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# **When and how to stop palliative antineoplastic treatment and to organise palliative care for patients with incurable cancer**

Mette Raunkiær, Jahan Shabnam, Kristoffer Marsaa, Geana Paula Kurita, Per Sjøgren and Mai- Britt Guldin

## **Abstract**

**Background:** Improving the organisational aspects of the delivery of palliative care in order to support patients throughout their disease trajectory has received limited attention.

**Aim:** To investigate the opportunities and barriers related to organising palliation for people with terminal cancer and their families.

**Methods:** An explorative interview study was conducted among 31 nurses and three physicians concerning an intervention facilitating a fast transition from treatment at a cancer centre at a university hospital to palliation at home. A thematic analysis was conducted.

**Findings:** This article presents three out of seven themes: 1) improvement in the cessation of antineoplastic treatment in palliation; 2) improvement in organisations delivering palliation; and 3) improvement in multidisciplinary and cross-sectoral collaboration.

**Conclusions:** The results demonstrate the demand for flexible, family-centred and integrated palliation at all levels, from communication and the collaborative relationship between healthcare professionals and families to service sectors.

**Key words:** palliative care, terminal cancer, organization, collaboration

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This article presents results based on three out of seven themes from a qualitative study nested within a randomised clinical trial (RCT) intervention encompassing a fast transition from treatment at a comprehensive cancer centre at a university hospital to palliation at home for patients with terminal cancer in Denmark (*Table 1*). Results relating to the other themes are published elsewhere (Raunkiær et al, 2020). The study focuses on the improvement of the organisation of palliation for patients with terminal cancer. This is important as, in recent years, international palliative care (PC) research has been increasingly focused on symptom assessment and management (Hansen et al, 2020), quality of life improvement (Verkissen et al, 2019; Lund et al, 2020) and the effects of integrating services early in the palliative trajectory (Rugno et al, 2014; Groenvold et al, 2017; Vanbutsele et al, 2018). To date, improving the organisational aspects of services supporting patients in their palliative trajectory has received limited attention (Bergenholtz et al, 2015; Ikander et al, 2022).

**Table 1. Participants**

<b>Organisational units</b>	<b>Number of interviews and identification number</b> Time from 0.5 hours to 1.5 hours	<b>Professions</b>	<b>Number of participants</b>
<b>Specialised palliative care teams from seven out of nine units</b>	Three group interviews with: Four informants (A) Three informants (B) Two informants (C) Two individual interviews (D, E)	Eight nurses One nurse manager Two physicians (managers)	11
<b>Oncology clinics</b>	Two group interviews with: Eight informants (F) Three informants (G)	Seven nurses Three nurse-managers One physician	11
<b>Home care nursing from five communities</b>	Three group interviews with: Five informants (H) Three informants (I) Two informants (J)  Two individual interviews (K, L)	12 home care nurses	12
<b>Total</b>	Nine group interviews Four individual interviews	28 professionals Six managers	34

In Denmark, PC is organised at two levels: basic PC, and 2) specialised palliative care (SPC) (Sundhedsstyrelsen, 2017). Basic PC is provided in organisations in which the primary objective is not to provide PC (e.g., nursing homes, home nursing care, general practices and hospitals). Accordingly, the professionals in these organisations are expected to possess only basic PC skills

and knowledge, and are capable of providing PC for patients with life-threatening conditions as an integral part of standard clinical practice. SPC is intended for patients with life-threatening conditions who have complex physical, psychosocial and/or spiritual PC needs (referral criteria) that require attention from professionals with specialist PC skills and knowledge. The organisations who provide this care (e.g., SPC teams, hospices and PC units in hospitals) have PC as their primary objective and involve at least four different professions, two of which must be nurses and doctors (Radbruch and Payn, 2009; Sundhedsstyrelsen, 2017).

**Box 1.** The randomized clinical trial

**Aims:** To enable someone to stay in their own home and die at home; to improve quality of life; to improve professional collaboration.

**Intervention:** The randomised clinical trial consisted of a fast transition intervention from treatment in an oncology ward to specialised palliation in a person's own home. This transition also included conversations with a psychologist. The specialised palliation was delivered by regional outgoing teams. A home visit took place within 5 days from randomisation with the ill person, close relatives, the specialised palliative team, a GP if possible, a home nurse and a psychologist employed at a Danish Palliative Care Trial (DOMUS). All these professionals then agreed on who was responsible for that palliative treatment and tasks. The patient and caregiver had at least two sessions with the psychologist. The control group received standard care (Nordly et al, 2014; 2019)

In 2020, 17 348 people died of cancer in Denmark (World Health Organization (WHO), 2021). As palliation at the basic level is an integral part of other healthcare services, there are no statistics on how many cancer patients were offered PC at this level. However, health registries show that almost half (49%) of patients with cancer in 2020 were offered SPC, and the median survival time from the referral time was only 37 days (Murtagh et al, 2014; Hansen et al, 2021). In 2020, the National Audit Office of Denmark (Rigsrevisionen) examined access to SPC (Rigsrevisionen, 2020), and concluded that lack of screening for palliative needs early in disease trajectories and lack of clear referral criteria for SPI delayed referral of patients with palliative needs. This indicated organisational barriers in the delivery of palliation to people with terminal cancer. Several Danish studies have formerly indicated challenges in providing palliation and a need to conduct research focusing on organisational issues concerning PC (Raunkiær and Timm, 2010; Bergenholtz

et al, 2015; Bergenholtz et al, 2016).

Due to the organisational structures, cancer patients with palliative needs frequently move between different healthcare services, because the increased/changing demands of care and treatment entail delivery of palliation from healthcare professionals at different levels in healthcare systems (Vissers et al, 2013; Raunkiær et al, 2020). This demands collaboration between patients' family members and professionals in the primary and secondary sectors. However, insufficient organisational capacity, stemming from lack of time and inadequate staffing, poor service delivery, limited financing and effective organisational regulations, has been reported in earlier studies (van Riet Paap et al, 2014; Centeno et al, 2017; Ikander et al, 2021; WHO, 2021; Ikander et al, 2022). To overcome these barriers and further develop the organisations delivering palliation, implementation of new organisational models derived from clinical trials into daily clinical routine may be required (Burgers et al, 2020). However, studies on how to improve the organisations delivering palliation, from the users', healthcare professionals' and managers' perspectives, are still absent (Turriziani et al, 2016; Oosterveld-Vlug et al, 2019).

This study focuses on managers' and healthcare professionals' perspectives on palliation in terms of understanding where opportunities for organisational improvements and barriers to change are present. Therefore, the aim of the study is to investigate opportunities and barriers related to the organisation of palliation for people with terminal cancer and their families.

## **Methods**

Based on this aim, an explorative interview study was conducted at oncology clinics (OCs) at a university hospital, nine SPI teams and home care nursing (HCN) from 29 municipalities (Raunkiær et al, 2020) in the Capital Region of Denmark from 2016 to 2017. The healthcare professionals and managers were recruited by the employees in the RCT study from the different OCs, SPC teams and HCN. The inclusion criteria were: professionals should have participated in the treatment/care of one patient in the RCT study and managers should have experience and/or be familiar with the study. In total, 34 healthcare professionals participated (*Table 1*).

### ***Interviews and data collection***

The interviews were conducted as group interviews and individual interviews and were all semi-structured (Lave and Kvale, 2006; Kvale and Brinkmann, 2009). The interviews were completed in person at the participants' workplaces, and were recorded and transcribed verbatim. The participants were given the opportunity to read and correct the interview transcripts. However, none were interested in doing so. The interview guide related to healthcare professionals' and managers' experiences concerning the following themes within the RCT (*Box 2*).

#### **Box 2. Themes in the interview guide**

- The palliative care services delivered to the patients and relatives
- The organisation and barriers and facilitators
- The cross-sectorial and inter-professional collaboration—the barriers, and facilitators
- The future organisational perspectives regarding structures, tasks and actors of palliative care based on experiences with the randomised controlled trial study

### ***Data analysis***

Inductive thematic data analysis was conducted (Braun and Clarke, 2006; Thomas, 2006; de Casterlé et al, 2012), and Braun and Clarke's (2006) six phases structured the analysis:

- Becoming familiar with the data: Transcripts were read and checked against the recordings for precision
- Generating initial codes: The transcripts coded on paper using a pencil. Based on statements in interview transcripts, abstract and conceptual codes were developed, which were listed in a code list with page numbers linking back to the transcripts
- Searching for and reviewing themes: based on phases 1–2, three themes were identified
- Defining and naming themes
- Writing the manuscript: the first author provided a figure that illustrated the codes/ themes. These were discussed between the first author and the study group and adapted.

**Table 2** is an example of phases 2–6.

**Table 2. Example analysis**

Phase 2. To generate initial codes	Phases 3–4. To search and review themes	Phases 5-6. Themes	
<p>‘It is a huge security for the patients and relatives to have someone to call. They might also be offered a stay at the hospice when that time comes. There are not so many organisational obstacles when calling a hospice. It is not as bureaucratic as hospitals (A nurse SPC).’</p> <p>‘A day hospice or day centre with courses on nutrition, talking to someone equal ... and where someone could facilitate conversations, for example about being ill ... The day hospice also could have a possibility to stay overnight. Sometimes, the ghosts appear at night—also for the relatives. Some kind of “Come and stay here a couple of nights. Then you can go home again, possibly combined with a day hospice (D, manager (nurse) SPC).’</p>	<p><b>Abstract/conceptual concepts</b></p>	<p><b>Preliminary theme</b></p>	<p><b>Final theme</b></p>
	<p>New organisational possibility (palliative phone, day hospice) Minimal bureaucracy Access to resources Psychosocial palliative care</p>	<p>Organisational changes are needed</p>	<p>Improvements of palliative care organisations</p>

**Ethics**

This study and the RCT study were approved by the Data Protection Agency (2007-58-0015), the Ethics Committee (H-4-2013-016) and registered at clinicaltrials.gov (NCT01885637) (World Medical Association (WMA), 2013; Nordly et al, 2014). The participants received written informational material about the study and its aim and were informed that participation was anonymous and voluntary, and that there was a possibility to withdraw from the study.

**Results**

The following three (out of seven) themes were identified: 1) improvement in the cessation of antineoplastic treatment in palliation; 2) improvement in organisations delivering palliation; and 3) improvement in multidisciplinary and cross-sectoral collaboration.

***Improvement in the cessation of antineoplastic treatment in palliation***

It was requested that healthcare professionals at OCs develop an awareness of when to stop antineoplastic treatment. A manager stated:

**‘We must stop the antineoplastic treatment earlier. Would the patients have said ‘yes’ to chemotherapy for the next 7 months if they knew they were only here for 9?’ (G, Manager (Nurse), OC)**

After completion of antineoplastic treatment, the managers and the healthcare professionals at the OC found that they were ‘forced due to resource reasons’ to discharge the patients to ‘nothing’. Three healthcare professionals elaborated on this:



**‘The patients need a network when they get home and someone who takes care of them. The GP is often non-existent.’ (F, Nurse, OC)**

**‘The patients are rejected if we refer them to SPC prematurely.’ (F, Nurse, OC)**

**‘Yes, because they think the patients do not have complex enough needs. It may well be that they do not need so much PC at that time, but if they are inside the healthcare system when the need comes, the support is there.’ (F, Nurse, OC)**

As these quotes show, the participants demand supportive/palliative organisational structures to be established between the OCs and possibly specialised palliation, in addition to the GPs.

The professionals and managers of SPC also experienced that the hospitals were pressured to discharge the patients:

**‘The hospitals are so strained. They try to get rid of their patients, but what should we do for them? They do not belong in a hospice or a SPC team. However, basic PC services are missing. Where can we guide them to get care?’ (C, Manager (Nurse), SPC)**

This quote shows a lack of referral options in PC.

### ***Improvement in organisations delivering palliation***

Six new improvements to existing PC organisational structures were suggested to secure palliation for patients with terminal cancer. Three suggestions concerned structures supporting discharge from hospitals to PC at home; two suggestions aimed to improve PC for people affiliated with SPC; and the last suggestion focused on the HCN possibility for counselling.

The first suggestion relating to organisational structure in regards to discharge from hospital to home was the introduction of ‘a discharge coordinator’. These were healthcare professionals following the patients during admission to the hospital, assessing their needs and ensuring relevant help was provided at discharge from the hospital.

The second organisational structure suggestion was an opportunity to arrange a joint home meeting for patients with basic palliative needs between the patients’ family, home care nurse, a GP and professionals from the hospital. On this, three professionals stated:

**'Then one can completely agree on medication and the plans.'** (F, Nurse, OC)

**'Yes, but it collides with the GPs' planned workday.'** (F, Nurse, OC)

**'Yes, but the GPs are important in PC and they must take responsibility.'** (F, Doctor, OC)

The third suggestion was a direct phone line, established with palliative resource persons/ teams, that the patients and relatives could call when they arrive home, even if they did not have immediate PC needs:

**'It is a huge security for the patients to have someone to call. They might also be offered a stay at the hospice when that time comes. There are not so many organisational obstacles when calling a hospice. It is not as bureaucratic as hospitals.'** (A, Nurse, SPC)

This quote illustrates the need for prevention and care planning with the families and reducing organisational bureaucracy.

Two suggestions regarded SPC and included the establishment of additional palliative beds at hospitals and a new kind of day centre/hospice with the possibility of accommodation:

**'A day hospice or day centre with courses on, for example, nutrition, talking to someone equal [...] and where someone could facilitate conversations, for example, about being ill [...] The day hospice also could have the possibility to stay overnight. Sometimes the ghosts appear at night, [and this is] also [the case] for the relatives. Some kind of "come and stay here a couple of nights. Then you can go home again, possibly combined with a day hospice."'** (D, Manager (Nurse), SPC)

Two other managers from SPC suggested that a day hospice also could offer physical training to patients with rehabilitation needs and services for relatives. One explained:

**'Now, we do not have the right services because it is in the yard zone between early PC and rehabilitation. Services like that are not established in SPC.'** (E, Manager (Doctor), SPC)

Regarding services to relatives, another manager said:

**'[...] and courses on being a relative. They have many questions.'** (C, Manager (Doctor), SPC)

As shown, a day hospice could offer flexible, comprehensive rehabilitation and palliation for the whole family both early and later in the disease trajectory and during the day and at night.

The sixth suggestion regarded the HCN opportunity for counselling. The HCN requested the opportunity to contact a doctor from SPC, which was supported by professionals from SPC:

**'HCNs can get guidance from one of the nurses from SPC ... but if a home nurse has a really difficult problem, then she is not allowed to contact our doctor. I think it is a shame because then she is going to call the out-of-hours GP.'** (B, Nurse, SPC)

### ***Improvement in multidisciplinary and cross-sectoral collaboration***

One important task in professional collaboration concerned the planning alongside, and conversations with the patients and relatives regarding the end of antineoplastic treatment. The professionals considered it to be a task for the doctors at the OC, as this profession was responsible for the treatment.

**'At the hospital, you are treatment-oriented, offering more chemotherapy and radiation therapy. We sometimes receive patients who have been offered cancer treatment that was difficult for them to refuse. The treatment represents hope, and they are afraid to be abandoned.'** (E, Leader (Doctor), SPC)

Several professionals highlighted that, if SPC and OCs collaborate regarding the patients' symptom management and treatments early in the disease trajectory, this could contribute to 'more consensual agreement about the patients' treatments' (D, Nurse, SPC). In addition, if the patients and relatives were informed about palliation at the time of diagnosis at OCs, this may contribute to better care planning and conscious choices, such as those decisions made about antineoplastic treatment:

**'Already, when the patients are diagnosed, I would like the knowledge about**

**palliation to become part of the information. PC should become a conscious alternative part of the service palette patients can choose in their disease trajectory.’ (D, Manager (Nurse), SPC)**

The collaboration and division of labour between GPs, home nursing, OCs and/or SPC were important for care at home. The home nurse often had a tutoring function for the family: ‘My role is often to be the liaison between the citizen and other professionals and departments,’ a home care nurse (I) reported. Affiliation to an OC and/or a hospital-based palliative ward or SPC team may be required when patients were at home. Among other things, HCN had to have direct contact with doctors outside daytime hours, on weekends/holidays, to avoid unwanted admissions:

**‘The patient had atypically been approved for an open admission, which was necessary for us to continue at home. It would have been bad if I had not been able to contact a doctor on duty at the ward.’ (K, Home Care Nurse)**

An affiliation to SPC could imply access to professional resources for patients and relatives, that the primary sector could not offer. This could contribute to safe palliation for the families: ‘Future generations will be pleased with receiving services from SPC. It can create security,’ a home care nurse (J) explained.

## **Discussion**

This study identified three themes of significance according to healthcare professionals and managers on opportunities and barriers concerning organising palliation for patients with terminal cancer. The first theme—timely cessation of antineoplastic treatment for advanced cancer patients—has been discussed in international studies (Baszanger, 2012; Skov Benthien et al, 2018; Wiersma et al, 2019; Hauge, 2020). Debates about ending or prolonging the treatment for terminal cancer patients have taken place, and new treatments are added, rather than replacing treatments which already exist (Baszanger, 2012). New treatments may provide hope for patients with terminal cancer, as well as the stakes have to define the moment to withdraw treatment, both for the sake of saving costs and to provide patients with better

quality of life and dignified death (Hauge, 2020). This indicates a need for greater awareness from oncologists in the planning of and initiating conversations with families regarding the cessation of antineoplastic treatment. A Japanese study (Mori et al, 2019) showed that oncologists viewing life completion as important for a good death were more likely to consider the end of treatment for patients with terminal cancer. Other studies demonstrate that early palliation and timely end-of-life discussions prevented intravenous chemotherapy near death, which resulted in a better quality of life for the patients (Temel et al, 2010; Yoong et al, 2013). These results indicate that physicians in oncology must initiate communication with the patients and their families to clarify their goals and preferences and reflect on their perception of life completion as part of a good death, possibly using advanced care planning (ACP) (Mori et al, 2019). According to the European Association for Palliative Care, ACP enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate (Rietjens et al, 2017). That means that ACP is an ongoing conversation and, if PC is organised around the patients' and informal caregivers' involvement, this ongoing conversation about values can make the patient experience the conversation about life as more of a continuous process. In this way, ACP could be an integrated part of treatment and care, but implementation of this tool will require education for both physicians and other professionals.

In relation to the next two themes, in the national PC recommendations (Sundhedsstyrelsen, 2017), the need to raise the quality of palliation at the basic level is highlighted, including the recommendation that hospitals must ensure communication and coordination with relevant actors in the municipality and with GPs. However, this study indicates a weakness in PC services. The hospitals cannot ensure access to specialised palliation, because some patients do not have complex palliative needs that require referral to specialised palliation. The GPs do not follow up, and patients may not need home nursing. In these situations, and more generally, when patients are transferred to a new level of care or specialisation, they experience gaps in the service provided (Rotter et al, 2010). Thus, there is a need to improve the structure in PC as suggested by this study's participants, through the implementation of, for example, a dedicated phone line or a discharge coordinator; additionally, a palliative key person would also be beneficial, as mentioned in the Danish

recommendations for PC (Sundhedsstyrelsen, 2017).

These structures could be managed by nurses from hospitals and/or primary care. However, a phone line nurse may need opportunities to contact a physician in SPC to discuss severe problems and symptoms. Furthermore, improvement of PC structures could be inspired by international palliative structures and organisations. However, according to the Lancet Oncology Commission, there are too few international agreements on the content/ standards of the organisation of palliation in oncology (Kaasa et al, 2018). Still, there is a strong consensus for the integration of oncology and PC contemporarily in cancer care; due to the complex processes, it is proposed that SPC is a means by which future efforts could promote integration (Kaasa et al, 2018). Nevertheless, this does not necessarily solve the collaboration and communication challenges between OCs at hospitals, SPC and organisations that deliver palliation in the primary sector, as this study illustrates. The international literature on the integration of oncology and primary PC is limited and, as cancer treatment/care becomes more specialised, GPs often lose contact with patients during cancer treatment; in addition, due to poor communication between oncologists and GPs, it is a challenge for GPs to re-engage with patients in PC (Kaasa et al, 2018).

### **Limitations**

The study has methodological limitations. The interviewed professionals and managers talked about their experiences associated with only one RCT study (Nordly et al, 2014) and future healthcare perspectives. In addition, the professionals had experience with limited patients from the RCT study, because the patients were affiliated with nine different SPC teams, five OCs in one comprehensive cancer centre and home nursing in 29 municipalities. If each participant had had contact with more cancer patients in the RCT study, this likely could have provided more nuanced reflections on the organisation of PC. Although GPs are considered important professional partners in PC (Sundhedsstyrelsen, 2017), they are not represented in this study. This is a weakness, as GPs are not only highlighted as a significant organisational partner in PC, but also as a partner who is often difficult to communicate and collaborate with.

### **Conclusions**

This study demonstrates the demand for flexible, family-centred and integrated palliation at all levels, from

the establishment of communication and a collaborative relationship between families and professionals to service sectors— for example, specialised palliation integrated into oncology; integration of palliation and rehabilitation; specialised palliative counselling options for families early in the disease trajectory; and cross-sectorial and joint multidisciplinary meetings between the patient, their relatives and professionals.

## References

Baszanger I. One more chemo or one too many? Defining the limits of treatment and innovation in medical oncology. *Soc Sci Med.* 2012;75(5):864–872. <https://doi.org/10.1016/j.socscimed.2012.03.023>

Bergenholtz H, Hølge-Hazelton B, Jarlbaek L. Organisation and evaluation of generalist

palliative care in a Danish hospital. *BMC Palliat Care*. 2015;14:23. <https://doi.org/10.1186/s12904-015-0022-2>

Bergenholtz H, Jarlbaek L, Hølge-Hazelton B. Generalist palliative care in hospital—cultural and organisational interactions. Results of a mixed-methods study. *Palliat Med*. 2016;30(6):558–566. <https://doi.org/10.1177/0269216315619861>

Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. <http://dx.doi.org/10.1191/1478088706qp063oa>

Burgers J, van der Weijden T, Grol R. Clinical practice guidelines as a tool for improving patient care. In: Wensing M, Grol R, Grimshaw J. *Improving patient care* (3rd ed). Hoboken (NJ): John Wiley and Sons; 2020:103–129. care challenge: analysis of barriers and opportunities to integrate palliative care in Europe in the view of national associations. *J Palliat Med*. 2017;20(11):1195–1204. <https://doi.org/10.1089/jpm.2017.0039>

de Casterlé BD, Gastmans C, Bryon E, Denier Y. QAUQOL: a guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49(3):360–371. <https://doi.org/10.1016/j.ijnurstu.2011.09.012>

Groenvold M, Petersen MA, Damkier A et al. Randomised clinical trial of early specialist palliative care plus standard care versus standard care alone in patients with advanced cancer: the Danish palliative care trial. *Palliat Med*. 2017;31(9):814–824. <https://doi.org/10.1177/0269216317705100>

Hansen MB, Nylandsted LR, Petersen MA et al. Patient-reported symptoms and problems at admission to specialised palliative care improved survival prediction in 30,969 cancer patients: a nationwide register-based study. *Palliat Med*. 2020;34(6):795–805. <https://doi.org/10.1177/0269216320908488>

Hansen MB, Adersen M, Grønvold M. Dansk Palliativ Database: Årsrapport 2020. 2021. [http://www.dmcgpall.dk/files/aarsrapport\\_dpd\\_2020\\_med\\_3\\_reglen23\\_6\\_21.pdf](http://www.dmcgpall.dk/files/aarsrapport_dpd_2020_med_3_reglen23_6_21.pdf) (accessed 7 September 2023)

Hauge AM. One last round of chemo? Insights from conversations between oncologists and lung cancer patients about prognosis and treatment decisions. *Soc Sci Med*. 2020;266:113413. <https://doi.org/10.1016/j.socscimed.2020.113413>

Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB. Patients and family caregivers report high treatment expectations during palliative chemotherapy: a longitudinal prospective study. *BMC Palliat Care*. 2021;20:37. <https://doi.org/10.1186/s12904-021-00731-4>

Ikander T, Raunkiær M, Hansen O, Dieperink K. Nurses' involvement in end-of-life discussions with terminal cancer patients and family caregivers: an integrative review. *Palliat Support Care*. 2022;20(4):570–581. <https://doi.org/10.1017/S1478951521000596>

Kvale S, Brinkmann S. Interview: Introduktion til et håndværk [Interview: Introduction to a



craft]. Copenhagen, Denmark: Hans Reitzels Forlag; 2009

Kaasa S, Loge JH, Aapro M et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol*. 2018;19(11):e588–e653. [https://doi.org/10.1016/S1473-2045\(18\)30415-7](https://doi.org/10.1016/S1473-2045(18)30415-7)

Lave J, Kvale S. What is anthropological research? An interview with Jean Lave by Steinar Kvale. *Int J Qual Studies Ed*. 2006;8(3):219–228. <https://doi.org/10.1080/0951839950080301>

Lund L, Ross L, Ewing G et al. Feasibility of a stepped-wedge (cluster) randomised controlled trial (SWRCT) assessing the effect of the carer support needs assessment tool (CSNAT) intervention in the specialised palliative care setting in Denmark. *Palliative Medicine*. 2020;34(S1):28–28. <https://doi.org/10.1177/0269216320958098>

Mori M, Shimizu C, Ogawa A et al. What determines the timing of discussions on forgoing anticancer treatment? A national survey of medical oncologists. *Support Care Cancer*. 2019;27(4):1375–1382. <https://doi.org/10.1007/s00520-018-4423-7>

Murtagh FE, Bausewein C, Verne J et al. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med*. 2014;28(1):49–58. <https://doi.org/10.1177/0269216313489367>

Nordly M, Benthien KS, Von Der Maase H et al. The DOMUS study protocol: a randomized clinical trial of accelerated transition from oncological treatment to specialized care. 2014; 13(44):1–10. <https://doi.org/10.1186/1472-684X-13-44>

Nordly M, Skov Benthien K, Vadstrup ES et al. Systematic fast-track transition from oncological treatment to dyadic specialized palliative home care: DOMUS—a randomized clinical trial. *Palliat Med*. 2019; 33(2):135–149. <https://doi.org/10.1177/0269216318811269>

Oosterveld-Vlug M, Custers B, Hofstede J et al. What are essential elements of high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC Palliat Care*. 2019;18(1):1–10. <https://doi.org/10.1186/s12904-019-0485-7>

Raunkiær M, Buch MS, Holm-Petersen C, Timm H. Professionals' experiences with palliative care and collaboration in relation to a randomised clinical trial: a qualitative interview study. *Scand J Car Sci*. 2020; 34(1):305–313. <https://doi.org/10.1111/scs.12729>

Radbruch L, Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 1. *Euro J Palliat Care*. 2009;16(6):278–89

Raunkiær M, Timm H. Development of palliative care in nursing homes: evaluation of a Danish project. *Int J Palliat Nurs*. 2010;16(12):613–620. <https://doi.org/10.12968/ijpn.2010.16.12.613>

Rigsrevisionen. Access to specialist palliative care. Extract from Rigsrevisionen's report

submitted to the Public Accounts Committee. 2020. <https://uk.rigsrevisionen.dk/Media/7/D/18-2019.pdf> (accessed 7 August 2023)

Rietjens ACJ, Sudore LR, Connolly M et al. European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol.* 2017;18(9):e543–e551. [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X)

Rotter T, Kinsman L, James EL et al. Clinical pathways: effects on professional practice, patient outcomes, length of stay and hospital costs. *Cochrane Database Syst Rev.* 2010;(3):CD006632. <https://doi.org/10.1002/14651858.CD006632.pub2>

Rugno FC, Paiva BSR, Paiva CE. Early integration of palliative care facilitates the discontinuation of anticancer treatment in women with advanced breast or gynaecologic cancers. *Gynecol Oncol.* 2014;135(2):249–254. <https://doi.org/10.1016/j.ygyno.2014.08.030>

Skov Benthien K, Adsersen M, Petersen MA et al. Is specialised palliative cancer care associated with use of antineoplastic treatment at the end of life? A population-based cohort study. *Palliat Med.* 2018;32(9):1509–1517. <https://doi.org/10.1177/0269216318786393>

Sundhedsstyrelsen. Anbefalinger for den palliative indsats. 2017. <https://www.sst.dk/da/udgivelser/2017/anbefalinger-for-den-palliative-indsats> (accessed 7 September 2023)

Temel JS, Greer JA, Muzikansky A, Gallagher ER et al. Early palliative care for patients with metastatic non–small-cell lung cancer. *N Engl J Med.* 2010;363(8):733–742. <https://doi.org/10.1056/NEJMoa1000678>

Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval.* 2006;27(2):237–246. <https://doi.org/10.1177/1098214005283748>

Turriziani A, Attanasio G, Scarcella F et al. The importance of measuring customer satisfaction in palliative care. *Future Oncol.* 2016;12(6):807–813. <https://doi.org/10.2217/fon.15.359>

van Riet Paap J, Vernooij-Dassen M, Brouwer F et al. Improving the organisation of palliative care: identification of barriers and facilitators in five European countries. *Implement Sci.* 2014;9(1):130. <https://doi.org/10.1186/s13012-014-0130-z>

Vanbutsele G, Pardon K, Van Belle SL et al. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. *Lancet Oncol.* 2018;19(3):394–404. [https://doi.org/10.1016/S1470-2045\(18\)30060-3](https://doi.org/10.1016/S1470-2045(18)30060-3)

Verkissen MN, Hjermsstad MJ, Van Belle S et al. Quality of life and symptom intensity over time in people with cancer receiving palliative care: results from the International European Palliative Care Cancer Symptom study. *PloS One.* 2019;14(10):e0222988. <https://doi.org/10.1371/journal.pone.0222988>

Vissers KC, van den Brand MW, Jacobs J et al. Palliative medicine update: a multidisciplinary approach. *Pain Pract.* 2013;13(7):576–588. <https://doi.org/10.1111/papr.12025>

Wiersma M, Ghinea N, Kerridge I, Lipworth W. ‘Treat them into the grave’: cancer physicians’ attitudes towards the use of high-cost cancer medicines at the end of life. *Sociol Health Illn.* 2019;41(2):343–359. <https://doi.org/10.1111/1467-9566.12830>

World Health Organization. Palliative care. 2021. <https://www.who.int/europe/news-room/factsheets/item/palliative-care> (accessed 7 September 2023)

World Health Organization. Denmark. Globocan 2020. 2021. <https://gco.iarc.fr/today/data/factsheets/populations/208-denmark-fact-sheets.pdf> (accessed 7 September 2023)

World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA.* 2013;310(20):2191–2194. <https://doi.org/10.1001/jama.2013.281053>

Yoong J, Park ER, Greer JA et al. Early palliative care in advanced lung cancer: a qualitative study. *JAMA Intern Med.* 2013;173(4):283–290. <https://doi.org/10.1001/jamainternmed.2013.1874>

