Advances in Patient Education

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For Elisabeth A. Johnson, "Bibby," and for Freddie,
both interesting and faithful companions

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Preface

I have long been committed to the rights of patients to freely obtain unbiased education about their health conditions. Lack of general availability of these services and lack of attention to their quality and freedom from conflict of interest, represent a lack of respect for persons and thus an ethical violation when it occurs. While especially a problem for groups such as women, whose traditional oppression was and is carried out in part through medical teachings, the same principles apply to all patients and families. And clinical decisions that restrict access to quality patient education services represent a form of unexamined rationing.

Today, much turmoil exists in patient education, which may eventually move us closer to meeting ethical responsibilities noted above. Because this field is so far flung with no cohesive organization, advances are difficult to ascertain. This book focuses on seven advances; I have no doubt missed others. Advances are evident in the very basic underpinnings of patient education, such as philosophy, learning, and measurement of need for and outcomes from educational services. Other advances are also clear (self-management preparation for chronic disease) or emerging (mental health psychoeducation and education related to ethically sensitive areas). And some (delivery of patient education) are perennially shifting with the organization of health services and incorporation of new technology.

This book documents and interprets these developments. It takes advantage of the many reviews and meta-analyses that exist and frames their findings in a broader context. It is my hope that this kind of integrative analysis of new advances in patient education will be necessary every 5 years or so, always with an eye to assessing movement toward meeting the standards of quality and availability our patients deserve.

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Chapter 1

Status of Patient Education and Its Philosophical Base

The beginning of the 21st century is a fine time to take stock of the incredible progress that has occurred in patient education in the past 30 years. Presumably swept along by social currents of antipaternalism, its rise should be viewed incontrovertibly as a means to create better outcomes for individuals, families, and society, and morally as evidence of respect for persons. At the same time it remains marginal. While now seen by regulatory agencies as essential for quality, standards for patient education are generally not enforced and not fully internalized by the medical community and thus the payment system.

Because the change has been both so fast and so slow, it is important to document the cutting edge as well as the failures in use of this therapy, which can also be seen as a social and political movement. This book presents an interpretation of the status of patient education, considering its philosophical base and recent historical evolution, issues currently engaging the field, new insights in the fields of learning and human development, the evolution of areas of practice, and development of methods to ensure its validity and quality. First, a few broad brush perspectives.

Each cultural institution has an educational component. Because health has been so dominated by a limited medical model, the educational component has been not only dramatically underdeveloped but actually thwarted by medicine's total focus on immediate enforcement of compliance with a prescribed regimen. While this position is still apparently sustainable politically, it does not pass muster morally. It does not meet standards of patient autonomy and provider beneficence. Issues of justice are very difficult in the health care arena; suffice it to say that availability and quality of patient education must be at least as good as other elements of care for a particular population. And because it is the key to being able to make use of health care resources, for vulnerable and oppressed patient populations, patient education must be different from and even better than other elements of care.

There is still no vision of how educational services that are effective, patient-centered, and easily available would transform the health care system in many ways. People would feel free to choose education in all the ways necessary to reach their own life goals, be free of physician oversight and control except as negotiated, and control and cope with their illnesses so that their illnesses fade into the background. In addition, lack of educational services for patients is a major source of medical errors, because people who do not seek professional care when they should unwittingly commit errors when carrying out self-care regimens, and they do not catch errors made by professionals.

As further evidence of the marginality of patient education, we are unwilling to invest in it even in instances when its benefits are as good as or better than other therapies more traditionally reimbursed, such as pharmacologic treatments. In addition, we still do not think of educational progress longitudinally as we do diagnosis and treatment of disease, even though "lay" models and readiness to adopt a health behavior (which change over time) are known to be important determinants of response to a disease. And we are far from believing that health care ought to be a learning experience, ensuring satisfaction and a feeling of confidence in whatever self-care is important.

The field still lacks a viable economic model. Several arrangements have been tried and have not been significantly sustained. First, some managed care organizations have adopted chronic disease management programs, which have shown long-term savings over the cost of education. But the churn of subscribers in and out of managed care organizations means that those who have been educated are disenrolled before the savings are realized. Second, although many surveys show patients are dissatisfied with the amount of information they receive about their health problems, a patient-oriented, available-when-they're-ready business model has not been developed. Thus, it is difficult to determine what patient demand there might be for direct payment for educational services or for pressuring insurers to cover these services. Third, free Internet access to health information and support and chat groups has proven helpful but limited by variable information quality and by its general disorganization. People frequently need the help of a teacher to organize and make sense of information as well as to gain skills. Fourth, pharmaceutical companies' investment has been in direct-to-consumer marketing rather than in services that ensure people will use their products effectively. Finally, unlike some health care services, a global market in patient education services seems to be stymied both by local cultural and practice differences and by lack of a universal set of outcomes and measures to reliably assess them.

Some (Neuhauser, 2003) believe that personal empowerment will be the third health care revolution—one that is just starting, both for ideological and economic reasons. Economically, the first revolution was cost cutting, the second disease management. The personal empowerment revolution involves patients and families learning to care for themselves. Because nurses provide the services that prepare patients for self-care, this movement will reduce reliance on physicians.

PHILOSOPHICAL BASE OF PATIENT EDUCATION

The language of patient education continues to privilege the provider's world and marginalize the patient's. Because they are legitimized by society and law as the health experts, doctors make limited attempts to enter the patient's conceptual world. Professionals remain the legitimate gatekeepers to all health services. The ideal patient is both compliant and self-reliant but always judged by standards set by experts. The majority of individuals with a chronic illness develop self-management strategies that would be labeled as noncompliant by health care professionals because they alter the regimen and include alternative therapies. Many health professionals do not believe that patients have the ability to make decisions on their own behalf (Wilson, 2001).

Bioethics has championed the right of patients to make a choice (Benner, 2003). It has ignored other life goods such as being understood and given the tools to reconstruct one's life. It has also focused on ethical dilemmas precipitated by technology, with far less emphasis (except possibly for feminists) on ethical analysis of low-tech processes of care considered to be "normal."

Occasionally, one finds startling examples of such analysis including the one by Mardorossian (2003) describing childbirth education and laboring from a feminist perspective. This author takes as her starting point patient experience of being taught natural childbirth techniques in childbirth education and realizing too late that these techniques have little effect on pain. She believes that a high percentage of couples give up on the pain control during labor. The "husband-as-coach," a rarely successful process, succeeds in passing responsibility for the failure of the natural childbirth model on to the couple. According to Mardorossian, calling this function "coaching" puts labor into a male perspective and frames it as a sporting event. Because he is not competent in carrying out the coach role or in controlling labor pain, the husband is unable to live up to the norms of controlling masculinity prescribed by the system. Interpersonal conflicts between the partners ensue as a result of unfulfilled and unrealistic expectations raised in childbirth class.

Other misleading information is thought to be common, for example, in teaching patients about risk factors. A risk factor is statistically associated with the presence of disease. Correcting it may sometimes, but not always, prevent or cure disease. The probabilities of epidemiology do not allow us to tell whether the person in front of us is one in the group concerned, who will develop the illness. Moreover, we cannot always trust that correction of an assumed risk factor will be safe and harmless. Practitioners who imply to a patient that his risk of stroke will change from 100% to 0% if his blood pressure is reduced would be advising on false premises (Hollnagel & Malterud, 2000).

These kinds of critiques of current practice are no doubt encouraged by serious self-examination of the philosophy of care. With strong earlier roots but accelerating interest in the past decade, philosophies of patient-centered and family-centered care are gaining ascendance. While these philosophies represent ideals with various definitions and no clear sense of how frequently they are translated into practice, both place patient education, patient self-management, and family involvement front and center.

Patient-centeredness can refer to patients' perceptions of how understood they feel; the similarity of professionals' and patients' beliefs about the illness, treatment, and patient concerns; or a jointly negotiated and agreed upon plan between health professional and patient with the patient given resources needed to achieve these goals, such as information and skills. Studies testing providers' ability to elicit and discuss patients' beliefs and ability to activate patients to take control in management of their illnesses find both of these strategies associated with patient adherence to the regimen (Michie, Miles, & Weinman, 2003). Other authors (Stewart et al., 2000) found patient-centered practice to be associated with less discomfort and concern, better mental health, and fewer diagnostic tests and referrals. Patients' perception of finding common ground with the provider was more strongly associated with positive outcomes than were patients' perceptions about exploring the illness experience with the provider.

Family-centered care views a patient's family as the unit to be cared for, recognizing needs of its members as well as the important role they play during a patient's illness. Patients have a choice to include their families or not. This philosophy is most likely encountered in pediatric and critical care settings. During a critical illness, families benefit from guidance and structure to help them cope, and they need information, reassurance, support, and the ability to be near the patient. The American Academy of Pediatrics (2003) policy statement on family-centered care is based on the understanding that the family is the child's primary source of strength and support and that its role is promoting health and well-being of its children. This statement acknowledges numerous studies showing improved outcomes and efficiency of care provided with a family-centered model, such as family presence during health care procedures yielding decreased anxiety for child and parent, and improved follow-through when the plan of care is developed collaboratively with families.

Both patient- and family-centered care philosophies take the patient's point of view on health and health care. Evaluations of medical effectiveness occur in patients' lives rather than in doctors' hospitals. Subjective health measures are as predictive of mortality and of health care utilization as are the most objective health measures. Sullivan (2003) notes how hard fought the battle to bring patient subjectivity into medical decision-making has been. Initially, bioethics forced medicine to recognize patients as autonomous beings who are entitled to choose among medical treatments. But the battle is still in opening stages as patients need real choices that represent their needs, not a choice between two physician-defined options.

GOALS OF PATIENT EDUCATION

The overriding goal of patient education should be to support the patient's autonomous decision-making, not (as it has been conceptualized) to get patients to follow doctor's orders. This represents a dramatic shift of goals and requires that health professionals who teach patients are free from a requirement to merely support the physician's orders. Truly patient-centered education may be critical of physician and institutional performance, limitations in medical knowledge, and rationing disguised as clinical judgments. Even more important, true patient autonomy requires creating new options to meet patient needs, not just as is now frequently the case, having the right to refuse a treatment option. As much as possible, patients must have a range of significant options from which to choose. It is important to note that developing and supporting patient autonomy goes well beyond informed consent and infuses every interaction with the patient.

An autonomous person makes decisions with a sense of control, creating and evaluating options and reflecting on how values, preferences, attitudes, and beliefs function in the final decision. Perhaps the view of autonomy most compatible with patient education is Diana Meyers's (1989) theory of autonomy competency—a cluster of different skills and capacities of self-discovery, self-direction, and self-definition. The range of skills may be more or less developed, exercised, and coordinated.

Certain kinds of socialization encourage the development of some skills that make up autonomy competence at the expense of others. For example, traditional gender socialization compromises women's capacity to achieve full autonomy in several areas of life and so can interfere with women's ability to trust themselves to choose and act in ways that are consistent with their goals and values. An example of an oppressive social norm is that women alone are responsible for what happens during pregnancy (Mackenzie & Stoljar, 2000; McLeod, 2002). If patient education accepts and assumes that norm, it can add to oppression and diminish patient autonomy. Another example of an oppressive norm is denial of patients' bodily knowledge as legitimate clinical evidence. Such can be the pattern for all groups that are not socially dominant.

Ignorance is a primary obstacle to autonomy, and clinicians and health care systems that allow ignorance crucial to patient self-care and decisions have contributed to oppression. If patients leave interactions with clinicians not feeling capable of making decisions on their own, their options are decreased. Their only remaining option is to defer to the clinicians' authority. Patients from lower socioeconomic classes get their primary medical identity from their disease; those from higher classes get to retain their identities. When a group is oppressed, society at large operates as if that group is less worthy and less competent than others and devalues its members, who in turn internalize these attitudes and accept society's devaluing of their ability to make appropriate choices. It takes energy to oppose oppression and is easier to "go along" or to experience the benefits of conforming to dominant stereotypes or interests (McLeod & Sherwin, 2000). This is an old, accepted pattern in health care.

The traditional framework of thought and interaction in health care is a setup for seriously limiting patient autonomy. The emphasis on disclosure and understanding of physician-recommended treatment limits what patients can believe about their health care options. So is the indirectly paternalistic practice of tailoring information provided, in order to ensure selection of what the health care expert considers to be the best choice for the patient (McLeod & Sherwin, 2000). The options are further diminished by lack of research on health problems of nondominant groups.

STRUCTURE OF PATIENT EDUCATION FUNCTIONS

Patient education is increasingly differentiated by goal and by population group. Preparation for self-management of chronic disease is the most clearly differentiated (see chapter 5), requiring the patient to develop significant clinical judgment and confidence. Though educational models exist for many common chronic diseases (diabetes, asthma, arthritis), mental illness has lagged (see chapter 7), presumably based on the assumption that disturbed thought patterns would preclude learning self-management skills. A second area is education to assist with event management—a diagnostic test, surgical or obstetrical intervention, and hospitalization. A third area is the screening and monitoring function, for everyday symptoms and for breast, testicular, or skin self-examinations. A fourth area is caregiving of others. A fifth is newly emerging—helping patients and families understand the basis for ethical decisions such as brain death, futility, randomization in research studies, or informed consent to participate (see chapter 3). In all of these areas, the goal of patient education is development of patient competence, confidence, and self-trust in their ability to carry out health behaviors consistent with their life plan.

Some populations have special needs: (a) those whose limited health literacy keeps them from being able to carry out ordinary health actions including taking medicine as directed; (b) those whose health problems have a strong genetic base, who must understand the partial technologies of genetic testing in order to make good decisions; (c) those whose cultural beliefs vary from assumptions of Western medicine; (d) those with memory loss or thought disorders, who need special help to learn; (e) those who have been oppressed by other individuals, groups, or society so that they do not trust their ability to make decisions; and (f) others such as children.

Some of these areas of patient education and special patient needs have long been recognized, and there is little new in the approach to them. Direction about how to deal with them may be found in standard texts in the field. Sections of this book document advances believed by the author to be on the cutting edge of new developments in patient education.

EDUCATION TO ASSIST WITH EVENT MANAGEMENT

Patient education associated with event management is common. Although there are few new approaches to this area of patient education, a cluster of studies document new health areas where education for event management should be routine and new, frequently theory-based, ways to meet goals.

Three studies of educational needs not routinely being met all fall within women's health. Women who during the second stage of labor had an operative delivery felt unprepared for this event. Many expressed difficulty fully understanding why they'd needed an operative delivery and suggested that either they or the baby had failed to achieve a normal delivery. Shortcomings in the postnatal review were not expressed immediately but emerged after discharge (Murphy, Pope, Frost, & Liebling, 2003).

A second example occurred with women whose confirmed pregnancies ended in miscarriage. Again, these women had poor recall and understanding of the event, needed and desired formal follow-up plans, and suffered from guilt and false assumptions, with significant anxiety symptoms (Wong, Crawford, Gask, & Grinyer, 2003). A final example is need for education to control anxiety before an event. In women undergoing cervical screening, 7% are diagnosed with an abnormality that requires follow-up examination with a colposcope, a large magnifying glass with a light source that allows detailed examination of the cervix. In the United Kingdom, many of these women had to wait for colposcopy and during this time were very distressed, assuming they had cancer because the physician did not explain dyskariosis. Precolposcopy educational sessions were established to deal with fears about the procedure itself and fears of cervical cancer (Neale, Pitts, Dunn, Hughes, & Redman, 2003).

Education during the preprocedure period was also used in Canadians waiting to undergo an elective coronary artery bypass graft (CABG). During this time the patient's functional and psychological status can deteriorate. A randomized controlled trial of 8 weeks of twice-a-week individualized physical training in a supervised setting, education, and reinforcement, as well as monthly nurse-initiated phone calls to answer questions and provide reassurance were compared with usual care. Median length of hospital stay after the surgery for patients in the intervention group was 1 day shorter than for those in the control condition (Arthur, Daniels, McKelvie, Hirsh, & Rush, 2000).

Preoperative preparation among first-time cardiac surgery patients used social learning theory, introducing vicarious experience with former patients exemplifying the active lives they were leading. The former patients were trained in how to provide this intervention. In this randomized controlled trial, patients receiving the experimental intervention had decreased anxiety, increased self-efficacy, and more self-reported activity of walking and climbing stairs than did patients in the usual care group (Parent & Fortin, 2000).

The literature is filled with other examples of needs for patient education associated with critical events. Hupcey and Zimmerman (2000) found significant need to know among critically ill patients during the event—information to help them grasp what was going on and a continual need to be oriented. Once extubated or in stable condition, most patients wanted information about what happened during “the time I lost.” Critically ill patients should be provided with continual reassurance and reorientation and asked what information they need about the intensive care unit (ICU) experience, repeated as often as they need it. The majority of patients undergoing first elective percutaneous coronary revascularization had unrealistic expectations about long-term benefits and were not aware of potential risks such as arterial injury, stroke, myocardial infarction, and death (Holmboe, Fiellin, Cusanelli, Remetz, & Krumholz, 2000).

Finally, older patients are at special risk of not understanding aftercare instructions. Those managing their pain at home after outpatient surgery consistently undertreated it and dealt with it by remaining immobile, which of course set them up for complications. More than a third did not remember receiving instructions, many said they’d had written instructions but had not read them, and even those who recalled instructions did not follow them to manage the pain (Kemper, 2002). And elderly postsurgical cancer patients transitioning from hospital to home had extensive information needs, ranging from concrete instructions about how to care for a surgical wound, to complex information about options for cancer treatment. In addition to instructions for self-care, patients and families needed clarification of the illness experience (Hughes, Hodgson, Muller, Robinson, & McCorkle, 2000).

Patients and families have been expected to give care without adequate resources including educational preparation for these roles. A 1998 survey of more than a thousand informal caregivers found more than half who helped with an activity of daily living such as feeding, bathing, using the toilet, or lifting said that they received no formal instruction for how to perform these tasks. Eighteen percent of caregivers who helped with medications reported that they received no instruction about how to do so; approximately 12% reported they were aware of a mistake they had made in the administration of a medication. One-third reported receiving no instruction on changing dressings or bandages or on the use of equipment. For years, we have conceptualized the caregiving experience as something that is inherently difficult and stressful, in part because of the lack of educational support for such roles. The Family Caregiver Support Act, implemented in 2001, may expand assistance for these individuals (Donelan et al., 2002).

The needs of these patient groups should be expected. What is startling is that these recent studies should find so many of the needs unmet.

SUMMARY

To date, patient education has been seen as supportive to medical treatment and not as an independent function, with the goal of respecting and developing patient autonomy. Development and enforcement of patient education standards are at very early stages because they are part of a vast power shift for who defines the goals of health care and who evaluates work of the medical establishment. Most other cultural institutions, each of which has an educational component parallel to patient education, have successfully made this transition to client-centeredness but continue to struggle with it.

Viewed through this new set of lenses, patient education can be seen as a central component of an exciting set of developments that promise to redefine health care and better serve patients, with a clear potential for increased efficiencies.

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