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# **Participation in Care Encounters in Heart Failure Home-care**

## **Abstract**

The purpose of this qualitative study was to observe care encounters during home visits in HF home-care in order to identify and describe participation in care. Seventeen patients diagnosed with heart failure and ten registered nurses participated. Data from nineteen video-recorded home visits were analysed using qualitative content analysis. Two themes were identified (*i*) Participation in the care encounter is made possible by interaction, including exchanging care-related information, care-related reasoning, collaboration, and (*ii*) Participation in the care encounter is made possible by an enabling approach, including the patient expressing their own wishes, showing an active interest, while the nurse is committed and invites to having a dialogue. The heart failure home-care context showed good potential for patient participation. Room for discussions and collaboration facilitated for the patients to be active partners in their care, which in turn may have positive effects on outcomes.

## **Keywords**

heart failure; home-care; involvement; patient participation; qualitative research

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## **Introduction**

The importance of patient participation has received much attention during the last few decades (Larsson, Sahlsten, Segesten, & Plos, 2011a; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007; Tritter, 2009). Legal and policy documents based on human rights of self-determination and respect for integrity, emphasise that care should be designed and conducted in collaboration with the patient (Ministry of Health and Social Affairs, 1982, 2014; WHO, 2013). Active patient participation in self-care management is considered as essential in chronic illness (Riegel, Jaarsma, & Stromberg, 2012). Heart failure (HF) is a common chronic condition affecting about 23 million people worldwide (Bui, Horwich, & Fonarow, 2011). The condition leads to symptoms that limit activities in daily life (Lee et al., 2010; Moser et al., 2014), thereby often decreasing quality of life (Azevedo et al., 2008; Rector, 2005). Therefore, patients with HF need to continually reflect upon symptoms, lifestyle and treatment options (Riegel, Vaughan Dickson, Goldberg, & Deatrck, 2007). The condition often leads to deterioration requiring hospitalisation (McMurray et al., 2012), but self-care management can be taught in an attempt to limit hospitalizations (Lainscak et al., 2011). Interventions carried out in the patients' homes have shown very positive effects on outcomes (McAlister, Stewart, Ferrua, & McMurray, 2004). In the patients' home, healthcare professionals can observe particulars of the patient's life enabling him/her to tailor the intervention to the patient's needs. Partnership in care is also facilitated by a neutral relationship of power when the patient is on his/her home turf (Brannstrom, Brulin, Norberg, Boman, & Strandberg, 2005). However in Europe, as well as in the US and worldwide, access to home-care for patients with HF varies greatly (Clark & Driscoll, 2009; Jaarsma et al., 2006; Madigan, 2008).

Patient participation in care is a multifaceted concept that includes aspects such as relationship, shared information and knowledge, a surrounding of power and control, and

mutual engagement in activity (Cahill, 1996; Sahlsten, Larsson, Sjostrom, & Plos, 2008).

Both patient and staff behaviour and attitudes may influence participation. Participation is affected by the care environment and is reported to have positive effects on outcomes (Arnetz, Hoglund, Arnetz, & Winblad, 2008; Nasstrom, Jaarsma, Idvall, Arestedt, & Stromberg, 2014). From the patient's point of view these are: satisfying conditions for communication (Eldh, Ekman, & Ehnfors, 2010; Frank, Asp, & Dahlberg, 2009; Larsson, Sahlsten, Sjostrom, Lindencrona, & Plos, 2007), knowledge from receiving and understanding information (Eldh, Ehnfors, & Ekman, 2004; Eldh, Ekman, & Ehnfors, 2006; Eldh et al., 2010; Hoglund, Winblad, Arnetz, & Arnetz, 2010), as well as being treated with respect (Eldh, Ekman, et al., 2006). Furthermore, being confident, having a sense of control (Eldh et al., 2004), and responsibility were also of importance (Eldh, Ehnfors, & Ekman, 2006). Studies of patient participation in care including patients with HF are sparse (Eldh et al., 2004; Eldh, Ehnfors, et al., 2006; Nasstrom, Idvall, & Stromberg, 2015). Only one study includes patients' with HF receiving home-care. Patients described that home-care facilitated participation. Participation in care meant communication between patients and healthcare professionals, having access to care, active involvement in care, trusting relationships with healthcare professionals, and having opportunities for decision-making (Nasstrom et al., 2015). However, what actually happens during the care encounter in a HF home-care context has not been studied previously. The aim of this study was therefore to observe, care encounters during home visits in HF home-care in order to identify and describe participation in care.

## **Methods**

### **Design and Setting**

In order to identify and describe participation in care encounters, a qualitative design was applied. Data were collected by video-recorded observations during home visits to patients with HF, which enabled the collection of rich data material (Botroff, 1993). Qualitative content analysis was applied during analysis to reach an increased understanding of participation during care encounters (Berg, 2009).

The patients received home-care from one care provider in a metropolitan area and two care providers in a medium-sized Swedish city. The home-care was organised with registered nurses and physicians in the team, and the patients could contact the home-care team at all hours. The team members followed The Heart Failure at Home Model (Jaarsma, Larsen, & Stromberg, 2013), which is based on six cornerstones: a multidisciplinary team, healthcare professionals educated in HF care, joint care plans and/or care paths, optimised treatment according to guidelines, educational strategies for patients/families/caregivers, and increased access to care. The model focuses on values such as safety, participation, and having knowledge about the illness and treatment.

### **Participants**

A purposive sampling was used to ensure variation regarding the severity of HF, the need for care, age, and gender. Patients were asked for study participation by study nurses and received verbal and written information. Those patients interested in participating were contacted by the first author within a week and given additional information. In total, nineteen video-recorded observations were performed, including seventeen patients, where two of the men

were observed twice during the home visits. Included patients received home visits according to The Heart Failure at Home Model. The frequency, content and numbers of interventions during home visits depended on the patients' present health status, medical and care needs. The visits included symptom monitoring, blood samples, adjusting the dosages or new prescriptions of drugs, intravenous diuretics due to acute deterioration of the heart failure symptoms, evaluation of given care, heart failure education or preparation and information for up-coming treatment.

Patient characteristics are presented in Table 1. During the home visits, ten registered nurses participated (Table 2). The nurses were asked to participate by the study nurses and thereafter given further information by the first author.

## TABLES 1 AND 2

### **Data Collection**

Data were collected through observations to reach a deeper understanding of participation during home-care encounters. The first author video-recorded all observations during the home visits, being present in the setting, but only as an onlooker (Patton, 2002). The location in the home where the encounter took place was decided by the patient. The recording started when the patient and the nurse stated that they were ready, after they had introduced themselves and consent had been confirmed. The camera was switched off when they stated that the home visit was ended. In total, 6 hours and 57 minutes were documented (mean 22 min), ranging from 5 minutes to 35 minutes.

## **Analysis**

Data were analysed inductively using qualitative content analysis. Manifest content representing the surface structure and latent content representing the underlying meaning were analysed (Berg, 2009). In order to perform the analysis as consistently as possible, verbal communication from the video-recorded observations were transcribed verbatim, and complemented with non-verbal communication (Botroff, 1993). The extensive set of data required a systematic approach during the analysis. Therefore, we performed the analysis in several stages. During the analysis, three of the authors worked in parallel. The video recordings and transcripts were studied repeatedly to obtain an overall impression of the situation. Situations that displayed patient participation were identified and summarised with an open coding. Initially, these steps were carried out in five observations. Subsequently, the video-recordings were examined repeatedly to further capture the non-verbal communication. Non-verbal communication was identified both as being integrated among the existing codes, but also as parts that had not been identified and coded earlier. The video-recorded observations provided extensive material, and this has entailed going back and forth between the parts and the whole, emphasising verbal expression and thereafter focusing on the non-verbal communication. The process was repeated several times before the final structure of the findings was established. These different steps were necessary to be able to grasp the whole. We repeatedly discussed the findings in all observations and made adjustments where categories were developed and merged during the analysis. The findings were further developed to include two themes, where each theme represented a thread of the underlying meaning from the categories within the theme (Graneheim & Lundman, 2004). When the structure of the findings was stable, the first author went through all the video-recordings again to verify that the themes and categories were consistent with the data. A description of the themes, their relation to one another, and detailed descriptions of the categories were

made, instead of using quotations when presenting the findings. Finally, the classification was scrutinised by a fourth author who agreed with the overall findings and commented on parts that could be clarified. This strengthens credibility, dependability and confirmability. N-Vivo 10 (QSR International Pty Ltd, Doncaster, Australia) a management tool for qualitative analysis was used.

### **Ethical Considerations**

Ethical approval was given by the Regional Ethical Review Board. Respect for the participants' autonomy and integrity is of importance in all research, and this becomes even more important when video-recordings of care are performed (Hallgren, Kihlgren, & Olsson, 2005; Hansebo & Kihlgren, 2002). Patients gave written informed consent, and nurses gave verbal informed consent to participate. Both patients and nurses were told that they could terminate their participation at any time, and patients were reassured that this would in no way affect their future care. Patients are in a dependent situation and participating in this study, may lead to that patients experiencing that their privacy was intruded upon. Being sensitive to this risk was important before, during and after data collection. This included the preparedness to set aside time for arranging support and management contacts. None of the participants expressed that they had been inconvenienced.

### **Findings**

During the analysis two themes were identified: Participation in the care encounter is made possible by interaction and Participation in the care encounter is made possible by an enabling approach, which consisted of three and four categories respectively (Table 3). These two

themes are related to each other, but separated by content. Together, they constitute participation in the home-care encounter. Both themes were represented in all observed care encounters, but the extent and depth of each category varied. Some of the care encounters were characterised by a multifaceted approach to participation based on all categories, while participation in other encounters was characterised on the basis of content from fewer categories. The visits that included fewer aspects were characterised either by the patient having an impaired capacity, or the visits being short or focused on routine follow-up. Visits focused more on the exchange of care-related information or collaboration regarding check-ups included less room for the aspects included in an enabling approach.

TABLE 3

### **Participation in the Care Encounter is Made Possible by Interaction**

This theme was characterized by an interaction between the patient and the nurse throughout the care encounter, enabling participation. The two parties interacted with mutual influence on each other. Interaction was expressed through verbal communication between the parties, but could also be enhanced by, or expressed through, non-verbal communication. The interaction within the care encounter can be understood from the three categories: Exchange of care-related information, Care-related reasoning, and Collaboration. The expression of and the degree of interaction, differed between the three categories and reached a higher level in care-related reasoning and collaboration. The intensity of the interaction also differs within the categories.

**Exchange of care-related information.** Participation by interaction became visible when the patient and nurse shared information with each other. The information exchange was initiated by one of the parties and led to some kind of response from the other part, where participation was made explicit. The nurse asked questions about the patient's status and symptoms, or the patient communicated this information to the nurse. Information was given by the nurse about the planned actions for the home visit and treatment, or the patient provided information for instance plans for diuretic therapy. Patients described performed self-care or the nurse provided information about self-care management. Information-sharing also occurred when the nurse asked for previous measurements, upcoming check-ups, or gave results. The nurse gave feedback to the patient based on what had been observed, documented in charts, or information provided by the patient. The interaction often resulted in more activity among the nurses, but the patients also responded to the nurses, which emphasised participation in the care encounter.

**Care-related reasoning.** The analysis demonstrated that participation was made explicit by interaction through care-related reasoning between the patient and nurse. The reasoning was developed by interplay between the patient and the nurse, for instance while other tasks were being performed. The reasoning was initiated by one person, which generated a clear response in the other. The parties reasoned about planned measures and check-ups, e.g., estimation of breathing difficulty or results of inspections, such as assessment of oedema. Current medication therapy or expected effects of new medication were also targeted. The care encounter often focused on reasoning about the patient's symptoms and experiences of these symptoms. This could mean that the parties reasoned about e.g., the impact on activity capacity, or how the patient managed fluid restriction.

The intensity of the interaction varied between the different persons involved. The interaction could reach a higher level, which was made visible when the parties reasoned about a specific topic, e.g., the appropriate dosage of diuretics in relation to oedema control. The dialogue was also characterised by the parties filling in for each other. Room was also given for “time to think”. The interaction was reinforced through body language, for instance by the parties looking at each other, leaning forwards, or making gestures.

**Collaboration.** Participation occurred by collaboration on tasks performed, where both parties were involved and active. Collaboration was expressed integrated through both verbal and non-verbal communication. Collaboration took place in the preparation of, during, and after the implementation of measures. For instance, the nurse and patient collaborated when taking blood samples and bandaging occurred. Patients and nurses also collaborated in the implementation of various check-ups, e.g., weight and inspection of leg oedema.

Collaboration could occur without prior verbal communication. This happened when oxygen saturation or blood pressure were checked, where the patient acted spontaneously in advance of the nurse's action. Participation was made visible when these actions showed that the patient was familiar with the procedures. The intensity of interaction could shift from a lower to a higher level of interaction. This higher level of interaction occurred, for instance, when choosing the needle size before blood sampling, or when facing problems when taking blood samples.

## **Participation in the Care Encounter is Made Possible by an Enabling Approach**

The theme was characterised by an enabling approach, reflected in both patients and nurses during the care encounters, which contributed to participation. An enabling approach was expressed through verbal communication, but was also reinforced through non-verbal communication. The enabling approach can be understood from four categories: The patient expresses their own wishes, The patient shows an active interest, The nurse is committed, and The nurse invites to having a dialogue. The patients' enabling approach was made visible when expressing their will and views explicitly and displaying an active and interested attitude during the care encounters. The nurse's enabling approach was manifested through showing and expressing commitment to the patient's specific situation, and also by inviting the patient to having a dialogue. Through these approaches participation in the care encounter was clarified.

**The patient expresses their own wishes.** Participation was enabled when patients explicitly expressed their will during the care encounters. The patients expressed their own views on the nurse's conduct when performing specific actions, such as disinfection before inserting a needle into the subcutaneous venous port. The patients also gave instructions to the nurse before check-ups and measures, for example, by suggesting a vessel before sampling. The patients expressed their own will regarding the planned measures, e.g., a desire to postpone home visits or specific preferences regarding medication. Through this approach, when patients clearly expressed their own wishes, participation in the care encounter became visible.

**The patient shows an active interest.** Participation became visible when the patient was active and showed an interest during the care encounter by asking questions e.g., about medication or by asking for the results of check-ups. The patients also described their own oedema or heart rate check-ups, or initiated the check-ups during the visit. The patients complained about needs, such as supplementing pharmaceuticals among the materials stored in their home. This behaviour showed that the patients were well acquainted with the procedure. Active patients illustrated that they had knowledge and that participation was made possible when they had this knowledge of HF. The patients displayed knowledge of e.g., symptoms, monitoring and treatment. Knowledge also became evident when they confirmed that they understood the plan for care or information given. Participation by activity was reinforced by non-verbal communication, such as the patient asking for an inspection of their legs while lifting the covers and showing their legs.

**The nurse is committed.** The nurse showed commitment during the care encounter, which enabled participation. The commitment was manifested at an overall level, where a slow pace expressed presence and allowed participation. This also was apparent in more specific contexts, by expressing an understanding of the patients' description of symptoms. The nurse also showed an interest in the patients' descriptions of their daily lives. The nurse listened to the patient, paused in relation to the patient's description or recorded patient data. The nurse took a starting point from the patient and gave explanations or concrete suggestions. Furthermore, the nurses supported the patient through movement or showed empathy for the patient, for instance, when they showed distress because of deterioration. An enabling approach through commitment was reinforced through body position or change of body position, change of tone of voice, pausing when the patient explained something and

actively showing that “I am listening to you”. Participation in the encounter became visible by this approach.

**The nurse invites to having a dialogue.** The nurse displayed an enabling approach when he/she invited the patient to engage in a dialogue which enabled participation. This was done by asking comprehensive questions, showing trust in the patient’s data, asking explicit questions about the patient's opinion, or making a joint decision. Patients were invited to ask questions at any time, although this was often done at the end of the visit. An open question could also initiate the visit. The nurse showed trust in the patient’s information about treatments, such as prescription of medications or blood samples ordered by another caregiver. The nurse also showed confidence in controls carried out by the patient prior to the visit, e.g., blood pressure, and recorded this data. The nurse explicitly asked for the patient’s opinion of a planned measure, or the plan to discuss the patient's problems with a physician. Participation was made possible by joint decisions and expressed explicitly. Participation through the nurse's invitation to having a dialogue was reinforced through non-verbal communication, for instance, when the nurse turned towards the patient.

## **Discussion**

This study aimed to identify and describe participation in HF home-care. Our findings revealed good conditions for participation during HF home-care, where both the patients and nurses contributed to making participation possible. Participation in care was identified as an ongoing interaction between the patient and the nurse and also became visible by an enabling approach, reflected in both patients’ and nurses’ actions. This interplay leads to different levels of participation. In this study we applied an additional perspective of how patient

participation actually took place when observing care encounters in HF home-care. Our findings are consistent with findings from a previous interview study, where patients have described their participation when receiving HF home-care (Nasstrom et al., 2015). The home-care setting was found to facilitate patient participation. When care is being performed in the patients' homes, this probably facilitates for patients to take a more active role compared to when receiving institutional care. Previous studies in a home-care context describe how healthcare professionals act as a guest in the patient's home (Brannstrom et al., 2005; Ohman & Soderberg, 2004). This implies that healthcare professionals adapt to the patients' habits, and thereby make room for the patients to act (Brannstrom et al., 2005). This is probably one explanation as to why there is more room for the patient to be actively involved when receiving HF home-care. Our findings differ somewhat from observations made in a nurse-led HF-clinic, where the nurses more often took the initiative with regard to the structure and content of the clinic visit, although the patients collaborated or asked questions (Eldh, Ehnfors, et al., 2006). Initiatives taken by nurses were also observed in our study, but an important finding was that the patients also took spontaneous initiatives, which were taken into consideration by the nurses. The nurses also encouraged the patients to participate in the encounters. When giving the patient room to participate, in line with their preferences, home-care lives up to legal standards for participation as described in the Swedish Health and Medical Services act and the Patient Law (Ministry of Health and Social Affairs, 1982, 2014), and thereby respects the patient as a person (McCormack & McCance, 2006).

Active patient participation in self-care management is essential in chronic illness (Riegel et al., 2012). Living with an HF diagnosis involves a constantly fluctuating condition that requires the patient to understand the need for medication and monitoring, and also for dealing with the situations that arise because of their condition (McMurray et al., 2012; Riegel et al., 2012; Riegel, Lee, & Dickson, 2011). The participation revealed in the care encounters

during home-care might provide support for patients to better manage their situation. The patients' situation and how they manage self-care can be more appropriately discussed if room is given for the patient to actively interact with the nurse. Our study findings reinforce that discussions conducted in the home environment may be more effective compared to when the patient is hospitalized, or comes for a visit to an outpatient clinic. Heart failure home-care showed good potential to deliver this type of intervention that facilitates for patients to be active partners in their care process. Most of the care encounters in the home-care context included a dynamic process consisting of the majority of aspects of patient participation, where patients showed an active interest and also expressed their own wishes in interaction with a committed nurse.

To experience participation, patients with HF receiving home-care emphasise the need for time and room for communication and care based on individual needs (Nasstrom et al., 2015). However, if the care is time-restricted and task-oriented, there is a risk that the scope for participation is reduced, and that the patient holds back needs or requests. Previous observations from in-patient care found how task-oriented care gave limited opportunities for participation (Wellard, Lillibridge, Beanland, & Lewis, 2003), this was also found in a few of the observed care encounters in this study. Participation is facilitated when patients experience themselves as team members (Larsson, Sahlsten, Segesten, & Plos, 2011b) and feel that they are respected in the relationship (Eldh et al., 2010). Furthermore, patients' views of their participation are individual, and some do not want to take an active part in their care (Ekdahl, Andersson, & Friedrichsen, 2010; Larsson et al., 2007; Nasstrom et al., 2015). This could be manifested by patients not expressing their will, or being passive and relying on the healthcare professionals to do what is best for them. Therefore it is of importance that healthcare professionals recognise this and ask the patient how involved they want to be in their care, and not just take for granted that it is one way or another.

Home-care may improve outcomes for patients with HF (Blue et al., 2001; McAlister et al., 2004) and overall we found that it facilitated patient participation. In terms of improving care and supporting patient participation, home-care may be the best care model for patients with moderate to severe HF. However, currently, there are very limited opportunities for this type of HF home-care in Europe (Jaarsma et al., 2013).

## **Limitations**

Our inclusion of participants was planned to ensure variation. Patients' need for care varied from having visits once or twice a day, to having a visit only once a month. The age range was also quite wide, but the average age was slightly lower (77 years) than among the whole group of patients with HF receiving home-care at the three home-care units (82-84 years). Furthermore, we have only video-recorded home visits conducted by nurses. Home visits are often made by nurses, but can also be conducted by other professionals. Due to practical reasons, the home visits in our study were performed by nurses. All these factors need to be considered in connection with the transferability of the findings from our study.

There are two major advantages of using video-recording for data collection. First, having access to both verbal communication and non-verbal behaviours gave data with high density. Second, video-recordings make it possible to review the data repeatedly and allow for a thorough analysis (Botroff, 1993). However, the risk that the presence of the camera might have affected the visit cannot be disregarded. In most recordings (15/19), short comments were made by the parties and we noticed that, in brief moments, they were aware of the video-recording. Our overall impression was that this effect decreased quickly and they became occupied with tasks and focused on content related to the visit. The first author had been

involved in several home visits beforehand and could not see any major differences between these recorded home visits compared to non-recorded visits.

In the presentation of the findings there are frequent examples of what was focused upon, for example during care-related reasoning, or what happened in connection with collaboration. As the analysis includes video-taped home visits with both verbal and non-verbal communication, we chose to present the findings this way, instead of using quotations from the communication during home visits, which could be considered as a limitation.

### **Clinical Implications**

This study addresses a highly relevant and challenging topic for healthcare, both professionals and stakeholders, as well as for patients and their organisations. The findings emphasize the importance of healthcare professionals being organized and planning care so that there is room both for discussions and collaboration which facilitate for participation in care. It is also important to strive for interplay in the care encounter, meaning that the patients are given room to express their own wishes and also have room to act, which in turn is met by a committed nurse who invites the patient to engage in a dialogue. Together, this facilitates for the patients to be active partners in their care, which in turn may have positive effects on outcomes. How patients acted or expressed preferences for participation differed, thus it is of importance to always explore the patient's preferences for participation in the caring encounter.

## **Conclusions**

The findings from this study indicated that the HF home-care context showed good potential for facilitating patient participation. During the home-care encounters participation occurred when the patient and nurse interacted with a mutual influence on each other. Furthermore, the parties contributed to patient participation by an enabling approach, reflected in both patients and nurses.

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## **Declaration of Conflicting Interest**

The Authors declare that there is no conflict of interest with respect to the research, authorship, and/or publication of this article.

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Table 1 Description of patient characteristics

Patient characteristics ( <i>n</i> =17)	
Age mean years	77
Men <i>n</i>	11
Women <i>n</i>	6
Cohabitation <i>n</i>	8
Housing <i>n</i>	
<i>Apartment</i>	14
<i>Own house</i>	2
<i>Block of service flats</i>	1
Home help services <i>n</i>	5
NYHA class <i>n</i>	
II	1
III	16
Need for home-care <i>n</i>	
1-2 visits/day	4
2-3 visits/week	2
1 visit/week	8
1-2 visits/month	3

NYHA class = New York Heart Association  
Functional Classification

Table 2 Description of participating nurses

Nurse characteristics ( <i>n</i> =10)	
Age mean years	40
Women <i>n</i>	8
Men <i>n</i>	2
Time working as a nurse <i>n</i>	
1-5 years	4
6-10 years	2
11-20 years	3
> 20 years	1
Time working as a nurse in home-care <i>n</i>	
< and 1 year	4
2-5 years	4
6-10 years	2

Table 3 Identified themes and categories describing participation in care encounters during home visits in heart failure home-care

Themes	Categories
Participation in the care encounter is made possible by interaction	Exchange of care-related information
	Care-related reasoning
	Collaboration
Participation in the care encounter is made possible by an enabling approach	The patient expresses their own wishes
	The patient shows an active interest
	The nurse is committed
	The nurse invites to having a dialogue