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Professionals’ experiences with palliative care and collaboration in relation to a randomized clinical trial: A qualitative interview study

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Conflicts of interest and data

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The authors declare that there are no conflicts of interest regarding the publication of this article. Data are deposited in secured it-systems at VIVE and Odense University Hospital and can be accessed by the authors only.

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**Ethics statement**

The DOMUS RCT, including this study, has been granted permission by the Ethics Committee (H4-2013-016) and the Data Protection Agency (2007-58-0015) and is registered at clinicaltrials.gov (NCT01885637)
Abstract

**Background:** International evidence on the outcome of generalist versus specialist palliative care provision in palliative care trajectories is limited and varied. In general, intervention studies can influence the organization of palliative care practice and professional collaborations. However, randomized clinical trials in palliative care rarely consider the organizational significance of the studies, as experienced by the professionals involved. DOMUS is the abbreviation for a Danish intervention study designed as a randomized clinical trial, investigating an accelerated transition from oncological to specialist palliative care at home for patients with incurable cancer. Alongside conducting the palliative care intervention study, we wanted to discover the perspectives of the health care professionals involved.

**Aim:** To explore the organizational significance of the DOMUS intervention study as experienced by the professionals involved.

**Design:** A qualitative interview study, using thematic content analysis and inspired by organizational theory.

**Setting/participants:** Thirty-eight professionals from four units involved in the DOMUS intervention study took part in 10 group and six individual interviews.

**Results:** The DOMUS randomized clinical trial intervention influenced and sometimes disrupted both the ways of organizing, collaborating and practicing palliative care, and patients’ and relatives’ understanding of their own situation. It did this by 1) referring a broader palliative care target group to specialist palliative care, leading to 2) different palliative care needs, professional tasks, and perceived impact on 3) the organization of palliative care and 4) professional collaboration.

**Conclusion:** Professionals involved in the DOMUS palliative care intervention found that the study had organizational significance, with an influence on professionals, patients and relatives. Specialist palliative care in Denmark is devoted organizationally and professionally to patients with severe or complex palliative care needs. Hence, new ways of organizing palliative care for people in the earlier stages of their disease are needed.
Keywords

Specialist palliative care, accelerated transition, target groups for palliative care, professionals’ experiences with RCT intervention studies, organizational significance of intervention studies.
Introduction

In this article, we present findings from a qualitative interview study with professionals (nurses, doctors and psychologists) and leaders of oncology clinics at a hospital, and leaders of specialist palliative care teams (SPT) involved in a randomized clinical trial (RCT). The RCT was called DOMUS (“at home”) and involved specialist palliative care (SPC) and generalist palliative care (GPC) (Box 1). DOMUS is an abbreviation for a Danish randomized clinical trial of accelerated transition from oncological treatment to specialist palliative care at home supplemented with a psychological intervention (Box 2). The qualitative interview study was nested within and took place alongside the DOMUS RCT.

International palliative care and palliative care research has increased over the past 10-15 years (3). Thus, there has been a growing effort to document evidence of GPC and SPC outcomes to gain a better understanding of their applications. Temel et al. (4) demonstrated a significant effect on quality of life (QoL) for patients with metastatic non-small cell lung cancer receiving early palliative care. A meta-analysis (5) of 10 RCT studies concluded that SPC is associated with a small effect on QoL, and that effectiveness seemed to be related to early intervention (at the time of diagnosis) and to patients with unmet palliative care needs. A RCT study, DanPaCT (6), showed no significant effect of early integrated SPC on patients with advanced cancer. The DOMUS RCT, which included an accelerated transition from oncological treatment to SPC at home, showed a small but significant effect on time spent at home and a clinically relevant improvement on QoL and social and emotional functioning after six months (7, 8). The same study also demonstrated that psychological intervention could significantly decrease psychological distress in caregivers for
patients with advanced cancer (9, 10). From these studies, it is evident that the palliative care field uses different terms to define the time perspective on provision of palliative care: for example, early palliative care (4), early integrated SPC (6) and accelerated transition to SPC (7, 8). The inconsistency of terminology, outcomes and application of accelerated and/or early integrated SPC across the globe may have resulted in a lack of understanding of best practices that might improve QoL and increase home deaths. To gain a better qualitative and quantitative understanding, consideration should be given to the specifics in timing of SPC provisions and study designs as well as the different methods used to measure outcomes.

Recent work has suggested that RCT is ideal for identifying the effects of intervention (11, 12). RCT, however, may not be adequate when interventions become complex by involving various organisations and staff with different goals and tasks (13). While RCTs can measure statistically significant outcomes on selected variables, the design cannot be used to identify the social and organizational processes involved in an intervention and its influence on the outcomes – or lack of outcomes. Rather, it may be better to identify social and organizational processes through observational studies, interviews, the inspection of documents and theoretical analysis – for example, by analysing the perspectives and logical rationale of the people and organisations involved in a study (12, 14, 15).

In recognition of the two facts that a) the DOMUS RCT was complex relative to intervention and b) the experiences of the involved professionals constituted a significant contribution to understanding the success or lack of success of the intervention, we conducted an interview study of professions and leaders nested in the RCT.

The aim of this study was to explore the organizational significance of the DOMUS RCT intervention, as experienced by the professionals and leaders involved.

**Theoretical framework and concepts**

According to organisation theory, the concept of organisation may comprise structures (as ways to organise and collaborate), tasks (e.g. as exemplified in health care practices), technology (e.g. new interventions) and actors (e.g. the people involved) (16-18). We applied this organizational framework to guide our interviews and data analysis.
Methods

Based on the aim and the theoretical framework of our study, we wanted to explore how the participants (actors) experience the influence of the DOMUS intervention (new technology) on patients and caregivers (also actors). The research questions were:

- Did the DOMUS intervention (new technology) affect the palliative care practice (tasks), and if so, how?
- Did the DOMUS intervention (new technology) affect the way of organising palliative care (tasks) in the settings involved (structures), and if so, how?
- Did the DOMUS intervention (new technology) influence the collaboration (structure) between the various professions (actors), and if so, how?

Sampling and recruitment

The participants were recruited from the DOMUS RCT as described under the following organizational units:

a) The five clinics at the Department of Oncology, Copenhagen University Hospital (nurses, nurse leaders and a doctor)
b) The nine outgoing specialist palliative care teams (SPT) in the Capital Region (nurses, nurse leader and doctors (leaders))
c) The 29 municipalities of the Capital Region (home care nurses)
d) DOMUS employees (psychologists).

There were no pre-existing relationships between the researchers and the participants from the organizational units, with the exception of HT knowing the DOMUS employees. Because of her prior relationships, HT was able to ask more specific questions. On the other hand, the prior relationship could also mean that some things were not said.

The criteria for inclusion were a) the professionals were to have collaborated with at least one DOMUS patient, b) leaders were to have experience and/or be familiar with the DOMUS RCT and intervention, and c) there was to be maximum diversity of professions due to palliative care being an interdisciplinary practice. The DOMUS RCT in particular was comprised by hospital doctors,
GPs, hospital and home care nurses, and DOMUS psychologists. In addition, there were occupational therapists, physiotherapists and social workers, who were employed in the SPT. The participants were recruited via the leaders of the organizational units. As we could not identify the general practitioners (GP) involved in the intervention, they were not invited to take part in the interviews.

Data collection
The interviews were conducted by the authors between May 2016 and September 2016. The interviews were semi-structured (19, 20) and the guide was inspired by the theoretical framework as introduced above, encompassing four themes: 1) The informants’ (actors’) knowledge of the DOMUS intervention (technology), 2) the informants’ (actors’) experiences with (the care for and collaboration regarding) patients and caregivers (actors) in DOMUS (technology), 3) the informants’ (actors’) experiences with the influence of the DOMUS intervention (technology) on palliative care practice (tasks), the organisation (structure) and 4) the cross-sectorial and inter-professional collaboration (structure).

We chose to conduct group interviews in order to generate dialogue and reflection between the participants (19-21). However, two doctors and two home care nurses were unable to participate in the planned group interviews and hence were interviewed individually. All interviews were conducted in person at the informants’ workplaces, audio recorded and transcribed verbatim, except for one phone interview with a home care nurse. The data collection process fulfilled the aim of data saturation (19). Thirty-eight informants participated in nine group and four individual interviews (Table 1).

Data analysis
Inspired by the theoretical framework and concepts, a thematic content analysis was conducted (22-24). To optimise rigour, as well as sensitivity, in the data analysis, we moved back and forth among study method, research question, literature, recruitment, data collection strategies and analysis (25). All authors were involved in the process. Joint meetings were used to reach agreement and consensus on the interpretation of the data and findings. The thematic analysis was structured according to Braun and Clark’s six phases (23). 1) To become familiar with the data, the authors read the 16 transcripts to identify common aspects and phrases in the contexts of the interviews and
checked the transcripts against the original audio recordings for accuracy. 2) Generating initial codes: one author (MR) analysed and open-coded the 16 interview transcripts (using paper and pencil). Then the open codes were recoded, resulting in an adapted code list with concepts at a more abstract and conceptual level. The recoded list was then read and discussed in relation to the interview transcripts by all authors and, if indicated, revised. 3) Searching for themes and 4) reviewing themes; the different codes were organised into themes. The themes and the meaning of the separate fragments were discussed by all the authors. 5) Defining and naming themes and 6) writing the article; the themes were defined and redefined several times. Finally, the authors arrived at four themes corresponding with our understanding of organisation (16-18, 23).

Ethics statement

The DOMUS RCT, including this study, has been granted permission by the Ethics Committee (H-4-2013-016) and the Data Protection Agency (2007-58-0015) and is registered at clinicaltrials.gov (NCT01885637) (7). Furthermore, this study was a part of an overarching agreement between the authors MSB’s and CHP’s workplace and the Data Protection Agency. The participants received written information material about the study and its aim. They were also informed that participation was voluntary and anonymous, and that they were free to withdraw from the study at any time. In this article, we have anonymised participants by using their professional designation and a letter to identify which interview they took part in (see Table 1).

Findings

The following themes were identified from the data analysis: 1) an extended palliative care target group in relation to specialist palliative care, 2) different palliative care needs and professional tasks, 3) perceived impact on the organisation of palliative care and 4) perceived impact on professional collaboration.

An extended palliative target group in relation to specialist palliative care

The professionals expressed some similarity between the patients usually referred to SPC and DOMUS patients. However, many DOMUS patients had much better functional performance levels. For instance, some DOMUS patients had jobs and lived a daily life where they described going to the “beach” and “fitness centre”.

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We thought that we would have the patients for a month or so. We knew from The Palliative Care Database that they generally only lived for about 30 days after being referred to a SPT. (A psychologist, m)

In DOMUS, we know of some long-lasting and complex care pathways, with some having a rehabilitative aim. (A home care nurse, i)

The professionals from the SPTs also expressed that the better performing patients and their families were “surprised” or “scared” by the early contact. Others were “disrupted in their daily life”, and some had asked: “What is the meaning of your involvement? Am I dying?” A home care nurse gave an example of how this influenced her work:

There was this young woman. After the SPT had gone, it took me a long time to calm her down. I made an appointment so that she could call me when she needed to. She called after a couple of months and was pleased to see me. I was afraid she was angry. (A home care nurse, h)

As the quote shows, the home care nurses found that early contact with the families also meant that they often had to spend a considerable amount of time talking about thoughts and feelings with the patient/family after the first home conference. Regardless of these challenges, the professionals found that the early SPC in DOMUS could give the families more “security” compared to families that received a later referral to the SPTs: “Those who have received the intervention express a feeling of security and gratitude due to being affiliated to ‘something’”. (A nurse, oncology clinic, f)

**Different palliative care needs and professional tasks**

The professionals expressed that the generally good functional performance status of the patients also influenced their work due to the patients/families having fewer or different palliative care needs:

Firstly, less treatment of physical symptoms was required:
Pain in connection with the treatment and disease along with periods of nausea or nutritional problems is typical. However, in DOMUS we are involved so early in the palliative care trajectory that there are no acute problems. (A doctor, leader SPT, d)

Secondly, there were more social worker tasks:

> When patients are affiliated to us so early in the disease trajectory, as in DOMUS, there are a lot of social worker tasks. (A nurse, SPT, a)

The DOMUS patients’ good performance status led to more applications for compassionate leave, pensions and questions related to legacy and economy than was usually the case for SPT patients.

Thirdly, the specific DOMUS psychologist intervention contributed to the psychologist having a special role in the families:

> If you hadn’t been here, I wouldn’t have stayed in the DOMUS project, a patient said to me. We had a special role because the patients were much better than we thought at the beginning of the project. We became their way into the health care system—they were too well functioning to get specialist palliative care. (A psychologist, m)

As the quote shows, the psychologists felt that they became a key person for the families.

**Perceived impact on the organisation of palliative care**

The professionals from the SPTs found that the well performing patient group in DOMUS changed the requirements to the organisation of palliative care with regard to three conditions:

Firstly, prolonged and more sporadic association with the organizational units: Both professionals from the home care units and the SPTs said that they did not visit many of the DOMUS patients. The patients were seen as well functioning, and some families were stated to have been associated with the SPTs for “1½-2 years”. Therefore, both types of units often had “sporadic” contact with
the patients/families. For example, phone calls every other month and several SPTs had compiled a DOMUS list with “patient sleeping”.

I started the care earlier than usual. In the beginning, I came once a week and then every 14 days. Then he went on holiday. After that, I only called him on the phone. (A home care nurse, k)

They don’t need SPC. Usually they would have been discharged. (A doctor, leader SPT, c)

Even though the professionals found that several of the patients in DOMUS had no SPC needs, the professionals at oncology clinics required palliative care services in between oncology clinics and specialist palliative care because:

The patients have many problems [eds. regarding medicine, job, pension etc.]. The GPs are difficult to involve. We need to refer them to ‘something’. (A doctor, oncology clinic, f)

Secondly, DOMUS was thought to lead to increased resource requirements and capacity problems for the units involved; several of the professionals expressed concerns about the DOMUS model, if it were to be implemented on a larger scale:

It is an expensive solution and leads to delays for other patients who need palliative care (A nurse, leader SPT, e)

Thirdly, professionals expressed concerns about whether the current SPTs were able to provide for the needs of the better performing group of patients in DOMUS and suggested new ways of organising PC:

They [eds. the well-performing patients] fell within the grey area of rehabilitation, and the SPT is not geared for that. (A doctor, leader SPT, d)
We do not have the right services for patients like those in DOMUS. Maybe a day hospice with courses, lectures and groups with the possibility of talking about experiences or education of relatives could be interesting for people early in the trajectory. (A nurse, leader SPT, e)

Seemingly, it was considered that some patients had rehabilitation needs rather than, or concurrently with, palliative care needs.

**Perceived impact on professional collaboration**

The nurses and doctors from the SPTs and home care nurses did not feel that there was much communication and collaboration regarding the DOMUS patients. This was not unexpected, as the better performing patient group rarely required collaboration, and when the need did arise the collaboration was described as being “as usual”. Although the DOMUS psychologist conversations started as soon as the patients were included in the DOMUS intervention arm, this did not lead to any special collaboration between the psychologists, home nurses, SPTs or oncology clinics. “I cannot remember any actual collaboration with the DOMUS psychologists”, a doctor (c) from the SPT stated. The psychologists explained the limited collaboration as follows:

The other professionals just work as usual. (Psychologist 1, m)

If the patients do not talk about us, then we are invisible – they [eds. the other professionals] only meet us at the first home visit. (Psychologist 2, m)

You have to push hard in the busy working day of the SPT to make contact, and we are also busy every day. So the work with the patients is prioritised over the teamwork. (Psychologist 3, m)

Most of the professionals saw the cross-service and multidisciplinary first home conference in DOMUS as a good foundation for future interdisciplinary collaboration. However, three particular challenges and uncertainties were presented as barriers to achieving the intended outcome:

One challenge was increased resource consumption. The first home conference in DOMUS was defined according to the calendar of the SPTs, though they had difficulties making the visit within
five days. Furthermore, it involved sizeable resource consumption: “We have to clear the calendar and spend up to half a day on the first visit.” (A nurse, SPT, b)

Another challenge was that there were many professional participants but no GPs: The professionals considered that if they all participated in the first home conference there were too many people: “It is not an advantage for the patient/user” (A nurse, SPT, a). The GPs rarely participated, probably because “they were unable to meet the five-day deadline for the meeting” (A nurse, SPT, a). Furthermore, GPs often withdrew from the palliative trajectory when the SPTs were involved. This was also said to depend on the personal relationship between the family and the GP.

A third challenge was clarifying the roles of the professionals. The psychologists and home care nurses expressed that it was the doctor from the SPT who guided the first home conference. However, they had difficulties in finding their professional roles:

We are mostly involved by listening and asking the occasional question. Sometimes the doctor and nurse from the SPT have already started when you arrive, even though you get there on time. [...] Usually, you have a lot of authority as a psychologist – you frame the session. Suddenly you are a subordinate – the doctor decides [...] Doctors and nurses have a different approach from psychologists – it can be very direct and disease-oriented. (A psychologist, m)

There was no particular role for me at the first home visits [...] It would have been nice to have had contact with the SPTs before the first home visit. (Three home care nurses talking together and agreeing on this, h)

Discussion
The study shows that the DOMUS RCT intervention influenced, and sometimes disrupted, the ways of organising, collaborating and practicing palliative care, as well as patients’ and relatives’ understanding of the disease trajectory and their situation. Referring patients with a better performance status than those normally referred to SPC may have increased anxiety in families. Additionally, the accelerated interdisciplinary home conference within five days of referral was
experienced as too early by the professionals and changed their roles and tasks. These issues are related to both the DOMUS intervention and the RCT design.

Firstly, accelerated transition implemented as a planned home conference within five days after referral from the oncology clinic, including the patient, family, SPT, home care nurse, GPs and a DOMUS psychologist, was seen to be too demanding and involve too many professionals.

Secondly, although accelerated referral to the SPT could have positive outcomes, it was seen as premature and could lead to both positive and negative outcomes. Early first contact was seen as positive for some families, optionally supplemented with follow-ups if needed. The early contact could provide the feeling of security and allow for relevant social problems to be addressed. However, the overall assessment of the outcome was negative. Partly, because the professionals felt that a too early first contact could worry the families and that it took important resources from the SPTs and patients with severe or complex palliative care needs, who are defined as the target group of SPC by the authorities in Denmark (1). In line with this, the professionals from SPTs expressed that they were not equipped to meet the needs of the group of relatives and better-performing palliative care patients included in DOMUS. Hence, the DOMUS patients often were put on a kind of “waiting list” or referred to “sleeping patients”. The professionals found that the group of better performing palliative care patients in DOMUS had a significant impact on the families’ reaction to the offer of SPC, and also on the professionals’ considerations about tasks and roles within the organizational structure of specialist and generalist palliative care.

At this point, it is important to consider whether DOMUS actually included a palliative target group with better performing patients than the patients usually referred to SPC. Performance status of 3-4 as an inclusion criterion was stopped 16 months after the start of the project (see box 1) due to the low numbers of patients included; 52 % of the patients in the DOMUS intervention arm had a performance status of 0-1 (26); and the Danish patients’ median lifespan after first contact with SPC was only 42 days in 2016 (27). All this substantiates the professionals’ assessment that DOMUS included a better performing palliative target group compared to SPC.

The better performing palliative care target group in DOMUS was not referred to SPC based on the current referral criteria for SPC in Denmark (severe or complex palliative care needs (1, 28)). This and other studies (4-6) indicate that an accelerated or early integration of SPC may not be relevant
for patients without severe or complex palliative care needs. That said the professionals from the
generalist palliative care units in this study asked for referral possibilities in between specialist and
generalist palliative care units. In their experience, the patients had early palliative care needs, for
example concerning social economic issues. This indicates that new ways of organising specialist
and generalist palliative care are needed that focus on palliative care early in the disease trajectory,
for example outpatient clinics in hospitals, community nurse clinics and/or outreach teams.

According to organisation theory (16-18), interventions like DOMUS imply organizational changes
and insecurity among the staff involved with regard to the collaboration, coordination and
expectations to their own and other professionals’ roles and tasks. DOMUS is a RCT study of a new
model for accelerated transition to SPC at home involving many units, professions and
professionals providing specialist and generalist palliative care. This study suggests that complex
interventions – designed as RCTs – dealing with organizational changes would benefit from
exploring the perspectives and the practice of the professionals and the leaders involved. It must be
considered whether RCT designs are suitable for complex health care interventions or whether they
should be conducted systematically and using a variety of designs and methods (12, 15, 29). As this
study shows, if care model interventions are to be implemented without a deep understanding of
what is already happening, they may be seen as being misguided and too resource intensive.

To our knowledge, this is the first study involving an empirical investigation of the organizational
challenges related to the complexity of the organisation of a palliative care RCT. However, the
study has methodological limitations. Firstly, it is important to consider the validity, for example
the basis on which the interviewed professionals talked about their experiences of DOMUS. The
individual professionals only had experience with a few DOMUS patients, because the patients
were affiliated to nine different SPTs, five oncology clinics and home care in 29 municipalities.
However, the interviewed psychologists were responsible for the psychological intervention and
therefore knew many more of the patients and families included in the study, and they seemed to
share the central experiences expressed by the other groups of professionals. This, we believe,
supports the validity of the data as a whole.

Secondly, palliative care is a multi-professional discipline, but only three different professions were
included in this study, of which 31 were nurses (n=38). It would have been desirable for other
professions to be represented, for example social workers, because they had many tasks in relation to the DOMUS patients. This might have increased the number of perspectives on the DOMUS intervention and thus the validity of this study. Unfortunately, the leaders of the various organisations who recruited the informants were not able to prioritise the participation of all professions. One argument was that some professions were only affiliated to an organisation for a few hours per week and therefore had to prioritise their clinical work.

Thirdly, though GPs are considered an important professional partner in community palliative care (26), they are not represented in this study. This was due to difficulties in identifying GPs who fulfilled the inclusion criteria. GPs participated in only 14% of the home conferences (8). It would have been interesting to know why the GPs were seldom able to prioritise the first home conference in DOMUS.

This study only focused on the significance of DOMUS as experienced by the professionals involved. Exploring the perspectives of the patients and families would have been highly relevant, particularly from an ethical perspective. According to the professionals, the DOMUS RCT intervention could increase anxiety for the families. On the other hand, we do not know whether this is correct, because the families were not interviewed in this study or in the DOMUS RCT. From an individual as well as a societal resource allocation perspective, it is an important ethical issue that the users’ perspectives should be sought before the establishment of new and resource demanding palliative care services, which may not be suitable for real life situations.

**Conclusion**

This study shows, that new ways of organising palliative care may lead to changes and insecurity among the staff involved with regard to collaboration, coordination and expectations to professionals’ roles and tasks. Moreover, the study shows that the current SPC in Denmark is not geared organizationally and professionally to provide palliative care for patients without severe or complex palliative care needs. Hence, new ways of organising palliative care for people in the earlier stages of their disease are needed in the Danish health care system.
References


Box 1. Generalist and specialist palliative care

**Generalist palliative care** is for patients with life-threatening diseases who require input from professionals with good basic palliative care skills and knowledge. The main role of these organizations is not to provide palliative care. Examples are nursing homes, home nursing care and general practice (1, 2).

**Specialist palliative care** is for patients with life-threatening diseases with complex palliative care needs that require the input of professionals with specialist palliative care skills and knowledge. The organizations that provide this care have palliative care as their main role and involve at least four different professions, two of which must be nurses and doctors. Examples are specialist palliative care teams, hospices and palliative care units in hospitals (1, 2).

Box 2. The DOMUS RCT: Aims, intervention, inclusion and exclusion criteria

**Primary aim:** Prolonged residency in patients’ preferred place of care and death.

**Secondary aims:** Relief of symptoms, problems and the bereavement process, prolonging life for patients, improvement in cooperation among professionals and improved cost-effectiveness.

**Intervention:** DOMUS consisted of an accelerated transition from oncological treatment in the Department of Oncology, Copenhagen University Hospital to a regional outgoing specialist palliative care team (SPT), with a home conference within five days. The participants in the conference were the patient, the caregiver, representatives of the SPT, a district nurse, and if possible the GP and a DOMUS psychologist. The SPT, in collaboration with the GP and the district nurse, was then responsible for the distribution of tasks related to further treatment and care. Alongside this, the patient and caregiver might have conversations with a DOMUS psychologist. The patients were recruited from June 2013 to June 2015.
Inclusion criteria: Adult (at least 18 years old) cancer patients treated at the Department of Oncology, Copenhagen University Hospital, patients who want to spend as much time as possible in their own homes supported by a SPT, patients with incurable cancer, patients with no or limited antineoplastic treatment options or patients who refuse antineoplastic treatment, second-line treatment, performance status 3-4, patients who live in the Capital Region of Denmark and have given written informed consent. The performance status 3-4 was given up 16 months after project start, because of too few patients.

Exclusion criteria: patients who had already been referred to a SPT, hospitalized patients who were not deemed fit for discharge, patients who were admitted to other hospitals, patients who did not speak Danish.

Inclusion criteria for caregivers: Adults (at least 18 years of age) who have given written informed consent (in addition to that from the patient).

Table 1. Participants in the interview study

<table>
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<th>Organizational units</th>
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<th>Interview id</th>
<th>Professions</th>
<th>Number of participants</th>
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<td>3 group interviews (with 4, 3 and 2 informants) 2 individual interviews</td>
<td>a, b, c, d, e</td>
<td>8 nurses 1 nurse leader 2 doctors (leaders)</td>
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<td>2 group interviews (with 8 and 3 informants)</td>
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<td>7 nurses 3 nurse leaders 1 doctor</td>
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