

Experiences of relatives with outpatient palliative care: a cross-sectional study

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Abstract

Aim: The authors aimed to evaluate the experiences of the relatives of dying people, both in regard to benefits and special needs, when supported by a mobile palliative care bridging service (MPCBS), which exists to enable dying people to stay at home and to support patients' relatives. **Design:** A cross-sectional survey. **Methods:** A standardised survey was performed, asking 106 relatives of dying people about their experiences with the MPCBS (response rate=47.3%). Descriptive statistics were analysed using SPSS 23. **Findings:** Many relatives (62.5%) reported that their dying relations when discharged from a facility to stay at home were not symptom-free. The MPCBS helped relatives maintain home care, and this was reported to be helpful. Support provided by the MPCBS made it easier for 77.6% of relatives to adjust care as soon as situations changed, and helped ensure that symptoms could be better controlled, at least for 68.2% of relatives. Younger relatives felt more encouraged by the MPCBS to care for their relatives dying at home.

Key words: ● Cancer ● Mobile care ● Nursing ● Outpatient ● Palliative care

Cancer is the leading cause of death worldwide and affects not only patients but their families as well (Hopkinson et al, 2012; Orri et al, 2017). For decades, the situation of people with cancer has been improving across Europe (Froggatt et al, 2013). Mobile palliative care can help to provide patients; care at home until death, by reducing the burden of patients' symptoms (Gomes et al, 2013a; de Graaf et al, 2016; Hendricks-Ferguson and Ott, 2016).

In terminal care, relatives often remain in the background, and attention is focused on the patient (Osse et al, 2006). However, there is a relationship between the illness experience in cancer patients and their relatives (Hodges et al, 2005; Coelho et al, 2020). Relatives suffer greatly from the patient's disease, but the mutual suffering is caused and experienced very differently and leads to different prioritisation of factors that cause distress. For example, loss of appetite causes more distress for relatives (Gott et al, 2004; Amano et al, 2019) than for the patient. The spouse bears most of the caregiving burden and, from the patient's perspective, relatives are so-called 'fellow sufferers' (Proot et al, 2004).

For dying people and their relatives, the preferred place to die is at home (Gomes et al, 2013a; Rasch-Westin et al, 2019). Public health strategies, including home-based and palliative care, are essential for providing different kinds of relief for patients and relatives (World Health Organization, 2015; Bergqvist and Ljunggren, 2019). The need for mobile palliative care is rising as the number of deaths is increasing and dying patients spend most of their last months of life at home (Gomes and Higginson, 2013). However, care at home also leads relatives to multi-faceted experiences of psychological, social and spiritual stress (Gomes and Higginson, 2006; Coelho et al, 2019), as well as financial stress (Sadath et al, 2017).

The last weeks and days of life—when relatives carry the full burden of responsibility—are an important challenge. Palliative care focuses on relieving suffering during the last phase of life; it includes all other aspects besides physical symptoms that cause critical situations and crises at home (Proot et al, 2004).

Proactive care, in the form of timely, community-based palliative care, aims to protect vulnerable people at the end of life

and their relatives from stressful events and to provide relief with the situation at home (McNamara et al, 2013). Mobile palliative care can outperform traditional services and can enhance possibilities of terminal care at home (Gomes et al, 2013b; Bergqvist and Ljunggren, 2019). However, research is needed to ‘systematically assess the impact of the end-of-life home care on caregivers’ (Shepperd et al, 2011).

Mobile Palliative Care Bridging Service

The Mobile Palliative Care Bridging Service (MPCBS) (Palliativer Brückendienst) is offered by the Cancer League of Eastern Switzerland (Krebsliga Ostschweiz). Its focus is on providing counselling and support for seriously ill and dying people and their families. It serves as a bridge between hospital and home care to make dying at home possible. Those affected are not only confronted with diverse experiences due to their life-limiting condition, but also suffer from a variety of different symptoms (Schnell and Schulz, 2014). The existence of multiple and severe ailments is challenging for relatives and requires special support, which makes multi-professional cooperation in a network of health experts indispensable. In this network, family doctors, oncology specialists, psychologists and nursing staff exchange medical information with each other; social workers, pastors and volunteers are also involved in the exchange. MPCBS offers 24-hour availability, conversations, roundtables, advanced care planning and bereavement care for relatives (www.palliativecare-winterthur.ch [website in German]). The MPCBS can provide support in complex situations. After 10 years of the existence of the service, the authors decided to evaluate how the service affects relatives.

Aim

To evaluate the perspectives of relatives, including benefits and special needs, of former patients supported by MPCBS.

Methods

Design

A cross-sectional study on MPCBS.

Sample

The questionnaire was sent by post to relatives of patients who were supported by MPCBS. The survey was limited to the previous 5 years (2012–2017) (Figure 1). The envelope contained a cover letter, informed consent, the questionnaire, and a stamped return envelope.

Questionnaire

A standardised questionnaire including 36 items was developed following a literature search performed in PubMed and CINAHL. In a pre-test (Colton and Covert, 2007), two MPCBS experts, one palliative care expert and two nurses evaluated the questionnaire for intelligibility, comprehensibility and completeness. This was followed by validation by MPCBS experts and a senior physician in palliative care.

Ethics

The study was approved by the responsible and independent cantonal ethics committee in St.Gallen, Switzerland (EKSG 14/077/U).

Data analysis

Data were analysed by an independent statistician using SPSS. Descriptive statistics describe the variables, including frequency distributions, means, median and standard deviation. Ratings on Likert scales were treated as ordinal data and explored using nonparametric tests. Differences between groups were assessed using the Mann-Whitney U-test and Kruskal-Wallis test. Correlations between ratings on Likert scales and age were assessed based on Spearman’s correlations. Statistical significance was defined as $p \leq .05$.

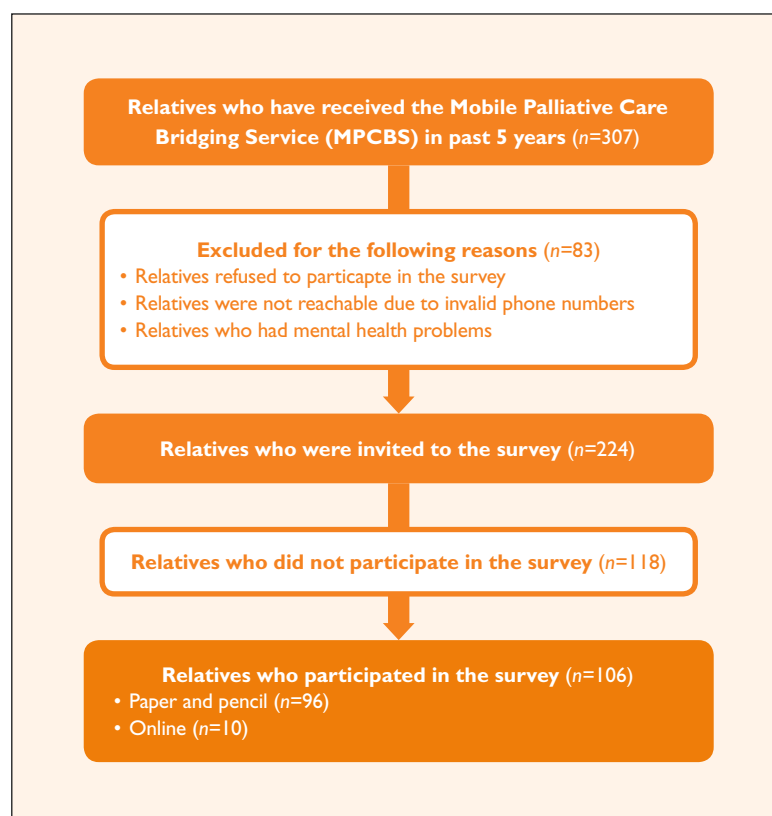


Figure 1. Flowchart of participant recruitment

Results

Sampling

Relatives of all patients who received services from MPCBS in the past 5 years (2012–2017) were selected for recruitment. A total of 307 patients could be identified. For different reasons, 83 people were excluded from the

survey. A total of 224 people were invited, of whom 106 participated. This is a response rate of 47.3%.

Participants were on average 59 years old and mostly (70%) male. Most cared for partners (63%) and parents (22%), who were on average 65 years old and suffering from cancer (Table 1).

Table 1. Characteristics of participants (patients and carers)

Characteristic	n	%	
Total number of carers	106	100	
Carer sex	Female	32	30.2
	Male	74	69.8
Patient relationship to carer	Child or stepchild	8	7.8
	Parent or in-law	23	21.6
	Partner or spouse	67	62.7
	Sibling	3	2.9
	Other	5	4.9*
Patient diagnosis	Cancer (not specified)	105	100**
Characteristic	Mean±SD	range	
Carer age (years)	59±13	23–89	
Patient age (years)	65±12	22–89	

Note: *=2x girlfriend, 1x member of a religious congregation, 2x neighbour; **Missing value: n=1

Table 2. Information regarding service support

Support by MPCBS	n	%	
Total number of participants	106		
Became aware of service through	Cancer League	10	9.8
	Family physician	11	10.8
	Friends	3	2.9
	Home care service	9	8.8
	Hospital	67	62.7
Duration of service support	Other (not specified)	5	5
	1–7 days	28	26.7
	2–4 weeks	36	33.7
	1–3 months	28	26.7
	3–6 months	7	6.9
	6–12 months	5	5
Frequency of service use	More than 1 year	1	1
	Only once	22	20.6
	Two or three times	47	44.3
	Daily	17	16.5
	Several times a day	1	1.1
Previous inpatient facility	Regularly	19	17.5
	At home*	42	39.6
	Hospital	36	33.7
	Nursing home	1	1
Patient diagnosis	Palliative care	27	25.7
	Cancer (not specified)	105	100**

Note: *home care service or family physician; **Missing value: n=1

Access and stay at MPCBS

The majority of participants stated that they were informed about MPCBS by the hospital (62.7%), the family physician (10.8%) or the Cancer League of Eastern Switzerland (9.8%) (Table 2). The high visibility of the Cancer League on the internet encouraged relatives to access supporting services in end-of-life situations at home. Relatives who became aware of MPCBS through the Cancer League were significantly younger than those made aware of it through the GP (p=0.035).

Most people (87.1%) were looked after by MPCBS for between one week and three months. The remainder (12.9%) were looked after by it for periods of up to half a year and, in one case, to a year or more. During this time, MPCBS was mainly used (64.9%) on up to three occasions. Caring children of dying parents received MPCBS interventions significantly more often compared with the partners of a dying person (Kruskall-Wallis: p=0.032; Mann-Whitney: p=0.015). Moreover, the older the deceased person, the more frequently was MPCBS used (Spearman: rs=0.256; p=0.006).

The duration and frequency of service use provide information about the domestic situation, and the kind of professional treatment that the persons concerned had received beforehand. Before MPCBS was used, 39.6% of patients were at home and were cared for through outpatient care or by their family physician. Some 33.7% were previously cared for in hospital, or in a palliative care unit (25.7%). If the dying people had previously been cared for in specialised palliative care, then MPCBS was used significantly longer than for patients who were already supported at home by home healthcare services (p=0.005).

Condition of the person concerned

At the time of their return home from an institutional setting, the symptoms of the patients were under control in only 37.5% (n=40) of the cases. The remaining 62.5% (n=66) experienced one or more of the symptoms given in Table 3.

Based on these data, it appears that pain management is a major challenge and leads to domestic crises. This is followed by loss of

Table 3. Symptoms experienced

Symptom	%
Pain	47.4
Loss of appetite/nutrition-related problems	32.6
Fatigue/sleeplessness	29.8
Nausea/vomiting	22.1
Fear	19.1
Dyspnoea	10.5
Delirium	9.6
Depression	6.4
Other*	7.4

Note: *Other symptoms included: unconsciousness, wound healing, digestion problems, unstable social situations, excessive suffering

appetite and problems related to food intake. These findings indicate that social crises often begin with nutrition-related problems and lead to severe suffering for all persons involved in end-of-life situations.

When relatives ($n=106$) were asked for which particularly challenging situations they had received support from MPCBS for, they stated that it was the management of the major symptoms of the dying persons (Table 4).

Relatives' perspectives on MPCBS

MPCBS support was mostly experienced as positive and helpful. MPCBS helped most participants to gain a better understanding of the disease (73.1%), associated symptoms (72.8%), and the prognosis of the disease (63%). The older the dying person was, the more likely it was that the MPCBS had helped them gain a better understanding of the disease process ($p=0.010$) and symptoms ($p=0.036$).

Respondents (81.5%) were involved in the care of their family member through MPCBS. Additionally, almost all relatives (89.1%) stated that MPCBS responded adequately to the needs of those affected, as well as contributing positively to alleviating symptoms (82.6%). Owing to support received from the MPCBS, 87.4% of participants felt encouraged to take care of their relatives at home. In particular, older relatives were motivated by MPCBS to look after the ill person at home ($p=0.034$).

In the clarification of social issues, MPCBS was not seen as supportive by just over half (51.2%) of participants. However, for 73.7%, MPCBS increased their confidence and security in interaction with their relatives, as well as making the home situation more bearable. The older the dying person was, the more likely it was that MPCBS had helped to make the domestic situation more bearable ($p=0.047$).

Table 4. Major symptoms mentioned by the relatives as requiring support

Symptom	%
Pain	60.0
Loss of appetite/nutrition/swallowing difficulties	25.5
Vomiting/nausea	21.3
Dyspnoea	21.3
Mobilisation/weakness	18.1
Gastrointestinal symptoms	15.8
Fear	9.6
Delirium	7.4
Sleeping disorder/tiredness	7.2
Cardiovascular problems	5.3
Cachexia/loss of weight	4.1
Epilepsy	3.2

Support from MPCBS enabled some respondents (64.4%) to successfully determine the course of everyday life, while 35.6% felt it restricted their daily routine. Older relatives ($p=0.045$) and older dying people ($p=0.050$) felt free in their daily routine, while younger relatives or dying people felt rather restricted.

Impact of MPCBS on caring relatives

Support from MPCBS helped relatives, especially in dealing with the dying patient. Support provided by MPCBS made it easier for relatives to adjust care as soon as situations changed (77.6%), and symptoms could be better controlled, as reported by 68.2% of relatives. Just over half of the participants (55.3%) could sleep better, and 59.3% were better able to cope with mental stress, especially when the dying person was older ($p=0.015$). Financial matters could not usually be clarified by MPCBS (79.7%). Especially where younger dying people were concerned, financial matters were not supported by the MPCBS ($p=0.046$).

MPCBS had helped some relatives receive information about possible support services (64%) and helped bring normality and safety to everyday life (60.5%). In general, hospital stays could be either delayed or avoided entirely (72.3%). Just over half of the relatives (55.4%) said they did not have time for themselves despite MPCBS, but support from MPCBS helped most relatives (65.9%) to make decisions of their own volition.

Discussion

Implementation of MPCBS

The hospital, family physicians and the Cancer League played the most important roles in informing patients and relatives about MPCBS

and referring them to it. Cancer specialists were responsible for referral of >60% of patients to specialised palliative care in hospital (Johnson et al, 2008). Besides the family physician (Neergaard et al, 2009), the hospital and Cancer League were very important specialised gatekeepers for a referral to MPCBS. In this study, only 10% of people were referred through family physicians. Therefore, the authors believe that more attention should be paid to dovetailing basic and specialised palliative care services (Alonso-Babarro et al, 2011). As family physicians play an important role in mediation with the MPCBS, but few study participants learned about MPCBS through their family physicians, it can be assumed that the family physicians are not familiar with the service, and networking could be improved.

The highly specialised care for dying people in palliative care is often provided for a very short time. It happens that terminal patients must be discharged either to other healthcare institutions or to their home (Van den Block et al, 2007). For all involved, this means a very difficult and stressful situation, especially for the vulnerable (Jha et al, 2009). The results of this study showed that, if the dying person had previously been cared for in a specialised ward, then the MPCBS was more often used after discharge to home. Making matters worse, the respondents said that, in 62.5% of the cases, symptoms were not under control, despite previous specialised palliative care in hospital (Vassal et al, 2011).

Challenges for patients and relatives

Pain and nutritional problems are the most common challenges for patients and relatives and are often also the most feared, as shown in international studies (Strömberg et al, 2006; Oechsle et al, 2013). The most frequent symptoms identified by Yennurajalingam et al (2007) about the impact of a palliative care mobile team were fatigue, pain and depressed appetite. Fatigue does also play an important role in the present study, as do pain and reduced appetite. It is known that nutritional problems are very challenging and a cause of suffering, fear and concern (Fringer and Macleod, 2003; Raijmakers et al, 2013). Pain and reduced appetite are symptoms that are particularly depressing for relatives (Raijmakers et al, 2013). Relatives are extremely distressed and challenged when they are responsible for the pain management of their family member (Northfield and Nebauer, 2010). Through MPCBS, relatives were significantly supported in coping with

difficult situations and the symptoms of the person they cared for.

Dumont et al (2006) had shown that 40–60% of family carers experienced a high level of psychological distress and uncertainty, even as the patients' level of autonomy diminished. The MPCBS helped them to better understand both the disease process and symptoms. This is more evident for older relatives when they increasingly assume a role of responsibility for the dying person.

Information is an important aspect for relatives (Adams et al, 2009). Relatives need and seek information on treatments, medications and side effects and how best to help loved ones, because lack of knowledge results in increased stress and anxiety (McCarthy, 2011). MPCBS acts as a back-up service for this necessary information. MPCBS encourages older relatives to care at home more, helps to make their domestic situations more bearable and helps them to cope better with their own psychological stress. This may indicate that older relatives feel an unusual sense of responsibility for younger palliative patients or that, for younger relatives, their information needs are met and dealt with quite differently (Melcher et al, 2015).

Further research

More attention should be paid to—and more research undertaken for—comparing partners and significant others of dying people, as it was shown that partners are significantly less likely to access MPCBS. There were also differences among carers of different ages, with the result that younger relatives were more likely to access the service, while older relatives were less likely to. It would be valuable to find out what reasons are cited for non-use. There should be more research on communication competencies in transitions, trajectories and the terminal phase (Stajduhar et al, 2008; Fringer et al, 2015). Multiple transitions could jeopardise the continuity of care at the end of life (Abarshi et al, 2010; Fringer et al, 2018). As a practical implication of the results, MPCBS should put more emphasis on the anxiety and uncertainty experienced by relatives, as well as their stress.

It is known that differences exist in prioritising dimensions in the quality of palliative care, symptom burden and individual experiences (Vedel et al, 2014). Particularly for pain and nutritional problems, an educational concept could be a possible intervention to help family carers. In particular, prospective case study research (Fringer and Schnepf, 2015) is a

possible way to obtain richer information and insight into the lives of family caregivers.

Strengths and limitations

This is the first study reporting the experiences of relatives with an MPCBS from the perspective of bereaved relatives (Shepperd et al, 2011). A strength of this investigation that can be emphasised is that its retrospective study design allowed the authors to evaluate the experiences of relatives. We consider it unlikely that the relatives' views of the MPCBS would be positively distorted, since the included participants had already ceased to be cared for by the MPCBS and, therefore, were no longer socially dependent on the institution.

However, some limitations affect the generalisability of these results, chiefly that they present the evaluation of only one MPCBS. There are no comparable data to ensure the external validity of the results. It may also be possible that response behaviour is positively biased, because some family carers were very grateful for the support of MPCBS. Concrete evidence of this assumption is that several letters of thanks were enclosed with the questionnaires that were returned. Questionnaire development is another weakness of this study. Given the available budget, although the standards for questionnaire development could be met, an extensive pre-test phase was dispensed with.

Conclusion

The findings of the present study show that family carers had, in general, good experiences with the MPCBS, which stabilised palliative care or the terminal care situation at home. Family carers of cancer patients are a valuable resource, but they are also a very vulnerable group. Finally, it is clear that family carers help to delay transfer to a nursing home and that MPCBS supports them to reduce crises at home, to continue care at home, and to reduce hospitalisation and unnecessary cost-intensive emergency department visits.

Key points

- **Two thirds of all patients are discharged from hospital without symptoms being under control**
- **The mobile palliative care bridging service (MPCBS) is accepted, especially by the children and less often by the partners of dying persons**
- **The MPCBS helps relatives to better understand the disease and to react adequately to the rapidly changing situations in the dying process**
- **The MPCBS helps to make home care possible and reduce domestic crises**

In future, MPCBS should be further developed and professionally extended. Two main aspects should be addressed: reduction and treatment of uncontrolled symptoms; and establishment of comprehensive family support concepts to sensitise the health professions involved regarding what it means to be a family carer and to understand their needs. More research about the meaning of uncontrolled symptoms from relatives' perspectives is also needed. It is also important to consider the age of the family carers and patients when considering the contribution of MPCBS, because the results show that subgroups of different ages have different needs. Besides, pain and nutrition-related symptoms are a considerable challenge for relatives. The refusal of the patient to consume food and fluids leads to social conflicts and crises in the family system. Thus, family carers need more information and educational support on these topics. Support for family carers needs to be more individually tailored. Since palliative care is also interdisciplinary, these aspects should also be viewed and researched from the perspectives of different professionals, to establish holistic palliative care support for patients and family carers. [IJPN](#)

Conflict of interest: None

Availability of data and material: All data

Continuing professional development: reflective questions

- **At what point in time would it be advisable to familiarise the patient and their relatives with the offers of the mobile palliative care bridging service (MPCBS) in order to ensure the transition from the inpatient setting to home care and beyond?**
- **Consider the possibilities of providing an MPCBS in your region and the advantages of the offers—how could this be established in your region?**
- **What would need to be done to raise awareness of the MPCBS in the region? Which form of information should be promoted and how can patients and their relatives be reached?**

generated or analysed during this study are included in this published article; the methodological approach and some results of this study have already been presented at the National Palliative Care Days Congress in Bern (Fringer et al, 2015)

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- Abarshi E, Ehteld M, Van den Block L, Donker G, Deliens L, Onwuteaka-Philipsen B. Transitions between care settings at the end of life in the Netherlands: results from a nationwide study. *Palliat Med.* 2010; 24(2):166–174. <https://doi.org/10.1177/0269216309351381>
- Adams E, Boulton M, Watson E. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Educ Couns.* 2009; 77(2):179–186. <https://doi.org/10.1016/j.pec.2009.03.027>
- Alonso-Babarro A, Bruera E, Varela-Cerdeira M, Boya-Cristia MJ, Madero R, Torres-Vigil I, De Castro J, González-Barón M. Can this patient be discharged home? Factors associated with at-home death among patients with cancer. *J Clin Oncol.* 2011; 29(9):1159–1167. <https://doi.org/10.1200/JCO.2010.31.6752>
- Amano K, Morita T, Koshimoto S, Uno T, Katayama H, Tatara R. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Support Care Cancer.* 2019; 27(8):2869–2876. <https://doi.org/10.1007/s00520-018-4590-6>
- Bergqvist J, Ljunggren G. The impact of integrated home palliative care services on resource use and place of death. *J Palliat Med.* 2020; 23(1):67–73. <https://doi.org/10.1089/jpm.2018.0639>
- Coelho A, de Brito M, Teixeira P, Frade P, Barros L, Barbosa A. Family caregivers' anticipatory grief: a conceptual framework for understanding its multiple challenges. *Qual Health Res.* 2019; 30(5):693–703. <https://doi.org/10.1177/1049732319873330>
- Colton D, Covert RW. *Designing and constructing instruments for social research and evaluation.* 1st edn. San Francisco (CA): Jossey-Bass; 2007
- de Graaf E, Zweers D, Valkenburg ACH, Uyttewaal A, Teunissen SCCM. Hospice assist at home: does the integration of hospice care in primary healthcare support patients to die in their preferred location? A retrospective cross-sectional evaluation study. *Palliat Med.* 2016; 30(6):580–586. <https://doi.org/10.1177/0269216315626353>
- Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vézina L. Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med.* 2006; 9(4):912–921. <https://doi.org/10.1089/jpm.2006.9.912>
- Fringer A, Büche D, Praxmarer R, Schreyer I, Schnepf W. Relatives' experience with the palliative care service: evaluating the 'mobile palliative bridging service' (MPBS). Paper presented at the Nationale Palliative Care Tage, Berne (CH). 2015. <https://tinyurl.com/ybqtjtrj> (accessed 24 April 2020)
- Fringer A, Hechinger M, Schnepf W. Transitions as experienced by persons in palliative care circumstances and their families—a qualitative meta-synthesis. *BMC Palliat Care.* 2018; 17(1):22. <https://doi.org/10.1186/s12904-018-0275-7>
- Fringer A, Macleod S. Pflege sterbender Angehöriger [article in German]. In: Macleod S, Schulz C, Dein S, eds. *Psychiatrie in der Palliativmedizin: Behandlung psychischer und psychosomatischer Probleme am Lebensende.* Bern: Huber; 2003:88–92
- Fringer A, Schnepf W. Case study: Methodik - Methodologie – Forschungsstrategie [article in German]. *Journal für qualitative Forschung in Pflege- und Gesundheitswissenschaften.* 2015; 1(2):62–70
- Froggatt K, Reitingner E, Heimerl K, Hockley J, Brazil K, Kunz R, Morbey H. *Palliative care in long-term care settings for older people: EAPC taskforce 2010-2012 report.* Milan: EAPC; 2013
- Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev.* 2013; (6):CD007760. <https://doi.org/10.1002/14651858.CD007760.pub2>
- Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care.* 2013b; 12(1):7. <https://doi.org/10.1186/1472-684X-12-7>
- Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ.* 2006; 332(7540):515–521. <https://doi.org/10.1136/bmj.38740.614954.55>
- Gomes B, Higginson IJ. Evidence on home palliative care: charting past, present, and future at the Cicely Saunders Institute – WHO Collaborating Centre for Palliative Care, Policy and Rehabilitation. *Prog Palliat Care.* 2013; 21(4):204–213. <https://doi.org/10.1179/1743291X13Y.0000000065>
- Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. *Palliat Med.* 2004; 18(5):460–467. <https://doi.org/10.1191/0269216304pm889oa>
- Hendricks-Ferguson V, Ott R. Palliative care considerations for patients with head and neck cancer with children at home. *Clin J Oncol Nurs.* 2016; 20(6):585–587. <https://doi.org/10.1188/16.CJON.585-587>
- Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med.* 2005; 60(1):1–12. <https://doi.org/10.1016/j.socscimed.2004.04.018>
- Hopkinson JB, Brown JC, Okamoto I, Addington-Hall JM. The effectiveness of patient-family carer (couple) intervention for the management of symptoms and other health-related problems in people affected by cancer: a systematic literature search and narrative review. *J Pain Symptom Manage.* 2012; 43(1):111–142. <https://doi.org/10.1016/j.jpainsymman.2011.03.013>
- Jha AK, Orav EJ, Epstein AM. Public reporting of discharge planning and rates of readmissions. *N Engl J Med.* 2009; 361(27):2637–2645. <https://doi.org/10.1056/NEJMsa0904859>
- Johnson CE, Girgis A, Paul CL, Currow DC. Cancer specialists' palliative care referral practices and perceptions: results of a national survey. *Palliat Med.* 2008; 22(1):51–57. <https://doi.org/10.1177/0269216307085181>

- McCarthy B. Family members of patients with cancer: what they know, how they know and what they want to know. *Eur J Oncol Nurs*. 2011; 15(5):428–441. <https://doi.org/10.1016/j.ejon.2010.10.009>
- McNamara BA, Rosenwax LK, Murray K, Currow DC. Early admission to community-based palliative care reduces use of emergency departments in the ninety days before death. *J Palliat Med*. 2013; 16(7):774–779. <https://doi.org/10.1089/jpm.2012.0403>
- Melcher U, Sandell R, Henriksson A. Maintaining everyday life in a family with a dying parent: teenagers' experiences of adapting to responsibility. *Palliat Support Care*. 2015; 13(6):1595–1601. <https://doi.org/10.1017/S1478951515000085>
- Neergaard MA, Vedsted P, Olesen F, Sokolowski I, Jensen AB, Søndergaard J. Associations between home death and GP involvement in palliative cancer care. *Br J Gen Pract*. 2009; 59(566):671–677. <https://doi.org/10.3399/bjgp09X454133>
- Northfield S, Nebauer M. The caregiving journey for family members of relatives with cancer: how do they cope? *Clin J Oncol Nurs*. 2010; 14(5):567–577. <https://doi.org/10.1188/10.CJON.567-577>
- Oechsle K, Goerth K, Bokemeyer C, Mehnert A. Symptom burden in palliative care patients: perspectives of patients, their family caregivers, and their attending physicians. *Support Care Cancer*. 2013; 21(7):1955–1962. <https://doi.org/10.1007/s00520-013-1747-1>
- Orri M, Sibeoni J, Bousquet G et al. Crossing the perspectives of patients, families, and physicians on cancer treatment: a qualitative study. *Oncotarget*. 2017; 8(13):22113–22122. <https://doi.org/10.18632/oncotarget.12770>
- Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP. Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nurs*. 2006; 29(5):378–388, quiz 389–390. <https://doi.org/10.1097/00002820-200609000-00005>
- Proot IM, Abu-Saad HH, ter Meulen RH, Goldsteen M, Spreuwenberg C, Widdershoven GA. The needs of terminally ill patients at home: directing one's life, health and things related to beloved others. *Palliat Med*. 2004; 18(1):53–61. <https://doi.org/10.1191/0268216304pm818oa>
- Raijmakers NJH, Clark JB, van Zuylen L, Allan SG, van der Heide A. Bereaved relatives' perspectives of the patient's oral intake towards the end of life: a qualitative study. *Palliat Med*. 2013; 27(7):665–672. <https://doi.org/10.1177/0269216313477178>
- Rasch-Westin M, Helde-Frankling M, Björkhem-Bergman L. Death at home: predictive factors in a medical home care unit. *BMJ Support Palliat Care*. 2019. <https://doi.org/10.1136/bmjspcare-2019-001932>
- Sadath A, Muralidhar D, Varambally S, Gangadhar BN, Jose JP. Do stress and support matter for caring? The role of perceived stress and social support on expressed emotion of carers of persons with first episode psychosis. *Asian J Psychiatr*. 2017; 25:163–168. <https://doi.org/10.1016/j.ajp.2016.10.023>
- Schnell MW, Schulz C. Der Mensch als sterbliches Wesen und die Diversität am Lebensende [article in German]. In: Schnell MW, Schulz C, eds. *Basiswissen Palliativmedizin*. Berlin/Heidelberg: Springer-Verlag; 2014
- Shepperd S, Wee B, Straus SE. Hospital at home: home-based end of life care. *Cochrane Database Syst Rev*. 2011; (7):CD009231. <https://doi.org/10.1002/14651858.CD009231>
- Stajduhar KI, Martin WL, Barwich D, Fyles G. Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nurs*. 2008; 31(1):77–85. <https://doi.org/10.1097/01.NCC.0000305686.36637.b5>
- Strömberg AS, Sjogren P, Goldschmidt D, Petersen MA, Pedersen L, Groenvold M. Symptom priority and course of symptomatology in specialized palliative care. *J Pain Symptom Manage*. 2006; 31(3):199–206. <https://doi.org/10.1016/j.jpainsymman.2005.07.007>
- Van den Block L, Deschepper R, Driekens K, Bauwens S, Bilsen J, Bossuyt N, Deliens L. Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. *BMC Health Serv Res*. 2007; 7(1):69. <https://doi.org/10.1186/1472-6963-7-69>
- Vassal P, Le Coz P, Hervé C, Matillon Y, Chapuis F. Return home at the end of life: patients' vulnerability and risk factors. *Palliat Med*. 2011; 25(2):139–147. <https://doi.org/10.1177/0269216310385876>
- Vedel I, Ghadi V, Lapointe L, Routelous C, Aegerter P, Guirimand F. Patients', family caregivers', and professionals' perspectives on quality of palliative care: a qualitative study. *Palliat Med*. 2014; 28(9):1128–1138. <https://doi.org/10.1177/0269216314532154>
- World Health Organization. *Cancer*. 2015. <http://www.who.int/mediacentre/factsheets/fs297/en/> (accessed 24 April 2020)
- Yennurajalingam S, Zhang T, Bruera E. The impact of the palliative care mobile team on symptom assessment and medication profiles in patients admitted to a comprehensive cancer center. *Support Care Cancer*. 2007; 15(5):471–475. <https://doi.org/10.1007/s00520-006-0172-0>

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