

Review

Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm

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Received 13 October 2003; received in revised form 3 April 2004; accepted 17 May 2004

Abstract

Diabetes is a self-managed illness in which the decisions most affecting the health and well being of patients are made by the patients themselves. Many of these decisions involve routine activities of daily living (e.g., nutrition, physical activity). Effective diabetes care requires patients and health care professionals to collaborate in the development of self-management plans that integrate the clinical expertise of health care professionals with the concerns, priorities and resources of the patient. Collaborative diabetes care requires a new “empowerment” paradigm that involves a fundamental redefinition of roles and relationships of health care professionals and patients. The challenges of fostering the adoption of a new paradigm differ substantially from those associated with the introduction of new technology. Those challenges are discussed in this paper.

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Keywords: Diabetes care; Collaborative care; Patient empowerment; Paradigms

1. Introduction

Thomas Kuhn popularized the term *paradigm* in his classic work “The Structure of Scientific Revolutions” [1]. Kuhn defines a paradigm as a worldview that is essentially an interrelated collection of beliefs shared by scientists (for our purposes, health care professionals), i.e., a set of agreements about how problems are to be understood. Kuhn recognized that the way problems are defined, in large part, determines the nature of the strategies designed to solve them. In that work, Kuhn offered several insights into the nature of paradigms. For example, Kuhn noted that:

1. The underlying beliefs of the current or dominant paradigm form the epistemological foundation of professional education.
2. The beliefs learned during professional education exert a “deep hold” on the student’s mind.

3. New paradigms are strongly resisted by the professional community.
4. A paradigm shift “resembles a Gestalt shift, a perceptual transformation.”

This essay is based on our insights and experiences over the last 16 years while introducing and promoting the patient empowerment approach to diabetes care. It represents knowledge acquired phenomenologically, rather than empirically, which is consistent with Kuhn’s assertion (#4 above) that paradigm shifts occur as “Ah ha!” moments rather than through logic or empirical study. Our experience is limited to care of diabetes, and we will confine our discussion to that experience, although we believe that the issues and insights presented in this paper apply to a variety of chronic diseases.

During our 20 years on the faculty of medical and nursing schools, we have observed that health care professionals are socialized to a paradigm (Kuhn #1 above) derived from the treatment of acute illnesses [2,3]. In the acute-care system, patients surrender varying amounts of control to health care

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professionals in order to gain the expertise, technology, and compassion available from health care professionals. In this acute-care paradigm, health care providers take responsibility for solving their patients' problems. This feeling of responsibility leaves many health care professionals feeling frustrated when their patients with diabetes do not follow their self-care recommendations.

More than 25 years of behavioral research in diabetes resulting in hundreds of published studies focusing on the "problem of noncompliance/non-adherence" have failed to solve the problem [4]. A cursory Medline search produced over 1450 citations addressing the issue of noncompliance in diabetes, reflecting a continuing search for new knowledge and strategies that will solve the problem of patient noncompliance. Although the issue of patient noncompliance has been addressed frequently, the assumptions embedded in the traditional approach (the acute-care paradigm) have seldom been called into question [5,6] (Kuhn #3 above). Attempts to address noncompliance assume that:

1. noncompliance is a valid and useful construct for understanding the behavior of patients,
2. the patient is the source of the problem, and
3. the solution to the problem of noncompliance is for patients to defer to the expertise (and authority derived from it) of health care professionals and follow the recommendations they have been given to change their behavior.

Viewing diabetes care and education as an effort to improve compliance, i.e., persuading patients to comply with the recommendations of health care professionals, often fosters conflict and tension [7–10]. Patients often feel judged and blamed for not following the advice given by health care professionals, even when that advice involves lifestyle changes that are very difficult to implement and sustain [8–10]. It has become increasingly evident that the acute-care paradigm does not work for the majority of patients with diabetes because its underlying assumptions do not fit the facts of diabetes self-management. Treating diabetes within the acute-care paradigm can make problems worse rather than better because in their efforts to control the patient's diabetes, many health care professionals are perceived by patients as trying to control their lives [11]. These attempts at control are often felt as criticism and/or an encroachment on the patient's personal autonomy. For many patients "noncompliance" is an attempt to maintain and reaffirm control over their own lives. Ironically, patients can harm themselves physically in order to protect themselves psychologically [7].

Others and we have advocated the adoption of a new paradigm that is based on the fundamental differences between the treatment of a self-managed chronic illness such as diabetes and the treatment of acute illnesses [12–35]. People with diabetes provide the great majority of their health care themselves, much of which is interwoven into the

fabric of their daily lives. Diabetes self-management calls for a collaborative approach in which health care professionals and patients evaluate self-management decisions in terms of how well they are helping patients to achieve their own health care goals [12–35].

2. Barriers to the adoption of the empowerment paradigm

We have learned that recognizing the need for a new empowerment paradigm is only the first step on the long journey to its adoption. Below is a description of some of the barriers to the adoption of the empowerment paradigm in diabetes that we have experienced over the course of our work.

2.1. Old paradigms trump new techniques

For many years we have written books and articles [12–19,32–35] in an attempt to elucidate empowerment as a paradigm, i.e., a philosophy or overall approach [13] to diabetes care. Over time an increasing number of health care professionals, especially diabetes educators, became interested in the empowerment philosophy and the data supporting its utility [36]. It became clear to us that these health care professionals needed a way to operationalize the empowerment paradigm with individual patients. In response to this need, we adapted a person-centered approach from counseling psychology [37–41] to the needs and realities of diabetes education. We then developed a 3-day training program [42] to provide educators with a set of skills and strategies that were consistent with the empowerment paradigm and were well suited to diabetes care and education. During the training programs, educators practiced the empowerment-counseling model and reviewed videotapes of their practice sessions.

While reviewing the videotapes of practice sessions, we realized that although most of the educators agreed with the empowerment approach intellectually, they had not changed their underlying behavior inherent to the acute-care paradigm, i.e., they still felt responsible for "getting" patients to follow the recommendations they had been given by their physician. The educators had taken a step-by-step empowerment-based approach to facilitating self-directed behavior change and converted it (unconsciously) into a technique for improving patient compliance. The traditional acute-care paradigm had such a deep hold (Kuhn #2 above) that they applied it almost instinctively.

This observation provided one of our most important insights about the relationship between paradigms to practice, i.e., no matter what educational/counseling technique is used; it becomes an expression of the health care professional's underlying philosophy of care. We have encountered many "practical" health care professionals who believe that a paradigm or philosophy of care is abstract

and therefore largely irrelevant. Our experience indicates that quite the opposite is true.

2.2. Paradigms are powerful but often invisible

One of the most challenging aspects of fostering the adoption of a new paradigm is that the paradigms learned by health care professionals during their training exert a strong influence on how they interact with patients. Yet, for many of them their paradigm (and its influence) is so embedded in their consciousness that they are unaware of its existence. They do not realize that they were socialized to a paradigm during their professional education, i.e., they adopted the worldview of their mentors and role models without understanding a paradigm is one view of reality not reality itself (Kuhn #2 above). They learned what it “means” to be a health care professional without ever considering the fact that alternative definitions for the roles and responsibilities of health care professionals can and do exist. Their paradigm becomes part of their professional (and often personal) identity. Once in practice they do not see their paradigm at work but rather see their work through the paradigm.

Once adopted, a paradigm can have such a deep hold (Kuhn #2 above) on us that it acts like a psychological “eye” with which we see the world but which we cannot see. For example, after giving a presentation about empowerment, it is not uncommon for a health care professional in the audience to ask “but will it improve patient compliance?” The acute-care paradigm is not only embedded in the minds of individual health care professionals, but is also the basis for most of the policies and procedures of health care organizations and third-party payers: for example, reimbursement for care is based on the treatment of acute conditions and often does not cover services necessary for effective diabetes care such as dietary counseling.

2.3. Paradigm shifts can take a generation

Even today medical schools continue to socialize physicians to the acute-illness approach to care [2,3] (Kuhn #1 above). Although some physicians and health care systems have changed, most have not. The rate of change may increase as more health care professionals and researchers recognize the need for a fundamentally different approach to the care of diabetes and other chronic illnesses [43]. Nonetheless, the process will take longer than the introduction of a new drug or technical innovation. We have encountered a number of health care professionals who are employing a collaborative approach to diabetes care but are frustrated by a lack of support from their colleagues and/or health care systems. This makes their work more challenging because while the adoption of a new empowerment paradigm takes time, the frustrations they feel in trying to provide collaborative diabetes care in a context dominated by the acute-care paradigm are immediate and tangible.

2.4. Empowerment as “politically correct” (PC)

We have encountered health care professionals who are skeptical about the empowerment approach to care because they view it as the latest “politically correct” terminology and/or a sociopolitical effort to wrest the control of diabetes care from physicians and other health care professionals. This view is incorrect. The empowerment approach simply recognizes that patients are already in control of the most important diabetes management decisions. Even though these facts are virtually self-evident they go unseen because of the deep hold of the acute-care paradigm. When we acknowledge that the control of diabetes self-management rests with the patient, it follows logically that the responsibility for making self-management decisions and living with their consequences rests with our patients as well. When we first began presenting the empowerment approach to collaborative diabetes care, it was not uncommon for health care professionals to say to us “You’re asking us to give up control.” The illusion that health care professionals control diabetes care derives from “looking” at the facts of diabetes self-management through the lens of the acute-care paradigm. The persistence of this illusion is testimony to the power of paradigms. The empowerment approach requires a change from feeling responsible *for* patients to feeling responsible *to* patients. This means acting as collaborators who provide patients with the information, expertise and support to make the best possible diabetes self-management decisions based on the patient’s own health priorities and goals. This view of diabetes self-management is based on the reality of diabetes self-management, not on a sociopolitical agenda for change. Nonetheless, in our experience the patient empowerment paradigm is often perceived as an assault on deeply imbedded professional roles and responsibilities (Kuhn #3 above).

2.5. The medical industrial model

Health care professionals are under increasing pressure to become more efficient [44]. The physicians, nurses, and dietitians with whom we interact on a daily basis tell us that they are being asked to see more patients in less time, practice evidence-based medicine and evaluate measurable health outcomes. Consequently, many health care professionals are concerned that shifting to an empowerment paradigm will “take too much time.” Thus, it is critical to demonstrate through research that patient-centered, relationship-oriented, collaborative care can improve outcomes without significantly extending the time required for patient visits [45]. We have and will continue to develop interventions based on patient empowerment whose impact can be scientifically evaluated in terms of measurable outcomes [36,42,46].

However, these efforts in and of themselves cannot provide an evaluation of the underlying empowerment paradigm because a paradigm is a worldview or philosophy of

care and cannot be evaluated scientifically. While programs and strategies arising from a paradigm can and should be evaluated, we should note that valuing only the tangible, measurable “products” of medicine could contribute to a dehumanization of the health care system, which can ultimately fail to nurture either patients or health care professionals.

3. Conclusion

3.1. Reflective practice

We encourage health care professionals to reflect on their experience with the assumptions underlying the acute-care paradigm when applied to diabetes. Such reflection can create the psychological “space” necessary for the adoption of a new paradigm truly appropriate to the reality of diabetes care. A useful way to actually “see” the existing acute-care paradigm is to employ a psychological “mirror,” i.e., to reflect on care behavior in an attempt to understand our paradigm/philosophy of care and the ways in which it shapes our interactions with patients. Those interested in this process could answer the following questions:

1. Do I have the right to expect my patients to defer to my judgment about how they conduct their daily lives to manage their diabetes?
2. Do I feel responsible for my patients’ level of blood glucose control?
3. Do I find myself trying to persuade my patients to follow my advice?
4. Do I feel frustrated if my patients do not follow my recommendations?
5. Do I feel like my “noncompliant” patients are undermining my effectiveness?

In our experience such reflective practice can and has led to paradigm shifts. Fostering the kind of discourse among our colleagues that subjects the assumptions embedded in the acute-care paradigm to critical examination is an available and potentially potent method to stimulate the kind of perceptual shift (Kuhn #4 above) that results in the adoption of a new paradigm.

3.2. Taking responsibility

We believe that health care professionals who agree with and value the empowerment paradigm have a responsibility to become advocates for patient-centered collaborative diabetes care. This often means addressing resistance from supervisors and systems wedded to the acute-care model. No single one of us can bring about a paradigm shift, but we can accept responsibility for working toward that end. Trying to provide diabetes care in an acute-care paradigm diminishes the adequacy of the care being received by patients. Because

it is an attempt to do the impossible, i.e., be responsible for what is not in our control, the acute-care approach frustrates and limits the effectiveness of health care professionals as well. Seeing the futility of applying the acute-care approach to diabetes care liberates the health care professional to consider the adoption of an empowerment paradigm that is grounded in the reality of diabetes self-management. It has been our experience that the adoption of the collaborative care approach to diabetes self-management empowers health care professionals as much as it does patients.

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