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Keeping the maintenance of daily life in spite of Chronic Heart Failure. A qualitative study

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Abstract

Background: Patients with CHF (Chronic Heart Failure) is an increasing group in the society. They often experience increasing powerlessness and depression in daily life as well as difficulties adhering to other physical symptoms. Many patients have difficulties to deal with daily demands.
Aims: To describe how persons, living with CHF, perceived the maintenance of their daily life.
Methods: This study was following a phenomenographic method in order to describe variations of perceptions. Data was collected through taped interviews, taken from 17 patients. The sample was selected from patients attending a specialist Chronic Heart Failure day care unit.
Results: Five main categories were identified from 345 statements describing variations in how patients with CHF kept maintenance in their daily life. The categories include: dealing with the realities of life, dealing with thoughts about life's infinity, taking responsibility, dealing with the surrounding world and keeping up with values of life.
Conclusion: The illness symptoms clearly affected daily routines but participants showed remarkable resolve and showed that values in life could be maintained albeit with a few adjustments. No patient expressed a desire to give up. Understanding patients' perceptions the specialist nurse can transfer these knowledge to other patients in similar situations.

Keywords: Daily life; Chronic Heart Failure (CHF); Phenomenography

1. Introduction

Chronic Heart Failure (CHF) is an illness that is increasing among older people, foremost within the industrialised society [1–3]. In Europe 5% of medically related emergency admissions are linked to CHF [3,4]. The illness increases substantially with age, which correlates with symptomatic CHF manifesting in 10% of patients aged over 80 years. Approximately 80% of those suffering from CHF are older than 75 years. Even so suffering from CHF is likely to have an impact on people's everyday life regardless of their chronological age. Debilitating symptoms of CHF include fatigue and breathlessness [5–8] as well as thirst [6,7,9]. Other physical symptoms include—lack of energy, drowsiness, disturbed sleep [6–8], frequent urination [8], appetite loss, constipation, palpitations, swelling of arms or legs [6] and chest pain [6,7]. Following Mårtensson et al. [10,11] the apprehension experienced by people suffering from CHF might include feelings of weakness and physical restraint. Other commonly described symptoms of CHF include psychological symptoms and difficulties with concentration, feelings of nervousness, sadness and irritability have also been described as common [6].

In the study by Boyd et al. [8] the patients in CHF described how they became experts in the logistics in their lives and household planning was required. Dependency on others increased and some patients developed coping strategies such as humour. Zambroski [12] performed a qualitative study in patients with CHF. The results showed that the patients through self-assessment, planning and acting had developed individual problem-solving strategies. They had different personal resources and family members, neighbours or friends

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cared for them. They also expressed that contacts, telephone calls and use of services in emergencies was important.

There is a high likelihood that suffering from CHF may intrude on people's daily life to such an extent, that they are forced to make large lifestyle changes [13,14]. Ekman [5] and Strömberg [15] explain that even when nurses teach patients about their medication and required lifestyle changes, it is still difficult for many patients to deal with daily demands. Unrealistic expectations, enforced changes to their environment, frequent re-admissions and increases in financial demands may contribute to feelings of depression amongst these patients [16].

Following review of previous research it seemed theoretically viable to study and understand patients with the diagnosis of CHF. However, it is important that nurses understanding and support are based upon patients' perceptions in order to enable independency as long as possible. The aim of this qualitative study was to describe how persons, living with CHF, perceived the maintenance of their daily life.

2. Method

This study was following a phenomenographic approach which is an empirically grounded research approach developed at the Department of Education at Gothenburg University [17]. The purpose of phenomenography is to constitute the frame within which knowledge is gathered or the foundation on which reasoning is built. By using phenomenography the variation in people's perceptions of phenomena is described in an unreflective way. In this approach a distinction is made between how things actually are and how they are conceived through first-order and second-order perspectives [17]. In first-order perspectives facts are described, for example, describing external observations. Second-order perspectives focus on people's way of experiencing physical, biological, social and cultural variations. It is consequently applicable when exploring the different ways in which people are aware of a certain situation or phenomenon.

2.1. Sample

In order to capture a diversity of perceptions patients attending a heart failure out-patient clinic, nurse led, for regular review were invited to participate. The informants' CHF was classified according to New York Heart Association [NYHA] functional classification III and IV [18].

The nurse at the nurse led clinic was asked to select patients from the given criteria: ability to speak and understand Swedish and sufficient strength to participate. All of the participants should have been in-patients at the hospital at least twice. Eleven were classified as NYHA III and six as NYHA IV. The patients included varied in sex, age and cohabiting as follows: five women and twelve men, aged between 55 and 83 years, ten of them cohabitated and the remaining seven lived alone. Characteristics of patients included are presented in Table 1.

2.2. Ethics

The performance of the investigation conforms with the principles outlined in the Declaration of Helsinki [19]. Both the Ethical Committee at the medical faculty, Lund University, Sweden [LU 511-01] and the chief physician at the clinic approved the study. The proposed participants were sent an informative letter 4 days before their planned review at the out-patient clinic. This letter informed patients about their potential involvement and the purpose of the study. All were asked to answer a few questions regarding their perceptions of living with CHF, in addition the study aim was verified. Patients were informed that any information would be kept confidential, that participation in this study was voluntary and that declining to participate would not affect future care and treatment. The heart outpatient clinic nurse ensured that potential participants were well enough to participate by conducting a physical entry assessment. Informed consent was sought from participating patients and written information provided about their right to withdraw at any time. None of the selected informants declined to be interviewed.

2.3. Data collection

A semi-structured interview technique was used with open-ended questions [20]. This is a common technique for collecting data for qualitative studies [17,21]. Two pilot interviews were carried out to test how the questions were understood. These two interviews were included in the analysis as they did not lead to any changes of the questions. All interviews took place in a secluded office at the clinic. Data collection ended during 2003. They were tape-recorded and lasted in general for about 1 hour. Each interview started with questions about how the illness started and how it has developed over time. The interviews focused on the informant's ability to manage daily life and the interviews were ended with a question about how the informants perceived their future. When necessary probing such as: "What do you mean?" and "Can you elaborate further?" were used. Two researches (SF, A-KW) participated at the interviews. The

Table 1
Characteristics of the 17 CHF patients interviewed

Gender	
Male	12
Female	5
Age	
Mean	72
Range	55 – 83
Residential property	
Flat	14
Owner-occupied house	3
Civil status	
Single	7
Cohabitating	10
Time (years) of illness	1–12

researchers transcribed verbatim half of the recorded interviews each, after the completion of interviews. Following this, the material was reviewed by the researchers separately and thereafter data comparisons made. Analysing of the data was done by the researchers, who all are registered nurses and factual CHF-knowledge and are familiar with the research method. Tapes and discs holding the interview data were kept secure [22].

2.4. Data analysis

Tape recordings and transcriptions were repeatedly read to gain a general impression of the material. The researchers reflected on the data independently during the analytical process. Upon completion of the independent data review, comparisons were made and discussed until unanimity in data interpretation was determined by the researchers. Thereafter statements expressing the informant's perceptions were extracted. In total 345 statements were found. An internal comparison was made to determine any variations in authors' perceptions of what participants meant. Eventually, the statements were grouped into patterns which resulted in 14 subcategories. These subcategories were distilled into five main categories through analysis of interactions between perceptions, specific statements and wholeness. The analytical process is reflected through this statement:

> *"My husband // has learnt how to manage the machines downstairs and he manages everything. // He does the washing and he hangs it up and he...yes, and then I do the ironing and folding when it comes upstairs"*

This perception statement was assigned to the "*to work in collaboration*" subcategory. This, together with the perceptions grouped under other subcategories entitled "*to adjust activities*" and "*to use creativity*" formed the main category entitled "*dealing with the realities of life*". Quotations from the interviews illustrate the context of each category. The categorisation process continued until unanimity was reached (Table 2).

Table 2
Categories and subcategories emerged from perceptions maintenance of daily life in CHF

Dealing with the realities of life:
- *to adjust activities*
- *to work in collaboration*
- *to use creativity*

Dealing with thoughts about life's infinity:
- *to live with thoughts — past, present and future*
- *to live with the state of mind*

Taking responsibility:
- *to follow treatment regime*
- *to make one's own decisions*
- *to use one's knowledge*

Dealing with the surrounding world:
- *to experience continuity*
- *to feel trust*
- *to be part of a social network*
- *to deal with the local environment*

Keeping up with values of life:
- *to retain spare time activities*
- *to retain lifestyle*

3. Results

The five categories and their respective subcategories are reported below without order of precedence.

3.1. Dealing with the realities of life

This main category describes the perceptions of how routine activities were perceived and managed. The gradual behavioural changes were used to accept the shift from independency to dependency.

3.1.1. To adjust activities [Interviews 2–17]

To adjust activities describes that every day activities nowadays took a longer time to perform than earlier. Instead of every day activities being performed quickly and easily they demanded a seamless amount of time and energy. Accepting that fact and adjusting to the changes were ways of managing this. Adjustments by for example re-arranging the schedule of the day taking to account the present strength and energy available could help to make the best of the day. Others described that on the whole it was difficult to plan any activity. Adjustment could also mean going shopping and realising that energy was running out. This might be solved by: '*just carrying in the perishables and leaving the cold food in the car until sufficient energy for carrying in the rest returned*' [6].

3.1.2. To work in collaboration [Interviews 1–2, 4–12, 15–17]

The subcategory to work in collaboration describes that different kind of collaborative relationships increased. The collaborations could be expressed in the form of getting help to go to the hospital, getting to the shop. It could be expressed as: '*I have a friend living at the fourth floor // she is cleaning the apartment // and when it is food-time she invites me... we are eating all meals together. // Sometimes I am washing the dishes*' [5].

Other patients described how collaboration with other family members had increased to assist with transportation to the hospital and also to do some shopping. For the activities in the home, the help from close friends and relatives became very important to make everything work out. '*When I need medications from the pharmacy a friend of mine helps me with that*' [6].

3.1.3. To use creativity [Interviews 1, 3, 5, 8, 11–12, 15, 17]

This subcategory describes the perception of how creativity might be used in order to handle daily life and facilitate the patient's existence.

Patients described how demanding preparations could be to be able to go out. To get dressed and put shoes on and at the same time be able to keep the balance is challenging task. To put the foot on a stool in order to put the shoe on was one method expressed to reduce the effort required. Another concern expressed was thirst which was perceived as enormously annoying for many patients. To handle the restrictions of fluid, one patient gave an example of how smaller glasses were used instead of normal sized. '*It's like to take a glass. I've now taken out small glasses. // because I'd like to empty everything*' [5].

In terms of the need for daily cooking, one patient described how many meals were prepared at the same time and frozen meals were used on suitable occasions. Another patient described that he loved his vegetables that he had been growing for several years. The interest and urge was still there, however his strength was failing. To facilitate this, the patient used a chair to sit on in the vegetable garden to be able to water as well as to harvest the plants.

3.2. Dealing with thoughts about life's infinity

This main category describes the perceptions of how life was influenced by the illness and had been a factor to handle every day. The perception showed that the best was to follow the medical prescriptions. It also demonstrated participant's alteration in mental state and the impact of that on their life in general.

3.2.1. To live with thoughts—past, present and future [Interviews 1–4, 8–9, 11–12, 14, 16–17]

Here participants describe perceptions of the importance of reflection:

One man described how his life has been filled with different cultural activities. These can no longer be carried out, however the memories are kept in different kinds of albums. Instead he could now use his time to look in the albums over and over again to recollect the memories, which created a feeling of having lived a rich life.

The zest for life was affected by the thoughts regarding the heart illness. An elderly man described it as: '*Not the same zest for life. // Not so good with the heart. You have to do something else to forget about it*' [16].

One of the patients portrayed the thoughts regarding an eventual heart transplant. The thoughts concerned the supply of organs as well as how the body would respond to such a serious surgical procedure, that was, what the result would involve, including the possibility of death.

Another patient expressed a clear anxiety for the future. Despite diuretic treatment there was a weight increase. The patient, who was afraid of dying, was starting to consider that it might be useful to follow the advice and recommendations that were given at the re-visits to the clinic.

3.2.2. To live with the state of mind [Interviews 2, 5–6, 7, 9–11, 13, 15, 17]

This subcategory describes perceptions of how the state of mind was affected by, and affected the living conditions, from being able to stay positive to not being able to accept the condition: '*I mean, there are some that have it a lot worse, but I still can't accept that I got this. I just can't. No, … it just keeps going round and round and round. How could I get this…I'm so tired when anyone comes…Why would I get it like this*' [11].

One woman expressed how despite her serious CHF, she was filled with zest for life and energy. This was another example of a positive attitude to life. She highlighted that she did not want to die, especially as her life with her aging husband felt very significant and plentiful.

3.3. Taking responsibility

This main category describes perceptions of different ways of dealing with guidance. Own decisions or ignorance contributed the patients getting worse. Patients described the need of character to manage the daily life's hardships.

3.3.1. To follow treatment regime [Interviews 1–17]

The subcategory describes perceptions of how education was being used in daily life: '*Don't drink too much. Up to 1,5 litres. Not more. // I have taken a decilitre measurement that I have used to measure my glasses and cups. I know exactly how it's supposed to look in cups and glasses when there's a decilitre in them. // I've got a list W for water, C for coffee and S for soured milk*' [2].

Patients described how in their head they could count the liquid measurement, being well aware of that all liquid had to be included. However, one of the patients believed that one glass more or less was of no significance. When the quantity of water was consumed, another form of fluid was chosen such as Coca Cola.

3.3.2. To make one's own decisions [Interviews 2–3, 5, 7, 11–15, 17]

This subcategory illustrates perceptions of how character and inner strength became a driving force: '*The body adjusts itself according to your thoughts. I believe. I sometimes think, what difference does it make if I drink another glass of water? And I may go and fill the glass up. No, I think to myself, I'm so stupid. You're not supposed to do that. It's crazy. Oh well, and then I tip the drink out. You're not having it*' [17].

A patient, who explained how daily activities, such as driving, was rejected when it was burdensome to breath was another example. It might even be that the patient sat in the car, then made the decision not to drive.

Medical treatment was of great importance. Patients portrayed how their decisions to take extra diuretic were made once the liquid limit had been exceeded and their weight had increased.

3.3.3. To use one's knowledge [Interviews 15, 17]

The subcategory describes perceptions of how knowledge formed the basis for reactions: 'But here they weigh me with the clothes on. And count it. But I just weigh myself with a thin nightgown on. // Down at (the reception) where they weigh you, they take a kilo off for the clothes, but they don't do that here. They add the clothes to your weight. I think that's wrong' [17].

From another interview the patient described how he/she had been instructed to take notes and to bring the notebook to the clinic. The staff then did not even bother to look at the notes, consequently the instructions became insignificant.

3.4. Dealing with the surrounding world

This main category gives insight into participants' perceptions of interaction with the surrounding world. Of importance for the patients are trust and continuity.

3.4.1. To experience continuity [Interviews 3–6, 12, 14–15]

This subcategory describes perceptions of the value of continuity of care provided by the same/small group of professionals wherever possible. Clearly this built participants' confidence in health care providers and illustrated the importance of developing a rapport, as demonstrated here: '*The same doctor and the same nurse // to tell your litany for someone new every time, makes you not tell it at all*' [15].

Patients stressed the importance of the ability to be able to contact the nurse at the nurse led heart failure clinic. The ability to call when in doubt or when information or education given cannot be remembered, or the ability to quickly make an appointment, was stressed. Nurses specialized in taking care of heart failure patients follow-up the medical treatments and the patients could have continuity of care with the same nurse. This contact between patient and nurse resulted in that a trust was established.

3.4.2. To feel trust [Interviews 1–3, 5–6, 8, 11, 13–14, 16–17]

These participants' have highlighted perceptions of the importance to have trust in people as well as an inner trust, as illustrated here. '*The absolute worst is our anxiety and agony. // Oh, just a phone call with a nurse would have helped many times*' [14].

Faith in someone well known in the surrounding environment that the patient could confide in was another example of trust. This was illustrated through the patient whose neighbour received the key to enter his home when he became hospitalised following that the cat was able to stay at home and be fed in its own environment.

3.4.3. To be part of a social network [Interviews 1–4, 9, 12–14, 17]

This subcategory describes perceptions of how social networks played an important part when living with heart failure and interdependency amongst people was highly prized as reflected here: '*I have had relationships and stuff, but it was a while ago so maybe I should try it again because maybe — because you do need to have someone. It's not real good to be alone in a situation like mine*' [12].

Another patient expressed the importance of having someone to come with them to the doctor's appointment to listen to and share the information received. Sometimes it was difficult to comprehend everything that was being said and hence it was an assurance that someone else had heard the same thing and was able to then ask. To have someone nearby to share and reflect on the experience provided a feeling of security.

Moreover, several patients expressed the importance of the contact with children and grand-children. It was believed to be important to meet and socialise with family as well as to obtain support.

3.4.4. To deal with the local environment [Interviews 1–8, 10–16]

This subcategory describes the perceptions of the importance of the residence in dealing with the daily life.

The patients provided different portrayals on aspects that facilitated living in their home despite physical changes. For instance, to have the bedroom close by to the toilet was of importance since the symptoms of the disease might result in rapid access to toilets. Another example was how the patient herself might revise walking up the stairs in cases where there was no elevator. A chair could be placed on the landing between the levels to provide rest before the patient's own apartment had been reached. Even though the complex situation might provide an elevator there might still be additional stairs to reach the elevator itself. This in itself might be exhausting when energy was lacking due to the CHF. '*It's the ground floor. The only time I have to walk the stairs is…walk up stairs, 10 steps from the apartment to the refuse*' [16].

Moreover, it was perceived to be of great importance that the home was situated close to a bus stop. The energy could then be saved to the actual errands.

3.5. Keeping up with values of life

This main category describes participants' perceptions of the significance of maintaining the same quality of life as experienced before the disease onset. They express the importance of remaining in the same network, to stay among friends, and to feel sense of safety in their homes.

3.5.1. To retain spare time activities [Interviews 1, 7, 10, 13]

This subcategory describes the perceptions of how leisure activities could be adapted through reducing the level of activity: '*I've been bowling now for many years. So we go down to the bowling-alley and there you meet…yes one has for thirty years and then it's the same people who return. // And then every one you played with when you were young come. Always come. // Now I just chat when I'm there. I have to content myself with that. I don't take any risks*' [13].

A patient, who had been extremely interested in soccer during his whole life, provided another example. He no longer had energy to play himself, however he had a son who was an active soccer player. As a result, he was able to maintain his interest but this time from the sidelines.

Patients described how they maintained their interest in swimming. It was believed to be an affirmation of their health to be able to swim at their own speed when the energy level would let them.

3.5.2. To retain lifestyle [Interviews 2–4, 6, 10, 12–14, 16–17]

This subcategory describes the perceptions of the importance of retaining their previous lifestyle. A patient described how he all his life had been interested in different sports. The comments below illustrate the importance of lifestyle continuity: '*I go to Aqua-kul (swimming pool) five times a week and down in the basement is Nautilus (fitness center). That's where I go. But of course, I don't do much when I'm there, but that's where I go. I'm taking it really easy. // I don't have any energy (to swim). I just lie and relax at Aqua-kul. They've got pools outside too so it's perfect. As soon as it gets warm I'll be spending my time there*' [12].

4. Discussion

The results showed that patients with CHF demonstrated strong desires to live as normal life as possible, despite fatigue, diminishing strength and fear of the disease.

In some cases the patients were independent in their decisions of how to live their life, in other cases people in the surrounding environment were involved and included. Household duties would be allocated according to the partners' circumstances, but no one stated that this was a burden for the people around. Mårtensson's study [11] revealed that women perceived themselves as burdensome with this illness, more so than men. Domestic duties which had been routinely completed now took exhausting effort and with little strength to accomplish them assistance was not easily sought. The way one's life situation is being dealt with seems to be dependent on both attitudes to life as well as personal characteristics. These thoughts are well in accordance with the results provide by Boyd et al. [8]. When one's strength is ceasing home care could be considered as a means of strengthening. However, Ekman [5] shows that patients do not accept help easily as it displaces independence. Nurses should give patients opportunities to share their ideas with others. This would perhaps have a positive effect on other patients with heart failure and their situations may be improved.

Memories seemed to be of great importance in daily life. The opportunity to reflect on enjoyable experiences appears to ease the current burden of life. The thoughts of death exist. These affect the zest for life and become in themselves energy draining. It seems that when death becomes a threat there is a strong consciousness that the prescribed recommendations should be adhered to. It is therefore important for the nurse to pay attention to the signals given by the patient and to be able to give support to patients and their relatives. However, other studies indicate that the loss of inner peace and tranquillity casts gloom over daily life [16,23].

The study results indicated that participants' attitudes towards prescribed care varied. A good example of this includes fluid restriction. Monitoring liquid intake was manageable if fluid intake was written down otherwise there was a danger that it would be overlooked, but most informants in this study were mature in years. Maturity brings with it memory lapses, indeed, thought processes take longer [24] but undoubtedly making a note of fluid intake assisted. Accuracy in recording and 'strict' adherence to advice was evident in this study which helped control participants' fluid intake, however, their heart failure continued to deteriorate despite their best efforts, which must impact on patients' motivation to continue.

Another area where participants could take responsibility was weight control. Evidence of accurate weight monitoring is apparent in participants' 'heart notebooks'. Unfortunately it appears that these notes were not always followed up during patient next visits, which could negatively impact on patients' motivation.

How informants perceived their state of health was also important. If patients' were unaware of the severity of their illness this would clearly create difficulties with compliance to suggested medical treatments and lifestyle changes, a point which Ekman confirms [5]. There is a possibility that knowledge about potential deterioration in health is crucial in order to stimulate patient compliance at the outset of intervention. However, professionals, must assure patients' comprehension of what is being said through use of a commonly understood language which often excludes use of specialist terminology [25]. Carnevali [26] reinforces this need by stating that the ability to manage daily living is highly dependent upon how knowledge is applied. It therefore becomes imperative that professionals tailor patient's education to maximise their knowledge base. In turn, this creates opportunities for patient empowerment and with it administration of self-care. This will result in minimal deterioration, re-admissions and a reduction in associated costs [13]. It is worthy of note that there is a heavy reliance on patients individual abilities to internalise this information and on occasions patients may experience immense difficulties comprehending or absorbing it [5,15]. Hospitalisation is often stressful for patients, which can inhibit an individual's ability to learn and comprehend health care information. Therefore, it would seem logical, wherever possible, to include relatives during patient educational sessions to maximise the knowledge base amongst potential care providers as well. Even though Strömberg [15] has previously conveyed these views, it is not common practice today.

Continuity of care and availability of nurses were important needs amongst the participants in this study. A sense of comfort was associated with the possibility of meeting the same nurse repeatedly, even though patients knew that information about their care was documented. The Nurse Led Clinic was also of great importance to them. Our thoughts are that the patients sound knowledge, with regard to symptoms of the illness and treatment, brought with it cognisance about when to make contact with professionals. This may have resulted from the education informants had received which concurs with Strömberg's study [15].

Comfort was also highlighted through trust in life-partners, children, good friends and neighbours. This is in accordance with the result found by Riegel and Carlson [27]. Partners or children, who escorted the patient to the clinic, always evoked a sense of comfort for patients. The opportunity to include relatives in consultations also improved participants' abilities to comprehend information. It would seem logical therefore, to reserve time for the next of kin to ask questions, express queries and receive follow-up education. Professional follow-up telephone contacts were also noted as an important source of support and comfort to participants as reflected in The COACH study [a multicenter randomised Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure] initiated by Jaarsma et al. [28]. This study focused on the importance of telephone contacts, patient education and access to specialist nurses. In other studies the importance of a specialty nurse visiting the patient in his or her home to monitor how prescribed recommendations are adhered to as well as give individual advice, is highlighted [8,29].

The results show that the informants kept up interest and lifestyle as important, even though they had been modified. The activities included areas such as exercising and physical activities, sports, shopping and cultural activities. In the studies conducted by Mårtensson et al. [10,11], the patients expressed limitations in carrying out activities. In our study, limitations were also reflected, but also the results demonstrated how interests were successfully maintained and how new conditions were created. These results correspond with the results of Riegel and Carlsson [27] and Zambroski [12]. Both studies are conducted in American cultures. Both interests and lifestyle contributed to a high extent to the maintenance of life-quality and created structure in daily life. This was perceived as an aid in maintaining the balance in daily life. The importance of exercise and being active is highlighted by Strömberg [15] and Mårtensson [16].

Under most circumstances the interviewed patients prefer to live at home so assessments should be made to determine the appropriateness of the living space, for example, easy access to toilet facilities. The external environment also requires investigation including access to elevators for those living in upper story flats and the position of local amenities and public services relative to their home. In Swedish society, access to a car is perceived as an important means of maintaining independence but taxi services for the disabled and special public transport can offer viable alternatives.

5. Limitations

There are some limitations in this study. It was just used a few variations due to patients available. However, the variations in the sample characteristics that were presented ought to secure varied perceptions. The patients' statements may have lost nuances when they are condensed during the analysis process. Study limitations may have included the use of a clinical environment to conduct interviews; however, the interpretation was that the location had not caused any essential problems during the interview.

6. Conclusions and implications

CHF impacts on peoples' internal resources but regardless of this, participants clearly found ways to compensate by reducing the demands put on themselves, by motivating themselves and by altering their environment in order to cope. Some showed great self-control over associated fears and anxieties; others overcame the psychological impact of their illness with support from family, friends' and professionals, whilst others did not accept the new situation. The illness symptoms clearly affected daily routines but participants showed remarkable resolve and showed that values in life could be maintained albeit with a few adjustments. Plans for the future varied but no one expressed a desire to give up.

Understanding patients' perceptions of balancing life with this illness has created an opportunity to suggest complimentary clinical support. This includes planning healthcare availability though a variety of channels including outreach clinics, telephone contact and rapid access appointments. This will assure patient continuity, decrease patients' vulnerability and enhance their valued independence. Specialist heart failure nurses should maximise their skill and education by developing nurse led heart failure clinics within primary care settings as an additional resource to services already available in hospitals. The nurses have to take the patient's perspective in understanding the single patient's specific needs and support that person to be independent as long as possible.

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