

‘Who is going to explain it to me so that I understand?’ Health care needs and experiences of older patients with advanced heart failure

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Abstract Heart failure is a leading cause of death and can result in significant palliative care needs. The aim of this study was to explore the needs of older patients with advanced heart failure, and their experiences with health care delivery in Germany. Qualitative interviews were carried out with 12 patients (6 men, 6 women; age 73–94 years; heart failure in an advanced stage according to the New York Heart Association Functional Classification) recruited in two geriatric hospitals. The interviews were analyzed by a qualitative descriptive approach. The main categories derived from the patient interviews were: understanding of illness and prognosis, health care services and social life. The patients expressed the need for better information and communication regarding illness and prognosis, and the desire for more respectful treatment by health care providers. Heart failure was not recognized as a potentially life-limiting disease, and the patients had no experience with palliative care services. The study

emphasizes the need for improving communication with patients with advanced heart failure. To achieve this, strengthening the palliative care approach in all relevant services that deliver care for these patients and introducing advanced care planning appear to be promising strategies.

Keywords Palliative care approach · Advanced care planning · Communication · Qualitative research · Advanced heart failure · Aged

Introduction

Heart failure affects approximately 2–5 % of those aged 65–75 and more than 10 % of those aged 80 and above (McMurray and Stewart 2000). In an advanced stage of heart failure, patients often suffer from severe physical and psychosocial symptoms and problems such as fatigue, pain, breathlessness, fear and social isolation (Murray et al. 2002; Pantilat and Steinle 2004; Horne and Payne 2004; Small et al. 2009).

In a review including 48 studies on the perspectives of patients and carers, Low et al. (2011) worked out that health and social services for patients with advanced heart failure need to incorporate good communication between patients, families and health professionals; good coordination of care; and awareness of the broader patient needs beyond those specifically linked to heart failure. However, most of the studies available on the needs of patients with advanced heart failure have been carried out in the UK with uncertain transferability of the results to other countries that have a different organization of health care delivery.

The aim of this study was to explore the needs and experiences of older patients with advanced heart failure in Germany.

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The German health care system

In Germany, public health insurance covers about 90 % of the population. The remaining 10 % is covered by private health insurance. This mainly involves higher income groups and civil servants. In contrast to e.g. the UK, there is no mandatory gatekeeping by general practitioners (GPs) in the German health care system. This means that patients have a free choice of physicians, and direct access to medical specialists of all relevant disciplines available in group or single practices as well as in the hospitals. However, most patients (>90 %) have a GP and consult their GP first. A further relevant difference from e.g. the UK is that physicians in Germany working in medical practices usually have no fixed income. There is a mixture of fees applied depending on time and medical procedure, favoring technical procedures and high throughput of procedures. Often, these incentives are not in line with the needs of older, chronically ill patients (ADVISORY COUNCIL 2009; Brueckner et al. 2009).

Methods

Setting

The study forms a part of an ongoing qualitative longitudinal research project with patient interviews once in three months for up to 18 months. With regard to older patients with severe heart failure, the project aims to understand and describe the clinical information and psychosocial needs of the patients and their utilisation of health, social and voluntary sector services as their disease progresses over time. According to the study protocol, 25 patients were recruited between May and September 2010. 25 patients were selected based on experience from other qualitative longitudinal studies (Murray et al. 2002), anticipating attrition of approximately 60 % over the study period of 18 months due to death and withdrawal.

This contribution reports on the initial interviews with the first 12 patients recruited (baseline interviews). These were the first interviews analyzed within the project to provide the starting point for longitudinal analyses (e.g. comparison of the patients' narratives at baseline, after 6 months, 12 months, etc.).

Participants

Participants were purposively recruited in two geriatric hospitals in Hannover and Heidelberg, Germany, to reflect a range of old and very old age, sex and the presence of a carer.

The main inclusion criteria were participants of age 70 and above and with heart failure in an advance stage

according to the New York Heart Association Functional Classification. Furthermore, to identify patients with poor prognosis, the recruiting senior physicians in the geriatric hospitals used the 'surprise question' ('Would I be surprised if my patient were to die in the next 12 months?'). The 'surprise question' is a simple clinical prognostic screening tool. It has been demonstrated that there is an increased odds ratio of dying if the answer to this question is 'No'. The 'surprise question' has been validated in cancer patients and its use is also recommended to identify patients with non-malignant diseases at the end of life (Moss et al. 2010; Murray and Boyd 2011). In the present study, patients were included if the physicians' answer to the 'surprise question' was 'No'.

Exclusion criteria were moderate/severe dementia and inability to participate in the interviews for language reasons (non-German speaking). Furthermore, patients with severe frailty and patients with progressive cancer were excluded as these patients are likely to follow other illness trajectories (Murray et al. 2005).

Data collection and analysis

Taking up the work of others (e.g. Boyd et al. 2009; Small et al. 2009) and based on our own experience in the field, we developed an interview guide to cover the patients' experience of having heart failure to identify their main concerns at present, the information they have received about their condition and treatment and their views on care and treatment, focusing on the outpatient setting rather than treatment in the geriatric hospital. The interviews were designed not only to capture the range and depth of the subjects' experiences but also to allow sufficient flexibility to enable the interviewer to respond to individual patient and caregiver needs and circumstances. All interviews were carried out at the place of recruitment by the same interviewer (KK) who was externally supervised. The patient interviews were digitally recorded and verbally transcribed.

Firstly, all 25 transcripts of the baseline interviews as described above ('setting') were scrutinized for the initial incorporation into the data material. Secondly, the transcripts were analyzed by a qualitative descriptive approach (Sandelowski 2000; Neergaard et al. 2009). All meaningful text units were identified and open-coded separately by two researchers (MG and KK). The codes were then grouped into several relevant subcategories which were subsequently summarized into three main categories. No new categories emerged after the analysis of the 12th interview and consequently at this point we stopped the baseline analysis. The analytic process and the emerging categories were continuously discussed in the study group until a consensus was reached. The analysis was supported by the

software program MAXQDA® for the analysis and organization of the material.

The quotes presented in the ‘Results’ section were verbatim translated from the German and cross-checked.

Ethics

The study was approved by the Ethics Committee of Hannover Medical School (No. 5387, 25 August 2009).

Results

The socio-demographic data of the interview participants are shown in Table 1. The interviews lasted between 18 and 60 min with a mean of 44 min. From the interviews, three main categories with several subcategories emerged:

- Understanding of illness and prognosis
 - Information needs
 - Source of information
 - Dealing with prognosis
- Health care services
 - Hospitals
 - In the community
 - Finances
- Social life
 - Social activities
 - Communication about illness with family, friends and neighbours.

Understanding of illness and prognosis

Two main aspects became obvious with regard to *information needs*: On the one hand, there was a basic desire for information about the illness; on the other hand, however, a

number of patients remarked that too much or too explicit information could be overwhelming.

Well, certainly I would like to learn more. However, if I do know more it may well be too worrying (P9, male, 89 years).

Patients reported that they had been informed about their illness, but the patients’ understanding of their heart disease seemed rather unspecific. Thus, for example, one patient explained only that ‘something was wrong with his heart’ (P7, male, 90 years).

The interview participants expressed the wish for easily understandable information and found it partly difficult to find health professionals who meet patient’s information needs.

[...] But who is going to explain it to me so that I understand? I haven’t met anyone yet who can do that (P6, female, 85 years).

For the majority of patients, the treating physician, in most cases, the GP was the main *source of information*. One patient revealed that all information he had received came from a magazine. As far as he remembered he had received no information about his illness, the cause or treatment from the physicians:

No one told me anything, but by chance I happened to read a report about my illness in a magazine and it told about all that is involved [...], it was described wonderfully [...] exactly what you need to pay attention to and so on, the way the whole thing looks (P3, male, 92 years).

It seemed that the *prognosis* of heart failure was rarely discussed between patients and carers. Heart failure was not recognized as a potentially life-limiting disease, and issues of death and dying were not directly mentioned by any of the patients interviewed. However, it was explained that it would be necessary to wait and see how the situation further develops and that it would be best to live from one day to the next.

Nah, what’s past is past and what will come, I have to wait and see what will come (P11, male, 90 years).

No, I’m not really worried. I’ll just let it happen. It will happen the way it has to happen, and I can’t change anything about that (P9, male, 89 years).

The fear of becoming dependent on others, to be a burden to the children and to be no longer be able to decide for oneself was broached in a number of interviews.

Having to depend on others, that’s my greatest fear. I never want that to happen, but it will happen (P6, female, 85 years).

Table 1 Socio-demographics of the participants ($n = 12$)

	Men	Women	Total
Patients	6	6	12
Age			
Mean	84.8	84.2	84.5
Range	73–92	73–94	73–94
Living arrangements			
Alone	3	3	6
With spouse	1	2	3
Assisted living	1	1	2
Nursing home	1	0	1

Health care services

Although there was overall satisfaction with the quality of medical treatment, some patients described dissatisfaction concerning the coordination of care in *hospitals* as well as the personal interactions with patients.

The operation itself was perfect. But the way one was treated afterwards, I've never experienced anything like that anywhere (P2, male, 75 years).

They left me for five hours in the hallway. No one took care of me. And then all of a sudden someone said: Oh man! He's already dead. And then they all started to run (P4, male, 73 years).

Concerning health care delivery *in the community*, all patients had a GP, and some of the GPs also provided basic cardiac diagnostics. Almost all patients described the contact with the GP as greatly positive, and they appreciated the GPs medical competence as a friendly, sensitive attitude and good communication skills. However, some patients complained about the lack of time given for communication in the daily practice. Most of the patients had also seen a cardiologist and were overall greatly satisfied with the specialist's treatment. In some cases, the cardiologist was the primary contact person rather than a GP.

With respect to nursing services in the community, the interview participants overall were satisfied with the quality of the care delivered. However, some criticized how certain matters were organized, e.g.:

I'm not going to wait until they show up, maybe at 8 or 8:30—or maybe at 5. One morning it happened, they came, we had agreed on 8:30 AM. At 7:30 the doorbell rang. I wasn't even out of bed yet. I didn't open the door, just the window and I said, 'What's going on? You're an hour too early. Goodbye. Come back at 8:30, no earlier' (P7, male, 90 years).

In some cases, patients felt *financially* overburdened by private expenditure for services that were necessary for domestic assistance, but were not covered by public health insurance (e.g. panic button and meals on wheels). Furthermore, it was mentioned that the amount of money that caring relatives received from the public nursing insurance was not sufficient. One patient described the feeling that one has 'to beg for services' although having paid taxes and insurance for several decades.

Social life

The social activities of patients were often diminished as a result of their illness. Some patients felt too exhausted to actively maintain contact with their friends. In other cases,

the patients' friends were too ill to visit the patients or their friends had already died. Furthermore, participation in social life activities was limited due to long walking distances e.g. to church.

Well, I had some acquaintances, they've all died. That's the way it is with friends, to find some, real friends. I'm sure you know how that is yourself. One can't call everyone a friend (P6, female, 85 years).

On the one hand, *communication about the illness* with family or friends was described as 'open'; on the other hand; it was also mentioned that it was difficult to talk to friends and family members about illness and fears. One reason for difficulties in talking about illness and contiguous fears was that the patients interviewed wanted to avoid being a burden to others. In these cases, communication tended to be short and functional:

I only speak about it when I'm asked. I only give a short answer and then change the subject (P3, male, 92 years).

Sometimes patients wanted to avoid communication about their illness and fears, and therefore tried to play a strong role.

He really scolded me, told me that I don't always have to play the strong guy. Every once in a while I have to admit that I have something (P1, female, 73 years).

Discussion

This study is the first that explored the experiences and needs of older patients with advanced heart failure in Germany. The major topics addressed in the patients' narratives include an understanding of the illness and its prognosis, experiences with health care services and experiences related to social life. These findings are mainly consistent with those from other studies (Low et al. 2011).

Our data highlight barriers concerning in-depth communication about the end-of-life issues which may be prompted by the fear of not knowing how to deal with distressing information. None of the patients had discussed end-of-life issues with families and health professionals. Avoiding the discussion of end-of-life issues in their personal, social environment may be due to various reasons. Apart from a reduction of personal contacts on grounds of age, some patients seemed to be inhibited by their attitudes, for example, being too humble concerning their own needs and too shy expressing their discomforts. However, avoidance and cautiousness may, in these cases, be a strategy to deal with their illness (Lidén et al. 2010) and to

reduce patients' fears of being a burden to others. Likewise this behaviour could increase the barrier on the relatives' side to speak to the patient regarding end-of-life issues (Small et al. 2009).

Some patients stated that they had a long life and that at some point it has to be over. According to this, Murray et al. (2002) found that patients thought about dying more in the context of ageing rather than in the context of heart disease; furthermore, health professionals not only wanted patients to understand their illness but also wanted to protect them from the negative connotations and potential seriousness of their illness implied by cardiac failure. As a consequence, prognosis was rarely discussed and there was little acknowledgment that end-stage cardiac failure is a terminal illness.

Thus, improving the health professionals and patients understanding of heart failure as a potentially life-limiting disease and improving health professionals communication skills appear to be essential in encouraging open discussion of end-of-life issues in advanced heart failure. A better understanding of the illness and a more open discussion about the prognosis may also contribute to more respectful treatment of the patients—some of our interview participants described negative experience in this context.

To improve communication with patients and their families, decision-making and goal setting, introducing a palliative care approach and advanced care planning (ACP) seem to be appropriate strategies (e.g., Low et al. 2011; Horne and Payne 2004; Schellinger et al. 2011). According to the definition of the World Health Organization (2010), 'palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. The Council of Europe (2003) recommends that all health professionals involved in delivering care for people at the end of life should be confident with the basic palliative care principles and be able to put them into practice. For most people at the end of life, integrating the basic palliative care principles in health care settings such as family practice, community nursing and general hospitals is the optimal response. However, some patients (estimated 5 % of the severely ill and dying non-cancer patients) require specialist palliative care due to complex needs and problems (Radbruch et al. 2009).

Therefore, the European Association for Palliative Care suggests a two step model: Firstly, a palliative care approach available for GPs and staff in general hospitals, as well as for nursing services and for nursing home staff; and secondly, specialist palliative care delivered by palliative care teams, palliative care units and in hospices (Radbruch et al. 2009).

Specialist palliative care services have been developed considerably over the last years in Germany as well as internationally, but the available services focus on cancer patients with other patient groups, in particular older patients, being largely neglected (World Health Organization 2011). Remarkably, none of the patients interviewed in this study had any experience with palliative care services. From our data it could not be concluded that specialist palliative care would have been appropriate for the patients interviewed. However, our data at least suggest that there is room for improvement regarding the palliative care approach.

Good communicational culture is essential in palliative care and aims to improve the communication between patients and relatives, as well as between health professionals and services interacting with the families (Radbruch et al. 2009). Generally, the GP should be able to discuss end-of-life concerns in a sincere and careful manner with their patients and by involving the families could facilitate dealing with their wishes and fears. Patients' feelings such as being a burden to others then could be defined and met in an appropriate manner. In the situation where these feelings are identified and the informal caregivers are overstressed, respite care may offer these patients and their caregivers a planned or unplanned break. Respite care is a part of the holistic palliative care concept and can be provided, e.g. in day-care facilities. In addition, the volunteer hospice teams may provide assistance. Volunteer hospice teams contribute to the psychosocial and emotional support of patients and relatives (Radbruch et al. 2010).

ACP is a relatively recent approach to improve the communication with patients and their families, and decision-making and goal setting. It re-introduces advance directives, but within a new framework, including 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 and in the community (In der Schmitzen et al. 2010). There is evidence that disease specific ACP for heart failure results in an improved understanding of patient goals, more frequently fulfilled end-of-life wishes, and reduced stress, anxiety and depression among family members (Detering et al. 2010; Kirchhoff et al. 2010; Schellinger et al. 2011). Thereby, ACP may help to relieve patients' fears, revealed during our interviews, of being a burden to others and to set up a more open discussion among all the persons involved. However, in none of the patients in this study was ACP made use of. This is not surprising since overall ACP has not yet been developed in Germany, which suggests the need for further explorative research and interventional trials (e.g. to identify and overcome barriers for the implementation of ACP).

In contrast to studies from other countries (Low et al. 2011), and also in contrast to group discussions with health

professionals in Germany (Brueckner et al. 2009), poor coordination of health care delivery did not emerge from this study as a major concern of the patients. Nevertheless, it is unlikely that there are no deficits concerning coordinating health care delivery for older people with advanced heart failure since interdisciplinary rivalry and strong fragmentation of inpatient and outpatient services are well known problems in the German health care system. Furthermore, in Germany, patients have a widely free access to generalists and specialists of all relevant disciplines, often resulting in many different professionals taking care of the patients without a particular person coordinating. It may be possible that the patients interviewed in this study were not aware of coordination problems that occurred ‘behind the curtain’ or that they had a good coordinator, e.g. their GP, although there is no mandatory gatekeeping in the German health system. Almost all patients described the contact with the family physician as very positive, possibly indicating a strong patient–physician relationship.

Limitations

As this is a cross-sectional analysis, the results reflect patients’ perspectives at one point of time only. It is possible that their perspectives change over time with further progression of the illness. Since the patients included in this study will be followed up for 18 months, with interviews every 3 months, it will be possible to conduct further longitudinal analyses and to compare the results with those presented here for the baseline interviews. The patients were recruited from and interviewed in two geriatric hospitals. Selection bias is possible due to the recruitment by the treating physicians. There may be a tendency towards socially desirable statements. To reduce social bias, the interviewer was not involved in the delivery of health care for the patients and not employed by one of the geriatric hospitals.

Overall, our study emphasizes the need for improving communication with patients with advanced heart failure. To achieve this, strengthening the palliative care approach in all relevant services that deliver care for these patients, and introducing ACP appear to be promising strategies.

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