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<http://ebn.bmj.com/content/18/3/76>

<http://www.sherpa.ac.uk/romeo/issn/1367-6539/>

<https://researchspace.auckland.ac.nz/docs/uoa-docs/rights.htm>

Study type: Integrative review

Citation: Guo, Q, Jacelon, CS. An integrative review of dignity in end-of-life care. Pall Med 2014; 28(7): 913-940

Implications for practice and research

- The paper has significant implications for policy and practice given the increasing mention of 'dignity' as a preferred outcome for healthcare, particularly within a palliative and end of life care context.
- The findings point clearly to a need for future research to develop a more nuanced understanding of dignity which takes into account cultural differences in how the term is understood.

Context

A key aim of palliative care is to provide patient-centered care that encompasses both the person at their end of life and those they are emotionally close to. In this frame the purpose of palliative care is to enable people with life-limiting conditions to 'live well', and to achieve a death compatible with their cultural needs, personal views, and preferences. One commonly discussed feature of 'living well' is retaining dignity. This study by Guo and Jacelon looks at how dignity has been defined in existing studies.

Methods

This paper critically examines the concept of dignity through an analysis of previous literature. The study used Whitemore and Knaf's method for an integrated review, producing a matrix of 28 studies discussing aspects of "dignified death" and "dignified dying" in an end of life, palliative care, or hospice care context.

Findings

The authors concluded that dying with dignity is a human right that comprises the following characteristics: autonomy and independence, relieved symptom distress, respect, being human and being self, meaningful relationships, dignified treatment and care, existential/spiritual satisfaction, privacy, in a safe and calm environment.

Commentary

The authors' aim is to "provide a comprehensive understanding of dignity in the context of end of life care." Given the growing popularity of the concept of dignity within research, service development, and policy, this is an important focus and the paper helps inform thinking about the agenda for future research in this area.

However, we would argue that an important next step is to develop a more nuanced understanding of the concept of dignity itself. In line with Street and Kissane (1) we understand dignity as a socially constructed phenomenon which is defined differently within various cultural, social and historical contexts. Through this lens there are limitations to addressing the question of 'what dignity is.'

Of note is the relatively large number of health care professionals (23 of 47 studies) discussing dignity from their specific context. It cannot be assumed that HCP's definitions of dignity are an adequate substitute for the opinions of those actually facing the end of life.

One particular issue that requires further exploration is the authors' assertion that "with the approaching of death, maintaining dignity always requires professional support . . . qualified care becomes a necessity to maintain dignity". This places the process of dying within a very specific, and potentially limited, socio-economic, cultural and political context. It assumes that medical intervention or professional care is affordable, accessible, and is desired by either/both the dying person or their family. It also fails to recognise that the bulk of care as death approaches is provided by family carers, not professionals, including in relation to maintain a dying person's dignity.

It is also worth noting that the authors identify "autonomy" as a key characteristic of dignity. Whilst evidence is provided that this is indeed the case for some people, our previous research has also identified contrary evidence. For example, we have found that older people frame end of life in terms of inter-dependence, not autonomy (2). Similarly, we have found that autonomy is not only valued differently, but also understood differently, within different cultural and ethnic groups (3).

The study points to the opportunity, as the authors discuss, to extend research exploring how dignity is constructed by a wider variety of people from a range of cultural, ethnic, and socio-economic groups.

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Competing interests

None

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