

Commentaire/Commentary

Maturation of Patient Self Management of Chronic Disease: Empirical and Normative Issues

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Long practised in diabetes and more recently in asthma, patient self-management (PSM) of chronic disease is now expanded in concept (although not in everyday practise) to hypertension,[1] chronic obstructive pulmonary disease,[2] chronic stable angina,[3] oral anticoagulation,[4] mental illness,[5] heart failure[6] and lower urinary tract symptoms,[7]among others. Currently defined as ability to detect and manage signs and symptoms, treatment and physical and psychosocial consequences inherent in living with a chronic condition,[8] PSM is a robust and growing example of the moral ideal of a patient/provider partnership. Some also suggest its expansion is part of a move away from the welfare state, toward marketization. As countries

move to become competitive in the global market, they pass increasing responsibility to patients for management of chronic disease, especially important in countries with large ageing populations.

Ethical implications of the increasing adoption of PSM have largely remained unexamined. The purpose of this paper is to provide perspective on areas of agreement and those, both normative and empirical, that require ongoing work.

There are a number of areas of agreement. Given current treatment, PSM is inevitable and often improves the quality of care by close and timely monitoring and adjustment of treatment. In no healthcare system is preparation and support for PSM reliably available for most individuals who need it. PSM preparation and support has been most fully developed for diabetes; yet, experts suggest that one reason the toll of diabetes morbidity and mortality continue to increase is that the evidence-based therapies (including PSM) are not reaching patients in need.[9] PSM acknowledges the importance of integration of lifestyle elements into care,

both as a treatment and as integrator of self-management tasks into everyday life. Although self-efficacy is a consistent predictor of patient ability to carry out PSM, experience also suggests that patients need objective measures to detect symptom deterioration and that an action plan and electronic record keeping with regular provider feedback are important. Since some authority is transferred to the patient, traditional patient-provider roles require adjustment to the PSM mode.

Several important areas require further research. What benefits over provider-centred practise does PSM provide, including error rates for both provider and patient, and resulting harm? Predictive criteria for safe PSM must be developed and must include evidence about quality of technology used in that care. Patients whose conditions cannot be diagnosed and lack current treatment options also desire the sense of control that can come from PSM. Understanding factors related to symptom fluctuation allows them to optimise their performance and reduce disability.[10] And surprisingly little work has been done on what it takes to create expert SM performance among patients.

At the system level, do accreditation programs and reimbursement policies work to protect quality and availability of PSM support, or do they ignore it or create negative incentives? And very little is known about competencies and quality of practise of the workforce to deliver PSM preparation and ongoing support.

While data-based answers to these questions will provide important input into the ethics of PSM, normative questions require ongoing conversation. The field is not currently engulfed in fierce ethical conflicts; rather, much is to be gained in providing direction by identifying embedded ethical questions and dealing with them upfront. Most important is a cluster of questions regarding the ends of PSM – is it focused primarily on development of patient agency or capability? What responsibilities do patient and provider have for compliance to the treatment plan and to attainment of medical goals? Given that there is no known effective treatment that resolves chronic diseases, for what outcomes can the PSM team be held accountable?

Other questions focus on ethical delivery of PSM preparation and support. What is the nature of “truth” that should be taught, especially in light of the commercialization of “truth” and scientific evidence by corporations selling their products? Is it appropriate to change patient cognitive structures or belief systems that run counter to current scientific understanding about disease management? Since most PSM models to date assume a middle class lifestyle, what is our responsibility to

the educationally and socially challenged? What criteria help patient and provider decide that PSM is not advised even if, as in some national health systems, patients have a right to it?

Addressing these questions requires an ethical framework, incompletely developed at this point. Important ethical constructs include avoidance of harm from inadequate PSM, optimising benefits over provider-focused care, and allocation of access to PSM preparation and support. Nussbaum’s[11] capability theory offers a moral framework, operating within a broader goal of developing capabilities that will serve in all areas of life. Learning is a basic life skill and chronic disease offers a long-term opportunity to hone it in a cumulative fashion useful to all areas of living.[12]

Next developmental steps

The PSM movement has so much benefit to offer and is eagerly being examined, largely in developed countries around the world. Such a movement requires careful attention to next developmental steps to avoid being prematurely abandoned as “ineffective”. Three steps are examined here.

One important next step is a greater level of standardisation in the science and in technologies used by patients. In order to be cumulative, the science should establish definitions, means to check the fidelity of interventions, and outcome measures that actually assess patient ability to make critical judgments and carry out complex actions. Most measures that exist today test only important elements such as knowledge and self efficacy

Using standard technology assessment methods, machines used by patients to provide care should be tested for safety, effectiveness and affordability. Perhaps more important than the machines is the evolving electronic personal health record, which has as one of its purposes helping patients to self-manage. How can it effectively do so?

Successful financial and regulatory incentives to assure availability and quality of support also require definition. Are PSM support systems stable and available throughout the long-term course of the disease(s)? Much PSM preparation and support has been offered through “programs” which can be defunded by the institutions offering them or in the case of a central health service by policy change and thus no longer available.

Secondly, we need to examine ways to improve outcomes. Early models of group PSM preparation and support demonstrated common psychological and social tasks

across chronic diseases. But, it's also important to study characteristics that likely differentiate PSM for various patients, requiring individualised models of preparation and support. These may include:

- for some diseases there is more effective treatment than for others, both for the basic disease and for symptom control, which affects patient confidence in his ability to meet standard medical outcomes;

- while some degree of PSM is necessary for all chronic diseases, for some PSM is mandatory (diabetes) while for others hour to hour monitoring and adjustment of therapy is less important;

- social and economic environmental conditions inhibit or support PSM, as do co morbidities including depression;

- competence of patients' health care teams and the quality of the relationship with the members enable PSM or not;

- patients operate according to their cognitive disease models; when these are largely discrepant from models of providers, PSM may be contentious;

- PSM is not a uniform intervention. Because patients' values vary, explicit description of the practise including goals, roles and support is necessary;

- PSM involves an individual journey, using prior management within one's lifeworld,[13] with varying attachment to medicine's management of the condition.

Finally, bioethically, several issues should be examined. We need to generate trust that PSM isn't just a way to dump the old and the sick back onto their own resources. And providers should be brought along to be competent SM support practitioners, assuring it is as safe as possible, to deal with required role changes from authority to partner, and to support patients making SM choices according to their own values.[14] National health systems have been interested in PSM as a way to manage resources but must further explicate its value in patient choice and development of health skills by the population. Extension of appropriate PSM models to developing countries, in which SM is often the dominant form of care available, is important.

But the most central bioethical issue is the historical exclusion of patient perspective and logic in medical practise and the payment and regulatory systems that support it. PSM embodies a reality long unacknowledged by the health

care system – that all persons with chronic disease have a great deal to manage. This movement is about finally openly clarifying and supporting that patient responsibility. It is rarely acknowledged in public policy, which remains oriented to the medical perspective and builds systems of care around that perspective. True to its orientation, this system requires that if PSM is to be recognized, it must pass the test of being economically efficient, a standard not uniformly applied to many established medical therapies. Reification of medical logic excludes lay logic that helps patients cope with disease.[13] Thus, people are left to make the journey on their own if they can. Consonant with the moral ideal of a true patient-provider partnership, the standard of care should require integration of medical and lay perspectives to yield the best outcome for the patient.

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