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### Chapter 3

## What cardiovascular patients have to say about psychosocial support

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## Abstract

**Aims:** This paper is a report of a study of expectations and experiences of people with cardiovascular disease of psychosocial support.

**Background:** Research has demonstrated that patients with chronic cardiovascular disease experience a lack of psychosocial support. Practice improvements are mainly proposed from the perspectives of health care practitioners and do not sustainably meet patients' expectations.

**Methods:** In 2009-2010, a naturalistic qualitative study by a team of academic researchers and cardiovascular patients has been conducted. 24 patients aged 37-79 participated in in-depth interviews and two focus groups. The interviews focused on articulating the perspectives of patients concerning psychosocial support. The focus groups were organised to share data and triangulate interviews.

**Results/findings:** The results are grouped in two major clusters. The first cluster involves 'perspectives on psychosocial care and support' and is divided into three subthemes: organization, intervention, normative-ethical expectations. The second cluster concerns 'knowledge and understanding from information gathering'.

**Conclusion:** Patients ascribe great value to the continuous provision of psychosocial support on a daily basis instead of primarily during framed interventions. Patients articulate a need for a personalized and 'human' approach. According to patients, psychosocial support should be more solution-oriented and empowering. This includes sharing knowledge with patients and among professionals. The study is of great importance for nurses because they may bridge the gap between patients' expectations and the current provision of psychosocial support.

**Keywords:** cardiovascular; nursing; patient perspectives; patient-led care; ethics; psychosocial care; qualitative research.

## Introduction

People with cardiovascular disease (CVD) experience fear, uncertainty, hope, anger and fragility as they adjust to and accept their situation (Clarke, 2009; Hirani & Newman, 2005; Jensen & Petersson, 2003; Karlsson et al., 2005; Leegaard & Fagermoen, 2008; Peterson et al., 2010). These studies report that patients express a need for counselling, support and dialogue (Karlsson et al., 2005; Hawthorne, 1993) both from professionals and a lay network (Jensen & Petersson, 2003, Arenhall et al., 2011). Generally, psychosocial support is provided in the form of specific interventions (Child et al., 2010; Linden et al., 1996, 2007; McGillion et al., 2004). In addition, there is general agreement that multidisciplinary teams that provide cardiovascular care and rehabilitation should include a psychologist and a social worker. As a result, attention for the psychosocial dimensions of cardiovascular disease is growing. This can also be observed in other areas, for example in the update of guidelines and protocols.

Despite these significant developments, interventions are, as a rule, developed by healthcare practitioners and policymakers. Despite their genuine intentions, a number of problems have come to light. Even though educators make an effort to help practitioners develop the right competences to enhance their understanding and sensitivity to patients' perspectives (Charon, 2004), there is still a rift between both worlds, and this requires further attention. Whilst practitioners operate in a healthcare system that is mainly characterized by fragmentation and subspecialties, a patient's world is episodic, dialectic and integrative. Another problem is that the main focus tends to be on developing and standardizing interventions for psychosocial care. For example, the renewed Dutch guidelines focus mainly on interventions, whereas patients may also expect support in other areas, e.g. on the relational, informational fronts or on the daily aspects of their contact with practitioners. As far as we are aware there have, to date, been relatively few empirical qualitative studies on what cardiovascular patients expect of psychosocial care and support (Jensen & Petersson, 2003). This article reports on a qualitative study that examined how patients view the psychosocial dimensions of their cardiovascular disease and how they evaluate psychosocial care. Information was systematically gathered on what patients consider important and on what they expect of psychosocial support from healthcare practitioners such as clinicians and nurses.

## Method

### *Aim and design*

A naturalistic, qualitative study was performed between November 2009 and December 2010, using interviews and focus groups. Naturalistic studies broaden the scope of evidence-based medicine by providing an enhanced understanding of how patients make sense of their situation (Britten, 1995). A naturalistic study maps out the complexity of a situation. Our main research question focused on how, from a patient's perspective, psychosocial care can be improved. The transdisciplinary research team consisted of two

academic researchers and three men with cardiovascular disease who actively participated as 'research partners'. Research partners are people who have personal experience with their disease and cooperate with academic researchers in all phases of the research (Schipper, 2011). Personal experience with the disease is not available to most researchers and complements the scientific perspective of the researcher. Furthermore, it grounds research in clinical need (Hewlett, 2006). Active involvement of patients in research is emerging (Schipper, 2011; Abma & Broerse, 2010; Entwistle et al, 1998) and it is expected it will enhance the relevance and implementation of knowledge (Oliver, 2009). The transdisciplinary team was trained in how to combine scientific and experiential knowledge by an external trainer.

### *Sample, recruitment, participants*

The respondents were selected using maximum-variation sampling, which involves sampling as wide a range of perspectives as possible to capture the broadest set of information and experiences (Reeves et al., 2008). This meant that we sought to find as many as possible perspectives on how people experience psychosocial support. Respondents were eligible to participate when they suffered from a cardiovascular disease, experienced psychosocial challenges and if they were able to give informed consent. Recruitment occurred in collaboration with the Dutch Cardiovascular Foundation (CF) and the Dutch Cardiovascular Group (CG, patient advocacy organisation) and general practitioners. A call for interview respondents has been posted on the websites of the CF and CG and the CG newsletter. Two general practitioners were briefed in person by one of the researchers (the second author). The call for respondents has been written by the researchers in collaboration with the research partners, the CF and CG, and included general information on the study purpose, research activities and ethical considerations like informed consent and anonymity. The researchers were informed by the recruiters about potential respondents. The researchers approached the respondent by phone to explore whether respondents met the selection criteria. If that was the case, an appointment for an interview was scheduled.

We aimed to include new respondents who were not yet interviewed for two focus groups. A call for focus group participants was published on the website of the CG. Two new participants were recruited, which was not sufficient to organize a focus group. It was therefore decided to recruit amongst the included interviewees as well. Finally, a total of 10 people with cardiovascular disease participated in two focus groups, of which 8 were already included in the study (by interviews).

### *Data collection*

In the first stage of the study, a total of 24 interviews were conducted with patients who had suffered a heart attack, heart failure or CVA (Cerebro Vascular Accident). The interviews were held at home. On request of the people who suffered a CVA, the interviews with them were conducted in the presence of a relative of the respondent (2 spouses, 2 parents). The relatives participated actively in the interview on behalf of their spouse or child.

A semi-structured interview guide, which included a topic list, was based on a literature review. The list has been pilot tested and adjusted after four interviews. The topic list included topics that focused on important turning points in the illness history of the respondent; their values concerning rehabilitation and recovery; past and present challenges in daily life; contact with health care professionals and topics on psychosocial, financial, relational and employment themes.

The in-depth interviews lasted ~1.5 hr. In-depth interviewing is a conversation with a specific purpose, and focuses on the informant's perception of self, life and experience, expressed in his or her own words. It allows the researchers to understand the particular and private interpretations of social reality that individuals hold (Nussbaum, 1994; Minichiello 1991). The interview was guided by the academic researcher and the research partner asked questions for clarification purposes. The interview began with a general open question about the patient's perceptions of what had happened. The interviews were digitally audio-recorded and transcribed ad verbatim (line by line). To reduce bias, every respondent received a report of the interview to check for accuracy (member check). In some cases (n=13), this resulted in additional (phone) conversations to specify the respondent's perspective.

Sampling stopped when data saturation was reached. This meant that repeatedly no new themes were mentioned by new respondents.

In order to share data and triangulate interviews we planned 2 focus groups (Murdoch et al., 2010). Focus groups are semi-structured discussions with groups of 4-12 people that explore a set of issues. Participants are encouraged to interact and explore these issues together in order to deepen their perspectives (Tong et al. 2007). In advance all focus group participants received a preparatory text with a brief report on the major themes that were found. A protocol was developed and included three themes to discuss. The focus groups lasted ~2.5 hours, were held in a central place in The Netherlands and moderated by the first author with support of the second author. The sessions started with an introductory round. Subsequently the participants discussed several themes. The sessions were digitally recorded and a secretary who was also present at the group sessions wrote a report. The participants received the report on the outcomes of the focus group either by email or by regular mail and were asked whether they confirmed the report or had any additional remarks (member check). All participants agreed with the report.

During all data collection activities all team members shared their experiences during monthly team meetings.

### *Data analysis*

We focused on patients' perspectives in all phases of the disease. The acute phase has been defined as the phase from hospitalization to discharge (Jensen et al., 2003). The adjustment phase is the phase immediately after discharge. Most people in this phase undergo some form of rehabilitation. The chronic phase starts after the rehabilitation phase has come to an end, and the frequency of people's contact with healthcare services diminishes.

We opted for an inductive approach to analyse our data (interview transcripts and focus group reports) using a content analysis (Krippendorff,

2004). Themes were derived from the data. In total, there were 5 data coders. The analysis was conducted in pairs that consisted of one academic researcher and one research partner. The research partner was trained by the researchers how to analyse a transcript. The outcomes of the inductive analysis was discussed with the other team members till consensus was reached. In detail, the process was as follows: first, the transcripts were read several times. Each person divided the transcripts into fragments to which labels (themes) were assigned (open coding). Gradually, a coding scheme emerged which was used to analyse all transcripts deductively. Subsequently, themes were clustered into two major clusters, and finally the clusters of the transcripts were related (axial coding). The clusters are presented in the finding section below.

### Validity and reliability/rigour

To guarantee validity and trustworthiness of the research, several quality procedures were followed (Mays & Pope, 1996; Blaxter, 1996; Reeves et al., 2008). Internal validity is enhanced by conducting member checks and (reflexive) peer debriefing. In our study, respondents actively participated in member checks. On a regular basis (every four to five weeks) the research team discussed the upcoming methodological decisions and interpretations of data. Reflexive peer debriefing gained special meaning due to the participation of the research partners who shared their experiential knowledge on cardiovascular diseases. They stimulated the scientific researchers to explain certain methodological decisions or interpretations in lay language and confronted the scientific teammembers with their own prejudices.

Combining several data collection methods (triangulation) also enhances quality. Triangulation enhances validity and trustworthiness because it facilitates the detection of data incongruencies. In our study we combined interviews with focus groups to detect that. Analysing the data in pairs of research partner and scientific researcher may have enhanced the quality of the study as well.

The generalizability of a qualitative study involves transferability: it focuses on translating the themes we have developed to other socio-cultural contexts (Kuper et al., 2008). Currently, the outcomes of this study are translated to an inpatient care setting.

### Ethical considerations

We conducted this project from a specific ethical stance. We appreciated the patient participation, and aimed for informed consent, anonymity, respect for privacy/confidentiality and transparency. In our situation, the project did not require approval by an accredited Medical Research Ethics Committee (aMREC).

## Findings

The interviews in stage one involved 24 participants: people with heart failure (n=5) with their relative (n=1), people who suffered from a myocar-

dial infarction (n=8) and people who suffered from a CVA (n=6) with their relative (n=4) (see Table 1).

**Table 1:** Schematic overview of characteristics participants of interviews (n=24 )

	Total	Male	Female	Average age
Heartfailure	5	4	1	52 (37-61)
Myocardial infarction	8	3 <sup>1</sup>	5	63 (38-79)
Relatives heartfailure	1		1	
CVA	6	4	2	59 (37-76)
Relatives CVA	4	1	3 <sup>2</sup>	68 (57-76)
Total	24	12	12	

<sup>1</sup> partner of CVA patiënt <sup>2</sup> also suffered a myocardial infarction

A similar amount of male and female respondents participated. One male respondent had a cardiovascular disease and his wife suffered from CVA. One female relative of a male CVA respondent suffered from a myocardial infarction herself. We noticed that almost all respondents were confronted with cardiovascular diseases in their direct surroundings (friends, family, fellow patients). Although the interview primarily focused on their individual experiences, they may have been influenced by experiences in their social surroundings. Subsequently, 10 participants, of which some new participants with myocardial infarction (n=2), attended two focus groups. The average age of all participants (interviews and focus groups) corresponds to the national average of Dutch citizens (www.vtv2010.nl).

The study led to two major clusters of findings, each of which can be divided into several themes (Table 2):

- professional care and support;
- knowledge and understanding from information gathering.

**Table 2:** Structure of clusters and themes according to people with cardiovascular diseases

Cluster	Themes	Articulated needs
Professional care and support	Organization of psychosocial care and support	<ul style="list-style-type: none"> <li>- Customized aftercare</li> <li>- Proactively provided, during acute and chronic phase</li> <li>- Timing</li> <li>- Integration of psychosocial support with rehabilitation</li> <li>- Financial support</li> </ul>
	Psychosocial interventions	<ul style="list-style-type: none"> <li>- Health care professional with similar age/life-experience</li> <li>- Care should be solution- focused on 'empowerment'</li> <li>- Psychoeducation</li> </ul>
	Normative-ethical expectations of professionals	<ul style="list-style-type: none"> <li>- Being understood and heard by clinicians</li> <li>- Being taken seriously</li> <li>- Being involved in care as an equal partner</li> <li>- Proactive professionals</li> <li>- Self control in treatment and care</li> </ul>
Knowledge & understanding from gathering information	<ul style="list-style-type: none"> <li>- Reducing insecurity</li> <li>- Understanding</li> <li>- Forms and quality of information (e.g. on practical issues, up-to-date)</li> <li>- Information exchanged in dialogue</li> <li>- Internet as a source of information</li> </ul>	

*Cluster 1: Professional care and support*

**Theme: organization of psychosocial care and support**

In general, people with CVD report negative experiences when it comes to psychosocial care and support. They either face insufficient support or do not receive any support at all. However, there are exceptions. For example, one respondent shares an experience she had when her cardiologist talked with her children and told them in simple language about their mother's disease. After that, one of her children had a few sessions with a psychologist, which she saw as being positive.

The respondents have specific ideas about the timing of psychosocial support. During hospitalization or immediately after being discharged from hospital, they report on professionals who ask them whether they would be interested in psychosocial support. However, people tend to decline this kind of support because they are primarily focused on regaining their physical strength. Some time later, when back home and after rehabilitation, people feel as though they are 'in limbo'. They have a hard time accepting and adjusting to their new situation. The respondents admit that at this juncture they might like to have had psychosocial support. But the threshold to actually seeking out support is too high:

*'To me, psychosocial support is very poor. The medical side of things is absolutely perfect. But they're not really interested in the psychosocial side (...) It may be that someone in the hospitalization phase says: no thank you, but when they've been home for a month they might think: maybe now's the right time [to seek psychosocial support].'* (male, 48)

Most respondents argue that psychosocial care should be offered proactively:

*'And when you actually reply: 'I don't need it', they shouldn't really listen to you. They should provide it actively, it should be routine. Half a year or three quarters of a year later, you've become a different person. They should always make it possible for you to come back.'* (male, 61, interview)

Some respondents do actively seek out support themselves, but the majority were unable to find support because waiting lists are too long, or little is known about where the right kind of support can be found.

**Theme: psychosocial intervention**

Patients expect psychosocial interventions to cover a range of issues. They believe psychosocial interventions should be customized: from support in coping with existential questions to practical advice on how to relate to colleagues when they return to work, how to prepare for a vacation, or how to make sense of what has happened. This respondent tells of his negative experience in this context:

*'There was this resident-cardiologist and he told me: 'You'll have to get used to your new lifestyle. Don't smoke', I don't smoke, 'Don't drink too much', I don't drink a lot, 'Sport's good for you,' I get exercise every week....so he just tells you anything...he's learned to say these things, but it really annoyed me.'* (female, 55, interview)

Other people endorse this wish to have genuine communication with someone who is able to respond in a meaningful way. The psychosocial intervention should give new information or introduce a new approach: For example:

*'We've had four of them now [psychologists], we liked the first one the most. Our cardiologist referred us. This lady had a clear plan, it was very clear. But the other ones, no: they told us the same things we knew already.'* (male, 57, interview)

Respondents suggested that psychosocial support should be more empowering and solution-focused, and its approach should be clear. Particularly in the acute and rehabilitation phases, people focus mainly on regaining their physical balance. They experience a wide range of physical difficulties (e.g. severe fatigue) and rehabilitation is their main concern. Rehabilitation helps them find renewed confidence in their bodies. The ability to go out, to work out with fellow patients three times a week gives them a sense of security. As a result, most people find the end of the rehabilitation phase rather difficult. Although some rehabilitation programmes inform participants about possible aftercare, most respondents in our study feel 'abandoned' when they are not welcome to come back. This leads to a feeling of insecurity. In the long term, some respondents find other ways to keep working out, but this is not possible for everyone for financial reasons.

In the chronic phase, people feel a need to be supported in dealing with recurrent symptoms, which often cause fear and anxiety. In this phase, people

focus on regaining a sense of 'personal strength'. After a rather turbulent time of finding a new physical balance, respondents report their need to feel independent again. An important element here is to reduce insecurity and fear, for example, of a myocardial infarction happening again. One person says: 'It feels like there's a time bomb in your body.' Another respondent agrees:

*'I've always been afraid of going outside. But now I just take my mobile. It sets my mind at rest. I also take extra medication everywhere as well, and my medication list. What if something happens? You prepare and that puts you at ease.'* (female, 39, interview)

In those cases where psychosocial support is incorporated in a rehabilitation programme, respondents advocate differentiating between different kinds of cardiovascular disease. When they do decide to see a psychosocial professional, they want to see someone of a similar age or life experience. Respondents are not keen on a wide age gap, as explained below by a 74 year old male patient:

*'There I am, with a girl of 19 or 20. And she's asking you all kinds of questions and tells you things. What sense does it make? I understand they have to learn too (...) but I need someone with experience, someone I can talk to and who reacts to me.'* (male, 74, interview)

### **Theme: normative-ethical expectations of professionals**

People with CVD need to feel supported by clinicians and specialized nurses on a day to day basis. Respondents are certain that this contributes towards their psychosocial wellbeing. Most respondents find that their contact with clinicians, nurses and general practitioners has a considerable impact on their psychosocial wellbeing. Respondents say that they really feel supported by their healthcare professionals when professionals take them seriously and when their humanity is addressed. It gives them a feeling that they really 'matter'. Most respondents experience contact with their cardiovascular nurses as positive and affirming. They are more critical about their contact with cardiologists. Respondents prefer to be seen and treated as unique human beings, as a person, instead of as a disease or a 'case':

*'I don't want to be seen as a 'case'. My cardiologist is rather paternalistic: he doesn't actually want to talk with me because he thinks he knows better. As a patient, you've always got to be alert, ask the right questions to find out what's going on.'* (female, 48, focus group)

Moreover, respondents really appreciate professionals who listen, who function as a 'guide'. It makes them feel safe. Respondents expect clinicians and nurses not only to provide them with personalized information, but also to talk with them about it. In addition, respondents would also like to have the option to have a say in their treatment and be 'in control'. This respondent addresses both humanity and having a say:

*'There was one cardiologist who responded satisfactorily to my complaints. He had a completely different story, a 'human' story: 'Yes,*

*those diuretics, you have to play with them a bit, then you just take one more or one less'. I liked that, it puts things into perspective. He put the ball in my court, a bit of knowledge, responsibility and that's what you want.'* (male, 48, interview)

### **Cluster 2: Knowledge & understanding from gathering information**

People with cardiovascular diseases are positive about gathering knowledge and information. It diminishes their insecurity. It gives them peace, and confidence. One respondent would only rest when she knew how all her medication worked: 'Only then can I accept it. (...) This was very important [to me]. (...) All I wanted was to lead as normal a life as possible.' In her trial and error, she discovered her need for regularity and a daily routine. To help her maintain a balance, she set fixed times for getting up, taking her medication, resting and working. The internet in particular seems to have become indispensable in the search for information, testing and evaluation. Of particular importance to respondents is how their healthcare providers respond to the information they give them. One respondent has positive experiences:

*'My cardiologist always smiles at me when I come in, he always asks 'and, did you find something new?' I really appreciate it that he understands what I mean, also because he's not as familiar with this disease as I am.'* (female, 39, interview)

Her cardiologist uses her information and shares it with colleagues. Unfortunately, another respondent has had the opposite experience, and he believes it has a negative impact on his recovery:

*'[He] Only looks at the tests, he's not interested in how I'm experiencing things (...) [a] clear mistake has been made and that is the support and supply of information.'* (male, 61, interview)

People appreciate written information (brochures) but they prefer to exchange information with healthcare professionals. They report a need for 'customized answers', for example this respondent:

*'A conversation where I can say what I have to say and get an answer to my questions. Yes, it may take the cardiologist more time, but that's a pity. The specialist nurse gave me a web address and some brochures. Actually, that was all the guidance I got.'* (female, 75)

## **Discussion**

The study has some limitations. Despite our effort to recruit as many respondents for the focus groups as possible, the sample of focus groups participants is relatively small. We believe, however, that the interview sample is sufficient and that findings can be used as a starting point to explore patients' perspectives in a wider and more thorough manner. It may, for example, be a starting point for the design of a quantitative study. Next, this

study focused on three variations of cardiovascular diseases (heart failure, myocardial infarction and CVA). We found no substantial differences regarding the themes that were raised by the respondents of these groups, but this may be due to the small sample. We recommend research that focuses on specific perspectives of people with one of the diseases in particular.

To illustrate how the findings relate to current knowledge and if they add new insights, three themes will be discussed in more detail. Firstly, patients would like psychosocial support to involve all the facets of their treatment and care. Not only psychosocial interventions in themselves, but also during meetings with practitioners. Patients believe that 'good' psychosocial support is characterized by professionals who take them seriously, who 'see' them as a human being, who respect them and who do not solely regard them as a 'patient'. They expect professionals to address them as a 'person'. This is linked to the way they perceive their disease: it is not separate from their daily lives, it is closely interwoven with it (Todres et al., 2007; Johanson et al., 2003). However, whilst practitioners work in a system of fragmented care delivery, the study shows that patients express (tacit) expectations that professionals should function in an integral manner. In patients' eyes, professionals, especially clinicians, tend to focus primarily on physical functioning and technical issues such as the effectiveness of medical interventions or improving diagnostic processes. Other studies confirm our findings (Ekman, 2011; Silva et al., 2010; Lapum et al., 2010; Karlsson et al., 2005; Teunissen et al., 2011). They all reveal an ample number of significant issues including the relationship with healthcare professionals and quality of care from a patient's perspective.

On the one hand, the findings show that patients prefer to have a say in their treatment and care. On the other hand patients would also like professionals to sometimes insist on addressing emotional and mental dimensions. When patients initially reject the offer of psychosocial support, they would appreciate it if professionals were to attempt to encourage them to reconsider. Hence, the findings show that patients prefer professionals who are able to balance between engaging with them from a dialogical and deliberative stance, whilst sometimes identifying with and acting from a more paternalistic role. This does not mean the patients' self-determination or autonomy should be overruled. Instead, both parties could explore how the 'grant of authority' to professionals could best occur (Tronto, 2009).

Nurses appear, more so than clinicians, to be more inclined to work from a deliberative stance which takes the patients' lifeworld and humanity into account (Emanuel & Emanuel, 1992; Charon, 2004; Dahlberg et al., 2009). Nurses may further explore what it means to address a patient's humanity and lifeworld. This may for example include nurses asking: 'Who are you?' rather than 'How are you?' (Abma et al., 2009) or 'What do you want?'. It may actually mean that nurses reveal certain aspects of their own personality, as research in another context demonstrated that this makes patients feel acknowledged as people (Radwin, 2000; Izumi et al., 2006). When a nurse discloses some personal detail, the relationship between the nurse and the patient becomes more humane. Knowing something about a nurse helps patients feel bonded with and connected to the nurse (Rchaidia, 2009). Nurses could explore the boundaries with other disciplines, such as psychology or (spiritual) counselling in more depth. Other studies show

patients' growing need for professionals who span several disciplines and cross organizational boundaries (Visse et al., 2010). They stress the importance of trained nurses in supporting patients in the community (Voogdt, 2011; Condon & McCarthy, 2006). Regarding primary care, nurses could work together with general practitioner assistants and GPs themselves on the specific needs of several patient groups.

A final subject for discussion is the need patients express for empowerment and a solution-oriented approach of psychosocial support. This deals with the question how they perceive 'recovery' (Jacobson & Greenley, 2001). Instead of focusing on the pathology or disease itself, integral approaches that focus on resilience, for example on re-establishing a sense of self-coherence and autonomy or self-determination can be of benefit (Antonovsky, 1987; Frankl, 1959). This study demonstrated, that for patients, sharing their own knowledge and information with professionals, plays an important role in their recovery. The literature demonstrates that respecting and affirming patients' autonomy and self-determination and enhancing their self-efficacy has a positive effect on recovery, adherence and lifestyle adjustments (Russell & Bray, 2010; Schouten, 2007; Korpershoek et al., 2011). Nurses could guide patients along the path to regaining a sense of personal coherence and meaningfulness.

## Conclusion

We conducted a qualitative study to learn about the perspectives of people with cardiovascular diseases on psychosocial support. The study, that consisted of several ways of data collection by a transdisciplinary research team, led to the identification of two main clusters with several subthemes. The study indicates that patients need psychosocial support to be included in their personal encounters with health care professionals, and not solely by framed interventions. The findings confirm existing theory on the significance of the relationship between professionals and patients. Despite their desire to have a say in treatment and care, patients also expect to be guided in a more proactively and sometimes even paternalistic manner when it concerns psychosocial support. We conclude with the need that patients articulate for an empowering and personalized approach. Herein lies an important opportunity for nurses.

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## Chapter 4

# *‘Why Me?’* Phases of understanding in chronic illness: learning from a narrative account

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