



“There won’t be anything else...it’s over”: Perceptions of women referred to palliative care only



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A B S T R A C T

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Background: It is not well-known how women with advanced breast and gynecological cancers cope with the transition to palliative care (PC) only, but we anticipate that this is a challenging situation for them.

Objective: To investigate women’s understanding on the reasons of anticancer treatment withdrawal, their ideas about PC, and also perceptions of the communication of bad news.

Method: Twenty women were interviewed by a single researcher after being informed that their anti-neoplastic treatment would be discontinued and they would be exclusively monitored by PC staff. The interviews were audiotaped, transcribed verbatim, and analyzed according to content analysis.

Results: Three categories were identified in the participants’ narratives: (1) an understanding of the meaning of PC; (2) a lack of understanding of the shift in treatment and follow-up; (3) differing perspectives about hope. The PC Unit was stigmatized as a place to die, resulting in a “place to die” subcategory. The narratives of the participants who previously had experienced PC converged on a subcategory that reveals better recognition of the importance of the PC Unit as “a place that enhances the quality of life”.

Conclusion: The participants manifested little knowledge about PC and the forthcoming strategies for their clinical follow-up. In addition, the PC Unit was patently stigmatized as a place to die. Early referral to PC seems to be associated with a less painful therapeutic transition, based on more accurate knowledge of the importance of PC.

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Introduction

Palliative care (PC) is one of the pillars of the comprehensive treatment of patients in the advanced stages of disease (Gaertner et al. 2012). According to the National Comprehensive Cancer Network (NCCN) (NCCN, 2013), PC must be included in antineoplastic treatment from the moment that a diagnosis is established, rather than at the end of life. When both types of care are performed simultaneously, the transition from the “therapeutic” to the

“palliative” model of treatment is gradual and has less impact on the patients and their relatives (Meyers et al. 2004).

The addition of PC to chemotherapy in patients with metastatic non-small cell lung cancer improved their quality of life, reduced the frequency of emotional disorders and the number of invasive and futile procedures at the end of life, and induced a significant increase in the patients’ overall survival (Temel et al. 2010). Patients with advanced cancer underwent to a psychoeducational intervention focused on palliative care concurrently with standard treatment had better quality of life and improved mood in comparison with those patients who received standard care only (Bakitas et al. 2009).

Hui et al. (2012) reviewed the charts of patients with advanced cancer from Houston area who died in a determined period of 6 months at the MD Anderson Cancer Center. They pointed out 1.4 months as median interval between first PC consultation and patient’s death, concluding that PC still begins late, even if available at

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a comprehensive cancer center. Several factors hinder the early application of PC (Miyashita et al. 2008). The major challenge is likely the lack of knowledge about PC and prejudice against PC of the patients themselves.

Communication of the discontinuation of anticancer treatment is a challenge in oncology practice (Smith and Hillner, 2010). Certain protocols are available to make the communication of bad news more adequate (Back et al. 2005; Baile et al. 2000; Girgis and Sanson-Fisher, 1995). However, these protocols are mainly based on the opinions of experts and do not necessarily include the patients' perceptions (van Vliet et al. 2013). Few studies have addressed the transition in the model of treatment.

Coping strategies are different between men and women with cancer (Cho et al. 2013; Peleg-Oren et al. 2003). Compared to men, women have higher levels of distress (Cassileth et al. 1986; Gil et al. 2012; Keller and Henrich, 1999; Thomas et al. 2010), and more frequently they also need social support and religion/spiritual resources (Jacobs-Lawson et al. 2010). It is not well-known how women with advanced breast and gynecological cancers cope with the transition to PC only, but we anticipate that is such a challenging situation for them.

Therefore, the aims of this study are to investigate women's understanding the reasons of anticancer treatment withdraw, their ideas about PC, and also perceptions of the communication of bad news.

Methods

A qualitative descriptive study was conducted at Barretos Cancer Hospital (BCH) and approved by the local Research Ethics Committee (HCB70/2012). All participants received full information regarding the study and signed a consent-to-participate form.

Study setting

BCH includes a unit exclusively dedicated to PC (PCU, Unit II), that is located in a building apart from the main hospital facility (Unit I), and in a different area of Barretos (São Paulo, Brazil). If the clinical oncologists determine that no antineoplastic modality of palliative treatment has benefit, the patients are discharged from the clinical oncology department and referred for exclusive follow-up at the PCU. Some patients, who usually present more severe symptoms, are earlier referred to the PCU, whereas keeping the antineoplastic treatment.

Eligibility criteria

The patients enrolled in this study were all women >18 years old with a diagnosis of advanced breast or gynecological cancers after being referred for exclusive follow-up at the PCU. Patients were considered as having advanced cancer when presenting clinical evidence of distant metastases or a not curable locoregional disease. All participants had been discharged from the clinical oncology department and referred for exclusive follow-up with the BCH PC staff. Significant neuropsychiatric disorders or hard-to-manage symptoms that could hinder the participants' ability to answer questions were considered to be exclusion criteria.

Data collection

Potential participants were identified during visits with clinical oncologists (consecutive sampling). In sequence, one of the authors (FCR) was contacted to assess the patient's eligibility. Written informed consent was obtained from each patient who understood and accepted to participate in the study. The interviewer was

previously trained on how to conduct qualitative research by one of the authors (BSRP, nurse professor) who provided additional supervision. Interviews typically lasted for approximately 15–25 min.

The interviews were based on one guiding open question: "What has the doctor told you about your disease?" Once they started talking about their conversation with the doctor, the interviewer asked questions about the reasons to discontinue treatment, the participants' ideas about PC, and their perceptions concerning the communication of the bad news.

The clinical and sociodemographic characteristics of the patients were extracted from the medical records.

Data analysis

For this content analysis (Bardin, 1994), the interviews were audiotaped and then transcribed verbatim. In the phase of preparation, the researchers were immersed in the data in order to obtain the sense of whole. Then, in the phase of organization, all transcribed scripts were read carefully again and similar statements, expressions and content were grouped together, summarized, and coded. Generated codes were categorized and conceptualized based on similarities in the content and became "subcategories". A similar group of subcategories was combined into a "category". Two authors (FCR and BSRP) performed the initial identification of the contents, which were later discussed and refined together with other author (CEP). The findings also were reported in a conceptual framework (Fig. 1).

Results

Characteristics of participants

Twenty women with advanced cancer (breast, $n = 14$; cervical, $n = 4$; ovarian, $n = 1$; and endometrial, $n = 1$) were interviewed from August to November 2012. Patient's characteristics are shown in Table 1. After the eighteenth interview, the authors noted that no new information emerged from the interviews. Thus, it was decided to conduct two other interviews to confirm data saturation.

Content analysis

Three categories were identified: (1) an understanding of the notion of PC; (2) a lack of understanding of the shift in treatment and follow-up; and (3) hope-related problems. The first and the third categories were divided in further subcategories. Below, each category/subcategory is represented by a fragment of the participants' narratives.

Category 1. Understanding of the notion of PC

The meaning attributed to the term "palliative care" by the participants and their understanding of the work performed by the staff and the mission of the PCU were identified in following narratives.

a. A place for the control of pain and other symptoms

According to a few of the women, the staff of the PCU comprised a team specialized in the relief of troublesome symptoms.

Patient 1: *I'm followed up there... the focus there is on pain.*

Patient 13: *I go to that other unit for pain relief and for the relief of belly distension.*

b. A place to die

Upon admission to the PCU, the patients' functional performance often exhibits a significant decline, and their life

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