

## Original Article

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# Dying at home: What is needed? Findings from a nationwide retrospective cross-sectional online survey of bereaved people in Germany

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**Abstract**

**Objectives.** According to the “Last Year of Life in Cologne” study, 68% of patients with a serious and terminal illness wanted to die at home, but 42% died in hospital. Only 1 in 5 died at home. Most people want to spend their last days and hours at home, but the reality is that this is not always possible. Recommendations are needed on how best to support families to enable people to die at home – if this is their preferred place of death. Our aim was to identify the factors that make it possible for people to die at home and to analyze factors of dying at home.

**Methods.** Germany-wide quantitative cross-sectional online survey of bereaved adult relatives.

**Results.** The needs of 320 relatives of patients who wished to die at home were explored. Of these, 198 patients died at home and 122 did not. In the last 3 months of life, caregivers needed support in managing out-of-hours care ( $p < 0.001$ ), financing ( $p = 0.012$ ), preparing and organizing home care (both  $p < 0.001$ ), communicating with the patient and medical staff ( $p = 0.012$  and  $p = 0.009$ , respectively), and pain management ( $p < 0.001$ ). Relatives whose next of kin did not die at home had higher needs, suggesting that these factors are key to home care of the dying.

**Significance of results.** The process of dying at home begins long before the actual dying phase. To minimize caregiver burden and improve symptom management, advanced home care plans are needed, with ongoing reassessment of family preferences and abilities.

**Introduction**

Caring for dying people at home is complex and requires a great deal of support for the families helping them. Some patients may need specialized palliative care to remain in their preferred place until death; for most patients, general palliative care (e.g. provided by long-standing general practitioners with support from nursing services) may be sufficient (Peter et al. 2021). However, the majority of seriously ill and dying patients are cared for by their families, friends, or neighbours. Providing this care is another challenge, as caregiver burden is very common among primary caregivers (Del-Pino-Casado et al. 2021). Not only are patients exposed to various physical, emotional, and psychological stressors, such as loss and grief and role changes. Their families and relatives are also affected by the situation (Chió et al. 2010). It is, therefore, important to actively involve families in decision-making and communication and to offer them personal support now and after the death of the patient.

Factors predicting and influencing death at home for patients are cancer, advanced age, a non-working carer, pain control, better financial position, living in a rural area, and access to health services (Gao et al. 2019; Garcia-Sanjuán et al. 2021; Neergaard et al. 2019). In Germany, associations have been found between home as the place of death and cancer, social support, a non-working carer, nursing care, and living in a rural community (Escobar Pinzón et al. 2011). A recent study in Australia found that family support, regular nursing visits, and equipment were factors in dying at home. People who had to go to the emergency department in their last year of life and who lived alone were more likely to die elsewhere (Dowd et al. 2023).

Much is known from the literature about the factors that contribute to dying at home, but little is known about the support that can help families (Becqué et al. 2021). The aim of this work was to explore and compare the needs of carers of those who died at home and those who did not.

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What can we learn from those who “managed” to die at home? How can we best support families to enable them to die at home?

## Methods

This article reports quantitative data from a larger, cross-sectional, mixed-method study designed to explore the support needs of families of patients who wish to die at home. The study was prospectively registered in the German Clinical Trials Register (DRKS00026229) on 25 November 2021. Ethical approval was granted by the Ethics Committee of the Medical Faculty of Cologne (#21-1466). This study was conducted in accordance with the Declaration of Helsinki and according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach 2004). The observational online post bereavement survey was designed to be completed via computer or mobile devices with free text options and consisted of 3 parts: (i) items generated from a qualitative, multi-method study combining the results of semi-structured interviews and focus group discussions to explore the support needs of primary caregivers of patients who wish to die at home. More details are described elsewhere (Kasdorf et al. 2023), (ii) a German version of the Carer Support Needs Assessment Tool (CSNAT) (Ewing et al. 2013; Kreyer et al. 2020), and (iii) sociodemographic and patient characteristics. A total of 80 items with adaptive questions were used to assess support needs related to home care, finances, daily living, work, and other aspects. Results of the free text options and analysis of the CSNAT will be published elsewhere. The survey was open from 19 September 2022 to 13 November 2022.

**Inclusion criteria and recruitment:** Bereaved primary caregivers aged 18 years or older, living in Germany, giving informed consent, and whose deceased relative was confronted with death at home were included in the study. Deaths before 2016 or accidental deaths were excluded. Recruitment for the online survey was carried out through panel with the support of UZBonn. UZBonn conducts online surveys and operates several high-performance survey servers in a secure data center. Their main survey software used is UNICOM® Intelligence™ (formerly IBM SPSS Data Collection™). Additional recruitment was conducted via online media, collaborators, networks, and online announcements, with no significant differences in response behavior when comparing mean response values. Panel members were incentivized to participate, and an open link was shared via social media. For ease of access, the survey link was posted on a study-specific website with a memorable URL. Two participants chose to complete the survey in paper form (Figure 1). The first section of the anonymous survey provided details of data protection and asked for informed consent. This was followed by items that screened the participant for inclusion based on the inclusion criteria, items about the relationship to the patient, diagnoses, cause of death, questions about the length of time they had cared for the patient, place of death, and care provided during the last 3 months of life and the last 2 days of life, respectively. Other questions related to the integration or possible discussion of palliative care, night care, communication about the illness and its progression, and support needs (i.e. financial, activities of daily living, emotional support, and medical support). The questionnaire ended with sociodemographic information. The participation rate was 79.6%.

**Analysis:** All data analyses were performed using SPSS 28©. Continuous variables were compared using the independent *t*-test, and categorical variables were compared using the  $\chi^2$  test. Odds ratios (ORs) were performed for variables correlated with place

of death (Spearman Rho). A *p*-value below 5% was defined as statistically significant and 1% for correlation analysis.

## Results

Of the 482 respondents, 320 said that their relative had wanted to die at home (Figure 1). Of these, 38.1% (122) died away from home. The characteristics of the participants and their deceased relatives are described in Table 1. Gender and age were balanced between patients who died at home and those who did not. Among relatives, those whose relative died elsewhere were more likely to be male. Those who died elsewhere were most likely to live alone. More informants of patients who died at home were unemployed ( $p = 0.008$ ).

Financing home care was a particular challenge for certain groups. Among participants caring for people who died away from home at the time of the COVID-19 pandemic or who had been cared for more than 1 year, 1 in 2 reported that there was not enough money to pay for care ( $p = 0.033$  and  $p = 0.012$ , respectively). This was the case for 7 out of 10 participants (aged 50–64 years) caring for someone who did not die at home ( $p = 0.019$ ).

### Stakeholder and settings involved in home care in the last 3 months of caregiving

As shown in Figure 2, among those who died at home, those who had more than one family carer ( $p = 0.017$ ), specialized home palliative care (SHPC) ( $p \leq 0.001$ ), and/or home nursing care (HNC) ( $p \leq 0.001$ ) were significantly more likely to be involved in care until death. Participants were also less likely to report hospital admissions ( $p \leq 0.001$ ) or respite care ( $p = 0.007$ ) compared to those who died away from home.

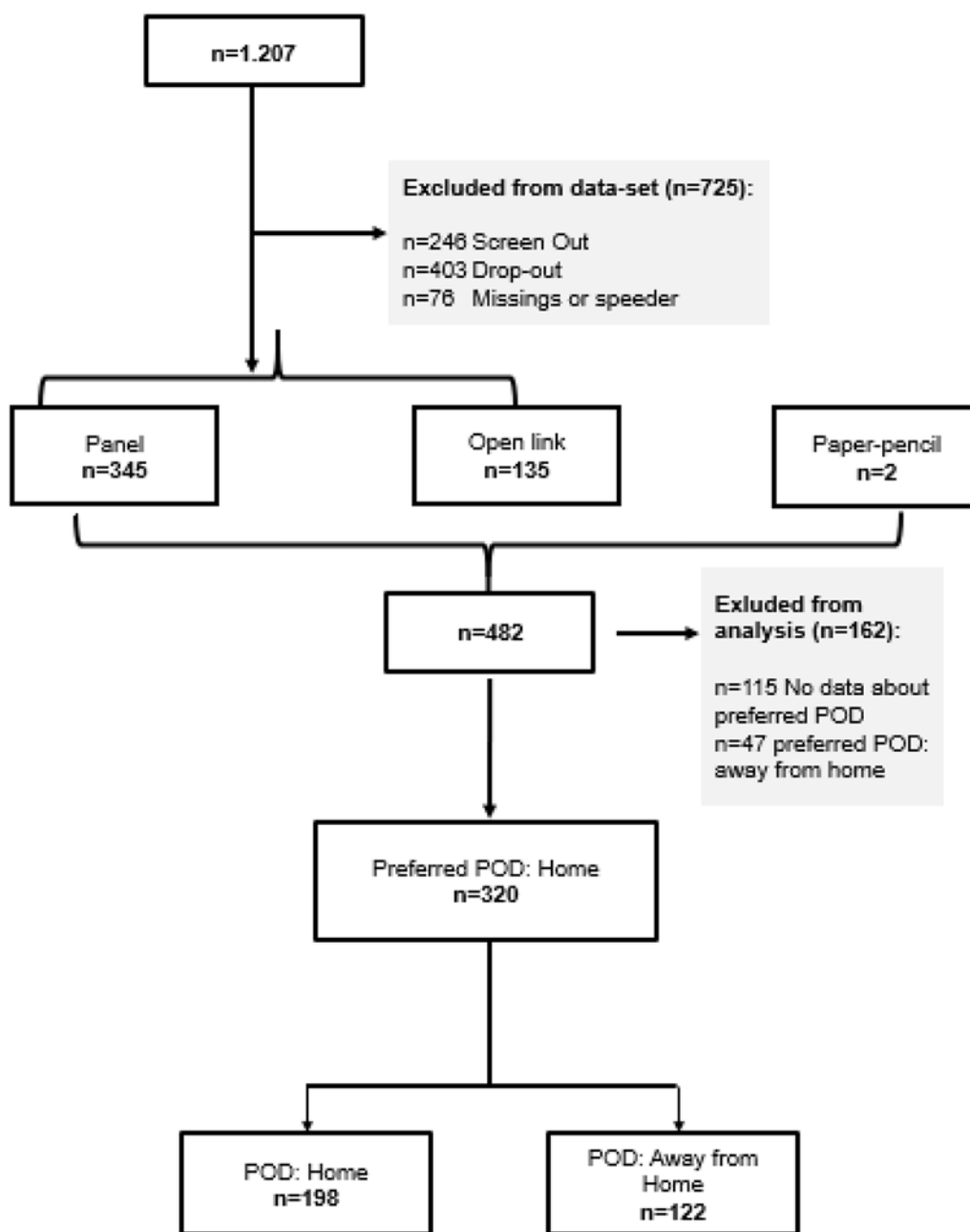
Among those who were hospitalized, those who died at home were 1.5 times more likely to have received advice about home care options during their hospital stay ( $p = 0.020$ ).

### Out-of-hours care

In 15.2% of participants who cared for people who died at home, no night care was needed. Among those who required overnight care, more patients died at home when multiple relatives shared care ( $p = 0.029$ ), when HNC provided overnight care ( $p = 0.050$ ), or when SHPC provided overnight care ( $p = 0.003$ ). In an emergency, the likelihood of dying at home was increased if SHPC was called ( $p = 0.011$ ), the contacted service visited the patient at home ( $p = 0.002$ ), or the contacted service gave advice over the phone ( $p = 0.019$ ). Calling an ambulance or being admitted to hospital decreased the likelihood of dying at home (both  $p < 0.001$ ).

### (Unmet) Needs of primary caregivers

There are significant differences in the needs of relatives of patients who died at home compared to those who died away from home. As shown in Figure 3, caregivers of patients who died away from home have higher support needs than caregivers of patients who died at home, e.g. preparing for care at home (76% vs. 51%,  $p < 0.001$ ), home care options and services (83% vs. 50%,  $p < 0.001$ ), or knowing what to expect when providing care (45% vs. 28%,  $p = 0.002$ ). Support needs for knowing the right “moves” in caring (71% vs. 69%), having more time alone (both 58%), gender sensitive care (both 47%), taking care of own health (32% vs. 33%), and



**Figure 1.** Flowchart of study participants. Participation rate was calculated using the number of unique site visitors and screen outs (the participant does not belong to the desired target group). POD: place of death. Missings or speeder: high rate of missing answers or fast processing time of the survey.

having medicines at home (20% vs. 19%) were also similar between groups. More participants caring for someone who had died at home wanted help with housework or overnight help. Dressing and toileting were areas where most participants needed more support, with only a small but significant percentage wanting less help with these daily activities. The same was true for home care equipment or being able to contact someone during the day or night. About 1 in 2 participants wanted more support in finding information about grief (pre-/post-death). About 3 out of 10 people needed information about culturally sensitive care (e.g. taking into account the needs of observant religious people or ethnic minorities). Medication management was not identified as a relevant need for most carers nor was dealing with religious and spiritual issues.

The likelihood of dying at home was lower for those who needed significantly more support to prepare for care at home, who did not receive offers of home care services, and who needed significantly more support to understand the relative's illness, to manage finances, legal, or professional issues related to care, to talk to the patient or medical staff about their illness, to be informed about what to expect when caring for a dying person, and to have pain management at home (Figure 4). Communication with the patient about the diagnosis, but also with health and social care professionals about care issues, was very unsuccessful for those whose loved one died away from home and therefore needed support (item: Do you need more support in talking with [i] the patient about the illness and [ii] medical staff, see Figure 3). The odds of death

**Table 1.** Characteristics of bereaved caregivers (N = 320)

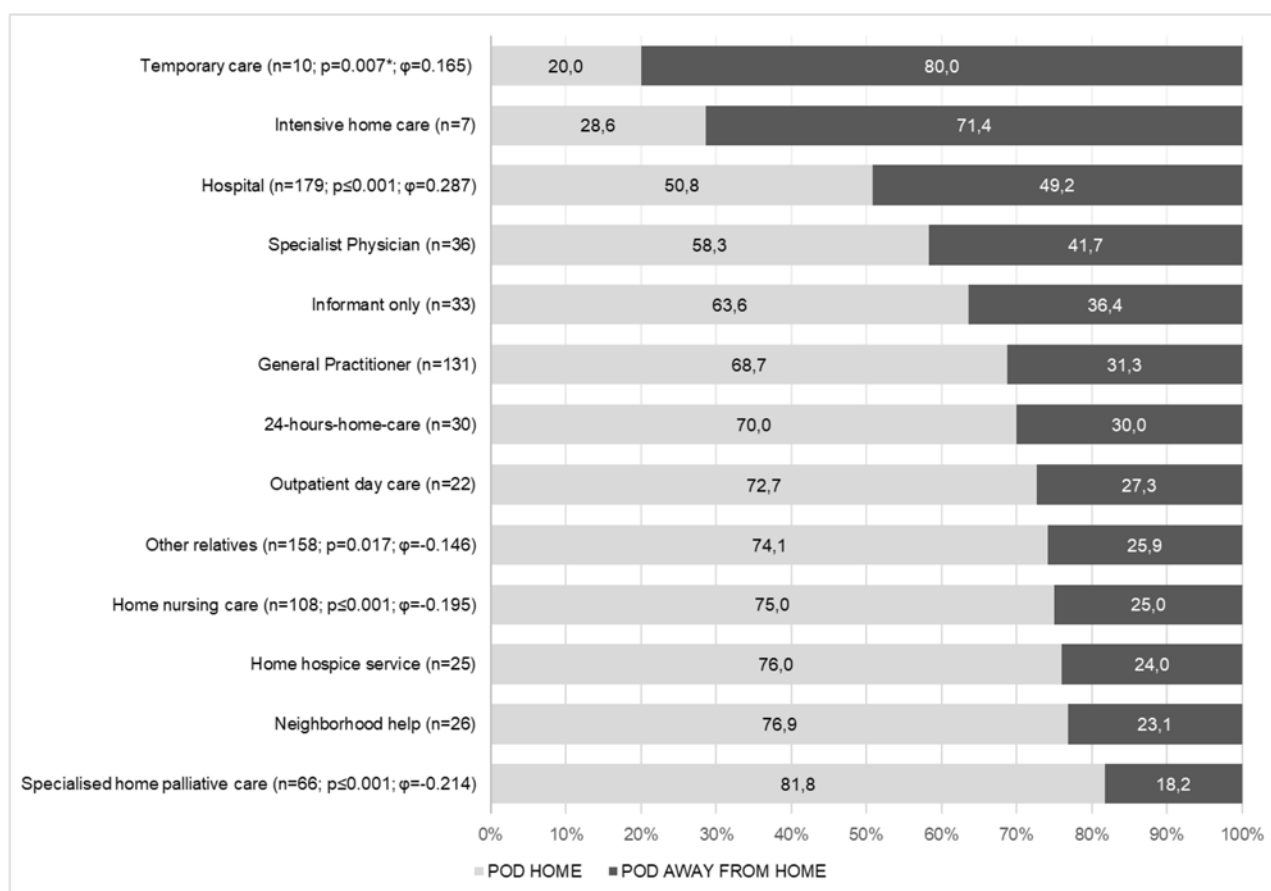
Characteristics	Relatives of those who died at home		Relatives of those who died away from home		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Primary caregiver</b>						
<b>Age</b>						
Median (SD, Min–Max)	50.4 (14.6, 18–80)		50.2 (12.6, 22–82)		50.3 (13.8, 18–82)	
<b>Gender</b>						
Male	50	25.3	43	35.2	93	29.1
Female	145	73.2	79	64.8	224	70.0
Diverse	3	1.5	-	-	3	0.9
<b>Relationship</b>						
Spouse/partner	25	12.6	8	6.6	33	10.3
Son/daughter	74	37.4	58	47.5	132	41.3
Brother/sister	4	2.0	5	4.1	9	2.8
Son/daughter-in-law	13	6.6	8	6.6	21	6.6
Grandson/-daughter	13	15.7	20	16.4	51	15.9
Friend	13	6.6	7	5.7	20	6.3
Neighbor	14	7.1	6	4.9	20	6.3
Volunteer	7	3.5	4	3.3	11	3.4
Other	17	8.6	6	4.9	23	7.2
<b>Employment status</b>						
Was employed	113	62.1	84	77.1	197	67.7
<b>Deceased</b>						
<b>Age</b>						
Median (SD, Min–Max)	78.2 (13.4, 19–105)		76.8 (14.5, 25–98)		77.7 (13.8, 19–105)	
<b>Gender</b>						
Male	97	49.0	67	54.9	164	51.3
Female	100	50.5	55	45.1	155	48.4
Diverse	1	0.5	-	-	1	0.3
<b>Length of disease (months)</b>						
<24 hours	3	1.6	4	3.4	7	2.3
24 hours–1 week	5	2.6	5	4.3	10	3.3
1 week–1 month	8	4.2	10	8.6	18	5.9
1 month–<6 months	23	12.2	17	14.7	40	13.1
6 months–1 year	38	20.1	19	16.4	57	18.7
>1 year	112	59.3	61	52.6	173	56.7
<b>Diagnosis<sup>a</sup></b>						
Cancer	68	34.3	43	35.2	111	34.7
Neurological disease	65	32.8	33	27.0	98	30.6
Cardiovascular disease	66	33.3	43	35.2	109	34.1
Respiratory disease	26	13.1	17	13.9	43	13.4
<b>Cultural background</b>						
Had migration background	14	7.1	8	6.7	22	6.9

(Continued)

**Table 1.** (Continued.)

Characteristics	Relatives of those who died at home		Relatives of those who died away from home		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Household situation</b>						
Lived alone	49	25.1	39	33.6	88	28.3
Lived with others	146	74.9	77	66.4	223	71.7
<b>Year of death</b>						
Before the COVID-19 pandemic (2016–2019)	104	55.9	53	46.5	157	52.3
During the COVID-19 pandemic (2020–2022)	82	44.1	61	53.5	143	47.7

<sup>a</sup>Multiple responses were possible.



**Figure 2.** Who was involved in care of your deceased relative in the last 3 months of his/her life? Multiple responses were possible. Results are reported within Pearson  $\chi^2$  test; \*p reported from Fisher’s test. POD: place of death.

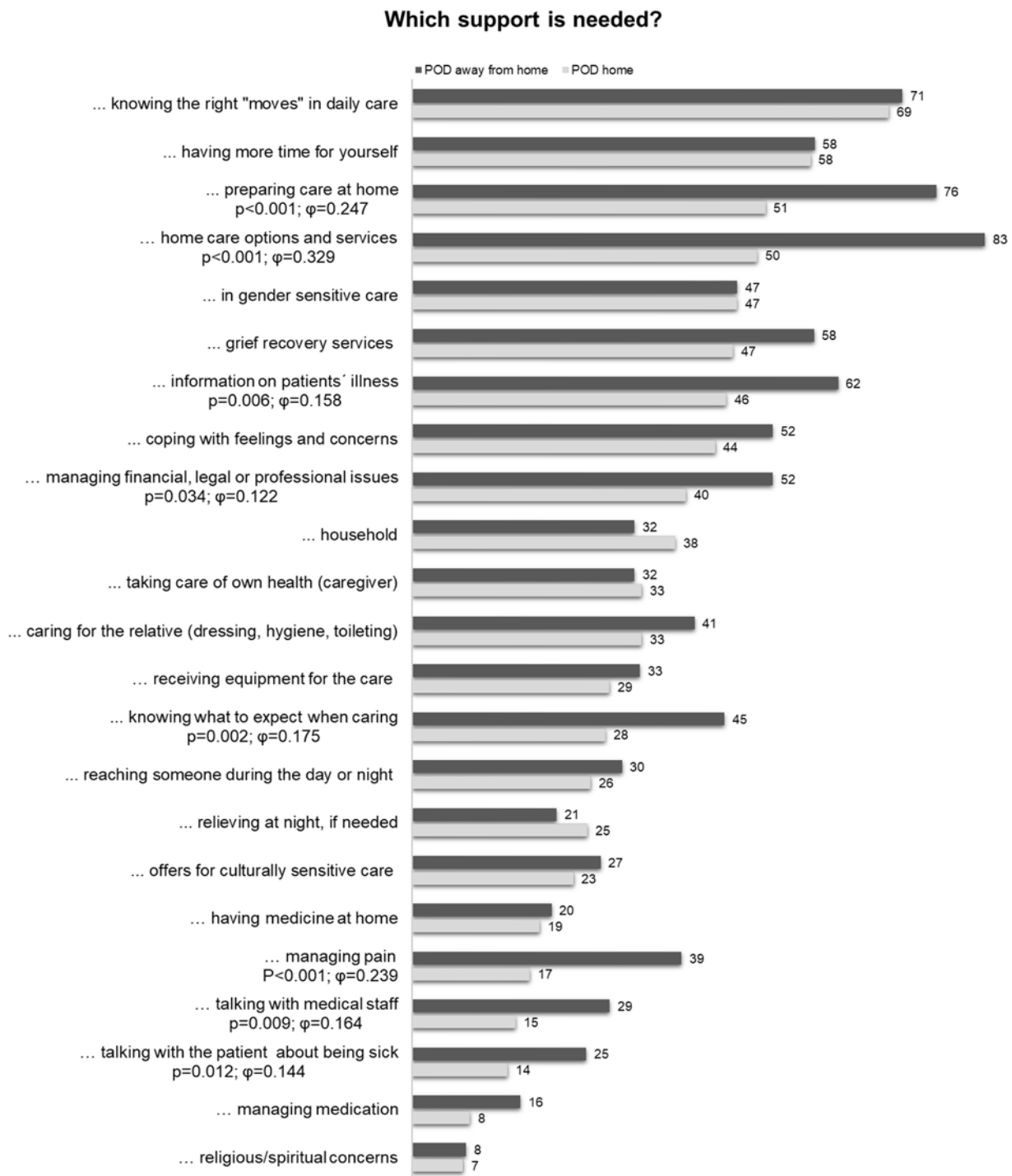
away from home are lower for those who do not need support in talking with medical staff vs. those who need support (OR, 0.442 [0.237–0.825],  $p = 0.009$ ). The odds of death away from home are higher for those who need support in talking with the patient (OR, 2.114 [1.172–3.815],  $p = 0.012$ ).

**Discussion**

This study compared the experience needs of family carers of those who died at home with those of those who died away from home in the last 3 months of the patient’s life. Those who died at home as their preferred place of death were more likely to have received

medical care provided at home and to need less support in preparing or organizing these care structures while also having multiple family carers – especially for night care. One of the main findings is that to maximize the chances of dying at home and minimize caregiver and symptom burden, advanced home care planning is needed, with ongoing reassessment of family preferences, financial situation, social support, and capabilities.

Death at home has been proposed as a measure of quality in end-of-life care (de Roo et al. 2014). However, there has been criticism that the place of death should not be used as a desirable outcome, but rather to assess whether patients died in their preferred place (Billingham and Billingham 2013). Our results show



**Figure 3.** Caregiver needs of patients who died at home vs. patients who died away from home. Data are presented in %. Results are reported within Pearson  $\chi^2$  test. POD: place of death.

differences in the experiences in the last 3 months of life of those who died at home and those who did not die at home – although preferred. As recommended, we used information from family carers, as general practitioners are usually unaware of patients' preferences (de Roo et al. 2014). Although the preference to die at home seemed to be stable over time and did not change with deteriorating health and disease progression (Nysæter et al. 2022), our results suggest regular reassessment of the patient and family situation

to reduce the likelihood of overburdening and discontinuity in care management. The implementation of a "buddy system" could serve as a model to support families in sustaining care (e.g. by informing them about respite care options) and to reduce unnecessary hospital admissions and increase home deaths by proactively reassessing the family situation, including preferred place of death (Kasdorf et al. 2023). The presence of a family carer and the burden placed on them were key variables associated with deaths at



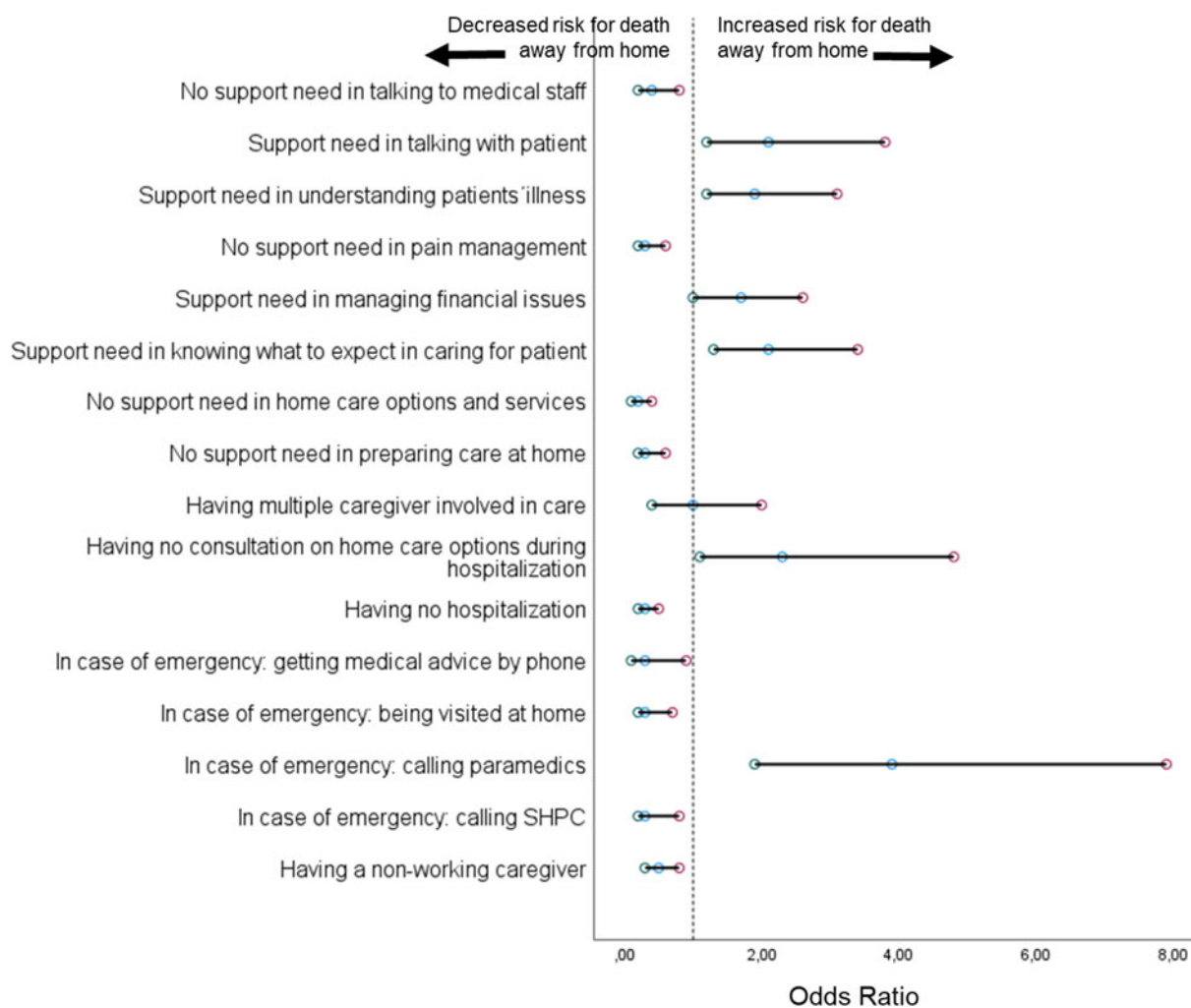


Figure 4. OR of the statistically significant outcomes on “place of death” independent of the different needs in support (95% CI).

home (Kasdorf et al. 2023). Home care support did not eliminate this association. Healthcare professionals may be more likely to refer patients to home care if there are more care resources at home (Grande et al. 1998).

The out-of-hours period is a potentially crucial time for medical and social support (Firth et al. 2023). Out-of-hours care is predominantly focused on acute illness and does not take into account seriously ill and dying patients with complex needs. Our study showed that the out-of-hours period is problematic for patients and families, but having multiple carers reduces the likelihood of needing medical support. It is important to remember that carers and patients may be reluctant to use out-of-hours services – even if they are available. They may not want to “disturb” doctors, or they may feel uncomfortable accepting help. This again shows that there are many factors involved in the provision of home care and that there is a need for a better understanding of how home care, which is mainly provided by families, and the home care setting itself affect dying at home (Morris et al. 2015). We validate these findings by identifying deficits and gaps in the support families receive to provide care at home. It is necessary to offer proactive care to families with a seriously ill and dying patient, and this may be even more important in situations where there is a long-term disability progression (e.g. amyotrophic lateral sclerosis). Overall, higher levels

of family support are associated with an increased likelihood of dying at home (de Conno et al. 1996).

The participants who cared for patients who died at home were less likely to call an ambulance in an emergency and the patients were less likely to be hospitalized overall, which may be because the relatives of those who died at home were better informed about the diagnosis and prognosis and knew how to reach out to medical staff.

Our results show that family carers need advice and support to take on caring responsibilities, and that this support often goes unmet, which is consistent with previous findings (Bee et al. 2009). In addition, palliative care education needs to be improved, not only for health professionals and the public but also for family carers. Providing courses in end-of-life care is one way of increasing and strengthening people’s knowledge and skills and has been shown to be feasible and well accepted (Bollig et al. 2019). In addition, caring communities should be emphasized as a support network to follow the principle of shared responsibility, characterized by co-productive cooperation between professionals, families, and volunteers (Klie 2016).

Families need well-organized support to strengthen the provision of care at home until death. Studies have shown that support, such as fulfilled home medical care (Akiyama et al. 2010), can help

to minimize caregiver regret during bereavement. A home care service system adapted to the ever-changing needs of patients and families is crucial, and despite many studies supporting this, families still suffer emotionally, physically, and financially, as our results have shown. The exception is carers who are able to provide care at home and are financially stable and not employed, which is a contradiction in itself. Data from the UK suggest that each carer saves the economy around £18,000 per family per year (Office for National Statistics 2017). Assuming similar figures for Germany, this should result in a compensation payment that far exceeds the payment for care.

The Montreal model (Karazivan *et al.* 2015), proposed based on a framework for developing interventions and policies to support patient and family engagement, considers the patient as an equally valued member and partner of the healthcare team, e.g. as a healthcare provider. Patients can be involved in health care at 3 different levels: micro or clinical (peer support), meso or organizational (design of health services), and macro (governance or health policy). They can also be involved in research, teaching, and professional training, among other areas of the health system. The Montreal model also emphasizes the importance of interdisciplinary collaboration. Healthcare professionals from different disciplines, such as doctors, nurses, social workers, and chaplains, work together as a team to address the patient's physical, emotional, social, and spiritual needs. This comprehensive approach ensures that all aspects of the patient's well-being are considered and addressed, promoting a dignified and comfortable end-of-life experience at home. By implementing and following these recommendations, communities can strive to create a fruitful partnership between healthcare providers, patients, and their families, ensuring that the choice to die at home is a viable option for all.

### Strengths and limitations

To our knowledge, this is the first study to examine and compare preferred and "successful" deaths at home in Germany with non-preferred deaths away from home. The data may contain recall bias, but this is minimal according to previous evidence (Dust *et al.* 2022). By using a panel, we achieved a high response rate and generalizability across different conditions and across Germany. However, there may have been a risk of self-selection bias, as most of the respondents were panel members.

### Conclusion

We have identified several support options for consideration:

- (i) The organization of home care is a starting point for care at home until death. The "classical" forms of counselling need to be intensified (e.g. hospital discharge management, case management, and social work). A notable finding was the increased use of short-term inpatient care for the population who died away from home, which could be an indication of disrupted continuity of care. Additional mechanisms to identify and support at-risk groups could be developed. For example, all patients seeking temporary care could receive an automated request for assistance in organizing care at home.
- (ii) We also recommend the standardized use of tools (Grande *et al.* 2017) or clinical guidelines (Domröse and Lichte 2018) by family carers, as this allows the support potential of family carers to be recorded in a structured way.

- (iii) Caregiver preparation, including information about caregiving techniques, can be expanded. Similar to palliative care knowledge, courses in terminal care are not well known. Better promotion of existing services could help. It can also be assumed that the need for pain relief support would be eliminated if adequate care was available.
- (iv) Those who have been carers for a long time or are close to retirement should receive more financial support.
- (v) Carers could also be trained in communicating with healthcare providers and patients about diagnosis and prognosis. Questionnaires are recommended for this purpose.
- (vi) Emergency management is an important issue in the care of dying people at home. It is important to have services that provide telephone or face-to-face support in the home, as well as advance care planning to manage avoidable hospital admissions.

**Data availability statement.** The datasets used and analyzed in the current study are available from the corresponding author on reasonable request.

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**Author contributions.** Julia Strupp (JS) and Raymond Voltz (RV) are the principal investigators of this project and designed the research project. Alina Kasdorf (AK) and JS developed the survey instruments. AK conducted the data collection and analysis. AK drafted the original manuscript. JS and RV revised the manuscript. All authors read and approved the final version of the manuscript.

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**Competing interests.** The authors have no competing interests to declare that are relevant to the content of this article.

**Ethical approval.** This study was conducted in accordance with the tenets of the Declaration of Helsinki. Ethical approval was granted by the Ethics Committee of the Medical Faculty of the University of Cologne on November 2021 (#21-1466). Informed consent was obtained from all study participants. All participants could withdraw from the study at any time.

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