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Hospital–community interface: A qualitative study on patients with cancer and health care providers' experiences

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ABSTRACT

Background: Patients with cancer must deal with complex and fragmented healthcare systems in addition to coping with the burden of their illness. To improve oncology treatment along the care continuum, the barriers and facilitators for streamlined oncologic care need to be better understood.
Purpose: This study sought to gain insight into the hospital–community interface from the point of view of patients with cancer, their families, and health care providers on both sides of the interface i.e., the community and hospital settings.
Methods and sample: The sample comprised 37 cancer patients, their family members, and 40 multidisciplinary health care providers. Twelve participants were interviewed individually and 65 took part in 10 focus groups. Based on the grounded theory approach, theoretical sampling and constant comparative analyses were used.
Results: Two major concepts emerged: "ambivalence and confusion" and "overcoming healthcare system barriers." Ambiguity was expressed regarding the roles of health care providers in the community and in the hospital. We identified three main strategies by which these patients and their families overcame barriers within the system: patients and families became their own case managers; patients and health care providers used informal routes of communication; and nurse specialists played a significant role in managing care.
Conclusions: The heavy reliance on informal routes of communication and integration by patients and providers emphasizes the urgent need for change in order to improve coordinating mechanisms for hospital–community oncologic care.

Introduction

Patients with cancer face a wide array of challenges in the course of their care. In addition to dealing with disease symptoms, emotional stress, social and financial pressures, and self-management needs, patients often encounter a disarrayed healthcare system and are charged with care navigation and bureaucratic challenges. Care of patients with cancer is typically provided across several settings, with a variety of providers delivering various types of care at different stages, often with no clear understanding of each other's role (Stalhammar et al., 1998). The difficulties encountered by patients and their families in navigating complex and fragmented healthcare systems have been well documented in various healthcare systems worldwide (Berendsen et al., 2009; Farquhar et al., 2005). While barriers to cancer care coordination are well acknowledged (Walsh et al., 2010), to date, little is known of the mechanisms by which patients and their providers overcome system barriers to achieve seamless cancer care.

Background

Uncertainty about the division of responsibility, poor communication among health care providers, and inadequate transfer of information between hospital-based physicians and primary care

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physicians (PCPs), constitute preventable breaches in care (Farquhar et al., 2005; Sada et al., 2011). A recent qualitative study identified six barriers to effective cancer care coordination: confusion regarding roles and responsibilities of the health care team, lack of multidisciplinary team meetings, lack of continuity in transitioning across care settings, inadequate communication between specialists and primary care providers, inequitable access to health services, and scarce professional resources (Walsh et al., 2010). In addition, several studies have addressed communication gaps, uncertainty about divisions of responsibility, and differences in professional strategies of cancer management between PCPs and oncologists (Babington et al., 2003; Barnes et al., 2000; Smeenk et al., 2000; Klabunde et al., 2009).

While current literature acknowledges the deficiencies in cancer care integration, little is known on how patients and their providers manage their care across providers and care settings. This study aims to fill this gap by examining the experiences of patients, their families, and health care providers from community as well as hospital settings.

Methods

This qualitative study is part of a larger study aimed at investigating the factors influencing the nature and quality of cancer care at the hospital–community interface (Shadmi et al., 2010). The theoretical orientation for this qualitative study was based on grounded theory, which develops a theory about phenomena of interest from a corpus of data. Grounded theory is a complex iterative process consisting of a series of steps, which after careful data analysis, generates a theory (Glaser and Strauss, 1967; Lingard et al., 2008; Strauss and Corbin, 2008).

Sampling

A purposive sampling method was employed to select participants, which included patients, their family members, and multidisciplinary health care providers. Participants were selected for the purpose of exploring their experiences with care provided in both the hospital and the community care settings. The settings for this study included oncology units and day care clinics in both hospital and primary care clinics.

The eligibility criteria of patients and their family members were: (1) a diagnosis with any type of cancer, (2) over 18 years of age, (3) able to speak and understand Hebrew (4) agreement to participate in focus groups or one-on-one interviews. Patients were excluded if they met hospice care criteria or end-stage disease to protect them from unwarranted emotional and physical exhaustion at this point in their lives.

The health care staff participants were selected for their ability to confirm or challenge the emerging theory. They represented a multidisciplinary team from the community and the hospital health care sites. They all had extensive clinical and managerial experience in the field of oncology and agreed to participate in focus groups or personal interviews. All interviewees were willing to share from experiences within their context. Individual interviews and focus groups were used in this study to increase the probability of credible findings and interpretations (Lincoln and Guba, 1985).

Cycles of simultaneous data collection and analysis were conducted where analysis informed the next cycle of data collection. Sample sizes were determined based on ongoing data collection, analysis and refinement. Recruitment of participants continued until data had reached saturation (Lingard et al., 2008).

Data collection

Five focus groups that included patients and their families were conducted. Each group comprised five to eight members. Four focus groups were conducted within a hospital setting among hospitalized and day care patients, and one within the community in a primary care clinic. All potential participants were approached and recruited voluntarily by local health care personnel. Patients and their family members were asked about their community, hospital, and transitional care experiences.

Triangulation technique is used to improve credibility of findings and interpretations (Lincoln and Guba, 1985). In this study we used three modes of triangulation: multiple and different modes of sources, methods and investigators. A mixed data collection approach allowed for both proliferation of ideas (focus group) and confidentiality of in-depth personal interviews. Depth of perspective was made possible by involving several investigators from different disciplines; their examination of the findings as a group helped avoid interpretive bias.

Interview guide

All focus groups and interviews took place during 2008. Focus groups and interviews were led by seven researchers (three nurses, three physicians, and one social worker) using complete topic guided open-ended questions. For the study purposes we developed three sets of interview guides, each one addressed to a specific group of participants from both the community and the hospital: patients and their families, health care personnel, and policy decision makers. Each interview guide included questions in accordance to the study aim tailored to the unique perspective of the different participants. Examples of questions to patients included: “What do you do when you are at home and realize you have a health problem? Who is managing your care at present? How would you describe the types of care you received from your PCP? What types of care do you receive from the oncology unit?”

Initial “grand tour” questions were designed to promote open discussion and specific probes were pre-designed for subsequent stages of the interview. Health care providers were asked: “How do you view the relationships at present between the PCP, oncologist, and oncology nurse? In your opinion, what should be the PCP’s involvement during hospitalization of oncology patients under their responsibility? What obstacles/difficulties do you face in the community–hospital interface at present? In your opinion, what should be done to ensure continuity of care?”

Each session lasted 60–90 min. All interviews were audio-recorded and transcribed verbatim.

Analysis

Based on the grounded theory approach, purposive sampling and constant comparative analysis were used (Glaser and Strauss, 1967). All interview and focus group transcripts were reviewed line by line to search for coding, themes, concepts, and propositions that emerged from the data.

Four evaluative criteria (credibility, transferability, dependability, and confirmability) for judging the rigor of qualitative inquiries were applied to increase trustworthiness of the analysis process (Lincoln and Guba, 1985). To increase credible findings, all transcribed interviews were analyzed independently by at least three of the researchers, followed by peer debriefing. Reflections on the data and interpretations were discussed until consensus and saturation of emerging themes were achieved. Theoretical sampling continued, and the topical guide for interviews and focus groups was modified after initial analysis.