PROMs: A Critical Step, But Only One of Many

COMMENTARY

Sholom Glouberman, PhD
President
Patients’ Association of Canada

ABSTRACT

Bringing the patient perspective into healthcare is now widely recognized as a somewhat-urgent need, and patient-reported outcome measures (PROMs) are an excellent example of attempts to do more of this. In this commentary, the author puts PROMs into a broader perspective and then speaks more specifically about this particular initiative. The question addressed is, how well can PROMs increase patients’ participation in their care?

Bringing the patient perspective into healthcare is now widely recognized as a somewhat-urgent need, and patient-reported outcome measures (PROMs) are an excellent example of attempts to do more of this. In this commentary, I first put PROMs into a broader perspective and then speak more specifically about this particular initiative.

Patient reporting on outcomes is one of many attempts to increase patients’ participation in their treatment – a relatively recent phenomenon in healthcare. Our healthcare systems were born in the 1880s in response to acute infectious diseases such as influenza, typhoid fever and tuberculosis, which, at the time, caused the vast majority of deaths. Robert Koch and Louis Pasteur led the scientific work that showed that these diseases could be easily identified by the microorganisms that caused them, their course could be well described and they could be averted with appropriate vaccines. The healthcare system...
that grew out of these discoveries had the acute hospital as its hub, professional scientist physicians as its key personnel and research laboratories as the sources of its knowledge.

"Person-centred care would require that the data for PROMs be based not solely on disease-focused systems but on a holistic view of the person.

Two aspects of the healthcare system that began in 1880 are worth noting: the lack of patient participation in treatment and its research orientation:

• **Patient role in the post-1880 healthcare system.** In a system focused on acute infectious diseases, there was almost no need for patients to participate in their care or to report on the outcomes. For such diseases, this made good sense because they were acute and life threatening and required expert knowledge of the body, not the person. Patients did not have to report the outcomes since they were clearly measurable independent of the patients’ perspective.

• **Research orientation of the post-1880 healthcare system.** The research and treatment program focused on finding the cause and cure of all diseases whether infectious or not. This included determining definitive tests that would indicate the presence of a particular disease, clear protocols for the treatment of that disease and public health initiatives such as vaccinations that might prevent the disease from occurring.

The great success of the healthcare system was a dramatic reduction of deaths due to acute infectious diseases in the developed world. By 1970, the majority of deaths were no longer caused by such diseases but, rather, by chronic non-communicable diseases. The success of the system reinforced the prevailing approaches to research programs. For example, in 1970 Richard Nixon declared his “War on Cancer,” which proceeded to fund cancer research for the next 40 years at an average rate of US$1 billion per year in order to find the cure for cancer. Patients continued to have little role in their treatment.

Between 1970 and today there has been a growing recognition that non-communicable diseases such as heart disease and diabetes cannot be “conquered” by the kinds of research programs that deal with acute infectious diseases. And it is also becoming widely accepted that chronic non-communicable diseases require patient involvement in their treatment to avert acute episodes and to control morbidity. Chronic conditions cannot be treated with surgical or pharmacological interventions alone – they usually are linked to emotional, behavioural, social and environmental factors. The lead essay states that of the nine million Canadians who suffer from chronic diseases, 30% have more than one (McGrail et al. 2011). As a consequence, the complexity of treatment is geometrically increased and patient participation is even more important.

PROMs are a critical step in this direction. Almost everyone is aware that the entire healthcare system must be adjusted to engage patients in the care of non-acute, non-communicable chronic diseases if it is to deal appropriately with the morbidity of the population. Perhaps it is worth stressing the slowness of this change. Early on, the system focused primarily on acute episodes of chronic diseases. In the 1950’s and 1960’s, there was less talk of heart disease than of heart attacks. In Canada, acute hospital care was covered by publicly funded health insurance before primary care was added.
The introduction of the patient perspective on outcomes is obviously a valuable addition to the evaluation of all outcomes in healthcare: it adds a critical dimension to the assessment of healthcare. The question that remains is, how well can PROMs increase patients’ participation in their care? The lead paper makes three recommendations, which I review below in sequence.

**Recommendation One: PROMs for Elective Surgery**

Most elective surgeries are acute interventions for chronic conditions. In the UK National Health Service (NHS), hip and knee replacements seem to be the most prominent surgical procedures reviewed by means of PROMs. When the focus was almost entirely on acute care, clinicians alone were the ones to decide if such surgeries were successful. Patients’ limbs were tested for the effects of the surgery without considering impacts on lifestyle, social activity and so on. At times, a successful surgery on these measures would leave a patient without the gains in capacity needed to revive social, work and recreational functions. (This perhaps is the source of the old joke, “The operation was successful, but unfortunately the patient died.”)

Bringing the patient’s perspective into the outcomes of elective surgery is clearly an important step forward. The lead paper does not give an example of the data that are collected by the NHS. It is important to note that typical PROM questionnaires used by the NHS, like the Oxford Orthopaedic Scores, were developed with significant patient input and revised and finalized only after patient consultation and review. The knee questionnaire has been simplified and streamlined to ask only 12 questions pre- and post-operatively; and patients answer the following question on a scale of one to five:

**During the past four weeks:**

1. How would you describe the pain you usually have from your knee?
2. Have you had any trouble with washing and drying yourself (all over) because of your knee?
3. Have you had any trouble getting in and out of a car or using public transport because of your knee? (whichever you tend to use)
4. For how long have you been able to walk before the pain from your knee becomes severe? (with or without a stick)
5. After a meal (sit at a table), how painful has it been for you to stand up from a chair because of your knee?
6. Have you been limping when walking because of your knee?
7. Could you kneel down and get up again afterwards?
8. Have you been troubled by pain from your knee in bed at night?
9. How much has pain from your knee interfered with your usual work (including housework)?
10. Have you felt that your knee might suddenly “give way” or let you down?
11. Could you do the household shopping on your own?
12. Could you walk down a flight of stairs?

The questionnaire appears to consider the surgical intervention as the single pivotal causal event that has any bearing on the outcomes. Surgical method and skill, though unmentioned, appear to be the factors that differentiate more effective knee replacements from less effective ones. This hardly allows for patient contributions to the success of knee replacements. Patient-initiated strategies to prepare for knee replacements can go well beyond the hospital measures and include...
careful attention to exercise regimes that increase post-operative mobility, and preparation for and acceptance of strong pain control to speed up post-operative mobilization of the joint to allow earlier and more intensive physiotherapy. In fact, engaged members of the Patients’ Association of Canada who have experienced knee replacement surgery tell us that patients can do a lot to prepare for and follow up from the actual knee surgery that can make a large difference to the outcome. Although this is widely acknowledged, it is not reflected in the PROMs structure as described.

The results that have come in from use of PROMs in the NHS indicate that knee replacements are successful in reducing pain and increasing general health and activities of daily living. The NHS reports that “91.5 per cent of knee replacement respondents recorded joint related improvements following their operation as measured by their response to a series of questions about their condition (Oxford Knee Scores)” (NHS 2011). Using the scale, patients overwhelmingly confirm the value of these surgical interventions. In policy terms, if the measures we are to identify and concentrate on are the ones listed and the success rate is as high as indicated here, then the clear policy solution is to lower the threshold for surgical interventions and provide even more joint replacements. This consequence is not atypical in a system that focuses on acute interventions, and much of the evidence-based research provides measures to support this.

**Recommendation Two: PROMs for Chronic Conditions**

Knee and hip deteriorations are chronic conditions, and we must ask what can be done to avert or delay the need for surgery. This does not easily lend itself to the PROMs approach, which uses structured questionnaires that focus on degrees of disability and pain states. The possible variation in factors that can contain and work around joint deterioration is much wider than individual patient strategies for coping with surgery, and many alternatives must be explored, including everything from weight loss to weightlifting regimens. Moreover, in most chronic conditions, interventions must often be customized to individuals. It is not unusual in the case of chronic conditions, such as joint deterioration, that what works for one person is not effective for another, and may not even work for the same person at a different time. To some extent, this may be due to the fact that 30% of people with chronic conditions have more than one.

While it is clear and glaringly obvious that patient participation in the care of chronic diseases is essential, it is less clear how PROMs can contribute to this kind of participation.

The limited application of PROMs to elective surgeries suggests that it would be relatively difficult to apply them in their present form to more pervasive and even more complex areas of healthcare such as the vast array of chronic diseases that do not lend themselves to surgical interventions. While it is clear and glaringly obvious that patient participation in the care of chronic diseases is essential, it is less clear how highly standardized instruments such as PROMs can contribute to this kind of participation. Without much patient participation in their care, our healthcare system leads very quickly to pharmacological or surgical interventions. It is unlikely that annual PROMs reports on the condition of patients with chronic diseases
will include patient initiatives to contain the condition and avert acute episodes, such as the use of alternative therapies, customized regimens of diet and exercise, relaxation therapies and psychological counselling. Many of these strategies for dealing with chronic conditions lend themselves to narrative accounts of both the condition and the therapeutic consequences of particular interventions. Coming to understand how a patient learns to respond well to a chronic condition requires time and listening. These are rarely part of the current standard medical approach for dealing with chronic conditions, and it is hard to see how PROMs would make this change easier.

**Recommendation Three: A Pan-Canadian Working Group on PROMs**

Any working group to consider the use of PROMs for elective surgery must include patients as active contributors. Care must be taken to gain a better understanding of the patient experience of undergoing and recovering from elective surgeries in order to learn more about their outcomes. If there is to be an expansion of efforts to study effective ways of dealing with chronic diseases, then the patient perspective is doubly necessary. Certainly, there needs to be a pan-Canadian task force to think about and develop more robust strategies to deal with chronic disease in our country. That, after all, is thinking about the present dilemma of a healthcare system that is less and less appropriate to our needs. And patients must be part of those discussions.

**References**


---

*All around us, people are at work leading change in healthcare. All of these leaders have a journey of experience from which they have learned (and are learning!) lessons.*

- Paul Batalden, Editor