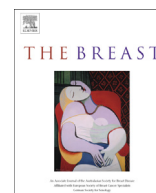


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Original article

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.

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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

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
	None/incomplete	0
Educational level	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

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.

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?

expectations); (2) *exchanging information* (i.e., recognising information needs; integrating clinical information with patient illness representations; overcoming barriers related to health literacy); (3) *responding to patients' emotions* (i.e., eliciting patients' emotional distress; responding with validation, empathy and support); (4) *managing uncertainty* (through cognitive strategies and support); (5) *making decisions* (i.e., enabling involvement in the exchange of information and deliberation at the different phases of the decision-making process); and, (6) *enabling patient self-management* (i.e., supporting patient autonomy and providing guidance, skills and access to resources). These communication functions are neither hierarchical nor independent, and can therefore interact and overlap.

Results

The results are shown using the four standard phases of the acute cancer care process (a–d), from detection of suspicion to the early period of survivorship (participants' quotes are shown in Table 4). The six core functions of the NCI framework on patient–professional communication allowed us to identify the key communication components along the process of breast cancer care:

Detection of suspicion of cancer

Managing uncertainty

Uncertainty arising from a cancer suspicion was differently perceived depending on the specific health care provider. Most patients expressed particular despair over GPs' lack of sensitivity when it came to addressing uncertainty arising from a cancer suspicion, sentiments that contrasted starkly with the type of case management reported in the context of screening programmes.

Several patients commended the coordinated and efficient response afforded by fast-track referral programmes, which streamlined the management of suspicions from primary to specialised care. Some of these women were specifically told that they met the clinical criteria set up with these mechanisms. Patients also stressed their great relief at being admitted to hospital by a professional providing supportive communication and ensuring prompt access up to definitive diagnosis, usually a nurse case manager.

Responding to patients' emotions

According to patients, fear, anxiety and even terror following a cancer suspicion ranked distress levels at the very forefront of the whole care process. In fact, the denial of symptoms before diagnosis confirmation was not rare among women, regardless of their age and educational level. It did not seem paradoxical, therefore, that—emotionally speaking—they found facing the reality of cancer preferable to enduring the inevitable wait entailed by suspicion, something that placed their entire personal life (family, plans, etc.) in quarantine. Some were even ironic about being referred to as “almost” patients, when their vulnerability brought them wholly within the emotional sphere of “real” patients.

Confirmation of a diagnosis

Exchanging information and fostering healing relationships

When asked about HCPs' first reaction after diagnostic confirmation, only a minority of patients reported that they received oral and written information about the organisation and the HCPs of reference across the pathway and were able to voice any doubts or impressions. These patients indicated that this helped them understand that communication and information issues were not going to hinge on one professional alone.

Table 4

Sample quotes from the focus groups by phase of cancer care process.

Detection of suspicion of cancer	<p>“I found it myself and pretended that there was nothing wrong.”</p> <p>“The GP told me, ‘Go home, they’ll call you’.”</p> <p>“It was such a blow that I think, afterwards, my husband and I spent two hours just wandering around the city without saying a word ... We could only walk, we couldn’t actually digest it.”</p>
Confirmation of a diagnosis	<p>“There has to be some professional who deals with the patient with sensitivity and tact because possibly the doctor may not have the time ... that’s to say, somebody else who’s more relaxed.”</p> <p>“You get to find out about things by fits and starts ... if they had told you, well then you prepare yourself, but this way, you keep on having doubts, you suffer, and you have experiences that you could have avoided”.</p> <p>“They tell you about the examinations that you have to have but nothing at all about anything else”.</p> <p>“The doctor told me the headline; the nurse case managers explained the news.”</p> <p>“I was really lucky, because at a routine check-up, they did a routine mammogram on me, and there was something suspicious, very incipient, and so, from there we went on to the echography, and 2 days after that to a biopsy, and then a CAT scan ... and in practically less than a month I had already been operated on.”</p>
A treatment is to be decided	<p>“The doctor told me, ‘You know more than you need to.’”</p> <p>“You know how it works”. [Clinician’s first reaction with respect to a woman who had relapsed]</p> <p>“It came as a shock to see myself, perhaps even a bigger one than actually getting the diagnosis. At the hospital, they took everything off me so I could go in the shower and afterwards they bandaged me up again. When I got home and went into the bathroom and saw myself, well, I felt utterly destroyed. No one had warned me.”</p> <p>“They presented me with the possibility of receiving chemotherapy using percentages together with the remaining treatments, and that only represented 5% and, if anything, served to prevent relapses. I took the decision to go ahead because it was my body and because I thought that, if I have a relapse some day and haven’t done it, I’m going to blame myself forever. But I was the one who made that decision!”</p> <p>“You see yourself as having less energy and that’s the problem with diabetes, and you traipse from one specialist to another (traumatologists, rheumatologists, internists), with all that that involves.”</p>
Survivorship is envisaged	<p>“I’ve got another doctor who specialises in naturopathic medicine, for diet, because nobody had ever prescribed any particular kind of diet.”</p> <p>“I’ve got three months to disconnect and put all this behind me, what a relief! But I also feel insecure, and what if something happens to me in that time?”</p> <p>“Take it as a breather”. [5-year hormone therapy treatment]</p> <p>“Suddenly, in the middle of the examination, I looked at myself and said to myself, ‘we’re going to do a CAT scan to rule out a possible brain tumour’.”</p> <p>“Three months after leaving the hospital, I went straight downhill; I was making such an effort to overcome the situation when they diagnosed me, in the treatments ... All of a sudden, I just fell apart.”</p> <p>“What I wanted to do was to get back my old life, in fact I quit the radio and immediately went to work, and my body itself slowed me down; I need more time but I want them to see I’m the same person.”</p>

There was wide consensus among the women regarding HCPs' efforts to ascertain the pace at and degree by which they were provided with illness-related information. This was of great importance for both patients who were eager and not eager for information. Remarkably in the latter case, an explicit definition of preferences limited the disclosure of unwanted aspects of the disease and contributed to the uptake of the process. Indeed, a few patients' opinions suggested that this moment was used to elicit their level of distress and, in case of need, to provide access to psychosocial-support counselling.

Exchanging information and enabling patient self-management

A minority of patients described that they were encouraged to be prepared in advance for emotional and practical issues deriving from treatments. This allowed them to obtain a wig/shawl in advance, ensure a proper diet or become emotionally aware of the potential impact of "the day after mastectomy". Furthermore, several women associated the "rationale" of preparation with the global experience of the disease, as this approach had given them a specific place in the care process. This type of perception led one participant to consider that the lack of engagement with HCPs implied a loss of care opportunities for her.

A treatment is to be decided

Making decisions

A commonly perceived professional malpractice was skirting key questions related to treatment options and side effects, leaving patients with uncertainty and making them feel alone. In contrast, patients positively viewed any opportunity to discuss the different therapeutic options available with their clinicians, as well as their related benefits and risks on the basis of clinical scenarios. By comparing concise key information, patients felt guided and rationally able to weigh the implications of each decision. Some women who felt that they had not been properly involved said that they still experienced distress knowing that some treatment-related adverse effects could have been mitigated.

Fostering healing relationships, responding to patients' emotions, and enabling patient self-management

Clinicians' communication style was widely discussed. Three types of experiences in patient–clinician encounters were particularly able to capture patients' feelings, namely, lack of tact, banality with respect to situations that patients saw as relevant and moral judgement. For example, a number of women relapsed and were addressed by professionals who did not provide tailored information and support to them, although their health and emotional status clearly differed from the first diagnosis.

Patients with comorbidities also faced special challenges because their reference health services (mainly, medical oncology departments and GPs) were unable to provide specific guidance and coordination to integrate all their needs. Such shortcomings forced them to act as case managers of their own care process in the search for appropriate services.

Fostering healing relationships and exchanging information

Professionals' degree of acquaintance with patients' pathway when changing clinical departments, especially after diagnosis staging and between treatment modalities, was critical. Patients pointed out how mutual trust and understanding toward HCPs was reinforced when they experienced such personalised care. In contrast, several patients witnessed information gaps between professionals in situations of real relevance, such as second procedures. While patients tolerated professionals' turnover, they were very disturbed when they received different clinical messages,

particularly with regard to therapeutic strategies, as typically occurred between surgeons and gynaecologists.

Survivorship is envisaged

Managing uncertainty and responding to patients' emotions

For many patients, the return to "normalcy" meant a difficult coexistence with the risk of relapse and the occurrence of adverse effects. One good care practice identified was a post-treatment interview to provide guidance on follow-up implications. Such encounters were regarded as consistent with the need to address the feeling of helplessness and emotional exhaustion that many patients experienced after long treatments. Experiences with GPs were extremely polarised: while some patients were able to share the process and focus on rehabilitation issues, most felt frustrated and witnessed defensive reactions.

Enabling patient self-management

Surveillance of a possible relapse and physical and psychological rehabilitation—as different targets—were poorly perceived by patients. With the exception of lymphoedema, there was a widespread lack of information and specificity with respect to the scale of potential treatment-related effects and known risks (e.g., fatigue, memory loss, etc.). Only a few patients received tailored information and were specifically advised on how to manage these problems, in one case, in coordination with a breast cancer patients' association. Patients who benefited from this stressed the importance of being advised and receiving adequate education when ending treatments in order to take the necessary preventive measures.

Discussion

This study sought to assess the impact of HCP communication on breast cancer patients using a qualitative research framework. On the basis of the four phases of the care process, specific communication issues were identified for primary and specialised care. A high degree of consensus within the FGs showed that the most important components underlying the need for good communication with and guidance of patients were: firstly, re-assurance and prompt access to the diagnostic department as a way of coping with uncertainty following the detection of a symptom perceived as cancer risk; secondly, anticipatory information to supply patients with the tools that they required to cope with practical and emotional illness-related issues, thereby fostering understanding and opportunities for self-care before delivering treatments; thirdly, clinician guidance on the discussion of the different therapeutic options with patients, through use of clinical scenarios that showed the benefits and risks of each decision; and lastly, an approach providing supportive communication when ending treatments, eliciting the feeling of helplessness and emotional exhaustion that patients may experience, and addressing the management of potential treatment-related effects.

Our study confirms previous research inasmuch as it highlights the fact that good communication can improve patients' experience [19] and, in accordance with the NCI framework, can impact on intermediate outcomes (engaging in health-enhancing lifestyles, etc.) [20,21]. This conceptual framework possesses two main advantages, the first of which is the assumption of overlapping communication between the wide range of professionals and the patient, in contrast to most of the literature, which has traditionally focused on a dyadic patient–clinician relationship [3]. Furthermore, allowing ties and avoiding a hierarchy in the six-function model enabled us to identify key components of patient–clinician communication involving specific organisational contexts. An example of such involvement included GPs' use of fast-track referral systems for streamlining

suspicions up to reaching diagnosis, as shown by other experiences [22–24]. We suggest that such a tool helped physicians to disclose a cancer suspicion to patients.

The way clinical information was communicated to patients emerged as critical at all stages of care, especially when patients had to deal with a diversity of specialists and health professionals. It was not rare for some patients to encounter different clinical messages, which undermined the reliability of their clinical team. Also, most women stressed the importance of having user-friendly information to make informed decisions, including with regard to adverse effects of treatments and their implications for quality of life. However, the focus on prognosis seemed to have the effect of excluding any other information for some clinicians. Likewise, in spite of GPs losing touch with their patients while the latter were undergoing specialist treatment [25], a widespread perception emerged in this study concerning their lack of responsiveness, indicating a specific problem linked to this level of care. At bottom, we found that patients saw encounters with GPs as having a different nature from typical specialised care visits, with the former being perceived as more voluntary and open.

Some strengths and limitations must be taken into account when assessing the results of this study. Regarding its strengths, mention should be made of the wide range of patients included in the sample, namely women drawn from most of Spain's Regions and showing different clinical situations. However, as with all qualitative studies, there was not a large number of participants, and this implicitly ruled out the possibility of capturing all the experiences and best practices that might exist in the health system. A further strength lay in the selection criteria in terms of the different patient profiles, since the study included not only women who had been recently treated but also those who had not. This limited recall bias regarding experience of the process and gave voice to women who were able to express opinions from a more reflective perspective. A potential limitation of our study was the participant selection process, based on proposals put forward by FECMA, which could have biased selection towards individuals with formed opinions.

Conclusions

This study has highlighted most of the existing good practices and meaningful communication components for breast cancer patients in the Spanish health care system, as perceived by women diagnosed with and treated for breast cancer. Inadequacies may represent a missed opportunity for HCPs in delivering good care and helping patients to take an active role in the process. In this regard, a reference experience is the HuCare project, developed in Italy in 2009 for the purpose of implementing evidence-based interventions to improve the psychosocial status of patients and their families [26]. Measures included provision of specific training for professionals to screen for distress across the care process, which has been shown to be effective in impacting patients' behaviour [27,28].

In summary, good communication and adequate information require skills, time and a specific approach embedded along the cancer care pathway. The important mechanisms mediating communication and intermediate and/or health outcomes at every phase of the process entail the need for a strategy to foster patients' roles and their effective empowerment. Further research is needed in order to identify the key elements of a communication framework and the resources for its implementation.

Ethical approval

None required.

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Conflict of interest statement

None declared.

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