

Framework to assess the effects of using patient-reported outcome measures in chronic care management

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Abstract

Purpose The inclusion of patient-reported outcome measures (PROMs) in the routine clinical care of chronically ill patients has the potential to add valuable information about the impact of the disease and its treatment and promotes effective patient self-management in which patients become more active participants in their own care. PROMs provide clinicians with timely information on patients' symptoms as well as functional and emotional status. PROMs are a useful tool for enhancing patient–clinician communication.

Methods We develop a conceptual framework describing the potential effects of the use of PROMs in chronic care management. The framework summarizes insights from the methods for evaluating the clinical effectiveness and methods for the health technology assessment of diagnostic technologies and results from the relevant studies.

Results The framework describes potential effects, from proximal to distal, including communication (patient–clinician, patient–relative, clinician–clinician, and clinician–relative), engaging patients in shared clinical decision making, patient management (clinician management and patient self-management), and patient outcomes. Important

potential effects also include enhancement in patient activation as well as improvements in clinician and patient satisfaction, and patient adherence to recommended treatment. Previous frameworks have described patient–physician communication, patient satisfaction, and health outcomes. Our framework adds unique domains, including patient engagement, patient activation, shared clinical decision making, and patient self-management.

Conclusions The framework can be used as a tool to guide the development of interventions to improve chronic care management through the use of PROMs.

Keywords Patient-reported measures · Chronic care management · Patient–clinician communication · Patient engagement · Patient self-management · Share decision making · Patient outcomes

Introduction

Chronic diseases impose a burden on patients and health care systems. The incidence of chronic disease is rising especially in low- and middle-income countries [1]. In 2008, thirty-six million people living with chronic conditions died including a large proportion of young individual at the most productive period of their lives. Many who are chronically ill have more than one chronic condition [1–8] that include a variety of physical and mental illness such as cardiovascular disease, cancer, chronic lung disease, and depression [1–4]. The prevalence of chronic conditions is directly related to risks of adverse events, risk of medication interactions, and conflicting medical advice [4]. The complexity of treatment has led to the development of new strategies to reduce the burden on patients and health care systems. Among these strategies is the patient-centered

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care model with a focus on self-management. Wagner et al. [5] emphasized that productive patient–clinician interactions are essential in order to optimize chronic disease management. Tools are needed to foster such interactions. The routine use of patient-reported measures (PROMs) in chronic care management has the potential to play an important role because these measures, in a standardized fashion, provide health care providers with timely information on patient’s symptoms as well as functional and emotional status. This information can be used to manage patients more effectively and efficiently.

The scientific evidence about the use of PROMs in clinic care started to emerge in the mid-1900 s. During the late 1900 s, conflicting evidence on the effectiveness of using PROMs surfaced [9–13]. Some physicians found it useful while other physicians thought it was a waste of time. In a 1989 paper, Deyo and Patrick identified the barriers [9] to implementing the use of PROMs in routine clinical care. Barriers included skepticism about the validity of patient self-report, unfamiliarity with PROMs, a preference for physiologic measures, the need for rapid data processing, and uncertainty about how to interpret information from PROMs and make it actionable in clinical care. More than two decades of methodological development of PROMs, creation of technologies allowing rapid data capture and processing [14–16] and the accumulation of experience in the use of PROMs in a wide variety of clinical settings have substantially reduced these barriers.

In general, the evidence about the use of PROMs in routine clinical care is mixed [15–31]. In addition, there is still a latent skepticism, particularly in primary care settings where most chronic diseases are managed [17, 18]. Some studies, mostly randomized clinical trials (RCTs), have shown benefits and others have shown no difference. A recent study by Boyce et al. [31] describes potential issues surrounding the inconclusive results. These issues include adequate training to clinical staff, methodological concerns (study design, unit of randomization), consideration of potential bias (selection, measurement, and attrition), and appropriate measure (using measures at individual level when the measures have not been design for this purpose). These issues are factors that limit successful implementation of PROMs in clinical practice. Greenhalgh et al. [22] suggested a potential explanation and recommended theory-driven approaches to understand the mechanism by which PROMs may stimulate changes in practice.

However, despite the inconclusive evidence [15–31], the routine use of PROMs has been adopted in a wide variety of settings (Cancer Care Ontario and Dana Faber Center in Boston, and pediatric clinics like the Emma Children Hospital in Amsterdam), has received support from the health authorities (The Quality and Outcome Framework in

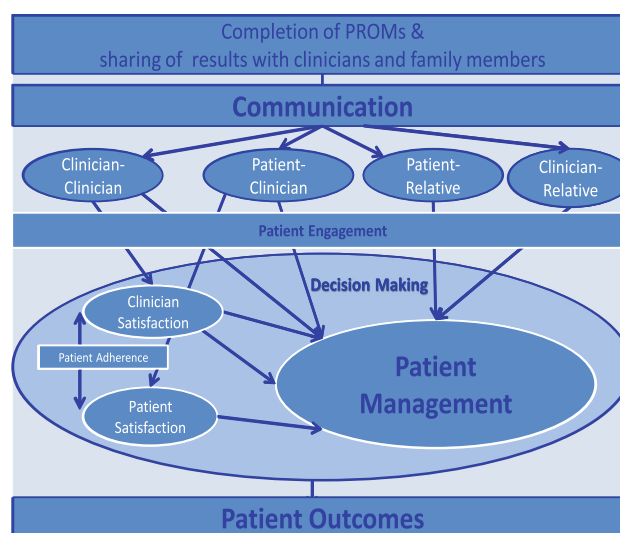


Fig. 1 Framework

the UK), and key documents describing the implementation issues in clinical practice have been generated [32, 33]. The paper aims to develop a conceptual/theoretical framework that conveys potential effects of using PROMs in routine clinical care of chronically ill patients and the potential effects for using PROMs in chronic care management.

Framework overview

We theorize that patient completion of PROMs and the incorporation of PROMs could result in a cascade of effects generating improvements in communication (patient–clinician, patient–relative, clinician–clinician, and clinician–relative), promoting the discussion of issues reflected in the PROMs, and the sharing of the goals treatments and patient preferences about treatments. Figure 1 illustrates potential effects associated with the use of PROMs in routine clinical management of chronically ill patients. All in all, the use of PROMs could potentially enhance patient engagement and activation, thus facilitating shared decision making that could ultimately affect patient management and outcomes. Finally, discussion between patient and clinicians during the decision-making process and sharing of goals of treatment could potentially help to develop a patient-centered care plan. The framework could be used as a template in future studies assessing the effects of the use of PROMs in routine care.

Components of the framework

Communication

Communication is a fundamental step in health care having a positive impact not only on patient management but also

Table 1 Framework components and description

Framework components	Description
Communication	Clinician–clinician Patient–clinician Patient–relative Clinician–relative
Patient engagement/ activation	Individual better understands their role in the care process and has the knowledge, skill, and confidence to carry it out Patients who are activated are ENGAGED in more preventive behaviors, healthy behaviors, self-management behaviors
Shared decision making	Process by which patients and clinicians discuss patient preferences and outcome probabilities to agree mutually on a plan for care
Patient management	Patient self-management of chronic disease Clinician management of patient with chronic disease
Patient satisfaction	Enhanced communication positively affects patient satisfaction Actively engaged patients are more satisfied with their treatment and have better outcomes
Clinician satisfaction	Enhanced communication positively affects clinician satisfaction Clinician satisfaction affects positively the management of patient with chronic disease
Patient adherence	Actively engaged patients involved in the decision-making process tend to adhere to treatment advice
Patient outcome	<i>Reduction</i> Adverse outcomes Medical mismanagement Readmission rates Length of stay in hospital <i>Improvement</i> Overall health status and health-related quality of life Survival rates

and particularly on patient self-management of chronic diseases. Patient–clinician communication positively improves clinician and patient satisfaction, as well as patient adherence to recommended treatment. Table 1 displays and briefly introduces the components of the framework.

Communication is multifactorial. Roter and Hall extensively discussed patient–physician communication in their book *Doctors talking with patients/Patients talking to doctors: improving communication in medical visits* [34]. The authors described the factors affecting the optimal communication between patients and physicians. Some of

the factors include socio-demographic characteristics and patient health literacy. The authors state that improvement in the communication skills of doctors and patients has the potential to improve quality of patient care [34–36].

The effectiveness of communication can be enhanced by rapport building, up-front agenda setting, and addressing social and emotional issues [37]. The effect of enhancing communication is twofold: (1) when physicians acquire these skills, there is an improvement in quality of care and (2) once patients are exposed to this type of clinical encounter, they use the skills with other members of the team. Furthermore, Feldman-Stewart et al. [38, 39] describe one-to-one, in-person communication that occurs between patient and physician. The authors developed a conceptual framework that includes important factors needed for successful patient–clinician communication [38, 39].

Our framework theorizes that the completion of PROMs could affect communication among patient–clinician, patient–relative, clinician–clinician, and clinician–relative by raising patient’s awareness of his/her condition and facilitating the description of his/her symptoms to clinicians. Simultaneously, the provision of the information from PROMs to clinicians could trigger discussion of issues about which the patient is aware and concerned. Patients feel more relaxed and comfortable with the clinician, disclosing more information about his/her symptoms and health status. The availability of these results to clinicians and relatives could raise awareness about patient’s health status, and may prompt discussion among members of the multi-disciplinary team as well as relatives. These iterative and dynamic processes could result in an improvement in patient–clinician communication.

There are several studies that provide evidence that using PROMs improves patient–clinician communication [15, 21, 23, 40–43]. Detmar et al. [21] provided important evidence that PROMs improve patient–clinician communication and suggested that patient self-awareness and patient satisfaction (the patient feels more involved in his/her care) may also be improved.

In the routine care of cancer patients, Velikova et al. [15] assessed the effect of PROMs, detecting positive impacts on patient–physician communication. The completion of the PROM while allowing patients to express their concerns more effectively prompted discussion with the physician without increasing the time of consultation.

Takeuchi et al. [41] examined the effect of PROMs feedback on patient–physician communication over time to gain a better understanding of its influence on patient care. The authors assessed the dynamics of patient–physician interaction and the association between the use of PROMs and content of clinic discussion, and noted a positive impact on discussion of symptoms. Lately, Greenhalgh

et al. [43] found that when clinicians made reference to the PROMs, data communication between patient and clinician was affected. The authors suggested that in order to affect patient–clinician communication, clinicians needed to be trained in how to talk about the PROMs data.

During our study at the lung transplant outpatient clinic [16], we observed the potential effect of PROMs in enhancing communication between patient–clinician, clinician–clinician, and patient–relative. An example of the latter comes from a young male patient who visited the clinic with his mother. He was not a very communicative person but the completion and sharing of PROMs data with his mother and clinicians enabled him to discuss his emotional issues as well as being able to discuss potential solutions. In this instance, the use of PROMs prompted an iterative and dynamic process. In our study, we did not assess how the intervention affected patient engagement but in view of the observation, we assume that a potential result was the patient and his mother taking a more active role, and understanding of the importance of the information provided by the patient and family members brought to the encounter in the patient care.

Patient activation/engagement

We think that PROMs could improve communication between patient and clinicians involving patients in their own care. In situations in which clinicians use the PROMs data to discuss and educate patients, the use of PROMs data could have the potential to enhance patient engagement and activation.

Patients are activated when they understand their role in the care process and have the knowledge, skill, and confidence to carry it out. Bodenheimer et al. [44] suggested a patient-centered chronic care model in which patients and families have the knowledge and motivation to be effective partners in the care team. “When patients and their families are educated and understand why and how they need to actively participate in their care, and when they feel empowered to do so, their involvement can help to prevent medical errors and enhanced safety” [44]. Activation is enhanced by patient taking ownership, by listening, being involved in problem-solving and collaborating in the decision-making process. Patients need to understand their role, otherwise they would not be proactive [45–49]. The challenge presented to patients is to see health care providers as partners providing advice and strategies to patients to allow them to take charge of their health and engage in self-managing behaviors. By empowering patients to understand that providers are not merely professionals to see when one gets “sick,” but valuable partners that can provide advice and tools for individuals to take charge and achieve health outside the clinical setting.

To realize the value this partnership can bring, we first need to understand *how* to activate and maintain engagement [45–49]. Patient engagement affects management; it not only facilitates clinician management but also promotes patient self-management [45–49].

Patient management

Improvement in communication may help clinicians to detect under- and unrecognized problems [15, 16, 21, 42, 44, 49]. A potential effect of completing the PROMs may be that patients more frequently talk about the issues with the clinician and the clinician gains insight about patients’ perspectives. Consequently, once clinicians recognize the issues as clinically important, they could initiate changes (ordering new tests, changing medications and dosages, and referring patients to other specialists) and monitor patients’ progression at the clinic visits as well as between visits. Potentially, this process could improve patient management. We assumed that the routine use of PROMs in chronic care management provides useful information to engage patients and their relatives more effectively and efficiently. The patient and her/his relative share information about patients’ health status.

Santana et al. [16] detected modest effects on patient management in aggregate, while at the individual level, many patients benefited from the use of PROMs. For instance, the PROMs data from a female recently transplanted displayed severe knee pain. When the PROMs data were discussed during consultation, clinicians initiated changes: X-rays were ordered, analgesia was prescribed, and the patient was referred to a rheumatologist. In this case, the use of PROMs affected the clinical management of a recent lung transplant recipient. Potentially, the sharing of information coupled with clinicians empowering patients to understand her/his condition promotes patient–clinician partnership.

Shared decision making

Shared decision making is a process by which patients and providers consider outcome probabilities and patient preferences to reach a clinical decision based on mutual agreement.

We theorize that the routine use of PROMs in chronic care management could be used as a tool to aid in the shared decision-making process. PROMs data provide information about patient experiences and patient own preferences for health outcomes and the processes of treatment. Such information is not known by clinicians but is nonetheless important in choosing a specific treatment plan. The discussion between the clinician and the patient about the optimal treatment is of great importance given

the availability of treatment options and the uncertainty of medical treatment outcomes [48–55]. The clinician provides information about the range of treatment options, what they entail, and how likely they are to be effective given the characteristics and status of the patient. In chronic care management, shared decision making is an important strategy for improving both the quality and the outcomes of care [55–57]. Greenhalgh et al. [22] suggested that the effect of the use of PROMs data on clinical decision making was multifactorial and depended on the design of the intervention, clinician acceptance of the PROMs used, and the desire to discuss PROMs data with patients. Further studies suggested that the effect on decision making could be improved by teaching clinician how to use and interpret the PROMs data [43].

Once more, we theorize that the routine use of PROMs in chronic care management could play an important role in the decision-making process. PROMs could be used as a tool to aid in the decision-making process. To illustrate this hypothesis, an example derived from a particular clinical case at the lung transplant clinics in Edmonton follows. The PROMs from a recently transplanted patient displayed impaired cognition, in particular poor memory. Because the treatment was complicated, in order to maximize adherence to treatment, the patient care plan was modified through a discussion between the patient and the team (pulmonologist, pharmacist, and transplant nurse) about potential treatment alternatives.

Patient satisfaction

Patient satisfaction is determined by patient expectations and patients' characteristics [58, 59]. Patient satisfaction is multifactorial. Patient satisfaction could be affected when patients express dissatisfaction with elements of care and clinicians respond to these expressions by improving practice. Also, communication is one of the elements that contribute to patient satisfaction. Existing evidence suggests that poor communication is the most frequent source of dissatisfaction [58–61]. The enhancement of communication helps to develop treatment goals with patients. Patients feel more involved in their care; patients are more engaged and activated. The discussion of treatment goals and management changes empower patient and increase patient and clinician satisfaction. Satisfied patients are more responsive to the advice of clinicians. This improvement in patient satisfaction can change the patient's behavior. Patients became more adherent to medication, exercise, and diet [58, 59]. Enhancement in patient satisfaction not only affects adherence to recommended treatment but also affects length of stay in hospital as well as continuity of care and health status. Unsatisfied patients are less likely to receive appropriate care;

“patients make services less effective, either by neglecting to seek care when needed or refusing to comply with the prescribed course of treatment” [59].

The use of PROMs in management chronic disease patients could potentially enhance communication and improve patient satisfaction. This is illustrated by the use of PROMs in primary care. A study by Lyndon et al. [17] revealed that patients were satisfied with the use of depression questionnaires, while visiting the general practitioner clinics, as an adjunct to the general practitioners' clinical judgment [17, 18].

Patient outcomes

In an ideal world, the widespread of PROMs in routine clinical care of chronically ill patients has the potential to reduce the incidence of adverse outcomes and medical mismanagement, reduce readmission rates, and decrease lengths of stay in hospital as well as improving survival rates and overall health status and health-related quality of life. For instance, the ongoing use of PROMs after hospital discharge has the potential to enhance the early detection of problems and complications before they become more serious.

Methods for the clinical and health technology assessment of diagnostic technologies

The inclusion of PROMs in routine clinical care of chronically ill patients can be regarded as the introduction of a new screening and/or diagnostic tool. Therefore, the effects of such an innovation could be evaluated using the health technology assessment framework for diagnostic technologies developed by Guyatt et al. [62]. Health care-related technologies were defined by Banta and Behney [63] as “The set of techniques, drugs, equipment, and procedures used by health care professionals in delivering medical care to individuals, and the system within which such care is delivered.” According to this definition, using PROMs in routine clinical care is a health care technology. The evaluation consists of six steps: technologic capability, range of possible uses, diagnostic accuracy, impact on health care providers, therapeutic impact, and patient outcome.

1. *Technologic capability* refers to the ability of the technology to perform to specifications in the selected clinical setting. For the case of using PROMs in routine clinical care, the PROMs should be easy to administer, score, and interpret. These measures should be able to assess a full range of health among diverse patient groups at a single point in time and

overtime. PROMs should exhibit minimal floor and ceiling effects and should be valid, reliable, and responsive to change.

2. *Range of possible uses* refers to the potential for the technology to provide important information in a number of clinical situations. For this study, the characteristics of the measure and its acceptability to patients and clinicians are relevant. The choice of measure depends on the purpose of the measurement, type of measure, performance characteristics, and other factors relevant to clinical practice. For example, using PROMs in routine clinical care of chronically ill patients may require a different measure from the one selected in routine clinical care of the general population. Specific measures focus on a particular disease or condition. Generic measures assess all types of patient populations and allow for comparison among them. At this step of the evaluation, we get answers to questions such as the following: Which of the measures add information to the routine clinical care of the patients? Help with patients' management? Help to improve patient health status?
3. *Diagnostic accuracy*. The technology should permit more accurate identification of the problems (diseases, conditions) and their severity. PROMs should be valid, reliable, and reproducible. The measure should be able to discriminate (identify patients with no, mild, moderate, or severe disease) and evaluate (assess within-person change over time). The ability of the routine use of PROMs to predict future events and outcomes is also relevant.
4. *Impact on health care providers*. The technology should enhance the confidence of clinicians in their identification of problems. Health care providers are able to interpret the results and use the PROMs measure in the routine care of their patients. Health care providers find that using PROMs improves communication, prompting their patients to reveal information otherwise not shared. This may be especially important for revealing information on emotional issues.
5. *Therapeutic impact*. The provision of additional information should alter decisions made by health care providers. PROMs may provide information that changes therapy. As a result of improved patient–clinician communication, changes in management may occur and health care provider and patient satisfaction may increase.
6. *Patient outcome*. The use of technology should benefit patients. If the use of PROMs has an impact on health care providers and on therapy, the routine use of PROMs has the potential to improve patient outcome. Thus, the use of the PROMs in routine clinical care

may improve patient–clinician communication, patient management, and patient outcomes.

In summary, following Guyatt et al. [62] guidelines for the assessment of new health care technologies, if the selected PROM is acceptable to patients and clinicians, adds information in the routine clinical care of the patients, if it helps with patients' management and helps to improve patient health status, then the PROM selected could be systematically incorporated to clinical practice.

Discussion

We developed a conceptual framework using a narrative review and summary of experience with the use of PROMs in clinical practice. The proposed framework describes potential effects of the use of PROMs in chronic care management, summarizing insights from the methods for evaluating clinical effectiveness, methods for the health technology assessment of diagnostic technologies, and results from the relevant studies.

The framework describes potential effects, from proximal to distal, including communication (patient–clinician, patient–relative, clinician–clinician, and clinician–relative), engaging patients in shared clinical decision making, patient management (clinician management and patient self-management), and patient outcomes. Important potential effects also include enhancement in patient activation as well as improvements in clinician and patient satisfaction, and patient adherence to recommended treatment.

Previous frameworks have described patient–physician communication, patient satisfaction, and health outcomes. Our framework adds unique domains, including patient engagement, patient activation, shared clinical decision making, and patient self-management. Our framework overlaps with a description provided by Greenhalgh et al. [26] but adds additional domains such as patient engagement/activation, shared decision making, and self-management.

Our framework builds on Feldman-Stewart and colleagues and adds evidence on the benefits of using PROMs in clinical practice to improve communication including communication among clinicians, clinician–relative, and patient–relative [38, 39].

The framework is simple enough to be actionable and use as a tool to assess potential effects of the use of PROMs in chronic care management. Patient engagement/activation and shared decision making are two new factors added and emphasized as responsible for patient self-management and patient management in general. Patients, who are engaged in more preventive behaviors, healthy behaviors,

and self-management behaviors, are activated. Patient activation can predict health utilization and health outcomes [46]. Evidence provided by Hibbard and colleagues suggests that activated patients are less likely to use emergency department services, be hospitalized, and re-admitted to hospital [48].

The framework includes the importance of patient and physician satisfaction, both affecting patient adherence to recommended treatment. There is some overlap between patient satisfaction measured by patient's experiences with care received and patient engagement. But it is important to differentiate between the two. While patient's experience is based on the patient's perception of quality of care received, patient engagement builds on patient's activation and self-management and includes the actions undertaken by patients on their own behalf.

It is also important to acknowledge the limitations of the framework. As noted above, the focus is on the potential effects of using PROMs in routine chronic disease management. Furthermore, there is empirical evidence that many of the potential effects discussed have in fact been observed in randomized controlled trials and observational studies. But in many other studies, the use of PROMs has not resulted in changes in communication, patient management, and patient outcomes. The evidence is mixed. The use of PROMs is not a panacea for improving the quality of care and patient outcomes.

Up to this point, the paper has focused on the potential effects of the routine use of PROMs for patients and clinicians engaged in chronic care management. The routine use of PROMs, however, has additional potential effects at the system level [49, 64–66]. Olsen et al. [64] discuss the concept of learning health care system, a system in which data on outcomes are routinely collected, that data are used to identify areas for improvement, new initiatives to address those areas are undertaken, and data on the results of the change in policy are examined, perhaps leading to additional refinements to the new interventions. A key to a learning health care system is measuring outcomes: what happens to patients? The routine use of PROMs plays an important role in monitoring the performance of the health care system. Furthermore, the accumulation of data on patient outcomes, especially when linked to comprehensive electronic medical records, has the potential to enhance comparative effectiveness research [49, 64–66].

Conclusion

The framework can be used as a tool to guide the development of interventions to improve chronic care management through the use of PROMs and as a research and evaluation tool to assess the effects of such interventions.

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