The Biobehavioral Effects of Gentle Stretching in Patients with Heart Failure

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Dedication

I dedicate this dissertation to my husband, Chance Platz, who has been a constant support throughout the doctoral program.

Acknowledgements

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Chapter 1: Introduction

Heart failure (HF) is the number one cause for hospital admission in the U.S. for adults over the age of 65. HF has the highest 30-day readmission rate at 23.5%, and despite only 2.4% of the U.S. population suffering from HF, the total cost was $30.7 billion in 2012 and it is projected to rise to $69.8 billion by 2030.[1–3] Currently there is no cure for HF and 50% of patients die within 5 years of a diagnosis.[3] HF is characterized by a progressive health decline marked by episodes of acute decompensation until ultimate pump failure and death.[1,4]

From the patient's perspective HF is experienced as a "debilitating and unpredictable condition that engenders bewilderment, fear and hopelessness" and requires daily management to prevent exacerbation resulting in hospitalization.[1,5] In a narrative review of qualitative studies by Jeon et al.[6], everyday life for a person with HF was characterized by social isolation, living in fear of pain and death, and a loss of control. Patients described "feeling imprisoned in illness"[6] and attributed this feeling to unpredictable and distressing HF symptoms such as shortness of breath and fatigue, and required medications such as diuretics that cause increased urgency and frequency of urination. These obstacles can make leaving the home problematic contributing to social isolation and feelings of imprisonment and loneliness.[6] Being isolated from others due to the disease process of HF and losing a sense of control is echoed across multiple qualitative studies and qualitative literature reviews examining the lived experience of HF.[6–10] In a phenomenological study of patients with HF, data show that individuals with HF face the prospect and/or fear of death daily.[11]

Palliation of Heart Failure Symptoms through Physical Activity

One way in which a patient with HF may improve his/her symptoms and quality of life is through physical activity. The Physical Activity Guidelines for Americans [12] and the American Heart Association [13] recommend adults with chronic conditions participate in at least 150 minutes per week of moderate-

intensity physical activity. They further emphasize and Kraus et al.[14] confirm in their recent systematic review that any amount of movement is better than being sedentary.[12,13]

For HF patients, exercise-based cardiac rehabilitation (CR) is recommended as it comprises both structured exercise as well as heart healthy education and counseling.[15] As inferred by the term 'rehabilitation', CR entails a supportive and teaching environment typically provided over the course of 36 in-person sessions, in order that the patient upon graduation would have the skills necessary to continue with heart healthy lifestyle changes including consistent exercise.[16,17] CR has been found to reduce all-cause mortality in the long-term, reduce all-cause and HF-specific hospitalization, improve health-related quality of life, and reduce depression and anxiety through multiple physiological benefits.[15,18,19]

Barriers and Potential Physical Activity Solutions

Despite numerous benefits to participation in CR, only 2.7% of eligible HF patients attend. There are several reasons for non-attendance of cardiovascular disease patients including patients with HF that include: lack of transportation and/or living alone, low referral and enrollment, lack of local CR programs, competing demands, comorbidities, fear of exercise, cost, and physical limitations, among others.[20–26]

Barrier: Physical Limitations

Most CR programs typically include walking or jogging on a treadmill.[16,27] However, in our previous study we estimated from a sample of 200,087 American adults with cardiovascular disease that more than two in five have serious difficulty walking.[28] Similarly, Supervia et al.[29] found that 60% of CR eligible patients reported a musculoskeletal limitation that limits their walking ability and that though it did not affect enrollment in CR, it did significantly impact attendance rates. Conventional CR exercise including treadmill walking may be additionally daunting to HF patients. Charuel et al.[30] found in their qualitative study of perceptions and experiences of HF patients with physical activity, that many cited

breathlessness, fatigue and side effects from their prescribed medications as reasons for not engaging in physical activity. Many were afraid they may overexert themselves or fall, and half admitted that neither their primary care practitioner nor cardiologist had discussed the need to exercise. The most cited reason for not engaging in physical activity was osteoarthritic impairments of the legs.[30] Alternative models of CR that accommodate physical limitations and also provide symptom relief to HF patients are needed.

Yoga is a low impact form of exercise that integrates low to moderate aerobic activity in addition to deep breathing and relaxation techniques. No equipment is required and yoga can be practiced in most any space. Among the benefits of Yoga found in HF patients are: improved LVEF, exercise capacity, peak oxygen consumption, reduced heart rate, increased heart rate variability and rate pressure product, and decreased inflammatory markers.[31–34] Yoga is adaptable to various fitness levels and physical disabilities ranging in difficulty from chair-based to continuous flow.[33] Selman et al. (2015) found in their qualitative study examining the perspectives of HF patients with a Tele-Yoga intervention that several participants found the chair-based exercises mitigated the difficulty with getting up and down from the floor, keeping pace with the exercise, and limiting the uncomfortable feeling of breathlessness during exercise. As breathlessness is a distressing, unpredictable, and common symptom for HF patients, the breathing exercises (pranayama) of Yoga have particular relevance for HF patients.[6,33] Selman et al.[35] found that some participants were able to integrate the breathing exercises of yoga into daily life and could even reverse shortness of breath when it occurred.

Barrier: Social Isolation and Loneliness

The issue remains that HF patients are "imprisoned in illness" [10], and any exercise intervention, no matter how adaptable to physical limitation, must be accessible and address barriers to attendance. In our previous study we estimate that one-fifth of adults with cardiovascular disease reported dependence on another person to attend medical appointments.[28] For patients with HF, this

dependence is likely more prominent due to lifestyle changes, medications and/or distressing symptoms that complicate leaving the home, securing transportation and/or socializing. Over time these barriers can contribute to a shrinking social network size and number of social interactions.[6] Gorji et al.'s[36] meta-analysis found that the prevalence of objective and perceived social isolation among HF patients was greater than 37%, and that socially isolated patients experience a 55% greater risk of hospital readmission than non-socially isolated patients.[37] Both social isolation and loneliness have been linked to early mortality, outweighing obesity as a risk factor.[37] Objective social isolation is defined as having a lack of social connections or infrequent social interactions, whereas perceived social isolation, commonly referred to as loneliness, is the mismatch between one's desired and actual relationships.[38,39] The pandemic intensified social isolation and loneliness for many in this vulnerable population and made the already limited access to CR programs even scarcer as programs suspended or reduced participation to limit contagion.[40–42] The clinical implications are twofold: CR locations should be more accessible to patients with HF, and that clinicians explore ways to improve social isolation and loneliness.

Home-based CR, sometimes called telerehabilitation, can be offered virtually either through live-video conference or a variety of asynchronous methods such as a web dashboard, text, or phone.[43,44] Chiefly, the intent of home-based CR is to reduce or eliminate the patient need for physical presence at the CR center for exercise sessions.[45–48] According to a Cochrane review there is no difference in patient outcomes in home-based vs. center-based CR, and there is a slightly higher program completion rate in home-based CR programs.[45] Home-based models of CR may also reduce overall costs associated with brick and mortar programs as was found in the FIT@Home study.[49]

Interventions to reduce social isolation and loneliness in older adults have been conducted, but evidence is not definitive regarding intervention type, and for whom and how and in what context social isolation improves.[50–53] Fakoya et al.[50] found that group as opposed to one-on-one interventions were more likely to improve social connections. Gardiner et al.[51] found that qualities of successful

interventions were: 1) the adaptability of an intervention to address the specific needs of its participants, 2) the involvement of the users in the design and implementation, and 3) that interventions that have productive engagement, i.e. an active activity with a common goal and purpose, are more successful at reducing social isolation than those with passive activities i.e. watching and listening. Hagan et al.[52] found that explicit conversations about social isolation and loneliness were unsuccessful citing negative associated stigma. Rather they found that relationships were better built through communal activities[52].

Engaging in group physical activity can take the focus and pressure off of intentional social interactions. Relationships and connectedness are instead built through shared group experience, implied/silent emotional support, and improved individual self-esteem from physical activity.[54] Shvedko et al.[54] found a small, but significant positive effect on social functioning in their systematic review of physical activity interventions to reduce social isolation and loneliness for older adults. The strongest effects were found in interventions for chronic disease populations, group setting, and delivery by a medical healthcare provider. Brady et al.'s cross-sectional study[55] found that older adults with a membership in Silver Sneakers, a Medicare option which offers live online group exercise classes, had lower social isolation and loneliness than matched nonparticipants.

Heart Failure Self-Care

Prior evidence demonstrates that social isolation and loneliness are contributing factors to poor self-care behaviors such as smoking, alcohol misuse, medication non-adherence, poor sleep hygiene, unhealthy dietary choices and sedentary behavior.[6,7] There are several possible mechanisms to explain the underlying associations between social isolation, loneliness and poor health outcomes (e.g. physiological, psychological and sociological[6,15]); Self-care behavior, however, may have particular importance for patients with HF who have daily complex self-care needs that are integral to health stability.[3,12] Adequate self-care is a key component found in all major guidelines for HF management[1,2]

and involves patient engagement in specific activities that limit illness related complications and promote health and well-being.[3] HF self-care behaviors include self-care maintenance (e.g. taking prescribed medications, exercising, maintaining a low-sodium diet), self-care monitoring (e.g. daily weights, observing for symptoms of fluid overload), and self-care management (e.g. responding to signs and symptoms as they occur).[3,4] Patients with HF who engage in effective self-care practices have better quality of life, lower risk of all-cause and HF-related hospital readmissions and risk of mortality.[5]

Study Purpose and Specific Aims

Alternative models of CR that use an alternative gentle exercise and an alternative (i.e. home-based) location may potentially mitigate physical limitations, access, and social isolation barriers to exercise for patients with HF, however, patient experiences with these models have been understudied. Given the dismal adherence to physical activity guidelines among patients with HF, it is imperative to examine if and how these models could improve exercise adherence and thereby improve health outcomes. Lastly, though social support has been investigated with regard to HF self-care, it is unknown whether social isolation and loneliness as distinct concepts can predict HF self-care scores.

The specific aims of this study were to first review the literature to (1) explore qualitative patient experiences with alternative models of CR; then, in patients with HF who participated in the GENTLE-HF study (2) explore patient perceptions of initial and continued exercise engagement in gentle non-aerobic exercise; and (3) investigate the relationship between social isolation, loneliness and HF self-care.

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Chapter 2: Manuscript One

Benefits, Facilitators, and Barriers of Alternative Models of Cardiac Rehabilitation: A Qualitative Systematic Review

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Abstract

Purpose: Cardiac rehabilitation (CR) improves health outcomes and quality of life for patients with cardiovascular disease (CVD), yet only a quarter of eligible patients enroll. A myriad of CR models that use either an alternative location (i.e. home-based) and/or an alternative exercise have been developed to overcome known attendance and physical limitation barriers, however patient experiences with these models have not been systematically reviewed. Our aim is to review patient experiences with these models of CR.

Review Methods: We conducted a systematic review and thematic analysis of qualitative studies published between 2009 and January of 2022 from CINAHL, PubMed, Web of Science and PsychINFO.

Summary: Twenty-five studies were included, representing the perspectives of 487 individuals who participated in an alternative model of CR. Exercises included: walking, tai chi, yoga, aquatic exercise, exergaming, chair-based exercises, aerobics, physical activity trackers, and individualized exercise plans. Nineteen of 25 studies used home-based models and 2 used live-video. Twelve studies included patients with heart failure. Patient perspectives comprised three central themes: (1) Exercise Benefits; (2) Exercise Facilitators; and, (3) Participation barriers. Some thematic categories were reported variably by particular model/study design (e.g. Home-based) than by others. All alternative models of CR were found to be physically, psychologically, and/or socially beneficial to patients. Participants described facilitators and barriers that were influential in the decision to initiate or continue exercise. These patient insights are critical for innovative delivery of CR that is appealing, accommodates physical limitations, and broadens access to improve health equity.

Keywords: Cardiac rehabilitation, cardiovascular disease, qualitative research, telerehabilitation, musculoskeletal pain

Condensed Abstract

We conducted a systematic review of qualitative studies examining patient perspectives of cardiac rehabilitation models that use either an alternative location (i.e. home-based) and/or an alternative exercise. Benefits, facilitators and barriers were reported by patients. These insights can help improve the delivery of cardiac rehabilitation and provide new directions for research.

Key Perspective

- Alternative models of CR improve self-efficacy which is an important predictor of physical activity and health-related quality of life.
- Top two facilitators: family/peer support and convenience
- Top two barriers: fearful preconceptions about exercise, and complaint with the specific exercise or aspect of the program
- Patients described numerous physical, psychological, and social benefits not typically measured in research indicating new directions for clinical practice as well as future study designs.

INTRODUCTION

Cardiovascular disease (CVD) is the number one cause of death in adults worldwide.[1] Cardiac rehabilitation (CR) is utilized as a CVD secondary prevention measure and combines education and exercise to reduce and reverse risk factors for CVD related death.[2] Standard CR programs are typically in-person at an outpatient center or hospital and include 36 sessions of prescribed aerobic exercise using a treadmill or cardio exercise machine over the course of 12 wk. CR has long been shown to reduce CVD related death, hospitalization, and to improve health-related quality of life (HRQOL).[3] Despite clear health-related benefits, CR participation rates are low and long-term adherence is even lower.[4] In the United States, it is estimated that one-quarter of all eligible patients initially attend CR, but just one-quarter of those patients will complete all recommended sessions.[5]

Lack of local CR programs (CR deserts), suspended CR programs for COVID-19, cost, lack of provider referral, rural living, lower socioeconomic status and underinsurance are factors that lead to low CR enrollment.[6–8] Patient-related factors also limit CR attendance including transportation, time conflicts for competing demands, depression, maladaptive coping and physical limitations to exercise.[8–13] Access to physical activity has been defined by U.S. Department of Health and Human Services as a social determinant of health. Lack of access to resources for positive health behaviors, such as CR and physical activity programs can perpetuate health inequity.[14] By providing alternative models of physical activity that are more accessible and accommodate physical limitations, health inequity can be better addressed.

Accordingly, researchers and providers have recognized the need for alternative models of CR.[6] For the purposes of this review, an alternative model of CR is defined as a model using either an alternative form of exercise and/or an alternative location such as a home-based or community-based setting. The aim of an alternative exercise model can be two-fold: to accommodate the physical limitations of patients due to past injuries, comorbidities, or low existing physical fitness, or to provide a type of exercise that may be more convenient or accessible to the patient. Examples of alternative exercises include swimming, exergaming (videogaming for exercise), mind-body exercises, and chair-based exercises, among others. Home-based or community-based CR models reduce or eliminate patient travel needs. Home-based CR models can use either synchronous or asynchronous communication via phone, text, web dashboard or live-video to communicate, potentially increasing CR access both geographically and for scheduling flexibility.[15]

While a systematic review has been undertaken to determine the effectiveness of alternative models of CR[16], a synthesis of qualitative data that describe the effectiveness has yet to be published. A systematic review of qualitative studies is well-suited to capture the participant perspective that can better inform CR program design and implementation, as well as to identify new directions for

research.[17] Therefore, our aim is to systematically review the qualitative evidence exploring patient experiences with alternative models of CR.

METHODS

This review follows the 6 stages for developing a qualitative systematic review protocol outlined in Butler, Hall, and Copnell's guide: (1) Developing a research question, (2) Developing a search strategy, (3) Designing a review process, (4) Critically appraising the studies, (5) Extracting the data, and (6) Synthesizing the data.[18] Additionally, we used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines[19] as well as the enhancing transparency in reporting the synthesis of qualitative research statement.[20] The review was pre-registered with PROSPERO (no.261207) and conforms with the principles outlined in the Declaration of Helsinki.

SEARCH STRATEGY

We searched databases PubMed, CINAHL, Web of Science and PsychINFO in January of 2022 in consultation with an expert health sciences librarian using Boolean operators combining the following keywords: cardiac disease, heart disease (MeSH term), heart failure, walking, Wii (gaming console), home-based, yoga, tai chi, stretch, dance, qigong, aquatic exercise, water exercise, calisthenics, gardening, weight-support exercise, mind-body, tele-rehabilitation (MeSH term), qualitative research (MeSH term), interviews, and focus group (MeSH term). Date restrictions were set to studies published since 2009 in order to capture the most current CR studies. We restricted the search to peer-reviewed studies published in the English language. We also hand-searched reference lists of relevant papers. We saved all articles to a citation manager and removed duplicates prior to screening.

STUDY SELECTION PROCESS

The search resulted in 459 studies after duplicates were removed. We reviewed the title and abstracts of all articles for inclusion criteria (Figure 1), and reviewed the full text of remaining articles for exclusion criteria. We included studies if they used qualitative study methods to assess the participant experience of an adult with CVD in a multi-component or stand-alone exercise intervention for the secondary prevention of CVD. We excluded studies if they did not have results, if the exercise protocol was poorly described, or if the intervention was standard CR.

Figure 1

PRISMA Flow diagram describing search strategy and study selection

CRITICAL APPRAISAL

Two researchers (K.P. and J.H.E.) independently conducted a critical appraisal of each study using the Critical Appraisal Skills Programme (CASP) qualitative checklist that comprises 10 questions to evaluate the quality, trustworthiness and rigor of the findings (Table 1).[21] Disagreements in scoring were discussed between reviewers until consensus was achieved. A third person was designated to resolve disagreements in scoring if necessary, however that third person was not needed.

DATA EXTRACTION AND THEMATIC ANALYSIS

We analyzed the coded data using the three stages of thematic analysis.[22] First, we inductively coded every word of the results section of each study including only that which pertained to participant perspectives of alternative models of CR. Second, we organized and combined codes into related categories. Lastly, we compared categories and merged them into analytical themes. The cross-platform program Dedoose© was used to manage data analysis. Discussion among authors was ongoing during each stage of data extraction and synthesis and was facilitated with memos to track decision-making and thematic conceptualizations.

RESULTS

STUDY CHARACTERISTICS

Twenty-Five studies were included in this review (Supplemental Table 2) representing eight countries and 487 individuals (female patients = 144, male patients = 295, caregivers = 37, professionals = 11) with an age range of 34-85 yr who participated or supported patient participation in an alternative model of CR. A variety of alternative models of CR were represented (Table 3). Exercises included: walking, tai chi, yoga, aquatic exercise, exergaming (videogaming for exercise), chair-based exercises, aerobics, physical activity trackers, and individualized exercise plans. Nineteen of 25 studies used home-based models, two of which were live-video. Twelve of the studies included patients with heart failure (HF)[23–34], one included patients with stable angina[35], one included patients with paroxysmal atrial fibrillation (PAF)[36], and one focused on patients who experienced transient ischemic attack (TIA)[37]. Qualitative study methodology varied and the majority used either thematic or qualitative content analysis. Twenty study designs included individual semi-structured interviews and five included focus groups.[24,32,37–39]

RESULTS OF THEMATIC ANALYSIS

Participant perspectives can be summarized in three central themes: (1) Exercise benefits, (2) Exercise facilitators, and (3) Barriers that influenced or prevented participation. Themes and categories along with supporting studies are provided in Table 4.

Theme 1: Exercise benefits

All study participants reported benefit(s) from study participation. Five categories of benefit are listed in order of prominence (Table 4). Improvement in self-efficacy was the most commonly reported benefit noted in all 25 studies. Participants described self-efficacy in terms of exercise or in managing

health conditions and symptoms, including making important lifestyle changes. Many participants remarked that exercise participation gave them confidence to increase and try new exercises or activities they would not have previously attempted. Some participants expressed that they were able to return to activities they had enjoyed earlier in life.

A number of participants reported improvements in managing bothersome symptoms. For example, a participant in a center-based group yoga intervention reported improved stress self-management which in turn, eliminated bothersome atrial fibrillation symptoms.[36] Similarly, a home-based yoga group participant with HF experienced improved management of breathlessness during exercise.[23] The authors speculate that self-efficacy is more likely to occur when participants also experience psychological improvements, physical or health improvements, being accountable, improved access to health related care, convenience, and tailoring or individualizing to preference or ability as these categories frequently co-occurred. These frequent co-occurrences could signify the potential mechanism by which patients came to have feelings of improved self-efficacy.

Lifestyle changes encompassed prioritizing and planning for exercise by increasing either the intensity of or time spent completing exercise. Changing diet and quitting smoking were also among the lifestyle changes reported by study participants.

Physical benefits were the next most prominent category with evidence in 22 studies. Physical improvements included enhanced balance, flexibility, coordination, range of motion, strength, increased physical activity and a return to activities previously enjoyed. An older male adult with HF attributed participation in center-based group tai chi with improvements in his balance and restoring a steady gait from his previous shuffling walk.[28] Improvements in health or comorbid conditions included weight loss, improved blood sugars, symptom control, blood pressure, cardiac function, sleep quality and avoiding

invasive procedures. A participant in a home-based walking intervention stated that her blood sugar levels were normal for the first time in 30 yr.[32]

Reported psychological benefits included decreased anxiety and stress, increased resilience, motivation to exercise, alertness, and positive mood. The authors speculate that psychological benefits are more likely to occur when participants also experience self-efficacy and physical or health improvements as these categories frequently co-occurred. Additionally, participants from all six programs that used either tai chi or yoga reported psychological benefit. Five of those programs were in person and the sixth used live video instruction, suggesting that peer support may also contribute to psychological benefit.

Improved access to physical activity and/or medical care was expressed as a benefit in 15 studies. Improved social support whether in the form of peer or family support were also important benefits noted among participants in 11 studies.

Theme 2: Exercise facilitators

Participants in all 25 studies reported factors that facilitated initiation and continued engagement with physical activity participation. Facilitators comprised eight categories (Table 4). Equally cited as a facilitator were the categories of convenience and family or peer support, each represented in 20 studies. Exercise as being adaptable to a participants' environment was highlighted by study participants who remarked that they used yoga at work or even sitting in a traffic jam.[36] Convenience also related to the alternative setting. For example, one participant commented on the convenience of a home-based live-video group exercise class as eliminating the burden of driving for his wife.[29]

The presence of peer or family support was an equally referenced facilitator across studies regardless of whether the exercise was center or home-based, despite wide variations in social connection and study designs. Participants in center-based programs noted the importance of, and

positive, motivating influence of group meetings with peers who shared their diagnosis. One participant in a center-based group tai chi class for HF patients remarked that the social interactions among group participants was the most enjoyable part of exercise participation and reason for adherence.[28]

Peer and family support was also an important facilitator in home-based programs. For some participants, having their exercise program at home meant that family or caregiver support could naturally occur as family members and caregivers were frequently present during exercise sessions, some of them joining in alongside the participant.[29] Some participants noted friendly competition or accountability to exercise occurred with family members.[37] Family and peer support was mentioned as a facilitator in all 12 HF programs and in 5 of the 6 center-based programs.

Across 19 studies, participants cited that feeling safe through staff contact was an important exercise facilitator. This contact ranged from an initial medical endorsement, to asynchronous monitoring or communication (email, messaging, dashboard), to direct communication (phone calls, video-calls, home visits). Feeling safe and/or supported was mentioned in 16 of 19 home-based programs and 10 out of 12 programs for patients with HF.

Being held accountable to exercise participation was a facilitator mentioned in 17 studies, but one that was implemented in a variety of ways by the research teams. Accountability to exercise strategies included: performance feedback, goal setting, logging exercise, and prompting. Whether accountability was enacted by the individual or the health team, and to what extent, varied by individual study design. Accountability was not referenced by any of the center-based programs, but was mentioned in 17 of 19 home-based programs.

Tailoring or individualizing exercise to physical ability or preference was an equally cited facilitator as referenced in 17 studies. Tailoring could mean increasing or decreasing the difficulty, or suggesting an alternative exercise if previous injury prevented certain activities or simply if the patient

disliked an aspect of the exercise that could be modified. Feeling safe, tailoring to preference or ability and being accountable were frequently mentioned together suggesting a potentially significant relationship.

Thirteen studies referenced enjoyment and preference as facilitating participation; often enjoyment acted as a distractor which participants said enabled exercise to pass without their notice, sometimes resulting in exercising longer, as was noted in a study that examined pairing music to walking.[40] Equally cited facilitators were anticipating or experiencing desirable physical or psychological health benefits, reported in 12 studies, and perceiving exercise as attainable or realistic.

Theme 3: Barriers that influenced or prevented exercise participation.

Exercise barriers that influenced or prevented participation were reported in 22 of the 25 studies and comprised nine categories (Table 4). A fearful, negative or false preconception about exercise by the participant or their family presented a barrier to exercise in 14 studies. Many participants or their family members were concerned that exercise or too much exercise may cause further heart damage. Some were unsure of what kind of exercise was appropriate for their heart condition. Others were concerned that exercise would exacerbate a previous back or knee injury or that frailty would prevent exercise participation.

Complaint with a specific exercise or an exercise program design was cited in 12 studies as a barrier to participation. For example, a participant who found an exercise boring or stated that they preferred outdoor exercise limited their study participation.

Physical and/or health conditions such as back pain, arthritis, knee pain and CVD symptoms altered or prevented participation in 11 studies. One participant remarked of a home-based walking program that her knee pain simply prevented her from walking and that the music intervention could not change that.[40]

Weather, terrain, and transportation also emerged as barriers to participation in 11 studies; nine of these studies were home-based programs that included walking outdoors as the primary mode of exercise. Weather was often the cited barrier that altered or prevented participation in these studies.

Competing obligations such as work or caring responsibilities was a barrier in nine studies. Other barriers included technical difficulties and/or technology illiteracy, lacking motivation, and misunderstanding or confusion about the exercise. There were no frequent co-occurrences of barriers with any other category.

DISCUSSION

This qualitative systematic review revealed that all alternative models of CR were beneficial to participants physically, psychologically, and/or socially despite differences in types and delivery methods found in exercise programs. We agree with past reviews that there is no need to rely on the traditional model of CR.[16,41,42] Rather, CR models that offer an alternative location and/or an alternative exercise should be made available in order to better meet patient need and preference. Participants described influential facilitators and barriers that informed the initiation and continuation of exercise. These insights offer pragmatic data with which to improve the delivery of CR to be accessible and appealing. Our qualitative systematic review also reveals a wide array of physical, psychological, and social benefits over and above exercise capacity and CVD risk factor modification that are typically presented as benefits in quantitative systematic reviews examining the effects of alternative and traditional CR.[41–45] Thus, our findings reveal many new directions for clinical practice and future research.

EXERCISE BENEFITS

Physical and health benefits were reported in the vast majority of studies. Physical benefits included improved balance, flexibility, coordination, range of motion, strength and increased physical activity. Though numerous patients with CVD stand to gain from these important benefits, many of

these benefits are critical in reversing sarcopenia (muscle loss) commonly associated with aging.[46,47] Older adults with CVD are currently under-referred to standard CR[4]; these findings suggest that this absence represents not only the lack of secondary CVD prevention measures, but also a missed opportunity to reverse sarcopenia and potentially avoid associated adverse outcomes.

Increased exercise self-efficacy was a psychological benefit in all included studies. Self-efficacy is a well-documented determinant of physical activity engagement and maintenance and is the only consistent predictor of physical activity benefits; high self-efficacy predicts low exercise lapse and relapse.[48,49] Self-efficacy is also associated with better HRQOL among patients with CVD[50]; Among patients with HF, improving self-efficacy, attitudes and managing relapse are integral to long-term exercise adherence.[51] That said, self-efficacy was measured in only 10 of 83 studies in Clark et al.'s alternative models of CR systematic review.[16] Knowledge of which models of CR result in high self-efficacy and the further isolating of key ingredients to support self-efficacy is imperative to improving exercise initiation and adherence.

Participants reported psychological benefits that included decreased anxiety and stress, increased resilience, motivation to exercise, alertness, and positive mood. Our findings mirror and potentially provide important qualitative context to quantitative studies that show significant improvements in anxiety and depression among patients with CVD completing exercise-based CR.[52–54] Some studies have suggested a bidirectional relationship between depression and cardiovascular health.[55,56] These pathophysiological pathways are not fully understood and require additional examination. Additionally, qualitative studies are also needed to explore for whom psychological benefits occur, and what ingredients of CR facilitate those outcomes.[57]

We found participants reported improved family/peer support in nearly half of the included studies. Previous data shows that psychosocial factors, such as family and peer support, are a protective

factor for all cause and early mortality associated with social isolation in patients with CVD.[58–60] Further, family/peer support was associated with improved mental health in one study.[61] Importantly, our review found that two-thirds of the participants who reported an improvement in family and peer support had HF, a population with highly prevalent social isolation and loneliness and increased risk for adverse effects from social isolation and loneliness.[58] Thus, it is possible that alternative models of CR could serve the additional purpose of improving social isolation and loneliness. Further research examining how and why improvement in social support occurs and for whom is needed.

EXERCISE FACILITATORS

Family/peer support was also one of the most prominent facilitators across all reviewed studies. Family and peer support often naturally occurred as a result of the CR program design. For example tai chi was taught in person to a group of patients with HF; patients described the shared diagnosis, space, and learning experience as contributing to a unique social environment that many stated was the best aspect of their participation.[28] One home-based design meant family support could naturally occur because family were often present when the patient exercised.[29] Similar to findings in previous reviews, future CR design models may involve or augment existing family and peer relationships to improve exercise adherence.[62,63]

Convenience was an equally cited facilitator and was mentioned more often by participants in home-based programs as well as programs for patients with HF. This is a significant finding in that geographic distance from CR, lack of transportation, difficulty leaving the home, and inability to drive are known barriers to traditional CR that home-based programs could potentially allay.[6,7,9] Though there is preliminary evidence that home-based telerehabilitation programs may have higher adherence than traditional CR[15], further research is needed to determine if convenience mitigates CR access barriers and improves adherence. Interestingly, though convenience was a prominent facilitator in home-based

programs, barriers such as weather, terrain, and transportation as well as competing responsibilities were still mentioned by participants in nearly half of the home-based programs. However, these home-based programs all included walking as a primary exercise; inclement weather for walking accounted for many of these barriers.

Another exercise facilitator in home-based programs was accountability. Accountability was reported by participants in 90% of home-based programs whereas this was not reported by center-based participants. This is unsurprising given that home-based programs can have less physical visibility and many rely on the participant to be self-motivated.[35,64] Also comparatively higher in home-based programs than center-based programs were the facilitators of feeling safe and/or supported, as well as tailoring or individualizing the exercise to preference or ability. Participants with HF also seemed to value feeling safe and/or supported, and participants in all of the included HF programs referenced family and/or peer support as a facilitator. These facilitators are consistent with the specific challenges of living with HF such as difficulty leaving home, social isolation, loneliness, and navigating bothersome, unpredictable and physically limiting symptoms.[65]

EXERCISE BARRIERS

Similar to the qualitative review by Neubeck et al.[9] that examined traditional CR participation, we found no predominant exercise barrier across studies, but rather barriers were individual or program dependent. Barriers ranged from mere participation hesitancy to unwillingness. Each barrier could pose a threat to the individual while forming the intention to exercise and/or while choosing whether or not to continue long term exercise. Overall, barriers were inconsistently reported and not reported in three of the included studies.

Our results revealed that participants or family members in over half of the included studies feared that exercise could cause negative cardiac consequences. We provide qualitative context to the

study by Farris et al.[66] who similarly found 40-50% of patients attending CR feared negative health consequences of exercise. Interestingly, a previous qualitative systematic review that examined traditional CR does not mention fear of exercise as a reason for CR non-attendance.[9] Armed with knowledge that many patients with CVD are uncertain whether or not exercise will cause negative cardiac consequences, or are unsure of the amount of exercise that is appropriate, clinicians can work to address these concerns when describing CR. Providing reassurances early on in an exercise program and throughout can provide support to facilitate exercise participation. Our broad recommendations for the future design of CR programs that incorporates the facilitators while minimizing the impact of barriers can be found in Figure 2.

PHYSICAL ACTIVITY AS A SOCIAL DETERMINANT OF HEALTH

Physical limitations to exercising such as back pain, knee pain, etc. were barriers reported in nearly half of the included studies. Our results provide a qualitative comparison to the study by Platz et al.[67] that estimates 42% of US adults with CVD have difficulty walking or climbing stairs. The Centers for Medicare and Medicaid Services has included physical activity as a social determinant of health. Physical activity is included in the Health Resources Social Network (HRSN) screening tool used to identify all potential sources of health inequity.[68,69] Recently, the Million Hearts think tank has called for innovative delivery of CR in order to broaden access and address health inequity.[70] Many of the models of CR in this review represent less resource-intensive models that could potentially expand program capacity to address the worldwide underutilization of CR.[71] These patient insights could also aid in upstream public health efforts to develop programs to launch physical activity programs for adults and simultaneously combat the 40% U.S. obesity prevalence, a large risk factor for CVD.[72]

STRENGTHS AND LIMITATIONS

The primary limitation of this review is that the included studies are not uniform either in type of intervention nor in qualitative design. Lack of direct contact with the interview data limits our ability to fully understand the participant experiences. Though all included studies received good to excellent CASP scores, the authors complete the analysis and interpretation process with implicit biases. Half of the studies did not include participant demographic information. Without demographics we cannot ascertain if patients from underrepresented communities are offered CR, participate, and/or have similar or unique facilitators and barriers to participation. We offered our interpretations of the frequent co-occurrences of categories which we speculate signify underlying mechanisms and relationships. However, there is a need to analyze which combinations of benefits, facilitators and barriers work best and for whom, and how it relates to program adherence.

CONCLUSIONS

All alternative models of CR were found to be physically, psychologically, and/or socially beneficial to participants. Despite the variety of program designs, there were several common facilitators identified across studies that led to both initial and ongoing participation such as: peer and/or family support, convenience, feeling safe through contact with staff or medical endorsement, being accountable, tailoring to individual preference or ability, enjoyment, anticipating or experiencing health benefits, and the perception that prescribed exercise is attainable. Exercise barriers included: fearful, negative or false preconceptions about exercise, complaint with the specific exercise or aspects of the program, physical limitations to exercise, weather, terrain, or transportation, competing responsibilities, technical difficulties or technology illiteracy, lacking motivation, and misunderstanding that resulted in participation hesitancy and unwillingness. These patient insights offer pragmatic data with which to design CR that is appealing, accommodates physical limitations, and broadens access in order to address health inequity and worldwide underutilization of CR.

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Table 1 Qualitative critical appraisal skills program (CASP) scores of included studies

Article	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
Adsett et al. (2019)[73]	1	1	1	1	1	1	1	1	1	1	**10**
Cacciata et al. (2021)[82]	1	1	1	1	1	0.5	1	1	1	1	**9.5**
Clark, Baker and Taylor (2016)[88]	1	1	1	0.5	1	0	1	1	1	1	**8.5**
Conboy et al. (2020)[115]	1	1	1	1	1	0.5	1	1	1	1	**9.5**
Dale et al. (2015)[116]	1	1	1	1	1	0	1	1	1	1	**9**
Devi et al. (2014)[83]	1	1	1	1	1	0	1	1	1	1	**9**
Dinesen et al. (2019)[117]	1	1	1	1	1	1	1	1	1	1	**10**
Frost et al. (2019)[75]	0.5	1	1	1	1	1	0.5	1	1	1	**9.0**
Hagglund, Boman, and Brannstrom (2017)[76]	1	1	1	1	1	0.5	0.5	1	1	1	**9.0**
Hannan et al. (2021)[118]	1	1	0.5	1	1	1	1	0.5	1	1	**9.0**
Heron et al. (2017)[85]	1	1	0.5	0.5	1	0.5	1	1	1	1	**8.5**
Hwang et al. (2017)[77]	1	1	1	1	1	1	1	1	1	1	**10**
Jones et al. (2007)[86]	1	1	1	1	1	0	0	0.5	1	1	**7.5**
Jones, Greenfield, Jolly (2009)[119]	1	1	1	1	1	0	0	0.5	1	1	**7.5**
Klompstra et al. (2017)[74]	1	1	1	1	1	0.5	1	1	1	1	**9.5**
Klompstra et al. (2021)[79]	1	1	1	1	1	1	1	1	1	1	**10**
Knudsen et al. (2021)[120]	1	1	1	1	1	0	1	1	1	1	**9**
Murphy et al. (2021)[87]	1	1	0.5	1	0.5	0	1	0.5	1	1	**7.5**
O'Shea et al. (2020)[121]	1	1	1	1	1	0.5	1	1	1	1	**9.5**
Okwose et al. (2020)[80]	1	1	1	1	1	1	1	1	1	1	**10**

Selman et al. (2015)[35]	1	1	1	1	1	0.5	1	1	1	1	**9.5**
Smith et al. (2021)[78]	1	1	1	1	1	1	0.5	1	1	1	**9.5**
Thorup et al. (2016)[81]	1	1	1	1	1	1	1	1	1	1	**10**
Wahlstrom, Karlsson, Medin (2018)[84]	1	1	0.5	1	1	0	1	1	1	1	**8.5**
Yeh et al. (2016)[72]	1	1	1	1	1	0.5	1	1	1	1	**9.5**

Yes: 1; Unsure: 0.5; No: 0

Table 3 Alternative models of cardiac rehabilitation

Author (Yr)	Further specified CR population	Exercise Type	Home-Based	Center-Based	Group-Based	Live-Video	CR Monitoring	Pedometer or Wearable	Communication
Adsett (2019)[73]	HF	Aquatic		X	X				
Cacciata (2021)[82]	HF	Exergaming	X						Phone
Clark (2016)[88]		Walking	X						Phone
Conboy (2020)[115]		Tai Chi		X	X				
Dale (2015)[116]	IHD	Individualized Exercise Prescription	X						Text Website
Devi (2014)[83]	Angina	Individualized Exercise Plan	X						Website Chat room
Dinesen (2019)[117]		Individualized Exercise Plan	X				X	X	Web portal
Frost (2019)[75]	HFrEF	Chair-based or Walking	X						Home visits or Phone
Hagglund (2017)[76]	HFrEF	Tai Chi		X	X				
Hannan (2021)[118]		Personal Activity Intelligence Score	X					X	Face to Face visits
Heron (2017)[85]	TIA	Moderate Physical Activity	X					X	Phone
Hwang (2017)[77]	HF	Exercise Class	X		X	X	X		
Jones (2007)[86]		Exercises and Walking	X						Home visits Phone
Jones (2009)[119]		Exercises and Walking	X						Home visits Phone
Klompstra(2017)[74]	HF	Exergaming	X						

Klompstra (2021)[79]	HF	Exercise Advice and Motivational Support	X					Hospital visits or Phone
Knudsen (2021)[120]		Biking or running or local gym	X				X	Phone, text, or e-mail
Murphy (2021)[87]		Yoga		X	X			
O'Shea (2020)[121]		Aerobic and Resistance Exercise Class with Avatar Coach	X				X	Dashboard Text
Okwose (2020)[80]	HFrEF	Walking	X					X	Phone
Selman (2015)[35]	HF/ COPD	Yoga	X		X	X		
Smith (2021)[78]	HFpEF	Chair-based or Walking	X					Home visits or Phone
Thorup (2016)[81]	Includes HF	Walking	X				X	X	
Wahlstrom (2018)[84]	PAF	Yoga		X	X			
Yeh (2016)[72]	HFrEF	Tai Chi		X	X			

HF = heart failure, COPD = chronic obstructive pulmonary disease, pEF = preserved ejection fraction, rEF = reduced ejection fraction, PAF = paroxysmal atrial fibrillation, TIA = transient ischemic attack, IHD = Ischemic heart disease.

Table 4 Themes and categories from qualitative studies

THEME	CATEGORY	SUPPORTING STUDIES	Center-Based (6)	Home-Based (19)	Heart Failure (12)	Total Studies (25)	Total Studies (25)
BENEFITS	**Self-Efficacy and Lifestyle Changes**	23–40,73–79	6	19	12	**25**	**25**
	Physical or Health Improvements	23–40,73,77–79	6	16	12	**22**	
	Psychological Improvements	23,24,27–31,34–40,73,76,77,79	5	13	8	**18**	
	Improved Access to Health Related Care	23,25–27,29,33–38,76–79	2	13	7	**15**	
	Increased Peer or Family Support	24–26,28–30,32,34,39,73,79	5	6	8	**11**	
FACILITATORS	**Convenience**	23,26–38,73,75–79	3	17	10	**20**	**25**
	Family or Peer Support	23–34,37–39,73–75,77,79	5	15	12	**20**	
	Feeling Safe and/or Supported from Staff or Medical Endorsement	23,25–33,35,37,38,73–75,77–79	3	16	10	**19**	
	Being Accountable	26,29–35,37,38,40,74–79	0	17	7	**17**	
	Subcategory: Performance Feedback	26,29–35,37,40,74–79	0	16	7	**16**	
	Subcategory: Goal Setting	26,30–35,37,74–78	0	13	6	**13**	
	Subcategory: Logging Exercise	30,31,33,35,75–79	0	9	3	**9**	
	Subcategory: Being Prompted	32,33,38,74,77,79	0	6	2	**6**	
	Tailoring or Individualizing to Preference or Ability	23,27,29–33,35,39,40,73–79	2	15	8	**17**	
	Enjoyment or Preference	23,25,26,28,29,31,33,34,36,38,40,77,78	3	10	8	**13**	
	Anticipating or Experiencing Physical or Psychological Benefits	23,29,30,33,34,36–38,73,76,78,79	2	10	5	**12**	
	Perceiving the Exercise as Attainable	23,25–28,30,32,40,73,74,77,78	3	9	7	**12**	
BARRIERS	**Fearful, Negative, or False Preconception about Exercising**	23,25,27–29,31,32,35,38,73,75–78	3	11	7	**14**	**22**
	Complaint with Exercise or Program Design	23,25,26,28,30,33,34,38,73,75,76,79	3	9	7	**12**	
	Physical Limitations to Exercising	23,26,27,30,31,33,38,40,76,77,79	0	11	6	**11**	
	Weather, Terrain, or Transportation	28,31–33,35,38,40,73,76,77,79	2	9	4	**11**	
	Competing Responsibilities	26,31,35,38,40,73,76,77,79	1	8	2	**9**	
	Already have an exercise routine	26,28,30,35,38,40,74,76	1	7	3	**8**	
	Technical Difficulties, Technology Illiteracy,	23,29,37,40,74,76,79	0	7	2	**7**	
	Lacking Motivation	26,27,34,35,38,76,78	0	7	3	**7**	
	Misunderstanding or Confusion	25,27,30,38,76,79	1	5	3	**6**	

Chapter 3: Manuscript Two

Initiating and Continuing Long Term Exercise in Heart Failure: a Qualitative Analysis from the GENTLE-HF Study

Target Journal: ***Journal of Cardiovascular Nursing***

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Abstract

Background: Exercise is a Class 1A Recommendation to improve the lives of patients with heart failure (HF), yet less than one-third adhere to physical activity guidelines and less than 3% attend cardiac rehabilitation.

Objective: To determine the effect of gentle non-aerobic exercise on long-term adherence in patients with HF.

Methods: We used a qualitative descriptive approach with qualitative content analysis to analyze previously recorded interview data collected as part of the 6 month GENTLE-HF study and looked for trends in responses among subgroups. Thematic statements, representing salient aspects of the participants' experiences were created and supported by illustrative excerpts from the data.

Results: Twenty-Two interviews were analyzed. Eight participants had ≥80% adherence, and the remaining 14 participants were super-adherers (>100% adherence). Super-adherers tended to be male sex, age ≥65, no exercise for 3 months prior to the study, BMI ≥30, and poor to good Kansas City Cardiomyopathy Questionnaire scores. Participants initially enrolled because they saw the program as an opportunity to improve a health issue and to exercise. Long-term adherence was facilitated by convenience, individualization, experiencing psychological and physical improvements, and peer fellowship.

Conclusions: The GENTLE-HF study that used home-based gentle non-aerobic exercise had 64% of participants come *more* than was asked. It is imperative that clinicians incorporate what participants with HF have directly stated is important for their initiation and long-term adherence to exercise so that we can work towards bridging sedentary patients to the full exercise guidelines to improve morbidity and mortality.

Introduction

Physical activity is a Class 1A Recommendation for patients with heart failure (HF) to improve functional status, exercise performance, health related quality of life (HRQOL), and to reduce HF hospitalizations.[1] In fact, any physical activity amount is associated with improved cardiovascular outcomes.[2] That said, less than one-third of patients with HF meet current physical activity guidelines and fewer than 3% attend exercise-based cardiac rehabilitation (CR).[3,4] Most HF exercise research has addressed facilitators and barriers to aerobic exercise in CR.[5–8] In contrast, few researchers have investigated the effect of gentle non-aerobic exercise on exercise initiation and continuation. Patients with HF are generally older, frailer, multimorbid, and more socially isolated. They navigate a significant daily symptom burden of breathlessness, fatigue, edema, and disruptive medication side effects.[9] Alternative forms of exercise that are gentler and/or modifiable to past injuries, comorbidities, frailty or low existing cardiorespiratory fitness may help to initiate exercise habits and instill exercise self-efficacy.[10] Alternative and innovative exercise models also represent a financially viable alternative to brick and mortar programs and simultaneously increase exercise access, an important social determinant of health.[11,12]

In a recent qualitative systematic review, we identified models of CR that used either an alternative gentle exercise and/or an alternative location (i.e. home-based).[10] Benefits, facilitators and barriers were described; adherence rates were not. Therefore, the extent to which these factors impacted long-term adherence remains unknown. The specific aim of this qualitative study is to explore patients' with HF perceptions about initial and continued exercise engagement with gentle non-aerobic exercise after study completion. If clinicians better understand from the perspective of a patient with HF, factors that increase likelihood of agreeing to participate in and continue long-term exercise, then they will be better equipped to address the disparity of care in existing programs.

Research Design and Methods

Design

Employing a qualitative descriptive approach, we analyzed previously recorded interview data collected as part of the GEtting iNTo Light Exercise – Heart Failure (GENTLE-HF) study. A qualitative descriptive design aligns well with our pragmatist paradigm and our goal of obtaining an accurate yet rich summary of the participants' experiences. [13]

Parent Study

The GENTLE-HF study is an IRB approved (#21869) randomized controlled trial that recruited stable patients with HF (N=61) with either reduced or preserved ejection fraction from HF clinics located in central Virginia. Eligibility with inclusion and exclusion criteria are previously described.[14] Patients were randomly assigned to the intervention group (IG) or education control group. The GENTLE-HF intervention[14] was a twice weekly, live-video group home-based 60-minute gentle exercise program using iPads. Exercise consisted of yoga-like stretching modified on an individual basis for physical limitations throughout class by the instructor. Each class was limited to 6-10 participants and was comprised of 4 phases: well check (3 minutes), relaxation (10 minutes), movement (35-40 minutes), and inspiratory training/meditation (8-10 minutes). Participants were asked to log on 10 minutes early to ensure they were ready for class to begin. Participants were asked to come to two live classes weekly for the first 12 weeks, and then one live and one recorded class for the remaining 12 weeks for a total of 36 live classes in 24 weeks over 6 months. Five classes were offered weekly: 2 daytime, and 3 evening. Participants were encouraged to make up any missed classes via the website[15] that has 8 recorded videos.

Data Collection

Individual semi-structured interviews were conducted with the first 22 of the 28 remaining IG participants within one week of study completion (4 participants dropped out: two developed non-

cardiac health concerns, and two did not enjoy the study). Interviews were recorded over the phone (with participant permission) and lasted 15-30 minutes. No participant declined an interview. One interviewer, J.H.E., conducted all of the interviews to ensure consistency and used an interview guide (**Figure 1**) of open ended questions focused on understanding the participant experience of the GENTLE-HF intervention. We used all interviews in the analysis. Other data included field notes, sociodemographic and clinical variables obtained from participants and electronic health records.

Data Management and Analysis

Audio-recordings were transcribed verbatim (KP) using 2021Otter.ai© transcription software. Deidentified transcripts were uploaded into Dedoose Version 9.0.46 (2022), a qualitative data management system, and analyzed using well-established qualitative content analysis techniques[16]. First, interviews were read in their entirety to gain a sense of the whole. Then line-by-line coding using a deductive coding schema derived from the study aims and interview questions was completed (KP). Next, code families or categories were created, and then matrices, one for each category were developed to facilitate within and across case comparisons (KP). We looked for trends in responses among subgroups. Thematic statements, representing salient aspects of the participants' experiences, were created and supported by illustrative excerpts from the data.

Several techniques, including parallel coding (MM), peer debriefing (MM, JHE), member checking (JHE), and detailed recording and review of analytic procedures and decisions (KP, MM), were used to enhance the trustworthiness of the findings.[17] We collected sex, age, exercise habits, high body mass index, depression, employment status and HRQOL as evidence suggest these factors may influence adherence.[8,18]

Results

Of the 22 interview participants, all were White, 12 were male (56%) with a mean age of 68, ranging from 48 to 87. Eight participants had ≥80% adherence, averaging 33 live classes with a range of 28 to 36 classes; the remaining 14 participants were super-adherers exceeding attendance guidelines, averaging 50 live classes (range 37 to 79). A breakdown of demographic and clinical characteristics were collected (**Table 1**) with adherence data (**Table 2, Figure 2),** along with characteristics of adherers and super-adherers (**Figure 3)**. Super-adherers tended to have the following characteristics: male sex, age ≥65, no exercise in the 3 months prior to the study, history of obesity, and poor to good Kansas City Cardiomyopathy Questionnaire (KCCQ) scores.

The results are organized by subheadings into the following conceptual categories: participant perceptions regarding initial enrollment, long-term adherence, and suggestions for improvement with sub-group response trends incorporated throughout. Verbatim excerpts were extracted from the interview transcripts to support and illustrate key findings. Main findings are summarized in **Figure 4**.

Initial Enrollment

Reasons cited for study enrollment included: the desire to improve a health issue, viewing the study as an exercise opportunity, encouragement by a healthcare provider or the study manager, a desire to contribute to research, and having an interest in the study. Most participants desired the opportunity to improve a health issue(s) such as balance, flexibility, state of mind, momentum to exercise, HF symptoms, general health, being less sedentary, and learning safe exercise for HF. For example, Participant (P) 20 stated: *"I was just kind of hopeful that, you know, I can start getting some of my mobility back."*

The opportunity to exercise was discussed in various ways. For some, the pandemic had disrupted their normal exercise routine. *"And until things closed with COVID, I was walking at the mall every morning. But I, you know, with COVID, I have not been doing that." (P1)* Others expressed they

were seeking opportunities to exercise, especially as CR was unavailable due to distance or pandemic-related closures. Other participants viewed study participation as a way for them to exercise safely and/or receive instruction from trained experts. *"I just didn't know exactly how much of exercise, what kind of exercises I could do that wouldn't do more harm than good. And I figured that this program is being shaped for people with heart conditions and would take all that into consideration." (P9)* Of note, 80% of participants with BMIs >30 specified that the opportunity to engage in exercise was a primary motivator for enrolling in the study.

While the majority of participants readily enrolled, a handful of patients expressed skepticism before deciding to enroll. Four patients expressed skepticism about yoga*. "I'm not quite sure that I was a quote, unquote, yoga person… My personality is not, you know,…voodoo medicine."(P21).* One participant expected to dislike the program because he does not regularly exercise, while another was unsure about virtual classes. *"I am so technology deficient. So I was afraid that would be a problem…" (P1).*

Long-Term Adherence

Study participants discussed multiple factors, including convenience, ability to modify exercises, perceived benefits, peer support and companionship, that contributed to their long-term adherence.

Convenience

As illustrated by the following excerpts, the convenience of a home-based virtual gentle exercise was a key facilitator for nearly all participants.

> *I first and foremost want to thank you for the opportunity to try on something that I think I can continue as far as an exercise routine that works for me, I don't have to dress up or change clothes, it's right here. (P2)*
>
> *It's not just the fact that it would be a drive… There's also the fact that in my life I have learned… that sometimes I can't show up… I'll wake up sometimes and I'm just really not feeling well… and*

> *so online was perfect for me, and honestly if it had been a requirement to come into class, I wouldn't have been able to do the study. (P36)*

A component of convenience was that the iPad was easy to use, and for those who were technologically challenged, the project manager was quick and responsive to needs. "*It was very easy, and I'm technically challenged." (P36)*

Over half of the participants, particularly women and employed individuals, commented on the added convenience of having the recorded class videos in addition to live classes. *"Even though they were not you know, as perfect as the live interaction, it did give me a vehicle to still get the same type of activity when I had them as class, so that was a good fallback when I had to do it."(P2)* For some participants, the convenience of being at home was in the context of the pandemic, while others stated they were home regardless. Nearly every participant articulated that having multiple days and class times available mitigated scheduling conflicts and other issues that would have prevented attendance.

Individualization by Instructors

Nearly half of the participants gave an example of an instructor making an individual modification for an existing physical injury or limitation that supported their continued class participation. *"When I was having some issues which came up with both my hip and my knee, and ankle, she was able to tell me how to modify things a bit so that they were less stressful, less painful, and I could work around some of it. So instead of just stopping, it was possible to make adjustments." (P32)*

Individuals with BMI $\geq$30 and/or who had not exercised in the 3 months prior to the study tended to find individual modifications by the instructor to be particularly helpful. For a handful of participants with advanced exercise capabilities, certain instructors would give suggestions on how to make the exercise more challenging. Those participants looked forward to the challenge and sought out those instructors' class times for that purpose.

Most participants appreciated having a variety of instructors just for the sake of having variety in a 6-month program. However, for those few participants who did have challenges with a particular instructor, having other instructors to choose from was crucial. *"There was one instructor particularly… I found that class very tough…. I chose not to try that time period ever again because I was afraid I'd get that class again." (P1)*

Personal Exercise Goal

Though not part of the GENTLE-HF intervention protocol, over two-thirds of participants stated that a personal goal to exercise influenced their long-term adherence. For many this was a specific goal such as to lose weight, improve HF symptoms, build strength for an upcoming surgery, or simply to exercise, and for others it was following through on the commitment they had made by enrolling. *"The reason I kept coming back was I wanted to do some exercise. I know I need some exercise. I know that exercise is better than lying around on your butt doing nothing. So I kept coming back as much as often as I possibly could in order to get the exercise." (P16)* For two individuals who did not particularly enjoy the gentle exercise study, they had a personal goal to finish the study to honor their commitment. "*I managed to make that (class time) work because I felt like if I was going to commit to the study, I needed to do that." (P10)*

Psychological and Physical Improvements

The majority of participants reported they were benefitting from the gentle exercise program and this motivated them to continue. Two-thirds of participants reported physical improvements including flexibility, strength, balance, mobility, reduced pain, breathing and endurance. For several participants, as illustrated by the excerpts below, experiencing these physical improvements provided concrete evidence to them that class was worth continuing.

> *I make the time to do it because I immediately, when I say immediately, I would say after the first week to ten days, I noticed a noticeable change in my mobility, in my flexibility and in my balance. And those are all areas that I have been concerned about. (P40)*

> *We have a couch that sits very low, and it's always been a struggle to get up. Somewhere, and I don't know when it happened. Somewhere, I started getting up without having help.* (P15)

> *The first few weeks of the program, I'm thinking like this ain't exercise, this is too easy. This is just what I've been reduced to doing… But after a few weeks, I began to realize that it was doing some things for me that actually nothing else had done. And although it wasn't really an aerobic exercise, it was helping my breathing. (P9, a previous athlete)*

Of note, all participants who had not exercised in the 3 months prior to the study, and 90% of participants with BMI ≥ 30 stated they experienced physical improvements.

Though the majority of participants had subjective physical improvement, a few participants did not report any significant physical changes or attributed change to other factors at play such as medications, medical procedures, or other exercise. "*I think the class is helpful. I call it more complementary. I think it's probably not the primary thing that's going on with me, but it's certainly been helpful." (P45)*

Most participants expressed perceived psychological benefits including a reduction in stress, anxiety, depression, or an escape from pandemic-related stress.

> *I would say probably the number one, the biggest benefit I would say was mental and emotional. And then the physical part. (P40)*

> *I tend not to attend much to myself. And this was an opportunity, perhaps more this was a requirement, if you will, where I would have to stop and not consider other people for a period and focus on myself and that was a significant break in pattern. (P32)*

Of note, every participant that was identified as either employed, depressed and/or anxious independently reported experiencing psychological improvement.

Lastly, a few participants reported overall enjoyment of the program as their primary motivation.

> *Two a week wasn't enough for me. I just loved it. I just loved it. At the beginning was a little hard for me. But then I was getting it getting it getting it. So I was doing it eight times a week I*

was doing it. Five with instruction from the great instructors you had and I was doing three online videos, so I did eight a week for the six months. (P41)

Peer Fellowship

Over half of the participants reported enjoying the peer fellowship from the 10 minutes before class began and this motivated them to continue attending. The opportunity to socialize was contextualized in various ways. For example, P47 enjoyed seeing the same people over time: *"We started to create relationships. I mean, it was basically, you know, some of the same people every day. And they started, they began to look out for each other."* For P2 and many others, socializing was meaningful due to social isolation as a result of the pandemic: *"I look forward to it because I'm not going out as much socially and the grandkids are not coming in as much. So, I looked very forward to it."* Similarly, P38 who was rurally located stated: *"I live by myself and in the mountains. So I don't' really get to interact much. So that's why I logged on earlier."*

While many appreciated peer fellowship, a few expressed that they did not connect socially or did not want to. *"We weren't encouraged to, you know. I mean, it wasn't a family get together. It was an exercise program for heart patients. We weren't encouraged to interact with one another."(P13) "I had no interaction with them. I mean, I muted myself as soon as I got on, but I could hear them yik yaking back and forth. And they were visiting and I don't have a problem with that, but that's not what I signed up for." (P33)*

Suggestions for Improvement

Most participants suggested ways to improve the exercise classes. Most suggestions pertained to offering more and varied class times though there was no consensus among the suggestions regarding time of day or day of week. One third of participants suggested that class difficulty be

advanced during the 6 month long study. *"Halfway through, the exercises should have been increased… Nobody ever stays in a beginner program for six months." (P13)* Another participant cautioned, however, that new participants should avoid challenging classes too early on so they do not get scared away. One participant suggested making an orientation class to Yoga terminology and intentions. It was suggested that peer fellowship could be strengthened if the instructor intentionally introduced new classmates and if more designated social time were added before, after or separately from class. Other participants suggested that instructors turn on closed captioning and invite attendees to mute their microphones before class begins to assist those with hearing deficits.

Discussion

The purpose of this qualitative analysis was to better understand patients' with HF perspectives on what factors influenced their decisions to enroll and then continue with a home-based gentle exercise program. This understanding will better position providers and researchers to design and implement exercise interventions that in turn will improve daily symptom burden and reduce mortality. Participants initially enrolled because they saw the program as an opportunity to improve a health issue and to exercise. Long-term adherence was facilitated by convenience, individualization, experiencing psychological and physical improvements, and peer fellowship. Super-adherers tended to be male, age ≥65, no exercise in the 3 months prior to the study, BMI ≥30, and poor to good KCCQ scores.

Initial Enrollment

The decision to initially enroll was separate from the decision to continue exercising. This finding is consistent with the Health Action Process Approach health behavior theory wherein intending to exercise and actually exercising are separate stages; the former requires perceived self-efficacy and the latter requires recovery self-efficacy, or the ability to adapt and bounce back.[19–21] Regarding initial enrollment, participants felt the proposed exercise was logistically and physically possible; In other

words, participants had perceived self-efficacy with the intervention, an essential ingredient for exercise initiation.[22] Consistent with studies by Platz et al. and Albert et al., some participants stated they did not know what exercise was safe with HF, thus having supervision in GENTLE-HF eliminated safety as a barrier to exercise.[8,10] Most participants had a personal goal to exercise that positively impacted their decision to exercise. This finding should prompt clinicians to ask about individual goals and where appropriate, strengthen the existing goal to make it specific, measurable, attainable, relevant, and timely (S.M.A.R.T.). A verbal or written commitment to a goal has also been shown to help with long-term adherence, and was referenced by multiple participants in this study.[23] Additionally, participants confirmed, providers' recommendation and exercise prescription is still of great importance to initiating exercise.[5,23–25]

Long-Term Adherence

Convenience was mentioned by nearly every participant as a key facilitator of continued participation. This is echoed by Platz et al. wherein 10 out of the 12 studies including patients with HF mentioned convenience as a key facilitator and multiple studies wherein access to exercise is a main barrier to participation.[5,10,26] It was not just the convenience of not having to drive to an in-person location, or socially distancing during the pandemic. Participants articulated that it was convenient to have multiple days and times the classes were offered and recordings to watch if they missed a live class. This was especially so for the employed participants.

Another key facilitator to long-term adherence was the instructor modifying exercise to individual need(s). This was true across groups from participants who were new to exercise, BMI $\geq$30, had existing physical limitations, or were physically fit. Previous research has emphasized individualization to be an important facilitator for exercise in patients with chronic disease.[10,23] Indeed, much of the widespread medical appeal for Yoga is its adaptability to a range of physical fitness levels.[27]

The most common modification is to simply convert a standing posture into a supported or seated posture, and for patients with HF who are commonly prescribed beta blockers, to avoid postures that put the head below the heart.[27] Our study confirms that patients with HF find yoga to be adaptable to a variety of physical limitations; this finding is significant as musculoskeletal impairments, and peripheral muscle atrophy are commonly cited reasons for sedentary behavior by patients with HF.[9,27,28] Additionally, participants with BMI ≥30 contributed two-thirds of the remarks about individualization and 80% came to more classes than were asked. This is significant as greater than 80% of patients with HF (with preserved ejection fraction) are overweight or obese and can have symptoms of exercise intolerance from obesity independent of HF.[29,30] A possible explanation for this remarkably high adherence by this sub-group is that the GENTLE-HF intervention may have addressed weight stigma by normalizing individual exercise modification and being virtual rather than in-person.[31]

Another powerful facilitator for long-term adherence was experiencing subjective psychological and physical improvements from yoga. Previous research has shown that depression is a barrier to exercise adherence, and we did note more depression in the less adherent group, though the difference was small.[7,8,18,32] However, similar to previous studies examining yoga, every depressed, anxious, or employed participant reported experiencing psychological improvements from participation.[27,33–35] Our results also support previous research that physical improvements increasing independence and the ability to perform daily activities are powerful motivators for exercise.[23,36] Several participants noted improved breathing and future research should explore whether the pranayama (breathing) portion of classes could function as inspiratory muscle training, a muscle training shown to improve maximal inspiratory pressure in patients with HF.[37] All study participants who had not exercised in the 3 months prior to study start stated they experienced physical improvements, as did 90% of participants with BMI ≥30.

Lastly, many participants enjoyed the peer fellowship occurring before and during exercise and found it motivational to continuing class participation. Family and peer support is a frequently cited facilitator for exercise for patients with HF.[10,22,23,36] Our study adds participant suggestions on how they would improve socialization such as having the instructor introduce new members in order give permission, so to speak, for socializing to occur, and adding more time before, after or separately from class to converse with peers.

Limitations and Strengths

As with secondary analyses, interviews were collected for a different purpose and we were unable to access participants for follow up questions. For example, we found that employed individuals found class recordings to be convenient which we expected, however we were unable to follow up with female participants, 80% of which commented on the convenience of class recordings. That said, we were able to answer our research questions and achieve data saturation with the available interviews. As with all qualitative work, the findings are limited to our sample which was White, and, as is typical with exercise studies, consisted of patients who were willing to exercise. Despite these limitations, the strength of our study is in the qualitative findings alongside the quantitative findings that gave deeper understanding of how and why participants had remarkably high long-term adherence. Our research reveals many new directions for changes in clinical practice and future research.

Clinical Implications and Future Research

Given the gentle and adaptable nature of the GENTLE-HF exercise intervention and the remarkably high long-term adherence by participants with BMI ≥30, our findings have broader implications to promoting exercise initiation and adherence for the 40% of Americans who are obese, and the 42% of adults with cardiovascular disease that report difficulty walking.[38,39] Additionally, these

programs and the GENTLE-HF intervention represent innovative delivery of exercise that are less resource intensive and simultaneously increase exercise access.

Starting small with home-based gentle exercise, and acknowledging that some exercise is better than none,[2] clinicians could help bridge sedentary patients to the full exercise guidelines by instead helping to initiate gentle exercise and instill the mindset of living with exercise. For example, the 2010 HF guidelines for exercise were the same as for the general population (150 minutes of moderate exercise per week); and currently, neither the American nor European guidelines provide a *standard minimum exercise dose*.[1,40,41(p6),42] As clinicians that strive to make S.M.A.R.T. goals, it is imperative that we make exercise guidelines for patients with HF that are both attainable and measurable.

Currently, there are several existing live tele-yoga programs such as through Medicare's Silver Sneakers, Veteran Affairs' Whole Health, and the YMCA 360 that potentially incorporate the key facilitators of long-term adherence expressed by patients with HF in this study.[43–45] Mixed methods studies with a larger and more diverse sample of patients with HF are needed to evaluate the long-term adherence to and subjective experience with these programs. Additionally, evaluation of psychosocial outcomes such as depression, anxiety, social isolation and loneliness that are linked to poor health outcomes are needed. Future research should also consider examining whether these programs might be of particular relevance for older adult patients with sarcopenic obesity.[46]

Conclusion

It is imperative clinicians prioritize incorporating what patients with HF have directly stated is important for their initiation and long-term adherence to exercise: convenience, individualization, goal setting, psychological and physical benefits from gentle exercise/yoga, and peer fellowship.[3,4] For more than a decade, the leading HF authorities have designated exercise as a Class 1A Recommendation to improve the lives of patients with HF, yet we have failed in helping patients to initiate and adhere to

exercise. The adherence rates, facilitators and barriers of aerobic in-person exercise have been well established.[5,7,47,48] The verdict is in; less than one-third of patients with HF adhere to physical activity guidelines, and less than 3% attend CR.[3,4] Our study lets us hear directly from patients as to why they enrolled and then adhered to a gentle home-based exercise program for 6 months with 64% of participants coming *more* than was asked. It is our hope that others will build upon our work. Together we can move toward our vision of substantively improving the quality of life for persons with HF; for many of our patients, it is not a “couch to 5K”, it is “couch to standing up”.

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"What's New?":

- Participants with heart failure enrolled because they saw the home-based non-aerobic gentle exercise program as logistically and physically possible; they had perceived self-efficacy, the essential ingredient for exercise initiation.
- Participants adhered to the exercise long-term because of the convenience, individualization, psychological and physical improvements, and peer fellowship they experienced in the program.
- Characteristics of super-adherers offer several new directions for research, in particular that a common characteristic of super-adherers was a BMI ≥30.

Table 1: Demographic and Clinical Characteristics of Sample

	Intervention Group (N=22)
Age (years), mean (SD)	67.7 (10.1)
Male sex, n (%)	12 (54.6%)
Married, n (%)	20 (90.9%)
Race, n (%) White	22 (100%)
Education, n (%)	
Less than High School	0 (0%)
High School Graduate	3 (13.6%)
Some College	8 (36.4%)
Bachelor's degree or higher	11 (50%)
NYHA Class, mean (SD)	
Class 1	5 (22.7%)
Class 2	17 (77.3%)
Retired/Unemployed, n (%)	15 (68.2%)
Income, n (%)	
<20K	1 (4.5%)
20-40K	1 (4.5%)
40-75K	7 (31.8%)
>75K	10 (45.5%)
Declined to answer	3 (13.6%)
Exercise in previous week, n (%)	
None	4 (18.2%)
<30 min/week	4 (18.2%)
30-60 min/week	4 (18.2%)
1-3 hr/week	6 (27.3%)
3+hr/week	4 (18.2%)

BMI, mean (SD)	29.9 (5.8)
HFpEF, n (%)	6 (27.3%)
HFrEF, n (%)	16 (72.7%)

Table 2: Adherence Data

Participant Number	1	2	7	9	10	13	15	16	20	21	27	32	33	34	36	38	40	41	45	47	48	53
Total Live Classes First 12 Weeks (_/24)	32	26	20	35	19	17	19	23	22	21	21	25	17	18	20	28	19	36	23	18	23	21
Average Live Classes per Week in First 12 Weeks	2.7	2.2	1.7	2.9	1.7	1.5	1.6	1.9	1.8	1.8	1.8	2.1	1.4	1.5	1.7	2.3	1.7	3.0	1.9	1.6	1.9	1.8
Total Live Classes Second 12 weeks (_/12)	25	17	9	31	9	14	15	20	18	19	16	24	14	16	15	33	17	43	20	16	23	23
Average Live Classes per Week Second 12 Weeks	2.1	1.4	1.1	2.8	1.3	1.6	1.4	1.9	1.6	1.6	1.3	2.0	1.2	1.3	1.3	2.8	1.4	4.3	1.7	1.3	1.9	1.9
Total Live Classes in 24 Weeks (_/36)	57	43	29	66	28	31	34	43	40	40	37	49	31	34	35	61	36	79	43	35	46	44

Figure 1: GENTLE-HF Interview Guide (could be supplementary if needed)

1. Thinking back…. Can you tell me how you came to the decision to enroll in the study?
2. What did you expect going into the study?
3. How do you remember your well-being at that time?
4. One of the participant requirements is a diagnosis of heart failure. What are the challenging aspects of this illness for you personally?
5. Can you describe your previous experiences with exercise prior to this study?
    a. Did you have any previous experience with Yoga or stretching?
        i. If so, in what ways were those experiences similar or different than the classes in the study?
6. Some patients are recommended to attend cardiac rehabilitation, is this something you have considered before or have discussed with your provider?
    a. (If so), what led to the decision to participate or not participate?
7. Heart failure is often accompanied by symptoms that make exercise challenging, what has been your experience in this study with yoga?
8. If you were ever prevented from coming to class when you wanted to come, can you describe the factors that prevented you from attending?
9. Did you ever log on early to class?
10. What were your experiences with other study participants? What are your thoughts on the group setting?
11. Tell me about your class instructors; how did they impact your experience?
12. What did you think about the times classes were offered?
13. As you look back on the past 6 months in the study, can you describe if and how your participation has impacted you?
    a. (Were there times you used the techniques outside of class? What for?)
14. What were the best aspects of the class? What makes them the best?
15. Did the pandemic affect your experience with this study? If so, how?

16. We are really interested in knowing what isn't going well. If you were designing the classes or the study, what would you do differently and why?
    a. What is your previous experience using Zoom video-conferencing?
    b. Did you have any difficulties with that or the iPad?
    c. How did you feel about the education links on the iPad?
17. If this same class were offered in person rather than virtually would you be more or less likely to attend? What factors weigh in on that decision?
18. Do you think you'll continue doing any aspects of the classes in the future?

Figure 2: Comparison of Adherence of Patients with HF with Current Physical Activity Guidelines and the GENTLE-HF Intervention

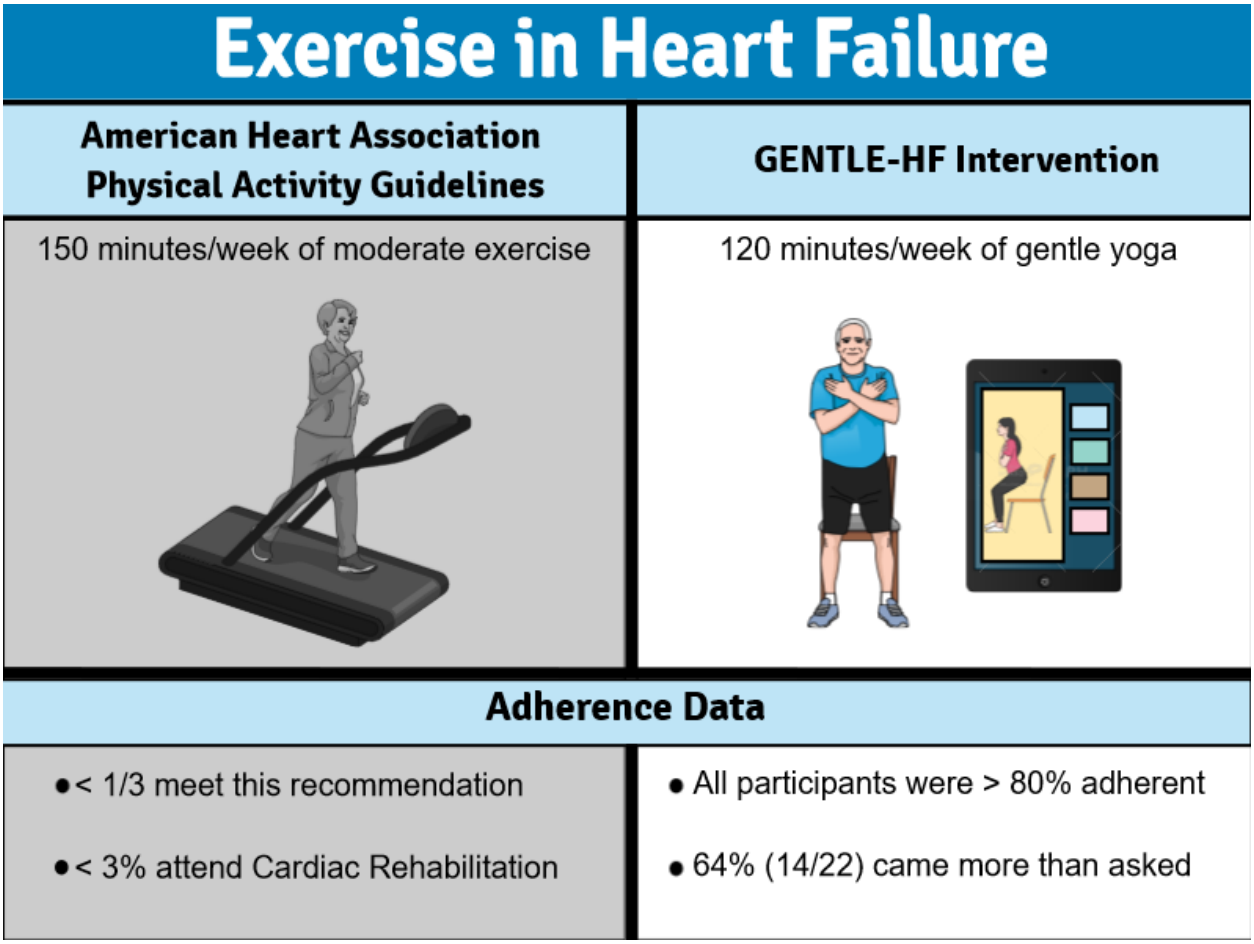

Figure 3: Characteristics of Adherence Groups

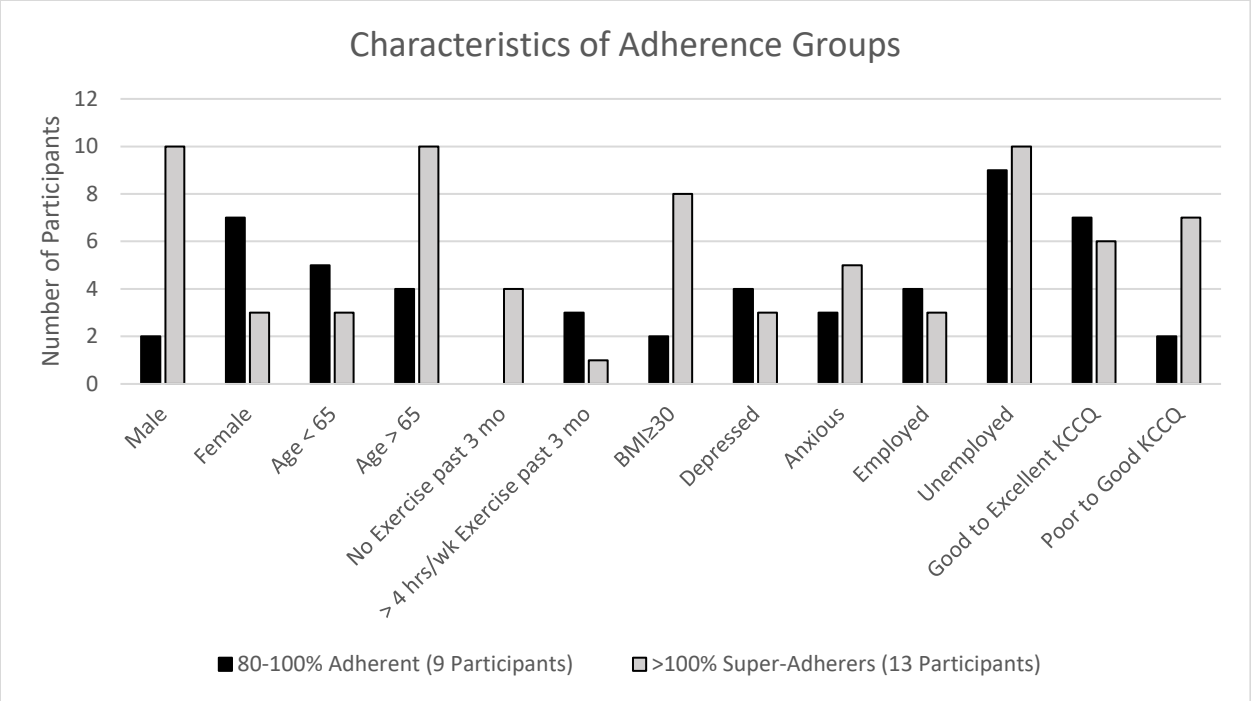

Figure 4: Summary of Qualitative Findings

Gentle Live Group Yoga for Patients with Heart Failure

Decision	To Enroll	To Adhere
Reasons / Participants	• **To Exercise:** *intervention seen as safe, and logistically and physically possible*	✓ **Convenience:** *at home, recordings available if needed, multiple days and variety of class times* ✓ **Individualization:** *for physical injuries/limitations or fitness*
	• **To Improve**: *balance, flexibility, state of mind, exercise momentum, HF symptoms, learning safe exercise for HF* • **Provider recommended**	✓ **Personal Exercise Goal** ✓ **Experiencing Psychological and Physical Improvements:** *reduction in stress, anxiety, depression; increase in flexibility, strength, balance, mobility, breathing and endurance, reduced pain*
		✓ **Peer Fellowship**

Chapter 4: Manuscript Three

Effects of Social Isolation and Loneliness on Heart Failure Self-Care

Target Journal: *European Journal of Cardiovascular Nursing*

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ABSTRACT

Aims: Patients with heart failure (HF) who engage in effective HF self-care have better quality of life, lower risk of all-cause and HF-related hospital readmissions and lower risk of mortality. It is unclear if social isolation and loneliness, which are prevalent among patients with HF and known to affect other self-care behaviors, can predict HF self-care. The aim was to explore the relationship between social isolation, loneliness and HF self-care.

Methods and Results: This was a cross-sectional secondary analysis (n=49) of the GENTLE-HF randomized controlled trial, a 6 month home-based live group gentle exercise intervention for patients with HF. Measures included the 6-item Lubben Social Network Scale for social isolation, the Patient Reported Outcomes Measurement Information System (PROMIS) Social Isolation survey for loneliness, Self-Care of Heart Failure Index for HF self-care, and the PROMIS Depression questionnaire that measured depressive symptoms. Multiple linear regression modeling was used to examine the relationships of four self-care processes to social isolation and loneliness, adjusting for depression and grouping (control or intervention). Scores indicating less social isolation predicted higher Self-Care Maintenance (B=.937, p=.015), Monitoring (B=.799, p =.041), and Management (B=1.812, p<.001). Loneliness was not statistically significant in predicting HF self-care.

Conclusions: To our knowledge, this is the first study to predict HF self-care using distinct measures for social isolation and loneliness. Patients who were less socially isolated engaged in better HF self-care, however loneliness had no relationship with HF self-care. Prospective studies are needed to investigate causal relationships between social isolation and HF-self-care engagement to determine the effect on outcomes such as hospital readmissions and mortality. Additionally, interventions to decrease social isolation and loneliness are needed.

Keywords: Self-care, Loneliness, Social Isolation, Heart Failure

NOVELTY

- Less social isolation predicted better heart failure self-care as measured by the structure, size and frequency of contact within a participant's social network.
- Family and friends may influence the different processes of HF self-care (maintenance, monitoring, management).
- A participant feeling lonely did not predict heart failure self-care. However, further research is needed as qualitative studies have indicated that HF self-care is circular and therefore loneliness may equally positively and negatively affect HF self-care.

INTRODUCTION

Adequate self-care is fundamental for maintaining stable health in patients with heart failure (HF) and is a key component found in all major guidelines for HF management.[1,2] Self-care involves patient engagement in specific activities that limit illness related complications and promote health and well-being.[3] Adequate self-care behaviors are of particular importance for patients with HF due to the daily complex treatment needs integral to clinical stability; These include self-care maintenance (e.g. taking prescribed medications, exercising, maintaining a low-sodium diet), self-care monitoring (e.g. daily weights, observing for symptoms of fluid overload), and self-care management (e.g. responding to signs and symptoms as they occur).[3,4] Patients with HF who engage in effective self-care practices have better quality of life, lower risk of all-cause and HF-related hospital readmissions and risk of mortality.[5]

Prior evidence demonstrates that social isolation and loneliness are contributing factors to poor self-care behaviors such as smoking, alcohol misuse, medication non-adherence, poor sleep hygiene, unhealthy dietary choices and sedentary behavior.[6,7] Social isolation refers to a lack of social connections, whereas loneliness is the mismatch between one's desired and actual relationships; each are independently linked to all cause and early mortality.[6–8] Though often used interchangeably, these

concepts are distinct, as one can be surrounded by people but remain lonely.[6,8,9] Patients with HF can experience a shrinking social network and fewer social interactions leading to social isolation and loneliness in part due to unpredictable and distressing HF decompensations, shortness of breath, fatigue and effects of prescribed medications such as diuretics that can restrict activity and work.[10–13] Over one-third of patients with HF are socially isolated or lonely, and for those that are, there is a 55% greater risk of hospital readmission.[14] There are several possible mechanisms to explain the underlying associations between social isolation, loneliness and poor health outcomes (e.g. physiological, psychological and sociological[6,15]); Self-care behavior, however, may have particular importance for patients with HF who have daily complex self-care needs that are integral to health stability.[3,12]

Study results have established the relationship between social support and self-care and acknowledge the contribution care partners make in assisting with self-care activities and decisions.[4,12,16–20] Social support is defined as the belief that help is available from others but does not include an objective measure of one's social network, nor does it assess loneliness.[21] Researchers have yet to examine the relationship between social isolation and loneliness with HF self-care as separate concepts, nor in the context of a physical activity intervention. By determining whether one's social network or one's loneliness, or both predict HF self-care, clinicians will be better positioned to modify interventions to improve HF self-care and, in turn, improve HF health outcomes. This research can help fill the gap of understanding the connection between social isolation, loneliness and health outcomes, a topic that gained considerable recognition during the COVID-19 pandemic.

The purpose of this cross-sectional secondary analysis was to investigate the relationship between social isolation, loneliness and HF self-care.

METHODS

Study Design

This was a cross-sectional secondary analysis of the GEtting iNTo Light Exercise (GENTLE-HF) Randomized Controlled Trial (RCT) (IRB approval #21869). The methods of the GENTLE-HF RCT have been previously described.[22] Participants were randomized into either the education control group (CG) or the intervention group (IG). IG participants joined twice weekly one hour Zoom sessions for 6 months using an iPad to participate in gentle stretching/yoga classes. Study participants in both the CG and IG groups also participated in weekly web-based HF education. The primary aim of the GENTLE-HF RCT was to test the effect of a yoga and education intervention on adherence, physical function and psychological outcomes.

Sample

Stable patients with HF (N=61) with either reduced or preserved ejection fraction were recruited from central Virginia cardiology and HF clinics into the GENTLE-HF study. Eligibility criteria included reading and writing English, 19 years of age or older, access to a telephone, home access to internet capable of videoconferencing, and NYHA class I-III with no changes in medications in the prior 30 days. Patients were excluded if they were hospitalized for HF within 3 months, had unstable angina, coronary artery bypass graft, myocardial infarction or biventricular pacemaker <6 weeks prior, orthopedic or medical impediments to yoga-like exercise, or cognitive impairment as measured by the Mini-Cog.

Four participants dropped out, and 8 participants completed the study before social isolation and loneliness were measured. Given the available sample size, we completed a power calculation expecting a moderate effect size and approximated that we could enter a maximum of three predictors into each linear regression model, or approximately 10-15 participants per predictor. We chose depression[23,24] and grouping in addition to either social isolation or loneliness as our three predictors, thus the total sample size for this secondary analysis was N=49.

Measures and Data Collection

Baseline clinical and demographic characteristics were obtained. All GENTLE-HF study questionnaires were given to each participant in a paper packet completed in person at the clinic. Randomization took place after baseline measures were taken. During the initial period of the pandemic, three participants were unable to come to the clinic in person to complete the measures, so questionnaires were mailed and returned upon completion.

Social Isolation was measured using the 6-item Lubben Social Network Scale (LSNS-6). Internationally one of the most widely used scales to measure social isolation, the LSNS-6 was designed to measure social network size and number of social interactions in older adults and has high internal reliability (Cronbach's alpha of .83).[25–27] A total score is an equally weighted sum of the six questions with scores ranging from 0 to 30 with lower scores indicating smaller social network size and thus greater social isolation. A score of 12 and lower can be used as a clinical cut point to determine individuals at high risk of social isolation.[26]

Loneliness was measured using the Patient Reported Outcomes Measurement Information System Version 2.0 Social Isolation Short Form 4a survey (PROMIS) featuring four questions adapted from the 20-question UCLA Loneliness Scale.[28] The PROMIS is used for adults 18 and older to "assess the perceptions of being avoided, excluded, detached, disconnected from, or unknown by others" and has high reliability (Cronbach's alpha of .83).[28,29] Total raw scores range from 4 to 20 with higher scores indicating greater loneliness. A score greater than 8 can be used as a clinical cut point to determine individuals at high risk of loneliness.[30]

Heart Failure Self-Care was measured using the Self-Care of Heart Failure Index version 7.2 (SCHFI).[31] The SCHFI is comprised of 4 sections with a total of 39 questions assessing 4 processes: self-care maintenance, self-care monitoring, self-care management, and self-care confidence. Each section is scored separately with response items in each section summed and standardized (range 0 to 100) with higher scores indicating better self-care. A section score of 70 or better can be used as a cut point to

identify adequate self-care within that section. The reliability, as measured by the global reliability index for multidimensional scales, was 0.75, 0.85, and 0.70 for self-care maintenance, symptom perception, and self-care management respectively.[31] Reliability of self-care confidence was a Cronbach's alpha of 0.84, as it is a unidimensional scale.[32]

Depression was measured using the PROMIS Short Form v1.0 8a Depression scale featuring eight questions to detect depressive symptoms. Total raw scores range from 8 to 40. A score of 50 is average for the U.S. general population and used as a normative measure for depression. Higher scores represent greater depressive symptoms.

Data Analysis

Analyses were performed using SPSS® Statistics for Windows Version 28.0 Released 2021 (IBM Corporation, Armonk, NY). We performed descriptive statistics to obtain baseline participant characteristics. Normally distributed data are presented using means and standard deviations. PROMIS depression and loneliness raw scores were converted into T-Scores using a conversion table. Categorical variables are presented using frequencies and percentages. We used multiple linear regression modeling to examine the relationships of the four SCHFI processes to social isolation and loneliness, adjusting for depression and grouping. Due to the highly skewed distribution of loneliness data which is not ideal for linear regression, we choose to dichotomize loneliness using the clinical cut score of 8, where scores >8 represent greater risk for loneliness. We followed the SCHFI author recommendations for missing data and calculated those participants' scores individually by modifying the summation equation.[33] When running the multiple linear regression, we assessed the variance inflation factor (VIF) to assess how related our predictors were; all values were below the threshold that would indicate multicollinearity.

RESULTS

The sociodemographic characteristics of the CG and IG are shown in Table 1. At baseline, the two groups have comparable demographic and clinical characteristics with age being the only statistically significant difference between groups; The IG was significantly older that the CG. Table 2 show the means, standard deviations of the outcomes of interest by CG and IG. The data underlying this article will be shared on reasonable request to the corresponding author.

Social Isolation and HF Self-Care

A multiple linear regression was conducted with each of the four SCHFI processes with social isolation, depression and grouping held constant (Table 3, Figure 1). Scores indicating less social isolation predicted higher SCHFI Self-Care Maintenance (B=.937, p=.015, 95% CI [.194, 1.679]), Monitoring (B=.799, p =.041, 95% CI [034, 1.565]), and Management (B=1.812, p<.001, 95% CI [.898, 2.726]). Social isolation explained 26% of the variance of HF Self-Care Management (Adjusted R^2 = .261). Though not statistically significant, scores indicating less social isolation predicted higher SCHFI Self-Care Confidence. Multiple linear regression was conducted on each of the four SCHFI processes using individual questions from the social isolation LSNS-6 survey to isolate which type of social relationship and social action was significant in predicting HF self-care (Table 4). SCHFI Self-Care Maintenance was predicted by how many relatives and friends the participant could talk to about private matters (B=4.47, p=.036, 95% CI [.314, 8.634]; B=5.45, p= <.001, 95% CI [2.742, 8.158]). SCHFI Self-Care Monitoring was predicted by how many relatives the participant could call on for help (B=5.39, p=.007, 95% CI [1.564, 9.212]). SCHFI Self-Care Management was predicted by all the questions (B=7,p=.011, 95% CI [1.708, 12.293]; B= 8.22, p=.002, 95% CI [3.301, 13.147]; B=6.94, p=.014, 95% CI [1.465, 12.410]; B= 3.78, p=.046, 95% CI [.074, 7.482]; B=5.27, p=.005, 95% CI [1.633, 8.898]; B=5.84, p=.004, 95% CI [1.983, 9.7]). Lastly, Self-Care Confidence was predicted by how many relatives the participant felt they could talk to about private matters (B=4.25, p=.017, 95% CI [.789, 7.716]).

Loneliness and HF Self-Care

A multiple linear regression was conducted with each of the four SCHFI processes including loneliness, depression, and grouping held constant (Table 3). No variable was statistically significant in predicting self-care. Interestingly, higher Self-Care Confidence was correlated with greater loneliness. Linear regression on each SCHFI process with each loneliness question did not reach significance. The GENTLE-HF dataset had a proxy question for perceived social support which was also not a significant predictor of the SCHFI processes.

DISCUSSION

To our knowledge, this is the first study to predict HF self-care using distinct measures for social isolation and loneliness rather than social support, thus isolating two distinct factors that are independently linked to all-cause and early mortality. Participants who were less socially isolated engaged in better HF self-care, however loneliness had no relationship to HF self-care. Furthermore, in examining each individual question of the LSNS-6 (social isolation) questionnaire, we found that particular aspects of the type, size and frequency of interaction within a participant's social network was significant in predicting the HF self-care processes of maintenance, monitoring, management and confidence. These findings signal clinicians that HF self-care and thereby HF health outcomes may be improved by strengthening or adding to one's existing social network. However, the relationship between loneliness, HF self-care and HF health outcomes requires further elucidation so that optimal patient outcomes can be achieved.

Social Isolation Predicts Heart Failure Self-Care

Unique to our study is the participant's objective social network rather than their perceived social support. Social network is a measure of the structure, size, and frequency of contact in one's social network and is an antecedent and channel of social support, defined as the assistance and

protection given to others or the belief that help is available from others.[4] This distinction helps to tease apart that structure, size and frequency of contact are central when predicting self-care behaviors. Graven and Grant[4] found that social support improves HF self-care via family members assisting in maintaining the treatment regimen and helping in the decisions regarding management of symptoms. However, the quantitative studies included in their integrative review had mixed findings and mainly focused on HF self-care maintenance.[4,34,35] This may be in part related to the more subjective nature of assessing social support. For example, an item in the Multidimensional Scale of Perceived Social Support (MSPSS) questionnaire asks participants to rate the statement, "My family really tries to help me." In contrast, the LSNS-6 asks for objective information; For example, "How many relatives do you feel close to such that you could call on them for help?" The LSNS-6 is brief with just 6 questions making it an ideal clinical screening tool for social isolation. The tool was specifically designed for older adults[36] and was used in large studies assessing outcomes with HF patients.[37] Additionally, we controlled for depression in our analysis given the relationship between depression and HF self-care.[38] Our results indicated that depression was not significant in predicting HF self-care when social isolation remained significant in the final regression model.

In assessing the LSNS-6 questions individually with HF self-care processes, we found that the type of relationship and the action taking place significantly predicts particular types of HF self-care. Previous data suggests that a patient's relatives are the most influential members of their social network.[4] We found that on average, participants had more relatives than friends in their social network, averaging 10 and 8 respectively. Relationships with relatives significantly predicted self-care monitoring behavior (e.g. weighing daily, observing for symptoms of fluid overload) and self-care confidence underscores the importance of care partners in self-care.[4,20,32] However, we found that both relatives and friends were very important in regards to self-care maintenance and management. Specifically, participants having accessible relatives and friends was significant in predicting self-care

maintenance (e.g. medication adherence, maintaining exercise, and a low-sodium diet). This is supported by the middle-range theory of self-care of chronic illness, recognizing that an individual acquires and maintains health habits from their culture and the people they surround themselves with.[16] Self-care management (e.g. responding to signs and symptoms of fluid overload as they occur) was significantly predicted by all LSNS-6 questions. Notably, the prevalence of adequate HF self-care behaviors in our sample was higher for self-care maintenance and confidence, but almost 10% lower for self-care management compared to the scores published in the literature.[21,39]

It was interesting to find that social isolation explained 26% of the variance of HF self-care management. This fits well with current research indicating that several factors influence self-care engagement that could explain the remaining 74% of variance, including: personal finance, mood states (e.g. clinical depression, anxiety), personality, social factors, and clinical factors.[5] Therefore, clinicians may need to consider interventions that address these factors.

Loneliness Does Not Predict Heart Failure Self-Care

To our knowledge, these data are the first to assess loneliness in relation to HF self-care. As previously stated, social support is the assistance and protection given to others,[4] whereas loneliness is the negative experience caused by the mismatch between one's desired and actual relationships.[27] Though loneliness is correlated with depression and depression with inadequate self-care, loneliness did not predict HF self-care in our study.[38] That said, qualitative researchers have shown that the process of HF self-care is circular, wherein a patient promotes particular values and demotes others.[40] For example: a lonely patient chooses to attend a social event that leads to the choice to skip their diuretic and veer from HF dietary and fluid restrictions thus leading to a decompensation that once again causes one to prioritize HF self-care behaviors that then limit social capabilities.[40] It is possible therefore, that

loneliness can predict HF self-care behavior, but that the process is circular in affecting healthy and unhealthy self-care choices and thus was unable to be captured quantitatively.

Implications for Practice and Future Research

Our results suggest that investigators developing interventions to improve HF self-care should consider ways in which they can simultaneously decrease social isolation or strengthen the patient's existing social network. The current AHA guidelines for reducing social isolation for patients with HF suggest determining eligibility for home care services and referring patients to a support group.[1] There is, however, a growing literature base exploring interventions that aim to reduce social isolation and loneliness in older adults. There is not yet a consensus of which intervention type works for whom and how and in what context, however evidence suggest that group as opposed to one-on-one interventions may be more effective for older adults with fewer social connections.[41] Additionally, interventions that have productive engagement, (i.e. an activity with a common goal and purpose) have been more successful at reducing social isolation than those with passive activities (e.g. watching and listening).[42,43] One example of productive engagement includes group physical activity interventions which have shown promise in reducing social isolation and loneliness, and bring with it all the other many health advantages of physical activity.[44,45] The GENTLE-HF study was unique in its design in that it incorporated group physical activity twice weekly for 6 months and occurred via live videoconference, which was noted by participants to be of particular convenience. In a qualitative analysis of the GENTLE-HF study[46], participants shared the importance of the social interaction to their long-term adherence and made suggestions to strengthen and optimize the opportunity for social connection.

Future research recommendations include assessing social isolation, loneliness and HF self-care at multiple times points during a long-term study in order to estimate the effect of live group physical activity interventions on social health and HF self-care outcomes. Additionally, in the design of future HF

self-care interventions, it is important to note that diuretics, low-sodium diet and burdensome symptoms present social and professional disruptions to patients with HF; open discussion with healthcare providers should be encouraged and incorporated to help patients to negotiate this reality.[40] Other interventions that include productive interactions for social networking might include dancing, cooking, "remote" walking partners where walking takes place simultaneously with chatting, etc.[47] Not all interventions will be effective for all patients with HF, but social interactions have potential to improve self-care for many patients with chronic illnesses.

Limitations and Strengths

A limitation of our study was a small sample size (N=49) which limits the power and generalizability of the results. The sample size also limited the number of variables we could run in our regression and the cross-sectional design limited causal inference. That said, we were able to achieve medium effect sizes for social isolation with HF self-care implying that the prediction would remain in a larger study. The prevalence of loneliness in our sample as opposed to that found in the literature was considerably smaller, and due to the highly skewed distribution of the loneliness data, we had to dichotomize the loneliness variable; both factors reduced our effect size of loneliness. Our sample was almost completely White and all participants were required to pass the Mini-cog screening test for cognition to be eligible for inclusion. This limits our generalizability to other HF populations and to patients with cognitive decline that is an additional barrier to HF self-care, above social factors.[18] A strength of this study is that we used the PROMIS measure to assess loneliness and the LSNS-6 to assess social isolation/social network. These measures have good internal reliability and have been used in large studies assessing outcomes for patients with HF and thus facilitate comparison.[1,37,48] Finally, although the study was impacted by the pandemic, the pandemic highlighted the importance of assessing for social isolation and loneliness.

Conclusion

Participants who were less socially isolated had better HF self-care. However, in this quantitative study, loneliness had no bearing on HF self-care. Interestingly, we found that the type, size and frequency of interaction within a participant's social network was significant in predicting different HF self-care processes (maintenance, monitoring, and management). For example, our results suggest that a patient struggling with adherence to daily weights (self-care monitoring) may benefit by including relatives in that education. Whereas, a patient struggling with medication adherence, low-sodium diet, or exercise recommendations (self-care maintenance) might benefit from inclusion in a similar health peer group. These results help further uncover the connection between social isolation, loneliness and health outcomes for patients with HF, as well as the importance of assessing both social isolation and loneliness acknowledging that they play distinct roles in the lives of patients with HF. Future research that includes a prospective design measuring the effect on social isolation, loneliness, and HF self-care over time will provide greater understanding of the relationship between social network and self-care.

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Table 1. Sociodemographic and Clinical Characteristics

	Control Group (n=26)	Intervention Group (n=23)	p-Value
Age (years), mean (SD)	56.96 (13.3)	66.65 (13.3)	**.01***
Male, n (%)	16 (61.5%)	15 (65.2%)	.79
Married, n (%)	19 (73.1%)	21 (91.3%)	.08
Living Alone, n (%)	4 (15.4%)	2 (8.7%)	.48
Race, n (%) White	25 (96.2%)	21 (91.3%)	.48
Education, n (%)			.50
Less than High School	1 (3.8%)	0 (0%)	
High School Graduate	3 (11.5%)	3 (13%)	
Some College	14 (53.8%)	9 (39.1%)	
Bachelor's degree or higher	8 (30.8%)	11 (47.8%)	
NYHA Class, mean (SD)			**.03***
Class 1	7 (26.9%)	5 (21.7%)	
Class 2	13 (50.0%)	18 (78.3%)	
Class 3	6 (23.1%)	0 (0%)	
Retired/Unemployed, n (%)	17 (65.4%)	15 (65.2%)	.99
Income, n (%)			.48
<20K	3 (11.5%)	2 (8.7%)	
20-40K	6 (23.1%)	2 (8.7%)	
40-75K	8 (30.8%)	6 (26.1%)	
>75K	5 (19.2%)	9 (39.1%)	
Declined to answer	4 (15.4%)	4 (17.4%)	
Exercise in previous week, n (%)			.60
None	8 (30.8%)	5 (21.7%)	
<30 min/week	4 (15.4%)	4 (17.4%)	
30-60 min/week	6 (23.1%)	5 (21.7%)	
1-3 hr/week	1 (3.8%)	4 (17.4%)	
3+hr/week	7 (26.9%)	5 (21.7%)	
BMI, mean (SD)	30.17 (5.9)	30.48 (6.3)	.86
Ejection Fraction, mean (SD)	42.08 (17.4)	37.65 (14.9)	.35

*denotes statistically significant difference

Table 2. Social Isolation, Loneliness, Depression and Self-Care Outcomes

Variable	CG Mean, SD	IG Mean, SD	p-Value	Cronbach's α
Social Isolation (LSNS-6)	18.19 (5.12)	17.70 (5.78)	.75	.83
Loneliness (PROMIS-SI)	41.60 (6.98)	41.30 (7.79)	.89	.84
Depression (PROMIS-Dep)	47.56 (8.47)	45.02 (6.36)	.25	.90
SCHFI Self-Care Maintenance	80.95 (14.29)	82.85 (13.72)	.64	.87
SCHFI Self-Care Monitoring	77.59 (14.43)	76.48 (15.02)	.79	
SCHFI Self-Care Management	65.04 (18.28)	62.64 (20.09)	.66	
SCHFI Self-Care Confidence	87.55 (12.59)	83.70 (11.55)	.27	

CG= Control Group; IG = Intervention Group; SD = Standard Deviation; SCHFI (Self-Care of Heart Failure Index)

Table 3. HF Self-Care in Association with Social Isolation and Loneliness

Outcomes (N=49)	**Social Isolation *B, p value***	CI	Adjusted R^2	Effect Size (f^2)
SCHFI Maintenance	**.937 (.015)***	.194, 1.679	.091	.14
SCHFI Monitoring	**.799 (.041)***	.034, 1.565	.12	.09
SCHFI Management	**1.812 (<.001)*****	.898, 2.726	.261	.33
SCHFI Confidence	.627 (.056)	-.017, 1.271	.104	.08
	Loneliness	CI	Adjusted R^2	Effect Size (f^2)
SCHFI Maintenance	-1.428 (.795)	-12.416, 9.561	-.038	.00
SCHFI Monitoring	-3.035 (.584)	-14.102, 8.033	-.04	.01
SCHFI Management	-.511 (.945)	-15.24, 14.217	-.001	.00
SCHFI Confidence	2.993 (.518)	-6.249, 12.235	.036	.01

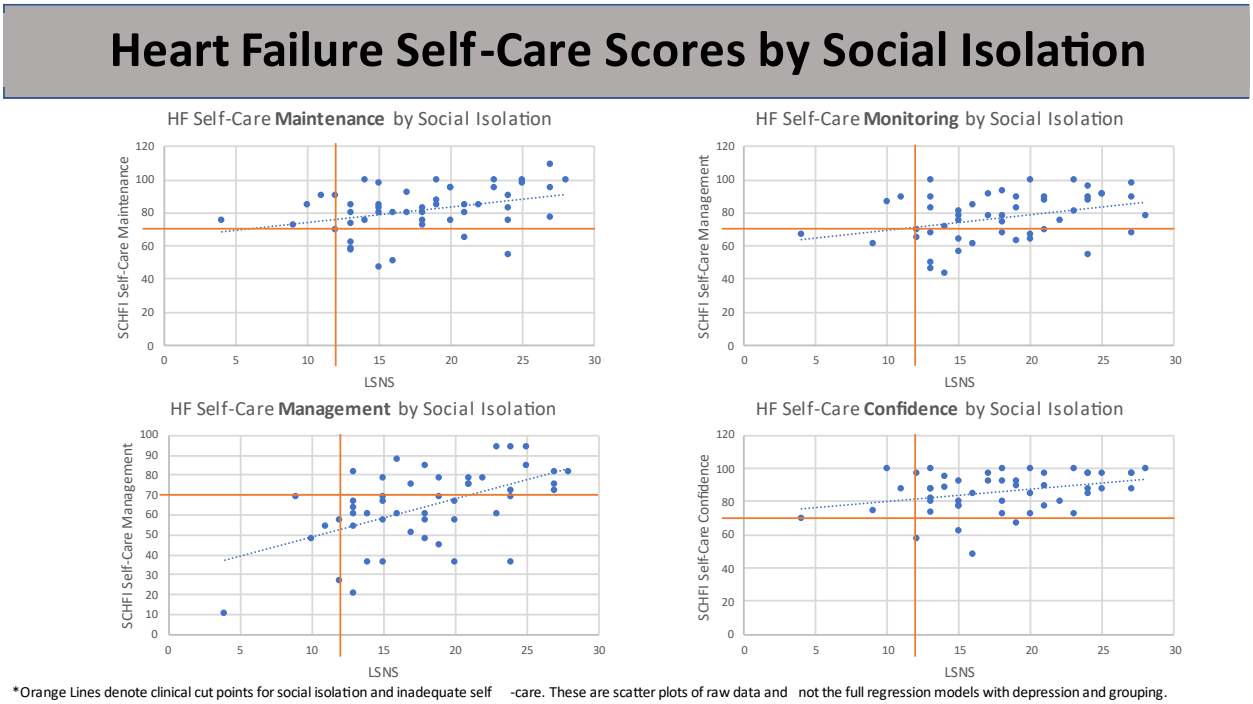
*p<.05, **p<.01, ***p<.001. Control Group = 2 for Grouping Variable. f^2=.02 small effect; f^2=.15 medium effect; f^2=.35 large effect; CI= confidence interval.

Table 4. Predicting HF Self-Care with Individual Social Isolation Questions

LSNS-6 Individual Question	Self-Care Maintenance B, p-value	Self-Care Monitoring B, p-value	Self-Care Management B, p-value	Self-Care Confidence B, p-value
How many *relatives* do you *see or hear* from at least once a month?	4.04(.052)	3.88(.065)	**7(.011)***	3.07(.081)
How many *relatives* do you feel close to such that you could *call on* them for help?	.84(.682)	**5.39(.007)****	**8.22(.002)****	2.87(.093)
How many *relatives* do you feel at ease with that you can *talk* about private matters?	**4.47(.036)***	3.39(.119)	**6.94(.014)***	**4.25(.017)***
How many of your *friends* do you *see or hear* from at least once a month?	1.89(.188)	.32(.828)	**3.78(.046)***	.52(.671)
How many *friends* do you feel close to such that you could *call on* them for help?	1.83(.212)	2.41(.101)	**5.27(.005)****	1.05(.4)
How many *friends* do you feel at ease with that you can *talk* about private matters?	**5.45(<.001)*****	2.44(.121)	**5.84(.004)****	2.51(.055)

*p<.05, **p<.01, ***p<.001.

Figure 1. Heart Failure Self-Care Scores by Social Isolation



*Orange Lines denote clinical cut points for social isolation and inadequate self -care. These are scatter plots of raw data and not the full regression models with depression and grouping.

Chapter 5: Conclusions

For more than a decade, the leading HF authorities have designated exercise as a Class 1A Recommendation to improve the outcomes of patients with HF, yet we have failed to facilitate access, provide multimodal exercise, and to access patient concerns regarding exercise. The adherence rates, facilitators and barriers of aerobic in-person exercise have been well established.[1–4] The verdict is in; less than one-third of patients with HF adhere to physical activity guidelines, and less than 3% attend CR.[5,6] This dissertation presents evidence of the benefits of alternative models of CR through a qualitative systematic literature review and the qualitative and quantitative findings of a randomized controlled clinical trial that tested an alternative type of exercise where 64% of subjects participated *more* than was required.

Summary of Findings

The first manuscript of this dissertation systematically reviewed the qualitative evidence regarding the patient experience with alternative models of CR. All alternative models of CR were found to be physically, psychologically, and/or socially beneficial to participants. Despite the variety of program designs, there were several common facilitators identified across studies that led to both initial and ongoing participation such as peer and/or family support, convenience, feeling safe through contact with staff or medical endorsement, being accountable, tailoring to individual preference or ability, enjoyment, anticipating or experiencing health benefits, and the perception that prescribed exercise is attainable. The most prevalent barrier was that participants feared that exercise could cause negative cardiac consequences. Our results also revealed that HF participants more highly valued family and peer support along with convenience and feeling safe compared to participants with CVD. In all included studies, participants reported improved *exercise self-efficacy* which is a well-documented determinant of PA engagement and continuation, though it is seldom quantitatively measured.

The second manuscript of this dissertation focused in on a singular 6 month alternative exercise program, GENTLE-HF, for patients with HF wherein 64% of participants came *more* often than was asked in the study protocol. We qualitatively analyzed patients' with HF perspectives on what factors influenced their decisions to enroll and then continue with the home-based gentle stretching/yoga-like exercise program. Our results revealed that participants initially enrolled because they saw the program as logistically and physically possible; in other words, participants had perceived self-efficacy with the proposed intervention, an essential ingredient for exercise initiation. Though not part of the GENTLE-HF protocol, most participants also had a personal goal to exercise that facilitated their decision to exercise. Long-term adherence was facilitated by convenience (of home-based, multiple times and days), individualization for existing physical limitations, experiencing psychological and physical improvements, and peer fellowship. Super-adherers tended to be male, age ≥65, no exercise in the 3 months prior to the study, BMI ≥30, and poor to good quality of life (KCCQ) scores. Our results provide direct participant perspective for study enrollment and subsequent adherence to an exercise program. Further, that participants with no exercise in the 3 months prior to study enrollment and/or BMIs ≥30 tended to comprise the super-adherer group suggests that the GENTLE-HF intervention may have addressed important barriers to exercise such as weight stigma by normalizing individual exercise modification and being virtual rather than in person.

The third manuscript of this dissertation used multiple linear regression to predict the relationship between HF self-care and social isolation/loneliness. Participants who were less socially isolated engaged in better HF self-care, however loneliness had no relationship to HF self-care in this quantitative study. Additional analysis of the social isolation questionnaire revealed that particular aspects of the type, size and frequency of interaction within a patient's social network was significant in predicting the HF self-care domains of maintenance, monitoring, management and confidence. For example, a patient struggling with daily weighing (self-care monitoring) may benefit by including family

in that education. Whereas, a patient struggling with taking prescribed medications daily or adhering to a low-sodium diet or exercise recommendations (self-care maintenance) might benefit from inclusion in a similar health peer group.

Nursing Implications

The results of this study provide several nursing implications for healthcare providers and researchers. In terms of clinical implications, there is no need to rely on the traditional model of CR, but rather CR models that offer an alternative location and/or an alternative exercise may better meet patient need and preference. Many of the programs outlined in our systematic review represent less resource-intensive models that could potentially expand program capacity to address worldwide underutilization of CR.[7] The qualitative data that define benefits, facilitators and barriers to exercise offer pragmatic data with which to improve the delivery of CR. CR programs that are easily accessible and provide appealing modes of exercise potentially increase physical activity adherence. Specifically, our focus on a single gentle home-based exercise program for patients with HF, provide direct participant perspective for study enrollment and subsequent 6 month adherence. Given the remarkably high long-term participant adherence in the GENTLE-HF study with BMI's ≥30, our findings have broader implications to promoting exercise initiation and adherence for the 40% of Americans with a BMI ≥30, and the 42% of adults with CVD that report difficulty walking.[8,9] Starting small with home-based gentle exercise, and acknowledging that some exercise is better than none, clinicians could help bridge sedentary patients to the full exercise guidelines. Additionally, our results suggest that clinicians seeking improved HF self-care engagement should consider ways in which they can simultaneously decrease social isolation or strengthen the patient's existing social network.

Regarding research implications, live group tele-yoga programs such as through Medicare's Silver Sneakers, Veteran Affairs' Whole Health, and the YMCA 360 potentially incorporate the key

facilitators of long-term adherence expressed by patients with HF in the GENTLE-HF study.[10–12] Prospective mixed-methods studies with a larger and more diverse sample of patients with HF are needed to evaluate both the patient experiences and the effect of these existing widely available exercise programs on patient psychosocial outcomes such as exercise self-efficacy, depression, anxiety, social isolation and loneliness. Outcomes such as hospitalization and mortality are needed for comparison to studies of more vigorous physical activity interventions. Additionally, our qualitative findings indicate that assessing physical function benefits such as improved balance, flexibility, coordination, range of motion and strength may be important outcomes to measure rather than only exercise capacity and CVD risk factor modification which is typically measured.

Strengths and Limitations

This dissertation provides novel guidance for clinicians, researchers and patients with HF. To our knowledge, this was the first qualitative systematic review of alternative models of CR, the first qualitative analysis focused on initial and long term adherence to a home-based gentle exercise program, and the first study to examine the relationship between social isolation and loneliness with HF self-care. A strength of this dissertation is that we used the PROMIS measure to assess loneliness and the LSNS-6 to asocial social isolation/social network. These measures have good internal reliability and have been used in large studies assessing outcomes for patients with HF and thus facilitate comparison.[13–15] Additionally, although the GENTLE-HF study was impacted by the pandemic, the pandemic highlighted the importance of assessing for social isolation and loneliness.

There are several limitations that should be considered when interpreting the results. The qualitative systematic review included studies of different exercise intervention types. Also, adherence information was not available which meant that though benefits, facilitators and barriers were described, we were not able to determine which, if any, corresponded with better adherence. The

second study was a qualitative analysis of interviews collected in the GENTLE-HF study, and thus the interviews were collected for a different purpose though we were able to answer our research questions and achieve data saturation. The sample was predominately White and as is typical with exercise studies and consisted of patients who were willing to exercise which does not represent the entire HF patient population. Lastly, a limitation of the third study was the small sample size which limits the power and generalizability of the results. The sample size also limited the number of variables we could run in our regression and the cross-sectional design limited causal inference. That said, we were able to achieve medium effect sizes for social isolation with HF self-care implying that the prediction would remain in a larger study.

In conclusion, this dissertation presents evidence of the benefits of alternative models of CR through a qualitative systematic literature review and the qualitative and quantitative findings of a randomized controlled clinical trial where 64% of subjects participated *more* than was asked. This research not only serves individuals with HF, but also the broader population of individuals with CVD or approximately 11.9 million of whom are estimated to have difficulty walking, dependence on another person to attend medical appointments, or both.[9] It is imperative that we find new ways to adapt CR programs so that all individuals can have the opportunity to improve their health outcomes. Sandesara et al.[16] have urged that the current model of CR is not financially viable nor sustainable due to referral, accessibility, and affordability barriers that limit attendance and consequently capitalization. COVID-19 has pressed the issue as US CR programs suspended or reduced their services to limit contagion.[17] Home-based adaptive exercise models are a promising alternative model for CR that may mitigate exercise barriers and simultaneously reduce social isolation and loneliness to improve outcomes in patients with HF.

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Appendices

Appendix 1. Study Measures

Lubben Social Network Scale Abbreviated 6-item Version

LUBBEN SOCIAL NETWORK SCALE—6-Item Version

LSNS-6

FAMILY: *Considering the people to whom you are related either by birth or marriage . . .*

1. How many relatives do you see or hear from at least once a month?
   0 = *none* 1 = *one* 2 = *two* 3 = *three or four* 4 = *five thru eight* 5 = *nine or more*
2. How many relatives do you feel close to such that you could call on them for help?
   0 = *none* 1 = *one* 2 = *two* 3 = *three or four* 4 = *five thru eight* 5 = *nine or more*
3. How many relatives do you feel at ease with that you can talk about private matters?
   0 = *none* 1 = *one* 2 = *two* 3 = *three or four* 4 = *five thru eight* 5 = *nine or more*

FRIENDSHIPS: *Considering all of your friends including those who live in your neighborhood . . ..*

4. How many of your friends do you see or hear from at least once a month?
   0 = *none* 1 = *one* 2 = *two* 3 = *three or four* 4 = *five thru eight* 5 = *nine or more*
5. How many friends do you feel close to such that you could call on them for help?
   0 = *none* 1 = *one* 2 = *two* 3 = *three or four* 4 = *five thru eight* 5 = *nine or more*
6. How many friends do you feel at ease with that you can talk about private matters?
   0 = *none* 1 = *one* 2 = *two* 3 = *three or four* 4 = *five thru eight* 5 = *nine or more*

LSNS-6 total score is an equally weighted sum of these six items. Scores range from 0 to 30. Family and Friend Subscales are an equally weighted sum of their three items respectively. Subscales scores range from 0 to 15.

Patient Reported Outcomes Measurement Information System Version 2.0 Social Isolation – Short Form 4a.

PROMIS Item Bank v2.0 - Social Isolation – Short Form 4a

Social Isolation –Short Form 4a

Please respond to each item by marking one box per row.

		Never	Rarely	Sometimes	Usually	Always
UCLA11x2	I feel left out.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
UCLA13x3	I feel that people barely know me.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
UCLA14x2	I feel isolated from others	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
UCLA18x2	I feel that people are around me but not with me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Self-Care of Heart Failure Index (SCHFI)

SECTION A:

Listed below are behaviors that people with heart failure use to help themselves. How often or routinely do you do the following?

	Never		Sometimes		Always
1. Try to avoid getting sick (e.g., wash your hands)?	1	2	3	4	5
2. Get some exercise (e.g., take a brisk walk, use the stairs)?	1	2	3	4	5
3. Eat a low salt diet?	1	2	3	4	5
4. See your health care provider for routine health care?	1	2	3	4	5
5. Take prescribed medicines without missing a dose?	1	2	3	4	5
6. Order low salt items when eating out?	1	2	3	4	5
7. Make sure to get a flu shot annually?	1	2	3	4	5
8. Ask for low salt foods when visiting family and friends?	1	2	3	4	5
9. Use a system or method to help you remember to take your medicines?	1	2	3	4	5
10. Ask your healthcare provider about your medicines?	1	2	3	4	5

SECTION B:

Listed below are changes that people with heart failure commonly monitor. How often do you do the following?

	Never		Sometimes		Always
1. Monitor your weight daily?	1	2	3	4	5
2. Pay attention to changes in how you feel?	1	2	3	4	5
3. Look for medication side-effects?	1	2	3	4	5
4. Notice whether you tire more than usual doing normal activities?	1	2	3	4	5
5. Ask your healthcare provider how you're doing?	1	2	3	4	5
6. Monitor closely for symptoms?	1	2	3	4	5
7. Check your ankles for swelling?	1	2	3	4	5
8. Check for shortness of breath with activity such as bathing and dressing?	1	2	3	4	5
9. Keep a record of symptoms?	1	2	3	4	5

The last time you had symptoms…

(circle **one** number)

	Have not had symptoms	I did not recognize the symptom	Not Quickly		Somewhat Quickly		Very Quickly
1. How quickly did you recognize that you had symptoms?	N/A	0	1	2	3	4	5
2. How quickly did you know that the symptom was due to heart failure?	N/A	0	1	2	3	4	5

SECTION C:

Listed below are behaviors that people with heart failure use to control their symptoms. **When you have symptoms, how likely are you to use one of these?**

(circle **one** number for each treatment)

	Not Likely		Somewhat Likely		Very Likely
1. Further limit the salt you eat that day?	1	2	3	4	5
2. Reduce your fluid intake?	1	2	3	4	5
3. Take a medicine?	1	2	3	4	5
4. Call your healthcare provider for guidance?	1	2	3	4	5
5. Ask a family member or friend for advice?	1	2	3	4	5
6. Try to figure out why you have symptoms?	1	2	3	4	5
7. Limit your activity until you feel better?	1	2	3	4	5

Think of a treatment you used the last time you had symptoms… (circle **one** number)

	I did not do anything	Not Sure		Somewhat Sure		Very Sure
1. Did the treatment you used make you feel better?	0	1	2	3	4	5

SECTION D:

In general, how confident are you that you can:

(Circle **one** number for each statement)

	Not Confident			SomewhatConfident	Extreme Confide
2. Keep yourself stable and free of symptoms?	1	2	3	4	5
3. Follow the treatment plan you have been given?	1	2	3	4	5
4. Persist in following the treatment plan even when difficult?	1	2	3	4	5
5. Monitor your condition routinely?	1	2	3	4	5
6. Persist in routinely monitoring your condition even when difficult?	1	2	3	4	5
7. Recognize changes in your health if they occur?	1	2	3	4	5
8. Evaluate the importance of your symptoms?	1	2	3	4	5
9. Do something to relieve your symptoms?	1	2	3	4	5
10. Persist in finding a remedy for your symptoms even when difficult?	1	2	3	4	5
11. Evaluate how well a remedy works?	1	2	3	4	5

Appendix 2. Conceptual Frameworks

Health Action Process Approach by Schwarzer 2008

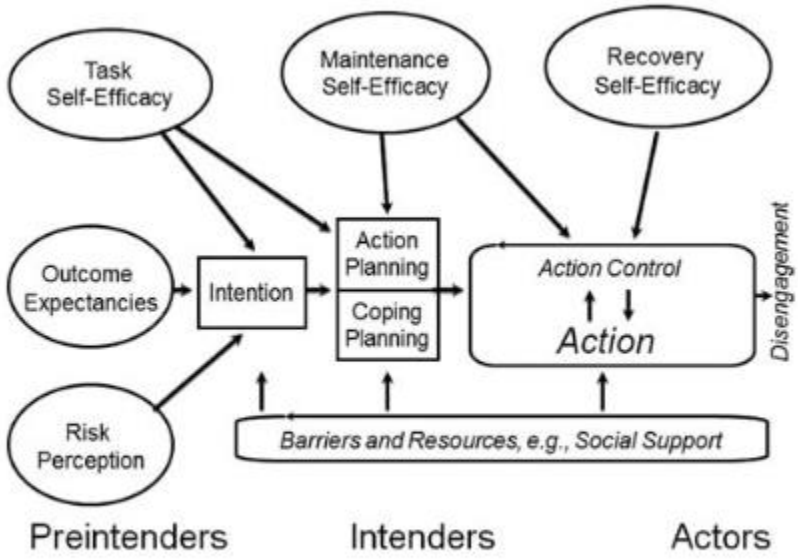

Figure 1. The HAPA (Schwarzer, 2008).

Hodgson et al. (2020) Conceptual Framework demonstrating mechanisms underlying associations between loneliness, social isolation, cardiovascular disease and mortality.