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# Experience of general hospital care in older patients with cognitive impairment: are we measuring the most vulnerable patients' experience?

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## INTRODUCTION

Healthcare is more than a technical exercise in meeting physical healthcare needs; it has emotional, psychological, social and cultural dimensions. Patients, the public and government expect healthcare providers to ensure that patients' experiences are good. This represents an important outcome for health services<sup>1</sup> and is one of the five outcome domains in the UK NHS Outcomes Framework,<sup>2</sup> which is intended to inform healthcare commissioning.

Two-thirds of general hospital beds are occupied by older people<sup>3</sup>; half of these older people have cognitive impairment—mostly dementia and/or delirium. Cognitive impairment is a spectrum and for some (particularly those with delirium) cognition will fluctuate during their hospital stay, but a quarter of older patients in hospital will have moderate or severe cognitive impairment (with a Mini Mental State Examination score of <18).<sup>4</sup> They will be disorientated to time or place, have problems of attention and memory and following simple commands. These patients are mostly very old (half will be over 85 years old), acutely ill and have many comorbidities.<sup>4</sup> Many are reaching the end of their natural life<sup>5</sup>; there is a palliative element to their care, making the quality of their care and their experience of being in hospital of greater importance. Such patients have many functional problems (incontinence, needing help when moving and assistance with meals) and behavioural and psychological problems (delusions, hallucinations, agitation and aggression and apathy), which together with their

acute illness and comorbidities make them especially vulnerable to a poor experience.<sup>4</sup> Reports have criticised the quality of care of these patients<sup>6 7</sup> and poor quality care is likely to result in poor patient experience. Therefore we examined the methods currently used to measure patient experience or care quality and considered their feasibility for use with older people who are cognitively impaired.

## APPROACHES USED TO MEASURING PATIENT EXPERIENCE OR CARE QUALITY

A variety of methods are used by hospitals to measure patient experience or care quality, including provider self-assessment, regulatory inspection, surveys, interviews, focus groups, feedback from patients, complaints and non-participant observation.

### Provider self-assessment

In the UK, individual healthcare organisations use a self-assessed framework—the Patient Environment Action Teams (PEAT)<sup>8</sup>—for inspecting standards to demonstrate how well they believe they are performing in key areas, including privacy, single sex accommodation, dignity and respect, assistance with eating, drinking and personal care, how quickly staff respond to requests for help and management of visiting hours and visitor numbers.

A PEAT assessment has the benefit that it may stimulate internal reflection and analysis and could be a useful approach to change management. However, because it is self-assessed it is open to bias and it does not directly measure

patient experience, just some factors which may affect experience, and even these are problematic. Poor patient mobility means that private rooms for consultation are unlikely to be used. Clinicians may need to raise their voice to be heard by patients who are deaf further reducing privacy. Side rooms offer more privacy, but are usually used for infection control purposes and are often undesirable as they increase social isolation. Family visits are likely to improve patient experience in such an alien environment and should be encouraged not restricted, as expected by PEAT.

#### Regulatory inspection

The Care Quality Commission (CQC) in the UK inspects hospitals for the extent to which patients are treated with dignity and respect—important aspects of patient experience. The specific needs of people with dementia are not included in these inspections. For example, the CQC report on call bells not being in reach or not being responded to in a timely manner.<sup>9</sup> However, the problem may not be the positioning of the call bell, but whether the patient is able to get timely assistance to get to the toilet. In this regard, the needs of this patient group are varied as some do not understand how to use a call bell and others may use the call bell inappropriately, constantly pressing it when they do not require assistance. Another group may not realise they need the toilet and require prompting by staff.

#### Surveys

The USA and UK have the longest tradition of measuring patient experience,<sup>10</sup> with surveys commonly used to measure acute care patient experience. In England, the National in-Patient Survey includes quality indicators for patient experience and in the USA the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) is used. Surveys are attractive because they can target large populations in a systematic way, relatively cheaply and can show trends over time. However, surveys are completed retrospectively and those with memory problems will find them difficult. Many older patients who are cognitively impaired also have comorbid physical and sensory disabilities, such as visual problems or arthritis, which hinder completion of a questionnaire. Completing surveys while the patient is in hospital is also difficult for patients who are cognitively impaired due to problems of insight, communication, comprehension and abstract thought. The patient is typically fatigued and physically ill, often with delirium superimposed on dementia, resulting in fluctuations in mood and greater levels of disorientation. It is meaningless to ask a patient what their experience of hospital is if they do not recognise that they are in hospital. The ward environment and ward routine also make it difficult to interview patients where there will be a lack of privacy and constant

interruptions from clinicians. There is some evidence that people with mild to moderate cognitive impairment can be interviewed about their experience,<sup>11</sup> but our own attempts to interview patients who are cognitively impaired in the general hospital proved unsuccessful in providing information which could be used to measure a difference in patient experience.

The Picker Institute<sup>12</sup> recommends the use of proxies to complete surveys on behalf of the patient as an alternative. These are typically family carers. Family carers know the patient well and are likely to be concerned for their best interests. However, proxy respondents provide less positive evaluations of patient healthcare experiences than otherwise similar self-reporting patients on subjective global ratings; though differences are smaller on more specific report items (such as whether waits for clinical appointments are less than 15 min) and spouse responses are more similar to patients than other family members.<sup>13</sup> In addition, almost one in ten older patients with cognitive impairment in a general hospital have no identifiable carer.<sup>4</sup> A quarter of patients are cared for by a spouse who may also have age-related health problems, making it difficult for them to complete surveys.<sup>14</sup> The nature and closeness of relationships for the remainder is variable, which could confound or distort reports. Also, in many UK hospitals visiting time is restricted, often to the afternoon. Family visits may be short and some family members are unable to visit at all. The evidence on which family carers base the patient's experience may be limited. Most care is delivered when family are not present and staff tend to interact less with the patient when family are present. Family carers are often under significant strain prior to and during the hospital admission<sup>14</sup> and they may have had previous negative hospital experiences.<sup>15</sup> Families often feel their need for information have not been met, and this, rather than the quality of direct care, may result in family reporting negatively on the patient's experiences.<sup>16</sup> Family or other carers at best provide a partial view of patient experience.

Furthermore surveys may not measure what is important to older people who are cognitively impaired. Many of these patients are reaching the end of their natural life. They face a future of increasing disability, care home placement and ultimately death<sup>5</sup> and many do not have capacity to make their own decisions about treatment and care. These surveys place little emphasis on the psychological needs of the patient, such as being socially included, occupied, treated with warmth and able to maintain their identity.<sup>17</sup>

#### Other methods

Other methods such as interviews, patient feedback, focus groups and complaints are all prone to bias and require patient ability to remember the experience,

understand what is being asked and communicate the experience. Alternatively a reliable informant is required to speak on the patient's behalf.

### Structured non-participant observation

Obtaining information from patients, carers or hospital staff is likely to result in an incomplete or inaccurate assessment of patient experience. Direct observation may be a useful alternative<sup>12</sup>; if the observation is structured, a measure of patient experience can be made. But observations have their drawbacks. They are time consuming, experience is subjective and an observer can only infer experience from behaviour or demeanour. Observers may not be neutral and staff may change their behaviour due to the presence of the observer. However, observation does enable the experience of older people with cognitive impairment to be measured.<sup>12</sup> In the UK observation has been used by the English National Audit of Dementia and the CQC to measure care quality. The National Audit of Dementia<sup>6</sup> used the PIE tool (Person, Interaction, Environment) which measured what the patient does and how it affects them, staff interactions and how the environment impacts on the patient. However, this tool is not sufficiently structured to be used quantitatively and cannot be used for comparative purposes.

### Dementia care mapping

Many care homes and mental health hospitals use the Dementia Care Mapping tool<sup>18</sup> to measure care quality. Dementia Care Mapping is a structured non-participant observational tool specific to people with dementia. It quantifies the person's experience in terms of their mood and engagement, activity and process of care ('enhancers' and 'detractors'). Many consider that the behaviour or demeanour of a patient who is cognitively impaired does indicate their experience. If a patient is visibly sad or distressed, or positively happy, it is easy to infer their experience is negative or positive. Facial expression is much reduced in Parkinsonism and associated with most types of dementia. However, even in late-stage dementia, and for people with moderate to moderately severe dementia, emotion can be seen through the face, the voice, the body language, the eyes and touch.<sup>19</sup>

High engagement in a purposeful activity may also suggest a better patient experience. Cohen-Mansfield defined engagement as 'the act of being occupied or involved with an external stimulus'.<sup>20</sup> She considered engagement to be important to relieve boredom, loneliness and problem behaviours associated with dementia, and to increase interest and positive emotions.

Patients who are cognitively impaired in hospital are acutely ill, some dying or distressed by their circumstance. In this situation delivering dignified care may or may not result in the patient appearing to be in a

more positive mood. Nevertheless, the patient's experience is still likely to be better if care is delivered in a dignified manner than if care is delivered in a disinterested or insensitive way. It is therefore important to measure process of care as a proxy measure of patient experience.

The Dementia Care Mapping tool measures important variables which are relevant to patients' experiences of care. The tool has high face validity; however, it has weak psychometric properties.<sup>18</sup> It is also an insensitive tool, with patient mood being coded as neutral for the majority of time, and has been developed for community settings and mental health hospitals where patients are not acutely ill. Training is mandatory and expensive and it is resource intensive to use.

### CONCLUSION

The high prevalence of older people with moderate to severe cognitive impairment in the general hospital combined with their vulnerability to poor quality care makes the issue of measuring these patients' experience an important one. These patients are unlikely to be able to describe their own experience and family carers may not be aware of the patients' full experience. There may be a need to use multiple methods to describe patient experience, but structured non-participant observational tools appear to be the most promising method. Such tools, with good psychometric properties, suitable for measuring the experiences of patients who are cognitively impaired in the general hospital, need to be developed.

### Key points

- ▶ Older people form two-thirds of hospital admissions. Half have cognitive impairment; a quarter have moderate or severe impairment.
- ▶ Experiences of hospital care in older patients who are cognitively impaired cannot be reliably measured by survey or interviews with the patient or their carer.
- ▶ Structured non-participant observation is a promising method to measure the experiences of care in patients who are cognitively impaired.
- ▶ Cost-effective observational tools with good psychometric qualities need to be developed.

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