

The context of health care communication in chronic illness

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Abstract

Patient–professional communication is a critically important element of effective chronic illness care. However, the dynamics of health care communication in supporting self-care management and effective coping with various chronic diseases is not well understood. The present study examined health care communication from the perspective of 38 patients with four distinct chronic conditions: end-stage renal disease (ESRD), non-insulin dependent diabetes mellitus (NIDDM), multiple sclerosis (MS), and fibromyalgia (FM). Analysis revealed the dimensions of courtesy, respect, and engagement to be inherent in communication priorities across conditions. However, distinct “disease worlds” among and between these chronic conditions illuminated salient differences within these dimensions, thereby illustrating the way in which relevant variables such as legitimacy, the availability of conventional treatments, and lifestyle implications shape the meaning of health care communication. The findings enlarge upon patient-centered approaches to health care communication and inform further analysis of the interactional dynamics associated with chronic conditions.

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1. Introduction

Chronic diseases are by definition those for which no cure is available, and conventional intervention is limited to symptom control, preventing progression, and promoting self-care management [1]. Over the past two decades, research into chronic illness experience has shifted from the classic grounded theorizing of depicting basic social processes in such metaphoric conceptualizations as illness trajectory [2], erosion of self [3] or unending work [4] toward nuanced representations aimed at balancing aspects common to many chronic conditions with distinct experiential differences among and between specific chronic conditions and health care contexts [5–8].

Among these variations is the recognition that encounters between health care professionals and chronically ill patients may be variously sporadic or ongoing, occasional or intensive, and may involve one primary care provider or an array of specialist practitioners. Because the vast majority of chronic disease management is typically conducted by the patient in the context of his or her own life, encounters be-

tween patients and the health care professionals with whom they engage become a critical intersection for information exchange, decision-making and motivation. The ability of the health care professional to engage in effective communication may therefore make a profound difference in whether the encounter supports or discourages decisions and subsequent actions that will optimize the patient’s ability to live as well as possible with that particular disease [8].

Communication between professional health care providers and persons affected by chronic disease has long been recognized as critically important to providing care and supporting self care management [9–13]. Despite overwhelming evidence that communication can facilitate or inhibit health promotion and general wellness among those with chronic diseases, it has been difficult to generate a body of research to extend our understanding of this phenomenon beyond generalizations about the value of good communication [14], and equally difficult to discern what it is about different communication instances that make them effective or ineffective [15–20]. Health care communication research has been dominated by studies of individual consultation dyads in isolation from larger systems of ongoing care delivery [21]. Further, because we assume that communication styles and preferences are so inherently contextual and relational, we sometimes assume that gener-

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alizations about communication in health care are inevitably misleading [15,22–24].

Despite these challenges, the power of communication to effect a significant difference in the disease outcome and illness trajectory of persons with chronic diseases makes this an important area of study [25,26]. In this paper, we describe results from a comparative inquiry into patterns and themes arising from qualitative interviews with 38 individuals representing four discrete chronic diseases. Our purpose in this inquiry was to examine commonalities and variations across theoretically selected disease categories in order to develop some beginning conclusions about the general field of health care communication in chronic illness. Through an examination of what constitutes effective and ineffective health care communication from the perspective of those who are living with four distinct chronic conditions [27], we believe that our findings: add richness and texture to our understanding of why communication makes a difference to the chronic illness experience; illuminate the principles that can be extracted from subjective accounts; and extend the evidence bases upon which we can develop authoritative standards for the quality of communication that patients ought to expect from their professional care providers.

2. Methods

2.1. Study design

The design for this study relied upon interpretive description [28], a naturalistic applied methodology derived from grounded theory, which has been used for several decades in the health and social sciences to develop theory from the taken-for-granted assumptions by which people conduct their lives [29]. The inquiry was guided by the research question: How do individuals with distinct chronic diseases explain and describe helpful and unhelpful communication in their encounters with professional health care providers? We focussed our inquiry on end-stage renal disease (ESRD), non-insulin dependent diabetes mellitus (NIDDM), multiple sclerosis (MS), and fibromyalgia (FM), selected to represent distinct theoretical dimensions of chronic illness experience as depicted in the current research literature [1], such as the presence or absence of visible disease manifestations, pain, or functional limitations and the availability or lack of availability of accepted diagnostic conventions and biomedical interventions.

2.2. Sampling

The primary data for this study were drawn from audiotape-recorded interviews with 38 persons representing four chronic diseases. Following clearance from the local university ethical review board, a theoretical sample of volunteer participants was recruited from various local clinics and health care practices. Our sample included 12 persons

with MS, 10 with FM, 7 with ESRD, and 8 with NIDDM. While the eventual sample included more women than men (only eight male participants), it included a reasonably balanced age range (18 < 50 years, 20 > 50 years) and, although the majority were Canadians of Anglo-European ancestry, the sample included various economic, occupational and social backgrounds. All had extensive experience obtaining health care for their chronic disease; in all but two cases, participants were more than 5 years post-diagnosis.

2.3. Data collection

Data collection took the form of audiotape-recorded, face-to-face interviews and focus groups. All participants took part in individual interviews, which were loosely structured around their perceptions of what makes health care communication effective and ineffective. Interviews were conducted at participants' homes or other convenient locations and lasted 1–2 h each. Demographic data and narrative accounts of the individual's health care history in relation to the chronic illness were included in all interviews to ensure that the basis for interpreting accounts was well represented. In-depth focused interviewing techniques were used to enhance clarification, elaboration, and illustration of issues, and to ensure that each participant, as much as possible, articulated his or her perceptions regarding helpful and unhelpful health care communication. As patterns and themes began to emerge from the interview data, participants were invited to take part in focus group discussions in which preliminary findings were presented, reviewed, discussed and further developed. Eight participants were involved in this phase of the project. A final phase of the research involved interviews with eight health care professionals experienced in the care of persons with chronic illness. Our purpose in conducting these interviews was to ensure that our interpretations and recommendations made "clinical sense" and were formulated in a manner that would be as acceptable as possible to clinicians working with the chronically ill.

2.4. Analytic approach

We used a constant comparative analytic process to generate patterns and themes within the interview accounts, and to test ongoing hypotheses as they evolved from the analysis process [29,30]. Constant comparative analysis represents a strategy in which data analysis commences as soon as data collection begins, and the ongoing data collection is informed by the unfolding analytic hunches. It capitalizes on periods of immersion in the data and periods of strategic withdrawal or distancing, in which a more reflective analytic process is made possible. Once the initial interviews were completed and preliminary analysis concluded, focus groups were held. In contrast to individual interviews, in which the unique aspects of each person's experience are examined in depth and context, focus groups create a mechanism whereby analytic patterns and findings from the synthesized

data can be validated, clarified or refined through group discussion [31–33]. Analysis in each of these phases occurred both within and between disease groups, leading to a preliminary set of conclusions with regard to disease-specific communication issues as well as principles inherent in effective and ineffective communication in the general context of chronic illness [34]. The final phase of the inquiry, involving interviews with health care professionals, served as an external clarification and validation for the emerging thematic conclusions.

3. Findings

3.1. Common communication themes

The significance of health care communication to self-care disease management and therefore to quality of life with a chronic condition seemed self-evident to all of our study participants. Each had ongoing reasons to engage in interaction with health care professionals over time as their health management was evaluated and revised, information was exchanged and their condition was monitored. Further, in most instances, persons with the chronic condition believed that relationships with professionals were formed in the context of ongoing care management and support, and that these relationships were critical to their ability to access needed information and assistance, to trust its quality, and to feel confident that their self-care management practices were appropriately informed.

Across each of these conditions, the patients explained the importance of health care communication at three distinct levels: courtesy, respect, and engagement (see Table 1). Their explanations for why each level was significant illuminated dimensions of the meaning that communications held for them as they attempted to effectively manage life with a chronic condition. The “courtesy” dimension reflected the general tone of interaction related to scheduling, everyday politeness, remembering names, and feeling welcome within the clinic or office. Where office practices reflected a dis-

interested or patronizing tone, patients found it difficult to trust the model of care, the competence of the practitioners, and the beneficence of the health care organization. Thus, these “simple courtesy” functions revealed a critically important aspect of the fundamental motivation of health care service from their perspective. The “respect” dimension pertained to the individual consultations between the patient and the individual health care practitioner. All participants expressed a distinct preference for communication styles and behavioral attitudes that reflected respect for them as intelligent consumers of health care information, and a recognition of some aspects of the context of their lives beyond their chronic illness. Similarly they were uniformly antagonized by communication styles that seemed to discount their opinions about disease management or over-estimating the relevance of scientific evidence for decisions pertaining to living well with disease.

Finally, the “engagement” dimension was described by a majority of the participants as an extension of courtesy and respect. When a health care professional was engaged with the patient in problem-solving and care management, there was a feeling of teamwork, of investment in supporting positive outcomes, and of enthusiasm for working together to create the best decisions possible under the circumstances. In all instances described, this engagement was considered as a highly valuable and important feature of effective health care relationships. Conversely, a number of patients explicitly described certain health care professional attitudes and behaviors as blocks to such engagement, specifically attitudes such as maintaining a professional distance, disinterest in the patient’s perspective or opinion, or blocking access to information or resources. Thus, these three dimensions seemed to represent a useful typology with which to understand commonalities within desirable and less desirable health care communication across the four chronic conditions.

3.2. Distinct disease worlds

Despite these common patterns expressed by all of the study participants, we were struck by a number of distinct

Table 1
Common themes in effective health care communication

Domain	Effective communication	Problematic attitudes and behaviors
Courtesy (the general consideration of others)	Politeness Acknowledgement Sincerity Accommodating office practices	Disinterest Rudeness Patronizing Disrespectful office practices
Respect (the expression of regard for a specific individual)	Listening Recognition of patient expertise Awareness of social context Empathy Offering information	Discounting opinions Withholding information Uncritical acceptance of scientific evidence
Engagement (the sense of commitment to the encounter)	Coaching Teamwork Shared decision-making	Distancing Dismissing Blocking access

variations within the accounts among and between specific chronic conditions. As we examined the logic with which individuals explained their rationale for articulating specific health care communications as either helpful or unhelpful to them, we became aware of the importance of the experiential dimensions of each disease that renders it distinct from others. For each of these chronic diseases, patients depicted what we have termed a “disease world”, or the cultural knowledge of the implications of illness and care that become known to those who have lived in that world and come to know its nature. We therefore recognized that the specific features of health care communication that made certain kinds of interactions more or less significant for persons affected with a particular disease were best understood in the context of the tacit “culture” that ongoing care for that disease represented.

3.2.1. NIDDM

NIDDM is the most common of these conditions, and indeed is endemic in Western society [35]. Persons with NIDDM tend to consider their chronic condition as less serious than do those with the other diseases we studied. NIDDM typically develops later in life in conjunction with other co-morbidities. Beyond brief periods in diabetes education programs, the majority of participants obtain their ongoing disease monitoring and treatment recommendations from a general medical practitioner, often one with whom they had a pre-existing relationship. Although oral hypoglycemic medications are one element of a treatment plan, the aspect that features most in health care communication is the lifestyle change involved in a diabetes management regimen. Health care interaction typically centers around control of diet and activity, with the expectation that compliance in healthier lifestyles will positively influence outcomes. Because diet and activity are central to culture, identity, and quality of life, especially among older adults, modifications in these areas may require complex social and psychological adjustments. When glycemic control is attained, health care communication can be cordial and supportive; however, when it is not, health care communication may be interpreted as judgmental, critical or even punitive. For persons with NIDDM, therefore, a critical feature of effective patient–professional communication is the respect dimension, in which professionals recognize that blood sugars are not always predictable or cooperative, and assume patients are doing the best that they can to live as well as possible with this disease. One patient wished all health care professionals would treat their patients “with respect and courtesy and patience That’s what people should be striving for.”

3.2.2. ESRD

Because of its life-threatening nature and highly technical treatment, a diagnosis of ESRD invokes a considerable amount of fear and anxiety [36,37]. While effective in maintaining life, the treatment is also enormously intrusive, requiring significant lifestyle adjustments such as pro-

hibitive diet and fluid restrictions, complex medication regimens, and a reliance on technology that often creates as many physical problems as it solves [38]. Life with ESRD is fraught with uncertainties, and acute illnesses superimposed on the renal disease are common, resulting in frequent hospitalizations. Consequently, learning about the recommended lifestyle changes, monitoring health status and accessing dialysis or transplantation involves a close working relationship with a multidisciplinary team of health care providers. As one patient explained,

If I have a concern, I want to be heard, I want them to take the time to hear me, I want to feel that they are present, I want to feel that they care, I want the support, and I want an answer If they don’t know, I would love if they’d tell me, and then take action somehow and pursue it. And I’d want to know if there is something serious that I need to consider.

The number of health care providers involved in one patient’s care can be considerable, sometimes resulting in a sense, on the part of patients, that care is fragmented and confusing. According to one participant, “I think they’re just so used to doing what they’re doing, and some of them need to be reminded that there’s a *real* patient with *real* feelings, even if they cannot relate or understand.”

“Control” is a dominant theme in ESRD care [39]. In the absence of a cure, control of the symptoms is the goal, and relies, to a large extent, on the willingness of patients to comply with the treatment recommendations. However, compliance with the regimen is quite difficult, and often results in poor quality of life. Hence, patients with ESRD and their care providers are often at odds due to conflicting agendas and a culture of care that is dominated by biomedical measurements (lab values, computerized projections and prescriptions) aimed at controlling the disease, with less emphasis on living a satisfactory life. Patients with ESRD, in turn, are often labeled as “controlling” due to their high level of knowledge and expertise about their disease, and their ability to identify their needs and routines of care. From the perspective of the patients, however, this behavior is more appropriately understood as a necessary vigilance to ensure that health care remains appropriate and optimal [40,41]. As one individual explained, “The changes you have to make, you’re suffering so much physically, also emotionally and mentally, which people do not understand because of the poisons and the changes to your body; these facets are not intact, everything has changed.”

Patients with ESRD seem somewhat unique in their experiences of health care communication because relationships with providers are frequent, ongoing, and often fraught with tension. Thus, for this population, the importance of highly engaged health care relationships is particularly acute.

3.2.3. MS

A central feature of the disease world of MS is the complexity inherent in its diagnostic process. One patient re-

called, “I had a real hard time getting them to believe me that there was something wrong. They figured it was psychosomatic and that something dramatic must be happening in my life.” Another explained,

I went to an internist and he said to me then that there was nothing wrong with me, I just needed a good psychiatrist. And, um, so that was that, you know, but then I didn’t go. Its funny, when I look back at that, I remember feeling bad. I said to him, “Yeah, maybe I do,” like, you just don’t know, right? I mean you can get to that point when everybody seems to do all these diagnostics and they all come out normal.

As has been well recognized in the literature [42–45], MS patients often undergo years of frustrating diagnostic workup before the final diagnosis is issued. Although many perceive a physical diagnosis to be a relief, in contrast to the suspicion that their symptoms might be psychological in origin, the aftermath of diagnosis confronts them with the relative absence of viable management and treatment recommendations. They often feel that they are encouraged to prepare for life as an invalid rather than to actively engage in self-care or health promotion activities. As one woman explained, “They basically take away your hope and they talk about it in such dispassionate clinical terms, there’s nothing you can do.” Indeed, the prognostic information that is typically provided features pessimistic predictions of functional impairment, immobility, social withdrawal, and cognitive deterioration, although the trajectory of these losses is often articulated as highly unpredictable. While comfort measures and symptomatic relief may be mentioned, they tend not to be afforded much significance in altering the inevitable disease progression.

Once individuals are diagnosed with MS, they are therefore already highly guarded in their relationships with health care providers and hesitant to accept professional advice, particularly where it is pessimistic. In many instances, they actively seek out alternative therapies and self-care practices, and try to avoid unnecessary interactions with health care professionals who interpret active self-care management as a form of psychological denial. For this group of patients, engagement in constructive ongoing conventional health care relationships is less common but highly valued when it does occur. More typically, persons with MS are attuned to the courtesy dimension of health care communication assuming that, in its absence, respect and engagement are unlikely. They report highly adversarial responses in communicating with health care professionals, except under circumstances in which they are dependent upon the professional’s good will and feel obliged to feign gratitude and cooperation. Indeed, many describe themselves as having learned to “play the game” mainly to ensure that they can obtain the help that they need during times of crisis.

3.2.4. FM

In contrast to NIDDM, ESRD, and MS, FM constitutes a chronic disease for which there are no biomarkers or definitive physical diagnostic features [46–49]. Persons with this disease experience many of the same diagnostic challenges as those with MS, in that their symptoms are often attributed to psychological problems. However, the eventual diagnosis does not provide the “credibility” that an explicit neurological diagnosis might confer. Instead, they suffer from profound symptoms which are invisible to others and undetectable biologically, and often have dramatically compromised life circumstances by virtue of their symptomatology and the stigma associated with which the disease, especially in medical circles. As one patient recalled,

It’s the kind of thing that nobody else understands, you know what I’m saying? Like some of my friends—really, one day maybe they’ll have something like this and they’ll know what its about—they say “Oh you can do it, you can do it.” No, I can’t do it! And even my good friends, they’ve known me for a lot of years, said “I can’t understand why you can’t just get up and go.”

Like persons with MS, many with FM find little in the way of effective disease management offered by conventional health care professionals, and often seek advice and treatment outside the conventional Western tradition to augment that which is offered. The futility of their help-seeking efforts adds to the intense frustration associated with feeling “betrayed” by a health care system that discredits their disease and shows little interest in its self-care management.

Because feeling discredited is a major feature of the experience of FM in our society, the most critical dimensions of health care communication for these patients are respect and engagement. Although they realize that there may be little tangible support that health care professionals can offer, their need for moral support from within the conventional health care system is often intense. As one woman recalled, “He told my husband and myself that you’ll just deteriorate with fibromyalgia, you will not get any better. And I was very resistant. I knew that was wrong, that I could get better.” Another explained,

What I needed to know about was the physical things, like getting dressed in the morning, and how to blow dry my hair with my arms above my head. Just little things just to take care of yourself would become a problem, let alone trying to, you know, keep working and keep a relationship going and keep the house going.

Although many of them describe anger and frustration as pervasive within their experience, they may be especially vulnerable to perceived discrediting from health care professionals. One woman’s recollections illustrate:

They’ve got the file outside the door and they pull it open and look at it, and they look at the notes that are made there for whatever reason—she has fibromyalgia. And then they

Table 2
Disease-specific dimensions of health care communication

Chronic disease category	Disease world dimensions (distinct features of the chronic illness experience relevant to the communication context)	Social judgement (pervasive social stigma associated with each disease according to participants in this study)	Communication challenges
NIDDM	Perceptions of non-serious nature Emphasis on dietary compliance, lifestyle management	“Couch potato”	Maintaining respect for complexity of blood glucose management Avoiding judgmental attitude about lifestyle choices
ESRD	Life-threatening nature of disease Reliance on technology Emphasis on compliance Uncertainty, vigilance, control	“Control freak”	Engaging in ongoing monitoring Recognizing potential for control struggles
MS	Protracted diagnostic process Limited medical interventions Gloomy prognosis Fear and mistrust	“Neurotic”	Fostering trust Maintaining hope Avoiding adversarial relationships
FM	Disease legitimacy Profound but invisible symptomatology Anger and frustration	“Malingering”	Recognizing vulnerability Avoiding discrediting subjective experience Responding to frustration

automatically have a preconceived idea of what they're going to have to deal with when they go in there and it colors everything that they do or say or don't do or say while you're in there.

Conversely, when they believe that health care professionals genuinely care about the predicament within which they find themselves, they obtain a meaningful kind of comfort. As one patient explained, “He always had time for me, and he made me feel like a human being and not just some chronic complainer who was saying something that was so far fetched it was like a psychological problem.”

Thus, for each of these four diseases, the characteristics of the condition and the experiential responses to it creates an illness context within which health care communications come to have distinct and particular meanings (see Table 2). From this analysis, it would appear that several factors inherent in the disease experience may directly influence the manner in which health care communications take on importance and are interpreted. These include: the patient's dependence upon technological and medical intervention, assumptions about the role and effect of lifestyle management, the prognostic interpretations, and the “legitimacy” of the disease. It is apparent that elements in the diagnostic and treatment trajectory can create predictable patterns in the communication barriers that arise for these distinct types of patients.

4. Discussion

From this analysis, it seems apparent that effective health care communication in chronic illness involves features common across diseases and also aspects specific to the circumstances and trajectories inherent within distinct con-

ditions. Comparing and contrasting the experiences with health care communication across these four distinct diseases has allowed us to illuminate the manner in which specific characteristics of the condition may distinctly influence the kinds of health care encounters that take place, the manner in which the importance of health care communication is understood, and the elements of health care communication that can be most facilitative or problematic in supporting chronically ill patients to live as well as possible. Our findings make evident the critical importance of appreciating the nature and trajectory of distinct chronic diseases so as to apply common principles in an appropriate and meaningful manner.

4.1. Comparative analysis

Comparing NIDDM and ESRD with MS and FM, for example, we can see the powerful effect that biomarkers and other objective indicators may have upon the legitimacy of symptomatic experience in a chronic condition. Although both NIDDM and ESRD can influence a patient's psychological state, the experience of neither disease is tainted by suspicion that health care professionals disbelieve your symptomatic reports and interpret your complaints as psychosomatic. Where the dynamic of suspicion develops, it seems to pervade the disease experience, even when, such as in the case of MS, a biological explanation is eventually found. As one woman with MS noted,

You can divide the world into two kinds of people—those who will take you seriously and those who won't, those who have enormous egos and those who can manage to keep their egos in check. Those who can manage to keep their egos in check are much more likely to take you seriously.

It seems likely that persons suffering with chronic diseases for which objective measures are absent are particularly vulnerable to communications which appear to discredit their subjective symptomatic reports [43,50]. Where biomarkers exist, however, they can afford credibility when they confirm subjective experience but introduce considerable disbelief when they are unreliable in this regard. The relationship between objective indicators and social legitimacy seems to be a potent variable influencing the experience of individuals with chronic diseases and their communications with professional health care providers.

These two sets of diseases also provide a comparison with regard to assumptions about the impact of treatment compliance upon disease outcomes. It is commonly assumed that compliance with medical orders is fundamental to self-care management in both NIDDM and ESRD, while MS and FM create few contexts in which compliance is relevant. In diseases for which it is assumed that patients are adhering to recommendations and their health outcomes support that assumption, health care communications can be cordial and unproblematic. However, when outcomes are less than optimal, non-compliance is typically assumed, and interactions between patients and professionals can quickly deteriorate. When treatment options are sufficiently evidence-based that compliance is necessary, the power dynamics between patients and professionals can become critical within health care communication.

Another relevant variable illuminated by the contrasts between diseases is the assumption of lifestyle contribution to etiology. Typically, NIDDM and FM are linked to unhealthy lifestyle and behavior (specifically overeating/underactivity and overwork/stress). In contrast, MS and ESRD are not (with the explicit exception of ESRD resulting from longstanding problems in diabetes management). From the perspective of the participants in this study, the lifestyle implications of the disease itself seem to influence the potential for judgmental communications throughout the illness trajectory, and they remain highly vulnerable to suggestions that they are somehow to blame for what has befallen them. It seems evident that, in such situations, effective health care communication will require special sensitivity so as not to trigger this dynamic.

4.1.1. Practice implications

Although courtesy, respect and engagement are important dimensions of effective health care communications across the spectrum of chronic illness care, the unique features and dynamics of distinct chronic diseases become influential in determining which aspects of patient–professional encounters are most vulnerable to misunderstanding and communication breakdown. In diseases in which medical and social legitimacy are contentious, clinicians should be particularly alert to the potential for mistrust and perceptions of disrespect as these can powerfully overwhelm the communication context. While biomarkers and other objective indicators may play a useful role in disease monitoring

and management, it is important not to overestimate their meaning; skilled clinicians should remain attentive to the subjective reports of their patients as well as the interpretations their patients make of their symptoms.

Where disease management is linked to treatment or lifestyle compliance, clinicians should guard against communication styles that can be interpreted as judgmental. Recognizing that the average patient is doing their best to manage their illness in the context of a complex life, discussing lifestyle and treatment choices in a non-judgmental manner may increase the likelihood of open and honest information sharing. The findings of our study confirm and elaborate upon the value of the “patient-centered” approach [12,19,51–53] to medicine and health care, informed by an understanding of the particular context and features of each distinct chronic condition.

5. Conclusions

According to the participants in this study, self-care management of a complex chronic condition is difficult, frustrating and, at times, overwhelming. It requires persistence, courage, and enormous adjustments, often involving considerable emotional turmoil and disappointment. NIDDM, ESRD, MS, and FM each constitute a distinct constellation of pathological, social and experiential features that profoundly influences the manner in which health care communications affect the patient’s ability to live as well as possible and attain optimal health outcomes. While courtesy, respect and engagement are valued across each of the chronic conditions, the specific manner in which they are enacted and interpreted can be highly dependent upon the particular vulnerabilities associated with each distinct disease experience. Professional health care providers who are most helpful and supportive of patients as they live through this process are those with compassion, flexibility, and an interest in arriving at decisions that provide a balance between discrete clinical goals and overall quality of life. For patients, that attitude is the gold standard of effective health care communication.

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References

- [1] Thorne SE, Paterson BL. Two decades of insider research: What we know and don’t know about chronic illness experience. *Ann Rev Nurs Res* 2000;18:3–25.
- [2] Strauss AL, Corbin J, Fagerhaugh S, Glaser BG, Maines D, Suezek B et al. *Chronic illness and the quality of life*. 2nd ed. St. Louis: Mosby; 1984.
- [3] Charmaz K. *The self, control, illness and time*. New Brunswick, NJ: Rutgers University Press; 1991.

- [4] Corbin JM, Strauss AL. Unending work and care: managing chronic illness at home. San Francisco, CA: Jossey-Bass; 1988.
- [5] Wellard S. Constructions of chronic illness. *Int J Nurs Stud* 1998;35:49–55.
- [6] Conrad P. Qualitative research on chronic illness: a commentary on method and conceptual development. *Social Sci Med* 1990;30:1257–63.
- [7] Gerhardt U. Qualitative research on chronic illness: the issue and the story. *Social Sci Med* 1990;30:1149–59.
- [8] Thorne SE. Negotiating health care: the social context of chronic illness. Newbury Park, CA: Sage; 1993.
- [9] Buckley LM, Vacek P, Cooper SM. Educational and psychosocial needs of patients with chronic disease: a survey of preferences of patients with rheumatoid arthritis. *Arthritis Care Res* 1990;3(1):5–10.
- [10] Clark NM, Nothwehr F, Gong M, Evans D, Maiman LA, Hurwitz ME, et al. Physician-patient partnership in managing chronic illness. *Acad Med* 1995;70(11):957–9.
- [11] King GA, King SM, Rosenbaum PL. Interpersonal aspects of care-giving and client outcomes: a review of the literature. *Ambulat Child Health* 1996;2(2):151–60.
- [12] Simpson M, Buckman R, Stewart M, Maguire P, Lipkin M, Novack D, et al. Doctor-patient communication: the Toronto consensus statement. *Br Med J* 1991;303:1385–7.
- [13] Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. *Ann Intern Med* 1997;127:1097–102.
- [14] Lewin S, Skea Z, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. 2003 [Systematic Review].
- [15] Shields CE. Giving patients bad news. *Prim Care* 1998;25(2):381–90.
- [16] Robinson JW, Roter DL. Psychosocial problem disclosure by primary care patients. *Social Sci Med* 1999;48:1353–62.
- [17] Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. *J Am Med Assoc* 1996;276:496–502.
- [18] Miller WL, Yanoshik MK, Crabtree BF, Reymond WK. Patients, family physicians, and pain: visions from interview narratives. *Fam Med* 1994;26(3):179–84.
- [19] Lambert BL, Street RL, Cegala DJ, Smith DH, Kurtz S, Schofield T. Provider-patient communication, patient-centered care, and the mangle of practice. *Health Commun* 1997;9(1):27–43.
- [20] Iversen MD, Fossel AH, Daltroy LH. Rheumatologist-patient communication about exercise and physical therapy in the management of rheumatoid arthritis. *Arthritis Care Res* 1999;12:180–92.
- [21] Bensing J, van Dulmen S, Tates K. Communication in context: new directions in communication research. *Patient Educ Couns* 2003;50:27–32.
- [22] Takman CAS, Severinsson EI. A description of health care professionals' experiences of encounters with patients in clinical settings. *J Adv Nurs* 1999;30(6):1368–74.
- [23] Kruijver IPM, Kerkstra A, Bensing JM, van de Wiel HBM. Nurse-patient communication in cancer care: a review of the literature. *Cancer Nurs* 2000;23(1):20–31.
- [24] Crabtree BF, Miller WL, Aita VA, Flocke SA, Stange KC. Primary care practice organization and preventive services delivery: a qualitative analysis. *J Fam Pract* 1998;46:403–9.
- [25] Bartz R. Beyond the psychosocial model: new approaches to doctor-patient interactions. *J Fam Pract* 1999;48:601–7.
- [26] Rosenow EC. The challenge of becoming a distinguished clinician. *Mayo Clin Proc* 1999;74:635–7.
- [27] Neufeld VR, Maudsley RF, Pickering RJ, Turnbull JM, Weston WW, Brown MG, et al. Educating future physicians for Ontario. *Acad Med* 1998;73:1133–48.
- [28] Thorne S, Reimer Kirkham S, MacDonald-Emes J. Interpretive description: a non-categorical qualitative alternative for developing nursing knowledge. *Res Nurs Health* 1997;20:169–77.
- [29] Glaser BG, Strauss AL. The discovery of grounded theory: strategies for qualitative research. Chicago: Aldine; 1967.
- [30] Lincoln YS, Guba EG. Naturalistic inquiry. Beverly Hills, CA: Sage; 1985.
- [31] Carey MA. The group effect in focus groups: planning, implementing, and interpreting focus groups. In: Morse JM, editor. Critical issues in qualitative research methods. Thousand Oaks, CA: Sage; 1994. p. 225–41.
- [32] Morgan DL. Doctor-caregiver relationships: an exploration using focus groups. In: Crabtree BF, Miller WL, editors. Doing qualitative research. Newbury Park, CA: Sage; 1992. p. 205–27.
- [33] Stewart DW, Shamdasani PN. Focus group research: Exploration and discovery. In: Bickman L, Rog DJ, editors. Handbook of applied social research methods. Thousand Oaks, CA: Sage; 1998. p. 505–26.
- [34] Miles MB, Huberman AM. Qualitative data analysis. 2nd ed. Thousand Oaks, CA: Sage; 1994.
- [35] Hjelm K, Mufunda E, Nambozi G, Kemp J. Preparing nurses to face the pandemic of diabetes mellitus: a literature review. *J Adv Nurs* 2003;41(2):424–34.
- [36] Gregory DM, Way CY, Hutchinson TA, Barret BJ, Parfrey PS. Patients' perceptions of their experiences with ESRD and hemodialysis treatment. *Qualitative Health Res* 1998;8(6):764–84.
- [37] Beanlands H. Engulfment among adults with chronic renal disease: a study of self-loss and its correlates [Doctoral Dissertation]. Toronto, Ontario: University of Toronto; 2001.
- [38] Devins G. Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. *Adv Ren Replace Ther* 1994;1(3):251–63.
- [39] Bevan MT. Nursing in the dialysis unit: technological enframing and a declining art, or an imperative for caring. *J Adv Nurs* 1998;27(4):730–6.
- [40] Curtin R, Mapes D. Health care management strategies of longterm dialysis survivors. *Nephrol Nurs J* 2001;28(4):385–92.
- [41] Mahoney KM. Vulnerability and vigilance: exploring experiences of and responses to communication in renal disease care [Masters Thesis]. Vancouver, BC: University of British Columbia; 2003.
- [42] Elian M, Dean G. To tell or not to tell the diagnosis of multiple sclerosis. *Lancet* 1985:27–8.
- [43] Kralik D, Brown M, Koch T. Women's experiences of 'being diagnosed' with a long-term illness. *J Adv Nurs* 2001;33(5):594–602.
- [44] O'Conner P, Detsky AS, Tansey C, Kucharczyk W. Effect of diagnostic testing for multiple sclerosis on patient health perceptions. *Arch Neurol* 1994;51:46–51.
- [45] Sencer W. Suspicion of multiple sclerosis: to tell or not to tell? *Arch Neurol* 1988;45:441–2.
- [46] Vanderhaeghe L. Fibromyalgia: the invisible illness. *Total Health* 2000;22(2):52–3.
- [47] Söderberg S, Lundman B, Norberg A. Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qualitative Health Res* 1999;9:575–87.
- [48] Prince AB, AL, Edsall PA. A descriptive analysis of fibromyalgia from the patients' perspective. *J Musculoskelet Pain* 2000;8(3).
- [49] Hellstrom O, Bullington J, Karlsson G, Lindqvist P, Mattsson B. A phenomenological study of fibromyalgia: patient perspectives. *Scand J Prim Health Care* 1999;17(1):11–6.
- [50] Hadler NM. If you have to prove you are ill, you can't get well. *Spine* 1996;21(20):2397–400.
- [51] Stewart MA. Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J* 1995;152(9):1423–33.
- [52] Weston WW, Brown JB. Teaching the patient-centered method: the human dimensions of medical education. In: Stewart M, Brown JB, Weston WW, et al., editors. Patient-centered medicine: transforming the clinical method. Thousand Oaks, CA: Sage; 1995. p. 117–31.
- [53] van Dulmen AM, Bensing JM. Health promoting effects of the physician-patient encounter. *Psychol Health Med* 2002;7(3):289–300.