



## Measuring staff perception of end-of-life experience of older adults in long-term care



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### ABSTRACT

**Background:** Quality of dying and death receive far less attention than quality of life. Measuring the quality of care at end-of-life (EOL) in long-term care (LTC) is essential, to ensure high standards.

**Methods:** A questionnaire measuring staff perception of their patient's end of life experience (SPELE) was developed. Content validity (CVI) was assessed by a panel of experts, and piloting was conducted with dyads of healthcare assistants (n = 15) and nurses (n = 15).

**Results:** The SPELE captures facets of the quality of the death and dying experience from healthcare staff's perspective. Good group inter-rater reliability was observed among subscales. One exception was the pain and symptom experience scale. Kappa values showed little agreement between nurses and healthcare assistants for certain symptoms, including pain.

**Conclusion:** Further testing of the questionnaire is required. However it is described as a useful mechanism to enable researchers and clinicians to explore quality of care at EOL.

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### 1. Introduction

Setting and maintaining high standards in healthcare is paramount, however the emphasis on quality healthcare is primarily focused on improving patient outcomes and quality of life (QOL) (Batalden & Davidoff, 2007; Fung, Lim, Mattke, Damberg, & Shekelle, 2008). As the population ages, emphasis moves from acute to chronic care, and the assessment of QOL is necessary to our understanding of its relationship with patient outcomes (Han, Kim, Storfjell, & Kim, 2013). In 1999 Stewart *et al.*, Stewart, Teno, Patrick, and Lynn (1999), argued that the quality of care provided during the last few months of life could strongly affect the length of life and the QOL of patients and family. However, quality of dying and death, still receives far less attention than QOL. In fact, outside of hospice care, healthcare professionals often see death as synonymous with failing in their duty of care, where the culture is focused on cure and preserving life at all costs (Coffey *et al.*, 2013; Ellershaw, Ward, & Neuberger, 2003; Hamric & Blackhall, 2007). More recently, substantial efforts have taken place to evaluate and improve care of the dying in long-term care (LTC) (Badger, Clifford, Hewison, & Thomas, 2009; Hall, Goddard, Stewart, & Higginson, 2011; Hanson, Reynolds, Henderson, &

Pickard, 2005; Molloy, 2011), which is prudent given the incidence of expected annual deaths.

By 2050, the population aged over 65 years will have almost tripled to 1.4 million in Ireland (Central Statistics Office, 2008), 5% of whom reside in LTC. Increases in the ageing population will be even more dramatic in those over 85 years. Over 21% of this age group currently resides in LTC. In Ireland alone it is estimated that approximately 1000 extra LTC beds will be required each year, over the next 10 years, to accommodate the growing need (Layte *et al.*, 2009). In the US, approximately 1500 citizens, living in LTC, die each day (Munn *et al.*, 2007). It is inevitable that more and more of us will die in LTC, so it is essential that LTC facilities provide the highest quality end-of-life care.

### 2. Background

LTC facilities are coming under increasing pressure to provide high standards of care at end-of-life. Good end of life care is a litmus test for good care generally (Department of Health, 2008). Staff want to work in environments that are providing evidence-based quality care. Indeed healthcare professionals strive to facilitate a 'good death' for patients. However, what constitutes a good death and can we measure it? Vig, Davenport, and Pearlman (2002) explored older adults' (n = 16) perceptions of a good death, and found that dying during sleep was considered a good way to die. Other descriptors reported by participants

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included no pain, quick, and no suffering. Some participants wanted no knowledge of impending death while others wanted to be prepared. Likewise, Schwartz, Mazor, Rogers, Ma, and Reed (2003) suggest that for a good death, personal control, closure and clinical aspects are three important domains to consider. The Institute of Medicine define it as “one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards’ (Field & Cassel, 1997). Given its multi-faceted nature it is evident that a good death is difficult to define. However, there are some key attributes that are consistently referred to in the literature e.g. the importance of maintaining body integrity; pain and symptom management; completion and respect of the dying person’s will; adopting a holistic approach to the person; and allowing families to stay close to the patient (Cipolletta & Oprandi, 2014; Ko, Cho, Perez, Yeo, & Palomino, 2013). It is critical that if a ‘good death’ is part of our care goals for older adults living in LTC, we need to be able to measure it, recognize it. Measuring the quality of care provided, and the dying and death experience, is very challenging, particularly from the person’s own perspective due to issues such as alertness, dyspnea, emotional state etc (Sulmasy, McIlvane, Pasley, & Rahn, 2002).

Researchers and healthcare professionals have designed measures to capture the quality of the experience from other perspectives, namely family, as an accepted proxy (Curtis et al., 2002; Miyashita et al., 2008). Modification and adaptation of various instruments have enabled measurement of staff perspectives also (Cheng et al., 2008; Hodde, Engelberg, Treece, Steinberg, & Curtis, 2004). However, these have mostly been applied in the intensive care or palliative care setting. A systematic review on measures of quality of dying and death revealed 18 prominent studies (Hales, Zimmermann, & Rodin, 2010). The most commonly used instruments in this research were the Quality of Dying and Death (QODD) (Patrick, Engelberg, & Curtis, 2001), the Good-Death Scale (Tsai, Wu, Chiu, Hu, & Chen, 2005) and the Quality of Dying in Long-Term Care (QOD-LTC) (Munn et al., 2007). The QODD is an interviewer-administered questionnaire containing 31 items, which asks family members to rate the quality of the dying experience, for the deceased last 7 days, or for the last month, if the patient was unconscious or unresponsive. The Good-Death Scale is a 5-item scale that asks healthcare staff to rate the person’s awareness and acceptance of death, preparation of the person and their family for death, and the degree of physical comfort. The QOD-LTC measures the quality of dying, from staff and family perspectives, and is the first instrument to be tested in LTC settings. The review indicated that the psychometric properties of these instruments varied and the QODD had the best validity and reliability (Hales et al., 2010). Yet, the construct validity of the QODD has been questioned and recommendations made for its revision (Downey, Curtis, Lafferty, Herting, & Engelberg, 2010). Some instruments, described in the review, were conceptually underpinned by the definition that a death was ‘good’ if it occurred in accordance with a person’s wishes. Others took a more multifactorial approach and measured constructs such as closure, and focused on physical parameters to depict quality of care i.e. symptom management.

Measuring the quality of care provided, at end-of-life, in LTC, is fundamental to quality improvements, and service provision. van Soest-Poortvliet et al. (2011) contends that quality of care measures include aspects of the care context, whereas symptom control and adherence to care preferences, are more closely akin to indicators of the quality of the dying experience. Previously developed questionnaires, like those outlined earlier, measure either the quality of care, or the quality of the dying and death experience, but not both.

The development of this questionnaire is part of a larger project examining the systematic implementation of advance care directives and palliative care education, using the ‘Let Me Decide’ program (Molloy, 2011). The project is being conducted in three LTC facilities in Ireland. The number of residents involved in the study exceeds 230. Outcomes under investigation are family perception of quality of dying and

death experience, place of death, transfers to hospital, mortality rates, compliance with advance care directives (ACD)/advance care plans (ACP), control of symptoms in the last week of life, healthcare utilization and costs, and staff confidence in providing quality end-of-life care. During this 2 year-long study, we received continuous informal feedback from staff on the deaths occurring in the home, in relation to symptom management, adherence to patients’ wishes and communication issues with family and the broader healthcare provider community. It was evident that perceptions of quality of care at end of life needed to be measured in a more structured way, to facilitate reflection and learning from each death in each home, and to correlate these with chart data and family perceptions of care. Measuring staff perception of patient experience allows for practice-based reflection to occur. Reflecting on practice is an essential tool of practice enhancement and an antecedent of improved care. By capturing the quality of care provided and the dying and death experience from the staff perspective others and self can learn from deaths that went well and those that did not go according to plan. This questionnaire was developed to assist staff to evaluate what went right, what could have been improved, and what practice implications are required. Against this background a multi-dimensional questionnaire was designed.

Consequently, the purpose of this paper is to describe the initial development and pilot testing of the staff perception of End-of-Life Experience questionnaire (SPELE) to measure the end-of-life experience in older adults, in LTC. Additionally, healthcare assistants are often underrepresented, and their contribution to end-of-life care is under-recognized (Wholihan & Anderson, 2013). In this regard, the sample included dyads of nurses and healthcare assistants. Unlike most, the questionnaire developed in this research, simultaneously addresses the quality of care, and quality of dying and death experience. This article reports on the development of the questionnaire and outlines the process of initial validation, including content validity and inter-rater reliability.

### 3. Method

A two-phase approach was taken; phase 1 focused on the development of the questionnaire, and phase 2 was a pilot study evaluating the inter-rater reliability of the instrument in a sample of 15 healthcare professional dyads composed of nurse/health care assistants. The rationale for this mixed dyad was threefold; 1. The role of healthcare assistants is often understated in this type of research, yet they make up the largest staffing force in most long-term care facilities; 2. staff involved in the study requested that both types of healthcare professionals were included and not just nurses as more often than not it is a nurse/nurse assistant duo that primarily cares for a person at end-of-life and not nurse/nurse or nurse assistant/nurse assistant; finally, the real-life context in which the questionnaire will be used will include mixed dyads.

#### 3.1. Procedure

##### 3.1.1. Phase 1: Instrument development

Item generation and refinement, measurement format and content validity are fundamental stages in questionnaire design and development (DeVellis, 2003).

**3.1.1.1. Item generation and refinement.** Three main sources were used for item generation; literature, the Hospice Friendly Hospice/Health Service Executive of Ireland National End of Life Audit (Lovegrove, McKeown, & McLoughlin, 2013) and focus group discussions with healthcare staff working in long-term care, geriatricians and senior nursing management. Table 1 describes the domains measured, operational definitions and, number of items.

The questionnaire measures if individual preferences and advance care directives were complete and includes global perception scores on the quality of care provided. It also captures information on the physical aspects of end-of-life care through the domain of pain and symptom

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