Terminal Patients’ Awareness of Impending Death

THE IMPACT UPON REQUESTING ADEQUATE CARE

In this qualitative study, 19 Dutch terminal patients and 23 relatives of deceased patients were interviewed. The interviews revealed that a timely request for care and anticipation of “what was going to happen” was determined by the degree to which patients and their relatives realize that the end of life was close, that the symptoms would get worse, and that the family would have to bear an increasing burden. When awareness of the severity of the situation dawns late, shortly before death, the patient and family may not receive the right sort of care, nor have access to the appropriate facilities. In the concluding part of this article, there is a plea for adopting a proactive approach. Nurses and other caregivers must try to prepare patients and relatives early for the care that will become necessary in the later stages.

Timely satisfaction of care needs is of crucial importance particularly for terminal patients, as they only have a short time to live and their health often deteriorates rapidly. In this connection, it is preferable that patients and their relatives should not just wait passively, but also anticipate their approaching care needs. Inevitably, this requires awareness of the severity of the situation.

Since the 1960s, a number of studies have been carried out on patients’ awareness of dying. Some of these studies revealed considerable differences among terminal patients with respect to their awareness of a rapidly approaching death. In what has become a classic study, Glaser and Strauss describe this awareness and the various social contexts of awareness on the basis of conversations with and observations of American hospital patients, relatives, and care providers. According to Glaser and Strauss, “unaware” patients often have doctors and nurses who do not speak openly about the illness, do not have contacts with other dying people, and are often admitted to institutions where medical information is concealed. They identify “closed awareness contexts” and “open awareness contexts” as the extremes. In a closed awareness context, the patient is not aware of the imminence of death, while doctors and nurses know that the patient will die in the near future. In an open awareness context, terminal patients are aware that they are going to die soon and this is accepted and discussed in contact between patients and care providers. Patients who are aware of their approaching death would be in a better position to bring their lives to a satisfactory conclusion and could take leave of those dear to them in a more suitable way. However, maintaining open awareness is not always
accompanies benefits; the context of open awareness is sometimes fraught with uncertainty and ambiguity.²

Glaser and Strauss carried out their study more than 35 years ago, and this raises the issue of the extent to which terminal patients still have this limited awareness of their approaching death. Using the typology of awareness contexts developed by Glaser and Strauss, in the early nineties, Seale et al.⁶ investigated the prevalence and consequences of different awareness contexts. In terminal cancer patients, open awareness of dying was the most frequently encountered context (about 50% of the relatives responded that the deceased patient certainly knew that he or she was likely to die, and another 17% said that this was probably the case). Seale and colleagues also noted that when compared with people in closed awareness, those dying in full awareness were able to plan the course of their death better, and that they were more satisfied with the choice they had of their place of death and were apparently more likely to die in their own homes.

In the late nineties, The and colleagues⁴ undertook relevant ethnographic research among Dutch patients with small cell lung cancer. These authors described how terminal patients and family are often unjustifiably optimistic and are not aware that the patient has a very short time to live. Just as Glaser and Strauss² described more than 35 years earlier, The et al. relate the fact that some people are not aware that they are going to die soon, due to lack of information provided by care providers. Even in this age, which is characterized by an emphasis on “informed consent” and “open communication,” the course of the disease and its fatal conclusion are often not communicated explicitly. The and colleagues relate this to the fact that patients often view their prognosis through rose-colored spectacles. Temporary responses of tumors to palliative chemotherapy and a need to keep hopes alive prevent many people from becoming aware that death is close and inevitable. The and colleagues do, however, indicate that optimism on the part of patients and family gradually diminishes. In some cases, it is only just before death that the attending physician takes away their last hopes and then they are faced with the imminence of death.⁴ In another recent study of end-of-life care for patients with hematological malignancies, McGrath³ also points to the relation between hope and the extent to which people are aware of the prognosis that they are going to die soon. McGrath suggests that the challenge of accepting the reality of a terminal diagnosis is so emotionally difficult that patients often oscillate between acceptance and hopeful denial.

The objective of this article was to increase our understanding of terminal patients’ awareness of their impending death and the consequences this has for expressing care needs. The article is based on a broader qualitative study into the needs of Dutch terminal patients and relatives in the area of palliative care.⁷ As is usual in qualitative research, the initial research questions were rather broad (“What care needs do terminal patients and their relatives have?” and “What factors influence these care needs?”). During the cyclical process of data collection—data analysis, data reflection, data collection, etc.—, some central concepts were explored among which was the concept of “awareness,” which was connected to the development of more specific research questions. The following specific research questions discussed in this article are related to the awareness concept:

To what extent are terminal patients aware of the severity of the situation?

How is this awareness related to expressing and meeting demands for care?

METHODS

Selection, Recruitment, and Sample Characteristics

A total of 19 Dutch terminal patients and 23 relatives of deceased patients were interviewed in the period 1998–2000. The criteria for inclusion of patients were as follows:

a. suffering from an incurable cancer or another chronic terminal disorder;

b. life expectancy of less than 6 months (predicted by the general practitioner or other care providers who recruited patients);

c. ability to communicate verbally in Dutch;
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The inclusion criteria (c) and (d) also applied to relatives. In addition, the following criterion was required for relatives:

e. close family member or relative of a patient who had died of cancer or another chronic terminal disorder within the last year.

All relatives had been directly involved in providing care to the dying patients (who were patients other than those interviewed).

Children and dementia patients, as well as their relatives, were not included in the study, because we surmised that children suffering from terminal illness and terminal dementia patients had specific needs that differed in part from those of other terminal patients. In addition, the fact that interviews with terminally ill children or people with dementia are difficult to carry out played a role in this decision.

Our sampling was guided by the fact that we wanted to involve cancer patients as well as noncancer patients cared for in different care contexts (home, hospital, nursing home or home for the elderly, hospice). Accordingly, the research proposal called for 25 to 30 patients and 25 to 30 relatives, a relatively large sample for a qualitative study. Although we mentioned in the research proposal that the principle of “theoretical saturation” would also determine the definitive sample size, we expected that the sample sizes cited would be required to do justice to the variety of care contexts and the various types of terminal patients.

General practitioners, managers and caring staff of home care organizations, volunteer organizations, hospitals, and nursing homes were approached to act as intermediaries in recruiting respondents. Advertisements were also placed in patient organization bulletins. However, the selection of patients and, to a lesser extent, relatives caused some difficulty. In practice, the intermediaries often hesitated to approach a patient or family member because of the mental or physical burden expected. However, by repeated and frequent requests we were finally able to select 19 patients and 25 relatives, who were all interviewed once. Even though we did not achieve the number of interviews planned in the research proposal (see above), the actual number proved large enough to answer the research questions in a satisfactory way. Whether or not we reached “theoretical saturation” on the basis of the analysis of the interviews with the 19 patients and 25 relatives will be discussed in the “Discussion” section.

Although all patients interviewed had a life expectancy of only 6 months or less (according to their general practitioners or other “recruiting” care providers), there was variation in the phase in which the interview took place. Some patients had very few symptoms of their illness, while others had many complaints and were not expected to live for more than a few months. Most of the patients interviewed belonged to this last group. For other characteristics of the interviewees, see Table 1.

[ TABLE 1 ]

Inteviews

A list of open questions was used to guide the semi-structured interviews. A first draft of the list was tested and discussed in the project steering group, which included a representative of a patient organization, representatives of professional and volunteer care organizations, and scientific experts.

Initial questions to patients were, for example: What problems do you face? What care are you receiving at present? Does it meet your needs? Examples of initial questions for relatives were as follows: What care did your spouse, parent, or ... receive? Were his or her care needs and your own care needs satisfactorily met? If not, why not?

The list with open questions had a nondefinitive character, and interim analysis inspired some new questions, such as questions eliciting the awareness issue. In the case of patients, open, indirect questions on awareness were asked, for example: How do you view the future? What kind of care do

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you want to receive in the coming period? In the case of relatives, open questions on awareness were put, for example: How did your parent/spouse/sibling or ... view the fact that the disease was incurable?

The interviewer (one of the persons mentioned under the “Acknowledgments” section or one of the authors) conducted all the interviews at the respondents’ home or place of care. The patient interviews lasted about 60 minutes on average, and interviews with relatives lasted approximately 75 minutes on average.

Each respondent received written as well as verbal information about the content and objectives of the study. Informed written consent was requested and obtained in all cases. A medical-ethics committee was not involved in the study, since particular treatments or interventions were not withheld from or offered to respondents as a consequence of participating in the study (which is a main criterion in medical-ethics procedures in the Netherlands).

Analysis

The interviews were analyzed in a qualitative way, based to a large extent on procedures described by “grounded theorists” (see references 2, 8, and 9). A central characteristic of the grounded theory approach is the cyclical process of collecting and analyzing data. In our study this meant that interviews were recorded on tape, typed out, and read. All fragments that appeared to be relevant in answering the research questions were provided with keywords that were inductively derived from the interview material (main keywords are reflected in the titles of the subheadings under the “Results” section, see below). Then interview fragments were compared with fragments with the same keywords in previous interviews. Insights from intermediate analysis were repeatedly tested and refined in subsequent interviews and analyses. This ongoing comparison of data with material collected earlier resulted in the final answers to the research questions.

To improve the credibility of findings at several points in time, independent interim-analyses and results were discussed in the project group (consisting of the 2 authors and fellow researcher A. de G., see “Acknowledgments” section). Furthermore, interim and end results were discussed with the steering group Suggestions and criticism were included in the final analyses. Finally credibility was improved by the large-scale literal citing of interview fragments.

RESULTS

In what follows, the results of interviews with terminal patients and relatives are presented, insofar as these relate to patients’ awareness that the end was approaching, that the symptoms would deteriorate, and that the relatives would bear an increasing burden. We shall also indicate the consequences of this awareness in expressing care demands.

Awareness of Impending Death

Among the patients interviewed, there appeared to be great differences in the degree to which they understood that they had a short time to live. On the basis of interviews with the bereaved, it became clear that patients who had been aware, in an early phase, of the imminence of death often displayed a positive attitude expressed as “how can we make the best of it”? These patients clearly indicated the care they wanted in this last phase of their lives. Their primary concern was that the remaining time they had with their relatives should be “quality time.” They expected doctors, nurses, and other care providers to help them to make it as pleasant as possible.

*We looked it [death] straight in the eye, we realized immediately that for us only one thing was important; that was the quality of life, we wanted A. to have a pleasant time. We did not talk about recovery. We said, ‘Doctor, don’t do anything else, just help us to ensure some dignity at the end.’* (woman, aged 55, about her partner of 56 who was suffering from cancer and died at home)

When people know that it is sure that they will die soon, they often more certainly think about which palliative or complementary treatments to choose: what do you want and what don’t you want.
Right, it was just like: okay, she is dying, what shall we do now? Yes, you have to make decisions about which treatment is worth trying, or do you want her to die without further treatments - that is the point. Do you have to allow more treatments? ... She asked questions that were to the point, such as “How am I going to die?” And he answered, “Look, we have these treatments for you ...” And you just want to hear what will happen if she is given radiotherapy and what if not. (woman, aged 40, about her partner of 46 who was suffering from cancer and who died in a hospice)

Patients who had no awareness of the approach of death, or those with a very limited one, hoped for a cure or, at any event, some remission of the disease. As a result, some of these patients carried on with all sorts of tests and treatment. There were also patients whose limited awareness resulted in a “wait and see” attitude, a passive anticipation of “what’s going to happen.” However, both types of unaware patients hardly showed any interest in the care they would need in their last few weeks and days. This was illustrated in the account of a man who, despite the fact that he was very sick, was not aware that he would probably be dead within a few weeks:

I really don’t know what my needs are. I don’t know how things will develop in the future. (male cancer patient, aged 75, at home)

Terminal patients who are aware of the imminence of death are often more prone to approach their doctors and nurses with specific care demands. This increases the chance that they will receive the required care and facilities on time and will not end up in a crisis. This also allows the patient to take leave of his or her loved ones and to arrange together practical aspects.

For as far as I can arrange things, even my own gravestone, I have done so already; really, I did. I have written down all the addresses, and my children know almost all of it. They want to drop by some evening to find out what exactly I want and how. My eldest son, who is an real organizer like me, said, “Mum, I want to know that, because I feel that as your eldest child I must help Dad as much as I can...” In other cases, something unexpected happens to someone and it is all in a mess... (female cancer patient, aged 57, at home)

The more patients are aware of their situation, the more they seem to be intended to equip themselves with the required aids and facilities, that is, if they are still able to do so. This creates possibilities to stay as long as possible at home.

No further treatment would give results, so I wanted to go home. At home, we have made arrangements. We have divided the living room with a large sliding door ...we have installed a ventilator in the window, you can produce the most horrible smells and after five minutes it is gone ... We have also organized to have a shower installed downstairs ... The home care organization gave me a commode, a shower chair, and a frame and I use all of these. (male cancer patient, aged 58, at home)

In addition, some of these “aware” patients arrange sufficient informal care, which also facilitates staying at home.

She has created a care group around her. This group slowly came nearer, not all at the same time, but gradually. She has built a real close circle around her ... she made herself very clear about who she wanted and who not, it was the people who looked after her she wanted, so she could stay at home as long as possible. We made a timetable and divided the tasks. (woman, aged 40, about partner of 46 who suffered from cancer)

In general, awareness increases as death comes closer, but some people are quicker to understand the situation than are others. It partly depends on what the attending physician says when breaking the bad news and what the patient understands by it. After it has become clear to the physician that treatment is not going to lead to recovery, patients are generally told for the first time that they are not going to recover. However, if the doctor suggests chemotherapy or some other treatment, patients may think that there is still a chance of recovery. When the attending physician clearly states that the treatment will not cure the disease, patients often do see that death is inevitable.
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The doctor said straightaway, “I can help you to stay in a reasonable condition for a long time, but I cannot cure you, because the cancer has spread...” Anyway, he has always said that he cannot cure me, so I knew how it was. (female cancer patient, aged 56, in hospital)

Patients sometimes develop a distorted perception of the prognosis as a result of the way in which the disease develops. Sometimes, unexpected improvements do take place, and pain or symptoms disappear temporarily. This can lead to patients and relatives thinking that the patient is getting better. Here again, whether a temporary improvement prevents a patient from becoming aware that death is near partly depends upon what the doctor says and probably how information is interpreted and understood by the patient and family.

He said, “Everything points to stabilization at this time ... to your body being able to handle things.” This was good news. But the GP also said, “It’s fine, but don’t draw a false sense of security from it. You know how it is with this disease. Everything is OK now, but two weeks later it will be bad again. And that’s what I am thinking of.” (female cancer patient, aged 57, at home)

The interviews revealed that patient’s awareness that he or she was going to die soon was also related to the duration and nature of the disease. In the case of older patients, who had already been suffering from a number of chronic diseases for a long time, patients, family, sometimes even doctors and nurses, realize that the condition is terminal at a late stage. Being seriously ill may be such a “normal” state of affairs with such patients that it is sometimes very late before they realize that the end is truly nigh. A consequence of this may be that a patient does not get the special care and attention he or she needs.

There was no “tender loving care.” They should have seen that things were going very badly for him, but they did not. Yes, the doctor was desperate too. He was very upset. It was on the last day of his life that the doctor said to him: “you are going to die.” (woman, aged 78, about a spouse of 81 who suffered from various chronic complaints and who died in a nursing home)

Awareness of the Worsening of Symptoms

Patients who are aware that death is close may often look for information about what to expect in the last few weeks or days before they die. Information from care providers helps patients and family to understand that the final stage may include serious symptoms. Awareness of a possible rapid exacerbation of the symptoms is important, because it helps the patients and family to think about the help they will need, about who should give it, and where it should be given. The following interview fragment concerns a female cancer patient who did not have much pain at the time of the interview, but who was aware that pain would probably be a severe problem in the last weeks of life.

I've made the doctors promise me to give medication. And my sister and husband also got a form saying that I do not want to suffer... And that when I feel pain, that they will give me painkillers, till I die. No suffering at all. I don't want that. (woman, aged 57, at home)

This awareness helps patients to prepare for the last phase, in which they will need a lot of help and support. Such patients sometimes have a network of professional and nonprofessional care providers who look after them until the end.

When my body started to let me down, I had to face it and the fact that other people would have to help. You are glad of all the help that other people give you. And I really must say that I had nothing to complain about. (female patient, aged 71, suffering from several chronic diseases, at home).

On the other hand, patients who are not aware that their situation may soon get worse scarcely pay any attention to the care that they will need in the near future.

This last month I have been able to deal with things very well physically. I don’t think that I do need help now. I have no idea whether it is going to get worse in future or what to expect. (male cancer patient, aged 73, at home)

These patients are more vulnerable as a result, and in the last days of their lives they run the risk of not receiving the right help and care. If these people suddenly and rapidly deteriorate, they and their family may be confronted with acute problems to which they do not have any answers.
Awareness of the Increasing Burden on the Family

When people perceive their end as very close, they are likely to foresee that there will be an increasing physical and emotional burden on the family. Among the patients and relatives interviewed, there was a clear distinction between people who were aware of the probable increase in the burden of care on the family and those who were not. The first group understood that care for a terminal patient in the last weeks or days of life is often a heavy physical and mental burden, and that they had to arrange timely professional help.

*I want to stay at home as long as possible, but it has to be possible. It must not become too much of a burden on my family. It really depends on the duration and the seriousness of the situation. One may need a great deal of home care.* (female cancer patient, aged 57, at home)

Yet those patients who are scarcely aware, if at all, of the heavy care demands they will probably make on their relatives in the last stage wait to see what happens. They assume that the family will look after them and will be able to handle all their care demands in future.

Terminal patients who have little awareness of the increasing burden on relatives are more vulnerable. They do not anticipate the professional care that they will need when the close relatives are no longer able to provide sufficient home care, and this can lead to emergencies. The following illustrates clearly which situations of real crisis can develop.

*One day, the GP told her that it could no go on like this any further...in the morning my father had no control over his bowels and the whole place was in a mess. He had tried to go to the toilet, but it was too late. When my mother came in the room the place was covered in pooh, my father flat on the floor, unable to do anything at all, in his own excrement.* (man, aged 49, about father, 77, who suffered from cancer and who died in a hospice)

DISCUSSION

In this article, we have looked at the levels and areas of awareness and unawareness among terminal patients and their relatives in respect to expressing and satisfying the need for care. The central message of the article is that patients who realize that death is imminent, that symptoms will become exacerbated, and that the burden upon the family will increase, make concrete care demands earlier. As a result, they may have a better chance of getting the help required and assistance in the final phase.

In the beginning of the article, we mentioned the work of The et al. These authors related the fact that some terminal patients are not aware that they are going to die soon, due to a lack of information. Despite current Western thinking about “open communication,” doctors often do not communicate explicitly about a fatal diagnosis and as a consequence patients tend to have an optimistic view about the situation. Although we did not undertake direct observation of patient-doctor communication, our research based on patient and family stories also points to the importance of information provision by care providers in creating awareness. Among our respondents we saw, on the one hand, people who were aware of the seriousness of their situation and who stated that the doctor said very clearly that there was no chance of cure. On the other hand, some of the bereaved relatives said that the physician had informed the patient and family at a very late stage about the fatal prognosis. As a result they did not ask special care and attention on time.

In addition, The et al. and also McGrath pointed to the relation between hope and the extent to which people are aware of the prognosis that they will soon die. In our research too, terminal patients who still hoped for remission of the disease were interviewed. Some “hopeful” patients carried on with all sorts of tests and treatment, while others passively waited for what the future would bring. However, these types of unaware patients shared a lack of interest in the care they would need in the last phase of life, which increased the chance that adequate care would not be available when needed.

Previous studies strongly emphasized the consequences of (a lack of ) awareness for bringing life to a satisfactory conclusion. Our study has provided particular insights into the consequences of awareness/lack of awareness for the adequate expression and meeting of care demands. When terminal
patients are not aware of the seriousness of the situation, it may prevent them from seeking appropriate help, which increases the chance of emergencies and hospital admissions just prior to death.

This may be a good reason for nurses and other professional care providers to adopt a more proactive attitude, and to speak to relatives and patients about their future care needs in relation to the probability of a worsening of symptoms and increasing care burdens on the family. The doctor in attendance and nurses too can inform patients and the family about what may happen and about the facilities available if necessary. Although terminal patients themselves often want to die in their own homes,\textsuperscript{10} care at home should not be presented as the only option. The patients we interviewed often did not know what nursing homes, hospitals, and hospices can provide in terms of palliative care. Only when there is sufficient information available, is it possible to choose the best option.

In some previous studies it was concluded that an open awareness may also have disadvantages: open awareness would sometimes be accompanied with uncertainty and ambiguity, and would sometimes give rise to divergent expectations of patients, relatives, and care providers of “appropriate dying.”\textsuperscript{2,5} However, our interviews pointed only to positive consequences of being aware as far as the request for care was concerned.

A preference for open awareness of dying is now well established in terminal care settings in the industrialized countries.\textsuperscript{1,6} Among others, Copp\textsuperscript{11} points to the fact that tension may develop among nurses in particular when patients do not talk openly about their situation or when they seem ignorant of their rapidly deteriorating situation. However, nurses and other care providers have to accept that there will be always a group of terminal patients who do not want to speak openly about their condition and who have a limited awareness of their impending death. Nevertheless, on the basis of our study, it appears to be important to note that these patients risk a crisis shortly before death and it is important that intensive (home) care can be delivered rapidly. There must also be sufficient options for acute admission to hospices, nursing homes, or hospitals.

In this connection too, good coordination of care appears to be essential. A care coordinator (eg, the general practitioner, a home care nurse, or another care provider who knows the patient and family well) has to ensure that a terminal patient gets priority and is not held up by time-wasting diagnoses or admission procedures.

A limitation of this article is that the awareness of relatives is not described. The choice of a focus on patient awareness in this article relates to the fact that we reached “theoretical saturation” as regards patient “awareness,” but still do not know enough about possible differences between patients’ and relatives’ awareness on the basis of these interviews. Additional research in this area is required. This seems important since the qualitative research of Yates and Stetz\textsuperscript{12} indicates that developing an awareness of dying is also a crucial process for the family, which is often characterized by uncertainty and anguish.

Another limitation is that results presented are, for a main part, based on indirect accounts of family. Quantitative research on terminal phase symptoms reveals that answers provided by relatives on behalf of terminal patients often diverge from the answers given by the patients themselves.\textsuperscript{13} A study by Hinton,\textsuperscript{14} however, indicates that the reliability of retrospective family reports about patient awareness of dying is higher than retrospective reports on patient symptoms. This is in line with the fact that we did not find clear differences in our study between what patients themselves and their relatives stated about patient awareness and its consequences in requesting and receiving adequate care. It should, however, be noted that bereaved relatives who were interviewed were not related to the terminal patients interviewed. Since we used 2 different, independent samples, no specific insight can be given into the agreement between patient reports and family reports.

However, the choice to make use of a sample of bereaved family members who gave retrospective information about patient awareness also had advantages. Since relatives were interviewed some time after the death of their loved one, they were able to give a thorough review of the total illness trajectory (also including the important last days of life) in relation to patient awareness.
ACKNOWLEDGMENTS

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TABLE

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REFERENCES

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