Information needs of female Italian breast cancer patients during their first oncological consultation

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A B S T R A C T

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Purpose: Questions asked by patients during consultations reflect their most immediate information needs. The aim of this study is to observe the frequency and type of questions asked by Italian breast cancer patients and to explore associated factors.
Methods: Breast cancer patients at their first meeting with the oncologist were asked to complete five questionnaires (STAI-X1, PHQ-9, GHQ-12, CPS and DSES) before the consultation and three other questionnaires (PEI, SDM-Q, SWD) after. Consultations were audio taped and subsequently analyzed for the content and number of questions to identify patients' information requests.
Results: Patients asked an average of 18 questions, mainly about illness management: patients who were prescribed chemo-therapy asked more questions ($t = -3.17$, dof $= 23.45$, $p < 0.01$). Other factors related to a greater number of questions were younger age ($r = -0.24$, $p = 0.05$), being employed (t-test $= 0.32$; $p = 0.04$), and longer consultation length ($r = 0.47$, $p < 0.01$).
Conclusion: Italian breast cancer patients asked on average more questions than in other countries. Knowledge of the factors associated with information needs can contribute to achieve a major involvement and consequently a better quality of patient-centered care.

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Introduction

In recent decades a growing attention for patient involvement in health care has been reached, considering patient as an expert of his or her role. Patients experience as the meaning given to their illness, their values, their point of view and preferences, have become increasingly incorporated into the assessment of patient health and treatment considerations, in particularly regarding the information giving process. Different patients may have different treatment preferences and they may want different types and amount of information. Accordingly, physicians have to adapt their information giving process to the information needs and to the comprehension level of each individual patient (Jefford and Tattersall, 2002). If the expression of such needs is not encouraged, they will tend to remain hidden, with the risk that the information given will be perceived as either too much or too little. Good clinical practice entails the recognition of what patients want and gives them the space to play a more or less active part in the consultation, according to their preferences (Del Piccolo and Goss, 2012). A patient-centered approach, which includes information-giving and shared decision-making processes, is known to be associated with better quality of care, better coping with illness, and better treatment adherence (Joosten et al., 2008).

Patients cannot express their treatment preferences and participate in decisions regarding their illness unless they had received sufficient and appropriate information. Therefore, the greatest attention has to be given to their concerns, to their information requests and to their preferences. Most efforts by the researchers have been concentrated on the information needs of cancer patients in general (Jenkins et al., 2001; Finney Rutten et al., 2005) and, in particular of breast cancer patients (Lobb et al., 2004; de Bock et al., 2004; Vogel et al., 2008). Breast cancer patients

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consider the information on side effects, treatment long-term effects and prognosis as very important topics (de Bock et al., 2004).

Information needs have been found to be related to several factors. Patients have the highest information need at the beginning of treatment with a decrease in the course of treatment (Vogel et al., 2008). During the diagnostic and treatment phase, patients are usually primarily interested in finding out the diagnosis, including stage of disease, treatment options as well as they are interested in understanding the side effects associated with those options. In post-treatment phase there was still a need for information about treatment, but the most interest was related to the information about rehabilitation (Finney Rutten et al., 2005). The type of treatment is another factor affecting information needs. While Jenkins et al. (2001) found no differences in specific information needs between patients receiving curative or palliative treatment and those who were in remission (all type of cancer); other authors (de Bock et al., 2004) found higher information needs associated with receiving adjuvant therapy or chemotherapy in breast cancer patients. Younger age was associated with a greater information need about all possible available treatments (Jenkins et al., 2001; de Bock et al., 2004). Lower information needs were related to higher quality of life scores, and to greater satisfaction with the doctor–patient relationship (de Bock et al., 2004).

Information needs in health care is a well-defined concept (Ormandy, 2011), based on theories derived from information science. Information needs emerge because of an underlying dissatisfaction with the existing situation and/or deficiency in a person's knowledge self-defined and recognized. They motivate the person to seek answers and form questions to find a solution for a particular problem (Ormandy, 2011). In this framework the number of question asked by the patient during the consultation can be considered as an expression of the most immediate information needs and a first indicator of an active participation in the consultation (Siminoff et al., 2000). Some studies have explored possible factors associated with question asking. They show that older patients (all type of cancer) asked fewer questions while better-educated patients asked more (Eggly et al., 2006). To our knowledge, no data are available on how Italian breast cancer patients express their information needs during the consultation.

Studies show that there are different patterns of doctor–patient communication related to national culture (Meeuwesen et al., 2009; van den Brink-Muinen et al., 2008) and differences in patients' information needs (Harding et al., 2013). In Italy we might expect more fixed roles of doctors and patients, less biomedical information exchange, and less patient question asking, according to Meeuwesen et al. (2009) results.

The present study aims to explore the frequency and type of questions asked by Italian breast cancer patient during a first oncological consultation and to explore associated patient and consultation characteristics.

Methods

This is an observational study describing patients question asking behavior within their first oncological consultation. Specifically the type of information was gathered by qualitative (audio-taped consultations) and quantitative (questionnaires) tools.

Patients and setting

Patients (n = 95) were recruited during the first six months of 2010 in the outpatient clinic of the Medical Oncology Unit of the Hospital Trust of Verona in the Veneto region, Italy. This hospital has an outpatient clinic dedicated to patients with breast cancer, with a rotation of 2–5 oncologists and it has been chosen due to its association with the "Gruppo Senologico Veronese" (GSV). The GSV members adopt a multi-disciplinary approach to breast cancer in order to offer a personalized care, from prevention through diagnosis, treatment, and post treatment support.

Visits for breast cancer patients were scheduled on fixed weekdays, from four to eight patients a day. Patients have already been diagnosed with cancer, often have undergone the first breast surgery (e.g. lumpectomy) and were referred to the medical oncologist by the surgeon or by the radiologist. Generally, in the first visit with the medical oncologist the aim was to communicate the histological results and to decide further medical treatments (e.g. chemotherapy or hormone therapy). The consultation could vary from 30 to 60 min.

Eligible patients were all female patients with an age between 18 and 75 years old, with a recent diagnosis of breast cancer at an early stage. Exclusion criteria were the presence of metastasis or relapse, severe mental deterioration and a difficult comprehension of Italian language.

Data collection procedure

Oncologists informed consent to participate and socio-demographic data were collected at the beginning of the study.

On fixed days the oncology nurses, in accordance with the oncologists, gave to the researcher a list of scheduled patients. At the department waiting room, all consecutive breast cancer patients at their first out-patient visit with the oncologist were asked to give written informed consent to participate in the study. Consenting patients were then accompanied to a dedicated room where they received an envelope containing five questionnaires to complete before the consultation. Consultations were performed as usual by oncologists according to their clinical practice and were audio recorded. Just the recording device was present during the consultation and it was managed independently by the oncologists. After the consultation, patients returned to the researcher and completed three other questionnaires. Oncologists reported on a form the cancer stage and type, when the patient had been informed about diagnosis and the therapeutic options appropriate for each patient. The local ethic committee approved the study.

Pre-consultation measures

Socio-demographic and clinical data collected were age, education, family status, employment status, cancer stage and time since diagnosis. Consultation characteristics collected were presence of a relative or companion, type of treatment prescription and consultation length, including the doctor–patient communication attitude of the oncologist, measured with the Doctor–Patient (DP) Scale (De Monchy et al., 1988). The instrument has 48 items, with an average score of 1 indicating a "doctor centered-disease oriented" attitude and an average score of 5 indicating a "patient centered-problem oriented" attitude. Other variables likely to be associated with patients' expressed information needs were assessed with the following instruments (Table 1):

- the State-Trait Anxiety Inventory (STAI-X1) (Spielberger et al., 1983) assessing the level of anxiety;
- the Patient Health Questionnaire depression scale (PHQ-9) (Kroenke et al., 2001) detecting the presence of depression;
- the General Health Questionnaire (GHQ-12) (Politi et al., 1994) indicating psychological distress;
- the Control Preference Scale (CPS) (Giordano et al., 2008) measures patients' preferences in the shared decision making process.

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