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5 **“We are all there for the same purpose”: Support for an integrated community**

6 **exercise program for older adults with HF and COPD**

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

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

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

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

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

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

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1 **Abbreviations List**

2 COPD = Chronic obstructive pulmonary disease

3 FEV₁ = Forced expiratory volume in 1 second

4 FVC = Forced vital capacity

5 HF = Heart failure

6 HRQL = Health-related quality of life

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1 **Introduction**

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

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

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

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

7 **Methods**

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

15 ***Setting***

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

20 ***Sampling***

21 Purposive sampling was applied. Consecutive patients from both institutions were

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

7 ***Data Collection***

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

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

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

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

3 *Data Analysis*

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

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

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

6 **Results**

7 *Participants*

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

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16 [Table 1 about here]

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

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

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5 Theme #1: Transitioning to Community Exercise is Challenging

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

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

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

15 *“Just to know where these places are would be a big benefit and how to get into*
16 *them.” (ID 7)*

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

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

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

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

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

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

1 Theme #2: A Structured, Group-Based Program Tailored to Functional Ability

2 Facilitates Adherence

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

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

9 *“I know the instructor has set aside that time for me, it’s gets me there, I’m going*
10 *to be there.” (ID 5)*

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

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

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

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

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

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

20 *“You’ve got to have a really upbeat personality that is able to motivate people*
21 *and able to get people to do what she is asking them to do.” (ID 10)*

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

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

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

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

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

19 *“I don’t have the incentive and I don’t have anybody to kick my ass and tell me to*
20 *get it done.” (ID 1)*

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

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

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

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

10 Theme #3: “We are all there for the same purpose”- Participant Support for Integrated
11 Exercise

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

19 *“You feel sorry for yourself ‘cause you had no shoes until you saw a man who*
20 *had no feet.”* (ID 3)

21 *“It’s always kind of broadening to meet other people and other ... I mean you are*

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

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

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

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

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

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

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

1 multiple populations.

2 **Discussion**

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

9 Community-based programs offer the potential to reduce the use of healthcare resources,
10 but require a strong link between healthcare and community facilities. Previous work by
11 Adsett et al. (Adsett, Hickey, Nagle, & Mudge, 2013) highlighted the importance of
12 establishing central coordination and a supported referral pathway in achieving and
13 sustaining program success. Results from the current study suggest that referrals not only
14 facilitate the transition from rehabilitation to a community program, they inspire
15 confidence that the program is appropriate for older adults with chronic disease.

16 Including individuals across a variety of chronic conditions further optimizes the use of
17 resources by improving program reach and overall economy of scale. It is important to
18 note that an integrated strategy will not be for everyone as some individuals demonstrate
19 a higher level of function than others following the completion of rehabilitation.

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

1 successful maintenance (Desveaux, Beauchamp, Rolfe, Goldstein, & Brooks, 2014). The
2 characteristics of the instructor were especially emphasized and included empathy, focus,
3 and effective communication skills. The presence of an instructor provides an
4 overarching sense of safety and comfort, while empathy increases trust (Desveaux et al.,
5 2014; Winward, 2011). These features are critical for individuals with chronic disease
6 who asked to manage symptoms of breathlessness while engaging in exercise. This
7 supportive design is likely to facilitate the maintenance of health behaviour through
8 improved maintenance self-efficacy (Schwarzer, 2008). Integrating programs into
9 existing community facilities provides the added opportunity for participants to
10 experience social connections with members of the general community, which promotes
11 feelings of social inclusion and makes participants of community-based programs feel
12 valued (Desveaux et al., 2014).

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

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

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

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9 **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)

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

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