

Discourse

Chronic Disease Management: What Is the Concept?

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In 2002 the World Health Organization reported that chronic conditions accounted for 46% of the global burden of disease (World Health Organization, 2002). While chronic conditions have always been part of the human experience, advances in medicine and biomedical technologies have extended the expected lifespan for many chronic diseases and have transformed a number of previously fatal illnesses, such as HIV infection, into chronic conditions. An increasingly toxic nanomaterial environment may well be implicated in the proliferation of newer chronic conditions, such as fibromyalgia, as well as increased prevalence rates for well-established conditions, such as asthma. Thus, we now have more chronic conditions and are recognizing them more often.

As a result of the WHO report, health-care systems across the Western world have been scrambling to respond to the increasing awareness of the pervasiveness of chronic disease, by enacting service delivery and process reform. This has created a new appreciation for the extent to which our health-care systems are built upon an acute-care ideology that all but ignores the plight of the chronically ill. To the extent that they are precursors of devastating and costly health problems, chronic diseases must be recognized as appropriate and cost-effective points of intervention and support. There is clear evidence that our health-care systems can no longer afford their predilection for tertiary care innovation as the solution to society's health problems. Thus we are witnessing a renewed enthusiasm for a complete revision of health-service delivery.

A Welcome Shift

This is a welcome sea change for nurses and others who for decades have been qualitatively documenting the experience of persons with chronic illness. An expanding body of "health-care consumer" research has faithfully reported the impact of an acute-care ideology on the social experience and health-care journey of a patient population increasingly

afflicted with chronic conditions. It has surfaced the tension that exists between what our systems offer and what patients think they need (Thorne, Paterson, Acorn et al., 2002; Thorne & Paterson, 2000).

This body of research has revealed to us just how poorly the structures and systems originally designed to meet the needs of the urgent and episodic fare in preventing people from having to use them. It has oriented us towards the need to rethink who holds expertise and within which aspects of the illness constellation, to reconsider the optimal timing and orientation of service delivery, and to critically reflect upon the relevance of population-based evidence for handling complex “n of one” living problems. In so doing, it has alerted us to the extent to which our professional turf battles, embedded reimbursement schemes, and misplaced scientific logic compromise access to the resources and supports that optimize the ability of the chronically ill to live well and independently despite their conditions (Thorne, 1993).

The plight of those with chronic disease has come to epitomize the essential mismatch, within our existing systems, between health-service investment and the social reality of illness. Consequently, reconfiguring health-service delivery from an underlying acute-care philosophy to something that more effectively addresses the chronic illness context has become the focus of massive system-level change, including examination of an array of options for more efficient and effective deployment of scarce resources (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). As we reflect on these various new service models, careful attention to the language signifiers may provide cues to the ideological slant that each represents in its consideration of the fundamental nature of the problem of chronic disease and what we ought to be doing about it.

Language and Conceptualization

The Chronic Disease Management, or CDM, concept underpinning many initiatives to redesign the current system typically references two prominent approaches. Chronic Disease Self-Management, aligned with the work of Kate Lorig and colleagues, references a system of supports designed to better inform health professionals as to what they have to offer and educate patients as to their responsibility to understand and cope with their own disease (Holman & Lorig, 2004; Lorig et al., 1999, 2001). The Chronic Care Model proposed by Ed Wagner and colleagues is a population-based comprehensive approach to aligning health-care encounters within redesigned delivery systems (Bodenheimer, Wagner, & Grumbach, 2002; Gately, Rogers, & Sanders, 2007; Wagner et al., 2001). Prioritizing what are known as “frequent flyers” — those individuals with preventable and costly sequellae of chronic disease — this latter approach

focuses on biomarkers as the best form of population-based evidence of system effectiveness.

These conceptualizations contain elements of inspired insight, and are presented in a form that is palatable to health-policy planners. Change agents such as Lorig and Wagner have helped to establish an evidence basis for system reform without limiting their scope to that which can be fully grounded in hard evidence. While neither of these approaches explicitly acknowledges qualitative work on patient experience with chronic illness, they seem informed by much that this body of scholarship has systematically surfaced. Thus they recognize that the processes associated with such elements as access, referral, prescriptive authority, and gatekeeping — all designed to accommodate acute and episodic illness — have become barriers to obtaining appropriate health services even among the most insightful, articulate, and competent of chronically ill patients.

These models, often collectively referred to as CDM, have been extremely helpful in illustrating, at the system level, that the vast majority of chronic disease management occurs not in a 15-minute medical visit but, rather, in the hours, days, months, and years that patients and families invest in their own health and well-being. They have forced a kind of engagement that is different from the tradition of giving “orders” and expecting the patient to “comply.” (I use the word *comply* instead of the currently more popular *adhere*, since the latter is simply a polite way of continuing to entrench the idea that population-based data and professional perspectives are inherently the optimal approach to a chronic illness problem.) Rather than gloss over the expertise imbalance with a trick of language, CDM forces us to respectfully acknowledge that the diseased body in question is entrusted to the care of the patient (and his or her family/community) rather than being the rightful property of the health-care system. So this shift has countless advantages, and for the most part it is orienting us in a highly appropriate direction — towards meaningful change in how we do business with regard to the delivery of chronic care.

But Will It Solve the Problem?

Despite these significant advantages, a population-based, CDM approach is not without limitations (Gately et al., 2007). However, much of the effort to date has been focused on “selling” CDM rather than on entertaining thoughtful critique. As one step towards opening up a space for constructive dialogue on possible “course changes” along the implementation journey, I turn to insights from the qualitatively derived evidence of what patients experience. In my opinion, these serve as a primary

source for interpreting what CDM will and will not resolve within the mandate of optimally serving society.

Most worrisome to me is the fact that the CDM model still views the crux of the problem as the disease, implying the goal of bringing the best of what science has to offer to bear in controlling the effects and progression of organ system malfunction. This “disease” orientation inherently privileges professional expertise in naming, defining, and theorizing what is relevant about a particular condition. Few would deny that science has produced enormous gains in understanding and ameliorating untoward aspects of certain chronic diseases. Relatively rare, however, are instances of medical prescription providing meaningful benefit in isolation from a comprehensive and coherent plan for “living with” the illness. By focusing on diseases, we continue to misrepresent the fundamental locus of authority, which is the patient rather than the professional. When we blind ourselves to the context in which lives that include chronic conditions are lived, we limit the benefits we are able to realize from this major investment in system redesign.

The focus on “management” signals a shift away from the dominant notion of “treatment,” in which the diseased organ is the singular focus, implying a search for a medical intervention to resolve it. Because they are by definition incurable, chronic diseases have long been a source of frustration for the health-care system. Reframing the problem as one of management shifts the intended outcome from “cure” to stewardship. It therefore extends the frame of reference from short to long term and also challenges us to consider outcomes that become increasingly difficult to isolate from their embedded and dynamic social as well as pathophysiological environments.

Despite this more enlightened orientation, the notion of management remains slippery when it obscures clarity as to who is actually doing the managing — the patient or the professional. While nursing has paid considerable attention to the ongoing work of the individuals and families who live with chronic conditions, system planners have demonstrated little capacity to conceptualize the nature of that work or the mechanisms by which it is facilitated or hindered in producing optimal outcomes over time. In the context of exponentially rising health-care costs, there is a natural resistance within the health-policy community to blur the edges of what constitutes the responsibility of the formal health sector within society. Therefore, chronic illness management systems have focused on the oversight and monitoring of chronic disease biomarkers by professionals — despite an increasing recognition that known biomarkers are a mere drop in the bucket in the larger scheme of relevant indicators — rather than on the complexities of the everyday life of the person affected by chronic disease. In some contexts, this emphasis on the

professional contribution to the messy constellation of what accounts for living well with chronic disease has been recognized as problematic. In response, language around “shared care,” “patient self-management support,” or “patient as partner” has emerged to justify initiatives that begin to shift that balance of attention.

Expanding the Conceptualization

In our attempts to understand the challenge from the perspective of the patient rather than the professional, my colleagues and I inductively generated the concept of Everyday Self-Care Decision-Making to capture what is involved in living daily with a diversity of chronic conditions (Paterson & Thorne, 2000; Thorne, Paterson, & Russell, 2003). This conceptual approach reflects the core idea that living as well as possible with a chronic condition requires an increasingly sophisticated and integrated capacity to weigh alternatives, make choices, attend to evidence, listen to one’s unique body cues, and develop an individualized system by which to know whether one is doing better or worse over time. It orients us to the attention required to handle disease-related matters within the inherent complexity of relational and contextual changes and challenges over the life trajectory.

From the everyday self-care decision-making angle of vision, disease management often constitutes a minor element within the context of living what for most of us is an incredibly complex life. Although the facts and principles underlying medical management are important and useful, they tend to be the focus for relatively short periods of time in the scheme of things, taking prominence at the time of initial diagnosis and during changing conditions but reverting to “background noise” for much of one’s everyday existence (Paterson, 2004). And as one might imagine, the competencies required to consult with a patient around disease management tend to be quite different from those required to support healthy living on an ongoing basis.

Forms of disease management based on mass population tend to focus on patients with the most serious problems understanding the basic principles of healthy living and adhering to medical recommendations. They are careful to emphasize doing things correctly (i.e., following orders) rather than engaging in experimentation or creative variation. While they may begin to address the needs of the least thoughtful or reliable of patients, they paradoxically risk alienating or misleading those with the greatest potential to do well despite their disease.

Studies with patients who have become expert in everyday self-care decision-making reveal that they do not achieve that expertise through compliance with recommendations or adherence to standardized approaches.

Rather, those who attain expertise figure out at some point along the way that it is their life that will be lived and they must become the ultimate authority on that life. They learn through informed strategic experimentation what their own limits are, identify their own unique disease activity markers, and find creative ways to minimize the extent to which disease management characterizes their everyday life. When conditions change or symptoms worsen, experts may rapidly shift to intense preoccupation with their illness, but for the most part relegate disease management to what become patterned practices and health habits that enable optimal wellness.

Patients on the road to such expertise often experiment with complementary (non-Western) therapeutic approaches, since symptomatic relief and feelings of wellness are their key objectives (Thorne, Paterson, Russell, & Schultz, 2002). They become quite comfortable disregarding scientific critique about the lack of evidence, since they understand both the irrationality of assuming that population norms match individual cases and the politics of what warrants a clinical trial (generally, that which is predictably lucrative to BigPharma, rather than that which can be grown in one's backyard). They often express frustration with the current care delivery system, noting the complexity added to their lives by such dysfunctions as waiting times, controlled prescriptive authority, and the politics of referral, and recognizing that these disjunctures often extend beyond the nuisance factor to become iatrogenic health hazards. Emerging and established experts are often somewhat alienated from that system, using it as they must and manipulating it when they can.

Although the CDM movement orients certain elements to conventional care systems in recognition of the dynamics of chronic illness, for the most part it continues to position the problem of chronic illness squarely in the domain of population-oriented, evidence-based service delivery. Thus, it may ignore some aspects of what expert chronically ill patients have been telling us for some time, and thereby runs the risk of failing. As a population-based approach, CDM strives towards system standardization; in contrast, expert patients tell us quite convincingly that what works best for the average patient will not work for all. CDM bases its outcome evidence on discrete measures, while expert patients know that individual lives and physiologies have their own unique manifestations and that biomarkers reflect only one measurement point in an evolving kaleidoscope of what constitutes both disease progression and effective living. It claims a multidisciplinary team approach, while expert patients know that this approach remains dominated by a medicalized perspective on what is truly needed and warranted within a system designed to serve health. Indeed it rarely extends the idea of the health-care team beyond conventional practitioners to a truly integrated approach to support a new way of living.

Conclusion

What we have learned from the study of expert patients alerts us to a looming problem worthy of our attention. Although the current philosophy of CDM may be efficient and effective in producing baseline disease management competence, it can detract from our ability to support the acquisition of genuine expertise in living with a chronic disease. By focusing on systematic services for the newly diagnosed and detection of the most obstinate and recalcitrant of patients, it may hinder the development of genuine patient expertise within this complex living challenge.

Nursing seems ideally positioned to adopt the perspective of expert patients that there is no singular way to live well with a chronic condition, that the learning process is complex and incremental, and that the role of medical science must be contextualized within an understanding of the living that is taking place. Because our discipline inherently operates in the world of generalized knowledge applied to unique and particular individual cases, we sustain a foundational conviction of the value of individualized relational practice in meaningful intervention, even as we acknowledge the challenge of creating hard evidence that it works. We know that every patient we encounter lives within a unique social and material context that shapes both the diseases acquired and the manner in which he or she responds to them.

Therefore, as we embrace the CDM movement, it is incumbent upon us to remain vigilant to the inherent tension between standardization and individualization, between people and systems. It seems prudent to look to informed and expert patients as a vital source of knowledge about how to achieve optimal individual results across a diversity of patient contexts and conditions. We must also be on guard against the allure of quick fixes such as CDM measures and “patient navigators,” in lieu of true health-system reforms.

The angle of vision that nursing has always brought to chronic illness is one whose time has come. As we move forward in this new wave of thinking about chronic disease, we must clearly demonstrate the difference that is made when nurses are well positioned to engage in the ongoing, dynamic, and proactive care of which we are capable. Nursing research has a pivotal role to play in informing the alignment of management approaches with these complexities of human experience. Armed with such knowledge, we can ensure that the problem of chronic illness is universally conceptualized not simply as an organ system to be monitored or a physiological process to be contained, but as a life to be fully lived.

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