Patient—Provider Communication in Chronic Illness
A Health Promotion Window of Opportunity
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As chronic illness takes its rightful place as an imperative for planners and policy makers globally, the obligation to provide appropriate self-care management support and promote optimal health among the chronically ill is attracting considerable attention. A generation of insider research into the chronic illness experience has yielded powerful evidence of the critical importance of communication between the chronically ill and those who provide their healthcare services. In this article, insights gained from the body of chronic illness research shape recommendations for attitudinal and structural adjustments that might steer our course toward promoting improved health for those affected by a chronic disease. Keywords: chronic disease, chronic disease management, chronic illness experience, communication, health promotion

CHRONIC ILLNESS CARE is at last being formally recognized by planners and policy makers at all levels as an urgent priority issue.1–5 In the current context, a major emphasis is being placed upon effecting a shift from an emphasis on provider-dependent care to self-care, in recognition that most of what constitutes chronic disease management occurs outside the context of what is conventionally considered the healthcare system.4,5 While this shift is necessary and appropriate, an uncritical adherence to its predominant agenda might well leave significant gaps in service for those affected by chronic conditions. The community of scholars and healthcare professionals who have been studying chronic illness experience from a qualitative perspective are ideally placed at this unique moment in time to advance an understanding of the kinds of systems and structures that might actually make a difference for health promotion among the chronically ill. One such aspect is the healthcare communication between professionals and patients—the focal point at which information, attitudes, and agendas are communicated. By generating an informed understanding of what it is that we ought to be preventing and promoting on the basis of what we know from the available body of qualitatively derived knowledge, we may be able to make optimal use of this interactional context for the benefit of those we serve and effect a significant improvement in outcomes.

A GENERATION OF INSIDER RESEARCH

Over the past 25 years, the experience of persons affected by chronic illness has become a significant focus of qualitative research.6–8 Using a cadre of research methodologies originally derived from the
social sciences, applied health researchers have advanced the value of experiential knowledge for informing healthcare and service delivery. An early adopter of this methodological approach, nursing has been particularly prominent in advancing the value of the qualitative angle of vision into understanding complex health and health service problems. As medicine and the allied health professions have also expanded their research agendas to embrace qualitative approaches, the body of qualitatively derived knowledge has matured to the point that it can contribute significantly to the interpretation and application of empirical evidence.

On the basis of this body of qualitatively derived knowledge, healthcare providers now have access to a well-grounded understanding of what it is like to be affected by a chronic condition.8–10 We know a great deal, for example, about the social and emotional impacts of such phenomena as fatigue, pain, and mobility impairment.11–13 We understand the mechanisms by which discrediting and stigmatizing conditions influence people’s choices and perceptions as they manage their everyday lives.14–17 We recognize that blind adherence to standardized protocols over extended periods of time rarely serves chronically ill persons as well as does intelligent self-management of symptoms and thoughtful individualization of conventional recommendations.18–21 We have documented some of the double binds into which chronically ill persons become trapped when they are simultaneously trying to seek appropriate support while normalizing their conditions.22,23

From the body of qualitative evidence, we further understand something of the complex dynamics within which chronically ill persons are often caught when they attempt to negotiate health services in the context of systems designed for the needs of the acutely ill.24 We know that they feel that they are confronted by a system in which chronic diseases are not nearly as “interesting” to the system and the professionals within it as are acute and episodic conditions.25 Beyond this perceived disinterest, we recognize specific attitudinal barriers that the disjuncture between chronic and acute illness can create.26 Not only are the gatekeeping and referral patterns for most healthcare services set up to protect patients from their own ignorance and to privilege the expertise of the professional healthcare providers but many healthcare interactions also are shaped by the assumption that knowledge and power are appropriately maintained within the system itself.27 Thus, although persons with chronic illness report being confronted on a daily basis with the limits of science for answering the immediate questions of how to live life with their particular condition, the healthcare professional sector still functions, for the most part, as if scientific expertise is its singular prerogative and the ultimate source of all meaningful and pertinent knowledge.19,26

Because of these natural tensions between how we healthcare professionals tend to do business and what chronically ill people experience, direct communication between patients and providers has come to be recognized as a pivotal moment within which damage can be done or benefit can be gained.28–30 In the past, communication has often been relegated to the domain of “soft” science and understood as a nicety but not a vital element in effective healthcare service delivery. On the basis of a growing body of evidence of dominant patterns in chronic illness experience from the insider perspective, we now know that communication between chronically ill patients and their healthcare providers has tremendous potential to be instrumental in facilitating coping, self-care management, and an optimal quality of life, or, conversely, in being toxic and damaging to those ideals.30 Thus, communication is gaining increasing recognition as a high priority in health system improvement.

THE CURRENT URGENCY

A current sense of urgency for resolving the problems associated with chronic illness becomes apparent when we examine recent
trends in research infrastructure, health economics, and outcomes measurement. Although much of the conventional research into chronic illness experience has been conceptualized in the context of diseases, organ systems, or both, it has long been recognized by social scientists and qualitative healthcare researchers in the health disciplines that the illness experience of various chronic conditions actually have a great deal in common. Despite major funding systems and scholarly community infrastructures that orient scholars toward disease-specific research (cardiovascular disease, renal disease, neuromuscular disorders, immune system disorders, and so on), a subset of clinicians and researchers has recognized important parallels among and between these diseases and directed their attention toward the more generic focus of chronic conditions. This orientation becomes especially apparent when one considers that primary chronic illness coping challenges extend beyond biochemistry and physiology into the domain—as the qualitative healthcare researchers have consistently documented—of trying to live as well as possible in the context of physical discomforts and limitations and the associated ongoing dependence upon health services, therapeutics, interventions, or a combination of these.

On a global level, once the conceptual grouping of chronic diseases was popularized and tabulated as a coherent entity, it became immediately apparent within policy circles that the financial burden of responding to chronic disease represented a massive proportion of the overall healthcare expenditure of most nations. A primary policy driver has become one of economics, since it is becoming increasingly apparent that scarce healthcare resources must be used as efficiently and effectively as possible to support sustainable systems and respond to new (and inherently more costly) advances in health technology, molecular biology, and pharmacotherapeutics. Thus, uptake of the generic conceptualization of chronic illness as a meaningful emphasis of study has created the basis for a sharp illumination of its economic impact by the policy community and contributed to this sense of urgency.

Advances in thinking about outcomes measurement have also contributed to this climate of crisis. While conventional health measurement had tended to focus on short-range, measurable, and discrete relationships (such as the immediate outcomes of surgical or chemotherapeutic procedures), a body of evidence started to accumulate documenting the social and economic impact of long-range effects and effects that occurred in combination with one another. Thus, it has become increasingly apparent that failure to attend seriously and systematically to the ongoing support of persons affected by chronic illness results in increased morbidities as well as a costly level of excessive demand upon the acute care system. Although, until recently, primary prevention had not really hit the radar of most governments as a priority matter, and health/wellness promotion had been typically relegated to the individual’s responsibility, this new form of economic analysis has created an intensified appreciation for the hidden costs in failing to prevent predictable negative outcomes, such as those associated with badly managed chronic disease. In this context, the communication that takes place between patients and providers—the direct interactional arena in which health and wellness can either be promoted or ignored—has started to take on public policy priority status. Healthcare communication has now therefore been widely acknowledged as a critically important imperative of health service delivery in chronic disease, and a juncture deserving of considerable research and development.

HEALTH-INHIBITING AND HEALTH-PROMOTING INTERACTIONS

With the importance of the communication that takes place between persons affected by chronic disease and their professional healthcare providers achieving recognition as a priority concern, we can now begin to draw upon the available body of qualitative
research for clues as to the intricate interrelationship between certain kinds of communication encounters and the effectiveness of our general disease management strategies.\textsuperscript{39} Since most chronic disease management is self-management—the decisions and actions undertaken by people at home and in the context of their everyday lives—the accounts of patients as to how healthcare communication has positively or negatively influenced their success in this regard become an important source of insight.

What we do know from the available research is that many—if not most—persons with chronic disease report encountering disrespectful, discrediting, and distressing healthcare communications at some point in their illness careers.\textsuperscript{26} We know that such communications are not simply a nuisance factor, but rather may have a lasting negative effect, creating systemic distrust in the healthcare system, its recommendations, demoralizing people in their quest for solutions to problems and escalating the consequent drain on system resources as people seek additional services to fulfill their unmet needs.\textsuperscript{26,40} The frequency with which such counterproductive communications are documented across illness conditions, settings, and contexts reveals the extent to which they reflect systemic attitudinal and structural barriers to optimal care.\textsuperscript{26} In other words, the problem seems not simply the occasional misunderstanding or frustration, but a more systemic embedded set of assumptions within the professional healthcare sector—that persons with chronic illness are not high-priority patients, that there is little that can be offered that will make a difference in their lives, and that, unchecked, they will use up more than their fair share of health resources.\textsuperscript{26} Clearly, finding ways to adjust these attitudinal misalignments with regard to the chronically ill and to reduce the frequency of these kinds of problematic interactions in healthcare will be an important objective.

On the other side of the equation, this same body of evidence also confirms that many persons with chronic conditions are fortunate enough to encounter a more enlightened form of healthcare communication that is actually conducive to health promotion and the prevention of disease sequelae. Thus, the insider perspective provides us with considerable insight into the patterns of healthcare communications that facilitate problem-solving and the development of self-care management competencies.\textsuperscript{30} We know that, no matter how compelling population-based evidence might be, the patient is confronted with “the n of 1” approach. Each individual experiences his or her disease in a unique manner, reacts to interventions in a distinct way, and confronts disease-related stressors that are specific and particular to his or her life context. The work of learning a chronic illness is much less about accessing and interpreting scientific information than it is about analyzing the relevance of that information to a unique set of manifestations and responses.\textsuperscript{41} Patients typically tell us that they effectively accomplish such work through such mechanisms as “body listening” and experimentation, not through compliance to standardized protocols.\textsuperscript{42,43}

A vital element in effective communication within the chronic illness context is the healthcare professional’s recognition of the limits of science in solving the everyday problems that chronic illness entails. Thus, health-promotion communications in chronic illness care are those that reflect respect for the patient’s inherent expertise in matters pertaining to his or her own bodily experiences and contextual conditions.\textsuperscript{18,44} Where healthcare professionals recognize the limits of what they have to offer, and recognize the patient’s primary authority in matters pertaining to actually living with a chronic disease, they paradoxically become much more useful to their patients as consultants and resource brokers within a context of shared care.\textsuperscript{45}

**SYSTEMS AND STRUCTURES THAT MIGHT MAKE A DIFFERENCE**

If we accept the premise that it would be beneficial to minimize the prevalence of counterproductive healthcare communications
in chronic disease care and enhance the frequency of those that are health promoting, then it would also seem important to consider structural factors within our current health service delivery systems that may impede our progress toward those objectives. I have argued here that much of what underpins the attitudinal problem within health service delivery is the predominance of an acute care model for the delivery of chronic illness care. Our typical systems of diagnosis, referral, consultation, information access, and resource gatekeeping are all predicated on the assumption that patient safety and system integrity depend on the expertise and authority of the professional. This particular logic model creates an inordinately complex process whereby prescriptions are modified, laboratory tests ordered, and consultation sought. While this kind of gatekeeping is essential in the acute illness context, when the patient truly lacks the expertise to make good decisions on his or her own behalf, it is largely counterproductive in the delivery of chronic disease care. Rather than setting up systems designed to protect patients from their own ignorance, we would do well to facilitate and support competency development under the assumption that most patients can and will develop fairly high levels of expertise with regard to their own situations. Under such circumstances, we become true consultants, positioned to engage with them in finding solutions to their challenges.

It is now well recognized that newly diagnosed chronically ill patients typically enter into healthcare relationships with high expectations and the assumption that modern medicine will cure their problems. This initial naïve trust, common among those who have not had significant encounters with the healthcare system by virtue of a chronic condition, has been systematically fuelled by professional interests over the past 2 or 3 generations. For those whose illness is of a chronic nature, the inevitable shattering of this trust typically results in a period of dissatisfaction and even animosity that has been referred to as the stage of disenchantment. In the chronic illness care context, this unpleasant interactional pattern is eventually resolved through a form of guarded alliance in which the patient develops various new kinds of relationships with healthcare providers to accommodate his or her ongoing dependence on their services. When professional healthcare providers recognize this as a natural and necessary process, and ride out any unpleasantness in these early phases, they can take advantage of appropriate opportunities to rebuild new, different forms of interpersonal understanding more conducive to a long-standing care collaboration. Since it is the professional, and not the patient, who has the capacity to recognize these predictable interactional patterns in the early phases of the disease experience, he or she ought to accept a measure of responsibility for such matters as judgement and timing.

Where these communication tensions go unresolved, a struggle for control often ensues with regard to who has ultimate authority in managing the illness. A typical and very frequent manifestation of this tension is the physician rendering orders and the patient failing to comply. In an ideal situation, however, resolution of the aftermath of the patient’s shattered cure expectations will involve early dialogue about what it means to be entering a chronic illness journey and what roles the patient and the professional healthcare provider will variously play in steering the ship along its course. If the professional genuinely appreciates the importance of patient expertise in everyday self-care decision making as the hallmark of optimal chronic disease management, then he or she will orient the newly diagnosed patient to the process of expertise development and offer a strategic plan for explicit support and guidance along the way.

Because expertise will take time to establish, and because even the best of self-care management strategies will run afoul of illness trajectory challenges along the way, relationship building should be a high priority in healthcare delivery system, especially in the early illness stages.
reimbursement schemes within our healthcare systems severely restrict the time available for such "soft" aspects as relationship building, it will be necessary to challenge the conventional care and reimbursement models and build in the elements that hold the potential to set patients on a suitable course of action rather than hope they will eventually figure it out for themselves. Although it is difficult to attribute specific unnecessary costs down the road to inadequate early chronic disease management "orientation" in the early stages, an understanding of the complexity of the challenge and the imperative of expert self-care decision making in addressing it seems sufficient justification to realign our reimbursement priorities.

In an ideal system, we would eradicate the notion of "compliance" and instead find mechanisms for the study of effects of various patterns of self-care practice. From a patient perspective, uncritical adherence to medical regimens is at odds with the compelling need to develop expertise by discovering one's own responses and symptom patterns, learning to detect, monitor, and interpret bodily cues, and creating effective internalized problem-solving strategies. In our study of expert disease decision makers with type I diabetes,48 we discovered that our study participants (who, incidentally, were nominated by their physicians as "success stories" after at least 15 years of self-care management) were universally convinced that they would have fared badly had they not learned to creatively and strategically modify their prescribed regimen at an early point in their illness career. Thus, even for a disease in which there exists an established intervention and considerable "evidence" to support best practices in relation to it, the path to promoting health is not created on a foundation of abject compliance but rather on one of sound reasoning and experiential wisdom in relation to individualized data.

Additional elements of an ideal system could include a reconfiguration of access systems—something of a "pass-card" to self-prescription and referral, for example, for those who have established themselves as sufficiently expert in their own disease self-management. Instead of clogging up primary care and specialist practices with unnecessary consultations in order to approve the tests and treatments that chronically ill patients already know they need, such a mechanism could free up access for the genuine consultative needs associated with interpreting and applying new evidence, obtaining an objective opinion in relation to problem-solving, and weighing options where specific decisions must be taken. Instead of requiring that all transactions occur in the clinical office, regardless of whether a physical examination is required, an ideal system would permit ready access to phone or electronic consultation so that the time and energy of both clinicians and patients are managed efficiently. In this way, healthcare for chronic illness could shift its own orientation from a system characterized by "reimbursable moments" toward a more strategic system of care planning suited to that individual's particular stage within the chronic illness trajectory and the most pressing priorities with regard to expertise development and problem-solving consultation.

With structural adjustments such as these, we might begin to achieve more effective systems of chronic care delivery aligned with an agenda for enhancing health-promoting communications. Beyond the inherent moral imperative of providing the chronically ill with the best care possible, we now have a clear economic argument for ensuring that they develop the self-care management skills that they will require as early and as effectively as possible.4 From my perspective, the economic evidence is a powerful policy driver, catalyzing an opportunity for drawing upon what we have learned about chronic illness experience from the "insider" perspective as we design our healthcare delivery system reforms.

CONCLUSION

The tides of change are upon us with regard to systemic models for chronic illness...
care delivery, and the opportunities for meaningful reform are immense. Recognizing the inherent value of the insider perspective, we are well positioned to draw upon a generation of qualitatively derived empirical knowledge about chronic illness experience to advance a new and different approach to the problem of managing chronic disease within our societies. As we shift our sights from a provider-dependent orientation toward one of self-care management, we begin to fix our gaze upon the interactional intersection between patients and providers—the healthcare communications within which attitudes are conveyed, information exchanged, and problems articulated. From a consumer-based analysis derived from qualitative evidence, we can recognize the health-promotion potential of our patient-provider interactions, and take steps to ensure that we learn how to optimize these opportunities. Capitalizing on prevailing economic and policy priorities, we now have a window of opportunity to steer our systems toward what enlightened clinicians have always known to be the right approach—fostering chronic disease management and health promotion through enhanced attention to the patient-provider interface.

REFERENCES


