Abstract

Hospitalisation can be hazardous for older people, including from the harm of indignity; people with dementia are at increased risk. Multiple investigations revealing the abuse of older people, serve as a potent and perpetual reminder that health services need to enable older people to report on their experience of care. To do this, health services require measurement tools specifically designed and developed to meet the needs of older people. These tools also need to accommodate the older person's family / friends (referred to as their 'carer') if the patient is unable to report on their own experience of care.

There is compelling evidence, supported by concept analyses, policy, standards and rights, that the 10 Principles of Dignity in Care should be used to deliver and to evaluate the experience of care. Dignity is the word most prominent in rights and a word in common use in the community. To promote health literacy, there should be a shift away from the bureaucratic and poorly defined terms such 'person-centred' care and a shift toward the consumer empowering message contained in the 10 Principles of Dignity in Care.

The 10 Principles of Dignity in Care

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

The 10 Principles were generated from the feedback of hundreds of members of the public in the United Kingdom who were surveyed on their experience of dignity in care. The message 'Dignity in Care' has remained a powerful force for change in the provision of care in the United Kingdom. The 10 Principles are short, simple, easily understood and implementable statements, that can be used as a proxy for the more elusive 'person-centred' care.

Additionally, the 10 Principles cover content, important to older people, that is absent from the ‘attributes’ used to define ‘person-centred’ care.

My original contribution to knowledge was the development of a Patient Reported Experience Measure in the form of a Dignity in Care Questionnaire based on the 10 Principles of Dignity in Care. I have developed a patient version and a carer version of the Dignity in Care Questionnaire. The process of developing the patient and carer versions of the Dignity in Care Questionnaire was robust and resulted in achievement of each of the three aims of the study.

The first aim was to gain consensus from a panel of experts on the content to be used to measure each of the 10 Principles of Dignity in Care, for the patient and carer versions of the questionnaire that were to progress to the pilot study. This aim was achieved by a Delphi panel of 57 experts, including 19 consumers, were able to reach consensus on 69 items to include in the pilot study version of the questionnaire.

The second aim was to assess the: face validity of the items, ease of administration, number of items, time demands on respondents, scoring and interpretation with patients and carers in the hospital setting. This aim was achieved through the completion of an in-hospital pilot study in which 52 patients and carers participated in a cognitive interview while they completed the questionnaire, and in doing so, helped to refine the items and scoring used in the revised 50-item questionnaire.

The third aim was to collect questionnaire data to commence the process of assessment of the psychometric properties of the instrument. This aim was achieved through the collection of 200 patient and 77 carer questionnaires, which allowed the preliminary analysis of unidimensionality, validity and internal reliability using ‘modern methods’ of Rasch analysis.

The Dignity in Care Questionnaire includes 13 items in common across the patient and carer versions of the instrument. These 13 items represent 8 (of the 10) Principles of Dignity in Care. The final patient version of the instrument included an additional 10 unique items, resulting in a 23-item instrument, which demonstrated robust fit to the Rasch model, supporting unidimensionality, construct validity and internal reliability. The final carer version of the instrument included an additional 5 unique items, resulting in an 18-item instrument which demonstrated acceptable fit to the Rasch model, supporting unidimensionality, construct validity and internal reliability, but the carer results should be

considered exploratory and preliminary as the findings need to be verified with a larger sample.

Both the patient and carer versions of the Dignity in Care Questionnaire warrant further development. Measuring experience of care is difficult, many instruments are developed to this point and progress no further, thus perpetuating a gap in the research for sound instruments, to be filled by yet another instrument that does not reach its potential. A robust instrument cannot be developed to its final form in one research study. The case for a patient and carer questionnaire, based on the 10 Principles of Dignity in Care, is sound, and this preliminary assessment of validity and internal reliability indicates the basis of a sound instrument of measure. Further development of items and further analysis of validity and reliability for both the patient and carer versions of the instrument are required.

The items that constitute the 23-item patient version and the 18-item carer version of the Dignity in Care Questionnaire, herald the evolution of a new PREM that can be used to measure aspects of care that are important and relevant to older people (and their carers).

The items included in the questionnaire hold messages that can be used by health services to improve the experience of care for older people. They can be used, as designed, in the form of a questionnaire and they can be used as the foundation of a discussion about experience of care, with those unable to complete a questionnaire. The messages contained in the items can be used in education and training and to guide the implementation of quality improvement activities.

In Australia, in 2020, there were two Royal Commissions underway. The Interim Report of the Royal Commission into Aged Care in Australia was titled ‘Neglect’. Dignity in Care is an obvious and compelling response. The title of the Disability Royal Commission is ‘Violence, Abuse, Neglect and Exploitation of People with Disability’. Again, ‘Dignity’ needs to be the headline response. Dignity is not a fad, it is a human, health and aged care right.