Advanced Practice Nursing Ethics in Chronic Disease Self-Management

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Advanced Practice Nursing
Ethics in Chronic Disease
Self-Management

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Abbreviations

ADE  adverse drug event
ADHD  attention-deficit/hyperactivity disorder
AF  atrial fibrillation
BGSM or SMBG  blood glucose self-management
BP  blood pressure
CCM  Chronic Care Model
CD  compact disc
CHW  community health workers
CKD  chronic kidney disease
CMS  Center for Medicare and Medicaid Services
COPD  chronic obstructive pulmonary disease
CTI  care transitions intervention
DSN  diabetes specialist nurse
DVD  digital video disc
ECG  electrocardiogram
EBM  evidence-based medicine
GAS  goal attainment scaling
HbA1C  hemoglobin A1C
HCV  hepatitis C
INR  international normalized rate
MI  motivational interviewing
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>NHS</td>
<td>United Kingdom’s National Health Service</td>
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<tr>
<td>OMERACT</td>
<td>outcome measures in rheumatology clinical trials</td>
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<tr>
<td>P4P</td>
<td>pay for performance</td>
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<td>PCORI</td>
<td>Patient-Centered Outcomes Research Institute</td>
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<td>PHR</td>
<td>personal health records</td>
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<td>PSM or SM</td>
<td>patient self-management</td>
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<td>RA</td>
<td>rheumatoid arthritis</td>
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<td>RCT</td>
<td>randomized controlled trial</td>
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<td>SDM</td>
<td>shared decision making</td>
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<td>SE</td>
<td>self-efficacy</td>
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<td>TA</td>
<td>technology assessment</td>
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<td>UTI</td>
<td>urinary tract infection</td>
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<td>VA</td>
<td>Veterans Administration</td>
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Preface

Patient self-management (PSM) is defined as an individual’s capability to detect and manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes (e.g., exercise and diet) inherent in living with a chronic disease (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Many acute illness episodes and treatment plans in health care are in fact but one phase in the course of a chronic condition. Efficacy of health care depends on addressing these happenings within an individual’s plan for long-term chronic disease management.

PSM has arisen to prominence as part of a broader concept of patient education for two reasons: (1) governments in many developed countries believe they must manage the ballooning costs of chronic disease in their aging populations by shifting care responsibilities to patients and their families, and (2) the patient empowerment movement stresses that a person makes care choices from available options and is free to incorporate these selections into his values and lifestyle. The freedom to choose care options is a growing philosophy in some countries and in others a legal right, instigating the move to PSM.

The reorientation of health care toward PSM invites us to re-conceptualize basic assumptions that have been problematic in patient education theory and practice. For example, a great deal of confusion cascades from our failure to consider the appropriate ends of PSM as well as its support. A common misperception is that the proper outcome of PSM is adherence with the prescribed medical regimen and its support must operate under the physician’s authority. At an obvious level, this provider-focused assumption denies the patient any say in the regimen and assumes (often incorrectly) that providers follow whatever standard of care is relevant for the patient. More significantly, this framework denies the patient the explicit goal of developing his own practice of PSM that is consistent with both his instrumental goals and the intrinsic value of education.
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A second misperception follows from the first; that a dose of patient education at the time of diagnosis is sufficient for support of PSM of chronic diseases. In truth, support must continue across a lifetime to accommodate changes in the patient’s body and psychosocial situation and to incorporate new scientific findings. The decisions patients are asked to make as part of PSM are clinically and cognitively (and frequently emotionally) complex. Research has focused on patient deficits in learning the complex skills required for PSM, when, in reality, its mastery should be expected to take considerable time as patients build increasingly sophisticated skills.

Underlying both these misperceptions is one even more basic. Statistically, nearly all individuals will have one or more chronic diseases as they age. (This is not to deny that children also have chronic disease.) Whether currently recognized or not, the fact is that all chronic diseases require PSM. Yet support services are widely unavailable to those who need them, even in countries where public policy indicates patients have a right to this support. The rhetoric of patient empowerment, an extremely important value base for PSM, often masks a transfer of responsibility to patients and families beyond their competency to handle care (Redman, 2007). While this proclaiming of values without really delivering their implementation is a common situation in policy, when it occurs it further victimizes patients who need the services, labeling them as the problem.

PSM is a fascinating movement that arouses perspectives on ethics, psychology, technology, and social policy, and one that requires nursing leadership. Advance practice nurses already care for patients with chronic diseases in varying stages and manifestations, including acute exacerbations and multi-morbidity. Yet PSM in health care is firmly stuck in an outdated medical model that, studies show, nurses find ethically problematic. The purpose of this book is to present a framework for a more just and equitable practice of PSM of chronic disease, including its preparation and support, and one that is congruent with a nursing philosophy of practice.

The book is organized as follows. Chapter 1 describes a philosophical approach using capability theory, especially that of Martha Nussbaum. This chapter also addresses other central ethical questions, such as the level of parity that can be reached with PSM—in itself, a question of equity. Also addressed are standard ethical questions about patient choice and safety, appropriate balance of benefit/harm, and standards of practice (currently very rudimentary). In their regard, I suggest a more ethically appropriate model for use.
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Chapter 2 summarizes current best practice for supporting PSM of common chronic diseases while Chapter 3 describes intervention strategies that help patients build the capabilities outlined in Chapter 1. These chapters provide a foundation for subsequent chapters that focus on issues that influence advance nursing practice and that have been viewed as problematic, suggesting an ethical resolution congruent with safe practice and the capabilities framework.

Chapter 4 addresses the changes in self (beliefs, motivations, and identity) that accompany effective PSM. Rarely do we consider what we are asking the patient to achieve from psychological, sociocultural, and moral perspectives, including the conflicts that inevitably arise between the patient’s “old” and “new” identities, as he or she obtains competency, or not, as self-manager.

Chapters 5 and 6 engage the ethical impact of technologies, including the often implicit perspectives incorporated into measurement instruments, both singly and across the totality of instruments available in the field, and the informational and equipment technologies used in PSM. Both chapters describe the huge amount of work that remains to be done. A stock of morally sufficient and well-validated measurement instruments does not now exist; yet without this infrastructure, the field cannot move forward. Instruments embody values and standards essential to making clinical and social judgments. Because an ethical analysis of the emerging technologies that make PSM possible is very rare, the impacts of these technologies after adoption are frequently problematic.

In some health fields PSM is manifested as part of a total revolution in the philosophy of care. Chapter 7 describes these shifting boundaries. The patient recovery movement in mental health is the best example of a normative shift. In other fields of practice, the boundaries between provider management and PSM are being dramatically pushed. Here, physician-directed self-monitoring of left atrial pressure in persons with advanced chronic heart failure, which can more adequately titrate drugs to the actual physiological condition of the heart (Ritzema et al., 2010), is an apt example. We must bear in mind, though, that other groups of patients present with symptoms that are never diagnosed or with a prolonged diagnostic phase and uncertain treatment plans. These patients often desperately need guidance in the ability to self-manage their symptoms, and all need an approach that encompasses the life span of the disorder, including its acute phases.
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Chapter 8 describes how the transition to PSM of chronic disease might transpire and proposes a structure to correct its very uneven development, at least up till now. Obviously, some of the tasks entailed must be political: Setting revised expectations for capability development and choice; naming the tools that can implement these political decisions; and a push for the necessary health care system change.

Any social movement, major new technology, or emerging change in health care practice requires examination of the ethical assumptions on which the trend is based and ongoing dialogue on how the course of its development will enhance human well-being. This book is one such step for accomplishing PSM of chronic disease. To engage the reader in the kind of reflection needed to play an authoritative leadership role in making PSM a reality for those with chronic disease(s), study questions conclude each chapter. And to assist the health care professional in documenting and improving the quality of PSM in the practice setting, the appendices present four instruments with an analysis of their psychometric characteristics as well as additional study questions and ethics definitions.

It is important to note that the book draws on extant research, much of which comes from countries other than the United States. The United Kingdom has most comprehensively adopted PSM as health policy, and the Scandinavian countries reflect patient empowerment as social policy.

Literature from these countries greatly enriches our understanding of how PSM can be developed philosophically and practically.
A Suggested Ethical Framework for Patient Self-Management of Chronic Disease

Statistically, chronic disease is the norm in human health events, yet it has long had a negative connotation in the public mind, linked to perceptions of “old” and “sick.” In a fully examined practice of patient self-management (PSM), this denigration can change to more positive perceptions and opportunities for growth and control. For this purpose, we need to turn beyond medicine.

PSM has the potential to meet several important ethical precepts that apply to chronic disease, such as: (1) if we can benefit someone without harming anyone else we ought to do so, (2) dignity of human life involves the freedom to live as one wishes, and (3) it is wrong to discriminate against the uneducated or the poor, who suffer more from chronic disease and its effects. To fully implement PSM, these precepts require policies that ensure patient choice, safety, an appropriate benefit/harm balance, and standards of practice for both patients and providers. Currently, however, we lack a framework to unite these precepts and their necessary policies. The usual ethical theories are less than helpful. Utilitarians (who value the aggregate good) don’t adequately recognize needs of individuals and ignore the fact that preferences are affected by traditions of oppression (Charlesworth, 2000). Deontologic schools of thought prescribe duties without describing a way to actualize those duties. Communitarians (who believe communities decide what is right and good) have not, in general, addressed the issue of PSM; local societies typically see preferred options as those put forth by the medical community, whose theory of practice does not embrace education of patients.
THE CAPABILITY APPROACH

The capability approach provides a good fit for PSM. It is a broad normative framework for assessment of individual well-being and social arrangements and the design of policies and proposals for social change (Robeyns, 2005). The approach focuses on developing what people are able to do or be, guaranteeing at the least a threshold level necessary for truly human functioning. Nussbaum (2000) asserts that capabilities can be the object of an overlapping consensus among people who have very different conceptions of the good. Of the ten central human capabilities described by Nussbaum, life (being able to live to the end of a human life of normal length, not dying prematurely), bodily health (being able to have good health), and practical reason (being able to form a conception of the good and to engage in critical reflection about the planning of one’s life) are the most relevant to health. These and other central capabilities are not mere instruments for human existence, but are understood to have intrinsic value and are vital to making possible any choice of a way of life.

Capabilities offer people the freedom and opportunity to choose and realize certain functionings. For health care, this is a radical framework because it calls for providing all individuals and groups with the capabilities to achieve a self-determined threshold of functioning. In education, that threshold is the level of development beyond which learning is purposeful and can be sustained by the learner. Because learning is an indispensable means through which individuals and groups can improve their lives, capability deprivation is a state that calls for remediation, whereas capability enhancement requires ongoing development (Young, 2009). Sadly, current health care data do not contain adequate information to allow us to conclude what capability sets people have or could develop.

The capability framework is based on the sense that certain human abilities exert a moral claim for development (Nussbaum, 2000). In contrast, to conceive of people as helpless and without agency is to denigrate them and to fail to respect their dignity. It is important to recognize that human capacities require support from the larger society in order for the person to exercise them. Respect for others mandates creating the conditions in which capacities can develop, unfold themselves, and support choice. In fact capacity, not functioning, is the appropriate political goal for all functional aspects of living, including health (Nussbaum, 2009). Sen (2009) notes that there are remediable injustices that can be addressed in the real world with the use of a capability framework. These include
women who live in oppressive circumstances but who would, under a capability approach, be guaranteed threshold level of skills to keep themselves and their families healthy to live longer lives. A capability approach would also ensure recognition of those with stigmatizing chronic diseases, for social support and skills that could help avoid health disparities with other populations that can occur with stigma.

The ideals inherent in the capability framework raise questions of how the approach could be operationalized in a fully examined practice of PSM. To address a first concern, collective and family capabilities are clearly important since they can protect vulnerable individuals who have limited capacities as well as protecting persons longitudinally through subsequent generations. However, a holistic view of family is rarely incorporated in a medical approach to PSM. A second concern is that some health care systems have proclaimed PSM a desirable, perhaps even mandatory, approach to treatment without installing appropriate professional support services, a situation that likely increases the caregiving burden, which historically has fallen predominantly on women, beyond its already high level.

A third issue regarding operationalization is whether we should spend the resources to build PSM capabilities in people even though they may choose not to use them, given that freedom of choice is a central tenet of the capability framework. But perhaps the most difficult questions are whether a capability approach to PSM could adequately address the many poor individuals and families with chronic diseases and whether a package of capability development programs included in health care could, in fact, reverse poverty or prevent it.

Clearly, such comprehensive programs would require significant investment to develop not only the instrumental skills but also the social recognition essential to self-confidence and self-respect. The strength of the capability approach is that it accommodates variability in individuals’ capacities and their abilities to convert resources into life functionings; its weakness is that priority-setting in the public sphere remains a problem. Chronic illness is both associated with poverty and a cause of it, for without the skills to control the illness and its symptoms, individuals become unable to work or go to school.

In spite of significant advantages of the capability approach to management of chronic disease, patient adherence to the medical plan of care is currently the most common framework used (Redman, 2009). The problem with this approach is that it admits of no patient choice in determining a
plan of care that is acceptable to the patient and incorporate the patient’s life goals. In addition, the adherence framework operates under two misassumptions: first, that the physician’s performance meets the standard of care (often not the case) and is worthy of adherence, and second, that lack of adherence (a behavior frequently associated with poverty) is grounds for excluding patients from treatments that are in short supply (e.g., organs for transplant).

Some PSM supporters have embraced a framework of patient empowerment (interventions to generate hope, confidence, and encouragement) to help people with chronic disease gain control of their lives. Meta-analyses using the empowerment approach through education, support groups, and consultation showed improvements in hemoglobin A1c and reduction in cholesterol in persons with diabetes as well as improvements in patient knowledge and quality of life (Joanna Briggs Institute, 2009). Others have described patient empowerment as a process designed to facilitate self-directed behavior change, with the aim of increasing the capacity of patients to think critically and make autonomous, informed decisions. In many empowerment-based education programs, content is presented based on questions and concerns raised by participants. Patients are in charge of determining which decisions they wish to make themselves and which they prefer health professionals to make (Anderson & Funnell, 2010).

But the empowerment approach contains inherent weaknesses. In the first place, it assumes that patients know what they want, but more seriously it does not commit to development of a guaranteed set of capabilities that patients can choose to use. In addition, while patient empowerment would appear finally to have redressed the imbalance of power between physicians and patients, the reforms necessary to employ this approach also represent a political technique of governing, seeking to manage the problem of rising costs by entrenching health care in a market sphere. This means that patients are “empowered” to care for themselves for the primary purpose of saving money in the market for health services. Thus patients are not emancipated but have traded traditional dependency on the medical profession for dependency on the market. In the British National Health Service (NHS), government can deflect political criticism of its management by passing responsibility onto patients and the choices they made (Veitch, 2010). As with the adherence approach, patient capability to allow functioning is not guaranteed.
Chapter 1. A Suggested Ethical Framework for Patient Self-Management

The empowerment framework in health care and other sectors is part of a neo-liberal political philosophy of citizenship (particularly as analyzed in the context of the United Kingdom) to “liberate” citizens from the state. It seeks to empower citizens by expanding their reach of choice and voice, accompanied by the responsibility to produce the conditions of one’s own independence. A critical analysis of this approach reveals the assumption that bad choices result from irresponsible people, as opposed to questioning the “structural distribution of resources, capabilities, and opportunities.” Its language of activation and empowerment can mask the dynamic of abandonment (Clarke, 2005). For these reasons a framework of empowerment for PSM of chronic disease must be carefully applied, with clear empirical evidence that it does not in actuality leave patients worse off. In thinking of available frameworks, however, the capability approach appears the best fit for the goals of PSM.

Several salient points can be made about the capability approach. First, it is open to a range of possibilities of individual lifestyle, although it doesn’t address the roles of groups and social structures. It does address a common confusion that financial poverty coincides with poverty of functionings; in truth, a paucity of functionings can’t always be solved with money. Third, because most available databases in any sector of life do not contain information about people’s capability sets, we must define and assess them on our own. Social norms and power relationships, which have solidified in the health care sector, may restrict people’s capability sets by normalizing those with less formal education as less capable. Finally, the capability framework can coexist with other frameworks such as empowerment and even partially with that of patient compliance if research supports its importance and patients negotiate goals of compliance.

Perhaps most importantly, the capability approach urges us to stop seeing patients as burdens who don’t know how to manage their chronic illnesses and instead understand what capabilities they have and how they want to develop them toward our mutual goals. But we have a second challenge. To a large extent the kind and range of opportunities that allow us to live a life we value depends on what institutions exist and how effectively they operate. Oppressive social structures preclude the building of capabilities (Alexander, 2010). To reflect, how would you rate the health care structures you know in their support or oppression of patients and their struggles to become capable in managing their health?
GOALS FOR PSM OF CHRONIC DISEASE

The underlying goals of the capability approach are protecting, restoring, and promoting the well-being of individuals. Similarly, goals for PSM of chronic disease focus on development of capability/agency to manage a regimen that incorporates personal and medical goals, including management of symptoms, effect of the disease on lifestyle, and maintenance of a sense of self and agency. These skills accumulate over a lifetime.

In thinking of patient goals and the link to development of agency, it is ethically relevant to understand how chronic disease has been framed. Despite the fact that it is now the leading cause of death and disability worldwide and by 2030 will cause more than three-fourths of all deaths, a series of pervasive myths persist that have the effect of blaming the victim or suggesting that nothing can be done. For example, many still believe that through choice of unhealthy lifestyles chronic diseases are self-inflicted, and/or because these are often diseases of aging, public resources would be wasted on those who have achieved a normal lifespan. In fact, chronic health conditions often originate in poverty, disproportionately affect the poor, and are exacerbated by inadequate education, social exclusion, long-lasting psychological stress, and poor access to weak health systems and poor environments (Geneau et al., 2010).

Coinciding with blaming the patient, chronic illnesses have largely been seen through a medical perspective and classified as diseases, which privileges professional expertise in defining what is relevant. The focus on oversight and monitoring of biomarkers by professionals is still dominant, although other indicators such as symptom management and quality of life have become more common. Considerably underdeveloped is an understanding of genuine patient expertise as patients learn through informed strategic experimentation to identify their own unique disease activity markers and find ways to minimize the extent to which disease management characterizes their everyday life (Thorne, 2008).

The current focus on evidence-based medicine (EBM), although touted in policy and practice as all-encompassing, is in fact quite limited in addressing the ethical questions about PSM of chronic disease raised in the preceding. While EBM should be instructive about patient efficacy, the currently available evidence is largely limited to studies of middle-class individuals followed for only one year and which excluded the aged with multiple chronic diseases, thus ignoring social and environmental causes of chronic illness. The effects of the broad social reorganization of
chronic illness work to target the individual to serve the government’s purpose of decreasing demand on health services is virtually ignored. The Expert Patient Programme in England, implemented by the National Health Service (Rogers, Bury, & Kennedy, 2009), has been hampered not only by the limited research base on PSM efficacy but also by lack of systematic evaluation of the impact of this policy on patients and their family caregivers.

All three current sets of logic—those who have chronic disease have caused it, following medical protocols is prime, and the evidence base is insufficient to undergird broad social policy—form excuses for not setting realistic goals to help patients learn the skills to manage their chronic illnesses.

**CONCERNS FOR EQUITY AND PROTECTION OF PATIENT SAFETY**

Because it contributes to the range of exercisable or effective opportunities open to us, health is of special moral importance. Failure to protect those opportunities when we could reasonably do so is unjust. We have an obligation to promote normal functioning and to distribute health resources equitably by properly designing social institutions and policies (Daniels, 2008). Development of skills important to successful PSM—capability for decision making, facility to absorb and act on health information often expressed in probabilities, self-confidence in information seeking—is doable. Still, some aspects of the PSM capabilities approach are clearly underdeveloped in the United States.

The threshold to which capability development is guaranteed is a political decision in each society. In the United States, serious health inequalities raise significant questions about inequities (morally problematic inequalities). Clinical practice guidelines for some chronic diseases such as diabetes, asthma, and hypertension include PSM education but do not commit to a level of capability development or to guaranteed financial coverage of such development for the population. Data found in financial coverage note that 40% of persons with diabetes and 15% of those with asthma get some exposure to education about their condition, which says little about their ability to safely practice PSM (*Healthy People 2010*).

In the United States most decisions about which health care services to reimburse are made by insurers (through benefits packages) who are
heavily influenced by what services physicians want to offer. Although PSM of chronic disease has rarely been included in health care coverage, there is no convincing argument why it should not. A relevant question to ask is, does PSM offer more or less value than other services in which currently the patient or provider is reimbursed, such as psychiatric care or other services with an insufficient evidence base? In other words, are like services being treated as like and unlike services as unlike? Considerations of equity presuppose explicit bases for relevant comparisons, which may include: (a) patient demand for the service, (b) cost-effectiveness in the short and long term on medical criteria such as morbidity and mortality, and (c) contribution to life-long capabilities to manage one’s health and its disruption.

As we ascertain from this situation, PSM is built on psychological theories such as social cognitive theory but doesn’t include the context of socioeconomic factors that exacerbate poor capability development and poor management of chronic disease. For example, low-income populations exposed to low-cost, nutritionally poor foods are particularly vulnerable to chronic disease. Adults with severe levels of food insecurity have more than twice the risk of diabetes and poorer glycemic control than do adult who have ready access to healthful foods (Seligman & Schillinger, 2010).

The health gradient by education is larger for chronic disease than for acute illness precisely because it is possible to learn how to manage chronic conditions (Cutler & Lleras-Muney, 2010). While it is undeniable that formal education level is associated with better health, the moral questions to ask are the degree to which those without that asset can still learn to adequately manage their chronic diseases and what resources are needed to assist the process, weighed against the psychological, social and economic costs of not acting in this direction. What is an appropriate level of equity in PSM of chronic disease?

PSM has lacked serious incorporation of the science of patient safety—witness the dearth of clear practice standards to which practitioners are held accountable, the primitive development and use of robust measurement tools for the range of valued outcomes, and inattention to harms from PSM and/or to the program of preparation for it. This situation is exacerbated by serious quality deficiencies in the medical management of chronic diseases; a recent study found that 30% of costs for six chronic illnesses are expended on services labeled as potentially avoidable complications (PACs). It is estimated that PAC rates might be reduced
by 50% for congestive heart failure and coronary artery disease, 40% for diabetes, 60% for chronic obstructive pulmonary disease (COPD) and asthma, and 75% for hypertension (deBrantes, Rastogi, & Painter, 2010).

In the health literature, many trials do not report harms at all, or they report them in a fragmented or suboptimal way, or they do not account for patient withdrawal owing to harms, and trials in some interventions (psychotherapies) almost never report harms (Ioannidis, 2009). This largely seems to be the case in PSM (Albano, Crozet, & d’Ivernois, 2008), although a summary of meta-analyses on the effectiveness of therapeutic patient education in chronic diseases and obesity (only some of which was likely PSM) showed 6% reported worsening of measured outcomes in the education group (Lagger, Pataky, & Golay, 2010). More directly, a medical record review of 111 diabetes patients with limited literacy in an automated phone health IT self-management (SM) program found 111 adverse events and 153 potential adverse events, 93% of which were preventable or ameliorable. Primary care providers were aware of only 13% of incidents and 60% of prevalent (ongoing) events. Diabetes is a communication-sensitive disease, requiring patient and provider collaboration to optimize SM and avoid complications. On the whole, little is known about patient safety in the ambulatory setting, where ongoing care of individuals with chronic disease is carried out (Sarkar et al., 2008).

Indeed, the process of preparing for and supporting PSM may hold risks as well as benefits. As one example, Rogers et al. (2009) report on the inevitable social comparisons among patients in SM skills training programs (many of whom are middle class), which may have the unintended consequence of lowering expectations and help-seeking activities among those in most need, including those from marginalized and lower socioeconomic groups. People are not always successful in resisting the negative emotional consequences of unwanted comparisons, therefore harming their presentation of self as morally worthy and deserving of care (Rogers et al., 2009). In addition, PSM training programs may not check for and correct common learning problems such as confusion or inability to integrate complex material, leaving patients with less self-confidence than they exhibited before the training program. The fact that harms are rarely detected or made legitimate in PSM initiatives can lead to lack of symptom control and poor disease outcomes as well as the unfortunate dynamic of blaming the patient or the family caregiver for not attaining good outcomes.
This lack of oversight in PSM training exists in the face of overwhelming evidence. For example, a meta-analysis of 35 studies totaling 7,413 patients with heart failure showed that only half of such patients received a complete set of instructions at discharge, much less evidence that they were able to act on such instructions (Boren, Wakefield, Gunlock, & Wakefield, 2009). And a meta-analysis of 47 randomized controlled trials (RCTs) that included 7,677 participants with type 2 diabetes showed that PSM interventions had a positive effect (Minet, Moller, Vach, Wagner, & Henriksen, 2010). While these reviews did not summarize results by socioeconomic status, other work shows clearly that the “education gradient”—the enormous differences in life expectancy by education—is true for every demographic group and is present across countries. Studies show that 30% of the education gradient can be accounted for by access to material resources such as gyms and smoking cessation methods, but 10% is due to explicit factual knowledge and 20% to general cognitive ability to acquire, evaluate, and act on information and feel confident in doing so (Cutler & Lleras-Muney, 2010; Pampel, Krueger, & Denney, 2010).

The capability approach addresses both issues of autonomy and justice (everyone should have an opportunity to reach capability to a politically defined minimum level) but doesn’t explicitly address the issue of how PSM, as an innovation, should be diffused in a just way. Buchanan, Cole, and Keohane (2011) address the issue of justice in the diffusion of innovations in general, with a frame that sheds light on important issues in PSM. The shortage of PSM education and support reflects a choice our society has made. Innovations like this create opportunity for promoting justice as well as undermining justice if it is not diffused widely (e.g., checked by domination and exclusion). And the fact that important innovations are not occurring can be a concern of justice. From this perspective, forms of PSM undertaken or that could be undertaken by disadvantaged groups must be seriously studied.

Most theories of justice converge on the belief that extreme deprivation is presumptively unjust, and surely so when it is undeserved and unchosen (Allen, 2011). Clearly, then, individuals who don’t have access to the support, skills, and materials to safely manage their chronic diseases suffer an injustice. By their nature, most chronic illnesses cannot be dealt with safely without PSM—diabetes must be managed on an hourly and daily basis; asthma and COPD can be managed more intermittently but take on crisis proportion in an exacerbation.
Chapter 1. A Suggested Ethical Framework for Patient Self-Management

AN ETHICALLY APPROPRIATE MODEL FOR PSM OF CHRONIC DISEASE

Current health systems contain many correctable flaws for PSM of chronic disease. It has been noted that the United States does not have a system for dealing with chronic illness, which means that efforts toward PSM of these conditions will be vulnerable to failure. The dual focus on PSM as compliance with a medical regimen and dependent on EBM should be nested within a much broader framework of capabilities development and the examination of ethical issues not addressed by EBM. Denigration of individuals as causing their own chronic diseases and being too old for investment and dismissal of the social and economic contributions to their situation serve to blame the victim. By avoiding commitment to explicit goals such as levels of capability and functioning, an empowerment ideology, and the move by governments to transfer responsibility for chronic disease care to the citizen can leave patients and their families responsible for care but without the skills for safety.

In the United States, current data show that few individuals with chronic disease get any exposure to education about how to care for themselves, much less a commitment to long-term coaching to develop capacities that will support PSM functioning. Insurance rarely covers such services, but without any rationale that covered services are more compelling. It is likely that even in countries with a more supportive health policy, implementation of PSM support is very incomplete.

Those committed to the PSM movement, philosophically or by government mandate, must recognize that significant work still remains. The present research base to test adequacy of PSM skills and the interventions needed to develop and sustain them must be greatly expanded to other populations and expanded longitudinally through families, and must furthermore acknowledge and correct harms as well as document benefits.

At the very least, an expanded PSM has the potential to increase patient safety and satisfaction, but to do this it must be patient-centered, caregiver-centered, and voluntary. Patient/caregiver choice in PSM should be accompanied by negotiation of treatment goals and measurement of current knowledge and skills, as well as an assessment of the socioeconomic situation. A “trial of (PSM) therapy” is appropriate.

Subsequent to initial skills development, patients/caregivers must be guaranteed access to coaching by health professionals for the length of their disease, whether in person or by telephone and/or electronic
communication. To support safe practice, patients/caregivers and providers should agree to report (with no consequences) evidence of poor practice in prescribing and implementing PSM, as judged against a range of benefits and harms. The resulting data can be used to put in place a program to increase the benefits and correct the harms. Such systematic data, aggregated over groups of individuals, have never existed and are important for discussions about an appropriate balance of benefits and harms from PSM practice. For example, at some point, after multiple trials, PSM may be considered effective or futile for a particular patient/caregiver at that time.

It is important to note that countries’ health policies vary widely in support of a defined level of equity, with the United States at the lowest level of this continuum among developed nations. Inequalities kill opportunity and create poverty, and our current haphazard system of offering or not offering PSM, or requiring it without support, is frequently not based on standardized measures of patient skills with good predictive validity, but on provider biases or insurance coverage protocols, neither of which is transparent.

REFLECTIONS ON CAPABILITY FRAMEWORK FOR PSM OF CHRONIC DISEASE

A capability framework (related to human rights) acknowledges that freedom is a good in its own right but also an instrument for attaining other ends (health). As a perspective, it counteracts increasing domination of the market perspective in health care and long-standing pressure from medicine to demand that patients do what physicians tell them to do. It challenges the continuing assumption that allocation of more funds to high tech health procedures will yield more well-being. The capability approaches takes us back to our roots of caring for people in our community, many times in partnership with patients and families. To illustrate, think of public health nurses in urban slums in the early twentieth century who effected change through patient education. Today, individual practitioners and groups can be a force for this positive change, which will nonetheless also require institutional reform.

All plans of life presuppose at least certain core health capabilities. But some have seen a conflict between the implied liberty in the capabilities approach and the freedom to make choices to realize multiple kinds
of valued existences and actions as well as how certain choices may affect the health of others. Allen (2011) asserts that these two values (freedom and health) can be seen as co-equal. Liberty is best interpreted in terms of its priority rather than as an absolute claim to noninterference and is democratically contestable.

This tension is best demonstrated in public health policies that target chronic disease control by monitoring lab values (such as HbA1c among persons with diabetes) and notifying patients and providers when values are high. While seen by some as interference in a private matter (particularly when choice to receive the monitoring is variant), a first inclination is to view such out-of-bounds lab surveillance as poor provider practice, lack of SM preparation and support to the patient, or even as a reasoned judgment on the part of both provider and patient that “normal” lab value is not possible or wise for this patient. As seen by this scenario, public health attention to chronic diseases will continue and escalate, reflecting its prominence as the major disease threat today. Occasionally, tension between values of freedom and health as a particular individual sees it will occur.

Ethical analysis, well-reasoned and informed by data when applicable, should be employed to provide clarification to the current system including the emerging PSM movement. We are yet in the early stages of such an analysis. While capability theory clearly expresses a commitment to social justice, gender equality, and a vision of human dignity, it doesn’t specifically address historical and structural roots of inequality and the institutional transformation necessary to ameliorate these (Feldman & Gellert, 2006). Subsequent chapters develop important elements of all of these concerns.

SUMMARY

A capability framework offers a better approach to the practice of PSM, with significant advantage over the current medical focus on patient compliance and even over an empowerment approach. Chronic illness, which is statistically very common, offers opportunity for positive growth and dignity in health care. Ethical analysis offers a tool for understanding how to avoid being punitive to those with chronic disease, focusing instead on an obligation to improve safety and equity in a health care system with serious issues in both of these realms.
STUDY QUESTIONS AND ANSWERS

1. What are the central purposes for PSM of chronic disease that benefit both individuals and society?

Answer: Several objectives can be fulfilled, such as: (1) better quality of life and ability to function, (2) saving resources, (3) better disease management including prevention of exacerbations and slowing of progression, and (4) self-making by incorporating disease management into life goals.

2. Any field of practice requires conceptual and ethical tools. Arguably, those are underdeveloped for PSM of chronic disease. What tools does the capability framework provide and what tools remain to be developed?

Answer: Most importantly, the capability framework provides an end goal which meets ethical criteria of good for patients and for society. By doing so, it ties health care to the same criteria as other societal aims, such as economic development and social justice, and removes it from the narrow authority of medicine. The capability framework is very short on details—for example for PSM we could ask what capabilities should be developed to allow which functionings, what is a justifiable boundary for patient authority/choice, and how does one get a society to set its limit for resources to be used for this project, justifying its level with other societal goods.

3. What research questions does the capability framework raise beyond those that are currently asked in the field?

Answer: A number of research questions emerge, such as (a) what are the variety of ways people choose to use their capabilities to SM their chronic diseases, (b) to what extent do capabilities developed for health extend into other areas of life and improve them, and (c) what rationales do societies use when required to explicitly set and justify the minimal level of guaranteed capabilities for health?

4. Some countries have a stated public policy advancing patient empowerment. How useful is this as an ethical/policy base for PSM of chronic disease?

Answer: Its value in support of development of patient agency is clear. But as a policy it lacks two things—a content goal (empowerment toward what?) and an implementing structure/strategy to
force the transition from a provider-focused health system to a more patient-centered health system.

5. How would you assess the following proclamation: “It is morally essential for the health care system to facilitate patient learning”?

Answer: Patient learning should be assessed against an end goal of human flourishing, and this would be supported by most philosophies that undergird our sense of what is ethical, including the moral framework outlined in this chapter. Perhaps the most important part of an analysis might be to question how our health care system got so far from this moral ideal, and perhaps an answer would be because it focused on a sense of entitlements among health professionals, slighting the welfare of patients.

6. The capabilities approach acknowledges a state of adaptive preference, a view that people’s stated preferences can be deformed because they have adapted to an oppressive culture (which they have deeply internalized) and know no other way. Is adaptive preference operating in management of chronic illness?

Answer: Yes, evidence of it can be seen in the views that the doctor is always right, that patients have no right to choose PSM or receive support for it that makes their care safer or their lives more livable. Adaptive preference can’t be identified as unjust or wrongly hierarchical without an overarching framework like the capabilities approach, and furthermore it can’t be fixed by information alone (Nussbaum, 2011).

7. Within the capabilities framework there is a huge moral difference between a policy that promotes health and one that promotes health capabilities. What is this moral difference and how does it relate to PSM?

Answer: Nussbaum (2011) notes that only a policy that promotes health capabilities honors the person’s lifestyle choices. As a foundation for PSM, the capabilities approach is quite distant from the current focus on adherence to a medical regimen, which does not admit to respecting patient choice.

8. Health is one of six essential dimensions of well-being, as is self-determination. In their theory of social justice, Faden and Powers (2011) indicate that institutions have two foci: (1) improvement of
well-being, in this case health, and (2) responsibility to combat adverse effects on well-being caused by patterns of systematic disadvantage that can profoundly compromise health. On these terms, how important is being able to manage one’s chronic disease(s)?

Answer: The better control PSM can bring to the person’s and family’s ability to function and exert some control over the disease, as well as the confidence to maintain direction over one’s life, can be profound, although not the same for everyone. This theory of social justice fits well with Nussbaum’s capabilities approach. The unresolved question is the degree to which the health care system, in conjunction with other social institutions, commits to avoiding or dealing with systematic disadvantage among patients. Currently, some health care systems have more or less unjust access embedded in racism and poverty (Faden & Powers, 2011). Nussbaum’s answer is that society must commit to a threshold capability for each individual.

9. How is patient education different from PSM, and is the capability framework relevant as well for patient education?

Answer: While consensus definitions for patient education and for PSM don’t exist, I believe those practices exist on a continuum. Patient education is more commonly used for a health issue that is likely to be resolved in one episode, such as an appendectomy, but of course the patient continues to learn SM skills in wound healing, ambulation, etc. PSM is more commonly used in long-term (chronic) health conditions (although surgery may be part of a long term condition) and thus focuses on day-to-day disease management and symptom control and psychosocial and lifestyle adjustment over the long term.