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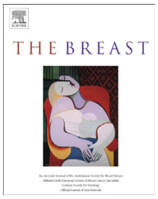

Original article

Core communication components along the cancer care process: The perspective of breast cancer patients

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SUMMARY

This study sought to assess the impact of health care professional (HCP) communication on breast cancer patients across the acute care process as perceived by patients. Methodological approach was based on eight focus groups conducted with a sample of patients ($n = 37$) drawn from 15 Spanish Regions; thematic analysis was undertaken using the National Cancer Institute (NCI) framework of HCP communication as the theoretical basis. Relevant results of this study were the identification of four main communication components: (1) reassurance in coping with uncertainty after symptom detection and prompt access until confirmed diagnosis; (2) fostering involvement before delivering treatments, by anticipating information on practical and emotional illness-related issues; (3) guidance on the different therapeutic options, through use of clinical scenarios; and, (4) eliciting the feeling of emotional exhaustion after ending treatments and addressing the management of potential treatment-related effects. These communication-related components highlighted the need for a comprehensive approach in this area of cancer care.

Introduction

“Empowered citizenship”, the emerging paradigm in health care, requires health services to cope with challenges such as increasing health system accessibility and promoting a new role for patients [1]. This perspective may improve the quality of cancer care and engagement with patients, whose survival rates are steadily rising for many tumours [2]. The capacity and opportunity for achieving effective communication between health care professionals (HCPs) and patients is an outstanding component of a new model of care and, interestingly, the National Cancer Institute (NCI) has developed a conceptual framework to provide guidance on communication research for cancer settings [3]. This framework structures the communication process and outcome analysis around six core functions: (1) exchange of information; (2) response to patients' emotions (these two dimensions have been widely studied); (3) management of uncertainty; (4) the process of deliberation in decision-making; (5) the ability to foster healing patient–clinician relationships; and (6) patient self-management.

A good deal of research on communication from the last decade has focused on “supply side” interventions to improve intermediate outcomes; in other words, on the quality of interprofessional communication and the effectiveness of coordination mechanisms [4]. However, important studies have also shown how communication may affect patients' perception of and response to treatments, for instance, with regard to their role in the decision-making processes [5–8] and their use of information sources beyond those provided by their reference HCPs [9,10]. Patients' experiences of care and perceptions of professional communication may act as a mediator in completing recommended health care or engaging in health-enhancing lifestyles, something that would seem to be especially helpful in coping with the challenges posed by survivorship.

Accordingly, this study adopted a qualitative approach and used the NCI framework as a theoretical basis to analyse the benefits and shortcomings posed by patient-HCP communication from a patient's perspective. By addressing acute phases of care, including presentation of symptoms, diagnosis and the early period of survivorship, analysis also included key elements in health care organisation associated with communication patterns.

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Materials and methods

We chose to conduct focus-group (FGs) discussions as the data collection method. FGs allow researchers to utilise group interactions to explore patients' personal experiences and knowledge of a certain topic and are ideal for capturing opinions and normative systems [11]. According to experts, groups' size should be between 4 and 8 people [12,13]. Eight FGs sessions, attended by an average of 4–6 participants each, were held from September to October 2012. The sampling strategy was purposive, with breast cancer patients being recruited in accordance with two profiles, namely: women who had finished their treatment and were in the first year post-diagnosis; and those within the 5-year survival period (see Table 1). Women who were unable to attend the FG due to their clinical situation were excluded from the study, and the number of participants from any given association was restricted to two in order to preserve a diversity of opinion.

Participants from across Spain gathered in four cities: Seville, Bilbao, Barcelona and Tenerife. Of the initially envisaged total of 40 women, 37 were finally enrolled. Two FGs sessions per profile were held in order to enhance saturation of information and increase the consistency of the results [14,15]. Internal heterogeneity of views was ensured by including participants undergoing hormonotherapy, participants who had relapsed and participants of varying ages. Sociodemographic characteristics of the sample are shown in Table 2. Women were recruited with the support of the Spanish Federation of Breast Cancer Patients (FECMA); 17 out of 36 patient associations were involved, which facilitated the enlistment of women from 15 of Spain's 17 Regions.

Sessions were held in neutral settings, such as universities, and lasted approximately 1.5 h. Two researchers (TF and JP) conducted the meetings, with one acting as moderator and the other as observer. A sheet containing information about the study goals, a consent form and a confidentiality form were handed out before starting. Spontaneous interaction was encouraged. Likewise, patients were assured that they could leave the session at any time if they felt uncomfortable. The sessions were recorded as well as transcribed *verbatim*, and both researchers checked for consistency between the recording and text. The script used to conduct the sessions is shown in Table 3.

To analyse the data, we applied thematic-analysis criteria, which emphasise the meaning of the text and interpret its thematic content [14,15]. After having checked saturation of information, we read through to identify general themes and specific categories within the themes ensuring interpreter consensus. The use of Grounded theory methodology, based on constant comparison, ensured that recurring views and experiences related to patient-HCP communication were obtained [16]. The coding process and emerging themes were derived, on the one hand, from *a priori* issues drawn from the issues of the NCI conceptual framework (e.g., mutual trust; see paragraph immediately below), which was used through the analysis as way to approaching the data. On the other, it was equally valuable to allow open coding to evolve and not affect the assigning of codes or the emergence of new ones [15,17]. A systematic process of data-treatment analysis was facilitated by the use of the Atlas-ti 6.2 software programme [18]. Such programme allowed for indexing to all the data in textual form and identifying co-occurring codes; however, we limited its use in rearranging the data and forming charts as well as in finding associations among themes. Preliminary results were discussed with the team researchers.

Table 1
Criteria used to define focus group composition.

First year of survivorship after treatment	Five years of survivorship after first treatment
Disease free	
In active hormonal therapy	
	Relapsed and disease free at time of study
	Several relapses and disease free at time of study
Relapse at time of study	
In active treatment	

Table 2
Breakdown of the selected 37 participants.

Age (years)	52.9 (37–64)	
Marital status	Married or with partner	24
	Divorced	9
	Single	2
	Widowed	2
Educational level	None/incomplete	0
	Primary school completion certificate	5
	High school diploma	14
	University degree	16
	Other	2
Occupational status	Gainfully employed	18
	Unemployed	6
	Retired	3
	Homemaker	6
	Permanent disability	2
	Other	2

The above-mentioned six functions [3] can be briefly outlined as follows: (1) *fostering healing relationships* (i.e., patient and professional mutual trust; agreement about each other's roles and

Table 3
Scripted prompts for focus groups.

Cancer suspicion
- How were you informed that you might have cancer?
- Who told you and where?
- At the time, did you consider that you were given adequate information?
- What kind of information and communication did you have from then until the diagnosis was confirmed?

Cancer diagnosis
- Who told you and where?
- How did they tell you?
- Could you ask questions?
- At the time, did you consider that the information you were given was adequate and that it allowed you to make decisions?

Treatment
- How did they explain the treatment you had to follow?
- Who told you and where?
- Do you think that you were given all the necessary information to make decisions about fertility, reconstructive surgery, etc.?
- Did you have the necessary information on side effects of the treatment?
- Do you think that you were given adequate information to take care of yourself, considering the circumstances entailed in some of the therapies, and to know where to go if necessary?

Relapse
- How were you informed of the new diagnosis?
- At the time, did you consider that the information you were given was adequate and that it allowed you to make decisions?

End of treatment
- How did they explain what to do upon completing treatment?
- Who told you and where?
- Do you consider that the information you were given was adequate and that it allowed you to make decisions on your own care?

Final questions
- How do you think the communication and the information you received influenced your personal experience?
- How would you have preferred them to inform and explain things to you?