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Crossing the border

Different ways cancer patients, family members and
physicians experience information in the transition to the
late palliative phase

Maria Friedrichsen



FACULTY OF HEALTH SCIENCES
LINKÖPINGS UNIVERSITET

Department of Biomedicine and Surgery
Palliative Research Unit
Faculty of Health Sciences
Linköping University
SE- 581 85 Linköping, Sweden
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- IV. Friedrichsen, Strang, Carlsson. Receiving bad news- experiences of family members. *Journal of Palliative Care* 2001; 17:4; 241-47.
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Abstract

Information in the transition to the late palliative phase is not a well-studied area, especially not from the perspective of patients and family members. The aim of this thesis was to describe how cancer patients, family members and physicians experience information during the transition from a curative or early palliative phase to a late palliative phase, i.e. when tumour-specific treatment could not be offered. Cancer patients (n=30) admitted to palliative hospital based home care, family members (n=20) of cancer patients, and physicians (n=30) working with cancer patients in different settings were included in order to create a maximum variation sampling.

Tape-recorded, semi-structured interviews and qualitative, phenomenographic analyses were done in all the studies.

Patients described the physician as an expert (study I), an important person during this event, despite characterising him/her in different ways ranging from the empathetic professional to the rough and ready expert. Their relationship with the physician was also stressed. Their own resources, i.e. a sense of well being, a sense of security and individual strength, and their previous knowledge, were important components regarding their ability to take part in the communication (study II). Patients interpret words and phrases carefully and can perceive them as forewarnings, as being emotionally trying, and as fortifying and strengthening (study III). The overall message could be interpreted as either focused on quality of life, on treatment or on death and threat.

Family members wanted to protect the patient during this period and could be very active and prominent in their protective role (study IV). However, other family members described themselves as being in the background more or less involuntarily. Family members also felt that there were expectations regarding their behaviour, either that they should take over in terms of communication, or that they should restrict their participation. When giving information, the physicians had a clear goal - to make the patient understand while being as considerate toward the patient as possible. However, the strategies for reaching this goal differed and included: explaining and convincing, softening the impact and vaguely suggesting, preparing and adapting. Some physicians had a main strategy while others mixed different strategies depending on the context.

The experience of receiving and providing information about discontinuing tumour specific treatment is like crossing a border, where patients experience the behaviour of the physician and the words they express of great significance. Family members assume the role of protectors. Physicians use different strategies in order to help patients cross the border.

Key words: communication, information, patient-physician relationship, family, prognosis, palliative care, cancer.

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BACKGROUND

Information and communication

The information given to patients has increased during recent years. Despite efforts regarding information and education for cancer patients, many patients are still dissatisfied (1-3). With few exceptions, patients and family members would like to receive more information than they are given (4-7).

Information is a general concept concerning the meaningful message that is transferred via communication in different forms. Information is described as a certain amount of more or less exact facts (8) and does not have to involve an interactive approach (9). When someone receives information, the information will become a part of different types of cognitive activities such as analysing, comparing and organising in a new way in order to make the reality comprehensible (10). According to Buckman (11), bad news is "information that drastically and negatively alters the individual's view of their future".

According to Fiske (12), communication consists of signs and codes that are individual constructions. A sender, a message and a receiver are prerequisites for transferring messages. Communication may be seen as a process or as a creation and exchange of meaning (12).

There are different perspectives concerning why individuals need information in health care, namely ideological and practical. The ideological perspective is related to ethics and stresses the patient's interests: autonomy, dignity and self-respect. The purpose of information is to make patients aware of their state of health (13) and to clarify the illness experience for them (14). In a palliative context ethical principles, such as respect for truth and the rights of the patient, should be considered (15). But ethical thinking may be different in different cultures. It is well known that in some cultures families rather than patients are given the cancer diagnosis and prognosis, and that the patients are unaware of their terminal illness (16-23). According to Swedish legislation the patient has a right to know and the physician a duty to inform the patient (24).

The practical perspective is related more to the health care staff and reflects that a well-informed patient facilitates the work of the health care organisation such as, for example, better patient co-operation with treatment regimens, quicker recovery and shorter lengths of stay in hospital (25).

Information regarding a cancer diagnosis

Information to cancer patients has been a matter of interest in the scientific literature. Cancer patients want information, even when facing a bad prognosis (5, 26-30). Several studies have been undertaken to clarify the informational needs of cancer patients as regards treatment, side-effects, in what context and by whom the information is given, as well as emotional support and participation in decisions (1, 26, 27, 31-38). A central and difficult issue stressed by medical professionals has been the question of how much to tell cancer patients about their illness and how to best provide that information (39). Several guidelines have also been constructed based on clinical practice, research and consensus meetings in order to improve information and communication (40-44).

Patient preferences when given information about a cancer diagnosis and prognosis seem to be different in different studies. The highest ranked information issues concern dealing with chances of cure, the spread and course of the disease (14, 35) and the importance of being told honestly, in private, with hope and compassion, and allowing time (45). Patients who experienced honesty and a good deal of time during disclosure are reported to be more satisfied than others (1, 46). A caring and empathetic physician is of great importance to patients (45), as is a personally interested physician with the ability to convey information (1) and to listen (29).

Demographic characteristics such as gender, social and economic factors have sometimes been described as influencing the kind of information the patient needs. Well-educated patients from affluent areas, women, and unmarried persons have been reported to want more information (5, 47, 48), while patients with limited secondary education are more likely to underestimate the seriousness of the illness (49) and request less information (5). Highly educated patients and females are also more often informed than males and patients with limited education (48). In some studies males have been

reported to want less information (26, 48) and dissatisfied patients to have more information-avoiding behaviour than those who are satisfied (50).

Despite extensive research, problems still exist when giving information to cancer patients. But what are the underlying problems in this area? One barrier to effective communication may be that patients cannot recall all of the information their doctors have given them (51); only 25 % of the important facts are remembered (52). This could be due to the "primacy" and "recency" phenomena, meaning that a patient remembers best what is said in the beginning and at the end of the consultation (25, 53). People may be blocked when they hear the word cancer. Cancer patients do not always discuss what they intended to discuss from the beginning. Identified obstacles include nervousness, the seriousness of the disease, and the specific situation, which might include a hurried or uninterested doctor or disturbances during the consultation (54). Getting on with life as well as maintaining a positive outlook and acting brave were perceived by patients as the approach to managing illness that was most respected by hospital staff, friends and family (55). This could also be an obstacle. Patients might also feel that language collapses, i.e. that certain aspects of the experience are impossible to communicate (56). Distancing tactics among doctors and nurses have been described as further barriers (57).

Information in a palliative cancer context

It has been stated that "nowhere in medicine is communication between the doctor and the patient more critical than in palliative care" (58). This was particularly obvious in the 1960s when patients were generally not told about their diagnosis and prognosis. The reluctance to provide information was based on the belief that information would cause anxiety and distress (25). Awareness of dying has been the central theme in many studies (59-62). Glaser and Strauss (63) identified four types of awareness contexts in dying people in San Francisco hospitals:

- Closed awareness, where professionals kept patients uninformed of their impending death.

- Suspicion awareness, where patients suspected an impending death and tried to confirm this from professionals and relatives.
- Mutual pretence, where patients, relatives and staff knew that the patient was dying but pretended that everything was normal.
- Open awareness, where all parties knew that the patient was dying and talked openly about it.

Since Glaser and Strauss' study there has been a move away from the first three types of awareness to open awareness (15), and most physicians in the US, Western Europe and Scandinavia do provide information to cancer patients (25). The doctor's own anxiety and fear of becoming too emotionally involved was suggested to be of central importance regarding whether the patient was informed or not and also regarding the way in which the bad news was communicated (64, 65). The patient's intelligence, personality and emotional stability, as well as the patient's desire to know, were the main criteria doctors used to determine whether or not they disclosed the cancer diagnosis to patients (18, 66). Nowadays doctors are more comfortable discussing a primary cancer diagnosis, but remain less inclined to discuss a terminal prognosis (65, 67). In one study it was pointed out that the information was related to biomedical questions to a greater degree than to emotional aspects (68).

Today it is suggested that honest information has several advantages such as decreasing anxiety, for example, and it therefore facilitates communication between staff and patient and/or family members and gives the patient time to prepare for dying (15). Information about prognosis is therefore of great value to patients and family members.

Patients with an advanced disease also want to have information (26, 30, 69). According to Canadian physicians at least 60 % of the patients wanted to have knowledge about the terminal stage of their disease (67). Gray et al (69) stressed the need for knowledge among patients with metastatic breast cancer, especially information with personal relevance such as the prognosis and course of disease progression, but that it should not be given in a deterministic way by using statistics. Another study reported that 26 % of lung cancer patients experienced a lack of information about prognosis (70). These studies suggest that patients do want to talk honestly about the seriousness of their

disease, but this does not mean that they are prepared to take the initiative. In one study only 46 % asked about their prognosis (46), which is in accordance with other studies reporting that patients took less initiative in discussing the nature of the illness, prognosis and psychosocial problems (28, 54, 71). There seems to be a discrepancy between preferences and reality. However, studies have reported that physicians spent more time and showed more concern with patients with a poor performance status and a blunting coping style (72, 73).

There is much misunderstanding about treatment intentions with respect to palliative chemotherapy and radiation therapy. For many patients hope is related to treatment and treatment expectations (74, 75) and the doctor may be seen as a protector against death (55, 76). Patients might believe that palliative treatment is curative and underestimate the seriousness of their illness (46, 49, 77, 78). In one study, one third of the patients had an incomplete understanding of their diagnosis (79). Communicating a poor prognosis may be difficult, as there is a risk for misunderstanding if the message not is sufficiently clear. But from physician perspective it may also be difficult to give a clear message when the physician is expected to save lives. Further, denial cannot be ruled out as a major reason for misunderstandings (80). Both patients and family members may avoid discussing end-of-life issues (81). If the patient/relative is very active and overestimates the chances of cure or demands that the physician do "everything", communication may be blocked or complicated and result in misunderstandings (81). However, Halstead (82) reported that evasive coping styles were not seen as effective or helpful by patients.

Transition

Transition is a concept related to change and process (83). In this thesis it will be related to a health-illness event and also a situational event (84), when information is given about discontinuation of tumour specific treatment. This can be regarded as a critical event for all parties involved, patients, family members and physicians. It should be pointed out that this thesis has not focused on the process of transition but rather on a critical event that often constitutes the start of this particular transition. Knowledge about transition therefore broadens the understanding of the context in which the bad

news about treatment was delivered. The concept of transition has been defined as a movement, a passage from one state, condition or place to another, and is characterised by flow and movement over time (85). When describing events in the cancer trajectory, transition has been used as a theoretical framework, or simply to define a critical point and process in the lives of the patient and family, as well as to indicate a critical task for the physician (14, 86-90). An attempt is made to link the results of this thesis to the theory of transition in the discussion. Some of the main characteristics of a transition will be described briefly.

Transitions are *processes* that occur over time (91). They may be preceded by or constitute a response to a critical event or crisis. The process indicates that there is a sense of movement, and it has an entry, a passage and an exit (83). It includes the ending of the old situation, a start of the transition, a period of distress, and leads to a new beginning in a partly new situation. Another characteristic is *disconnectedness* (83), which means a disruption of the linkages on which the person's feelings of confidence depend, i.e. a loss of familiar references. *Patterns of response* are related to observable and non-observable behaviours during the transition process. The behaviours reflect both intra psychic patterns and processes and can, for example, include changes in self-concept and role performance, as well as anxiety and depression, coping mechanisms and outcome indicators such as a feeling of relief, distress or neutrality (83, 85). *Awareness* is related to the perception, knowledge, and the defining and redefining of self and situation (83, 85). To be in a transition the person has to be aware of the changes that are occurring (83). *The conditions* in the process can facilitate or inhibit progress toward achieving a healthy transition (85). These conditions can be personal such as meaning, cultural beliefs and attitudes, or they can involve preparation and knowledge.

Curative, palliative and terminal care

Traditionally, curative care has been described as demanding and treatment-oriented, and palliative care, somewhat erroneously, as more passive and as being oriented more toward nursing and quality of life (92). Most studies about information to cancer patients have included patients in different stages, supposing that the need for

information is the same for all, despite the differences in outcome (curative treatment and recovery/ palliative tumour- specific treatment for a short time or over several years/ palliative symptom treatment without tumour- specific support). There are differences between receiving information about a diagnosis of cancer where death is a threat that is possible to fight, and receiving information about the spread of a disease that is no longer possible to fight with treatments. Death is not a threat anymore, but a reality. The patient's performance status may also be worse, which may hamper receptivity.

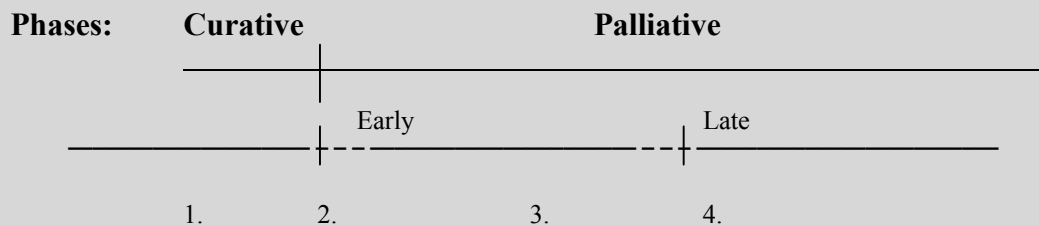
It is important to have knowledge about the prognosis when informing patients about completion of tumour specific treatment. But prognosticating survival time may be problematic. Statistical chances for cure and survival time as well as age and other simultaneous diseases may provide direction, but there are always individual differences (93). Several factors have been suggested to be indicators of an imminent death, such as low functional and performance status, serious nutritional problems and mental status (94). Consideration should be given to prior treatment, pre-existing diseases and the role of psychological status and social support as influencing factors (94). General condition and the progression of the tumour have been reported to be the factors most frequently used for prognostications (95). The decision to withdraw treatment should be based on the patient's wishes, medical indications, benefits and burdens of treatment, and anticipated quality of life that may result from treatment (96).

There has also been much discussion about when curative treatment ends and when palliative care starts. It is therefore relevant to state the viewpoint taken in this thesis regarding these definitions. Glimelius (93) describes this from an oncological perspective; the palliative phase starts when there is no longer any possibility of cure. This may be very clear from a professional perspective, but there is much misunderstanding on the part of patients about the intention of treatment (see previous chapter). Doyle et al (97) discussed the WHO definition, and stated that palliative care is greatly influenced by the hospice movement and the definition of terminal care. Terminal care is related to the last phase in life, where the dying process, whether imminent or ongoing, is central. This term is vague according to Doyle et al and leads to passive care and negativism, contrary to the intention of palliative care. According to WHO (98) palliative care is:

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families".

Health care professionals in the UK demonstrated a strong identification between the stages of palliative and terminal care (99). Defining exactly when palliative cancer care starts in terms of time is a complicated matter. Palliative care has been said to have an early and usually extended phase in which tumour- specific treatment aimed at prolonging life may be a part of the treatment (table 1). It also has a late phase, which can comprise days, weeks or months, in which tumour- specific treatment is usually not appropriate. This division was recently described in the report from the Swedish Social Ministry "Death concerns us all- dignified care at the end of life" (100). In this thesis we have also accepted the WHO definition.

Table 1. A simplified model to define phases of curative and palliative care



1. Curative intention and/or no active disease.
2. Verified tumour spread.
3. Early palliative phase. In some cases (e.g. breast cancer, prostate cancer, lymphomas) a period of several years. Tumour-specific treatment is given aiming at tumour control, symptom control, best quality of life and life prolongation.
4. Late palliative phase, in most cases weeks to months. Tumour-specific treatment is discontinued. The goal is best possible quality of life, but not to prolong or shorten life.

AIMS

General aims

The aim of this thesis was to describe experiences regarding information in the transition from a curative or early palliative phase to a late palliative phase, i.e. when tumour-specific treatment could not be offered, from the perspectives of cancer patients, family members and physicians.

Specific aims

Paper I. To study patients' experiences in relation to the physician during this event.

Paper II. To study patients' experiences in relation to their own participation and resources.

Paper III. To study patients' experiences in relation to verbal expressions and messages during this event.

Paper IV. To study experiences of family members with a focus on their role in this context.

Paper V. To study experiences of physicians when providing information in this context, with a focus on the strategies they used.

MATERIAL AND METHODS

Sampling

As phenomenographic research is focused on different experiences, a maximum-variation sampling was used in this thesis (101).

Study I-III. Different criteria were constructed in order to obtain a wide range of data. Inclusion criteria were used. The patients were to:

- Have disseminated cancer and be aware of their diagnosis and prognosis
- Be admitted to a palliative home care unit
- Have received their information less than three months before being interviewed
- Have no further ongoing oncological treatment
- Be in a steady state with the physical and psychological capacity to participate
- Be Swedish-speaking and agree to tape-recording
- Be included in order to achieve variation as regards age, gender, education, diagnosis and time since diagnosis.

In studies I-III, 30 patients participated (18 females and 12 males). Age varied from 29 to 86 years. The hospital based home care team made an assessment according to the inclusion criteria and approached the patients with oral and written information about the study.

Study IV. In study IV different criteria were used. The participants were selected for this study based on the following inclusion criteria. The family members were to:

- Be the family member of a cancer patient admitted to a palliative hospital-based home care unit (be a caregiver).
- Be present with the patient or alone when information was given about ending treatment.
- Have received this specific information less than three months previously
- Have the physical and psychological capacity to participate according to the judgement of the palliative care team
- Be Swedish-speaking, and agree to having the interview tape-recorded

- Be included in order to achieve variation as regards age, gender, relationship to the patient and educational level, as well as time since diagnosis and the patient's type of cancer.

Twenty family members participated in this study (11 females and 9 males). Their ages ranged from 21 to 83 years. The hospital based home care team made an assessment based on the inclusion criteria and approached the family members with oral and written information about the study.

Study V. In study V the following minimum inclusion criteria were used. The physicians were to:

- Have experience in delivering such information
- Be Swedish- speaking
- Accept tape- recording
- Be included in order to achieve variation as regards gender, age, speciality and experience.

Thirty physicians (21 men and 9 women) participated in this study. Their ages ranged from 29 to 65 years. The physicians were first asked to participate by the head of their department. They were then approached with oral and/or written information about the study via mail or e-mail.

Data collection

All the studies were begun by doing test interviews. These interviews were performed in an open manner to find out what seemed to be of importance to the participants, whether the interview guide was suitable for those being interviewed, and whether it covered different aspects of the phenomenon. The interview guides were then modified depending on the findings. A pilot-study was done in the first study. This provided the researcher with a framework for the other interviews.

Semi-structured interviews were performed in all the studies. There is some controversy concerning the definition and the performance of a semi-structured interview. In this thesis Patton's (101) description of an interview guide approach has been used. The interview guide is seen as an aid for the interviewer, not a slavish contract, and the researcher can use a conversational style. The experience of the informant is what is most important in phenomenographic interviewing (102). To achieve the goal of phenomenographic interviewing, the interviewer is required to adopt an accepting and relaxed attitude and a genuine interest in what the person has to say (103). In order to study the interviewed person's experience it was presumed that a conversational style would be more beneficial than a structured guide, which would not leave enough space for either the informant or the researcher.

All the interviews began with more general questions concerning, for example, the disease, how it started (I-IV), or why the physician had wanted to become a physician (V), and then continued with other questions about their experience. The questions were probing, of a follow-up character (how, why, what), as well as direct and interpretative (104) (see appendices).

The data were collected between 1998 and 2001. The interviews were performed in the homes of the participants, or in the office of either the researcher or the participant. All interviews were tape-recorded and transcribed verbatim by the researcher (I-III) or by secretaries (IV-V). All tapes transcribed by secretaries were scrutinised by the researcher. The interviews varied from 40-90 minutes (I-III), 50-120 minutes (IV), and 40-120 minutes (V).

Preconception

Preconception is an important concept in qualitative research, and differentiates phenomenology and hermeneutics, two influential philosophies. Phenomenology claims that bracketing or *epoche* should be used, i.e. that the preconception should be set aside (105), while hermeneutics claims that there cannot be any understanding without preconception (106). In phenomenography different conceptions have been suggested in this regard. Baker (102) states that phenomenography wants the informant to reflect

upon his/her experience, not to be pre-reflective or search for the lived experience. Baker speaks about the informant's pre-conception. Ashworth (107) argues that the researcher should set preconceptions aside during the interview. In an ideal situation there is an advantage to being open, and the intention in this thesis has been to endeavour to that, especially in the interviews. But being completely open during the whole research process is impossible, as the understanding of the phenomenon is based on discernment. The longer the interview process progresses, the more understanding the researcher will gain. However, the preconceptions and beliefs of the researchers were stated and followed during the process of analysis (108).

The researcher is a nurse with over ten years of experience in working with cancer patients in different stages. The thesis should be read with that in mind.

Phenomenography

Phenomenography is a research approach developed in Gothenburg in the 1970s by Marton et al in the domain of pedagogic research (109). This research- group (INOM = inlärning och omvärldsuppfattning) studied learning and teaching processes. From the start, phenomenography aimed at a description of people's conceptions of a certain phenomenon, described in a superficial interpretative way (110). The word conception has been described in different ways, such as in the following quotation from Svensson and Theman in 1983 (111).

"The nature of a conception is that it represents a relation between an individual and a part of the world. The relation consists of the activity, the thinking, of the individual in relation to the part of the world concerned."

However, over the years different expressions have been used for what is being researched. Examples are conceive, experience, perceive, thinking, understanding and recently, remembering a phenomenon (112). In 1995 Marton (113) started using "ways of experiencing" a phenomenon instead of "conception". A basic assumption in phenomenography is that people differ as to how they understand phenomena in the surrounding world.

Phenomenography was initially described as an empirical approach, but in the 1990s Marton began to describe a theoretical base for this research (113). A non-dualistic and internal person-world-relationship is of importance in phenomenography. Humans cannot describe a world that is not based on themselves and on their descriptions (113). In phenomenographic research the subject is considered to have a relationship with the outside world, of which the phenomenon constitutes one part (114). Ontological status is the central theme in phenomenography, i.e. how humans experience the world. This has often been described as the second-order perspective, how people conceive and experience the world, not the objective facts around the experience (the first order perspective). The aim of phenomenographic description is to preserve the content of each expressed conception (115). A phenomenographic researcher's function involves "stepping back from one's own experience and using it only to illuminate the ways in which others state an understanding for something" (116), irrespective of whether or not the researcher finds the perception to be correct. The second-order perspective is, however, a perspective that is filtered through a human's mind. During recent years Marton has added, "as described by the researcher" (117), and phenomenography is now developing towards a theoretical, interpretative hermeneutic approach (118).

Marton (119) also describes a what and a how aspect, and particularly the latter is in focus in phenomenography. The what-aspect relates to the object of attention, what is discerned by the human as being central. The how-aspect relates to the structure described and the act. The how-aspect consists of the structural and referential or meaning aspect (113). The structural aspect means that the individual organises and discerns the parts of the phenomenon that becomes figural and thematised. The structural aspect is built up by the external and internal horizons. The external horizon means that the phenomenon is delimited and relates to a context, and is the outer boundary of the understanding (103). The delimitation and relating of parts makes up the internal horizon, which is based on an understanding that is clear (113). The referential aspect constitutes a whole, a meaning where the whole and the parts of the phenomenon provide the meaning of the experience (117). Wenestam (112) describes this in terms of creating a meaning and meaningfulness. Humans have to organise their perception to make it meaningful.

In order to understand ways of experiencing a phenomenon, the four elements of discernment, variation, contemporaneousness and simultaneity are important (117). Discernment and variation are dependent on one another. If there is no variation, the human cannot discern, and without discernment there is no variation. To experience variation, the person must have a contemporaneous experience of instances encountered at different points in time (117). The previous experience helps us to discern the variation. But to be aware of our previous experiences and our new one, we have to be simultaneous. Briefly, this means that to experience, the human has to have previous experience to be able to discern and experience variation (117, 118).

Description of the phenomenographic analysis

All the analyses in this thesis have been done according to the seven steps of Dahlgren/Fallsberg (115) (illustrating examples from the analysis in study V):

1. Familiarisation. The researchers read the transcripts several times carefully to penetrate the text in detail. While reading, all sentences about the phenomenon being focused upon were marked. Comments were made in the margins, along with the researchers' direct associations, in this step based on intuition without any detailed strategy.

2. Condensation. The most significant statements made by the informants were selected to give the central theme of the experience. The researchers addressed questions to the text with the following approach ,e.g.: "What does this physician say about providing information during the event"? Perceptions that were repeated several times (the frequency), consistently in various ways and based on their own experience, were selected, as were single statements if the statements were explicitly stressed (the pregnancy) (114). Long statements were then condensed, with attention to the primary meaning. Each selected condensed statement was compared with the original text to assure its primary meaning.

3.Comparison. Each condensed statement that was selected was compared to the other statements to find sources of variation or agreement. The researchers addressed the following questions to the text e.g.: "What is in focus in this physician's mind?" (in phenomenography this is called the "**what-aspect**"). This focus gave the researchers an early and preliminary clue to the constitution of the categories.

A further question was, "Why and how is this focus important to the physician and how does he/she describe it?" (in phenomenography this is called the "**how-aspect**"). The answer to this question gave a preliminary description of the informant's thoughts and experiences concerning the phenomenon, an early start to the content in the categories. Other questions were: "Is this physician's statement similar to or different from statements from other physicians? If so, in what way"? The main perception/s were distinguished by comparing them with other physicians' perceptions about the same phenomenon. Similarities and differences that were found were also compared with the respective original transcripts in order to find out whether there were other variations, between the lines, in perceptions that were only described implicitly. The implicit text was compared to the explicit text to find similarities that confirmed or overruled the preliminary statements. Only compared statements that were described in an explicit and clear way were selected for step 4, with a confirming implicit text when possible.

4.Grouping. The compared statements were then grouped together based on the previous comparison and questioning. Statements, which according to step 3 appeared to be similar, formed groups or preliminary categories.

5.Articulation. In this step an attempt was made to describe the central content of the statements in each preliminary category. The preliminary categories were also questioned. An articulation was made for and against the previous interpretation in steps 2- 4, with an interaction between the inner perspective from the physicians' texts, and the outside perspective from the researchers'. A central criterion for the establishment of the categories was that the categories should be qualitatively and distinctly separated from each other. The content of each category was to be limited, without variations that were too great, and without obvious overlapping between the categories.

6.Labelling. The various categories were denoted by constructing a tailored linguistic expression, representative for each category. The labelling was not necessarily done using the expressed words from the interviews, but abstractions could be used based on the researchers' judgement.

7.Contrasting. All the categories were then compared and contrasted with each other, considering their mutual relationship, but this time in a more abstract way, using the researchers' perspective. The logic and the internal relationships were scrutinised. Finally, the categories were co-ordinated to constitute a common structure, which is called the outcome space in phenomenography. The outcome space was then compared to other similar studies or theories within the field.

Some aspects of validity

One common source for validating the data is feedback from the informants. This method is based on the logic that it is the person who has experienced the phenomenon who is the expert and the owner of the experience as regards a second-order perspective, and that person is therefore able to give the best reflections on it (120). This type of validation can be used during the interview by asking similar questions, but expressing them differently (104). This type of feedback from informants is also one way to ensure the genuine conception of the informant.

In studies I-IV a dialogical validation was used (121). All interview transcripts were sent to the patients to give them a chance to make comments and changes. Only minor comments were made. In studies I-III a dialogical intersubjectivity (104) was used where two of the researchers (M.F, P.S) analysed the interviews separately. In the next step all interview transcripts were worked through line by line by both researchers together, i.e. compared for differences and similarities. This work was done with inspiration from the first pilot study. The material was discussed until agreement was reached.

In study IV one type of face validity was used to test the results obtained from the participants (101). The researcher met five of the participants one year after the

interviews. The aim was to meet with six family members, but two of them representing the last category were not able to participate due to rapid deterioration of their own health. The family members were supposed to represent the six different categories. This test was done to be sure that the interpretation made by the researcher was representative of the perceptions of the participants, i.e. to ensure the second-order perspective. Further details are described in paper IV. The participants had only minor suggestions as regards details about the analysis. These suggestions were added to the final analysis.

In study V another form of face validity was used. This time the analysis and a simple questionnaire were sent to the participants. They were asked to read the analysis and indicate whether this was in accordance with their personal experience. They were also asked to make comments about their own strategy, what they thought were missing, and other things they found to be important (see appendix IV and V). When appropriate, the comments were added to the analysis.

Ethics

A central issue in palliative care is the question about the appropriateness of research in terminally ill patients. Research in this area may be problematic as the patients and their families are in a very vulnerable situation. To occupy their time when time is limited may be seen as an intrusion, especially when addressing sensitive questions about their experiences. Qualitative interviews may be personally upsetting. The researcher has to make an assessment about the pros and cons, the beneficence and maleficence, of the study. Wilkie (122) states that research in palliative care is not different from other research, and the same directives as those in the Declaration of Helsinki should therefore be used. Patient evaluations of a previous qualitative interview indicated that it was a positive and a therapeutic exercise (123).

Strang (124) claimed that not researching this area could be unethical. We cannot provide the best care if we do not know what the best care is. Several of the patients and family members participating in this thesis explicitly told the interviewer that they wanted to participate to advance knowledge so that others in the same situation would

benefit. This is also in agreement with the views of existential psychotherapists. Yalom (125) claimed that altruism, i.e. doing good things or helping others, is meaning creating and therefore of great value for the severely ill patient.

What is of special importance when doing research in palliative care is the informed consent of the participant and confidentiality (122). Participants (I-IV) in this thesis were primarily asked to contribute by someone in their palliative care team. They were provided with both oral and written information. There was no contact between the researcher and the participants before they had agreed to such a contact. The researcher contacted patients and family members by phone and told them more about the study and asked if they still wanted to participate. This information was repeated again before the start of the interview. If the participant got upset (cried) during the interview, the researcher stopped the tape-recorder, waited, holding hands if appropriate, and after a few minutes asked if they wanted to discontinue the interview. However, every participant wanted to complete the interview. If the patient or the family member felt distressed after the interview, the palliative care team was there to support them.

Physicians of today have limited time, and it is therefore appropriate to discuss the ethical circumstances in study V. Every physician in this study had the opportunity to decide when and where the interview should be conducted in order not to interfere with his/her clinical practice. Many personal and sensitive experiences were revealed to the researcher during the interviews. The physicians were told that the researchers were the only ones who read all the material from the interviews and that no person could possibly be identified. Secretaries who did the transcripts of the interviews were chosen in such a manner that they had no personal contact with the particular physician. Despite all of this, nearly all of the physicians said that these arrangements were unnecessary and that they would stand by their perceptions.

RESULTS

Paper I

The way the communication was perceived and evaluated by the patients was associated with the characteristics of the doctor. Personality, behaviour, manner of communication and experience were of great importance. Both the satisfied as well as the dissatisfied patients described the doctor as a medical expert, despite also attributing different qualities to him/her. Six different subcategories were found in this study:

1. *The inexperienced messenger*, where uncertainty and lack of experience and thereby also lack of knowledge were central. This character could not provide the patient with the sense of security that they needed, as they could not trust the message delivered.
2. *The emotionally burdened*, where sympathy and emotional feelings were essential. This sympathy could be perceived as distressing, as the doctor could become too emotionally involved. This expert could, however, also be perceived as very considerate and understanding.
3. *The rough and ready expert* was perceived as having great medical experience but as being devoid of any knowledge of psychology and as having a disinterested attitude. This was experienced as cold- hearted, as the message was delivered in a fast, frank way, without taking the status of the patient into consideration.
4. *The benevolent and tactless*, with a friendly manner but without the knowledge to communicate the message in a considerate way. The lack of reflection in this doctor's manner hurt the patient, even though the patient realised that this was not the intention.
5. *The distanced expert*, characterised by formality, dominance and avoidance. This uninterested character made patients feel as if they were simply one case among many others, as if the only thing that interested this expert was the disease, not the patient.
6. *The emphatic professional*, where a balance between medical competence and empathy for the patient was central. This expert was perceived as pedagogic, interested and as taking responsibility to arrange helpful measures.

The relationship was also described as important with respect to being able to handle the information. It had mainly been built up during previous encounters. Four different relationships emerged:

- *Personal relationship between well acquainted individuals.* In this category the relationship was characterised by confidence and security and the dialogue was a natural part of this.
- *Impersonal relationship between unacquainted individuals.* The doctor and patient had not met before and could not connect on the same level. There was no understanding, only distance between the two parties.
- *Personal relationship between unacquainted individuals.* In this category the two actors had not met before. Despite this the relationship was perceived as personal and respectful.
- *Impersonal relationship between well acquainted individuals.* In this relationship the patient and doctor had an established relation but could not meet on the same level, as they were talking at cross-purposes and did not understand one another.

Paper II

The patients described their own participation as either verbally passive or active. Verbally passive receivers did not feel any responsibility to participate in ways other than listening or avoiding information. Verbally active patients took active part and described their feeling of responsibility regarding how the information was given and which information was given. These patients showed receptivity and even expectation and openness for the coming information. Some patients also described an interpretative activity where the doctor was scrutinised.

Previous knowledge at different levels was also described as important:

- 1) *Unsuspectingly naive* included those patients who did not know anything about the coming information. They were totally surprised, which decreased their capability of receiving the message.
- 2) *Apprehensively suspicious.* At this level patients felt somewhat suspicions about the information. These patients had perceived indications of the forthcoming information,

such as physical symptoms or things they had heard from health care staff. The information was described as a confirmation by these patients.

3) *Well prepared*. Patients in this category had extensive knowledge about their disease and knew about the limitations of treatments. They had accepted that their disease had progressed. Some of these patients even suggested stopping treatment.

Patients also described their own resources as being valuable when they received this information. These included:

- *Sense of well-being*, i.e. the patient had to feel moderately well to be receptive to the information. Symptoms such as pain or fatigue were described as decreasing their understanding of the information.
- *Sense of security*. The patients related that they wanted to feel secure during the information. Family members were important creators of security, both as a psychological support but also because they could listen more carefully and communicate on behalf of the patient.
- *Individual strength* was also perceived as important when receiving the information. This strength was described as a way to cope with the delivered message and was related to long life-experience as well as a positive attitude or as power from God.

Some relationships between the categories were found. Patients who described themselves as unsuspecting naive also depicted themselves as verbally passive as well as they emphasised the presence of a relative as security. Patients who described themselves as apprehensive suspicious also had the actively chosen verbal passivity as well as individual strength in common. Patients who described themselves as well prepared also described themselves as to be verbally active and to have an individual strength. They emphasised the relationship with the doctor as most important regards sense of security.

Paper III

The data from this study showed that the doctor's exact choice of words and phrases as recalled by the patients was of significance in this situation and had a great effect on how the patient interpreted the information. In this study three categories of words and phrases emerged:

- 1) Words could indicate *indirect warnings* as being forewarnings, functioning as rapid mental preparation. Examples of such words were "unfortunately", "I'm sorry" or "I don't have any good news to convey". Words could also be perceived as evasive or ambiguous, indicating an indirect warning, with the possibility of one's own interpretation. These words could be about the transition to palliative hospital-based home care and the amount of time that was left.
- 2) Words could also be perceived as *emotionally trying*, as threats or abandonment. The patients experienced increased fear of death or felt they had been dumped. These words concerned time limitation or the statistical chance of survival. A typical abandoning sentence was "there is nothing more to do".
- 3) Other words were directly *fortifying* and strengthened the patient. Patients felt assured that the doctor was still interested in their case. Such phrases were "we are going to help/support/arrange ". Words such as "strong and open" were examples of confirmatory words about an individual.

The overall message given during the information could be interpreted differently:

- a) As focused on treatment, where the patient had understood that treatment had to stop, but without further elaborating their conception of the message.
- b) As quality of life oriented, where a forthcoming life without treatment was seen as a relief.
- c) As focused on threat and death and described here as indirect or direct metaphors for death.

Paper IV

The data from this study showed that family members wanted to represent or act on behalf of the patient, i.e. they wanted to protect and care for the patient in this situation. Some described themselves as assuming prominent roles:

1. *The demander-of-truth role*, where information was demanded and extracted from the doctor to test the evidence for the decision. The central motivation for this behaviour was to assure that this decision was right, that no more tumour-specific treatment was available.

2. *The secret-keeper role*, where the wish was to hide and conceal the information from the patient and create an alliance with the doctor. This was done in order to protect the patient from the unpleasant truth.
3. *The controller role*, where an active tactic was used in order to limit what was said during the information. By asking many questions the central issue could be avoided.

Others assumed more passive roles and stayed in the background, feeling that they kept at a distance more or less voluntarily:

1. *The surrendering role*, where all capacity to communicate was lost and they were emotionally stunned. These family members experienced chaotic feelings and had difficulty being supportive, and said they could "only" contribute with their presence.
2. *The considerate listener role*, where the relative took a subordinate position and was present in the background as silent support in order not to trouble the patient or the doctor with their own questions, as they did not want to hurt the patient.
3. *The excluded outsider role* was described as a loss of role function, as the task of being a representative protector was greatly diminished because the patient had long known the bad news. This family member described feelings of disappointment and anger because the truth had been kept from him/her.

Another main category comprised expectations regarding the family member's role and behaviour. These expectations came from themselves, the patient, the doctor or other family members.

- *The expectation to take over*. In this category the expectation was described as an implicit or explicit deal between the patient and the family member that it was the relative who should speak on behalf of the patient. Others described that the doctor expected them to take over the communication as they were expected to be strong and capable.
- *The expectation to be present but restricted*. In this category the family members felt as if they were expected to be present but without room for their own questions. The dialogue was to be between patient and doctor, and the family member was only supposed to be a source of security.

Paper V

The physicians participating in this study had a clear goal when giving information, which was to make the patient understand while being as considerate as possible.

However, the strategies for reaching this goal were different:

1. *Explaining and convincing strategy*, i.e. giving a detailed explanation about why treatment had to be discontinued. The goal was to have a medically well-informed patient.
2. *Softening the impact and giving vague suggestions*. In this category the doctor recommended discontinuation of treatment, but without deciding this by himself/herself. By avoiding an explicit confrontation, and by vaguely suggesting completion of treatment, the doctor could let the patient decide about this.
3. *Adapting or tailoring the information to the patient*, where the doctor tried to adapt to what he/she thought was the patient's level. When the doctor was sounding out the patient he/she was actively seeking knowledge about the patient in order to be able to adapt the information to the patient's level. When the doctor used verbal reduction he/she briefly described the situation and then remained silent, allowing room for the patient's reactions and questions, in order to let the patient take an active part.
4. *Preparing*. In this category the physician tried to prepare the patient for the forthcoming information in order to facilitate it. The information was given gradually in order to prepare the patient. The physician could also prepare by giving himself/herself a pep talk or by thinking out possible reactions.

Some doctors had a main strategy while others mixed different strategies. The strategy used was often described as depending on the context. A change of strategy could occur naturally, or the doctor could feel forced to change strategies. Factors that influenced choice of strategy were, for example, the previous doctor-patient relationship, empathy, feelings and expectations.

DISCUSSION

Patient perspective

Only a few studies have explored the experience of patients and family members when receiving information about discontinuation of tumour specific treatment. The patient and family member perspective in research is now growing rapidly, as health care providers are concerned about how they perceive their care/information/support, etc. (126). The obvious way to get knowledge about this is to ask them directly.

The results from studies I-III may be perceived as very gloomy, but the message is extremely serious, implying physical, psychological, social and existential concerns for receivers as well as for those delivering the message. It is important to remember that this message is grave and cannot be seen too positively, but that the potential still exists to improve the circumstances both for those providing the message and those receiving it.

The doctor

The doctor's manner when breaking bad news was described as being of great importance to patients (I). This has also been reported in other studies (127, 128). To some extent study I also emphasises doctors' compliance with patients' wishes, as seen from a patient perspective. The level of security the doctor is able to provide to the patient is of importance. When comparing the characteristics of the different perceived "experts", some of the factors that provide security appear to be: balancing medical and psychological knowledge, routine, experience, objectivity, sensitivity, interest and empathy. If there is a lack of balance between objectivity and sensitivity such as, for example, in the case of the benevolent and tactless expert, the patient may interpret this as insensitivity. If there is too much objectivity (the distanced expert) this is perceived as coldness and distance. When there is an imbalance between routine and experience, this could be perceived as in the description of the inexperienced messenger. A similar description of these elements was reported in another study (129) where the authors explored patients' experiences of trust.

Glaus and Grahn (9) describe three important dimensions concerning how to inform a cancer patient: the content of information (cognitive aspects), the emotional warmth (affective aspects), and patient centeredness (interaction). The authors stress the importance of balancing these dimensions. The sense of balance was described in a recent study by Wenrich et al (128), where patients wanted to have a balance between realistic and honest information and sensitivity. This balance does not mean that the patient only wants to have a very caring and sensitive doctor, even if some studies do suggest this (45, 127). Among palliative care physicians, compassion and reassurance have been reported to be essential components in their palliative care practice (130). However, if the caring attitude or the compassion goes "too far", this might result in a patient interpreting this as subjectivity, emotional embarrassment and even hopelessness (131-133), as in the emotionally burdened expert. It is also important to trust the doctor's objective knowledge. Professionalism is neither a distanced behaviour nor being too involved (134). It is about showing empathy-balancing distance and emotional concerns.

Study I also stresses the importance of an established relationship between the patient and the doctor when such information is given. When the patient meets a new doctor he/she has to spend time analysing the doctor's behaviour instead of communicating about the central issue, especially if the patient finds an imbalance. This analysing may also leave room for alternative interpretations on the part of the patient (76), and the central issue may be of less significance. But as shown in study I, it is nevertheless possible to attain a successful relationship even if the doctor and patient have not met before. Patients stressed that it was important that patient and doctor were "at the same level". This is what some doctors aim at, for example those who are trying to sound out the patient and adapt to the patients need. The relationship may be the result of a successful, conscious adapting strategy on the part of the physician (V).

However, from a physician perspective it might also be difficult to end a long-lasting treatment relationship (65, 135, 136), as the disruption of a well-established relationship might be hurtful. In several studies (18, 135, 136) physicians have expressed a fear of hurting the patient. Preserving hope is important when delivering bad news (132, 137).

American patients with recurrent cancer draw hope from faith, while newly diagnosed patients find hope in treatment and in health care professionals (138).

Own resources

In study II all patients stressed different levels of previous knowledge. This is in accordance with a recent study of lung cancer patients (139), where a distinction between denial of any inclination and suspiciousness was found. Study II also indicated another level, those who were well prepared and had extensive knowledge of what to expect. This level of knowledge is only possible if the patient has a previous cancer experience.

Mental preparation has also been seen when receiving a primary diagnosis (140) and must be considered as an important factor for patients. It is of great importance to prevent unpleasant surprises, especially in relation to this kind of information.

According to the cross analysis in study II, patients who perceived themselves as unsuspecting naive also lost their capacity to communicate because they were too shocked. An effort to prepare the patient might decrease the shock and level of stress by building up a gradual and slow acceptance. According to Maguire and Faulkner (141), the most important thing to do when providing information is to try to decrease the speed with respect to the patient's own insight about his/her new situation in order to prevent a gap. It has been reported that physicians sometimes are too neutral in their answers when patients want a confirmation of their suspicions during the examination (142). This neutrality may stop the patient's process of crisis. However, adaptation to cancer information is not only related to the physician's behaviour, but also to the patient's coping style (143).

Prerequisites and the patient's own resources had to do with the patient's well-being, sense of security and individual strength. It may seem that these factors are elementary, but according to the patient narratives they are not always taken into consideration.

Individual strength varies among patients, and for the uninitiated it may be difficult to influence. Constantini- Ferrando et al (144) suggest that psychological state as well as coping style, belief systems and social support must be considered when breaking bad

news to patients. It is also possible to use fortifying words and thereby strengthen the patient even in this situation, as the words used by the doctor will influence patients (139).

Words and phrases

One of the main findings in this thesis comprises the results from study III dealing with how patients perceive and interpret words and sentences. This perspective has seldom been studied in either a primary cancer diagnosis context or in a palliative setting. When the significance of words has been considered, the importance of not using medical and technical terms has been emphasised (40, 44, 128, 145), as this will hamper patient understanding. It was recently reported that patient understanding of the terminology used when delivering news about diagnosis varies greatly (139). Another study reported that patients related what was said during the consultation to hope (133). Hopeful sentences contained encouragement and support while sentences devoid of hope contained abandonment. Torrecillas (146) argued that words and expressions such as "there is no more treatment", "cancer" and "incurable" should not be used at all, as they will hinder patient comprehension.

Weisman (147) also stated that words might be injurious, which is in accordance with this study where it was found that emotionally trying words were perceived as frustrating. Some words were also perceived as evasive, which may cause some misunderstanding if the patient does not understand the underlying message. But it may also be appropriate to use evasive words if the patient is following what is said but does not want to hear the truth in clear words. There are a few patients who do not want to hear the message in a straightforward way (26, 73). It is also important to identify these patients and to respect their wishes.

What to tell the patient or not to tell the patient is a matter of cultural beliefs and attitudes. In a North European life context Torrecillas' (146) suggestions about not using certain words would be difficult to follow, as most patients want to get knowledge even if it is about a serious prognosis. The majority of patients do not prefer the use of euphemisms in countries such as the US (27), Australia (148), Sweden (30), and Great

Britain (139). The message must be clear, but it must be given in a sensitive manner, balancing medical knowledge and a humane approach (study I), by considering the use of words and body language. Time and place (environment) are other key issues (127, 128). However, the use of fortifying words could be appropriate without losing the real message. Patients seem to interpret these words as if something is still being done despite the difficult situation, even if the goal of the treatment is no longer the same. There is still some activity, interest and plan for the patient.

The message

The overall message could also be perceived in different ways, i.e. oriented toward quality of life, treatment, or death and threat. If the patient is focused only on treatment the discussion might have been aimed at talking about symptoms and treatments. In one study 45 % of the physicians perceived that a positive attitude would affect the outcome in later stages of breast cancer (149). In a previous study The et al (150) described a "false optimism" maintained by health care staff as well as patients throughout the illness trajectory, despite a palliative goal. By discussing typical medical facts such as laboratory results, treatments and symptoms, a "curative aura" emerged which supported both the patient and the doctor. But this orientation to treatment may also be a coping strategy to avoid talking about the central issue. A balance between medical facts (reality) and hope would be preferable. This positive interaction between patient and physician may also result in frustration and disappointment on the part of the patient, as the patient may feel cheated during the whole trajectory.

In some cases the message could also be perceived as focused on quality of life, where the patient was able to see the opportunities with a life without treatment, or else the opposite when the message was focused on death and threat. These findings can also be related to Weisman's (151) good copier and bad copier theory. The good copier is usually optimistic as well as aware of the risks, while the bad copier tends to give up easily and become addicted to hopelessness.

But the message is also influenced by the physician's behaviour. A recent study (4) showed that patients rated the message content as most important during information.

The content included what and how much information was given. If there are too many medical facts when providing this message, such as statistics with a focus on the negative factors, without hope, in this situation, patients may perceive this as death-oriented. If there is a balance between medical facts, hope, and on what real possibilities the patient has, the message may be perceived as focused on quality of life. The balance between hope and truth is an important factor (136).

Study III did not point out any direct misunderstandings among patients as shown in previous studies. This is probably due to the inclusion criterion that the patient was to be aware of his/her prognosis. Misunderstandings and coping mechanisms using denial may otherwise be a problem. Sher (152) suggested that this might apply to patients who distort the information in a positive direction, while Salander (76) stated that physicians might act as facilitators when leaving space for the patient's self-created illusions. Whether maintaining hope when facing an advanced disease is a form of denial or a coping strategy can be discussed.

Copp (153) and Feigenberg (154) concluded that patients appeared to function on a continuum of awareness that could fluctuate between denial and acceptance at any given time. "Misunderstandings" may therefore have a relationship to the timing and may vary depending on **when** the health care professional is speaking to the patient.

Family member perspective

Family members want to protect the patient. One of the worst things one can experience can be the suffering of a loved one, which may be the situation when receiving information about an incurable condition without the possibility of tumour specific treatment. Family members have been seen as a natural part of the situation when informing cancer patients, but without their own mandate (155). The physician's main task is to inform the patient, and it is beneficial if a family member is present, but the task is still focused on the patient.

This is in certain respects in conflict with the goal of palliative care (98) where the family is seen as a unit of care and where the support also includes the family.

Information of this type is of vital importance to the whole family to be able to gain a sense of empowerment and control (156). If the family member is not included in this essential information, as the case is in the excluded outsider role, and the patient and family member do not communicate, this has consequences regarding the daily care of the patient. Family members perceive themselves as responsible for the care, as they see the patient 24 hours a day. If they are not adequately informed about the progression of the disease, their sense of security and ability to help are hampered as they are uncertain of what is happening and therefore feel anxious (157-160).

Study IV also provides knowledge about the underlying way of thinking among family members. It is essential to realise that family members want to protect their loved one even if that means behaving in a manner perceived as troublesome to the health care staff. It is their way of coping with this vulnerable situation. The controller role could be compared with the coping strategy of doing other things for purposes of distraction (147). The demander of truth role is similar to a confronting and information-seeking coping strategy (147). A recent study reported that caregivers whose physicians listened to their needs and opinions about the patient's illness were less likely to be depressed (161). The secret-keeper role suggests that the physician is able to conspire with the next-of-kin. Wenrich (128) recently reported that some physicians avoided talking to the patient, and informed the family member instead. This is probably an unusual phenomenon in Swedish health care as Swedish and Norwegian doctors are reported to be forerunners in informing the patient (162, 163).

When receiving this information the family member's situation may also be difficult in other ways, as they may have to cope with many transitions simultaneously (87). They have to become caregivers as well as finding out that their loved one is dying (90). Slow, gradual information should also be given to them, if possible together with the patient, to prevent too rapid transition. Admission to hospital based home care should also be considered. Whether admission should take place before or after serious discussion should be weighed carefully so that both patients and family members have time to reach a state of acceptance. This is of course dependent on different levels of understanding and insight. Wrong timing may be devastating.

An important finding in study IV concerned the excluded outsider, who was very dissatisfied with being kept at a distance and having the truth withheld from him/her. The family member may also experience having restrictions placed on their role as patient advocate as a failure on their part, even if this was the patient's decision. Butow's (148) study showed that only 57 % of cancer patients wanted to have a next-of-kin present when they received their diagnosis. Cancer patients may find it difficult to express their concerns because of the presence of the person accompanying them (54, 148). These data partly explain the reason to why close relatives are excluded. However, being excluded or feeling restricted when important information is given to a loved one is a significant reason to feel dissatisfied with the information. Several studies have shown that family members are dissatisfied with information (157, 164-166). In one study one third of the informal caregivers had not discussed the illness with a doctor at all (167).

In recommendations (40, 44) it is suggested that a family member should be present during the information as two persons hear more than one, but family members are also important as psychological support. According to Labrecque's (72) study the physician spent more time with the patient when the family were present.

Physician perspective

Physicians from the Nordic countries have been said to be forerunners of open awareness, i.e. they want to provide information to patients (162, 163). The strategies for how to do this varied and were often related to the context, i.e. different factors within the patient, the relative, the physician or the situation. The use of more than one strategy was also reported in another study (168). Decision-making at the end of life, i.e. uncertainty about what is the right thing to do, has been reported to be an ethical problem among physicians (169, 170).

What is important in study V is the attitude toward whether the physician or the patient should be responsible for the decision to complete tumour-specific treatment. Physicians who used the strategy "softening the impact and vaguely suggesting" may think that it is the patient who should decide, while physicians who used the other

strategies decided themselves. It is important to focus on this difference, as it is often recommended that medical decision-making should involve the patient in the decision-making (96, 171). Weeks (172) states that the patient has a choice between life-extending treatment and comfort care. This is probably dependent on the individual case, but under these circumstances, when treatment can no longer be recommended, it is important not to let the patient decide, as patients believe that treatment is always the best solution, even if the chance of benefiting from the therapy is minimal (150, 173, 174). Patients tend to favour life-extending therapy over comfort care, as their understanding of the prognosis may be incorrect (172). If patients make a choice based on the knowledge of a layman, this may result in shortening their life. The patient may also regret his/her choice a few weeks later, which may cause feelings of depression and hopelessness.

Weisman (147) states that the prerequisite for a patient to be able to have a chance of coping well is sufficient information. Based on medical judgements and the experiences of other team-members, the physician is the most suitable person to make this decision. However, circumstances surrounding this decision-making may be problematic. Many physicians may be involved in the care of one patient (81, 127) and it may be unclear who is responsible for initiating and documenting the discussions (81). If the physician has not met the patient before, it seems to be easier for both parties to continue treatment if this is in accordance with the patient's wishes and expectations. This will probably save time for the physician, but not necessarily for the patient.

When asking physicians about their preferences regarding decision-making, only 2 % wanted the patient to decide. Physicians who used shared decision-making were in the minority (31%) compared to physicians who decided themselves (68%) (175).

The adapting strategies were the most commonly used strategies, followed by the strategy of explaining and convincing. According to the results of the validation process, the "softening the impact" strategy was the least frequently used strategy in this group. However, in another culture the results could be totally different, as attitudes and strategies may differ. Both different and similar strategies were reported in the studies of

Todd/Still (135) and Miyajis (136). Many of those strategies were interpreted as avoiding. This is not in agreement with the results of study V.

The information context when treatment is discontinued is not dependent only on one actor, even if one actor may be more influential than the others. Miyaji (136) argues that it is always the doctor who regulates what the patient's needs are. In a situation like this the patient might be weaker and not have the resources to participate. According to study V, all physicians tried to be interactive, although in different ways. Steinhauser (176) argues that it is not only the physician and not only the patient or his/her family who shape this experience; it is all participating parties, whether passive or active. But this does not mean that health care staff cannot prevent or facilitate this event. For example, preparing the patient would ease the event and the following transition. Ptacek (177) reported that weaknesses occurred when the physician prepared himself/herself as well as the patient for the encounter.

Today it is suggested that a physician's professional competence should include tolerance, emotional intelligence, respect and a caring attitude as well as communication skills (178). Physicians also have possibilities to participate in training courses. These courses have been reported to influence the empathic understanding and they give practical suggestions how to handle bad news (179, 180). This could be one alternative for physicians who feels uncertain when providing bad news.

Transition in relation to the results

The transition theory was used to link the thesis to a defined theory. It was not used during the data collection and analysis phases of this thesis. The aim was not to develop a new theory, but simply to contribute to the middle range theory of transition.

Transitions among advanced cancer patients and their families have been explored in several studies, such as in situations when patients are admitted to palliative care service and when they are dying (88, 181).

In this context the central factor is the giving of a message and the gained awareness of the message. When receiving information about a terminal prognosis where tumour

specific treatment no longer can be offered, a process starts in which the individual has to become aware that life is no longer open-ended and impending death is definitely a reality (182, 183). In this thesis the process for patients and family members should be interpreted as leaving their former situation, for example being healthy but undergoing examination or with a defined diagnosis and prognosis and receiving chemotherapy or other treatments. Patients and family members have to mentally enter a new situation where they cannot receive any treatment to fight the cancer. Several transitions may occur in palliative care, such as from an independent to an increasingly dependent lifestyle, and then the ultimate transition to death (184).

To be able to go into the transition process in this context, both external sources (information about completion of treatment) as well as internal sources (awareness) are required. This can be seen as mentally crossing a border. The change in medical status reminds the patient of his/her mortality (185). When receiving signals about the changing status, the patient starts becoming mentally aware of the new situation. But in order to become aware, he/she has to cross a border comprising one or several events, which are supposed to clarify and make things comprehensible.

All parties in the informational event have to be able to see a dividing line between the differences in status. The border should be seen as the connection between the previous situation and the new situation. One way of seeing this is found in study II, where some patients described themselves as verbally active when they asked the same question over and over again. This could be a way of testing the border, while patients who were verbally passive might have understood but did not want to discuss it further. Family members who described their role as being a demander of truth (IV) could be seen as testing the border by extracting as much as possible from the physician.

Patients who perceived the message as focused on treatment or quality of life (study III) could be understood to be denying what they had heard. But according to previous research by Feigenberg (154) and Copp (153), patients are in a process in which two opposites always occur, for example being aware- not being aware, knowing- not knowing, etc. Therefore it is possible to say that in some circumstance awareness appears even if the patient or the family member denies the message that was given.

Otherwise, what is causing the denial? This could also be seen as a way of testing the border.

From a physician perspective the situation is also similar to crossing a border, but their task is to provide information, to be the external source that starts the transition (86). The physician's action is aimed at getting the patient to become aware. The physician must also be aware as well as sure of the situation in order to transfer the message in a comfortable, clear manner. The physician has to help patients and family members in confronting the information so that they will become aware of the new situation. The task of physicians is to create a link between the previous and the present, to make the new situation comprehensible.

Pre-transition

The pre-transition phase is a phase that may occur before the event (83). This phase is characterised by mental preparation to facilitate crossing the border, but in different ways depending on the actor.

From a receiver perspective the level of pre- understanding was emphasised (study II). Being prepared or "apprehensively suspicious" before this event was preferred. In a theoretical perspective this indicates that the preparation of the transition process should start before the actual event- the information context. Some doctors (study V) seemed to be aware of this and tried to prepare the patient before the critical point, i.e. they tried to be pre-active and prevent a sudden message by giving information gradually during the whole trajectory. To be able to do this they must be sure that the border is to be crossed sometime in the future, i.e. the prognosis must be very clear from the beginning, even if the patient is offered treatments. This could be seen as creating an association between the previous situation and what is forthcoming in a longer-term perspective. In the Chick/Meleis model, suddenness is closely related to the response in the transition event (83). In this thesis both patients and doctors have confirmed that the prevention of suddenness is of importance.

Family members might also have heard the early signals from the doctor and tried to assume a role as a secret-keeper, i.e. in a transitional way of looking at this the relative wanted to prevent crossing the border by hindering the patient from becoming aware of the new situation. They wanted to prevent possible patterns of response (depression, anxiety, etc.) that they anticipated would occur if the patient got this knowledge. Being active in the pre-transition phase by contacting the doctor in order to get the information themselves, it was possible to stop the forthcoming information.

Facilitators and inhibitors before and while crossing the border

During the event, the meeting at which the border was to be crossed and the transition process was to start, several factors were important. From a patient perspective the characteristic of the medical expert with his/her personality and behaviour and ability to provide security, were influential either as facilitators or inhibitors (study I). Imbalance between medical and psychological knowledge, routine, experience, objectivity, sensitivity, interest and empathy could result in inhibition. Physicians who used an adapting strategy or a “softening the impact” strategy were certainly aware of this (study V). They tried to facilitate the patient’s experience of this difficult event, but in different ways. Physicians who used an adapting style tried to find out the patient’s level of knowledge, experiences, mood, etc., to be able to adapt to the exact level of the individual. But they still had their goal clear, to provide the message in order to make the patient understand, to cross the border and to start the patient’s transition. Physicians who used a “softening the impact” strategy did not have an explicit goal; they wanted to try to facilitate crossing the border as much as possible, but only if the patient did not object to this. If the patient wanted to continue treatment the mission was partly a failure, as the patient did not cross the border even though he/she was satisfied.

Schumacher et al (91) showed several important factors that influence a positive transition outcome. One of the conditions was the level of planning. The level of planning occurs before and during the event. Extensive planning is said to help achieve a smooth transition, and communication is one of the key elements during this phase (91). An active pre-transitional phase is therefore suggested in order to facilitate

crossing the border. By receiving gradual information it will become possible to achieve some insight and thereby acceptance of the new situation before the actual critical event.

One important prerequisite and resource was the sense of well-being of the patient (II). This well-being could be recognised before crossing the border. It is possible for the physician to use an adapting strategy to get knowledge of the patient's well-being in the initial phase of the talk. This is in agreement with Schumacher/Meleis (91) who suggest that subjective well-being is an indicator of a healthy transition.

From a patient perspective a sense of security was an important factor (study II). This is individual, but a supportive person should be present. This person may be a family member, but it could also be the physician or someone else from the health care staff. The patient should have the chance to decide which person he/she finds most supportive. This support has been described to facilitate understanding and the creation of meaning in a life-changing process (186).

Individual strength was also described as a prerequisite but it may be difficult to support the patient with this. But one way of doing so is to use fortifying words and sentences that are applicable to the patient (study III). The use of certain words and phrases, such as emotionally trying words, described in study III may also be seen as inhibitors.

Methodological discussion

Phenomenography was used in this thesis. There has been much discussion about phenomenography and its similarities to phenomenology (103, 116). There are, however, a few differences. Phenomenography is mainly aimed at describing variations (the how-aspect), whereas phenomenology focuses on the essence (the what-aspect). Phenomenology aims at describing the lived experience, while phenomenography aims at describing the relationship between the individual and his/her life world, his/her perception of the experience. It is also directed at people's reflections about a phenomenon, not pre-reflective thoughts as in phenomenology (105). The phenomenographer wants people to reflect upon an experience, and share their conscious thoughts about it. In this thesis this was seen in study V, where the doctors

were asked by phone, e-mail or in person to think about their experience when providing information to cancer patients. The reflections may be a crystallisation of what the physician wanted to convey to the interviewer, but they are still the perceptions of the physicians.

The use of phenomenography in this thesis has many advantages. The area of communication between doctor and patient in this context is new and not well studied, especially not from a patient or family member perspective. Therefore it is useful to start with a descriptive approach and scan the field as a basic work. These descriptions will constitute a start and may be continued using both quantitative research and qualitative research with more in-depth interpretation, such as by using hermeneutics, or a process-oriented method like grounded theory.

Phenomenography also has some drawbacks, as it is not possible to carry out more in-depth interpretation, which may be appropriate and interesting when studying people's way of thinking and reflections about a vulnerable situation. According to the basic principles of phenomenography, the researcher's knowledge about coping strategies cannot be used if the patients do not explicitly talk about coping –strategies. This is a limitation in phenomenography. The pre-understanding may instead be used in further research. However, today phenomenography is moving towards hermeneutics, with the possibility of deeper interpretation (118). Hasselgren /Beach (116) provide a description of hermeneutic phenomenography. As long as the second-order perspective is central to the method, however, this may be a problem.

A limitation in this thesis, especially in studies IV and V, is the architecture of the phenomenon (187). These studies are just a limited piece of the participants' description of the phenomenon. Their experience of information is much greater than their perceived roles or strategies. No method, qualitative or quantitative, can describe the total picture. However, there is also a practical obstacle when using a qualitative method. It is almost impossible to describe people's whole experience of a phenomenon when the space to describe this is limited in scientific papers. The upper limit is often set at 3000 to 5000 words in medical papers and at about 3000 to 8000 words in sociological and nursing papers.

As the interviews were not done in direct association with the information event, a recall bias might have been present. The reflections may be a construction of what happened obtained from all participants involved. This is not necessarily a drawback, as the final perception, true or constructed, will constitute the patient's final memory, which will affect his/her life. Nevertheless, previous studies have shown that people recall events that have been of great significance to them (25, 188). One study (45) reported that 75 % of the cancer patients believed they could clearly recall what the physician had said, even though this had occurred three months previously. According to Christianson (189) an emotional event creates a network of associations because this kind of event is more intensive and others more neutral. The emotionally distressing event requires extensive investment in terms of physical stress (increased heart frequency, muscle strain) as well as mental effort to analyse associations related to words, sentences and perceptions. Such events are easier to remember as there are many more physical and mental associations (189).

The ability to remember the most important details is not decreased in emotionally distressing situations, not even after a period of time. But the ability to remember general details is decreased. This phenomenon was seen in a study from the UK where negative comments about previous rather than current difficulties were reported, often regarding the diagnosis, when questions were asked about the palliative care service (190). According to Christianson's theory (189) and Ley's suggestion (25), human beings select what they think is most important, and their selection of essential "facts" may not be the same as that of professionals.

In this thesis feedback from the informants was used. This was done with the second-order perspective in mind. As the second-order perspective was to be present in the results, this was judged as a relevant method in order to give the results a reasonable trustworthiness. Trustworthiness should be seen here as the truth in the eyes of the informants. According to the ontological perspective truth is something that every individual creates (191), i.e. each person will have their own perspective even if they share a specific event with others. Every interview is also contextual, as the inquirer interacts with those being researched and the findings may be a creation of the

interactive process (104). From one perspective this could be regarded as a bias, but from an epistemological, non-dualistic perspective this could also be seen as a way to get access to the informants' genuine thoughts about a phenomenon (192).

An interesting contribution to the search for validity was the feedback from the physicians. The process of letting the informants read the analysis might be appropriate when dealing with health care staff, but it is less appropriate when dealing with patients and family members. The analysis is an abstraction of the reality, not the individual's own reality, and may be difficult to understand. Even if categorisation simplifies reality in order to structure phenomena, health care staff have the skills to read abstractions from education etc. The quantity of the perception/category is still the physician's ideal description of the use of each strategy, not what strategy is actually used in this situation. It is possible that an observational method would obtain different results (193).

A limitation of this thesis is that it is not possible to directly transfer the results to other settings or groups, as the cancer context and the geographical context, i.e. the county of Östergötland and a Swedish health care organisation and culture, is a specific context. On the other hand it is possible to transfer the results to patients, family members and physicians living in a situation and culture similar to this Swedish context (194).

The strength of this thesis is that an attempt was made to include patients, families and physicians with different backgrounds in order to create a heterogeneous group. In small samples homogeneity may problematise a study, as such a sampling may decrease the range of perceptions because of similar answers. This might decrease the transferability of the results as the researcher will not know what relevance the study may have to other samples outside the homogenous group. In studies I-III heterogeneity was reached with respect to different forms of cancers (both short-term - pancreatic cancer, and long-term disease - prostate cancer). The largest group was between 70-89 years of age, which may have influenced the results, as older people may have other expectations about information and a different ability to cope with such an information (195). A risk in this thesis is that health care staff could have chosen patients and family members that were very satisfied, very dissatisfied, or who were strong persons, and so on. Patients who are

very verbal and have a blunting coping style may be over-represented. This may create a risk, as it will influence the results. This is, however, a universal problem in all research. Nor will weak patients answer questionnaires. Many of the patients and family members were good storytellers, while others were not. The lasting impression when meeting both patients and family members was that each one had their own experience and their own reflections to share.

Patients and family members who did not want to participate are not described in this thesis, as the aim was not generalisation, but to gain understanding. The author's perception of why patients and family members did not want to participate is that they did not have the capacity to communicate about such a vulnerable topic due to physical, psychological, social or existential concerns.

Selection of the physicians could have been done differently, i.e. randomly. But making a random selection may create risks, as the researcher cannot be sure of the differences in each characteristic. There might be very similar individuals who choose to participate. In this study it was most essential to choose physicians with different characteristics, such as, for example, those with great, moderate and little experience, respectively. The only person who had access to the physicians and could assess this was the head of department.

Further research

Studying communication may be a never-ending endeavour as it is an area that never can be resolved completely. It is only possible to reflect different views from experiences, observations, questionnaires and so on. Moreover, issues change. What was important yesterday might not be as interesting tomorrow, in a new context.

An alternative to continued research in this specific area is to go deeper into the patients', family-members' and doctors' experiences by using another, more interpretative method which, for example, allows the direct use of a theoretical framework when designing the study. This could provide many new aspects of this event. Another alternative is to continue researching the nursing task during this

information, and especially after it. Studies have pointed out that nurses think that information about diagnosis and prognosis constitutes a difficult ethical question (170, 196).

It would also be interesting to quantify the results of patients, family members and doctors to obtain knowledge about the frequency of behaviours, roles and strategies. There are, however, some ethical issues to address before using questionnaires about such a vulnerable situation with cancer patients.

What this thesis adds

Weisman (151) stresses the importance of awareness and insight as one of the main issues in appropriate dying. This awareness and insight among patients and family members must, however, be expanded slowly and with care. This thesis has shown that patients perceive the physician as a medical expert despite the presence of various good or bad qualities (study I). It was important to them that the physician could provide security, balancing medical and psychological knowledge, routine, experience, objectivity, sensitivity, interest and empathy. These elements are important characteristics for a physician and can be considered to be facilitating factors when crossing the border. This is also confirmed in other studies and theories (128, 134).

Previous knowledge before receiving this information was stressed by the patients (study II). According to the results from study II, it was beneficial for the patient to have some kind of knowledge about completion of treatment, as this decreased the surprise aspect and thereby the shock. In study V the preparing strategy was used in order to build up some knowledge within the patient from a physician perspective. Seen from a theoretical perspective this indicates that there is a pre-transitional phase as suggested by Chick and Meleis (83). The physician might use this pre-transitional phase to prepare both the patient and the family member. This preparation is also a facilitator during the forthcoming border crossing.

Patients interpret words and phrases very carefully during this event. This has seldom been studied before and is a new contribution to this kind of research. The use of words

might be perceived as forewarnings, emotionally trying, as well fortifying (study III). This knowledge can easily be used by physicians, such as using words of forewarning in the pre-transitional phase as well as in the initial phase of border crossing. This would give the patient and the family member an opportunity for preparation. Emotionally trying words can be seen as inhibitors, as these words may hamper or hinder border crossing. Fortifying words may have a facilitating effect as the use of these words and sentences may make progress smoother.

The family member perspective has seldom been studied in this context. The exploration of perceived roles and underlying thoughts gives additional knowledge about the event of providing information about a progressing cancer without treatment options. This study can also provide one explanation as to why family members are dissatisfied with information. Being excluded or perceiving different expectations when important information is given to a loved one is a significant basis for being dissatisfied with the information, which has been confirmed in studies performed in a palliative (165) as well as an oncological context (164).

The results from study V provide additional knowledge about physicians' perception of different strategies during this event. Commonly used strategies were the "adapting strategies", "convince and explain" as well as "preparing". The least used strategy was "softening the impact and vaguely suggesting". This is not in agreement with other studies that have reported more avoiding strategies (135, 136). The results of study V can be explained by the fact that the study was performed in a Swedish context and that it focuses on the second-order perspective. What were also important in this study were the physicians' perceptions of decision-making. Most of the physicians decided themselves about completion of treatment, while a few made recommendations or left this to the patient, as they wanted to soften the information as much as possible.

CONCLUSIONS

Study I. Patients perceived the physician as a medical expert despite different characteristics where the balance between medical and psychological knowledge was emphasised. The previous relationship between patient and physician was also important for the communication.

Study II. Patients perceived their participation as either verbally passive or active, or interpretative and active. Their previous knowledge was described in three levels: unsuspectingly naive, apprehensively suspicious, or well prepared. A sense of well-being, a sense of security and individual strength were part of the prerequisites and the patient's own resources.

Study III. The study showed that patients interpreted words and phrases very carefully, in particular if they found an emotional negative or positive meaning in the sentences. The overall message could be perceived in three different ways, focused on treatment, on quality of life, or as death and threat oriented.

Study IV. Family members stressed their role as being important during this encounter as they wanted to protect the patient. In order to be able to protect they used different roles, prominent or background roles. Family members also perceived demanding expectations on their presence.

Study V. All physicians tried to make the patient understand while being as considerate as possible when providing information. Physicians used different strategies to convey the message and the strategy that was used was often described as depending on the context.

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APPENDIX I-V

APPENDIX I

I. Interview guide- patients

1. Do you want to tell me about how your disease started?
2. How did you experience receiving information about your disease?
 - Where were you (physically, when you received the information)? Under what circumstances did you receive this information?
 - Who gave you the information? Did you know this doctor? Could you describe the doctor?
 - What was said (what words were used)? What did these words mean to you?
 - What did you do? Did you ask questions? Why/why not?
 - How did you feel? Your reactions?
 - How did you perceive this information? Good/bad/neutral? Why?
3. Do you feel that this information has influenced your life? In what way?
4. What was necessary for you when receiving bad news?
5. Do you have any advice to give to physicians?
6. What kind of support is needed when receiving bad news?
 - From relatives?
 - From health care staff?
 - From others?
7. What is most important when receiving such bad news? Why?
8. Is there anything else that we haven't talked about that is of importance to you regarding this kind of information?

APPENDIX II

II. Interview guide- family members

1. Do you want to tell me about how your relative's disease started?
2. Do you want to tell me how you experienced the information? What happened? Who did you meet? What was said? What did you do?
3. What was your role during the information? Why did you act the way you did? Were there pros or cons to acting this way?
4. What was your function during this information?
5. How do you think family members should act during this kind of information?
6. What was expected of you? By other family members, the physician or yourself?
7. How did this information affect you?
8. How do you assess the information today?
9. What is important to you when receiving this kind of information? Why is this important to you?
10. What do you think is important for you to know? Why is this important?
11. Is it possible for a family member to influence the information? How?
12. Is there anything else that you think is of importance that we haven't discussed? Why is this important to you?

APPENDIX III

III. Interview guide- doctors

1. Why did you want to become a doctor? Why did you choose this speciality? How do you feel about working with cancer patients?
2. Which doctor do you think is best at giving this kind of information? Why?
3. Do you want to tell me about one case in your experience when you felt that this information was easy to provide? What kind of circumstances created this feeling?
4. Do you want to tell me about one case in your experience when you felt that this information was difficult to provide? What kind of circumstances created this feeling?
5. Do you think it is difficult to give this kind of information? Why?
6. Does this kind of information affect you as a person?
7. Is there anything that can facilitate giving this kind of information? Please give me some examples.
8. Is there anything that can hamper giving this kind of information? Please give me some examples.
9. Do you prepare yourself in some way before providing such information? How?
10. Do you have any special thoughts about what you want to convey? What do you think is important for the patient to know?
11. Do you use any particular technique when you give this kind of information? How do you give it? How do you start? How do you conclude this kind of information?
12. How do you know if the patient has understood the information? Do you look for anything in particular?
13. How do you handle reactions from the patient or family member (crying, anger etc)? Why?
14. If you have a patient who wants treatment even though you do not want to provide it, how do you handle this?
15. What would an ideal situation be like when giving information?
16. What do you think is most important for the patient during this kind of information? For a family member?
17. Are there any problems with family members? Why?
18. What is most important to you when providing this information? What is your goal?
19. Is there anything else of importance that we haven't discussed?

APPENDIX IV

IV. Doctors' Questionnaire

1. Read the analysis.
2. Compare the analysis with your experiences concerning strategies when providing information.
3. Answer the following questions. Use the other side of the paper if you need to. Indicate the page number.
4. Please return the questionnaire in the enclosed envelope before 1 September.

Thank you for your help!

1. Could you find your own strategy/strategies in the results?

Yes, totally Yes, in part No Don't know

Comments:

2. What strategy/strategies do you use?

3. Do you recognise the described strategies from your colleagues?

Yes, totally Yes, in part No Don't know

Comments:

4. Do you think that the results concerning choice of strategy are representative of your experience?

Yes, totally Yes, in part No Don't know

Comments:

5. According to your judgement, are there any direct misinterpretations in the analysis?

Yes, totally Yes, in part No Don't know

Comments:

6. Is there something you think is missing? If so, what?

7. Other comments:

APPENDIX V

V. Comments made by doctors in the validation process

You have different strategies, one or several of which you use more often than the others.

I'm well aware that my strategy is not always successful. The patient has to be receptive to argument.

I think maybe there's a mix of strategies depending on the patient's reaction.

It depends a lot on the situation!

Some of my colleagues experience anxiety. The temptation to do more examinations in order to win time is too great for some doctors.

Anyway, I believe that many of my colleagues use different strategies or a mixture of strategies.

I don't recognise the explaining and convincing strategy.

I'm not that experienced yet...

As doctors, we are very much alone in these kinds of situations.

Patients are individuals just as doctors are, which means that you can't have specific patterns to follow even if the state of the disease is about the same.

As a specialist, you don't get that much experience concerning other doctors' strategies.

Strategies based on the situation are totally okay.

Difficult to judge, as I don't know what my colleagues' thinking is on that.

Of course I don't know what others do, but if certain of the described strategies (for example, softening the impact) are actually used, then I feel sorry for the patient.

A mixture of strategies is often used depending on the patient, the particular situation, etc. I don't think anyone uses a pure strategy.

Many doctors don't have any strategy at all.

The serious discussion is more difficult after having spent a long period of time together during treatment, as compared, for example, to refusing an operation.

I would like to know how being the conveyor of messages of hopelessness affects doctors. What kind of mechanisms do doctors use? (discussions with colleagues-depression- a night at the pub- stamp collecting, or a strictly biological response to the passage of life)

It's useful to read the analysis, it makes you give more thought to how you give information. It's interesting that we have such different ways of doing this. The quotations certainly provide insight about how differently we think and act.

I think it's unprofessional to let stress influence the encounter in such a situation. You have to be able to give all to the patient and possibly the relatives during such a discussion.

This task is complex just as we are as individuals, especially in relation to other complex persons (patients and relatives). I think it's difficult to have a strategy and then slavishly follow it - impossible if I may say so.

The starting point when giving information must be insight and competence on the part of the doctor.

The description is too conventional and simple. The doctor-patient relationship is simply a relationship, an interaction between two individuals, although in very special situations, but still. I use all strategies, but not always with the same patient and not always in the same time period / medical care event. What is the aim of the information the patient is to get? For my part I can say that my goal is to give the patient a realistic picture of the course of the disease and the prognosis, but nevertheless an optimistic undertone if that's possible. The reason for this is to give him the information that will allow him to plan or direct his future life as much as possible as he thinks best. This is what determines the strategy I use in giving information to the patient and possibly concerning treatment.