Challenging conversations with terminally ill patients and their loved ones: Strategies to improve giving information in palliative care

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Abstract
Objective: The aim of the study was to explore the skills and strategies employed by professionals when having difficult conversations to provide information to loved ones as part of palliative care.
Method: A qualitative design was chosen with in-depth interviews with nurses, assistant nurses and doctors a Hospital in Sweden and were analysed using content analysis.
Results: The interviews produced examples of strategies used by professionals when imparting difficult information to patient and loved ones. The results fell into three areas: ‘Who is giving information’, ‘Structuring the conversation’ and ‘Different ways to convey a difficult message’.
Conclusion: Using conversational skills and strategies in combination with a carefully planned structure appeared to facilitate difficult conversations with patients and loved ones. Further research is required, related to the specific circumstances in which the conversation takes place.

Keywords
Conversation, skills, strategies, caregivers, end-of-life questions

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Introduction

When a patient is diagnosed as terminally ill, life suddenly changes into an existence marked by the symptoms of the disease. This not only includes the life of the patient but also the lives of family members and other loved ones. They are forced to develop a new way of living and seek further sources of control and support.¹ Symptoms and thoughts could revolve around physical, psychological, social and existential matters.²,³ Healthcare professionals who meet the patients and their loved ones as part of their day-to-day work become involved in a whole range of conversations dealing with the patients’ thoughts and the consequences of the disease. Professionals need to be prepared for such discussions. Different studies⁴–⁶ have shown that healthcare professionals could feel ill-equipped to deal with issues related to death and dying. Kuupelomäki⁷ showed that the professionals’ views of death and dying could mean that at times they are more afraid of death than the patients and their families. Several studies have produced examples that show that what the patients and their loved ones really want to have is information about the prognosis, the treatment of the disease and how to manage pain.⁸–¹⁰ They also want to be supported to sustain hope and maintain some degree of ambiguity about the future.¹¹–¹³ Other studies have investigated and identified stress among professionals regarding the difficulty of talking about these subjects with patients and loved ones. This highlights the need for training in how to provide information.⁵,¹⁴,¹⁵ A previous study concluded that most professionals felt there was a good level of understanding among patients and loved ones although they still encountered problems when providing information.¹⁶ There is a need for profound skills and strategies among professionals when conducting difficult conversations with

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patients and their loved ones.\textsuperscript{17–20} This study is founded on in-depth interviews conducted with healthcare professionals in order to increase knowledge about the approaches which are adopted by professionals when providing this kind of difficult conversations. The aim of the study was to explore the skills and strategies employed by professionals when having difficult conversations providing information to patients and loved ones as part of palliative care.

**Significant concepts**

‘Loved ones’ is an expression denoting those persons who are close to the patient, regardless of whether they are spouses, significant others, relatives, adult children or friends.

**Methods**

A qualitative design was chosen to gain a deeper understanding of the various methods used by the professionals to provide information to terminally ill patients and their loved ones in order to support their actions and their understanding of what will happen.

**Settings and participants**

The study was conducted at the geriatric, oncology and urology departments at a university hospital in western Sweden. The patients in the urology and oncology departments were suffering from cancer and those clinics treat patients with cancer in a curative stage as well as in early and late palliative stages. The patients in the geriatric department were suffering from multiple diseases, in late palliative stage.

The participants who were interviewed were nurses, assistant nurses and doctors working at those clinics and they had already participated in the previous questionnaire study.\textsuperscript{16} Those who were willing to participate in this interview study were asked to send their informed consent to the researcher. Of the 48 persons who gave their consent, 35 finally participated. The reasons for non-participation were that the person was no longer working at the hospital, did not want to participate or could not be reached.

**Data collection**

Data were collected over a 3-month period between February and May 2010. The interviews took place at the hospital and were conducted using a conversational approach. That means that the interview was like a conversation, with their story of how they give information in various ways and with specific questions from the interviewer to clarify the research questions. To ensure adherence to the research questions throughout the interview, certain key questions were highlighted: *How do you convey difficult information? What do you do if you feel that a loved one does not understand?*

**Data analysis**

The transcribed interviews were analysed using content analysis. The interviews were conducted by the first author (I.B.) and were transcribed verbatim. The analysis was carried out in close cooperation with the co-authors to ensure the results were interpreted as objectively as possible. Any differences were discussed and a common description was formulated.

The analysis comprised several steps. Initially, text that was relevant to the research issues was marked. Units of meaning were then identified and grouped into codes. These codes were subsequently discussed, compared, categorised and labelled. In the final step, the categories were structured into sub-themes and themes.\textsuperscript{21,22} The study was approved by the Regional Ethical Review Board in Gothenburg (680-06).

**Design**

Many factors need to be taken into account to ensure trustworthiness and validity in qualitative research. Compared to using a questionnaire, in-depth interviews make it possible to acquire a deeper understanding of the participants ‘strategies’ in conversation.

**Trustworthiness**

To ensure credibility, all the participants in this study were professionals who worked on a daily basis with patients with an incurable disease and who also met the patients’ loved ones. Despite the differences in age, gender and profession, the results reveal many similarities. To reduce the impact of the investigators’ pre-understanding, the interviews included questions that elucidated the experiences of the participants.\textsuperscript{21,22}

**Findings**

The majority of the respondents were aged 30–49 years, a few were over 50 years and a small number were under 30 years. Most of the participants had worked for up to 20 years in health care, split equally between 0 and 10 years and 11 to 20 years. The majority of the participants were women who work daytime (see Tables 1–4).

**Overall results**

The interviews provide examples of strategies used by professionals to convey difficult information to patients and loved ones. Crucial factors were the conversational structure and how the professionals provided the information. The results are presented under three headings: *Who is giving the information, Structuring the conversation and Different ways to convey a difficult message.*
Who is giving the information

In general, the nurses were of the opinion that it was the doctor’s responsibility to provide difficult information about diagnosis and disease progression. The assistant nurses were of the same opinion, and they also thought that the nurses were thrust with the responsibility of having difficult conversations about daily medical issues and daily care. The assistant nurses felt the difficulty of the conversations about daily care, especially when the patient was dying. Many mentioned the benefit of having a nurse present when information was provided by the doctor, primarily because it offered the opportunity to continue and confirm the information as part of daily care. It was also important to ensure that all the different categories of professionals’ accounts concur to avoid confusing the loved ones by providing disparate information:

It’s up to the doctor to explain. If you are sure what the doctor said – perhaps you were present at the time – then you have the courage to have the discussion. But you want to be sure about what the doctor said to avoid contradicting the doctor.

For all categories of professionals, it was obvious that as the illness progressed more information was needed, and in the interviews, this was provided mostly by the doctors and the nurses. The nurses felt confident about providing information about the patient’s condition, both on a daily basis at the beginning of the disease during the treatment period and later on, when death was imminent. However, if the nurses felt that the loved ones did not understand, they asked for a further meeting with the doctor to make sure the loved ones were fully aware of the patient’s condition.

Structuring the conversation

Many of the participants structured the conversation in almost the same way, that is, they divided into three separate parts: introduction, message and closure.
**Introduction.** The rationale behind starting the conversation with an introduction is that it helps to establish a relationship and create a comfortable situation:

We spoke very briefly about the snow and her journey here …

Another introduction strategy was to ask for information the patient and loved ones already knew by enquiring about how things had been since the last meeting or what information they had been given:

The classic approach is to ask what information they had received from the doctor.

**Message.** It was important for patients and their loved ones to have a moment of silence to reflect on the information they had received and to focus on what form the upcoming conversation would take. It also seemed important to have an opportunity for further conversation. This could depend on the nature of the information conveyed and how the patient and the loved ones understood and coped on hearing it:

After a long conversation, I usually say that I’ll call again in two or three days.

**Closure.** Closing the conversation involves giving an indication about future contact and what form the contact would take. This can be done, for example, by talking about certain questions: *Who is responsible for the follow-up?* and *What form will it take?* The questions depend on the situation, that is, whether the patient is at home, at the hospital or somewhere else. The focus is on clarifying how the patient and the loved ones can obtain further information if they need it:

The patient and the relatives know who they can turn to with all manner of questions.

I promised her I would call on Monday. This gave her a few more days to think.

**Different ways to convey a difficult message**

Difficult messages can be given directly or by using metaphors and symbols. Most of the participating doctors preferred to use direct communication. To facilitate this, they prepared the patient and the loved ones by saying that a straight message was about to be given. The professionals emphasised the importance of listening to the patient and their loved ones to determine how they assimilate the information. They also pointed out the necessity of being aware that some people may not want a straight message and that they must be given the opportunity to say so.

An important factor to consider when providing information is the stage of the disease. When presenting the diagnosis and at the beginning of the illness, many professionals stated that it was important to impart hope. This gives the patient and the loved ones a chance to seek support to handle the situation:

You often try to provide information in a way that makes it possible for the patient to live on.

Hope can take various forms – hope of recovery, treatment to prolong life or elimination of pain and anxiety. As one doctor said,

Being allowed to have hope is important. I believe that it is easier to die if you retain hope for as long as possible.

Telling the patient and their loved ones that no further treatment was available was regarded by the professionals as depriving them of hope:

Saying that there is no more treatment means that there is no straw to clutch at.

Some professionals changed the information by saying that they could provide palliative treatment to maintain the hope of creating as good a life as possible:

The treatment is not helping and now we need to switch to treatment that will alleviate the symptoms.

When the professionals noticed the patient was deteriorating and understood that death was approaching, they felt a need to say that the patient was dying. A large number of the professionals were not very comfortable using the words death or dying and used other words instead when they informed the loved ones about the coming death, such as,

There’s not long left; It looks as if it will be over soon; It’s getting worse; I’m not certain that NN will live for very much longer; We’re entering the final period, you should perhaps stay; Is there anyone else we should call.

To use metaphors or symbols instead of giving a straightforward message when talking about death was experienced as common by the professionals as well as by the patients and their loved ones. The professionals found it easier for the loved ones to face and talk about death when death was obvious than at the beginning of the disease.

**Discussion**

This study has highlighted strategies to facilitate conversations professionals can use to provide information to patients and their loved ones. Knowledge of the different subjects that patients and their loved ones want to discuss during the course of a fatal disease is increasing in the literature. But there is still a lack of knowledge and practical skills among professionals regarding the way such
information should be provided; this study has proposed a new approach and skills, which can be incorporated into such conversations. Even if the nurses suggest that only the doctors should give the difficult information, all professionals including the nurses and assistant nurses meet the patients’ and the loved ones’ questions and thoughts in the daily care and have such conversations. All those categories of professionals have a lot of conversations with the patients and their loved ones about the caring and the symptoms according to the progress of the disease and must be prepared to have such difficult discussion at all times. The quality of communication in terms of content and exchange of information are key factors when meeting patients and their loved ones with regard to a fatal disease. Many other studies describe the need for training skills and the consequences of shortcomings in this area in terms of missed or incorrectly provided information. We have found in this study several strategies used by the professionals, which has helped them to give clear information in difficult matters. When a patient and his or her loved ones receive information about a life-limiting disease, they often hear different parts and they formulate their own version of the information. This means that it is important to ask them what information they already have, which is one of the findings. Some studies found that professionals’ avoidance of informing the patient’s prognosis can be attributed to a lack of training, uncertainty regarding the prognosis, a request from family members or the futility of further treatment. Other studies highlight the difficulty of deciding when, during the course of the disease, they should discuss end of life with patients and the loved ones. The professionals in this study met patients at different stages of the disease, and there was an agreement among the professionals that hope was strongest at the beginning of the illness. It was important for the professionals to provide the patients and their loved ones with information that prolonged hope and helped them to live life as well as possible. The professionals also found that it was easier for the loved ones to talk about death and dying when it was obvious that the patient’s death was approaching.

Nevertheless, it was also deemed important to discuss the progression in all stages of the disease, and this led to suggestions regarding skills and strategies to facilitate these conversations. In line with other studies, the professionals reported that the strategies for conducting difficult conversations comprised several steps. The first step was an introduction, which gave the professional, the patient and the loved ones time to meet and establish a relationship. This was followed by the professional asking about the information the patient and loved ones had been given. It was important to explore their level of knowledge to obtain a picture of their perceived experience. The next step comprised a discussion of the current stage and the prognosis, followed by closure of the conversation where they were assured that it was not the end of the relationship and that there would be a continuation, including a follow-up plan. This stage of the conversation should also include a summary of what had been talked about in order to assess how well the information had been understood. A similar structure was described in a physician’s guide to difficult conversations in palliative care, which also highlights the advantages of step-by-step conversations as a strategy to establish good conditions for providing information. It also describes the steps involved, starting with an opening discussion, moving on to clarifying prognosis and concluding with treatment goals and goals related to understanding.

As the disease enters the final stage, it is crucial to communicate this to the loved ones. In this study, different means were used to inform about impending death. Dealing with issues related to death and dying is most difficult for the professionals, although in this study the professionals adopted specific strategies when talking to patients and their loved ones. A key element was the use of metaphors or symbols for the word ‘dying’, such as ‘there is not long left’ and so on, which made it easier for the loved ones to link the visible sign of the patient’s worsening condition to approaching death. Using alternative formulations is a way of talking about difficult problems without causing anxiety. Using wording for death that causes less anxiety during the course of the illness appeared to make it easier to talk about difficult subjects.

Strengths and limitations

The study comprised interviews with professionals who care for patients with an incurable disease. Despite the relatively large number of interviews with different professionals, we acknowledge that generalisation could be called into question although qualitative research has the advantage of revealing a more balanced insight. Further research is required and the result must be related to the specific circumstances in which the conversations take place.

Conclusion

Using conversational skills and strategies in combination with a carefully planned structure appeared to facilitate difficult conversations with patients and loved ones. All conversations are not the same and therefore there must be worked-out skills and strategies that are suitable for the current topic even if there are some similarities which can be generalised to many situations. The result can be a foundation for further discussion when working out skills for such conversations. The results can also be useful in further research and discussion on this topic.

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