

## **Summary**

### **BACKGROUND**

Appropriate physician-patient communication and meeting the needs of patients are preconditions for effective cancer treatment. In contrast, ineffective communication can result in unrealistic treatment expectations, psychological stress, inappropriate coping and reduced patient satisfaction and quality of life.

The most important communication tasks of physicians in cancer care are building and maintaining a relationship with the patient, information giving and decision making. Patients' narratives and studies worldwide show that communication problems are prevalent in clinical every day life. Cancer patients complain a lack of time, support, information and participation. Physicians often underestimate communication-, information- and emotional needs of their patients. Research has shown that more than half of all cancer patients do not have a choice to fulfil their preferred decision making role.

At the same time political and scientific discussions on health care are focusing more on patients as individually responsible partners and claim a more intense integration of patients' needs for self-determination, information and participation. Closely related to the paradigm of patient-centered care is the concept of shared decision making. To what extent cancer patients wish and experience shared decision making and which factors affect the process of decision making is not clearly understood so far.

In order to improve communication and patient oriented treatment the subjective patient perspective and the knowledge of patients' needs and experience is essential. So far however, our knowledge on communication needs and experiences during the course of cancer treatment is limited.

### **OBJECTIVES**

The aim of this study was to explore breast cancer patients' preferences and experiences with physician-patient communication. Information needs, decision making preferences and needs, and expectations regarding physician-patient communication were to be assessed from the patients' perspective with a longitudinal design. The second aim was to explore the complex interplay of expectations and experiences regarding information, communication and participation and its' impact on patients' quality of life and psychological adjustment.

## **METHOD**

A consecutive sample of newly diagnosed, primary breast cancer patients was solicited from the two breast cancer centers in Freiburg, Germany. Study staff approached patients within a week of the beginning of their initial treatment (either mastectomy, breast conserving surgery or neo-adjuvant chemotherapy) and invited them to participate in the study. Patients were asked to complete a self-explanatory questionnaire including topics on information, participation and communication. Additionally, quality of life, psychological adjustment and medical and socio-demographic information was assessed. Three and six months after baseline assessment all participants received the questionnaire again via mail and were asked to return it in a pre-paid envelope.

Semi-structured interviews were conducted with eight breast cancer patients attending the hospital in the first week after the beginning of treatment. Interviews were transcribed verbatim and analysed according to the principles of Grounded Theory and a typological approach.

## **RESULTS**

Needs and expectations regarding physician-patient communication are organised in a hierarchical structure containing four levels. On the bottom levels, patients expected medical expertise (level 1) and willingness to give information and advice (level 2) from their physicians. The physician was supposed to have communication skills and to see and accept the patient as individual person from a holistic perspective (level 3). Furthermore, patients desired an emotional supportive physician, who has empathy with the patient and gives hope, reassurance and comfort (level 4). At the same time, patients do not take emotional support from their physicians for granted. Therefore, a shortcoming in emotional support did not result in a negative evaluation of the experienced communication.

Patients had high information needs at beginning of treatment. All eight information topics diagnosis, prognosis, treatment, medication and side effects, examinations and medical tests, aftercare, support services, impact of illness and treatment on social, family and sexual life and aftercare were rated as important. Concerning these topics patients had the highest information needs at beginning of treatment, with a significant decrease of needs in the course of treatment. Information on support services and on the impact of illness and treatment were significantly less important compared to the other information topics at all assessment points. Information on aftercare was the most important topic six months after treatment.

Most patients rated the the quality of received overall information as high at all assessment points. Satisfaction with received information from the physician was rated significantly better at beginning of treatment compared to six months later.

At beginning of treatment most patients (40%) had a passive decision making preference, another 29% wished to share the decision with the physician, while 31% desired to make the treatment decision on their own. According to patients' statements it was irrelevant for most of them who should make the decision. Much more important to them was the need to feel secure and the assurance to receive the best treatment available. At beginning of treatment, only 42% felt they had had a choice regarding different treatment options. Patients with a choice of treatment options more often had an active decision making preference compared to patients without a choice. Remarkably, patients with passive decision making preferences were significantly more depressed than patients with active decision making preferences. At beginning of treatment, 63% were able to fulfil their preferred decision making role. Patients with passive or active decision making preferences were more likely to have their preferences met (76% and 78%, respectively) than patients who wished to share the decision (31%). There were no differences in the satisfaction with decision making depending on whether patients participated actively, collaboratively or passively. However, patients who participated as much as they had wanted to were significantly more satisfied with the decision making process than patients who were less involved than they had preferred.

Analysis of decision making preferences over all assessment points revealed that half of all patients had stable decision making preferences. Compared to the preference at beginning of treatment 13% wished less involvement, while 25% wished more involvement three months later. After six months, 62% preferred the same level of involvement as three months before. Patients who changed their decision making preference wished in nearly equal parts more (17%) and less involvement (15%).

Patients reported that in their actual experience shared decision making rarely took place in the first six months of treatment (17%). Nearly half of all decisions were made by the physician alone (48%), while 35% of all decisions were made by the patients alone. Satisfaction with decision making was high at all assessment points and did not differ in the course of treatment.

Furthermore, besides socio-demographic variables the perceived threat moderated patients' needs and experiences. High threat was associated with low information needs and passive decision making preferences, whereas the highest information needs and decision making preferences were associated with a medium level of threat. Depending on the level of experienced threat three different patients types could be identified from

the qualitative data: The emotionally needy patient, the actively acting patient and the trustfully adapting patient.

The analysis of outcome criteria showed that after controlling for baseline variables (depression, quality of life, respectively) experienced communication and participation at the beginning of treatment had a significant impact on patients' later psychological well-being. Also, patients who were more satisfied with the experienced communication at baseline had lower depression scores after three months compared to patients who were less satisfied with the experienced communication. Similar results were found for information: Patients who rated themselves as well informed at baseline were less depressed and had better quality of life scores after three and six months compared to patients who were less satisfied with the received information. The actual experienced decision making style per se was not associated with any changes in psychological adjustment after three and six months. However, patients who participated as much as they had wanted had significantly lower depression scores after three months compared to patients who participated less than they had wanted.

## **CONCLUSIONS**

The results emphasize the significance of physician-patient communication. Physicians have the possibility to positively influence the adjustment of their patients in the first three to six months of breast cancer treatment by applying effective patient-oriented communication and information giving as well as by tailoring participation in decision making to patients desired level. The above mentioned patient-typology may help physicians to identify the needs of their patients.

Contrary to the political demand for more patient participation, many patients wish and experience a paternalistic oriented decision making process. The finding that patients with collaborative decision making preferences less frequently experience a match between their preferences and experiences emphasises the need for improvement. The small rate of shared decisions could be do to physicians' limited willingness to involve patients as well as shortcomings in their communication skills. Physicians should be educated to create the preconditions for shared decision making and learn communication skills to implement the concept.

Techniques of patient- oriented communication skills, offering treatment choices, the establishment of an equal and collaborative relationship, treatment of depression and support in decision making could facilitate patient participation. The role of perceived threat and of other emotions has been neglected so far and should be addressed in the

future. Patient-centered communication means to take patient needs seriously; therefore communication and interactions should be tailored to patients needs. This can also mean to match the patient's wish not to be involved in decision making.