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Heart failure patients' descriptions of participation in structured home care

Lena M. Näsström RN,* Ewa A-C. Idvall RN PhD†‡ and Anna E. Strömberg RN PhD*§¶

*Doctoral student, Department of Medical and Health Sciences, Division of Nursing Science, Linköping University, Linköping, †Professor, Department of Care Science, Malmö University, ‡Professor, Department of Intensive Care and Perioperative Medicine, Skåne University Hospital, Malmö, §Professor, Department of Cardiology, County Council of Östergötland and ¶Professor, Department of Medical and Health Sciences, Division of Nursing Science, Linköping University, Linköping, Sweden

Correspondence
Lena M. Näsström, RN
Doctoral student
Division of Nursing Science
Department of Medical and Health Sciences
Linköping University
Linköping
SE-581 85
Sweden
E-mail: lena.nasstrom@liu.se

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Abstract

Background To strengthen the patient's position in health care, patient participation has been decreed in policy documents and legalizations. For patients suffering from heart failure, self-care is an important part of disease management and participation is crucial to succeed with this.

Objective To examine how heart failure patients receiving structured home care described participation in the care.

Design Qualitative study.

Setting and participants Thirteen men and six women, aged between 63 and 90 years, were interviewed. The informants received structured home care at four home care units in Sweden. The interviews were analysed using qualitative content analysis.

Results Five categories with associated subcategories describing participation in care were identified: communication between patients and health-care professionals (HCPs) including time and space for dialogue and exchange of care-related information, accessibility to care through awareness of the plan for home visits or feasibility to initiate home visits, active involvement in care by engaging in self-care and collaboration with HCPs, trustful relation with HCPs, with confidence in competence and individually adapted care, options for decision making, by making decisions or entrusting decisions.

Conclusions Patient participation could be strengthened through structured home care. Participation was facilitated when there was a balance between the patient's own preferences to influence care and the health-care professional's actions and values and the organization of care. Barriers to participation could depend on the health-care organization, lack of continuity and confidence in HCPs.

Introduction

The importance of patient participation is stated in health policy documents,[1] and several Western countries have taken initiatives during the last few decades to strengthen the patient's position within the health-care system.[2–4] Patient participation as expressed in legal texts is often associated with receiving information and taking part in decision making. However, the concept of patient participation itself includes more aspects, such as to comprehend, to be confident in one's ability and to have a sense of control.[5,6] Patient participation involves an existing relationship and an ambient level of strength or control. There is also a need for exchange of information and knowledge between the patient and health-care professionals (HCPs).[7,8] Participation must be offered throughout the care process, guided by the patient's own wishes.[8] Previous studies show that patient participation is a complex phenomenon and that there may be a discrepancy in how patients and HCPs view patient participation.[9–11] These circumstances must be taken into consideration when meeting different patients within the health-care system.

Previous research states that when patients with chronic diseases such as heart failure (HF) are more involved in their care, adherence to medical treatment and self-management increases, leading to better patient outcomes.[12–15] Heart failure is more common with increasing age and is also the leading cause of hospitalization among people over 65.[16] Patients with advanced HF suffer from a number of symptoms and limitations.[17–20] Their long-term prognosis is very poor, and HF is often associated with several comorbid conditions.[16] The health-care organization has and is continuously undergoing changes; the number of inpatient beds has been reduced, and an increased proportion of care is provided in patients' homes instead. In Sweden, the extent of home care is increasing, and patients with HF can be offered home care as an alternative form of care.[21] Previous studies have found that structured home care for patients with HF reduced the number of readmissions significantly[22–24] and increased survival,[24] thereby resulting in lower medical costs for home care compared to traditional health care.[25] However, more moderate effects have been seen after interventions with intensive support for HF management, where these interventions also included home visits.[26] Also, a recent meta-review identified deficiencies in descriptions of populations, interventions and comparisons in several intervention studies for HF management programmes, making it difficult to judge the efficacy of these interventions.[27] However, home care can lead to more holistic care of the HF patient and can improve patient's ability to manage his or her illness and become more involved in their own care.[28] Patient participation in care is important with respect to autonomy and holism, but also for improving both patient-reported and mortality/morbidity outcomes.[13] Already today HF care can be conducted in the patients' home, and this will increase even more in the future. Based on this, increased knowledge of how participation in home care is experienced by HF patients is therefore needed to meet the specific expectations and requirements now and in the future. The aim of this study was to examine how HF patients who receive structured home care described participation in the care.

Methods

Design

The study had a qualitative design and was based on interviews, which were analysed with an inductive approach using qualitative content analysis.[29] Ethical approval for the study was given by the Regional Ethical Review Board in Linköping (Dnr M210-09).

Setting and informants

The informants were recruited from a group of HF patients in Sweden who were receiving structured home care at four different home care units. The home care was organized according to *The Heart Failure at Home*

Model,[30] meaning that the patients received care that involved (i) a multidisciplinary team with a minimum of physicians and nurses where the team members were specialists in general care, (ii) HCPs educated in HF care, (iii) joint care plans and/or care paths, (iv) optimized treatment according to guidelines, (v) educational strategies for patients/families/caregivers, and (vi) increased accessibility to care. *The Heart Failure at Home Model* aims at facilitating the patient's journey within care and focuses on values such as safety, participation and having knowledge about illness and treatment. The patients could contact the home care team at all hours. Two units provided home care in a metropolitan area, and two others provided the care in a medium-sized city.

A quota sample of 19 patients was chosen in order to include sufficient variation to represent the group of HF patients receiving home care. All patients were diagnosed with HF in accordance with the definition of the European Society of Cardiology.[16] They were over 18 years of age and were able to speak and understand Swedish. The sampling was guided to reach variation regarding age, gender, severity of HF, and different home care needs. The informants were in NYHA-class III-IV, and the home care they received varied from twice a day to once a month. Ages ranged between 63 and 90 (mean age 77 years) and 6 women and 13 men participated (Table 1). In this study, the information and consent requirements were considered, and the participants'

Table 1 Demographic and clinical characteristics of the informants

Id	Age	NYHA	Gender	Comorbidity	Cohabiting	Education level	Received home visits
P1	83	III	Male	a, b, c, d	No	1	1/week, more often if necessary, iv diuretic
P2	65	III	Male	a, b, c	Yes	1	Every third week, more often if necessary
P3	65	III	Male		Yes	3	1/week, more often if necessary
P4	74	III	Female	d	No	3	Sparse visits, planned for follow-up by primary care
P5	87	III	Female	d	No	1	1/week, more often if necessary
P6	64	III	Male	a	Yes	1	1/week, more often if necessary
P7	70	III	Male	a	Yes	3	1/week, more often if necessary
P8	73	III	Male	a	No	1	Every fourth week, more often if necessary
P9	82	III	Male	a, b	Yes	1	Alerts home care if necessary, twice a day with iv diuretic
P10	84	III	Female	b, c	Yes	1	A period with frequent visits and telephone contact with nurses
P11	80	III	Male	a, d	No	3	Sparse visits, planned for follow-up by primary care
P12	63	III	Female	b	No	2	Every fourth or eight week, more often if necessary
P13	77	IV	Male		Yes	3	Twice a day, more often if necessary
P14	86	III	Male	d	Yes	1	1/week, stable, will receive more sparse visits, more often if necessary
P15	88	III	Female	b, c	No	1	Every day, stable, will receive more sparse visits, more often if necessary
P16	90	III	Male	d	No	2	Every day, stable, will receive more sparse visits, more often if necessary
P17	68	III	Male	b	No	3	1/week, more often if necessary
P18	85	III	Female	c	No	1	1/week or every second week, more often if necessary
P19	81	III	Male	a, b	No	3	Once or twice/week, more often if necessary

Comorbidity: a, COPD; b, diabetes; c, moderate-to-severe renal insufficiency; d, cancer.
Education level: 1, Elementary, primary and secondary school; 2, high/trade school 2–4 years; 3, higher education/university.

consent was given through written informed consent.

Data collection and analysis

All interviews were performed by the first author (LN) in the informants' homes. Initially, an introduction question was asked: 'What does it mean for you to receive home care due to your HF?' Subsequently, questions were asked about participation and various aspects of this. Follow-up questions were used in which the informants were asked to develop their descriptions. The interviews lasted between 16 and 64 min. On four occasions, the interview was terminated early because the informant was tired and affected by poor health. Interviews were digitally recorded (Olympus DS 2300, Digital voice recorder; Olympus Imaging America Inc, Center Valley, PA, USA) and transcribed verbatim.

Analysis of the interviews was conducted using qualitative content analysis in which the development of categories was done inductively. Both manifest, the surface structure and latent levels, the underlying meaning of the text, were analysed.[29] Initially all three authors read two of the transcribed interviews separately and marked parts of the text that described participation. Subsequently, the authors came together and discussed their impressions of the text to establish a mutual basis for the analysis. Two of the authors worked in parallel on the analysis of six interviews (LN & EI), and the first author (LN) analysed the remaining 13 interviews. The analysis was performed in several steps inspired by the structure described by Graneheim and Lundman.[31] During the analysis, the interviews were read repeatedly to get an overall understanding of the whole, and there was also a constant movement between the parts of the analysis to the text of the whole interviews. Meaning units were identified, and these were condensed and labelled with codes. The codes were sorted into a preliminary structure of categories and subcategories. The structure of the categories was discussed, and adjustments to the categories were made. Finally, the classification was examined by all three authors (LN, EI, AS), and a final revision was carried out.

Rigour

To establish qualitative rigour, openness, methodological congruence and awareness of the researchers' self-understanding were considered.[32] Systematic data collection and analysis were used consistently throughout this study. To establish credibility, a quota sample of informants was used to ensure variation. Other aspects of credibility concern the analysis and findings. During the analysis, two of the authors worked in parallel, and in the final critical review of the content of the categorization, a third author scrutinized the findings. The basic structure of five categories existed after sorting the codes from nine of the 19 interviews, and the structure was thereafter stable. Detailed descriptions of the categories were made, and these were strengthened with quotations from the informants. These steps also strengthened credibility. A detailed description of the procedure for data analysis and a critical examination of the structure of the categories by the third author were further steps to ensure dependability. The confirmability of the study was strengthened by the fact that some of our findings were confirmed by previous studies. The preliminary findings have also been discussed and audited in seminars with clinicians working in HF home care and by researchers in the field. Further, testing of alternative explanations and revision of negative cases were carried out during the whole process of analysing the data. All three authors had pre-understanding as nurses; two of the authors were well experienced in qualitative analysis, and one of the authors was a specialist nurse in cardiac care.

Results

From the analysis of the 19 interviews, five categories describing patient participation in structured home care emerged: (i) communication between patients and HCPs, (ii) accessibility to care, (iii) active involvement in care, (iv) trustful relation with HCPs, and (v) options for decision making. Each category also had two associated subcategories (Table 2).

Communication between patients and health-care professionals

This category described time and space for dialogue and for receiving care-related information. Home visits provided increased time and space that improved communication between the parties. Through care-related information, the patients received advice and answers to questions that facilitated self-management. When information was given continuously and communicated openly, the patients perceived participation.

Time and space for dialogue during home visits

The dialogue itself was perceived as important for participation, as it was an exchange between the parties. The conversations could take place undisturbed, sometimes while other tasks were being performed. Home visits were perceived as involving less time pressure, compared to other forms of health-care contact, and this made it easier for the patients to raise concerns.

> No, you can talk with them. It is easier than if you have to call the doctor and talk, then you always have to hurry, it is not really the same// but they are never in a hurry in that way, they know, they are never stressed really but they can sit there and have a minute of peace and quiet. Yes if there is something else I want to ask about (P5).

During the talks, there was the opportunity to raise psychological issues, and in such cases, the dialogue provided relief and support. During home visits, the patients described how they received confirmation of their own reasoning related to health. The dialogue could support the patient in the decision to seek other health care if necessary. This provided an opportunity to manage the situation from a more holistic perspective, rather than the fragmented approach that was experienced with several other forms of health-care contact. However, if the home visit was short and task related, this could restrict the dialogue, thereby adversely affecting the possibility of participation.

Table 2 Categories and subcategories describing HF patients' participation in structured home care

Categories	Subcategories
Communication between patients and health-care professionals	Time and space for dialogue during home visits Exchange of care-related information during home visits
Accessibility to care	Awareness of the plan for home visits Feasible to initiate visits
Active involvement in care	Performing self-care Collaborative care with health-care professionals
Trustful relation with health-care professionals	Confidence in the competence of health-care professionals Individually adapted care
Options for decision making	Making decisions Entrusting decisions to the home care service

Exchange of care-related information during home visits

Participation was perceived through communication, in which practical advice and answers to questions were given in relation to the patient's situation. Advice was given on self-care and on how to manage in other care situations, and specific questions were answered. Patients were encouraged to be active and contact the HCPs in case of deterioration. The patients described themselves as asking questions and often receiving direct answers, but some patients expressed a further need to ask questions.

Continuous information about the care was important — what was done and why – including straightforward and clear information on health status, test results, results of treatment and new treatment alternatives.

> Yes, first give information to the patient, that is the alpha and omega, that is my opinion, so you know what you have and what you are dealing with (P7).

Information given by HCPs should not be favourably arranged, and patients believed themselves to be managing the true situation. The patients wanted information, as knowledge helped them to understand HF and the rationale for the treatment. Lack of information about how the care was structured and organized impaired the patient's ability to participate.

There was transparency in the care, in which follow-up of activities and documentation were visible to the patient. The patient listened when the nurses contacted the physicians on the phone, if something was unclear or needed to be discussed. Physicians sometimes called for more information about the patient's condition. Patients said that they understood how and why this monitoring was done.

Accessibility to care

This category described good access to care when the visits were planned in advance or could be initiated by the patient if necessary. Being able to influence whether and when the visit should take place led to participation and safety.

Awareness of the plan for home visits

Patients were well aware of the time for planned home visits. They also expressed knowledge about the content and aim of these visits. Patients and HCPs agreed on an appointment in advance. The scheduled time for planned home visits could be influenced by the patient. Having knowledge of the planned visit and the opportunity to influence meant that patients experienced participation. Planned visits gave the security that patients knew they would receive help if symptoms emerged or worsened since the previous home visit.

> It is when you are to have a checkup visit, that is when they come here, the visiting nurses, it is once a week just now when they check my weight and if I am gaining too much fluid, it is then that I get injections, right then. So I never have to wait for until I get really bad. They help me and they keep an eye on me (P2).

Feasible to initiate visits

Patients described a perceived control in that they could contact the home care service if their state of health deteriorated. Home care was available at all hours, which was a security and helped them relax. Based on the severity of symptoms, for example gaining weight or oedema, an assessment was made of when a visit was needed and whether the visit should be made by a nurse or a physician. The patient described himself as involved and able to influence his treatment course through direct contact with home care. The ability to initiate contact was described as increasing participation and as differing from other care experiences.

> Yes, if I am beginning to feel really bad, even more than the usual, and then as I said, then I get in touch with them, the staff that is, and then they get in touch with her (the visiting nurse), and then she (the nurse) calls me // I think that is good, for quite often you have your doubts about doing this if you know you contact them and all they say is yes, you can come in, yes // That is the way it used to be //and that really did not help, and I would say I really felt so bad that I just couldn't(make it). (P18).

Active involvement in care

This category described activity either based on the individual's own actions through self-care or collaboration with HCPs, prior to, during and between home visits.

Performing self-care

The patients were involved by using knowledge and experiences about HF and exercised self-care. Patients reasoned about their symptoms, treatment, future prognosis and described themselves as trying to interpret and influence their symptoms. Sometimes patients made their own adjustments of drug dosages due to symptoms. In this regard, their experience of previous symptoms and treatment was important.

> I can feel when it begins to take hold, then I take those extra things (diuretics) and then I know that it will let up…, I have been living with this so long that I know my body (P6).

Some patients obtained knowledge on their own by reading about treatment and side-effects. Being active was experienced as a means to achieve quality of life.

Collaborative care with health-care professionals

Patients reported collaboration with HCPs; this was a mutual activity to improve the patient's health. The patient prepared for a home visit in order to be able to describe and discuss symptoms with the HCP. Collaboration took place with regard to practical care, drug adjustments, discussion of the appropriate target weight or need for visits and the patient could make suggestions of his or her own. Participation through collaboration was described as a positive outcome that helped the patients to manage their situation.

> We discuss medicines and things like that many times, back and forth; which one is good, which one isn't good and which one works quickly (P12)

Patients acted as a connecting link between their various health-care providers regarding changes in prescriptions but could also receive help through home care to contact other health-care providers for specific needs. Participation through collaboration was experienced when one's opinions were taken into consideration, even when the patient claimed not to be willing or able to make decisions.

Trustful relation with health-care professionals

This category described the importance of trusting the expertise of the home care team, including having confidence in their competence and the care given, with continuity in care based on individual needs. To experience trust was an important foundation for participation.

Confidence in the competence of health-care professionals

Confidence in the HCPs' competence was important for participation. Patients described a lack of sufficient knowledge to be able to manage all aspects of HF. They trusted the care given and were confident that deterioration would be recognized and treated.

> Yes, I mean that I have always relied on the doctors and all that. That is really what I have done, and I, I do not know in what context, I would question them, I do not have any knowledge about some things (P11).

Previous experience and knowledge were used to consider whether the care was relevant. Careful documentation of symptoms was perceived as important and inspired confidence.

On the other hand, lack of trust or confidence in the competence of the HCPs had negative effects on participation, as a defective exchange of information between the parties occurred. Questions were not asked and symptoms of deterioration were not described correctly, when the patient experienced not being listened to or not being involved in decisions about the treatment.

Individually adapted care

Patients said they received care based on individual needs, with a genuine concern for the patient. To experience true interest in the patient was essential for participation and also gave security. Home care was perceived as flexible and open to influence compared to other forms of health-care contact. Established relationships with continuity, in which the HCPs understood the patient's knowledge and wishes, facilitated participation. When continuity was missing, the patient had to start over again with a new HCP.

> There is a kind of gap there that I noticed when I talked about continuity, because just this thing with participation, it just becomes a lot of empty talk when you keep repeating the same thing all the time and then know that the person who is coming, who has never met me before, who may come just by chance, they do not know what I know and they do not know about my medication. But someone who has known me for a relatively long time knows what I know and that I know what I need to know (P8).

Participation could also be negatively affected if the care was not based on individual needs, for example, if the patient's knowledge or ability to assess his or her symptoms was underestimated.

Options for decision making

This category described options for making decisions. The majority of informants expressed preferences for participation, but also said that there were barriers to choice in certain contexts. Participation could be expressed explicitly as the person′s will to make decisions. Being offered an option was a prerequisite for decisions. Sometimes the patient chose to entrust the decision, either passively or actively, to the HCPs in home care and was pleased to do so.

Making decisions

Patients expressed their will by being involved in discussions and influencing decisions in order to experience control over their situation. Willingness to participate and influence was related to the patient's knowledge. Patients expressed their own responsibility to speak up if something was not in line with their wishes. Patients said that it was their decision to accept home care. Some patients outlined participation as being related to personality and personal experience of independence.

> That they talked to me // That they ask me what I want and do not want. Not just saying things (like) "this is the way it will be", that I have not been part of and decided, that maybe I do not want (P4).

To be offered options such as choosing physicians or declining treatment enabled participation, but sometimes no options were given. Patients described how the health-care organization affected possibilities to choose. In some home care units, access to care was restricted to needs related to the HF diagnosis alone. This limitation negatively affected the patient's ability to influence the content of care. Sometimes no options regarding specific medical treatment or the discharge plan were offered, which limited the patient′s influence, and no participation in the decision was perceived.

Entrusting decisions to the home care service

Patients also described themselves handing over the responsibility for decisions to the HCPs, either by a passive acceptance or a more active approach. The HCPs were viewed as having superior knowledge. Patients wanted information and participated in discussions, but not in making decisions. To entrust decisions was ranging from waiting for tomorrow's planned visit and receiving help, to a more active seeking of contact during deterioration and handing over the responsibility. Patients' described feeling relief about not having to decide whether or not to seek another level of care. Now they could entrust the home care service to decide and no longer needed to fight to receive treatment and care, which they had experienced before.

> I have felt good with this thing about letting others… they examine me and they contact a doctor and they make their evaluation on the basis of the information they have received from me. Of course, I tell them how I feel and about those things but I do not get in the way and have not done that during all of the time that …// … no for me they can decide (P1).

Discussion

Heart failure patients' participation in structured home care involved five main aspects. Participation was made possible as communication between the parties was given space during home visits. The possibility of influencing accessibility to care was important for participation. The patients were active in performing self-care and collaborating with HCPs. To have trust in HCPs facilitated participation. The option to make decisions or entrust decisions to HCPs was described as participation and varied depending on the context of care. Heart failure patients' experiences of receiving care in their homes were predominately in correspondence with their preferences. Home visits facilitated participation, and the findings revealed that patients' experiences of participation in home care sometimes differed from their former experiences of care.

At an overall level, patient participation in this study was in line with some of the objectives of the Heart Failure at Home Model.[30] Care was planned in consultation with the patient, as revealed in the patients' descriptions of participation in home care. Patients described how they conducted self-care but also collaborated in care with HCPs. Performance of self-care could be influenced by previous experiences, but could also be linked to receiving home care. The model emphasizes patient education with a focus on self-care where optimization of treatment also includes follow-up monitoring of self-care.

A more specific discussion related to the five categories follows.

Communication between patients and health-care professionals

Home visits facilitated communication that involved an undisturbed dialogue and knowledge exchange, which in turn enables participation. Findings from previous studies in other patient populations in hospital context[33,34] and specific studies, of HF patients at the outpatient clinic, show the importance of mutual communication to experience participation.[5,9] Time and space for dialogue involved the opportunity to receive confirmation of one's own thoughts and was also a help in managing the situation from a more holistic view. The HF patients gave examples from the time before admission to home care, where limited communication and the rapid pace of the care had limited their participation. This is probably especially critical for older patients who more often suffer from cognitive problems or hearing impairment,[35] which lead to a need for conversation in a peaceful and relaxed environment. Receiving care-related information is important for participation.[34,36] Heart failure patients in home care were often well informed about the care, which is in line with present legalization.[37] They described how follow-up was made visible to them, and the care became understandable through a better transfer of knowledge and transparency in the home care setting.

Accessibility to care

Participation was experienced by providing accessibility to care. The patients with HF were able to influence their situation and did not have to fight every time they required contact with the care services, which was often the case before they were enrolled in home care. This was expressed as a safety net for the patients and could be seen as a way for them to be in control of their situation. A similar finding was also seen in Bastiaens *et al.*[38] where easy access to care through home visits and telephone counselling was related to increased patient involvement.

Active involvement in care

Participation was also expressed as the patient being active, performing self-care and collaborating. For HF patients, it is important to engage in self-care to influence health status, symptoms and number and duration of hospitalizations[39]. The ability to engage in self-care is important for the outcomes of care and treatment.[13] Meaningful participation is achieved through information and support, which helps patients manage self-care activities and find their own solutions for achieving health objectives.[40] The HF patients' descriptions clearly showed that they participated in their care and performed self-care.

Heart failure patients in home care also said that collaboration with HCPs in different forms increased their involvement in their care. Tutton[41] describes partnership as a process that provides the basis for participation. Partnership helps patients to take control of their own activities. Heart failure patients' descriptions of collaboration gave the impression that this mutual activity with HCPs helped them to gain control of their situation.

Trustful relation with health-care professionals

Being a patient means that you have to rely on HCPs. Heart failure patients in home care described how they felt trust in HCPs, which facilitated for participation. The importance of an interaction with HCPs based on respect has been described in a previous study.[5] Also within other patient groups, the importance of a good relationship with HCPs built on trust facilitates the making of shared decisions regarding treatment and care.[42–44] When HF patients in home care are confident, they dare to ask questions and feel involved. However, a few examples were given showing that lack of trust in HCPs leads to patients holding back questions or not describing their symptoms. This may have negative consequences for participation, but there is also a risk that quality and safety are compromised.

Options for decision making

To be offered choices revealed a range of wishes for making choices among the HF patients in home care, which previous studies also revealed.[38,45–48] The HF patients described a desire to make their own choices, and they emphasized that the desire for choices was associated with their own knowledge, which is in line with other findings[6,49] Some HF patients had a complex situation with multiple needs, which led to uncertainty about how to deal with their situation, and this was described as a limitation for participation. Restrictions on making choices can also be traced to specific care meetings. Patients described that if you meet a variety of HCPs, this can have negative consequences for participation. Larsson *et al.*[50] also identified these structural barriers to participation, which lead to difficulties building a relationship. However, the HF patients in home care expressed a high degree of understanding of these organizational difficulties.

In recent studies examining willingness to participate in medical and care decisions, the patients said that they wanted a more passive role[34,45,51] and this view was also expressed among HF patients receiving home care. The patients expressed relief on being able to hand over responsibility to HCPs. In this regard, some waited passively for help while others actively handed over the decisions. These findings demonstrate the importance of an ongoing discussion with patients about their preferences for making decisions.

Methodological considerations

To establish credibility, quota sampling was used and the informants were included to ensure variation. Additional demographic factors could have been considered in the sampling such as marital status, education and former occupation, as previous studies have shown that these can affect preferences regarding participation.[52] However, there were variations in the informants' backgrounds regarding these variables also. Another aspect of credibility concerns the quality of the interviews, which varied in depth and length. Some informants found it easy to express themselves and provided rich and detailed narratives, while other narratives were shorter, but succinct. Four interviews were terminated early due to the informant's poor health. Nevertheless, these short interviews provided important experiences reflecting patient participation among those very severely affected by symptoms of HF. The findings in this study can be transferable to other HF patients who receive home care and possibly to other patients with similar symptoms as HF patients who are receiving home care in a similar context.

Conclusions

These findings reveal important experiences from the patient's perspective namely that patient participation could be strengthened through structured home care. Participation was facilitated when there was balance between the patient's preferences for influencing their care and the HCPs' actions, values and care culture. Heart failure patients' descriptions of participation in home care allowed them some control, for instance being able to influence when they received care, a help to manage their situation and when suitable, make decisions. However, the findings also revealed barriers to participation, which depended on the healthcare organization, or if there was a lack of continuity or confidence in HCPs.

To respect the individual and meet requirements from existing legalization, care should be designed to meet the patient's request for participation.

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Conflict of interest

None declared.

References

1 WHO. The health for all policy framework for the WHO European Region, Update 2005. Copenhagen: WHO, 2005. Available at: http://www.euro.who.int/__data/assets/pdf_file/0008/98387/E87861.pdf, accesed 10 May 2012.

2 Guadagnoli E, Ward P. Patient participation in decision-making. *Social Science & Medicine*, 1998; **47**: 329–339.

3 Socialdepartementet. Kommittédirektiv. Stärkt ställning för patienten genom en ny patientlagstiftning. Stockholm: Socialdepartementet, Direktiv, 2011: 25. Available at: http://www.regeringen.se/content/1/c6/16/46/08/1ffd2177.pdf, accessed 10 May 2012.

4 Tritter JQ. Public and patient participation in health care and health policy in the United Kingdom. *Health Expectations*, 2011; **14**: 220–223.

5 Eldh AC, Ehnfors M, Ekman I. The phenomena of participation and non-participation in health care-experiences of patients attending a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing*, 2004; **3**: 239–246.

6 Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. *Mayo Clinic Proceedings*, 2010; **85**: 53–62.

7 Cahill J. Patient participation: a concept analysis. *Journal of Advanced Nursing*, 1996; **24**: 561–571.

8 Sahlsten MJ, Larsson IE, Sjostrom B, Plos KA. An analysis of the concept of patient participation. *Nursing Forum*, 2008; **43**: 2–11.

9 Eldh AC, Ehnfors M, Ekman I. The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing*, 2006; **5**: 45–53.

10 Florin J, Ehrenberg A, Ehnfors M. Patient participation in clinical decision-making in nursing: a comparative study of nurses' and patients' perceptions. *Journal of Clinical Nursing*, 2006; **15**: 1498–1508.

11 Nordgren L, Asp M, Fagerberg I. An exploration of the phenomenon of formal care from the perspective of middle-aged heart failure patients. *European Journal of Cardiovascular Nursing*, 2007; **6**: 121–129.

12 Lainscak M, Blue L, Clark AL *et al*. Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Failure*, 2011; **13**: 115–126.

13 Lee CS, Moser DK, Lennie TA, Riegel B. Event-free survival in adults with heart failure who engage in self-care management. *Heart and Lung*, 2011; **40**: 12–20.

14 Stromberg A, Martensson J, Fridlund B, Levin LA, Karlsson JE, Dahlstrom U. Nurse-led heart failure clinics improve survival and self-care behaviour in patients with heart failure: results from a prospective, randomised trial. *European Heart Journal*, 2003; **24**: 1014–1023.

15 Wu JR, Corley DJ, Lennie TA, Moser DK. Effect of a medication-taking behavior feedback theory-based intervention on outcomes in patients with heart failure. *Journal of Cardiac Failure*, 2012; **18**: 1–9.

16 McMurray JJ, Adamopoulos S, Anker SD *et al*. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: the Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *European Heart Journal*, 2012; **33**: 1787–1847.

17 Brannstrom M, Ekman I, Norberg A, Boman K, Strandberg G. Living with severe chronic heart failure in palliative advanced home care. *European Journal of Cardiovascular Nursing*, 2006; **5**: 295–302.

18 Ekman I, Cleland JG, Swedberg K, Charlesworth A, Metra M, Poole-Wilson PA. Symptoms in

patients with heart failure are prognostic predictors: insights from COMET. *Journal of Cardiac Failure*, 2005; **11**: 288–292.

19 Patel H, Shafazand M, Schaufelberger M, Ekman I. Reasons for seeking acute care in chronic heart failure. *The European Journal of Heart Failure*, 2007; **9**: 702–708.

20 Yu DS, Lee DT, Kwong AN, Thompson DR, Woo J. Living with chronic heart failure: a review of qualitative studies of older people. *Journal of Advanced Nursing*, 2008; **61**: 474–483.

21 Socialstyrelsen. Hemsjukvård i förändring. En kartläggning av hemsjukvården i Sverige och förslag till indikationer. Stockholm: Socialstyrelsen. Available at: http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8800/2008-126-59_200812659.pdf, accessed 10 May 2012.

22 Blue L, Lang E, McMurray JJ *et al*. Randomised controlled trial of specialist nurse intervention in heart failure. *BMJ*, 2001; **323**: 715–718.

23 Morcillo C, Valderas JM, Aguado O *et al*. Evaluation of a home-based intervention in heart failure patients. Results of a randomized study. *Revista Espanola de Cardiologia*, 2005; **58**: 618–625.

24 Stewart S, Horowitz JD. Home-based intervention in congestive heart failure: long-term implications on readmission and survival. *Circulation*, 2002; **105**: 2861–2866.

25 Patel H, Shafazand M, Ekman I, Hojgard S, Swedberg K, Schaufelberger M. Home care as an option in worsening chronic heart failure – a pilot study to evaluate feasibility, quality adjusted life years and cost-effectiveness. *European Journal of Heart Failure*, 2008; **10**: 675–681.

26 Jaarsma T, van der Wal MH, Lesman-Leegte I *et al*. Effect of moderate or intensive disease management program on outcome in patients with heart failure: Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart Failure (COACH). *Archives of Internal Medicine*, 2008; **168**: 316–324.

27 Savard LA, Thompson DR, Clark AM. A meta-review of evidence on heart failure disease management programs: the challenges of describing and synthesizing evidence on complex interventions. *Trials*, 2011; **12**: 194.

28 Jaarsma T, Luttik ML. Home care in heart failure: towards an integrated care model. *European Journal of Heart Failure*, 2011; **13**: 823–824.

29 Berg BL. *Qualitative Research Methods for the Social Sciences*, 7th edn. Boston: Allyn & Bacon, 2009.

30 Jaarsma T, Strömberg A, Alonso A. A description of EU-criteria/components for optimal based management of heart failure patients. 2010. Available at: http://integratedhomecare.eu/uploads/Diverse%20uploads/D2_Homecare%20222954.pdf, accessed 10 June 2012.

31 Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 2004; **24**: 105–112.

32 Grove SK, Burns N, Gray JR. *The Practice of Nursing Research. Appraisal, Synthesis and Generation of Evidence*. 7th edn. St. Louis, Missouri: Elsevier, Saunders, 2012.

33 Frank C, Asp M, Dahlberg K. Patient participation in emergency care – a phenomenographic study based on patients' lived experience. *International Emergency Nursing*, 2009; **17**: 15–22.

34 Larsson IE, Sahlsten MJ, Sjostrom B, Lindencrona CS, Plos KA. Patient participation in nursing care from a patient perspective: a Grounded Theory study. *Scandinavian Journal of Caring Sciences*, 2007; **21**: 313–320.

35 Kiely KM, Gopinath B, Mitchell P, Luszcz M, Anstey KJ. Cognitive, health, and sociodemographic predictors of longitudinal decline in hearing acuity among older adults. *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 2012; **67**: 997–1003.

36 Sainio C, Eriksson E, Lauri S. Patient participation in decision making about care. *Cancer Nursing*, 2001; **24**: 172–179.

37 Socialdepartementet. Hälso- och sjukvårdslag 1982:763. Stockholm. Available at: http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Halso–och-sjukvardslag-1982_sfs-1982-763/, accessed 5 November 2012.

38 Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries. *Patient Education and Counseling*, 2007; **68**: 33–42.

39 Riegel B, Lee CS, Dickson VV. Self care in patients with chronic heart failure. *Nature Reviews. Cardiology*, 2011; **8**: 644–654.

40 Shearer NB, Cisar N, Greenberg EA. A telephone-delivered empowerment intervention with patients diagnosed with heart failure. *Heart and Lung*, 2007; **36**: 159–169.

41 Tutton EM. Patient participation on a ward for frail older people. *Journal of Advanced Nursing*, 2005; **50**: 143–152.

42 Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making? *Health Expectations*, 2004; **7**: 317–326.

43 Ommen O, Thuem S, Pfaff H, Janssen C. The relationship between social support, shared decision-making and patient's trust in doctors: a cross-

sectional survey of 2,197 inpatients using the Cologne Patient Questionnaire. *International Journal of Public Health*, 2011; **56**: 319–327.

44 Sainio C, Lauri S. Cancer patients' decision-making regarding treatment and nursing care. *Journal of Advanced Nursing*, 2003; **41**: 250–260.

45 Ekdahl AW, Andersson L, Friedrichsen M. "They do what they think is the best for me." Frail elderly patients' preferences for participation in their care during hospitalization. *Patient Education and Counseling*, 2010; **80**: 233–240.

46 Ekdahl AW, Andersson L, Wirehn AB, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey *BMC Geriatrics*, 2011; **11**: 46.

47 Foss C. Elders and patient participation revisited – a discourse analytic approach to older persons' reflections on patient participation. *Journal of Clinical Nursing*, 2011; **20**: 2014–2022.

48 Thompson AG. The meaning of patient involvement and participation in health care consultations: a taxonomy. *Social Science & Medicine*, 2007; **64**: 1297–1310.

49 Hoglund AT, Winblad U, Arnetz B, Arnetz JE. Patient participation during hospitalization for myocardial infarction: perceptions among patients and personnel. *Scandinavian Journal of Caring Sciences*, 2010; **24**: 482–489.

50 Larsson IE, Sahlsten MJ, Segesten K, Plos KA. Patients' perceptions of barriers for participation in nursing care. *Scandinavian Journal of Caring Sciences*, 2011; **25**: 575–582.

51 Burton D, Blundell N, Jones M, Fraser A, Elwyn G. Shared decision-making in cardiology: do patients want it and do doctors provide it? *Patient Education and Counseling*, 2010; **80**: 173–179.

52 Florin J, Ehrenberg A, Ehnfors M. Clinical decision-making: predictors of patient participation in nursing care. *Journal of Clinical Nursing*, 2008; **17**: 2935–2944.