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Towards an understanding of PREMS and PROMS in COPD

Summary

Evaluation of healthcare is evolving, with the patient perspective increasingly sought to provide a more patient centred service. Self-report questionnaires are being used to gather information about patients' health-related quality of life; outcomes with, and experience of a treatment, and perceptions of the care delivered by the healthcare team. Patient satisfaction measures may be familiar to clinicians and researchers, as they are used routinely in many clinical settings. Patient satisfaction measures have a ceiling effect, masking the negative healthcare experience. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are measures that provide a patient-centric view of healthcare. In this article, we aim to untangle for the reviewer, the distinctions between patient satisfaction, PROMs and PREMs measures with a focus on chronic obstructive pulmonary disease (COPD) and introduce work in progress around the development of a new PREM for COPD.

Statement of Interest

M. Hodson has received previous funding to attend the ERS Annual Congress from pharmaceutical companies (these companies were not involved in the present work), and has received honoraria for education talks or in advisory capacity as a nurse consultant. C.M. Roberts has received payment for lectures including service on speakers' bureaus from GlaxoSmithKline, Almirall and Boehringer Ingelheim.

Chronic obstructive pulmonary disease (COPD) is a major cause of emergency hospitalisation, and death in the EU and worldwide [1–4]. Quality of life, other clinical outcomes and the patient perceptions of their care may be improved with effective management of COPD [2, 4, 5]. Traditionally clinicians and researchers have tended to use “objective” technical measures of outcome such as change in forced expiratory volume in 1 s (FEV₁) or Medical Research Council dyspnoea scale to measure success of an intervention

and whilst these provide valuable information they may not correlate well with, or address, what is important to the patient. The accompanying paper from the European Lung Foundation [6] highlights this issue and provides an insightful account of what is important to the patient with COPD and how they might choose to measure the success of COPD care.

A realisation of this fundamental difference in the evaluation of healthcare has stimulated a growing change in the quality

ERS 2013

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assessment of healthcare delivery and outcomes. The focus is evolving from an emphasis on morbidity, mortality and adverse outcomes in healthcare to that of health status, outcomes related to a treatment, health-related quality of life, experience of treatment and the healthcare team, all from a patient's perspective using self-reported questionnaires. There are three categories of measurement instruments being used: patient satisfaction measures; patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). There is much confusion about what PREMs and PROMs actually measure, the context in which they are used and how they differ from each other. This article aims to assist in clarifying these distinctions.

Untangling patient satisfaction, PROMs and PREMs

Patient satisfaction and measurement of the quality of care provided by healthcare services have become intertwined in the last 20 years. Patient satisfaction surveys are routinely used in hospitals in many European countries [7]. In a variety of National Health Service (NHS) hospitals in the UK, it is possible to complete satisfaction surveys at electronic booths in hospital foyers while still receiving care.

Application of the principles underpinning satisfaction with healthcare were borrowed from the service industry, backed by a tenet of consumerism and an increasing recognition of service user opinion [8–11]. A plethora of patient satisfaction scales abound today. Satisfaction tools may be generic, measuring satisfaction with care given by a health professional or service, for example “Would you recommend this practice to others?” or be condition specific, for example “Did your respiratory physician give you sufficient

information about how to manage your COPD?”.

Patient satisfaction scales, however, have a ceiling effect in that most patients score their care highly and there may be little discrimination between items [12–14]. In clinical circles, they are irreverently referred to as the “happy scales”. Clearly, however, not all patients are happy with their care and satisfaction scales may mask negative experiences [12, 15]. A study of 21 EU countries [16] indicated that satisfaction is also linked to “broader societal factors”, such as the wealth and prosperity of a country.

Dissatisfaction with patient satisfaction surveys [15, 17, 18] has led to recommendations that the focus shift from satisfaction with care to patient experience of care:

“High satisfaction ratings do not necessarily mean that patients have had good experiences in relation to that service [...] If the underlying policy purpose of satisfaction surveys is to provide patients with a voice in the assessment and continuing development of services then it is not adequate to utilise satisfaction survey results. Effort must be put into designing methods of accessing patients' experiences of services and the meaning and value they attach to them, whether these are positive or negative and whether they can be improved.” [15].

PROMs and PREMs are considered alternative ways of richer and more relevant information than patient satisfaction surveys [19].

PROMs

PROMs are self-report questionnaires, completed by patients, and seek to measure their perceptions of their health status and health-related quality of life. They will be familiar as research tools but are now increasingly used to manage individual patients and to provide patient-related comparative data across healthcare providers. Although variable in application

Table 1. Patient satisfaction

Definition of patient satisfaction

Patient satisfaction is the congruence between the ideal care a patient expects to get and their perception of the care actually received [12, 20].

Example of patient satisfaction items

How satisfied are you with the care given to you by your respiratory physician?
Would you recommend your respiratory physician to a family member?

to a population or to a specific condition, the content tends to focus on one or more of the following: physical functioning, symptoms, social wellbeing, psychological wellbeing, cognitive function and role activities. Patients score their perceived status against a statement with a scale. The European quality-of-life instrument, EQ-5D [21, 22], is an example of a generic PROM and the Oxford Knee Score [23], a condition-specific tool. For PROMs to be used in routine clinical practice, they must be simple to complete and contain few items concentrating on those relevant to the patient. The EQ-5D has three questions in each of five domains whilst the Oxford Knee Score uses just 12 questions covering pain, mobility and activities.

Since 2009, following reports recommending the introduction of the use of PROMs in the NHS [8, 9], all NHS hospitals have been required to ask patients to complete a PROM questionnaire before and after four specific elective surgical procedures: hip replacement, knee replacement, hernia repair and varicose vein treatments. The data from these PROMs is available on the Health and Social Care Information Centre (HSCIC) website (www.hscic.gov.uk/proms) where national-level data are published monthly and organisation and record-level data quarterly. While PROMs for long-term medical conditions, such as COPD, as yet, do not feature in this formalised UK NHS data collection, they may in the future. PROMs for elective procedures are usually administered before and after the intervention to measure effect. Such an approach may be more difficult for some medical conditions, for example, an exacerbation of COPD when a contemporaneous baseline measure may be difficult to collect.

The inclusion of such measures provides a new element to the “value” equation with which we assess the effectiveness of an

intervention. For example, a patient with knee arthritis who has low levels of pain is unlikely to obtain a PROM benefit judged using the Oxford Knee Score from joint replacement, unless there is a major functional disability. In the same manner, a patient who perceives that after a knee replacement they have gained little or no functional improvement may demonstrate a negative PROM score implying an adverse outcome for the patient even though the operation may have been a technical success. In this way, clinicians will need to reconsider the impact of medical care from the patient’s perspective.

There are many PROMs for COPD in use throughout the EU, although few are administered outside of research projects. The UK-based PROM Group have developed reports [22, 24] with details of the generic PROMs evaluated for use with people with COPD for example the SF-36 and condition-specific PROMs in use, for example the Chronic Respiratory Disease Questionnaire and COPD Assessment test (CAT).

PREMs

A PREM is a measure of a patient’s perception of their personal experience of the healthcare they have received. PREM instruments should focus on the aspects of the care that matter to the patient [25]. PREM results can be used to improve services and provide a patient view on these improvements that moves away from the technological or economic model that is often employed in service design.

In contrast to PROMs, which have been utilised widely for elective surgical procedures there has been very little research or practical application of PREMs. The Picker Institute UK has come closest with a number of questions within the UK-based national patient survey that explore generic patient experiences

Table 2. PROMs

Definition of a PROM

PROMs are self-report questionnaires, completed by patients, which seek to measure their perceptions of their health status and health-related quality of life.

Example of a PROM item

Generic

I generally get enough sleep at night (yes/no)

Condition specific

Difficulty with my breathing and frequent coughing means I have difficulty sleeping at night. (rating scale 1 (no difficulty) to 5 (great difficulty))

[26, 27]. The website for the Royal College of Paediatrics and Child Health describes in detail the steps involved in the development of a PREM for urgent and emergency care [28]. To date, there are no condition-specific PREMs for COPD.

Whilst generic PREMs are important, they risk losing elements of a patient's experience that are specific or weighted towards a particular disease or illness that is the dominant reason for a patient to seek healthcare assistance. These issues are even more complex in that a disease specific healthcare experience for a patient may involve different facets of care that reflect different aspects of a patient pathway or journey, for example, a hospitalisation for a severe exacerbation compared with a routine review in primary care.

UK national audit [29] and European international audit [30] have shown significant deficiencies in hospital care for COPD when measured against guidelines, and wide variation between hospitals when using benchmarking. In response to these alarming statistics, the UK Department of Health has produced a national service strategy document supported by the National Institute of Health and Care Excellence (NICE) quality standards and suggested outcome metrics [31]. These metrics recommend the recording of both PROMs and PREMs for COPD in order to provide a new perspective to both healthcare managers and clinicians which emphasises that services should put patients at the centre and not the priorities of clinicians or managers. PROMs and PREMs also have the potential to dramatically affect the consultation dynamic altering the focus from what the clinician wishes to communicate to an interaction based upon what is important to the patient. In this context, a disease specific PREM is essential. The need to support and focus on patient's experience and capture significant episodes such as "exacerbations" are key to defining the experience of a patient's journey through the healthcare system. At the present time there are no disease specific

PREMs that can be employed to gauge the quality of the patient's interaction with healthcare and reliance may have to be placed on generic measures.

Current work: development of a PREM-COPD

In the absence of any existing COPD-specific PREMs, the authors are currently involved in the development of such a tool. How people feel about their care is often expressed using their emotional (affective) domain and this is an area largely neglected in PREMs. The authors have conducted research to develop a PREM for COPD derived from interviews with patients who were asked about the experience with their healthcare in the community setting and with recent hospitalisation [32]. The development of our PREM-COPD is a move away from traditional medical model questionnaires, to look at the patient journey with COPD and identify the principal moments of quality care and affective experiences to benchmark future service provision. Our aim is to create a valid and reliable PREM for patients with COPD that puts the patient experience and patient outcomes as the metrics for quality improvements in healthcare.

64 patients with COPD across the community of northeast London, north Central London and Essex, with a range of severity and presentation capturing their experiences of COPD as a long-term condition and their interaction with health services [32]. A further 19 patients with recent hospitalisation, due to COPD related conditions underwent the same process but with a focus on their experience of hospital. The experiences for both groups were itemised and coded separately leading to the development of items pertaining to both patient situations.

20 affective (emotive or felt) responses were identified from patient responses in the interviews [32]. The negative affective responses described by both the community

Table 3. PREM

Definition of a PREM

A PREM is a measure of a patient's perception of their personal experience of the healthcare they have received.

Example of items from a PREM tool

Do you feel confident in the care given to you by your respiratory physician?

Table 4. The PREM–COPD with a focus on the affective domain

Example of items from the PREM-COPD instrument

- I am frightened of being breathless
- I feel anxious about my current health

and hospital patient groups included: scared; anxiety; worry; fear/frightened; frustration; annoyance/anger; confusion; embarrassment; surprise/shock. The negative affective response “feeling depressed” was only identified in the community group and “guilt” was only identified in the hospital group.

Positive affective responses identified for both groups were: gratitude; reassured and happy/enjoyment [32]. Altruism, hope and acceptance were also mentioned in the community group. Self-motivation, control and respect were either negative or positive affective responses according to their context with the first two only identified in the community group.

Future work on developing a PREM for COPD

An expert review panel of respiratory clinicians and academics reviewed the preliminary items from the affective responses for both patient groups, and identified a total of 52 items. These items have been incorporated

into statements with which the patient is asked to agree/disagree using a five-point scale. It is likely that many of the 52 statements will cross-correlate in their content. Stage 2 will involve testing of these items with the aim of reducing the questionnaire to between eight and 12 items that will provide the basis of a practical patient-reported experience tool.

Conclusion

The inclusion of PROMs and PREMs as measures of the success of medical interventions and the quality of medical services respectively portends a new era in patient–healthcarer relations. The information gained from these responses can be used to provide a more patient-centred service. Patient-reported outcomes for PREMs could become both vital elements of clinical interactions and be key measures in determining the success of interventions in research studies. Whilst PROMs focus on the impact of healthcare interventions, PREMs provide feedback on the quality of the service provided either for a specific interaction, *e.g.* an admission to hospital, or as an indicator of the overall care delivered to a patient, in other words, the value of the whole healthcare system. Such measures will challenge healthcare staff to think differently about the care they provide to patients and may stimulate managers and clinicians to deliver services around patients and not just around buildings and clinical teams.

Key points

- There is a move towards using patient measures to provide a different perspective on the effectiveness of medical care.
- Patient satisfaction measures have low discriminatory value.
- Patient outcomes measure changes to patient perceived health status after a medical intervention.
- Patient experience measures provide an insight into the quality of medical care as experienced by the patient.

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