

# Perceptions of terminally ill patients and family members regarding home and hospice as places of care at the end of life

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**Perceptions of terminally ill patients and family members regarding home and hospice as places of care at the end of life**

To enable demand-based palliative care, it is important to know the perceptions of terminally ill patients and their family members regarding home and hospice as places of care at the end of life. Eight women and five men suffering from cancer and with a life expectancy of 3 months or less were interviewed. In each case one of the family members was also interviewed. Four patients spent their last phase of life at home, nine in a hospice. This paper provides further insight in the patient perspective in palliative care. The results reveal that a cohabiting partner seems an important prerequisite for terminally ill patients to stay at home. For spouses it is an obvious choice to facilitate the patients' stay at home, even when it becomes too demanding, something not discussed between spouse and patient. When sufficient care at home seems impossible and the negotiation between patients and family members results in the opinion that living at home is no longer an option, it is decided that the patient moves to a hospice. The choice for the specific setting of the patients' new residence seems to be random; one possibility is pointed out to them and seems appropriate.

*Keywords:* patient perspective, home, hospice, end of life, palliative care, interviews.

## INTRODUCTION

Palliative care is aimed at improving the quality of life of patients and their families and therefore goes beyond biomedical issues. As well as the prevention and relief of pain and other distressing symptoms, early identification and treatment of problems in the physical, psychosocial and spiritual domain are important in the last phase of life (World Health Organization 2009). Currently a shift from supply-driven to demand-based approaches in the care sector can be discerned. Nowadays care organisations are encouraged to take the demands of their patients as a basis for their care provision (McLaughlin & Kaluzny 2000, Van

der Kraan & Van der Grinten 2004; Bosselaar 2005, Rijckmans 2005; De Gooier 2007), including palliative care. To enable demand-based palliative care it is essential to comprehend perceptions of terminally ill patients and their families regarding the place of care at the end of life.

The scant literature reveals that terminally ill patients are irritated by several aspects of hospital visits and stays (Raynes *et al.* 2000; Addington-Hall & O'Callaghan 2009), value living at home, especially due to the possibility of continuing everyday life together with family and friends (Appelin & Berterö 2004), and at the same time are eager to ease the burden on their family (Raynes *et al.* 2000; Proot *et al.* 2004; Kaldjian *et al.* 2009). Furthermore, terminally ill patients want to be in control of their own life and health care and things related to those they love (Proot *et al.* 2004). In addition, feelings of safety are of utmost importance for terminally ill patients at home (Goldschmidt *et al.* 2006). Based on interviews with older people receiving municipal care six categories can be

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revealed encompassing the experience of aspects that constitute a good life in the last phase of life: (1) maintaining dignity; (2) enjoying small things; (3) feelings of 'being at home'; (4) being in the hands of others, trying to adjust; (5) still being important to other people; and (6) completing life while facing death (Andersson *et al.* 2008).

Knowledge about what is important to terminally ill patients is now deduced mainly from the perspective of (healthy) elderly people (Gott *et al.* 2004; Andersson *et al.* 2008; Gott *et al.* 2008), family members (Addington-Hall & O'Callaghan 2009), or literature review (Kaldjian *et al.* 2009), and therefore remains somewhat superficial, fragmented and limited. When terminally ill patients themselves are studied, the focus is rarely on their perceptions. We therefore focus on the perceptions of terminally ill patients and their family members regarding their place of care at the end of life. We limited our study to home and hospice as places of care. Although most people prefer to die at home in their own safe environment (Agar *et al.* 2008; Grande & Ewing 2008), this is realised by only a small proportion of people who do not die suddenly, e.g. 22% of people dying of cancer in England and Wales (Gomes & Higgingson 2008) and 32% of Dutch persons dying of a chronic disease [such as cancer (52%), stroke (13%), dementia (10%), COPD and heart failure (8%)] (Van der Velden *et al.* 2007, Van der Velden *et al.* 2009) died at home. When living at home is no longer an option, there are several specialised facilities. In the 80s of the 20th century inpatient hospices came to existence in the Netherlands, and nowadays represent a considerable share of the facilities and available beds specialised in palliative care. A low care hospice is a small scale facility (three beds on average) which strives for a home-like atmosphere. These facilities are managed completely by volunteers, while professionals, such as a general practitioner or home help, who were involved in the caregiving at home, remain involved. A high care hospice is larger than a low care hospice, but still a small-scale facility (six beds on average) with volunteers and professionals in employ, taking care of terminally ill patients (Mistiaen & Van Ruth 2006; Van den Akker *et al.* 2006). Moreover, in hospices living and dying are of equal importance and these facilities are supposed to represent the best of palliative care (Addington-Hall & O'Callaghan 2009; Grande 2009). The central research question in this paper is therefore:

What are the perceptions of terminally ill patients and their family members regarding home and in-patient hospice as places of care at the end of life?

The study was conducted in the Dutch health care system in which the starting point is that everyone has

access to care, preferably as close to home as possible. General palliative care is the aim; general care organisations, such as home-care organisations, care or nursing homes, but also general practitioners should have the facilities to provide adequate palliative care. Out of eight Comprehensive Cancer Centres, consultation teams support regional and local care organisations in providing palliative care at home or in the institution by giving advice and enhancing their knowledge and competence (Mistiaen & Van Ruth 2006; Comprehensive Cancer Centres 2010). To support family members in their care for a terminally ill patient at home, in the Netherlands volunteers in palliative care can be called in to give care, time, attention and support to terminally ill patients and their family members. Volunteers thus enable family members to rest, renew their energy and continue providing care for as long as possible (Luijkx & Schols 2009).

When living at home is no longer an option there are several facilities specialised in palliative care, such as inpatient hospices and palliative units at nursing homes or in hospitals (Mistiaen & Van Ruth 2006). In the Dutch health care system, the same criteria hold for the financing of both palliative care at home and palliative care in a hospice. Either the general practitioner or medical specialist determines a life expectancy of 3 months or less. According to the wishes of the patient and family members an indication 'palliative care without residence' to stay at home or go to a hospice is given, or an indication 'palliative care with residence' to go to a palliative unit of a care or nursing home (Ministry of Health, Welfare and Sport 2010).

## METHOD

To comprehend the perceptions of terminally ill patients and their family members regarding home and hospice a qualitative study has been conducted by means of face-to-face interviews with patients having a life expectancy of 3 months or less, determined by either a general practitioner or a specialist. As has been said, such a short life expectancy is a condition for receiving palliative care at home or in an inpatient hospice (Ministry of Health, Welfare and Sport 2010). We did not determine the actual date of death. As well as the patient, one of the family members was also interviewed because palliative care aims to support both the patient and their family (World Health Organization 2009), and the opinion of family members seems to influence the opinion and actions of terminally ill patients and vice versa (Casarett *et al.* 2004, Gomes & Higgingson 2006, Grande & Ewing 2008). The patient and his/her family members were approached as a system.

**Table 1.** Characteristics of the thirteen respondents

Patient	Place of residence	Marital status	Family member	Age patient	Social support	Interview
Mrs P.	Home	Married	Spouse	65	One married son	Together
Mrs B.	Home	Married	Spouse	64	One daughter, one son, both married	Together
Mrs Ma	Home	Partner relationship	Female partner	51	Family	Together
Mr Mo	Home	Married	Spouse	70	Three married sons	Together
Mrs P.	Low care hospice U	Widow	Daughter	76	One married daughter	Separate
Mrs S.	Low care hospice U	Spouse has dementia	Spouse	78	No children	Separate
Mrs Va.	Low care hospice K	Injured spouse	Spouse	59	None; son and daughter do not provide support	Together
Mrs A.	Low care hospice C	Widow	Daughter	82	One daughter, two sons, all married	Separate
Mr R.	High care hospice S	Widowed	Son	71	Two sons	Together
Mr P.	High care hospice S	Widowed	Son	70	One son, one daughter	Separate
Mr A.	High care hospice S	Widowed	Daughter	71	Three children	Separate
Mrs X.	High care hospice B	Single	Friend	80	Friends	Separate
Mr C.	High care hospice B	Separate household	Partner	69	Friend, family	Separate

To enable comparison of perceptions regarding home and hospice, this study includes people spending their last phase of life *at home* and in a *hospice*. Due to the cooperation of a manager of a home-care organisation, a general practitioner and five coordinators of inpatient hospices, four terminally patients at home, four terminally ill patients in three low care hospices and five respondents in two high care hospices could be included in the study. Medical-ethics approval was not necessary since particular treatments or interventions were not offered or withheld from respondents as a consequence of participating in the study (this being the main criterion in medical-ethical procedures in the Netherlands) (Central Committee on Research Involving Human Subjects 2010). Nevertheless, we did consider our ethical responsibility to the patients we wanted to include in our study. First, only patients who were capable to make decisions were kindly invited to voluntarily participate in the study. We agreed with the professional caregivers and volunteers who approached the potential respondents first, not to pressure patients to participate in the study. Terminally ill patients could therefore decide for themselves whether the benefits, such as someone who listens to you, would counterbalance the costs of being interviewed. Second, potential respondents were informed about (the aim and method of) the study by the professional caregivers or volunteers who approached them, and again by the interviewer at the beginning of the interview. Moreover, the interviewer emphasised that the respondent was free to refuse to answer a question and to end the interview at any time. All respondents gave their informed consent verbally. Besides, the interviewers were sensitive to signals of emotional or physical exhaustion and terminated the interview when necessary. Finally, the interviewers knew, in each setting, who

to contact in case the patient or family member became too distressed.

Three experienced interviewers conducted the face-to-face interviews with thirteen terminally ill patients. We aimed to interview the family member separately, but in six cases patients preferred to be interviewed together with their spouses (4 times at home, once in a hospice) or son (once in a hospice), which of course was respected by the interviewer. The other six family members were interviewed separately: one patient said an acquaintance took care of her and she did not want to burden him with a request for an interview. The interviewers used a topic list focusing on the experience and perceptions of the present place of residence and the choice of a specific place of residence, in addition to personal characteristics such as age and family situation. The illness and the course of it were addressed as briefly as possible, since biomedical issues were not central in this social scientific study. Not the topic list, but the respondents determined the order of the questions; the interviewers encouraged the respondents to tell their story and chiefly encouraged them to elaborate further on specific topics. The interviews were tape-recorded (with permission) and transcribed. Two of the interviewing researchers conducted the descriptive analyses. Both researchers read through all the transcribed interviews to determine the important issues, which were discussed to reach consensus and more detailed results.

## RESULTS

Eight women and five men with a life expectancy of 3 months or less were interviewed. The age of the patients ranged from 51 to 82 years, with an average age of 69.7 (see Table 1). Although this was not an inclusion criterion, all the patients suffered from cancer and knew that their life

expectancy was short. We used randomly chosen letters to refer to the respondents and the hospices involved, thus ensuring anonymity.

### **A cohabiting partner**

The presence of a cohabiting partner who is capable of taking the burden of care, specifically intensive palliative care, seems an important prerequisite for terminally ill patients to spend their end of life stage at home. The four respondents living at home all had a spouse or partner who was able to take care of them. Five of the respondents who spend their end of life stage in a hospice were widowers, one a lifetime single and one had a relationship, but he did not live together with his partner. Two of the respondents in a hospice were married, but their husbands were unable to take care of them. The husband of Mrs S had dementia and had moved to a nursing home a year before she went to the hospice. The husband of Mrs Va stayed in the spare room of the same hospice, due to a broken shoulder which prevented him from taking care of his wife.

### **Enough care**

Terminally ill patients often need intensive care, sometimes even 24-h supervision. The availability of sufficient care is therefore important. A cohabiting partner is frequently present to provide supervision, to make the necessary arrangements and to give care when necessary. Due to the high intensity of the care needed, it is generally necessary to rely on support from professional or volunteer caregivers in addition to the care given by spouses and other family members. The spouse of Mrs B said:

I experience a lot of support from professional caregivers, also from the general practitioner whose patient I have been since birth; he pays a visit daily. The support from the home care organisation is good; it is necessary. Without the home carers it would not be possible; we are very satisfied with them.

In the eyes of terminally ill patients the only valid reason for considering options other than home is when problems with the availability of medical treatment for pain or pain relief, or severe dyspnoea might be expected at home. Mr Mo said:

It has to be possible to stay at home without experiencing pain or severe breathlessness.

For the terminally ill patients in a hospice, the continuous presence of caregivers (professionals or volunteers) is a reassurance, as it is for the family. The presence of care-

givers provides them with feelings of safety; someone will be around to respond to emergencies, to provide care and to keep them company. When Mrs A (low care hospice) was asked about important aspects of the hospice, she answered:

Safety, that there is always someone around to help when necessary. I am never alone in the house, neither during daytime nor at night. And I do like the attention they give me here.

Mrs Va (low care hospice) said:

There is always someone around, without forcing themselves on you. Besides, there is always someone around who knows how to provide palliative care. I feel very safe here.

In both low and high care hospices, the contribution of volunteers in giving time and attention is crucial: due to their presence there is always someone around with whom patients can talk, smoke a cigarette or take a walk.

### **The role of family**

The four patients we visited at home were determined to stay at home, which is clearly illustrated by these citations from Mrs B and Mr Mo:

I was born in this house, I want to die here.

I am at home, and I want to stay here until my dying day.

For the spouses of these four terminally ill patients, it was an obvious choice to facilitate the patients' stay at home. The spouse of Mrs B said:

My wife decided to die at home. I want to do everything to make that possible.

Although they are determined, it is not easy for them. They were not very explicit about it, but did give indications of the heavy burden to the interviewer. The spouse of Mr Mo, for example, felt she needed to stay with her husband every minute of the day (she would never forgive herself if something happened when she was not there), which was a heavy burden for her, she said:

I totally support his decision to die at home. We decided this together with the children. And we said: 'Whatever you want, we (spouse and children) want'.

Although the patients at home were interviewed together with their spouses, the possible burden for their partner was not an issue that emerged.

In contrast to the partners of terminally ill patients who stay at home, the family members of the respondents in hospices bring their own limitations and risk of being overburdened to the fore. They stress the fact that they are instrumentally as well as psychologically unable to take care of the terminally ill patient at home. The daughter of Mrs P. (low care hospice), who is an only child, said:

I could not take my mother into my house; I have a full-time job and I am unable to cope with it psychologically. She is a nice person, but I do not like having her around all day.

The daughter of Mr A (high care hospice) left a little more room for the opinion her father:

If he had insisted on going home, we would have searched for solutions. The happiness of my father is most important, even though we (the 3 children) would have more worries.

Like their family members, the terminally ill patients in hospices stress the importance of avoiding being a burden to their family, and not making too great demands of them emotionally or instrumentally. They have an eye for the possibilities and needs of their family members. They prefer to be with them, without being dependent upon them; they want to enjoy being together. Mrs Va. (low care hospice) whose spouse has been seriously injured in an accident is very conscious of the impact her staying at home could have on her family:

I preferred to stay at home, but that is not only my decision, but also my family's'. Would my husband be able to handle it?

Mr P. (high care hospice) answered the question why he decided not to stay at home as follows:

I was totally dependent of my children, but they are young and have to be able to live their own life.

In the narratives of both patients who are at home and their spouses, the preferences of the patient seem to be paramount in the decision where to spend the end of life stage. If the patient wants to stay at home, that is obviously facilitated by the spouse. For patients who eventually decided to move to a hospice, there seems to be a debate or negotiation between the patient and the family members, in which the perspective of the patient and that of the family members seem to be equally important, while professionals just stay on the fringe. The realisation at a given moment in time that living at home was no longer an option is the result of this debate. They both refer to the irresponsibility of staying at home. Patients

and family members fear something happening while being at home alone and that they will be found – dead in the worst case scenario – hours or even days later. The son of Mr P. (high care hospice) said:

Suppose he had said: *'I want to go home'*, then we would have had to confront him with the less pleasant things in life. Suppose you fall while taking a shower or you get sick while lying in bed, then you can have an alarm, but it is so much better if someone is standing immediately besides your bed.

#### A difficult decision but a random choice

Although all the patients we interviewed were aware that their life would end soon, the decision to move to a hospice, a facility that is specialised in end of life care, has been a confrontation. The realisation that this will be the place to die is hard. Mr C. (high care hospice) said:

Living here gives mixed feelings; you know what you are here for. When you are home, you could maybe hide it more, from the outside world, but maybe also from yourself.

The daughter of Mrs P. (low care hospice) mentioned:

At first, my mother did not like the suggestion of moving to a hospice. I can imagine that – it will be her final station. Now that she is here, she does not want to leave anymore.

Although the decision to spend the end of life stage somewhere other than home is difficult but taken deliberately, the choice for a specific facility seems to be random. Due to the unfamiliarity with low and high care hospices in the Netherlands, people often have to have this possibility pointed out to them by others. Six of the respondents in a hospice were referred to this facility by a link-nurse or social worker in hospital, a general practitioner or a home help. It then depends on the experiences, preferences and knowledge of their referrers as to what seems an adequate facility in the end of life stage. Mrs P. (low care hospice) said:

I did not know of the existence of a hospice. I did not know what it was. No-one I know had gone there.

Mr A. (high care hospice) said:

The doctor gave me information about this hospice. I immediately thought: *'this is it!'*

Two other respondents had read about the high care hospice in a newspaper or a magazine, and one had heard of this facility through a neighbour who works there. For

these patients too it was a coincidence that they heard of the facility in which they now reside. Mrs A (low care hospice) said literally:

Before I came here, I didn't know of the existence of hospices. My son found it by accident. But I didn't have a choice; there is no other option.

### Feeling at home

Independent of the place of residence, feeling at home is important for all the terminally ill patients we interviewed. Especially the feeling of being in control of daily life is valued. Mrs Ma (at home) said for example:

I can do whatever I want, whenever I want. Everything is familiar.

Mr R. (high care hospice):

Actually I have all liberties here that are common at home, plus medical care and medical certainty whenever something happens. That is what I like.

The freedom to prepare their own meals and to furnish the room according to their own wishes contributes to feeling at home. For Mrs S (low care hospice) it was very important to have her own paintings surrounding her:

All the paintings on the walls are painted by me. It has become a real living room.

The continuation of important relationships as desired, without limitations or regulations, also provides a very important contribution to feeling at home. The most important relationships obviously are those with the partner and children, but people also appreciate visits from other family members, friends and neighbours. The spouse of Mrs B (at home) said:

It is important for my wife to be at home with the children, the family and friends. She can have company whenever she wants.

For patients residing in an inpatient hospice key words regarding the continuation of important relationships are freedom, not too many rules and regulations and sufficient privacy. The absence of fixed visiting hours in combination with enough privacy is appreciated highly because this enables patients to continue relationships that are important to them as they wish. Mrs P. (low care hospice) said:

I can do whatever I want. I can go to the kitchen or to the garden. I have my own room. My daughter always cooks dinner here and together with her husband she eats with me.

Some of the patients in a hospice remark that, particularly due to the number of caregivers that could be involved, being at home does not necessarily imply feeling at home. This is illustrated by the citation from Mrs S. (low care hospice):

I would not be able to live my life, when every moment some caregiver whom I do not know might enter, who picks and plucks me for a few minutes. . . . and when they are needed, they are not around.

### DISCUSSION AND CONCLUSION

Interviews with thirteen terminally ill patients and in each case one of the family members show perceptions of terminally ill patients and their family members regarding home and hospice as a place of care at the end of life. This paper provides further insight in the patient perspective in palliative care. How our insights relate to existing literature and the questions that still remain unanswered, will be elaborated below.

Literature shows that for terminally ill patients who do not have a partner in residence it seems more difficult to stay at home, certainly when they become more care-dependent (Visser *et al.* 2004). In general, partners are known to be the most reliable informal caregivers, providing intensive and also intimate personal care, even when it becomes too demanding (Arber & Ginn 1990; Finch & Mason 1993). This is also the case in palliative care; terminally ill patients at home with cohabiting caregivers, such as spouses, were in general more functionally limited than those that did not live with their caregivers (Visser *et al.* 2004). Our study indicates that a cohabiting partner who is capable of providing adequate palliative care is an important prerequisite for terminally ill patients to spend their end of life stage at home. They arrange 24-h supervision and care by providing it themselves, even when it is at their own expense; sometimes they arrange care from others as well. To enable more terminally ill patients to spend their end of life stage at home and to prevent spouses from being overburdened it is important to study possibilities to support spouses in palliative care giving.

The continuous presence of caregivers (professionals or volunteers) is an important benefit of facilities like hospices (Casarett *et al.* 2004), and a sense of safety is of utmost importance for terminally ill patients living at home (Gott *et al.* 2004; Goldschmidt *et al.* 2006). In relation to dying, many fear pain, personal suffering and breathlessness (Gott *et al.* 2008). Our study confirms these findings and stresses the importance of not being alone; patients as well as family caregivers fear something will happen when being alone. At the same time, they are

aware of the added value of having someone around for sharing emotions when desired.

Terminally ill patients, independent of the place of residence, seem to be concerned to ease the burden of family caregivers (Raynes *et al.* 2000; Gott *et al.* 2004; Proot *et al.* 2004; Kaldjian *et al.* 2009). Our study confirms this finding for terminally ill patients who reside in an inpatient hospice. These patients were reluctant to be overly demanding of their family members, something strengthened or even inspired by family members themselves. However, for the patients at home, the possible overburdening of their spouse was not mentioned at all in the interviews. Two of the four spouses did make remarks indicating the heavy burden. This result might have been influenced by the fact that patient and spouse wanted to be interviewed together. Other research reveals that caregivers and patients try to protect each other from emotional distress by being reserved in sharing feelings (Proot *et al.* 2003). Another study confirms that family members find it hard to admit that caregiving might become too demanding (Luijkx & Schols 2009). Moreover, it is known that family members, specifically spouses, feel obligated to care (Finch & Mason 1993). However, it remains unclear why these patients did not refer to the possibility of overburdening their spouses.

The importance of the perspective of family members has been established in other research; the likelihood of dying at home is dramatically reduced if family members do not support this (Gott *et al.* 2004; Grande & Ewing 2008). The actual choice where to spend the last phase of life seems to be the result of negotiation between patient and family, in which the perspective of both is important (Gomes & Higgingson 2006). Our study confirms this and adds a new dimension. For spouses, it is obvious that they facilitate the patient in staying at home when (s)he wants to do so. Even when it is at their own expense, they continue to care and do not bring the possibility of their being overburdened to the fore. Between spouses there seems to be hardly any negotiation. Other family members, such as children, seem to be more explicit about their limitations and the possibility of being overburdened, thus starting negotiations in which the perspective of the

patient as well as that of family members is important. This often leads to the patients' choice to go to a facility like a hospice.

Both our study and other research shows that for terminally ill patients it is important to feel at home, which can also be experienced by those living in a specialised facility like a hospice (Andersson *et al.* 2008). Continuing everyday life with relatives and friends is valued in the last phase of life (Appelin & Berterö 2004; Gott *et al.* 2004), which makes facilities (including privacy) for families visiting dying relatives very important (Townsend *et al.* 1990).

There seems to be a general lack of knowledge about possibilities in palliative care, amongst professionals as well as patients and family members, something which can deprive people of good palliative care (Ahmed *et al.* 2004; Casarett *et al.* 2004). Our study shows that the decision not to stay at home but go to a facility is taken deliberately and is the result of negotiations between patient and family. The choice for a specific setting seems to be fairly random; often just one possible facility was pointed out by a professional caregiver, leaving no choice at all. To facilitate making choices in the last phase of life, it is important for terminally ill patients and their family members to have access to information about facilities providing all sorts of end of life care. Because spouses and other family members might feel obliged to care for the patient and are therefore not in search of palliative care, professionals also have to be aware of the possibilities and bring options to the front when appropriate.

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