



EXPERIENCE OF PHYSICAL ACTIVITY DESCRIBED BY PATIENTS WITH HEART FAILURE WHO HAVE RECEIVED INDIVIDUALIZED EXERCISE ADVICE: A QUALITATIVE STUDY

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Objective: To describe the experience of physical activity in patients with heart failure who were randomized to a control group in which they received exercise advice and motivational support.

Design: A qualitative descriptive interview study, using qualitative content analysis.

Patients: Fifteen patients with heart failure.

Methods: Interviews with members of the control group in a physical activity trial (Heart Failure-Wii study), who received exercise advice and telephone follow-ups.

Results: The experience of physical activity was described by 4 categories: (i) affected by study participation; (ii) impact of having heart failure; (iii) mixed feelings when physically active; and (iv) influence of the social and physical environment. Study participation made patients feel encouraged or obliged, or they gained a sense of security in connection with becoming more physically active. Symptoms, side-effects and barriers could hamper their physical activity. They changed their type and level of physical activity, or used resources or equipment to become physically active. Patients experienced physical and emotional improvements and developed routines and structures, and their environment and caregivers were able to influence their physical activity.

Conclusion: The role of study participation, having heart failure, and psychological and environmental factors describe the experiences of physical activity in patients with heart failure who were randomized to a control group, and are important in evaluating and motivating patients' physical activity.

Key words: content analysis; physical activity; exercise; heart failure; adherence.

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Being physically active is beneficial to patients with heart failure (HF) and can reduce hospital readmission, improve exercise capacity and decrease all-cause mortality (1, 2). Physical activity also improves functional mobility and balance, and reduces the risk of falling and of developing metabolic and cardiovascular disease

LAY ABSTRACT

Non-adherence to physical activity is common in patients with heart failure. As a consequence, these patients are more likely to have worse health outcomes and to be readmitted to hospital. Patients who are in the control group of an exercise trial can change their physical activity behaviour. In order to effectively advise patients to be physically active, or to evaluate exercise trials, it would be useful to gain more insight into the physical activity experiences of patients participating in control groups of exercise trials. The aim of this study was to describe the experiences of physical activity in patients with heart failure who were randomized to a control group in which they received exercise advice and motivational support. The study found that experience with physical activity was described by 4 categories: (i) affected by study participation; (ii) impact of having heart failure; (iii) mixed feelings when physically active; and (iv) influence of the social and physical environment.

among older people with moderate deficits or frailty (3). In addition to commencing being physically active, a major challenge is the long-term commitment to physical activity, both in the general population and in those with chronic conditions. Adherence to physical activity recommendations in patients with HF is significantly lower (30–60%) than for most other self-care activities, such as appointment-keeping (>90%), diet and fluid restrictions (90%), and monitoring their weight (83%) (4, 5). Lack of adherence to recommendations regarding physical activity could be due to barriers experienced by patients, such as depressive symptoms and lower self-efficacy. Women and people with chronic illnesses, such as HF, are known to be less physically active (6).

Patients in physical activity trials are often not blinded to their randomization, and researchers have to deal with issues of crossover, adherence and site variation. Patients randomized to the control group might modify an aspect of their behaviour in response to their awareness of being observed (7, 8). A randomized controlled trial, HF-ACTION (9), found that more than half of patients in the usual care group (55%) were not satisfied with the study group to which they were randomly assigned, and many performed some level of physical activity.

A recently completed physical activity study (HF-Wii study (10)) including patients with HF evaluated exergaming at home. Exergaming is video gaming in which the patient needs to be physically active to be able to play the game. The findings of this study showed no treatment effect from exergaming on exercise capacity, as measured by the 6-min walk test after 3 months. The mean change between baseline and 3 months in both the exergame group and the control group was 16 m, with the same number of patients (62%) improving their exercise capacity. Patients in the control group received physical activity advice and motivational phone calls during the first 3 months of the study, and were asked to keep a diary to collect data on their activities. Other studies show that physical activity advice and/or motivational support are effective in terms of participating in physical activity (11, 12). The role of participating in a control group and other factors affecting physical activity in patients with HF must be explored to be able to determine the effect of the interventions associated with the most participation and the maintenance of exercise behaviours.

Therefore, the aim of this study was to describe the experiences of physical activity in patients with HF who were randomized to a control group for a physical activity trial (HF-Wii study) in which they received exercise advice and motivational support.

METHODS

Design

A qualitative descriptive study using qualitative content analysis.

Participants and sampling

The patients in the current study participated in the control group for the HF-Wii study, in which they were given individual physical activity advice by their HF nurse or their physiotherapist, in accordance with national guidelines (13), based on the European Society of Cardiology guidelines (14). They also were called 2, 4, 8 and 12 weeks after enrolment to encourage them to be active. As part of the trial, follow-up visits took place at the hospital 3, 6 and 12 months after inclusion for physical assessments, but no further physical advice or instructions were given (15).

Patients were included in the HF-Wii study (15) if they were diagnosed with HF, were in New York Heart Association (NYHA) class I–IV, were over 18 years of age, had no problems with mobility, balance or sight, no severe cognitive dysfunction or other severe psychiatric illness, had a predicted chance of survival of more than 6 months, and did not have difficulties understanding or reading the language in which the intervention took place.

In addition to the inclusion criteria for the HF-Wii study, to be eligible for this study patients had to be participating in the control group for the HF-Wii study and enrolled at 1 of the 5 Swedish centres taking part in the study, and must have participated in the physical activity trial no more than one year previously. For geographical reasons, patients from 2 centres were first invited to

participate. The research nurses were asked to invite patients with a range of ages and of both sexes. From these 2 centres, a total of 11 patients (4 women, mean age 69 years, age range 48–81 years) were included. The data were analysed concurrently and after these 11 interviews, and no new issues were identified during the interviews (data saturation (16)). To ensure variation, it was determined that the study needed to include more women and younger patients. The 3 additional centres were asked to include younger, female patients. Four more patients were included (2 women, mean age 60 years, age range 37–70 years).

Approval was obtained to conduct qualitative interviews among the control group for this study (reference number 2017/517-32) in addition to the approval for the main study (reference number 2012/247-31).

Data collection

Two researchers who were not part of the HF-Wii study team, and were not involved in developing the questions, performed the interviews. These 2 researchers had experience of HF and performing interviews. The quality and consistency of the interviews was examined by the research group. The interviews were semi-structured, and were performed at the homes of the patients with HF ($n=12$) or by telephone ($n=3$). The patients themselves decided which alternative was most suitable. Research shows that face-to-face interviews in qualitative research have the same results as telephone interviews (especially when chosen as the preferred method for being interviewed), and may allow respondents to feel relaxed and able to disclose sensitive information (17).

With permission, the interviews were tape-recorded and transcribed verbatim for data analysis. The following introductory question was asked: “Can you tell me about the exercise advice you received at the HF clinic in relation to the HF-Wii study?” Subsequently, questions were asked about physical activity and various aspects of this, exploring preferences and attitudes. Probing questions such as “What do you mean by that?”, “How did you feel about that?” and “Could you give an example?” were used to encourage the patients to develop their descriptions.

Data analysis

Qualitative content analysis, based on an inductive approach, was performed in 3 steps using the structure described by Elo & Kyngäs (18): (i) preparation phase, (ii) organizing phase, and (iii) reporting phase.

Preparation phase. Initially, 2 of the authors (LK, ML) read 5 of the transcribed interviews separately and selected units of analysis in the text that described experiences of physical activity. Units of meaning were sentences and could contain several meanings (19). The authors subsequently discussed their impressions of the text (only the manifest content and not the latent content) and the units of analysis in order to establish a mutually agreed basis for the analysis. The first author (LK) analysed the remaining interviews. During the analysis, the interviews were read repeatedly to gain an overall understanding of the whole, and there was constant comparison between the parts of the analysis and the text of the whole interviews (16, 19).

Organizing phase. The organizing phase included open coding, creating categories and abstraction (18). In open coding, notes and headings were written in the margin next to the meaningful units in the text. There could be more than one code for each meaningful unit. These headings were collected from the coding sheets and (sub)categories were freely generated (20). The first author kept a journal in which the headings and ideas about relationships bet-

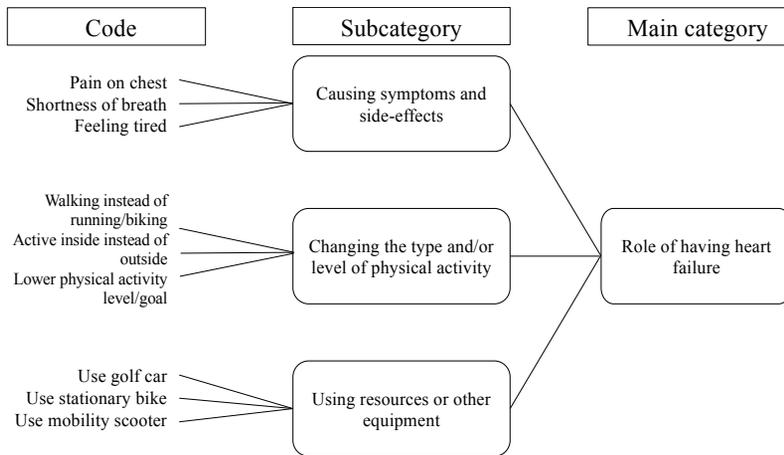


Fig. 1. Example of the organizing phase with open coding, creating categories and abstraction describing the experiences of physical activity in patients with HF who received individualized exercise advice.

between categories were recorded. In the abstraction, the structure of the (sub)categories was discussed among all authors and subcategories with similar content were grouped together into categories (16). An example of the organizing phase is shown in Fig. 1.

Reporting phase. In this phase the analyzing process and the results were reported

Methodological considerations

Methodological rigour was aimed for, and an awareness of pre-conceptions was emphasized throughout the study (21). To ensure trustworthiness, each step of the analysis process was discussed until consensus was achieved (19). To avoid bias, the interviewers were not part of the research team for the physical activity trial. Presenting quotations offered insights into what was said and further elucidated the findings. Recording and transcribing interviews verbatim and using open coding initially, based on words, increased trustworthiness. The fact that the first author kept a journal in which ideas about relationships between categories were recorded further strengthened the trustworthiness. In addition, a systematic approach to analysis was used, which allowed the investigators to share and explore charted data together (18). To ensure confirmability, analyst triangulation was applied, with the researchers independently coding and categorizing data and having discussions to reach consensus on the final categories.

RESULTS

Of the 15 patients interviewed, ages ranged between 37 and 82 years, 6 were women, 10 patients were in

NYHA II (ordinary physical activity results in symptoms), and 5 were in NYHA III (less than ordinary activity causes symptoms). Four patients had finished primary school, 7 had finished high-school, and 4 had attained an education level higher than secondary school. Physical activities that were described as being carried out regularly were (Nordic) walking, gym (in-hospital or retirement gym), golf, gardening and household work. Former activities, that were carried out when the patients were younger or before they were diagnosed, but could no longer be performed, were competitive swimming, long walks or hiking, golf and cycling.

From the analysis of the 15 interviews, 4 categories described the experiences of physical activity in patients with HF receiving activity advice: (i) affected by study participation; (ii) impact of having HF; (iii) mixed feelings when physically active; and (iv) influence of the social and physical environment (Fig. 2).

Affected by study participation

Patients experienced that they had received advice on physical activity from healthcare professionals, but few perceived themselves to be participants in a trial, as they were randomized to the control group. Instead, they thought that this advice was provided to all patients with HF and was not part of the study protocol.

Not receiving enough guidance on how much physical activity one can perform, or which kinds of physical activity are recommended, could prevent patients from becoming more physically active.

Patients felt encouraged to change their level of physical activity because of the advice they received.

It was an incentive for me to see that I improved my results in the tests. The physiotherapist always compared my results with the previous time. How long I could hold the weights, how many times I could bend, stretch and stand. How far I could walk and the walking distance. I improved my results every time. [Male, 70 years old]

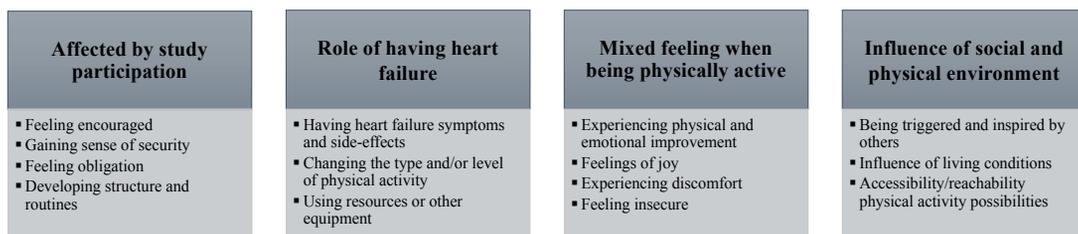


Fig. 2. Categories and subcategories describing the experiences of physical activity in patients with HF who received individualized exercise advice.

Patients realize that increased physical activity can bring different health benefits. The telephone calls also increased their motivation to adhere to the activity advice, because they were encouraged to do well. Knowing that the healthcare professionals were evaluating test results compared with previous visits during the clinic appointments served as a motivator for achieving a higher level of activity. Patients felt safe and secure performing physical activity, because they underwent testing at the follow-up visits.

Patients also felt an obligation towards the research team to comply with the physical activity advice, and increased their physical activity in accordance with this advice.

Developing structures and routines for physical activity and exercise, such as diaries or schedules, helped patients to become and remain physically active.

Role of having heart failure

As result of their HF, some patients could not perform their usual activities, mostly due to a loss of exercise capacity. For patients, it was important to assess the physical activities performed when they were younger or before the diagnosis of HF.

In order to be able to be active with their current condition, patients changed their mode of physical activity to be able to be active in their current condition. They chose types of physical activity different from their usual ones, such as cycling instead of walking or visiting a gym for elderly people. Patients described using tools or resources to carry out physical activities that they enjoyed when they were younger or before they had HF, but were no longer able to perform. For example, they used a stationary bike if they did not feel safe cycling outdoors, or used a golf cart instead of walking on a golf course.

Patients adapted their level of physical activity to their physical exertion. For example, they adapted their speed and distance when walking or cycling, and took regular breaks during physical activities when necessary.

Heart failure symptoms, such as shortness of breath or loss of energy, were experienced as preventing them from being more physically active, especially if these symptoms increased markedly during physical activity.

I do not know if it was due to a deterioration, maybe it was caused by the exercise training. Suddenly, it was impossible to go on. I got chest pains and so on. That led to more heart examinations, which was good. I wondered what it was that caused this problem. Maybe an obstruction in the blood vessels in the heart. [Male, 72 years old]

Mixed feelings when physically active

Patients experienced that, after being physically active for some time, they could increase their physical exer-

tion and, for example, work longer in the garden than before. They also felt more capable in managing their heart failure and other comorbidities. They felt healthier, more physically fit, more confident and happier in themselves. Furthermore, they experienced participating in physical activity as joyful and rewarding.

I started a little over one year ago with table tennis. The first time it was quite tough, and I had to rest to recover a bit at the end of the 2-hour session. However, now I have no such difficulties, I can really hang in there. So, in that respect it feels like I have really improved. (Male, 70 years old)

Patients also felt discomfort during and after physical activity. Symptoms such as pain in their limbs or myalgia, could distress them or even result in fear of being physically active.

Patients could feel insecure, as they expressed not knowing how much physical activity they could perform, or which kinds of physical activity they could perform.

Influence of the social and physical environment

Patients felt inspired to be physically active by others who were, or who encouraged them to be, physically active. These could be their partners, family members, neighbours, co-workers or friends. They also said that being physically active with others made it easier to be physically active compared with doing so on their own. Patients felt that having no social support from those around them made it more difficult to participate in physical activity or to increase their physical activity. Patients said that having family members who discouraged physical activity or living with a partner who was unwell prevented them from being physically active.

Patients stated that they changed their physical activity according to their living conditions. Living close to nature encouraged them to go outdoors to pick berries, for example, while living in areas with no smooth road surfaces or pavements prevented them from being physically active. Attractive scenery was described as promoting walking outdoors. Having a job that promoted physical activity was also experienced as a positive influence on physical activity. Difficulties finding a place to park near sports facilities, bad weather, and poor hygiene at sports facilities were barriers to being physically active.

I have not been in public places [to swim] because I do not like this, since the hygiene there is not optimal nowadays. In the past, everyone would shower and wash before bathing, but things are different nowadays. [Male, 70 years old]

DISCUSSION

The results of this study show that patients with HF who participated in a control group for a physical

activity intervention, in which they received activity advice and motivational support, felt encouraged to be physically active and had a sense of security due to being monitored throughout the study. Awareness of being observed and knowing that one's physical activity behaviour is being assessed could engender beliefs about the researcher's expectations. Conformity and social desirability considerations could lead physical activity to change in line with these expectations (7).

Regarding the experience of patients' physical activities, the current study found that it may be important to assess the physical activities performed when patients were younger or before the HF diagnosis. Being physically active can be the result of having always been physically active throughout life, whereas others who had never engaged in any regular physical activity were reluctant to start exercising (22). Patients found ways to adapt their former physical activities so they could still be physically active as they used to be. Therefore, both previous and current physical activities to motivate patients should be considered and could help patients to adapt or find new ways of maintaining an active lifestyle. However, research has identified several barriers to continued activity for cardiac patients. For example, some are afraid of falling when exercising, while others might fear that their physical condition could get worse when they are active or they might be afraid to perform activities alone (23, 24).

Patients were motivated to stay active because of physical gains from physical activity. These findings confirm previous studies describing patients' perceptions that physical activity is beneficial for digestion, blood circulation, weight control, sleep quality, breathing and mental alertness, all of which acted as motivators to stay active (24).

Some patients described physical activity as not being fun, or being boring or too time-consuming. Recognizing these barriers and addressing them in clinical practice might help patients to find the activity that best fits their situation. Specific detailed planning of when, where and how physical activity will be performed and providing instructions and reinforcement efforts towards physical activity have been shown to be associated with significantly higher levels of self-efficacy (confidence to overcome barriers when these occur, and important for patients with HF (25)) and physical activity (26). This so-called action planning could be offered together with schedules and diaries, and could be beneficial for patients who, for example, experience lack of time as a barrier to physical activity.

The physical and social environment was found to be important. Patients valued interaction with peers, and felt that encouragement from others could positively influence physical activity. Pleasant scenery

or good weather encouraged them to take walks outdoors, whereas access difficulties were experienced as a barrier to performing physical activity. The use of telerehabilitation, or even virtual reality, could make physical activity easy to access and possible to perform at home. In telerehabilitation, interventions consist of telehealth solutions that enable patients to participate in the programme in a home-based setting as an alternative to the hospital-based programme (27). With the use of virtual reality, patients can be independent and safe, and engage with minimal supervision in activities that are otherwise difficult to engage in (28, 29).

Patients in the current study felt encouraged and secure in increasing their physical activity, thanks to the motivation support and study participation. However, there were also patients who found that the physical activity advice was not sufficient to increase their physical activity. These different experiences between patients were also found in the intervention group in the HF-Wii study, where some patients were enthusiastic about the physical activity provided, while others thought that the forms of physical activity provided were not suitable for them (30). Patients in the control group felt obliged to follow the activity advice, and this was also seen in the intervention group (30).

Facilitators that should be considered when assessing cardiac care were using physical activities diaries or developing structures and routines. Providing knowledge about the benefits of physical activity or what kinds of physical activity the patient can perform is a responsibility of healthcare professionals working with patients with HF. Sufficient, tailored information about the disease, its trajectory and possible treatments is important for patients to make informed decisions and to comply with treatment. Knowledge is necessary, but insufficient, to change the level of physical activity (31–33).

Methodological issues

Several steps were taken to ensure trustworthiness (34) in this study. The credibility of the study was strengthened by the fact that some of our findings were confirmed by previous studies on experiences of physical activity (25, 26, 31–33). The data were collected through interviews, which made it possible to ask follow-up questions if necessary. The interviewers had no care relationship with the participants and had never met them prior to the interview. They had experience of caring for patients with HF and knowledge about the importance of physical activity for patients with HF, which could have influenced the interviews. All interviews were tape-recorded and transcribed verbatim, and all data were included in the analysis.

To ensure trustworthiness, analyst triangulation was applied, with the researchers independently coding and

categorizing data, and each step of the analysis process was discussed until consensus about the interpretation was achieved.

This study aimed for subjects with a range of ages and of both sexes. A limitation was that it was not possible to include variation in severity of HF. Therefore, caution should be applied in terms of transferability of these results to patients who experience minor symptoms due to their HF (NYHA I) and severe HF (NYHA IV).

Although the study was performed in Sweden, the issues raised are likely to be transferable to other countries. Further research is needed to collect data on experiences of patients with HF of being in a control group for a physical activity trial, receiving activity advice and motivational support, and of physical activity.

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