

Decision-related uncertainties perceived by people with cancer—modelling the subject of shared decision making

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Abstract

Aim was to survey distinctive qualities of decision-related uncertainty in cancer. Assessment of differential perception of uncertainties is a prerequisite for the study of cognitive coping as mediated by risk communication.

A theory building process was initiated. Using in-depth interviews with cancer patients subjective representations of uncertainty associated with medical decisions were explored. Grounded theory techniques were applied to extract categories out of the interview material.

The qualitative process led to an eight-dimensional model. Five raters achieved a Fleiss agreement coefficient of 0.61 attributing raw material from interviews to the categories. Patients expressed uncertainties concerning (1) disease-related issues (prognosis/diagnosis, treatment), (2) risk communication issues (deciphering information, role in the medical dyad, physician's trustability) and (3) aspects of coping with life considering the disease (mastering requirements, social integration, causal attribution).

We found support for a multidimensional model of uncertainty. This approach can be helpful in the investigation of further issues concerning communication and coping with uncertainty related to medical decisions in cancer and other diseases. It sharpens shared decision making theoretically and thereby provides the basis for a measurement concept.

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Introduction

Much work is currently being devoted to the evaluation of interventions to enhance *shared decision making* (SDM) [1] in medical encounters. This approach defines patient physician interaction as a *two way exchange of information* involving both parties in the decision [2,3]. The patient is provided with information on the evidence of efficacy of diagnostic or treatment options [4]. The physician explores the patient's personal values relevant for the particular decision. One of the most cited goals of SDM is to support medical decisions that are informed and coherent with patients' values [5]. However, the mediating principle by which SDM is hypothesized to achieve this goal has not yet been described [6]. The method itself remains insufficiently operationalized [7]. The various definitions given in the literature are inconsistent and act on the level of unconnected elements. For instance Towle and Godolphin [8] suggested competencies for both physicians and patients, whereas others have placed more responsibility on the physician to elicit or respond to

patients' views [9]. Some authors emphasize the importance of providing evidence-based information to the patient [10], while others prioritize the partnership in the medical dyad. There is also considerable overlap between SDM and other constructs, such as informed decision making [11], concordance [12,13], evidence-based patient choice [14,15] and mutual participation [16].

Without a clear concept of the task instruments to determine the extent to which SDM is achieved in a doctor–patient conversation are not convincing. Existing outcome measurement as reviewed by Kennedy [17] seems arbitrary. The parameters used lack a rationale about the mediating mechanisms [6,18] by which they can be affected in line with the concept. None of the available instruments takes into account the interactive character of the SDM approach [19]. Neither the performance of skills on one side of the dyad [20], nor the patient's *post hoc* perception of involvement (PICS [21]), gives an adequate estimate of the extent to which the communication was shared between the parties.

In summary, the promising paradigm of shared medical decision making urgently needs a concept

considering its interpersonal character and providing theorems about its mode of functioning. This would facilitate both appraisal of existing evidence in the field of SDM and future development of suitable research methods and SDM interventions.

Development of a convincing concept of SDM has to consider the following:

- Firstly, SDM serves a communicative purpose. The concept must therefore provide a structure including both the abstracted content of the given situation and an interpersonal strategy to arrange transfer of this content between the parties.
- Secondly, uncertainty is a feature of many aspects of physician–patient risk communication. Uncertainty is inherent in the individual prognosis and in the capacity of a treatment to improve the patient's health. Uncertainty is inherent in assessment of the physician's competence as well as in the assessment of the patient's understanding of given explanations. Uncertainty is also inherent in the interpretation of statistics, especially when evidence is lacking. Most of the uncertainties cannot be resolved within a conversation but nevertheless have to be managed. Abstracting from the particular decision, for instance on a prostate cancer screening or treatment for relapses of multiple sclerosis, we define *uncertainty* as the core content of the decisional communication.
- Thirdly, the *information exchange* [2] implicitly refers to a strategy to communicate uncertainties. By definition, SDM is based on the two-way character of the transfer and on equality in the interpersonal relationship. The missing link in the SDM concept is the answer to the question of how these axioms apply to the implicit subject of uncertainty.

A methodological concept of SDM has to specify a strategy to communicate uncertainty. Such a strategy might mean support for a patient, since, when uncertainties are suppressed, the patient is prevented from achieving a position of clarity. Negotiation of uncertainties in the medical encounter should lead to changes in the patient's cognitive representation of uncertain aspects. Beyond increasing or reducing uncertainty in the perception of the person concerned, such negotiation can change the state of the cognitive representation. There is a need for a theory about people's perception of decisional uncertainty and about the way it changes when they elaborate information relevant for this decision.

Uncertainty is referred to in some of the SDM literature [9,22,23]. However, both the use of the term and the treatment of uncertainty in this context differ from our concept. For instance, reducing awareness of uncertainty is seen as an important goal of risk communication by some

authors [22]. Using the decisional conflict scale to assess uncertainty implies a one-dimensional interpretation of the construct. However, even if certainty as a result of decisional communication were desirable, it is not at all specific for the SDM method. Another approach to uncertainty has been published by Mishel [24,25] with the 'Mishel uncertainty in illness theory' (MUIT). Although the MUIT considers various aspects of uncertainty and provides an instrument to assess the degree of its appearance, this approach does not deal with the same construct as we wished to consider. Mishel's taxonomy classifies uncertainty regarding the mechanisms or triggers which might affect the psychological state of an individual, such as ambiguity, complexity or unpredictability. As described below in detail, our modelling of uncertainty is based on distinct areas where it appears. In contrast to our concept the MUIT primarily stresses the emotional impact of uncertainty as being associated with burden and anxiety.

Some of the communicative dynamic of a risk communication might arise from a discrepancy in the way physician and patient focus uncertainty in a decisional process. On the other hand concordant perceptions of the presence and relevance of uncertain aspects might indicate high-quality communication and exchange of information.

The aim of this study was to survey distinctive qualities of decision-related uncertainty in cancer patients. Thereby, the phenomena affected by the SDM communication should be modelled to provide a basis for a measurement approach.

Patients and methods

As one of the most important chronic diseases associated with extreme uncertainty we selected the field of cancer diseases for investigation. The study sample consisted of patients using the psychosocial support service of the cancer centre at Kiel University Hospital, Germany, who agreed to participate and met the predefined sampling criteria. The number of participants to exhaustively generate the qualitative data pool could not be predefined, but should be ascertained by the research procedure. Participants were selected to include a variety of combinations of age, sex, diagnosis, severity and advancement of cancer as indicated by the existence of metastases. A random selection procedure would not have been able to identify key informants to cover a wide range of views. Between 12/2004 and 5/2005 patients meeting the above criteria were consecutively identified among the patients using the psychosocial support service and invited to participate in the study by the service's psycho-oncologists. All those who agreed to take part were informed of their right to withdraw and gave written informed consent. All

information gained in the interviews was confidential and was not passed on to the clinic personnel. Due to the potentially disturbing impact of the interviews people in an acute stage of the disease were not included. This proceeding was approved by the ethics committee of the German Society of Psychology. Finally six patients were selected to participate in in-depth interviews. They included three men and three women aged between 45 and 77 with various stages of cancer (affecting breast, kidney, tongue or lung). Each patient took part in one interview.

The research protocol included two phases. First we sought to identify as many distinct uncertainties as possible by interviewing the patients. Then we analysed their statements and extracted a model of uncertainty as it is represented in patients' perception.

In-depth interviews were conducted by two psychology students. The guided interviews began with a thorough explanation of the aim of the study and introduction of the interviewers. Thematically they focussed on the participants' experiences of uncertainty in relation to decisions regarding their disease. A psychotherapist (J. K.) experienced in qualitative research trained the interviewers in narrowing their subject down. The strategy aimed to specify the subject of uncertainty rather than the coping behaviour or emotional response associated with it. The interviews were conducted at the patients' homes or at the cancer centre in Kiel. The duration was unlimited. Depending on the course of the conversation and the condition of the participant the interviews lasted between one and two and a half hours. The two interviewers (A. S., S. F.) always worked as a team following clear arrangements regarding dominance in the conversation and responsibility for voice recording.

We used an iterative approach to recruitment and analysis. The transcript of each interview was evaluated before the next interview was conducted. To evaluate interviews data were first fragmented and statements and phrases indicating uncertainty were identified and examined. The resulting elements were entered in an Excel table. An element was defined as the smallest homogenous unit of text concerning uncertainty. With reference to the extracted material the interviewers were supervised regarding their interview technique. Communicative difficulties were discussed such as ways of supporting a participant in specifying an uncertain aspect mentioned in a statement. This procedure supplied insights which informed the research process progressively, both technically and as regards content, so that each interview started from a better information base than its predecessor. The process of iterative sequences of data generation in interviews and subsequent analysis of these data was limited by the criterion of informa-

tion saturation. The model was saturated after five loops of the procedure, or in other words after the fifth interview. We completed the process by carrying out an additional sixth interview for validation purposes.

Modelling

Techniques from grounded theory [26] were used to identify the components of a categorical model of uncertainty. Grounded theory is suitable for exploring the underlying issues (second-order constructs) relating to people's experiences of a subject (termed first-order subject). The basic assumption of grounded theory is that categories are inherent in the empirical data independent of the researcher's hypotheses. Research techniques have to enable the theory to emerge (from the material being studied) rather than imposing it from an existing theoretical framework. Therefore, the influence of prior assumptions must be kept to a minimum. This can be achieved by strict adherence to basic principles. Two of the most important basic principles are a focus on the data itself and the generation of insights using discourse in a group.

The analysis proceeded according to steps described by Strauss and Corbin [26]. Constant analysis was used to develop categories. Elements extracted from the interview material were successively read out in a group of four researchers (J. K., F. G., S. F., A. S.). Analysis of each element had to pass through two steps. Firstly a consensus was established on the meaning of a statement. Agreement had to be achieved among the raters on a salient sense even if it was ambiguous. Uncertainty was defined as the subjective absence of certain information on disease-related aspects as for instance the meaning of certain events or conditions. Though having in mind the potentially pronounced emotional impact of recognizing uncertainty it was defined exclusively as a cognitive state. Statements such as those describing emotional strain, extent of self-efficacy or coping style were excluded.

In a second step the element was categorized. This took place either by agreement among the raters on allocating the element to an existing category or by the emergence of a new category as a consensual abstraction of the particular uncertainty. The total number of categories in the model was limited by *a priori* agreement. With regard to feasibility of the model, a total of eight categories was seen as the maximum. The categorization of a new element sometimes made it necessary to restructure the set of categories so that all elements had to be reanalysed. The communicative structure in this research procedure was democratic and

discourse always had to lead to a consensus among all members.

As categorization of every single element functioned as an implicit test of the previous model, the system of categories was seen as stable after successfully assigning 50 successive elements without any contradictions. Two members of the panel categorized a further 100 elements out of the fifth interview. These ratings were checked independently by the two other members and disagreements were resolved in a discursive process.

To achieve a first estimate of the degree of distinctiveness of the categories within the given model it was subjected to further examination. One hundred elements from the remaining sixth interview were allocated to the categories by five raters independently. This step was conducted with participation of a psychologist who was not involved in the grounded theory process. Agreement was determined using the coefficient provided by Fleiss [27] to quantify observer agreement on nominal data between more than two raters. Disagreements are caused by both limited discriminatory power of the model and ambiguity of the first-order subjects. For instance a statement which is understood in varying meanings or which includes more than one aspect of uncertainty is not likely to be allocated consensually. Therefore, ambiguity would lead to the distinctiveness of the categories being underestimated.

Results

The subject focused by the interviews proved to be highly relevant for the participants. All interviewees appreciated the approach of investigating disease-related uncertainties and saw management of uncertainty as being a core challenge in coping with their decisions related to cancer diagnosis and treatment. Even though some of the participants were not experiencing pronounced uncertainty at the time of the interview, they were able to remember experiences of uncertainty and identified different aspects. One participant stated: 'The doctor went out of the room to make a phone call. I wondered whether I should see this as a bad sign.' We found several uncertainties expressed as their opposite. This occurred when it seemed essential for participants to perceive a particular aspect as certain. For instance: 'Actually I feel absolutely certain that taking up this chemotherapy was the right decision', or 'From the beginning of the disease I never was in doubt about what this disease wanted to tell me'. We learned to identify disclosures of this kind and to specify them by further questions. Information saturation was achieved in the fifth interview. However, a sixth interview was conducted to evaluate the category system with new material.

Altogether 545 elements were extracted and included in the grounded theory process.

During the process of categorizing the system oscillated between a six category model and an eight category model. By splitting two of the six categories we agreed on a final eight category model. The distinct qualities of uncertainty experienced by the interviewees are outlined in Table 1. The research panel achieved an interrater reliability of $F_{\text{leiss}K} = 0.61$ between the five raters, so indicating the model's suitability. The percentage of paired interrater agreement ranged from 71.7 to 78.6%. Definitions and exemplary statements of the kind of uncertainty included by each category are also outlined in Table 1.

Discussion

Analysing the persistent confusion in evaluating SDM measures we found it to be due to a lack of an overall concept in the paradigm. This led us to initiate a theory building process acting on the assumption that SDM basically means negotiation of decisional uncertainty. To get insight into the specific changes of patients' perception of uncertainty and to prepare a strategy to make those changes transparent the construct uncertainty itself had to be alighted. Our research was driven by the hypothesis that decision-related uncertainty is cognitively represented in patients' perception as distinctive qualities.

The qualitative research procedure resulted in the establishment of a stable set of eight distinct areas where patients experience uncertainty. The agreement coefficient (Fleiss' kappa) for five raters assigning statements to the eight categories was found to be $F_{\text{leiss}K} = 0.61$ which is seen as satisfactory. As residual disagreements resulted partly from ambiguity in the elements it is likely that higher levels of agreement will be achieved when the ambiguity has been reduced. This inter-researcher agreement can be valued as an indicator for theoretical discriminatory power. It encourages us to assume that it is possible to develop an instrument with good psychometric properties. The spectrum covered by the eight uncertainties goes beyond the aspects immediately associated with medical decisions. It became evident in our study that patients are concerned with aspects of uncertainty that, from the physician's perspective, are unlikely to be seen as relevant to the decision-making process. Uncertainty about social integration in a patient's usual life, for instance, or uncertainty about one's ability to cope with disease-related life changes, do not seem to be immediately linked to a treatment decision. However, from the patient's point of view these aspects might be salient. Furthermore, we found that patients perceived uncertainties concerning the

Table 1. Categories of uncertainty, definitions and exemplary statements from interviews with people suffering from cancer

Uncertainty	Regarding...	This category includes uncertainties concerning...	Typical statement
1	...social integration	... the reliability of social relationships in the face of the disease's dynamics.	'I often think about my wife. I wonder how long she can stand it.'
2	...diagnosis and prognosis	... the current state of the disease and its future course.	'I don't know how to interpret this kind of pain that I never felt before, you know?'
3	... deciphering information	... the interpretation of the behaviour of medical staff and other kinds of information received by the patient.	'My physician told me about this additional diagnostic procedure. I think he already knew about the tumour, but he didn't want to tell me.'
4	... mastering of requirements	... the ability to cope with disease related life changes.	'So, what about my job?'
5	... causal attribution	... cognitive integration of being affected by a chronic disease.	'Maybe I did something wrong in my life. Maybe God... Well, I don't know.'
6	... own preferred degree of involvement	... the extent to which a patient is willing to play an active role in the physician patient interaction.	'I worry if I drive my doctor mad by expressing all my doubts.'
7	... physician's trustability	... both the professional and the personal competencies of the medical staff.	'I think he is up to date... I hope so at least.'
8	... treatment	... the efficacy of a treatment as well as of other supporting activities.	'In the beginning, I read some books about Chinese medicine and acupuncture and so on. But fortunately the chemotherapy was not so hard.'

communication itself. These are uncertainties about how to interpret hints and signs picked up during contact with the medical system, uncertainty as to their particular role in the communicative dyad and uncertainty about the trustability of the medical personnel. This group of uncertainties is unlikely to be discussed between physician and patient although their relevance in the consultation process is obviously high. Negotiation of such uncertainties would require metacommunication skills, that is the ability to make communication the subject of communication. The third group of aspects reported by our interviewees includes uncertainties immediately associated with a medical decision: uncertainty about diagnosis and prognosis and about the right treatment choice.

This model emerged during a rigorous research procedure including several validation steps. However, it is based on statements from a small number of patients. All of them were users of the psychosocial support service which is consulted only by a minority of the cancer patients being seen at the university hospital. This selection might have caused some bias due to sample-specific perception of the uncertainty issue.

A competent negotiation of uncertainties might not require the use of this term but would probably involve detailed consideration of uncertainties relevant for a decision on both sides of the physician patient dyad. A physician providing a patient with a good explanation of the pros and cons of treatment could still fail to support that patient in working towards an informed decision by ignoring the patient's need to discuss an uncertain aspect which the patient considers important.

Furthermore, one of the most important insights from the interviews is that the need to make uncertainty a subject of communication is not perceived as dependent on the chance to reduce it. By adding this new perspective to the debate on appropriate risk communication the concept of SDM could be improved.

- The *two way exchange of information*, established in 1997 by Charles *et al.* [2] and traded for a decade as the core procedure of SDM without any further specification, could become operationalized. Exchange of the implicit information in the decision-making process is reflected in the concordance achieved by the dyad on aspects of uncertainty perceived as relevant for the patient.
- A sensitive instrument for monitoring changes in the cognitive representation of uncertainties could inform the scientific debate about outcome parameters for SDM [17,18]. By describing basic mechanisms in dealing with the challenge of uncertainty in a medical

decision, the concept could also be freed from elements belonging to similar concepts rather than SDM (such as patient centeredness).

The uncertainty model can be useful to study research questions concerning states of progress in coping with disease or life shortening diagnoses. Changes in perception of uncertainty indicating integration of a break in the lifeline have already been described in the literature [28,29]. Our approach complements this work with a measurement concept.

The concept needs to be supplemented by exploration of the physicians' perspective. We expect to find extensive overlap with aspects of uncertainty perceived by patients in the medical encounter. Results regarding these issues will be reported elsewhere.

The discussion on informing patients about a lack of scientific evidence always has an ethical dimension. To do so means to contradict some authors who argue that certainty should be the goal of an evidence-based information process [22]. As evidence on many medical questions is scarce, taking certainty as a parameter of quality for patients' decision making seems specious and therefore not suitable to the SDM paradigm. We would support McNutt's [30] plea to take enhancement of decisional conflict as an indicator for honest information. Open negotiation of uncertainties will probably not result in their reduction. Even so, we feel that patients would benefit from negotiating various uncertainties with their physician. Transition of uncertainty to another state rather than its replacement with an illusive certainty can nevertheless empower the patient in his or her decision-making process.

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