

PATIENT EDUCATION AND SELF-CARE*

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ABSTRACT

This author clarifies the philosophical, strategic, and operational differences between patient education as traditionally practiced and self-care education as a relatively new initiative. The essential and most fundamental distinction has to do with locus of control in health care. Patient education generally accepts the role of the patient, as a recipient of services where compliance to appropriate, professionally defined health care regimens is a valued outcome. Self-care education, in contrast, attempts to build an individual's capacity to self-diagnose, self-treat, and in general self-sustain their health. Patient education views people as health consumers; self-care views people as "prosumers," *both* consumers and self-providers. Self-care education places the individual primarily on the supply side of the health care equation with important consequences for the professional care system, the individual, and the community.

The concept of patient education communicates its intent easily among health professionals and laypeople. Of course, the nuance of strategy and content are another matter. But the essence of intent remains: to teach the patient those ideas and skills which will be effective in coping with immediate medical problems and even, perhaps, in health maintenance and disease prevention. The precise boundaries of activities defined as patient education are often determined by the realities of a particular institution rather than the idealism of health education philosophers. This is not to denigrate the role of those of us who build models. I only am suggesting that time, values, place, personalities, priorities, and sometimes the patients themselves profoundly influence what ultimately emerges in practice.

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Thus, if we set aside the accepted academic and professional criteria as the basis for accounting, I think we would be surprised to note that almost all hospital inpatient and outpatient institutions could (using their *own* criteria) point to some form of activity they label as patient education. I hope it is not too cynical to say that patient education has achieved some degree of motherhood status. Out and out opponents to *any* form of patient education are an embattled minority, perhaps devilishly clever in blocking the progressive growth of patient education in more generous and contemporary terms, but on the whole, impotent in stamping it out entirely. Critics are limited in their attacks to issues of for whom the service should be provided (issues of access), what should be taught (issues of patient privilege), who should teach it (issues of *professional* privilege), and the nature of evaluation (issues of process vs outcomes). Now, these are all serious concerns and they engender lively debates (some of which we may engage in here). The fact remains, however, that we have gone remarkably far beyond the earlier and more fundamental arguments of to be or not to be. And that, I submit, given the snail-like pace of changes in professional values and the rigidities of institutional habits, is not at all bad. After all, patient education as a purposeful, organized endeavor has been with us for less than one professional generation and we have come to *assume* its legitimacy if not the nature of its impact.

All is well so far. Patient education is recognized by the American Hospital Association and the Blue Cross Association, although reimbursement has yet to supplant rhetoric. But this will surely come. It is now a matter of finding the right formula (I am told) which will assure quality, equity, and accountability of educational services rendered.

The search for ways and means of financially securing patient education is, of course, heightened by the fiscal crisis facing institutions. Hospital operators, both administrative and professional are anxious to at least recover costs—even if it only involves parsing out the existing components of medical care and labeling some of them as patient education, but it contributes to the institution's survival effort. As painful as it is to face it, face it we must. Patient education is becoming an attractive interest in terms of its income producing potential and, even more significantly, its potential for bending patient behavior to accommodate the needs of the system. Now, you say, what matters the motive as long as the programs continue and may be expanded? A moment's reflection reveals the problem: interest in income producing or efficiency enhancing health services is in profound conflict with values of prevention, much less health promotion. In concentrating on income efficiency producing services we restrict our goals and strategies to those whose effects, while of obvious benefit in disease-specific patient care, will not threaten long range institutional or professional security and will not weaken the labor intensive character of professional health care. As long as patient education does not tamper with the fundamental locus of control resident in the caregiver's role, it is a safe and appealing undertaking. We can com-

fortably offer patients' skills in care which are not competitive with professional services for various reasons including lack of professional interest or availability of professional resources, e.g., maintenance management of arthritis and diabetes.

During most of this decade there is evident a rising sentiment among health educators for more emphasis on health education's "practical" contributions in systems and economic benefits. Suggested high priority outcome values have included reduced broken appointments, increased bill payments, reducing the likelihood of malpractice suits, maximizing use efficiency of professional resources, and reducing delay and increasing patient compliance.

Many have expressed the view that patient education cannot become a universal benefit until its contributions to the care system are demonstrated. One need not labor the painful irony of such an empty victory beyond pointing out the self-defeating "benefit" of equal access to the social control of the medical trust.

But enter now a new perspective on health education which challenges both the economic and philosophic lifelines of professional health care services. Let me give an example of one reaction. Recently, in considering the hospitals role in promoting *self-care* oriented health education, a state hospital association committee concluded with the following question:

Is it counterproductive, from a practical financial standpoint, for hospitals, which derive the greatest part of their resource from inpatient care, to urge courses of action for people which, if followed, may conceivably reduce hospital income?

One must admire the honesty of the query if not its insensitivity to the public good. It is also a demonstration of how some perceive the difference in economic terms between orthodox patient education and self-care education. What are some of the other perceived differences? Let me highlight a few that stand out clearly. I shall exaggerate the distinctions for the sake of clarity, but I believe the points are generally valid.

The most obvious distinction between patient education and self-care education is captured clearly in the terms themselves.

Patient education assigns a unique social role to the learner—that of a sick person under the care of another. Self-care education makes no necessary assignment of sickness thereby assuming a generic meaning of care, i.e., to look after. And in an *autonomous* way. Patient education goals are initiated in response to a state of diseases. Self-care educational goals, in contrast, are generally anticipatory of risk.

These are radically different starting points for formulating educational objectives, methods, and measurement of outcomes. Patient educators can apply a clinical approach as the physician would in planning therapy: diagnose the needs, decide on acceptable outcomes, select a method appropriate to the condition of the patient, administer the educational treatment, and observe results. Im-

plicit in this educational strategy is the professionals responsibility to help the patient achieve optimal compliance with professionally prescribed health behavior. Granted that some professional and patient goals may often be identical, the fact is that professional regulation of the process and outcomes avoids the opportunity to reinforce the shift in locus of control resulting from the transfer of skills to the patient. Phrased another way: the methods of patient education, aside from matters of content, are not usually coordinate with the aim of reducing dependency. For example, patient education algorithms, protocols, decision-trees, and instruction tear sheets may be considerably more useful to patients than the virtual doctor-patient communications vacuum which they fill. But we must be aware that these devices are the product of the professionals' construction of reality and thus, by definition, are strategies which standardize and regulate the health behavior of the patient. Beyond the direct political consequences of this regulation of behavior, is the potentially serious iatrogenic effect of deprecating, reducing, or even shutting down the patient's own autonomous healing capabilities. The result could be further increase and reenforcement of patient dependency with all of its counterproductive effects. This is transparently a danger which could co-opt the patient as a malleable component in the professional health care system; as a minor stockholder in the complex firm of medical care.

Self-care education derives its goals from the learner's perceived needs and preferences regardless of their conformity to professional perceptions of the learner's needs. Outcomes are learner determined and correspond to their choices regarding risk avoidance (and non-avoidance). Content is learner determined. Similarly, learner preferences for educational methods are honored. Evaluation follows criteria proposed by the learners. Both content and methods in self-care education contribute to shifting the locus of control in health decision-making and health care from the professional to the layperson. This educational approach is not viewed as therapeutic in the sense of modifying client behavior to improve health status, although clearly the health status can be expected to benefit—but on the learner's terms. The results may not always conform to professional values, particularly when the layperson opts for quality of life values in preference to quality of health values. And as we are aware at the level of our own personal experience, health and happiness are not synonymous and, indeed, are often not correlated. What we can expect from the self-care orientation is a lowering of dependency and its negative sequelae.

Patient education and self-care education differ on substantive bases as well as educational strategy. The most single difference has to do with the range of learner concerns which are perceived by the educator as legitimate and/or appropriate. When dealing with prevention and risk reduction, patient educators usually have in mind the *insultive* diseases and disabilities caused by biological, psychological, and environmental factors. There has been negligible interest in the control of *assaultive* diseases; namely, those caused by the health care givers.

To be sure, there are patient education programs which include information on how to use the health care system. Criteria and guidelines are offered regarding when to seek professional care; information on what services are available and on what basis is explained; and, in the case of in-patient education, there has been a good deal of emphasis on assisting the patient in making a good adjustment to the hospital, i.e., understanding hospital routine. Considered together, the “how to use the system” component of patient education may have saved some bruises, but it by and large reflects the expectation of the patient having to adapt to the system rather than encouraging awareness of the hazards of medical care, how to reduce risk of iatrogenic illness, and how to change the system to conform to patient needs and preferences.

Self-care education, often born out of people’s desire to avoid or reduce iatrogenic illness (note self-care in the feminist clinics), gives special emphasis to lay skills in the *management* of the professional care system. The themes represented by such works as Arthur Levin’s *Talk Back to Your Doctor* (1975) and Marvin Belsky’s *How to Choose and Use Your Doctor* (1975) are central to self-care education. It is, of course, understandable that education for iatrogenic control, as it were, is more feasible when undertaken in the nonstressful circumstances of people not already under care. One can imagine the difficulties the institutionally based patient educator would have in cautioning the patient regarding the potential dangers of the care she is now receiving. Further, patients are often too sick, too frightened of retaliation, or too embarrassed to demand information or question authority.

There is another substantive distinction which can be made between patient education as now practiced and self-care education. Patient education is often designed to impart new knowledge and skills in situations where it is assumed that the patient has little or no previous experience, e.g., taking insulin. Self-care education, with more diffuse goals of health promotion and decision making and disease prevention, detection and treatment at the level of primary care relies heavily on already established knowledge and skills, many in the category of traditional family health practices or home remedies, and on autonomous self-healing capabilities. Education in self-care, assumes that *most* if not all of such practices are either appropriate and beneficial or at least not harmful. Studies by Elliott-Binns (1973) in Britain and Poul Pedersen (1976) in Denmark found that 90 percent of health practices undertaken by patients prior to seeking a medical contact were relevant. Self-care builds on those current lay practices and supplements with medical-technical concepts, strategies, and skills not previously in the domain of family remedies or for that matter, public health education.

Patient education usually refers to patients of allopathic caregivers—those professions we customarily think of as part of, the mainstream, Western medical culture. Self-care education, while largely focusing on and giving emphasis to the transfer of allopathic skills to lay use, does not preemptorally exclude other healing strategies captured in the concept of holistic medicine. This is par-

ticularly important with regard to strategies of health promotion and chronic disease management and the role of an individual's personal resource of mind and body in diagnosing, monitoring, and healing.

A fourth substantive distinction between patient education as generally practiced and self-care education is the latter's relating personal health status to forces in the environment (Milio, 1977). Patient education appears to focus on the individual's personal health behavior and the activities in which the individual can exercise personal control, e.g., diet, lifestyle, dental prophylaxis. This, of course, is a valid focus. But as we awaken to the astonishing role environment appears to play in the etiology on exacerbation of many chronic diseases, it is necessary to consider skills that effect social change as well as personal risk reduction. Self-care education, therefore, attempts to place individual protection into the broader context of social protection. Here the goal is to avoid the "blaming-the-victim" orientation of some preventive health education efforts and help the learner identify these factors in society, the community, which are complicit in disease production and for which solutions require social action. Self-care education again is concerned with strengthening the lay resource in health as a civil as well as personal resource. Demystification of enviropolitics is as crucial as demystification of medical care practices.

Matters of educational methods also may be a basis for distinguishing patient education and self-care education. Methods used by the patient educator are those appropriate to learning specific skills (hence active learner trials under supervision) or strategies related to problem-solving, i.e., skills in self-observation and knowledge of how to use resources effectively. Self-care educators clearly employ similar techniques but go beyond these to include exercises designed to center health control in the individual. The key strategy here is to encourage circumstances where problem-posing skills are acknowledged and supported. That is where the power of health control begins, not in the mechanics of problem-solving per se. He who defines the problem defines the range of solutions. Paulo Freire in *Pedagogy for the Oppressed* (1973) offers a helpful elaboration of educational strategies appropriate to the goal of shifting the locus of health control from professional to layperson. It is not enough to transfer skills or even concepts. The educational method itself must exemplify the experience of gaining fundamental control over one's health destiny.

I have contrasted patient education and self-care education in an effort to dramatize what appear to me to be nodular distinctions. The comparisons were not intended to be invidious, but rather to provoke discussion which may help in clarifying the values we assign to *all* health education activity. It is clear that what is meant by self-care education communicates some goals, some methods, some outcomes which may be at variance with counterpart aspects of patient education. But it is equally clear to those involved with patient education and self-care education that it is dangerous to stereotype either. There surely are instances where patient education is aggressively testing the margins of its'

orthodox traditions; and it is equally true that there are self-care education programs timorously avoiding incursions into the professional domain of skills. Nevertheless, I think we are justified in characterizing at least the historical thrust of patient education and the current tenor of plans for promulgating self-care education. Health educators, health planners, and health service administrators sense the difference although the whats and wherefors are allusive. There is debate, even anger expressed; all are wholesome indications of the growing acknowledgment of health education's crucial role in the next round of changes in health in our society.

There is no doubt in my mind that health education, generically speaking, is entering a period of rapid transition as a result of forces beyond our control or effect (Levin, Katz, & Holst, 1976). Changes in morbidity patterns (chronic disease rising from 30 to 80% of all diseases in a 40-year period), demographic shifts, accelerated transport and communication, and significant potentials in society's mediating institution (Berger, 1977) (family, neighborhood, church, voluntary associations) all operate to effect not only health needs, but preferences and priorities. On the other hand, some professionals have come to accept certain values and beliefs about society's interests and intentions as givens. Indeed, when evidence is marshalled which threatens these assumptions, the reaction is predictably negative. This is particularly true when there is evidence of one's own agency's culpability in causing or exacerbating the very needs or problems we seek to abate. In-patient education is a case in point. The hospital environment may in itself be hostile to the educational goal of reducing patient dependency. Nurses dispensing medication by dose and physicians' refusal to provide medical records to patients are examples. We don't always practice what we preach; indeed, we often send out double signals to our clients. Is it possible—or even moral—to attempt to reduce patient dependency through education when the very environment in which that education takes place has the effect of increasing dependency?

The question before us now is should patient education adopt a stronger self-care orientation beyond its present boundaries of service associated with an individual's patienthood? Some argue that it should and must (Simonds, 1977). Others point out the danger in further extending the influence of the health professions in our lives (Zola). My own view is that we should *not* strive for synonymity among programs in self-care and patient education. Each has some unique contributions to make that in their own way are timely and appropriate. I am not convinced that the hospital patient is in the best position to learn about issues of life-style, health promotion, and protection from iatrogenic assault. Conversely, I need to be shown evidence that education regarding the management of disease for which a healthy individual may some day be at potential risk is practical and lasting.

My preference would be for us to recognize that health education is a continuous process where organized programs for learning can be planned in a reason-

ably systematic way; where we respond without compromise or control to the learning needs of people for growth, fulfillment and freedom and maximum self-use sufficiency; and where each component of the health education enterprise is consistent in adherence to these values.

It appears that the demand for health education reflects a wider interest in gaining more self-control in an increasingly "massified" society. The magnitude of demand for health information specifically and the diversity of interest involved is not waiting for health education planners to do much planning. Marketplace demand has encouraged the growth of a health education industry. In my view, the impact of this phenomenon on self-care has been, on the whole, positive and relatively free of exploitation, although we must be exceedingly vigilant here. Patient education, on the other hand, has not fared so well. Commercializing of patient education in the predigested, pre-packaged forms is an obvious money-maker. The ominous aspect of this trend is the nature of their intended use, casting suspicion on both their content and methods. One supplier of patient education materials, for example, promises that their approach will leave the patient "... less frightened . . . more cooperative . . . less likely to sue" (Patient Audio Visual Information System, Inc.). It sounds like a prefrontal lobotomy. *That* brand of patient education in its extreme is easily recognized as inconsistent with self-care values. But it is the more subtle forms of repressive content in patient education which cause most of the trouble. Examples are the concepts of compliance and cooperation. Patient educators must examine these concepts as potentially hazardous to the patient's health. Compliance and cooperation, we must be aware, are *not* necessarily in the exclusive or even primary interest of the patient (Cousins, 1976). If we encourage questioning decision-making active patients we must anticipate and honor the potential benefits of disobedience.

As the self-care interest in society advances, we should be able to discern important changes in patterns of illness, if not disease. People's rejection of clinically defined and labeled deviance at the psychological, social, and economic levels will be their major interest. And we see this now in the form of 500,000 mutual aid or self-help groups. Five million people are turning to the support group as a resource to avoid or overcome the disabling effects of social and professional labeling. Yet, most members of categorical disease or disability groups remain in medical care contact. These groups are an impressive resource in concert with patient education. Here is an area where patient educators can make a major contribution through referral while at the same time forswearing the temptation to manage the group. Unfortunately, signs of this latter possibility already are present and ominous (Parsell & Tagliareni, 1974). Control of the mutual aid group would only serve to destroy the benefits of the lay initiative in self determination in health and dilute the meaning of mutual aid. On the other hand, patient education programs can derive new perspectives and technology from the experience of the mutual aid group. Simond's concept of "hospital patient coun-

seling” fits nicely with my view of patient education’s bridging and continuing contribution to persons in mutual support groups (Simonds, 1977, p. 43). Patient education in this sense is a component in a system of health education. It is not necessary and may be counterproductive for patient education programs to attempt comprehensive continuous coverage of the hospital discharge. We must identify the core expertise of patient education in concert with other community resources which provide a progressively client controlled environment. If the goal in patient education is to contribute to the patient’s self-sufficiency, then we must restrain our professional instincts to identify *more* needs, organize *more* educational care. The task is to seek the *minimal* necessary professional inputs and to evaluate our success by a reduced client dependency on *our* services. That is a difficult perspective to achieve in the environment of this “serviced society” (Gordon et al., 1974). But it is the crux of the matter in drawing patient education closer to the self-care values with which society is now challenging us.

In effect, patient education in the context of self-care values defines its goals in terms of reducing disability as a sequel to disease *and* disability as a sequel to professional help. To achieve the latter goal will require that patient education programs broaden their client system to include *care-givers*. An analysis of care-giver contributions to patient disability in the form of dependency evoking activity should form the central curriculum for in-service education. There is little doubt that such a program for care-givers will call for extraordinary sensitivity and creativity in helping distinguish between activities stimulated by needs *of* patients *vs* the need *for* patients. Perpetuation and expansion of services beyond minimum need, may be of benefit to the provider, but surely cause difficulties for the consumer (McKnight, 1976). Unfortunately motivation for minimizing unnecessary and counterproductive services, be they clinical or educational, is confronted with the fiscal pressures on institutions to maintain services, as noted earlier. Here our recourse is to help in the phase-down period of institutional care (and, later, ambulatory care) services by assisting those care-givers involved to drop unproductive dependency evoking procedures as a way of preparing for a more rational reduction of surplus services. In my view this will be an important new responsibility for patient educators as they define the total institutional environment as contributory to patient growth in self-sufficiency.

We are in an exciting era of transition in health and health care from a professionally dominated world of service to one of self-service. The process of demystifying medicine and demedicalizing society is just now rising in our consciousness as a profound turning point in the history of health. We must come to terms with changing patterns of morbidity, emerging pluralism in chronic disease care, less rigid and moralistic perspectives on avoidance of risk, recognition of iatrogenic effects, and appreciation of the lay resource as the primary and least dangerous health resource.

The integrity of patient education in the service of enhancing the power of the individual to self-heal and self-regulate is at stake now. The social demand for more self-control in health is palpable and there are no signs that it will abate. Realities of demographic and epidemiologic changes and the diminishing utility of professional services and commodities within the context of those changes argue that health educators must examine the character of their allegiance and adjust their efforts accordingly.

In the instance of patient education our task is to define our role in more limited and more precise terms, starting with the caveat, *primum non nocere*—first do no harm. During acute phases of illness, particularly those involving periods of institutional care or tight medical management on an ambulatory basis, patient education's role is centrally one of helping patients maintain their integrity. The task, put another way, is to minimize the dependency producing impact of medical care. Some may find this perspective on patient education too conservative. It is indeed conservative—not in the political sense, but in the sense of prevention being conservative in avoiding unnecessary risk. In a very practical and non-polemical way, patient education and self-care education are advocacy strategies which can contribute to the public's health competence at different points on the same continuum. Now is the time to clarify the mutuality of their values and to identify their special contribution to health education uncompromisingly operating in the public interest.

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