

Disclosing and responding to cancer “fears” during oncology interviews[☆]

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Abstract

Video-excerpts from routine oncology interviews are examined to reveal how patients demonstrate and doctors respond to “fears” about cancer. Vocally and visually, embodied impacts of dealing with dreaded consequences of cancer are apparent when addressing both good and potentially bad cancer news. Even a “brush” with cancer can promote negative and ongoing impacts provoking unresolved illness dilemmas. We reveal how, in the midst of extending answers and initiating concerns, patients exhibit trepidations when volunteering narrative information about their medical history and experience of symptoms. In response, doctors are shown to acknowledge yet exhibit minimal receptiveness to patients’ lifeworld disclosures and demonstrations (e.g., redirecting attention away from patients’ concerns by offering “textbook” symptoms and related pursuits of biomedical agendas). Discussion focuses on interactional criteria for identifying “fears”, patients’ lay orientations to medical visits, and implications for refining educational workshops for oncologists.

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Introduction

During medical encounters patients may directly verbalize that they have concerns, are experiencing problems, or even fearful about their condition. Patients have also been shown to indirectly offer “cues or clues” when speaking and bodily demonstrating their problems (e.g., through gesture, gaze, and related actions) (Gill, 1998; Gill, Halkowski, & Roberts, 2001; Beach & Dixon, 2001; Jones & Beach, in press; Lang, Floyd, &

Beine, 2000; Levinson, Gorawara-Baht, & Lamb, 2000; Ford, Hall, Ratcliff, & Fallowfield, 2000; Suchman, Markakis, Beckman, & Frankel 1997; Heath, 2002; Beach & LeBaron, 2002). Some of these “cues or clues” include repeating phrases or topics (Frankel & Beckman, 1988; Lang et al., 2000), being tentative when explaining or speculating about what is wrong with them (Gill, 1998; Stivers & Heritage, 2001; Beach, Good, & Pigeron, 2004), embodied expressions of embarrassment, suffering and/or emotional distress (Heath, 1986, 1988, 2002; Beach & LeBaron, 2002), offering a self or “lay” diagnosis (Beach, 2001a; Jones & Beach, in press), constructing indirect questions and requests (Gill et al., 2001), and even having family members or friends present during the interaction (Lang et al., 2000).

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In this study, we examine how patients display being impacted by and, at times, fearful of cancer. In turn, doctors' responses to patients' fears are shown to be consequential for achieving what has historically been described as *patient-centered care*, "in which the physician respond(s) to patients in such a way that allow him/her to express all of the patient's reasons for coming, including symptoms, feelings, thoughts and expectations" (Ong, de Haes, Hoos, & Lammes, 1995, p. 911; see Barbour, 1995; Engel, 1977; Stewart, 1984; Ford, Fallowfield, & Lewis, 1996a; Felitti, 1997). A central tenet of patient-centered care is to recognize that "patients provide cues to their feelings, fears and expectations, which, if responded to appropriately, will lead to their disclosure" (Ford et al., 2000, p. 554). Because responses to patients' "lifeworld" concerns vary widely (Mishler, 1984; McWhinney, 1989; Frankel & Beckman, 1989; Roter & Hall, 1992; Ford et al., 2000; Beach & Dixon, 2001), criteria for assessing "appropriate" orientations will best emerge from close examination of actual clinical moments. So doing requires an orientation to *fears* as primal and socially constructed emotions situated within ordinary medical interviews (see Goodwin & Goodwin, 2000).

Considerable and increasing attention is being given to patient–doctor interactions in oncology clinics (e.g., see Ben-Sira, 1980; Lichter, 1987; Faulkner & Maguire, 1994; Fallowfield et al., 2002; Baile, Kudelka, & Beale, 1999a; Fallowfield & Jenkins, 1999; Ford et al., 1996a,b; Ford, Fallowfield, & Lewis, 1996b; Ford et al., 2000; Maguire & Faulkner, 1988a–c; Lutfey & Maynard, 1998; Sandén, Linell, Sätterlund Larsson, & Starkhammar, 2001; Maynard & Frankel, in press). Ongoing research, and related attempts to refine communication skills for enhancing clinical care, are designed to understand and address cancer as the most ubiquitous and deadly disease in the world today (Kumar & Clark, 1990). A recent survey (2001) by the American Institute for Cancer Research AICR, (2001) reveals that cancer is the most fearful health concern for more than 1/3 Americans, and that over half of those people believe cancer is difficult or impossible to prevent. A statistical basis exists for cancer "fears":

- More than 1.2 million Americans will be diagnosed with cancer this year alone, resulting in at least 1/2 million deaths. Men have an approximate 50% and women a 33% lifetime risk of being diagnosed with cancer (American Cancer Society, 2002).
- Greater than 50% of all cancer patients cannot be cured (MacDonald, 1996). If rates of incidence remain stable, the total number of cancer cases is expected to double by 2050 (Edwards et al., 2002).
- Three out of four families in the Western world are somehow impacted by cancer diagnosis and treat-

ment (American Cancer Society, 2002; Bigel, Sales, & Schulz, 1991; Lichtman & Taylor, 1986).

Although cancer is feared more than any other serious medical condition by Americans and British alike (see Brooks, 1979), and certainly is a primary health concern worldwide, "few studies have documented fears of cancer" (Berman & Wandersman, 1990, p. 82). Indeed, while a fundamental and intuitive focus of cancer care involves understanding and responding to patients' fears, very limited empirical attention has been given to the interactionally organized and distinct nature of fearful events. In Excerpt (1), for example, a leukemia patient states being "afraid" that his pneumonia-like symptoms are similar to symptoms brought on by toxicity from earlier chemotherapy (see transcription symbols in the appendix):

(1) SDCL: Oncology#5:5

PAT: U:m (1.5) I w- (0.2) was afraid that (0.5) i:t was some sort of:- (0.2) i:t was maybe related- (0.2) li:ke (·) before, to the toxicity [of the] chemo I had in
Ja:nua:ry. =

In Excerpt (2), another leukemia patient expresses "concerns" about her swollen lymph node:

(2) SDCL: Oncology#4:6

PAT: [No.] No I don't either. ((Patient points to right side of her neck)) That concerns me about the ly:mph no:de over here. So you think that its increased in size [a little bit?]

And in Excerpt (3), a patient experiencing problems with "gallstones" makes clear that "cancer, cancer, cancer" is in his family and clearly on his "mind":

(3) SDCL: Oncology#3:24

PAT: The first thing that re- >tha- tha- that was on my mind and I don't mean to sound < like a fatalist or- or- or hypochondriac, but cancer cancer ((Clenches fists)) [there's been so much] =
DOC: [(O:h I hear ya.)]
PAT: ((Hits fist to hand)) = cancer in my- in my fa:mily and all. =

In the data examined herein, patients also exhibit subtle, delicate, and often troubling orientations to moments comprising discussions about cancer diagnosis, treatment, and prognosis. We argue that vocally and visually, the embodied consequences of dealing with

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