ORIGINAL ARTICLE

The Buddy intervention: designing an additional support system for the last year of life. Qualitative insights from triangulated interviews and focus group discussions

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Abstract

Aim Health and social care structures available for the last year of life care are still not always adequately used. Palliative care, for instance, is still provided late in the disease course, contradicting early integration. We therefore aim to define elements of a possible complementary support concept based on specific experience to help facilitate death at home.

Subject/methods Qualitative triangulation of data was conducted from countrywide individual interviews (patients and relatives, $n = 45$) and focus group discussions (health and social care professionals, $n = 22$), in Germany. Data were transcribed verbatim and analyzed within a framework analysis. Using Bradshaw's sociological construct of needs, qualitative data sequences were converted into needs and sorted by the theory of social support.

Results Informants described having needs in *emotional*, *informational*, *appraisal*, and *instrumental* dimensions. Unmet needs for information were frequently reported, affecting all other need dimensions. To address these concerns, informants expressed a need for someone proactively providing emotional, appraisal, and instrumental support, such as organizing respite support, giving feedback on care provision, and validating caring relatives.

Conclusion We assume an impact of insufficient information about care options on instrumental, emotional, and appraisal needs and help-seeking actions, increasing the risk of inpatient death. Proactive support is required to address patients' and families' needs, connecting the existing care structures. A "buddy" for the last phase of life serving as a low-threshold contact person with real-time knowledge to support patients and families could be one model to support and guide patients and their families and enable dying at home, if possible.

Keywords Palliative care · Qualitative triangulation · Needs assessment · Home death · Support interventions · Personalized care

Introduction

Home is the most preferred place of death for patients who are seriously ill (Ali et al. 2019; Fereidouni et al. 2021; Voltz et al. 2020). Eight out of ten people who are in need of care are cared for at home; many of them are in the terminal care period (Statistisches Bundesamt 2021). This means that just as many families/relatives are involved to assist with care and may need support themselves in order to provide adequate care (Statistisches Bundesamt 2021). Studies have shown that caring for a seriously ill next-of-kin at home is a task that can sometimes take many years and drain all emotional and physical resources (Ateş et al. 2018; Pinquart and Sörensen 2007). To achieve adequate care at home for patients with life-threatening illness, several factors need to be considered, such as available home care

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services such as specialized home palliative care (SHPC) (Burge et al. 2015; Kim et al. 2021). Many patients and families are not receiving adequate support due to a lack of or late integration of services mentioned above (Götze et al. 2018; van Baal et al. 2022). The number of patients receiving palliative care is far below the actual need (Gothe et al. 2022). This disadvantage is even more common in patients with a non-oncological disease (Driller et al. 2022; Just et al. 2022; Kasdorf et al. 2022).

In the last year of life, and especially in the terminal care period, patients and caregivers experience high security needs, including the need for availability of services. In addition to professional care at home (e.g., provided by a palliative home care team), the main responsibility for care falls largely on the family, thereby challenging and testing the stability of the family (Barlund et al. 2021). Previous research has focused on the impact of illness on the patients; therefore, a knowledge gap exists to understand families' needs when providing care at home to their terminally ill family member (Morris et al. 2015). The match between support offered and its utilization appears to be low.

Home hospice services provide the support needed, but are accepted at a very late stage of illness. To better support caregivers caring for a person dying at home, there is a need for additional services. Navigator programs or comparable structures designed to support and connect patients and their relatives to resources throughout the home care trajectory, including the last year of life and regardless of the diagnosis, are missing or not extensive (Frick et al. 2019; Porzig et al. 2018). Within this work, we aim to develop an intervention designed for patients and their caregivers in the earlier stages of their life-threatening illness to support dying at home.

Materials and methods

Study design

This is a qualitative multi-method study combining results from individual semi-structured interviews and focus group (FG) discussions. This article reports data from a larger mixed-methods study undertaken to explore support needs for families of patients who wish to die at home. The study was prospectively registered on 25th November 2021 in the German Clinical Trials Register (DRKS00026229). Ethics approval was granted by the Ethics Commission of the Faculty of Medicine in Cologne (#21-1466).

Sampling and recruitment

Interviews: The inclusion criterion for patients was having a life-threatening illness. Caregivers were included if they were adults with current or past experience of caring for someone at home with a life-threatening illness (e.g. spouse, friend). All participants were recruited via a newspaper article and flyers displayed by the cooperating partners of the study. We aimed to purposively recruit 40 participants, ensuring heterogeneity in the main diagnosis (or cause of death), living situation (living alone vs. with relatives), ethnic background, region, and gender. Deaths that occurred before 2020 were excluded.

Focus group (FG) discussion: For each of the four FG discussions, we aimed to purposively recruit four to six participants per group via e-mail and telephone, ensuring heterogeneity in occupation, qualification, region, and gender, if possible. All potential participants were randomly selected via a nationwide online search on medical, nursing, and counselling services. The inclusion criterion for participation in the FG discussions was experience in end-of-life care (physicians, volunteers, emergency assistants, nursing staff, outpatient specialists and members from hospice, and outpatient palliative care teams).

All informant groups were included in the study if they were older than 18 and had given written informed consent to participate in the study (referred to as "informants" hereafter). Data collection was done until an adequate degree of information power was achieved (Malterud et al. 2016). All potential participants received invitations and an information sheet by email or letter to encourage participation. FG participants received an incentive for taking part (€50).

Data collection

The interviews started in December 2021 and continued until April 2022. The FG discussions were conducted between May 2022 and June 2022. Two researchers with experience in qualitative methods (AK: research associate holding a master's degree; JS: project lead and senior researcher, holding Dr. Dr.) and one study nurse conducted the interviews and FGs. They were unknown to all study participants except one at the time of data collection. Interviews were held online via Zoom, by telephone, or face-to-face. One informant provided written notes instead of an interview. All interviews and FG discussions were conducted in German, with exception of two, which were held in Russian and Turkish. All FGs were conducted online. Interviews and FGs were both semi-structured following a topic literature-based guide (Barlund et al. 2021; Escobar Pinzón et al. 2011; Gomes and Higginson 2006). FG-participants received the questions in advance to prepare themselves. Demographic data of all participants were collected. During the interviews, the participants were asked which support they perceived as crucial and helpful and which support was missing to enable dying at home. During the focus group discussions, the participants were asked to describe support options for patients dying at home and their caregiver and when and where other services were needed but missing.

Three interviews were conducted as triads with respect to the patient's health status.

Data analysis

The qualitative data were audio-recorded, transcribed verbatim in German, and then coded using MAXQDA©. All places, names, and identifiable information were anonymized during transcription and were given a unique code (e.g., "1S1: position in transcript" for interviews or "F1" for FG). The consolidated criteria for reporting qualitative research (COREQ) were used to report this study (Tong et al. 2007). Regular meetings were held among the two coders (AK, JS) throughout the analysis process to minimize biases. A multi-method qualitative approach was used to synthesize the perspectives of patients, bereaved informants, family caregivers, and health and social care professionals (HSCPs). The social support theory is made up of four aspects of support: *emotional support* (personal experience of feeling cared for), *instrumental support* (physical services or items), *informational support* (information on care services), and *appraisal support* (affirmation of behaviors and actions), also known as companionship support (Uchino 2004). Support needs were extracted from the literature, used as a deductive basis (Barlund et al. 2021; Escobar Pinzón et al. 2011; Gomes and Higginson 2006), and were extended by new aspects synthesizing qualitative data. Using a sociological construct of needs, classified into normative, felt, expressed, and comparative needs (Bradshaw 1972), we converted qualitative data sequences into need-codes ("*And I didn't even know* [groans] *what other support might have been available*" [1S35: 1] — Code "*Need to know which support is available*"). These codes then were sorted by the theory of social support (Kaplan et al. 1977; Uchino 2004; Veiel 1985) and determinants of help-seeking (Arnault 2018). While the model assumes internally motivated activities of a person, we also summarize needs induced from external circumstances to better analyze and fulfill the (unmet) needs (e.g., utilization of care, accessibility of medical staff). Using the framework analysis, data were initially broken down into small segments (codes) which were reassembled into categories and subcategories along the needs dimensions. Then codes were raised to a higher level of abstraction within an interpretative concept to describe and explain identified needs (Gale et al. 2013).

Results

Participant characteristics

A total of 67 participants were interviewed. Sociodemographic and participants' and patients' characteristics are presented in Table 1. The running time of 45 interviews was between 21 and 116 minutes (average 47 min), and four FGs were 67 to 83 min (average 74 min). Prospective interviews were conducted with patients, volunteers, and family caregivers who are currently involved in last-year-of-life home care and reporting on future expectations ($n = 15$). Retrospective interviews were conducted with bereaved relatives of patients who were cared for at home, reporting about their past experiences ($n = 30$).

Main findings

The results are summarized as the iterative development of a "buddy" approach with particular focus on the caregiver, following the Knowledge to Action Framework (Graham et al. 2006).

Knowledge creation: problem identification

Based on the perceived burden situations that arise for those having a life-threatening illness and their relatives, various needs constellations are described from participants. (Unmet) needs were reported, in all four dimensions of social support. The largest dimension in which (unmet) needs were communicated was *informational support*, followed by *instrumental support*, *emotional support*, and *appraisal support*.

Help-seeking actions

Although there are institutional support structures for most needs, they are not being used. As illustrated in Fig. 1, by the help-seeking actions, defined as being able to accept help or support, these actions are linked to the use and provision of existing institutional support structures (e.g., outpatient hospice service, palliative outpatient care) (Arnault 2018).

Various barriers arise that affect the utilization of institutional support structures. Some informants communicated difficulties articulating their needs for help or being too shy to ask for help:

I didn't always have the courage to call SHPC right away and say, "Listen, I don't know anymore, can you help me." Yes, and otherwise I'm just someone who can somehow cope with any situation […].

(1S79: 57) Informant about her deceased husband who died at home from lung cancer (53 years)

Other informants do not perceive support needs by themselves, saying that they do not know if they need anything:

What might I need? We had everything.
(1S104: 75) Participant about his deceased mother who died in hospital from cancer (81 years)

Table 1 Interview participant characteristics ($n = 67$).

	Prospective interviews $n=15$	Retrospective interviews $n=30$	Four focus group discussions $n=22$
Informant characteristics			
Median age in years (min–max)	65.9 (48–88)	56.4 (28–75)	54.7 (21–77)
Female	61.5 (8)	86.7 (26)	86.4 (19)
Informant's educational level			
Low	–	10.0 (3)	n.a
Intermediate	7.7 (1)	26.7 (8)	n.a
High	92.3 (12)	63.3 (19)	n.a
Informant's relation to patient			
Patient is reporting him-/herself	13.3 (2)	n.a.	n.a
Spouse	38.5 (5)	40.0 (12)	n.a
Son/daughter	15.4 (2)	40.0 (12)	n.a
Sibling	–	10.0 (3)	n.a
Son/daughter-in-law	7.7 (1)	–	n.a
Father/mother	–	3.3 (1)	n.a
Grandson/granddaughter	–	3.3 (1)	n.a
Volunteers	38.5 (5)	3.3 (1)	27.3 (6)
HSCP[a]	n.a	n.a	59.1 (13)
Other[b]	n.a	n.a	13.6 (3)
First experience in caring for a dying person	23.1 (3)	60.0 (18)	n.a
HSCPs: palliative care qualification available	n.a	n.a	27.3 (6)
Work experience (for HSCPs only)			
Under 5 years	n.a	n.a	9.1 (2)
5–10 years	n.a	n.a	31.8 (7)
11–20 years	n.a	n.a	40.9 (9)
Over 20 years	n.a	n.a	18.2 (4)
Patient characteristic			
Median age/deceased age at death, in years (range)	77.8 (56–94)	73.3 (45–93)	n.a
Female	50.0 (5)	58.6 (17)	n.a
Preferred place of death: at home	62.5 (5)	85.7 (24)	n.a.
Actual place of death: at home	n.a.	82.8 (24)	n.a.
Monthly income			
Under 1.500€ per month	–	16.7 (5)	n.a
1.500€–2.500€	20.0 (3)	23.3 (7)	n.a
More than 2.500€	26.7 (4)	30.0 (9)	n.a
No answer or "don't know"	53.3 (8)	30.0 (9)	n.a
Patient's educational level			
Low	–	13.8 (4)	n.a
Intermediate	30.0 (3)	24.1 (7)	n.a
High	70.0 (7)	62.1 (18)	n.a
Patient's ethnic group			
German	80.0 (8)	89.7 (26)	n.a
Other	20.0 (2)	10.3 (3)	n.a
Patient's family situation[c]			
Lived together with informant	87.5 (7)	55.2 (16)	n.a
Had a partner	70.0 (7)	72.4 (21)	n.a
Lived together with partner	70.0 (7)	65.5 (19)	n.a
Lived together with children under 18 years	10.0 (1)	13.8 (4)	n.a
Lived together with children over 18 years	20.0 (2)	20.7 (6)	n.a
Lived together with someone else	40.0 (4)	13.8 (4)	n.a
Lived alone	–	17.2 (5)	n.a

Table 1 (continued)

	Prospective interviews $n=15$	Retrospective interviews $n=30$	Four focus group discussions $n=22$
Patient's main diagnosis			
Main diagnosis/cause of death is cancer	30.0 (3)	75.9 (22)	n.a.
Place of death: *at home*	n.a.	82.8 (24)	n.a.

Data presented in % (n). *n.a.* not applicable

[a]HSCPs: health and social care professionals (nurses, doctors, and a psychologist working in the areas of oncology, general medicine, intensive care/emergency/rescue medicine, urology, neurology, and psychiatry)

[b]Other: self-employed outpatient counselling for elderly, employee consulting (employed unpaid caregiver) for insurance organizations, case management, volunteers according to German Social Security Code V § 123g

[c]Multiple responses were possible

Contrary to the internally motivated help-seeking actions is the limited availability of health care services. As an example, emergencies at night cannot be supported by primary care physicians. For this reason, HSCP propose an additional support system, as one family physician expressed:

Yes, actually additional services are needed, i.e., additional groups of people, services that fill this gap, I think. So neither the outpatient nursing service, nor... nor the communities or so now simply take over, but actually it would need again an additional ... palliative service or... Such a caretaker, who, of course, does not have to visit very often [...].

(F4: 35) Family physician talking about her experience

Some of the informants reported experiences with not assessing certain things properly any longer. One participant said, "[...] *you need a coach. You need counselling*" (S86: 23). Participants criticize the gap in the current care system and stress the importance of a coordinating authority for care for the patients with a life-threatening illness and the lack of stakeholders feeling responsible:

...such a person to guide them is missing. Someone who has an overview of everything, which is supposed to be the oncologist. In SHPC, most of the patients were connected to an oncologist in private practice, who was supposed to coordinate everything somehow. But that was often not the case, and that is very, very bad. Then you somehow have a very burdened family and a very, very seriously ill person, and they run from A to B and everyone says yes, I'm not responsible. That is very unfortunate.

(F2: 25) Nurse in a palliative unit speaking about her work

[...] I would see a person who really cares intensively and who coordinates [...] whether it's a legal representative, [...] whether it's someone from the hospice organization or from a care service, [...] it has to be someone who feels responsible and doesn't say, "Oh, come on, the legal representative will do it now and the neighbor will do it" [...].

(1S13: 58) Hospice volunteer about her two clients, one dying alone in hospice and the other being cared for by her daughter

Fig. 1 The "buddy" intervention integrated into the theoretical framework of Arnault (2014) and Uchino (2004)
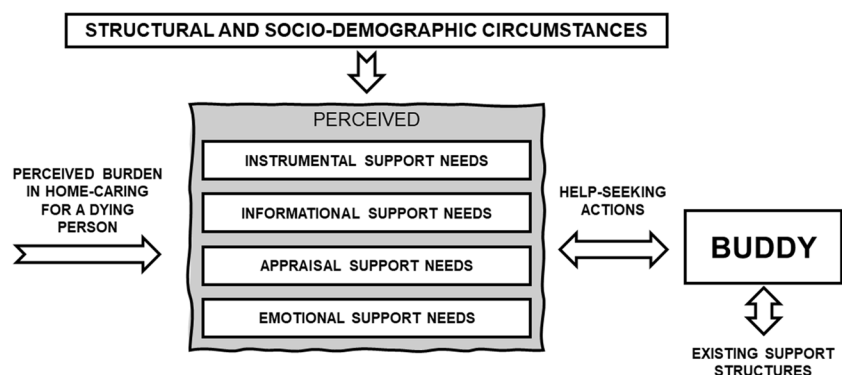
Informational support

Informational support is defined as advice, guidance, and other information on end-of-life care at home (Uchino 2004). The lack of knowledge about the possible support services is the next common explanation for not using existing institutional support structures. Informants frequently reported that awareness of the possibilities of palliative care is low or completely lacking. For example, the initiation of palliative care can take place by HSCPs (in the traditional way):

And then the doctor had informed me about this SHPC that this exists, because I did not know THAT before.

(1S51: 95) Widow of a deceased woman who died at home from cancer (52 years)

Palliative care can also be initiated by informed relatives or by coincidence:

So if I hadn't had this palliative care partner as a general practitioner here at the home visit, I would NOT have figured it out. And not everyone HAS that luck.

(1S42: 77) Informant about her deceased mother who died at home from breast cancer (89 years)

In other cases, the initiation of palliative care does not take place at all. For most informants, palliative care remains an unknown form of care:

Of course, I don't know if she would be eligible for something like that, or if she would even be eligible for palliative care in a case like that. I don't know, because her focus, I say, is not the pain or something. She, she's (that just dying?). I don't know if there is such a thing.

(1S4: 93) Informant about her mother suffering from dementia and blood cancer (94 years)

Informational needs were articulated to prepare for the future care situation. For respondents, it was crucial having someone explain what to expect in caring for a person at home. HSCPs reported sparse knowledge of families on support options at home, especially for palliative care. Some kind of "guide" or "companion" is needed from the time of diagnosis, according to one participant:

[…] It is clear that a cure is no longer possible (for the patient). Then it can also be that someone lives longer. And I think that's what it really takes. Yes, I really imagine a guide, from the diagnosis and then also really a companion. What are the possibilities?

(F1: 7) Consultant about the needs of patients and their relatives

Information on diagnosis, prognosis, and the death process is lacking, as reported by the respondents. Particular importance is placed on *proactive* communication of support possibilities, according to one informant:

So because you CAN'T know on your own and because it's also a hassle to always ask for everything or […] my friend said […] "Hey, I have a booster seat for the toilet. I'll bring it to you." Things like that too.

(1S110: 151) Participant about her deceased husband who died at home from a brain tumor (89 years)

Informants stated that they often do not know who they can contact with everyday issues or questions regarding terminal home care. Some of the interviewees also considered it important to have someone showing a practical guide in caring for a dying person at home or someone who is familiar with information on financial, job, or legal issues. Respondents also reported difficulties in obtaining information. Existing Internet information is insufficient, from the respondents' perspective:

And, of course, one is there again on the mobile phone. And I think there is actually, maybe THAT would be something, if there was a good page, such a page "How do I care for a relative?" or these last aid courses would come even more into focus.

(1S117: 326) Informant about her deceased sister who died at home from breast cancer (52 years)

Consultation services are perceived as being provided on a one-sided basis if they are offered by health insurance funds and are not linked to individual needs:

[…] of course I would have liked to have had such a consultation appointment, such a conversation for MYSELF. […] even when I had questions for my mother, no matter whether it was about aids or whatever, it was simply not useful. He (insurance fund agent) only referred me to the Internet. […] As my mother had a wheelchair, he could have told me that there are better models with pneumatic tires instead of rubber tires and something like that, so that I don't have to know what I actually have to ask, because I mean, when you need advice, you sometimes don't even KNOW what you could or should ask or […] that, for example, I knew that I had to ask for advice. For example, I didn't know that I could have actually obtained a sick note from my mother […].

(1S82: 65-69) Participant about her deceased mother who died at home from heart insufficiency (93 years)

In the context of transitions between different health facilities, participants expressed the need for information related to the transition from hospital to home:

There are also a lot of people who, even though they have been discharged from hospital... we can't do anything for them anymore. They are at home and are actually not at all aware of everything that is coming up for them.

(F2: 4) Emergency physician, rescue service

Because when they told me at the hospital that they couldn't keep my mum there temporarily because they needed the bed for someone even sicker, but she couldn't be on her own anymore, so she needed 24-hour care, I had LITTLE support from all sides, because there is simply no possibility in our country to get 24-hour care at short notice or temporarily. That disappointed me a lot, except for putting her in a home, yes. And that disappointed me a lot. And, of course, there was this medical outpatient palliative care, which would have been free, which always came. But now, when I don't have anyone who can be there 24 hours a day, just in the transitional phase, until maybe something has been found, a solution, I found that VERY bad, because at that time I was on the verge of a breakdown, asking around everywhere and phoning everywhere, because I wanted my mum to be allowed to go home.

(1S113: 51) Informant about her deceased mother who died at home from heart insufficiency and liver cirrhosis (87 years)

Instrumental support needs

An adequate professional home care team was found crucial to enable dying at home, in terms of providing practical care, symptom management, or respite support (Uchino 2004). Informants explained the need for someone who helps to initiate an appropriate outpatient care service at home (health and social care) and someone who knows what support is needed and where to get it. Getting (quick and easy) access to health care structures and having a continuous (professional) home care support are important aspects for patients with a life-threatening illness, as mentioned by the informants.

Yes, in fact, everything was taken care of by the SHPC team. So it [...] already started that the medication was delivered to us, and we didn't have to clarify everything with the health insurance. So that was [...] completely new territory. I didn't know that there was such

a thing, that it was completely covered by the health insurance, that we didn't have to deal with anything— that was, yes, great. And then we also got someone from the SHPC team who advised us on social law, so, no, it was good.

(1S79: 47) Widow of a deceased man who died at home from cancer (53 years)

Additional support in organizing the equipment was articulated by the informants:

The health insurance company, because every time you order something, an electric wheelchair or something else, it takes far too long. You have to argue with the health insurance company why I need a normal wheelchair for the flat area and an e-wheelchair for outside. And you have to argue with the quality of life, and they say "No, you don't get both"... These are such battlegrounds that you have, and they weigh you down to no end.

(1S111: Pos. 63) Informant about his deceased wife who died at home from ALS (56 years)

Additional support was also necessary in helping to decide if the transition becomes avoidable. One HSCP stated:

There are a lot of people there who pick up the phone and say, "We'll call the emergency doctor again", and then, of course, there is the procedure. They are taken away, and then they are really in the dying phases that they come to the hospital again.

(F2: 68) Coordinator of an ambulatory hospice service talking about her work

Besides the information on bureaucratic regularities, participants reported a great need for practical help with legal issues, perceiving the bureaucratic regularities and hurdles as a burden:

Now I am perhaps, better able than the average person to communicate with some authority or whatever. Yes, my problem was that I was torn between just taking care of it and also having a job and children.

(1S118: 21-23) Informant about his wife suffering from ALS (56 years)

Emotional support needs

Emotional support is defined as offering empathy and affection and the experience of feeling valued (Uchino 2004). The importance of emotional support is emphasized by respondents:

I think the personal one is someone who comes and says, "I'll take you by the hand". Besides that, discharge management is very mature, and most clinics do it very well. But that's the way it is. It's such a skeleton; there's no meat to it, so it says everything nicely on it that you're supposed to do. But there is no one who says, "Come, we'll do it together". I would. I would consider it more important. It's also about emotions. It's also about taking someone by the hand.

(F4: 55) Hospice volunteer and her opinion about discharge management

Informants mentioned a great need for a good, sensitive, continuous, and supportive relationship with the key HCSP:

It takes a lot of calm and composure because these people notice if the person holding their hand is on the verge of a heart attack themselves.

(F4: 11) Hospice volunteer about emotional support

Informants also mentioned just having someone to talk to or discuss concerns with who is not emotionally involved:

And when families are in an acute situation and don't have anyone to talk to on the left or right or just to get rid of their worries, it's really enormous what builds up.

(F2: 43) Coordinator of an ambulatory hospice service explaining the importance of having someone to talk to

I think it's important to have someone to talk to outside the house. It doesn't have to be like me, where you have 15 people, but it's enough to have one person who really listens all the time and doesn't roll his eyes in annoyance. I think that's really important, that you just, well, let's put it another way: I'm a person who processes everything by talking, like this. So everything that runs through my head has to get out of my head. And that's done by talking. I sometimes feel sorry for my husband because I sometimes text him too much, but that's the way it is with me. Of course, there are people who are more introverted, who tend to deal with everything themselves. And yet I wish everyone had at least one person with whom they could talk about what moves them.

(1S12: 91) Participant about her deceased mother who died at home from cancer (78)

Support needs were articulated in dealing with mental or physical deterioration of the patient. Additionally, informants reported a need for someone expressing appreciation and gratitude for the care work done by the family caregiver:

What I would have needed, I would have liked to have had a "thank you," but that is also an internal family thing.

(1S102: 186) Informant about her deceased father who died at home from cancer (82 years)

Oh, yes, what I also think is important for the relatives, for example, is that they get something like commendation in between. [...] So I think they need an exchange of praise from time to time.

(1S106: 114-118) Participant about her deceased mother (and father-in-law) who died at home from cancer (93 years)

For a sense of security, respondents found it important to have someone who is always reachable (out of hours), both by phone and in person:

This support service [...] that you know you don't have to go to 25 different agencies, but [...] maybe one person or one agency....

(S13: 238) Hospice volunteer

So a combination of a hotline, [...] that the entire course of the disease or the course of the last few years is comprehensible and the current situation can therefore be classified [...] in terms of what has happened so far. And THAT combined with a network of contact persons on site.

(1S88:151-152) Informant about her mother suffering from dementia and rheumatism (90 years)

[...] that I would absolutely wish, of course, from this palliative team I had a 24-hour emergency phone number. [...] And they completely refused that I could still keep that. So they referred me to this general practitioner [...] But I don't call him in the middle of the night or [...] on the weekend [...]. How can he help me then? Why can't I keep this 24-hour number?

(1S94: 46) Informant reporting on her husband (84 years) suffering from dementia and Parkinson's disease.

Appraisal support needs

Appraisal support needs are defined as validating the caregiver and providing them with a sense of belonging (Uchino 2004). Some of the informants also considered it important to have a person critically re-evaluating whether care at home is still the best option for everyone, with special focus on caregiver burden and quality of care.

[...] she [deceased] said, "My sister will do all that now and that's good". And then, I noticed after the first

day that it was completely too much for me to give her any medication and to do it in the right amount. And the nurse noticed that very sensitively.

(1S117: 71) Participant about her deceased sister who died at home from breast cancer (52 years)

Informants who have had little to no experience with caregiving in a home setting most often wished for an external assessment of whether caregiving at home can be carried out by themselves, if they were the right "fit," or someone validating their care provision to increase self-confidence to continue and be able to provide home care. Some of the informants stated a great need for receiving validating feedback on critical issues such as management of medication or care in the dying phase: "*That's always such a ride on the razor's edge, […] to say, yes, what am I doing right, what am I doing wrong*" (1S86: 51). Informants reported that it would have been helpful to have another person present to instil confidence:

[…] If there had been a caring person, maybe two, yes, who would have taken me by the hand again and again in a human way, to say "You'll do it."

(1S41: 41) Participant about her deceased husband who died at home from pancreatic cancer (89 years)

…that she showed me other ways of thinking and said "Mrs […], you're doing it well, like this." She always gave me good words of encouragement. I always thought that was great. She said "You're doing it just right". Yes, and that also helped me a lot.

(1S79: 103) Informant about her deceased husband who died at home from lung cancer (53 years)

The need for someone who looks over the shoulder of caregivers on sensitive issues was stated. Informants also reported a need to be reminded of their own needs as a family caregiver:

I wrote to her [palliative care nurse], "My husband is coming now." I thought that was good. My husband came on the day she died. At some point I realized that I couldn't take it anymore. And then the palliative care nurse said, "Now it would be good if you got someone else by your side."

(1S117: 114-119) Informant about her deceased sister (52 years)

Informants also reported a need for someone who asks about the patient's well-being and the dying situation post-mortem:

Oh yes, that would be another point, my suggestion as well as posthumous discussion groups, which are non-denominational, for example. My husband and I, we are not denominationally bound. One can exchange such experiences, yes, that from, for example, the outpatient palliative service, after a quarter of a year, someone comes and says, what you are doing now basically, no, "Tell me, how was your experience?" I mean, that's a bonus. It's not really important in the strict sense of caring for the sick. But it would be nice to have.

(1S41: 156) Informant about her deceased husband (89 years)

The importance of this need is also confirmed by the providers for their practice:

I often ask people afterwards again... We always do another grief contact: "What was helpful for you?" Because I believe that the people themselves can best describe what carried them through this time. And at least in the last phase of life, where we are involved, they simply say just knowing where I can get in touch in a crisis situation. That gives us so much security and stability. And I think that's what SHPC offers with its 24-hour, seven-day-a-week, on-call availability.

(F1: 5) SHPC nurse specialist explaining the importance of asking about the care experiences

Clear differences were found in the description of the needs of informants reporting their experiences retrospectively and those currently in the care situation. Those currently caregiving expressed fewer support needs and were less specific in their wording compared to bereaved informants. In the dimension of informational needs on prognosis, diagnosis, and course of disease, there are also few statements regarding support needs among those currently caregiving. Compared to the retrospective interviews, caregiving informants mostly reported needs in observing and dealing with mental or physical deterioration of the patient, caregiver burden, respite support, a named support contact, and personal care support.

Discussion

Our study showed that proactive support is needed to address seriously ill and dying patients' and families' needs. For this purpose, a "buddy" serving as a low-threshold contact person with real-time knowledge to support and connect patients and families or friends to health and social structures as an addition could be one beneficial intervention. There is a paradox of two co-existing worlds: on one side, a well-developed outpatient palliative care structure, where, for example, outpatient palliative and

hospice services strive to inform and accompany patients about dying at home and guide them on the right home care pathways, and on the other side, patients and family caregivers and also health care providers who know little or nothing about these structures. The integration of adequate end-of-life care is important. For example, patients receiving home palliative care have their chances of dying at home more than doubled (Gomes et al. 2013). Our results show the wide range of unmet needs of families and family caregivers in end-of-life home care. Most of the needs already identified in the previous work of Carer Support Needs Assessment Tool, e.g., need for respite support, understanding patient's illness, or getting support on financial or legal issues (Ewing and Grande 2013), remain unmet. It can also be assumed that the existing services are reaching their limits in meeting this need. Structural reasons may also explain the disparity in access to palliative care for patients with a life-threatening illness. In this regard, the population's palliative care need was calculated by one outpatient team for 100,000 residents, which is currently not being met at all (Gothe et al. 2022).

Most respondents expressed a high need for information, and we can assume that the other unmet needs (instrumental, emotional, appraisal) are explained by this. Lack of knowledge, skills, and support among unpaid caregivers and health care providers was already identified as one of the key barriers to dying at home (Wahid et al. 2018). Adequate information transfer is fundamental to home care for patients with a life-threatening illness and their relatives. Prior research found that one in two knows nothing about palliative care (Maciasz et al. 2013). To close this gap, respondents wished to have a companion, coach, navigator, or mentor who proactively supports providing the last year of life home care by giving information in real time, and being there emotionally, instrumentally and in self-appraisal. This impression was confirmed for patients, caregivers, and health care professionals. Most of the unmet needs arise due to missing/insufficient information on possibilities of end-of-life home care. A standardized information process is lacking in such a vulnerable phase, thereby shaping the care trajectories. When existing health and social care providers fail to guide the care according to patients' and families' needs, more support structures are needed to combine the existing ones (e.g., outpatient hospice service). In this regard, navigation models are considered, but they focus mainly on cancer patients or those in the terminal course of disease (Robinson-White et al. 2010). For this reason, we argue for a support concept that helps all those in need at a much earlier stage. It is therefore useful to have information about the support structures in place at the time of diagnosis.

Another key finding of this study is that the help-seeking actions of the family caregivers should be taken into account. Differences in communicating support needs prospectively and retrospectively can be explained by the fact that caregivers, who do not have an appropriate home care support, only learn later or after death about what options they would have had. As an unpaid caregiver, there is not enough time/opportunity to deal with home care possibilities while also dealing with anticipatory grief and exhaustion from providing care on top of everything else. Therefore, it is significant to have a person proactively offer support possibilities and assess family caregivers' needs. Research has shown that social support reduces the burden on family caregivers (Stensletten et al. 2016). Therefore, support should be available for all dimensions—instrumental, emotional, informational, and appraisal—at best all combined into one concept, a "buddy." This name was already suggested by a senior lecturer from Worcester, describing a "buddy" for patients at the end of life as helping with advance care planning and discussing physiological aspects and practicalities of death (Nyatanga 2018). It is essential to choose the name of the intervention wisely, since practice and research show that "palliative care" was more likely equated solely with end-of-life services, whereas "supportive care" was perceived as a service that provides medical communication and information as well as psychological, mental, and social support (Maciasz et al. 2013). This supports the idea of using the term "buddy" to reach those who are unsure or even irritated by the terms "palliative," "hospice," or "terminal care," allowing the support to be taken up earlier.

A "buddy" may connect patients and families to relevant stakeholders and help navigate the health and social care system. The "buddy" should be intended to address the level of emotional support in addition to the group of existing care structures, regardless of the main diagnosis, as shown in our results. Based on our findings, we recommend an intervention to support and guide families facing the last year of life, called a "buddy," who…

- guides and supports a family caregiver in caring for a dying person at home;
- checks regularly whether care at home is still the best option for everyone involved;
- helps to initiate appropriate outpatient care service at home (health and social care);
- knows what support is needed and where to get it;
- can provide independent advice on a wide range of topics;
- looks over the shoulder of caregivers on sensitive issues;
- expresses appreciation and gratitude for the care work done by the family caregiver;
- is looking after the family caregiver concerning his/her well-being;
- can have a supportive relationship with caregivers;
- helps to deal with mental or physical deterioration of the patient;

- is not emotionally involved;
- is reachable (out of hours);
- guides and supports family caregivers in transitions;
- asks about the patient's well-being;
- evaluates the dying situation post-mortem.

Volunteers play an important role in community work. They not only have shaped the modern hospice movement, but also perform a significant part of the palliative care work (Wright et al. 2008). The work of volunteers extends to all dimensions of the social support (instrumental, emotional) (Burbeck et al. 2014; Candy et al. 2015), with great ambitions to fulfill the "buddy" qualifications. It must be taken into account that long-term implementation cannot be achieved on a voluntary basis alone, but requires funding. "Buddy" could be expanded as a skill/qualification to different groups of people to reach those who need help the most. The "buddy" intervention could be conceptualized and implemented similarly to the project of an English study, developing and testing social action befriending services (Walshe et al. 2016). This study aimed to evaluate a series of social action initiatives which use volunteers to deliver befriending services to people anticipated to be in their last year of life and to determine if receiving care from a social action volunteer befriending service plus usual care significantly improves quality of life in the last year of life. While there are increasing opportunities for volunteers to contribute to care, there is also an expectation that the outcomes and user perceptions of that care should be known and that services should be transparent and accountable (Dodd et al. 2018). A "buddy" could be a volunteer with experiences in end-of-life care structures but available at a low threshold and on short notice. The "buddy" can be someone who is not emotionally involved, but able to provide emotional support to families. The details on designing, adapting the "buddy" intervention to the local context, implementing, and evaluating are described in the action approach of the Knowledge to Action Framework and will be published elsewhere.

The development or structuring of the support intervention is derived on the basis of the Knowledge to Action Framework (Graham et al. 2006), a conceptual framework intended to help those concerned with knowledge translation to deliver sustainable, evidence-based interventions. Within this publication, we describe the process as shown in the center of the diagram "*Knowledge Creation*," gathering the knowledge available on this topic (i.e., *research*), summarizing this knowledge, and creating a support approach that can be used to improve health care for patients in their last year of life and for their loved ones. The phases "*Select, tailor, and implement*" will be published elsewhere, since "buddy" is planned to start as an intervention in Cologne (Germany) and to be formative evaluated.

Strengths and limitations

To our knowledge, no earlier studies have reported on the multi-perspective experiences in caring at home until death with regard to support intervention development. This study utilizes the deductive basis of established models (Uchino 2004; Arnault 2018) and applies them to develop an integrative supportive intervention approach, known as "buddy." A robust method of analysis, combining a deductive basis with inductive enrichment of the data material, has enabled multiple perspectives to be brought to bear on a complex issue. The significant strength of this work is its multi-perspective and multi-method approach. This enabled us to identify needs from the perspective of patients, their primary caregiver, bereaved caregiver, HSCPs, and volunteers. The size and composition of the sample and the national range of respondents are further strengths. A diversification in terms of main diagnosis (or cause of death), living situation (living alone vs. with relatives), ethnic background, region, and gender has been achieved. Moreover, the multi-methods design applied in this study adds value and is an appropriate method to develop an intervention in palliative care (Farquhar et al. 2011). However, as a limitation of the study, it is unclear whether the different methods of conducting interviews (virtual/face-to-face) had an impact on the results. Further research is needed to understand and overcome the paradox of the coexistence of a well-developed outpatient palliative care structure and patients and their relatives who know little or nothing about these structures.

Conclusion

To connect existing home health and social care structures for those wishing to die at home and their families, an additional support infrastructure is needed to pool them. This way, many more family caregivers can benefit from health and social care services based on their needs and preferences. A "buddy" could be an additional support system, not duplicating existing structures. The key is to combine knowledge and information in a "buddy" who then acts as a caretaker, focusing on navigating families with a seriously ill relative through the fragmented health and social system. The generated data will be condensed into a questionnaire in the further course of the study and will be reported elsewhere.

Declarations

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