

Heart Failure in the Oldest Old: A Qualitative Case Study on Patients' Perception of and Communication about Illness and Prognosis

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Abstract

Symptomatic heart failure affects approximately 2-5% of those aged 65-75 and more than 10% of those aged 80 and above [1] and has a poor long-term prognosis. Half of the patients diagnosed with heart failure will die within 4 years, and in patients with severe heart failure more than 50% will die within one year [2]. Studies have documented unmet needs of patients with advanced heart failure such as symptom management, difficulties performing activities of daily living and psychosocial concerns [3-6].

Good communication about illness and prognosis with the patient and family is crucial but in clinical practice communication about end of life issues is often poor. Physicians often feel helpless in delivering prognosis and communicating [7,8]. Hope should not be eliminated in the dialogue but a realistic estimation of the situation is required to assess further treatment and make informed decisions [4,9]. It is also important to consider that patients and relatives have different information needs and strategies to deal with psychosocial burden [10].

The aim of this study was to gain an in-depth understanding of the perception of and communication about illness and prognosis of patients, aged 85 and over (the oldest old) with advanced heart failure, over a period of time, by contrasting two cases that differ with regard to their social support. The study forms part of an ongoing qualitative longitudinal research project with patient interviews 3 monthly for up to 18 months [11]. First results of the baseline interviews directly after recruitment of the patients had shown that perception of and communication about illness and prognosis was a major topic for the patients in this study [12]. Therefore the present study additionally aimed at specifying the analytic framework at the half of the project time.

Keywords: Case study; Palliative care approach; Heart failure; End of life issues; Health care professionals; Advanced care planning

Methods

Participants

From the total of 25 patients participating in the main project [11], we selected two patients for the present case study. For selection, we firstly identified patients who had attended at least four serial interviews covering a time period of 9 months and from these, eight persons were selected. For each patient a "social network card" was drawn to identify a variety of significant aspects of their social support. The aim was to analyze these specific cases in detail in their real life context [13]. We chose the two persons with the most contrasting living situations: One person lived in a household together with five family members, ensuring a strong social network. The other person lived on her own in a small apartment with a weaker family network, receiving support in her daily life from a neighbor and occasionally from a relative. The social network cards are presented in tables 1 and 2.

Data collection

All interviews were conducted by an experienced qualitative researcher (KK) using an interview guide covering aspects such as history of illness, current discomforts, daily support and health care, communication with caregivers as well as their thoughts on illness and prognosis. The initial interviews took place in a geriatric hospital and the follow-up interviews at the patient's home. The interviews were digitally recorded and transcribed verbatim.

Non-verbal communication was observed and noted during the interviews and considered for analysis together with ambience protocols which reflect each interview from the interviewer's perspective.

Data analysis

The interviews were analyzed using both coding and a narrative approach. We adopted the conceptual framework of traditional case studies with the aim of describing and understanding the "how" and "why" in specific circumstances [13]. According to this, our leading research question was framed to study how the patients perceived their heart disease and its consequences, and how they communicated about it.

Firstly, transcripts were read thoroughly to discern the character of the person and to identify habits and behavior patterns. The analytical process began by coding the material on the base of our leading research question, generating codes to open-up the data and to identify possible "hidden meanings" [14]. Alongside the coding process a narrative approach was used to study their verbal reaction, manner of speech, usage of words and to observe repeated expressions as well as communicational barriers [15]. The process of analysis was regularly discussed in the multidisciplinary study group which included a health

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scientist (KK), psychologist (MP) and a public health and medical specialist (NS).

The study was approved by the ethics committee of Hannover Medical School (No 5387, 25-08-2009). All patients gave their informed consent for participation.

Results

The cases are presented consecutively according to the main themes.

Case 1: Mrs. G.

Communication on illness: Mrs. G. has had a long history of illness spanning 20 years. From her point of view the heart disease started when she was prescribed two adverse drugs at the same time. She had been a long time smoker and expressed guilty feelings about this.

Mrs. G. mentioned that she is aware of her heart failure through her physical dysfunction. As a consequence she reports of her common symptoms of heart failure such as sleep disturbance, edema, breathlessness and fatigue which she observes burdensome but as part of everyday life, indeed, part of her own identity.

“Yes, that (sleep disturbance) remains. That’s my second self.”

Mrs. G. emphasized she likes being on her own because since the death of her husband she has become accustomed to it. Moreover, she pointed out, there is no need for conversation or for there to be someone “who is entertaining” her. It is the same with communication regarding illness: she does not like talking about it and strongly denigrates others who do so.

“Generally I hate it when everybody just talks about their illness. It is disgusting. I don’t want to hear that. When you come together, you must not speak about illness, must you? ... No, I don’t want that.”

Questions on her health status were repeated in every interview session and her answers were always denying, such as “I’m always saying, I’m fine”. It is here where a coping strategy probably comes into effect for dealing with her discomforts and health status by means of deflection onto others who feel worse than her:

“I always do it that way: don’t look upwards, look downwards!”

This behavior occurred not just in regard to her illness, but also to other issues that she did not want to think or talk about, more precisely her feelings.

I: “What kind of feelings occurred since the last time?”

Mrs. G. (doubting): “Feelings? (...) Do I have feelings?”(I: “For sure.”) “Mmh, then I don’t know at the moment.”

As a consequence of the increase in the deaths of most of her acquaintances and the decrease in her own physical function she has maintained contact with just a few persons. Her family life is sparse. Personal contacts are limited to her neighbor and occasionally to her granddaughter.

Her trust in those around her seems to be generally low. It became clear in the interviews, where her neighbor, who is responsible for taking care of her daily needs was not present (1. and 3. date), that especially against this person there is a lack of trust. Mrs. G. believes that the willingness to care for her is motivated by the money.

“We don’t wanna fool ourselves; everything is a matter of money, isn’t it? Without money she (neighbor) wouldn’t do anything, I think.”

Though the level of trust in her granddaughter is greater, communication is also restricted to few time-limited dates. Therefore conversation remains superficial and does not touch on deeper personal or emotional issues. The contact with both these persons seems to be mainly restricted to the basic daily functional support.

Mrs. G. neither asks questions nor requests general or specific medical care. Pain and discomforts are to be “suffered with patience” in the Christian way, and expressed to the family doctor in a reserved way, but preferably not at all.

“(.) He (family doctor) drew blood yesterday and he rummaged around in there (in the veins), not one word I have said!”

It becomes clear that the patient does not complain and bravely accepts those incidents. Furthermore it seems that Mrs. G. tries to regulate herself verbally, particularly as she has insisted she is without any demands or needs.

“I don’t have any demands in my life any longer.”

“No. I don’t require anything of anyone.”

In the four interviews with Mrs. G. it became repeatedly obvious that, for her, communication about her illness is limited and difficult. This came into view because neither she showed any awareness of her own health status nor her needs. The interviews revealed many a time her preferred tendency to be alone without conversation within her social environment. Defensive answers such as “Oh my god, don’t ask me, I’ll go crazy, (...) I don’t know anything at all.” occurred often to avoid conversation on topics concerning illness and personal issues.

Information: From the first interview it was not easy to ascertain the amount of information which Mrs. G. possessed concerning her illness. Many times she emphasized that she knows nothing in this regard.

Person and illness	<ul style="list-style-type: none"> Female, 86 years Heart failure NYHA III, heart trouble since 20 years, multiple co-morbidities (coronary heart disease, hypertension, obesity and COPD)
Living situation	<ul style="list-style-type: none"> Living alone in a small urban apartment Mostly bound to a nursing bed in her kitchen
Social support	<ul style="list-style-type: none"> Her neighbor looking after her several times daily (e.g. grocery shopping, body care), receiving Mrs. G.’s attendance allowance grade one of the statutory nursing care insurance in return Only few other social contacts remaining by telephone (sport colleague, stepson)
Family situation	<ul style="list-style-type: none"> Married two times, the second husband died 20 years ago Only son died 4 years ago Relationship to her daughter in-law and grandson is estranged since then. Her granddaughter and four great-grandchildren are her only remaining relatives, helping her with household and laundry two times a week (also in return for payment), holds general power of attorney for Mrs. G.’s concerns
Professional health care providers	<ul style="list-style-type: none"> Family doctor for many years Further health providers: urologist, dentist, internist and physiotherapist for lymph drainage and massages

Table 1: Social network card of Mrs. G.

"No, I don't know. Actually I am rather stupid in this regard, or have become stupid in old age."

Also, in the subsequent interviews this status did not change. Neither could she remember any detail of the information given, of the test results from physicians, nor the genesis of the illness. It is important to note that she was obviously unable to understand the information she was given by the hospital doctor.

"And I tell you the truth, when the doctor tells me that (the diagnosis), I can't catch it so fast and take it all in."

Mrs. G. expressed repeatedly that the family doctor did not adequately inform her about her illness, nor the prognosis and the overall situation. Nevertheless it did not become explicit if she has a need to gain more information than she received. Further health care, e.g. diagnostic tests, treatment and information from a cardiologist and internist were refused.

Family doctor role: One core issue is that the medical support given by her family doctor was assessed by her as insufficient. The relationship with her doctor is contradictory. On one hand Mrs. G. disputes her professional competence, as seen here in some of her comments about their relationship:

"(..) I can talk to him like I talk to anyone else; I don't give respect. Respect, no, I don't have any. I talk to him like to everybody else."

"Yeah, what shall I say? Inwardly I actually have a giggle about him."

On the other hand the interviews revealed a strong loyalty towards him. She wants assurance that the doctor to whom she feels obliged manages her health issues. This loyalty is due to the fast response and assistance given to her husband 20 years ago just before he died. Mrs. G. asked for better health support on many occasions particularly if her condition had worsened, but she did not want to engage another doctor.

Death and dying: In the first interview Mrs. G.'s answer to the question about the thoughts she has on the progress of her heart illness was:

"No, no. It's already arranged, that I said to my granddaughter, with the funeral, an anonymous funeral, nothing else."

She jumped directly to her funeral which had already been pre-arranged by her granddaughter. Also in the following interviews she did not mention further thoughts of her heart failure. Dealing with death and dying is focused on the funeral or 'being dead'.

Furthermore, all interviews revealed a strong association with her experiences of the death and funerals of her loved ones. Her narratives showed those issues must be pre-arranged otherwise problems may occur. Financial questions were always at the forefront; emotions were given less importance. In her description of her son's funeral a familiar escalation had arisen over financial questions which hurt strongly. This incident has estranged both Mrs. G. and her daughter-in-law even until today. A further incident was the recent death of her sister; where she experienced once again in her family that financial - less emotional issues - were of the main importance. This perception of what we termed 'regulated conditions' emerged markedly, out of the interviews as her core principle.

Despite the fact, that Mrs. G. wants to regulate all her affairs as seen e.g. in the general power of attorney for her granddaughter, it could not be definitely clarified from the four interviews whether she

has already drafted an advance directive. Here, she blamed her family doctor quoting his old age and forgetfulness.

From her point of view dying should happen fast and without suffering or life prolonging treatments.

"Anyway, it must happen only fast. And, above all not putting it off - torture!"

"(..) Not being attached to machines or something like that for a long time."

This perspective probably evolved out of experiences with her husband she actively had cared for at home as well as with her sister who had suffered from Alzheimer's disease for a long time before death.

"Death can also be salvation", she stated in the second interview and expressed the wish to die because "everything bothers" her, meaning that the physical pain substantially affects her life. Consequently her habitual self body concept is diminished and her autonomy restricted in such a way that her life seems not worth living.

"Because, I think simply, well the life is, don't know (..) nothing worth at all."

Mrs. G. does not signal her complaints to the persons concerned, e.g. her family doctor, and does not ask for help to alleviate her symptoms such as edema, breathlessness and fatigue. As a consequence, she suffers from her symptoms, which influence her thoughts in an unpleasant manner and strengthen her wish to die. One should take into consideration that alleviation of her symptoms and improvement in her pain could decrease her wish to die.

"Indeed, maybe it (wish to die) will be better if I probably -uh- think again in a normal way."

Case 2: Mrs. T.

Communication on illness: Mrs. T. has a short history of illness; prior to her heart attack she experienced no complaints. She could not understand why she of all people had succumbed to this illness.

She notices her heart failure in terms of physical limitations as "legs of elephants" - i.e. edema - breathlessness and a decreasing independence. Since the third interview she has also reported an indefinable feeling in the left chest, "it appears hollow, as if something is missing". She tries to manage these discomforts with a rest period and to maintain an upright bearing to ease her respiration. However, she professed not to have a problem in adapting to these limitations:

"I always say to me, that's not the worst, I'm not in a hurry and have nothing to do, au contraire."

She remembers the moment of her heart attack - at night while visiting her niece in the countryside - as a defining experience with its unfamiliar pain. Even though, she thought "Now my time is coming.", she opened the window to get fresh air and realized at the same time the picturesque location of her niece's house was a reason to stay alive. This desire to live was repeatedly expressed by her in all interviews. Mrs. T. is constituted with a positive attitude, which emerged several times in her narratives:

"Here, upwards we have to look, not to the ground; gold pieces don't exist any more."

All interview situations have demonstrated an open exchange on various topics within the family. Especially health issues which were discussed thoroughly between Mrs. T and her niece but on a more general level; for example the pharmacy magazine which gives rise to a

Person and illness	<ul style="list-style-type: none"> Female, 95 years Heart failure NYHA III, heart attack in 2010, multiple co-morbidities (arterial hypertension and coronary heart disease)
Living situation	<ul style="list-style-type: none"> After her heart attack moving from assisted living to the rural house of her niece – occupying two rooms and a bathroom
Social support	<ul style="list-style-type: none"> Five persons of her niece's family look after her all around needs and accompany her to appointments with doctors and acquaintances Her niece has general power of attorney, receiving Mrs. T.'s attendance allowance grade one of the statutory nursing care insurance Weekly contact with acquaintances of an "oldest-club" from the assisted living
Family situation	<ul style="list-style-type: none"> Her husband died a long time ago on the street from a heart attack Her sole daughter died after two years with tuberculosis during Second World War
Professional health care providers	<ul style="list-style-type: none"> Family doctor for 20 years, now replaced by one in near area

Table 2: Social network card of Mrs. T.

discussion of current topics although they bear no relation to her own illness.

Questions addressed to Mrs. T. on her perception of her heart failure were often answered with memories of her husband who had suffered from several diseases after the war and later from cardiac failure. These experiences had left a deep hurt that determined her view of her own health status and her wishes for further treatments. In every interview session she repeated her request never to be taken into hospital again.

"Me, in a hospital? I will never go into hospital again, no way."

Information: Her request for information regarding her illness is made in the same general way that she discusses all health issues. Mrs. T. said repeatedly that she feels adequately informed, good enough to "be steady on the legs". In the second interview, by contrast, she stated that she has no idea from where she could get more information. Her niece also called for further information from the interviewer.

Thus the statements regarding information show a lack of knowledge and some uncertainty. At times she reacted uneasily to questions for information about her heart failure and passed the question to her niece or referred to other narratives, at most times memories of her husband.

Family doctor role: Physical consultation took place regularly with the family doctor. Mrs. T. appreciates both her previous and current family doctors as friendly and communicative, which contributes to a confident relationship.

She remembers past visits to the doctor and to the hospital and retells of them in the interviews. She tries to take care of her own affairs by her own means with the help of her family doctor. Therefore she pro-actively uses the plural form in her sentences, such as "Yes, Mrs. Doctor, how we are going to do that?".

Another example is in her handling of the application for attendance allowance, made in the first interview, that she already received by the second interview:

"Yes, I want to apply for it [attendance allowance]. And this I'll do with my family doctor Mrs. Doctor."

Death and dying: Mrs. T. is satisfied with her own situation since she lives at her niece's house, and is able to look calmly towards her death.

"I can say I'm pleased inwardly and calmer and let it happen and say, one fine day it will happen."

She does not seem to be afraid of death, except for one superstitious story which stems from a prior experience with her husband; thus she relates to her own death in the present.

"Yeah, [the kitchen clock] had fallen from the wall and a short time later he [husband] died.", explained by her niece)

Experiences with the death of others such as her siblings, her daughter and husband determined her stories of dying. Important are 'regulated conditions' of the anonymous funeral which was already pre-arranged with her husband during his life-time. One core aspect for Mrs. T. is not to be a burden after death for the remaining family, especially her niece.

"But why should I bother her, then she has to run to the cemetery again and again, and, uh, she won't be able to do that (...)."

Life must remain worth living and dignified. During the first interview an incident with her room-mate gave her the opportunity to express her own wish for human care. Her room-mate was left naked, sitting on her bed in front of the open door to the hallway after having vomited for a while. It took some time before the nurse came back to dress her and return her to bed.

"See, if you are at the end of your life like this woman [quietening the voice] (...) she can't say yes or no, must endure everything. She wouldn't sit there naked on her own. And that is still a life? No. Then there must be really someone above who says: "We should stop this." That makes no sense anymore."

Mrs. T. voiced her wish not to receive any life-prolonging treatments, in the unwanted event that she needed to go to hospital another time. For that reason she had intentionally drafted an advance directive some time previously and deposited it with her niece, who has general power of attorney, and with her family doctor. It unfolded during the conversation with Mrs. T. that her advance directive is made not only for the preclusion of life-prolonging treatments, but also for adequate support during her remaining lifetime.

Family role: Her niece's family, although not Mrs. T.'s own, is another relevant issue in her life. After the death of Mrs. T.'s sister her niece's family has become the main reserve in her life, which is based on reliance. In all four interviews she expressed strongly her emotions of feeling securely supplied by her family.

"As long as my niece has still her eyes open, I know, I am well supplied."

Practical needs are not the only relevant issue in this respect, the presence of mental support was also identified in the interviews. She rated "family coherence" as most important thing in her life. The family contains hope and meaning to keep alive; proceedings within the family become anchor points, e.g. the school exam and apprenticeship of her great-grandnephew. In the first interview she expressed that the certainty of "coming home" discharged from hospital, makes her life worth living. Also her family tries to balance her complaints about her decreasing independence by occupying her with daily tasks, e.g. peeling

potatoes and sewing on buttons, to give her confirmation that she is still needed.

"I'm needed, and that's a need for me!"

Discussion

The cases show both commonalities and differences in manner of dealing with advanced heart failure in the oldest old.

Commonalities

Communication about heart failure: Feelings and emotions were expressed carefully or preferably not at all. Both ladies have a similar perception - possibly ascribed to their age, such as modesty and reservation. The focus while storytelling is not on their own lives but rather on the lives of others. Both follow the same strategy: they do not focus on their own position but rather mentally deflect to somewhere else. Mrs. G. looks downwards to persons who feel worse than herself and Mrs. T. more upwards seeking spiritual power that gives reason to live. At times both refer to other narratives - at most times of beloved ones - which is probably a coping strategy to deny feelings, to keep them at distance.

Acceptance of doctor's role: The quality and quantity of information from the physician will be taken on without deepening raised topics; paternalism is known and wanted for many elderly as the way of dealing with a doctor in prior life periods and maintained in these presenting cases. Both patients in this case study basically rely on their family doctors however, whereas one vehemently criticizes him, the other not so.

Anticipating Death: Both patients defocus from their own death and concentrate on the death of beloved one's. This exposes the principle of 'regulated conditions'. Both women had already pre-arranged their funerals. It became clear, particularly in Mrs. G's case, that avoiding (financial) problems is an important issue.

Differences

Term of illness history: The term of illness history significantly determines the method of handling the illness. In Mrs. G's case the long illness seems to contribute to an attitude, in which the illness becomes part of her identity. Although she has a strong wish for independence, she handles herself rather passive and adapts to the decreasing condition. As a consequence she gives up the responsibility for her illness to others. In contrast, Mrs. T. whilst still concerned about the illness in her life accepts it and takes active care of her own affairs.

Manner of using health care and social services: Both women differ in how they make use of the persons and facilities around them. Mrs. T. makes active use of her family doctor; furthermore she considers herself fortunate to have her niece on hand to care for her in issues that she can no longer manage. Mrs. G., however, takes a less active part in issues regarding her illness. On the one hand she complains she is lacking information about health issues; whilst at the same time refuses further information from various health careers, even though she has limited understanding - an ambivalent situation.

End-of-life decisions: Thoughts concerning the last phase of life had both: they do not want suffer, nor do they want life-prolonging treatments. For this reason Mrs. T. has drafted an advance directive and made clear that she does not want to go into hospital again. In contrast, Mrs. G. ambiguously mentioned her wish not to be attached to a machine for a protracted period of time. Problems may occur in complying to this vague request, particularly as she has not yet drafted

her advance directive. She expects her family doctor to draft the document and thereby to take over responsibility for her.

Summary

This case study on the two oldest old patients with advanced heart failure suggests insufficient support regarding communication about end of life issues. Both women lack knowledge about their illness and the availabilities to meet their needs of daily support. Generally, the lack of knowledge could be improved by good communication in the family but incongruences regarding care needs and end of life issues between the patient and the caregiver are at times a significant barrier [16].

In Mrs. G.'s case appropriate assessment and treatment of her discomforts and symptoms may improve her quality of live, possibly resulting in strengthening her will to live. Therefore, implementing palliative care seems an obvious strategy. In general, palliative care can be delivered in different ways depending on the patient's needs, including a palliative care approach, generalist and specialist palliative care [17]. The palliative care approach should be made available for all professionals who are involved in delivering health and social care for patients facing the end of life. It includes not only measures for symptom control but also optimal communication with patient and family, decision-making and goal setting, with the aim of improving quality of life of all patients whose disease is not responsive to curative treatment. Therefore, appropriate training and education of health and social care professionals is necessary.

In many elderly patients health careers will not find an 'informed patient'. Elderly people are often conditioned by the use of traditional health care structures in which paternalism was common [18]. They generally prefer decision-making made by the doctor [19] more so with increasing age [20]. Also, they consider that there are no means of easing their pain and other symptoms [21]. Furthermore, it should be considered that many heart failure patients have cognitive dysfunctions [22] which could result in limited understanding of information given. The physician should be aware of these factors and adjust his style of communication to his patient adequately and his language to the patient's knowledge of the illness. The aim should be to be prepared for the potential need for clarification, to elicit the patient's wishes and to offer information on health care issues if required. Thereby delivering information should be initiated as early as possible [23].

Hence, the discussion of end-of-life issues should be a natural part of communication between family doctor and patient. As both cases revealed, practical issues are of more importance for the oldest old, e.g. the pre-arrangement of the funeral. Nevertheless, questions about the last phase of life are less addressed. Patients with advanced heart failure think about dying more in the context of ageing rather than in the context of their heart disease [3]. Furthermore, health professionals need to protect patients from the negative connotations and potential seriousness of the illness implied by cardiac failure [3]. As a consequence, prognosis is rarely discussed and it is seldom acknowledged that end stage cardiac failure is a terminal illness.

A relatively recent approach to improving communication between patients and families is Advanced Care Planning (ACP). It incorporates advance directives within a new framework and includes a communicative process facilitated by specifically qualified personnel (e.g. trained nurses, social workers or physicians). ACP requires a systemic intervention addressing all relevant levels of care and can be introduced in hospitals or in the community [24-25].

Strengths and Limitations

It is in the nature of case studies to have a small number of participants and therefore, the findings cannot be generalized. However, they provide specific in-depths insights into the perception and personal experience of patients and human interactions in particular cases.

Conclusion

This case study emphasizes that the open discussion of end-of-life issues is difficult in oldest old patients with advanced heart failure and does not take place often especially if social support is lacking who initiates it. Closely involved health professionals such as the family doctor should be aware of patient related barriers and actively address end-of-life issues within the scope of advanced care planning involving other professions.

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