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'BEING KNOWN': PATIENTS' PERSPECTIVES OF THE DYNAMICS OF HUMAN CONNECTION IN CANCER CARE

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SUMMARY

In the context of a large study of effective and ineffective cancer care communications from the perspective of patients with cancer, the authors documented the pervasiveness of the desire for human connection. Analyzing accounts from 200 patients with diverse cancer experiences, they concluded that, while anonymity is generally antithetical to a comfortable cancer care encounter, there are wide variations in what it means to 'be known' in a meaningful way. In this discussion, a description of the dynamics of being known and not being known within the cancer care encounter is presented, and a range of variations considered. By illuminating the manner in which communication influences human connection within the cancer care context, the findings of this study challenge some current research directions and propose alternative conceptualizations that might better orient future inquiry to enhance practice. Copyright © 2005 John Wiley & Sons, Ltd.

INTRODUCTION

Communication between persons with cancer and those who provide their care is critical to effective health services for this population. Ineffective communications not only complicate emotional self-preservation, information processing, decision making and quality of life (Roberts *et al.*, 1994; Degner *et al.*, 1997; Feldman-Stewart *et al.*, 2000; Fallowfield *et al.*, 2001; Friedrichsen *et al.*, 2002), but may also create system inefficiencies (Brown *et al.*, 2002; Liang *et al.*, 2002) and clinically compromised outcomes (Stewart, 1995; Bakker *et al.*, 2001; Arora, 2003).

Whereas much of the recent research literature has focussed on the 'structure and mechanics' of communication within cancer care, we lack a comprehensive understanding of communication experiences (and difficulties) from the patients' perspective (Finset *et al.*, 1997; Thorne, 1999; Harris and Templeton, 2001; Freedman, 2002). In this paper, we describe one aspect of findings from a large qualitative study designed to answer the question: 'How do persons with cancer describe and explain helpful and unhelpful communications in their health care?' In this aspect of the analysis, we present the perspectives of cancer patients as they articulate what it is to feel that one is 'known' within the cancer care context.

BACKGROUND TO THE LITERATURE

Recent research has illuminated certain aspects of communication, including the context and structure of cancer care encounters and their influence

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on the quality of life or psychological well-being of persons with cancer. Much of this research is designed to isolate specific aspects of the mechanics and dynamics of effective communication encounters, such as identifying what information needs are expressed by certain types of cancer patients, or how specific forms of information ought to be delivered. This body of work represents an attempt to generate empirical evidence with regard to the effectiveness of certain communication skills or strategies. While the perspective of cancer care consumers is recognized as an important outcome, attempts to measure it typically isolate discrete variables such as anxiety, patient satisfaction, or unmet need. Thus, while we have some evidence of correlations between certain clinical communication factors and specific patient variables, we have much less knowledge about how patients experience our efforts to communicate with them, especially as they pertain to such subjectively complex aspects as human connection.

Considerable research activity has occurred in the area of documenting what it is that patients require from communications within the cancer care context. For example, we know that patients tend to want a great deal of information about their illness and its treatment (Meredith *et al.*, 1996), that many (but by no means all) patients want to participate in decision making related to treatment options (Degner *et al.*, 1997; Gattellari *et al.*, 2001), and that, in most instances, patients resent being protected from difficult information even when they perceive that the failure to disclose is motivated by health care providers' good intentions (Wallberg *et al.*, 2000; Jenkins *et al.*, 2001; Parker *et al.*, 2001; Fallowfield *et al.*, 2002b). Importantly, the body of evidence to date reveals that few general communications principles hold true for all cancer patients, and that there is considerable variation across all elements of patient perspective. Thus, much of the research points to the possibility that what patients prefer in communication encounters may be influenced by such factors as culture, education, age, or gender (Bruera *et al.*, 2000; Wallberg *et al.*, 2000), and that their preferences may change according to context and over time.

A substantial volume of research addresses the structure and mechanics of communication within cancer care encounters, focussing on the specific actions and behaviors of professionals as they interact with patients during times of vulnerability. This growing body of knowledge includes evidence related to such dimensions of communication as the relative effectiveness of various types of questioning (Butow *et al.*, 2002), the proper approach to disclosure of information to patients and families (Fallowfield *et al.*, 2002b; Gordon and Daugherty, 2003), the usefulness of audio or visual adjuncts to information giving (Bruera *et al.*, 1999; Lipkus and Hollands, 1999), and the optimal strategies by which to obtain informed consent (Baile *et al.*, 1999; Tattersall *et al.*, 2002). Although this body of evidence confirms the importance of these issues for patient well-being and satisfaction, results from studies using various outcome measures and variables tend to be somewhat conflictual (e.g. Eide *et al.*, 2004; Maguire *et al.*, 1996; Fallowfield *et al.*, 2002a), making it difficult to identify an evidence basis upon which clinicians can attempt to enhance cancer communication with their patients.

The limitations inherent in the 'structure and mechanics' approach to studying cancer communication seems most apparent in the body of work addressing communication skills training for health professionals. Contrary to the assumption that, if health care professional students learn the right skills, their more effective communication will bring about increased patient satisfaction with the communication encounter, recent literature shows that such training may not directly translate into improved communication in the clinical encounter (Ishikawa *et al.*, 2002; Beckman and Frankel, 2003), and that skills training may be useful, but insufficient to shape health care provider communication behaviors (Heaven and Maguire, 1996). Although the body of knowledge generated by these studies partially informs our understanding of cancer communication encounters, it has failed to produce a comprehensive and grounded set of principles and guidelines upon which to formulate consensus on what constitutes effective and appropriate communication practice. Despite good intentions on the part of most health care practitioners, cancer communication remains a significant problem, such that most patients do encounter suboptimal communication experiences at some point during their illness (Ishikawa *et al.*, 2002).

Each of these important bodies of research brings into focus certain ways in which characteristics and behaviors of patients and health professionals may shape dimensions of the communication encounter. Although we know that failed communication encounters impact negatively on

patients (Arora et al., 2001; Bakker et al., 2001), we cannot explain these failures in terms of predictable professional behaviors and patient decisional patterns. Experiential accounts suggest the influence of more subtle dimensions within the health care interaction, such as the affective quality of the professional's engagement with the patient (Finset et al., 1997; Bakker et al., 2001; Harris and Templeton, 2001) and the extent of trust that can be established within that relationship (Thom and Campbell, 1997; Thom et al., 1999, 2002). Although it seems understood that these dimensions profoundly influence the encounter, they have received relatively little attention in the body of cancer communication research. Where such research exists, it tends to be characterized by very small sample sizes and restricted participation according to type of cancer, age, gender, or ethic origin. Thus, a study that permits a more in-depth examination of these more subtle aspects of communication creates the potential for making an important contribution to our understanding of the phenomenon.

RESEARCH DESIGN AND METHOD

In this study, 200 cancer patients articulated their experiences with helpful and unhelpful communications in cancer care and their interpretations of what might constitute effective communication practice within the cancer context. Following a protocol approved by our university's ethical review board, we recruited from urban, suburban, and rural settings across a Western Canadian province to obtain a sample that was purposively recruited to draw voluntary representation from a wide range of demographic, disease and treatment, and contextual factors (Table 1).

Face-to-face interviews with these patients were carried out over a two-year period between 2001 and 2003, with the average interview lasting 1.5–2 h. Following preliminary introductions, explanations, and the collection of demographic and health status information, we conducted open-ended interviews using a common set of trigger questions (Table 2). All interviews were conducted by trained project staff with health professional backgrounds, and were audiotaped and transcribed verbatim. In addition to individual interviews, we also employed collateral methods to expand our access to a range of accounts; these

Table 1. Study participant characteristics

Factor	Category	Number (%)
		$n = 200$
Gender	Male	53 (26.5)
	Female	147 (73.5)
Age (years)	<30	1 (0.5)
	30–39	9 (4.5)
	40–49	36 (18)
	50–59	65 (32.5)
	60–69	53 (26.5)
	>70	36 (18)
Ethnicity	Caucasian	178 (89)
	Chinese/South Asian	12 (6)
	Aboriginal	6 (3)
	Other	4 (2)
Residence	Urban	128 (64)
	Rural	72 (36)
Stage of illness	In active treatment	36 (18)
	Post treatment	130 (65)
	Palliation	34 (17)
Cancer sites	Breast	100 (50)
	Prostate	28 (14)
	Gastrointestinal	20 (10)
	Lymphoma/leukemia	14 (7)
	Head and neck	10 (5)
	Cervix/uterus/ovary	10 (5)
	Other	12 (6)

included several focus groups comprised of 4–6 individuals and telephone follow-up interviews with selected participants. We also extended an invitation to all participants to continue their communication with us as new ideas or experiences arose, either electronically by e-mail or via a project website, by mail, or by voicemail message.

Our methodological approach was interpretive description (Thorne et al., 1997, 2004), an approach which guides the systematic generation of themes and patterns within qualitative data sets, reflection, critical examination, and informed questioning. This method provided theoretical scaffolding underlying our sampling, data collection and analytic strategies. Data collection and analysis occurred concurrently (Lincoln and Guba, 1985). As thematic patterns emerged among and between the individual accounts, ongoing targeted participant recruitment allowed us to ensure that an adequate range of relevant contextual and

Table 2. Interview trigger questions

Interviews were not formally standardized, but rather loosely guided by a set of trigger questions. Some questions required minor modification for adaptation to focus group format.

- Can you give me a brief description of your cancer experience? When you were diagnosed and generally what has happened to you since that time?
- The focus of our interview today is the issue of communications in cancer care. Can you begin by saying something about why you think communications is/is not important in cancer care?
- When in your own personal cancer experience was professional–patient communication most helpful?
- When in your cancer experience was professional–patient communication most problematic or unhelpful?
- In your opinion, what explains the difference between helpful and unhelpful communications by health care professionals?
- In what ways do you think you might be similar to or different from other patients with cancer?
- In order to be as effective as possible in their communications with their patients, what would you like health care professionals to know? To do? Are there general rules or guidelines that you would have to make communications in cancer care better?

demographic factors was represented within the overall sample.

Data analysis began with intensive reading and reflecting upon transcripts and progressed through active discussion of emergent relationships and categories in the context of our research team meetings. Because of the extensive database involved, we also used qualitative software (NVivo™) to assist with the complex challenge of data sorting and management. This technology enabled us to index all reported instances of helpful or unhelpful communication from the consumer perspective so that they could eventually be cross-referenced against the full range of communication and contextual variables. To date, we have tapped only a small subset of the overall potential of this large database; in the future we hope to use it to further our understanding of group differences that may contribute to various conceptions of human connection through secondary analysis.

The analysis presented in this paper represents an interpretive rendering of a thematic pattern among and between individual cases. It reflects what emerged as a powerful common theme throughout the entire data set, a phenomenon so pervasive that it demanded explication on its own to provide a context for subsequent analysis of other aspects of the findings. Although no attempt is made to suggest that it holds formal representative authority on behalf of populations of cancer patients, the strength and frequency with which the issue of human connection arose within this large data set suggests a meaningful commonality that is shared across the range of contexts and cases.

FINDINGS

The importance of human connection constituted a clear thematic pattern among all the study participants, such that it might be considered a universal ingredient of effective cancer care communication. Although no specific prompts related to human connection were employed in the interview strategy, almost all of the patients spontaneously shared narratives that included explicit descriptions of human connection or personal theories about its contribution to effective communication. Drawing upon the diversity and depth of detail available with this extensive database, explicitly looking for patterns and themes as well as variations and contradictions, we were able to deepen our understanding, from the perspective of persons with cancer, of the meaning of human connection.

The language of 'being known' emerged as a prominent theme in the findings, central to the overarching concept of human connection, in that some variant within the linguistic form was often used to explain both helpful and unhelpful communication encounters (e.g. 'my doctor knows me' or 'I didn't feel as if they knew me at the clinic' or 'I need to feel known'). As study participants recalled specific encounters, it became clear that a powerful force often shaping their entire cancer care experience was the degree to which they had felt 'known' in profoundly fundamental ways by their health care providers. Implicit or explicit was the sense that one had made some form of human connection distinct from the diseased organ or

mechanical body, that one was recognized for being a unique human being. Being known, therefore, as we refer to it here, reflected an acknowledgement of elements of one's personhood within the context of the inherently difficult nature of this disease.

BEING AND NOT BEING KNOWN

Interviewing patients across the entire trajectory of cancer care provided a broad angle of vision encompassing a variety of critical times and perspectives. Perhaps due to our approach of asking for examples of helpful and unhelpful communication encounter experiences, being known took on a strongly dichotomous valence within the overall data set.

Being known, for some, was depicted as a matter of holistic care. 'The surgeon was focused on his specialty. But my...doctor here is focused on me and he knows, he knows me well and he knows the whole of me.' It recognized that the human encounter within cancer care took place for a particular reason and within a particular life trajectory, '...that comforting, somebody just saying to you, I care who you are, I know who you are, I know where you have come from and I believe that we should be doing these things for you.' Further, it typically involved recognition that the clinical gaze extended beyond the particular role or task within the cancer care system toward the sensate and vulnerable person within it. As one patient recalled an exemplary physician, 'She was extremely busy, but the three minutes she had with you she was totally focused on you...and it was never the medical stuff, it was "how are you feeling?"'

In contrast, not being known often reflected a technical orientation to the clinical encounter. One patient commented:

> I mean he—the oncologist—even said to me, "You know, I put all my data into a computer and I come up with what's the best recommendation for you, you know." ...And I'm thinking well, what are you putting into the computer? You haven't even asked me anything about what I'm prepared to do in the future to help myself.

Not being known also typically involved a sense of disinterest or disregard for the active agency of the patient or of his or her individual uniqueness. As one patient explained, 'My life is not like everybody else's life and I do things to take care of myself. But it didn't mean anything to them.'

To illustrate the phenomenon of being known by the individuals involved in their cancer care, many patients alluded to feelings that they were special, and that their well-being was important to the professional. 'She was so compassionate and she made me feel that um, my welfare mattered most to her in the world right at that moment ...I thought I was loved.' And similarly, 'He has been so encouraging and so good.... . He just gives me confidence, I guess. And again I'm a person, you know; he has lots of time, he never forgets. I really feel I'm his only patient.' Thus, the positive power of the experience of being known, in contrast to the very negative power of not being known, seemed an overwhelmingly strong explanatory theme within consumer perspectives of helpful and unhelpful communication.

THE DYNAMICS OF BEING KNOWN

In explaining what they meant by being known, people with cancer commonly reported specific cues from their health care professional as 'evidence' of a human connection. Commonly reported in this context were cues such as eye contact, sitting down rather than standing, remembering the patient's name and case details, and unrushed consultations. However, we were intrigued to note considerable variation among individuals in the relative value they placed on these different cues, and in a number of instances, patients reported somewhat idiosyncratic illustrations of aspects within their encounters that made them feel either dismissed or acknowledged.

Frequently, patients described feeling either acknowledged or dismissed within just the first few moments of the initial encounter with a health care professional. As one recalled, 'I asked her if I could call her by her first name and she said, No She'd rather I didn't. She'd like me to call her doctor. So I thought from the beginning that said—you patient, me doctor—and I'm up here and you're down there.' This immediate reaction could arise as a result of seemingly innocuous professional behaviors as easily as it could from what might be described as more overt affronts.

Common to the accounts of being known were instances in which space was made within the

clinical encounter for elements of their unique personhood. At its core, being known involved acknowledgement of several specific elements within the unique and difficult nature of the disease. These elements included individual preferences, knowledge, intuitions, emotional needs, beliefs, and values—all considered within a context of intrinsic worth. In general, narratives of overtly helpful encounters were characterized by validation of one or more of these components, whereas the overtly unhelpful encounters were characterized by their dismissal or disregard. As one patient recalled, 'It was more that there was someone who seemed to be able to acknowledge the emotional state of mind I was in and just hold my hand.' Another explained, 'She knew enough about me to give me information that she knew would be right for me.' Similarly, a third linked strategic use of accessible language with communications that created a feeling of inclusion. 'When it was good, when it was personal, and when it was in a vocabulary that I could understand, you know, I just felt like I was included...Like I was part of the treatment—I wasn't just being treated. I had options.' For many patients, these acknowledgements were subtle and highly nuanced. For example, one recalled the profound importance of a physician's willingness to recognize the non-rational. 'He did not necessarily acknowledge my belief in Christianity but acknowledged the faith I had and the miracle that had happened. That meant a lot to me. That created a very fond bond between me and my doctor.' Thus, either acknowledging or dismissing their patients' active agency, knowledge or beliefs was strongly associated with subsequent feelings of being valued or not valued within the encounter.

Another core element in being known involved a sense of acknowledgment of the inherent difficulty associated with having cancer. Among cancer patients, it seemed axiomatic that cancer is of a special status in the realm of diseases, and therefore it was expected that encounters with health care professionals would reflect this. As one patient recalled, 'I had nurses that were fabulous, that made the difference for me, because they took the time to really talk with me and listen to me and validate what I was going through. I guess that was the thing—the validation that what you're going through is a horrible experience.' Another remembered the powerfully calming effect of professional communications that tastefully acknowledged the inherent mortality fears associated

with the disease. 'He said, "I can't lengthen your life and I won't shorten it. But I promise to be with you every step of the way and make it as comfortable as possible for you." And that's all it took from him to calm some of the fears I had.'

VARIATIONS IN BEING KNOWN

Despite some apparently universal elements, the ways in which people sought, perceived, and experienced being known were somewhat diverse, and influenced by various individual factors. Our initial impression in the case of some patients was that human connection represented a relatively minor aspect of their cancer communication needs. However, with the advantage of a sufficiently large data set to draw upon a wide range of accounts, we came to recognize significant and relevant variations within the phenomenon. For some study participants, being known manifested itself as simply the need for clear guidance and information about the disease and its treatment, and competent care. In some instances, this could occur even when the clinician's communication skills were somewhat limited; as one explained, it does not matter that 'he doesn't have a good bedside manner...as long as he's doing what he's supposed to do.' Others described being known in terms of strong decisional partnerships with their health care professionals. As one individual recalled, 'Everything I said she picked up on and she heard me. And we talked it through and it was either a problem or not. And if it was a problem, we solved it.' In other instances, being known was associated with explicit and meaningful relational connectedness, sometimes operating outside of what might be considered the conventional boundaries of professional roles. For example, one patient's recollection of his physician included this powerful encounter: 'He hugged me, if you can imagine! You feel untouchable. You feel very untouchable, like, I've got cancer...and nobody wants to touch me.' Within these parameters, we identified four aspects of the communication encounter upon which there seemed to be especially noticeable variation; these included personal information, non-medical dialogue, the use of touch, and the expression of emotion.

For many, personal information that the professional disclosed within the context of the clinical encounter was a precious bit of evidence that the

professional was willing to extend the relationship beyond functional boundaries in an effort to know the patient. As one patient's perspective illustrates, 'The fact that they were willing to share a part of themselves that way, it made such a difference. Like suddenly I wasn't this hysterical loser who just has so many troubles.' For a number of others, however, personal information was interpreted as slippage in relation to whose needs warranted priority within the therapeutic relationship, and could even detract from confidence in the professional's competence. Thus, self-disclosure on the part of clinicians was very differently interpreted among and between individual patients and contexts.

Similarly, we noted variance in the interpretation of non-clinical conversation. For some patients, such behavior was interpreted as 'chitchat,' time taken away from the primary focus of clinical work, which was the immediate priority of the patient; for others it was a strategically important element in the development of an effective health care relationship, as the following recollection illuminates:

> She just came and brought a coffee and stretched out in the lounge chair beside me for 15 minutes and just talked to me about life in general and do you have any questions and what do you think about this? And I thought that was very informed, that she made me feel that she cared about me, you know...It was more like it wasn't just a patient type-of-thing.

Again, it was apparent within our sample that such communications as joking or referring to topical public events could produce quite various effects, ranging from effective to disastrous, in creating human connection within the clinical encounter.

Physical touch was another dimension upon which we noticed significant variation within the sample. Instances of hugs or physical contact were explicitly referenced by a number of patients as clear evidence of effective communication toward building human connection within the health care relationship. 'This guy was wonderful, he wanders in, gives me a big handshake, takes the stool that's right there and brings it 'til our knees are touching.' However, for some others, while physicality within the health care context was generally expected, touch not recognized as clinically necessary was described as frightening or confusing. Thus, touch became another context within which communications directed toward enhancing human connection could become problematic.

Finally, we detected significant variations in relation to interpretation of emotional expression. Some patients expected health care professionals to moderate their emotionality in order to remain rational, and could be somewhat disturbed by what they interpreted as excess feeling on the part of the professional. For many others, however, willingness to feel seemed an essential element in creating the human connection they valued. As one explained, 'Crying along with the patient isn't the worst thing in the world, it might even be the best. Like for me, it was like that person cared enough.' Similarly, expressions of happiness when things went well were equally important to many of the patients. 'I just felt vibrationally he was giving me a hug, he was so happy with the results... Because the tumor had gone at this point, they were absolutely elated.'

Detecting within the accounts these significant variations with regard to communication style preferences and interpretations, sometimes explicitly articulated as such and in many instances gleaned from an interpretation of the meaning of the overall narrative, we initially surmised that some patients seemed not to be particularly interested in being known within the clinical encounter. However, the opportunity to examine variation across this large data set has permitted us to examine patterns and themes among and between a wide range of individual preferences and experiences. On this basis, we can therefore conclude that, within the cancer care context, 'being known' represents a wide range of unique manifestations of the common desire for human connection. Although we understand human connection to be desirable across cancer care encounters, it seems apparent that the communicative conditions under which individual patients come to feel that they are or are not known in this manner can be markedly diverse. Thus, we can also conclude that, although being known cannot be attributed to any singular behavior or pattern of behaviors on the part of the health care professionals, it can be achieved through effective use of individualized communication approaches.

DISCUSSION: THE MEANING OF BEING KNOWN

The findings of this study suggest that being or not being known is a useful conceptual construction

with which to interpret how cancer patients differentially respond within various discrete communication encounters. Further, they provide a beginning explanation for some of the significant variations that may be observed in the clinical context, and which can frustrate those who attempt to simplify communications training and skill development principles.

A number of authors writing within the general health care communication literature have drawn attention to the existential aspects of health care professional relationships and the importance of human connection for patient well-being. Many of these authors have articulated recommendations for facilitating human connection in the context of such concepts as therapeutic relationships, the therapeutic use of self, and 'knowing' the patient (Liaschenko, 1997, 1999; Luker *et al.*, 2000). Our findings provide convincing evidence of the extent to which human connection is highly valued by cancer patients, perhaps to the extent that it might be considered a universal value. However, they also make us acutely aware that the manifestations of that preferred connection are sufficiently various to make standardized or routinized communication prescriptions untenable. Instead, it seems that the communications that will convey to the patient the feeling of being known must be those that respect his or her own uniqueness and personhood within the complex experience that is cancer care. Having been thrust into the alien and sometimes terrifying domain that the cancer care context represents, the patient may not fully understand what it is that he or she requires from a health care encounter; thus the obligation lies with the health care professional to try to discover it.

Different contextual factors such as stage of illness, culture, personality or gender seem to play a role in shaping the manner in which patients prefer to be known as well as the attributes of the encounter that will signal to them that they have made a meaningful human connection with their cancer care provider. It also seems that features associated with such variables as the disease trajectory, the treatment modality and the decisional context can be critically important in creating the context for an effective clinical encounter. Basic personality and communication style preference variations also seem to exert a powerful influence upon the degree to which a specific communication episode will or will not be considered effective in creating human connection.

As we observed, different patients may express entirely different levels of comfort with health care professional responses and behaviors. Although we may eventually be able to document thematic patterns associated with these variations by virtue of the extensiveness of our database, it seems unlikely that much of the variance within human connection will be attributable simply to discrete demographic, personality or disease-related variables. Further, our analysis suggests we are unlikely to find health care professional behavioral and communicative patterns that are universally recognized as consistent with human connection. Rather, our findings confirm that complex alignments between professional behaviors and the needs of unique individuals create the conditions under which the experience of being known within the clinical encounter is produced. For example, while the objective distance and affective neutrality on the part of a clinician might effectively match one patient's desire for a technical or businesslike encounter at one particular time in his or her cancer care process, for another patient, or for this patient in a different time and context, the more technical communication style might be experienced as profoundly dismissive and invalidating. Similarly, the more emotionally and physically exuberant responses described in some of the examples cited earlier as evidence that their subjective experience mattered and that their lives were intrinsically valued might be interpreted by other patients or at other times as disrespectful or undignified, thereby creating unnecessary distress.

This human variation which seems to characterize the contexts and conditions in which different patients come to experience 'being known' suggests that much of the current research directed toward optimal communications may be relatively ineffective in producing knowledge that is directly applicable to the diversity inherent in the practice context. Because much of the communication research relies upon correlational analyses to determine variables associated with particular patient communication preferences or satisfaction rates following various communication approaches, even the most thoughtfully designed of such studies may not allow for the range of variation that will be encountered in any clinical setting. Where the diversity in patient needs is acknowledged, researchers tend to conclude that decisions about disclosure or information giving should be based on specific patient information rather than the application of generalizable

knowledge (Butow *et al.*, 1996). According to de Haes and Koedoot (2003), there are many paradoxes inherent in the experience of cancer that influence the communication context, particularly related to decision making processes. Patients want to sustain hope, yet be fully informed; control and autonomy are generally seen as ideals, yet certain patients at certain times want to avoid information and relinquish control. These paradoxes cannot be resolved through looking solely at the structure and mechanics of discrete communication encounters; indeed the tendency to oversimplify the complexities inherent in cancer care communication may obscure dimensions that are vitally important. Thus, it seems imperative that, while we should continue to develop research designs oriented toward eliciting rich and finely textured explanations of cancer communication phenomena, we are especially in need of those that explicitly capitalize upon mechanisms by which documentation of commonalities can be balanced with interpretation of exceptions.

An important body of literature that begins to bring together the mechanics and dynamics of communication with patients' contribution to the process has to do with what is variously referred to as 'patient participation in decision making' or 'shared decision making.' Within this body of work there is considerable variation in what is meant by such terms, ranging in focus from fairly standardized approaches to information delivery to highly complex approaches to interpersonal decisional dynamics (Guadagnoli and Ward, 1998). Findings from such studies highlight the dynamic nature of effective communication encounters and the importance of taking into account such interpersonal issues as attending to patient preferences and individual coping styles (Charles *et al.*, 1999; Edwards *et al.*, 2003), being flexible in the communication encounter, and being respectful of cultural differences (Mitchell, 1998; Ballard-Reisch and Letner, 2003). This body of literature tends to cast light on the inherent complexity within cancer communication encounters, at the same time demonstrating that satisfaction with health care encounters improves for most patients when they feel involved in the decision making process (Guadagnoli and Ward, 1998; Dowsett *et al.*, 2000; Gattellari *et al.*, 2001). This observation has created a general understanding that encouraging patient participation is the safest standard approach (Gattellari *et al.*, 2001). However, research into patterns within cancer patient

participation processes also confirms that active participation in decision making is not a goal for all patients, and that variations must be anticipated (Degner, 1998). Thus, researchers who have attended to the problem of variation within their samples have concluded that, while shared decision making models have considerable merit, they must be grounded within strategies that elicit patient preferences for communication (McPherson *et al.*, 2001; Parker *et al.*, 2001).

Studies addressing the problem of 'knowing the patient' have explicitly oriented their attention toward the challenge of eliciting patient preferences (Radwin, 1996). Drawing on findings from ethnographic studies in a variety of settings, Liashenko (1997) has articulated three distinct levels of knowledge that are helpful in this regard: knowing the case, the patient and the person. 'Case' knowledge represents the generalized (usually biomedical) knowledge that has to do with a theoretical patient. Knowing a patient in this way places that individual in a passive position, an object upon which the clinician acts. 'Patient' knowledge, a kind of knowledge that requires 'the particularity of a body' (p. 26), includes knowing something about the individual person's story, their history and demographics, and even that person's physical and emotional responses to treatment. 'Person' knowledge, the third form of knowledge in Liaschenko's model has to do with knowing the person, 'as a subject who acts with her or his own desires and intentions' (p. 26), thereby representing knowledge that implies understanding how the person is situated in the world and how he or she engages in that world. From Liaschenko's perspective, the ideal decisions are those with the capacity to integrate all three forms of knowledge.

The findings of this study suggest that the client on the receiving end of case, patient or person knowledge can discern the difference between that which is standardized and that which 'feels' individualized. Further, our findings seem to suggest that patients perceive that communication has been tailored toward their unique needs when it derives from a combination of all three types of knowledge rather than simply a close interpersonal relationship. Thus, it becomes understandable that feeling that one 'is known' within the clinical cancer context can arise from exchanges ranging from the most profound to the most mundane.

In order to justify the development of initiatives to improve cancer communication in the clinical

context, it seems important that we understand 'knowing' as something quite different from human intimacy or having access to the full details of another's life. The accounts provided by participants in our study clearly confirm that the experience of 'being known' can arise in seemingly fleeting health care encounters, not just in those of a longstanding nature. Such encounters may share the characteristic of occurring at one of the most profoundly troubling and challenging periods of an individual cancer patient's life and, in conjunction with this, also representing a moment where the he or she is made to feel special, important, and relevant within the machine that is the cancer care system. Communications within any aspect of this system that induce feelings of alienation, anonymity, depersonalization or disregard could induce unnecessary suffering, thus complicating cancer care outcomes in various ways. It seems therefore imperative that we make efforts to eliminate these kinds of communications within our cancer care systems. However, rather than simply advocating skills training of a form that has not, to this point, proven widely effective in rectifying cancer communications problems, we clearly require an approach that will shift our conceptualization and reorient our understanding to the opportunities inherent in a 'personhood' perspective. It seems self-evident that, in order to meet the needs of a diverse clientele, our preferred approach to communication training will require some skilful blend of thoughtful inquiry techniques, accurate cue interpretation, and genuine expression of interest. However, it is apparent that we still have much to learn before we can confidently declare exactly what it is that we ought to advocate, teach, or support with regard to communications skills among all cancer care providers.

sustain a healthy reverence for human variation in this phenomenon at the same time as we uncover patterns and commonalities. In our continued search for an evidentiary basis upon which to position the complex challenge of communication in cancer care, it will be important that we regard human connection as a communication outcome central to the healing encounter. While we may never be able to quantify a relationship between communication experiences and physiological aspects of disease progression, it seems evident that communication between patients and providers has a profound impact on the human experiences of undergoing care for cancer, living with cancer, and making choices in relation to the challenges of that disease. It is therefore imperative for both pragmatic and humanitarian reasons to create a clinical climate within which this aspect of the patient-centered cancer care challenge is fully appreciated and nurtured (Dowsett et al., 2000).

Human connection may prove a useful conceptual orientation for the clinical encounter in that it attunes the provider to the subjective experience that is cancer and shines light on a range of options that might be put into play to support effective communication. From the insights gleaned across a diverse array of contexts, it seems apparent that trying to ensure that the patient feels 'known' within the clinical encounter, the health care relationship, and the cancer care system may represent an essential element in any effective cancer communication strategy.

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CONCLUSION

On the basis of our analysis of communication accounts deriving from 200 diverse cancer patients, we illuminate the reasons why even the most skillfully applied of standardized communication techniques is insufficient to solve the complex problems associated with poor communication. We hope that, in documenting some of the diversities within communication experience as articulated by cancer care consumers, we will help

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