# “We are all there for the same purpose”: Support for an integrated community exercise program for older adults with HF and COPD

**Background:** Despite well-established improvements following rehabilitation, functional gains often diminish following discharge.

**Objective:** To explore the attitudes of older adults with HF and COPD, who have completed rehabilitation, towards community-based exercise maintenance.

**Methods:** Semi-structured interviews were conducted with 11 individuals with HF or COPD.

**Results:** Deductive thematic analysis uncovered three themes: 1) transitioning to community exercise is challenging, highlighting participants' struggle with unstructured maintenance and a lack of appropriate programs; 2) a structured, group-based program tailored to functional ability facilitates adherence, describing participants views on the importance of routine, and accountability; and 3) "We are all there for the same purpose"- participant support for integrated exercise, including the benefit of multiple perspectives and sustainability.

**Conclusions:** A motivating program leader and access to appropriate facilities are key features to support adherence to prescribed activity. Tailored programs can be delivered consecutively to older adults with HF and COPD.

**Keywords:** heart failure, COPD, barriers, exercise, program design, rehabilitation, qualitative

**Abbreviations List**

COPD = Chronic obstructive pulmonary disease

$FEV_1$ = Forced expiratory volume in 1 second

FVC = Forced vital capacity

HF = Heart failure

HRQL = Health-related quality of life

## Introduction

Congestive heart failure (HF) and chronic obstructive pulmonary disease (COPD) are highly prevalent in older adults (van Mourik et al., 2014), with concurrent diagnoses observed in 23-38% of individuals with HF (Arnaudis et al., 2012; Brenner et al., 2013) and 16-31% of individuals with COPD (Divo et al., 2012; Jancin, 2008). Systemic manifestations are remarkably similar despite differing underlying pathologies. They include symptoms of fatigue, dyspnea, reduced exercise capacity, reduced health related quality of life (HRQL) and intermittent exacerbations (Gosker et al., 2003). The two populations have been successfully integrated in a rehabilitation setting, with participants achieving comparable outcomes to disease-specific programs (Evans et al., 2010).

Despite well-established improvements in exercise capacity and HRQL following cardiac and pulmonary rehabilitation (McCarthy et al., 2015; Sagar et al., 2015), these gains often diminish within 6-12 months of program completion (Brooks, Krip, Mangovski-Alzamora, & Goldstein, 2002). This decline is associated with decreased physical activity, with older age, and multi-morbidity (Henwood & Bartlett, 2008; Patel, Schofield, Kolt, & Keogh, 2013; Thorpe, Johnston, & Kumar, 2012; Tierney et al., 2011). As physical inactivity is correlated with increased morbidity, mortality and disease burden (WHO, 2009), it is important for strategies post discharge from rehabilitation to encourage community-based physical activity.

Understanding how patients' experience this transition from hospital-based rehabilitation to community-based maintenance is helpful as it informs healthcare providers on the approaches most likely to encourage the patients' subsequent maintenance of their

exercise routine. No studies to date have explored the perspectives of older adults with HF and COPD regarding this transition and its impact on activity maintenance. The objectives of the current study were to 1) explore the experiences of older adults with HF and COPD with respect to maintaining physical activity following completion of cardiac or pulmonary rehabilitation; and 2) explore their preferences around the design of programs to promote community-based activity maintenance.

## Methods

This was a prospective, cross-sectional qualitative study to obtain individual views around pre-identified themes. Participants were eligible if they had a diagnosis of HF (with an ejection fraction ≤ 40%) (Yancy et al., 2013) or COPD ($FEV_1/FVC < 0.70$) (GOLD, 2015) and had successfully completed formal, hospital-based rehabilitation. Ejection fraction and pulmonary function data were collected at the beginning of the rehabilitation program. The study protocol was approved by the XXXX Research Ethics Board and the XXXX Research Ethics Board.

### *Setting*

Participants were recruited from two formal rehabilitation programs in XXXX. Both cardiac and pulmonary rehabilitation programs were delivered by an interdisciplinary team and included supervised exercise, risk factor and lifestyle education, and psychosocial support (Morgan, 2001; Sagar et al., 2015).

### *Sampling*

Purposive sampling was applied. Consecutive patients from both institutions were

recruited immediately prior to discharge from their respective rehabilitation programs. Twenty four consecutive patients who met the inclusion criteria were asked to participate in the study. Those who expressed interest were contacted three months later to schedule the interview. This time frame was selected to ensure participants had sufficient time to transition to the maintenance of their prescribed exercise routine at home, optimizing their ability to provide insight and recommendations.

### *Data Collection*

An informal interview schedule consisting of open-ended questions was developed by the research team and informed by the literature relating to community-based maintenance exercise (refer to Appendix). The schedule was then reviewed and revised according to feedback from clinicians (n=4) and patients (n=5) involved in cardiac and pulmonary rehabilitation to ensure the questions stimulated narratives focusing on community-based maintenance.

Individuals took part in a face-to-face interview three months following completion of rehabilitation with a member of the research team (XX) in a quiet room at the participant's rehabilitation hospital. All interviews were audio-recorded and were approximately 40 minutes in duration. A third party not involved in the research study transcribed the interviews verbatim. Transcripts were checked by the researcher for consistency. Interviews were conducted until themes were convergent and data saturation was reached (assessed by XX and XX), with subsequent participants repeating information that had already been collected.

At the end of the interview, participants were asked to confirm their living situation (i.e. living alone, with family) and the extent to which they currently maintained their exercise

routine. Socio-demographic information, including age, gender, and number of comorbidities, were extracted from the participant's medical records.

### *Data Analysis*

All data were analyzed using the NVivo 10 qualitative data analysis software (QSR International Pty Ltd., 2012) for data management. A deductive thematic framework approach was used and interviews with individuals with COPD and HF were analyzed simultaneously (Braun & Clarke, 2006). Analysis consisted of six stages, as described by Braun and Clarke (Braun & Clarke, 2006): 1) familiarization with the data (undertaken by XX); 2) organization of initial codes derived from the research aims (capturing barriers and facilitators to maintenance exercise and thoughts surrounding the design of community-based maintenance programs). Two researchers (XX and XX) independently coded the first two transcripts and compared the results to ensure a consistent approach before XX coded the remaining transcripts; 3) iterative searching for themes, which allowed the researcher (XX) to move back and forth between transcripts as new themes were established; 4) reviewing generated codes (XX and XX); 5) defining and summarizing themes using thematic mapping to explore relationships between themes (XX and XX); and 6) writing the report.

**Several strategies were used to ensure the credibility and trustworthiness of the data, including a stepped analysis process whereby there was an initial independent review of the data by 2 reviewers (XX and XX) who then met to reach consensus around the common themes (reliability) (Kidder, 1986). These initial themes were used to guide analysis, while the development of final themes included consultation with a third reviewer (XX).** Throughout the project, the authors created and maintained

a comprehensive study database that detailed the data supporting emergent findings. Points of convergence and divergence within and amongst the dataset were examined to ensure internal validity through cross comparative analyses. Key collaborators participated in the analysis and the return of findings to achieve construct and external validity.

## Results

### *Participants*

Of the 24 participants who were approached regarding the study, 14 expressed interest in completing an interview. Three individuals failed to schedule an interview (two were unwell, one was no longer interested), resulting in 11 participants. Data saturation occurred after nine participants, with no new themes emerging from the data. An additional two interviews were conducted to confirm saturation. Interview participants included six individuals with a primary diagnosis of COPD and five with HF. The characteristics of interview participants can be found in Table 1.

[Table 1 about here]

All themes were considered by patients in the light of their experiences of formal rehabilitation, which were largely positive. As the benefits of formal rehabilitation are well understood (Halding, Wahl, & Heggdal, 2010; Wurgler, Sonne, Kilsmark, Voss, & Sogaard, 2012; Zakrisson, Theander, & Anderzen-Carlsson, 2014), these quotes were largely ‘bracketed’, but were used to inform the interpretation of additional themes.

Analysis revealed three themes: 1) transitioning to community exercise is challenging; 2) a structured, group-based program tailored to functional ability facilitates adherence; and 3) "We are all there for the same purpose"- participant support for integrated exercise.

*Theme #1: Transitioning to Community Exercise is Challenging*

Participants described the transition from hospital-based rehabilitation to community-based maintenance, voicing concerns about their ability to maintain prescribed exercise following discharge. Participants described difficulty adhering to their exercise program at home, citing a lack of appropriate facilities.

> *"Well, you know, we used to have a treadmill. We didn't use it very much so we got rid of it and I now wish that the treadmill were back. ... and our house isn't big enough for me to walk from one end to the other type of thing."* (ID 8)

Additional information, specifically improved discharge materials and information on community-based support, was expressed as assisting the transition.

> *"Just to know where these places are would be a big benefit and how to get into them."* (ID 7)

Six participants expressed a desire to find an organized, community-based exercise program that was appropriate for their level of fitness and establish a permanent routine. Participants identified that they had not yet actively explored community exercise options, despite their intentions, but readily acknowledged it was their responsibility to do so.

> *"Where I live there are a couple of very active community centres that I was… my wife and I are going to look into it with regard to doing exercises for seniors such as yoga, etc, which we haven't done."* (ID 4)

Participants stated that chronic disease populations exhibit different levels of fitness and function, and voiced concerns that standard exercise classes in community facilities did not allow for individual variation to the same extent as rehabilitation programs.

> *"I find it boring just by yourself and I know they have an exercise class in my building twice a week but I went in one day to watch it and they do all kinds of exercises I've never done and I'm not sure what's appropriate for me and what's not."* (ID 6)

The role of healthcare professionals in providing information relating to the availability of appropriate programs was identified by nine participants as important to inspire trust in the program.

> *"If they think it's a good programme then I am likely to check it out. I think that [healthcare professionals] know… they know what to look for and expect in people. Definitely the cardiologist knows … he, my cardiologist is an older man who has seen a lot of this. He would know what to look for and therefore whether the programme will address it and the people, again, the people that are here they have seen thousands of people with heart conditions over the course of working here and they would know if they are good or not as well. Whereas who else could I listen to? You know, but a friend or somebody at the gym? I don't think they understand."* (ID 9)

*Theme #2: A Structured, Group-Based Program Tailored to Functional Ability Facilitates Adherence*

Participants expressed that adherence to exercise would be facilitated by a structured program, which included a specific time and place, delivered in close proximity in a group-based format. Acceptable facilities included public community centers, churches, and gymnasiums.

> *"If I knew every Tuesday morning I was expected to be here for, you know, half a day or whatever, I would be here and I would do it."* (ID 2)

> *"I know the instructor has set aside that time for me, it's gets me there, I'm going to be there."* (ID 5)

Exercise was cited as the most important aspect of maintaining function and overall health status across all narratives, with participants expressing a desire for 2-3 days of exercise per week. Participants qualified this by highlighting the need for functionally appropriate exercises and appropriate exercise progression. Participant's narrative portrayed the importance of including social activities and goal–setting. Three participants recommended including psychological support or establishing a direct referral network, as they had observed the impact of anxiety and depression on their peers during the rehabilitation program.

> *"I think that one of the things that I saw or that I observed anyways that some people are dealing with a lot of psychological issues over these things and I don't think it's addressed as well as it could be."* (ID 9)

Both participation in a group and exposure to an instructor were described as helping with ongoing support. All participants acknowledged the importance of an instructor who is knowledgeable about equipment and exercise progression. They considered a ratio of one instructor to eight to ten participants as appropriate to enable access as well as feedback and monitoring. Although the instructor did not have to be a healthcare professional, participants expressed the importance of a healthcare professional being involved with the program for ongoing support to both the program instructor and program participants.

> *"I think that whoever … if you are not having a physiotherapist lead the class and you are having a trained instructor I think that they should report to the physiotherapist right away on each person, how they are doing, what they are not doing." (ID 5)*

Participants portrayed a strong desire for program leaders who were able to motivate and inspire program participants, stating these attributes as being as important as their knowledge of chronic conditions.

> *"To me is just being able to have somebody that's willing to realize limitations of certain people but who doesn't feel like it's a drag to work with these individuals because not all of us are totally disabled. We are disabled to a certain point."* (ID 6)

> *"You've got to have a really upbeat personality that is able to motivate people and able to get people to do what she is asking them to do."* (ID 10)

Six participants described the benefits of affiliating community-based programs with hospitals to emphasise ongoing support from the healthcare system.

> *"If it is associated with a hospital it carries that much more credence with me, okay? Because you know that the healthcare system is interested in what's going on with your exercise program."* (ID 8)

Participants explained that programs endorsed by a hospital were perceived to have an appropriate level of exercise and staff with some degree of disease-specific knowledge. Participant narratives referenced barriers that informed their preferences for program design and delivery. Participants cited barriers related to program cost, distance, lack of appropriate equipment, and weather. Lack of equipment prevented the continuation of exercises at home while the required travel distance to reach appropriate programs was seen by individuals to prohibit participation. Weather was described as a barrier to exercising outside, which many participants explained as their primary method of completing their prescribed walking routines.

> *"What happens to the ground when it snows or ices up and you can't really do a serious walk if it's all ice, right?" (ID 9)*

Self-motivation was highlighted by six participants as challenging in the absence of a structured group environment.

> *"I don't have the incentive and I don't have anybody to kick my ass and tell me to get it done."* (ID 1)

Eight participants described feeling that the lack of an ongoing program negatively

affected their health. Narratives described the episodic nature of chronic disease, with participants citing the need for support following an exacerbation.

> *"I used to do 30 minutes a day or when I did it like three times a week or four times on the treadmill for 30 minutes and you know five minutes now at a slower speed is … so I'm going to have to start sort of at the bottom and work my way back up again because it's … it's hard and uh … but I know how much it helps me."* (ID 2)

Participants further expressed that a program with structured classes would help to mitigate decline by establishing a formal routine to maintain prescribed exercise.

*Theme #3: "We are all there for the same purpose"- Participant Support for Integrated Exercise*

All but one participant articulated their support for the integration of multiple chronic disease populations in a single program, including conditions beyond COPD and HF. Participants expressed the importance of having individuals with similar functional abilities and recognized that individuals with different chronic conditions often have similar fitness levels. Narratives outlined the benefits of including individuals with varying primary diagnoses, such as exposure to alternate perspectives and the opportunity to learn from others' experiences.

> *"You feel sorry for yourself 'cause you had no shoes until you saw a man who had no feet."* (ID 3)

> *"It's always kind of broadening to meet other people and other … I mean you are*

*not the only person around who has got a problem and how they cope with it and how you've, you know…I think it could be really beneficial."* (ID 10)

One individual expressed that his fitness level was much greater than his peers in cardiac rehabilitation and indicated that he preferred to exercise alone so as not to be limited by the abilities of a group. The remaining participants unanimously expressed their willingness and motivation to attend an integrated, community-based exercise maintenance program.

*"And I just want to be able to go… and I don't care if the class has all different kinds of abilities or whatever, we are all there for the same purpose, to improve."* (ID 6)

*"That would be all the… all the best, you know, I'd love to know and be able to get into it."* (ID 7)

Participants expressed that it is unlikely that enough individuals would live in a given area to support a disease specific program long-term.

*"So it would be more important to have let's say a group located in your immediate area with enough people for quorum or whatever, even if they are different conditions versus making it mandatory to have everyone with the same condition then someone has to drive ten miles away to find enough people with that condition, right?"* (ID 11)

The majority felt that a program integrating multiple conditions was the most feasible option, but that this would require staff supervising the program to be familiar with

multiple populations.

## Discussion

The current study highlights key gaps in care during the transition from formal rehabilitation to community-based maintenance exercise among older adults. Participants expressed the need for minimally supervised community-based programs to support adherence and highlighted the importance of a program tailored according to functional ability with a motivating program leader. The results reflect similar perspectives relating to exercise and community-based exercise among older adults with HF and COPD.

Community-based programs offer the potential to reduce the use of healthcare resources, but require a strong link between healthcare and community facilities. Previous work by Adsett et al. (Adsett, Hickey, Nagle, & Mudge, 2013) highlighted the importance of establishing central coordination and a supported referral pathway in achieving and sustaining program success. Results from the current study suggest that referrals not only facilitate the transition from rehabilitation to a community program, they inspire confidence that the program is appropriate for older adults with chronic disease. Including individuals across a variety of chronic conditions further optimizes the use of resources by improving program reach and overall economy of scale. It is important to note that an integrated strategy will not be for everyone as some individuals demonstrate a higher level of function than others following the completion of rehabilitation.

Our results align with previous work reporting poor motivation, lack of support, physical symptoms and financial constraints as barriers to exercise (Barbour & Miller, 2008; Thorpe et al., 2012) and supervised, group-based exercise as a key factor contributing to

successful maintenance (Desveaux, Beauchamp, Rolfe, Goldstein, & Brooks, 2014). The characteristics of the instructor were especially emphasized and included empathy, focus, and effective communication skills. The presence of an instructor provides an overarching sense of safety and comfort, while empathy increases trust (Desveaux et al., 2014; Winward, 2011). These features are critical for individuals with chronic disease who asked to manage symptoms of breathlessness while engaging in exercise. This supportive design is likely to facilitate the maintenance of health behaviour through improved maintenance self-efficacy (Schwarzer, 2008). Integrating programs into existing community facilities provides the added opportunity for participants to experience social connections with members of the general community, which promotes feelings of social inclusion and makes participants of community-based programs feel valued (Desveaux et al., 2014).

While the findings of the current study are promising, the study is not without limitations. Participants were recruited from two urban rehabilitation programs and therefore the results may not be reflective of older adults from other clinical populations or institutions. As we enrolled only patients who had already completed a formal hospital-based rehabilitation program, the results may not be generalizable to individuals without previous rehabilitation experience.

The results of this study suggest that community maintenance programs based on functional status and symptoms instead of primary diagnosis can be delivered consecutively to older adults with HF and COPD, which aligns with previous pilot work (Adsett et al., 2013; Woo et al., 2009). Amidst ongoing conversations around a value-based approach to healthcare (Elf et al., 2017; Weeks & Weinstein, 2015), integrated

community-based programs offer the potential to maintain the gains that currently diminish following the completion of rehabilitation (Brooks, Krip, Mangovski-Alzamora, & Goldstein, 2002), shifting the focus beyond the program cycle itself to include the patient's experience of their entire cycle of care. This practical strategy also extends the availability of exercise to older adults with HF and COPD, who reported a dearth of available and appropriate community-based programs following discharge from rehabilitation. The results of the current study will inform the development of programs that facilitate the successful transition to community based maintenance exercise. This integrated approach may be an effective strategy to improve outcomes among several chronic conditions with minimal healthcare resource utilization.

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**Table 1: Characteristics of Interview Participants**

| | Primary Condition | Gender | Age (years) | Lives With | Number of Comorbidities | Current Home Exercise |
|---|---|---|---|---|---|---|
| ID 1 | COPD | Female | 68 | Family | 1 | None |
| ID 2 | COPD | Male | 70 | Spouse | 3 | None |
| ID 3 | COPD | Female | 71 | Spouse | 6 | Partial (aerobic) |
| ID 4 | HF | Male | 82 | Spouse | 0 | Partial (aerobic) |
| ID 5 | HF | Female | 85 | Alone | 3 | None |
| ID 6 | HF | Female | 66 | Alone | 2 | None |
| ID 7 | COPD | Male | 65 | Alone | 5 | Partial (aerobic) |
| ID 8 | COPD | Male | 74 | Spouse | 5 | Full |
| ID 9 | HF | Male | 64 | Spouse | 0 | Partial (aerobic) |
| ID 10 | COPD | Female | 72 | Alone | 3 | Partial (balance) |
| ID 11 | HF | Male | 54 | Spouse | 4 | Partial (aerobic) |

Note: Full exercise maintenance includes all prescribed components, including aerobic exercise, resistance training, and balance training. 6MWD=six minute walk distance; COPD=chronic obstructive pulmonary disease; HF=heart failure.