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'End of life' conversations, appreciation sequences, and the interaction order in cancer clinics

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ABSTRACT

Objective: To address the organization of conversations in oncology visits by taking an "interaction order" perspective and asking how these visits are intrinsically organized.

Methods: Conversation analysis.

Results: Using audio recordings of talk in oncology visits involving patients with non-small cell lung cancer, we identify and analyze an "appreciation sequence" that is designed to elicit patients' understanding and positive assessment of treatments in terms of their prolongation of life.

Conclusion: An "appreciation sequence," regularly initiated after the delivery of scan results and/or treatment recommendations, simultaneously reminds patients of their mortality while suggesting that the treatment received has prolonged their lives, and in some cases significantly beyond the median time of survival.

Practice implications: We explore the functions of the appreciation sequence for cancer care and set the stage for considering where and when physicians have choices about the order and direction the talk can take and how to allocate time for end of life and quality of life conversations.

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1. Introduction

In the popular press [1,2] and in medical research [3], investigators suggest that, beyond managing symptoms and pain, cancer care should include maintaining quality of life, knowing patients' attitudes toward aggressive treatment and resuscitation orders, and facilitating a sense of completion by allowing for timely life review, saying goodbye, and resolving unfinished business. However, as doctors, nurses, patients and caregivers work diligently to stave off death, conversations by which they address quality and end of life are at best infrequent and at worst nonexistent [4,5]. This matter has been documented again and again in various ways—through surveys and experiments [6,7], patient ratings of doctors [8] ethnographic studies [9,10:1380], content analysis, coding, or conversation analysis of audio recordings [11–14], and clinical experience and research [1]. These investigations, from Britain, Canada, the Netherlands, Sweden, and the U.S., use concepts such as avoidance, allusiveness, routinizing, vagueness, and withholding to characterize physician behaviors and patient contributions—or lack thereof—regarding end of life and quality of life discussions. In other cultures as well, it appears that "most patients do not know the implications of their illness, and they do not know their prognosis" [15:148,cf. 16].

2. Theory and methods

In the face of cross-national consensus about what is *not* occurring in oncology clinics, it seems compelling to ask exactly what *is* going on. Our approach to these questions is to follow the notion of the "interaction order" as the sociologist Erving Goffman formulated it. The interaction order is a "substantive domain" whose elements or features "fit together more closely than with elements beyond the order" [17:2]. Elements from beyond the interaction order could derive from economic, political, demographic, ethnic, and other domains that social scientists often investigate for their *effects* on interaction without treating interaction on its own terms.

Our use of interaction order theory [18] is to highlight how studies that employ survey questions to evaluate cancer communication draw on extra-situational concepts and measures to characterize occurrences within a social situation that has its own parameters.

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Studies that utilize ethnographic observations or interviews also may gage interaction—often with a focus on physician behavior—using concepts such as "open communication" or what the researchers know is potentially communicable between doctor and patient. Hence, investigators regularly use rubrics that have their provenance outside of the interaction and deflect full attention from the issues that emerge from within, according to the displayed orientations of doctor, patient, and caregiver. Accordingly, our goal in this paper is not to document further how—or explain why—prognostic conversations are largely absent from the oncology clinic. More modestly, we aim only to say what does happen during interaction in the clinic and how a particular facet of that interaction is configured. In so doing, we first explore the overall organization of the routine post-diagnosis oncology interview, and then document a phenomenon—the occurrence of an "appreciation sequence," which bears on a particular communicative challenge for physicians: achieving positivity when presenting news about a patient's ongoing cancer that, whether the tidings are relatively bad or good, also can serve as a reminder of the ultimately fatal nature of the disease.

We draw on the field of conversation analysis (CA), which is a sociological approach to the study of talk and interaction among humans. Applied to encounters in medical settings, CA regards the arena as one of "naturally occurring" interaction, where it is possible to use audio or video recordings and transcripts thereof to capture real-time utterances and other behaviors of participants (see Appendix A for transcribing conventions) [19]. Doctors, patients, and (if co-present) family members together construct actions relevant to their small, collective endeavors, whether it is talking sociably, taking or giving a medical history, doing diagnosis, discussing treatment recommendations, or engaging in other such efforts [20]. Maynard and Heritage [21] discuss other features of CA as applied to medical settings, including the primary orientation to sequencing as a feature of interaction and a methodological tool for capturing structure, an orientation to detail as a site of order and organization, the grounding of analysis in participant orientations, and working with both single cases and collections of patterns for developing generalizations.

Our data are audio recordings from an earlier study [22] evaluating the effects of an internet-based support system for patients and caregivers. Patient-caregiver dyads were recruited and recorded at four cancer-center hospitals in the East, Midwest, and Southwest U.S. between September 2004 and May 2009. Although patients with a variety of cancer types participated in several different studies, we had access only to recordings involving only patients with locally advanced (stage IIIB) and metastatic (stage IV) non-small cell lung (NSCLC) cancer. Of 128 recorded visits, half (64) were transcribed for intensive study, involving 51 triads of patient, caregiver, and doctor (some patients had more than one visit). Given the practicalities of doing conversation analytic research including the effort require for detailed transcriptions [21], our selections of interviews excluded those that had no delivery of scan results, discussion of ongoing treatment, or physician involvement (only the nurse saw the patient). Of the 51 patients in our collection, 29 were female and 22 were male, with a mean age of 64 years. Forty patients were white and 6 were non-white; for 5 patients, we did not have ethnic information. Twelve of the caregivers were adult children of the patient, and 36 were a spouse or partner (with no information for three).

3. Results and discussion

Just as medical interviews in primary care have an organization of component activities [23–26], oncology care (consultations that follow the initial diagnosis) has a phase structure. Beside the opening and closing, in our data there are three central components that regularly follow this order: review of symptoms (including medication side effects), presentation of imaging test results (e.g., X-ray, computerized axial tomography or CAT scan), and treatment discussions or recommendations, a necessary and vital consideration as physicians monitor the progress of the disease using their symptom reviews and scan results. It is within this organization that the appreciation sequence appears, just after the presentation of scan results and before treatment recommendations.

3.1. Delivering scan results

In the oncology clinic, physicians deliver news that is post-diagnosis and involves the results from scans or X-rays rather than initial identification of illness [28–31]. Ideally, because physicians have disclosed that there is no cure and that the median time from diagnosis to death is about 12 months, subsequent news deliveries about symptoms and scans occur in a context of "open" death awareness, where patients and family members as well as clinicians know that the person is dying [32–34]. In fact, however, for many reasons patients may be in other kinds of "awareness contexts" about the imminence of death, from "closed" to "suspected" to "mutual pretense" [32:11]. When oncologists have the results of an imaging test to report, the news falls into one of three categories as the cancer may have improved, remained stable—the patient's tumor is found neither to have grown nor subsided within a standardized range [35]—or worsened. Patients are more or less cognizant of these distinct possibilities, and these news deliveries about an ongoing cancer have the typical talk-based asymmetries associated with favorable and unfavorable diagnoses [29,36,37]. It is in the context of stable news that we first noticed what we have come to call the appreciation sequence. Accordingly, we begin by considering such news and how the appreciation sequence emerges and is organized. Subsequently, we show its presence in relation to both bad and good cancer news.²

3.2. Tumor stability; occasioning appreciation

The most frequent kind of news in our data is that which suggests the patient's tumor had neither grown nor subsided. Physicians use different expressions of this stability, as in "It doesn't look any different (5.19), "looked exactly the same as before (16.16), "things look stable" (12.31), or "Your lung scan looked pretty darn uh stable" (11.19). Physicians deliver such news mostly as they do with good tidings,

2

¹ Sandén et al. [27] discuss a three-phase core to the interview that differs slightly from ours. Their subjects were patients with testicular cancer, and they refer to updating, discussion of news regarding test results and X-rays, and planning. What we are calling treatment recommendations could be considered as planning, although Sandén et al. [27] refer mainly to scheduling next visits and the like. When their and our three phases are put together with openings and closings, it would appear that oncology visits have similar structures across types of cancer.

² Fifty-four of our cases have deliveries of scan news; approximately 15% were good news, 24% were bad news, and 56% involved stable news. The remaining 5% involved a mixture of two types of news, usually bad and stable.

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