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## How to Estimate Understanding: Professionals' Assessment of Loved Ones' Insight into a Patient's Fatal Disease

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### Abstract

**Background:** Loved ones of a patient with an incurable disease will accompany the patient to the end of life. Health care professionals must discuss difficult matters with loved ones and be sure that they really understand the seriousness of the patient's disease. The study explore how the professionals do when they explore the grounds on which they make their assessment of loved ones' insight into a patient's fatal disease.

**Method:** A qualitative design was chosen to gain deeper knowledge of professionals' perception of loved ones' understanding. The transcribed interviews were analysed using content analysis giving a richer understanding of the meaning of the content.

**Result:** The participants assessed loved ones' insight into the fatal disease based on the course and content of the conversations they had with the loved ones. The professionals' assessments were based on how the loved ones talked and expressed themselves in words and behavior and on the type of questions posed by the loved ones. The loved ones' observations and hope as denial or a strategy also contributed to their assessment.

**Conclusion:** Ways to communicate with loved ones are crucial when making an assessment. The different ways loved ones use hope and other strategies made it problematic for the professionals to use these as indicators of state of mind in this matter. Training in conversation skills could be one way to support professionals when discussing and managing these difficult situations.

### Introduction

**B**EING A LOVED ONE of a patient with an incurable disease involves embarking on a journey together to the end of life. In such situations, loved ones use strategies that enable them to manage difficult events, both in terms of how to think and how to act.<sup>1-3</sup> These strategies do not necessarily mean denial but could be based on hope. It is important to support hope for the remainder of the patient's life.<sup>4</sup> Both loved ones and patients have stated that fostering realistic hope is crucial even though they understand the incurable nature of the disease. Apart from using hope as a strategy, loved ones also express a strong need to be informed and talk about the disease and its consequences in terms of treatment, incurability, palliative care, and pain management.<sup>4-8</sup>

According to the literature, some loved ones feel ambivalent about receiving too much information,<sup>9</sup> whereas others prefer straightforward information provided with empathy.<sup>10</sup> This raises questions about how health care professionals can discuss these difficult matters with loved ones and the indi-

cators they can use as a basis for their assessment of whether the loved ones fully understand the seriousness of the patient's disease and its consequences. Inspired by an earlier questionnaire study<sup>11</sup> with professionals utilized to obtain information about their assessments of loved ones' understanding of a patient's life-limiting disease, we wanted to explore the grounds on which professionals make their assessment of loved ones' insight into a patient's fatal disease.

### Significant concepts

*Loved ones* is an expression used for persons who are close to the patient, regardless of whether they are spouses, significant others, relatives, grown-up children, or friends.

*Strategy* is the means a person employs to cope with a difficult situation.

*Hope* is a common and useful strategy with a positive effect on quality of life. The definition of hope can vary but is essentially a positive view of the future.

*Denial* is a psychological defence mechanism where the person does not take in reality and suppresses it.

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### The aim of the study

The aim of the study is to explore *the conditions* on which professionals make their assessment of loved ones' insight into a patient's fatal disease.

### Method

#### Design and analysis

A qualitative design was chosen to acquire deeper knowledge of the professionals' perception of loved ones' understanding of the course of an incurable and fatal disease. The study was conducted at geriatric, oncology, and urology wards at a university hospital in western Sweden. The urology and oncology wards had cancer patients in both the curative and palliative phase. The geriatric wards had patients with several types of disease, all in the palliative phase. The questions only concerned patients in the palliative phase.

Data were collected over a 3-month period between February and May 2010. To ensure the crucial themes of the study were explored, certain key questions were formulated in advance. The transcribed interviews were analysed using content analysis, which results in a richer understanding of the meaning of the content. The analysis was performed in several steps. First, text relevant to the research questions was marked. Units of meaning were then identified, condensed, and grouped into codes. Second, these codes were discussed, compared, and put into labelled categories. In the third and final step, the categories were structured into subthemes and themes.<sup>12-13</sup> (See Table 1.)

The study was approved by the Regional Ethical Review Board in Gothenburg (680-06).

#### Trustworthiness

To ensure trustworthiness and validity in qualitative research, there are many aspects to consider. The use of in-depth interviews as opposed to questionnaires leads to a deeper understanding of the participants' discussions of their assessments and the grounds on which they assess loved ones' insight into a patient's fatal disease.

To ensure credibility, all participants in this study were professionals working on a daily basis with patients with an incurable disease and their loved ones. The interviews were performed by the first author and transcribed verbatim. The analysis was made in close cooperation and discussion with the co-authors. Any differences were discussed and an agreed description was formulated.<sup>12-13</sup>

#### Participants

Forty-eight doctors, nurses, and assistant nurses working at the various clinics were invited to participate in the study. They had all been part of a preceding questionnaire study<sup>11</sup> on the same subject and were therefore asked by an information paper at their ward if they were interested in taking part in this more comprehensive interview study. If they were interested, they were asked in to send informed consent by letter, and 35 professionals did so. Of the 48 participants from the questionnaires study, 13 did not participate, providing the following reasons: no longer working at the hospital, had changed their mind about participating, or could not be contacted at the telephone number given.

### Results

#### Characteristics of the participants

The participants in this study were doctors, registered nurses, and assistant nurses. The detailed characteristics of the participants are presented in Table 2.

#### General understanding

The results indicate that regardless of professional category, age, gender, or type of clinic, the participants assessed loved ones' insight into the fatal disease based on the *course and content* of the conversations they had with the loved ones. In general, the professionals considered the loved ones' realization of the seriousness and consequences of the disease to be closely related to the information provided. However, insight varied during the course of the illness depending on the symptoms. The professionals' assessments were also

TABLE 1. EXAMPLES OF THE ANALYTICAL PROCESS

<i>Interview question</i>	<i>Unit of meaning</i>	<i>Condensed unit</i>	<i>Code</i>	<i>Category</i>
How do you assess the loved ones' insight into the patient's expected death?	If they talk about the information given and the current situation they have insight.	If they talk about the disease openly. If they talk about subjects other than death. Hope is more common when death is not imminent.	Assess using the content of the conversations. How the questions are connected to death.	How they talk and express themselves in words and behavior. How the loved ones assess their observation of the patient's condition.
On what grounds do you assess the loved ones' insight into the fatal disease?	In the encounter and in the content of the conversation with the loved ones, where the loved ones can express their insight.	What they say. How they act.	If they seem to understand when they speak and how they behave when they are together with the patient.	The type of question the loved ones ask the staff. How hope is assessed as denial or as a strategy.

TABLE 2. CHARACTERISTICS OF STUDY PARTICIPANTS

	N
Profession	
Registered nurse	18
Assistant nurse	6
Physician	11
Gender	
Male	6
Female	29
Age	
20–29 years	5
30–39 years	7
40–49 years	9
50 and greater years	12
Years of employment	
1–10 years	9
11–20 years	8
21–30 years	9
31 and greater years	7

based on *how* the loved ones talked and expressed themselves in words and behavior and on the *type of questions* posed by the loved ones. The *loved ones' observations* and *hope as denial or a strategy* also contributed to their assessment.

#### **How the loved ones talk and express themselves in words and behavior**

The professionals assessed the loved ones' insight according to the way they talked about the patient's condition, such as alternative means of treatment, questions about the symptoms, and if they spoke as if the symptoms were the problem and not the disease. The professionals made their assessments based on the content and quality of the questions put to them by the loved ones. If, for example, questions revealed that the loved ones were asking about things they should already know, the professionals concluded that the loved ones had not taken in the information that had been given and consequently they did not have insight into the course of the disease. Typical questions that reflect this lack of insight could take the form of asking about the possibility of the patient going home or traveling away somewhere as soon as the patient's symptoms had improved. The content of the conversations and whether the loved ones' behavior confirmed or conflicted with what they were saying were used to assess the loved ones' understanding. The professionals' assessments were also based on the loved ones' expectations regarding the patient's appetite, thirst, or mobility.

*They laugh and they're happy and that makes you wonder whether they've taken in what has been said. The way they react...they could sometimes go away for a week.*

The more expectations the loved ones expressed concerning the above, the less insight the professionals felt they had about the course of the disease. The professionals' observations regarding the various ways of coping, behaving, and talking within the families were also taken into account. What they felt was difficult was assessing whether the family used specific forms of communication that were unfamiliar to the professionals or if the way they communicated was a result of lack of information.

*"It depends very much on how open the loved ones and the patient were in their communication before the patient became ill."*

The professionals also observed the way loved ones cared for and protected each other to reduce anxiety and fear about the course the disease will take. Consequently, not every subject was discussed.

*"Some patients feel a need to shelter their family from anxiety."*

Several of the professionals highlighted the influence of culture on the level of insight, both with regard to differences within the unique family culture and more generally with regard to differences between nationalities.

*"I have observed that in some cultures they don't want to talk about the disease...They want to protect each other."*

#### **Common questions posed by the loved ones**

The professionals stated that they regarded the content of questions put to them as an indication of how much the loved ones really understood about the seriousness of the disease. Questions such as how long it would be before the patient died were considered to be an indication that the loved one had insight. When presented with this kind of straightforward question from loved ones, the professionals either told them that it was not possible to give an exact answer or they gave a broad time span.

*"They ask how many hours or days they have left...They say that I have experience of what can happen...but I can't say...Sometimes it can be quick."*

On the other hand, questions related to the patient's status, rehabilitation, food, dreams, and future expectations were more difficult and more uncertain as a basis for assessing the level of insight.

#### **The loved ones' observations**

The professionals' assessment was that as the disease worsened, the patient's visual appearance changed and this helped the loved ones to realize and understand the seriousness of the disease. Nevertheless, this insight was sometimes camouflaged by a strong focus on how actual symptoms influenced the patient at that particular moment. They also declared that it was more difficult to assess the level of the loved ones' insight during the initial stages of the process when the patient felt better, compared with the later stages when the loved ones were affected by the deterioration in the patient's condition.

*"They see how sick the person in question [the patient] is and they realize that he or she can't take any more. When they perhaps see that they have stopped eating and drinking...that they can't manage their ADL...then they realize that things are going downhill."*

#### **Hope as denial or strategy**

Whether or not the loved ones had insight into the current situation and whether hope was denial or a coping strategy, were crucial issues when making an assessment. When hope was considered to be denial, the professionals felt that the loved ones needed more information.

*"There is no hope and yet they still hold on to the idea that something can be done."*

Regardless of whether hope was used as denial or a coping strategy, the phenomenon was more common in the beginning of the illness, compared with when death was approaching. Many of the professionals stated that loved ones do not realize in the early palliative stage that the patient is going to die soon.

*"They do not want to lose hope."*

*"They are conscious of the fact that the patient will die but not soon."*

The professionals understood that the use of hope as a strategy was necessary for the loved ones and the patient to cope with the situation and thus regarded it as something positive.

*"They want to hope...Doing so is a strategy."*

*"I realized the person understood but did not want to take it in."*

## Discussion

When estimating the loved ones' level of insight into the patients' fatal situation and the ensuing consequences, the professionals base their assessment on several conditions. Cherlin and colleagues<sup>9</sup> stress that the discrepancy between what the doctors have said and what the loved ones have understood can hinder the assessment of loved ones' insight. Dougherty et al.<sup>14</sup> show increased stress among professionals due to the difficulty of talking about serious subjects, which can influence assessment and highlights the need for training in the provision of difficult information. Being informed is a crucial support insight in a critical situation. Nevertheless, this study shows that even though information had been given at an early stage, several conditions influenced the professionals' assessment of the loved ones' understanding of the course of the patient's disease. A common reflection among the professionals was that even though loved ones were aware of the patient's condition, they were able to suppress its fatal consequences. It was more common to suppress the seriousness of the disease as long as the disease seemed treatable, but once impending death was obvious there was an expression of knowledge and awareness of what was happening. The way the loved ones talked and expressed themselves was used by the professionals as a basis for assessing insight. The choice of subject, that is, talking about the disease, the treatment, or dreams and wishes, was used by the professionals as a basis for assessing the level of knowledge among the loved ones. If the loved ones avoiding talk about the disease itself, this was considered a lack of insight. It is well known that communication differs between families according to what is permitted to be said or not said, which can have an effect on coping mechanisms, as reported by Payne and coworkers.<sup>15</sup> This fact, combined with the professionals' pronounced lack of competence concerning these matters, was highlighted as a challenge to the correct assessment of insight, with the risk of assessment based on the professionals' own way of communicating becoming the norm. The professionals felt that being confronted with a straightforward question from the loved ones about the time the patient had left was difficult to handle but at the same time it was considered an indication of significant insight into the fatal

situation. One can assume that this type of question plays an important role in loved ones' preparation for the impending death and it could reflect a wish to talk about existential questions regarding life and death. It could be an opportunity for the loved ones to discuss in what way they could prepare themselves for a future without the patient and thus act as a source of support in bereavement.<sup>16</sup> Other subjects for conversation were more diffuse, such as focusing on current symptoms. According to Lobchuk and Degner,<sup>17</sup> focusing on a symptom and hoping it could be treatable may ease the suffering among the loved ones in the present situation, but it is probably more of a strategy than lack of knowledge. It seemed as if it was easier to talk about specific symptoms rather than death, because treatable symptoms could be a symbol of hope of a prolonged life. Other areas used as a basis for the professionals' assessment of the loved ones' level of insight were questions about nutrition, rehabilitation, or traveling, even though the patient was in a condition where such an activity was very much impeded by the progression of the disease and the situation as it really was. These kinds of questions from loved ones, which were put in a way that they were really meant to be a genuine option, were considered by the professionals to be a reflection of poor insight. In these situations, it is crucial that the professionals are aware that insight might fluctuate depending on the loved ones' coping capacity at the time, varying between strategies of hope and denial and where hope could be seen as a more or less unattainable task or wish.

According to Benzein,<sup>18</sup> hope is a strategy used by both patients and loved ones, even if the level of hope normally seems to be lower among family members than among patients. Kylmä and colleagues<sup>4</sup> and Fitzgerald Miller<sup>19</sup> have shown that hope is an essential dimension for dealing successfully with illness and preparing for death. It is a multi-dimensional, complex construction with the anticipation of a good state of mind and is not possible to measure. When the loved ones express hope, the professionals' assessment of their insight into the situation will depend on the professionals' own opinion of whether hope is a strategy or a denial with the risk of making a personal rather than a professional assessment. Telford et al.<sup>20</sup> saw that it is common among health care professionals to use the terms *acceptance* and *denial* when describing a person's response to being chronically ill. Travis and coworkers<sup>21</sup> points out that when dealing with denial, the first step is to explore whether it actually is denial and not a strategy in order to cope with the situation.

According to findings by Mårtensson et al.,<sup>22</sup> nurses tend to overestimate the patient's emotional stress and underestimate their coping resources. It thus ensues that if professionals consider hope as denial, and therefore something negative, it could lead, for example, to referring to the doctor to explain once again the fatal situation to the loved ones in order to reveal denial. It would appear to be important to increase the ability of the staff to consider the role hope plays for loved ones and patients, thus ensuring they receive adequate assistance to retain strategies and hope when these are needed.

## Strengths and limitations

This study comprises interviews with professional carers involved in the treatment of incurable and dying patients.



There were several interviews with different professionals. Despite the variation in age, gender, and profession among the professionals, the analysis revealed many similarities. We acknowledge that generalization could be called into question, although qualitative research has the advantage of allowing a more balanced insight to be revealed. The result can be useful in further research and discussion on this topic.

### Conclusion

It would seem as professionals base their assessment of loved ones' insight on a number of grounds. Ways in which to communicate with loved ones in a critical and difficult situation, such as when a close family member is dying, as well as awareness of circumstances are crucial when making an assessment. This can be an area for further training among health care professionals to assist them to become more skilled and secure when talking to loved ones. Training in conversation skills could be a way to support professionals when discussing and managing these difficult situations. This would probably also have positive effects on the well-being of the loved ones and the patients.

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### Author Disclosure Statement

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