

Prognosticating futures and the human experience of hope

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ABSTRACT

Objectives: Communication between health care providers and patients with cancer and other chronic diseases typically references probabilities that certain future events will or will not occur. Beyond the context of diagnostic encounters and the transmission of “bad news,” such “prognostic” communications take place in various forms throughout the illness trajectory. It is well known that such information transmitted badly can have devastating psychosocial consequences for patients and their families and, conversely, that difficult information exchanged with sensitivity can lend tremendous support. This study aimed to extend our understanding of how such communications are received and interpreted by patients, so that we might optimally apply what we know about general principles of effective communication within the particularly challenging context of predicting futures.

Methods: We conducted a combined secondary analysis of two prior qualitative studies into patient perceptions of helpful and unhelpful health care communication with 200 cancer patients and 30 persons with chronic illness. These data sets offered a rich resource for comparing perceptions across a range of contextual variables, and secondary analysis focused on future-oriented interactions, including both prognostication and prediction.

Results: The accounts of patients with cancer and chronic illness reveal various ways in which health care communications involving future projections interact with their human experience of hope, powerfully shaping their capacity to make sense of and live with serious illness. They include a synthesis of what patients recommend health care professionals know and understand about this challenging dynamic.

Significance of results: The findings of this study offer a distinct angle of vision onto the various communications that involve future predictions, illuminating a patient perspective with the potential to inform health care communication approaches that are both informative and therapeutic. As such, the study supports a dynamic understanding of the tenuous balance between hope and honesty in the clinical encounter.

KEYWORDS: Communication, Cancer, Chronic illness, Hope, Prognosis

INTRODUCTION

The field of health care communication is well recognized to be methodologically challenging (Roter et al., 1988; Lambert et al., 1997), with discrete

measurable aspects representing only a fragment of the overall context and complexity (Boon & Stewart, 1998), and with human diversities complicating attempts to articulate generalizations and common patterns (Bensing et al., & Tates, 2003; Clark et al., 1995; Ong et al., 1995; Thorne, 1999). The findings of our prior studies and others working in this field reflect a tentative balance between claims that can be made about standard best communication

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practices and those aspects that remain sufficiently varied between individual people and contexts that they defy generalization. What seems clear from the existing body of knowledge emerging within this field is that we require the rich and nuanced insights that can be derived from rigorous and systematic qualitative inquiry to balance the general themes that can be extracted from conventional correlational research. Attending to both of these knowledge sources, the evidence-based guidelines and standards for communication in the clinical context that we create not only derive from a body of empirical knowledge but also remain relevant and applicable to a diverse patient population.

An important theme that arises within the general field of patient–professional communication research is the delicate tension between receiving adequate and appropriate information (Mushlin et al., 1994; Baker, 1998) and being supported in constructive self-care and treatment decision making (Degner & Sloan, 1992; Shidler, 1998; Severinsson & Luetzen, 1999). The intersection of these dimensions occurs most frequently in the discourse surrounding prognostication (Weil et al., 1994; The et al., 2001; Yardley et al., 2001; Walsh & Nelson, 2003), which includes such issues as the typical course of events, the frequency with which certain outcomes will occur across a population of similarly affected persons, the likelihood of various untoward clinical events, and the likelihood of success in relation to various treatment options (Salander, 2002). These discourses are powerfully shaped by the legal requirements of “informed consent” (Siminoff, 1992; Quill & Suchman, 1993; Daugherty et al., 1995; Gordon & Paci, 1997; Gafni et al., 1998; Baile et al., 1999; Sainio et al., 2001; Cox, 2002; Freedman, 2002; Brown et al., 2004) as well as the moral obligation felt by most clinicians (and articulated by many—but not by any means all—patients) that “complete” information is a fundamental patient right (Girgis & Sanson-Fisher, 1995, 1998; Laerum et al., 2002). At the same time, it is well recognized by those involved in the supportive, psychosocial aspect of care for these complex and chronic conditions that existing knowledge relative to any condition or option is inherently limited and changing, that the human person must interpret, transform, and judge information according to a unique set of meanings and priorities, and that excessive or inappropriate information can create significant distress for both patients and families as well as the conditions for sub-optimal patient outcomes (Faulkner et al., 1995; Ellis & Tattersall, 1999; Fallowfield & Jenkins, 1999; Butow et al., 2002a; Maguire & Pitceathly, 2003; Thorne et al. 2005a). Thus, each instance of prognostic information, explicit or implied, reflects a careful tension between providing “enough” and “too much”

information, selecting that which is useful and necessary in order to make effective decisions and distinguishing it from that which is potentially unhelpful or even counterproductive (Finset et al., 1997; Kralik et al., 2001). Using the language of patients, the challenge is typically one of being sufficiently informed to act responsibly on one’s own account without “losing hope” (Sardell & Trierweiler, 1993; Bishara et al., 1997; Surbone, 1997; Salander et al., 1998; Hope et al., 2000; Butow et al., 2002b; Fallowfield et al., 2002; de Haes & Koedoot, 2003; Gordon & Daugherty, 2003).

Background to the Research

The current research capitalized on the availability of extensive qualitative data sets derived from two interpretive studies of patient perspectives of what constituted helpful and unhelpful communications with health care professionals in the context of chronic illness and cancer, respectively. The first study (2000–2002) involved interviews with 30 patients with multiple sclerosis, fibromyalgia, or non-insulin-dependent (type II) diabetes (see Table 1). This investigation documented patterns and themes arising from both comparative and disease-specific analyses, and the results have been reported elsewhere (Thorne et al., 2004a, 2004b, 2004c). The second study (2001–2005) used a parallel methodological approach to data collection through interviews and focus groups representing a large sample of 200 cancer patients (see Table 2). Although analysis of this large database continues into current longitudinal work to track changes in communications patterns over the course of the illness trajectory, aspects of those findings have also been published (Thorne et al., 2005b, 2006). Among the themes arising from both primary studies was an emphasis on matters of prediction and

Table 1. *Chronic illness study participant characteristics, n = 30*

Factor	Category	Number (%)
Gender	Male	5 (17)
	Female	25 (83)
Age (years)	<30	1 (3)
	30–39	7 (23)
	40–49	5 (17)
	50–59	11 (37)
	60–69	4 (13)
	>70	2 (7)
Disease	Type II Diabetes	8 (27)
	Multiple Sclerosis	11 (37)
	Fibromyalgia	11 (37)

Table 2. Cancer study participant characteristics, *n* = 200

Factor	Category	Number (%)
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)
Residence	Urban	128 (64)
	Rural	72 (36)
Stage of illness	In active treatment	36 (18)
	Posttreatment	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)

prognostication as a particularly vulnerable context for health care provider–patient miscommunications. Because the approved ethical protocol for both original studies included the provision for ongoing secondary analysis on related themes, we were able to focus particular attention on the data pertaining to the challenging problem of “honesty” in the transmission of information between health care professionals and their patients.

METHODS

Qualitative secondary analysis (Thorne, 1994) requires a close relationship between the original research questions and methodologies in order that the ultimate findings will be credible. Driven by a formal design logic such that the data retrieval, management, and analysis processes are all auditable and transparent, its quality is highly dependent on the quality of the original data sets. In this instance, because the nature, scope, and quality of these databases were known in advance, we entered the study with confidence that the phenomenon of interest was well represented and reliably available throughout the database and therefore that the findings of the secondary analysis would yield applicable and useful new knowledge to complement existing evidence.

Study Design

The methodological orientation to this secondary inquiry was Interpretive Description (Thorne et al., 1997, 2004d), which has been explicitly designed to

ask clinical questions for which the intended outcome is thematic analysis of patterns (both commonalities and variations) among and between individual cases within the phenomenon of interest. It draws upon elements of Grounded Theory (Glaser & Strauss, 1967) and Naturalistic Inquiry (Lincoln & Guba, 1985), using existing knowledge as a “sensitizing framework” to guide an iterative analytic process (Miles & Huberman, 1994). The products of an interpretive description include elements of both thematic summary and an integrative interpretation of the phenomenon under study.

Using interpretive description to guide the logic of this inductive secondary analysis, we created an efficient means to fine-tune our examination of the dynamics of “hope and honesty” in the context of prognostic information exchanges between patients and their health care providers (usually physicians) as they appeared from the patient perspective. The research question guiding this secondary analytic approach was “How do patients with cancer or chronic illness describe the balance between hope and honesty in their communications with health care professionals, particularly in the context of information exchange associated with prognostication?” Our research objective was to generate a richly detailed and interpretive examination of this complex problem, articulated from the perspective of individuals experienced in seeking health care in the context of living with chronic illness or cancer.

Data Collection and Analysis

The available databases consisted of over 5500 single-spaced pages of verbatim transcription of face-to-face interviews between the two research teams and study patients. The transcribed interviews for both studies were entered into a qualitative software management format (NVivo), permitting systematic indexing, retrieval, and analysis. To collapse the two data sets and focus our analysis on prognostic information communication, which was not a primary analytic focus in either original study, we manually recoded the full data set such that all instances of prognostic information communication could be extracted, sorted, and indexed. This process allowed us to systematically analyze the full data set in relation to this particular aspect according to patient perspectives of their relative effectiveness in balancing hope and honesty.

Our coding system allowed us to consider as “prognostic” all reported communications in which health care professionals forecasted what patients could expect regarding such events as survival, recurrence, or effectiveness of various treatments. Within that context, we coded the specific accounts of

communications into the general categories of “helpful” and “unhelpful.” Additional codes were “neutral,” depicting those reports of prognostic information encounters that the participant did not qualify as either helpful or unhelpful, and “recommendations,” those accounts whose purpose seemed to be articulation of preferred guidelines for more helpful communication. Finally, within these accounts, we also coded for the presence of “hope” as a central element of the communication (see Table 3). In this manner, we capitalized upon the range of individual patient accounts available to us and the indexing and sorting capacity of the software program to generate information about patterns that may not be typically accessible through qualitative methods because of the smaller samples associated with inductive analytic work.

Beyond pattern recognition, we also had the capacity to engage in deeper inductive analysis by considering the prototypical and variant instances of prognostic information communication within the larger context of the original textual record. Thus, we were able to move logically and systematically between thematic analysis of patterns across cases and the more in-depth analytic interpretation that is possible when specific instances of communication are examined within their larger temporal and relational context. Although many accounts reflected the retrospective nature of human “narrative,” we were able to identify themes and patterns through basic frequency analysis and simple correlations to create a line of inquiry that took us more deeply into the subtle and nuanced context of the individual experiences within which each relevant instance occurred. In this manner, we protected against the overly superficial interpretations that might be made on the basis of mere frequencies and

instead sought to grasp the underlying meaning inherent in patterns among and between individual cases. In so doing, we hoped to generate findings that reflected a measure of empirical “validity” as well as “ringing true” to the clinical audiences to whom our findings were primarily directed.

Rigour and Credibility

The primary standards for evaluating products of studies using this design approach are trustworthiness (the explicit logical relationship between the data that are used and the analytic claims made on the basis of them), fit (the context within which the findings are rendered applicable), transferability (the overall generalizability of the claims), and auditability (the transparency of the procedural steps and the analytic moves) (Altheide & Johnson, 1994; Thorne et al., 1997). Therefore, as an element of the analytic approach, we explicitly engaged in systematic and rigorous evaluation of our evolving findings within the context of the available body of empirical knowledge. In this case, the relevant “science” constituted not only the results of formal research, for which there are often more claims than formal conclusions, but also the body of “clinical wisdom” that has emerged in the form of guides for effective communication between health professionals and their patients (Brown et al., 1992; Clark et al., 1995; Weston & Brown, 1995; Bartz, 1999). Thus, we hoped that our study would allow us to expose current ideas within the literature that may represent misinterpretations of empirical evidence when it is taken outside of the “messy” context of everyday contextualized and relational clinical practice. By ensuring that we carefully consider any recommendations we might propose on the basis of this study within the context of this larger available knowledge, we hoped to enhance its immediate relevance to the intended audiences, including clinicians, health educators, and those who are charged with developing and articulating clinical standards and guidelines.

Table 3. *Data codes*

Coding category	Total instances	Total respondents
Prognostic Information/ Helpful	502	149
Prognostic Information/ Unhelpful	509	143
Prognostic Information/ Neutral	143	72
Prognostic Information/ Recommendations	186	93
Prognostic Information/ Hope	128	60
Prognostic Information/ Helpful/Hope	38	25
Prognostic Information/ Unhelpful/Hope	30	19

RESULTS

Many of the more memorable and powerful communication exchanges between health care professionals and patients that were reported to us in these studies related to discussions of prognosis and prediction related to future events. Typically, patients might experience an initial communication with a clinician in which the nature and extent of the disease was described, typically in the context of a numeric representation in some form of the likelihood of cure or the anticipated effectiveness of treatment. Following upon that encounter, which

often required considerable adjustment, coping, and sense making on the part of the patients and their families, many reported a subsequent series of communications with the same clinician or other health professionals and specialists that shifted or altered that initial numeric representation in some manner. Thus, the context of communications regarding prediction was typically interpreted in relation to the information that had previously been available, and later reinterpreted in the context of subsequent new information. This dynamic adjustment to new (or differently framed) pieces of prognostic information became for many patients an important feature of their experience with the disease, shaping their health care encounters and decisions in disease management. In this manner, their reflections about what they did and did not find helpful in relation to these prognostic communications sheds light on the phenomenon from their perspective.

Among study participants, there was considerable commonality of perspective interspersed with a range of individual unique responses. In general, the more specific the interpretation or recommendation, the more variation found within the data set. For example, although participants generally favored communications conveyed in a timely manner, some strongly advocated reporting such information immediately by telephone (even for difficult information, such as anticipated diagnostic test results), whereas others strongly preferred face-to-face dialogue for important information. Proponents of both of these perspectives could be equally confident that their perspective was widely shared by other patients with their diagnosis; however, the frequency with which we encountered reports of what seemed diametrically opposite recommendations alerted us to the underlying principle that the mechanism of reporting critically important information in a timely manner ought to be individually tailored to the needs of the patient. Thus, where new and potentially difficult information is anticipated, such as when awaiting pathology reports or other key laboratory findings, the solicitation by clinicians of the patient's preferred mechanism for transmitting information was highly valued. In fact, even when patients subsequently recognized that waiting for the face-to-face appointment or hearing difficult news abruptly on the phone was more agonizing than they had anticipated, they consistently perceived the communications with their health care professionals to have been helpful. Through analysis of patterns and themes throughout the data set, we came to recognize that there may be very little by way of concrete examples of communication techniques that are inherently helpful or unhelpful during these difficult times. However, the way in which clinicians

considered the unique and particular needs and capacities of individual patients can make a powerful difference in their perceptions of being well or poorly supported.

Our findings are presented in the context of three themes. The first reflects the general kinds of communications that patients found helpful in relation to these prognostication and prediction information exchanges as compared to those they found unhelpful. The second is their perception of the impact of these helpful and unhelpful prognostic communications on hope. And finally, we conclude with some of the recommendations these patients make with regards to what they would want health care professionals to know to ensure that communications with their patients about predictions can be handled in such a way as to preserve hope and support patient illness experience.

Helpful and Unhelpful Communications

As might be expected, patterns within the patient descriptions of prognostic communications that were helpful were generally those that provided information in a timely, appropriate, and compassionate manner. Common among the accounts were comments about clarity, fullness, straightforward approach, receptiveness and responsiveness to questions, providing written information to complement what was said, and contact information for them to follow up with further questions. Although many made reference to an appreciation for "honesty," they also qualified that in relation to appropriate dose and specificity of information to the context. In general, they reported that helpful communications left them feeling relatively calm and capable of handling the information. To illustrate, one patient described a segment of communication with a physician that had particularly lasting helpful impact on her experience confronting a devastating diagnosis:

He said something to me something that I will never forget—word for word—at that first visit after the diagnosis. . . . 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. He answered those questions, but with that statement and the moment that it took for him to say it, it just made all the difference in the world.

In some instances, prognostic information was explicitly helpful because it reduced uncertainty, which for many was inherently anxiety producing in and of itself. It was not uncommon to hear patients

report that hearing bad news was not as difficult as anticipating it. For some, communications about bad news were perceived as helpful because they were paired with an emphasis upon the aggressiveness with which the disease would be managed or, conversely, with overt expressions of compassion for the difficult nature of the news. For many patients, being inspired with confidence (either in the projected effectiveness of treatment or in their ability to cope despite serious challenges) was a highly valued outcome of the communications related to these difficult times. As many reported, communications with health care professionals were especially helpful when they were thought to “prepare you for what is going to happen next.”

Similarly, there were a number of common themes related to communications perceived to be decidedly unhelpful. In general, the dominant theme was a mismatch between what patients felt their information needs to be at a particular time and the form or manner in which health care professionals provided them with information. Many reported on extreme distress in relation to too much information (or too much at one time), inconsistent information among and between professionals, an overabundance of negative or discouraging information, and/or gaps in the information they were able to access. One woman recalled being frightened by her oncologist:

He scared me in the way that he approached my disease. He seemed to be very quick in his meeting with me—very quick in his examination of my breasts, then basically gave me some ultimatums, and gave me some statistics regarding death right away. That did not sit well with me.

This mismatch between their perceived information needs and what they believed had been forthcoming created considerable emotional distress, illness management challenges, and distrust in the professionalism or even competence of the clinician. Patients generally perceived that health care professionals ought to have expert knowledge about the general needs of patients under such difficult circumstances and the capacity (and interest) to assess the individualized needs of particular patients and provide information in a manner that was tailored to their unique disease trajectory and personal attributes.

Although not all patients expected or apparently required overt expressions of human compassion from their health care professionals during these difficult encounters, much of what they reported as unhelpful took the form of what patients considered particularly insensitive remarks under the circumstances. Such expressions as “There’s nothing we can do,” “Be glad you’re not pushing up

daisies,” “Go home and put your affairs in order” were all offered as examples of approaches that patients believed would be universally understood as poor communication, regardless of the circumstances. Where they perceived professionals to be rushing them in their communications, irritated at their questions or lack of understanding, blaming them for failure to seek medical advice leading to delayed diagnosis, or disinterested in their case, the emotionality arising from the encounters clearly complicated their capacity to absorb, interpret, and respond to the new information. In many instances, the retelling of the story even many years after the encounter would evoke distress and tears during the interviews. For example, one cancer patient recalled the following encounter with her physician:

She was abrupt, like I was just a number on a piece of paper. And [it felt like] “So we’re going to lose you, so that’s okay.” . . . I think she wanted to get on with somebody who she thought was going to survive and she didn’t think I was going to be a survivor. That was my impression.

Thus, despite noteworthy discrepancies between various study participants with regard to appropriate or inappropriate use of humor, the preference for bluntness versus softening of difficult information, comfort or discomfort with overt expression of emotionality, these general patterns were apparent in accounts of what was considered helpful or unhelpful in the communication approaches of clinicians during critical moments in the experiential disease trajectory.

The Impact of Prognostic Communications on Hope

The concept of hope represented a powerful theme throughout the narratives of helpful and unhelpful communications involving projections of future events. Because a diagnosis of cancer or chronic illness represents a disruption to anticipated biographical course, it evokes anxiety about the future and a challenge to the tenuous balance between expectations and uncertainty. Hope reflects a natural language expression of matters of faith and belief. In referencing hope, people are paradoxically acknowledging that untoward outcomes may occur, but indicating that they prefer to set their sights on those that are more optimistic. As one man explained:

The way I would say it is that, when you get a diagnosis of cancer, or any life-threatening illness, you need to be committed to life. Okay, so I needed to put all of my energy into life-giving experiences—

people, situations, places—everything that could be life giving to me. And any thoughts of death just took me . . . to more of a fatalistic attitude.

Hope blends emotionality with cognition, creating a mental frame of reference that influences feeling and perspective. It is widely understood to be a powerful force, not only in its capacity to generate attitudes consistent with better outcomes, but also in its metaphysical relationship with the unexplained forces that play a role in shaping futures. One study participant eloquently articulated the relationship between these experiences and cancer:

I would describe it as “hope” which, I believe, is a powerful force in effectively dealing with cancer. A positive communication of the facts will generate a feeling of hope appropriate to the circumstances: hope for a cure, hope for a good quality of life where a cure is not possible, hope for pain control, hope to see an important family event or milestone before death. These expressions of hope assist in driving forward into the days, weeks, and years ahead. Hope lets you set goals for living. Goals are the *raison d'être* of life without which you might as well succumb to the disease.

Among the 60 individuals who explicitly referenced hope in relation to helpful or unhelpful prognostic communications with health care professionals, there were equivalent frequencies of reference to the potentially positive or negative effects of communication on hope. Where communications were detrimental to hope, they challenged the ideational structures to which patients were clinging for security in the midst of their chaos and turmoil. As one participant explained:

I do not want to know that in six months I won't be here. Because I don't think like that, and I don't want to hear that from a doctor. . . . What it did to me was that it took me very down, and it took a lot of people to bring me back up again. To think that, okay, no I can do this. I can get through this as opposed to no, you know, sort of giving up hope and thinking “Well what's the point?” Because that's what he was basically saying to me was “What's the point of your being here? Why are we wasting our time on you?” That's what came out.

In many instances, communications were associated with the introduction of statistical predictions that intruded upon thinking in a manner that was detrimental to psychological comfort. They described numeric information as having the potential to haunt their waking dreams and overpower other

ways of thinking about their circumstances. They often found it more difficult to reframe or compartmentalize numeric information than prognostic information communicated to them in other forms, and they described facts and numbers as conveying a level of certainty that was incompatible with an uncertainty that supported the value of hope. Thus, when general information indicative of population patterns took precedence over individualized information that might account for differences in their unique and individual case, hope became an increasingly complex challenge.

In contrast, prognostic communications were helpful in finding or sustaining hope when they provided a frame of reference by which patients could exercise some judgement in drawing on elements of the certainties and uncertainties selectively. In other words, where statistical prediction went in their favor, they could find comfort, and where it did not, they could find a strategy for putting it into perspective. Many patients depicted hope as a fundamental necessity for living, especially when the circumstances presented them with so many profound challenges. As one individual explained, “If you don't have that—even if it's just a tiny little glimmer of hope—you're just not going to make it. I don't care what your prognosis is, you're just not going to make it.” Thus, although they valued the information they needed in order to plan and make appropriate decisions on their own behalf, they also tried to avoid or reject information whose only purpose seemed to be the destruction of optimism and the acceptance of negative certainty.

Just as numeric facts seemed to have the capacity to stick in the minds of patients with much more persistence and intrusiveness than did other forms of information, certain words and expressions attributed to health care professionals within these clinical conversations became pivotal mantras from which to draw courage or against which to sustain resistance.

For example, one woman recalled an encounter in which her physicians informed her that her tumor was reduced in size as a result of treatment:

I remember the smile and the wonderful facial expressions that both of them had. It was absolutely overwhelming for me because that's all I needed to know. They didn't have to tell me anything. It was like the tumor had shrunk—it's half of what it was. And the joy that they were feeling.

In contrast, another participant recalled a physician who had “the bedside manner of a blacksmith,” although he was undoubtedly “a good surgeon.” As he remembered it, on the eve of surgery, the surgeon explained that, “Out of 100 of these operations, only 10 really work, and when people have pancreatic

cancer, only 5 out of 100 live past 1 year.” As he reflected back on that experience, he realized that those words eventually became the focus of a determination to prove that surgeon wrong in his case.

Thus, the study participants depicted a kind of hope that was quite delicate and vulnerable, especially during times of major realignment and adjustment such as initial diagnosis, negotiation around treatment decision making, or disease progression. Although some individuals clearly seemed more vulnerable than others to the shattering effects of health care communications and the power of communication for building or destroying hope was a common theme across participants in the two studies. From the patient’s perspective, once hope was shattered it could be exceedingly difficult to rebuild. Shattered hope was typically associated with significant emotional distress, accompanied by problematic coping or disease management. It brought the power of disease to ruin lives to the forefront and reduced the capacity of the individual and his or her family to conceive of options toward any kind of valuable future. For this reason, once attained, hope was fiercely preserved, even when that required significant cognitive reframing of events or reinscription of the meaning of remembered health care communications.

Patient Recommendations for Supportive Prognostic Communications

The accounts revealed that many study participants framed their perspectives on prognostic communication in the form of recommendations for health care professionals. These were both explicitly offered and also implied in their explanations of what they thought health care professionals ought to know or do. Within these recommendations, an overarching theme was their desire for communications that found an appropriate balance between “hope” and “honesty” through individualizing information, guiding interpretation, and facilitating uncertainty management.

The first set of recommendations pertained to individualizing the information that health care providers offered to their patients. Although participants universally recognized that prognostic information pertains to large populations rather than individual cases, they had encountered various challenges in negotiating the balance between general information and particular cases as they engaged in prognostic communication with their clinicians. As one explained:

There’s the initial stage of informing people as to treatments and what you’ve got and everything.

I guess really its developing empathy—either you’ve got it or you don’t. But, saying, “Do you understand?” “Is this too much information?” “Do you need more information?” You know you’re going to see these people over the long haul, and you sort of need to establish right from the beginning and get the feel of what people want.

In particular, patients recommended that health care professionals understand that they are providing information within a larger context of an illness experience and a care trajectory. As patients, they absorb, interpret, and frame new information in the context of what has been said previously, and they will continue to reframe that same information in the context of what will be said in the future. Thus, when clinicians restrict their explanations to the current moment, patients are deprived of linkages that they may require in order to identify consistent or inconsistent information or whether something may have changed. Thus, placing new information within a larger context becomes an important part of supporting the guesswork and interpretation that complicates the ongoing process of making sense of the information with which one is presented. As one woman recalled, “I think it would have broken the ice that morning if the three of us had talked over what had happened in our past life, what our hopes were and so forth. But we were not given a chance. . . . Instead, we were presented with two hours of nonstop negative factors about chemotherapy.”

A second and related set of recommendations relates to patients’ need for guidance in managing information. Although access to information was a frequent complaint in the past, the more common current experience relates to learning what to do about an excess of information. Not only are health care professionals increasingly required to inundate patients with specific information requisite to informed consent, but also patients, friends, and family increasingly have access to complex and various information from diverse sources. Patients report particular difficulty with the dose and intensity of difficult or painful information, especially when it comes in numerical form. From their perspective, their capacity to place particularly difficult information into some context, to make some sense of it and decide how to interpret it, requires space and time for reflection, and often continued interaction. One patient elaborated:

Doctors are more inclined now to give you the whole holus bolus of the whole thing, whether it’s applicable in your particular circumstances or not. . . . Well I think one has to realize

that . . . they want to know something about it—what’s happening to them. Whether or not they can assimilate all of that information in one sitting, because you have to wait until the shock subsides. You have to understand the person—the individual’s background. I think in our very hurried lives, you have to make sure that the individuals understand, are satisfied, know that they can go back if they want to know more.

Thus, isolated or episodic consultations with clinicians create a particularly challenging context within which difficult information is delivered. If the clinician cannot personally provide that additional reflective opportunity, some mechanism is required to ensure that patients do have that opportunity with a professional who is fully conversant with the implications.

The third set of recommendations related to facilitating patients’ capacity to manage the uncertainty associated with prognostic information. From their perspective, patients may seek out certain knowledge as an instinctive response to anxiety. Typically, they come to appreciate that there are very few matters about which medical science can be absolutely certain in relation to individual cases. One participant, for example, suggested that “they should get rid of that word ‘cure.’ I think that word should go, because it’s not about being cured, it’s about prolonging our lives and that should be exactly what we are told and we know, because there are no guarantees, and there are no guarantees anywhere in life, so don’t start trying to give some now.” In the absence of full and certain knowledge, patients come to value information as medical opinion. Unlike clinicians, their concern is not primarily about accurate calculation of predictive values in relation to population data, but rather with mustering the emotional resources that will enable them to confront what lies ahead and make the most appropriate decisions on their own behalf.

Thus, to the extent that information and support received help patients make meaningful sense of their disease experience, communication shapes their capacity to be active agents in their illness experience and to maintain essential feelings of control over aspects of their lives. As one participant expressed it, “As long as the physician has sort of prepared that road for you, you might not know where it’s going to lead, but you know that you are on the road to recovery, or that something positive might happen.” In this context, they appreciate consistency and authenticity in their communications, and find inconsistencies or disingenuous communications particularly troublesome. For instance, they report being highly attuned to discrepancies between the

verbal and nonverbal communications of their health care providers. In one example, a patient reported an encounter in which the health care professional’s act of holding her hand during a clinical consultation convinced her that the news was in fact much worse than the clinician was letting on. For many, uncertainty management was intimately related to an authentic acknowledgement of their circumstances and a respect for the challenges they were facing on a daily basis. As one explained:

I think the easiest way to get into the proper frame of mind is to look at these people and think “There but for the grace of God go I.” And that they are individuals—perfectly normal, no different than you or anybody else. They’re just going through a really rough time in their lives. And they don’t need you to pick them up and carry them; they just need you to give them a little bit of hope and strength to walk themselves down that road. Dignity is a very important thing. You lose your hair, you lose body parts, sometimes you lose control of body functions. . . . You have all these indignities that go on on a daily basis. You need somebody that doesn’t treat you like some kind of sick animal. That’s where the respect comes in. I mean it should be like that for everybody.

These accounts of individuals with cancer and chronic illness have revealed much of what they consider helpful and unhelpful about the health care communications within the context of predicting future events. They clearly recall communication encounters in which prognostic information is conveyed or interpreted as among the most critical occasions for influencing their cognitive and emotional responses to their diagnosis and disease trajectory. Further, they have clear opinions with regard to the power of such communications to sustain or to shatter the hope they require in order to live as well as they can with the serious health challenges with which they are confronted. From their perspective, there is much that can be done in the context of these communications to attend to the tenuous balance between hope and honesty, and to enhance the capacity of the patient to retain the hope that is a necessity for life.

DISCUSSION

It is increasingly well recognized that communication plays a significant role in patient care, not only in such psychosocial dimensions as anxiety reduction, treatment compliance and patient satisfaction but also, as is increasingly being empirically established, in terms of health outcomes (Simpson

et al., 1991; Stewart, 1995; King et al., 1996). The findings of this study address a critical element in what has been acknowledged as one of the most challenging of health care communications—that of providing patients with information of a prognostic nature, often in the form of bad news (Ptacek & Eberhardt, 1996; Sheilds, 1998; Walsh et al., 1998; Fallowfield & Jenkins, 2004)—in such a manner that it maximizes their capacity to retain a measure of hope and sustain their optimal coping. Despite widespread agreement that there is an inherent clinical challenge associated with communicating prognosis, many gaps within our understanding remain (Schofield & Butow, 2004). On the basis of a recent systematic review on communicating prognosis in cancer care, Hagerty et al. (2005a) concluded that there is as yet little firm evidence upon which to support best practices in this area. Thus, recent clinical practice guidelines pertaining to the psychosocial care of cancer patients provide somewhat tentative recommendations related to this aspect of communication (Baile & Aaron, 2005; Turner et al., 2005).

Although the findings of this study are limited by the constraints of secondary analysis and the extrapolation of themes from two distinct data sets, they extend our existing understanding by illuminating patient perspectives of some of the mechanisms by which health care communication sustains or jeopardizes hope within the context of serious disease. As has been noted by many others (including Chesla, 2005; Clayton et al., 2005; Hagerty et al., 2005b; Kim et al., 2006; Elliott & Olver, 2007), the human desire for hope becomes a powerful force shaping the way in which one is able to “live with” the disease, its impacts, and its uncertainties. According to the patients in our study, hope becomes a vital determinant of the mental attitude with which one approaches all aspects of living, and it carries with it a measure of the mystery of life transcending that which we can know or predict.

In describing health care communications related to projected futures, patients report being highly attuned to the nuances of language and the subtle behaviors of the clinicians as they impart information. They report a wide range of responses when such information is delivered, and align these with their need to apply an interpretive lens to what is being communicated. Among the responses they report within the clinical dialogue are such variants as titrating the information dose, putting a positive spin on distressing news, reframing the meaning underlying facts, and selectively recalling that which they need in order to sustain hope. Evident throughout the accounts in this study is the sharp critique patients express when they

believe communications are suboptimal, and their correspondingly intense gratitude where they feel communication is effective. From their perspective, compassionate, informed, and appropriate communication is indeed possible, even within the complex contexts of predicting futures; because of this, the exposure of patients to substandard communication seems to them a significant focal point around which meaningful improvements in health care might be achieved.

These patients with cancer and chronic disease envision a care delivery system in which communication would be increasingly acknowledged as a vital component of safe and responsible health care. In particular, in the context of future thinking in relation to serious disease, they believe that the capacity to attend to the delicate balance between sustaining hope and providing full and complete information should be a fundamental communication competency for health care providers. Their recommendations for enhancing health care communication in this regard reflect themes that have been well documented by others, such as individualizing care and supporting patients to make meaning of complex and difficult information (Back et al., 2005). Their viewpoint accentuates the significant problem inherent in accommodating the inevitable diversity among patients, a challenge that has also been acknowledged by others (e.g., Hagerty et al., 2005a) as a formidable barrier to generating general communications recommendations with widespread applicability.

A less anticipated finding was the challenge that patients describe related to dialogue around matters of certainty and uncertainty. Although they almost universally seek out information that will help them develop an understanding of what might befall them, they also feel that health care professional expert knowledge ought to pertain not only to facts but also to how patients make sense of them within their individual life contexts. This form of expertise has been depicted by others (e.g., Butow et al., 2002b; Hagerty et al., 2005b) as something of a balance between realism and compassion. From the patient point of view, professionals ought to be well positioned to recognize that there will be a wide range of individual responses within an illness experience and apply that knowledge toward supporting human uniqueness and diversity. In particular, although patients commonly acknowledge that an initial need for information reduces their discomfort with uncertainty, many come to believe that an undue attachment to certainty by their health care providers ultimately becomes the more problematic stance. Thus, they contest the notion that any disease trajectory can ever be predicted with any

certainty in an individual case and tend to reject probability projections that interfere with their need for hope.

As these findings illustrate, it is difficult to articulate with any confidence a specific set of communication behaviors that will meet the needs of all patients in all circumstances. However, what findings such as these can contribute to the larger body of literature is a feeling for the human variation that challenges our attempts to improve health care communication. By exploring patterns and themes within which patients describe successes and failures, we can begin to fine-tune our understanding of the strengths and the limits of general communication principles applied within the practice context. In this manner, the results of both qualitative and quantitative inquiries can deepen and extend our ability to create truly evidence-informed communication recommendations.

CONCLUSIONS

A key feature of the communication challenge to which this study was addressed is the power of hope—hope lost and hope restored—in the lives of those with incurable illness. We believe that the findings of this study add value to the body of existing knowledge by expanding upon and refining our current understandings in a manner that can subsequently be applied within clinical training programs and patient-oriented clinical guidelines. Through the patterns uncovered and the poignancy of the accounts with which they are illuminated, we hope to help clinicians understand more fully the power of their human potential to enact healing through their everyday communication with their patients.

By integrating that which can be gleaned from the unique and particular experience of individual patients with that which can be obtained through studies of large population patterns, we are collectively striving toward evidence-informed guidelines for the conduct of prognostic communications which simultaneously attend to the ethical obligations of informed consent and the clinically compassionate requirements for attention to human sensitivities and variations. Such guidelines, once attained, would provide an evidence-based reference point in support of those clinical practices that currently demonstrate excellence as well as a basis on which suboptimal clinical practices could be challenged and changed. Drawing on evidence derived from these multiple inquiry perspectives, we must also begin to build resources for patients so that they are able to understand their communication rights, seek out the therapeutic communication they need,

and demand that the communication culture of their health care settings be of the highest possible standard.

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