

Cancer Patients' Perceptions of Their Participation and Own Resources after Receiving Information about Discontinuation of Active Tumour Treatment

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The focus of most studies on informational needs has been on primary cancer diagnosis. The aim of this study was to explore how cancer patients in a palliative care setting perceived their own participation and resources after receiving information about the discontinuation of active tumour treatment. Thirty cancer patients admitted to a hospital-based home-care unit participated in the study. Semi-structured interviews were conducted and analysed using a phenomenographic method. The patients described their own participation as being either verbally passive or active, in order to receive more information or to avoid information. Furthermore, previous knowledge, at different levels, was described as important: 1) Unsuspecting naive, 2) apprehensive suspicious, 3) well prepared. Patients' own resources included a sense of wellbeing, a sense of security and individual strength. In conclusion, patients' previous knowledge and own resources are important components for their capacity to take part in the dialogue when receiving information.

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Several studies have been undertaken to clarify the informational needs of cancer patients (1–3). Central themes have concerned treatment, side effects and the context in which the information was given and by whom. Some studies have found that women, unmarried as well as well-educated patients, want more information in this respect (4–7).

Many recommendations are given in the literature on how to inform a patient about a diagnosis of cancer (8–11). Attention should be paid to the 'primacy and recency phenomena', which means that the patient remembers best what was said first and last during the information (12, 13). Cancer patients who get emotionally upset when learning of the diagnosis have difficulties remembering other facts after the given message (12, 14). Common reactions include shock, distrust, fear and anguish associated with death (15–17).

However, scientific data are sparse on how they perceive the information in the transition from a curative or early palliative state to an incurable state when no further tumour treatment is possible. Many studies have included cancer patients in different stages of disease, and the presumption is that cancer information is the same for all

in all phases. There is some ambiguity concerning the definition of the terms 'curative' vs. 'palliative'. The WHO definition of palliative care is discussed by Doyle et al. (18). It has its roots in hospice care and 'terminal care' and therefore it comprises late stages of palliative care and the dying process, rather than the early palliative phase, when palliative tumour therapy is still possible. These authors argue that here the phrase 'terminal care' is vague and ambiguous and leads to negativism and passivity, without any possibilities of doing anything for the patient, contrary to the intention with palliative care, which is an active approach, although cure or prolongation of life is no longer possible. Glimelius (19) describes these terms from a classical oncological perspective; the palliative phase starts when there is no longer any possibility of cure. In the early phase, life prolongation is often a goal, but not always possible. In the late (terminal) phase, which mainly coincides with the WHO definition of palliative care, the goal is not to prolong (or shorten) life, but to aim at the best quality of life. Misconceptions exist among patients, according to a study by Mackillop et al. (20); 33% of the cancer patients in their study believed that their palliative treatment still had a curative intention.

In this study we define the palliative state as having an early phase characterized by possible tumour treatment, and a late phase when no further tumour treatment is meaningful (see Figure 1). This phase can extend from months to weeks and has in the end a limited terminal phase when the patient is actually dying.

Research focusing on patients in this late phase has investigated patients' knowledge about their disease and its prognosis (21, 22). In an earlier study (23), the doctor was described as being responsible for how the information was created in the communication process between the doctor and the patient.

However, Street (24) found that the way a patient communicated influenced the way doctors gave out information. Patients who asked many questions or were apparently anxious, as well as younger patients, received more information than other patients. Blanchard et al. (25) found that patients' perceptions of physicians' behaviours were stronger predictors of patient satisfaction than the actual occurrence or absence of those behaviours. This is probably due to different interpretations among observers, staff and patients (12). Describing patients' perceptions can therefore give additional knowledge. The aim of this study was to explore how cancer patients in a palliative care setting perceived their own participation and resources when receiving information in the transition from curative or early palliative state to a late state, meaning a phase beyond any possibility for life prolongation, when tumour treatment is no longer meaningful.

MATERIAL

Thirty cancer patients (18 females, 12 males) admitted to a hospital-based home-care unit in Sweden participated in this study. A maximum variation sampling was used for gender, age, education, diagnosis and time since diagnosis, in order to select a wide range of data variations (26). Demographic data are shown in Table 1. Age varied between 29 and 86 years (n = 68). The hospital-based home-care team made an assessment according to the inclusion criteria. The following inclusion criteria were used. The patients should:

- Have a disseminated cancer disease and be aware of the diagnosis and prognosis.
- Be admitted to a palliative home-care unit.

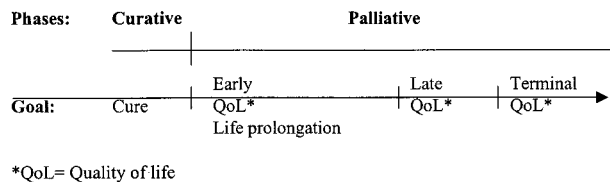


Fig. 1. A simplified model to define phases of cure and palliation.

Table 1
Patient characteristics

Demographic data	No.
Total number of patients	30
Gender	
Male/female	12/18
Age	
20–49	4
50–69	10
70–89	16
Primary malignancy	
Gastrointestinal	11
Urogenital	6
Haematological	4
Sarcoma	4
Others	5
Education	
Elementary	12
High school	15
University degree	3
Marital status	
Married/cohabits	20
Widow/er	6
Single	4
Time since primary cancer diagnosis	
– 1 year	12
1–5	12
> 5	6
Time since receiving information	
– 1 month	8
1–2 months	6
2–3 months	16

n = 30.

- Have received their information less than three months before being interviewed.
- Have no further ongoing oncological treatment.
- Be in a steady state, with physical and psychological capacity to participate.
- Be Swedish-speaking and agree to tape-recording.

METHODS

The study was approved by the Research Ethics Committee, Faculty of Health Sciences, Linköping University. The physician or nurse responsible for the care approached patients with oral and written information about participation in this study. Semi-structured interviews were conducted by one of the authors (M.F.), in the patients' homes, using an interview guide approach (26). Questions were addressed about the patients' experiences of receiving this specific information and descriptions of themselves during this event. The data collection was done during 1998–1999. The time taken for interviews varied between 40 and 90 min. The interviews were tape-recorded and then transcribed verbatim. The transcribed interviews were sent to the respective patients to give them the opportunity to make any comments and alterations.

Analysis

A phenomenographical approach was used. This qualitative method has an empirical approach and was developed in the domain of pedagogic research by Marton and co-workers in Sweden (27). Marton describes a distinction between the first-order perspective, explaining how things really are (i.e. facts), and the second-order perspective, describing how people experience and conceive the world (28, 29). Phenomenography as a research method uses the second-order perspective. The method aims at a description of people's experiences from interview data, without deep interpretation. A basic assumption in phenomenography is that people vary in experiences and in their understanding of phenomena in the world.

The analysis in this study was carried out mainly according to Dahlgren & Fallsberg's (29) seven steps, here presented very briefly:

1. Familiarization: The material was carefully read.
2. Condensation: The most significant statements were selected, if they were repeated several times, or if patients explicitly stressed single statements.
3. Comparison: The statements were compared in order to find sources of variation or agreement.
4. Grouping: Similar answers were combined based on the previous comparison and questioning.
5. Articulation: The statements within respective preliminary groups were critically analysed and compared.
6. Labelling: The categories found were denoted by constructing a suitable expression.
7. Contrasting: The obtained categories were finally compared with each other, considering their mutual relationship.

A cross-analysis was also made between subcategories. This analysis was based on previous analysis and was a comparison across each interview. Every interview was structured numerically with each category recorded in a table. The tables were compared for similarities and patterns. This analysis started by comparing similarities between previous knowledge and participation, and continued by comparing the description of prerequisites and own resources. When the same patterns, with same categorizations were repeated several times, in different interviews, this was seen as a relationship between categories. A dialogical intersubjectivity (30) was conducted by two of the authors (M.F, P.S), where the interviews were analysed separately and then compared in order to find similarities and differences. Discussion continued until agreement was reached.

RESULTS

The main categories identified in this study were participation, previous knowledge and the patients' prerequisites and own resources (Table 2).

Participation

This main category describes how the patients acted and participated when receiving the information (Table 2).

Verbal passivity. Some patients described themselves as verbally passive, as passive receivers of the given information, without the responsibility to participate in any other way than to listen and without the capacity or wish to open up a dialogue. The patient became or remained passive during the information. The given information could be experienced as emotionally too upsetting; the capacity for verbal communication just disappeared.

No, I was a little bit shocked, I think so. I don't think I was available to what the doctor told me, so my husband did the listening instead.

Some patients described themselves as being very aware of the situation, but chose actively to remain passive. These patients avoided addressing questions or supporting a dialogue in other ways. The fear of getting 'too much' information was central.

I didn't want to ask ... didn't want to get knowledge of it; all the details ... how much time left. I didn't want to know that.

Verbal activity. This subcategory was characterized by active dialogue. Certain patients took an active part and described responsibility for how the information was given and which information was given. Clear signals were given to the doctor in order to show receptivity and even expectation and openness for the coming information.

I think it might be very difficult for doctors, as we are so different. But if patients are like me, chatty, and ask questions and demand knowledge ... then it must be easier for the doctor to know how to behave.

The patient could also describe himself as a verbally active participant, but in an unplanned way or on a subconscious level. Some patients described being forced into an undesired dialogue, because of pressure from the doctor. The patient could also be very active verbally; for example, when emotionally upset, addressing the same

Table 2

Main and subcategories

Participation
Verbal passivity
Verbal activity
Interpretative activity
The previous knowledge
Unsuspecting naive
Apprehensive suspiciousness
Well prepared
Prerequisites and own resources
Sense of well-being
Sense of security
Individual strength

questions over and over again, but without understanding the answers.

I saw everything in black, dark ... as if something happened in my head. And I said, can't we do this, or can't we do that, or can't we do that?

Interpretative activity. In this subcategory the patients described an activity inside, not visible on the outside. The patient here used his perception very actively in order to interpret words and/or body language. For example, hearing and vision was described as augmented.

I did not react in that moment, because I was paralysed in a kind of way ... The doctors have such important things to say, such as this, so you focus on their lips and ... the whole face and the expression of the face and try to see if there is some hope.

Previous knowledge

In this category, perceptions of the previous knowledge are described. Three subcategories of the conception of previous knowledge emerged: unsuspecting naive, apprehensive suspicious and well prepared (Table 2).

Unsuspecting naive. Some patients described themselves as being unsuspectingly naive prior to the information. A lack of external (from the environment) or internal (cancer-symptoms of one's own body) indications as a forewarning was central.

Because the doctor never said what it was all about. No one had said anything about this before ... I was totally unprepared for what I really had inside my body.

This patient was negatively surprised, despite the fact that the patient had been at a department for examination, or had been called to a doctor's visit. The lack of mental preparation was described as obstructing the capability to receive information.

Apprehensive suspicious. In this subcategory, suspiciousness and intuition were central themes. Clear signals were described as indications of the forthcoming information. The warning signals were described as originating from internal sources such as one's own body, from physical discomfort, or from health care. Examples could be the body language or addressed questions from someone from the health-care team. For the apprehensive, suspicious patient, the information was described as a confirmation of what they already had suspected.

There was nothing that could be done about it, not worth treating, so I did not ask anything. And I had my suspicions in a strange way. My sister had the same in the pancreas, and she died.

Well prepared. Central in the perception of being well prepared were insight and knowledge about the treatments, possibilities, and limitations, and about the progress of the disease. Knowledge and acceptance had given the patient this preparation.

I don't think it was strange at all (to end treatment). But as I said, I was prepared ... even before the doctor informed me about it.

Some patients could also be so well prepared that they themselves suggested to the doctor to end treatment, as they experienced the treatment as too burdensome.

Prerequisites and own resources

The patients described some of their own fundamental resources, important for receiving and understanding the information, and also for being able to communicate in the difficult situation. Identified resources were: sense of well-being, sense of security, and individual strength (Table 2).

Sense of wellbeing. A sense of wellbeing was central to how the information could be received. A state of perceived physical and psychological stability without debilitating symptoms was a desirable prerequisite. Experiences of pain, sickness, fatigue or depression were described as decreasing the possibility of following and comprehending the information.

And I was stable and was feeling moderately well and had the capacity to receive. You have to feel well ... be in a reasonable form to be able to receive.

Sense of security. The sense of security was described from both short- and long-term perspectives. Factors creating security under these circumstances were family, and in some cases, the informing doctor. Next-of-kin had the function of supplying emotional support; just the presence of a relative was comforting. Next-of-kin also had a role as 'stand ins', listening more specifically to the medical information. They were also expected to communicate instead or on behalf of the patient, when the patient was not able to.

I'm not that attentive, but my wife, she understands every single word, and she also takes notes and asks the right questions. That's really good, also in a psychological way to have someone with you, if you feel worried.

It was also central that patient's next-of-kin was given information about the serious situation from a longer-term perspective, as they were the ones expected to take care of the patient in the future.

Individual strength. The extent to which the patient managed to receive the information and cope with it was described here as depending on personal individual strength. Strength was related to a long life experience and advanced age, which made it easier to accept the information. One's own strength of character, often described as being of positive nature, was also of importance.

You don't have to get too absorbed, I think ... I don't think it helps being negative. I've said that we have to fight ... I don't know if it has helped me or not, but I think it has.

Table 3
Relations between subcategories

	No.
Unsuspecting naive—verbal passivity (loss of capacity)—lack of sense of security (presence of a relative desired)	8
Apprehensive suspicious—verbal passivity (active chosen)—individual strength (life experience)	6
Well prepared—active verbal participation (dialogue desired)—individual strength (strong personality)	5
No relationship found between categories	11
n = 30.	

Previous experience of difficult incidents in life could also contribute to the patient's opinion of himself as being capable of receiving the information. Individual strength was also used consciously to avoid the given message. The strength was seen here as a help in repressing unpleasant thoughts related to the message. Individual strength could also be conceptualized as power from God.

Relations between subcategories

In the cross-analysis, three relationships were found (Table 3). Patients who described themselves as unsuspecting naive also depicted themselves as verbally passive, without the capacity to speak. These patients also emphasized the presence of a relative as security during the information giving. Patients who described themselves as apprehensive suspicious also had the active chosen verbal passivity, as well as individual strength in common. Individual strength was described here as life experience and acceptance of the situation.

Patients who described themselves as well prepared also described themselves as verbally active, with expectations to receive information and take part in the dialogue. These patients had individual strength in common, described as a strong personality. They also emphasized the relationship with the doctor as the most important person to give them security.

DISCUSSION

When receiving information about discontinuing tumour therapy, the prerequisites of information change. A central difference compared to the curative or early palliative phase is that there are no realistic possibilities and hope for cure or life prolongation using further tumour treatment. Until now, death was a threat that was possible to fight, at least temporarily with anti-tumour treatment. But now, in this transition, the process towards death becomes a reality. The patient can no longer control the disease with oncological measures. The current study has shown that many of the strategies used for dealing with bad news in other phases of the disease were also used in this far-advanced stage, although there were also differences.

The patients in our study described their various ways of reacting; some patients asked the same questions over and over again, i.e. were blocked, while others described their capacity to participate actively in getting a real knowledge about the situation, i.e., they used information-seeking as a coping strategy. The active participation also gave them a feeling of shared responsibility with positive effects, even if tumour treatment was not possible. Still, information seeking as a strategy seems to work in coping with the situation, even if the possibility of being given oncological treatment has now ended, and even though the questions and the focus of the dialogue have changed. This finding is in agreement with Cassileth et al. (31) who found that patients with metastatic cancer who preferred to be more active also felt more hopeful. But the patients in that study still had treatment to hope for. However, knowledge seems to help patients control the situation, even if the disease can no longer be controlled.

Blanchard et al. (5) identified a group of patients who sought all the information, but did not want to take an active part in any decisions, a strategy which Degner et al. (32) would have regarded as a passive role. The opposite is described in the current study where chosen passivity was described as an avoidance strategy, to escape from the threatening information. Our finding is in agreement with Gamble's study (33), where some patients declared that they did not want to be more worried by the information than necessary.

Some patients in this study described sense of wellbeing as very important. Pain and fatigue decreased the possibility of following and comprehending the information. This is especially important to consider when informing this patient group. Patients in this late palliative phase are in a poorer condition than most primary cancer patients. But even if the patient explicitly seems passive, the inner self could be very active, here described as interpretative activity, where the patient intensively scrutinizes the doctor. This kind of activity was also described in a Norwegian study (34), and is an important factor to take into consideration when breaking bad news to patients. Even subtle body language might influence the patients' coping capacity. Patients' impressions and interpretations of the information given are what they remember and have to live with for the remainder of their lives, even if the doctor's interpretation of the same situation is quite another.

Previously, the physician has been described as the active and paternalistic participant in the communication, while the patient has been described as the passive receiver. Possibly, this is undergoing a transition, as several cancer patients describe themselves as active, and as feeling responsible for the amount of information given (35, 36), even during this transition to an incurable state without further treatment.

The current study can be criticized for its patient selection—only patients regarded as mentally stable were in-

cluded. However, when undertaking research in such a vulnerable group of patients, it is important to consider their physical and psychological state. Patients who are depressed or in a very bad condition, and therefore probably less hopeful, should not be encouraged to participate, according to ethical directives.

Several studies have paid attention to the information process. Knowledge about the impact of the patient's own resources would improve the understanding. Antonovsky (37) developed the concept of sense of coherence, which includes three components (comprehensibility, manageability and meaningfulness) that are essential when handling stressful situations. The information in the current study was only comprehensible if the patient was to some extent prepared for it. Furthermore, the conscious use of defence mechanisms was seen as a strength and resource to manage this situation. Salander et al. (38) described how patients with brain tumours made space for themselves in order to create an illusion based on both reality and fantasy. This illusion made it possible for them to manage the situation. Perhaps this is what happens in the patient's mind when being very passive.

In this study we identified that previous knowledge constituted a psychological preparation important to patients. It is easier to handle and cope with these kinds of hard facts if the patient has some knowledge of them before the bad news breaks. Even if the cross-analysis cannot be counted in the statistics, it can give us some information about patterns in patients' experiences. For example, a relationship was found between unsuspecting naive and verbal passivity. Furthermore, Borgers et al. (39) concluded that cancer patients found it difficult to communicate after unpleasant surprises. Efforts should therefore be made to prepare patients before breaking bad news, also considering defence mechanisms, which may hamper the preparation (34). A contributory factor is that sometimes the patient is not informed at all, until all the planned examinations are completed, in order not to worry the patient.

CONCLUSION

From the patients' perspective, giving information in the transition to the late palliative phase has certain differences compared with primary information. Death is now a definite reality. Patients are also more physically affected by their disease, which is important to consider when delivering the message. It is an easy task for the physician to ask the patient about his condition and previous knowledge of the situation, to give the patient the opportunity to participate but also to give the physician a better opportunity to tailor this message. The patient's own resources as well as his previous knowledge are important components for the patient's capacity to take part in the communication.

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