Capturing experiences of patients living with COPD

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1. Methods of measuring patients’ experience of care
2. The role of patient satisfaction and patient-reported outcome measures in capturing views of nursing
3. Initial stages of a project to develop patient-reported experience measures for COPD

Capturing patients’ experience and outcomes is crucial if services are to provide high-quality care for patients living with chronic obstructive pulmonary disease.

Chronic obstructive pulmonary disease was the fifth leading cause of death worldwide in 2002, and is predicted to have moved to fourth position by 2030 (Bousquet and Khahaev, 2007). It is estimated that 3.7 million people in the UK may be living with the condition but only 900,000 are diagnosed (National Collaborating Centre for Chronic Conditions, 2010); this mismatch between numbers indicates that a huge proportion of the population with COPD remains undiagnosed.

While there are a number of national and international guidelines on its diagnosis and management (Global Initiative for Chronic Obstructive Lung Disease, 2014; National Institute for Health and Care Excellence, 2010), the term COPD itself is relatively new (Russell et al, 2011). It refers to a chronic respiratory condition encompassing a number of diseases (chronic bronchitis, emphysema and chronic asthma) (Russell et al, 2011).

Smoking is a major associated causal factor in COPD (Russell et al, 2011) but factors such as socioeconomic class and environment, as well as host factors, such as alpha-1 antitrypsin deficiency and airway hyperresponsiveness, all have a role in the disease (Russell et al, 2011).

Owing to its chronic nature, the symptoms of COPD are gradually progressive over a number of years. Shortness of breath (dyspnoea) is the principal and most disabling feature; this frequently affects the ability to exercise, and has a concomitant impact on health-related quality of life (Calverley, 2004). Many people may not seek help until a considerable loss of lung function has occurred.

COPD places a huge financial burden on the NHS in both primary and secondary care. Much of this money is spent on treating acute exacerbations of the disease (British Thoracic Society, 2006), and spending is increasing (NICE, 2010). The Department of Health (2011) has published outcome strategies for COPD and identified six objectives to achieve these, including early identification, diagnosis and intervention.

The NHS Constitution offers a clear vision and statement that the care provided by the NHS aspires to be of the highest standard, so health policies focus on defining a clear patient journey on a pathway of care (NHS, 2013). This has

Key points

1. Patients may have different views and prioritise care differently from nurses and other health professionals
2. Self-report surveys dominate as a method of capturing patient outcomes and experiences
3. Nursing needs to consider how to contribute to PROMS and how findings can be used in patient-centred care
4. More research is needed to establish the need for COPD-specific instruments
5. Questionnaire items for patient-reported experience measures that use patients’ own words can be designed
opened opportunities to question how nurses and other health professionals deliver care to patients, and to question what patients think about that care. Although the collection and collation of patient-specific data or feedback has increased considerably over the last few years, the terminology used can be confusing as interpretation of what we mean by patient experience varies nationally and locally.

Patient satisfaction, experience or outcomes?
Patients with COPD frequently present late in the onset of their disease (Price et al, 2010), and may already have reduced exercise tolerance. This leads to an inability to participate in activities of daily living and a reduced health-related quality of life (Casaburi, 2006).

A systematic review of qualitative research studies found many COPD patients report having good and bad days (Giacomini et al, 2012). The review identified 101 papers published over a 10-year period about aspects of patients’ experiences of living or dying with COPD. The challenge is to translate that research into clinical practice.

Our beliefs, as nurses, about what is important for providing high-quality patient care, may be different from those of patients to whom we deliver care. There is a drive nationally and internationally to capture patients’ own voices about how they experience their illness and their opinions about the care they received, and to increase patient involvement in the care process, including decision-making.

Self-report surveys
While there are many ways of capturing patients’ opinions, self-report surveys dominate.

Patient satisfaction surveys have been the preferred method for at least 20 years, but there is now a shift from satisfaction with care to patient experience of care (Hodson et al, 2013); this requires healthcare providers to think differently about how they capture and interpret patients’ views of care they have received.

To borrow from qualitative research, there are multiple views of reality: patients may prioritise care differently, view events differently and have different opinions about what is important to them when interacting with nurses, other healthcare workers and the healthcare system. We need surveys that capture information about what is important for an organisation and those that focus on what is important to individual patients’ experience of their care. The items of patient satisfaction and patient experience surveys therefore differ in their structure and focus (Hodson et al, 2013).

Patient-reported outcome measures
Another major development in patient data collection is patient-reported outcome measures (PROMs). These are self-report questionnaires, completed by patients, which seek to measure their perceptions of their health status and health-related quality of life (Hodson et al, 2013).

They have been described as capturing patients’ assessment of their own health at various points in time and, by comparing these snapshots, measure any changes in health that have taken place (Barham and Devlin, 2011). PROMs can be used to compare data across different health institutions (see for example the Health and Social Care Information Centre website www.hscic.gov.uk/proms) and, while they are currently used for elective surgical procedures in NHS hospitals, it is possible they may be extend to long-term conditions such as for COPD (Devlin and Appleby, 2010).

Respiratory services are currently using COPD-specific PROMS such as the COPD Assessment Test (GlaxoSmithKline, 2009; Jones et al, 2009), but they are not used as a benchmark of quality across the NHS in areas such as pulmonary rehabilitation. Barham and Devlin (2011) noted that there has been little direct engagement with nurses in developing DH-led PROMS but suggested ways of identifying the challenges and opportunities PROMS may have for nursing. Validated nurse-driven “add-ons” to PROMS that cover specific nursing outcome measures may be one way in which the profession can contribute to PROMS.

Why COPD-specific surveys?
As expected, surveys that are developed for, and used with, COPD patients are better than generic surveys at identifying the evidence, views, opinions or experiences being sought (Weldham et al, 2013; Pickard et al, 2011).

A systematic review of quality-of-life surveys for COPD care and research found that the strongest positive evidence was obtained when COPD-specific surveys were used, such as the COPD Assessment Test, Chronic Respiratory questionnaire, Saint George Respiratory questionnaire (SGRQ) and the Living with COPD questionnaire (Weldham et al, 2013). Similarly, a small study comparing the SGRQ with the generic EQ-5D health questionnaire and SF-36 health survey found that the SGRQ was able to provide more meaningful information about the differences in clinical severity for COPD patients (Pickard et al, 2011). However, a report prepared for the DH (Davies et al, 2009) indicates that generic measures such as the SF-36 and EQ-5D may be suitable for use with COPD patients if combined with a condition-specific respiratory survey such as the Short Form Chronic Respiratory Questionnaire.

When reflecting about the types of surveys discussed above, a key point to consider is “What purpose will they serve?” De Silva (2013) suggested more information can be obtained from surveys than they currently provide as they are an “untapped resource for monitoring patient experience because most documents reviewed merely reported the findings of the survey rather than using it for trend analysis or improvement initiatives”. Russell (2013) stated: “The focus to date has been on collecting data on patients’ experiences rather than using the findings to improve service quality. In fact, little is known about how such feedback can be used to improve patient-centred care”. In this context Russell (2013) used the term patient experiences to encompass satisfaction and patient-reported outcomes, and suggested that the greatest impact may be
gained from data collected close to the time of an experience.

While Devlin and Appleby (2010) stated that routine use of PROMS “has the potential to put the views and values of patients squarely at the heart of NHS management and clinical thinking about the provision of health care services”, the challenge is to extend this data collection from being about “productivity and performance in the NHS” to be used to improve the patient experience.

Patient-reported experience measures for COPD

New instruments to capture patients’ experiences are emerging, including patient-reported experience measures (PREMs). These aim to enable clinicians to understand the experience of the patient’s journey. Accordingly we define PREM as “a measure of a patient’s perception of their personal experience of the healthcare they have received” (Hodson et al., 2013).

There is currently no specific PREM for COPD but Roberts and Cornwell (2011) provided examples of what they envisaged items of a PREM for COPD might look like. For example: “I was treated with dignity and respect by the staff.”

We worked on a project for the Health Innovation and Education Cluster for the North East and Central London and Essex (2012). It involved interviewing just under 100 patients with COPD about what it was like living with the condition from diagnosis, hospital care and their interaction with their COPD team and general practice. Following these interviews, we have taken a different approach to how we view items for PREMs and hence the development of a PREM for COPD.

While instruments may be developed from patient interviews, we felt that questionnaire items sometimes do not reflect the emotions underlying a patient’s experience nor use the actual words used by patients to express that emotion. Our journey on the development of a PREM for COPD has focused on the affective or emotional domain of patients’ views about their care (Hodson et al., 2013; HIEC, 2012).

However, developing new validated instruments to use in clinical practice takes time and energy and must be done within a research framework. The first phase of our study based on the interviews culminated in the generation of 53 items (Box 2 gives an example). The second phase has involved using the items identified in phase one to survey COPD patients. The aim was to reduce and refine the items and develop a valid and reliable PREM for COPD that will be available for widespread use by those involved in care of COPD patients.

Box 2. SAMPLE PREM-COPD ITEM

<table>
<thead>
<tr>
<th>Everyday life</th>
</tr>
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<tbody>
<tr>
<td>● “I worry about the season and my COPD”</td>
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<tr>
<td>● “I feel I am in control of my condition”</td>
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Source: HEC (2012)

Conclusion

It is evident that capturing the patient’s experience and outcome are key aspects of providing high-quality care for patients living with COPD.

There is a call to generate more nurse-focused research to add value to the growing number of instruments aimed at capturing different aspects of a patient’s journey. The development of a specific patient-reported experience measure in COPD should complement the current plethora of outcomes, and will ensure that both outcome and experience are central to the compassionate care being delivered by nurses.

References

GlaxoSmithKline UK (2009) COPD Assessment Test. www.cateonline.co.uk/