

Original Article

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Unsolved problems and unwanted decision-making in the last year of life: A qualitative analysis of comments from bereaved caregivers

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Abstract

Objectives. Patients in their last year of life, as well as their relatives, often feel that existent care structures of the healthcare system do not adequately address their individual needs and challenges. This study analyzes unmet needs in terms of unsolved problems and unwanted decision-making in the health and social care of patients in their last year of life from the perspective of bereaved caregivers.

Methods. This qualitative study is based on free-text comments from informal caregivers of deceased patients collected as part of the Last-Year-of-Life-Study-Cologne (LYOL-C) using a postal survey. With qualitative content analysis, a category system with main and subcategories was developed in a multi-step process.

Results. Free-text commentaries and demographic data were collected from 240 bereaved caregivers. Particularly outside of hospice and palliative care services, study participants addressed the following unsolved problems: poor communication with medical and nursing staff, insufficient professional support for informal caregivers, inadequate psycho-social support for patients, and poor management of pain and other symptoms. Respondents often stated that their relative had to be cared for and die outside their own home, which the relative did not want.

Significance of results. Our findings suggest the necessity for greater awareness of patients' and their relatives' needs in the last year of life. Addressing individual needs, integrating palliative and hospice care in acute hospitals and other healthcare structures, and identifying patients in their last year of life and their caregivers could help to achieve more targeted interventions and optimization of care.

Introduction

The last year of life (LYOL) is a particularly vulnerable period for patients and their relatives, during which they usually come into contact with various health and social care structures (Bekelman et al., 2016; McDermott et al., 2019). Studies suggest that patients in their LYOL and their relatives frequently do not feel that existing healthcare structures adequately address their needs and individual challenges (Weber et al., 2012; Robinson et al., 2014; Bussmann et al., 2015; Bainbridge et al., 2018). In this context, general patient satisfaction often varies greatly depending on the particular care setting. Hospices and specialized palliative care services are perceived more positively than care in acute hospitals (Addington-Hall and O'Callaghan, 2009; Bainbridge and Seow, 2018).

Informal caregivers play an integral part in the care of patients in their LYOL, gaining valuable insight into their specific needs and challenges in the last phase of life. Their experience can thus serve as a substantial help for the improvement of end-of-life care structures (Bussmann et al., 2015; Bainbridge et al., 2017, 2018; DiGiacomo et al., 2017; Donnelly et al., 2018; Zavagli et al., 2019). Seeking the views of bereaved relatives should be considered to ascertain the quality of care by both quantitative and qualitative approaches. One way to gain insight into the care experiences of patients in their LYOL is to analyze free-text comments from the perspective of informal caregivers. In addition to the use of quantitative data, the analysis of free texts allows a deeper understanding of individual experiences, shows potential improvement possibilities of care deficits, and generates possible new research approaches (Riiskjær et al., 2012).

The Last-Year-of-Life-Study-Cologne (LYOL-C) is a cross-sectional, mixed-methods study exploring the LYOL until the death of patients deceased in the greater Cologne area

(Germany). Cases are investigated regardless of patients' age, underlying diagnosis, or healthcare facility used, aiming to gain insights into the optimization of healthcare processes and structures (Strupp et al., 2018). It is one of three research projects initiated within the Cologne Research and Development Network (CoRe-Net) (Karbach et al., 2018).

This paper seeks to qualitatively explore unmet needs in terms of unsolved problems and unwanted decision-making in the care of patients in their LYOL from the perspective of informal caregivers.

Methods

Study design, population, and data collection

This qualitative analysis is based on free-text answers to a postal survey of informal caregivers of deceased patients conducted as part of the LYOL-C. Further data obtained from the questionnaire were analyzed in a separate publication (Voltz et al., 2020).

Participants were a purposive sample of relatives, friends, and voluntary workers acting as proxy respondents (all will be referred to as "informants" hereafter). Inclusion criteria required informants to be aged 18 years and older, to have recently cared for a person who lived their LYOL in the Cologne area and to have returned the questionnaire by the closing date of the data collection (November 2017 data collection start, October 2018 data submission deadline). We excluded deaths of people under the age of 18, as well as accidental and suspicious deaths. Informants were free to choose scope of time and location for completing the postal questionnaire. The methods for the full survey are described in more detail elsewhere (Voltz et al., 2020).

The self-completed questionnaire consisted of a German version of the Views of Informal Caregivers' Evaluation of Services–Short Form (VOICES-SF) (Hunt et al., 2019; Voltz et al., 2020). The questionnaire comprises a total of 106 items, of which 103 are exclusively quantitative, two are mixed, and one is a qualitative item in the form of an open question. Furthermore, on the last page of the questionnaire, the informants were given a chance to make general comments on the survey in free-text form.

The items of the questionnaire with a qualitative dimension relevant to the research question were as follows:

- Item no. 101: "Looking back over the entire last year of life, were any decisions made regarding the care that your relative did not want?" (mixed item; possible answers: yes, probably yes, probably no, no, do not know, and invitation for additional free-text comment if answer "yes" or "probably yes")
- Item no. 102: "Looking back over the entire last year of life, were there any problems regarding the care that could not be solved?" (mixed item; possible answers: yes, probably yes, probably no, no, do not know, and invitation for additional free-text comment if answer "yes" or "probably yes")
- Item no. 106: "Do you have any comments on the care of your relative in the last year of life?" (exclusively qualitative item)
- Free-text field without specific question with option for further comments on topics considered relevant by informants.

The items of the questionnaire were numbered chronologically according to their appearance in the postal questionnaire, so that items 101, 102, and 106 with the option of free-text comments could be found in the posterior part of the questionnaire. Included in the qualitative analysis of this paper were the informants who used at least one of the four free-text fields for comments in bullet point or sentence form (items 101, 102, 106,

free-text field for additional comments on the last page of the questionnaire). In addition, the demographic data of the deceased relatives as well as the informants of this subgroup (participation in at least one of the four free-text fields) are provided.

Analysis

Free-text comments were analyzed using MAXQDA version 2018.1. Demographic data of informants and deceased relatives were analyzed using SPSS Statistics version 25 (IBM Corp., Armonk, NY, USA).

By using qualitative content analysis, we analyzed the free-text content and developed a qualitative category system with main and subcategories in a multi-step process (García et al., 2004; Elo and Kyngäs, 2008; Mayring, 2014). GD and NiS designed the survey instrument and collected data. JK coded and analyzed the entire data set as agreed upon with GD and JS. GD and JS familiarized themselves with a random sample of the responses. Afterwards, the codes and categories were discussed and negotiated between the authors (JK, GD, JS) to reach consensus and adjustments were made if necessary.

First, the original free-text comments were prepared for coding by identifying relevant text passages to the research question ("unmet needs in terms of unsolved problems and unwanted decision-making in the LYOL"). Then we divided comments with several relevant aspects into text modules for individual coding. Following this, preliminary codes were developed by inductive analysis of the relevant text passages previously identified for the research question. In the course of further analysis, we continually compared, critically discussed, and re-evaluated newly emerging codes and summarized thematically identical text passages in preliminary categories. After coding all text passages, they were sorted thematically, repeatedly refined in terms of intercategory distinctiveness, and main and subcategories were established for a higher level of abstraction.

Information was collected on the frequency of text passages assigned to the main categories and subcategories. Exemplary free-text quotes were selected by the team based on the criteria of representativeness, thematic frequency, and verbal expressiveness. Occurring differences of opinion in the development of the category system were resolved by critical discussion and, in the case of continuing differences of view, by majority opinion.

Results

From a total of 351 questionnaires collected in the LYOL-C, free-text data of informants could be analyzed in 240 cases (68%) which means that 240/351 informants added comments to at least one of the four available free-text fields in their questionnaires (Voltz et al., 2020). There were 64/351 (18%) responses to free-text item 101, 113/351 (32%) responses to free-text item 102, and 179/351 (51%) responses to free-text item 106. Besides, 89/351 (25%) informants used the voluntary option to make general comments on the survey in free-text form on the last page of the questionnaire.

Of the informants to item 101, 63/351 (18%) answered "yes" or "probably yes," with 59/63 (94%) of these informants subsequently writing a free-text comment. The higher number of total free-text responses ($n = 64$) is explained by the fact that five informants also decided to enter free text, even though they had previously answered "probably no" or "no."

As for item 102, 116/351 (33%) of informants answered "yes" or "probably yes," with 106/116 (91%) of these informants then

writing a free-text comment. The higher number of total free-text responses ($n = 113$) is due to the fact that seven informants also opted to provide free-text comments, even though they had previously answered “probably no” or “no.”

The survey results reflect informants’ experiences from January 2015 to July 2018. Table 1 presents demographic data of survey informants and their deceased relatives.

The developed category system for the analysis of unsolved problems in the LYOL comprises a total of 5 main categories and 20 subcategories and for the analysis of unwanted decisions in the LYOL a total of 2 main and 2 subcategories. The main categories represent protagonists in the LYOL, such as patients, caregivers, and health professionals. Subcategories subsume thematic motives and complexes associated with protagonists from the perspective of the bereaved informants. To provide a better illustration of the category system in our publication, we opted for the tabular presentation with representative citations for each subcategory (see Tables 2 and 3). In addition, in the continuous text, each paragraph of a main category is preceded by a selected citation.

Information on the frequency of citations in each main and subcategory was collected and describes the number of text fragments from the informants’ comments that could be assigned to the respective main and subcategories. The number of citations assigned to a main category is the sum of citations assigned to the subcategories of that main category. These allow the identification of recurring themes but do not necessarily indicate the importance of the thematic complexes mentioned by informants (Garcia et al., 2004).

Informants most often addressed the following unsolved problems: poor communication with medical and nursing staff, insufficient professional support for informal caregivers, inadequate support for patients with psychological coping, and poor management of pain and other symptoms. The most frequently cited care decision against the patient’s preference was to be cared for and to die outside his or her own home.

Main category: Patient as person in need of care

“He wanted to die at home, but it was practically impossible.”

This category focuses on the deceased patient in his/her LYOL as the protagonist. A large number of informants stated that the central wish of their deceased relative was to be cared for and to die at home, but this was usually not possible due to a lack of medical and nursing care services. As a result, they had to resort to inpatient care. Some informants reported burdening unsolved conflicts in the patient’s family or private environment, and in some cases, also former social contacts turning away from the deceased patient in the course of the disease. Others described patients’ inadequate psychological coping with the disease and lacking respective support offers during the LYOL. Denial of their disease, social withdrawal, and anxiety and depressive disorders were mentioned. Some of the informants also raised the issue of their seriously ill relatives’ desire for physician-assisted suicide.

Main category: Relatives as informal caregivers

“What was completely missing, however, was the offer of psycho-oncological/psychological support or further support measures. In this situation (for us altogether more than three years), we felt overwhelmed as a family and especially left alone in the end.”

Many informants found themselves and other caregivers faced with a variety of unsolved psychological, social, and spiritual

Table 1. Demographics and characteristics of LYOL-C subgroup ($n = 240/351$)

	<i>n</i>	(%)
Deceased age at death (years)		
18–29	1	(0.4)
30–49	4	(1.7)
50–64	51	(21.3)
65–79	75	(31.3)
80+	109	(45.4)
Deceased sex		
Male	111	(46.3)
Female	129	(53.8)
Deceased ethnic group		
German	232	(96.7)
Others	8	(3.3)
Deceased family situation ^a		
Had a partner	112	(46.9)
Lived together with partner	91	(38.1)
Had children	115	(48.1)
Lived together with children	19	(7.9)
Lived together with someone else	16	(6.7)
Lived alone	74	(31.0)
Diseases in the last year of life ^a		
Cancer	145	(60.4)
Cardiovascular disease	93	(38.8)
Neuro-psychological disease	161	(67.1)
Disease of the respiratory system	62	(25.8)
Liver or kidney disease	38	(15.9)
Diabetes mellitus	26	(10.8)
Informant relation to deceased		
Spouse	101	(42.1)
Son/daughter	93	(38.8)
Sibling	13	(5.4)
Son/daughter-in-law	4	(1.7)
Father/mother	3	(1.3)
Other relatives	9	(3.8)
Friend	10	(4.2)
Others	7	(2.9)
Informant age (years)		
18–29	2	(0.8)
30–49	32	(13.3)
50–64	109	(45.4)
65–79	81	(33.8)
80+	16	(6.7)
Informant sex		
Male	65	(27.1)
Female	175	(72.9)

^aMultiple responses were possible.

Table 2. Unsolved problems regarding care in the LYOL

Main category		Frequency of quotation
Subcategory	Sample quotation	
Patient as person in need of care		28
<i>Coping & psychological adaptation</i>	“My husband refused to acknowledge his disease and always pretended to be healthy. He was a master of denial. [...] When nothing helped anymore, I called ‘112’ against his will. They took him with them right away.” “She had many fears and no longer dared to leave her apartment with no one around.”	18
<i>Social environment</i>	“Turning away from work colleagues in the year of disease.”	5
<i>Legalization of euthanasia</i>	“There was no legal way to commit assisted suicide.”	5
Relatives as informal caregivers		60
<i>Mental, social, and spiritual needs</i>	“Day after day, several hours at the hospital bed, whether it be the regular ward, palliative, or hospice, keeping him company often brought me to the very edge of exhaustion! [...] Finally, the nurses saw me, some of them admired me, saying, ‘You are so great to be here all the time!’ However, nobody really asked how I was doing with it.” “Still, I felt left alone, because in this situation there was no time to take care of me.”	27
<i>Need for information</i>	“In my opinion, we should try to support and encourage patients and relatives more strongly to take this step [to hospice]. Most of them are not sufficiently informed and simply do not dare to take this step.”	15
<i>Excessive workload and overload as an informal caregiver at home</i>	“Nursing service could only help me to the extent listed in the ‘time catalog.’ But I would also have needed help when it came to shopping, a visit to the hairdresser, etc. I used ‘good’ friends, but they became fewer and fewer as time went on.” “The care of dying at home with all its problems (mucus, restlessness, water retention, etc.) is very difficult to bear.”	12
<i>Possibilities of accompanying the dying loved one</i>	“In the last days of his life, I would have liked to be with him as his wife in a two-bed room (at own expense), but in the hospital, none was free.”	6
Healthcare provider		233
<i>Communication — information and involvement in decisions</i>	“Poor communication with me as a family member about the prospects with the disease in the hospitals. If at all, between the door and the hinge.” “As a wife, I did not feel informed by the physicians in the hospital. A conversation took place only once, despite persistent request.”	75
<i>Communication — way of communication</i>	“In the emergency room, she was left lying with her lower body naked. I had to cover her with her coat. The tone towards her was almost entirely disrespectful.” “After my aunt had passed away in hospital and we said goodbye to her in the hospital room, a nurse told us that we had to clear out the cupboards/bathroom, etc. right away. This was humiliating. My aunt was lying dead in bed, and we had to hustle around her and collect her belongings.” “The treatment by the nursing staff in the hospital should have been more respectful and sensitive. That is why my mother had herself discharged early, despite the high risk of death.”	60
<i>Communication — sole focus on somatic care</i>	“My father was sent to the hospital by his family doctor with a suspected stroke shortly before his death. Despite being in palliative care, he was diagnosed there until the evening (it was on his last birthday). The diagnosis was not confirmed, he was allowed to go home again. However, the brain metastases detected on that day put an additional strain on my father.”	7
<i>Staffing level & continuity of treatment</i>	“I spent hours every day at the clinic to make up for the lack of care. The staff, pardon me, was far beyond what they could do.” “The physicians and nurses were totally overworked because there were not enough staff in the intensive care unit. I was with him 24 h a day in the end.”	39
<i>Pain control and other symptoms</i>	“In the last night + last day before his death, the pain could not be completely taken away from him, despite morphine. Even before that, there were always problems with the pain control.”	21
<i>Coordination, cooperation, & information exchange between medical care entities</i>	“We saw no cooperation between the medical providers (GP, oncologist, hospital).” “Care in the individual specialist clinics was very different [...]. Much referral, no networking, and concept.” “Due to the many changes in location, considerable amounts of information are lost; everything is asked for and set up anew instead of using existing data.”	9
<i>Missing home visits</i>	“It would be nice if family physicians at least made house visits to old and seriously ill people.”	9
<i>Capacity and infrastructure of palliative and hospice facilities</i>	“The hospice place did not become available until two days after the death.” “It was not possible to get a hospice place in time for my father to spend his last days in dignity.”	7

(Continued)

Table 2. (Continued.)

Main category Subcategory	Sample quotation	Frequency of quotation
<i>Care of dementia patients in the hospital</i>	“My impression is that people with dementia have an awful time in the hospital. ‘If anything happens, ring the bell.’ It is a mockery of the person who cannot even do that anymore.” “Solutions with dementia patients often mean fixation, sedation by medication, not very respectful treatment, being annoyed, beds with bars (sometimes with complete nets over them), etc.”	4
<i>Activity programs in hospital and care homes</i>	“The usual things in an elderly home: too few offers for mentally active people.”	2
“Insurance providers & other administrative bodies”		23
<i>Allocation of care levels</i>	“Despite my mother’s deplorable condition, the medical service refused to upgrade the level of care until the end, which meant that I could not get a place in a nursing home for her.”	14
<i>Time delay</i>	“The disability pass came only after his death so that the benefits (e.g., free travel with an accompanying person) were not available to him.” “In some cases, we waited for 5 to 8 weeks for the health insurance company to pay the submitted bills.”	6
<i>Coordination with each other</i>	“My mother had to wait two weeks in the nursing home for a mobile oxygen unit and, therefore, could not leave the room because of communication problems between the providers.”	3

Table 3. Unwanted decision-making regarding care in the LYOL

Main category Subcategory	Sample quotation	Frequency of quotation
Patient as person in need of care		51
<i>Care & death at home</i>	“I have been working as a volunteer in a Cologne hospice since the beginning of 2015. In most conversations with the patients, it becomes clear that the desire to die at home is the top priority.” “The last three months she was in a home for the elderly because we could no longer provide care at home (dementia). She wanted to be at home.” “Since the care at home was not ensured and the family system would have been overwhelmed with the care and the passing, we had to make the decision to let my husband die in a hospice.”	51
Healthcare provider		17
<i>Overtherapy & treatment against the patient will</i>	“During the last hospital stay, treatment and examinations, possibly also medication, were given which the relative [patient in the last year of life] no longer wanted, despite a living will, despite a personal conversation between the head physician and the patient.” “The nursing staff found it difficult to accept that my mother did not want to drink at the end. It was always checked how much she had drunk and when she did not want to drink any more, they wanted to connect her to a drip, although my mother explicitly rejected exactly this in her power of attorney.” “My husband approved therapies that prolonged life, but the quality of life was no longer there.”	17

issues in the last year of the deceased patient’s life. Recurring themes were lacking offers of conversations to process experiences and grief, neglecting one’s own needs, and dealing with spiritual questions. In our study, some informants expressed the wish to have obtained more information about the way the healthcare system works, which they did not seem to sufficiently understand and which often led to a feeling of helplessness and being at the mercy of others. Several informants also reported that their situation as caregiving relatives often pushed them to the limits of their resilience and beyond. Occasionally, informants complained about a lack of ways to accompany their relatives adequately when they were dying.

Main category: Healthcare provider

“His neurologist was only interested in MRI images and blood counts. He was less interested in human beings in any way.”

This category centers around the role of physicians and nurses as protagonists in the last year of a patient’s life. It addresses various aspects of problems in care from the perspective of the informants. We could attribute most of the quotations of the entire analysis to the motive “communication.” In particular, many informants saw significant deficits in the way physicians and nurses communicate, “shared decision-making” not being practiced, and a sole focus on somatic care. Recurring themes include impersonal and unemphatic communication, a general lack of time for discussions, an inappropriate setting for communication, insufficient information about the patient’s state of health and treatment options or prospects, missing participation in therapeutic decisions, and a feeling of disinterest in the patient’s psychological well-being.

Furthermore, some informants mentioned a strong understaffing in hospitals and nursing homes, which primarily affected seriously ill patients and patients with dementia, as they are unable to care for themselves. Other informants described deficits in pain

management and other symptoms like dyspnea, nausea, pruritus, and obstipation in the last year of the deceased patient's life. Likewise, life-prolonging measures in the dying process were often viewed critically. Some study informants also reported a lack of cooperation and coordination between different medical providers and loss of information when switching between different providers. They criticized as well that many physicians did not offer home visit services for severely ill patients. Some informants saw a further problem in the inadequate care of patients who have dementia in hospitals and in the lack of activating services for older people in hospitals and nursing homes. Furthermore, experiences with overtherapy and treatment against the will of the patient were mentioned.

A large number of study informants commented very positively on the palliative and hospice care of their relatives in the LYOL, despite the explicit question about unsolved problems and unwanted decision-making. However, some complained about too few available places in palliative care facilities and hospices, so that their relatives had to wait a long time or could not be accommodated.

Main category: Insurance providers and other administrative bodies

“Delivery of the hospital bed was delayed by the health insurance company to the extent that it was only delivered five days before my husband's death.”

This category comprises problems in the care of patients in the LYOL by health insurance companies, authorities, and other relevant administrative institutions. Several informants perceived applying for the care level¹ for their relatives to the health insurers as not satisfactory and associated with obstacles. Often the assessment of the need for nursing care by the medical service of the health insurers was considered inadequate to the actual severity of the disease. As a result, they granted less financial assistance for nursing services than would have been necessary for adequate care according to the informants' opinion. In many cases, the time taken to process applications for assistance was perceived as too long, resulting in care services and aids not being provided in time (sometimes even after the applicant has passed away). Moreover, there were reports of poor coordination between the individual providers, which also delayed and hindered the provision of care services.

Discussion

Based on free-text comments, this qualitative analysis was able to identify five key themes that may have a negative influence on the quality of life and care of patients in their LYOL and their social environment from the perspective of bereaved informal caregivers. The results of this paper confirm deficits in the care of patients at the end of life, which have been reported in the previous research literature, adding regional facets and providing a comprehensive panorama of unsolved problems and unwanted decision-making of patients and their relatives in the LYOL.

Communication with medical and nursing staff

Previous studies emphasize the benefits of adequate and early communication with patients at the end of life and their families

¹In the German healthcare system, a patient's need for nursing care is classified by so-called levels of care. Depending on the level of care assigned, the health insurance companies provide support services.

following their individual need for information and participation in treatment decisions so that conversation training has become part of global guidelines in palliative care, as, for example, in the national guidelines in Germany (Brighton and Bristowe, 2016; Brighton *et al.*, 2017; Alt-Epping *et al.*, 2020). The results of our study, in which most of the quotations of informants addressed deficits in communication with physicians and nurses, confirm the central importance of successful communication between medical providers and patients in their LYOL. In particular, the patient's feeling of having been treated with dignity and respect, of being involved in therapeutic decisions, and the consideration of psychosocial needs were key indicators of patient satisfaction in the previous study of our research team (Voltz *et al.*, 2020).

While physician-patient communication in hospice and palliative care facilities usually met patients' needs, informants often described their experiences in acute hospitals as impersonal and disrespectful. As one possible explanation for this phenomenon and a target for intervention, we suspect a work culture often prevalent in acute hospitals that places a greater emphasis on somatic components and neglects a holistic approach, encompassing psychosocial elements, when treating patients. In view of the fact that the hospital is still the most frequent place of death for patients in the Western world, it might be useful to raise awareness among healthcare professionals working in acute hospitals regarding the specific psychosocial needs of patients in their LYOL and, based on this, to communicate in a way that is appropriate to their needs (Cross and Warraich, 2019; Dasch and Zahn, 2021). Sinuff and colleagues developed a set of quality indicators related to end-of-life communication and decision making that can serve as a guide for educating healthcare professionals and evaluating communication with patients in their LYOL in daily clinical practice (Sinuff *et al.*, 2015).

Care and death at home

For patients in our study, the hospital was the most common place of death, and only about 30% of them were able to have their wish of dying at home fulfilled (Voltz *et al.*, 2020). Informants stated that the wish of their loved one to die at home often could not be realized due to insufficient or unavailable medical and nursing care services. Wherever available, palliative home care services were favored in the free-text commentaries compared to others and predominantly perceived positively. Our findings underline the central desire of the majority of patients to die in their own homes and encourage efforts for establishing a comprehensive infrastructure of outpatient palliative care.

Unmet needs of informal caregivers

Caring relatives play a key role in end-of-life care. They are exposed to a variety of physical, emotional, and social demands that can harm their health and lead to increased mortality (Schulz and Beach, 1999; Ullrich *et al.*, 2017; Zavagli *et al.*, 2019). These results are reflected in the experiences of informants in our study. The informants describe several situations in the care of their relatives in their LYOL that repeatedly brought them to the limits of their physical and psychological capacity.

Previous work has shown that the quality of life of caring relatives and that of end-of-life patients are interdependent, which means that patients in their LYOL also benefit from interventions to improve the quality of life of informal caregivers (O'Hara *et al.*, 2010; Krug *et al.*, 2016). These insights make it all the more

important to identify informal caregivers of patients at the end of life as targets for interventions at an early stage and to create barrier-free access. A validated assessment tool for analyzing informal caregivers' need for assistance in different domains is the evidence-based Carer Support Needs Assessment Tool (CSNAT). This tool enables healthcare professionals working in palliative and end-of-life care to identify caregivers with a need for intervention and to provide them with targeted, tailored support (Ewing et al., 2013; Ewing and Grande, 2013). Another validated assessment tool to quantify caregiver burden is a short form of the Zarit-Burden interview specifically adapted for the palliative setting by Kühnel et al. (2020) *Klicken oder tippen Sie hier, um Text einzugeben*. A 2013 Cochrane Review provides an overview of the evidence regarding a variety of supportive interventions in terms of their effect on the physical and psychological health of informal caregivers (Candy et al., 2011).

Coping and psychological adaptation

Insufficient psychological coping by patients at the end of life correlates strongly with their subjective quality of life and can also negatively influence the perception of physical symptoms such as pain, shortness of breath, or nausea (Block, 2006; van Laarhoven et al., 2011). Based on the results of our study, we assume that the inadequate psychological coping with the disease in several patients in their LYOL aggravated the experience of physical symptoms and significantly affected their quality of life. In this context, it seems all the more important to raise the awareness of patients in their LYOL and their relatives about available psychosocial support services to keep access as low threshold as possible.

Pain control and other symptoms

Pain and dyspnea are among the most common and most feared symptoms of seriously ill patients in the LYOL. There is evidence that adequate pain and symptom management is still not achieved in many patients at the end of life (Bhatnagar and Gupta, 2016; Frankenhauser et al., 2017). In our study, informants likewise report deficits in the symptom management of the deceased patients. In comparison with hospices and palliative care units, the pain management of general wards in hospitals and at home is perceived as of lower quality (Voltz et al., 2020). This suggests a relationship between clinicians' competence and experience in effective symptom management and the degree of successful symptom relief in patients in their LYOL.

Research so far has identified several barriers faced by patients and healthcare providers that prevent effective assessment and treatment of pain and other symptoms at the end of life. On the part of patients, these include fears and mistaken assumptions about the effects and side effects of pain medications and the lack of communication of symptomatic conditions. Deficits among healthcare providers comprise clinicians' lack of knowledge and experience in effective symptom management, as well as systemic barriers such as higher prioritization of curative over palliative care, restrictive use of high-cost medications, or staff shortages that prevent adequate patient care (Fineberg et al., 2006; Imhof and Kaskie, 2008; Schrader et al., 2009; Wilkie and Ezenwa, 2012).

Strengths and limitations of the study

With a high participation rate of 240 informants, our free-text analysis gave detailed and immediate insight into unsolved

problems and unwanted decision-making regarding care provided to patients in their LYOL from the perspective of their bereaved relatives. To the best of our knowledge, our publication is one of the first qualitative works expanding the time frame of analysis of care experiences and needs of patients and their social environment to a whole year before death, regardless of the place of death, the underlying diagnosis, and the care providers involved. The method of qualitative content analysis of free texts used here enabled us to gain a deeper and more detailed understanding of individual experiences of patients in the LYOL, complementing the quantitative analysis of questionnaire data we published elsewhere (Voltz et al., 2020).

The informants' retrospective perspective serves as an approximation of the patient's own experience, but it is not equal to it and may be influenced by the quantity of time spent together, the quality of the interpersonal exchange between informants and patients in the LYOL, as well as socio-psychological phenomena such as social desirability, individual expectations, or limited and selective memory (Baddeley, 1990; Funk et al., 2012). Nonetheless, it can be assumed that a certain level of agreement between the patient and informant will emerge in the long term concerning the perception of experiences, although other accentuations are possible (Tang and McCorkle, 2002; McPherson and Addington-Hall, 2003).

Furthermore, readers should keep in mind that our analysis is based on free-text answers that were collected in a more comprehensive questionnaire. In this context, participation and depth of content similar to that of comparable analyses based on personal interviews may not have been achieved, and informants may have limited themselves to a few aspects that they considered should be given the highest priority. Since it was necessary to speak German to participate in the study, specifically migrant perspectives may also be missing or underrepresented.

Discrepancies regarding the demographic data of the total group of deceased relatives respectively the informants of the postal questionnaire ($n = 351$) and the subgroup of the study ($n = 240$) which was used for this qualitative analysis were at most smaller/larger than 5% in each category. The exception to this is the proportion of deceased relatives with at least one neuropsychological disorder which was more than twice as high in the subgroup for this qualitative analysis as in the general group (67.9% vs. 32.8%). In this respect, it may be the case that the results of our analysis are disproportionately affected by this patient population. For a detailed presentation of the demographic data of the general group of the study ($n = 351$), refer to the publication by Voltz et al. (2020).

Finally, it should be noted that the results of this study reflect the experiences of informants from the greater city of Cologne, Germany, with an established palliative care infrastructure and hospice facilities. Our results may not be fully transferable to countries and regions with different healthcare structures. For a detailed description of the set-up of the palliative and hospice infrastructure in Cologne, Germany, also see the publication by Voltz et al. (2020).

Conclusion

Our findings suggest the necessity for greater awareness of patients' and their relatives' needs in their LYOL. The findings reveal that patients and their relatives faced diverse problems affecting their care and that they were not involved in decisions about their care as much as they wanted. There is a need to

identify patients to be in their LYOL and consider their needs, especially outside hospice and palliative care structures. Integrating palliative care concepts in acute hospitals and other structures of regular health care can ensure that patients receive high-quality care.

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