

Dorthe Goldschmidt
Lone Schmidt
Allan Krasnik
Ulla Christensen
Mogens Groenvold

Expectations to and evaluation of a palliative home-care team as seen by patients and carers

Received: 30 September 2005
Accepted: 12 April 2006
Published online: 16 May 2006
© Springer-Verlag 2006

A. Krasnik · M. Groenvold
Department of Health Services
Research, Institute of Public Health,
University of Copenhagen,
Copenhagen, Denmark

D. Goldschmidt (✉) · M. Groenvold
Department of Palliative Medicine,
Bispebjerg Hospital,
Bispebjerg Bakke 23, 20D, 1,
2400 Copenhagen NV, Denmark
e-mail: dorthe.goldschmidt@dadlnet.dk
Tel.: +45-3061-4085
Fax: +45-3531-2071

D. Goldschmidt · L. Schmidt ·
U. Christensen
Department of Social Medicine,
Institute of Public Health,
University of Copenhagen,
Copenhagen, Denmark

Abstract *Objectives:* Although the number of palliative home-care teams is increasing, knowledge of what patients and principal informal carers expect from a home-care team is sparse. We aimed to elucidate this as well as evaluate a home-care team.

Patients and methods: Individual semi-structured interviews with nine patients and six carers before receiving home care and 2–4 weeks after. In total, 26 interviews were conducted. Interviews were analysed with Template Analysis. Peer debriefing was performed. *Main results:* Patients

and carers expected the team members to have specialised knowledge in palliative care and to improve their sense of security being at home. They also expected respite for carers and activities for patients. They evaluated the team positively but missed respite for carers and 24-h on-call service.

Conclusions: Patients and carers found the home-care team essential to their sense of security being at home. Primary health care professionals must receive any necessary training outside patients' homes. Offering respite for carers and 24-h on-call service would be an improvement.

Keywords Palliative care · Home-care services · Health services research · Qualitative research · Patient satisfaction

Introduction

More and more patients have the possibility of receiving palliative care. Since St. Christopher's Hospice opened in 1967, the number of hospices, palliative care departments, and palliative care teams has been increasing. The organisation of palliative care differs greatly [2, 11, 12, 22, 25, 59, 60, 68]. However, knowledge is sparse about what impact the organisation has on patients' quality of life [59]. The conclusion in one review was that 'we are far from identifying high-quality, effective and appropriate palliative care services' [11], while another review concluded that multidisciplinary teams appeared to have an advantage over uni-disciplinary teams [12]. The way health care is

financed and organised affects the delivery of palliative care [8]. This is especially true for palliative home care, as home care in countries with an extensive primary health-care system often aims towards cooperation between specialists and primary care [16, 52], while countries with less extensive primary health care have to organise palliative home care differently.

Papers regarding evaluation of palliative care have focussed on symptom control [19, 23–26, 64, 65], quality of life [6, 19, 23, 25, 59, 65], 'quality of death' [25, 55], satisfaction with care [19, 23–25, 35, 45, 68], help to carers [22], use of health resources [19, 23, 28] and participants' experiences with care [4, 17, 30, 32, 33, 47, 57, 58, 60]. Studies specifically focussing on palliative home care have

additionally focussed on place of death [3, 18, 55, 66], reasons for hospitalisation despite palliative home care [5, 9, 27] and carers' experiences of caring for a patient at home [7, 21, 29, 41, 46, 48, 54, 56, 61, 67].

Past research can be categorised as 'expectation studies', which asked patients and/or carers for their expectations to palliative home care *before* receiving it, and 'evaluation studies', which asked recipients either *during* or *after* home care. We identified two expectation studies [32, 67]: one focussed on patients and carers; the other focussed on carers only. The participants in both studies were interviewed while home care was ongoing; therefore, the studies cannot be regarded as true expectation studies, as the participants' expectations must have been influenced by what the home-care team offered. Evaluation studies were commoner: five focussed on patients [4, 5, 56, 58, 60], ten on carers [7, 17, 21, 29, 45–49, 54] and six on patients and carers [24, 26, 28, 30, 33, 41]. We did not identify any prospective, longitudinal studies focussing on expectations and evaluation of palliative home care.

We report semi-structured interviews with patients and their principal informal carer (hereafter referred to as 'carer') conducted before start of palliative home care and 2–4 weeks later. Our aims were to investigate expectations to and evaluation of a palliative home-care team. Based on this, we recommend ways of optimising health care for palliative care patients at home and their carers.

Patients and methods

Setting

Denmark has 5.4 million inhabitants and currently 16 palliative home-care teams [15]. Consequently, most patients with palliative care needs are treated by general practitioners (GPs) and district nurses and, if needed, supplemented by visits to outpatient clinics. If patients need acute medical attendance, they can call the doctor's out-of-hours clinic. When necessary, patients are hospitalised at appropriate hospital wards. Most medical care is financed by public taxes.

The Department of Palliative Medicine at Bispebjerg Hospital, Copenhagen, has a 12-bed inpatient ward, an outpatient clinic, and a palliative home-care team. Specialised doctors and nurses worked in all three units, while psychologists, physiotherapists, social workers, occupational therapists, dieticians and clerks worked in the inpatient ward and outpatient clinic only. Doctors from the home-care team visited patients during the day on weekdays, while nurses visited throughout the week during both the day and evening. At night, only telephone advice from the teams' nurses was available. Patients still received their primary care from GPs and district nurses, while the home-care team had a consultancy role, i.e. proposed changes to the patients' care and treatment.

Patients who had pronounced palliative needs and advanced cancer for which there were no curative or life-prolonging treatment could be referred to the department by a GP or a hospital doctor. After a maximum of 1 week, a head nurse made a referral visit to decide if the patient met these criteria and then to decide to which unit to attach the patient. For patients attached to the home-care team, a home conference was arranged within another week where the patient, carer(s), GP, district nurse and doctor and nurse from the home-care team participated. If patients attached to the home-care team needed hospitalisation, they were admitted to the department of palliative medicine if beds were available. Otherwise, they would be admitted elsewhere.

Inclusion criteria for study

Patients should: be attached to the home-care team, be 50 years or older, have a minimum life expectancy of 2 months, be considered well enough by the head nurse and the primary investigator (D. Goldschmidt) to participate in an interview lasting between 30 min and 1 h, be Danish-speaking, be cognitively coherent and give informed consent. No patients had been previously treated by specialists in palliative care. Patients should consent that the carer participated; then patients chose the person whom they wished to participate. Carers should be 18 years or older, give informed consent and be cognitively coherent.

Inclusion procedure

DG attended the referral visits. When a patient met the inclusion criteria, DG informed the patient and carer about the study; it was stressed that participation was voluntary. They received written information and were asked to consider their participation until the next day when DG contacted them by telephone.

Participants and non-participants

From July 2000 until June 2001 and September–December 2002 (15 months in total), DG attended 33 referral visits where 16 patients met the inclusion criteria for the study (Fig. 1). Nine patients and six carers participated in the first interviews, which were conducted before the home conference in the participant's home. Six patients and five carers participated in the second interviews, which were 2–4 weeks after the home conference. Two patients were hospitalised and their only experience with the home-care team was the home conference. The others received at least one additional visit from the home-care team. In total, 26 interviews were conducted. Interviews with two patients, and one carer were conducted as pilot interviews;

a second interview was not planned. However, the pilot interviews concerned similar issues as the other interviews and were, therefore, included in the analysis.

Initially, we wanted to sample to gain maximum variation concerning sex and cohabitant status. However, due to the slow inclusion rate, we did not exclude any eligible patients and thus got a convenience sample [53]. The participants were disparate: four men and five women, and three lived alone. Patients were 55–88 years old (median 69) and had been diagnosed with cancer 1–79 months (median 11) previously. Three lived less than 2 months after being informed about the study. Participating patients lived longer (mean 4.3 months) than non-participants (mean 1.6 months, information available for 9/12 non-participants). The carers comprised three wives, one husband and two daughters. Participants were from all occupational social classes [20]. Table 1 shows characteristics of participants and details of the second interviews.

Interviews

Semi-structured, individual interviews based on interview guides were conducted by DG as described by Kvale [37]. The interview guides were based on WHO's definition of palliative care [69]. As we were not aware of any specific theories concerning patients and carers' expectations to and evaluation of palliative care, the study was explorative [50]. Summaries and questions regarding the interviewer's understanding of what the participants had said were used to validate the interview while it was ongoing. No patient or carer overheard the interview with their relative.

In the first interview, participants were asked to recount the patient's case history, describe the problems related to the illness, and express their expectations to the home-care team. The second interview was based on the participant's answers in the first interview, i.e. questions focussed on problems and expectations described in the first interview. Initial questions were broad, allowing the participants to describe areas they had not mentioned in the first interview. Equally, the first question regarding the evaluation of the home-care team was broad: for example, "please describe your experiences with the home-care team". The partici-

Fig. 1 Participants and attrition. **a** Reasons not to ask: two patients were too hoarse, one had language difficulties, one was moribund and one was confused. **b** Patients' reasons for declining participation: four did not have energy to participate, two were hospitalised and one did not want the interview to be tape-recorded. **c** Reasons why carer did not participate: one declined participation, one patient did not want the carer to be asked and one carer suffered from dementia

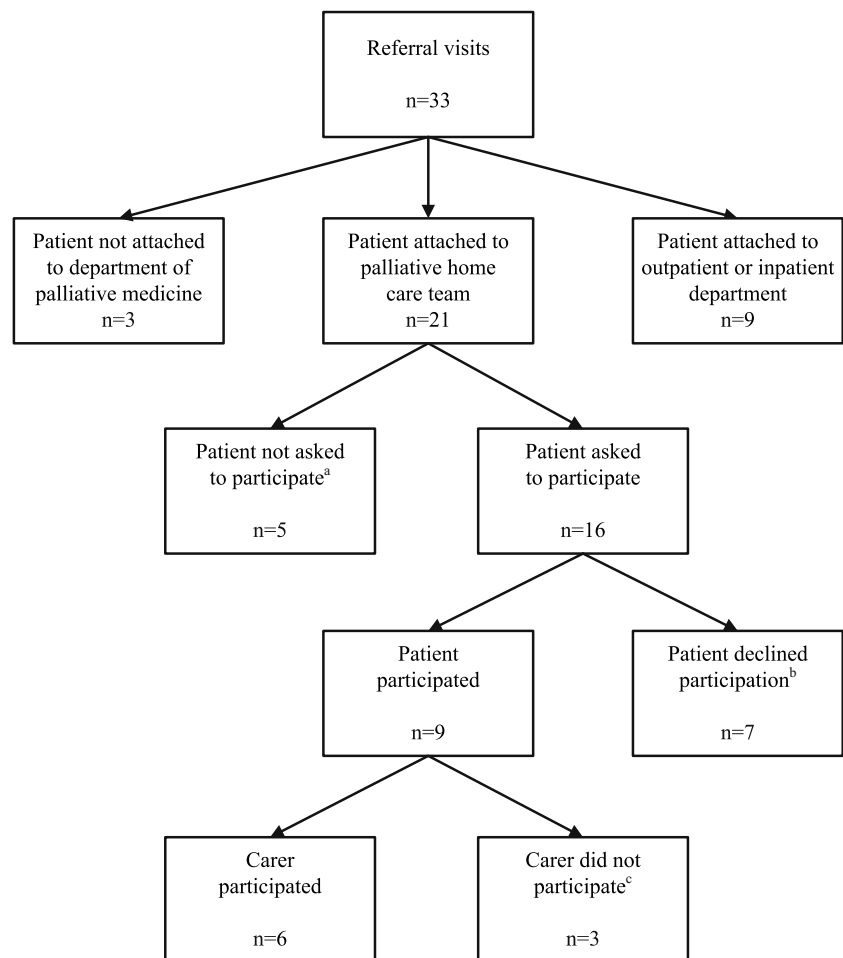


Table 1 Characteristics of participants and details about the second interview

	Patients n=9	Carers n=6
Women	5	5
Lives alone	3	–
Age at interview:		
30–39	–	1
50–59	2	2
60–69	3	2
70–79	3	1
80–89	1	0
Relationship to patient:		
Spouse	–	4
Daughter	–	2
Occupational social class ^a		
Class I	1	0
Class II	2	1
Class III	2	1
Class IV	2	1
Class V	2	2
Class VII	0	1
Months since cancer diagnosis:		
≤3	4	–
4–12	1	–
13–24	3	–
≥25	1	–
Months from survey information to death:		
<1	2	–
1–2	1	–
>2	6	–
Place of second interview:		
Home	5	4
Hospital	1	1
Not conducted ^b	3	1

^aOccupational social class: class I (high)–class V (low); class VII—outside classification, for example, housewives

^bOne patient had died. The second interview with two patients and one carer was not planned (see text for details)

patients were then asked to elaborate on positive and negative effects of the contact with the team. Finally, specific questions about the organisation of the home-care team were asked (for example, concerning waiting time for referral to the team and 24-h coverage). Interviews lasted between 15 and 90 min. All interviews were tape-recorded and confidentiality was ensured.

Transcription of interviews

Two interviews were transcribed by DG; the others were transcribed by the same secretary who received detailed oral and written instructions on how to do the transcrip-

tions. Subsequently, the transcriptions were corrected twice (by a research assistant and DG) by reading the transcriptions while listening to the tape recording.

Analysis

The level of interpretation in the analyses concentrated on finding key themes that could shed light on the expectation to and evaluation of the home-care team. These themes were further analysed with Template Analysis [10, 34]. New categories were made whenever significant statements could not be classified according to the existing codebook. After coding all interviews, the most significant categories were compared with the interviews to detect statements that should or should not be classified in the specific category. To further increase the validity of the analysis, DG conducted a peer debriefing [38] with five other peers: two medical doctors (LS, MG), a psychologist, a philosopher and a historian (UC). In this debriefing, the codebook and the categorisation of the statements in the main categories ‘expectations’ and ‘evaluation’ were discussed. This resulted in sub-categorisation of these categories.

Quotations from the interviews, which were conducted in Danish, were translated into English by a professional language consultant. Emphasis was on semantic equivalence rather than direct translation [44]. Quotations are selected to include statements that fulfilled one of these criteria: typical/average, extraordinary or containing ideas for improvement of the palliative home-care team. The analysis was made using the qualitative data analysis program NVivo 2.0 [1].

The interview guide was developed by DG, LS, MG and AK, while the analysis was conducted by DG, LS and UC. All authors have commented on the drafts and accepted the final manuscript. The Scientific Ethical Committees of Copenhagen and Frederiksberg municipalities and the Danish Data Protection Agency approved the study.

Results

All themes have been analysed to identify differences and similarities between patients and carers as groups, as well as between the individual pair of patient and carer. No themes showed more importance to one group than the other. Therefore patients and carers are described as one group and referred to as ‘participants’.

Expectations to the home-care team

The expectations concerned four main categories: *specialised knowledge*, *sense of security*, *respite for carers* and *offering activities*.

All participants expected to receive access to *specialised knowledge* from the home-care team, and most (14/15) mentioned this as a reason for wanting contact with the team. Receiving the best possible pain management was very important, while treatment for other symptoms was seldom mentioned. It was also important that the team had experience with these patients and knew what to do. A wife who took care of her 55-year-old husband at home said:

What I would like is some people who look at things differently to the way I do—people who are used to seeing cancer patients and who have the right, what shall we say, attitude to what should be done. (Carer 4)

Some carers worried about how they would react when the patient was close to death or had died, and they hoped to receive help from the home-care team so that they would be able to handle the situation better.

The importance of feeling secure was mentioned by 14/15 participants. Some had experienced feeling insecure at home because when they needed medical attendance outside office hours; they had had to call the doctor's out-of-hours clinic and they would have been seen by a doctor who did not know them. A 75-year old man said:

I have no one to turn to. The times I've phoned the night doctors, they come and they are very nice and say "Well, but you've got the complete repertoire here!" I've also got Ketogan [an opioid], I have it all. And the doctors say, all I have to do is to sit up and take my pills. Sometimes they've helped, sometimes they haven't. (...) But I can tell you, I feel completely powerless. I have really been booted home. (Patient 8)

Most participants expected their sense of security to improve due to the contact to the home-care team, because they could contact the home-care team by telephone and get advice from people who knew them and had specialised knowledge about their problems. However, it was also very important that the participants knew where they would be hospitalised if this was needed. A 55-year-old man described how he had experienced discussion about where he should be admitted:

The talk—I can't manage that at all in these situations; it makes my condition worse, both physically and mentally: to hear the telephone conversation between the hospital and my wife about whether the ambulance people should take me here or there. It's things like this that I really wish were totally clear. (Patient 4)

It was very important that the home-care team was part of a specialised department with inpatient beds so that patients could be hospitalised there if needed. For some participants, including all patients living alone, this

possibility was a very important reason for wanting referral to the home-care team.

Some patients and carers wished the home-care team would offer the carers *respite*. This could take different forms: offering someone to stay with the patient for a few hours, night sitters or hospitalising the patient for a few days.

A few participants wished the patient could be *offered activities*, such as being taken for a walk or to a day-care centre.

Evaluation of the home-care team

The evaluation focussed on five main categories. Four of these were the same categories that had been mentioned in the first interview regarding expectations: *specialised knowledge*, *sense of security*, *respite for carers* and *offering activities*. The last category, *organisation*, focussed on how the participants evaluated the organisation of this specific team.

The participants had only positive statements regarding the home-care team's *specialised knowledge*, and most mentioned decrease in symptom severity. Some also mentioned that they valued the home-care team's attention to all symptoms and their willingness to change treatments. This also meant that the participants' felt that the home-care team listened to what they said and took their wishes seriously, which was important to their sense of security.

The patient's attachment to the home-care team did improve most participants' *sense of security*. As in the first interview, the participants in their evaluation expressed the importance of being able to contact the team, if needed. One woman said:

Now I feel safe if something happens. I know I can turn to you. (Patient 7)

However, a 56-year-old patient did not feel that the attachment to the home-care team offered him the security he needed. He had lived alone and felt secure only because he had been admitted for inpatient care:

I've found security by coming here [inpatient ward], which was what I needed. And there are also people here who are very nice and take their time to talk about everything. So this is very good. But the conversation and the security, well, you could have the conversation at home if someone came by sort of regularly. But the security, well, that might just slip a bit. Because the staff couldn't be there everyday. (Patient 3)

Another patient did feel that the home-care team offered him the security he needed, but he doubted the district nurses' capability of managing his syringe driver. He described a situation in his home where the home-care team

had taught the district nurses how the syringe driver worked:

I shouldn't have been involved at all. I feel, well, I would have felt more secure if I hadn't heard some of the conversations; for example, "Is this supposed to be here?", "Are you sure this is right?", "Could you just come, I wrote something wrong on the pump". "Don't start doubting about anything, because what's in it is right". Why should I be involved in that? I don't understand it. If it had been a situation where experience showed that something could happen, which I could manage myself, then I could have been given information about what to do. (Patient 4)

The home-care team did not offer *respite for carers or activities*. The participants who had wished to be offered this acknowledged that this was not offered, but they did not express any discontent, although remarks were passed on the matter. One patient said:

I think it would boost things a bit, if there was a break—that would make her endure it a bit longer, making things work a little better. (Patient 6)

In general, the way this home-care team was *organised* worked well from the point of view of patients and carers. Generally, the waiting time of 1 week for referral visits and another week for the home conference was perceived as reasonable. Some participants wished the home-care team could visit during the night, and all thought the team should be accessible by telephone 24 h a day. Some found that too many people took part in the home conference. No participants described counteraction between the home-care team and the GP or district nurse. Some participants thought that the home-care team should consist of more professional groups (for example physiotherapists and psychologists).

Discussion

The goal of this longitudinal, prospective study was to investigate patients' and carers' expectations to and evaluation of a palliative home-care team.

The overall results showed that the participants expected to receive and experienced access to specialised palliative knowledge and improvements in the sense of security. Most did evaluate their contact with the team positively. Some wished to be offered respite for carers and activities for the patients, which was not offered by the home-care team.

As previously described, we analysed the material for differences and similarities between the groups of carers and patients. However, we did not find any themes more important to one group than the other. Studies comparing

patients' and carers' ratings have shown good agreement on factual information, whereas agreement on, for example, pain, feelings and thoughts is poorer [43]. Our study concerns expectations and evaluations and not factual ratings, and the results, therefore, cannot be directly compared. Nonetheless, our study shows that patients and carers value the same aspects of palliative care. This is an important finding because palliative home care can be organised to serve the needs of the patients, as well as the carers, as described in WHO's definition of palliative care [69].

All participants expected to receive access to specialist knowledge in palliative care. In a paper focusing on primary palliative care, carers described GPs' failure to control symptoms [17]. Others report that participants value the knowledge that specialist palliative home-care teams possess [32, 49]. Many participants in our study experienced reduction in the severity of the patients' symptoms. This is very encouraging and supports the results from a longitudinal questionnaire study from our department, which showed significant alleviation of: pain, lack of appetite, nausea/vomiting, insomnia and constipation and improvement in overall quality of life [65].

Sense of security was the second very important issue that participants expected from their attachment to the team. To feel secure at home, the patients and carers had to know that they could get in contact with specialists who knew them 24 h a day, and they had to know where the patient could be hospitalised. Despite this being so important, most palliative teams in Denmark do not offer this [15]. Others have similarly reported that participants find accessibility of health-care professionals very important in palliative home care [17, 26, 28, 29, 41, 46, 48, 49, 54, 67].

The participants expected that the home-care team would help the carers, for example, by offering respite. Other studies have also shown that carers needed time to themselves [6, 7, 21, 29, 41, 46, 56, 67], although the impact of respite on carers is yet to be established [31].

The participants neither described cooperation nor counteraction between the primary health-care professionals and the home-care team. It has previously been found that participants mentioned cooperation only when it did not succeed [28]. The results from our parallel questionnaire study showed that 89% of GPs and district nurses were satisfied with the cooperation with the home-care team [16]. Thus, the cooperation between the home-care team and the GPs/district nurses seemed to have succeeded, as no patients or carers reported counteraction.

The effect of expectations on satisfaction as an element of evaluation

To our knowledge, no theory of the connection between expectations and evaluations exists, but there are several

theories about the connection between expectations and satisfaction [39, 40]. However, some authors have highlighted that health-care experiences are not always expressed in terms of satisfaction [13, 62]. Studies specifically focussing on satisfaction with palliative care have found that the Discrepancy Theory (referred in [35, 39, 40, 45]) can account for 29–72% of variance in care satisfaction [35, 45]. Equally, Staniszewska and Ahmed [62] concluded that ‘the evidence for a relationship between expectations and satisfaction remains mixed, with some studies indicating that no relationship exists, while other studies suggest that expectations do have some effect on satisfaction’. They describe that patients are able to distinguish between ideal and realistic expectations of care. In our study, no participants expected the home-care team to cure the patients from their disease, neither did any participants express discontent, because the home-care team did not offer respite for carers or activities for patients. This probably reflects that the participants in our study viewed such wishes as unrealistic. Cure is no longer seen as an option, and respite for carers, as well as activities for patients, might after all be accepted as functions of the private social network rather than the public health-care system.

Feasibility, strengths and limitations

Conducting prospective, longitudinal studies that include palliative-care patients is difficult but nonetheless feasible. Only nine of the 21 patients who were attached to the home-care team were interviewed. Non-participation was mainly due to medical reasons, reflecting the advanced illness of patients referred to the department. Participating patients lived longer than non-participating patients. However, we interviewed three patients who lived less than 2 months from the referral visit and, therefore, we have information from patients close to death. Only one carer was male. Most other studies also have a majority of female carers [7, 17, 21, 24, 26, 29, 30, 33, 41, 45, 47–49, 54, 56, 61, 63, 67]. A study showed that the majority (71%) of carers are women and that male carers report lower caregiver strain and rarely mention their own struggle [14].

We included only patients older than 50 years, because 89% of patients attached to the department are above this age, and also we wanted to avoid focussing on the needs in families with young children.

We conducted 26 interviews with 15 different participants. This number of interviews enables a thorough knowledge of the study group [42]. The number of participants lies within the proposed range of 5–20 participants [36]. All participants were attached to the same home-care team and, therefore, we are unable to evaluate different models of organisation of palliative home care. It is a strength that the participants were

interviewed before the home conference [39], because their expectations to the home-care team, therefore, were not influenced by what the home-care team offered.

The Danish health-care system is characterised by a high level of public financing, a sharp organisational and functional division between primary health care and the hospital sector, and within primary health care between general practice and district nursing, and by about 98% of the citizens being connected to a specific GP [51]. The results from this study are, therefore, most easily transferred to countries with health-care systems resembling the Danish health-care system. However, the specific organisation of the health-care system probably does affect the patients’ and carers’ wish for extensive palliative care knowledge and flexible attachment to a palliative home-care team with a 24-h coverage, and, consequently, some results can be transferred also to countries where the health-care system differs from the Danish health-care system.

To our knowledge, this is the first prospective, longitudinal study where patients and carers have been interviewed before and during attachment to a palliative home-care team. We chose qualitative interviews because we wanted detailed descriptions of the participants’ expectations to and evaluations of the home-care team, and because most patients would not have had the energy to give this, for example, in a questionnaire. We consider this combination of design and methodology ideally suited for the research question of this study.

Conclusions and implications

This study shows that the participants found a great need for a palliative home-care team and that they valued the team being an integrated part of the department of palliative medicine. This meant that they could be attached to the unit (inpatient, outpatient or palliative home care) that best served their needs. The palliative care team members must have specialised palliative knowledge, the attachment to the team should be flexible, the possibility of contacting the team by telephone 24 h a day should be maintained and, preferably, be supplemented by a 24-h on-call service by the home-care team. The home-care team should ensure that primary health-care professionals receive any necessary training before visiting patients in their homes.

Acknowledgements Patients and carers are thanked for their time and interest in the study, Anna Thit Johnsen and Anne Gammelgaard for participating in the peer debriefing and Pia Hoej Christiansen for transcribing the interviews. The study was supported by grants from the Danish Cancer Society (no. 99 150 05), Else and Aage Groenbech-Olsens Foundation, Augustinus Foundation, Beckett-Foundation and M. Brogaard and Spouse Recollection Foundation.

References

1. (2002) NVivo qualitative data analysis program. Version 2.0. QSR International, Melbourne, Australia
2. Abu-Saad HH (2000) Palliative care: an international view. *Patient Educ Couns* 41:15–22
3. Ahlner-Elmqvist M, Jordhoy MS, Jannert M, Fayers P, Kaasa S (2004) Place of death: hospital-based advanced home care versus conventional care. A prospective study in palliative cancer care. *Palliat Med* 18:585–593
4. Appelin G, Bertero C (2004) Patients' experiences of palliative care in the home: a phenomenological study of a Swedish sample. *Cancer Nurs* 27:65–70
5. Armes PJ, Addington-Hall JM (2003) Perspectives on symptom control in patients receiving community palliative care. *Palliat Med* 17:608–615
6. Axelsson B, Sjoden PO (1998) Quality of life of cancer patients and their spouses in palliative home care. *Palliat Med* 12:29–39
7. Brobäck G, Berterö C (2003) How next of kin experience palliative care of relatives at home. *Eur J Cancer Care* 12:339–346
8. Bruera E, Sweeney C (2002) Palliative care models: international perspective. *J Palliat Med* 5:319–327
9. Costantini M, Higginson IJ, Boni L, Orengo MA, Garrone E, Henriquet F, Bruzzi P (2003) Effect of a palliative home care team on hospital admissions among patients with advanced cancer. *Palliat Med* 17:315–321
10. Crabtree BF, Miller WL (1999) Using codes and code manuals. A template organizing style of interpretation. In: Crabtree BF, Miller WL (eds) *Doing qualitative research*. Sage, Thousand Oaks, pp 163–177
11. Critchley P, Jadad AR, Taniguchi A, Woods A, Stevens R, Reyno L, Whelan TJ (1999) Are some palliative care delivery systems more effective and efficient than others? A systematic review of comparative studies. *J Palliat Care* 15:40–47
12. Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AG, Hood K, Douglas HR, Normand CE (2002) Palliative care in hospital, hospice, at home: results from a systematic review. *Ann Oncol* 13(Suppl 4):257–264
13. Fitzpatrick R, Hopkins A (1983) Problems in the conceptual framework of patient satisfaction research: an empirical exploration. *Sociol Health Illn* 5:297–311
14. Fromme EK, Drach LL, Tolle SW, Ebert P, Miller P, Perrin N, Tilden VP (2005) Men as caregivers at the end of life. *J Palliat Med* 8:1167–1175
15. Goldschmidt D (2006) Evaluation of palliative home care: views of patients, carers, general practitioners and district nurses. Ph.D. thesis. University of Copenhagen, Denmark
16. Goldschmidt D, Groenvold M, Johnsen AT, Stromgren AS, Krasnik A, Schmidt L (2005) Cooperating with a palliative home-care team: expectations and evaluations of GPs and district nurses. *Palliat Med* 19:241–250
17. Grande GE, Farquhar MC, Barclay SI, Todd CJ (2004) Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions. *Br J Gen Pract* 54:772–778
18. Gyllenhammar E, Thoren-Todoulos E, Strang P, Strom G, Eriksson E, Kinch M (2003) Predictive factors for home deaths among cancer patients in Swedish palliative home care. *Support Care Cancer* 11:560–567
19. Hanks GW, Robbins M, Sharp D, Forbes K, Done K, Peters TJ, Morgan H, Sykes J, Baxter K, Corfe F, Bidgood C (2002) The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *Br J Cancer* 87:733–739
20. Hansen EJ (1984) Social classes in Denmark [Danish]. The Danish National Institute of Social Research, Copenhagen
21. Harding R, Higginson I (2001) Working with ambivalence: informal caregivers of patients at the end of life. *Support Care Cancer* 9:642–645
22. Harding R, Higginson IJ (2003) What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 17:63–74
23. Hearn J, Higginson IJ (1998) Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliat Med* 12:317–332
24. Higginson I, Wade A, McCarthy M (1990) Palliative care: views of patients and their families. *BMJ* 301:277–281
25. Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A, Douglas HR, Normand CE (2003) Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 25:150–168
26. Hinton J (1994) Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliat Med* 8:183–196
27. Hinton J (1994) Which patients with terminal cancer are admitted from home care? *Palliat Med* 8:197–210
28. Hinton J (1996) Services given and help perceived during home care for terminal cancer. *Palliat Med* 10:125–134
29. Hudson P, Aranda S, McMurray N (2002) Intervention development for enhanced lay palliative caregiver support—the use of focus groups. *Eur J Cancer Care (Engl Ed)* 11:262–270
30. Ingleton C (1999) The views of patients and carers on one palliative care service. *Int J Pall Nurs* 5:187–195
31. Ingleton C, Payne S, Nolan M, Carey I (2003) Respite in palliative care: a review and discussion of the literature. *Palliat Med* 17:567–575
32. Jarrett N, Payne S, Turner P, Hillier R (1999) 'Someone to talk to' and 'pain control': what people expect from a specialist palliative care team. *Palliat Med* 13:139–144
33. Jarrett NJ, Payne SA, Wiles RA (1999) Terminally ill patients' and lay-carers' perceptions and experiences of community-based services. *J Adv Nurs* 29:476–483
34. King N (2004) Using templates in the thematic analysis of text. In: Cassell C, Symon G (eds) *Essential guide to qualitative methods in organizational research*. Sage, London, pp 256–270
35. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E (1996) Family members' perceptions of palliative cancer care: predictors of family functioning and family members' health. *J Palliat Care* 12:10–20
36. Kuzel AJ (1999) Sampling in qualitative inquiry. In: Crabtree BF, Miller WL (eds) *Doing qualitative research*. Sage, Thousand Oaks, pp 33–45
37. Kvale S (1994) Interview: en introduktion til det kvalitative forskningsinterview [Danish]. Hans Reitzels Forlag, Copenhagen
38. Lincoln Y, Guba E (1999) Establishing trustworthiness. In: Bryman A, Burgess RG (eds) *Qualitative research*. Sage, London, pp 397–414
39. Linder-Pelz S (1982) Social psychological determinants of patient satisfaction: a test of five hypotheses. *Soc Sci Med* 16:583–589
40. Linder-Pelz SU (1982) Toward a theory of patient satisfaction. *Soc Sci Med* 16:577–582

41. Low J, Perry R, Wilkinson S (2005) A qualitative evaluation of the impact of palliative care day services: the experiences of patients, informal carers, day unit managers and volunteer staff. *Palliat Med* 19:65–70
42. Malterud K (2001) Qualitative research: standards, challenges, and guidelines. *Lancet* 358:483–488
43. McPherson CJ, Addington-Hall JM (2003) Judging the quality of care at the end of life: can proxies provide reliable information? *Soc Sci Med* 56:95–109
44. Meadows K, Bentzen N, Touw-Otten T (1996) Cross-cultural issues: an outline of the important principles in establishing cross-cultural validity in health outcome assessment. In: Hutchinson A, Bentzen N, König-Zahn C (eds) *Cross cultural health outcome assessment; a user's guide*. European Research Group on Health Outcomes, Ruinen, pp 34–40
45. Medigovich K, Porock D, Kristjanson LJ, Smith M (1999) Predictors of family satisfaction with an Australian palliative home care service: a test of discrepancy theory. *J Palliat Care* 15:48–56
46. Milberg A, Strang P (2000) Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions. *Palliat Med* 14:533–534
47. Milberg A, Strang P (2003) Meaningfulness in palliative home care: an interview study of dying cancer patients' next of kin. *Palliative and Supportive Care* 1:171–180
48. Milberg A, Strang P (2004) Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers. *Psychooncology* 13:605–618
49. Milberg A, Strang P, Carlsson M, Borjesson S (2003) Advanced palliative home care: next-of-kin's perspective. *J Palliat Med* 6:749–756
50. Miller WL, Crabtree BF (1999) Clinical research: a multimethod typology and qualitative roadmap. In: Crabtree BF, Miller WL (eds) *Doing qualitative research*. Sage, Thousand Oaks, pp 3–30
51. Ministry of the Interior and Health (2002) *Health care in Denmark*. The Ministry of the Interior and Health, Copenhagen
52. Mitchell GK (2002) How well do general practitioners deliver palliative care? A systematic review. *Palliat Med* 16:457–464
53. Patton MQ (1987) Designing qualitative evaluations. In: *How to use qualitative methods in evaluation*. Sage, Newbury Park, pp 44–69
54. Payne S, Smith P, Dean S (1999) Identifying the concerns of informal carers in palliative care. *Palliat Med* 13:37–44
55. Peruselli C, Di Giulio P, Toscani F, Gallucci M, Brunelli C, Costantini M, Tamburini M, Paci E, Miccinesi G, Addington-Hall JM, Higginson IJ (1999) Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliat Med* 13:233–241
56. Proot IM, Abu-Saad HH, Crebolder HF, Goldsteen M, Luker KA, Widdershoven GA (2003) Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci* 17:113–121
57. Proot IM, Abu-Saad HH, ter Meulen RH, Goldsteen M, Spreuwenberg C, Widdershoven GA (2004) The needs of terminally ill patients at home: directing one's life, health and things related to beloved others. *Palliat Med* 18:53–61
58. Raynes NV, Leach J, Rawlings B, Bryson RJ (2000) Palliative care services: views of terminally ill patients. *Palliat Med* 14:159–160
59. Salisbury C, Bosanquet N, Wilkinson EK, Franks PJ, Kite S, Lorentzon M, Naysmith A (1999) The impact of different models of specialist palliative care on patients' quality of life: a systematic literature review. *Palliat Med* 13:3–17
60. Seymour J, Ingleton C, Payne S, Beddow V (2003) Specialist palliative care: patients' experiences. *J Adv Nurs* 44:24–33
61. Stajduhar KI, Davies B (2005) Variations in and factors influencing family members' decisions for palliative home care. *Palliat Med* 19:21–32
62. Staniszewska S, Ahmed L (1999) The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? *J Adv Nurs* 29:364–372
63. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulskey JA (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284:2476–2482
64. Stromgren AS, Groenvold M, Petersen MA, Goldschmidt D, Pedersen L, Spile M, Irming-Pedersen G, Sjogren P (2004) Pain characteristics and treatment outcome for advanced cancer patients during the first week of specialized palliative care. *J Pain Symptom Manage* 27:104–113
65. Stromgren AS, Sjogren P, Goldschmidt D, Petersen MA, Pedersen L, Hoermann L, Groenvold M (2005) A longitudinal study of palliative care. *Cancer* 103:1747–1755
66. Tang ST (2003) When death is imminent: where terminally ill patients with cancer prefer to die and why. *Cancer Nurs* 26:245–251
67. Wennman-Larsen A, Tishelman C (2002) Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scand J Caring Sci* 16:240–247
68. Wilkinson EK, Salisbury C, Bosanquet N, Franks PJ, Kite S, Lorentzon M, Naysmith A (1999) Patient and carer preference for, and satisfaction with, specialist models of palliative care: a systematic literature review. *Palliat Med* 13:197–216
69. World Health Organization (2002) *National Cancer Control Programmes. Policies and managerial guidelines*. World Health Organization, Geneva