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Safety and understanding: Support as experienced by women living with heart failure in middle age

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Abstract

To reformulate and adjust to their life-situation, women living with heart failure (HF) need help and support. However, the actual meaning of the phenomenon of support is not yet well described. The aim of the study was to uncover the meaning of the phenomenon of support as experienced by women living with HF in middle age. A reflective lifeworld approach within the perspective of caring science was used. Six women (aged 33–61 years) were interviewed. The findings show that the essence of support can be understood as safety, depicted by understanding. However, there is tension between what is supportive and what is not, meaning that even though intentions are good, intended support may involve limitations, uncertainties or insecurity. The meaning of support is further illuminated in the following constituents: “knowledge and understanding”, “finding balance”, “ambiguity of relationships” and “support and formal care—a matter of trust and mistrust”. Findings demonstrate the need for carers to find an approach that ensures both good quality medical care and, at the same time, acknowledges the uniqueness of each individual.

Key words: Support, heart failure, women, middle aged, caring science, phenomenology

Introduction

Within the context of cardiac care, it is well known that women do not receive the same kind of care or treatment as men. In addition, women are more likely to be under-diagnosed (cf. Jaarsma, 2002; Strömbäck & Mårtensson, 2003). Medical research has typically studied men (Jaarsma, 2002; Strömbäck & Mårtensson, 2003) and studies focusing on women’s care, treatment and health, therefore, are needed.

Living with heart failure (HF) means living in a limited and changed life-situation (Mårtensson, Karlsson & Fridlund, 1997; 1998; Ekman, Ehnfors & Norberg, 2000; Rhodes & Bowles, 2002; Nordgren, Asp & Fagerberg, 2007). The life-situations of men and women with HF differ, however, (cf. Strömbäck & Mårtensson, 2003). Women seem to have more difficulties than do men in accepting the limitations set by their failing heart; their reduced ability to support families or friends implies anxiety, insecurity and reduced self-confidence (Mårtensson, Karlsson & Fridlund, 1998). Furthermore, women may feel as if they are a burden to families or friends or even worthless (Mårtensson et al., 1998). More women than men express feelings of guilt and loneliness (Ekman & Ehrenberg, 2002), and younger women experience more mood disturbance, especially anxiety and depression than older women, whose expectations may be more consistent with their condition (Strömbäck & Mårtensson, 2003). Younger women are also not satisfied with their general or social life (Riedinger, Dracup & Brecht, 2000). Despite that women ascribe positive meanings to their illness, their overall quality of life seems to be low (Evangelista, Kagawa-Singer & Dracup, 2001). In addition, living with HF in middle age implies that personal and/or professional life-plans...
must change or be discontinued (Nordgren et al., 2007). A failing heart means an unpredictable health situation, as well as rapid emotional upheaval, where the relationship to life is strained. To reformulate and adjust to the life-situation people with HF need help and support (Nordgren et al., 2007).

Previous studies about support in relation to HF have examined topics such as depression (Konstam, Moser & De Jong, 2005; Friedmann, Thomas, Liu, Morton, Chapa & Gottlieb, 2006), anxiety (Konstam et al., 2005; Friedmann et al., 2006), social support (Krumholz, Butler, Miller, Vaccarino, Williams, Mendes de Leon et al., 1998), social isolation (Friedmann et al., 2006), or quality of life (Johansson, Dahlström, & Broström, 2006). These studies, however, have mainly been performed from a quantitative perspective, and they do not assess the phenomenon directly or what it means for a person to be supported.

**Description of the problem and study aims**

From a caring science perspective, patients are seen as suffering human beings—not as people diagnosed with a disease. The main goal of caring is to alleviate patients’ suffering and to improve well-being, i.e. to help and support patients. Accordingly, support is related to caring but it is not the same thing (cf. Finfgeld-Connett, 2007).

The concept of support is widely used in such diverse disciplines as sociology, psychology, medicine and nursing (Murray, 2000). However, the concept is complex and difficult to conceptualize and it is reasonable to assume that the concept of support may have different meanings in different contexts (Stoltz, 2006). Despite recent research (cf. Murray, 2000), support is often studied in terms of “social support” (commonly defined as potential numbers of supporters) (cf. Hupcey, 2001). Social support is often divided into emotional support and instrumental support (Finfgeld-Connett, 2005), but can also be defined as informational and appraisal support (Langford, Bowsher, Maloney & Lillis, 1997; Johansson, Fridlund & Hildingh, 2005). In the current study, we have chosen not to divide or categorise the phenomenon of support since any attempt at total categorization shuts down the openness for that which is new or indefinite. Dividing or categorising may also mean that the complexity of lifeworld phenomena is lost. From a lifeworld perspective, we believe support is more than “social support”. This is in line with Hupcey (2001), who claim that within the field of nursing, assessments of the quality of support or reciprocity in supportive relationships are rarely considered, and nursing literature and research usually do not consider support as a multidimensional concept.

In conclusion, on the basis of existing knowledge it is problematic to define the meaning of support in relation to HF. Several researchers (e.g. Hupcey, 1998a,b; Williams, Barclay & Schmied, 2004; Finfgeld-Connett, 2005) call attention to the fact that the increased abstraction of the concept of support promotes lack of clarity. The aim of the current study, thus, was to uncover the meaning of the phenomenon of support as experienced by women living with HF in middle age.

**Methods**

In accordance with the study’s aim, we used a reflective lifeworld perspective based on phenomenological philosophy (Dahlberg, Drew & Nyström, 2001). This particular perspective draws on epistemological understandings as outlined by Husserl and Merleau-Ponty.² The aim of reflective lifeworld research is to explore, illuminate or describe events of the lifeworld, i.e. phenomena, in their most original meaning (Dahlberg et al., 2001).

**Informants and data gathering**

Data were gathered in 2006 using interviews. The inclusion criteria were women aged 30–65 years, diagnosed with HF.³ Permission was applied for at three nurse-led outpatient HF clinics in Sweden, however, as no informants were found at one particular clinic informants were only recruited from two of the clinics. Nurses at the outpatient HF clinics received written and verbal information about the study and handled the recruiting in accordance to the inclusion criteria. The nurses chose informants perceived to have an ability to provide rich and in-depth descriptions of their lived experiences as relating to the phenomenon; they informed the women of the study verbally, supplied an introduction letter, and asked whether the informants approved the first author to call later seeking permission to proceed. In that way, the women had the opportunity to consider their participation cautiously and to reject if they did not want to participate.

The sample size was not decided on beforehand. Instead the sampling was determined by the informants’ ability to provide rich data. In research based on a reflective lifeworld perspective, variation in data is more important than the number of participants (Dahlberg et al., 2001). Six women diagnosed with HF were invited to participate. The six women were aged 33–61 years (age 33, 50, 57, 58, and two women were 61 years), which was considered to fulfil the demands for variation. One woman was single, two were retired, one was working and three...
were on sick leave. The first author called the informants and arranged for the interviews. Five interviews took place in the informants’ homes, and one was carried out at the outpatient HF clinic. The informants received both verbal and written information about the study. The audio-recorded interviews lasted between 45 and 100 min. No ready-made questions were used, except for the opening question (“Could you tell me about what it is like to live with heart failure?”). To deepen the descriptions, the interviewer (first author) posed questions such as, “What kind of support do you need with that?” The interviewer tried to be open to the informants’ descriptions, but at the same time she tried to bridle her own pre-understanding to gain a new understanding of the phenomenon (cf. Dahlberg & Dahlberg, 2004).

Data analysis

Verbatim transcriptions of the interviews (conducted in Swedish), were read by all authors. Each interview was divided into meaning units, which were put together into clusters of meanings. The clusters were described in everyday language. As the most invariant parts of the text—the essence—started to emerge, the descriptions were again examined to search for variations, i.e. the essences’ particulars or meaning constituents (cf. Dahlberg, 2006a). Unlike a more interpretive approach, intentional or theoretical explanations were not used in any phase of the analysis.

In the first draft of the description, the essence was described as “understanding”. However, given that the essence must be seen in each meaning constituent within the description of the phenomenon (Dahlberg, 2006a), the meaning of the essence changed after formulating the meaning constituents. Against the background of these meaning constituents, the figure of the essence stood out as “safety”. All authors took part in the analysis.

The essence of the phenomenon is described in the Findings section, followed by descriptions of the meaning constituents, further elucidating the meaning of the phenomenon. To clarify the particulars of the phenomenon, quotes from the interviews are provided as examples of explicated meanings.

Ethical considerations

In Sweden, ethical permission is not needed for this kind of research (SFS, 2003, p. 460). However, the managers at the HF clinics approved the study. The authors had no access to medical records. The informants had the opportunity to pose questions and they signed an informed consent form before the interviews started. The authors were careful during translation of quotes from the interviews so as not to alter original meanings. Quotations have not been labelled with participant numbers or pseudonyms in order to protect informant identity. When an ellipsis (…) appears within quoted speech, parts have been left out, as those parts are not considered essential for the reader’s understanding of the text.

Findings

The essential meaning of the phenomenon of support, as experienced by women living with HF in middle age, is understood in terms of safety. Support is a tool that the women use in order to handle their changed and limited life, despite fear or uncertainty. The meaning of safety is created in the women’s encounters and relationships with other people, as well as in daily life, and is depicted by knowledge and understanding. When the women experience that they are understood by others, they feel safe, and when they understand their condition and what their condition is about, they have a sense of control and safety. The phenomenon includes a dimension that can be understood as having inner assets, strengthening the women’s self-confidence, and meaning they are able to live a life that they consider as normal as possible. However, there is a tension, an ambiguity, between what is and is not supportive signifying that even though intentions are good, intended support may involve limitations, uncertainties or a feeling of being unsafe. The meaning of support and the tension between what is and is not supportive is further illuminated by the meaning constituents: Knowledge and understanding; finding balance; ambiguity of relationships; and, support and formal care—a matter of trust and mistrust.

Knowledge and understanding

Knowledge and understanding are supportive as they strengthen the women’s self-confidence, reduce fear or anxiety, and increase safety. Living with HF implies a life-situation marked by existential insecurity and uncertainty. In addition, the body’s shortcomings are noticeable, bringing on a sense of fear or discomfort, reminding the women of the condition’s seriousness and the frailty of life. Insufficient knowledge or fear of the life-threatening and incurable condition means they do not know how much they may strain their hearts, which put limits on their daily activities, signifying a life-situation that they feel they cannot control. Thus, they need to know how to control their unreliable bodies and their daily lives.
Initially, the condition is perceived as a nagging discomfort. Something is wrong, but the women do not know what; they search for answers or explanations, such as being unfit or getting older. They might go to a physician or a nurse at a health care centre or they might wait at home as long as possible, not seeking care and not comprehending the condition’s seriousness. Later, the inability to understand and grasp the seriousness of the condition may impose a sense of guilt over not seeking care earlier.

At first, the women cannot identify their bodily experiences as something involving their heart. They are surprised, not only over the fact that their heart is ill, but also because they associate HF with ageing, and not with persons of their own age. “What?” I said, ‘the heart, I don’t understand, I don’t get it.’ I said, ‘I’m simply unfit and I’ve got a cold’.

The diagnosis, thus, is received with surprise or fear; the diagnosis does not merely mean the condition is named, but a meaning is also brought on. At the same time, being informed about the diagnosis is supportive as it involves a confirmation of the women’s experiences and it brings an understanding about what is happening to them and why. However, it takes time to grasp the significance of the situation. To be struck by a serious and life-threatening disease means to realize one was lucky to survive, which means gratefulness; at the same time, this realization means fear about what is going to happen. Practical issues, concerning housing or professional interests might initially overwhelm existential questions. Knowledge about a poor prognosis involves fear, vulnerability and exposure, which may paralyse or set limits to life, meaning life may be perceived as meaningless or hopeless. In addition, experiences of losing someone close can increase one’s own fear for death; but at the same time personal experiences of previous life-threatening conditions can mean hope for survival once more.

When life is marked by disorder or existential chaos, the women are concerned about how their life-situation will be and about what they will and will not be able to do. They have questions about their future, and they try to pay attention to what is going on, with regard to new findings or new treatments, indicating hope for a new and different life-situation. However, the notion of undergoing advanced treatments, such as a heart transplant, can be difficult to relate to and can bring on fear or uncertainty.

There is, however, a tension between what the women do and do not want to know. An ambiguity exists in which uncertainty is preferable to finding out something distressing, implying that they might not ask certain questions or take in information, indicating insecurity or fear. While some women want to know what caused their condition others do not. “I’d say, it’s better . . . not knowing than knowing one caused it oneself.” In addition, if information about the prognosis, treatment, or condition is provided before they have grasped the significance of living with HF the information might be perceived as unimportant. Alternatively, when they know what they are dealing with they can spend time and energy finding ways and strategies to control their situation, instead of ruminating about causes or being afraid.

The women try to take control of their new life-situation in many ways. They change their diet or they search for information in brochures, on the Internet or on food packaging. They wish to understand the condition and wish to do what they can to take responsibility for their own health. If family members take part in the changes and have a positive attitude toward the lifestyle changes, the women feel supported. Thus, information and guidance on how to live and handle their health situation is supportive. Formal carers, such as HF nurses, may provide written or verbal information about the condition, which is supportive and provides an opportunity to understand and relate to the situation. Sometimes information about how the heart is functioning is provided via video or computer. However, the women might perceive such information as technical, fragmented, or too general, and if formal carers do not tell them about the seriousness of the condition, they perceive they do not receive sufficient information on how to handle their life-situation.

I thought it didn’t seem too bad. But then I started to understand . . . that it actually was. So . . . it took a while before I understood . . . what it meant, and it was more by accident that I started to understand this was actually something one would die from . . . unless one got help. . . . And I can understand that one . . . doesn’t want to paint the worst picture, just when one gets . . . the message, but, but, . . . No, it was . . . I wish I had received more information.

Being curious and putting questions to formal carers is another way to gain more knowledge and understanding. It also provides a possibility to be active in one’s health care process, and a sense of participation in one’s own care. Participation does not mean questioning treatments or formal care, but rather having knowledge, involvement and understanding. If formal carers do not follow up on lifestyle changes, the women feel uncertainty because they do not receive confirmation on whether or not their changes are sufficient. In addition, at
times they do not act as they are told, promoting a sense of guilt or a sense of fear about what harm they might have caused themselves.

“I’m rather useless; I’ve been told I should drink only one litre, between one and one and a half litres … a day. [Int.: Mm] But, I’m rather useless; I drink at least two litres a day. …”

When formal carers do not provide sufficient or relevant information, the women have doubts or uncertainty, and they feel deserted and they feel forced to search for information on their own. If they do not know whether their condition will improve, or if they are not able to identify useful information in order to know what can promote improvement, they may fumble as they search for answers. Furthermore, if formal carers are not confident about discussing existential issues, their information tends to be factual and related mainly to medical issues; the significance of what it means to live with HF may be disregarded or left out. “It’s difficult, I think, for all parties. It may be difficult for the staff as well, to deal with the lot. …” As time passes, the women realise life goes on in spite of the failing heart, and their need for knowledge changes. As they gain new understanding of their life-situation, they might also revalue it.

Finding balance

Finding balance means learning to adjust to the rapidly changing health situation. In HF the body’s condition constantly changes, meaning some days are perceived as good days, while other days are perceived as bad. On good days, the women enjoy life, doing purposeful and meaningful activities, hoping not to get worse. However, rapid episodes of deterioration mean despair and hopelessness.

But that night … the pain came back … and then … I thought it was dreadful. [Int.: How do you mean?] Well, I thought it was, one sort of ended up in … in a dark hole, sort of, like ‘now I’m going down again … in this …’ like ‘This, I won’t survive’. …

At the same time the women can learn to endure and to wait in spite of panic and discomfort, knowing temporary deteriorations can subside. The limits, which the failing heart sets, hinder them from putting themselves into action or engaging in tiring efforts. They can no longer do the things they used to do, and they can no longer be the people they used to be, which means a change in self-image. The limited life promotes doubts or questions for the future involving feelings of frustration, powerlessness, sadness or meaninglessness.

One cannot do the things one wants to do. That’s … that’s how it is. [Int.: Mm … Then, what do you feel?] Well, what does one feel? Anger, misery … depending on … what day it is and what mood one’s in … and, sometimes it’s just … sad and bloody awful and boring and … just like that.

Finding balance also means finding ways and strategies to handle and relate to the new and different life-situation, as well as inner supportive assets. Learning to live with HF involves a sense of not having any choice but accepting the circumstances, meaning the women try to appreciate what they have, and to perceive their life-situation as meaningful. To balance the changed and limited life, they seek relaxation in meaningful activities, which might make negative thoughts or emotions fade away for a while. Various activities also bring some structure to daily life, which they need to handle their situation. When the body is not constantly reminding of the condition, it means a possibility to live a life that the women consider as normal. Inner assets involve strength to stand up against the condition, not giving way for the limits that the body sets, signifying they might perform activities despite their serious condition or even against advice from others about cutting back. The women might also find ways to make use of the reduced ability to perform activities; they might ask for help, not only when it is actually needed, but also to be excused from certain activities that are perceived as boring or tiresome.

The women need balance between the threats from the unreliable, limited body and the constant attempts to control it. Medications, thus, are new, lifelong and life-supporting companions, which they must accept. However, adjustments must be made to daily life in line with the medications, meaning a need to find ways to handle and relate to these new requirements. In addition, medications are expensive, involving economic constraints. Medications also bring on bodily complaints, such as dizziness, cough, or nausea. When formal carers omit information about such side effects, these bodily complaints are perceived as unexpected or unpleasant surprises. At the same time, medications promote hope for improvement. When the heart’s condition improves, the women feel relief, pleasure or hope and when the treatments are working sufficiently, they might handle their situation and take responsibility for their health. At the same time, unexpected improvements can throw them from despair into hope,
signifying rapid emotional turns or experiences. The women’s understanding about their medication, thus, is ambiguous and having to take medications is perceived as odd; it takes time and needs balancing to get used to it. Medications become simultaneously supportive and not supportive, signifying a need to balance between the dependency on medications and the inconveniences they bring.

Ambiguity of relationships

To be struck by a life-threatening disease implies a need for help from others and for being cared for, i.e. a need for support and safety. However, there is a line between being cared for and being overly cared for, an ambiguity of relationships and a tension between what is supportive and what is not, meaning the women’s relationships to other people can change and relationships to others might be strained. When other people understand what the situation is about, adjust to the circumstances, or do not perceive the women’s limited performance as a source of irritation or frustration, the women feel supported and gain strength to handle their fear and anxiety. In addition, other people’s awareness of the condition is perceived as safety, in case something happens. Thus, being supportive means to be on hand and caring, but the line between being cared for and being overly cared for is fine. Support does not mean that others take over the women’s problems; instead support means the women have help to handle problems and to get through them.

When the women feel they are supported and cared for, they achieve inner assets for handling their life-situation, making up life plans and goals and for taking on responsibility for their health situation.

No, I think I’ve got the very best help [Int.: Mm] and ... I’ve got all the support I need and ... I’ve got an incredible lot of information and ... eh ... No, the biggest part of the work is on me now, I think. ... [Int.: How do you mean?] If I don’t, I’ll never get back. ... But it is, I do have my goals and I think ... I’ll get back, and that’s my goal. ... [Int.: Mm. Yes. And when you think about the future, how do you think?] ... No, I’ll, I’ll have my surgery and I’ll lose weight ... eh, and then I’ll take care of myself and I’ll ... I will do things I didn’t before, I will take care of myself, sort of, and I will ... start exercising and, and I’ll do things like that [Int.: Mm] O, yes, I certainly will.

When life can no longer be taken for granted, it means close relations to family and friends are more valued than previously and both women and family might be more concerned than before about staying in touch. Still, the unreliable health situation might prevent the women from planning family activities, which involves a sense of guilt over the limits they put on family life.

The reduced ability to perform activities means the women’s self-image changes, but so do other people’s image of the women. When family members have a positive attitude, knowledge and understanding, it is perceived as helpful and supportive; they might be able to help and support the women with matters concerning formal care or treatments as well as with practical issues. For example, the partner may take over some housework that the women did previously.

However, if the partner does not do the work in the same way as the woman, it might promote feelings of frustration or irritation over not being able to do the things she did previously. In addition, if family members take over housework, or try to get the women to refrain from doing certain activities, the women feel they are being overly cared for and overprotected, involving a sense of being fragile or vulnerable, meaning frustration or annoyance.

Initially one was, maybe one was like sitting in a bell jar ... sitting inside it, I was sitting in this little ... bell jar and my husband, he. ... Well, I was just to sit there and I wasn’t to move and I was to stay in there ... It was so fragile, so fragile. ... [Int.: Did they put you in that bell jar ...?] Yes, they ... [Int.: or did you put yourself in there?] No, they put me in there ... and ... I ... was not allowed to move and ‘now, you sit there and ... and don’t do anything and ... and so on. ... Because, they were worried, this was not supposed to happen ... .

Being overprotected and overly cared for deepens the women’s uncertainty and confusion, and they will find it even more difficult to handle and relate to their life-situation.

The women need to talk to other people about their experiences, but, at the same time, they are concerned about being too pushy, self-centred, or burdensome to others. Yet, the insight into the condition’s seriousness is shocking, not only to the women but also to family, friends, and colleagues as well, meaning there might be problems discussing it. The family might not want to talk about it in order not to show the women how concerned they are, or the women might be careful about what they say, in order to spare the family distress. In addition, fear of death may be overwhelming, and the women might not be able to talk to others about their situation. At the same time, being with and talking to people who do not know and do not understand the situation,
can be perceived as somewhat problematic; the relation between the woman and that person may be strained. However, when the women themselves are not worried or when the body does not constantly remind them of the condition, the need for having someone to talk to is reduced.

Sharing experiences or fear with people having similar experiences with a heart condition means the women might realize they can exert themselves without any risks and that it is possible to live with HF. Likewise, people who do not have similar experiences might listen, but they still might not quite understand what it means to have experiences of a life-threatening condition. “...they might listen cheerfully, but I don’t think they really understand. As for my spouse ... he doesn’t understand whatsoever what it’s all about.”

The women need self-confidence and faith to balance their life-situation. Other people, as well as a belief in God, might provide tools that are needed to deal with negative thoughts or emotions.

“That person and I talked it over and I received tools that I needed to handle such matters, so that I won’t drop down again ... into this ... self-pity thing again.”

To believe in God might bring comfort, safety, companionship and joy. In addition, a confident belief that one’s life and future is in the hands of God might reduce a fear of death and bring on safety and meaning to life. To be loved, by God or by other people, means one can love oneself and have sincere confidence in oneself and one’s ability to handle and control a situation. At the same time, having a flawed body might provide an idea that one is less valued in the eyes of other people. “... I’m not a worse kind of person only because I happen to have ... a body that is not working properly.” To feel one is precious and loved in spite of the faulty body involves safety, hope and a meaningful life.

And this, to feel one is valuable even though one is ... is ill and disable ..., not disabled, but ... that one’s not, one’s body’s not that good ... that makes ... life ... meaningful ... anyhow ... so to speak [Int.: How do you mean that. ... Could you expand on that?] Yes, I’m not done [Int.: No ... ] It gives you hope, it gives me ... it gives me ... a good self-confidence.

Being able to work, in spite of the condition, raises an opportunity to maintain one’s self-image. To have a job also means economic safety and a structure in daily life. Work also promotes a social network, as well as a sense of well-being and a meaningful life-situation. However, the women’s limitations might involve difficulties in performing activities at work, which promotes feelings of insecurity and uncertainty. The women feel supported when colleagues or employers understand the condition, as well as keep in touch while the women are on sick leave. It is also perceived as supportive if tasks at work or working hours are adjusted for the circumstances. However, if employers or colleagues do not stay in touch while on sick leave, the women feel deserted and unimportant as a person or an employee.

In addition, being on sick leave means the women must deal with the representatives from social security and welfare services that may place demands to return to work, to engage in vocational training or to apply for disability pension that may be perceived as unrealistic or unlikely and that may elicit anger, frustration or concern. If representatives for the social security services do not understand what it means to live with HF, it may signify a sense that the women are deemed as not trustworthy, which is experienced by the women as humiliating and implies further strains and uncertainty in their relationships to life.

“And I think one has worked all one’s life, sort of ... doing what is right, not ... Yes, you know, I was hardly ever sick ... and then one is treated like this.”

At the same time disability pension might be supportive, because it provides an opportunity to escape the stress and strains of vocational life.

Support and formal care—a matter of trust and mistrust

To live with HF means living with an unpredictable health situation, signifying dependency on formal care and treatments. The awareness that something is wrong with the body’s most vital part, the heart, is frightening and distressing and the women need to know how to obtain instant care and treatment if their condition deteriorates. Formal care involves relief, and a situation that can be controlled. Encounters with formal carers that are characterised by mutual respect, openness, and confidence promote feelings of trust, faith, and safety; encounters with formal carers who are perceived as ignorant or less competent, mean fear, hesitation or mistrust.

Initially, when the women receive the diagnoses, their life-situation is characterized by chaos, and they need structure in daily life. When formal care is well structured, organized and reliable, they know to whom they can turn, which brings trust and safety. Accessibility to HF nurses is highly valued by the
women. The HF nurse is a competent person to talk to, who understands the situation and the condition. Talking with an HF nurse reduces fear or anxiety, meaning a sense of safety and support. Furthermore, HF nurses are able to arrange supportive contacts with other professional carers or counsellors, such as welfare officers, who might provide an opportunity to sort out the situation by getting different perspectives and understandings of the life-situation.

Yes, it was scary at first...Because...I...I thought...The heart...I mean, the heart, that's rather serious...And I felt...pretty bad...for a couple of weeks...[Int.: Mm]...before I started to work it out...and also...when I talked to the HF nurse then...in peace and quiet...that I thought was, it gave me a lot...[Int.: Mm]...it was easier to talk to her [than the physician] and I've met with her several times and it felt good to...one could discuss diverse matters so...[Int.: Mm] It...it was good...

However, the women might perceive the HF nurses' competence as limited, and the support may be perceived as insufficient; therefore, visits to cardiologists are sometimes more highly valued. If the planning of those visits fails, the women have a sense of being deserted or forgotten, left to uncertainty, insecurity, fear or anxiety. At the same time, when help is needed to obtain medicines or medical certificates concerning sick leave, the HF nurse can work as a link to the physician. However, the women’s respect for the physicians might involve limitations; it might be perceived as difficult to talk to the physicians about their problems in daily life. Some carers appear as more supportive than others meaning support, information, or participation are tied to specific carers. Formal carers who demonstrate being careful, honest, and sincere—that is, they take their time and the women’s problems seriously—are seen as being engaged and as having a true wish to help. They are also perceived as comforting and caring.

“He may talk to me for an hour or so...and he tells me things and...We’re discussing things and he listens to me and...he explains and...yes, if I have any questions and so on.”

If formal carers contact the women, whether or not they have a formal purpose, it is perceived as a personal initiative, involving a sense of being valuable and safe, indicating participation and support. Moreover, insecurity is reduced when measurable values, such as blood pressure, blood tests, pulse, or ECG, are examined and controlled by formal carers. Appointments with formal carers, which are planned in advance, promote a sense of being cared for and are both helpful and supportive. Still, when the condition is stable, and the body does not constantly remind the women of their condition, the need for planned appointments decreases.

However, the support that the women receive within the context of formal care can be understood as a conditioned support. Routines can seem to have priority over personal needs when patients must endure long waiting times, as well as delayed, meaningless, or needless examinations and treatments. Furthermore, bureaucracy and slow routines within the care-giving organization mean the diagnoses’ objective value decides which care or treatment one receives.

...heart failure is...in some way quite odd...Maybe focus has been on heart attacks and things like that; that business seems to be working or...how to say...So, this is a bit left behind, there is no real...place for it or for what one should...say. I don’t know [inaudible]. It makes it rather hard...

If formal care is perceived as unstructured or badly planned, the women can have suspicion or hesitation toward carers and the care-giving organization, as well as fear of being forgotten or not receiving the care on which one is depending. When formal carers seem uncommitted or uninterested, they feel that information, care, or treatments are provided randomly or by coincidence. It may also bring on anger or powerlessness for them. At the same time, the power of formal carers implies that carers are the ones making decisions, meaning they have the authority to overlook the women’s own knowledge about their bodies and health, which can give the women a sense of anger, sorrow, or despair.

Yes, one becomes awfully frustrated. Because one is...one is completely...powerless...they are in charge of course, I can, I can force nothing...I can’t...they decide, just like that, no matter how foolish...I can do nothing.

If formal carers do not respect the women’s time, it means that meetings are perceived as meaningless, depersonalized or fragmented. When they are not taken seriously or are not respected, they experience frustration, uncertainty, or doubts over their own experiences, as well as over the carers’ professional competence. This also involves a sense of not participating in ones’ own care or treatment, helplessness and exposure. If the women experience that
formal carers consider the patient’s body as a machine to be programmed, it means technology is prioritized over personal needs and well-being.

“And I’m just lying there, feeling as a robot (laughing) … lying there, and they are programming me. … she’s an expert on the device, but she’s not an expert on me.”

In addition, insufficient care means the women must nag, watch, and check to make sure everything works. Sometimes they must insist, persevere or lie in order to receive the care or treatment they are depending on, and to avoid exposure to life-threatening or chronic states. This takes energy, causes worry, and is perceived as frustrating. In addition, when the women experience that knowledge about their own body, health, or treatment is ignored, it means their personal well-being is disregarded. Experiences of being neglected mean they might decide to seek care elsewhere despite being in a life-threatening state. However, the body’s serious condition forces them to surrender to care, despite doubts and powerlessness.

**Discussion**

The current study revealed the phenomenon of support as a multidimensional and subjective experience created in the women’s encounters and relationships with other people, as well as in daily life. Support, thus, is more than “social support”, or “instrumental support”. To be supported means to feel safe and to have the inner assets needed to handle one’s life and situation. The findings illuminate existential aspects, which are important for discussions in relation to individuals living with a chronic and life-threatening disease such as HF. Previous studies about women living with HF have mostly included older women and many of the results are somewhat contradictory; trying to compare the results of the current study to previous research reveals both discrepancies and similarities.

The women in our study had many questions about their future, which involved feelings of frustration, powerlessness, sadness or meaninglessness. Paton, Backlund, Barnes and Thirsk (2007) found, in line with the findings of the present study, that women living with HF balance their wishes and must be realistic about having hope, because of disappointment and an unknown future. This may be due to the continual, more or less present threat which the failing heart imposes on them; that the future is conceived as uncertain ( Europé, Axelsson & Tyni-Lenné, 2001; Nordgren et al., 2007). The findings of Mårtensson et al. (1998), however, which indicated that older women living with HF do not worry about their future and may be content with their past life and present situation, are not in accordance with the current study. The informants in the current study conceived a limited life-situation marked by existential insecurity and uncertainty, and they searched for control in order to reduce fear and anxiety. It is well-known today that people with HF suffer more from anxiety and depression than people with other cardiovascular diseases, as for instance myocardial infarction (Jøkels, van Elderen & Schreurs, 2007). In our study it was striking how fear suffused the women’s experiences of their situation; a finding in line with others (Mårtensson et al., 1998; Europe et al., 2001; Costello & Boblin, 2004). The women’s life-situation is derailed, interrupted, and their situation is marked by limitations and unwanted change, factors that have also been described by Roebuck and co-workers (Roebuck, Furze & Thompson, 2001). Roebuck et al. (2001) reported that several participants were fearful of doing too much or too little, meaning they were reluctant to resume normal activities of living which resulted in reduced life-satisfaction and well-being. Findings of Mårtensson et al. (1998) also illuminated that older women may be annoyed about their inability to do what they used to do, and may have a sense of worthlessness and may feel more burdensome to other person’s, which is in line with the middle-aged women participating in the current study. Rhodes and Bowles (2002), however, described that older women do not appear to be concerned with anxiety, even though they experience loss and a threat against possibilities to control their life-situation. However, to gain control over their life-situation they have to struggle (Rhodes & Bowles, 2002), which seems to be in line with the middle-aged women in the current study. Our findings, however, showed that the women seemed to be struggling foremost to be themselves, i.e. to stay involved in projects and activities that were directed toward realizing own life projects or goals.

With support from other people, women living with HF in middle age may achieve tools by which they can reduce their feelings of anxiety or fear, meaning they may experience well-being and a sense of having control over the life-situation. In addition, support may help a person who use avoiding coping behaviours, such as denial or disengagement, which are associated with poorer health outcomes for patients with HF (Konstam et al., 2005).

The women’s experiences of ambiguous relationships, which were found in the present study, have been described by others. Mårtensson et al. (1998) described that older women may experience a sense of insecurity in relation to themselves and in relation
to people in their surroundings. This conception ranges between a feeling of abandonment and a sense of devotion from those around them (Mårtensson et al., 1998). Furthermore, this reaction seems not to be limited to family members, but to relationships with friends and work colleagues, as well, because friends or colleagues may have limited understanding of the condition (Roebuck et al., 2001). According to Gary (2006), the extent to which social networks have positive or negative influences on women's self-care is not clear because many women seem to be ambivalent about their support systems. Feelings of vulnerability and insecurity coupled with worry may reduce the women's self-confidence, which results in strained family and social relations (Roebuck et al., 2001), implying ambiguity and tension between what is supportive and what is not. This ambiguity illustrates reciprocity of support, “a dark side to helping” (Lu & Argyle, 1992), which means that support can have negative consequences, such as feelings of dependence and guilt, implying a negative well-being/support link (Lu, 1997). When people receive support, they may feel as a burden to others, or in indebtedness, which correlates negatively with their health (Takizawa, 2006) and their well-being (Lu, 1997). This is because people receiving support may feel threatened if the support poses a threat to their sense of self-management or it may damage their self-esteem and evoke feelings of helplessness (Lu, 1997).

According to the findings of the current study, as well as others, women living with HF seem to experience a sense of being overprotected (Mårtensson et al., 1998; Europé et al., 2001). The experience of being over-protected is in line with findings also of other studies, which describe that people, after a myocardial infarction, may experience that personal relationships become strained because of their partners or family members becoming over-protective (Roebuck et al., 2001; Sjöström-Strand & Fridlund, 2007). A person can feel overprotected in different ways (e.g. emotionally or practically), and this can vary in intensity, from moment to moment and from situation to situation (Joekes et al., 2007). This implies feelings of frustration since the ill people may experience they are not allowed to perform activities that are within their capability or, activities they have been told to undertake, for example, mild exercise (Roebuck et al., 2001). According to Joekes et al. (2007), over-protection is associated with depression for people living with HF and can result in an individual becoming a “cardiac invalid”, which may reduce the ill person's health-related quality of life (Roebuck et al., 2001). Accordingly, it can be very important to women living with HF that formal carers meet and talk to their relatives, so that the relatives do not take over too much of the women's household duties or restrict and limit the women's daily activities.

The findings of the current study demonstrate that knowledge and understanding is supportive to women living with HF in middle age. We found in similar to Riegel et al. (2003), that as time passes the life-situation changes indicating that the need for information and support changes over time. In Sweden, people living with HF often are initially offered visits to HF clinics, i.e. over a shorter period. As soon as medication is up-titrated and works satisfactorily, the patients are referred to primary health care centres, where it is quite common that no cardiologists or HF nurses are available. This suggests that as soon as the women start to find out how to handle and relate to their new life-situation, suddenly the specialised information and care which they need is no longer available. Many people living with HF have modest knowledge about their condition or treatment, therefore, patient education is a main task for HF nurses who need to find teaching models in order to educate the patients so that they can actively participate in their own care (Strömbäck, 2005). Knowledge and understanding can make a situation more comprehensible and increases a sense of control (cf. Strömbäck, 2005). Women living with HF in middle age need support and information about the strains of activities they might put on their hearts, and they need help and support from formal carers to identify their fears if they are to handle and sort them out. However, the women themselves may not be aware of these problems and formal carers need to be sensitive and open-minded in order to grasp and understand the nuances of the ill person's life-situation. Formal carers can support women living with HF in middle age by talking to them about the future, e.g. about returning to the work situation or about developing their personal life-plans. Understanding patients’ experiences is essential in order to improve HF prevention and education. If formal care is carried out from out a lifeworld-led model for care (cf. Tordres, Galvin & Dahlberg, 2007) the carers may find an approach that ensures both good quality medical care and at the same time acknowledges the unique individual’s lifeworld. There is a need for evidence-based practices that have proven effective in addressing the life-altering experiences of HF.

Methodological reflections

All research needs to be validated and objective if it is to be valued as scientific (Dahlberg, 2006b). Research
findings must also be able to generalise. Our study has not produced knowledge that can be generalized to women with any type of heart disease or to all age groups; however, the knowledge obtained can be reflected upon and considered in other contexts. In human science research validity and objectivity means openness, susceptibility and sensitivity to the phenomena in focus (Dahlberg, 2006b). Openness means the researcher, through a reflective attitude, strives to reflect on, to question and to be aware of the influence of his/her own pre-understanding and to bridle it (Dahlberg & Dahlberg, 2004), which means that we cannot allow our pre-understanding to “affect our understanding in an uncontrolled way” (Dahlberg & Dahlberg, 2004, p. 272). To bridle pre-understanding means that the researchers strive to take on a self-critical attitude, to reflect on any pre-understanding, and then to bridle it, placing the analysis and the findings in question through systematic reflection and discussion with other members of the research team. The current study has been performed rigorously and carefully with a self-critical and reflective attitude. The researchers’ pre-understanding has been questioned, problematized, interrogated and discussed. Despite this effort, there is always a risk that the final findings convey traces of the researchers own pre-understanding.

Within the field of phenomenological research, findings are always contextual and are always infinite; therefore, phenomenological research findings cannot be understood as universal (Dahlberg, 2006b). However, the results must be meaningful to other people than those involved in the study. For instance, the findings from the current study may be meaningful also to another context. The meaning of the dimensions of the phenomenon of support may be applicable—albeit the content and the practical implications may change between contexts.

Furthermore, the idea of application can be useful when generalizing research results based on a life-world perspective (Dahlberg, 2006b). Application means that the findings can be practised and understood within its particular context (Dahlberg, 2006b), but also in different contexts. For instance, the findings of the current study illuminated that the women need to feel safe in order to handle their life-situations, which at times are incomprehensible or out of control. These findings are not only useful to formal carers who encounter middle-aged women living with HF, but can also be of interest when supporting other people living with HF, e.g. older persons or male patients. Some of the findings may also be useful for carers who are to support people with other chronic illnesses. In this capacity, the findings of the current study are possible and appropriate to generalize.

Formal carers can use these findings in practice in order to increase understanding during assessment and management; and when educating and offering support to middle-aged patients with this chronic, incurable, and debilitating condition. In particular, formal carers can adopt open communication strategies to explore the meaning of a diagnosis of HF for individual patients. They can provide ongoing support and screening for signs of depression, as patients adapt to living with HF. In addition, formal carers can ensure that patients receive information about their condition, so they feel able to participate in the self-management process.

Conclusions

- Women living with HF in middle age need support if they are to reformulate and adjust to their changed life-situation.
- The meaning of support is created in the women’s encounters and relationships with other people, as well as in daily life. Support, can be understood as a sense of safety. However, there is a line between being cared for and being overly cared for, an ambiguity of relationships and a tension between what is supportive and what is not.

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Notes

1. In the current study, a wide definition of “middle age” (30-65 years) is used in order to get rich variation in data in accordance with the methodological approach.

2. To deepen the understanding of the epistemology of reflective lifeworld research we suggest readings of, for instance, *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy* by Edmund Husserl (1913) or *Phenomenology of perception* by Maurice Merleau-Ponty (1945).

3. In the current study, the severity of the disease—e.g. in terms of the classification by the New York Heart Associations (NYHA) for heart failure—has not been considered as relevant, since the health condition in HF constantly changes, and the ill persons’ perceptions of their condition varies from one day to another. In addition, since patients and carers hold different perspectives on illness, objective assessment of the severity was considered as irrelevant.
References

Costello, J. A., & Boblin, S. (2004). What is the experience of men and women with congestive heart failure? Canadian Journal of Cardiovascular Nursing, 14(3), 9–20.

Dahlberg, K. (2006a). The essence of essences—the search for meaning structures in phenomenological analysis of lifeworld phenomena. International Journal of Qualitative Studies on Health and Well-being, 1(1), 11–19.

Dahlgren, K. (2006b). Editorial. International Journal of Qualitative Studies on Health and Well-being, 1(3), 130–132.

Dahlgren, K., & Dahlberg, H. (2004). Description vs. interpretation—A new understanding of an old dilemma in human science research. Journal of Nursing Philosophy, 5(3), 268–273.

Dahlgren, K., Drew, N., & Nyström, M. (2001). Reflective Lifeworld Research. Lund: Studentlitteratur.

Ekman, I., & Ehrenberg, A. (2002). Fatigue in chronic heart failure—does gender make a difference? European Journal of Cardiovascular Nursing, 1(1), 77–82.

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(2), 130–136.

Europé, E., Axésson, K., & Tyni-Lenné, R. (2001). Om upplevelse av sjukdom och livsställning hos kvinnor med kronisk hjärtsvikt. [Experience of disease and life situation in women with chronic heart failure]. Nordisk Fysioterapi, 5(2), 50–57. In Swedish.

Evangelista, L. S., Kagawa-Singer, M., & Dracup, K. (2001). Gender differences in health perceptions and meaning in persons living with heart failure. Heart & Lung, 30(3), 167–176.

Finfgeld-Connett, D. (2005). Clarification of social support. Journal of Nursing Scholarship, 37(1), 4–9.

Finfgeld-Connett, D. (2007b). Concept comparison of caring and social support. International Journal of Nursing Terminologies and Classifications, 18(2), 58–68.

Friedmann, E., Thomas, S. A., Liu, F., Morton, P. G., Chapa, D., & Gottlieb, S. S., (Sudden Cardiac Death in Heart Failure Trial Investigators). (2006). Relationship of depression, anxiety, and social isolation to chronic heart failure out-patient mortality. American Heart Journal, 152(5), 940.e1–8.

Gary, R. (2006). Self-care practices in women with diastolic heart failure. Heart & Lung, 35(1), 9–19.

Hupcey, J. E. (1998a). Social support, assessing conceptual coherence. Qualitative Health Research, 8(3), 304–318.

Hupcey, J. E. (1998b). Clarifying the social support theory-research linkage. Journal of Advanced Nursing, 27(6), 1231–1241.

Hupcey, J. E. (2001). The meaning of social support for the critically ill patient. Intensive & Critical Care Nursing, 17(4), 206–212.

Husserl, E. (1913/2004). Ideer till en ren fenomenologi och en fenomenologisk filosofi. [Ideas pertaining to a pure phenomenology and to a phenomenological philosophy.] (1913). Stockholm: Bokförlaget Thales.

Jaarsma, T. (2002). Are women different than men? Aspects of heart failure in special populations: elderly women. European Journal of Cardiovascular Nursing, 1(1), 29–31.

Joke, K., van Elderen, T., & Schreurs, K. (2007). Self-efficacy and overprotection are related to quality of life, psychological well-being and self-management in cardiac patients. Journal of Health Psychology, 12(1), 4–16.

Johansson, I., Fridlund, B., & Hildingh, C. (2005). What is supportive when an adult next-of-kin is in critical care? Nursing in Critical Care, 10(6), 289–298.

Johansson, P., Dahlström, U., & Broström, A. (2006). Factors and interventions influencing health-related quality of life in patients with heart failure: a review of the literature. European Journal of Cardiovascular Nursing, 5(1), 5–15.

Konstam, V., Moser, D. K., & De Jong, M. J. (2005). Depression and anxiety in heart failure. Journal of Cardiac Failure, 11(6), 455–463.

Krumholz, H. M., Butler, J., Miller, J., Vaccarino, V., Williams, C. S., Mendes de Leon, C. F., et al. (1998). Prognostic importance of emotional support for elderly patients hospitalized with heart failure. Circulation, 97(10), 958–964.

Langford, C. P., Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: A conceptual analysis. Journal of Advanced Nursing, 25(1), 95–100.

Lu, L., & Argyle, M. (1992). Receiving and giving support: Effects on relationships and well-being. Counselling Psychology Quarterly, 5(2), 123–133.

Lu, L. (1997). Social support, reciprocity, and well-being. Journal of Social Psychology, 137(5), 618–628.

Mårtensson, J., Karlsson, J. E., & Fridlund, B. (1997). Male patients with congestive heart failure and their conception of the life situation. Journal of Advanced Nursing, 25(3), 579–586.

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(6), 1216–1224.

Merleau-Ponty, M. (1945/2005). Phenomenology of perception. London: Routledge.

Murray, J. S. (2000). A concept analysis of social support as experienced by siblings of children with cancer. Journal of Pediatric Nursing, 15(5), 313–322.

Nordgren, L., Asp, M., & Fagerberg, I. (2007a). Living with moderate-severe chronic heart failure as a middle-aged person. Qualitative Health Research, 17(1), 4–13.

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(1), 7–14.

Rhodes, D. L., & Bowles, C. L. (2002). Heart failure and its impact on older women’s lives. Journal of Advanced Nursing, 39(5), 441–449.

Riedinger, M. S., Dracup, K. A., & Brecht, M.-L. (2000). Predictors of quality of life in women with heart failure. The Journal of Heart and Lung Transplantation, 19(6), 598–608.

Riegel, B., Moser, D. K., Carlson, B., Deaton, C., Armola, R., Sethares, K., et al. (2003). Gender differences in quality of life are minimal in patients with heart failure. Journal of Cardiac Failure, 9(1), 42–48.

Roebuck, A., Furze, G., & Thompson, D. (2001). Health-related quality of life after myocardial infarction: an interview study. Journal of Advanced Nursing, 34(6), 787–794.

SFS (2003). The act concerning the ethical review of research involving humans. The Ministry of Education and Cultural Affairs. (Centrala etikprovningsnämnden.) Retrieved April 12, 2007, from http://www.epn.se/eng/start/2003_460.aspx

Sjöström-Strand, A., & Fridlund, B. (2007). Stress in women’s daily life before and after a myocardial infarction: a qualitative analysis. Scandinavian Journal of Caring Sciences, 21(1), 10–17.

Stoltz, P. (2006). Searching for the meaning of support in nursing—a study on support in family care of frail aged persons with examples from palliative care at home. Doctoral dissertation. Faculty of Health and Society, Malmö University, Sweden 2006:2.
Strömbärg, A., & Mårtensson, J. (2003). Gender differences in patients with heart failure. *European Journal of Cardiovascular Nursing, 2*(1), 7–18.

Strömbärg, A. (2005). The crucial role of patient education in heart failure. *European Journal of Heart Failure, 7*(3), 363–369.

Takizawa, T. (2006). Stress buffering effects of social support on depressive symptoms in middle age: Reciprocity and community mental health. *Psychiatry and Clinical Neurosciences, 60*(6), 652–661.

Todres, L., Galvin, K., & Dahlberg, K. (2007). Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care, and Philosophy, 10*(1), 53–63.

Williams, P., Barclay, L., & Schmied, V. (2004). Defining social support in context: a necessary step in improving research, intervention, and practice. *Qualitative Health Research, 14*(7), 942–960.