Acta Oncologica, 2007; 46: 900–908

ORIGINAL ARTICLE

Breast cancer patients' narratives about positive and negative communication experiences

DORTHE K. THOMSEN[1], ANETTE F. PEDERSEN[2], MIKAEL B. JOHANSEN[2], ANDERS B. JENSEN[3] & ROBERT ZACHARIAE[4]

[1]*Department of Psychology, University of Aarhus, Aarhus, Denmark,* [2]*Psychooncology Research Unit, Aarhus University Hospital, Aarhus, Denmark,* [3]*Department of Oncology, Aarhus University Hospital, Aarhus, Denmark and* [4]*Psychooncology Research Unit, Aarhus University Hospital, Aarhus, Denmark*

Abstract

Health staff-patient communication is increasingly considered an important issue in cancer research. However, questionnaires addressing satisfaction with communication limit the issues patients can raise, do not address the context of communication and often show a strong positive skew in responses. Thus, qualitative studies of communication are also needed. Fifteen breast cancer patients were interviewed 3 months after finishing adjuvant treatment. They were asked to tell a 10 minute narrative and recall five experiences from treatment. Themes were extracted using categories derived from previous research while at the same time being sensitive to new elaborations and categories. The participants reported both positive and negative communication-related experiences from a wide range of treatment situations. Two major themes emerged: Information giving as professional care-giving and meeting emotional needs. The analysis suggests that appropriate information giving may have several functions, such as re-establishing the patient's future and reducing worst-case fantasies. Meeting emotional needs was seldom reported as directly talking about negative emotions, but rather through a variety of health staff behaviours. Also, the analysis points to problems in expecting or even pressurizing patients to feel and display negative emotions. The results highlight that meeting medical and emotional needs of patients may be closely intertwined in concrete treatment situations.

Patient satisfaction with cancer treatment is an increasingly important issue in research, both because satisfaction with treatment may be considered a goal in itself and because satisfaction has been shown to be linked with a number of health-related outcomes, e.g. increased treatment adherence, psychological and functional status, and pain control [1]. Patient dissatisfaction, on the other hand, can lead to low understanding and recall of information, poor adherence, lengthier recovery periods, and increased complication rates [1,2].

One important aspect of satisfaction with the treatment course is the communication between the health care staff and the patient, and there is an growing emphasis on the significance of the interpersonal dimension of the patients′ experience of health care [3]. This has led to a focus on "patient-centred interactions", which has been defined as health staff behaviours characterized by good communication skills, where the patient's point of view is actively sought by the physician [4]. The communicative skills of the health care provider have been associated with a range of medical and psychosocial outcomes [5–11], and poor communication have been suggested to have negative effects on both patients and staff as well as being an economic burden on the health care system [12].

Good communication has been suggested to include various elements, e.g. establishing rapport and trust, gathering information, addressing psychosocial issues and providing understandable information about treatment [6]. Problematic aspects of communication centre on gathering and giving information, poor listening, neglect of psychosocial concerns, lack of ability in identifying and responding to negative emotions, and failure to build an adequate relationship with the patient [3,6,8,13,14]. Thus, the patient-health staff communication may

---

Correspondence: Dorthe Kirkegaard Thomsen, Department of Psychology, Jens Chr. Skous Vej 4, DK-8000 Århus C, Tel: +45 89 42 49 11. E-mail: dorthet@psy.au.dk

(Received 14 July 2006; accepted 1 February 2007)

ISSN 0284-186X print/ISSN 1651-226X online
DOI: 10.1080/02841860701261550

be conceptualized as concerning medical and psychosocial issues [8], although the distinction should not be understood as implying an either/or choice [2].

Several studies of patient-health staff relations and communication have been conducted using questionnaires. Although this have yielded important findings on relations to other health care variables, questionnaires on patient-health staff relations and communication often show a strong positive skew [8,15], which may indicate response bias and make it difficult to assess potential problems in communication. By using questionnaires, the topics patients can raise are determined beforehand by the type of questions asked. In addition, the questionnaires focus on general statements, like "the physician wanted to understand, how I experienced things" and information on the concrete context of positive and negative communication experiences is often lacking. Previous qualitative interview-based studies have yielded information on aspects of communication perceived to be important by patients, like trust in expertise and being viewed as an autonomous person [16]. However, more studies emphasizing the patients' view of communication are needed, and the narrative method seems particularly suited for this purpose.

Narrative methods in the health sciences

The use of narratives in research, i.e. as a method of collecting and analyzing data, has generally increased and has also found application within the health sciences [17]. Narrative methods are considered especially useful when the researcher wishes to obtain data concerning subjective experiences [18]. Within oncology, narrative methods have for example been used to gain insight into the patients' coping with cancer, their experiences of changes in identity, bodily changes, and satisfaction across different treatment situations [19–22]. Also, a few studies have investigated communication using narrative methods and/or asking about critical incidents [23–26]. Whereas some of these findings emphasize the importance of feeling connected and being in a helping relationship [25,26] others highlight information giving and emotional support [24]. When investigating patients' view on communication, narrative methods seem particularly useful and may provide concrete examples of positive and negative communication experiences, which may yield a more contextualized and detailed understanding of communication.

The aim of the present study was to use patients' narratives and memories of positive and negative treatment experiences to gain knowledge on positive and negative aspect of patient-health staff communication.

Methods

Recruitment

The participants were women treated for primary breast cancer and they were recruited consecutively at their follow-up visit 3 months after finishing adjuvant chemotherapy at the Department of Oncology, Aarhus University Hospital. The follow-up visit is an offer to all patients who have had breast cancer and includes a clinical investigation of the patients to check for possible loco-regional reoccurrences of the cancer. The inclusion criteria were 1) a diagnosis of breast cancer, 2) treated with surgery and standard adjuvant chemotherapy (CEF × 7). Exclusion criteria were inadequate Danish language skills and recurrence of the cancer at the follow-up visit. Some of the patients had received additional radiation therapy after completing chemotherapy. Potential participants were identified through the booking list at the department and contacted by the first author in the waiting room. Those who agreed to receive further information about the project gave their telephone number and signed a permission to call them later to obtain an oral consent to participate in the study. The Local Science Ethics Committee approved the study.

Participants

A total of 20 patients were approached and 15 accepted to participate. Reasons for non-participation are unknown since potential participants who declined to be interviewed, were unavailable for further questioning. The average age of the participants was 46.80 years ($SD = 7.84$, range 36–60). Seven of the participants were employed outside the home either full-time or part-time. The remaining participants were either unemployed, had just received pension or were on transfer incomes. Twelve were married and three were divorced. The names used in the results section are not the participants' true names.

Interview

The participants were telephoned by the first author, who explained that participation would involve a two-hour interview session. The interview was described as focusing on the experiences related to the illness and treatment. The participants had not met the first author before they were asked to participate in the study and had no treatment relation with the interviewer, minimizing the potential influence of the interviewer on the telling of treatment-related experiences.

The interview was conducted by the first author and took place either in the participants' home or in the university office of the first author according to the preferences of the participant. To obtain data on the participants' experiences of treatment situations, three open-ended questions were asked. First, the participants were asked to tell the story of their illness and treatment in approximately 10 min, while the interviewer listened and asked no questions. The time limit was included in order to limit data for the analysis and because it was assumed that the time limit would induce the participants to tell about their most important experiences. This part of the interview seemed very easy for the participants although there were individual differences in the length of the narratives. Second, the participants were asked to recall and describe five specific experiences from their illness and treatment. It was explained that specific experiences usually pop up by themselves if one lets one's thoughts go back to the course of events, although it may take some time to recall a specific experience in this manner. The participants were asked to select those experiences that came to their mind first. While some participants immediately understood what was meant by a specific experience, some participants found this question rather difficult and took some time to report specific experiences. For a couple of the participants, who were at first unable to recall specific experiences, the interviewer asked them to tell about their experiences in a more loose form and then pointed out when they were talking about a specific experience. In this way all participants achieved recall of five specific experiences. Finally, the participants were asked why they thought they had developed breast cancer. The interviews were transcribed in a verbatim manner leaving out non-verbal communication, like crying and pauses.

Analysis

The first author was the interviewer and the primary responsible for analysis. Since the study was originally designed to explore the relation between specific memories, extended narratives and distress [27], the interviewer may be assumed to have had minimal influence of the content of experiences reported during the interview. Before conducting thematic analysis the first author studied research literature pertaining to communication in relation to cancer patients, thereby becoming familiar with generally accepted concepts within the area. We used content analysis of the narratives [28] as the focus was on identifying commonalities in the participants' narratives of treatment situations. Answers to each of the three open-ended questions were only analysed for communication-related experiences, because the remaining content is beyond the scope of the present study. Because memory research has shown [29] that important and emotional experiences are generally preserved in memory as specific experiences (i.e. "I remember the first time I went to chemotherapy, my contact nurse was very nice") rather than becoming schematized, abstracted knowledge (i.e. "when I came to chemotherapy, the nurses always appeared very engaged"), the identification of specific experiences may yield information on what patients consider important in treatment. Thus, the first author read through the material to identify specific experiences. The first author rated and discussed all episodes, whereas the second and third author each rated and discussed one half of the episodes. The analysis was conducted in three waves.

First, the first author sorted the specific experiences obtained through the interviews into different treatment categories in order to illustrate the types of staff contacts the following content analysis were based on. The treatment categories were derived through re-reading the transcriptions several times. The inter-rater agreement between the first author and the second and third author respectably was 85%. Disagreements were resolved by discussion.

Second, the specific experiences were categorized as positive, negative or neutral according to a manual developed by the first author. Experiences were classified as positive or negative, if 1) the participant expressed positive/negative emotions as a response to a treatment situation, 2) if the situation was explained as having had positive or negative consequences for the participant or 3) if aspects of communication that most people would consider positive or negative were mentioned. The categorization was attempted through separate ratings. However, the inter-rater agreement was only 61%. This may be because some episodes contained both positive and negative aspects and because positive and negative aspects were sometimes implicit in the episodes. Hence, co-rating and discussions between the three authors were used as a viable alternative and each episode was classified as positive, negative or neutral through discussions. Neutral episodes were often characterized by being straightforward descriptions with minimal information or implicit meaning concerning communication and were therefore omitted from the following analysis.

Third, themes of positive and negative communication experiences were identified through several readings of the experiences and final thematic categories were derived through discussions among the first, second and third author, while at the same time keeping existing knowledge on established concepts in mind (like information giving, joint decision making, addressing psychosocial needs, establishing a working relationship). It might be argued that keeping existing categories, established through previous quantitative and qualitative studies in mind, makes the authors preconceived about which content categories to develop. However, care was taken to be sensitive to the data in order to develop new categories and elaborate existing categories further. Keeping existing categories in mind has the clear advantage that the analysis may be used to extend established knowledge rather than running the risk of appearing disconnected from existing research.

Results

The participants generally told about several specific experiences from treatment, ranging between 2–10 experiences (Mean =4.93, SD =2.06). The types of treatments experiences that were mentioned are shown in Table I. The category "General practitioner" mostly covers the participants' visit to their GP for referral to mammography, "Mammography" represents experiences on the day of investigation as well as the conversation with the physician who had informed about the results of the mammography and the ensuing operation. "Operation" consists of experiences just before and after the operation, seeing one's body after the operation and being told about the result of the operation and possible spread to lymph nodes. "Irradiation", "first session of chemotherapy" and "other sessions of chemotherapy" cover different experiences with treatment and side effects. "Other oncological sessions" include experiences with receiving information on adjuvant treatment, control visits and examination for metastases and "Other" comprises experiences about needing drainage, rehabilitation and other visits to the GP. Table I shows a rather skewed distribution with most experiences relating to three types of contact with the health system: Visits to the GP, mammography and the operation. This is presumably because exactly these experiences may be considered turning points for the remaining course of events and because they are not routine events and hence not "forgotten" through schematization. Thus, Table I also highlights that the themes presented below may be especially prevalent in these types of contacts with staff.

Table I. Types of treatment experiences, including both positive, negative and neutral experiences.

General practioner (GP)	10
Mammography	15
Operation	19
Irradiation	5
First session of chemotherapy	4
Other sessions of chemotherapy	4
Other oncological sessions (adjuvant treatment, control visits, investigation for metastasis)	6
Other (drainage, rehabilitation, physician visits)	6

Information giving and professional caring

Many of the positive and negative experiences told by the participants were concerned with the communication of treatment related information in a professional and caring manner or conversely, with a lack of appropriate information. Thus, several of the patients mentioned that they felt well-informed and that they liked that everything was planned for them. Feline tells about her mammography: "*When we came, they told us calmly what they had found, that they would remove my breast surgically ... or, that is, they recommended my breast be surgically removed. They had made the necessary arrangements, you know ...*". Similarly, Vibe tells: "*I think they were good at informing me step by step*" and Elena tells of her mammography: "*but then I felt that it was really okay because they had planned my operation and fixed a date. Everything had been taken care of. Professional planning, you know, I didn't have to ask at all what do I do next ... or anything*". Elena also tells in relation to irradiation: "*... They know how to avoid giving you a fright beforehand [...] and they keep telling you that if you experience any kind of problem we will find a solution, and they actually do ... ointment and all kinds of stuff so in that way it was an incredibly nice experience*". The experiences of these participants indicate that planning and information giving was perceived as professional care giving, thus emphasizing that meeting the medical and emotional needs of patients is closely intertwined in the concrete treatment situation.

On the negative side, there were also examples of lack of appropriate information. One special feature of the negative communication experiences was that in some cases the participants perceived the non-verbal behaviour of the staff to indicate that something was wrong before verbal information was given. Laila tells about her mammography: "*And they start examining me and then I know there is something wrong. Their body language is showing it so clearly. They try to hide it, but I'm not in doubt about the glances they throw each other*". Perceptions of discrepancies between verbal and non-verbal communication may give rise to worst-case scenario fantasies and reduce trust in the health staff

It is worth noting here that information giving may have several functions. First, giving information on a treatment plan may give hope of cure [24]. Second, information giving about treatment may provide patients with a plan and a frame for their future [24,25]. While waiting for results on important clinical investigations the patient's future is in some sense suspended and when information on diagnosis and/or treatment is given this may be overwhelming to some patients, described as "*the world comes to an end [...] I enclosed myself in a bubble*" by Elena and "*in chaos*" by Sanne. However, if a sequential treatment plan is communicated in an understandable manner, order and the future is restored allowing predictions, planning and potentially some control over the future as seen is the following episode reported by Ursula: "*When I was told: Well it's this kind of cancer and we have to do this and that and then it was like I calmed down because then I had a plan, then I had a setting within which I could move*". However, some patients may not be able to take this information in at the time of diagnosis, as illustrated by Betsy: "*I can hardly remember what she said*". A few participants also told that talking through alternative plans with their spouses helped them calm down, again emphasizing that uncertainty and the perceived lack of a future may be remedied by making concrete plans. Third, information giving at an appropriate level may stop patients from having worst-case scenario fantasies, as illustrated by Sanne, who was told that she was to receive chemotherapy and thought: "*Then I won't survive, then I won't see my children grow up*" and only later found out that this was standard treatment. By giving appropriate information in a caring way the health staff also implicitly show respect. Mette tells about a situation where she is going to a consultation about the results of her mammography and hears a physician and a nurse refer to her CPR number in the corridor and talk about her date of operation. She receives the information, but it is given in a disrespectful way (although unintended) and this may give the patient a feeling of just being an object to cure.

Emotional needs

Another theme that clearly appeared in both the positive and negative experiences was when the staff met or failed to meet the emotional needs of the patients through a variety of behaviours. There was only one positive instance of staff directly inquiring about the emotional well-being of the patient, where Lissy tells about her visit to the GP: "*We had a long talk, and he asked me how I felt, and then I told him that I actually didn't know.*"

There were some negative examples with staff expecting or even pressurizing the patient to express negative emotions. Laila tells that she did not experience many negative emotions in relation to her cancer and treatment. One day before the operation she was asked to come and see the physician who diagnosed her. The physician asked her to recount the information she had been given at the mammography clinic. After she had done this, the physician told her that she was just checking to be sure that Laila had understood what was happening. Laila then says: "*I suppose I must have reacted in an a-typical manner that day when I got the diagnosis ... she just wanted to make sure that I knew all about it. When I left her, I simply didn't understand why I had to see her ...*". Laila tells that it did not have a negative effect on her. However, later in the interview she tells about how this and similar situations have made her feel that she reacted abnormally in relation to her breast cancer. Another example comes from Mette, who at the first consultation in the oncology ward thought she would only have hormonal treatment, but was told that she should have chemotherapy. She was upset about this and tells: "*What happens next is that [name of oncologist] would really like to know ... somehow I think that he has observed some kind of change in me because then he attempts to put pressure on me, psychologically you know, to find out whether I have been sad or angry, did I realize that I could be helped by a psychologist if I needed to work with something ... he also tries to get at me through my children. Somehow I suspect that he wanted me to produce the tears I hadn't shed. Finally he gives in*".

But some patients also reported lack of emotional support, as illustrated by Lotte, who at the round following the operation, was told by the physician that there were metastases in the lymph nodes and they had removed them all. She then tells: "*I remember that I started to cry. But the nurse, for instance, she was not a bit caring, not a bit. Actually, I could have used that, if she had talked with me for a while. [...] and since then I have often thought that the two of them-the doctor and the nurse-simply must have been cold hearted*". Jill feels that she had an unmet need for talking with the staff during irradiation: "*They call you in and let you out again, actually they seem to forget that you might need to talk with them. Having treatment is a good thing, but once in a while you still feel a need for talking to someone who will listen to you. Some professionals who understand you and who will enter your world*". However, it is not clear whether directly addressing negative emotions would have been helpful for these participants, it might well be that some other kind of behaviour could have met their emotional needs.

In the positive experiences, the staff seems to meet the emotional needs of the patients not by asking directly but by showing care more implicitly, for example by providing comfort through touch. Else tells about the consultation where she is told that the tumour was cancerous: "*. . . and they took me into that small room and found a chair for me and sat down and took my hands [. . .] and then I cried a bit and they consoled me.*" Mette tells about the consultation, where she was told that there was no spreading to her lymph nodes: "*And it was . . . it was like the first time I also reacted by grabbing her hand and then shedding a tear and then she said something about whether I was OK or if I just needed to cry*". Several participants also mentioned that they felt that the staff had somehow calmed them down, but not by directly addressing negative emotions. Betsy tells of her visit to the anaesthetist the day before surgery: "*He was actually really good at setting my mind at ease . . . well, you know, there was no need for me to worry about anything, and it was really quite nice that he could sort of set my mind at ease*". Sanne tells about her mammography, that she felt in chaos: "*but they calmed me down a bit and told me about the operation*". Vibe also tells about her operation: "*I remember them as being kind to me. They were talking very calming. I remember I was freezing and they were talking very calming*". In addition, referrals to further clinical investigations were sometimes perceived to remedy emotional distress, like Sanne who had back pains throughout chemotherapy: "*In order for me to get peace of mind and not worry about it, she [the physician] thought I should go through a bone scan*".

Thus, in the present study meeting emotional needs appeared to be positive when it was done implicitly by providing comfort through touch, acting in a manner that calmed patients down or by medical advice and/or referral.

Other themes

The themes of information giving and emotional needs materialized most clearly during analysis and discussions. There were, however, also other themes that were not mentioned as often or by as many. Some participants told about episodes, where they seem to appreciate a more personal relationship with the health staff. One example is Ursula, who tells of a situation where she has come for chemotherapy and her contact nurse is back from holiday. Ursula asks about the holiday and is told that the nurse's boyfriend and the nurse had been worried about a lump that he discovered in his breast while they were away. They talk about the anxiety and the worries. She then tells: "*And that . . . that was actually something that brought us closer [. . .] come to think of it, I really need to tell that nurse some time that the fact that she opened up to me as cancer patient actually made me feel like opening up to her*". Having the same health staff during part of the treatment was also emphasized as positive, perhaps because it gives a more personal relationship. Just as health staff meeting the emotional needs of the patients may make the patient feel as a person rather than merely an object to cure, having a personal relationship with the health staff may have a similar function. This may also increase the patient's self-esteem and feelings of being in a helping relationship.

Often the health staff were mentioned as being competent or nice, sometimes within the same episode, but because the episodes do not contain information about why patients perceived them this way and what effects it had, this is not analyzed further. However, it has been suggested that since patients generally do not have direct access to information about the qualifications of their health staff [23], they may act as detectives looking for cues of competence and helpfulness in their health staff. Sometimes, however, the course of events may show patients whether their health staff was competent or not, and the present study has several examples, where the GP delayed referral to mammography because they believed the lump to be non-malignant [25]. Some women indicated that this might have had dire consequences. Margrete saw her GP several times concerning a lump in her breast, but was only referred to mammography after a long delay and ends up filing an official complaint about her GP. She explains: "*So I called to tell him that in my opinion it was indecent of him to deny me medical examination for such a long period [. . .] Then he told me that if he referred everyone to medical examination-people coming with all kinds of symptoms-then the National Health Service system would collapse [. . .] I haven't been in touch with him since then. What I needed was an explanation or an excuse, instead I was met with a blank refusal.*" But there is also an example where the GP's communicative skills appear to have resolved the problem of a delayed referral. Else's GP did not believe that the tumour was cancerous and at first delayed referral for further examination. After a delay, the tumour is removed by normal surgery. But after the operation Else is told that it was cancer. Some weeks later she is asked to see her GP for possible problems with an inflammation. Although reluctant to see her GP again, she tells: "*We embraced and she felt very sad about it. So did I, of course. She didn't understand it and felt very sad but we made up. I forgave her, I mean: she couldn't help it, after all she's only human*". Thus, although patients may often have to rely upon arbitrary cues in order to feel safe in a helping relationship, when lack of competence is discovered, the patients may feel betrayed and one way to attempt to re-establish trust is to apologize for failures in judgement.

Discussion

In accordance with the existing literature in the area, information giving and meeting emotional needs also showed up as important themes in the present study (but see) [16,25,26]. The present study, however, extends these themes. Regarding information giving, several participants told about treatment situations, where they were given information in a professional manner, and it is suggested that appropriate information giving may have several positive functions. This may be especially relevant for the types of situations prevalent in the present study, i.e. situations that may be considered turning points in the illness and treatment course. However, the present findings should not be taken to indicate that as much as possible information should be provided, but that information giving should be considered in relation to the positive functions it may serve. Giving information with this perspective may also meet emotional needs of patients. The participants' appreciation of professional planning of treatment might seem to be in disagreement with always offering joint decision-making [see 8 for an overview]. This underlines the importance of considering the individual patient's needs in patient-centred treatment, and making joint decisions may not be seen as an advantage by all patients or in all stages of treatment.

Another major theme was meeting the emotional needs of the patients. Health staff met the emotional needs of patients in a variety of ways, but the most common positive experiences were of implicit emotional care, like comforting through touch and being talked with in a calming way. However, when health care staff attempted to address patients' emotions in an inappropriate manner, this was associated with distress in the patients. Some health care staff may believe that it is necessary for all patients to experience negative emotions. They may therefore believe that if the patients do not freely express these emotions, the patients need to be helped or convinced to express them. Some patients seem to experience this as negative, thereby making trustful mutual collaboration difficult. Increased awareness of the need for addressing patients' psychosocial needs and establishing patient-centred treatment might explain why health care staff react in this way towards patients who do not seem to express negative emotions. In addition, the staff may worry that unexpressed negative emotions can interfere with the patient's understanding of her condition and treatment [15]. Although it is possible that the participants who told about this kind of experiences are atypical or could have benefited from expressing negative emotions in other circumstances, the finding might also suggest that not all patients experience or wish to share negative emotions with the health care staff. Indeed, by insisting that patients should experience and express negative emotions, the staff may non-verbally communicate to those patients that do not, that their reactions are abnormal or inappropriate.

Thus, one implication of the present study could be that patient-centred treatment should not be understood as always explicitly addressing negative emotions in all patients, but only to the degree that the patient verbally or non-verbally invites the health care staff to address this. Even then, explicitly talking about negative emotions is only one way to react, providing comfort through touch, small-talk or giving information in a caring way are other possibilities recognized and appreciated by the patients. Relating this to previous studies emphasizing patients' need to be in a helping relationship, such behaviours may contribute to establishing a helping relationship and thus increase their hope of being cured or treated in an optimal way. This emphasizes that the staff need to be sensitive to the signals the patient is sending rather than following general rules for good communication.

Narrative method

The present study used a narrative method emphasizing specific experiences in the analysis, coding experiences as positive, neutral or negative and then using content analysis to derive important communication-related themes. This method has several advantages: 1) it does not constrain the issues that may be raised by the patients through preconceived questions, 2) the use of specific experiences highlight issues that may be assumed to be important – otherwise they would not have been retained over several months as specific experiences in memory, 3) rich descriptions are provided allowing for more detailed analysis of context and 4) by asking participants for their most accessible experiences rather than their most positive and negative experiences we circumvent participants' own "theories" of what might be positive and negative experiences – theories that could be wrong. In the critical incident approach often used to elicit specific experiences, participants are asked for positive and negative experiences [30]. While this may provide useful information, the problem is that participants need to have "theories" about what constitute positive and negative experiences. These theories influence what is reported and when are wrong or only partly right this is reflected in the experiences recalled, thus limiting the scope of analysis. The disadvantages of the present method on the other hand are 1) that some participants initially found it quite hard to recall specific experiences, which may strain the relationship with the interviewer, 2) that it may be difficult to assess whether an experience is positive or negative, possibly because some experiences are mixed and 3) that the specific experiences recalled may not be representative of communication experiences more generally [31]. In spite of these disadvantages the method used may reveal aspects of communication not addressed by other methods.

Limitations

One of the limitations of the study is that the participants told about their experiences after a relatively long period of time. Thus, up to one year may have passed between the operation and the interview, and the accuracy of the narratives may be affected by this time period. On the other hand, the delay between treatment and interview may in some circumstances also be an advantage, because this allows time for the participants to reflect on the consequences the experiences had for them, which may be important because the consequences may change over time, becoming more positive or negative. Being a small scale interview study and having some potential participants declining the invitation to the interview, the findings may not directly generalize to all breast cancer patients, but nevertheless the themes identified through the analysis could inspire further studies and theories of communication between health care staff and cancer patients. Still it must be kept in mind that communication needs of cancer patients will also depend on type and stage of disease.

Conclusion and perspectives

The study highlighted that appropriate information giving may have several functions and that meeting emotional needs may take on a variety of forms. This emphasizes that the distinction between meeting medical and emotional needs is analytical, rather than tied to concrete, distinctive behaviours. Intervention studies targeting the communicative skills of health care staff might address these problems by emphasizing that the medical and psychosocial needs of patients are closely intertwined and that patients may differ in the emotional reactions to cancer and their emotional needs.

Acknowledgements

We would like to thank the women who participated for their openness and interest in the study. We are grateful to the staff at the Department of Oncology, Aarhus University Hospital, especially Marianne Høgh Petersen, for their practical help with recruiting participants. We acknowledge Lise Bager Olsen for her valuable help with transcribing the interviews. The project received financial support from Aarhus University Research Fund (E-2004-SAM-1-97).

References

[1] Stewart MA. Effective physician-patient communication and health outcomes – A review. Can Med Assoc J 1995;152: 1423–33.

[2] Fallowfield L. The ideal consultation. Br J Hosp Med 1992; 47:364–7.

[3] Dickson D, Hargie O, Morrow N. Communication skills training for health professionals, 2 ed. Cheltenham, UK: Nelson Thornes; 2003.

[4] Stewart MA. What is a successful doctor-patient interview? A study of interactions and outcomes. Soc Sci Med 1984;19: 167–75.

[5] Arora NK. Interacting with cancer patients: The significance of physicians' communication behavior. Soc Sci Med 2003; 57:791–806.

[6] Baile WF, Aaron J. Patient-physician communication in oncology: Past, present, and future. Curr Opin Oncol 2005;17:331–5.

[7] Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. Eur J Cancer 1999;35:1592–7.

[8] Hack TF, Degner LF, Parker PA. The communication goals and needs of cancer patients: A review. Psychooncology 2005;14:831–45.

[9] Hall JA, Roter DL, Katz NR. Meta-analysis of correlates of provider behavior in medical encounters. Med Care 1988; 26:657–75.

[10] Maguire P. Improving communication with cancer patients. Eur J Cancer 1999;35:2058–65.

[11] Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, von Der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. Br J Cancer 2003;88:658–65.

[12] Thorne SE, Bultz BD, Baile WF. Is there a cost to poor communication in cancer care?: A critical review of the literature. Psychoonocology 2005;14:875–84.

[13] Ong LM, de Haes JC, Hoos AM, Lammes FB. Doctor-patient communication: A review of the literature. Soc Sci Med 1995;40:903–18.

[14] Roter DL, Hall JA. Doctors talking with patients, patients talking with doctors. Westport, CT.: Auburn House; 1992.

[15] Brédart A, Bouleuc C, Dolbeault S. Doctor-patient communication and satisfaction with care in oncology. Curr Opin Oncol 2005;17:351–4.

[16] Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: Qualitative study. BMJ doi:10.1136/bmj.38046.771308.7C (published 30 March 2004).

[17] Skultans V. Narrative illness and the body. Anthropol Med 2000;7:5–13.

[18] Overcash JA. Narrative research: A viable methodology for clinical nursing. Nurs Forum 2004;39:15–22.

[19] Crossley ML. 'Let me explain': Narrative employment and one patient's experience of oral cancer. Soc Sci Med 2003; 56:439–48.

[20] Langellier KM, Sullivan CF. Breast talk in breast cancer narratives. Qual Health Res 1998;8:76–94.

[21] Van der Molen B. Relating information-needs to the cancer experience. 1. Jenny's story: A cancer narrative. Eur J Cancer Care 2000;9:41–7.

[22] Van der Molen B. Relating information needs to the cancer experience. 2. Themes from six cancer narratives. Eur J Cancer Care 2000;9:48–54.

[23] Bendapudi NM, Berry LL, Frey KA, Parish JT, Rayburn WL. Patients' perspectives on ideal physician behaviours. Mayo Clin Proc 2006;81:338–44.

[24] Gamble K. Communication and information: The experience of radiotherapy patients. Eur J Cancer Care 1998;7: 153–61.

[25] Salander P. Bad news from the patient's perspective: An analysis of the written narratives of newly diagnosed cancer patients. Soc Sci Med 2002;55:721–32.

[26] Salander P, Henriksson R. Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. Lung Cancer 2005;50:155–62.

[27] Thomsen DK, Jensen A. Memories and narratives about breast cancer: Exploring associations between turning points, distress and meaning. Under review.

[28] Kvale S. InterView. En introduktion til det kvalitative forskningsinterview. København: Hans Reitzels Forlag; 1997.

[29] Conway MA, Pleydell-Pearce CW. The construction of autobiographical memories in the self-memory system. Psychol Rev 2000;107:261–88.

[30] Flanagan JC. The critical incident technique. Psychol Bull 1954;51:327–58.

[31] Thomsen D. An interviewer's guide to autobiographical memory. Tidsskrift for Kvalitativ Metodeudvikling 2006; 41:81–95.