, but local stakeholders feel the impact of these offers for a broad public access in the context of prevention and wellbeing to support healthy aging in the province of Styria. The proposed approach will help to stimulate the region's competitiveness in the international tourism sector and promote the development of sustainable, responsible and high-quality tourism. Ultimately, in line with the European Commission's perspectives and goals (25) it will consolidate the image and profile of Europe as home to sustainable and high-quality destinations.

Access to health services, care, cure and supporting technologies contributes efficiency and effectiveness to the process of healthy aging. The results of the interviews show that manufacturing companies could benefit in particular from the R&D strengths of universities, colleges, and research institutes in Styria. Interdisciplinary projects, diverse expertise in the field of developing technology and the healthcare professionals' knowledge of the target group can strongly complement each other. This result may also be viewed as system innovation, at least for the Styria region.

Based on the results of our work, a new structure of HAR can be established in the integrated neighborhood (11). New investigations of the EIP/AHA Reference Site illustrate that there is a need for a change in the communication between the meso- and micro-levels, which would promote knowledge transfer at all levels. New platforms and communication channels must be created in response to the demands of the people. Situated at the meso-level, developers of healthy aging services are not in contact with consumers of their products, e.g., AAL and Smart Home Solutions. Health Professionals, such as GPs, occupational therapists, physiotherapists, dieticians, care professionals and others, have a close connection with their clients. Detailed information about life circumstances, social relationships and socioeconomic status is required to provide recommendations to the clients. However, a close relationship and connection between health professionals and R&D organizations would allow incorporating the expertise and knowledge of the former into the development of new healthy aging services and products.

This implies the need for new communication pathways across the region to ensure citizen involvement in the topic of AHA. This is vital for high visibility of the topic of AHA in a region and ensures accessibility for many individuals. Structured exchange of information about innovation, information, projects and products (**Figure 1**) must become a key element for political action in the light of AHA. The major finding of our work was the lack of communication from top down and only little knowledge was available on individual needs of citizens for AHA in daily living. Making use of evidence-based methodologies like described in this paper will allow a citizen oriented and evidence driven political decision making for AHA.

Major strength of the work presented is the stringent co-creation process described. To the best of the authors' knowledge, this is the first description of the evidence-based development of an ecosystem for AHA in a region in Europe and it therefore reflects pioneer work. Readers get an overview on factors affecting AHA on all public health levels. Furthermore, authors were able to pinpoint the impact of communication pathways to facilitate accessibility of AHA offers within a region. The ecosystem presented in **Figure 3** may further be used by readers to test their own regional capacities and start evolutionary processes.

Major limitation of the work presented is its regional perspective and its duration of more than 14 months of work. Despite the fact that authors aligned the work with recommendations released by RSCN, results presented here still reflect a very regional picture. This may limit the impact of results, however, the method presented may serve as best practice model for readers to implement AHA offers, products and processes in their environment as the methods used represent a comprehensive toolbox of methodologies present to get information locally and globally and may be useful at different opportunities.

DATA AVAILABILITY STATEMENT

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

The Ethics Committee of the Medical University of Graz (Address: Auenbruggerplatz 2, 3. OG, 8036 Graz) waived the requirement for ethical approval for this study due to the method chosen without using or revealing any personal or patient data, in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

MB, KH-F, RR, KP, RW, GS, E-MA-K, RM, KPP, JH, KW, SL, CH, BR, and RR-W contributed to project conception and conduct. MB wrote the first draft of the manuscript. RR-W, SL, and MB wrote sections and finalized the manuscript. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fmed.2020.510475/full#supplementary-material

REFERENCES

1. Eurostat (European Commission). *People in the EU: Who Are We and How Do We Live?* Luxembourg: European Union (2015).
2. EuroHealthNet. *Healthy Aging.* (2019). Available online at: http://www.healthyaging.eu/steps-healthy-aging
3. European Innovation Partnership on Active and Healthy Aging. *Strategic Implementation Plan for the European Innovation Partnership on Active and Healthy Aging*. Steering Group working document. Brussels: European Innovation Partnership on Active and Healthy Aging (2011).
4. European Innovation Partnership on Active and Healthy Aging. *77 Regional and Local Organisations Are Awarded Reference Site Status - Results from the 2019 Call for Reference Sites.* (2019). Available online at: https://ec.europa.eu/eip/aging/news/77-regional-and-local-organisations-are-awarded-reference-site-status-results-2019-call_en
5. Bousquet J, Illario M, Farrell J, Batey N, Carriazo AM, Malva J, et al. The reference site collaborative network of the european innovation partnership on active and healthy aging. *Transl Med UniSa.* (2019) 19:66–81.
6. European Innovation Partnership on Active and Healthy Aging. *Call Text of the Call for Reference Sites of the European Innovation Partnership on Active and Healthy Aging.* (2015). Available online at: https://ec.europa.eu/eip/aging/library/call-text-call-reference-sites-european-innovation-partnership-active-and-healthy-aging
7. Regional Government of Styria. *Die Steiermark in Zahlen.* (2018). Available online at: https://www.landesentwicklung.steiermark.at/cms/dokumente/12650227_141979497/f8516e0d/STEIERMARK_in_Zahlen_2018_dt.pdf
8. von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol.* (2008) 61:344–9. doi: 10.1016/j.jclinepi.2007.11.008
9. Johnson G, Scholes K, Whittington R. *Exploring Corporate Strategy. Text & Cases*. 8th ed. Harlow: Prentice Hall (2009).
10. van Someren MW, Barnard YF, Sandberg JAC. *The Think Aloud Method. A Practical Guide to Modelling Cognitive Processes*. London: Academic Press. (1994).
11. Eurostat (European Commission). *Quality of Life. Facts and Views*. Luxembourg: European Union (2015).
12. Neumann A. *Integrative Managementsysteme. 3rd ed*. Berlin Heidelberg: Springer (2017). doi: 10.1007/978-3-662-47919-3_2
13. Domínguez R. Participatory Learning. In: Seel N, editor. *Encyclopedia of the Sciences of Learning*. Boston: Springer. (2012). p. 145. doi: 10.1007/978-1-4419-1428-6_1903
14. Mayring P. *Qualitative Inhaltsanalyse. Grundlagen und Techniken. 11th ed*. Weinheim: Beltz (2010). doi: 10.1007/978-3-531-92052-8_42
15. Statistik Austria. *Österreichische Gesundheitsbefragung 2014 Hauptergebnisse des Austrian Health Interview Survey (ATHIS) und Methodische Dokumentation*. Vienna: Statistik Austria (2015).
16. OECD. Addressing Dementia. *The OECD Response*. Paris: OECD Health Policy Studies, OECD Publishing, (2015).
17. Austrian Interdisciplinary Platform on Aging. *Österreichische Interdisziplinäre Hochaltrigenstudie. Zusammenwirken von Gesundheit, Lebensgestaltung & Betreuung. 1. Erhebung 2013/2014 Wien und Steiermark*. Vienna: Austrian Interdisciplinary Platform on Aging (2015).
18. Schober T, Winter-Ebmer R. *Ältere Arbeitnehmer, gesundheitliche Einschränkungen und Übergänge in den Ruhestand. Endbericht*. Linz: Institut für Volkswirtschaftslehre, Johannes Kepler Universität (2011).
19. Eurostat (European Commission). *Active Aging and Solidarity Between Generations. A Statistical Portrait of the European Union.* (2012). Luxembourg: European Union (2012).
20. Cameron R. A sequential mixed model research design: design, analytical and display issues. *Int J Multiple Res App.* (2009) 3:140–52. doi: 10.5172/mra.3.2.140
21. Ramírez-Montoya MS, García-Peñalvo F-J. Co-creation and open innovation: Systematic literature review. [Co-creación e innovación abierta: Revisión sistemática de literatura]. *Comunicar.* (2018) 54:09–18. doi: 10.3916/C54-2018-01
22. O'Hern MS, Rindfleisch A. Customer co-creation. In: Rindfleisch A, Naresh KM, editors. *Review of Marketing Research*. Emerald Group Publishing Limited (2010). p. 84–106. doi: 10.1108/S1548-6435 (2009) 0000006008
23. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving research impact through co-creation in community-based health services: literature review and case study. *Milbank Q.* (2016) 94:392–429. doi: 10.1111/1468-0009.12197

24. Naaldenberg J, Vaandrager L, Koelen M, Wagemakers A-M, Saan H, de Hoog K. Elaborating on systems thinking in health promotion practice. *Global Health Promotion*. (2009) 16:39–47. doi: 10.1177/1757975908100749
25. Gheno I. Healthy aging in the european union - tourism in the focus. *Pannon Manag Rev*. (2016) 5:19–27. Available online at: https://pmr.uni-pannon.hu/articles/5_3-4_gheno.pdf

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Multimorbidity in General Practice: Unmet Care Needs From a Patient Perspective

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Introduction: In the Netherlands, as in many other countries, current clinical guidelines are directed at single diseases. Patients with multiple chronic conditions may benefit from a more patient-tailored approach. Therefore, our objective is to explore the general practice care needs of patients with multimorbidity from a patient perspective. We also assessed their care experiences and the impact of chronic conditions on their daily functioning.

Methods: We conducted a qualitative study, using semi-structured interviews complemented with self-report questionnaire assessments for triangulation, with consenting community-dwelling patients with three or more chronic conditions. Participants were identified through purposeful sampling in three general practices. Two researchers independently coded and thematically analyzed the audiotaped and anonymously transcribed interviews using the constant comparative method. The self-report questionnaire assessments were used to describe the patient characteristics and for triangulation of the data retrieved from the semi-structured interviews.

Results: After 12 interviews, saturation was achieved. Overall, most participants were positive about their relationship with the general practitioner (GP) and practice nurse (PN) as well as the care they received in general practice. However, several unmet care need themes were observed: firstly, lack of a holistic approach (by the GP and PN), in particular, insufficient attention to the patient's state of functioning, their limitations in daily life, and their well-being; secondly, they mentioned that personal continuity of care was important to them and sometimes lacking; thirdly, lack of patient-tailored explanations about diseases and treatments.

Conclusion: From a community-dwelling multimorbid patient perspective, general practice care could benefit from improving personal continuity of care, attention to personal circumstances and daily functioning, and patient-tailored communication.

Keywords: chronic care, multimorbidity, continuity of care, care needs, person-centered care

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INTRODUCTION

The number of patients with multiple chronic conditions, i.e., multimorbidity, increases due to aging of the population and improvements in medical care (1). Patients with chronic conditions experience problems in multiple health areas and when using different health services. Besides physical issues, there are often psychological, social, and cognitive problems (2). Furthermore, multimorbid patients have a poorer quality of life and higher health care utilization than patients with one chronic disease (3).

In Dutch primary care, structured disease management programs are used for three highly prevalent chronic diseases: cardiovascular diseases, diabetes mellitus, and chronic obstructive pulmonary disease (COPD). The goals of these protocolized programs are to provide selective prevention and manage the chronic conditions (4). Within these programs, the general practitioner (GP), practice nurse (PN), and other primary healthcare providers closely collaborate. In the Netherlands, nearly all non-institutionalized citizens are enlisted at one particular general practice. The majority of the routine checkups are performed by the PN. These programs are *disease-oriented*, which in case of multimorbid patients may lead to inefficient and ineffective treatments and can possibly be even harmful in terms of complex medication interactions and more hospital admissions (5). Especially in multimorbid patients, it may be more helpful to adopt a more *person-oriented* approach, which takes account of the individual care needs, preferences, and the social context. A better understanding of the care needs of community-dwelling persons with multimorbidity from a patient perspective is essential to improve person-centered general practice care for this group.

In recent literature, different unmet care needs were mentioned, such as time pressure and lack of personal continuity of care. The qualitative study of Schiotz et al. (6) found three important concerns regarding chronic primary care for patients with multimorbidity: firstly, disease-centered rather than patient-centered care; secondly, lack of attention to comorbidities and patient preferences and needs; and lastly, involvement of numerous healthcare providers with limited care coordination.

Therefore, the objective of this study was to explore the care needs, and for this reason, we also assessed care experiences and the impact of chronic conditions on daily functioning from a patient perspective, in particular, the community-dwelling multimorbid patient.

METHODS

Study Design

This qualitative study with multimorbid patients is based on semi-structured interviews complemented with a comprehensive self-assessment, which was used for triangulation. The participants were identified through purposeful sampling in three general practices in the area surrounding Amsterdam, the Netherlands. GPs were sampled based on running their practice in diverse areas and populations (metropolitan area/rural area).

This study focused on community-dwelling patients with three or more chronic conditions from a list of selected chronic diagnoses (**Table 1**). We used this criterion because we expected these patients to have a higher disease burden and thus more care needs than patients with two chronic diseases. Moreover, this criterion was applied in earlier studies in a comparable setting on this topic (7–9). All inclusion and exclusion criteria are listed in **Box 1**. The participating GPs were instructed to select and invite patients with multimorbidity from their practice to participate in the study. The GPs performed a manual search in their electronic patient records system to identify eligible patients. In order to obtain a diverse sample, the GPs were instructed to select patients from two groups: (1) patients regarded to have self-care difficulties and (2) patients considered to be independent. Self-care difficulties were defined as problems in activities of daily living (ADL) or instrumental activities of daily living (IADL). When patients were willing to participate, the GP asked permission to give the patients' contact details to the researchers. Participants gave permission by written informed consent and were free to end participation at any time. Participants completed the comprehensive self-assessment, which was sent by post one week prior to the interview, and subsequently the interview.

Data Collection

The interviews were audiotaped, lasted approximately 1 h, and were conducted at the patient's home. They were semi-structured, guided by a topic list that addressed three themes: (1) the impact of chronic conditions on their lives, (2) care needs, and (3) care experiences. During data collection, debriefing of the initial interviews informed and shaped the following interviews, in particular with respect to (unmet) care needs. Moreover, comprehensive self-report questionnaire assessments were collected prior to the interviews and were used for triangulation during the analyses (10). Items were used from the Patient Assessment of Chronic Illness Care (PACIC) measure (11), a measure that captures experiences with chronic care; (2) European Health Literacy Short Survey Questionnaire (HLS-EU-Q16) (12); and (3) interRAI Check-Up Self-Report (CU-SR) assessment on functional health (13).

Analysis

Interviews were transcribed verbatim; two researchers (LR, BS) coded and analyzed the anonymized interview transcripts independently. The researchers (LR, BS, MB) conducted a thematic analysis of the interviews using the constant comparative method (14). A coding framework was developed from the initial interviews. Through an iterative process involving comparisons across the manuscripts, these codes were organized. For these codes, themes were developed. Coding and categorizing of the interviews were discussed with the other researchers continuously in the process of the analysis. ATLAS.ti software was used. The self-report questionnaire assessments were used to describe the patient characteristics and for triangulation of the data retrieved from the semi-structured interviews (14, 15).

A comprehensive patient self-assessment was used to corroborate the interview findings. The questionnaire was

TABLE 1 | List of included chronic diseases.

Clusters	Diseases
HIV/Aids	HIV/Aids
Cancer	All malignant cancer types
Bowel disorders	Diverticular disease
	Crohn disease
	Ulcerative colitis
Cardiovascular	Congenital heart disease
	Infectious disease of heart and/or blood vessels
	Acute rheumatoid heart disease
	Non-rheumatic Valvular Heart disease
	Heart failure
	Angina Pectoris
	Acute myocardial infarction
	Atrial fibrillation/flutter
	Hypertension
	Transient ischemic attack (TIA)
	Cerebrovascular accident (CVA)
	Intermittent claudication
	Aneurysm aortae
	Hypercholesterolemia
Musculoskeletal	Fibromyalgia
	Rheumatoid arthritis
	Cox arthrosis
	Gon arthrosis
	Other arthrosis
	Cervical spine syndromes
	Osteoarthritis spondylosis of the spine
	Low back pain with radiation
	Osteoporosis
Neurologic	Multiple sclerosis (MS)
	Parkinson's disease
	Epilepsy
	Migraine
	Cluster headache
	Trigeminal neuralgia
	Other neuropathies
Alcohol abuse	Chronic alcohol abuse
Psychiatric	Sleeping disorder
	Schizophrenia
	Affective psychosis
	Depression
	Anxiety disorder
	Personality disorder
Respiratory	Chronic obstructive pulmonary disease (COPD)
	Asthma
	Chronic bronchitis
Thyroid	Persistent thyroglossal duct/cyst
	Benign neoplasms of thyroid gland
	Hyperthyroidism
	Hypothyroidism
Diabetes Mellitus	Diabetes mellitus type I
	Diabetes mellitus type II
Urinary	Kidney disease
Psoriasis	Psoriasis with methotrexate use
Obesity	Adiposity
Smoking	Tobacco abuse
Eye disease	Macular degeneration

The following chronic diseases are also included if patients ever had contact with the GP with this diagnosis.
HIV/aids.
M. Crohn, Ulcerative Colitis.
Alcohol abuse.
Schizophrenia.

piloted, tested, and adapted. Prior to the interview, all participants completed the self-assessment. Based on the interview findings, items from the self-assessment were selected by the researchers (MB, LR) for triangulation. The selection of items from the assessment was discussed with and approved by the other researchers. In particular, we used methodological triangulation, which involves using more than one kind of method to study a phenomenon, providing confirmation of findings, more comprehensive data, increased validity, and enhanced understanding of studied themes (15–17). Descriptive analysis of these items was undertaken using SPSS (Version 26).

RESULTS

Sample

We invited six GPs running a practice in diverse areas and populations: some were located in a relatively deprived metropolitan area and some in a more rural area. Both areas were covered by the three participating GPs. The reason for refusal of the other three was lack of time. The GPs initially selected 14 eligible patients, and 12 of them were willing to participate. Reasons for refusal were lack of time and an unplanned hospitalization. Saturation was reached after 12 interviews, and therefore, no more patients were recruited. All 12 participants filled in the comprehensive self-assessment.

Two participants lived in a relatively deprived metropolitan area, and the other 10 participants lived in a more rural area. Participants were predominantly female (58%), between 47 and 87 years old with an average age of 72.8 years. All but one participant (92%) had cardiovascular disease (e.g., hypertension, hypercholesterolemia) or diabetes mellitus type 2. Other common chronic diseases included musculoskeletal disorders, cancer (no palliative care), and pulmonary disease. An overview of the participant characteristics can be found in **Table 2**.

Comprehensive Self-Assessment

The selected items from the self-assessment are presented in **Table 2** as well.

BOX 1 | In and exclusion criteria.

Inclusion criteria
- Aged 18 or older
- $\geq$3 diagnoses from the list "Chronic diseases" (**Table 1**)*
- Informed consent

Exclusion criteria
- Terminally ill
- Mentally handicapped (ICPC-code P85)
- Diagnosed with dementia (ICPC-code P70)
- Severe hearing or visual impairment (ICPC-codes: H86, F94)
- Insufficient command of the Dutch language
- Patients that are already included in another study

*This list "chronic diseases" is developed via multiple brainstorm sessions with the group of GPs who participated in the COPILOT study (7) and includes chronic conditions which are considered as "in need of chronic primary care." Conditions are coded using the International Classification of Primary Care (ICPC); Supplementary Material. Consensus was reached after comparing the developed list with existing lists of chronic conditions (8).

Interviews

The themes that were elicited from the interviews in terms of care needs, care experiences, and the impact of chronic conditions on patients' functionality are reported below, illustrated by particular quotes. The results of the selected items from the comprehensive self-assessment are presented at the end of this paragraph and in **Table 2**.

Holistic Approach

Participants found that the checkups for their cardiovascular diseases, diabetes, and/or COPD received from the PN contributed to their health. Some participants perceived they missed an approach that focuses on the patient "as a whole." For example, participants expressed the need for their GP and PN to pay more attention to their state of functioning, their limitations in daily life, and their well-being. Some participants stated that GPs and PNs seem to focus too much on the use of clinical guidelines that address prevention and management of diseases and that there is too little focus on the functioning and well-being.

> *"I found it important that healthcare providers look at patients as a whole. I am having trouble with that protocol thing. People like it when a healthcare provider pays attention to them, in addition to following protocols."*
>
> *"When I needed painkillers, I had words with my general practitioner about that. I had morphine, but she didn't want to prescribe anymore of them due to the risk of addiction. Pain medication is important for my functioning. She only thought of the addiction." (P1).*

Personal Continuity of Care

Participants stated that it is important that a primary healthcare professional knows them. They found it annoying to repeat their situation to a care provider who did not know them.

> *"I think my general practitioner knows what I am like. I have been his patient for a long time now. He knows me well and that helps in advising me. It would be frustrating if my general practitioner did not know me so well and I had to explain my situation to him all over again." (P10)*

Participants reported that personal attention is one of the most important aspects of a good therapeutic relationship between primary healthcare providers and patients. According to them, health care providers should treat their patients as equals and take their patients seriously.

> *"In my opinion, personal attention is the most important. No one likes to be treated as if they were a number. A doctor may see countless patients on a single day, so I understand that there is a risk of getting lost in a daily routine… However, every patient is different; every patient has a different story to tell." (P8)*

Time Constraints

Participants expressed concerns about the increasing time pressure and personnel shortage in the primary care system.

> *"GPs nowadays have less time for their patients than back in the days. Recently, I visited my general practitioner and mentioned that I had two physical complaints. The general practitioner told me that there was only time scheduled for one complaint. In the past, this would have never happened. There is not much the current general practitioners can do about it. It is a consequence of increasing time pressure. However, it is difficult for patients too." (P2)*

Communication Between Primary Healthcare Providers and Patients

About their relationship with the GP, participants were all positive during the interviews. They reported that their GP was reliable, approachable, and concerned with them. The participants felt safe and comfortable with their GP and felt that they could address the issues that they were concerned with, such as diseases or fears.

> *"My experiences are good. I see my general practitioner and practice nurse because of my diabetes. I have no complaints. The*

TABLE 2 | Participant characteristics & results of the selected items from the self-assessment.

Nr	Age (yrs)	Sex[a]	Chronic disease	How satisfied are you with the contacts with your GP in the last 6 months?[b]	Self-reported health[c]	To what extent do you experience physical complaints?[e]	How much impact do your chronic conditions have on your day-to-day live?[b]	How difficult was it for you to make a decision about your illness using the information provided by the GP?[d]	During the last 6 months I received written information on how I can improve my health[e]
1	69	M	Hypertension, diabetes mellitus type 2, COPD, decompensation Cordis, lower back pain with radiation, migraine, psoriasis	8	1	4	5	1	2
2	84	F	Hypertension, diabetes mellitus type 2, asthma, breast cancer, osteoarthritis	8	2	8	8	2	0
3	72	M	Hypertension, diabetes mellitus type 2, hypercholesterolemia, osteoarthritis, prostate cancer	7	2	6	1	1	0
4	85	F	Hypertension, hypercholesterolemia, lower back pain with radiation, rectum cancer	3	2	9	8	dk	0
5	58	F	Hypercholesterolemia, other disease peripheral arteries, hypothyroid	8	2	6	6	2	1
6	59	F	M. Crohn, COPD, osteoporosis, osteoarthritis, allergies	10	1	2	1	1	–
7	67	M	Diabetes mellitus type 2, myocardial infarction, rheumatoid arthritis, allergies	7	1	7	1	2	1
8	47	F	Hypercholesterolemia, stroke, hypothyroid, other disease peripheral arteries	10	2	1	0	1	–
9	77	M	Hypertension, diabetes mellitus type 2, myocardial infarction, colon cancer, bladder cancer, prostate cancer	6	-	-	7	1	0
10	82	M	Hypertension, diabetes mellitus type 2, hypercholesterolemia, atrial fibrillation, laryngeal cancer	8	3	5	5	2	–
11	86	F	Atrial fibrillation, stroke, osteoarthritis, osteoporosis, basal-cell carcinoma	-	1	7	1	1	–
12	87	F	Hypertension, stroke, hypothyroid, osteoarthritis, squamous cell carcinoma	8	2	6	4	2	0

[a] *M, male; F, female.*
[b] *On a 10 point scale from zero (no) to ten (enormous).*
[c] *0, perfect; 1, good; 2, reasonable; 3, bad; 4, could or would not answer.*
[d] *1, Very easy; 2, Relatively easy; 3, Relatively difficult; 4, Very difficult; dk, Don't know.*
[e] *0, almost never; 1, generally not; 2, sometimes; 3, most of the time; 4, almost always.*

> *connection with the doctor is good, I trust him 100%. If I have something, I know I can always call him." (P3)*

However, participants felt that explanations about diseases or treatments should be more tailored to their level of comprehension. For example, primary healthcare providers sometimes tended to use medical jargon, take too little time to explain matters, or only provided explanations verbally, and did not sufficiently check with the patients if everything is understood:

> *"My general practitioner tries to explain everything clearly to me, but he does not write it down. When I get home I have already forgotten what he said. For me, it would be helpful if he would write the treatment plans or explanations down. It is the same when I visit the practice nurse.*

> *She explains too much. I cannot remember all this information, and it is too theoretical." (P7)*

Physical Functioning

Half of the participants mentioned to need some support in ADL or IADL activities (P1, P2, P6, P10, P11, and P12). While some of these participants only needed help with IADL such as doing grocery shopping, there was one participant who needed help with ADL activities. Some of these participants reported problems in their mobility, mostly in walking. However, the other half of the participants did not feel chronically ill and did not experience physical limitations in their daily life.

> *"Honestly, I do not feel limited at all in my daily activities. Of course I can feel that I am almost old and no longer 65 but that is just a logical consequence of aging." (P2)*
>
> *"I am still surprised that I belong to the category of 'multimorbid patients.' In my opinion, I am not the prototype of a chronically ill patient." (P3)*

Psychological Functioning

Most participants felt that they could cope with their diseases in a good way most of the time. However, participants reported psychological consequences of their diseases. Fears for new diseases, death, dependency, and embarrassment about the consequences of their diseases were mentioned consistently.

> *"I do not want to get old and end up in a nursing home. The thought of having to ask my wife to take off my socks is already terrifying." (P3)*

Social Functioning

Support system

As for support from family, friends, and neighbors, the participants were satisfied. All participants had several people around them who could help or already were involved in activities like grocery shopping, driving long distances, and finances. Moreover, a lot of the participants not only were the receiving party but also provided help to others. Two participants were experienced volunteers.

Maintaining social contacts, especially with family, was very important to all the participants. They reported that their social contacts had a big share in their quality of life.

Social participation restriction

Even though the participants were satisfied with the support and contact they had with family and friends, some participants noticed that their social life was getting smaller. At times, they felt as if they no longer were seen as a full member of society due to their impairment.

> *"Sometimes I felt miserable. Because of my physical limitations, my social life was getting smaller, my work ended, and it felt like I no longer participated in society." (P5)*

Triangulation

Mostly, the findings of the interviews were in line with the results of the self- assessments, such as the self-reported health and the influence of the chronic conditions on their daily lives. Contradictions were also found. Based on the self-assessments, participants seem very positive about different topics, whereas in the interviews, points of improvements on those same topics are mentioned. For example, the decision-making process regarding their chronic conditions based on the provided information by the GP was assessed. In the self-assessment, the majority of the participants experienced the decision-making process "without difficulty." In the interviews, however, multiple participants mentioned that explanations about diseases and treatments tailored to the patients' level of comprehension and preferred mode during the decision-making process were needed (**Table 2**).

DISCUSSION

These findings contribute to our understanding of the care needs, care experiences, and the impact of chronic conditions on daily functioning of community-dwelling patients with multimorbidity.

In this study, participants expressed the need for a holistic approach. This is in line with our expectation that patients with chronic conditions and especially patients with multiple chronic conditions are in need of more attention to their contexts and preferences. On a similar note, patients experience a lack of focus on patients' functioning in the current structured disease management programs. In line with our findings, Noel et al. (18) found that patients were more concerned about their functioning and the way their diseases interfere with their lives than the symptoms *per se*. Moreover, Huber et al. (19) also found a discrepancy in impact of daily functioning on health between doctors and patients. Building upon the previously mentioned and our own findings, we postulate that GPs possibly prioritize care decisions based on disease management and long-term health risks, in contrast with patients, who prioritize care needs based on their functioning (short-term health gain).

The need for personal continuity of care emerged from the interviews. This result is consistent with those of other studies (20, 21). Schiotz et al. (6) reported that patients with multimorbidity are most likely to gain from continuity of care since they have a high treatment burden in terms of understanding and self-managing their conditions; they attend multiple appointments and sometimes manage complex drug regimens.

Concerning the care needs in the communication between the GP or PN and patient, participants mentioned that explanations about diseases or treatments should be more tailored to their level of comprehension and preferred mode (oral or written information). These findings are in line with previous findings (21–24). Regarding the impact of multimorbidity on functioning, most of the participants did not consider themselves chronically ill, despite having three or more chronic conditions. The participating patients appeared to accept their limitations and adapted their lives to it. Self-reliance, having social contact, and being mobile were important factors. This is in line with the newly proposed definition of health, which focuses more on the patients' ability to adapt and to self-manage (19). On the other hand, participants consistently mentioned fears for future dependency due to functional loss, and they were aware that they were living in a fragile system.

Most of the identified unmet needs with respect to general practice care may not be unique to patients with multimorbidity only. However, we think multimorbidity increases the probability that these needs are unmet. Building upon this, we suggest that multimorbidity magnifies the importance of the mentioned care needs.

Strengths and Limitations of This Study

Firstly, in this qualitative study, we triangulated our results by comparison with the self-assessments in order to strengthen the validity of our findings. Mostly the findings of the interviews were in line with the results of the self-assessments, such as the self-reported health and the influence of the chronic conditions on their daily lives. Secondly, different researchers were involved in the data analysis, which strengthens the interpretation of our findings in terms of objectivity. Thirdly, this study utilized purposive sampling to enable variation of our sample within the multimorbid population (three or more chronic conditions) in terms of (in)dependence in self-care and by selecting general practices in metropolitan and rural areas.

Some limitations can be identified. Firstly, although the GPs served diverse populations, only three GPs participated in our study. This limits the ability to address differences in GP–patient interactions and care experiences of the patients. All were experienced GPs (>10 years work experience). The three GPs had a comparable number of patients in their practices. Secondly, more importantly, possible selection bias might have occurred in patients who had no trouble with expressing themselves and their needs during an interview and in the self-report questionnaire or patients who were on good speaking terms with their GP. We remain uncertain whether and how needs and care experiences of patients from non-Dutch-speaking persons or persons who are less familiar with their GP might differ.

Implication for General Practice and Future Research

Despite these limitations, our study *results have some practical implications for improving care for patients with multimorbidity. Our findings suggest that in primary care, there is a need for more focus on context and functioning in care for patients with multimorbidity*. Better incorporation into the vocational training might be beneficial. Lastly, to improve continuity of care (especially relational continuity) in general practice, more research and practical solution on this important topic are needed.

CONCLUSION

This study explored unmet general practice care needs of community-dwelling multimorbid patients in the Netherlands. Overall, the current disease-oriented chronic care programs do have their benefits. However, there is a need for better personal continuity of care, patient-tailored communication, and more focus on patient's context and functioning instead of disease management alone.

DATA AVAILABILITY STATEMENT

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by ethical clearance was granted by the VU University medical center's ethical 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

MR obtained the funding and coordinates the study. LR, HV, and MR were involved in the study design. LR, MB, BS, HV, and MR were involved in the implementation of the study. LR, BS, and MB wrote the first substantial draft of the article and were guarantors. All authors critically revised the manuscript, read, and approved the final manuscript.

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REFERENCES

1. van Oostrom SH, Gijsen R, Stirbu I, Korevaar JC, Schellevis FG, Picavet HS, et al. Time trends in prevalence of chronic diseases and multimorbidity not only due to aging: data from general practices and health surveys. *PloS ONE.* (2016) 11:e0160264. doi: 10.1371/journal.pone.0160264
2. Fortin M, Bravo G, Hudon C, Lapointe L, Almirall J, Dubois MF, et al. Relationship between multimorbidity and health-related quality of life of patients in primary care. *Qual Life Res.* (2006) 15:83–91. doi: 10.1007/s11136-005-8661-z
3. Schousboe JT, Vo TN, Kats AM, Langsetmo L, Diem SJ, Taylor BC, et al. Depressive symptoms and total healthcare costs: roles of functional limitations and multimorbidity. *J Am Geriatr Soc.* (2019) 67:1596–603. doi: 10.1111/jgs.15881
4. Struijs JN, Baan CA. Integrating care through bundled payments–lessons from the Netherlands. *N Engl J Med.* (2011) 364:990–1. doi: 10.1056/NEJMp1011849
5. Boyd CM, Darer J, Boult C, Fried LP, Boult L, Wu AW. Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance. *JAMA.* (2005) 294:716–24. doi: 10.1001/jama.294.6.716
6. Schiøtz ML, Høst D, Frølich A. Involving patients with multimorbidity in service planning: perspectives on continuity and care coordination. *J Comorb.* (2016) 6:95–102. doi: 10.15256/joc.2016.6.81

7. Bogerd MJL, Slottje P, Schellevis FG, Giebels A, Rijken M, van Hout HPJ, et al. From protocolized to person-centered chronic care in general practice: study protocol of an action-based research project (COPILOT). *Prim Health Care Res Dev*. (2019) 20:e134. doi: 10.1017/S1463423619000550
8. O'Halloran J, Miller GC, Britt H. Defining chronic conditions for primary care with ICPC-2. *Fam Pract.* (2004) 21:381–6. doi: 10.1093/fampra/cmh407
9. Salisbury C, Man MS, Bower P, Guthrie B, Chaplin K, Gaunt DM, et al. Management of multimorbidity using a patient-centred care model: a pragmatic cluster-randomised trial of the 3D approach. *Lancet*. (2018) 392:41–50. doi: 10.1016/S0140-6736(18)31308-4
10. Green J, Thorogood N. *Qualitative Methods for Health Research*. London: Sage (2018).
11. Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the patient assessment of chronic illness care (PACIC). *Med Care.* (2005) 43:436–44. doi: 10.1097/01.mlr.0000160375.47920.8c
12. Vandenbosch J, Van den Broucke S, Vancorenland S, Avalosse H, Verniest R, Callens M. Health literacy and the use of healthcare services in Belgium. *J Epidemiol Community Health.* (2016) 70:1032–8. doi: 10.1136/jech-2015-206910
13. Iheme LO. *The Feasibility, Reliability, and Validity of Using the Self-report Version of interRAI Check-Up Among Community Dwelling Older Adults*. Waterloo: University of Waterloo (2019).
14. Ritchie J, Lewis J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage (2003).
15. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ.* (2000) 320:50–2. doi: 10.1136/bmj.320.7226.50
16. Given LM. *The Sage Encyclopedia of Qualitative Research Methods*. Sage Publications (2008).
17. O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ.* (2010) 341:c4587. doi: 10.1136/bmj.c4587
18. Noël PH, Frueh BC, Larme AC, Pugh JA. Collaborative care needs and preferences of primary care patients with multimorbidity. *Health Expect.* (2005) 8:54–63. doi: 10.1111/j.1369-7625.2004.00312.x
19. Huber M, van Vliet M, Giezenberg M, Winkens B, Heerkens Y, Dagnelie PC, et al. Towards a 'patient-centred' operationalisation of the new dynamic concept of health: a mixed methods study. *BMJ open.* (2016) 6:e010091. doi: 10.1136/bmjopen-2015-010091
20. Engamba SA, Steel N, Howe A, Bachman M. Tackling multimorbidity in primary care: is relational continuity the missing ingredient? *Br J Gen Pract.* (2019) 69:92–3. doi: 10.3399/bjgp19X701201
21. Gill A, Kuluski K, Jaakkimainen L, Naganathan G, Upshur R, Wodchis WP. "Where do we go from here?" Health system frustrations expressed by patients with multimorbidity, their caregivers and family physicians. *Healthc Policy.* (2014). 9:73–89. doi: 10.12927/hcpol.2014.23811
22. Ha JF, Longnecker N. Doctor-patient communication: a review. *Ochsner J.* (2010) 10:38–43. Available online at: https://pubmed.ncbi.nlm.nih.gov/21603354/
23. Ong LM, de Haes JC, Hoos AM, Lammes FB. Doctor-patient communication: a review of the literature. *Soc Sci Med.* (1995) 40:903–18. doi: 10.1016/0277-9536(94)00155-M
24. Smith ML, Bergeron CD, Adler CH, Patel A, Ahn S, Towne SD, et al., et al. Factors associated with healthcare-related frustrations among adults with chronic conditions. *Patient Educ Couns.* (2017) 100:1185–93. doi: 10.1016/j.pec.2016.12.033

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Adverse Life Events: Do Home Care Clients Have Resources for Mastering Them?

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Objectives: Research on life stressors and adverse life events has a long tradition. Few studies have addressed this topic in connection to very old people. Life stressors, especially major life stressors (MLSs) experienced by clients of home care services in the community have rarely been the subject of studies. Considering this gap, we investigated the prevalence of MLSs in home care clients. We examined the effects that MLSs have on their mood and health status as well as the impact of clients' social resources on MLSs and their outcomes.

Method: We used assessment data from 2,884 home care clients in six European countries. The methodological basis was the comprehensive and standardized interRAI Home Care Assessment (interRAI HC).

Results: Fifteen point four percent of the sample—that consisted of women and men with an average age of 82.89 years–experienced an MLS in the last 6 months before the assessment. They were more depressed than persons without these experiences, and their health status indicated a higher level of instability and deterioration. At reassessment after 6 months, the situation changed. Despite the fact that both outcomes of the MLSs, depression and health status became worse in the reassessment-sample, home care clients without MLS were more affected by the worsening, especially that of depression. The expected buffering impact of social resources was low.

Discussion: Although this study worked with limited information on MLSs, it could contribute to closing various knowledge gaps. The study shows that the MLSs represent a prevalent problem in a population of home care clients and that this problem has negative consequences for their mood and the stability of their health status. Furthermore, this research took up the situation of very old and vulnerable adults, who have previously rarely been considered in studies on major critical life events and stressors.

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Conclusion and Research Perspective: Future research on MLSs has to take up the issue of the time passage between the MLS and the impact on health and well-being of individuals dependent on care. It has to determine immediate as well as later consequences and identify those factors that are appropriate to reduce the MLS-effects on very old people dependent on care.

Keywords: major life stressors, depression, stability of health status, social resources, home care clients, functional dependency, interRAI-assessment, European study

INTRODUCTION

Research on critical life events and life stressors has generated a respectable body of knowledge. However, when studies on life stressors in health sciences and psychology are considered more closely, knowledge gaps become obvious.

Since the nineteenseventies, researchers have investigated events that cause a considerable change of life (1, 2). They have concentrated not only on negative and stressful experiences, but also on positive life changes, such as the birth of a child, job-related advancement, etc. Both types of changes have been recognized as having a pathogenic impact on the life course and overall health (3). Both have been identified as powerful risk factors for cardiovascular disease and hypertension (4). Researchers have developed typologies of people in middle age. Problems of behavior regulation, coping, and overcoming the stressors entered the research agenda (5–7). Yet, the risk of functional dependency in older people as a consequence of the life events was not considered in those days.

Later, the association between critical life events and depression moved to the foreground. Critical life events as flash points of mental illnesses (not only of depression) became an important subject of studies on clinical populations, for instance, on small samples of hospitalized psychiatric patients. Mazure (8) reported on 14 studies on life events and stressors completed between 1980 and 1990. Most of them worked with ∼33 participants, the largest one with 227 participants. Larger samples were addressed by some community-based studies (9). The common targets were younger females, university students, or children. The researchers developed diagnostic instruments and treatment strategies just for these groups.

Over time, a large number of possible life stressors has been described (10–12): death of a family member or close relative or other important person, divorce or separation from partner, loss of a friend, legal problems, serious health crises, e.g., notification of a serious diagnosis, or financial problems. Major stressors in older age include bereavement, financial loss, new physical illness or disability of oneself or of a family member, change in living situation, and interpersonal conflict (12). Bellingtier et al. (13) relate MLSs to the subjective experience of age (subjective age).

Despite this tradition and the large amount of existing studies, neither a unified definition of the term major life stressor (MLS) nor a consistent concept exist. A variety of terms overlap (10). Some authors speak about "traumatic events" (14) having the potential to affect psychological well-being, about "critical life events," or about "adverse life experiences" [(8), p. 291, 294]. Still others use "uncontrollable events" that have adverse biological and behavioral outcomes or the terms "loss" and "exit events" (15). Such variety reflects an ambiguity of concepts. Accordingly, a comparison of outcomes is difficult, and the evaluation of different stressors for individual people is hardly possible. Above all, the effects of short-term, acute stressors, which probably constitute the majority of the MLSs are less known (16). Studies with community dwellers in their normal environment are scarce. Research concentrates on the clinical environment of hospitals, on educational institutions, or on laboratory settings (17). As a consequence, little is known about the meaning of life stressors for older people in their everyday environment.

Researchers distinguish between acute and chronic stressors [(18), p. 174]. Chronic stressors are conceived as discrete events and conditions, or constellations of related events that persist over time (17). In the healthy population, both acute as well as chronic stressors seem to be associated with depression (19), with chronic stressors having a pronounced impact (20). As far as elderly people who already suffer from depression are concerned, both chronic and acute stressors seem to predict an increase in depression (11). However, in the context of long-term care, the topic of chronic stressors has almost exclusively been investigated in informal or professional caregivers of the elderly care receivers, not the elderly themselves (21–25).

Some studies have stressed a buffering or moderating effect of social support in the "stress – depression" relationship [(18), p. 177]. Independent causal effects were found in older women with depressive symptoms and in bereaved or physically disabled persons (26, 27). Tennant (18), who summarized corresponding findings underlined that buffering effects of social support and social relations were identified in children, adolescents, and young people, such as university students.

Against this background of existing research, our paper will direct the attention to issues that have not played a big role in available studies: life stressors in to date rather "invisible" clients of home care, very old and functionally dependent people who live in the community and are not institutionalized. Thus, we focus on the naturalistic context of long-term care, which is the prevailing form of care provision in European countries.

Our research questions are:

Abbreviations: ADLh, Activity of Daily Living hierarchy scale; B, Belgium; CHESS, Changes in Health, End-Stage Disease, Signs, and Symptoms; CPS, Cognitive Performance Scale; De, Germany; DRS, Depression Rating Scale; Fin, Finland; HC, Home Care; I, Italy; IADL, Instrumental Activity of Daily Living Scale; Ice, Iceland; MLS, Major Life Stressor; NL, The Netherlands; T_0, Baseline; T_1, First reassessment; T_2, Second reassessment.

How prevalent are major life events in an international sample of home care clients?

Does the level of the home care clients' dependency reduce the frequency of MLSs recorded by the assessment?

Do the MLSs affect mood and health status of the home care clients?

Do social resources buffer against negative MLS-outcomes, immediately and over the course of 6 months?

MATERIALS AND METHODS

We used data from 2,884 home care clients who underwent a standardized geriatric assessment (interRAI HC—see www.interRAI.org) and two reassessments, the first one (T_1) after 6 months, and the second one (T_2) after 1 year. This paper is based on the baseline (T_0) and the first reassessment (T_1). The study was carried out in six European countries: Belgium (B), Finland (Fin), Germany (De), Iceland (Ice), Italy (I), and the Netherlands (NL). More details about the entire IBenC-project are described elsewhere (28). Some information on the sampling procedure should be given here. In a first step, typical home care organizations were selected in the participating countries. In a second step, receivers of home care, home nursing, and home help were recruited. Only persons who were 65 years of age and older and who already were clients of the service for at least 14 days were included (**Table 1**). Persons with explicitly negative prospects for the next 6 months were excluded, i.e., clients receiving palliative care or end of life care, and people facing an impending ending of home care because of the admission to a hospital or nursing facility. In this way, a possible reduction of the samples between T_0 and T_1 was to be prevented. In the Netherlands, the exclusion criterion "probability of nursing home admission in the next 6 months" was implemented particularly strictly. Thus, this sample contains fewer cognitively impaired clients than samples from other countries. Moreover, access to home care for less impaired persons was relatively easy at the time of the assessment in the Netherlands. The fact that the Dutch sample contains less severe cases is reflected by some results (**Table 1**). Therein, it is apparent that the mean score of cognitive performance in the sample of the Netherlands is below zero, which means "cognitively capable and independent in decision making." The geriatric interRAI HC-assessment contains up to 320 variables covering health and functional status, cognition, mood, social capabilities, and behavior. Basic information on demography, living arrangement, and living environment is also included. Four sections are dedicated to the provision of health care.

The assessments were carried out by professional nurses who provided the normal, everyday care. In some countries, "routine data" were used. This term means that the data were collected in the course of regular health care and nursing. To ensure good quality of data, a special training was offered to this staff. Additionally, research nurses were available to support the nurses during the process of data collection. The procedure of the interRAI HC assessment is special. The assessors link three to four sources of information: their professional evaluation of the status and situation of the individual, self-reports of the persons under study, information documented in clients' records, and sometimes also the evaluation by other persons involved with the case of the client.

For the purposes of this paper, only selected variables and scales were analyzed. The scales are constructed with interRAI HC-variables.

Major life stressor in the last 90 days is a dichotomous variable. Participants reported whether or not they had experienced a major life stressor in the last 90 days. The assessment manual describes the MLS as an "episode of severe personal illness, death or severe illness of a close family member or friend, loss of the person's home, major loss of income or assets, being a victim of a crime, e.g., robbery or assault." Usually, such experiences disrupt or threaten to disrupt a person's daily routine and impose a readjustment (29).

The following measures were considered dependent variables, or outcomes in the present paper.

Depression Rating Scale: DRS describes the mood status of the clients (30). It ranges from "0" (no indication of mood problems or depression) to "14." A score of "3" indicates minor, and higher scores indicate major depressive disorder.

The *CHESS scale* (full name Changes in Health, End-Stage Disease, Signs, and Symptoms) is a six-point scale that helps to identify individuals whose health status is highly unstable and who are at risk of serious decline. It ranges from "0" (not at all unstable) to "5" (highly unstable), and the highest levels predict mortality, hospitalization, negative subjective health ratings, and other health deterioration (31).

The demographic characteristics considered in the present manuscript were age (in years), gender (male or female), marital status (never married, married or partnership, divorced, separated), and living arrangement (number of persons living with the client).

Clients' dependency was measured by ADL and IADL indices as well as by frequency and amount of home care and help services.

IADL "Performance" reflects the level of actual execution of the instrumental tasks of daily life by the client. The score ranges from "0" to "48" (32).

Functional performance in elementary activities of daily life is measured by the ADL hierarchy scale (ADLh) with seven levels, starting with "0" (independent) and ending with "6" (totally dependent) (32).

Services: We took the frequency and amount of services that help with completion of the everyday tasks as further indicators of dependency. We selected variables indicating the frequency of home health care and homemaking. Our question was: "On how many days of a week do clients receive these services?" Additionally, we used variables indicating the amount of both services (in numbers of minutes of the provision per week).

Social resources were measured by six variables:

Mutual visits with a family member and long-standing friends. Possible responses ranged from never (0) to more than 30 days ago (1) to 30 days ago (2), etc., up to in the last 3 days (4).

TABLE 1 | Study samples in participating countries with activities of daily living (ADL), instrumental activities of daily living—performance (IADLp), and cognitive performance (CPS) of the home care clients.

Country	Number of Participants at baseline	% of the sample	ADLh: Mean (SD)	IADLp: Mean (SD)	CPS Mean (SD)
Belgium (B)	525	18.2	3.16 (1.18)	33.99 (10.72)	1.35 (1.63)
Finland (Fin)	456	15.8	0.77 (1.31)	26.42 (13.05)	1.33(1.18)
Germany (De)	493	17.1	2.16 (1.72)	28.68 (14.85)	1.61 (1.72)
Iceland (Ice)	420	14.6	0.58 (1.06)	23.78 (11.47)	1.07 (1.17)
Italy (I)	499	17.3	3.82 (1.67)	39.34 (1.67)	2.32 (2.07)
The Netherlands (NL)	491	17.3	0.46 (1.13)	16.95 (12.26)	0.59 (.86)
Total	2,884	100	1.87 (1.90)	28.95 (14.24)	1.38 (1.60)

Differences between country-samples:
ADL: square sum = 4,950.571, df = 5, square middle = 990.114, F = 7,523.271, p < 001.
IADL: square sum = 128,308.645, df = 5, square middle=25,660, F = 167,281, p < 001.
CPS: square sum = 805.448, df = 5, square middle = 161.090, F = 70.871, p < 001.

Social interaction with family member and long-standing friends by telephone, e-mail, etc. The characteristics and response categories were the same as for the variable "visits."

Availability of a strong relationship with the family, which makes it possible that the person "feels able to rely on family members" (29).

Living arrangement (contains information about living alone or with one or more other people).

Number of informal helpers.

Believes in improvement potential: This variable contains two perspectives: the client's own belief that he/she will improve his/her status and physical performance, on the one hand, and the beliefs of the professional caregivers in the improvement potential of the client, on the other hand.

Potentially Stressful Factors

We used the *Pain scale* that measures the intensity and frequency of pain during the last three days before the assessment. It ranges from "0" (no pain) to "3" (daily severe pain) (33).

Problems in social relations were measured by three continuous variables: Conflict or anger with family or friends; fear of a family member or close acquaintance; neglect, abuse, or mistreatment. Possible responses were never (0), more than 30 days ago (1), 30 days ago (2), etc., up to "in last 3 days" (4).

Cognitive status was measured by the *Cognitive Performance Scale* (CPS), with seven levels and especially based on daily decision making, but including short-term memory and other items as well (34). The first level is "0" (cognitive performance is intact), the highest level is "6" (very severe impairment of cognitive performance).

RESULTS

The entire study sample contained 2,884 home care clients, 67.4% of which were women. The proportion of participants from the six countries ranged from 14.6% in Iceland to 18.2% in Belgium (see **Table 1**). The average age of the home care clients under study was $M = 82.89$ years ($SD = 7.26$; $Md = 84.00$, *age range* 65–105 years*).* Germany participated with the oldest clients ($M = 84.19$ years, $SD = 7.57$). The Italian sample consisted of the youngest individuals: their average age was $M = 81.85$ years ($SD = 7.91$). Age differences were considerable and significant [$F_{(5,1)} = 7.03$; $p < 0.001$].

Despite the fact that the Italian participants were younger than participants from the other countries, they had the highest level of impairments (**Table 1**). The average of the ADLh-score in Italy was almost 4 ($M = 3.82$, $SD = 1.67$), which means extensive need for help. The average ADLh-score of the entire sample of all countries was only $M = 1.87$ ($SD = 1.90$), which indicates "limited need for help." The Italian sample showed similar levels of impairment of the performance in instrumental activities and in cognition. In contrast, the Dutch home care clients were almost independent in ADLh ($M = 0.46$, $SD = 1.13$) and an average CPS-score that indicates that the cognitive performance of the Dutch home care clients was practically unimpaired ($M = 0.59$, $SD = 0.86$).

Prevalence of Major Life Stressors Within 90 Days Before the Assessment

At baseline, 15.40% of the clients (445 persons) reported that they experienced an MLS in the past 90 days before the assessment (**Table 2**). The frequencies differed significantly from country to country [$\chi^2(5) = 125.02$, $p < 0.001$]. 31.20% of the Dutch home care clients experienced an MLS. This figure is far above average. In contrast, the proportion of Finnish home care clients who experienced a major stressor was below average with 7.50%.

The likelihood of experiencing an MLS was higher in the Netherlands than in Germany (reference country) [$OR = 2.97$, $S.E.\ (B) = 0.17$, $Wald\ \chi^2 = 43.63$, $p < 0.001$]. The likelihood of reporting an MLS was lower in Finland than in Germany [$OR = 0.53$, $S.E.\ (B) = 0.22$, $Wald\ \chi^2 = 8.18$, $p = 0.004$].

Association of MLSs and Demographic Characteristics

Home care clients who experienced a major life event in the last 90 days were slightly and significantly younger: Their average age amounted to $M = 82.18$ years ($SD = 7.04$), whereas persons who did not report an MLS were $M = 83.02$ years old ($SD = 7.30$), on average. [$F_{(1,2842)} = 5.10$; $p < 0.05$]. This association was not found in all participating samples. In those samples, where the

TABLE 2 | Differences of the potential outcome scales (DRS and CHESS) in country-samples.

Country	% of clients with MLS in the last 90 days prior the assessment	DRS: mean- score (SD)	Chess: mean-score (SD)
Belgium (B)	16.5	1.76 (2.53)	1.09 (1.02)
Finland (Fin)	7.5	0.93(1.86)	0.68 (.90)
Germany (De)	13.2	1.59 (2.61)	0.65 (.94)
Iceland (Ice)	11.7	1.16 (1.82)	1.15 (.97)
Italy (I)	12.2	1.32 (2.03)	1.64 (1.27)
The Netherlands (NL)	31.2	1.60 (2.15)	1.23 (.99)
Total	15.6	1.41 (2.22)	1.07 (1.08)

Differences between country-samples:
DRS: square sum = 233.232, df = 5, square middle = 46.646, F = 9.589, p = 000.
CHESS: square sum = 327.650, df = 5, square middle = 65.530, F = 61.969, p = 000.

proportion of MLS reports was especially high (Dutch sample) or especially low (Finland), no significant association between MLS and age was found.

The prevalence of MLSs did not differ between men and women. Likewise, there was no significant difference by living arrangement (number of persons living in the household of the client). However, among the divorced and separated clients, the number of persons who reported an MLS was higher than in those who were married and single [$\chi^2(3) = 10.69$; $p < 0.05$].

Factors, Which Potentially Could Be Experienced as Stressful

We focused on pain and on problems of social relations. The average Pain-score of home care clients without the experience of an MLS was $M = 0.79$ ($SD = 0.97$); the average Pain-score of clients with MLS was higher ($M = 1.08$, $SD = 1.14$, $t_{(2836)} = -5.57$; $p < 0.001$).

We ran a logistic regression with MLS as the outcome and pain as the predictor. The higher the Pain-score, the greater the likelihood was that participants reported an MLS [$OR = 1.30$, $S.E.(B) = 0.05$, $Wald\ \chi^2 = 30.15$, $p < 0.001$]. There was no interaction between Pain-score and the belonging to a country-specific subsample, i.e., the effect of pain on likelihood of reporting an MLS did not differ by country.

Problems of social relations which potentially could be stressful: We focused on three variables. As far as persisting conflicts with family or friends were concerned, their presence was relatively more frequent in clients with MLS than without [$\chi^2(2) = 27.34$; $p < 0.001$]. However, it was irrelevant when such conflicts took place: The temporal distance between the conflicts and the assessment was not related to the occurrence of the MLSs.

Physical Dependency Does Not Reduce the Probability of Assessed MLSs, Cognitive Impairment Does

We ran a logistic regression with MLS as outcome and with ADLh scale and IADL performance scale as predictors. ADLh-score and IADL-score were unrelated to the probability of reporting an MLS.

A different picture emerged when impairment of cognitive performance was considered. The logistic regression with MLS as outcome and CPS as predictor showed that the likelihood of reporting an MLS decreased with increasing CPS-score (i.e., with the increase of cognitive impairment) [$OR = 0.87$, $S.E.(b) = 0.04$, $Wald(1) = 13.90$, $p < 0.001$]. We did not find an interaction between CPS and country, i.e., the effect of CPS on reporting of MLS did not differ between the country subsamples.

A logistic regression with MLS as outcome and frequency and amount of services as predictors showed: The higher the number of days of home health care in the past 7 days was, the greater was the probability that MLS would be recorded in the assessment [$OR = 1.05$, $S.E.(b) = 0.02$, $Wald(1) = 4.79$, $p < 0.05$]. The higher the number of minutes of homemaking services in the past week was, the higher was the probability that MLS would be captured by the assessment [$OR = 1.00$, $S.E.(b) = 0.08$, $Wald\ (1) = 20.89$, $p < 0.001$].

Outcomes of Experiencing the MLS

Depression as outcome: A clear difference was identified in mood status. Home care clients who experienced MLS were more depressed than those who did not. We conducted an independent samples *t*-test. Participants with MLS had a higher DRS-score ($M = 2.24$, $SD = 2.62$) than participants without MLS ($M = 1.25$, $SD = 2.10$), $t_{(2843)} = -8.73$, $p < 0.001$.

Stability of health status as outcome: The CHESS-score as an indicator for the instability and decline of health status showed differences between home care clients with and without MLS. We conducted an independent samples *t*-test. Clients with MLS had a higher CHESS-score ($M = 1.44$, $SD = 1.16$) than clients without MLS ($M = 1.01$, $SD = 1.05$), $t_{(2827)} = -7.81$, $p < 0.001$.

Influence of Social Resources on MLS-Outcomes

The majority of the home care clients maintain social relations with family members, friends, and other significant persons. Only 4.60% never cultivated mutual visits with these people; only 6.40% never communicated on the phone, via email, etc. 48.80% had such mutual visits in the last 3 days before the assessment, 16.70% in the last week, 10.00% in the last 2 weeks, and 4.60% a longer time ago. The communication by phone or digital tools occurred with about the same frequency: 47.00% communicated during the last 3 days, 13.00% in the last week, 7.10% in the last 2 weeks, and the rest a longer time before they underwent the interRAI HC-assessment. Home care clients with MLS reported more recent visits and interactions. Fifty six point six percent participated in a visit in the last 3 days ($K = 0.60$, $p < 0.05$), and 58.70% communicated with a close person in the last 3 days ($K = 0.09$, $p = 0.001$).

Neither visits [$b = -0.01$ $SE(b) = 0.09$, $F_{(1,2625)} = 0.86$, n.s.] nor other interactions with family and close friends [$b = -0.02$ $SE(b) = 0.08$, $F_{(1,2625)} = 0.27$, n.s.] had a buffering effect on depression (DRS-score).

Only two single social variables seemed to have some buffering impact on depression. On the one hand, it was the number of informal helpers. The more informal helpers participants had, the less depressed they reported being after a major life event [$b = 0.33$, $SE(b) = 0.16$, $F_{(1,2636)} = 4.38$, $p < 0.05$]. On the other hand, the self-evaluation of the improvement potential played a role: DRS-score was higher, if clients did not believe that their physical function could improve, whereas in participants with MLS, DRS was higher, if they thought that their physical function could improve [$b = 0.88$, $S.E.(b) = 0.34$, $F_{(1,2625)} = 6.47$, $p < 0.05$]. No meaningful influence of social resources on health status (stability measured by the CHESS-score) in terms of buffering was identified. Visits [$b = 0.01$ $SE(b) = 0.04$, $F_{(1,2584)} = 4.45$, $p < 0.05$] had little effect on "health status instability" (CHESS-score) since the effect size was very small (partial $\eta^2 < 0.01$), and the confidence interval of the parameter estimates included 0 (−0.07, 0.01). The item "other interactions with family and close friends" seemed to have a detrimental effect [$b = -0.05$ $SE(b) = 0.04$, $F_{(1,2584)} = 9.15$, $p < 0.05$], but again, the effect size was very small (partial $\eta^2 < 0.01$), and the confidence interval included 0 (−0.12, 0.03).

Changes Over the Course of 6 Months

We examined changes over the course of 6 months, i.e., from baseline (T_0) to the first reassessment (T_1) in persons who survived and were not discharged during these 6 months. Were some of the social resources from baseline still important for buffering against depression (as indicated by the DRS-score) and the instability of health status (CHESS-score) at the first reassessment?

First, we examined changes of the DRS-score from baseline to the first reassessment. It clearly increased from T_0 to T_1 [$M_d = 0.30$, $SD = 2.05$, $t_{(1971)} = 6.54$, $p < 0.001$]. However, the DRS-score increased more in participants without MLS ($M_d = 0.35$, $SD = 1.95$) than in participants with MLS ($M_d = 0.03$, $SD = 2.53$) at T_0; this difference was statistically significant, $t_{(1964)} = 2.47$, $p = 0.014$.

Afterwards, we tested, what effects social resources exhibited with regards to changes in DRS-score of people who experienced MLSs and those who did not. Our attention was directed to the following variables: strong relationship with the family, living together with one or more other people, mutual visits with family/friends, interaction by phone or email, number of helpers, own and staff's assessment of a potential for improvement. These resources did not play a role.

In a second step, we controlled for changes of the CHESS-score from baseline to the first reassessment. It changed similarly to the DRS-score. Health status became more unstable over the course of 6 months between the assessments T_0 and $T_{1,}$ as the CHESS-score went up [$M_d = 0.15$, $SD = 0.88$, $t_{(1950)} = 7.38$, $p < 0.001$]. In participants without major life event, the CHESS-score increased ($M_d = 0.18$, $SD = 0.87$), whereas in participants with MLS at T_0, the CHESS-score decreased, or more accurately, it almost stayed the same ($M_d = -0.05$, $SD = 0.90$). Changes in CHESS-score differed significantly between participants with and without MLSs [$t_{(1942)} = 4.03$, $p < 0.001$].

We tested what role social resources played for effects of MLS on changes in the CHESS-score. Across the whole sample, there was no effect of social resources on changes in CHESS-score from T_0 to T_1. For people who reported MLS at baseline, the availability of social resources played a role. The more social resources in form of mutual visits with family or other social contacts these clients had, the more their CHESS-score increased from T_0 to T_1. It means that the health status became more unstable just in those home care clients with MLS at T_0, who had social resources at their disposal. In clients without MLS at baseline, social resources were unrelated to changes in CHESS-score [$b = -0.11$, $S.E.(b) = 0.05$, $F_{(1,\ 1745)} = 4.28$, $p = 0.02$].

We investigated, if this could have been the result of the worsening of cognitive performance, which—as we could show in section 3.3—was related to the assessment of a smaller portion of MLSs. This seemed to be the case. The general linear model of the reassessment data showed a predictive role of the CPS-score on the CHESS-score both without the MLS at baseline [$b = 0.12$; $SE(b) = 0.02$; $t = 9.30$; $p < 0.001$] and with the MLS at baseline [$b = 0.12$; $SE(b) = 0.04$; $t = 2.96$; $p < 0.005$]. The same association was not found with regards to the DRS-score, which decidedly was not dependent on development of cognitive performance over the course of 6 months since the baseline assessment.

DISCUSSION

This contribution that is based on a European collaborative study shed light on very old people who receive long-term care while living in the community, not in a long-term care institution. We investigated to what extend they were burdened by MLSs and which consequences it had for them. According to our assessment, 15.40% of study participants experienced an MLS within 90 days prior to the assessment. The differences between country-samples were substantial. In particular, the Dutch home care clients were very different from the clients in other countries. The MLS was assessed in almost one third of them. This finding may be caused by the slightly different sampling by the researchers in the Netherlands who—as we already explained–did not include clients with a higher level of cognitive impairment into their sample for several reasons (see Material and Methods Sections and Results, this article). But this assumption must be handled with caution. We indeed saw that the likelihood of reporting an MLS decreased with the increase of cognitive impairment; yet, we did not find any effects of CPS-score on reporting of MLSs in individual countries.

We asked, if community nurses who collected the data for the IBenC-study paid sufficient attention to the MLSs even of very dependent clients. We assumed that a high level of dependency could be distracting of such adverse experiences. Two considerations lead us to this assumption. On the one hand, not much research on how well-community nurses assess life stressors has been published until today. Préville et al. (35) underlined that psychological distress and signs of depression are not easily detected by home care nurses, since these problems often are masked among older adults, particularly among frail elderly. On the other hand, studies on life stressors in the context of long-term care rather rarely focus on care-receivers. Much more often, the caregivers are the focus. Providing care for an ill or disabled relative represents a burden for the informal caregivers. For instance, spouses or adult children are frequently exposed to stressors that may place many caregivers at risk for depression (12). Research on these problems of caregivers seems to be more important for practical reasons of developing support strategies for them. In this context, the home care receivers seem to slip the attention of researchers.

However, we could not confirm our primary assumption that a higher level of dependency could reduce the proportion of MLS-reports. The functional dependency of the clients was unrelated to the MLS-reports. With a higher frequency and greater amount of professional care and help, it was more likely that MLSs were reported and recorded in the assessment. More service seemed to be an indicator for higher level of dependency. Yet, it may be that clients have a better opportunity to verbalize critical events and stressors vis-á-vis the care staff, if they get more services. Equally, they may be able to report their MLSs also to assessors.

Only cognitive dependency showed different effects. Two possibilities should be considered: Impaired cognition may be straining and may therefore redirect staff's attention away from problems like adverse life experiences. Or, because of their reduced cognitive capacity, clients with higher levels of cognitive impairment are not capable of expressing their critical experiences and MLSs.

We saw almost no significant association between demographics and the prevalence of MLSs. Age differences were small, and gender differences were non-existent, even if some authors argued that older women are especially vulnerable to life events and stressors (36).

Our assumption that MLSs will have negative consequences was confirmed fully. The DRS-score of home care clients who experienced MLSs was higher than the DRS-score of clients without such experiences. Our data could not answer the question about causality. However, this question remains open in many studies because the onset of depression is dependent on a multiplicity of factors, including genetic factors (37). Large numbers of life stressors and critical life events are listed (12). Nevertheless, it remains difficult do decide, which of them definitely causes depression (38), and which of them is the "major" life stressor (38). The explanation varies between individuals, life contexts, and different stages of life and–according to a review of studies (18)—it varies also between types of depressive disorders. We considered the pain-status of the home care clients to be what is called the "precipitating" or "incubating" factor (39) that precedes the life stressor experiences. Indeed, we identified the pain-score as a predictor. The higher the Pain-score was, the greater was the likelihood that participants would report an MLS. Our results could confirm our assumption that persistent interpersonal conflicts with family members and other significant acquaintances may be considered chronical life stressors. They seemingly promote the appearance of the MLSs in our sample and may have the function of social precursors [(16), p. 204].

We were interested in the issues of social resources that could moderate the negative consequences of the MLSs. However, activities of maintaining social contact and interaction did not have a significant impact on outcomes "depression" (DRS-score) and "health status instability" (CHESS-score). Both scores became worse during the time between the baseline assessment and the first reassessment. This development was significantly associated with the occurrence of MLSs in the last 90 days before the baseline assessment. But the direction of the association was surprising. The DRS-score and also the CHESS-score increased in home care clients who had not experienced an MLS, whereas they were almost unchanged in clients with MLS-experience at baseline. This may be the phenomenon described by Tennant (18), who underlined that an effect of stressors often "dissipates with the passage of time" [(18), p. 175]. This phenomenon was reported in connection to the "acute stressors," which may be similar to stressors which we call major life stressors in our investigation.

Strengths and Limitations

Our article reports on a study that has various strengths and weaknesses. The sample was not composed to be representative for the countries. Yet, it reflects typical home care services, the typical composition of their body of clients, and finally, typical individual clients who are taken care of by the community services in six European countries for a relatively long time. The sample was recruited in a naturalistic environment of communities—a situation which is rare as some life events researchers have stated (38). Moreover, the number of study participants is larger than in many other studies (8), especially in studies dealing with stressors of older adults [e.g., (40)]. We believe that the large sample size improves the information value of our analysis.

The target group of our study are older home care clients, i.e., older than 80 years, on average. Such a population was rarely targeted by studies on life stressors and critical life events. Even studies that proclaim "aging" and "older adults" in their title, mainly investigated much younger people, for example those around 55 years of age or people who were about 77 years old (40, 41). Kraaij et al. (11) undertook a meta-analysis of studies on "negative life events in elderly persons". It included 25 studies, but only three of them dealt with participants who were just reaching 80 years of age. Few studies focused on receivers of long-term care in the community, as our study did. Richardson et al. (40) investigated applicants for services provided by the Aging Services Provider Network. Here, clients of non-medical services, like advocacy, meals delivery, transportation, and care management, were targeted. Receivers of care or nursing were explicitly not included.

Existing studies in the long-term care environment either targeted the institutionalized population of nursing homes (42, 43) or the professional and informal caregivers of older people (22, 23, 25).

One weakness of our study is that our information on the MLSs is limited, since we only used a dichotomous variable indicating whether or not the client experienced a major life event in the last 90 days before the assessment. This weakness should be considered in view of the large diversity of the concepts of life stressors and life events. In an assessment like ours, no collection of information on details and different characteristics of life stressors was possible.

CONCLUSION

Our analysis offers a first approach to the impact of MLS in this special population and is therefore an appropriate point of departure for research on this subject. Continuing research into MLSs should take up the issue of the time passage between the MLS and the impact on health and well-being of individuals dependent on care. It should attempt to determine immediate as well as later consequences and those factors that are appropriate to reduce the deterioration of very old people dependent on care.

DATA AVAILABILITY STATEMENT

The datasets generated for this study are available on request to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the ethics committees of the institutions of all contributing study directors. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

HH, AD, VG-H, HF-S, and HR: design of the study, data collection. VG-H: paper design. VG-H and NN: data analysis, first draft of the manuscript. All authors contributed to the article and approved the submitted version.

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REFERENCES

1. Dohrenwend BS, Dohrenwend BP, editors. *Stressful Life Events: Their Nature and Effects*. New York: Willey (1974).
2. Dohrenwend BS, Dohrenwend BP. Some issues in research on stressful life events. The problem of confounded measures. *J Nerv Ment Dis*. (1978) 166:7–15. doi: 10.1097/00005053-197801000-00003
3. Dohrenwend BS, Dohrenwend BP. Life stress and illness: formulation of the issue. In: Dohrenwend BS, Dohrenwend BP, editors. *Stressful Life Events and Their Context*. New York: Prodist (1981). p. 1–27.
4. Friedman M, Roseman R. *Type A Behavior and Your Heart*. New York: Knopf (1974).
5. Friedman M, Rosenman R. Association of specific overt behaviour pattern with blood and cardiovascular findings. *JAMA*. (1959) 169:1286–96. doi: 10.1001/jama.1959.03000290012005
6. Lazarus RS, Folkman S. *Stress, Appraisal and Coping*. New York: Springer (1984).
7. Lazarus RS, Folkman S. *Hassles and Uplifts Scales*. Palo Alto, CA: Consulting Psychologists Press (1989). doi: 10.1037/t06473-000
8. Mazure CM. Life Stressors as risk factors in depression. *Clin Psychol Sci Prac*. (1998) 5:291–313. doi: 10.1111/j.1468-2850.1998.tb00151.x
9. Chapman D, Perry G. Depression as a major component of public health for older adults. *Prev Chronic Dis*. (2008) 5:A22 Available online at: http://www.cdc.gov/pcd/issues/2008/jan/07_0150.htm
10. Scarinci IC, Ames SC, Brantley PJ. Chronic minor stressors and major life events experienced by low-income patients attending primary care clinics: a longitudinal examination. *Int J Behav Med*. (1999) 22:2.
11. Kraaij V, Arensman E, Spinhoven P. Negative life events and depression in elderly persons: a meta analysis. *J Gerontol*. (2002) 57B:87–94. doi: 10.1093/geronb/57.1.P87
12. Fiske A, Wetherell JL, Gatz M. Depression in older adults. *Annu Rev Clin Psychol*. (2009) 5:363–89. doi: 10.1146/annurev.clinpsy.032408.153621
13. Bellingtier JA, Neupert SD, Kotter-Grühn D. The combined effects of daily stressors and major life events on daily subjective ages. *J Gerontol B Psychol Soc Sci*. (2017) 72:613–21. doi: 10.1093/geronb/gbv101
14. Hoves JGFM, Wiersma JF, Giltay EJ, van Open P, Spinhoven BW, Penninx BWJH, et al. Childhood life events and childhood trauma in adult patients with depressive anxiety and comorbid disorders vs control. *Acta Psychiatr Scand*. (2010) 122:66–74. doi: 10.1111/j.1600-0447.2009.01491.x
15. Paykel ES, Cooper Z. Life events and social stress. In: Paykel ES, editor. *Handbook of Affective Disorders*. New York: Guilford Press (1992). p. 149–70.
16. Moos RH, Schutte KK, Brennan PL, Moos BS. The interplay between life stressors and depressive symptoms among older adults. *J Gerontol*. (2005) 60B:199–206. doi: 10.1093/geronb/60.4.P199
17. Lepore SJ, Miles HJ, Levy JS. Relation of chronic and episodic stressors to psychological distress, reactivity, and health problems. *Int J Behav Med*. (1997) 5:39–59. doi: 10.1207/s15327558ijbm0401_3
18. Tennant C. Life events, stress and depression: a review of recent findings. *Aust N Z J Psychiatry*. (2002) 36:173–82. doi: 10.1046/j.1440-1614.2002.01007.x
19. Kendler KS, Karkowski LM, Prescott CA. Causal relationship between stressful life events and the onset of major depression. *Am J Psychiatry*. (1999) 156:837–41. doi: 10.1176/ajp.156.6.837
20. McGonagle KA, Kessler RC. Chronic stress, acute stress, and depressive symptoms. *Am J Commun Psychol*. (1990) 18:681–706. doi: 10.1007/BF00931237
21. Parris Stephens MA, Clark SL. Reciprocity in the expression of emotional support among later-life couples with stroke. In: Gotlib BH, editors. *Coping With Chronic Stress*. New York: Springer Science and Business Media (1997). p. 221–40. doi: 10.1007/978-1-4757-9862-3_8
22. Gignac MA, Gotlib BH. Changes in coping with chronic stress: the role of caregivers' appraisals of coping efficacy. In: Gotlib BH, editors. *Coping With Chronic Stress*. New York: Springer Science and Business Media (1997). p. 245–67. doi: 10.1007/978-1-4757-9862-3_9
23. Krause AM, Grant LD, Long BC. Sources of stress reported by daughters of nursing home residents. *J Aging Stud*. (1999) 13:349–64. doi: 10.1016/S0890-4065(99)80101-7
24. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging*. (2003) 18:250–67. doi: 10.1037/0882-7974.18.2.250
25. Pitfield C, Shahriyarmolki K, Livingston G. A systematic review of stress in staff caring for people with dementia living in 24-hour care settings. *Int Psychogeriatr*. (2011) 23::4–9. doi: 10.1017/S1041610210000542
26. Norris F, Murrel S. Social support, life events, and stress as modifier of adjustment to bereavement by older adults. *Psychol Aging*. (1990) 5:429–36. doi: 10.1037/0882-7974.5.3.429
27. Paulsen V, Shaver J. Stress, support, psychological states and sleep. *Soc Sci Med*. (1991) 32:1237–43. doi: 10.1016/0277-9536(91)90038-E

28. Roest HG van der, Eenoo L van, Lier L van, Onder G, Garms-Homolová V, Smit JH, et al. Development of a novel benchmark method to identify and characterize best practices in home care across six European countries: design, baseline, and rationale of the IBenC project. *BCM Health Serv Res*. (2019) 19:310. doi: 10.1186/s12913-019-4109-y
29. Morris JN, Fries BE, Bernabei R, Steel K, Ikegami N, Carpenter I, et al. *interRAI Home Care (HC) Assessment Form and User's Manual*. (2009). Available online at: www.interRAI.org (accessed December 20, 2019).
30. Burrows A, Morris, JN, Simon S, Hirdes JP, Phillips C. Development of a minimum data set-based depression rating scale for use in nursing homes. *Age Ageing*. (2000) 29:165–72. doi: 10.1093/ageing/29.2.165
31. Hirdes, JP, Frijters D, Teare, G. The MDS- CHESS scale: a new measure to predict mortality in the institutionalized elderly. *J Am Geriatr Soc*. (2003) 51:p. 96–100. doi: 10.1034/j.1601-5215.2002.51017.x
32. Morris JN, Fries BE, Morris SA. Scaling ADLs within the MDS. *J Gerontol*. (1999) 54:M546–53. doi: 10.1093/gerona/54.11.M546
33. Fries BE, Simon SE, Morris JN, Flodstrom C, Bookstein FL. Pain in U.S. nursing homes: validating a pain scale for the minimum data set. *Gerontologist*. (2001) 41::173–9. doi: 10.1093/geront/41.2.173
34. Morris JN, Fries BE, Mehr DR, Hawes C, Philips C, Mor V, et al. MDS cognitive performance scale. *J Gerontol.* (1994) 49:M174–82. doi: 10.1093/geronj/49.4.M174
35. Préville M, Coté G, Boyer R, Hébert R. Detection of depression and anxiety disorders by home care nurses. *Aging Ment Health*. (2004) 8:400–9. doi: 10.1080/13607860410001725009
36. Maciejewski PK, Prigerson HG, Mazure CM. Sex differences in event-related risk for major depression. *Psychol Med*. (2001) 31:593–604. doi: 10.1017/S0033291701003877
37. Breen G, Berglun AD, Levinson DF, Lewis CM, Ripke S, Sullivan NR, et al. Genome-wide association analyses identify 44 risk variants and refine the genetic architecture of major depression. *Nat Genet*. (2018) 50:668–681. doi: 10.1038/s41588-018-0090-3
38. Kessler RC. The effect of stressful life events on depression. *Annu Rev Psychol*. (1997) 48:191–214. doi: 10.1146/annurev.psych.48.1.191
39. Bebbington P, Hurry J, Tennant C. Adversity and symptoms of depression. *Int J Soc Psychiatry*. (1988) 34:163–177. doi: 10.1177/002076408803400301
40. Richardson TM, Friedman B, Podgorski C, Knox K, Fisher S, He H, et al. Depression and its correlates among older adults accessing aging services. *Am J Geriatr Psychiatry*. (2012) 20:346–54. doi: 10.1097/JGP.0b013e3182107e50
41. Meeks S, Murrell SA, Mehl RC. Longitudinal relationship between depressive symptoms and health in normal older and middle – aged adults. *Psychol Aging*. (2000) 15:100–9. doi: 10.1037/0882-7974.15.1.100
42. Choi NG, Ranson S, Willie RJ. Depression in older nursing home residents: the influence of nursing home environmental stressors, coping, and acceptance of group and individual therapy. *J Aging Stud.*. (2008) 13:349–64. doi: 10.1080/13607860802343001
43. Achterberg W, Pot AM, Kerkstra A, Ribbe M. Depressive symptoms in newly admitted nursing home residents. *Int J Geriatr Psychiatry*. (2006) 21:1156–62. doi: 10.1002/gps.1623

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REVIEW
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Fostering Well-Being in the Elderly: Translating Theories on Positive Aging to Practical Approaches

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This article overviews positive aging concepts and strategies to enhance well-being in the elderly and then presents a translation of theories on positive aging to practical approaches for Positive Aging. Drawing upon positive psychology and positive aging research and tools, this program is designed to help older adults improve their well-being by acquiring skills and strategies to cope with present and future challenges. The Mental Fitness Program for Positive Aging (MFPPA) can enhance seniors' quality of life by increasing their vital involvement and active engagement in life. This model is most appropriate for community dwelling individuals. It can easily be conducted in wide range of adult education programs in community centers, sheltered homes, and primary care clinics. It can also be conducted through online psychoeducational training.

Keywords: mental health, well—being, positive psychology, successful aging, positive health

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INTRODUCTION

The world is facing a demographic revolution; life expectancy has risen by more than two decades since 1950 and the population has grown considerably. According to the World Health Organization (1), the number of people over 60 in almost every country is growing faster than any other age group. This reflects a combination of influences including increased longevity, declining fertility, and the aging of the "baby boom" generation. These increases in longevity and the quality of life of older adults constitute a challenge to mental health professionals working to help the growing older population not only to live longer and healthier but also better and happier. How to age successfully and embrace well-being is the focus of much concern.

Traditionally, at least in Western societies, the elderly were viewed as "irrelevant" and a financial drain on society. Recent studies have shown that many older adults are relatively healthy, active, and independent, and have many more resources for aging successfully and maintaining high levels of well-being. A growing number of older adults are resilient, socially engaged, and involved in their families and communities (2–5).

Growing old in the twenty-first century is still a challenge and entails high risk, especially for the "old-old" and the "oldest-old." Thus, aging successfully depends to a large extent on coping effectively with age-related life events.

This article describes strategies and an intervention to enhance older adults' positive functioning and well-being (6, 7) based on theories of positive aging and positive psychology research and interventions. Positive psychology, in theory and practice, centers on the notions of well-being and optimal functioning. Research on positive aging deals with the comparative psychological well-being of older adults (8), their mental and physical health, concepts associated with aging successfully (9–12), and how psychological well-being can contribute to better health (13–15).

Rather than emphasizing dysfunction and psychopathology, the emphasis is on ways to flourish and increase functioning. Positive psychology studies have put forward techniques to deal more effectively with key transitions over the course of the lifespan (14–17). In this sense, research on positive psychology and its principles can be harnessed to support positive aging.

Many active seniors do volunteer work or have part-time jobs where they can still contribute to family and community welfare (5). However, although the elderly continues to make a contribution to their society, there are still extensive disparities in the way people experience aging and its many physical and cognitive impairments (6, 18). This makes it imperative to better understand what constitutes successful aging and in particular how the lens of positive psychology can support and foster mental and physical health.

POSITIVE AGING: A CHALLENGE FOR OLDER ADULTS' MENTAL HEALTH

Positive aging is a multidimensional concept that combines various characteristics of aging well such as optimal, successful, productive, and healthy aging. Positive aging consists of five independent factors: health, cognition, activity, affect, and physical fitness. It is described in practice by a broad set of biopsychosocial factors and is assessed through both objective and subjective indicators. The basic notion is that at any age, including the old and very old, people are to some extent in charge of and responsible for their own quality of life (2). They can enjoy positive well-being and experience "successful aging." Various models of successful aging (8, 9, 19–21) have explored the components and dimensions of well-being and positive function in older adults.

Ryff's integrated model (originally called "successful aging" and later psychological well-being), was first presented by Ryff (19) and Ryff and Essex (22) and later by Ryff and Singer (8, 23) and Ryff (20). It incorporates lifespan developmental theories, clinical theories of personal growth, and mental health perspectives. It comprises six dimensions of positive functioning: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth.

Research has revealed that these dimensions of well-being and healthy mental functioning are shaped by socio-demographic characteristics (e.g., age, gender, socio-demographic status, ethnicity, and culture), as well as by individual experiences, including both unexpected life stresses and planned, normative transitions (22–25). Hedonic well-being generally shows gains with age; that is, older adults tend to show increments in positive affect and decrements in negative affect, at least until very old age. In contrast, eudemonic well-being, reflecting a sense of purpose, is more inclined to reflect decrements in the later years, especially in terms of assessment of purpose in life and personal growth (8). In-depth measures across multiple domains as well as longitudinal follow-ups have been conducted since Ryff (19) first introduced the successful aging model. One of the most prominent studies is MIDUS (Midlife in the US, www.midus.wisc.edu).

The MIDUS findings documented that multiple psychosocial factors such as purpose in life, social relationships, mastery, and prosocial behaviors such as volunteering predict better self-rated health, less disability, healthier profiles of biological risk, greater well-being, and better cognitive function in aging adults, even in the context of disability and chronic illness (26). Other findings suggest that resilience in the face of age-related challenges may involve not only a better quality of life but also a reduced risk of future disability and death.

Growing neuroscientific evidence linking psychological well-being to physical health, and biological regulation shows that qualities such as purposeful engagement, self-realization and growth, and enlightened self-regard influence how long and how well people live. Some studies have linked illnesses and disabilities to different aspects of well-being. Epidemiological studies have documented the protective influence of well-being (especially purpose in life) in reducing later life ill-health and cognitive impairment (25). Even positive emotional experiences such as enjoyment can help reduce anxiety and thereby indirectly decrease cortisol production (26). Epidemiological studies have suggested that the degree of purpose in life predicts reduced risk for numerous diseases (Alzheimer's disease, stroke, myocardial infarction), and a proliferation of studies have begun to probe the underlying biological mechanisms of neuroendocrine regulation, inflammatory processes, gene expression, glycemic control, and cardiovascular risk on aging. Many more studies have linked phenomenological indicators of well-being to reduced amygdala activation in response to negative stimuli, sustained activity in the ventral striatum and dorsolateral cortex when viewing positive stimuli, and increased insular cortex volume [for more details see Ryff (25)].

All these analyses in the fields of phenomenology, biology, genetics, and neuroscience contribute to accounting for adaptive human functioning (20, 25). Positive aging studies have found that older adults can optimize their aging experience (20, 25, 27). They can maintain and implement preventive health behaviors, act on resources available to them to cope with age-related decline, and increase their well-being (7, 28). Thus, the focus should be on wellness, not illness in psychological research and in interventions for the older population.

INTERVENTIONS

The broad scope of studies on psychological well-being and its complex links to mind-body and socio-cultural factors have fostered important new directions in applications and education. Interventions to enhance and improve older adults' well-being are on the rise. These advances have been accompanied by preventive interventions outside the clinic (25, 29, 30).

Numerous intervention studies with older adults in the community, clinics, and in nursing homes have reported noticeable improvements in their psychological well-being (30–36), subjective happiness (36–39), and life satisfaction (30, 40, 41). These changes in well-being are accompanied by improvements in the quality of sleep (30, 33), better working memory (32), decreased anxiety (36), higher levels of overall mindfulness (42), and improvements in self-reported feelings of depression and depressive symptoms (30, 34–36, 38, 39, 42). Although these well-being interventions suggest that the older population's quality of life can be improved, studies with more rigorous designs and extended follow-up measurements are needed to consolidate these positive findings.

The major purpose of this wide range of interventions is to reach as many older adults as possible, especially those who avoid seeking psychological support because of their negative beliefs and attitudes toward psychotherapy or mental health professionals. Older adults should be provided with the necessary support to maintain a good balance between their decreased physical ability and increased transcendence, which can be significantly enhanced by tapping personal, environmental, and social resources. This equilibrium includes physical and mental health at the micro level (personal), social well-being, and spirituality/transcendence (process) at the meso level, while living in a favorable and appropriate environment (43). Many older adults constitute a resourceful group that can contribute actively to society, realize their own potential, cope with normal stressors of life, and contribute to their community productively and fruitfully. They implement what is called proactive coping, which is defined as "an effort to build up general resources that facilitate promotion toward challenging goals and personal growth" [(44), p. 349].

The challenge facing professionals working with older adults is to convey information about positive aging and suggest strategies to increase well-being by teaching new skills for positive functioning. This can be achieved by recruiting and training staff members in health centers, primary care, sheltered homes, and other community centers and services for older adults who can help incorporate strategies and tools for optimal functioning in their organizations and communities.

STRATEGIES TO ENHANCE POSITIVE AGING

Comprehensive Assessment of the Older Person's Positive Health in Primary Care Services and Mental Health Clinics

Many medical professionals, and specialists in particular, tend to overlook the constitutive unity of the person as a whole in the context of this individual's physical, social, and mental surroundings. Any comprehensive evaluation in mental health clinics, hospitals, and primary care should include an in-depth examination of the person's life, beyond his or her cognitive and physical condition. This means including information as to the person's social, cultural, historical, and spiritual background to assess the individual's positive health. This information can be obtained prior to the consultation by the secretarial staff, interns, or students and should be transmitted to the doctor. This is particularly true for depression, which constitutes the most common emotional disorder in older adults. Milder forms of depression such as dysthymia are known to affect 20–30% of all older adults (45). Nevertheless, older people are rarely offered psychological interventions (46). Many older patients who suffer from depression remain undetected in primary care. Studies show that somatization is one of the most important single problems associated with this missed diagnosis (47). The risk of suicide among older men is the highest mostly as a result of chronic physical illnesses and disability (48). Research has shown, however, that 20% of these individuals had consulted a physician that same day, and 40% in the same week that they committed suicide (49, 50). Medical staff are often "gate- keepers" who meet older adults who may be at risk for psychological and social problems. Awareness of the inseparable relationships between physical and mental health can lead to comprehensive assessment of the older person's positive health. This is necessary if we wish to prevent and detect mental health issues as well as to enhance optimal well-being of older adults.

Promoting Positive Health

The objective of positive health programs is to encourage seniors to be more cognizant of their own resources and their strong health points to cultivate their rich physical, cognitive, and social qualities. These programs should be conducted as wellness programs offered by primary care clinics or health clubs in the community that are designed to encourage better health through changes in diet, cutting down on cigarettes and alcohol, getting more exercise, and learning ways to manage stress and increase relaxation. Taking these steps toward maintaining a healthier lifestyle can reduce the impact of disease (51). These guidelines may also have a positive effect on cognitive decline and mood swings. Healthcare professionals may be engaged in the implementation of these interventions and reach out to older adults in their community to encourage them to join health promotion programs and engage in interventions that enhance positive aging. Primary care clinics can also offer a wide range of preventive interventions such as fall prevention and disability interventions for the frail and elderly (52, 53).

Promoting Optimal Aging

A systematic review and analysis of the effectiveness of 69 psychosocial interventions to promote the mental health of older adults (54) revealed that skill training interventions with educational and/or behavioral components had a significant effect on positive mental health outcomes. Promoting optimal aging can be achieved by implementing special training programs for older adults in the community including in leisure clubs, country clubs, retirement villages, sheltered homes, and homes for the aged. They can also be conducted through online psychoeducational training. These training programs can include, for example, the ABC model (Activating events-adversities, Beliefs-Consequences) of optimal aging, which is grounded in the notions of unconditional self-acceptance and the frustrations linked to the inevitable consequences of aging (55). Alternatively, the six "keys" for positive functioning can give the elderly more meaning and purpose (8, 13, 20) where seniors are encouraged to acquire a more positive attitude toward one's own self and the past including improving interactions with significant others. Seniors can work on their autonomy, learn to have a voice, and reinforce their capabilities to make decisions affecting their lives. Mastering one's environment by being able to handle daily life and create surroundings adapted to one's needs is another key. One way of having renewed purpose in life is to reassess the present and the past, or engaging in social activities. Senior volunteers, for example, were found to be happier, calmer, more content, more fulfilled, and more vital (56). Older adults who are able to capitalize on these five keys are more likely to experience the sixth key of personal growth and are more open to experiences and capable of greater further development.

Positive Assessment of the Older Person's Strengths and Reserve Capacities

Practitioners and therapists working with older clients should move away from the traditional medical assessment model. Instead of focusing on the older person's weaknesses (a frail body, depressive moods, or weak community relationships), professionals should assess and activate clients' strengths and reserve capacities, and the strengths of the key primary environment (family, friends, close associates, etc.) and secondary groups (large-scale organizations, communities, cultural groups, etc.) to reach personal goals and prevent predictable problems (57, 58). Thus, rather than asking "What is wrong?" (the typical question asked when visiting the physician), mental health professionals should aim to determine "What is good about me? What is still working? What is my reserve capacity?" (6, 59). Positive assessments can be combined with the physical assessments and should be given to the older person as part of the overall positive health assessment.

Positive Psychology Interventions to Cope With Loneliness and Depression

Loneliness is a significant risk factor in the emergence of mental and physical health problems (60). When meaningful social connections are perceived as severed or unavailable, loneliness can have deleterious effects on cognition and behavior (61). Interventions in healthy older adults such as physical or dietary changes and enhancing social and cognitive engagement can help diminish the impact of loneliness on the aging process and the emergence of psychiatric disorders (62).

Older people with depressive disorders can receive additional cognitive behavioral therapy, which is an effective treatment for depression and anxiety (46, 63, 64). In a systematic review (65) examining the utility of 34 loneliness alleviation interventions among older persons, the findings suggested that loneliness can be reduced by using educational interventions focused on social network maintenance and enhancement. These interventions can be implemented directly in face-to-face meetings, group psychoeducation encounters, or through tele-help online interventions. Today, mental health clinics are rapidly converting from face-to-face modes of care to virtual ones as a result of the COVID-19 pandemic. Since the beginning of the pandemic, many older adults have opted to stay at home and avoid attending adult day centers and other community programs. This underscores the importance of establishing a system of remote mental care, comparable to what is being implemented for physical healthcare (66–69).

The telephone and video substitutes for in-person meetings pose an enormous challenge but also an opportunity to reach out to many older adults who otherwise would not receive emotional support. A support system could be established, for example, by initiating substantive online conversations to ascertain that their emotional and mental needs are being met and to encourage them to ask for help, and to share. This would contribute to reducing the loneliness and isolation that accompany long-term lockdowns. Studies have shown that writing down three good things or blessings every day, as well as engaging in gratitude and savoring techniques, can contribute to positive states and reduce feelings of depression related to ill-being, negative thoughts, and loss of a sense of meaning (70–72).

Changing Professionals' Attitude Toward Positive Aging in Medical Staff, Old-Age Home Staff, and Other Professionals Working With the Older Population

Positive psychology programs are likely to have more impact when those running them are themselves positive and healthy. This includes a better understanding of the aging process in the medical profession, which may still see aging as purely negative (69, 73, 74). There should be a concerted effort to expand the basket of psychological health services offered to the elderly, which would alleviate the strain on the health system through prevention, detection, and rapid responses (75).

Enhancing a Sense of Community and Connectedness

Fostering dialogue and a sense of community can help seniors increase their social and emotional support, find ways to preserve and enrich family, friends, and community ties, and take advantage of neighborhood, community, and social activities to cope with anxiety and feelings of isolation. One major step involves proactive interactions to contact seniors without a strong social network by providing regular ways to "check in" by including them in social events and structured activities for older adults, as well as psychoeducation and support. Internet skills are a plus. Seniors can be taught to search for content of interest to their age group, read local newspapers, get medical information, find out about events likely to appeal to them, and ways to socialize through emails, WhatsApp, Facebook, etc. Studies have shown that being computer savvy reduces isolation and reinforces a sense of autonomy (76).

Overall, positive psychology interventions can be applied in health settings, but they should also be conducted in settings already designed for positive interactions, such as senior citizens' clubs and retirement communities. Modern media, including radio, TV, and the internet, are important ways to connect and reach out to the elderly. By teaching seniors fundamental techniques that can lead to greater optimism, enhanced positive thinking, and ways to define objectives that lead to higher involvement and meaningful participation in the community, older adults can benefit from an improved quality of life. Systematic reviews of interventions designed to enhance the well-being of older adults indicate that group-based interventions and interventions including social components have a very positive effect on participants' mental health (54). This suggests that group-based interventions should be prioritized.

THE MENTAL FITNESS PROGRAM FOR POSITIVE AGING

The Mental Fitness Program for Positive Aging is designed as a psychological journey with 12 stations, each addressing a different topic. The program can be applied in a group setting or individually through personal coaching or counseling. The program includes a "personal map, compass, sail and oars" to help senior citizens plan how they want to live their lives in the near future and what they wish to experience along the way (55). These combined tools provide participants with a way of developing positive attitudes toward aging by encouraging them to review their past accomplishments and their current personal resources and strengths. Various positive psychology strategies are introduced in each session, such as exploring personal strengths and practicing new ways to use them, learning how to invest in significant relationships, visualizing one's best self, keeping a gratitude diary or a list of good things occurring during the day, seeking out activities that create flow, practicing mindfulness and acts of kindness, or accessing stories from their own lives to hone their sense of hope (6, 17, 77). Homework assignments for practicing these strategies are included together with other assignments relevant to each session's topic and assignments that are addressed to maintaining healthy lifestyle.

Phase 1 The journey begins with an introductory lecture by the group facilitator, who reviews the core and the latest studies in positive psychology and positive aging. Then, attendees decide whether they want to continue as participants. Registering for the group can be viewed both as a proactive step toward change and an indicator of willingness and commitment to attend most of the sessions and execute the homework assignments.

Phase 2 The second phase addresses the issue of identity and the aging self. The focal task is to increase self-acceptance and positive self-image. Participants are guided in posing the following questions to themselves: "Who am I?" and "Who am I at this particular phase of my life?" Each participant is asked to write a personal introduction card in the form of several bullet points, by way of response to the above questions.

The purpose of this exercise is to discuss individual identity and activities toward reinforcing self-acceptance and positive self-esteem. Discussion questions are: "What does it mean to you to be 70+ years old? How do you feel as someone who is retired? What is your role as a grandmother or grandfather?" and others. By discussing this "business card" the third ager can evaluate his or her life satisfaction, mental and emotional engagements in life, and personal attitudes. The bulleted identity points written on the card raise important reflective questions such as "What are my roles and meaningful engagements in life? Do I present myself in a positive or negative light? Do I emphasize my achievements or my shortcomings? Do I dwell on the past and my losses or emphasize the positive aspects of the present?" By analyzing the "business cards," the group and facilitator can learn a great deal about the participants' well-being.

The facilitator then helps the participants highlight their positive experiences and strengths and to shift from thinking about what they can no longer do to what they can achieve in the present. Participants are asked to examine their reserve capacities.

Phase 3 The Mental Fitness Program encourages senior citizens to examine their rich pasts as well. Reviewing past experiences and applying understanding and acceptance to disappointments and failures allows the participants to "draw" a road map of their talents and skills and the domains in which self-efficacy has been cultivated. The focus of the discussion is on achievements and accomplishments in life rather than dwelling on negative experiences, which are nevertheless recognized. Each person is given a picture of a boat sailing in the ocean. The guiding questions are: "Where do I come from and where do I want to sail to in the near future?" Participants should provide a short description of their past experiences with a focus on significant events and milestones in which they can evaluate their strengths and personal resources. When discussing negative or traumatic experiences, participants should reflect on how those were overcome and what capabilities and internal strengths helped them cope and adapt.

Maintaining positive self-esteem is often associated with the quality of interpersonal relations; thus, the first three sessions also focus on mapping and assessing relations with meaningful others such as family members, friends, colleagues, or others. Positive self-esteem also relates to the senses of autonomy, environmental mastery, self-realization, and personal growth, with the latter serving to enhance the pursuit of life's goals. Senior citizens who were fully engaged in work or social roles, as well as widows and widowers who were assuming the role of care-giver, may need guidance in finding suitable alternative contexts for gaining a sense of control and purpose in their lives.

In gaining a sense of direction and a realistic view of identity and self-image, the participants are enabled to discuss their priorities, and personal and independent decisions, before planning and setting goals to maintain or increase their well-being. The program teaches the participants to identify positive, realistic goals and to use the adaptive mechanisms of selection, optimization, and compensation (SOC) (9) to promote continued maximization of their chosen activities in life, especially as they grow older and their resources decline (78).

Phase 4 In this phase participants focus on their purpose in life through the process of goal attainment. Setting clear, realistic, measurable, and significant goals and managing time and learning how to spend time effectively become increasingly important elements as people age and find they have more free time and fewer commitments to family, work, and other obligations (79).

Thereafter, participants identify and increase their health-promoting behaviors, to cope with the adversities encountered in growing old. Since unrealistic expectations, beliefs, and attitudes regarding old age affect well-being and impede goal attainment, they learn to identify and replace irrational beliefs and attitudes with rational, more realistic ones (28). Assisted by the group, the participants individually and collectively seek and create emotional and social support. Participants are encouraged to form a social network using the internet or phone communication, which is activated between the meetings for staying in touch, receiving support, and sharing experiences, thoughts, and feelings experienced during the week.

The Mental Fitness Program can also be an effective intervention tool to assess senior citizens' main areas of personal difficulty. It helps ascertain which components to positive well-being would benefit from enhancement, such as low self-esteem, unsatisfying relations with others, lack of emotional or social support, or difficulties in making decisions and taking the steps to fulfill personal needs. It may also indicate the phase in life where changes and losses require that personal goals be revised to promote emotional and psychological engagement and gratification. For seniors who suffer from emotional problems or mental disorders, positive psychology interventions can be integrated into general treatment, such as positive psychotherapy, CBT-REBT, or IPT (Interpersonal Psychotherapy) for depression (28, 80). These interventions can be successful for helping professionals who are themselves optimistic and in good health in facilitating seniors. However, many professionals still need to overcome their own ageist attitudes and phobias if they are to effectively assist what will be an increasingly larger proportion of their clientele (73, 74, 81). Professionals should also encourage clients to maintain a healthy lifestyle and are encouraged to engage in strategic advocacy for extended medical insurance for mental health services, mainly in the areas of prevention, screening, and early intervention.

Implementation: This model is most appropriate for community-dwelling individuals with a high level of functioning. It can easily be conducted in a wide range of adult education programs in group settings, in community centers and health clubs. Seniors can be recruited through seniors' communities online (Facebook). It can be offered to members of health-care insurance companies as part of programs suggested to promote health aging. It can also be implemented online as is currently the case via Zoom. The Mental Fitness Program has been applied in Israel in community centers, sheltered homes, and retirement programs and has proved to be very effective, as shown by the excellent feedback provided by the participants. Mental health professionals were recruited to lead the group sessions after attending a full-day training course on how to conduct the program. The instructions for the mental fitness program are clear, and social work or psychology students can also be recruited to lead the group sessions.

Limitations: The mental fitness program is one of many interventions suggested to enhance the well-being of older adults. Its advantage is that it is a comprehensive program of positive health combining the physical, cognitive, social, and emotional aspects of positive aging. The limitations of this model have to do with the fact that it is most appropriate for community-dwelling individuals with a high level of functioning as compared to individuals who have experienced cognitive decline. Another limitation is that to date, the model suggested has not been methodologically evaluated. An evaluation of this model should be performed and should be tested methodologically. The decision as to the type, frequency, and length of any strategy is, however, not easy to estimate. It depends on the institutions, and the older adults' current capacity, vulnerability, and subsequent adherence to the intervention (52, 62).

Systemic reviews of interventions designed to enhance the well-being of older adults indicate that group-based interventions and interventions including social elements have a very positive effect on participants' mental health (54). This suggests that group-based interventions such as the Mental Fitness Model for Positive Aging can be effectively prioritized.

We hope that the Mental Fitness Program will be evaluated shortly and will be approved as an effective intervention in promoting positive well-being of older adults.

SUMMARY

The demographic revolution constitutes a real challenge for society, but in particular for the older population and their helping professionals. The challenge for older adults is to maintain and, if possible, to increase their personal resources so as not to overwhelm societal resources with their needs. Thus, older adults should bear some responsibility for making sure that they maintain their health, maintain a healthy lifestyle, and are engaged in their families and communities. The challenge for helping professionals is to shift away from traditional stereotypes and ageism and suggest interventions that focus on wellness and older adults' reserve capacities rather than on illness, patients, and symptoms. Interventions should incorporate practicing positive aging and well-being strategies to increase autonomy, environmental mastery, and purpose in life, as well as a healthy lifestyle. A prime point of intervention is to identify the resources and facilitate the social network cooperation that will keep older adults socially and physically active and involved in their communities. It can be achieved together with the medical, physical, and mental health services given in health centers and primary care. Interventions should be adjusted to individual older adults' level of functioning, special needs, and motivation.

Although findings indicate that the majority of the older population has a resourceful interpersonal milieu, varied social networks, and positive well-being (82–84), there is also the risk of future disability and limitations in mobility, which can increase loneliness and reduce well-being. Increased loneliness and reduction in physical and mental health was also found in many older adults during the COVID-19 pandemic. It is recommended to recruit and train medical staff in health centers and primary care to incorporate strategies and tools for optimal functioning into their medical treatment approach. Crucially, the foundations for positive aging are laid down early in life by adopting a healthy lifestyle. It is important to develop healthy habits throughout the life cycle, which depends to a great extent on social and cultural contexts. Therefore, it is imperative to develop educational programs and interventions in the community to promote strategies for positive functioning and well-being. The challenge to present and future societies is to provide older persons with opportunities for self-realization, continued personal growth, and social engagements.

AUTHOR CONTRIBUTIONS

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

REFERENCES

1. World Health Organization. *Mental Health and Older Adults* (2016). Available online at: https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults
2. Hill RD. *Positive Aging: A Guide for Mental Health Professionals Consumers*. New York, NY: W. W. Norton (2005).
3. Hinrichsen AG. *Assessment and Treatment of Older Adults: A Guide for Mental Health Professionals*. Washington, DC: American Psychological Association (2020). doi: 10.1037/0000146-008
4. Sougleris C, Ranzijn R. Proactive coping in community dwelling older Australians. *Int J Aging Hum Dev.* (2011) 72:155–68. doi: 10.2190/AG.72.2.d
5. Williamson GM, Christie J. Aging well in the 21st century: challenges opportunities. In: Snyder CR, Lopez SL, editors. *Oxford Handbook of Positive Psychology, Part 3*. New York, NY: Oxford university Press (2009). p. 65–170. doi: 10.1093/oxfordhb/9780195187243.013.0015
6. Bar-Tur L. *The Challenge of Aging: Mental Health, Assessment and Therapy*. Jerusalem: Eshel (2019).
7. Bar-Tur L, Malkinson R. Positive aging: from negative to positive models on aging. In: Pachana NA, Laidlaw DK, editors. *The Oxford Handbook of Clinical Geropsychology*. London: Oxford Press (2014). p. 927–48.
8. Ryff CD, Singer B. Know thyself what you are: a eudaimonia approach to psychological well-being. *J Happiness Stud.* (2008) 9:13–39. doi: 10.1007/s10902-006-9019-0
9. Baltes PB, Baltes MM. Psychological perspectives on successful aging: the model of selective optimization with compensation. In: Baltes PB, Baltes MM, editors. *Successful Aging: Perspectives From the Behavioral Sciences*. London: Cambridge University Press (1990). p. 1–34. doi: 10.1017/CBO9780511665684.003
10. Baltes PB, Carstensen LL. The process of successful aging. *Aging Soc.* (1996) 16:397–422. doi: 10.1017/S0144686X00003603
11. Depp AC, Jeste DV. 'Definitions and predictors of successful aging: a comprehensive review of larger quantitative studies. *J Geriatr Psychiatry*. (2006) 14:6–20. doi: 10.1097/01.JGP.0000192501.03069.bc
12. Rowe JW, Kahn RL. *Successful Aging*. New York, NY: Pantheon Books (1998).
13. Ryff CD, Singer B. The contours of positive health. *Psychol Inq.* (1998) 9:1–28. doi: 10.1207/s15327965pli0901_1
14. Seligman, MEP. Positive Health. *Appl Psychol.* (2008). 75:3–18. doi: 10.1111/j.1464-0597.2008.00351.x
15. Seligman MEP. *Flourish: A Visionary New Understanding of Happiness and Well-Being*. New York, NY: Free Press (2011).
16. Diener E, Biswais-Diener R. *Happiness: Unlocking the Mysteries of Psychological Wealth*. New York, NY: Wiley (2008). doi: 10.1002/9781444305159
17. Lyubomirsky S. *The How of Happiness: A Scientific Approach to Getting the Life You Want*. New York, NY: Penguin Press (2008).
18. Jacobzine S, Cambois E, Robine J. *Is the Health of Older People in the OECD Countries Improving Fast Enough to Compensate for Population Ageing? OECD Economic Studies.* Paris: OECD (2002). p. 30.
19. Ryff CD. 'Beyond Ponce de Leon and Life Satisfaction: new Directions in Quest of Successful Aging. *Int J Behav Dev.* (1989) 12:35–55. doi: 10.1177/016502548901200102
20. Ryff CD. Psychological well-being revisited: advances in the science and practice of eudaimonia. *Psychother Psychosomat.* (2014) 83:10–28. doi: 10.1159/000353263
21. Rowe JW, Kahn RL. *Successful Aging*. New York, NY: Pantheon Books (1998).
22. Ryff CD, Essex M. 'Psychological well-being in adulthood old age: descriptive markers explanatory processes'. In: Schaie W, Lawton MP, editors. *Annual Review of Gerontology and Geriatrics*. New York, NY: Spring (1991). p. 144–71.
23. Ryff CD, Singer B. Psychological well-being: Meaning, measurement, and implications for psychotherapy research. *Psychother Psychosom.* (1996) 65:14–23. doi: 10.1159/000289026
24. Brim O, Ryff C, Kessler R. *How Healthy Are We?* Chicago: University of Chicago Press (2019). doi: 10.7208/9780226074764
25. Ryff CD. Well-being with soul: science in pursuit of human potential. *Perspect Psychol Sci*. (2018) 13:242–8. doi: 10.1177/1745691617699836
26. Ryff C. *New Directions in Understanding and Promoting Successful Aging 21st Bi-Annual Convention Israeli Gerontological Society Tel.* Aviv (2016).
27. Ryff CD. *Understanding Positive Aging as an Integrated Biopsychosocial Process.* Wisconsin-Madison: Institute on aging; University of Wisconsin-Madison (2012). Available online at: http://psych.wisc.edu/faculty/bio/kmRyff.htm
28. Malkinson R, Bar-Tur L. REBT with Ageing Populations. In: Dryden W, Bernard M, editors. *REBT with Diverse Client Problems and Populations*. Cham: Springer (2019). p. 837–55. doi: 10.1007/978-3-030-02723-0_17
29. Ruini C, Ryff CD. Using eudaimonia well-being to improve lives. In: Wood AM, Johnson J, editors. *Wiley Handbook of Positive Clinical Psychology*. Wiley Blackwell (2016). p. 153-66.
30. Friedman EM, Ruini C, Foy R, Jaros L, Sampson H, Ryff CD. Lighten UP! A community-based group intervention to promote psychological well-being in older adults. *Aging Ment Health*. (2017) 21:199–205. doi: 10.1080/13607863.2015.1093605
31. Bartholomaeus J, Van Agteren J, Iasiello M, Jarden A, Kelly D. Positive ageing: the impact of a community wellbeing program for older adults. *Clin Gerontol.* (2019) 42:377–86. doi: 10.1080/07317115.2018.1561582
32. Cantarella A, Borella E, Marigo C, De Beni R. Benefits of well-being training in healthy older adults. *Appl Psychol.* (2017) 9:261–84. doi: 10.1111/aphw.12091
33. Cesetti G, Vescovelli F, Ruini C. The promotion of well-being in aging individuals living in nursing homes: a controlled pilot intervention with narrative strategies. *Clin Gerontol.* (2017) 40:380–91. doi: 10.1080/07317115.2017.1292979
34. Meléndez JC, Fortuna FB, Sales A, Mayordomo T. The effects of instrumental reminiscence on resilience and coping in elderly. *Arch Gerontol Geriatr.* (2014) 60:294–8. doi: 10.1016/j.archger.2014.12.001
35. Preschl B, Maercker A, Wagner B, Forstmeier S, Baños RM, Alcañiz M, et al. Life-review therapy with computer supplements for depression in the elderly: a randomized controlled trial. *Aging Ment Health*. (2012) 16:964–74. doi: 10.1080/13607863.2012.702726
36. Ramírez E, Ortega AR, Chamorro A, Colmenero JM. A program of positive intervention in the elderly: memories, gratitude and forgiveness. *Aging Ment Health.* (2014) 18:463–70. doi: 10.1080/13607863.2013.856858
37. Greenawalt KE, Orsega-Smith K, Turner JL, Goodwin S, Rathie ER. The impact of "The Art of Happiness" class on community dwelling older

adults: a positive psychology intervention. *Act Adapt Aging*. (2019) 43:118–32. doi: 10.1080/01924788.2018.1493898

38. Ho HCY, Yeung DY, Kwok, SYCL. Development and evaluation of the positive psychology intervention for older adults. *J Pos Psychol*. (2014) 9:187–97. doi: 10.1080/17439760.2014.888577
39. Proyer RT, Gander F, Wellenzohn S, Ruch W. Positive psychology interventions in people aged 50-79 years: long-term effects of placebo-controlled online interventions on well-being and depression. *Aging Ment Health*. (2014) 18:997–1005. doi: 10.1080/13607863.2014.899978
40. Mayordomo T, Viguer P, Sales A, Satorres E, Meléndez JC. Resilience and coping as predictors of well-being in adults. *J Psychol*. (2016) 150:809–21. doi: 10.1080/00223980.2016.1203276
41. Sutipan P, Intarakamhang U, Macaskill A. The impact of positive psychological interventions on well-being in healthy elderly people. *J Happiness Stud*. (2017) 18:269–91. doi: 10.1007/s10902-015-9711-z
42. Turner J, Greenawalt K, Goodwin S, Rathie E, Orsega-Smith E. The development and implementation of the Art of Happiness intervention for community-dwelling older adults. *Educ Gerontol*. (2017) 43:630–40. doi: 10.1080/03601277.2017.1380894
43. Lak A, Rashidghalam P, Myint PK, Baradaran HR. Comprehensive 5P framework for active aging using the ecological approach: an iterative systematic review. *BMC Public Health*. (2020) 20:33. doi: 10.1186/s12889-019-8136-8
44. Schwarzer R. Manage stress at work through preventive proactive coping. In: Locke EA, editor. *The Blackwell Handbook of Principles of Organizational Behavior*. Oxford: Blackwell (2000). p. 342–55.
45. Sansone RA, Sansone LA. Dysthymic disorder: forlorn and overlooked? *Psychiatry*. (2009) 6:46–51.
46. Serfaty MA, Haworth D, Blanchard M, Buszewicz M, Murad S, King M. Clinical effectiveness of individual cognitive behavioral therapy for depressed older people in primary care: a randomized controlled trial. *Arch Gen Psychiatry*. (2009) 66:1332–40. doi: 10.1001/archgenpsychiatry.2009.165
47. Timonen M, Liukkonen T. Management of depression in adults. *BMJ*. (2008) 336:435–9. doi: 10.1136/bmj.39478.609097.BE
48. Conejero I, Olié E, Courtet P, Calati R. Suicide in older adults: current perspectives. *Clin Interv Aging*. (2018) 13:691–9. doi: 10.2147/CIA.S130670
49. Conwell Y. Physician-assisted suicide: a mental health perspective. *Suicide Life Threat Behav*. (1994) 24:326–33.
50. Conwell Y, Brent D. Suicide aging: I. Patterns of psychiatric diagnosis. *Int Psychogeriatr*. (1995) 7:149–64. doi: 10.1017/S1041610295001943
51. Kim ES, Strecher VJ, Ryff CD. Purpose in life and use of preventive health care services. *Proc Natl Acad Sci USA*. (2014) 111:16331–6. doi: 10.1073/pnas.1414826111
52. Bajraktari S, Sandlund M, Zingmark M. Health-promoting and preventive interventions for community-dwelling older people published from inception to 2019: a scoping review to guide decision making in a Swedish municipality context. *Arch Public Health*. (2020) 78:1-27. doi: 10.1186/s13690-020-00480-5
53. Niclasen J, Lund L, Obel C, Larsen L. Mental health interventions among older adults: a systematic review. *Scand J Public Health*. (2019) 47:240–50. doi: 10.1177/1403494818773530
54. Forsman AK, Nordmyr J, Wahlbeck K. Psychosocial interventions for the promotion of mental health and the prevention of depression among older adults. *Health Promot Int*. (2011) 26(Suppl. 1):i85–107. doi: 10.1093/heapro/dar074
55. Ellis A, Velten E. *Optimal Aging: Get Over Getting Older*. New York, NY: Open Court (1998).
56. Greenfield EA, Marks N. Formal volunteering as a protective factor for older adults' psychological well-being. *J Gerontol*. (2004). 59B:S258–64. doi: 10.1093/geronb/59.5.S258
57. Kivnick HQ, Murray SV. Life strengths interview guide: Assessing elder clients' strengths. *J Gerontol Soc Work*. (2001) 34:7–31. doi: 10.1300/J083v34n04_03
58. Klein WC, Bloom M. *Successful Aging: Strategies for Healthy Living*. New York, NY: Plenum Publishing Corporation (1997). doi: 10.1007/978-1-4615-5931-3
59. Bar-Tur L. Positive aging: a program designed to enhance positive functioning and well-being in older adults. *J Aging Stud*. (2018) 45:93–112. Available online at: http://www.gerontology.org.il/
60. Hawkley LC, Cacioppo JT. Aging and loneliness: downhill quickly? *Curr Direct Psychol Sci*. (2007) 16:187–91. doi: 10.1111/j.1467-8721.2007.00501.x
61. Cacioppo JT, Hawkley LC. Perceived social isolation and cognition. *Trends Cogn Sci*. (2009) 13:447–54. doi: 10.1016/j.tics.2009.06.005
62. Depp AC, Harmell AL, Jeste D. Strategies for successful aging: a research update. *Curr Psychiatry Rep*. (2014) 16:476. doi: 10.1007/s11920-014-0476-6
63. Malkinson R, Bar-Tur L. Bereavement and grief work. In: Pachana NA, Laidlaw DK, editors. *The Oxford Handbook of Clinical Geropsychology*. London: Oxford Press. (2014) p. 837–55.
64. Merriam SB, Kee Y. Promoting community wellbeing: The case for lifelong learning for older adults. *Adult Educ Q*. (2014) 64:128–44. doi: 10.1177/0741713613513633
65. Cohen-Mansfield J, Perach R. Interventions for alleviating loneliness among older persons: a critical review. *Am J Health Promot*. (2015) 29:e109–25. doi: 10.4278/ajhp.130418-LIT-182
66. Cohen MA, Tavares J. Who are the most at-risk older adults in the COVID-19 era? It's not just those in nursing homes. *J Aging Soc Policy*. (2020) 32:380–6. doi: 10.1080/08959420.2020.1764310
67. Hollander JE, Carr BG. Virtually perfect? Telemedicine for COVID-19. *N Engl J Med*. (2020) 382:1679–81. doi: 10.1056/NEJMp2003539
68. Vahia IV, Blazer DG, Smith GS, Karp JF, Steffens DC, Forester BP, et al. COVID-19, mental health and aging: a need for new knowledge to bridge science and service. *Am J Geriatr Psychiatry*. (2020) 28:691–4. doi: 10.1016/j.jagp.2020.05.029
69. Bar-Tur L, Brick Y, Inbal-Jacobson M, Brick-Deshen S, Zilbershlag Y, Pearl-Naim S. Telephone-Based emotional support for older adults during the Covid-19 pandemic. *Gerontol Geriatr*. (2021) 45:93–112.
70. Rashid T, Seligman MEP. An overview of fourteen sessions of PPT. In: Seligman MEP, editor. *Flourish: A Visionary New Understanding of Happiness and Well-Being*. New York, NY: Free Press (2011). p. 41–3.
71. Seligman MEP, Rachid T, Parks AC. Positive psychotherapy. *Am Psychol*. (2006) 61:774–88. doi: 10.1037/0003-066X.61.8.774
72. Seligman MEP, Steen TA, Park N, Peterson C. Positive psychology progress: empirical validation of interventions. *Am Psychol*. (2005) 60:410–21. doi: 10.1037/0003-066X.60.5.410
73. Eyal N, Bar-Tur L. A light on the psychology of aging; the missed dance, the therapist's refusal and the patient's refusal. *Psycho Actualia*. (2002) 24–8.
74. Helmes E, Gee S. Development of a training program in clinical Geropsychology. *Aust J Ageing*. (2000) 19:113–7. doi: 10.1111/j.1741-6612.2000.tb00160.x
75. Karlin BE, Humphreys K. Improving medicare coverage of psychological services for older Americans. *Am Psychol*. (2007) 62:637–49. doi: 10.1037/0003-066X.62.7.637
76. Raj A, Kumar P. Ageing and positive mental health: a brief overview. *Indian J Health Soc Work*. (2019) 1:10–19. Available online at: https://aiamswp.in
77. Kauffman C. *Applied Positive Psychology in Action: New Developments for Coaching, Consulting or Therapy*. Pennsylvania: Workshop presented at the International Positive Psychology Conference (2011).
78. Jopp D, Smith J. Resources and life-management strategies as determinants of successful aging: on the protective effect of selection, optimization, and compensation. *Psychol Aging*. (2006) 21:253–65. doi: 10.1037/0882-7974.21.2.253
79. Emmons RA. Personal goals, life meaning, virtue: Wellsprings of a positive life. In: Keyes CLM, Haidt J, editors. *Flourishing*. Washington, DC: American Psychological Association (2003). p. 105–28. doi: 10.1037/10594-005
80. Miller MD. *Clinical Guide to Interpersonal Psychotherapy in Later life*. New York, NY: Oxford, University Press (2009) doi: 10.1093/med:psych/9780195382242.001.0001
81. Bar-Tur L. Who cares for the caretaker? Professional and emotional skills of practitioners working with the elderly. *Gerontology*. (2010) 37:69–85. Available online at: http://www.gerontology.org.il/

82. Litwin H, Shiovitz-Ezra S. Social network type and subjective well-being in a national sample of older Americans. *Gerontologist.* (2011) 51:379–88. doi: 10.1093/geront/gnq094
83. Poon LW, Cohen-Mansfield J. *Understanding Well-Being in the Oldest Old*. New York, NY: Cambridge University Press (2011). doi: 10.1017/CBO9780511920974
84. Jopp DS, Boerner K, Cimarolli V, Hicks S, Mirpuri S, Paggi S, et al. Challenges Experienced at Age 100: Findings from the Fordham Centenarian Study. *J Aging Soc Policy*. (2016) 28:187–207. doi: 10.1080/08959420.2016.1163652

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Introducing Progressive Strength Training Program in Singapore's Elder Care Settings

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The use of progressive strength training among the elderly has become an accepted part of evidence-based practice for preventive and rehabilitative care. Exercise is undoubtedly one of the pillars for resilient aging. While research has shown impressive outcomes from strength training, the challenge remains to get elderly persons to exercise. Here we describe a Finnish-Singaporean cross-national project that provides a unique opportunity to evaluate the implementation of strength training in settings where it had previously not been applied. We report from the first 2 years of implementation using assessment data and surveys directed to frontline therapists responsible for the implementation. The strength training concept was progressively implemented in 24 elder care locations in Singapore including residential homes, day rehab/care centers, and senior activity centers. Each location was provided with training, support, gym equipment and technology solutions. It remained for individual sites to enroll elderly to the program, to perform assessments, and to direct the progressive strength training. Based on data from the first 2 years of implementation, improvements in lower body muscle strength were found in Leg Curl (ave 11.1–48.8%), Leg Extension (ave 10.2–24.0%) and Hip Abduction/Hip Adduction (ave 7.0–15.8%). Of the trained therapists, 95% strongly agreed or agreed to some extent that the implementation had been successful. The practice-based evidence from the project has demonstrated that it is feasible to implement progressive strength training in real life settings, using technology. While the implementation initially required handholding and support, the approach yielded consistent improvement rates in muscle strength comparable to results from randomized clinical trials (meta-analysis studies). Significant improvement rates in muscle strength were found in all three types of sites, demonstrating that gym training can be employed broadly in elder care. The Senior Activity Centers offer an interesting model for reaching seniors with preventive actions at an early stage. The data support a 3-month training as an effective intervention of introducing strength training in elder care settings, promoting healthy aging.

Keywords: strength training, exercise as medicine, elder care, implementation, interRAI

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INTRODUCTION

The aging population presents a global challenge. Old age is often associated with limitations of physical function, frailty, chronic diseases, and a consequent increase in the need for health services which translate into a higher economic burden for the society. The decline in physical functions and onset of chronic diseases also affect the elderly's quality of life. This has triggered a societal investigation in attenuating the age-related decline in physical function while increasing the years on independent living. A growing body of systematic evidence supports the importance of both exercise therapy and physical activity as prevention and treatment of specific diseases (1, 2) and for promoting healthy aging (3–8). Supervised intensive training has, according to the studies, clinically significant effects on strength and physical function (9–13). Global initiatives such as "Exercise is medicine" (14) demonstrates the awareness of the importance of exercise as a complement of the clinical treatments. Muscle strength can be improved regardless of age making it a broadly applicable remedy. The Finnish current national care guidelines have adopted "exercise is medicine" for an array of diseases and conditions (15). The Finnish FINGER and DR's EXTRA studies (16, 17) have highlighted physical activity and exercise as preventive factors against dementia. In the UK, The Academy of Medical Royal Colleges has in their 2015 guidelines referred to exercise as the "miracle cure" (18). The Lancet (19) initiated in 2012 its Series on physical activity and concluded (20) "that physical inactivity is as important a modifiable risk factor for chronic diseases as obesity and tobacco." WHO (21) has addressed the issue of physical (in)activity on a global level. WHO (22) has also recently introduced the concept of intrinsic capacity (IC) to emphasize the potential of healthy aging and combatting frailty though modifiable factors such as physical activity.

Progressive strength training in particular, is an important exercise therapy (23), indeed (24) "resistance exercise training should be considered a first-line treatment strategy for managing and preventing both sarcopenia and dynapenia." Since the 1990s, studies have shown the feasibility and effectiveness of progressive strength training for the elderly (25–28). Progressive strength training has recently (29) been emphasized by The Asia-Pacific Clinical Practice Guidelines for the Management of Frailty as a top priority method to combat frailty: "We strongly recommend that older adults with frailty be referred to a progressive, individualized physical activity program that contains a resistance training component." This echoes earlier reviews (30). Furthermore, there is also molecular evidence of the benefits of exercise (31).

While evidence-based research and practice have shown the importance of exercise and physical activity for health, the challenge remains to get people to exercise and to introduce exercise in clinical and other settings of elder care. There are many excuses not to exercise, but aging should not be one of them. The question is how to adapt academic research on evidence-based practices (EBP) to concrete situations "outside the laboratory" and embed them in the real world. This touches on the topic of "practice based evidence" (PBE) which is about developing evidence from real-life practices (32–34). Despite vast scientific knowledge, there are seemingly challenges and bottlenecks in moving from trial to practice. The barriers could be financial, technological, educational but also a shortage of therapists and trainers. Through a series of implementation projects in Finland, we have found that the availability of technology itself is often not enough. In most cases, there is a need for facilitators and a need to integrate multiple solutions into workable packages.

In the area of strength training Singapore's elder care has provided a unique opportunity for gathering practice-based evidence. Gyms for the elderly has not been part of standard practice, that is, none of the participating sites had previously applied gym technology for strength training. To facilitate the implementation three companies and a University partner came together to develop a solution. The package presents a combination of gym technology and assessment instruments making it possible to evaluate the persons' physical condition and training on a continuous basis. The project, Gym Tonic (35), was funded by the Lien Foundation to support the implementation. Using the PBE perspective we report on the results from the first 2 years of running the program. The key study questions include: (i) what we can learn from real-life practice patterns in introducing strength training for elderly, and (ii) how the results compare to studies performed in more controlled environments. The study object provided a unique opportunity to investigate the start-up phase of strength training in settings where these concepts had previously not been applied. This is the principal aim of the study. The conclusions are limited to this phase of adopting technology for strength training. Only limited data was available for longer follow-up periods.

METHODS

Each site was provided with a selected set of gym training machines (for core muscle group training), standardized assessments and targeted training for the therapists and specialists running the program. The adoption of new technology was planned as an implementation project. The companies provided the technological base for Gym Tonic (measurement devices, gym machines, and IT-solutions), and developed an integrated software solution for pulling different information systems together. The University partner played the role of research investigator, designing assessment protocols, training therapists and specialists from the participating organizations. To entice the elderly to first join and then stay on the Gym Tonic program, a behavioral change strategy was adopted, primarily making the exercise regime safe, simple, hassle-free and motivating.

Altogether the Gym Tonic concept comprises five key components:

- **Gym technology**: Six pneumatic machines which focus on the core muscle groups, which are safe (exercises in sitting position), and gentle on the joints.
- **Assessment technology**: standardized assessment instruments for measuring pre and post training status.

- **Training of therapists/specialists**: uniform training/education program for therapists and specialists from participating organizations.
- **Training intervention**: recommended progressive strength training periods, that is, 2 times a week for 12 weeks.
- **Behavioral change strategy**: allowing the elderly to exercise in everyday clothes, keeping training simple and short, pre-programmed exercises using RFID smart card to activate each machine.

Gym Technology

The gym technology used for the strength training includes the following machines, Leg Extension/Curl, Leg Press, Chest Press, Lat Pull, Abdomen/Back, and Hip Abduction/Adduction (36). The exercise equipment is based on air pressure technology making exercise safer for the elderly. The exercise equipment is designed to match the body's natural muscular movement. The software attached to the machines records all activity for automatic reporting. Individual exercise levels can be programmed into the system with a SmartCard/Touch technology. The system has also a built-in progressive resistance algorithm: whenever the person performs an excess two or more repetitions than programmed for during a session, the load will automatically increase the next session. The performance of each training session is saved in the training database. The Gym Tonic sites were encouraged to set up the gyms in "pleasant" environments to make the gym experience a positive one for the users.

Assessment Technology

The protocols for assessing physical functions were designed using existing and validated tests. The objective was to apply measurement technology whenever possible, thus giving the most accurate measures of physical functions. The assessment protocol (Welmed) included isometric strength measurements with Leg Extension/Curl and Hip Abduction/Adduction. The isometric strength measurements were conducted by attaching a Performance Recorder unit to the gym devices (36). All strength measurements have three performances with the best performance being recorded as the result. The result is measured in nominal units of kilogram force (kgf) but can also be converted to torque units Newton-meter (Nm). For most tests, the strength measurements are normalized by dividing the strength results by body mass (kgf/kg or Nm/kg). The assessment protocol also included grip strength and body composition (37), balance test [Hur force platform BT4[36]], functional tests, for example, five times sit to stand (FTSTS), Berg Balance Scale (BBS) (38), and 4 m timed walk. Information on functional dependency including Activities of Daily Living (ADLs), cognitive functions, and communication was provided by the interRAI assessment (39). Together, the assessments served as a basis for setting personal goals for the training period and to evaluate the effectiveness of the resistance training.

Training of Therapists/Specialists

The training of clinical staff was conducted in Finland. Two persons from each site, mainly physiotherapists and exercise therapists, were sent to Finland to be trained. The 4-day course included performing the assessments, how to conduct progressive strength training with elderly, how to create an individual exercise plan, and lectures on exercise as medicine. In addition, 2 days were allocated for site visits to demonstrate how gyms for elderly are being operated in Finland. Four batches of frontline staff were trained in Finland during the first 2 years of implementation. After the training, the students had to perform five Welmed assessments in their own facilities cases prior to a written and practical exam (with a real participant) to be certified for Gym Tonic. The practical exams were carried out in Singapore, also giving the Finnish educators a possibility to audit the gyms and test sites to ensure data quality. The persons trained were given time to learn in practice before the final exam. Additional support was provided through five webinars during the 2 years of implementation. Some support was also provided by the local vendor in Singapore.

Exercise Intervention

The recommended progressive strength training period for elderly was set at 3 months, twice a week with two sets of exercises at each machine. The average time for every session was around 30–45 min. The assessments were performed at the start and at the end of the training period, and follow-ups at 3-month intervals if the training continued. Printed participant profiles and progress reports were shared with the elderly when viable. The profile reports included target values developed for motivating the elderly to exercise. The progression of the training was suggested to be adjusted in terms of the repetition maximum (RM). The notation × RM means the resistance level at which one can do a given maximum number × of repetitions. A smaller number of maximum repetitions × mean s a higher resistance level. Resistance level had been set to 15RM for weeks 1–2, 10RM for weeks 3–7 and 8RM for weeks 8–12. Thus, with increasing load the maximum repetitions should go down. The sites were given freedom to roll out the implementation as they found best. It remained up to the Gym Tonic sites to enroll participants into the gyms, no rigid inclusion or exclusion criteria were used, as most people who have the capacity to function in a gym will benefit from strength training. The centers generally advised the elderly to seek doctor's clearance especially for those who had underlying medical conditions. It was up to the trained staff to perform the pre and post assessments, and to direct the progressive resistance training in the gyms with the help of assistants and other staff.

Behavioral Change Strategy

To entice the elderly to join (or even try) and stay on the program, we adopted a behavioral change strategy primarily to make the exercise regime safe, simple, hassle-free and motivating. Pre-training briefing was conducted, and the benefits of strength training was shared with them. To make it hassle-free, the elderly were welcome to exercise in their everyday clothes. Their pre-programmed exercises were automatically retrieved from their RFID smart card and there was no need for them to remember or manually adjust any loads. To make it simple and easy, training intervention was also kept short, around 30–45 min, and the elderly were only expected to exercise twice a week. During the training period, the therapists and specialists were encouraged to update the elderly on their progress.

PBE Approach

The sites were given considerable freedom to roll out the implementation. This was deliberate as we wanted to evaluate the adoption of strength training in real environments. The main goal of the research was to learn from the implementation using the data, subsequently randomization, control groups etc. was not part of the set up. It was up to the sites to recruit participants to the program, based on who they thought could participate in gym training. Participation was voluntary and safety considerations were assessed by the health professionals at the sites. From clinical trials, we already know that strength training is very effective for the elderly. The PBE approach means taking what is known for from clinical trials, putting knowledge into practice, and evaluating the results. The main issue is then whether the adoption of the concept has resulted in successful outcomes or not. This can be evaluated mainly by comparing the results from practice to results research (meta studies) in the field. In addition, we used reference groups in Finland and Singapore where we had applied identical technology for both strength training and follow up. Finally, we targeted the frontline therapists with questionnaires to gather data on the experiences from the implementation.

RESULTS

We limit the discussion to the adoption of strength training and measurable outcomes mainly strength improvements.

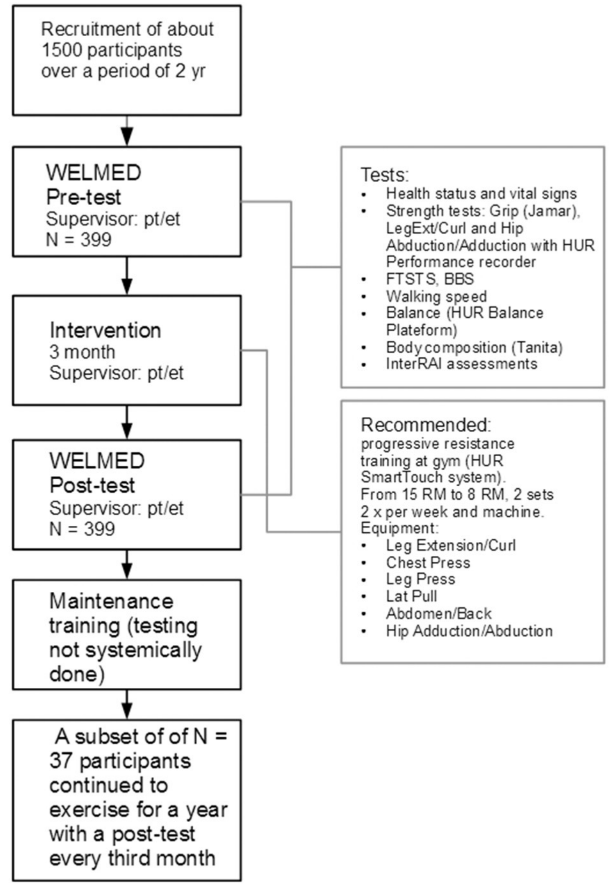

FIGURE 1 | The Gym Tonic process and the data collection. Thousand five hundred participants were registered. The sites were asked to deliver data on those who had properly completed the 12-week training and the pre and post assessments (*N* = 399). Welmed stands for a test protocol summerized by the upper right box. FTSTS, five times sit to stand; BBS, Berg balance scale; pt, physiotherapist; et, exercise therapist.

Participant Characteristics

A total of 24 locations in Singapore had adopted the Gym Tonic approach at the time of data analysis. Assessment labs/gyms had been successfully set up in three types of settings:

- Residential Facilities (7 sites)—RES
- Day Rehab/Dementia Day Care/Senior Care Centers (14 sites)—DAY
- Senior Activity/Community Centers (3 sites)—ACT.

These were the number of sites that had received funding by the Lien Foundation for setting up the gyms. The pooled data obtained from the first 2 years of implementation provided the research data. Measurement and assessment data from 399 persons (72 ± 11.4 y, M 53%, F 47%) were included in the research database. These persons were checked and confirmed to have participated in at least one 3-month gym intervention period. During the implementation period about 1,500 participants had registered for Gym Tonic (**Figure 1**). All who entered the training program were not assessed. In a real-life implementation there is naturally a learning period and not enough resources to assess everybody from the start. This explains the lower number in the data set available for analysis. For the analysis, the sites were asked to deliver data on those who had properly completed the 12-week training and the pre and post Welmed assessments (*N* = 399). Looking at outcomes mainly in strength this selection bias is necessarily not a problem as most people are regarded to benefit from strength training. This specific data set gives a profile of the clients recruited into the gym training groups, how the participants trained, and the effectiveness of the training in terms of improvement rates. The dropout rate from the training was about 10% mostly due to factors like hospitalization, acute events, death, house moving, and some for lack of motivation. A second smaller data subset included elderly who had completed 1 year of intervention and had also completed post assessments quarterly for us to analyze. While most people continued with one training session per week, not many organizations completed post-assessments diligently after the 3-month intervention. Most sites focused only on assessing the initial 12-week training period. Hence we had only 37 residential participants in the 1 year follow-up group.

Table 1 shows the basic characteristic of the participants using three interRAI scales; ADLh (Activities of Daily Living Hierarchical Scale, 0–6), CPS (Cognitive Performance Scale, 0–6), and COMM (Communication Scale, 0–8). These scales

TABLE 1 | Participant characteristics ($N = 399$) for the three types of organizations.

	Gender	**RES**		**DAY**		**ACT**	
Number of participants	**M**	**86**		**105**		**20**	
	F	**38**		**101**		**49**	
	Gender	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
Age (y)	M	65.3	11.8	72.4	11.6	69.8	7.8
	F	78.4	10.3	74.6	10.8	72.4	8.4
BMI (kg/m^2)	M	24.0	4.1	23.5	3.9	24.5	3.5
	F	23.6	4.9	24.6	4.4	25.8	4.7
ADLh (0–6)	All	0.85	1.06	0.67	0.88	0.00	0.00
CPS (0–6)	All	2.01	1.06	1.29	1.26	0.24	0.49
COMM (0–8)	All	1.95	1.86	1.22	1.53	0.27	0.83

ADLh = activity of daily living hierarchy scale (0-6), CPS = cognitive performance scale (0-6), COMM = communication scale (0-8). RES = residential facilities group, DAY = day rehab/dementia day care/senior care centers group, ACT = senior activity/community centers group, sd = standard deviation.

measure the performance status from independent to totally dependent. Most of the participants in the data set were relatively independent in ADLs which is a measure of physical functions. About 85% of the persons were independent or needing only supervision (ADLh = 0,1). More differences were seen in cognitive functions. The average cognitive performance in the RES groups was at the mild impairment level (CPS = 2.01), in the DAY group slightly over borderline intact level (CPS = 1.29), and for ACT close to intact (CPS = 0.24). The expression and comprehension level were relatively good among all clients, meaning the participants generally or usually understood instructions given.

Effectiveness of Strength Training

The effectiveness of training was analyzed from a before and after perspective comparing pre and post exercise assessments ($p < 0.05$). **Table 2** presents the results comparing the pre and post tests for females and males separately. The average improvement rates (post/pre %) in the lower body isometric strength tests were in the range of 6.1–48.9% depending on test and gender. The highest improvement rates were found in LegCurl (ave 11.1–48.8%), LegExt (ave 10.2–24.0%) and the lowest in HipAbd/HipAdd (ave 7.0–15.8%). Some significant improvements were seen in functional tests such as FTSTS with an 11.4% improvement rate for ACT participants (females) and an 8.9% improvement rate for DAY participants (females). Walking speed improved by about 8.7% for male RES clients. In balance, improvements were mainly seen among female DAY participants based on the Berg Balance Scale with an average improvement rate of 9.6%. A subset of 37 participants who had trained actively for 1 year and were assessed quarterly (approx. at 3, 6, 9, 12 months), was analyzed (**Figure 2**). In this group, the largest improvements in strength were received from the first 3 months of training followed by a leveling off effect. For LegExt strength improved by 20% from the first 3 months of training, after which the improvements leveled off. Only for HipAdd, there was a continuous improvement during the entire 1-year follow-up in this subgroup.

For comparison of outcomes, we used two smaller datasets, one from Singapore and one from Finland, where we had used identical assessment methods and gym technology for training with elderly (**Figure 3**). These groups had a tighter control in the intervention but otherwise applying the same exercise methods as Gym Tonic. Ageility refers to a Singaporean exercise group performed in the Gym Tonic demonstration gym operated by PulseSync (7M + 5F, 72 ± 6 y, 12 weeks of supervised strength training). FIN80 refers to an exercise group of Finnish community dwelling 80-year olds (9M+19F, 10 weeks of training). The results of the Gym Tonic sites in terms of improvement rates were comparable to these reference groups. Based on the interRAI assessments, some indications of clients becoming more independent functioning could also be detected: ADLh from 0.51 (pre) to 0.42 (post), CPS from 1.32 (pre) to 1.28 (post), and COMM from 1.27 (pre) to 1.17 (post).

Progressiveness of Strength Training

Individual exercise data was obtained from each training machine, providing the opportunity to analyze the progressiveness of the resistance training during the intervention period. The starting training load was calculated as the average for the first 2 weeks of training, and the ending load as the average of the final 2 weeks of the 90 days training period. The data indicated that the training was progressive with the load increment at an average of 21% toward the end of the intervention. Compared to the reference groups the progressiveness was somewhat lower. The average increase in training loads was 36% (F) and 57% (M) for the Ageility group and about 58% for FIN80 group.

Staff Responses

The implementation process was evaluated using surveys. The survey studies were done about 3 years after the start of the implementation giving the respondents enough time and perspective to evaluate the implementation. Survey #1 was sent to

TABLE 2 | Pre-post changes for tests ($N = 399$).

		RES				DAY				ACT			
Test		**m1**	**m2**	**ch%**	***P***	**m1**	**m2**	**ch%**	***P***	**m1**	**m2**	**ch%**	***P***
LegExt Right (kgf/kg)	M	0.97	1.07	10.2	0.021	1.08	1.20	11.0	0.000	1.47	1.56	6.1	0.307
	F	0.67	0.79	18.6	0.004	0.76	0.87	13.7	0.000	0.87	1.02	16.3	0.000
LegExt Left (kgf/kg)	M	0.96	1.07	11.5	0.021	1.04	1.17	12.6	0.000	1.39	1.61	16.0	0.006
	F	0.68	0.79	17.4	0.002	0.76	0.87	14.6	0.000	0.82	1	21.3	0.000
LegCurl Right (kgf/kg)	M	0.43	0.52	20.8	0.001	0.52	0.57	11.1	0.001	0.69	0.87	24.0	0.009
	F	0.33	0.39	19.8	0.079	0.34	0.43	28.3	0.000	0.38	0.52	36.0	0.000
LegCurl Left (kgf/kg)	M	0.40	0.53	31.6	0.000	0.49	0.55	12.7	0.008	0.67	0.85	27.7	0.000
	F	0.31	0.40	32.4	0.013	0.33	0.42	25.6	0.000	0.34	0.51	48.8	0.000
HipAbd (kgf/kg)	M	0.73	0.82	12.9	0.000	0.77	0.81	5.1	0.011	1.1	1.16	6.3	0.073
	F	0.60	0.68	13.9	0.011	0.60	0.66	11.4	0.000	0.77	0.84	9.3	0.001
HipAdd (kgf/kg)	M	0.77	0.86	11.7	0.001	0.88	0.95	7.3	0.000	1.26	1.35	7.0	0.037
	F	0.68	0.72	6.0	0.117	0.62	0.72	15.8	0.000	0.76	0.86	13.9	0.000
FTSTS (sec)	M	15.04	14.60	−2.9	0.298	15.73	14.65	−6.9	0.094	12.39	10.43	−14.6	0.067
	F	15.49	13.29	−14.2	0.295	17.67	16.09	−8.9	0.019	13.42	11.89	−11.4	0.005
BBS Short (score 0–16)	M	9.92	10.82	9.0	0.006	8.62	9.45	9.7	0.005	13.11	13.11	0.0	1.000
	F	9.31	9.84	5.7	0.329	8.05	8.83	9.6	0.017	12.2	12.33	1.0	0.698
FAT (%)	M	22.77	22.17	−2.6	0.164	22.28	22.22	−0.2	0.764	22.91	23.28	2.4	0.365
	F	33.18	33.68	1.5	0.685	35.05	35.64	1.7	0.033	36.59	36.7	0.3	0.774
SPEEDN (m/s)	M	0.81	0.90	11.4	0.030	0.69	0.69	−0.8	0.753	1.02	1.01	−0.1	0.980
	F	0.57	0.56	−1.7	0.697	0.60	0.65	8.5	0.061	0.89	0.94	5.2	0.197
SPEEDF (m/s)	M	1.11	1.21	8.7	0.024	0.95	0.97	1.8	0.576	1.56	1.6	2.7	0.679
	F	0.77	0.76	−0.8	0.869	0.83	0.86	3.3	0.263	1.29	1.33	2.8	0.367

LegExt Right, Leg Extension Right; HipAbd, Hip Abduction; HipAdd, Hip Adduction; FTSTS, five times sit to stand; BBS, Berg Balance Scale (sum of last four items); FAT, total body fat %; SPEEDN, normal walking speed; SPEEDF, fast walking speed; RES, residential facilities group; DAY, day rehab/dementia day care/senior care centers group; ACT, senior activity/community centers group. P-value (p) calculated with the paired t-test for the difference between pre (m1) and post-test (m2). Change expressed as percent change (ch); that is, 100(m2-m1)/m1. Gray are those values significant at $p < 0.05$ level.*

those who had participated in the training in Finland (Group 1), and a total of 40 out of 49 answered (response rate 82%). Survey #2 was posted to those actively working with Gym Tonic, but not trained in Finland (Group 2), and a total of 22 out of 41 answered the survey (response rate 54%). At the time of answering the questionnaire, 70–80% of the respondents worked full time or part time with Gym Tonic.

The results from the two surveys were similar, we have therefore pooled them (**Figure 4**). To the statement "I can highly recommend the Gym Tonic concept to seniors" 70% strongly agreed and 28% agreed to some extent. The respondents also felt the management had been supportive of the project. To the statement "The implementation of Gym Tonic has been successful in my unit" 44% strongly agreed and 46% agreed to some extent. To the statement "Performing the Welmed assessments were important" 67% strongly agreed and 30% agreed to some extent. Most of the respondents also wished the project would continue. Of the respondents over 44% strongly agreed and 49% agreed to some extent that the gym machines were well-adapted for elderly. Good compliance was generally seen in terms of few dropouts and the frontline staff had seen many improve their functional status and strength.

On the open ended questions what had contributed to the success of the implementation the following factors were emphasized: strong sponsorship by foundation, good support by management, user friendly system, motivated trainers, seeing elderly improve after post-tests, good location of Gym Tonic sites (near persons' homes), good support from vendors, safe machines, dedicated staff and volunteers, proper training and good planning. On the question what had contributed to the lack of success the following causes were mentioned: lack of manpower, lack of trained staff/physiotherapists, finding suitable pool of participants, lengthy assessments, lack of supervision/follow-up, restrictions from supervising levels, lack of understanding of concept in the business sense, and lack of management's understanding of the program.

DISCUSSION

This study has provided a comprehensive overview of implementing strength training in different elder care settings. Several lessons can be learned from the PBE viewpoint. The most important lesson is that strength training can be implemented successfully in real settings producing effective and repeatable outcomes. The study data showed significant improvements in muscle strength in each of the three settings including those living in the community and those residing in facilities. In terms of outcomes, the improvement rates in muscle strength

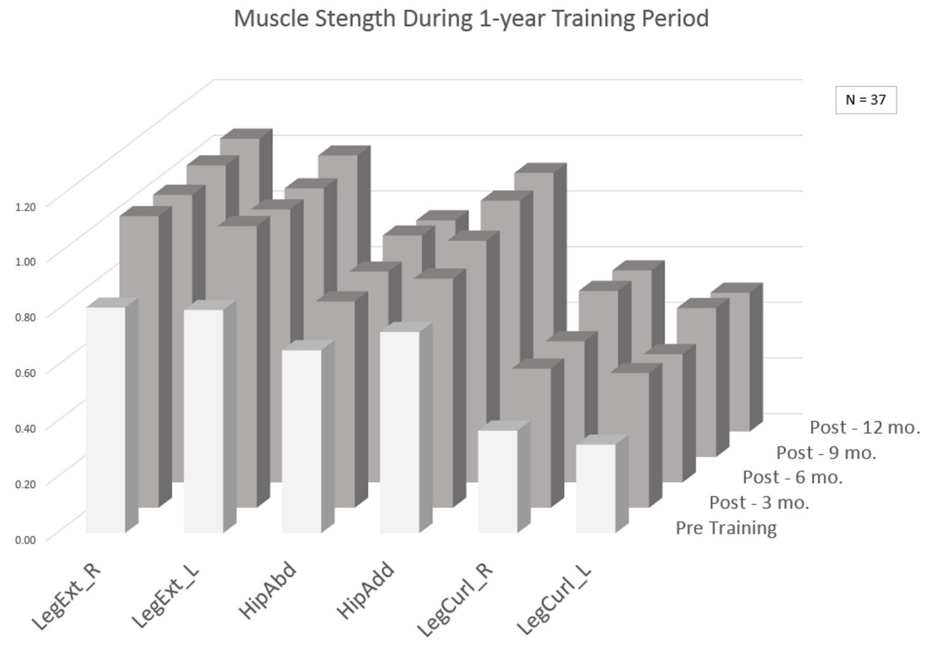

FIGURE 2 | Average strength results (kgf/body weight) for a subgroup of 37 participants who trained for an extended period. LegExt_R, leg extension right leg; LegExt_L, leg extension left leg; HipAbd, hip abduction; HipAdd, hip adduction; LegCurl_R, leg curl right leg; LegCurl_L, leg curl left leg.

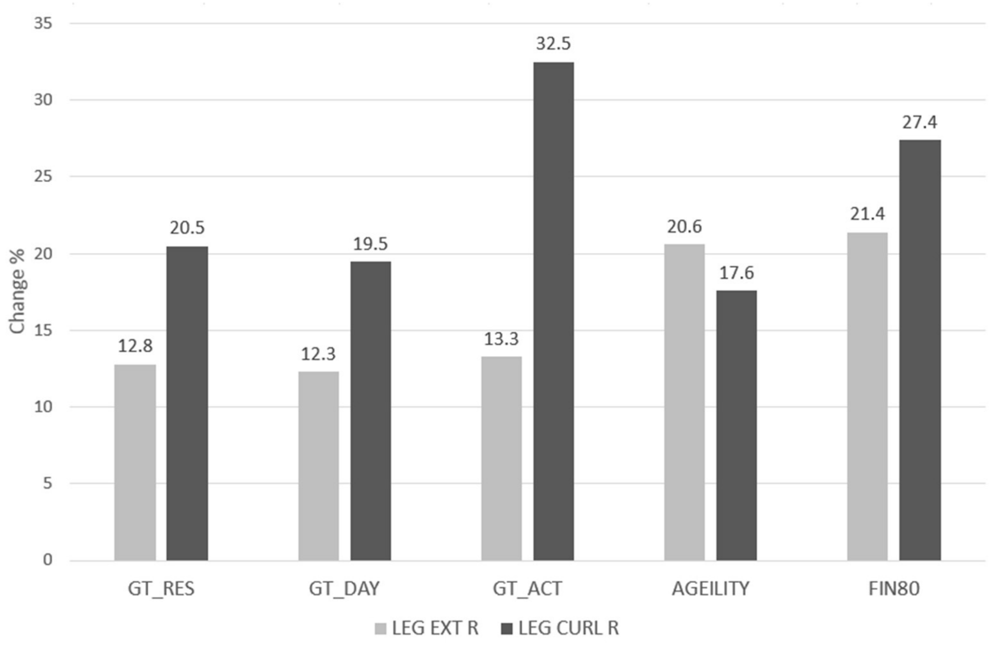

FIGURE 3 | Post-pre change in terms of improvement rate calculated as mean (post-pre)/mean (pre) for Right Leg Extension and Curl strength for Gym Tonic (*N* = 399) and "reference" groups and averaged over gender. AGEILITY (*N* = 12) and FIN80 (*N* = 28) were tightly supervised exercise groups.

were comparable to those reported in meta-analysis of research studies by for example, Lopez et.al., observing increases of 6.6–37% in maximal strength of strength training and multimodal training (40), and Peterson reporting an average of 33% increase in muscle strength on resistance training for muscular strength in older adults (10). The results of Gym Tonic also corresponded to reference groups using identical technology and progressive training.

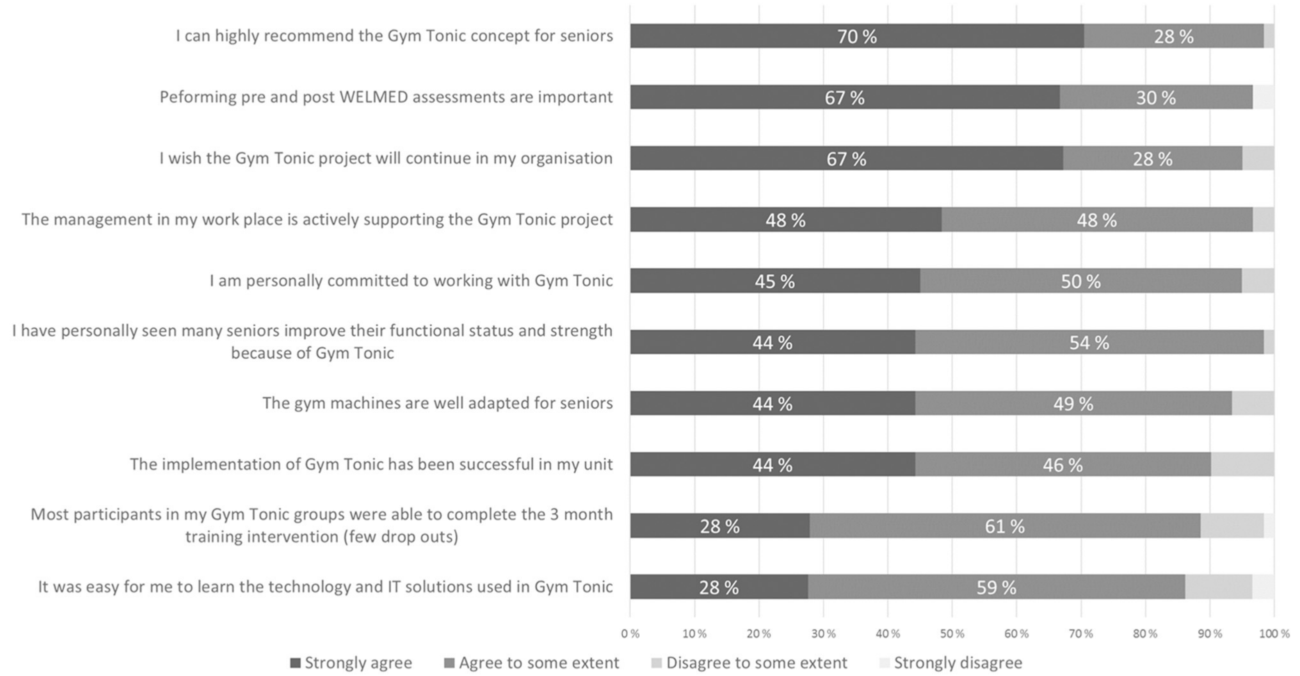

FIGURE 4 | Implementation questionnaire. Staff responses of those trained in Finland for Gym Tonic ($N = 40$) and those trained locally for Gym Tonic ($N = 22$).

The data driven approach provided relevant information for understanding the implementation process. Several practice patterns could be drawn from the data. The first 3 months of resistance training produced the largest improvements in muscle strength. This suggests that a relatively short exercise period can be used for improving physical strength, where after the challenge is to maintain it. This finding is based on a relativiely small data set ($n = 37$) and a pattern found for those in the residential group. The progressiveness of the resistance training succeeded to a degree, showing the users were able to apply the gym technology appropriately. In the progressiveness of training, some cautiousness was detected in raising the training resistance, which is to be expected in the introduction of new technology. Increased progressiveness and higher starting loads could potentially produce better outcomes. The data indicated no clear dose response relation between training load and improvement in strength. Therefore, the improvements in muscle strength were most likely due to improvements in neural activation (27) and/or improved muscular metabolic capacity (11). Longer training periods are generally needed for building muscle mass. In terms of changes in functional dependency, the post-tests of the interRAI assessments pointed in the right direction, but more data is needed to draw conclusions from the perspective of improving independency. The sites targeted relatively young persons and those who were physically relatively independent. Independent in ADLs doesn't necessarily mean that the person is in good physical condition and not in the need of training, as shown in this study.

The surveys suggested that the implementation had been successful from the view of frontline staff. The adoption of new technology succeeded without major hurdles. Both therapists and specialists could be trained with a relatively short training course in the use of different technologies and applying strength training for elderly. The sites were able to independently plan and carry out the proposed interventions based on the training given. This is encouraging as training is usually a major component of implementing new concepts. The main challenge in the training was the cultural change of putting elderly persons in gyms. These issues had to be covered relatively extensively in the transition from a physically passive fall prevention to physically active fall prevention. From a policy perspective, the Senior Activity Centers offers an interesting model for reaching a large number of elderly in the community. In a densely populated city like Singapore such centers can be set up conveniently. Finally we may point out that the comprehensive assessment approach adopted here is in line with the philosophy behind the concept of intrinsic capacity (IC) as promoted by WHO (22). The focus is shifted from symptoms to the mental and physical capacities of the person, which are important for healthy aging. One limitation of the study though is the lack of participant perspective which must be remedied in future studies.

CONCLUSION

The Gym Tonic project offers important insights and directions on how to implement progressive strength training on a large scale across different elder care settings. The following conclusions can be drawn from the study:

Positive outccomes:

- The approach yielded consistent improvement rates in muscle strength comparable to results from randomized clinical trials (meta-analysis studies) showing that effective outcomes can be achieved in real life environments.
- Significant improvement rates in muscle strength were found in all three types of sites demonstrating the vast potential of strength training to promote resilient aging.
- The data supported a 3-month training intervention as an effective way of introducing strength training, this could be useful for policy makers looking for practical solutions in the war against frailty.
- Frontline staff were successfully trained in the use of the technology for gym training and assessments, suggesting that technology solutions can be applied in real life practice for strength training.
- Practice patterns could be detected using the data-driven approach highlighting the need and capabilities of information and assessment systems for decision making and continuous quality improvement.

Lessons learned:

- Although frontline staff underwent structured training, some of them may not adhered fully to our assessment and training protocol due to manpower and other factors. To improve this, the project introduced regular refresher courses and also frequent on-site visits to improve the overall compliance.
- Initially most organizations were using physiotherapists to run Gym Tonic, thus limiting the scalability of the programme given the high manpower cost and scarcity of resources. Many of them switched to hiring exercise therapists or wellness coaches, while leaving the physiotherapists to handle the more complex cases, for example elderly who are very frail and/or with medical conditions (especially those in the nursing homes).
- While participants were briefed on their pre-assessment and post-assessment results prior and on completion of the intervention, some may not be able to comprehend and relate the results to their ADLs. Helping the trainers to explain and better relate the results this were improved and included in the training.
- Getting community-dwelling frail elderly to participate is logistically challenging as transport and sometimes, caregiver may be needed as many of them need at least supervisory assistance. In addition, the time needed for them to complete the exercise is typically longer. To address this, most sites are now using the afternoon non-busy/quiet period (from 1–3 pm) to handle such elderly so as to give them more quality time and supervision.

As the data grows more lessons can be drawn for introducing strength training for elderly. The greatest challenges do not seem to be technological, but rather changing of mindsets and implementing concepts that work. This study was done to increase that knowledge. More practice-based evidence is needed for the industry, policy makers, and for an aging population to motivate people to use exercise as a key remedy and medicine for resilient aging.

DATA AVAILABILITY STATEMENT

The datasets generated for this study will not be made publicly available The researchers were given access to the data for analysis, but not make it publicly available.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

MB and FB analyzed the data and wrote the paper. KT, GL, and LN have read and commented on the manuscript. All authors contributed to the article and approved the submitted version.

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REFERENCES

1. Kujala UM. Evidence on the effects of exercise therapy in the treatment of chronic disease. *Br J Sports Med.* (2009) 43:550–5. doi: 10.1136/bjsm.2009.059808
2. Pedersen BK, Saltin B. Exercise as medicine—evidence for prescribing exercise as therapy in 26 different chronic diseases. *Scand J Med Sci Sports.* (2015) 25 (Suppl 3):1–72. doi: 10.1111/sms.12581
3. Copeland JL, Good J, Dogra S. Strength training is associated with better functional fitness and perceived healthy aging among physically active older adults: a cross-sectional analysis of the Canadian Longitudinal Study on Aging. *Aging Clin Exp Res.* (2019) 31:1257–63. doi: 10.1007/s40520-018-1079-6
4. Mcleod J C, Stokes T, Phillips S M. Resistance Exercise Training as a Primary Countermeasure to Age-Related Chronic Disease. *Front Physiol.* (2019) 10:645. doi: 10.3389/fphys.2019.00645
5. Fragala M S, Cadore E L, Dorgo S, Izquierdo M, Kraemer W J, Peterson M D, et al. Resistance training for older adults: position statement from the National Strength and Conditioning Association. *Strength Cond Res.* (2019) 33:2019–52. doi: 10.1519/JSC.0000000000003230
6. Herold F, Törpel A, Schega L, Mûller NG. Functional and/or structural brain changes in response to resistance exercises and resistance training lead to

cognitive improvements—a systematic review. *Eur Rev Aging Phys Act.* (2019) 16:10. doi: 10.1186/s11556-019-0217-2

7. Lavin KM, Roberts BM, Fry CS, Moro, T, Rsamussen, B B, Bamman, M M. The Importance of Resistance Exercise Training to Combat Neuromuscular Aging. *Physiology.* (2019) 34:112–22. doi: 10.1152/physiol.00044.2018
8. Fisher, J P, Steele, J, Gentil, P, Glessing, J, Westcott, W L. A minimal dose approach to resistance training for the older adult; the prophylactic for aging. *Exp Gerontol.* (2017) 99:80–6. doi: 10.1016/j.exger.2017.09.012
9. Liu CJ, Latham NK. Progressive resistance strength training for improving physical function in older adults. *Cochrane Database Syst Rev.* (2009) 2009:CD002759. doi: 10.1002/14651858.CD002759.pub2
10. Peterson MD, Rhea MR, Sen A, Gordon PM. Resistance exercise for muscular strength in older adults: a meta-analysis. *Ageing Res Rev.* (2010) 9:226–37. doi: 10.1016/j.arr.2010.03.004
11. Seene T, Kaasik P. Muscle weakness in the elderly: role of sarcopenia, dynapenia, and possibilities for rehabilitation. *Eur Rev Aging Phys Act.* (2012) 9:109–17. doi: 10.1007/s11556-012-0102-8
12. Papa EV, Dong X, Hassan M. Resistance training for activity limitations in older adults with skeletal muscle function deficits: a systematic review. *Clin Interv Aging.* (2017) 12:955–61. doi: 10.2147/CIA.S104674
13. Haraldstad K, Rohde G, Stea TH, Lohne-Seiler H, Hetlelid K, Paulsen G, et al. Changes in health-related quality of life in elderly men after 12 weeks of strength training. *Eur Rev Aging Phys Act.* (2017) 14:8. doi: 10.1186/s11556-017-0177-3
14. Exercise is medicine. Available from: http://www.exerciseismedicine.org/
15. The Finnish national current care guidelines: Physical activity. Available online at: http://www.kaypahoito.fi/web/kh/suositukset/suositus?id=hoi50075 (accessed March 14, 2019).
16. Ngandu T, Lehtisalo J, Solomon A, others. A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial. *Lancet.* (2015) 385:2255–63. doi: 10.1016/S0140-6736(15)60461-5
17. Komulainen P, Kivipelto M, Lakka TA, Savonen K, Hassinen M, Kiviniemi V, et al. Exercise, fitness and cognition—a randomised controlled trial in older individuals: The DR's EXTRA study. *Eur Geriatr Med.* (2010) 1:266–72. doi: 10.1016/j.eurger.2010.08.001
18. Exercise: the miracle cure and the role of the doctor promoting it. Academy of the medical Royal Colleges (2019). Available online at: http://www.aomrc.org.uk/publications/reports-guidance/exercise-the-miracle-cure-0215/
19. Kohl HW, Craig CL, Lambert EV, Inoue S, Alkandari JR, Leetongin G, et al. The pandemic of physical inactivity: global action for public health. *Lancet.* (2012) 380:294–305. doi: 10.1016/S0140-6736(12)60898-8
20. Physical Activity 2016: Progress and Challenges (2019). Available online at: http://www.thelancet.com/series/physical-activity-2016
21. Physical activity and older adults. Available online at: www.who.int/dietphysicalactivity/factsheet_olderadults/en/ (accessed March 14, 2019).
22. WHO Clinical Consortium on Healthy AgeingTopic focus: frailty and intrinsic capacityReport of consortium meeting 1–2 December 2016 in Geneva, Switzerland (2019). Available online at: https://apps.who.int/iris/bitstream/handle/10665/272437/WHO-FWC-ALC-17.2-eng.pdf
23. Kraemer WJ, Ratamess NA. Fundamentals of resistance training: progression and exercise prescription. *Med Sci Sports Exerc.* (2004) 36:674–88. doi: 10.1249/01.MSS.0000121945.36635.61
24. Law TD, Clark LA, Clark BC. Resistance exercise to prevent and manage sarcopenia and dynapenia. *Annu Rev Gerontol Geriatr.* (2016) 36:205–28. doi: 10.1891/0198-8794.36.205
25. Sipilä S, Suominen H. Effects of strength and endurance training on thigh and leg muscle mass and composition in elderly women. *Appl Physiol.* (1995) 78:334–40. doi: 10.1152/jappl.1995.78.1.334
26. Stewart VH, Saunders DH, Greig CA. Responsiveness of muscle size and strength to physical training in very elderly people: a systematic review. *Scand J Med Sci Sports.* (2014) 24:1–10. doi: 10.1111/sms.12123
27. Borde R, Hortobágyi T, Granacher U. Dose-response relationships of resistance training in healthy old adults: a systematic review and meta-analysis. *Sports Med.* (2015) 45:1693–720. doi: 10.1007/s40279-015-0385-9
28. Stec MJ, Thalacker-Mercer A, Mayhew DL, Kelly NA, Tuggle SC, Merritt EK, et al. Randomized, four-arm, dose-response clinical trial to optimize resistance exercise training for older adults with age-related muscle atrophy. *Exp Gerontol.* (2017) 99:98–109. doi: 10.1016/j.exger.2017.09.018
29. Dent E, others. The Asia-Pacific clinical practice guidelines for the management of frailty. *J Am Med Dir Assoc.* (2017) 18:564–75. doi: 10.1016/j.jamda.2017.04.018
30. Weening-Dijksterhuis E, de Greef MH, Scherder EJ, Slaets JP, van der Schans CP. Frail institutionalized older persons: a comprehensive review on physical exercise, physical fitness, activities of daily living, and quality-of-life. *Am J Phys Med Rehabil.* (2011) 90:156–68. doi: 10.1097/PHM.0b013e3181f703ef
31. Russomanno G, Corbi G, Manzo V, Ferrara N, Rengo G, Puca AA, et al. The anti-ageing molecule sirt1 mediates beneficial effects of cardiac rehabilitation. *Immun Ageing.* (2017) 14:7. doi: 10.1186/s12979-017-0088-1
32. Benech I, Wilson AE, Dowell AC. Evidence-based practice in primary care: past, present and future. *J Eval Clin Pr.* (1996) 2:249–63. doi: 10.1111/j.1365-2753.1996.tb00055.x
33. Green LW. Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Fam Pr.* (2008) 25 (Suppl 1):20–4. doi: 10.1093/fampra/cmn055
34. Horn SD, DeJong G, Deutscher D. Practice-based evidence research in rehabilitation: an alternative to randomized controlled trials and traditional observational studies. *Arch Phys Med Rehabil.* (2012) 127–37. doi: 10.1016/j.apmr.2011.10.031
35. Gym Tonic. Available online at: www.gymtonic.sg (accessed March 14, 2019).
36. Hur Ltd. Available online at: www.hur.fi (accessed March 14, 2019).
37. Tanita: Segmental body composition. Available online at: www.tanita.com/en/body-composition-analyzer/ (accessed March 14, 2019).
38. Berg K, Wood-Dauphine S, Williams JI, Gayton D. Measuring balance in the elderly: preliminary development of an instrument. *Physiother Can.* (1989) 41:304–11. doi: 10.3138/ptc.41.6.304
39. interRAI. Available online at: http://www.interrai.org/ (accessed March 14, 2019).
40. Lopez P, Pinto RS, Radaelli R, Rech A, Grazioli R, Izquierdo M, et al. Benefits of resistance training in physically frail elderly: a systematic review. *Aging Clin Exp Res.* (2017) 30:889–99. doi: 10.1007/s40520-017-0863-z

Conflict of Interest: MB is a co-founder of RaiSoft. KT is a founder of Pulse Sync.

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.

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