Advances in Patient Education

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Springer Publishing Company

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SPRINGER PUBLISHING COMPANY
NEW YORK

Springer Publishing Company, Inc.
11 W 42 Street
New York, NY 10036

Acquisitions Editor: Ruth Chasek
Production Editor: Sara Yoo
Cover design by Joanne Honigman

04 05 06 07 08 / 5 4 3 2 1

Library of Congress Cataloging-in-Publication Data

Redman, Barbara Klug.
Advances in patient education / Barbara K. Redman.—1st ed.
p. ; cm.
Includes bibliographical references.
ISBN 0-8261-2735-5
1. Patient education.
[DNLM: 1. Patient Education. 2. Delivery of Health Care. W 85 R318a 2004]
I. Title.
R727.4.R425 2004
615.5'071—dc22 2004015665

Printed in the United States of America by Maple-Vail Book Manufacturing Group.

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.

Barbara Klug Redman, PhD, RN, FAAN

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.

REFERENCES

American Academy of Pediatrics. (2003). Family-centered care and the pediatrician's role. *Pediatrics, 112,* 691–696.

Arthur, H. M., Daniels, C., McKelvie, R., Hirsh, J., & Rush, B. (2000). Effect of a preoperative intervention on preoperative and postoperative outcomes in low-risk patients awaiting elective coronary artery bypass graft surgery. *Annals of Internal Medicine, 133,* 253–262.

Benner, P. (2003). Finding the good behind the right. In F. G. Miller, J. C. Fletcher, & J. M. Humver (Eds.), *The nature and prospect of bioethics* (pp. 113–140). Totowa, NJ: Humana Press.

Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P. H. Levine, C., et al. (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs, 21*(4), 222–231.

Holmboe, E. S., Fiellin, D. A., Cusanelli, E., Remetz, M., & Krumholtz, H. M. (2000). Perceptions of benefit and risk of patients undergoing first-time elective percutaneous coronary revascularization. *Journal of General Internal Medicine, 15,* 632–637.

Hollnagel, H., & Malterud, K. (2000). From risk factors to health resources in medical practice. *Medicine, Health Care and Philosophy, 3,* 257–264.

Hughes, L. C., Hodgson, N. A., Muller, P., Robinson, L. A., & McCorkle, R. (2000). Information needs of elderly postsurgical cancer patients during the transition from hospital to home. *Journal of Nursing Scholarship, 32,* 25–30.

Hupcey, J. E., & Zimmerman, H. E. (2000). The need to know: Experiences of critically ill patients. *American Journal of Critical Care, 9,* 192–198.

Kemper, J. A. (2002). Pain management of older adults after discharge from outpatient surgery. *Pain Management Nursing, 3,* 141–153.

Mackenzie, C., & Stoljar, N. (2000). Autonomy refigured. In C. Mackenzie & N. Stoljar (Eds.), *Relational autonomy* (pp. 3–31). New York: Oxford University Press.

Mardorossian, C. M. (2003). Laboring women, coaching men: Masculinity and childbirth education in the contemporary United States. *Hypatia, 18,* 113–134.

McLeod, C. (2002). *Self-trust and reproductive autonomy.* Boston: Massachusetts Institute of Technology.

McLeod, C., & Sherwin, S. (2000). Relational autonomy, self-trust, and health care for patients who are oppressed. In C. Mackenzie & N. Stoljar (Eds.), *Relational autonomy* (pp. 259–279). New York: Oxford University Press.

Meyers, D. T. (1989). *Self, society and personal choice.* New York: Columbia University Press.

Michie, S., Miles, J., & Weinman, J. (2003). Patient-centeredness in chronic illness: What is it and does it matter? *Patient Education & Counseling, 51,* 197–203.

Murphy, D. J., Pope, C., Frost, J., & Liebling, R. E. (2003). Women's views on the impact of operative delivery in the second stage of labour: Qualitative interview study. *British Medical Journal, 327,* 1132–1135.

Neale, J., Pitts, M. K., Dunn, P. D. J., Hughes, G. M., & Redman, C. W. E. (2003). An observational study of precolposcopy education sessions: What do women want to know? *Health Care for Women International, 24*, 468–475.

Neuhauser, D. (2003). The coming third health care revolution: Personal empowerment. *Quality Management in Health Care, 12,* 171–184.

Parent, N., & Fortin, F. (2000). A randomized, controlled trial of vicarious experience through peer support for male first-time cardiac surgery patients: Impact on anxiety, self-efficacy expectation, and self-reported activity. *Heart & Lung, 29,* 389–400.

Stewart, M., et al. (2000). The impact of patient-centered care on outcomes. *The Journal of Family Practice, 49,* 796–804.

Sullivan, M. (2003). The new subjective medicine: Taking the patient's point of view on health care and health. *Social Science & Medicine, 56*, 1595–1604.

Wilson, P. M. (2001). A policy analysis of the Expert Patient in the United Kingdom: Self-care as an expression of pastoral power? *Health and Social Care in the Community, 9*(3), 134–142.

Wong, M. K. Y., Crawford, T. J., Gask, L., & Grinyer, A. (2003). A qualitative investigation into women's experiences after a miscarriage: Implications for the primary healthcare team. *British Journal of General Practice, 53*, 697–702.

Chapter 2

Advances in Learning Theory for Patient Education

Advances in learning theory important to patient education have evolved slowly over time. General learning theories of constructivism and cognitive load provide new insights. More specific to patient education are learning more accurate symptom perception, the importance of assessing and incorporating lay models into teaching, and enlarging concerns about health literacy.

OVERVIEW

There is no unified theory of learning, but rather theories that cluster into perspectives. The objectivist perspective with an aim in making learning more scientific and measurable was dominant throughout most of the 20th century. It has included work on learning as a biochemical activity in the brain; the behaviorist approach, which aims for a relatively permanent change in behavior and notes that people respond in predictable ways if they are reinforced for their performance; and the cognitive approach, which holds that learning involves more sophisticated methods for processing, storage, and retrieval of information. The cognitive perspective incorporates a focus on critical thinking and on development of schemas, which will be further described in a following section on lay models (Jonassen, 2003).

The constructivist perspective defines learning as knowledge construction, in which individuals make sense of their world by constructing their own representations or models of their experiences. On this view, learning involves social negotiation of beliefs, out of which comes conceptual change. Individuals make sense out of domain concepts in such a way that they develop coherent conceptual structures—they organize and reorganize their naive models of the world in light of new experiences. The more coherent these theories are, the more meaningful and useful they are. Constructivists believe that learning requires activity with authentic materials and situations, with the goal of developing skills and abilities to be used in real life. We understand our reality only in the form in which it has been constructed by us, not that imposed on us. Under constructivism, teaching by transmitting prepared packages of knowledge divorced from concrete situations cannot be justified. Rather, the task of the teacher is to stage environments where learning can be constructed (Jonassen, 2003; Terhart, 2003).

Part of a cognitive perspective, recent work on cognitive load theory focuses on what makes things complex and difficult to learn. It holds that instruction should be structured to reduce unnecessary extraneous working memory load. Some of this load is intrinsic to the intellectual complexity of information, making it difficult to break into individual chunks and learn separately until learners develop sufficiently complex schemata (Pollack, Chandler, & Sweller, 2002).

Much patient and health education practice was developed during a time when cognitive theory was dominant and has also integrated a structured, scientific approach to learning with measurable objectives to be met through changes in knowledge and behavior. This still-dominant approach has not yet accommodated constructivist philosophy or approaches to learning (Soto Mas, Plass, Kane, & Papenfuss, 2003). It is easy to see that a constructivist approach would require a much different learning environment with realistic laboratories or instructor immersion in the patient's daily life. More important, patients would define the questions they need answered and the skills they are lacking. Instruction under this philosophy has the potential to be much more effective and useful than are current methods.

SYMPTOM PERCEPTION

Particularly in chronic disease, the patient's ability to accurately perceive symptoms is essential for triggering decision processes to initiate treatment. This ability is not necessarily closely related to intellectual knowledge of disease processes or treatment measures, which is the traditional content of patient education. Perceptual accuracy is the degree to which subject assessments of symptoms correlate with objective measures of severity (Yoos, Kitzman, McMullen, & Sidora, 2003). The most work has been done in diabetes with blood glucose discrimination training and to a lesser extent in asthma.

A highly disruptive example can be found in perception of heart palpitation. Benign palpitations with no comorbid cardiovascular disease are common, reported by as many as 16% of patients in general medical settings, the second most common reason for referral to cardiologists. Palpitations are experienced as an uncomfortable awareness of a beating heart, pounding or racing of the heart, missing a beat, or flip-flopping in the chest. More than half of patients reporting palpitations do not have clinically significant arrhythmias. These patients often undergo a variety of diagnostic procedures, frequently repeated because knowledge of negative test results doesn't seem to change patients' perceptions that their heart function is abnormal. They are difficult to reassure.

A short-term intervention consisting of information about causes of palpitations, discussion about the patient's beliefs about the symptoms, and advice on coping with them have been shown effective in decreasing symptoms and improving mood (Ehlers, Mayou, Sprigings, & Birkhead, 2000). This intervention aims to change the meaning of the symptoms, not necessarily the accuracy of their perception.

Blood glucose awareness training (BGAT), also called blood glucose discrimination training, teaches more reliable perception of physical symptoms such as mood changes or deterioration in mental function and external cues like food intake and physical activity. The training lasts 8 weeks with weekly sessions of 1–2 hours and aims to improve patients' ability to detect and predict extreme fluctuations in blood glucose accurately (Gonder-Frederick, Cox, Clarke, & Julian, 2000).

Blood Glucose in Diabetes

Because extremes in blood glucose (BG) levels can have an impact on nearly every organ system, including a dramatic impact on the central nervous system, the list of symptoms that can be caused by hypo- and hyperglycemia is long and not specific (can be caused by other physiologic states). In addition, BG symptomatology is highly idiosyncratic with no one symptom associated with hypo- or hyperglycemia for all patients. Some, such as fatigue, may signal low BG in one patient and high BG in another. Idiosyncratic symptom clusters are stable over relatively short periods such as 3–6 months but may change dramatically over time. In fact, symptoms may vary across different episodes of hypo- and hyperglycemia for an individual patient (Gonder-Frederick et al., 2000).

There are individual differences in the number and intensity of symptoms and the glycemic threshold at which physiological responses and subsequent symptoms occur. Thus, some patients become quite symptomatic with relatively mild hypo- or hyperglycemia, some notice nothing until their BG is extremely low or high and they are severely impaired, and some never recognize them. In general, hypoglycemia is more symptomatic than hyperglycemia, which tends to be associated with symptoms that are less intense perceptually and slower in onset. In contrast, hypoglycemic symptoms often onset suddenly and can be quite aversive. Patients need to be taught about the idiosyncrasy of BG symptoms and helped to identify those that are personally most reliable. There are large individual differences in accuracy, significantly poorer in younger age groups such as adolescents, with patients' confidence in their ability not related to objective measurements. Few patients demonstrate acceptable accuracy at every BG range. Self-measurement of blood glucose (SMBG) feedback is not obtained frequently enough to guide all self-treatment decisions (Gonder-Frederick et al., 2000).

The 8-week BGAT training requires patients to make diary entries at least four times a day before their routine SMBG and whenever they believe, because of internal and external cues, their BG may be too high; they then measure and plot actual BG and learn their most reliable symptoms. Week 3 is devoted to neuroglycopenic symptoms to increase patient sensitivity to the often-ignored, subtle, and early signs of deterioration in mental and motor function due to mild hypoglycemia. Patients learn to use self-tests, such as how long it takes and how much effort to do mental arithmetic, compared with their usual speed and difficulty, to assess their own ability to function. Patients learn to monitor the fat content of their food since high fat can cause a significant increase in digestion time, which can dampen and/or delay BG increase (Gonder-Frederick et al., 2000).

Only 15% of BGAT patients reported auto accidents while 42% of control patients reported one or more; there were also significant decreases in severe hypoglycemia and nocturnal hypoglycemia. Table 2.1 describes patient groups likely to benefit from BGAT. Strong intrinsic motivation and willingness to do SMBG several times are important because a large investment of time and effort is required. Good foundational knowledge about diabetes and its treatment is also required. As yet, this education has not been modified for children, who frequently make a high rate of errors (Gonder-Frederick et al., 2000).

In an attempt to reduce driving mishaps in patients with type 1 diabetes (who report twice as many driving accidents as do their spouses), Cox, Clarke, Gonder-Frederick, and Kovatchev (2001) have developed hypoglycemia anticipation awareness training (HAATT). It is designed specifically for patients who have problems with recurrent severe hypoglycemia. In driving simulation tests patients frequently did not recognize and failed to treat hypoglycemia before their driving performance began to deteriorate. Learning to test before their drive

TABLE 2.1 Patient Groups Likely to Benefit From BGAT

Poor ability to recognize/predict BG extremes
Using intensive insulin therapy
Reduced hypoglycaemic awareness
History of recurrent severe hypoglycaemia
High fear of hypoglycaemia
Recurrent DKA
Poor metabolic control

Note. From Gonder-Frederick, L., Cox, D., Clarke, W., & Julian, D. (2000). Blood glucose awareness training. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care.* New York: John Wiley & Sons. Copyright 2000. John Wiley & Sons, Ltd. Reprinted with permission.

and to detect low BG levels before they become impaired are important outcomes of HAATT.

Asthma

A similar large variation in ability to accurately perceive the severity of bronchoconstriction occurs in asthma. Adequate asthma self-management rests on the ability to detect changes in peak expiratory flow (PEF) of about 15% and then taking action to abort an impending attack. Smaller changes may not be detected by adults. Blunted perception of symptoms is associated with fatal asthma. A life-threatening attack of airway obstruction can develop within 1 hour. Asthmatics may consider themselves symptom-free in the midst of an asthma attack or suffer from severe breathlessness during mild airway obstruction. Other asthmatics may not feel well during airway obstruction but not know what is wrong. In fact, they may attribute their condition to having the flu or needing rest. Rapid awareness of symptoms and taking the required medications can be decisive. Likewise, overperception problems lead to excessive use of medications and unwarranted illness behavior (Rietveld & Everaerd, 2002).

As with diabetes, symptom perception accuracy in children and their parents was inaccurate about one third of the time and at sick times when the child's peak flow reading is at less than 80% of personal best, accuracy decreased markedly to one third of episodes being correctly evaluated. Yoos et al. (2003) note that peak flow meters are more sensitive to large airway than to small airway resistance; in addition, patient adherence to them is low (about 28%).

Unlike with diabetes, there have been only modest attempts to improve symptom perception in asthma. Measurement of perception of dyspnea should be performed at least once in all asthma patients, to identify those at risk for fatal attack (Magadle, Berar-Yanay, & Weiner, 2002), and especially in those who have frequent emergency room visits. Keeping a diary of perceived breathlessness and corresponding PEF and looking for the largest PEF change and its related perceived level of breathlessness is recommended.

PATIENT LAY MODELS OF DISEASE

Patient "lay," or commonsense models, provide an example of both cognitive and constructivist learning approaches—the models are cognitive but are constructed by the patient from his or her reality. Others have called these models schemata, explanatory, or implicit models. Everyone forms them and they are recognized as fundamental to how people react to new information and how they cope with illnesses. They are frequently very resistant to change. Leventhal proposed that people have representations of illness that include ideas about the identity, cause, time line, consequences, and cure associated with an illness (Donovan & Ward, 2001).

Traditional educational interventions are designed to give the same information to everyone and to teach new coping skills without first addressing the well-established beliefs that drive the selection of coping strategies. A more effective approach starts with the patient describing his or her illness along the five dimensions of illness representation noted above including experiences that led to misconceptions. Next, replacement beliefs and benefits to be expected from acting on the new information are introduced. Table 2.2 provides an example of this process with a program aimed at pain management of patients with cancer (Donovan & Ward, 2001).

Significant amounts of research support the importance of perceived controllability of illness and its positive relationship

TABLE 2.2 The Representational Approach to Patient Education With Examples from RIDPAIN

Step	Goals of each step	Examples from RIDPAIN
1. Representational assessment	Encourage patient to describe illness representations along the five dimensions (identity, cause, time line, consequences, and cure or control).	"Tell me about your pain." "What do you think is causing your pain?" "How has cancer pain affected your life?"
2. Exploring misconceptions	Encourage patient to think about what experiences led to misconceptions.	"Can you think about how you came to be concerned about addiction?" "Do you have any personal experiences with addiction?"
3. Creating conditions for conceptual change	Discuss limitations of misconceptions: what one loses by maintaining misconceptions. Make links between misconceptions and consequences of acting on them.	"Do you think your concerns about addiction affect how you use pain medications?" "It sounds to me like your concerns about addiction might get in the way of good pain relief. Many times people get in a situation where they have a lot of pain, but are reluctant to take pain medicines and they end up not being able to do the things they enjoy doing (tie to personal consequences shared by patient in assessment phase). I would like to give you some specific information about these concerns that comes from the most current research. My hope is that this information will help you feel more comfortable using pain medicines."
4. Introducing replacement information	Present credible information to replace current misconceptions.	Discussion of the difference between psychological dependence (addiction), physical dependence, and tolerance with links to experiences with withdrawal. Explanation that symptoms were expected effects of sudden withdrawal, but not symptoms of addiction. Discussion of the lack of evidence supporting a link between family or personal history of alcoholism and addiction to analgesics used to treat pain.

(continued)

TABLE 2.2 ***(continued)***

Step	Goals of each step	Examples from RIDPAIN
5. Summary	Discuss benefits associated with acting on new information.	"We talked about your concerns about addiction. I hope some of the information will help you to feel more comfortable taking pain medication to manage your pain so it doesn't interfere with your day-to-day life." (Refer to specific consequences associated with unrelieved pain, using information obtained from representational assessment).

Note. From "A representational approach to patient education," by H. S. Donovan & S. Ward, 2001, *Journal of Nursing Scholarship,* 33, pp. 211–216. Copyrighted material of Sigma Theta Tau International. Used by permission.

to problem-based coping strategies, adaptive outcomes, psychological well-being, social functioning, and negativity related to psychological distress and disease state. Both the Illness Perception Questionnaire and the Implicit Models of Illness Questionnaire have been used in this research (Hagger & Orbell, 2003).

Examples of Lay Models and Practices Discrepant With Modern Medicine

In some cases, lay models reflect cultural beliefs significantly discrepant with modern medicine. Kashmiri men in Leeds, with cultural norms that equate overweight with prosperity and well-being, are an example. Most of this population failed to control and manage their diabetic condition, with only 14% exercising and 84% continuing with their cultural foods, which were very rich in fats (Naeem, 2003).

In other instances, differences in cultural beliefs between providers and patients are bound up in distrust of the medical system. A study of beliefs of low-income African Americans about hypertension showed interpretation of the frequent changes in medication required to achieve blood pressure control and minimize side effects as evidence of a conspiracy among hospitals, physicians, and pharmaceutical companies to exploit their group in testing medications, that is, to use them as guinea pigs in a covert experiment. These patients expected medications to cure disease and so believed continual, prolonged administration of them to be unnecessary. Because of these beliefs, many of these patients did not adhere to the regimen and put their trust in advice from family members and friends instead of health care professionals (Lukoschek, 2003).

A final example shows how distress and dissatisfaction can result from differences between patients' and providers' models of illness and lack of attempts to understand and resolve them. Low-income Hispanic and African American women in primary care practice, who had abnormal findings on Pap smear, believed they had cancer and frequently believed it was caused by sex and sexual misbehavior. The concept of precancer was difficult for them to understand, as was the inherent ambiguity of low-grade Pap smear findings. The women were informed of their results by letter and did not understand what it meant or what they were supposed to do. The women's explanations and concerns emerged only after systematic probing, which was not routinely being done in these practices (Karasz, McKee, & Roybal, 2003).

Examples of Lay Model Usefulness

Studies of lay models in cardiovascular illness are instructive. Older participants awaiting coronary artery bypass graft (CABG) surgery were significantly more likely to believe they had no control over the disease and that it would be gone after surgery and reported fewer health behavior changes than did younger participants (Grump, Matthews, Scheier, Schulz, Bridges, & Magovern, 2001). Couples who had similar positive perceptions of the identity and consequences of myocardial infarction (MI) showed better physical, psychological, and sexual functioning with less impact of the MI on social and recreational activities (Figueiras & Weinman, 2003).

Petrie, Cameron, Ellis, Buick, and Weinman (2002) note that despite the fact that fewer patients now die in the acute phase of MI, progress in improving functional recovery including return to work has been slower. Patient beliefs about their illness, assessed a few days after the MI, were key determinants of recovery (so these patients could be identified for an intervention). Those who believed their MI would have serious long-lasting consequences had higher levels of illness-related disability and were slower to return to work, and those with weaker beliefs in the control of their heart disease were less likely to attend cardiac rehabilitation. In this randomized controlled trial, an intervention conducted within the patient's normal hospital stay significantly altered incorrect beliefs. The beliefs were maintained at 3-month follow-up and intervention patients were less likely than were control patients to report angina pain. The patient's model of his disease (as assessed by the Illness Perception Questionnaire) was the starting point. Frequently, patients' causal models had to be broadened to include lifestyle factors. Building on causes as identified by the patient, a personalized written plan was developed to include exercise, dietary change, and return to work. Patients were also helped to distinguish symptoms that are a normal part of the health and recovery process from those that constitute warning of additional myocardial damage.

In diabetes, personal models have been found to be stable over 3 months and predictive of outcomes in eating, glycolated hemoglobin, physical functioning, and mental health (Hampson, Glasgow, & Strycker, 2000). And a study of individuals with multiple sclerosis found illness representations to be the most significant predictors of social dysfunction, fatigue, anxiety, depression, and self-esteem. Lack of a coherent model of the illness predicted disability. As with the cardiac example given above, the suggested intervention is to explore patients' beliefs, assisting them to develop a more coherent understanding of their illness and identify symptoms that may be unrelated to multiple sclerosis. Similar results have been found for heart disease, rheumatoid arthritis, cancer, chronic obstructive pulmonary disease, and others (Jopson & Moss-Morris, 2003).

Yet another example is evidence that negative beliefs about the consequences of dizziness sustain long-term restriction of activity, which can be modified by therapy. Persons with dizziness frequently fear falling, fainting, or losing control. Therapy consisted of explaining to the participant (with the aid of a booklet) how the balance system functions, the causes of dizziness and vertigo, why symptoms can be provoked by movement, and how the process of compensation can be facilitated by exercises. The nurse then guided participants through a set of eight standard head and body movements, instructing them to perform the exercises twice a day, gradually increasing the pace as the movement-provoked dizziness decreased. These exercises stimulate the vestibular organs and provoke dizziness, thus providing the balance system with the repeated exposure to movement necessary to achieve neurological adaptation. Exercises were supplemented with walking and with training in relaxation, slow breathing, and graded resumption of activity. Significant reduction in negative beliefs was observed in the patients who received this treatment, whereas there was no such reduction in the untreated patients (randomly assigned). Beliefs were the primary longitudinal predictor of handicap (Yardley, Beech, & Weinman, 2001).

It is important to note what a profound conceptual and power shift is required to accommodate to this more effective approach. The old "compliance to medical regimen approach" treated the provider's perspective as an uncontroversial point of departure with no questioning of the underlying sociocultural assumptions on which the prescribed treatment regimen was based. Patients were expected to accommodate to this perspective. Compliance is built on providers' beliefs that technical control of the pathophysiology of the disease is the most important task, including control of the patient's behavior to that end. In this approach, education is focused on correcting resistance to complying. Patients are more interested in how they are feeling and how much the illness and its treatment are disrupting their lives (Hunt & Arar, 2001).

A meta-synthesis of 292 qualitative studies on chronic physical illness shows the importance of patients being able to put wellness in the foreground with the self and not the disease or the body being the source of identity. People are able to attain this perspective by learning as much as they can about the disease, developing personal skills such as negotiating, creating supportive environments, and identifying the body's unique patterns of response. Self-help groups can be counterproductive if they require the patient to focus on the disease instead of on a broader identity (Paterson, 2001).

HEALTH LITERACY

Basic statistics about health literacy have been understood for some while—that one in five American adults has low literacy skills with another 27% at marginal literacy. Health literacy is the ability to read, understand, and act on health information including such tasks as comprehending prescription labels, interpreting appointment slips, completing health insurance forms, and following instructions for diagnostic tests. Functional health literacy may be significantly worse than one's general literacy (Andrus & Roth, 2002) and is twice as common for Americans greater than 65 years of age and among inner city minorities (Davis, Williams, Marin, Parker, & Glass, 2002).

What is becoming clearer is a greater impact of low health literacy. These individuals are at great risk of misunderstanding diagnosis, directions for administering drugs, and self-care instructions (Andrus & Roth, 2002). Cancer care, for example, now contains more options of greater complexity including complex management of symptoms from chemotherapy. Health literacy may be an important predictor of increased cancer risk and poor participation in cancer control programs. Individuals of lower health literacy were significantly less likely to have an undetectable HIV viral load and were somewhat less likely to know their CD4 cell count and viral load, or to understand its meaning. Lower health literacy was also related to misperceptions that individuals on anti-HIV treatments can relax safer-sex practices (Kalichman, Benotsch, Suarez, Catz, Miller, & Rompa, 2000).

Low literacy also decreases ability to meet ethical standards and generate research knowledge for poor and vulnerable populations. More than 60% of individuals with low literacy could not understand a standard informed consent document. Current Internet formats are not suitable for audiences with low literacy skills. Many research instruments are not usable for individuals with low literacy and may involve their leaving items blank or providing inconsistent explanations for the meaning of items, increasing error variance in subject responses. Low literacy subjects may require more time to complete a battery of study instruments, increasing subject burden (Kimble et al., 2001).

Language simplification has been the principal technique used to make written materials more understandable and useful for people with low literacy skills. Video and audiotapes are effective but require that listeners remember the messages, thus limiting their usefulness to simple, important ideas. Pictographs (drawings representing instructions) are effective but require taking time to teach their meaning (Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001).

THE WEB

Much has been made about misinformation on the Web, which lessens its value as a medium for learning. Butler and Foster's (2003) survey of 60 Web sites about back pain found many were established to sell expensive products or benefits of particular treatments or surgical procedures. Twenty-three percent of the sites surveyed recommended bed rest, a treatment no longer a part of evidence-based practice guidelines. Other uses of the Web include Listserves and chat rooms for individuals who may, for example, be undergoing a bone marrow transplant. While the technology provides support for caregivers who cannot leave home, it can also include people who pose as cancer survivors and can leave some emotionally fragile survivors at risk of being victimized (Sharp, 2000).

A more positive use of the Web is to provide professionally available just-in-time education for patients and family members managing symptoms after a procedure. For example, Goldsmith and Safran (1999) completed a randomized controlled trial of patient access to pain management information on an ambulatory surgery Web site. More and more patients have complex surgical procedures on an outpatient basis; assisting these patients with their own care has become very important. Following such surgery, inadequate postoperative pain management is a common reason for unplanned hospital admissions. Patients often need to clarify information at a time when clinical staff may not be available. The trial showed significantly less postoperative pain among those using the Web-based instructions than among those given usual care.

Web-based instruction must be closely monitored for quality.

A DIFFERENT VIEW OF LEARNING IN PATIENT EDUCATION

Learning goals in patient education have been heavily focused on direct application to physician-prescribed actions. Another, potentially more powerful view, acknowledges that patients need basic thinking skills, that patient education can develop them, and that with additional effort they will generalize to other health care problems and beyond. Such general thinking skills include reasoning by analogy, understanding experimentation, means-ends analysis, and causal reasoning in the health domain. More specifically, they might include how:

1. Physiological, social, or psychological means are leverage points on a health problem
2. Specialty bodies of medical knowledge do not add up to a complete whole
3. Narrowness of the professional body of knowledge, skills, and goals must be supplemented with lay knowledge and skills, or conversely how professional knowledge can supplement lay understanding
4. Scientific knowledge dramatically and quickly shifts, and knowing how to identify and weigh scientific hype
5. My body provides feedback to me, how to read it and to know when I've reached an equilibrium or a serious disruption
6. Bodies and selves repair
7. Disease or distress happens to me through influence of genetic, environmental, social, and psychological factors

8. To harness motivation of oneself and others in one's environment, including family and health professionals, to solve a problem

It is reasonable to expect that patients who develop such basic thinking skills will be able to more quickly understand a health problem and work toward its resolution with less professional help. Wouldn't it be worthwhile to invest in development of such skills in patients? Does this development require a certain level of formal education to be successful?

SUMMARY

Each of the developments described in this chapter offers an opportunity for advancement of patient education. Although not yet widely acknowledged, the learning philosophy and theory of constructivism fits well with the purpose of preparing patients to manage their illnesses in real situations. The bridge to implementation is not yet constructed and would require considerable revamping of the traditional model of patient education. Understanding which patients are able to perceive symptoms in a way that is congruent with physiological indicators, and those who are not, offers a significant opportunity to improve safety in chronic disease. Some beginning interventions have been tested.

Patient lay models used to be thought of as a curiosity, frequently so obviously different from professional models. It has now become clear that those models do not go away and ignoring them significantly impairs learning. Last, cumulative negative consequences of low health literacy are now understood to be catastrophic; yet, a significant program to deal with it has not been forthcoming. This situation raises not only ethical concerns about denying patient education to large segments of the population, it also ignores immense economic and personal consequences of their inability to engage the health care system and manage their illnesses.

The constant thread throughout all of these topics is acknowledgment of the necessity of patient centeredness and of effort placed on developing basic patient thinking skills. Whether these developments can become true advances depends more on the willingness of health professionals to abandon a mind-set that privileges the provider's view and patient compliance with it and to seek resources necessary to ensure that patients are competent learners.

REFERENCES

Andrus, M. R., & Roth, M. T. (2002). Health literacy: A review. *Pharmcotherapy, 22,* 282–302.

Butler, L., & Foster, N. E. (2003). Back pain online: A cross-sectional survey of the quality of web-based information. *Spine, 28,* 395–401.

Cox, D., Clarke, W., Gonder-Frederick, L., & Kovatchev, B. (2001). Driving mishaps and hypoglycaemia: Risk and prevention. *International Journal of Clinical Practice Supplement, 123,* 38–42.

Davis, T. C., Williams, M. V., Marin, E., Parker, R. M., & Glass, J. (2002). Health literacy and cancer communication. *CA Cancer Journal for Clinicians, 52,* 134–149.

Donovan, H. S., & Ward, S. (2001). A representational approach to patient education. *Journal of Nursing Scholarship, 33,* 211–216.

Ehlers, A., Mayou, R. A., Sprigings, D. C., & Birkhead, J. (2000). Psychological and perceptual factors associated with arrhythmias and benign palpitations. *Psychosomatic Medicine, 62,* 693–702.

Figueiras, M. J., & Weinman, J. (2003). Do similar patient and spouse perceptions of myocardial infarction predict recovery? *Psychology & Health, 18,* 201–216.

Goldsmith, D. M., & Safran, C. (1999). Using the web to reduce postoperative pain following ambulatory surgery. *Journal of the American Medical Informatics Association Proceedings,* 780–784.

Gonder-Frederick, L., Cox, D., Clarke, W., & Julian, D. (2000). Blood glucose awareness training. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care* (pp. 169–206). New York: John Wiley & Sons.

Grump, B. B., Matthews, K. A., Scheier, M. F., Schulz, R., Bridges, M. W., & Magovern, G. J., Sr. (2001). Illness representations according to age and effects on health behaviors following coronary artery bypass graft surgery. *Journal of the American Geriatrics Society, 49,* 284–289.

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the commonsense model of illness representations. *Psychology & Health, 18,* 141–184.

Hampson, S. E., Glasgow, R. E., & Strycker, L. A. (2000). Beliefs versus feelings: A comparison of personal models and depression for predicting multiple outcomes in diabetes. *British Journal of Health Psychology, 5,* 27–40.

Houts, P. S., Witmer, J. T., Egeth, H. E., Loscalzo, M. J., & Zabora, J. R. (2001). Using pictographs to enhance recall of spoken medical instructions II. *Patient Education & Counseling, 43,* 231–242.

Hunt, L. M., & Arar, N. H. (2001). An analytical framework for contrasting patient and provider views of the process of chronic disease management. *Medical Anthropology Quarterly, 15,* 347–367.

Jonassen, D. H. (2003). The vain quest for a unified theory of learning. *Educational Technology, 43*(4), 5–8.

Jopson, N. M., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to multiple sclerosis. *Journal of Psychosomatic Research, 54,* 504–511.

Kalichman, S. C., Benotsch, E., Suarez, T., Catz, S., Miller, J., & Rompa, D. (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine, 18,* 325–331.

Karasz, A., McKee, M. D., & Roybal, K. (2003). Women's experiences of abnormal cervical cytology: Illness representations, care processes, and outcomes. *Annals of Family Medicine, 1,* 196–202.

Kimble, L. P., et al. (2001). Cardiac instrument development in a low-literacy population: The revised Chest Discomfort Diary. *Heart & Lung, 30,* 312–320.

Lukoschek, P. (2003). African Americans' beliefs and attitudes regarding hypertension and its treatment: A qualitative study. *Journal of Health Care for the Poor and Underserved, 14,* 566–587.

Magadle, R., Berar-Yanay, N., & Weiner, P. (2002). The risk of hospitalization and near-fatal and fatal asthma in relation to the perception of dyspnea. *Chest, 121,* 329–333.

Naeem, A. G. (2003). The role of culture and religion in the management of diabetes: A study of Kashmiri men in Leeds. *The Journal of the Royal Society for the Promotion of Health, 123*(2), 110–116.

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship, 33,* 21–26.

Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine, 64,* 580–586.

Pollack, E., Chandler, P., & Sweller, J. (2002). Assimilating complex information. *Learning and Instruction, 12,* 61–86.

Rietveld, S., & Everaerd, W. (2002). Symptom perception in asthma. In A. A. Kaptein & T. L. Creer (Eds.), *Respiratory disorders and behavioral medicine.* London: Martin Dunitz, Ltd.

Sharp, J. (2000). The internet: Changing the way cancer survivors receive support. *Cancer Practice, 8,* 145–147.

Soto Mas, F. G., Plass, J., Kane, W. M., & Papenfuss, R. L. (2003). Health education and multimedia learning: Educational psychology and health behavior theory (Part 1). *Health Promotion Practice, 4,* 288–292.

Terhart, E. (2003). Constructivism and teaching: A new paradigm in general didactics? *Journal of Curriculum Studies, 35,* 25–44.

Yardley, L., Beech, S., & Weinman, J. (2001). Influence of beliefs about the consequences of dizziness on handicap in people with dizziness, and the effect of therapy on beliefs. *Journal of Psychosomatic Research, 50,* 1–6.

Yoos, H. L., Kitzman, H., McMullen, A., & Sidora, K. (2003). Symptom perception in childhood asthma: How accurate are children and their parents? *Journal of Asthma, 40,* 27–39.

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Chapter 3

Patient Education and Ethical Standards

Ethical standards, both for patient care and particularly for research, continue to evolve. The legal standard of care has focused on disclosure of information but not on ensuring that patients possess sufficient understanding to make an autonomous and informed decision such as to enroll in a clinical trial or develop an advanced directive. The ethical (as opposed to the legal) view, that patients or research subjects should fully understand that to which they are agreeing, is gradually gaining ground. Not surprisingly, a patient education function will be required to accomplish this.

Very beginning work is addressing the ethics of patient education itself, that is, what moral precepts should guide decisions about whether education is available to patients and how it should be designed and delivered.

CONSENT FOR RESEARCH

Most potential research subjects have limited knowledge about randomized clinical trials (RCTs)—their aims as well as use of randomization, blinding, and placebo. Table 3.1 describes the type of information needed for ethical informed consent to be given. It is easy to see why potential subjects could be confused over these unfamiliar concepts.

In one study (Criscione, Sugarman, Sanders, Pisetsky, & St. Clair, 2003), 13% of subjects thought their symptoms would help determine the treatment assigned in the trial. Despite having received detailed information about risks prior to starting the trial, 37% believed study drugs were completely safe. Some also didn't understand the likelihood they would receive a placebo. Not only is it necessary to understand the basics of study design, being persuaded of clinical equipoise is also important for true informed consent and for subject willingness to be recruited and to accept randomization. In a study of men with localized prostate cancer, from a variety of educational backgrounds, all were able to understand and recall concepts of chance, comparison, and equipoise. Although they understood randomization, it was a struggle for them to accept it as a method of choosing a treatment (Mills, Donovan, Smith, Jacoby, Neal, & Hamdy, 2003).

In a study of patients with advanced cancer, who had given informed consent to participate in Phase I trials, 44% said the worst thing that could happen to them would be that the investigational agent would not work, and only 25% mentioned death as a possibility. Sixty-nine percent of those who had graduated from college understood the real purpose of Phase I trials was to determine dose, toxicity, or drug interactions. Only 26% of noncollege graduates understood this. A large portion clearly had therapeutic goals or expectations that simply were not achievable (Daugherty, Banik, Janish, & Ratain, 2000), although subjects in Phase I trials should be told that a chance or response is quite small and a cure should not be expected. Patients also often don't understand that some will

TABLE 3.1 Type of Information Needed for Ethical Informed Consent to Be Given

Explain the general rationale for clinical trials	Aim is to improve the current situation and to test new treatments before they are made readily available.
Equipoise	Trials are conducted only when it is believed that the experimental treatment will be at least as effective as the standard arm.
Beneficence	The trial is conducted to determine whether there is a significant additional benefit from the experimental treatment.
Nonmaleficence	There is evidence to suggest that being involved in a clinical trial will in no way worsen your chances. "NB research evidence suggests that participation in clinical trial improves outcomes in some patients. Presenting this evidence to patients may be coercive thus it was decided to avoid phrases such as "being involved in a clinical trial may improve your chances."
Ethics committees	All trials have to receive approval from ethics committees.
Inform the patient about the trial being offered	*Explain* the rationale for the randomized or nonrandomized clinical trial. *State* how important the question is, and how the results may change practice. *State* that the experimental treatment is only available on the trial if this is true. *Explain* how randomization works in the context of this trial. *Discuss* access to the treatment after the trial.
Describe the treatment arms available on the trial	Standard treatment has been already introduced, greater detail is likely to be required at this point, in order that the differences between arms can be highlighted.
Inform the patient about other possible clinical trials	If other suitable trials are known, then doctors should refer patients to an appropriate information source.
Refer to the information sheet	Patients should know the relevance of this document and how to use it.
Highlight any additional inconveniences associated with being on the trial.	These may include extra questionnaires, additional blood tests and scans, more frequent visits, additional expenses.

Note. From "Developing ethical strategies to assist oncologists in seeking informed consent to cancer clinical trials," by R. F. Brown, P. N. Butow, D. G. Butt, H. R. Moore, & M. H. N. Tattersall, 2004, *Social Science & Medicine, 58,* pp. 379–390. Copyright 2004 with permission from Elsevier.

get a subtherapeutic dose and others will suffer severe toxicities.

Additional deficiencies in patients' understanding include lack of awareness of being a subject in a research study, inadequate recall of important risks of procedures or treatment, lack of awareness of the ability to withdraw from a research study at any time, and confusion about dual roles of physicians/researchers. Twenty-five of 34 studies found that patients' understanding or recall showed improvement with a wide variety of interventions including providing corrected feedback, multiple learning trials, and well-organized and simplified consent forms with illustrated formats (Dunn & Jeste, 2001).

The term "therapeutic misconception" is used to refer to these various misunderstandings when they are part of a belief that patients will receive the same individually focused treatment that they would receive in a nonresearch clinical context. Many research practices support this misconception or at least do little to explicitly refute the natural assumption; there is reason to believe that its prevalence is substantial (Lidz & Appelbaum, 2002).

There is a general sense in the field that these misunderstandings cannot be corrected and must be tolerated. Yet, in these situations, subjects have not given valid informed consent. It is a health professional's responsibility to probe for and ensure understanding and voluntariness. Describing how and why treatment and research differ should be as much a part of the consent disclosure in a research project as the nature, purpose, overall risks and benefits, alternatives, and other disclosures required. The distinctive features to be called to potential subjects' attention are the nature and purpose of the research, the risks and benefits of being a subject, and the available options for obtaining the same or different therapeutic interventions outside of the research setting (Lidz & Appelbaum, 2002).

A neutral discloser, trained to teach participants how research participation would differ from clinical care and having no involvement with the research projects, has been successful in helping participants better understand randomization, placebos, double-blinding, and other research methods (Dresser, 2002). The understanding of potential subjects should be assessed continually and additional information provided to correct misperceptions or misunderstandings as they occur. Currently, no research shows that this will work or what impact it would have on subject recruitment and dropout rates from clinical trials (Lidz & Appelbaum, 2002). Clinical trial data managers not infrequently find themselves in the middle of these misunderstandings but without authority to correct them (Loh, Butow, Brown, & Boyle, 2002).

In the absence of a robust effort to teach potential participants accurate and meaningful information (regarding regulations that require it), it is disingenuous to blame the misconception of patients' psychological needs to find a cure (Dresser, 2002).

Other potentially correctable misassumptions and misunderstandings have been documented particularly in informed consent for clinical treatment. There has been an assumption that individuals with illnesses such as schizophrenia could not provide fully informed consent; such a diagnosis does not predetermine whether a person can understand key information. Several studies have found that consent-related capacity of persons with schizophrenia was enhanced with straightforward educational interventions (Carpenter et al., 2000; Dunn, Lindamer, Palmer, Golshan, Schneiderman, & Jeste, 2002; Styles, Poythress, Hall, Falkenbach, & Williams, 2001). In each of these studies, with the help of education, patients with psychotic disorders were able to significantly improve their understanding of the research involved, in one instance reaching a level not significantly different from normal comparison subjects who received a routine consent procedure. Educational approaches included corrected feedback, multiple learning trials, and summaries of information.

In fact, persons with medical or surgical conditions as well as those with psychiatric illnesses show variable ability to attain sufficient understanding to provide informed consent. Assuming they cannot consent, or withholding the repeated educational interventions necessary to prepare them to decide whether to consent, stigmatizes and deprives these individuals of the opportunity to participate in clinical trials. At the same time, such an attitude significantly retards development of a research base from which to better treat their disease. Without these additional educational assists, some subjects might agree to participate in protocols they might have otherwise refused (Dunn et al., 2002).

In general, there has not been a commitment to invest whatever it takes to provide whatever education is needed to ensure truly informed consent. The legal standard of disclosure, which does not require patient understanding, is dominant, and it should be noted that while federal research regulations acknowledge vulnerability of persons who are educationally disadvantaged, no guidance regarding appropriate protections is given. With the exception of articles pertaining to the readability of consent documents there is a dearth of literature addressing how institutional review boards (IRBs) should approach the review of research involving educationally disadvantaged persons (Stone, 2003). While ethics requires a higher standard than does the law, the ethics literature also does not address this issue.

THE CONCEPT OF RISK

Especially when the balance of potential harms and benefits from treatment options is close, patient understanding of numerical expressions of risk is central to health decision-making. Yet, many current practices in expressing and communicating risk are not research based. For example, in the field of genetic counseling risk has traditionally been expressed in proportions (1 in 112) rather than in rates (8.9 per 1,000). In two studies, respondents understood rates significantly better than they did proportions (Grimes & Snively, 1999; van Vliet, Grimes, Popkin, & Smith, 2001). Women with little formal education had difficulty understanding risks framed either way.

The European Community guideline descriptions of risk—very common, common, uncommon, rare, and very rare—led to significant overestimation of the likelihood of adverse effects (Berry, Raynor, Knapp, & Bersellini, 2003). And although drugs are exhaustively tested before marketing, the wording in the information sheets that accompany them is not tested at all.

Visual communication of risk is often helpful. Line graphs are excellent for conveying trends, and pie charts help in depicting proportions. Figure 3.1 depicts a visual means of communicating risk. Another helpful approach is to use a common denominator. If risk is expressed as 1 in 25 or 1 in 200, individuals frequently think 1 in 200 is a bigger risk, presumably because the denominator is larger (Paling, 2003).

Clearly, much work remains to be done in developing means of expressing risk reliably understandable by various populations.

END-OF-LIFE DECISIONS

Two ways in which educational interventions can be of help in making end-of-life decisions include encouraging a higher completion rate of advance directives (ADs) and information in managing end-of-life care.

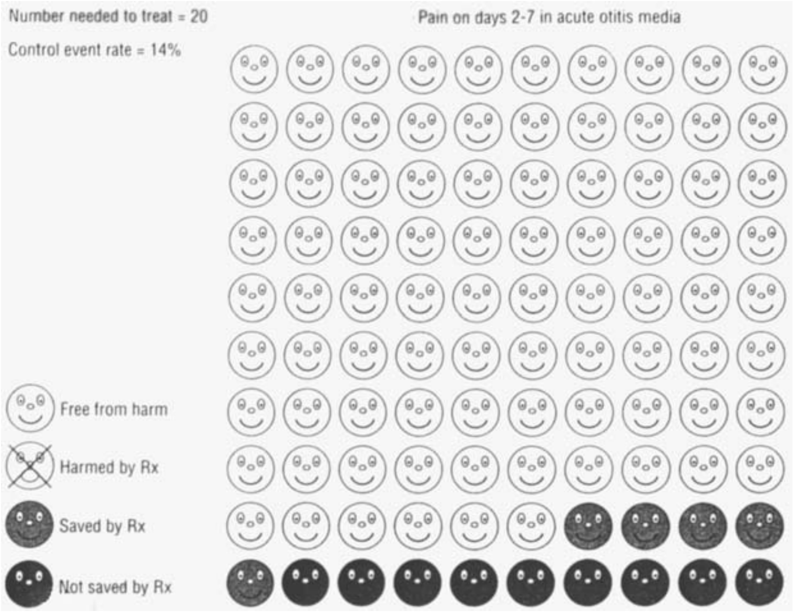

FIGURE 3.1 Visual means of communicating risk.
Portrayal of risk and benefits of treatment with antibiotics for otis media designed with Visual Rx, a program that calculates numbers needed to treat from the pooled results of a meta-analysis and produces a graphical display of the result.

Note. From "Explaining risks: Turning numerical data into meaningful pictures," by B. Edwards, G. Elwyn, & A. Mulley, 2002, *British Medical Journal, 324,* pp. 827–837. Copyright 2002 with permission of the BMJ Publishing Group.

Written materials alone fail to ensure completion of ADs. Supplemented with educational interventions by health care providers, individualized information and counseling sessions, and use of videos and case scenarios result in higher completion rates. Using such interventions, the Let Me Decide AD program showed a 49% completion rate among competent residents and a 78% completion rate among families of incompetent residents. Intervention in nursing homes resulted in fewer hospitalizations per resident and less resource use. However, this program did require investment in a full-time staff member for 6–8 months (Molloy et al., 2000).

At end of life, the balance between encouraging use of advanced supportive technology when it is of benefit, but limiting its burdens when it is ineffective, is frequently difficult to achieve. Because it is difficult for patients and families to accept that technology has become ineffective or will not result in a functional outcome that is acceptable to the patient, access to palliative care is often delayed for dying critically ill patients, and they continue to consume a disproportional amount of intensive care resources. One trial (Lilly et al., 2000) educated patients and family about appropriate clinical milestones and held formal family meetings after the provider team had reached consensus that restoration of function or survival were unlikely. Failure to meet these milestones allowed patient and family to know that advanced supportive technology had been ineffective and that it was time to explore alternatives including palliative care. Intensive communication in this intervention accomplished greater concordance among patients, families, and providers and resulted in fewer preterminal days of intensive care for dying patients. Because this trial was neither randomized nor double-blinded, additional evidence must be sought.

THE ETHICS OF PATIENT EDUCATION

Virtually no dialogue has occurred about special ethical challenges in the practice of patient education. Several points might be made.

1. Patient education poorly done can create harms such as loss of confidence and incapacitating confusion. Since

it is not possible to predict when this will happen, an essential step in patient education is outcome assessment. This is rarely done. In addition, lack of patient education services when they are needed can also cause harm. Likewise, there is no routine surveillance to see how often this occurs; many chapters in this book document patient education not being done.

2. Because paternalistic behavior among providers is still evident, patient education contains opportunities for witting and unwitting coercion/oppression. While it may be possible to achieve the value-free standard expected in genetic counseling, a more realistic goal would be to ensure that the patient's values are utilized and to negotiate or fully discuss those areas in which this is not possible.
3. Throughout this book much evidence has been presented that patient education as it is currently practiced is far less available for those with lesser educational levels and that educational level is significantly related to health outcomes. An old set of assumptions about who can and cannot (the mentally ill, the elderly, etc.) learn is beginning to be challenged. But to an unknown extent, current practice contributes further to oppression and lack-of-life opportunity these groups already experience.
4. Centrality of patient education is significantly different in the professional practice of various health disciplines, most particularly medicine and nursing. A negotiated consensus on the importance of patient education is unlikely. In this situation, each profession should be able to practice according to its philosophical dictates, and the team should be required to work out areas in which the patient could be disadvantaged by such practice. Such a scenario is preferable to the current one in which nursing's professional philosophy is violated in order to

accommodate medicine's. The standards of evidence-based practice should support common practice across disciplines but currently does not.

5. Practitioners should be held responsible for reasonably forseeable patient errors that could be avoided by patient education. Legal and quality-of-care standards to this effect would both protect patients and provide a clear signal that patient education is an accountable element of professional practice.

SUMMARY

Since Western ethics is heavily focused on patient-subject autonomy, many of the transactions involved in clinical care and research depend on patient-subject understanding. In this chapter, three examples have been provided—informed consent, the concept of risk that is essential to informed consent, and end-of-life decisions. Patient education has not been considered as central to bioethics, and although many studies have documented lack of patient-subject understanding, a sense of resignation and inevitability reigns. It does not have to, but even the threat of lawsuit from lack of informed consent does not seem to motivate toward more rigorous practice. We know how to help people understand these and many other concepts central to autonomy and informed decision-making; we just need to decide it's worth investing in. In addition, the long-standing lack of attention to the ethics of patient education must be addressed.

REFERENCES

Berry, D. C., Raynor, D. K., Knapp, P., & Bersellini, E. (2003). Patients' understanding of risk associated with medication use. *Drug Safety, 26,* 1–11.

Brown, R. F., Butow, P. N., Butt, D. G., Moore, A. R., & Tattersall, M. H. N. (2004). Developing ethical strategies to assist oncologists in seeking informed consent to cancer clinical trials. *Social Science & Medicine, 58,* 379–390.

Carpenter, W. T., et al. (2000). Decisional capacity for informed consent in schizophrenia research. *Archives of General Psychiatry, 57,* 533–538.

Criscione, L. G., Sugarman, J., Sanders, L., Pisetsky, D. S., & St. Clair, E. W. (2003). Informed consent in a clinical trial of a novel treatment for rheumatoid arthritis. *Arthritis & Rheumatism, 49,* 361–367.

Daugherty, C. K., Banik, D. M., Janish, L., & Ratain, M. J. (2000). Quantitative analysis of ethical issues in phase I trials: A survey interview study of 144 advanced cancer patients. *IRB, 22*(3), 6–13.

Dresser, R. (2002). The ubiquity and utility of the therapeutic misconception. *Social Philosophy and Policy Foundation, 19,* 271–294.

Dunn, L. B., & Jeste, D. V. (2001). Enhancing informed consent for research and treatment. *Neuropsychopharmacology, 24,* 595–607.

Dunn, L. B., Lindamer, L. A., Palmer, B. W., Golshan, S., Schneiderman, L. J., & Jeste, D. V. (2002). Improving understanding of research consent in middle-aged and elderly patients with psychotic disorders. *American Journal of Geriatric Psychiatry, 10,* 142–150.

Edwards, B., Elwyn, G., & Mulley, A. (2002). Explaining risks: Turning numerical data into meaningful pictures. *British Medical Journal, 324,* 827–830.

Grimes, D. A., & Snively, G. R. (1999). Patients' understanding of medical risks: Implications for genetic counseling. *Obstetrics & Gynecology, 93,* 910–914.

Lidz, C. W., & Appelbaum, P. S. (2002). The therapeutic misconception: Problems and solutions. *Medical Care, 9*(Suppl), V55–V63.

Lilly, C. M., et al. (2000). An intensive communication intervention for the critically ill. *American Journal of Medicine, 109,* 469–473.

Loh, W. Y., Butow, P. N., Brown, R. F., & Boyle, F. (2002). Ethical communication in clinical trials. *Cancer, 95,* 2414–2421.

Mills, N., Donovan, J. L., Smith, M., Jacoby, A., Neal, D. E., & Hamdy, F. C. (2003). Perceptions of equipoise are crucial to trial participation: A qualitative study of men in the ProtecT study. *Controlled Clinical Trials, 24,* 272–282.

Molloy, D. W., et al. (2000). Systematic implementation of an advance directive program in nursing homes. *Journal of the American Medical Association, 283,* 1437–1444.

Paling, J. (2003). Strategies to help patients understand risks. *British Medical Journal, 327,* 745–748.

Stiles, P. G., Poythress, N. G., Hall, A., Falkenbach, D., & Williams, R. (2001). Improving understanding of research consent disclosures among persons with mental illness. *Psychiatric Services, 52,* 780–785.

Stone, T. H. (2003). The invisible vulnerable: The economically and educationally disadvantaged subjects of clinical research. *The Journal of Law, Medicine & Ethics, 31,* 149–153.

van Vliet, H. A. A. M., Grimes, D. A., Popkin, B., & Smith, U. (2001). Lay persons' understanding of the risk of Down's syndrome in genetic counseling. *British Journal of Obstetrics and Gynaecology, 108,* 649–650.

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Chapter 4

Measurement of Patient Education Outcomes

One of the most significant recent advances in patient education is expansion of the number of measurement tools. Most of the 86 currently used measurement instruments included in a recent compilation (Redman, 2003) originated as research instruments or as part of validated and standardized programs of patient education, such as the Arthritis Self-Efficacy Scale developed for use in the Arthritis Self-Management Course. Most have limited amounts of psychometric data available to aid in their interpretation and to have confidence in their use. Little evidence suggests that measurement instruments are used in routine patient care, either to assess patients' need for education or to evaluate the outcomes of interventions.

WHAT IS BEING MEASURED?

Of the perhaps 200 instruments with some psychometric data and relevant to patient education, most are measures of self-efficacy, knowledge or need for information, and beliefs representing theoretical models (as in "lay" models or related to self-management).

Self-Efficacy

Because self-efficacy (SE) is believed to be behavior-specific, measures are needed for each behavior of interest. For example, there is the Children's Arthritis SE Scale (Barlow, Shaw, & Wright, 2001) and one for parents (Barlow, Shaw, & Wright, 2000), as well as one for rheumatoid arthritis (Hewlett et al., 2001). There is the Childbirth SE Scale (Lowe, 1993) and the Breastfeeding SE Scale (Creedy et al., 2003). In diabetes, the Confidence in Diabetes Self-Care Scale (van Der Ven et al., 2003), the Diabetes Management SE Scale for Adolescents with Type I Diabetes (Moens, Grypdonck, & van der Bijl, 2001) and the Foot Care Confidence Scale (Sloan, 2002) test confidence in specific behaviors necessary for diabetes self-management. There is the Seizure SE Scale for Children (Caplin, Austin, Dunn, Shen, & Perkins, 2002), the Epilepsy SE Scale (Dilorio & Yeager, 2003), and the Sickle Cell SE Scale (Edwards, Telfair, Cecil, & Lenoci, 2000). Barnason, Zimmerman, Atwood, Nieveen, and Schmaderer (2002) have developed and tested an SE instrument for coronary artery bypass graft (CABG) recovery.

Scales for women include the Perimenopausal Health SE Scale (Reece & Harkless, 2002), the English-Spanish SE Scale for Breast Self-Examination (Gonzalez & Gonzalez, 1990), and the Contraceptive SE Scale (Levinson, 1986). For pain there is the Chronic Pain SE Scale (Anderson, Dowds, Pelletz, Edwards, & Peeters-Asdourian, 1995) and the Back Pain SE Scale (Levin, Lofland, Cassisi, Poreh, & Blonsky, 1996). For respiratory diseases there is the Asthma SE Scale (Tobin, Wigal, Winder, Holroyd, & Creer, 1987) and the COPD SE Scale (Wigal, Creer, & Kotses, 1991). For parenting, the Infant Care Survey (Froman & Owen, 1989) tests SE in care of infants and the Toddler Care Questionnaire (Gross & Rocissano, 1988) for that age range.

Other SE instruments include the Macular Degeneration SE Scale (Brody et al., 1999), the Preoperative SE Scale (Oetker-Black & Kauth, 1995), the Endoscopy Confidence Questionnaire (Gattuso, Litt, & Fitzgerald, 1992), the Depression Coping SE Scale (Perraud, 2000), the Cancer Behavior Inventory (Merluzzi & Martinez, 1997), and the Medication Adherence SE Scale specifically developed for African Americans with hypertension (Ogedegbe, Mancuso, Allegrante, & Charlson, 2003) and others. Many of these instruments are reviewed elsewhere (Redman, 2003, 2004).

Self-efficacy scales are used to identify individuals who have low confidence in their ability to carry out essential behaviors and to evaluate the effectiveness of interventions designed to develop that confidence (persuasion, identification with another who is successful, and successful trial of the behavior). Item scores provide a way to precisely target areas in which SE is low. For example, several studies show breast-feeding confidence to be a significant factor related to early discontinuation of breast-feeding. Indeed, mothers with higher antenatal Breast-feeding SE Scale scores were significantly more likely to be breast-feeding at 1 week and at 4 months postpartum (Creedy, Dennis, Blyth, Moyle, Pratt, & Vries, 2003). Behaviors of interest in disease entities include ability to cope; accomplish activities of daily living; obtain and sustain social support; control symptoms such as pain, fatigue, and the uncertainty of chronic disease; obtain and take medication; avoid an asthma attack in multiple situations; and carry out self-management activities. Usable scales must have been demonstrated to be sensitive to intervention. In general, a higher SE score is considered better.

Outcomes from higher SE can include a better experience with fewer symptoms, improvement in health status, and decreased health care costs.

Knowledge of or Need for Information

Knowledge or assessment of a patient's or family's felt need for information is similarly specific to a particular domain of knowledge or information. Much has been made of the truism that knowledge is essential but not sufficient to create a change in behavior; this assumes that behavior change is the only valued outcome from patient education. Much evidence shows that patients or families value information for the perspective it provides and almost uniformly believe they do not receive enough from the health care system.

Redman (2003) reviews a number of knowledge instruments including for diabetes, rheumatoid arthritis, asthma, cardiac (including stroke), cancer (including breast and colorectal), maternal serum screening and phenylketonuria tests, Crohn's disease and colitis, osteoporosis, preoperative, schizophrenia, HIV/AIDS, and discharge learning needs. Information needs seem to be particularly high among persons with cancer. Mesters, van den Borne, De Boer, and Pruyn (2001) describe such a measure and test it with individuals with breast cancer, Hodgkin's disease, and head and neck cancer. Greater information needs were found to relate to higher levels of state-anxiety, more depression, and more psychological complaints. Need for information about disease and treatment changes over the course of the illness.

Knowledge assessment instruments also must be checked regularly for current content; for example, treatment patterns changed after the Diabetes Control and Complications and the United Kingdom Prospective Diabetes Study. Also important is precise definition of the domains of knowledge being tested and assurance that each domain is adequately sampled. Some instruments measure knowledge specific to a particular patient education program and cannot be considered universal. Many instruments measure knowledge essential for self-management; infrequently there is clarity about how much knowledge (what score level) is enough. Though patients may have the knowledge, they still may not be able to act on it. Additional instruments to assess information needs and knowledge levels are widely available.

Beliefs

Beliefs are measured for two reasons: (a) they represent a theoretical model that explains health behavior such as the Health Belief Model or (b) they describe a "lay" model by which people commonly understand a health condition. Several examples from the field of pain illustrate the difference. The Pain Stages of Change Questionnaire (PSOCQ) is derived from the Transtheoretical Model, which holds that intentional change requires movement through discrete motivational stages: precontemplation for considering changes, contemplation, preparation for change, taking action to change, and maintenance of change. PSOCQ is used to identify an individual's readiness to self-manage chronic pain. Interventions are matched to the individual's stage (Kerns, Rosenberg, Jamison, Caudill, & Haythomthwaite, 1997). The Pain Beliefs and Perceptions Inventory measures common beliefs about pain such as whether it will be an enduring part of life, that pain is mysterious and poorly understood, or that individuals are to blame for their own pain (Williams, Robinson, & Geisser, 1994).

The Osteoporosis Health Belief Scale is based on the health belief model (susceptibility to and seriousness of osteoporosis, benefits in preventive action, and barriers to accomplishing them) and is especially designed to assess beliefs related to exercise and calcium intake in the elderly. Scores should predict taking of preventive actions to avoid osteoporosis (Kim, Horan, Gendler, & Patel, 1991). The Menopause Representations Questionnaire (MRQ) is based on Leventhal's self-regulation model and measures a range of cognitions about menopause including identity, consequences, time frame, and perceptions of control and cure (Hunter & O'Dea, 2001). MRQ can be used in research of the theoretical model.

Other instruments measure patient beliefs about particular illnesses and provide a target for efforts to change incorrect beliefs or those that interfere with recovery. The Back Beliefs Questionnaire was developed to identify inappropriate beliefs that foster a reluctance toward early return to activities after back pain. Interventions to change those beliefs have been successful (Symonds, Burton, Tillotson, & Main, 1996). The York Angina Beliefs Questionnaire assesses for common misconceptions and maladaptive beliefs among those who have angina, which can then be targeted for change (Furze, Bull, Lewin, & Thompson, 2003).

Self-Management

Advances in self-management of chronic illnesses are discussed in chapter 5. Here, we consider measurement instruments, most of which involve self-report of recommended self-management behaviors. For example, the Self-Care of Heart Failure Questionnaire asks how frequently patients carry out the behaviors, how worrisome certain symptoms would be, and if patients had them, what they did about them. More experienced patients reported limiting their sodium intake and increasing their diuretic dose with a sudden weight gain, as would be expected (Carlson, Riegel, & Moser, 2001). The Epilepsy Self-Management Scale also asks patients to report how frequently they carry out particular self-management activities including safety measures such as not going swimming alone (Dilorio & Henry, 1995).

Other instruments measure skills such as ability to solve problems in self-management. The Diabetes Problem-Solving

Measure for Adolescents provides critical incidents that patients are asked to solve in an interview format. Adolescence is frequently a time of deteriorating glycemic control (Cook, Aikens, Berry, & McNabb, 2001). Finally, the Diabetes Self-Management Profile attempts to assess (again, through self-report) what parts of the complex regimen of exercise, management of hypoglycemia, diet, glucose testing and insulin administration, and dose adjustment individuals with type 1 diabetes are carrying out (Harris et al., 2000).

Other Measures

A cluster of measures focuses on the decision process including conflict experienced while the decision is being made and regret afterward. They are reviewed in Redman (2003).

Lack of culturally competent instruments for measuring relevant predictors, as well as study outcomes for groups such as Mexican American populations, is a barrier to addressing health disparities in non-English-speaking individuals. The work is complicated by low literacy rates in this community. The norm of developing instruments in English for middle-class populations means the instruments need not only to be translated but also to be made relevant to the local culture—a significant investment in time and skill (Brown, Becker, Garcia, Barton, & Hanis, 2002).

Others have described adapting objective structured clinical exams from professional education to lay caregivers. Using simulated patients, stations are set up to assess competencies and rated by faculty. For example, care for a tunneled line includes stations assessing dressing change skill, identification from photos of moisture under dressings and infected line, skill in flushing the line on a chest model, and cap change and contamination to be identified from a video. At each station, learners receive immediate feedback. This is a more realistic method than many reviewed above to assess when family members are adequately prepared to assume caregiving responsibilities or patients to do self-care (Heermann, Eilers, & Carney, 2001).

SUMMARY

Rapid expansion of the number of measurement instruments available in patient education is helpful. Many are in very early stages of development psychometrically, and there is little evidence that those that meet psychometric standards are being used routinely in clinical practice. This means that evaluation is based entirely on clinical judgment, without evidence of the predictive validity of those judgments. Setting of outcome standards (which has not yet been accomplished) would require evidence of meeting them and would perhaps force inclusion of objective measurements in addition to clinical judgment.

REFERENCES

Anderson, K. O., Dowds, B. N., Pelletz, R. E., Edwards, W. T., & Peeters-Asdourian, C. (1995). Development and initial validation of a scale to measure self-efficacy in patients with chronic pain. *Pain, 63,* 77–84.

Barlow, J. H., Shaw, K. L., & Wright, C. C. (2000). Development and preliminary validation of a self-efficacy measure for use among parents of children with juvenile idiopathic arthritis. *Arthritis Care & Research, 3,* 227–236.

Barlow, J. H., Shaw, K. L., & Wright, C. C. (2001). Development and preliminary validation of a children's arthritis self-efficacy scale. *Arthritis Care & Research, 45,* 159–166.

Barnason, S., Zimmerman, L., Atwood, J., Nieveen, J., & Schmaderer, M. (2002). Development of a self-efficacy instrument for coronary artery bypass graft patients. *Journal of Nursing Measurement, 10,* 123–133.

Brody, B. L., Williams, R. A., Thomas, R. G., Kaplan, R. M., Chu, R. M., & Brown, S. I. (1999). Age-related macular degeneration: A randomized clinical trial of a self-management intervention. *Annals of Behavioral Medicine, 21,* 322–329.

Brown, S. A., Becker, H. A., Garcia, A. A., Barton, S. A., & Hanis, C. L. (2002). Measuring health beliefs in Spanish-speaking Mexican Americans with type 2 diabetes: Adapting an existing instrument. *Research in Nursing & Health, 25,* 145–158.

Caplin, D., Austin, J. K., Dunn, D. W., Shen, J., & Perkins, S. (2002). Development of a Self-Efficacy Scale for Children and Adolescents with Epilepsy. *Children's Health Care, 31,* 295–309.

Carlson, B., Riegel, B., & Moser, D. K. (2001). Self-care abilities of patients with heart failure. *Heart & Lung, 30,* 351–359.

Cook, S., Aikens, J. E., Berry, C. A., & McNabb, W. L. (2001). Development of the Diabetes Problem-Solving Measure for Adolescents. *The Diabetes Educator, 27,* 865–874.

Creedy, D. K., Dennis, C. L., Blyth, R., Moyle, W., Pratt, J., & De Vries, S. M. (2003). Psychometric characteristics of the Breastfeeding Self-Efficacy Scale: Data from an Australian sample. *Research in Nursing & Health, 26,* 143–152.

Dilorio, C., & Henry, M. (1995). Self-management in persons with epilepsy. *Journal of Neuroscience Nursing, 27,* 338–343.

Dilorio, C., & Yeager, K. (2002). The Epilepsy Self-Efficacy Scale. In O. L. Strickland & C. Dilorio (Eds.), *Measurement of nursing outcomes: Self care and coping* (Vol. 3, 2nd ed., pp. 40–51). New York: Springer Publishing Company.

Edwards, R., Telfair, J., Cecil, H., & Lenoci, J. (2000). Reliability and validity of a self-efficacy instrument specific to sickle cell disease. *Behaviour Research & Therapy, 38,* 951–963.

Froman, R. D., & Owen, S. V. (1990). Infant care self-efficacy. *Scholarly Inquiry for Nursing Practice, 3,* 199–211.

Furze, G., Bull, P., Lewin, R. J. P., & Thompson, D. R. (2003). Development of the York Angina Beliefs Questionnaire. *Journal of Health Psychology, 8,* 307–315.

Gattuso, S. M., Litt, M. D., & Fitzgerald, T. E. (1992). Coping with gastrointestinal endoscopy: Self-efficacy enhancement and coping style. *Journal of Consulting and Clinical Psychology, 60,* 133–139.

Gonzalez, J. T., & Gonzalez, V. M. (1990). Initial validation of a scale measuring self-efficacy of breast self-examination among low-income Mexican American women. *Hispanic Journal of Behavioral Sciences, 12,* 277–291.

Gross, D., & Rocissano, L. (1988). Maternal confidence in toddlerhood: Its measurement for clinical practice and research. *Nurse Practitioner, 13*(3), 19–27.

Harris, M. A., et al. (2000). Validation of a structured interview for the assessment of diabetes self-management. *Diabetes Care, 23,* 1301–1304.

Heermann, J. A., Eilers, J. G., & Carney, P. A. (2001). Use of modified OSCEs to verify technical skill performance and competency of lay caregivers. *Journal of Cancer Education, 16,* 93–98.

Hewlett, S., Cockshott, Z., Kirwan, J., Barrett, J., Stamp, J., & Haslock, J. (2001). Development and validation of a self-efficacy scale for use in British patients with rheumatoid arthritis (RASE). *Rheumatology, 40,* 1221–1230.

Hunter, M., & O'Dea, I. (2001). Cognitive appraisal of the menopause: The menopause representations questionnaire (MRQ). *Psychology, Health & Medicine, 6,* 65–76.

Kerns, R. D., Rosenberg, R., Jamison, R. N., Caudill, M. A., & Haythomthwaite, J. (1997). Readiness to adopt a self-management approach to chronic pain: The Pain Stages of Change Questionnaire (PSOCQ). *Pain, 72,* 227–234.

Kim, K. K., Horan, M. L., Gendler, P., & Patel, M. K. (1991). Development and evaluation of the Osteoporosis Health Belief Scale. *Research in Nursing and Health, 14,* 115–163.

Levin, J. B., Lofland, K. R., Cassisi, J. E., Poreh, A. M., & Blonsky, E. R. (1996). The relationship between self-efficacy and disability in chronic low back pain patients. *International Journal of Rehabilitation and Health, 2,* 19–28.

Lowe, N. K. (1993). Maternal confidence for labor: Development of the Childbirth Self-Efficacy Inventory. *Research in Nursing & Health, 16,* 141–149.

Merluzzi, T. V., & Martinez, C. S. (1997). Assessment of self-efficacy and coping with cancer: Development and validation of the Cancer Behavioral Inventory. *Health Psychology, 16,* 163–170.

Mesters, I., van den Borne, B., De Boer, M., & Pruyn, J. (2001). Measuring information needs among cancer patients. *Patient Education & Counseling, 43,* 253–262.

Moens, A., Grypdonck, M. H. F., & van der Bijl, J. J. (2001). The development and psychometric testing of an instrument to measure diabetes management self-efficacy in adolescents with type I diabetes. *Scholarly Inquiry for Nursing Practice, 15,* 223–233.

Oetker-Black, S. L., & Kauth, C. (1995). Evaluating a revised self-efficacy scale for preoperative patients. *Association of Operating Room Nurses Journal, 62,* 244–250.

Ogedegbe, G., Mancuso, C. A., Allegrante, J. P., & Charlson, M. E. (2003). Development and evaluation of a medication adherence self-efficacy scale in hypertensive African-American patients. *Journal of Clinical Epidemiology, 56,* 520–529.

Perraud, S. (2000). Development of the Depression Coping Self-Efficacy Scale (DCSES). *Archives of Psychiatric Nursing, 14,* 276–284.

Redman, B. K. (2003). *Measurement tools in patient education* (2nd ed.). New York: Springer Publishing Co.

Redman, B. K. (2004). *Patient self-management of chronic disease.* Boston: Jones & Bartlett.

Reece, S. M., & Harkless, G. E. (2002). Testing of the PHS-ES: A measure of perimenopausal health self-efficacy. *Journal of Nursing Measurement, 10,* 15–26.

Sloan, H. L. (2002). Developing and testing of the Foot Care Confidence Scale. *Journal of Nursing Measurement, 10,* 207–218.

Symonds, T. L., Burton, A. K., Tillotson, K. M., & Main, C. J. (1996). Do attitudes and beliefs influence work loss due to low back trouble? *Occupational Medicine, 46,* 25–32.

Tobin, D. L., Wigal, J., Winder, J. A., Holroyd, K. A., & Creer, T. L. (1987). The Asthma Self-Efficacy Scale. *Annals of Allergy, 59,* 273–277.

Van Der Ven, N. C. W., Weinger, K., Yi, J., Pouwer, F., Ader, H., Van Der Ploeg, H. M., et al. (2003). The confidence in Diabetes Self-Care Scale. *Diabetes Care, 26,* 713–718.

Wigal, J. K., Creer, T. L., & Kotses, H. (1991). The COPD Self-Efficacy Scale. *Chest, 99,* 1193–1196.

Williams, D. A., Robinson, M. E., & Geisser, M. E. (1994). Pain beliefs: Assessment and utility. *Pain, 59,* 71–78.

Chapter 5

Preparation for Patient Self-Management of Chronic Disease

Patient preparation for self-management (SM) should commence if a chronic condition has lasted or is expected to last a year or longer, limits what one can do, and may require ongoing care. Optimum disease management by persons with chronic disease achieves the highest degree of functioning and the lowest level of symptoms given the severity of a condition (Clark, 2003). Table 5.1 provides examples of SM tasks in three common chronic diseases—asthma, diabetes, and heart failure.

Self-management is best taught in a formalized program aimed at teaching skills needed to carry out medical regimens specific to the disease, guide health behavior change, and provide emotional support for patients to control their disease and live functional lives. SM preparation requires that the patient develop skills in problem solving and clinical judgment, self-efficacy, and belief modification and symptom reinterpretation as necessary.

This chapter extends my earlier work (Redman, 2004) by looking briefly at further advances in diseases or symptoms

TABLE 5.1 Self-Management Tasks in Asthma, Diabetes, and Heart Failure

	Asthma	Diabetes	Heart failure
Self-monitoring	Peak flow expiratory rates	Blood glucose level	Daily weight
Recognizing early symptoms and acting upon them	Coughing Wheezing Breathing difficulties	Hypoglycemia Hyperglycemia	Increase of weight Breathing difficulties Thick ankles/feet Coughing, etc.
Medication	Daily inhalation medication	Insulin	Multiple medications
Self-regulated adaptations in medication	Extra medication with symptoms	Adaptation of insulin to blood glucose levels, food intake and activity level	Adaptations of diuretics if agreed upon
Diet[a]		Eating regularly Controlling body weight	Low fat and salt intake Controlling body weight
Lifestyle recommendations[a]	Regular physical exercise No smoking	Regular physical exercise Moderate alcohol	Regular physical exercise No smoking nor alcohol
Disease-specific tasks	No exposure to individual triggers of asthma attacks	Regular foot and eye control	No heavy physical activity

[a] A healthy diet and lifestyle are of course recommended for everyone, here we only refer to the additional recommendations for the three diseases.

Note. Reprinted from "Development, content and process evaluation of a short self-management intervention in patients with chronic disease requiring self-care behaviors," by K. M. G. Schreurs, V. T. Colland, R. G. Kuijer, D. T. D. de Ridder, & T. van Elderen, 2003, *Patient Education Counseling, 51,* pp. 133–141. Copyright 2003, with permission from Elsevier.

for which SM preparation has been acknowledged (cancer, arthritis, mental health, pain, cardiovascular, asthma and chronic obstructive pulmonary disease, and diabetes). It then examines SM preparation for diseases for which there is no well-established tradition but clearly patient need.

UPDATE ON SM PREPARATION FOR COMMON DISEASES

The Arthritis Self-Management Program (ASMP) is perhaps the best-known example of a SM program. It is based on social learning theory with a strong focus on strengthening patient self-efficacy, and taught by persons with the disease. A full review of this program may be found in Redman (2004). A mail-based ASMP called "Self-Management Arthritis Relief Therapy" or SMART uses computer-supported tailored print intervention with a series of interactive questionnaires and responses. Results have been similar to those with the ASMP course. Currently, a Web-based ASMP with an interactive "learning center" where participants can learn self-management techniques, and a "communications center" where participants and leaders can interact by use of bulletin boards and e-mail, is being developed (Fries, Lorig, & Holman, 2003).

The chronic disease most associated with SM is diabetes; a large literature describes preparation for SM of this disease. One of the most difficult skills to teach patients is an adequate level of problem solving to provide good control. Yet, the role of problem-solving skills in diabetes control has received relatively little empirical investigation. A recent study of very low-income inner-city and minority population affirms that those with good control of their disease and those in poor control have similar problems, presented in Table 5.2. Those in good control showed good problem-solving skills, reflected a positive orienta-

TABLE 5.2 Predominant Types of Diabetes Self-Management Problems

Self-management behavior	Themes
Sticking to prescribed diet	• Having to limit salt in addition to sugar • Cooking for others who do not have diet restrictions • Eating at the right times • Limiting favorite foods high in salt or carbohydrates • Breaking old established eating habits • Boredom from maintaining a healthy diet
Managing physical discomfort and functional limitations	• Pain associated with taking insulin injections and SMBG, resulting in desire to not perform behaviors • Exercise limited or prevented by pain in legs and feet from neuropathy, pain in joints from arthritis, and low endurance/fatigue • Undesirable side effects of medications • Vision problems impacting functional ability • Neuropathy impacting functional ability
Integrating self-care into daily living	• Problems integrating medications into schedule (e.g., work, nightshifts, busy days away from home, and wanting to sleep late) • Having to take medications with food, especially taking morning medications and having to eat when not hungry • Integrating exercise into schedule, especially between medication and eating times
Managing diabetes-related stress	• Frustration and anger about having diabetes • Pain and physical discomfort • Impact of diabetes-related problems on interpersonal relationships with family and friends • Problems encountered in health care system (e.g., physician turnover/inconsistency, copayment costs of multiple medications, and securing desired services)

Note. From "A qualitative study of problem solving and diabetes control in type 2 diabetes self-management," by F. Hill-Briggs, C. Cooper, K. Loman, F. L. Brancati, & L. A. Cooper, 2003, *The Diabetes Educator, 29,* pp. 1018–1027. Copyright 2003. Reprinted with permission from *The Diabetes Educator,* American Association of Diabetes Educators, 2003.

tion toward diabetes SM and a rational problem-solving process, and actively used past experience to solve current problems. Those in poor control had poor problem-solving skills with a negative orientation, impulsive or careless or avoidant problem-solving processes, negative transfer of past experience, and an insufficient fund of knowledge. More of these individuals reported having completed formal diabetes education than did those in the good control group. Depression is strongly associated with ineffective problem-solving styles and negative problem-solving orientation, both because the depression reduces problem-solving skills and because poor problem-solving skills exacerbate conditions that lead to depression (Hill-Briggs, Cooper, Loman, Brancati, & Cooper, 2003).

Consistent with the chapter 1 report of patient-centered care, Heisler and others (2003) found that patient adherence was more likely if patients and their doctors shared disease models and agreed on which medical problems were important and how to evaluate therapeutic success. Among 127 patient–care-provider pairs, agreement on top treatment goals and strategies was low, perhaps because collaborative goal setting is not a standard part of chronic disease management in many primary care practices. Since better agreement is associated with improved self-efficacy and self-management, increased patient-provider discussion of treatment goals and specific strategies to meet these goals seems important.

A prior review of standards for SM; evidence of the efficacy and effectiveness of interventions to develop skills, judgment, and confidence; and instruments to measure need and outcome from interventions found much of this infrastructure missing. This deficiency strongly impacts patient morbidity and mortality, patient and family well-being, and economic productivity, yet no organized effort to improve this error exists. Poor, elderly, and uneducated persons suffer disproportionately from this state of affairs. Redman (2004) notes that SM is frequently seen as an add-on to routine medical management including use of pharmaceuticals; the drugs are reimbursed while the SM preparation is not, even if they show equal positive effects. Philosophically, the strong focus on patient compliance with the medical regimen prescribed for them has diverted attention from attempting to understand a person's SM strategies and helping to develop them rather than judging them.

A story of the difficulties a group of patients had with self-management of heart failure provides detail of the challenge before us. Although too small a sample size to be widely generalizable, the learning difficulties these patients depict ring true (Horowitz, Rein, & Leventhal, 2004). These patients did not connect heart failure to their symptoms and did not have a clear understanding of acute and chronic heart failure–related symptoms. Many patients isolated symptoms and attributed them to other illnesses such as dyspnea caused by asthma, unaware they were also related to a weak heart. They didn't understand that they could detect fluid buildup at early stages by regularly assessing their weight and symptoms, and very few believed they could control their symptoms. Most thought diuretics were needed only when their symptoms (such as leg swelling) were severe. Despite strong interest in learning, most had inadequate information about heart failure and were not given the tools to prevent, thwart, or recognize mild or moderate exacerbations.

ORPHAN DISEASES FOR SM PREPARATION

The assumption that SM preparation should be limited to diseases and symptoms for which there is a recognized moderately efficacious medical treatment leaves many individuals suffering psychologically, socially, and economically.

Benign Heart Palpitations

Chapter 2 focused on work describing perception of heart palpitations diagnosed as benign and problematic, and not resolving with prescription of medication and reassurance, and briefly described an educational intervention. Mayou, Sprigings, Birkhead, and Price (2002) describe a randomized controlled trial of a brief, inexpensive intervention that yielded statistically and clinically significant benefit for 78% of patients in the intervention group as opposed to 43% in the control group. Most treated patients returned to what they saw as normal daily activities including involvement in more vigorous exercise. The intervention consisted of a cardiac nurse discussing likely causes of the symptoms and participants' beliefs, brief training in relaxation, and preparation of plans to return to full activities. Patients were confident they could now cope with the symptoms, clear about the implications, and were given the option to contact the nurse by phone if required. Exercise advice, anxiety management, and breathing management were to be undertaken as required.

Ménière's Disease

Another disease without a clear pathophysiology, an ill-defined clinical course, and uncertainty about the efficacy of many approaches to treatment is Ménière's disease. Its early stages are characterized by unpredictable attacks of violent vertigo, nausea, vomiting, visual disturbances, hearing loss, and tinnitus followed by relatively unsymptomatic periods of remission. If the disease becomes stable, vestibular rehabilitation programs (which use specific exercises to improve adaptation or habituation) may be available, but in the meantime patients are left with an extremely disabling disease and no means to SM. Education at early stages of the disease should focus on knowledge of the disease and available treatments, and preparedness for an attack and management of the sequelae (Dowdal-Osborn, 2002).

As many as half of people with Ménière's disease experience some kind of warning symptom. Individuals can be helped to identify (through a diary or journal) a predictive symptom that indicates an attack is imminent. During a vertiginous attack, patients should be taught how to use a visual target to help suppress nystagmus and stabilize their orientation. They also need to learn how to deal with the fatigue, disequilibrium, sensitivity, and nausea that frequently immediately follow an attack. Patients are frequently unaware of strategies to improve their safety and function and become socially isolated. Even though answers about cause, progression, and treatment are lacking, patients can still develop confidence and skill to take control of this disease through validation, realistic reassurance, and pertinent education (Dowdal-Osborn, 2002).

Chronic Obstructive Pulmonary Disease

SM preparation for chronic obstructive pulmonary disease (COPD) has not been established. Forty to fifty percent of patients with COPD discharged from the hospital are readmitted during the following year, frequently with an acute exacerbation. A randomized controlled trial of SM preparation showed hospital admissions for exacerbations of COPD decreased 40% more in the intervention group as compared with the usual care group; admissions for other health problems decreased by 57%, emergency room visits by 41% (32% in intervention group and 44% in the usual care group) and unscheduled physician visits by 59%. The intervention used a SM workbook and a plan of action to develop skills in: breathing and coughing techniques, employing energy conservation and relaxation, preventing and controlling symptoms through inhalation techniques, using a plan of action for acute exacerbations, living a healthy lifestyle, and carrying out a home exercise program (Bourbeau, 2003).

Bipolar Disorder

Bipolar disorder (manic-depressive psychosis) is a common mental illness characterized by two types of relapse—mania and depression. Five studies have shown identifiable and consistent prodromal symptoms of manic or depressive relapse at 2–4 weeks before full relapse in most patients with bipolar disorder. These prodromal symptoms are idiosyncratic to both the patient and to type of relapse (mania or depression). In a randomized controlled trial, teaching patients to recognize early symptoms of manic relapse and seeking early treatment is associated with clinical improvements in time to first manic relapse, social functioning, and employment. The intervention had no effect on time to first relapse or the number of relapses with depression. Producing and rehearsing an action plan to use once these prodromes have been recognized by the patient was central, as was recording them on a card in laminated plastic, carried by the patient (Perry, Tarrier, Morriss, McCarthy, & Limb, 1999). Colom et al. (2003) showed these effects could be created in a group (8–10 patients) psychoeducation format.

Chronic Pain Management in the Community

The prevalence of chronic pain problems among community-dwelling elderly persons is 58-70% and among older persons living in nursing homes 45-80%. Wellness-oriented pain management preparation in these communities is rare. One study (Ersek, Turner, McCurry, Gibbons, & Kraybill, 2003) describes delivery of a 7-week pain management preparation program in group format versus an educational booklet control condition. A no-attention control group was not used. Subjects had had pain that interfered with regular activities for more than 3 months. The experimental intervention provided basic education in pain mechanisms, pain self-management, and pharmacologic and nonpharmacologic therapies with a strong focus on regular practice of pain management skills, setting and working toward individualized pain management goals, and repeated practice of relaxation and pain coping skills. The self-management group showed significantly greater pre- to posttreatment improvement in pain intensity and physical role function than did the educational booklet control group. By 3 months similar proportions in each group had clinically significant improvement in pain, suggesting need for relapse prevention booster sessions. These individuals were highly motivated to participate in self-management approaches.

Highly Active Antiretroviral Therapy (HAART) for HIV-Infected Patients

Current data suggest patients must take 95% or more of HAART doses to maintain suppression of viral replication, that failure rates increase as adherence levels decrease, and that lack of strict adherence is a cofactor in clinical progression to AIDS. Because physicians have diverse ways of communicating with patients about adherence, a formalized psychosocial and behavioral intervention to improve patients' adherence to HAART has been highly recommended. A randomized controlled trial of an education/counseling intervention versus standard care yielded higher adherence in this group. A standardized intervention delivered by specially trained nurses through a session right after enrollment and then every 2 months included enhancement of patient self-efficacy skills; improvement in knowledge and personal beliefs about the disease and medications; and identification of fears, anxieties, uncertainty, and depressed mood (Pradier et al., 2003).

SUMMARY AND NEXT STEPS

Self-management preparation for chronic disease is one of the most well-defined purposes of patient education and probably the one with the highest potential for benefit. Yet, it remains underdeveloped with inadequate investment. Self-management preparation is distinctive in always incorporating problem-solving and skill development with significant practice in real-life contexts, to the point of mastery and generalization to all areas of life functioning, and development of self-efficacy. In some instances alteration of beliefs and attitudes is included. Video-assisted modeling, guided practice, role-playing, homework assignments, and assistance of family members in reinforcing the skills are important teaching methods. Relapse prevention and continued education at various intervals are required elements of such preparation, in part to adapt to changes in the chronic disease, the person, and the environment.

Most programs do not adequately address the impact of comorbidities on self-management, especially when the regimens for these various diseases make seemingly incompatible self-management demands.

It is also important to check to see whether preparation for intensive management of chronic disease leads to increased feelings of burden and negative well-being or quality of life. One study found that among diabetics, detrimental effects on adjustment and quality of life, depression, and anxiety did not accompany self-management preparation (Steed, Cooke, & Newman, 2003).

Since proven models for self-management preparation now exist for many chronic diseases, they provide a "gold standard." Unevaluated and inadequate programs should be replaced (Clark, 2003).

REFERENCES

Bourbeau, J., Julien, M., Maltais, F., Rouleau, M., Beaupre, A., Begin, R., et al. (2003). Reduction of hospital utilization in patients with chronic obstructive pulmonary disease. *Archives of Internal Medicine, 163*, 585–591.

Clark, N. M. (2003). Management of chronic disease by patients. *Annual Review of Public Health, 24*, 289–313.

Colom, F., Vieta, E., Martinez-Aran, A., Reinares, M., Goikolea, J. M., Benabarre, A., et al. (2003). A randomized trial on the efficacy of group psychoeducation in the prophylaxis of recurrences in bipolar patients whose disease is in remission. *Archives of General Psychiatry, 60*, 402–407.

Dowdal-Osborn, M. (2002). Early vestibular rehabilitation in patients with Meniere's disease. *Otolaryngology Clinics of North America, 35*, 683–690.

Ersek, M., Turner, J. A., McCurry, S. M., Gibbons, L., & Kraybill, B. M. (2003). Efficacy of a self-management group intervention for elderly persons with chronic pain. *The Clinical Journal of Pain, 19*, 156–167.

Fries, J. F., Lorig, K., & Holman, H. R. (2003). Patient self-management in arthritis? Yes! *The Journal of Rheumatology, 30,* 1130–1132.

Heisler, M., Vijan, S., Anderson, R. M., Ubel, P. A., Bernstein, S. J., & Hofer, T. P. (2003). When do patients and their physicians agree on diabetes treatment goals and what difference does it make? *Journal of General Internal Medicine, 18,* 893–902.

Hill-Briggs, F., Cooper, D. C., Loman, K., Brancati, F. L., & Cooper, L. A. (2003). A qualitative study of problem solving and diabetes control in type 2 diabetes self-management. *The Diabetes Educator, 29,* 1018–1027.

Horowitz, C. R., Rein, S. B., & Leventhal, H. (2004). A story of maladies, misconceptions and mishaps: Effective management of heart failure. *Social Science & Medicine, 58,* 631–643.

Mayou, R., Sprigings, D., Birkhead, J., & Price, J. (2002). A randomized controlled trial of a brief educational and psychological intervention for patients presenting to a cardiac clinic with palpitation. *Psychological Medicine, 32,* 699–706.

Perry, A., Tarrier, N., Morriss, R., McCarthy, E., & Limb, K. (1999). Randomised controlled trial of efficacy of teaching patients with bipolar disorder to identify early symptoms of relapse and obtain treatment. *British Medical Journal, 318,* 149–153.

Pradier, C., et al. (2003). Efficacy of an educational and counseling intervention on adherence to highly active antiretroviral therapy: French prospective controlled study. *HIV Clinical Trials, 4,* 121–131.

Redman, B. K. (2004). *Patient self-management of chronic disease.* Boston: Jones & Bartlett.

Schreurs, K. M. G., Colland, V. T., Kuijer, R. G., de Ridder, D. T. D., & van Elderen, T. (2003). Development, content and process evaluation of a short self-management intervention in patients with chronic diseases requiring self-care behaviours. *Patient Education & Counseling, 51,* 133–141.

Steed, L., Cooke, D., & Newman, S. (2003). A systematic review of psychosocial outcomes following education, self-management and psychological interventions in diabetes mellitus. *Patient Education & Counseling, 51,* 5–15.

Chapter 6

Advances in the Delivery of Patient Education

The benefits that education can bring are constantly expanding to new groups of patients, frequently requiring specialists who will ensure delivery of these services. These opportunities become available because research documents patient needs (congenital heart disease, urinary incontinence), a standard of care becomes clear (recovery from whiplash, diabetes), or new provider roles and delivery of care patterns are tested (low birthweight infants, high risk pregnancy, elders with cardiac diagnoses).

EXAMPLES OF NEW AREAS OF NEED

Like much back pain, after clinical assessment to rule out fractures or dislocation, patient information on whiplash injury should focus on its self-limiting nature, with advice to return to normal activities as soon as possible. Collars, rest, and negative beliefs are believed to delay recovery and contribute to chronicity. Patients are commonly frightened of movement and pain. Headache, arm pain, jaw pain, and dizziness are common and, it is suggested, are not areas of concern. Evidence also suggests that development of chronic symptoms is influenced by psychological, social, or cultural factors. There is almost no patient education literature on whiplash. A randomized clinical trial (RCT) should rigorously test whether delivery of this advice to patients results in improved outcomes (McClune, Burton, & Waddell, 2002).

Congenital heart disease is in many cases a chronic disorder because of the residual effects and sequelae of corrective or palliative procedures. These patients are thus prone to complications such as atrial arrhythmias, bacterial endocarditis, congestive heart failure, or pulmonary vascular disease. Adult patients with congenital heart disease have been found lacking in knowledge about their disease, treatment, and prevention of complications. Yet, understanding is associated with less distress and confusion, more satisfaction with care, and an improved emotional state. One study (Kamphuis, Verloove-Vanhorick, Vogels, Ottenkamp, & Vliegen, 2002) showed that a minority of patients with mild lesions and a majority of those with complex anomalies experienced difficulties in daily life directly related to their cardiac disease and felt they were insufficiently informed about their disease. Another study has shown poor understanding of symptoms of deterioration of the heart disease, risk factors of endocarditis, impact of smoking and alcohol on the heart disease, and the hereditary nature of the condition (Moons et al., 2001).

GENETICS LITERACY

Genetics is the study of biological variation. Today, patients and families must be able to evaluate the credibility of genetic information that has implications for personal health.

Many genetic misconceptions exist. In the example of breast cancer, people believed that genes are inherited in groups, so an individual who shows more resemblance in personality or physical appearance with relatives who have the disease is perceived to be more likely to develop the disease (Decruyenaere et al., 2000). In a family with familial adenomatous polyposis, members were not reassured with a blood test and requested to continue to have bowel screening. They didn't understand how a blood test works to predict a disease located in the bowel (Michie, Smith, Senior, & Marteau, 2003). Studies in the United Kingdom showed widespread beliefs that cancer may skip a generation, physical and character resemblances are related to those in a family who are affected and those who are not, and a person is likely to develop cancer at the same age as it developed in their nearest relative who had the disease. In addition, they had difficulty appreciating inheritance of breast or ovarian cancer via male family members (Meiser et al., 2001).

Cultural factors also affect understanding of genetic issues and acceptance of approaches to dealing with them. In Asian and Middle Eastern cultures, genetic counseling is less than acceptable because it involves disclosure of private and shameful (cancer) information to strangers. In Cambodia, some believe that a forebear, through his or her actions, can create a disease that will be transmitted to the offspring, to emerge in the second or third generations (Meiser et al., 2001). Clearly, work on genetic literacy has just begun.

NEW ROLES AND DELIVERY OF PATIENT EDUCATION SERVICES

While it is well recognized that persons with diabetes must be educated in self-management, this task is immense and can be accomplished more effectively. For example, 1 in 10 acute hospital beds is occupied by patients with coexisting diabetes, frequently admitted for vascular complications. An RCT of standard inpatient care for adults with diabetes with an intervention of a diabetes specialist nurse found a 3-day reduction of inpatient length of stay without any adverse impact on readmission rates and associated with improvements in diabetes knowledge and satisfaction with care, compared with those without such an intervention. The intervention included education and management assistance for patients and case-based feedback toward staff. Cost of the specialist nurse was easily offset by decrease in length of stay (Davies, Dixon, Curriet, Davis, & Peters, 2001).

In a similar RCT, a nurse care management system was designed to improve outcomes in patients with complicated and long-standing diabetes, with one or more major medical comorbid conditions and HbA1c of more than 10%. Patients in the experimental group met with a nurse care manager to establish individual outcome goals, attended group sessions once a week for up to 4 weeks, and received phone calls to manage medications and self-care activities. At 1 year, the mean decrease in HbA1c, total cholesterol, and LDL cholesterol were significantly greater in the intervention group compared with the usual care group and without increasing physician visits. Forty-three percent of these patients were able to achieve an HbA1c of less than or equal to 7.5%—impressive because these patients were selected on the basis of lack of control (Taylor et al., 2003).

Two U.K. studies document effectiveness of specialist nurse-led interventions to treat and control hypertension and hyperlipidemia in diabetes. In these settings, diabetes specialist nurses managed their own caseload, initiating and titrating drugs for glycemic control, and in this extended role saw patients with hypertension or hyperlipidemia in the diabetes center every 4 to 6 weeks for 30- to 45-minute appointments until biological targets were achieved. At these visits, lifestyle modifications were reinforced and reviewed and medications adjusted. In this trial, significantly more subjects randomized to the specialist nurse-led clinic achieved target level than did those who received normal care (New et al., 2003). Similar results were found by a different group of U.K. investigators using a hypertension nurse who emphasized need for tight blood pressure control, gave nonpharmacologic advice for healthy living, discussed problems with medication side effects, and initiated treatment changes (Denver, Barnard, Woolfson, & Earle, 2003).

Urinary incontinence is common and problematic, particularly for women. The nurse continence advisor role was established in England in 1974 and in Canada in 1995. These advisors follow a caseload of patients and provide consultation and educational services to generalist nurses (Skelly & Kenny, 1998).

Finally, a series of seven studies by Brooten et al. (2002) of transition care from hospital to home, delivered by advanced practice nurses (APNs) has shown excellent results. Patient education is a dominant part of this intervention. Groups chosen were vulnerable, high-volume and high-cost patient groups of women with high-risk pregnancies, women with unplanned cesarean births, and elders with cardiac medical and surgical diagnoses. Transitional care consisted of patient and caregiver preparation for discharge including patient demonstration of basic knowledge and skills, take-home materials, and a series of home visits with daily APN telephone availability and physician backup. Groups with APN-provided transition care were rehospitalized for less time and at less cost, reflecting early detection and intervention.

An RCT of a similar intervention to predominantly Latino and African American adolescent mothers, from the time of pregnancy through 2 years postpartum, showed lower total days of non-birth-related infant hospitalizations, fewer infants seen in ERs, and 15% lower repeat pregnancies than the control group. Results were sustained for a year following program termination and clearly decreased the higher rates of morbidity and unintentional injuries and hospitalizations seen in children of adolescents compared with children of adult mothers. The experimental group received preparation-for-motherhood classes and intense home visitation from public health nurses including training in self-management skills, life planning and decision-making, handling emotions, and coping with stress and depression. The control group had traditional public health nursing (Koniak-Griffin et al., 2003).

Just as advanced practice nursing roles have always included a major emphasis on patient education, now a traditional teaching role—that of the Certified Diabetes Educator (CDE) is expanding into diabetes clinical management as well as encompassing patient education. In 2000, a new credential was launched—Board Certified-Advanced Diabetes Manager (BC-ADM). It is available to nurses, dietitians, and pharmacy practitioners who hold an advanced clinically relevant degree and demonstrate skill including providing therapeutic problem solving, counseling, and regimen adjustment for patients with diabetes. In 2003, 300 individuals had earned this credential (Valentin, Kulnarni, & Hinnen, 2003).

Some countries such as Sweden have significantly developed nurse-led patient education and follow-up services. Between 1990 and 1998, nurse-led heart failure clinics opened in two thirds of all Swedish hospitals (Stromberg et al., 2003). Asthma educators are also being introduced in U.S. hospitals.

There is a fascinating description of a new role in transplantation, the family support counselor, whose responsibility is to provide bereavement support and unbiased education to enable families to make an informed decision about organ donation (Sade et al., 2002). The role resulted from division of the procurement coordinator position into five new positions including the bereavement counseling and education service. A major focus was on helping families of potential donors understand brain death and transplantation. The concept of brain death is widely misunderstood; it is believed to be something less than "real" death. The natural tendency to deny that death has occurred is reinforced by the belief that brain death is not really death, that there is hope even when death has been pronounced. Most hospitals are apparently not prepared to provide the lengthy support and specialized education now encompassed in this new role.

Remarkably, over a period of 4 years, the donation rate increased from 18.2 to 33.6 donors per million of population, while despite intensive educational efforts aimed at the general public, national rates remained virtually unchanged. The support service and aftercare program are not linked in any way to consent for donation and should not be. Although documented only as a case study in South Carolina's organ procurement organization, the family support counselor role addresses a need. Other research (DeJong et al., 1998) has documented a low level of understanding of brain death, particularly among nondonor families.

EMERGING OPPORTUNITIES WITH INTERNET-BASED PATIENT EDUCATION

Much of the patient education-oriented literature about the Internet decries the variable quality of the content. In 1996 the Health On the Net Foundation Code of Conduct (HONcode) was established to designate those sites with high quality information with its logo. A study of 99 sites so designated found their average readability level to be more than 10th grade. Average reading levels of U.S. residents is grade 8 and of those in Medicare and Medicaid programs grade 5; thus, 87% of HONcode-designated sites could be expected to be difficult for the average adult population to read (Kusec, Brborovic, & Schillinger, 2003).

As persistent as these difficulties with content and readability are, there have been significant advances in patient education using the Internet, frequently fully integrated with ongoing care. Four examples are cited here.

An interactive Internet site for management of patients with congestive heart failure is described by Delgado, Costigan, Wu, and Ross (2003). Because these patients are best managed by close follow-up, an Internet communicative Web site was used as a daily communication method between patients and health care providers. Patients were instructed to enter their first morning weight, heart rate, and blood pressure, and each day a research nurse examined this information, instructing whether to increase or decrease the diuretic according to weights and symptoms, asking the patient to obtain blood work, and reinforcing patients' education.

Many patients with type 1 diabetes are treated with intensive insulin regimens that they can adjust on a day-to-day basis according to food intake, activity levels, and other factors such as alcohol intake. These individuals can consume a relatively normal diet as long as they assess their carbohydrate intake in order to titrate their insulin doses. A patient education program utilizing Dias Net computer model (a decision support system) to display and manipulate patient data can be used as a training exercise in carbohydrate assessment and insulin dose adjustment. On their PCs, patients enter blood glucose values, insulin doses, and a food diary. From the data entered, a computer model generates a simulation of the blood glucose concentrations for the date collection period. I could then suggest alternative insulin doses or regimens or meal sizes to decrease the risk of hypo- and hyperglycemia. This system can highlight possible causes for erratic control. The educational program using this system consists of 4 weekly sessions for groups up to six, in which patient data for the prior 4 days are analyzed and discussed. This intervention improves overall diabetic control and increases confidence in self-management (Cavan, Everett, Plougmann, & Hejlesen, 2003).

Yet another approach with chronic disease management involves a randomized controlled trial supplementing traditional verbal and printed asthma education received by both groups of children and parents, with interactive multimedia asthma education. This was an Internet-enabled program using a secure server to deliver and customize tutorial sessions and to support communication between patients and the health care team. The experimental group had fewer asthma symptom days, emergency department visits, and a significantly lower-average dose of inhaled corticosteroids. The increase in knowledge in children was related to less frequent use of quick-relief medicine and fewer urgent physician visits (Krishna et al., 2003). It is important to note that the experimental treatment contained much superior instructional elements, which might have had the same effects delivered face-to-face. Yet, use of the Internet to reach large numbers of individuals and families inexpensively is an advantage that may help to improve the number of patients who receive needed patient education.

In many instances cancer education is focused on the time of diagnosis and active treatment, with little available for those later phases of managing the disease. The Life After Cancer Internet Web Site and message board were created at a comprehensive cancer center to provide information on different types of cancer treatments, late effects, and research findings. Message boards are also useful tools for sharing information with others who have similar experiences with social re-entry, recurrence, or secondary cancers. Message board discussions are monitored by staff to ensure appropriateness of content, and the home page contains a statement to clarify the institution's position about absence of a doctor-patient relationship, patient confidentiality, and the institution's right to delete messages that fail to comply with established standards. At HealthBoards.com, individuals have a choice of communicating through more than a hundred message boards, all concerned with health issues (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003).

These examples are experimental programs, not routinely available.

SYSTEM INDICATORS OF DELIVERY OF PATIENT EDUCATION SERVICES

Some local surveys in the United States show worsening of patient education care. Even though national guidelines published in 1997 for the diagnosis and management of asthma emphasized patient education, a survey of teaching hospitals with training programs in pulmonary and critical-care medicine showed only 64% having a formal asthma patient education program (Peterson, Strommer-Pace, & Dayton, 2001).

Between 1996 and 2001, a survey of asthma services in emergency departments (EDs) in Chicago found a significant decrease in use of instruction to inform patients what to do in the event of inability to attend their follow-up appointment (a written asthma action plan). While ED care in metropolitan Chicago had improved in some areas of care and worsened in others, most aspects of asthma care had continued to fall short of national asthma guidelines. It is likely that formal education according to a protocol was given to fewer than half of all patients. A similar portion received a written asthma action plan. The reasons for lack of more widespread ED asthma care improvements are not clear, although the increase in utilization and overcrowding of EDs may be a factor (Lenhardt, Malone, Grant, & Weiss, 2003).

SUMMARY

These are only examples of groups in need of patient education and of roles developing to meet these needs. They represent research studies documenting effectiveness of teaching interventions; little is known about how widely available these services are.

REFERENCES

Brooten, D., Naylor, M. D., York, R., Brown, L. P., Munro, B. H., Hollingsworth, A. O., et al. (2002). Lessons learned from testing the quality cost model of advanced nursing (APN) transitional care. *Journal of Nursing Scholarship, 34,* 369–375.

Cavan, D. A., Everett, J., Plougmann, S., & Hejlesen, O. K. (2003). Use of the Internet to optimize self-management of type 1 diabetes: Preliminary experience with DiasNet. *Journal of Telemedicine and Telecare, 9*(Suppl. 1), 50–52.

Davies, M., Dixon, S., Curriet, C. J., Davis, R. E., & Peters, J. R. (2001). Evaluation of a hospital diabetes specialist nursing service: A randomized controlled trial. *Diabetic Medicine, 18,* 301–307.

Decruyenaere, M., Evers-Kiebooms, G., Welkenhuysen, M., Denayer, L., & Claes, E. (2000). Cognitive representations of breast cancer, emotional distress and preventive health behaviour: A theoretical perspective. *Psycho-oncology, 9,* 528–536.

DeJong, W., Franz, H. G., Wolfe, S. M., Nathan, H., Payne, D., Reitsma, W., et al. (1998). Requesting organ donation: An interview study of donor and nondonor families. *American Journal of Critical Care, 7,* 13–23.

Delgado, D. H., Costigan, J., Wu, R., & Ross, H. J. (2003). An interactive Internet site for the management of patients with congestive heart failure. *Canadian Journal of Cardiology, 19,* 1381–1385.

Denver, E. A., Barnard, M., Woolfson, R. G., & Earle, K. A. (2003). Management of uncontrolled hypertension in a nurse-led clinic compared with conventional care for patients with type 2 diabetes. *Diabetes Care, 26,* 2256–2260.

Kamphuis, M., Verloove-Vanhorick, S. P., Vogels, T., Ottenkamp, J., & Vliegen, H. W. (2002). Disease-related difficulties and satisfaction with level of knowledge in adults with mild or complex congenital heart disease. *Cardiology in the Young, 12,* 266–271.

Koniak-Griffin, D., Lesser, J., Nyamath, A., Uman, G., Stein, J. A., & Cumberland, W. G. (2003). Nurse visitation for adolescent mothers. *Nursing Research, 52,* 127–136.

Krishna, S., Francisco, B. D., Balas, E. A., Konig, P., Graff, G. R., Madsen, R. W., et al. (2003). Internet-enabled interactive asthma education program: A randomized trial. *Pediatrics, 111,* 503–510.

Kusec, S., Brborovic, O., & Schillinger, D. (2003). Diabetes websites accredited by the Health On the Net Foundation Code of Conduct: Readable or not? In R. Baud, M. Fieschi, P. LeBeaux, & P. Ruch (Eds.), *The new navigators: From professionals to patients.* Amsterdam: IOS Press.

Lenhardt, R., Malone, A., Grant, E. N., & Weiss, K. B. (2003). Trends in emergency department asthma care in metropolitan Chicago. *Chest, 124,* 1774–1780.

McClune, T., Burton, A. K., & Waddell, G. (2002). Whiplash associated disorders: A review of the literature to guide patient information and advice. *Emergency Medicine Journal, 19,* 499–506.

Meiser, B., Eisenbruch, M., Barlow-Stewart, K., Tucker, K., Steel, Z., & Goldstein, D. (2001). Cultural aspects of cancer genetics: Setting a research agenda. *Journal of Medical Genetics, 38,* 425–429.

Michie, S., Smith, J. A., Senior, V., & Marteau, T. M. (2003). Understanding why negative genetic test results sometimes fail to reassure. *American Journal of Medical Genetics, 119A,* 340–347.

Moons, P., et al. (2001). What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart, 86,* 74–80.

New, J. P., et al. (2003). Specialist nurse-led intervention to treat and control hypertension and hyperlipidemia in diabetes (SPLINT). *Diabetes Care, 26,* 2250–2255.

Peterson, M. W., Strommer-Pace, L., & Dayton, C. (2001). Asthma patient education: Current utilization in pulmonary training programs. *Journal of Asthma, 38,* 261–267.

Sade, R. M., Kay, N., Pitzer, S., Drake, P., Baliga, P., & Haines, S. (2002). Increasing organ donation: A successful new concept. *Transplantation, 74,* 1142–1146.

Schultz, P. N., Stava, C., Beck, M. L., & Vassilopoulou-Sellin, R. (2003). Internet message board use by patients with cancer and their families. *Clinical Journal of Oncology Nursing, 7,* 663–667.

Skelly, J., & Kenny, K. (1998). The impact of the nurse continence advisor on continence care. *Clinical Effectiveness in Nursing, 2*(4), 4–9.

Stromberg, A., Martensson, J., Fridlund, B., Levin, L-A, Karlsson, J-E, & Dahlstrom, U. (2003). Nurse-led heart failure clinics improve survival and self-care behaviour in patients with heart failure. *European Heart Journal, 24,* 1014–1023.

Taylor, C. B., et al. (2003). Evaluation of a nurse-care management system to improve outcomes in patients with complicated diabetes. *Diabetes Care, 26,* 1058–1063.

Valentine, V., Kulkarni, K., & Hinnen, D. (2003). Evolving roles: From diabetes educators to advanced diabetes managers. *Diabetes Spectrum, 16,* 27–31.

Chapter 7

Mental Health Psychoeducation: A Case Example

Mental health is the latest field of health practice to incorporate patient education, called in this field, "psychoeducation." It follows earlier fields, beginning with diabetes, cardiovascular, and then respiratory diseases and arthritis in establishing the need for education, programs, and public campaigns to deliver it, a body of research that supports and directs it, and eventually measurement instruments and standards of practice. As noted in earlier chapters, the major fields of health practice have moved through all but the last two steps on this continuum, although none has yet made effective education available to all who need it. Since mental health is at the earliest stages of the continuum of incorporation of patient education into its practice, it represents a case study of the logic and organizational actions that accompany this transition.

Mental health's use of the term "psychoeducation" reflects an effort to incorporate educational interventions into its dominant psychotherapeutic treatment modality. The nature of the disorders (disturbed thought processes) no doubt led people to conclude that patients could not learn to care for themselves, and a past tradition of complete provider dominance meant patients did not have rights to learn information and skills. The earliest educational target was compliance with physician-prescribed treatment, believed to be especially important in those cases in which medication was administered for controlling symptoms and avoiding relapse. Most development of psychoeducation occurs by disease entity such as depression and bipolar disease, schizophrenia, dementia, and eating disorders and is driven by significant social need. The number of individuals suffering from these disorders is immense, causing significant disability and economic loss. The hope is to understand those areas in which psychoeducation can provide benefit by itself or in combination with other therapies. Discussion of patient preparation for self-management of these disorders may be found in Redman (2004).

DEPRESSION

A meta-analysis of 69 programs to decrease depression found those using educational methods showing an effect size of .27 and those not using educational methods an effect size of .14. The overall effect size for all interventions was .22, which represents an 11% improvement of the experimental group over the control. Programs with larger effect sizes used multiple component interventions including competence enhancement techniques and 60- to 90-minute sessions. Given the large population of individuals suffering from depression, effect sizes of this magnitude could make a large difference if implemented widely (Jane-Llopis, Hosman, Jenkins, & Anderson, 2003). A further summary of 25 articles found a substantial and significant relationship between depression and noncompliance with treatment regimen; the association between anxiety and noncompliance was variable and overall nonsignificant (DiMatteo, Lepper, & Croghan, 2000).

Psychoeducationally oriented treatments lend themselves well to self-administration. Bibliotherapy is widely used for depression, showing an effect size of .83 (large). The effect size is similar with self-administered treatments for anxiety, although they usually incorporate check-ins with a clinic or a degree of observation (Mains & Scogin, 2003). There are very few data to suggest patients for whom self-administered treatments may be best suited. While few of the numerous self-help books have been empirically tested, those used in clinical trials showed an average effect size roughly equal to that in psychotherapy trials (McKendree-Smith, Floyd, & Scogin, 2003).

A psychoeducational group for those who screened positively for possible postnatal depression (PND) reduced the level of depressive symptoms in comparison with a group in routine primary care. The intervention included educational information about PND—strategies for coping with difficult childcare and eliciting social support, use of cognitive-behavioral techniques to deal with women's erroneous cognitions about motherhood and to provide strategies for coping with anxiety, and instructions on the use of relaxation. While the effect was maintained 6 months after the group had ended, some women continued to show evidence of depressive symptomatology (Honey, Bennett, & Morgan, 2002). While only a single small study, this work is typical in mixing educational interventions with those from other theoretical origins. Since 13% of childbearing women will experience an episode of minor or major depression, it is important to know whether these findings can be widely generalized. Societal-level solutions dealing with isolation and stress in new mothers are generally not identified; instead, women are to be helped to develop the cognitive and emotional stamina for them to endure what may be fair, untenable, or even threatening situations (Lloyd & Hawe, 2003).

BIPOLAR DISORDER

Bipolar patients are at risk for relapse even when undergoing optimal pharmacotherapy. Two examples of randomized controlled trials of psychoeducational interventions showed similar decrease in depression and longer relapse-free intervals. Colom et al. (2003) provided fully compliant, complex bipolar patients with standard psychotherapeutic care and for the experimental group psychoeducation in groups of 8–12 and for the control noneducational meetings. Twenty sessions of 90 minutes focused on content and on exercises to develop illness awareness, treatment compliance, early detection of prodromal symptoms and relapse, and lifestyle regularity. At the end of the follow-up period, 36% of the control group and 8% of the treatment group had been hospitalized (significantly different at .01).

Likewise, Miklowitz, George, Richards, Simoneau, and Suddath (2003) provided psychoeducation to bipolar patients who were also receiving pharmacotherapy, and to their families. This randomized controlled trial provided family-focused psychoeducation in 21 sessions over 9 months following an episode of bipolar illness, and to the control group crisis management. The psychoeducational treatment taught about the disorder and provided communication-enhancement training and problem-solving skills. Again, the experimental group had longer relapse-free intervals and less depression during the 2-year follow-up.

Similar effects were found in four of five controlled trials of caregiver training for dementia. Such training was found effective in decreasing behavioral problems in the patients and in delaying institutionalization (Teri, 1999).

ILLNESS MANAGEMENT AND RECOVERY

It is becoming widely recognized that people with severe mental illness can participate actively in their own treatment. Illness management skills, ranging from greater knowledge of psychiatric illness and its treatment to coping skills and relapse prevention strategies, play a critical role in people's recovery from mental illness. While patient preparation to use some of these strategies is available in some settings, no empirically supported programs (such as the Arthritis Self-Management Program) are in widespread use (Mueser et al., 2002). This represents the level of development of these services.

Other challenges face the mental health field in full development of an appropriate patient education (psychoeducation) model. A nationally representative sample of adults with a self-reported mental health problem were found to have lower literacy than did other adults, even when education and other predictors of literacy were controlled. Low literacy is likely to limit the accuracy and validity of standardized diagnostic and outcome measures and to mean that written and educational materials are not understood by the patients. In addition, persons with low literacy may be unable to understand medication labels or follow their often complex medical regimens (Sentell & Shumway, 2003).

MEASUREMENT INSTRUMENTS FOR PSYCHOEDUCATION

A performance-based measure of medication management for persons with schizophrenia (Medication Management Ability Assessment or MMAA) uses role play of simulated prescribed medication regimens and asks the patient to hand the required pills (dried beans) to the tester at the appropriate time. MMAA requires 15 minutes to administer. Its 1-week test-retest reliability was .96. In general, patients undermedicated significantly in this test, with patients performing less well than normal controls and those with more severe cognitive deficits performing worst. Next steps in development of the MMAA include comparison with drug blood levels, and prospective and intervention trials to determine its sensitivity to changes in psychiatric symptoms (Patterson et al., 2002).

While research is very important to progress in treating mental health problems, there is a concern that ill subjects may not be able to understand well enough to provide informed consent to research participation. Buckles et al. (2003) have devised a test of the elements of informed consent in the Code of Federal Regulations (see Table 7.1) for a simple nontreatment research protocol and found that those with very mild and mild dementia could answer them while those with moderate dementia could not. Trials with more complex designs including placebo randomization and serious adverse events may be much more difficult to understand. The authors suggest developing such a test for each trial, to provide an objective measure of this one element (understanding) for informed consent. It should be noted that mildly demented individuals benefited from repetition of the informed consent information.

SUMMARY

In general, psychoeducation for persons with mental health problems focuses on improving the patient's and family's illness management skills, decreasing affective relapse and interepisode symptoms, and improving functional outcome. Development and testing of interventions and measurement of outcomes are at early stages of development.

TABLE 7.1 Test Items With Correct Responses and Percent Correct by CDR Group

	Test items	Correct response	CDR 0	CDR 0.5	CDR 1	CDR 2
1.	You are here for a birthday party. (Element 1)	No	100	100	99	82
2.	You are here to volunteer for a research study. (Elements 1 and 8)	Yes	100	99	91	67
3.	Part of today's tests include a chest x-ray. (Element 1)	No	99	95	78	64
4.	You will be asked questions to test your memory and thinking. (Element 1)	Yes	100	99	96	85
5.	Information from this research study may help people who have memory problems. (Element 3)	Yes	100	100	97	85
6.	You may benefit from learning about any memory problems you may have. (Element 3)	Yes	100	99	93	82
7.	A frequent side effect from taking part in this study is the development of a rash. (Element 2)	No	100	99	96	88
8.	You may become tired from answering questions. (Element 2)	Yes	79	65	63	55
9.	You will be asked to return for repeat evaluations every year. (Element 1)	Yes	100	100	97	82
10.	The confidential information we collect from you will be published in the newspaper. (Element 5)	No	98	99	92	67
11.	You can choose to stop answering our questions at any time. (Elements 4 and 8)	Yes	99	99	97	91

The elements referred to in this table correspond to the Elements of Informed Consent as stated in the Code of Federal Regulations discussed in Instrument Development.

CDR = Clinical Dementia Rating. 0 = no dementia; 0.5 = very mild dementia; 1 = mild dementia; 2 = moderate dementia.

Note. From "Understanding of informed consent by demented individuals," by V. D. Buckles et al. (2003), *Neurology, 61,* pp. 1662–1666.

REFERENCES

Buckles, V. D., Powlishta, K. K., Palmer, J. L., Coats, M., Hosto, T., Buckley, A., et al. (2003). Understanding of informed consent by demented individuals. *Neurology, 61,* 1662–1666.

Colom, F., Vieta, E., Reinares, M., Martinez-Aran, A., Torrent, C., Goikolea, J. M., et al. (2003). Psychoeducation efficacy in bipolar disorders: Beyond compliance enhancement. *Journal of Clinical Psychiatry, 64,* 1101–1105.

DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment. *Archives of Internal Medicine, 160,* 2101–2107.

Honey, K. L., Bennett, P., & Morgan, M. (2002). A brief psychoeducational group intervention for postnatal depression. *British Journal of Clinical Psychology, 41,* 405–409.

Jane-Llopis, E., Hosman, C., Jenkins, R., & Anderson, P. (2003). Predictors of efficacy in depression prevention programmes. *British Journal of Psychiatry, 183,* 384–397.

Lloyd, B., & Hawe, P. (2003). Solutions forgone? How health professionals frame the problem of postnatal depression. *Social Science & Medicine, 57,* 1783–1795.

Mains, J. A., & Scogin, F. R. (2003). The effectiveness of self-administered treatments: A practice-friendly review of the research. *Journal of Clinical Psychology, 59,* 237–246.

McKendree-Smith, N. L., Floyd, M., & Scogin, F. R. (2003). Self-administered treatments for depression: A review. *Journal of Clinical Psychology, 59,* 275–288.

Miklowitz, D. J., George, E. L., Richards, J. A., Simoneau, T. L., & Suddath, R. L. (2003). A randomized study of family-focused psychoeducation and pharmacotherapy in the outpatient management of bipolar disorder. *Archives of General Psychiatry, 60,* 904–912.

Mueser, K. T., Corrigan, P. W., Hilton, D. W., Tanzman, B., Schaub, A., Gingerich, S., et al. (2002). Illness management and recovery: A review of the research. *Psychiatric Services, 53*(10), 1272–1284.

Patterson, T. L., Lacro, J., McKibbin, C. L., Moscona, S., Hughs, T., & Jeste, D. V. (2002). Medication management ability assessment:

Results from a performance-based measure in older outpatients with schizophrenia. *Journal of Clinical Psychopharmacology, 22,* 11–19.

Redman, B. K. (2004). *Patient self-management of chronic disease.* Boston: Jones & Bartlett.

Sentell, T. L., & Shumway, M. A. (2003). Low literacy and mental illness in a nationally representative sample. *The Journal of Nervous and Mental Disease, 191,* 549–552.

Teri, L. (1999). Training families to provide care: Effects on people with dementia. *International Journal of Geriatric Psychiatry, 14,* 110–119.

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Chapter 8

Summary of the Current State of Patient Education

In many areas, interesting and important advances are being made in patient education, some of them addressing long-standing issues. The ability to train individuals to more accurately interpret bodily symptoms is one such advance. A gradual move (but certainly not yet in full bloom) toward patient centeredness is expressing itself in such areas as patient "lay models" of disease and the necessity of understanding and addressing their accuracy and congruence with provider perspectives. And new areas of need are emerging because of advances in scientific knowledge (genetics) or very beginning substitution of basic legal standards with ethical standards of good practice, such as truly informed consent in research and clinical practice.

Summaries of the quality of care provided in the United States, including patient education, continue to disappoint. A recent survey of adults living in 12 metropolitan areas and their medical records showed participants received 55% of recommended care, varying widely across medical conditions and processes of care. By far the worst provider compliance with standard of care occurred with counseling or education;

18.3% of patients received this recommended care. In comparison, medication was appropriately provided in 69% and physical examination in 63% of care. These deficits, which pose serious threats to the health and well-being of the U.S. public, persist despite initiatives by both the federal government and the private health care delivery systems to improve care (McGlynn et al., 2003).

An anonymous medication safety self-assessment undertaken by American hospitals showed lowest scores in patient education. About two thirds of respondent hospitals reported that physicians and nurses inconsistently educated patients about their drug therapy. Written information about critical drugs was sometimes provided to patients in 61% of respondent hospitals and always provided in 21% of hospitals. Respondents in 23% of surveyed hospitals reported that criteria for an automatic consultation by a pharmacist for patient education had been established (Smetzer et al., 2003).

A survey of a nationally representative sample of women of childbearing age in the United States ($N = 55{,}712$) indicated that more than 40% of them were unaware that treatment exists to prevent mother-to-child transmission of HIV. Even among pregnant women, who according to practice guidelines should be receiving counseling and the offer of HIV testing as early as possible in prenatal care, only 64.7% were aware that effective treatment exists to prevent perinatal HIV transmission. These data suggest that women of childbearing age, particularly those of lower education and socioeconomic status, could benefit from more education about the effectiveness of perinatal HIV transmission interventions (Anderson, Ebrahim, & Sansom, 2004).

Much smaller studies show disappointing results, even in areas in which patient education has been well established for years. For example, Kline, Martin, and Deyo (1998) found a lack of knowledge about typical postpartum health in focus groups of new mothers and clinicians, with mothers feeling unprepared for the health consequences of pregnancy and delivery. Decreased functioning was reported months after delivery. Women often felt poorly prepared for the postpartum period in part because functional health consequences of childbirth are not well understood; recovery time and effect of obstetrical interventions on long-term maternal health status are relatively understudied issues. Confidence in parenting and psychological adjustments to it were recurrent subthemes.

Yet other studies continue to demonstrate usefulness of patient education. For example, a randomized controlled trial of educational preparation for endoscopic exams showed a significant association with success of the exam. Cancellation of procedures because of poor preparation occurred in 4.39% of targeted education patients versus 26.31% of those who did not receive education and 15.38% of those who received phone instruction. Patients who did not attend educational sessions had a sixfold higher rate of procedural failures than those who did. Besides the accompanying risk to the patient of repeated procedures (bleeding, perforation, and complications from sedation) were additional days lost from work and school and additional use of medications, equipment, and staff time. Lack of education for preparation for procedures costs money (Abuksis et al., 2001).

BRIEF HISTORICAL DEVELOPMENT OF PATIENT EDUCATION

A historical look at patient education back to the 1970s provides perspective on its development. Popularity of *learning theory* has moved from behavioral to cognitive, then to social cognitive, and now to constructivism. *Models of health behavior* used to direct educational interventions began with the Health Belief

Model (emphasizing perceptual severity, susceptibility, and barriers), then to the PRECEDE model (emphasizing predisposing factors) and the transtheoretical (stage-based) model of behavior change; all are currently still in use. In the 1970s description of *patients' rights* first occurred, very gradually beginning to displace provider domination of the field. This trend has continued with the patient- and family-centered philosophy and recognition that some things are best learned from other patients. By the 1990s JCAHO had incorporated patient education into *accreditation standards*, perhaps in response to a Picker Institute study that showed one third of hospital patients had not been told about clear danger signals to watch for on discharge.

By the end of the 1980s a significant *research base* had accumulated and continues to grow. During the 1990s, *measurement instruments* continued to be produced. Validated educational programs for each of the common chronic diseases have now morphed into well-defined self-management programs that cross disease entities. Indeed, patient education has become more *differentiated* into self-management preparation, event management (such as for procedures), caregiver competency and coping, and crucial public safety issues such as communicable disease and blood donation.

Much more developed *provider roles* have also emerged as preparation for patient education practice has become well incorporated into degree programs for nurses. Currently, nurse-managed clinics for chronic diseases combine disease monitoring, case management and patient education functions very effectively. Pharmacists' roles in drug counseling and in clinical pharmacy in general added great strength.

URGENTLY NEEDED DEVELOPMENT

Some of the issues most urgently in need of resolution in order to professionalize patient education, are rarely addressed. Following are perhaps the several foremost issues remaining to be tackled.

1. *Ability to characterize or describe the active ingredients in educational interventions in order to study their effectiveness individually or in combination, thus to replicate them clinically or in research studies.* In a review of studies of patient education programs for adults with asthma (77 projects with 94 interventions), Sudre, Jacquemet, Uldry, and Perneger (1999) found most reports did not specify the educational objectives (60%); duration of education (45%) and number of sessions (22%) were often not recorded. It is important to note that the educational field in general has not solved this issue. Evidence to date suggests that time sufficient to reach mastery and presence of elements social learning theory posits to increase self-efficacy are critical.
2. *Use of objective measures (psychometrically sound instruments) to supplement clinical judgments in making assessments of adequacy of learning and thus of the need for and adequacy of educational interventions.* While examples of instruments well suited to the applied nature of patient education exist, they are rare. Most were developed for and appear to be used in research. There is little evidence of their use in routine clinical practice even though objective tests are very common in biologically based clinical medicine.
3. *Outcome standards for patient education, separated from disease outcome or more general outcomes of medical practice.* Redman (2004) has shown these are strikingly absent for preparation for self-management of chronic disease. In general, event management education has more well-accepted outcomes such as anxiety reduction, better preparation for diagnostic exams and quicker recovery.

4. *Delivery systems that ensure outcomes that meet standards and serve all patients.* This deficit is perhaps the most worrisome of all. While there is widespread evidence that people with less formal education and those of disadvantaged backgrounds have fewer of the verbal and numeracy skills to benefit from the usual version of patient education, there is little comprehensive evidence as to who gets access to these services and whether that access is biased against certain groups. What little information exists suggests that most patient education delivery systems are haphazard. Although the Internet offers an opportunity to provide education to large numbers of individuals, Web sites are still plagued by inaccurate information presented at high reading levels, and most innovative applications are still experimental.
5. *Full use of patient education to create safety.* An alarming study from Norway provides an example (Lindstrom & Rosvik, 2003). It found that nearly 40% of blood donors had inadequate knowledge about the immunological window period (the period of about 3–7 weeks after contamination), during which ordinary antibody tests will not detect HIV antibodies. During the window period, one is completely dependent on the donor's honest and correct understanding of the demands for donating blood. In addition, the questionnaire used to exclude donations from donors with drug abuse or multiple sexual partners, was ambiguous and could be interpreted several different ways. Since it is absolutely crucial that donors are adequately informed about the risks pertaining to the immunological window period, one wonders why mandatory patient education with outcomes tested by a sophisticated measurement instrument are not required.

SUMMARY

A field that lacks adequate description of its interventions and outcomes and a haphazard delivery system is not yet professionalized. Clearly, people must learn to take care of their health needs. The exceedingly slow evolution of patient education does not reflect a low priority need; rather, it reflects lack of priority on this development on the part of the provider community and its institutions. Because patients and families are increasingly expected to care for themselves and because significant developments in fields such as reproductive, transplantation, and genetic medicine now have significant impact on individuals, patient education is ever more critical.

REFERENCES

Abuksis, G., Mor, M., Segal, N., Shemesh, I., Morad, I., Plaut, S., et al. (2001). A patient education program is cost-effective for preventing failure of endoscopic procedures in a gastroenterology department. *The American Journal of Gastroenterology, 96,* 1786–1790.

Anderson, J. E., Ebrahim, S. H., & Sansom, S. (2004). Women's knowledge about treatment to prevent mother-to-child human immunodeficiency virus transmission. *Obstetrics & Gynecology, 103,* 165–168.

Kline, C. R., Martin, D. P., & Deyo, R. A. (1998). Health consequences of pregnancy and childbirth as perceived by women and clinicians. *Obstetrics & Gynecology, 92,* 842–848.

Lindstrom, T. C., & Rosvik, A. (2003). Ambiguity leads to uncertainty: Ambiguous demands to blood donors. *Scandinavian Journal of Caring Sciences, 17,* 74–77.

McGlynn, E. A., Asch, S. M., Adams, J., Keesey, J., Hicks, J., DeCristofaro, A., et al. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine, 348,* 2635–2645.

Redman, B. K. (2004). *Patient self-management of chronic disease.* Boston: Jones & Bartlett.

Smetzer, J. L., Vaida, A. J., Cohen, M. R., Tranum, D., Pittman, M. A., & Armstrong, C. W. (2003). Findings from the ISMP medication safety self-assessment for hospitals. *Joint Commission Journal on Quality and Safety, 29,* 586–597.

Sudre, P., Jacquemet, S., Uldry, C., & Perneger, T. V. (1999). Objectives, methods and content of patient education programmes for adults with asthma: Systematic review of studies published between 1979 and 1998. *Thorax, 54,* 681–687.

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