

## ORIGINAL ARTICLE

**Elderly women's experiences of support when living with congestive heart failure**

KARIN SUNDIN, RNT, Associate Professor<sup>1</sup>, ELISABETH BRUCE, RN, MSc<sup>1</sup>, & ANN-SOFI BARREMO, RN, MSc<sup>2</sup>

<sup>1</sup>Department of Nursing, Campus Örnköldsvik, Umeå University, Örnköldsvik, Sweden and <sup>2</sup>Västernorrland County Council, Sweden

**Abstract**

Heart failure is a chronic syndrome that has physiological, psychological and social effects. The aim of the study was to illuminate the meanings of support as experienced by elderly women with chronic heart failure. Narrative interviews were conducted with five elderly women with chronic heart failure. A phenomenological hermeneutic method of interpretation was used. The meanings of support were experienced by the women out of two perspectives, that is, when support is present and when there is a lack of support. The findings were revealed in two themes: "Feeling confident means support" and "Feeling abandoned". The women do not wish to be a burden. They want to be independent as much as possible to defend their dignity. An important support to the women is that they are understood and confirmed in their illness. Supportive relations are most valuable, that is, a relationship that supports the women's independence. If there is no supportive relationship, they feel like a burden to others and they feel lonely; this loneliness creates suffering and counteracts wellbeing and health.

**Key words:** *Support, heart failure, elderly women, life experiences, phenomenological hermeneutic*

(Accepted: 8 February 2010; Published: 4 March 2010)

**Introduction**

Living with a chronic disease can be a tumbling experience (Ekman, Ehnfors, & Norberg, 2000). People may experience loneliness, vulnerability and feel lost in their illness (Kralik, Brown, & Koch, 2001). Heart failure is a chronic syndrome where the heart is no longer able to maintain adequate blood circulation to the tissues. Despite medical treatment, half of those who are diagnosed with chronic heart failure die within five years. It is primarily people over 65 years that get sick and women are on average about 10 years older than men (Cline, Boman, Holst, & Erhardt, 2002; McMurray & Stewart, 2000; Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). Epidemiological research shows that the previous increase in incidents has decreased and the prognosis has improved (Levy et al., 2002).

The symptoms for people with heart failure are breathing difficulties (Souza & Lareau, 2004),

breathlessness, fatigue, oedema and decreased work capacity (Zambroski, Moser, Bhat, & Ziegler, 2005), which can affect life situations and wellbeing (Broström, Strömberg, Dahlström, & Fridlund, 2003; Broström, Strömberg, Dahlström, & Fridlund, 2004; Brännström, Ekman, Norberg, Boman, & Strandberg, 2006; Ericson, Westlake, Dracup, Woo, & Hage, 2003; Lennie, Moser, Heo, Chung, & Zambroski, 2006) and reduce quality of life (Bennet, Baker, & Huster, 1998; Riedinger, Dracup, & Brecht, 2002; Westlake et al., 2002). The symptoms may create difficulties in day-to-day life (Clarke, Frasure-Smith, Lespérance, & Bourassa, 2000). Heart failure could also cause depressive symptoms (Turvey, Schultz, Arndt, Wallace, & Herzog, 2002), especially to people with the most unpleasant form of heart failure (Vaccarino, Kasl, Abramson, & Krumholz, 2001). Nordgren (2008) has found that living with heart failure in the middle age is ambiguous in relation to other people, daily life and formal

care; it means a borderland between health and illness. Brännström, Brulin, Norberg, Boman, and Strandberg (2005) state that the course of the illness forces elderly people with heart failure to live a “roller coaster life”, with an ongoing oscillation between ups and downs. According to a study by Hägglund, Boman, Olofsson, and Brulin (2007), elderly people with heart failure had worse physical quality of life, and more general and physical fatigue than a matched control group.

The physical and psychological impact that heart failure causes these people may create a need for support. The need for support is, however, individual and can be experienced differently between individuals. It can also be experienced differently for the same individual during various stages of the illness (Sundin, Axelsson, Jansson, & Norberg, 2000). Research about peoples’ experiences of living with chronic heart failure displays a fragment that can indirectly be interpreted as the need for support (Mahoney, 2001). Support has been defined as plain help, i.e., information, education, economic support, auxiliary and external service. Support is also something that is individually adjusted, continuing and something that creates room for verbalisation, and feelings like mutual exchange between the parts (Stoltz, 2006; Stoltz, Pilhammar Andersson, & Willman, 2006).

Research shows that people with chronic diseases find support important (e.g., Pettersson, Appelros, & Ahlström, 2007). The need of support for middle-aged people with heart failure has been studied by Nordgren, Asp, and Fagerberg (2008a, 2008b). They found that the essence of support among middle-aged women can be understood as safety, depicted by understanding (Nordgren et al., 2008a). But no research has been found concerning elderly women with chronic heart failure and their experiences of support. The social situation of life differs between middle-aged and elderly women. There is a need for additional knowledge about what support means to elderly women with heart failure and how to be able to adjust the care according to those concerns (Brännström et al., 2005; Jacobsson, Pihl, Mårtensson, & Fridlund, 2004). The life situation of men and women with heart failure also differ (Strömberg & Mårtensson, 2003). Women may feel as if they are a burden to others (Mårtensson, Karlsson, & Fridlund, 1998). Studies have also shown that there are differences between men and women in diagnosis, and that women receive less care and support in their homes than men do (Paton, Backlund, Barnes, & Thirsk, 2007; Riedinger, Dracup, Brecht, Padilla, & Sarna, 2001). The aim of the study was to illuminate the meanings of

support as it is experienced by elderly women with chronic heart failure.

## Method

In this study a phenomenological hermeneutic method of interpretation is used (Lindseth & Norberg, 2004) with the aim to describe and understand the meanings of the phenomenon of support experienced by elderly women with chronic heart failure.

### *Participants and setting*

A heart failure clinic in a middle-sized hospital in northern Sweden was contacted. The clinic provides care for a population of 55,000, of which more than 200 people visit the clinic each year: 60% are men and 40% are women, with an average age of 70 years. A letter was sent to the head of the heart failure clinic to gain permission to choose informants from the clinic. When permission was granted, a letter was sent to a nurse at the heart failure clinic to ask for assistance with the recruitment of participants. The nurse was told to choose 10 elderly women with chronic heart failure that had visited the clinic from week 18 (2007) and as far back in time that was necessary to include the women. The inclusion criteria given by the researchers were: women over 65 years with chronic heart failure who had been diagnosed and classified III–IV according to the New York Heart Association (NYHA)-scale (The Criteria Committee of the New York Heart Association, 1994) for at least two years. Heart failure can be acute and/or chronic, and is classified I–IV according to the NYHA-scale. The mildest form of degraded heart function gives no symptoms, while the most severe form gives symptoms already at rest. Elderly women were chosen to participate in the study as previous studies have shown that women receive less care and support than men do (Riedinger et al., 2001). The exclusion criteria were: women with dementia or a mental disability. The nurse at the heart failure clinic sent a letter to 10 women with an enquiry about participation in the study. The women replied to the researchers by post. Three women agreed to participate, four said no and three didn’t respond. New letters were sent to the three women that did not respond; none of them was willing to participate. New invitations were then sent to seven new women; two of them agreed to participate and the rest declined. The five women willing to participate were contacted by phone by the second and third author. Time and date for the interviews were fixed. Their ages were 67–88 years; one was unmarried and

the remaining four were widows. The women had children, grandchildren, great-grandchildren or first full cousins nearby.

#### *Narrative interviews*

A natural and important way that humans use to communicate meanings is through narratives. A primary way of making sense of an experience is talking about an incident. For that, narrative interviews took place in autumn of 2007. Two of the interviews were conducted by the second author and three of the interviews were conducted by the third author. Three of the interviews were conducted in each of the women's homes, one at a short-time living facility and one in a conversation room at the hospital. The interviews were tape-recorded. Each woman was told to narrate as freely as possible about her experience of support (cf. Mishler, 1986). The women were further encouraged to reflect and talk about their experiences of the phenomenon in order to get as rich interviews as possible by using questions like "Can you develop that?" or "What do you mean?" The women's gestures to illustrate the narratives were noted. It was also noted if they got emotional. This were added to the interview text and taken into consideration within the interpretation. The interviewers tried to be as open-minded towards the women's narratives as possible and tried to create a sense of closeness, but at the same time hold back their own beliefs about the phenomenon, and thus during the interview not influencing the interviews (cf. Kvale, 1996). The interviews lasted between 40 and 90 minutes.

#### *Methodological consideration*

Several of the women who were asked to participate in this interview study declined. Maybe it was because of the high age of the participants in combination with the severe level of heart failure. Trustworthiness in a qualitative study is shown in rich content in the interviews, not in the number of participants (Sandelowski, 1995). The interviews were rich in meanings. Instead there is a question about if the result could have been different if more of the women asked have been willing to participate. The answer is maybe if the women that declined were sicker than the women that participated, as the women with severe physical handicap could have a need for more practical support. But apprehended on a comprehensive level, the result still could be the same. There were few interruptions during the interviews and the participants spoke freely, and with spontaneity and confidence when they talked about their experiences of support. This can be

interpreted as the participants narrated freely about what was important to them. Ricoeur (1976) states that there is always more than one comprehension of the text, but it do not mean that all interpretations have the same importance. To the researchers, the findings represented the most trustworthy comprehension of the text. This study's knowledge can be transferred to similar situations and it gives knowledge to care providers to reflect on and take into consideration in care situations.

#### *Ethical consideration*

The present study was approved by the ethics committee of the Faculty of Medicine, Umeå University, Sweden. The women participating in the study already had contact with the nurses at the heart failure clinic and were told to make contact with them if they, after the interviews, felt hard memories or feelings arise. The interviewers had no relation to the women that participated. Confidentiality was gathered and the women's right to discontinue or refuse participation was stressed.

#### **Interpretation and findings**

The interviews were transcribed verbatim and all interviews were worked up as one text. The interview text was interpreted using a phenomenological hermeneutic approach (Lindseth & Norberg, 2004). This approach is inspired by Ricoeur's (1976) phenomenological hermeneutical interpretation theory. The phenomenology aims to uncover and describe the internal meaning structures of lived experiences. The hermeneutics aims to interpret, to explain and to understand human consciousness. The methodological steps of this phenomenological hermeneutic text interpretation were comprised of *three steps*: the naive readings, the structural analysis and the comprehensive understanding. This means entering a hermeneutic circle. These steps composing a dialectic movement between the whole and the parts of the text, and also between understanding and explanation.

#### *The naïve understanding*

The *first step* of the interpretation consisted of several uncritical readings of the whole text, with an open approach and a phenomenological attitude, in order to grasp its meaning as a whole. These first naïve readings ended in a naïve understanding.

Elderly women with chronic heart failure have difficulty to explicit report on what support means. They experienced that they were not ill enough to require support. It is not always visible that they are

in need of support. Therefore, they are not met with understanding very often. Thus, they wish to manage without help as much as possible. They believe that if they get worse, they will be met with more understanding and can then verbalise what kind of support and help they desire. They strategically deny themselves practical support in hopes to keep their independence and self-esteem. Being an elderly woman with chronic heart failure could mean feelings of comfort, being confirmed and having a relation. These feelings are present when the women receive support. Asking for help from significant others but not having the ability or strength to offer anything back creates a feeling of being a burden and puts the women in a negative dependency position. An important experience of support consists of a good relationship with significant others which mediate a sense of comfort when the women feel confirmed through the relationship. They also feel supported when they were taken seriously and when they experience continuity with the health care system. If any of that support is missing, the experience of lacking support creates suffering, as the lack of support creates feelings of not being confirmed and of not feeling safe which influence the wellbeing negatively.

*The structure analysis*

The *second step* of the interpretation, the structural analysis, was a detailed analysis of the text, meaning-unit by meaning-unit, for the purpose of explaining the text. It was the step for systematic illustration of the interpretation. The structural analysis was used to seek, identify and formulate themes. The text was first divided into smaller parts: meaning-units. A meaning-unit could be a part of a sentence, a whole sentence, or a number of sentences. Meaning-units with no connection to the research question were taken into consideration during the interpretation but were not formulated into themes. The meaning-units were read through several times and were reflected on against the naïve understanding. Each meaning-unit was condensed and the meanings were presented in an everyday language. When all meaning-units were condensed, they were abstracted and sub-themes were created. The condensations, abstractions and sub-themes were read through to find similarities and differences. The ones that were alike were placed together and sub-themes that were alike “instilled” each other and created new sub-themes and themes with similar meanings. During this process, there was an ongoing dialog with the text by putting questions to the text: “What was the text saying?” “What was the meaning of the text?” “What was the text pointing to?” and “What new understanding

was the text opening?” The themes that occurred were compared to the naïve understanding and were examined if they validated or invalidated the naïve understanding. When the themes invalidated the naïve understanding, a new naïve reading was made. There was a constant movement between the whole and the parts and back to the whole. The structure analysis resulted in two themes and five sub-themes (Table I). The themes are presented as headings and the sub-themes as subheadings.

**Theme 1: Feeling confident means support**

This theme presented the phenomenon support; when support is present.

*Enjoying freedom and independence*

The women want support in their struggling towards dependency. They are enjoying freedom and independence. They know their limitations and wish to act out of them. They try to adapt to their present life situation and adjust to it. They have created possibilities and strategies to manage exertion and to maintain strength. Support means receiving help to defend independence through others facilitating of the women’s own activity.

... you have to take it carefully, and then it will go ... I have made a system where I rest at least once a day, because I feel much better then, otherwise I get so tired at night ... It’s better to take a break in the day.

The women wish to be powerful in themselves and feeling strong despite the illness and still being able to do most of things by themselves. This makes the women keep their independence and could create a feeling of being powerful in oneself. They feel satisfied in being able to receive support to manage to do daily duties and maintaining control over daily living. They then have a positive attitude towards life and they are happy with their existence, thus they have faith in life and trust in the future.

Table I. Overview of themes and sub-themes.

Themes	Sub-themes
Feeling confident means support	Enjoying freedom and independence
Feeling abandoned	Being confirmed mediates safety
	Suffering from dependency of others
	Longing for sharing
	Feeling neglected in care

... doing the best of the situation. That is how I am living ... because, I put it this way. I want to live my life as I used to, as long as it's possible, the way I used to do ...

The women feel supported when they could do what they want despite limitations. They defend their integrity and feel free and independent when they can do things by themselves by using aiding devices.

What I feel now is that I will stay here as long as I feel that it is pleasant and comfortable ... You feel the freshness out there so you try as long as you can to maintain there ...

#### *Being confirmed mediates safety*

The women feel supported when significant others, e.g., children, grandchildren, siblings, nephews, neighbours, care for them. Being paid attention to by significant others makes the women feel loved and supported. When they are treated with kindness and helpfulness and when the women experience themselves seen, heard and asked for, and when the significant others listen to their problems, they feel supported. They feel gratitude for having those significant others and they experience a warm feeling inside and are thus satisfied with the support their significant others provide. When relationships with significant others continue, they also experience being needed.

Then when I came home to my house my nephew were there and had made coffee and welcomed me and that gives you a warm feeling inside ...

A good relationship with significant others means not being alone, abandoned or forgotten, and mediates to the women a feeling of being safe and secure. The closeness and contact with significant others make them feel cared for; they experience pleasure and confirmation in the good relationship. That strong relationship gives them a feeling of confidence and they thus experience support.

... Then, I got such wonderful neighbours around me that gives me an enormous feeling of safety.

Continuous contact with care providers also increases the possibility of being known, cared for, calm, and of being safe and secure. The women feel safe and supported when they know who to turn to, and when health check-ups are made. This means that they experience safety through the continuous relationship because the care providers listen to

them and confirm them in a personal, thoughtful and humorous way, in their specific life situation.

... this is how I look he said, but we will see each other twice a year (laugh, laugh), so you will see me many times. Yes, it was quite funny actually. Yes he was very nice, humorous in every way ...

The women wish to be considered by care providers, in a holistic way, which means being confirmed, seen, heard and understood as a unique person and not only as an anonym sick patient. The women feel safe when care providers verify them, when they show interest in their story of illness, and when they examine them and try to find solutions and take measures. They feel confirmed and supported when care providers treat them well, care for them, listen, touch them and try to help them with what they ask for, and when they thus experience good caring and good medical treatment.

... well support ... it's when you ... when you come to the hospital and they take care of you, when you feel very ill, when they take care of the whole of you, you feel safe ...

#### **Theme 2: Feeling abandoned**

This theme presented the phenomenon support; when support is lacking.

#### *Suffering from dependency of others*

When the women feel a lack of supporting relationships and a lack of assistance to help them, take care of themselves, they feel handicapped and of no value. Thus they feel frustrated concerning their dependency on others' goodwill and help, and they worry about their future undesired alterations in daily life.

... that is what makes me feel most handicapped and frustrated, when I can't take care of myself in the same way; I am dependent on others ... if they do not do it by themselves I have to tell them what to do ...

When support in the form of a good relationship is lacking, the women worry about what others think of them when they need help. When they increase the load for others by asking for help, it creates feelings of guilt since they no longer are able to offer anything back. They feel ashamed when they feel that their behaviour affects their significant others. They put demand for themselves to keep up a good facade by trying to look healthy and to ask for less help than

they really need. Being dependent means that freedom is limited and they often feel like a burden to significant others and to society. The women are afraid of being a burden to others.

... and just cry out too. I did it a couple of times with my son, but he got all terrified. And I tell you that I am ashamed to put my children through this, but you have to do that sometimes (sniff) have to understand that you can't handle any more, I am only 70 years ...

#### *Longing for sharing*

The women desire support in form of someone to associate with when things are difficult. Loneliness creates suffering. Fellowship is not something that the women can call for. Not having significant others available means they have to handle the grief alone. They experience suffering when close relations no longer exist because of age and death, which also creates feelings of loneliness. Furthermore, they do not feel confirmed by significant others that live far away or are very sick themselves.

Sometimes when I feel that no dam ... then I wish to have someone to call and, and just cry out with ...

#### *Feeling neglected in care*

When there is no continuity in relation to care providers, i.e., when the women are not taken care of by the same people in the health care, they feel unsafe and not supported. They wish to be regularly contacted, controlled and followed up with. When there is no continuous contact, the women experience suffering. They feel that they are not seen or heard by care providers when no one specific person is responsible for their care. When the women do not know who to turn to or how to get help by care providers, it means feelings of forlornness.

... Well, it's like when you go to the medical health care centre, you want to meet the same care providers so that you have someone to turn to and talk to, and you see now, I feel like I have no support at all.

A lack of faith in care providers results in lack of support and suffering. Because of previous bad experiences, the women feel insecure when they have to receive care. Previous bad experiences make them choose to not contact the health care system. They have lost confidence in the health care system because they have asked for help, but not received any and when care providers do not have enough time for the patients. Instead, they have been

violated and humiliated. They sometimes experience that care providers have made them worse. They feel disappointed but at the same time guilty when their pride have been injured by the health care system.

... some of the ones that you meet is not that good, I do have to say ... They, they do not care ... the last thing he said when I was leaving ... Now I will start crying. You have to understand that you are 70 years and then you are, you do not have, oh ... as much strengths as before. And when you get this tired, go to bed ... I couldn't answer. I had to leave and when I got outside the door, walking a way, you know I cried so everyone looked at me. It is obvious that you should lie down and die. It's worth nothing.

The women wish to be seen and heard as unique persons by care providers. When this is not happening, they feel misunderstood and do not receive the help and support they need. They feel overlooked and under-prioritised, as if their problem is minimised and that care providers do not have enough knowledge about patients with heart disease. They feel unsafe and violated when they do not receive understanding, empathy or respect, when care providers are not complaisant or friendly, and/or when they feel accused.

... you talk about that you might need some help, or in different situations you want to see a physician or something like that. Or a nurse or anything. But you know how it is on hospitals nowadays. So you know the support ... that's nonexistent ...

The women wish to know what is going on and wish to be part of their own care. They feel run over when they do not receive any information, which creates feelings of being outside their own care. When care providers do not ask for the women's opinions and there is a lack of information from the care providers, the women feel omitted.

... (sniff) you speculate like this ... well, wonder how it is with that and I am a person who is curious and want to know and want to follow and when tests are made I want to know what I have and so on so that I can check my-self.

#### **Comprehensive interpretation and reflections**

The *third step* of the interpretation, the comprehensive understanding, amounts to a critical in-depth interpretation, taking into account the researchers' pre-understanding the sense of the naïve reading and

the findings from the structural analysis. The interpretation was further reflected on in relation to the research question, the context of the study and relevant literature (cf. Lindseth & Norberg, 2004).

The phenomenon support for elderly women with chronic heart failure is experienced out of two perspectives, that is, when support is present and when there is a lack of support. There is an ongoing dialectic between these two perspectives. The experience of support arises when the women receive a supporting relationship and help in a way which mediates a feeling of independence and confirmation that they still are capable human beings.

The women appreciate support which helps them to maintain things by themselves as much as possible. The women's experience of enjoying freedom and independence displays effects of having resources to take care of themselves, which mediates feelings of being independent of others and keeping their self-esteem. Similar to this is shown in a study by Hägglund, Boman, and Lundman (2008) about women with heart failure where the findings point to the joy women feel because of the capacity they still have left and the importance of perceiving these capacity. Our study shows that struggling towards independency reflects the experience of living life in the way they wish, without inhibition. It also shows the effects of having supporting resources that help them to self-govern. They want a supporting relationship with persons that consider them as they were before they fall ill and not only as a person with a disease, and furthermore in addition respecting their desire for adjusted help.

Nordgren, Asp, and Fagerberg (2007a) found that middle-aged people with heart failure try to find a balance in life by learning how much they can manage and acting from there. In our study this also is found. Further, the elderly women feel manageability when they realise that they have resources around them to compensate for their frailty, and when they have someone to concern about them. Westlake and Dracup (2001) show the importance of the emotional connection to significant others, which gives them hope for the future. Mårtensson et al. (1998) found that women with heart failure felt safe and supported when they were not alone and when they had a social network. In our study the women experience support when they feel themselves confirmed, asked for, loved and needed by significant others, thus a confirming and supportive relationship that supports the feeling of independence and worthy. That is, a relationship which comprises respect and dignity in spite of their need for help.

Our study also points towards feelings of calm and confidence when the women experience a supportive relationship with care providers created through confirming and continuous meetings. Having continuous contact with care providers and being met with understanding by competent care providers means support which mediates safety. Similar findings have been found in studies by Nordgren et al. (2008b) and Ekman et al. (2000). When people with heart failure experience support in form of continuity, suited information and being treated with dignity and humour by professional care providers, it means feelings of comfort, hope and confidence. Mahoney (2001) also found that an adequate relationship with care providers mediates feelings of receiving support. In the opposite. the feeling of being neglected in care means that there is a lack of support from the health care system, which leads to insecurity and suffering. When the people with heart failure were ignored and not taken seriously, they felt powerless and lost faith in their care providers (Ekman, Lundman, & Norberg, 1999), which our study also shows.

Our study shows that being dependent on others may cause guilt and shame. The dependency also results in limited freedom and feelings of being handicapped. Aldred, Gott, and Gabriballa (2005) found that elderly people experienced lost independence when they needed practical help, and not being able to take care of themselves resulted in feelings of frustration. Cortis and Williams (2007) also show that patients felt imprisoned in their own body because physical limitations stop them from taking care of things on their own, and they no longer feel like themselves. Our study points to similar findings. When the women's limitations are evident, their undesired dependence is shown. Several studies found that elderly people with chronic heart failure felt useless and very troubled about being a burden to their significant others (Aldred et al., 2005; Ekman et al., 1999; Mårtensson et al., 1998). Hägglund et al. (2008) describe how the women are in a daily struggle against fatigue in their will to reduce dependency on others. Similar is found in our study. When there is a lack of supporting relationship and the feelings of being dependent and a burden is present, the women feel a need for struggle against this feeling and it undertakes the women's self-esteem and creates suffering. Thus, they desire understanding and assistance that supports them to be as independent as possible and in the same time they need to be confirmed as a worthy person by significant others and care providers.

Buber (1990) states that everyone wishes to feel validated. Not being regarded as the person you are

is a way of not being confirmed, which may lead to suffering. The confirmation the women with heart failure experience influences their own true nature and their relationship to themselves. Not being seen by others as you are and experiencing alienation constitutes perhaps the deepest feeling of loneliness (Younger, 1995). In our study, the women wish to be confirmed and seen as competent and autonomous in spite of their fatigue and requirement for help. Support to the women does not mean too much of help if it is not necessary as it may abolish their self-esteem. Support rather means a supporting attentive relationship from both significant others and care providers. That is, the women want support which made it possible to manage by themselves as much as possible.

### Conclusion and nursing implications

A supportive relationship is a relationship that supports the women's independence, a relationship that bridges the women's feelings of being a burden, so that they would keep their dignity. The women wish to receive support in managing daily life by themselves as much as possible. This is possible within a relationship in which the significant others and/or care providers confirm the women's illness in a non-depreciate way and understand how to act to support and help the woman even without commands from them. This is practicable when significant others and/or care providers are being available with practical help and a supporting relationship when needed. If there is no supportive relationship, the women experience a lack of support and feel like a burden to others and they feel lonely; this loneliness creates suffering.

Care providers need to look for the lived experience and individual needs among the patients if they want to give support (Nordgren et al., 2007a). Nordgren, Asp, and Fagerberg (2007b) found that information and knowledge can be a support. When the person receives knowledge about what is wrong and how things are, it gives them feelings of security and control. Our study also points out that the women want to be a part of their own care. Otherwise they have feelings of lost control over their situation. They wish to become seen as persons that are able to share the decisions about their care. There is an importance that care providers consider the women's whole life situation and not only the medical treatment. To decrease the women's suffering; it is important to involve them *when* they wish to be involved and likewise in other situations let them decide to delegate the decisions about their situation and care to others when the women want to be

inactive, passive and/or are too tired to make the decisions by themselves. That is, the women desire different ways of caring when they are in different states of health or when they feel more or less safe. An adjusted treatment and caring make the women feel like a respected person and not just an object for care giving (Sundin et al., 2000). If that is functioning it means feelings of getting support.

Living with a chronic disease can bring feelings of a threatened existence. A supporting relationship may in those conditions be important in increasing their feelings of still being a valuable person. Meetings without understanding disappoint the women in our study, which destroy their trust in others and mediate feelings of being abandoned. Sundin, Norberg, and Jansson (2001) consider that communion and confirmation represents the base of human relationships. They show that a relationship is confirming when someone is being present, available, listening, understanding without judging and offering time and space, without being distrusted, being with and not only being there. Meanings in a confirming and supporting relationship as expressed by the women in our study, builds on communication, understanding and confirmation between the women, the significant others and care providers.

### Acknowledgements

We want to thank the women that participated in the study and the nurses at the heart failure clinic who assisted in the recruitment of participants.

### Conflict of interest and funding

The authors have not received any funding or benefits from industry to conduct this study.

### References

- Aldred, H., Gott, M., & Gariballa, S. (2005). Advanced heart failure: impact on older patients and informal carers. *Journal of Advanced Nursing*, 49, 116–124.
- Bennet, S. J., Baker, S. L., & Huster, G. A. (1998). Quality of life in women with heart failure. *Health Care for Women International*, 19, 217–229.
- Brännström, M., Brulin, C., Norberg, A., Boman, K., & Strandberg, G. (2005). Being a palliative nurse for people with severe congestive heart failure in advanced homecare. *European Journal of Cardiovascular Nursing*, 4, 314–223.
- Brännström, M., Ekman, I., Norberg, A., Boman, K., & Strandberg, G. (2006). Living with severe chronic heart failure in palliative advanced home care. *European Journal of Cardiovascular Nursing*, 5, 295–302.
- Broström, A., Strömberg, A., Dahlström, U., & Fridlund, B. (2003). Congestive heart failure spouses' support and the couple's sleep situation: A critical incident technique analysis. *Journal of Clinical Nursing*, 12, 223–233.

- Broström, A., Strömberg, A., Dahlström, U., & Fridlund, B. (2004). Sleep difficulties daytime sleepiness, and health-related quality of life in patients with chronic heart failure. *Journal of Cardiovascular Nursing, 10*, 234–242.
- Buber, M. (1923/1990). *Ich und Du*. [I and Though]. Berlin: Schocken Verlag. (Swedish translation: Jag och Du. Ludvika: Dualis Förlag AB).
- Clarke, S. P., Frasure-Smith, N., Lespérance, F., & Bourassa, M. G. (2000). Psychosocial factors as predictors of functional status at 1 year in patients with left ventricular dysfunction. *Research in Nursing and Health, 23*, 290–300.
- Cline, C. M., Boman, K., Holst, M., & Erhardt, L. R. (2002). The management of heart failure in Sweden. *European Journal of Heart Failure, 4*, 373–376.
- Cortis, J. D., & Williams, A. (2007). Palliative and supportive needs of older adults with heart failure. *International Nursing Review, 54*, 263–270.
- Ekman, I., Ehnfors, M., & Norberg, A. (2000). The meaning of living with severe chronic heart failure as narrated by elderly people. *Scandinavian Journal of Caring Sciences, 14*, 130–136.
- Ekman, I., Lundman, B., & Norberg, A. (1999). The meaning of hospital care as narrated by elderly patients with chronic heart failure. *Heart and Lung, 28*, 203–209.
- Erickson, V. S., Westlake, C. A., Dracup, K. A., Woo, M. A., & Hage, A. (2003). Sleep disturbance symptoms in patients with heart failure. *AACN Clinical Issues, 14*, 477–487.
- Hägglund, L., Boman, K., & Lundman, B. (2008). The experience of fatigue among elderly women with chronic heart failure. *European Journal of Cardiovascular Nursing, 7*, 290–295.
- Hägglund, L., Boman, K., Olofsson, M., & Brulin, C. (2007). Fatigue and health-related quality of life in elderly patients with and without heart failure in primary healthcare. *European Journal of Cardiovascular Nursing, 6*, 208–215.
- Jacobsson, A., Pihl, E., Mårtensson, J., & Fridlund, B. (2004). Emotions the meaning of food and heart failure: A grounded theory study. *Journal of Advanced Nursing, 46*, 514–522.
- Kralik, D., Brown, M., & Koch, T. (2001). Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing, 33*, 594–602.
- Kvale, S. (1996). *InterViews. An introduction to qualitative research interviewing*. London: Sage.
- Lennie, T. A., Moser, D. K., Heo, S., Chung, M. L., & Zambroski, C. H. (2006). Factors influencing food intake in patients with heart failure: A comparison with healthy elders. *Journal of Cardiovascular Nursing, 21*, 123–129.
- Levy, D., Kenchaiah, S., Larson, M. L., Benjamin, E. J., Kupka, M. J., Ho, K. K. L., et al. (2002). Long-term trends in the incidence of and survival with heart failure. *The New England Journal of Medicine, 347*, 1397–1402.
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences, 18*, 145–153.
- Mahoney, J. S. (2001). An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart and Lung, 30*, 429–436.
- Mårtensson, J., Karlsson, J.-E., & Fridlund, B. (1998). Female patients with congestive heart failure: How they conceive their life situation. *Journal of Advanced Nursing, 28*, 1216–1224.
- McMurray, J. J. V., & Stewart, S. (2000). Epidemiology aetiology and prognosis of heart failure. *Heart, 83*, 596–602.
- Mishler, E. (1986). *Research interviewing: Context and narrative*. Cambridge: Harvard University Press.
- Nordgren, L. (2008). När kroppen sätter gränser – en studie om att leva med hjärtsvikt i medelåldern. [When the body sets limits living with heart failure in middle age]. Acta Wexionensia No 140/2008. ISSN: 1404-4307 ISBN: 978-91-7636-593-9.
- Nordgren, L., Asp, M., & Fagerberg, I. (2007a). Living with moderate-severe chronic heart failure as a middle-aged person. *Qualitative Health Research, 17*, 4–13.
- Nordgren, L., Asp, M., & Fagerberg, I. (2007b). An exploration of the phenomenon of formal care from the perspective of middle-aged heart failure patients. *European Journal of Cardiovascular Nursing, 6*, 121–129.
- Nordgren, L., Asp, M., & Fagerberg, I. (2008a). Safety and understandin: Support as experienced by women living with heart failure in middle age. *International Journal of Qualitative Studies on Health and Well-being, 3*, 39–51.
- Nordgren, L., Asp, M., & Fagerberg, I. (2008b). Support as experienced by men living with heart failure in middle age: A phenomenological study. *International Journal of Nursing Studies, 45*, 1344–1354.
- Paton, B., Backlund, J., Barnes, M., & Thirsk, L. (2007). Recalibrating time and space: Women's challenges of living with heart failure. *Canadian Journal of Cardiovascular Nursing, 17*, 7–14.
- Petersson, I., Appelros, P., & Ahlström, G. (2007). Lifeworld perspectives utilizing assistive devices: Individuals lived experience following a stroke. *Canadian Journal of Occupational Therapy, 74*, 15–26.
- Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Fort Worth, TX: Texas Christian University Press.
- Riedinger, M. S., Dracup, K. A., & Brecht, M.-L. (2002). Quality of life in women with heart failure normative groups and patients with other chronic conditions. *American Journal of Critical Care, 11*, 211–219.
- Riedinger, M. S., Dracup, K. A., Brecht, M.-L., Padilla, G., & Sarna, L. (2001). Quality of life in patients with heart failure: Do gender differences exist? *Heart and Lung, 30*, 105–116.
- Sandelowski, M. (1995). Focus on qualitative methods. Sample size in qualitative research. *Research in Nursing and Health, 18*, 479–482.
- Souza, C. A., & Lareau, S. C. (2004). Descriptors of dyspnea by patients with chronic obstructive pulmonary disease versus congestive heart failure. *Heart and Lung, 33*, 102–110.
- Stewart, S., MacIntyre, K., Hole, D. J., Capewell, S., & McMurray, J. J. V. (2001). More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *European Journal of Heart Failure, 3*, 315–322.
- Stoltz, P. (2006). *Searching for the meaning of support in nursing*. Doctoral Dissertation, Malmö University.
- Stoltz, P., Pilhammar Andersson, E., & Willman, A. (2006). Support in nursing – an evolutionary concept analysis. *International Journal of Nursing Studies, 10*, 1–12.
- Strömberg, A., & Mårtensson, J. (2003). Gender differences in patients with heart failure. *European Journal of Cardiovascular Nursing, 2*, 7–18.
- Sundin, K., Axelsson, K., Jansson, L., & Norberg, A. (2000). Suffering from care as expressed in the narratives of former patients in somatic wards. *Scandinavian Journal of Caring Sciences, 14*, 32116–32122.
- Sundin, K., Norberg, A., & Jansson, L. (2001). The meaning of skilled care providers' relationships with stroke and aphasia patients. *Qualitative Health Research, 11*, 308–321.
- The Criteria Committee of the New York Heart Association. (1994). *Nomenclature and criteria for diagnosis of diseases of the heart and great vessels* (9th ed.). Boston, MA: Little Brown and Company.

- Turvey, C. L., Schultz, K., Arndt, S., Wallace, R. B., & Herzog, R. (2002). Prevalence and correlates of depressive symptoms in a community sample of people suffering from heart failure. *Journal of the American Geriatrics Society, 50*, 2003–2008.
- Vaccarino, V., Kasl, S. V., Abramson, J., & Krumholz, H. M. (2001). Depressive symptoms and risk of functional decline, and death in patients with heart failure. *Journal of the American College of Cardiology, 38*, 199–205.
- Westlake, C., & Dracup, K. (2001). Role of spirituality in adjustment of patients with advanced heart failure. *Progress in Cardiovascular Nursing, 16*, 119–125.
- Westlake, C., Dracup, K., Creaser, J., Livingston, N., Heywood, J. T., Huiskes, B. L., et al. (2002). Correlates of health-related quality of life in patients with heart failure. *Heart and Lung, 31*, 85–93.
- Younger, J. B. (1995). The alienation of the sufferer. *Advances in Nursing Science, 17*, 53–72.
- Zambroski, C. H., Moser, D. K., Bhat, G., & Ziegler, C. (2005). Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *European Journal of Cardiovascular Nursing, 4*, 198–206.