

Being “on the alert” and “a forced volunteer”: a qualitative study of the invisible care provided by the next of kin of patients with chronic heart failure

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Background: Relatives' support is an important factor in how well people with chronic heart failure (CHF) manage their illness and everyday life. Deepening professionals' understanding of the content of relatives' invisible care activities, often characterized as care burden, is necessary to strengthen support services.

Objective: To explore the next of kin's experiences of invisible care and the inherent responsibilities in caring for a relative with CHF.

Design, setting, and methods: Relatives were recruited from CHF outpatient clinics and home care services. Seventeen women and two men were interviewed, age range 45–83 years; 12 were partners, and seven were daughters. The qualitative interviews were taped and transcribed and thematic cross-case analyses were performed.

Results: Two main themes were revealed. The first, “being on the alert”, refers to a perceived need, real or assumed, to be aware day and night, whether present with the patient or not, that occupies the mind, emotions, and body. The second theme, “being a forced volunteer”, refers to two different dimensions: relatives' own perceptions of responsibility with regard to the patient's needs; and voiced or silent expectations from the patient, family members, and health personnel that the relative will help the patient. Both findings appeared to have positive and negative impacts on the relationship with the patient.

Conclusion: The identified themes reflect how challenging being a next of kin of CHF patients can be. The results may deepen professionals' understanding of the relatives' invisible care burden and the importance of their subjective task-related feelings. More studies on invisible care and the attendant responsibilities are needed and also on relatives' inherent resources.

Keywords: informal caregivers, task-related feelings, social support, care burden

Introduction

Chronic heart failure (CHF) is clinically defined as a syndrome in which patients have typical symptoms and signs resulting from an abnormality of cardiac structure or function such as sodium and water retention.¹ Nearly 21,000 outpatient clinic consultations and 12,000 hospitalizations for patients with a primary diagnosis of heart failure were registered in Norway in 2012.² The prevalence of CHF is expected to increase in future decades. Health policy and therapeutic trends promote early hospital discharge and home treatment as innovative solutions in health care.^{1,3} Thus, informal caregivers may provide the majority of care between acute exacerbations. It is increasingly evident that relatives' support is an important factor in how well people with heart failure manage

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their illness and everyday life at home.⁴ Carers' support is part of the natural care provided in close relationships, but is also characterized as care burden. Since the 1960s, practitioners in the fields of cancer care and chronic diseases have been busy documenting the strain of next of kin's informal caregiver role.^{5,6} Instruments have been developed to measure objective burden in practical and personal care, as well as in emotional and motivational care, including aspects of quality of life.^{6,7} Studies have shown that the next of kin's own depression, anxiety, and mental strength are factors that strongly affect the experience of caregiver burden.^{8–11} Next of kin to patients with chronic obstructive pulmonary disease have reported worrying as the most common and constant experience of being a next of kin, but few report additional health problems of their own.¹² One study of CHF relatives reported that older age, the next of kin's own health problems, and high numbers of care hours are other factors associated with the experience of care burden.¹⁰ Studies report that caregivers of patients with CHF experience psychological stress and reduced quality of life that may also make them susceptible to their own health problems.^{13–16} In the literature, the concept of care burden includes both visible and invisible dimensions of care.^{5,8} Exploring the impact on family members with ongoing responsibility and caregiving is necessary to deepen professionals' understanding of the content and dimensions of these invisible care activities.^{15,16}

The objective was to explore the next of kin's experiences of invisible care and the inherent responsibilities in caring for a relative with CHF.

Methods

Design, sample, setting, and data collection

This study had a qualitative exploratory design using individual interviews for data collection. Next of kin were recruited in heart failure outpatient clinics and through home care services by nurses who knew the patients and their families well; 14 from outpatient clinics and five from home care services. Inclusion criteria required the relatives to: 1) be able to give consent; 2) manage verbal Norwegian; and 3) have regular direct contact with the patient and preferably live with her/him. Verbal and written information about the study was provided to both the patient with heart failure and their next of kin. When the next of kin consented to participate in the study and the patient agreed, the next of kin was contacted by the researchers by phone to arrange a time and place for the interview. Most participants chose to have the interview at home, while others chose the researcher's

office or a public cafe. Seventeen women and two men were interviewed. The age range was 45–83 years (median 63), and there were 12 partners and seven daughters. Eleven partners lived together with the patient. The severity of the patient's heart failure was unknown to us.

The interview guide had open questions to explore the informants': 1) knowledge of heart failure and its treatment; 2) perception of confidence in their caregiving role; 3) invisible caregiving activities; 4) needs for any practical and psychosocial support; and 5) possible need for training, consultation, and/or guidance. Two researchers, well experienced in doing qualitative interviews, conducted the interviews in 2013. The qualitative interview was guided by these themes in an open dialogue taking into account the interviewee's perspective of what was important to convey. The interviews were taped and fully transcribed. This article focuses on invisible care experiences and presents findings related to interview questions 1–3.

Analysis

The analyses were done in the interpretative tradition and involved thematic cross-case analyses performed by the researchers. First, each researcher did an open reading of all interviews and wrote a holistic essence of every interview. Thereafter, three researchers met together to do the first thematic analysis. Several themes were identified and named in the interviewees' own words, eg, worrying, availability, watching, loneliness, and duties. The process proceeded with structural analyses, first of each interview, and then across all interviews to identify subthemes. The final thematic analysis revealed two main themes related to invisible care and another two to the relatives' need for support. Table 1 illustrates one part of the analytical process.

Ethical considerations

The Data Protection Official for Research in Norway approved the study (Reference number 31564/09 26 2012). The investigation conforms to the principles outlined in the Declaration of Helsinki. Study participation was completely voluntary, all participants provided written informed consent, and the patients with heart failure all agreed to their relative's participation.

Results

The themes characterizing invisible care were "being on the alert" and "being a forced volunteer". The first one refers to staying alert day and night whether the next of kin is with the CHF patient or not and whether the necessity for vigilance

Table 1 An example of the analytic process

| Preliminary themes | Meaning units | Subthemes | Main theme |
|----------------------------------|--|--|--------------------|
| Worrying | I sleep badly. In the beginning it was worse, but it persists. I lie there listening for his breath. | Monitoring Attending Being in a constant state of vigilance | Being on the alert |
| Being present | I think I need to be home and am afraid to leave him alone. | Managing the situation | |
| Watching | I'm watching both day and night and sense when he starts to get worse. | Monitoring | |
| Feeling responsible at all times | I look after him all the time as if he is a child. | Undertaking responsibility Being in a constant state of vigilance | |

is real or assumed. The second theme refers to the next of kin's perception of various expectations with regard to helping their relative.

Being on the alert

"Being on the alert" was the most prominent characteristic of invisible care. Core aspects were: being in a constant state of vigilance, attention, undertaking responsibility, monitoring, and managing the situation.

Constant state of vigilance, attention, and undertaking responsibility

The dramatic events of sudden or worsening heart disease symptoms caused significant anxiety. All next of kin told about being on the alert for a new acute event/events, and several also referred to this as being a permanent situation. Many of those who lived with the patient said they never felt completely confident. The carers' hyperawareness was most apparent when they were with the patient, but was also present when they were apart. One of the daughters said "I do not live far away, but I'm always ready to run". A wife described her situation when her husband was outside: "I look out of the window to see him. If he is gone for a long time then I go to call for him. So he cannot be away from me too long. If so, I become anxious". Taking on this responsibility was clearly associated with being on the alert and being present. This built-in obligation is further explored under the main theme of "being a forced volunteer".

Monitoring

This involves observing, checking, and keeping "a continuous record" of the patient's situation. The next of kin made open observations and asked questions about the patient's comfort. They were watchful for sudden worsening of obvious symptoms, such as swollen ankles, weight gain, and shortness of breath. The questioning and observations took place both day and night.

I'm concerned all the time. If I think something is going to happen, I often listen for his breath, for if it increases, then it's maybe too much water in the lungs and the heart is unable to pump enough around.

Relatives' keen monitoring of the patient also alerted them to early subtle signs of an exacerbation. Next of kin told about sensing impending exacerbations by seeing signs in the patient's face or eyes and by detecting restlessness. This reveals tacit and personal knowledge the relatives both have and develop. "I perceive when he starts to get a little bad. As my daughter says: 'Dad is very restless, so I think something else is coming soon'. It's so true".

Managing the situation

For some relatives, managing the situation meant doing things together, while others did so by taking charge. Many said that presence, companionship, and assistance made them feel more secure in the situation. Additionally, some gave examples of how they and the patient indirectly safeguarded each other: "We count the pills together. I read the medicine list and he puts the pills in the box, and it works very well". The interviewees' descriptions of themselves in their situation included words such as caregiver, nurse, mother, and "nag crow". "I have become accustomed to that I, in a way, always nag at him as if he's a little boy, looking after him all the time. He gets a little annoyed at me, but I'm anxious all the time".

When asked about the consequences of being on the alert over extended periods of time, the next of kin told about periods of poor sleep, fatigue, weight loss, and difficulty living intimately with each other. Also, some believed they had grown closer through their mutual cooperation in handling the situation.

Being a forced volunteer

This main theme includes the subthemes: natural care, expectations, and relational consequences.

Natural care

Most of the interviewees lived with the patients and helped them as such family members usually do. Also, the daughters who were not living with the CHF patient expressed the wish to help, both voluntarily out of love and as “payback time” to their loved ones. Some of this is natural and part of internal expectations in relationships: to help one another, sometimes to the extreme, whenever needed. The youngest participant in the study told about her experience of how her husband’s critical heart failure had completely changed the nature of their relationship.

We had very divided roles when he was healthy. Previously I could be very frustrated because he had his company, and I thought he helped me too little with the kids and stuff. I expected nothing from him, and we had no conflicts. Now it was suddenly changed. Now I was in control of everything. Now we knew where things stood. I must say that ... when people sometimes felt sorry for us and they really wanted us to return to how we had been before, I did not feel that way at all. We have an incredibly valuable life now, but it is a lot of work.

She experienced this as an extreme change in their roles and responsibilities, and it had been good for their relationship.

Expectations

While one’s own internal expectations are often part of natural care, external expectations were often perceived by the study participants as being more difficult to manage. In many cases, the patient expected voluntary contributions both in practical matters and mental support. Other family members also expected effort and presence from the next of kin. Furthermore, the participants reported that representatives from the patient’s various health services assumed and took for granted considerable efforts from them. One of the elderly wives had a few illustrative comments on such expectations: “The community nurse says: We do not reach back tonight, but we expect you to look after him”, and “the family says: It’s good you’re so strong and always present”. The next of kin living with their loved one experienced these expectations most strongly. For some, this was a mental and almost a moral burden. Living with the expectation of always being present, staying home, not leaving, and being proactive was manageable for most caregivers for at least some period of time. Many relatives thought they had to be available and present and found this quite natural. “So in that respect I’m trapped in a way, but that’s just how I feel, my

husband does not expect me to. I think I have to”. For others, the expectations were more challenging. Researcher: “What has it done with your freedom then? Can you go from here and feel safe?” Next of kin: “No, I cannot. That is really the biggest load”. The next of kin experienced both unreasonable and unnecessary expectations of being on duty, both from themselves, the patient, other family members, and health care providers.

Relational consequences

For some, the expectation of being on duty had become burdensome. Leisure activities and work outside the house provided a temporary retreat. However, for some, recreation time had become difficult because the patient could not or did not want to do the same activities as before. We found variations in the effect of expectations: feelings of guilt and burdens nearly impossible to bear.

The mental strain is difficult. I feel so trapped. The fact that I cannot do anything on my own is much harder than the physical strain anyway. It’s not easy to talk about. Even though I can share this with anyone – no one can take it away anyway.

Most interviewees stated that the patient, the rest of the family, or health personnel sometimes did not or would not see how difficult these expectations were for the next of kin.

I do book the trip, but I also think all the time: Can I go? What to do if something happens? Can I handle the criticism if something happens while I’m gone? I find things like that very difficult. Also that he (the patient) does not realize I need to get away.

Volunteering and natural care seem to be characteristic of good relationships. Being a volunteer is narrowly balanced with the forced expectations of attending and assisting the patient. This limited their self-expression.

Discussion

The characteristic experiences of providing invisible care with its inherent responsibilities were “being on the alert” and “being a forced volunteer”, and these reflect how demanding being a next of kin to a CHF patient can be. However, providing invisible care is not just a burden as for some, it also increased closeness in the relationship and a heartfelt desire to help. Our findings support and complement previous research in this field. In the studies on caregiver burden, we found none addressing the experience of providing forced

voluntary care and the long-term state of being on alert as factors affecting the burden of care.^{5,8-10}

Being on the alert and being a forced volunteer appear to be relevant in the construct of caregiver burden. Luttik et al² developed and tested measurement of objective burden in partners of heart failure patients (Dutch Objective Burden Inventory). This includes a wide array of concrete care tasks, such as personal care, and practical, motivational, and emotional support. Their study results suggest that the length of time as a CHF next of kin may influence how heavily caregiver burden is experienced. Few items in the instrument, however, focus on subjective, task-related feelings such as constantly being on the alert. Researchers testing this instrument's validity and reliability in a Canadian population argued upon this as an area of improvement.¹⁷

Our study revealed variations with regard to the next of kin's perceptions of what is considered a burden. Sharpened attention is a natural consequence of the possibility of unpredicted events in the CHF person. A systematic review focusing on informal caregivers' experiences after acute cardiac events revealed that the next of kin had a feeling of solidarity when they observed attentively and felt too anxious to sleep.¹⁵ Most of our participants claimed that their attentiveness was heightened during real events such as increasing shortness of breath and severe chest pain. It is natural to be on the alert in acute situations, but for many this was a persistent state.

Being the next of kin of someone with CHF is undoubtedly a significant role in their life and relationships. Next of kin for CHF patients may develop their own health problems, have reduced quality of life, and are most at risk when the disease first appears.¹³⁻¹⁵ Constantly being on the alert, a key finding in our study, is not described in previous research, but may be a predisposing factor for health problems or reduced quality of life. All age groups reported this constant feeling of being on the alert.

All participants in our study recognized the increased alertness, but experienced this differently. Some described alertness that changed over time, independent of whether the condition worsened or not. Others said this created psychological distress experienced as a heavy burden. How heavy the burden was perceived to be seems to be related more to how they coped with being on alert than to the seriousness of the patient's situation. Hence, the next of kin's need for support may vary with their own competence to deal with such situations. Many of the participants expressed that it was sometimes helpful to have support and get information without the patient being present. In contrast, a recently

published study of patient-partner dyads affected by heart failure found that the dyads felt that shared support from others and for each other enabled them to share the burden.¹⁸ It seems important to recognize and understand subjective feelings as part of the invisible care if one is to succeed in being a long-term caregiver.

The feeling of being on alert appears to be due to the inherent uncertainties of the situation. Many of the next of kin's experiences with their loved ones were filled with contradictions, complexity, lack of information, and low predictability. This may contribute to the experience of uncertainty and anxiety, a threat that needs to be dealt with. Lazarus and Folkman's theory on stress and coping describes two forms of coping: mobilization strategies, such as direct actions and information seeking; and strategies to gain control of the situation, such as use of humor and participation in support groups.¹⁹ These different coping styles are recognizable in our participants' experiences where some were more oriented toward action and others managed these issues emotionally.

The theme of "being a forced volunteer" sounds like a contradiction. In light of the relatives' descriptions of their role as caregiver, it appears to be a delicate balance between volunteering and being forced. Both the next of kin who lived with the patient and those who did not wanted to help like family members usually do. These examples reflect an internally driven expectation of volunteering. In many cases, the patient, other family members, and representatives of the health care system expected voluntary contributions and took for granted considerable efforts from the next of kin. Our impression is that it is demanding and difficult for next of kin to set limits for themselves, especially when they are living with a loved one who does not recognize or accommodate the next of kin's own needs. Studies of other long-term patient-primary caregiver relationships found that the lack of mutual support resulted in an increased perception of care burden for carers.^{11,20} Further, the interviewees' experience of being "taken for granted" by other family members and health service personnel adds to the burden. The daughters had breaks which made it easier for them to feel less "duty-driven", whereas partners were often "on duty" around the clock.

The varied experiences related to balancing between voluntary and forced care on an individual level may be reflected in examples of different close adult relations as described in attachment-theory.^{21,22} This theory describes the dynamics behind the formation and progression of close emotional bonds between humans. The theory identifies different

attachment styles, described as secure, anxious–preoccupied, dismissive–avoidant, or fearful–avoidant. Attachment style has a great impact on the experience of commitment, and regulation of distance and closeness.²²

People with a secure attachment style report a higher degree of commitment in their relations compared to people with a more avoidant and anxious style.²¹ Examples from our study are the very devoted daughters, who can travel for 14 days without guilt because they had a shared agreement with their parent about the trip. Also, partners with close relationships had a clear arrangement about the next of kin's need for engagement outside both the home and the relationship. When interviewing elderly wives, it appeared that for some their marital relationships had been ailing for a long time. These women found the opportunity to leave the home very difficult. This may be interpreted in alternative ways. In a secure attachment style, a positive association exists between the ability to be involved with someone else and making oneself dependent on close relations, and also being independent and engaged outside the relationship.²³ To feel distanced in an established relationship, being forced to stay home, and being cut off from involvement outside the home may indicate a less-secure attachment style. But feeling the need to be homebound and lacking the courage to leave home sometimes may be related to a generational-bound understanding of a wife's commitment.

Strengths and limitations

Study limitations are linked to the sample that had a wide age range, few male relatives, few children, and the fact that most informants were recruited through outpatient heart failure clinics. Interviews with a different sample might have revealed more nuances in next of kin experiences. Since the patients agreed to their relative's participation, the sample may have been recruited from collaborative partner–patient dyads. The strength of the study is the use of several systematic text analyses, performed individually and in the research-group with broad experience in qualitative analyses.

Conclusion

The experiences of the relatives of CHF patients were more varied than what is included in both the current conceptualization of care burden and a common understanding of the term “burden”. The identified themes reflect how challenging being a next of kin of CHF patients can be. In contrast, the next of kin's experiences also embraced joy and closeness. The results may deepen professionals' understanding of the relatives' invisible care burden and the importance of their

subjective task-related feelings. Although the study had a limited selection of participants, we believe the findings do provide a basis for further studies. The results indicate a need to increase more specific subjective burden items. Further studies are needed on invisible care, the attendant responsibilities, and the relatives' inherent resources in caring for the patient, as well as interview studies among both groups of relatives: those “living with” and “visitors”. Studies of male partners and longitudinal studies measuring subjective and objective burden in caregivers for CHF-patients are also sparse.

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Disclosure

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