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END-OF-LIFE CARE

Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland

Dympna Casey, Kathy Murphy, Aine Ni Leime, Philip Larkin, Sheila Payne, Katherine A Froggatt and Eamon O'Shea

Aim. The aim of this study was to explore key stakeholders and direct care managers' perspectives on the current provision of end-of-life care for older people in acute and long-stay care settings in Ireland and to construct a model of these.

Background. Although the literature reveals a number of factors that impact on end-of-life care, no study has examined staff perceptions concerning the provision of good end-of-life care for older people in an Irish context.

Design. Grounded theory was used. Semi-structured interviews were employed to collect data between 2007–2008.

Method. A purposive sample of 33 staff involved in the delivery of end-of-life care to older people working in six sites were selected.

Results. Factors that influence provision of end-of-life care in Ireland were identified. The core category was 'dying well'. The potential to 'die well' was influenced by three factors, namely philosophy, culture and organisation of care, knowing the person and physical environment and resources.

Conclusions. People are living longer consequently acute and long-stay care setting will increasingly become places where older people die. This study identified the factors that influence the provision of good end-of-life care for older people. Mobilising resources to ensure that these factors are considered is crucial to ensuring that regardless of where older people die in Ireland, they will receive the highest standard of care that nurses can provide.

Relevance to practice. Understanding the factors that influence the provision of end-of-life care in acute and long-stay facilities in Ireland can help health professionals give more focused support and ensure that influencing factors are addressed so that older people at end of life receive quality end-of-life care.

Key words: end-of-life care, long-stay care, nurses, nursing, older people, palliative care

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Introduction

As Europe, Ireland is experiencing the need to embrace a stronger public health policy approach to the care of older people as they reach end-of-life (EoL) (Davies & Higginson

2004). Palliative care a speciality of Irish medical practice since 1995 has been slow to embrace this message because the World Health Organisation revised the definition of palliative care from a 'speciality' to 'approach' (WHO 2002). Until recently, Irish palliative care was predominantly

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cancer-orientated, working from a hospice/EoL model of care. The Report of the National Advisory Committee on Palliative Care (Department of Health and Children 2001) advocated a more eclectic response to the needs for palliative care in the wider community. Although many aspects of the report remain unaddressed (Irish Hospice Foundation 2006), there are now several national initiatives designed to broaden the base of palliative care services. The Hospice Friendly Hospitals (HFH) initiative aims to address the lack of hospice/palliative care principles in hospital systems and structures. It promotes a comprehensive system of integrated care planning, ethical communication strategies for patient autonomy, and service planning and design to enhance dignity at end-of-life for all. The report of the Extending Access study Palliative care for all – integrating palliative care into disease management frameworks (Irish Hospice Foundation and Health Services Executive 2008) has adopted a focus towards those diseases directly attributable to longevity and age, chronic obstructive airways disease, heart failure and dementia (Hegarty & Currow 2007). Although there has been some criticism of this approach for 'medicalising' dying and giving insufficient emphasis towards 'social death' (Costello 2001, Johnson 2004, Grande et al. 2006), there is a perception that palliative care has shifted significantly towards a model which is now more appropriate for the older population. Given that most older people in Ireland are more likely to die in acute hospital settings, private/public nursing homes and other public long-stay care facilities, the extent to which services have shifted towards a model of care appropriate for older people at EoL and the factors that influence care provision at EoL care warrant investigation.

Background

End-of-life care has varied interpretations. Froggatt *et al.* (2006, p. 46) define EoL care as care provided 'any time in the final period of life where issues (physical, social, emotional and spiritual) arising from an individual's death and mortality' need to be addressed. Quality EoL care is further clarified as individualised care characterised by, '...shared decision-making and clear communication that acknowledges the values and preferences of clients and their families', (Steinhauser *et al.* 2000, p. 2482). EoL care is therefore intrinsically connected to quality of life issues for older people living in acute and long-stay care settings. There are many barriers, however, that affect the provision of quality EoL care.

Knowing the person, following their wishes and providing individualised care is considered key to quality EoL care (Hanson *et al.* 2002, Costello 2006, Froggatt & Payne 2006, Palan-Lopez 2007). Offering residents choices and control

over decision making is emphasised (Payne et al. 1996, Steinhauser et al. 2000, Aspinal et al. 2006). In long-stay units, residents become 'like family' members (Hanson et al. 2002, Cartwright & Kayser-Jones 2003, Phillips et al. 2006). In such relationships, staff are sensitive to the needs of the dying person, display kindness and take time to listen (Steinhauser et al. 2000, Costello 2001, Aspinal et al. 2006). In contrast, when staff fail to get to know the client, a poor relationship exists, making a good death less likely (Costello 2006). Furthermore, nurses' personal fears and concerns re-death and dying may lead to a self-protection process, what Renzenbrink (2004) refers to as 'relentless self-care'. In this context, staff circumvent developing close relationships and avoid emotional engagement with clients at EoL (Costello 2001, Hanson et al. 2002).

Staff may, therefore, resort to using superficial communication, and blocking techniques (Watson *et al.* 2006) ignore cues or change the topic when clients attempt to discuss death/dying (Costello 2001). This process creates a closed awareness around death, where everyone knows the client is dying but it is not openly discussed (Glaser & Strauss 1965, Costello 2001). An ethos of open communication between staff and clients regarding bad news, prognosis and treatment options are therefore important for good Eol care (Phillips *et al.* 2007).

Quality EoL care is also dependent on the culture, philosophy and organisation of care. Some studies found that organisational routines and the general busyness of the facility meant that caring for the dying was difficult (Costello 2001, Katz 2005). Hopkinson *et al.* (2003) explored EoL care in the acute setting and revealed a tension between what nurses felt care should be and the reality of practice where there was limited time and competing demands.

Lack of multidisciplinary team work and role ambiguity (Hanson et al. 2002, Anselm et al. 2005, Watson et al. 2006), staff shortages (Ling 2005, Cartwright & Kayser-Jones 2003, Costello 2006, 2001, Hanson et al. 2008); financial constraints (Ling 2005), time constraints (Hanson et al. 2002, Clarke & Ross 2006, Costello 2006), short-term relationships in busy acute settings, lack of support (Anselm et al. 2005) and poor communication between nurse and physician (Parish et al. 2006, Palan-Lopez 2007) all have a negative impact on EoL care. Furthermore, in acute hospitals, ensuring privacy when access to single rooms is limited can be difficult (Clarke & Ross 2006, Daaleman et al. 2008).

The literature also reveals a lack of palliative care and EoL training and education for staff (Hanson *et al.* 2002, Anselm *et al.* 2005). These include the need for medication management (Watson *et al.* 2006, Phillips *et al.* 2007) and symptom

management (Field & Froggatt 2003, Ling 2005, Froggatt & Payne 2006).

In summary, the literature reveals that staff knowledge of the person and their family, the organisation and ethos of care delivery, and the physical environment and resources influence provision of quality EoL care for older people. It is not known, however, if these factors are applicable to Ireland. It is important, therefore, to examine the provision of EoL care for older people in Ireland and compare these to the international literature.

Aims and methods

A grounded theory approach was used, and the aim of the study was to explore key stakeholders and direct care managers' perspectives on the current provision of EoL for older people in Ireland. This approach was deemed most appropriate as the focus of the study was on the meaning of events for people and the underlying social processes that shaped interactions (Glaser 1978, Chenitz & Swanson 1986, Smith & Biley 1997).

Sample

Study sites were randomly selected from 327 care facilities in Ireland who were surveyed to capture epidemiological data on death and dying facilities including staffing levels and training and educational needs of staff (O'Shea *et al.* 2008). Long-stay care facilities made up 93%, and acute hospitals and psychiatric hospitals the remaining 7%, while private nursing home accounted for the majority of facilities at 60%. The criteria outlined in Table 1 were then used to select six study sites representing the distribution of places of care in which older people die in Ireland and a purposive sample of 33 staff involved in the delivery of EoL care to older people from these sites were interviewed.

Initially, senior nurses were invited to suggest staff for interview. In later interviews, theoretical sampling was used

Table 1 Inclusion criteria for study sites

One acute hospital typically of the range of health care facilities across Ireland which should be >500 beds and <1000 beds to ensure an equal chance of selection beyond large Dublin teaching hospitals (usually >1000)

Two public extended care units with not less than 100 beds (one urban, one rural, representing the typicality of a large long-stay institution available in Ireland

Two private nursing homes (one rural one urban) typical of the 'for profit' sector

One long-stay unit attached to a palliative care centre

 Table 2 Gender and Occupation of participants

	Gender	Gender		
Occupation	Male	Female	Total	
RGN	1	19		
GP	2			
Occupational Therapist Assistant		1		
Physiotherapist Assistant		1		
Health Care Assistant	1	8		
	4	29	33	

to select participants and modify the interview guide, and in this way, concepts and emerging categories were developed (Strauss & Corbin 1998). This process continued until theoretical saturation was reached. Most participants were women (Table 2). The highest level of education attained by RGN's was a certificate in nursing (Table 3), and only 12 participants had attended a specialist course in palliative care.

Data collection methods

Semi-structured interviews with the use of an interview guide were used to collect the data. Data were collected over six weeks and interviews lasted between 45–60 minutes.

Ethics

Ethical approval was obtained from the University Research Ethics Committee. Informed consent was obtained from all interview participants 24 hours in advance of interview. Confidentiality was ensured by the removal of all identifying material. All participants were assured of their right to withdraw from the study at any time without fear of repercussion and that their anonymity would be preserved.

Data analysis

Data from all interviews were recorded and transcribed verbatim. Concurrent data collection and analysis were undertaken. A computerised qualitative data analysis package (Atlas Ti) was used to manage the data, and a grounded theory approach to data analysis was employed. This involved the use of the constant comparative technique (Glaser & Strauss 1967). First level or open coding (Strauss & Corbin 1998) was then undertaken allowing similar phenomena to be grouped together into categories. After the principle categories were established, axial or second level coding was undertaken. Finally, selective or level three coding was completed, where all the categories and subcategories

Table 3 Highest level of education attained by participants

Occupation	Highest educational qualification	Attended a specialist course or study day in Palliative care
Clinical Facilitator	Higher Diploma (Nursing)	No
Clinical Nurse Manager	Certificate (Nursing)	No
Clinical Nurse Manager	Masters (Nursing)	Yes
General Practitioner	MD	No
Health Care Assistant	FETAC*	No
Health Care Assistant	FETAC	No
Health Care Assistant	FETAC	No
Health Care Assistant	FETAC	No
Health Care Assistant	FETAC	No
Health Care Assistant	Post Primary Certificate	Yes
Occupational therapist assistant	Certificate (Nursing) obtained outside the EU	No
Physiotherapist assistant	Degree (Psychology)	No
RGN	Degree (Nursing)	No
RGN	Degree (Business studies)	No
RGN	Degree (Nursing)	No
RGN	Degree (Nursing)	No
RGN	Certificate (Nursing)	Yes
RGN	Certificate (Nursing)	Yes
Clinical Nurse Manager	Diploma (Counselling)	Yes
RGN	Certificate (Nursing)	Yes
RGN	Certificate (Nursing)	Yes
General Practitioner	MD	Yes
RGN	Certificate (Nursing)	Yes
RGN	Certificate (Nursing)	No
Health Care Assistant	Post Primary Certificate	No
RGN	Degree (Nursing)	No
Clinical Nurse Manager	Certificate (Nursing)	No
Clinical Nurse Manager	Postgraduate Diploma (Nursing)	Yes
Clinical Nurse Manager	Certificate (Nursing)	Yes
Clinical Nurse Manager	Postgraduate Diploma (Nursing)	Yes
Health Care Assistant	FETAC	No
Health Care Assistant	Certificate (Nursing)	No
RGN	Certificate (Nursing)	No

*FETAC, Further Education and Training Awards Council. This is a Level 5 Certificate in Healthcare Support for healthcare assistant, which focuses on core competencies needed to provide direct/indirect patient care, following allocation by and under the supervision of an RGN or RNM.

were united to form a core category (Charmaz 1990, Bluff 2005). In keeping with grounded theory, the literature was also used as data to help develop and define categories.

Rigour

The criteria developed by Lincoln and Guba (1985) – credibility, dependability, conformability and transferability – were employed to maintain rigour. All interviews were transcribed verbatim. A sample of participants were presented with a copy of their interview transcription to ensure that their interviews had been transcribed accurately. The data were then independently coded by two researchers, and

the comparisons of coding frameworks revealed overall agreement. Comments were also invited from two experts in EoL care who confirmed that the findings reflected their experiences of EoL care in contexts similar to Ireland.

Findings

A model of the factors that influence the provision of EoL care for older people was developed from the findings (Fig. 1). The core category was 'dying well' as this was the outcome that could be expected when good EoL care was provided. This model consists of three factors that govern the provision of good EoL care namely, philosophy, culture and

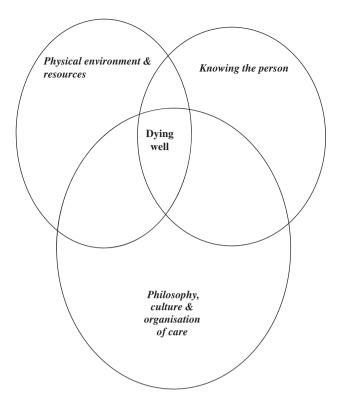


Figure 1 Factors that influence end-of-life care for older people.

organisation of care, knowing the person and physical environment and resources.

Philosophy, culture and organisation of care

This factor focuses on elements of the philosophy, culture and organisation of care, which shaped staff's approach to EoL care.

Most participants interpreted palliative care to mean care for people who were dying from cancer. They did not perceive that they had a key role to play in EoL care and were unsure as to whether they could to take on this role. These participants felt that palliative care should be provided by the hospice and palliative care teams:

...I associate it more with hospice and cancer, I think that's where I could have, respite care... we've palliative care here I suppose to a certain extent, I think I would have associated it more with hospice. (PIX048 Staff 3, Private Nursing Home)

When asked to describe the philosophical focus of EoL care within their facility, two main descriptions emerged. The first emphasised comfort and dignity in physical care terms. They perceived that the focus of EoL care was to make people as happy and comfortable as possible and believed that discussion of death was unsettling for residents and therefore not encouraged. The second description stressed the need to

prepare a person for dying and emphasised the need for holistic individualised care. It was recognised that this was not easy but was an essential part of their role. In these facilities, care was structured around clients' needs and there was recognition of the importance of clients' choice:

We are dealing with patients who are dying... we usually use the patient centeredness, ...if the patient wishes to get up at this what time, so you could give him a chance not like you will decide on your own like... (BLW004 Staff 3, Extended Care Unit)

Participants also described the support that they could expect within their facility when caring for people who were dying. Some felt supported by their managers and efforts had been put in place to provide formal counselling if required:

There's a counselling service available to staff for every issue here. I think it's fairly new but they're pushing the awareness of it now a lot, it's a great thing. (SAZ012 Staff 2, Acute Hospital)

For others, however, the ethos within their facility was 'carrying on' and containing emotions. It was evident that there was little support or understanding given to staff who were emotionally distressed, but the emotional labour of care was very evident:

...sometimes it could be hard if you get really attached to the patient which your not supposed to you know, really close attachment... and most of them are getting close to you but you have to be strong. (BLW004 Staff 3, Extended Care Unit)

The problem for staff in these facilities was that they often felt unsupported, and they therefore felt they were less able to give support to others.

The organisational routines in care facilities varied. It was evident that it was difficult for some participants to prioritise the needs of the dying within their workload. Participants suggested that time to 'be with' the dying person was key to good EoL care. However, they described the difficulties in giving that time as they lacked sufficient staff and their day-to-day work was so busy. There was, therefore, a tension between what participants believed to be best practice and the reality of care delivery. This tension resulted in stress and anxiety for staff:

Somebody dying needs more like one-to-one care, like they have upstairs (in the specialist unit) and here they have what – something like 10 nurses for 70 beds. That means at night you might have only one nurse to 24 beds. With that kind of staffing, you just can't have the kind of care you need when somebody is dying. (GRT005 Staff 3, Voluntary Hospital)

In some facilities, therefore the routine prevailed which often meant the dying person did not get the care that participants

felt they should. A few participants suggested that time and staffing levels were not the only issues in providing quality EoL care, and they also emphasised that there was a need to examine the way in which nurses' work to provide best care:

...sometimes we get it wrong because again the focus anyway is always about staffing...sometimes it's about you know what might need to be done in a different way to provide another way of looking at things, ...trying to get nurses to look differently about how their doing things, how they're working with patients ... (BLW004 Staff 7, Extended Care Unit)

In some facilities, a learning culture existed where staff shared information and knowledge. Staff participants from overseas described how they were unfamiliar with catholic death practices but they learnt from other members of staff or the ward manager. It was evident, however, that not all facilities shared this team ethos. A few participants who were care assistants felt that they were not given sufficient information about client's conditions or needs. While this was now changing one care assistant described how she felt 'locked out' when information was not given:

... when I started here three years ago and whenever you asked a question about a patient they'd say 'sorry it's none of your business...I think they were probably protecting confidentially, but you always felt you were sort of locked out, and I think that's changing now. (BLT004 Staff 1, Extended Care Unit)

It was evident therefore that there were perceived differences in the learning culture within facilities.

Participants also described a number of organisational practices and rituals they adhered to when a client was dying or died. Overall, participants reported rituals and practices relating to Catholicism. In such instances, reciting prayers at the bedside, putting a crucifix in the room and lighting candles were important considerations when a client was dying. A common practice routinely undertaken, as a mark of respect, was the switching off of televisions and radios. In addition, when a client died on a shared ward, the curtains were pulled around the other beds. It was clear that these rituals were undertaken in an effort to protect clients and to reduce their anxiety. However, participants recognised that clients were probably fully aware as to the purpose of this strategy:

QS5: ...they know that when the curtains are being pulled around they know why... but it's just not to be pushed in to their face you know.

P 6: BLT006 QS2. (Extended Care Unit)

In summary, the philosophy culture and organisation of care influenced the way in which EoL care was delivered. Across all facilities, there was an ethos of spending time with those who were dying. However, lack of time, staff shortages, lack of support and the organisational routines and procedures often hindered staff's ability to provide good EoL care.

Knowing the person

Participants felt that 'knowing the person' and creating a close relationship was a key determinant of quality EoL care. Many indicated that they did indeed form close attachments:

You get attached to them and then all of a sudden they're not there anymore and you still, we still mention (name), she's dead about two or three years, something would come up, 'oh do you remember (name) doing this.' (BLT6, Staff 02, Extended Care Unit)

In particular, participants felt that 'knowing the person' allowed them to interpret treatment and care wishes when communication with a client was no longer possible:

... you get to know the person's likes, dislikes, qualities...and then when it comes to the EoL, you have a good picture of what that person likes or the person doesn't like. (PIX48, Staff 04, Private Nursing Home)

Participants also described how getting to know the person enabled them to distinguish between normal behaviour patterns and episodes of distress that warranted referral and intervention.

Across all facilities, it was evident that participants were very sensitive to the needs of people approaching EoL. They described meticulous attention to certain aspects of care, for example holding a hand or talking to the person. Ensuring that the person was well groomed was also highlighted as important as this demonstrated respect for both the needs of the client and of the family.

it's,...the simple things, so simple that you nearly overlook them, a sip here, a word of encouragement... hold his hand for a few minutes you know if you get a chance... always cleanly dressed and shaved and that they would look well...its important. (BLW004 QS5, Extended Care Unit)

However, although 'knowing the person' was highlighted as important, most participants rarely, openly discussed death and dying with clients, and in many instances, they described the use of blocking techniques that closed down the potential for any discussion. Strategies such as keeping cheerful, distracting clients and offering reassurance that they would be fine were used.

...even if I know they have an hour left or whatever left, I keep on reassuring them like...'you will be fine, you will see, you will be fine',

yeah so try to reassure them... So you know to try reassure that there is a tomorrow there, and I know its not....but I try to reassure. (PIQ048 QS4, Private Nursing Home)

Some participants reported that lack of knowledge and skills was a key factor that prevented them from discussing death and dving. Others described instances where it was difficult to discuss death and dying with clients as the families did not wish them to know they were dying or vice versa. A system of 'closed awareness' was also in operation, whereby staff did not discuss dying with clients and clients were not give an opportunity to discuss dying with the staff, yet both parties appeared to know that death was imminent. Overall, it appeared that the acknowledgement of death was largely reserved for the time shortly before death and exhibited through the caring response of direct care staff rather than a discussion prior to the terminal phase of life. It was evident that in some facilities, EoL care had not been part of their normal business of care and they were not set up for this form of work as little formal EoL care planning which reflected an engagement with clients was undertaken.

Knowing the person therefore was viewed as crucial to good EoL care and to dying well, and across all facilities, staff demonstrated sensitivity to the needs of the dying. However, few staff openly discussed death/dying with clients and used various techniques to circumvent such conversations.

Physical environment and resources

Participants reported that the physical environment and adequate resources were an important issue in EoL care. In particular, the availability of a single room was deemed to be paramount as it helped to maintaining privacy and dignity of the client and family:

To have the dignity to die in a room on their own, I think would be very important. Because you can't grieve or say what they want maybe when there's other people in the room you know. (GRT005 S 4, Voluntary Hospital)

However, few facilities had single rooms and participants reported that they often found that these rooms were needed for other clients with an infection, which took precedence. In such instances, participants went to great lengths to meet the needs of families by procuring mattresses to enable families to be with their dying relative:

... the last few people that died we had mattresses that could just, throw on the floor and sleep in the room with the people themselves ... (GRT005 QS7, Voluntary Hospital)

Some participants felt that the death of a client in the same room was quite traumatic for other clients. However, others felt that moving a person to a single room may be inappropriate when s/he was used to living in shared accommodation.

Palliative care education and training was another key resource identified by all participants as central to providing good EoL care. A range of needs were identified including symptom management, pain management use of syringe drivers, counselling and psychosocial care. Access to educational opportunities, however, differed across facilities. Some participants reported that there were good training resources and opportunities, while others suggested that these were not always available:

...nurses need more education on palliative care and pain control. We should be sent by our hospital management to the hospice or whatever for one day, two days... I think we need it here in the care of the elderly as much as anywhere else. (BLT006 Staff 4, Extended Care Unit)

Participants also suggested that the increasing ethnic diversity of the population raised particular challenges for EoL care. They felt unprepared to give EoL care to people from different ethnic groups and felt strongly that this need should be addressed. In addition, staff participants from overseas described how they learnt appropriate cultural EoL care from their colleagues:

We just find out and we just ask what should be done...Normally [from] the manager ...So when I first came into this country, I didn't know what the rules were...But I find out what needs to be done so I know if they are Catholics I would put the beads, in their hands ... (PIQ048 Staff 4)

Physical environment and resources influenced EoL care. In particular, access to single-room accommodation and palliative care training and education hindered staffs ability to enable clients to die well.

Discussion

This research found that three factors influenced the provision of quality EoL care for older people in acute and long-stay care settings in Ireland: physical environment and resources, knowing the person, and philosophy culture and organisation of care. This work therefore strengthens the results from other international studies which have also identified these factors as important.

Participants recognised the needs of the dying and described examples of providing practical, sensitive and appropriate care. As in other studies, a key factor governing the provision of good EoL care revolved around building

relationships and getting to know the person as an individual (Costello 2006, Froggatt & Payne 2006, Phillips et al. 2006, Palan-Lopez 2007). Knowing the person, however, makes little difference if the facility lacks a care philosophy of open communication regarding death/dying. In this study, in an attempt to protect clients, a system of closed awareness dominated, whereby staff colluded and kept clients 'in the dark' regarding their terminal status (Glaser & Strauss 1965, Costello 2001). This closed awareness involved staff attempting to hide a death had occurred to maintain an atmosphere of normality believing that it would be upsetting for other clients (Katz 2005). Staff therefore seemed to engage in a 'professional performance' to conceal death (Komaromy 2000). These practices prohibit open discussions and preclude the establishment of meaningful relationships. However, staff may also engage in such behaviours because death and dying generates death anxiety. They, therefore, engaged in relentless self-care (Renzenbrink 2004). Thus, there is an urgent need to provide more support and education for staff on quality EoL care.

Similar to other studies (Hopkinson *et al.* 2003, Clarke & Ross 2006), this study also found that the culture, philosophy and organisation of care governed staffs approach to EoL care. Where the philosophical focus was holistic and individualised, care was orientated around client's needs and preferences. It is likely that the ethos is influenced greatly by the ward manager, and in the absence of a clear philosophy, the study found that clients were given little choice. Nurse Managers need to work with staff to support them to overcome any discomfort or fears re EoL care and help establish a clear understanding as to the care philosophy underpinning their work and how the terms EoL care and palliative care are operationalised in practice. In this way, staff may be more comfortable and confident in providing quality EoL care.

Lack of resources in terms of time and staff has a negative impact on staff ability to deliver quality EoL care (Hanson et al. 2008, Clarke & Ross 2006, Costello 2006). The situation in Ireland is not different and staff reported that they did not always have the time to give dedicated EoL care. However, although communicating and discussing sensitive topics with clients may require more time, more importantly, it requires a new way of working (Costello 2004, Clarke & Ross 2006). As suggested by participants in this study, the way in which time is allocated and care is prioritised must be reviewed to ensure that the dying person gets the care they need and that staff clearly feel they should receive.

Not being able to offer the dying person, the choice of single-room accommodation is a recognised problem (Clarke & Ross 2006, Daaleman *et al.* 2008). In acute hospitals and most public long-stay care facilities in Ireland, availability of

single rooms at the time of death is extremely low. The use of single-room accommodation and the actual physical structure of care facilities for older people therefore as recommended by Irish Health Information and Quality Authority (HIQA 2008) should be reviewed. However, it must be remembered that some patients like the company of others and prefer not to have a single room. The focus, therefore, should be on being able to offer residents at Eol the choice of single-room accommodation.

Lack of education training and skills in EoL care is well documented (Field & Froggatt 2003, Ling 2005, Watson et al. 2006, Phillips et al. 2007). Only 12 participants in this study had attended a palliative care training course, it was not surprising therefore that many requested further palliative care education. This deficit may be another reason why staff avoided and emotionally disengaged from older people at EoL. NICE (2004) stipulate that nursing staff should be educated in EoL care and in particular communication skills. There is an urgent need therefore to ensure that staff caring for older people receive adequate EoL education.

The study also reveals the need for multicultural education focusing on the EoL beliefs and needs of different ethnic groups. Traditionally, Ireland was predominantly catholic; however, recently there has been an influx of migrant workers in the care of older people. Recent statistics reveal that 43% of nursing staff and 32% of all staff in private nursing homes are migrant workers (INHO 2006). Nurse curricula therefore need to address these changes. Furthermore, migrant and overseas staff require induction programmes prior to commencing work in Ireland, which include Eol practices and needs of different ethnic groups.

Limitations

Although the sampling methods used was appropriate, asking senior nurses to identify initial participants for interview may have led to the inclusion of the more highly motivated and enthused direct care givers. In addition, had funding and time allowed a larger number of study sites could have been selected thereby adding to the robustness of the findings.

Conclusion and relevance to clinical practice

The majority of older people in Ireland die in acute and longstay care facilities. However, there is a dearth of information concerning the provision of Eol care for older people in these settings. Obtaining the views of staff about their experiences of providing EoL care therefore helps fill the current knowledge deficit. In addition, understanding the factors that influence the provision of good EoL care for older people in acute and long-stay care settings in Ireland: philosophy, culture and organisation of care, knowing the person and physical environment and resources; understanding extends prior knowledge and confirms the importance of these factors. This study presents compelling evidence that in Ireland, older people at EoL have several unmet needs and that the shift to providing appropriate palliative care services for older people at EoL has not yet occurred. Mobilising resources to ensure that it does and that the needs of older people at EoL are met is crucial to ensuring that irrespective of where older people die, they will do so while receiving the highest standard of EoL care nurses can provide.

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Contributions

Study design: KM, DC, PL, EOS, KAF, SP, ANL; data collection and analysis: KM, DC, PL, ANL and manuscript preparation: DC, KM, PL, SP, KAF.

Conflict of interest

None.

References

- Anselm AH, Palda V, Guest C, McLean F, Vachon M, Kelner M & Lam-McCulloch J (2005) Barriers to communication regarding end-of-life care: perspectives of care providers. *Journal of Critical Care* 20, 214–223.
- Aspinal F, Hughes R, Dunckley M & Addington-Hall J (2006) What is important to measure in the last months and week of life?: A modified nominal group study. *International Journal of Nursing Studies* 43, 393–403.
- Bluff R (2005) Grounded theory: the methodology. In *Qualitative Research in Health Care* (Holloway I ed). Open University Press, Berkshire, pp. 147–167.
- Cartwright J & Kayser-Jones J (2003) Endof-life care in assisted living facilities: perceptions of residents, families, and staffs. *Journal of Hospice & Palliative Nursing* 5, 143–151.
- Charmaz K (1990) Discovering chronic illness; using grounded theory. *Social Science Medicine* 30, 1161–1172.
- Chenitz WC & Swanson JM (1986) From Practice to Grounded Theory: Qualitative Research in Nursing. Addison-Wesley, Menlo Park, CA.
- Clarke A & Ross H (2006) Influences on nurses' communications with older people at the end of life: perceptions and experiences of nurses working in palliative care and general medicine. International Journal of Older People Nursing 1, 34–43.

- Costello J (2001) Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing* 35, 59–68.
- Costello J (2004) *Nursing the Dying Patient*. Palgrave Macmillian, Basingstoke.
- Costello J (2006) Dying well: nurses' experiences of 'good and bad' deaths in hospital. *Journal of Advanced Nursing* **54**, 594–601.
- Daaleman TP, Usher B, Williams S, Rawlings J & Hanson L (2008) An exploratory study of spiritual care at the end of life. *Annals of Family Medicine* 6, 406–411.
- Davies E & Higginson IJ (eds) (2004) *Better Palliative Care for Older People*. WHO Regional Office for Europe, Denmark.
- Department of Health and Children (2001)

 Report of the National Advisory Committee on Palliative Care. Department of Health and Children, Dublin.
- Field D & Froggatt K (2003) Issues for palliative care in nursing and residential homes. In *End of Life in Care Homes*. A Palliative Approach (Katz J & Peace S eds). Oxford University Press, Oxford, pp. 175–193.
- Froggatt K & Payne S (2006) A survey of end-of-life care in care homes: issues of definition and practice. *Health & Social Care in the Community* 14, 341–348.
- Froggatt KA, Wilson D, Justice C, Mac-Adam M, Leibovici K, Kinch J, Thomas R & Choi J (2006) End-of-life care in

- long-term care settings for older people: a literature review. *International Journal of Older People Nursing* 1, 45–50.
- Glaser B (1978) Theoretical Sensitivity:

 Advances in the Methodology of
 Grounded Theory. Sociology Press,
 Mill Valley, CA.
- Glaser BG & Strauss AL (1965) Awareness of Dying. Aldine Publishing, New York.
- Glaser B & Strauss A (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. Aldine de Gruyter, New York, NY.
- Grande GE, Farquhar MC, Barclay SIG & Todd CJ (2006) The influence of patient and carer age in access to palliative care. *Age and Ageing* 35, 267–273.
- Hanson L, Henderson M & Menon M (2002) As individual as death itself: a focus group study of terminal care in nursing homes. *Journal of Palliative Medicine* 5, 117–125.
- Hanson L, Eckert K, Dobbs D, Williams C, Caprio A, Sloane P & Zimmerman S (2008) Symptom experience of dying long-term care residents. *Journal of the American Geriatrics Society* 56, 91–98.
- Hegarty M & Currow D (2007) Palliative aged care: collaborative partnerships between gerontology, geriatrics and palliative care. *International Journal of Gerontology* 1, 112–114.
- HIQA (2008) National Quality Standards for Residential Care Settings for Older

People in Ireland. Health Information & Quality Authority, Dublin Ireland.

- Hopkinson JB, Hallett CE & Luker KA (2003) Caring for dying people in hospital. *Journal of Advanced Nursing* 44, 525–533.
- Hospital Friendly Hospitals (2010) Available at: http://www.hospitalfriendly hospitals.net (accessed 27 April 2010).
- INHO (2006) Irish Nursing Home Organisation Annual Private Nursing Home Survey, INHO, Dublin.
- Irish Hospice Foundation (2006) A Baseline Study into the Provision of Hospice/ Specialist Palliative Care Services in Ireland. IHF, Dublin.
- Irish Hospice Foundation and Health Services Executive (2008) The Report of the Extending Access Study Palliative Care for All Integrating Palliative Care into Disease Management Frameworks, IHF, Dublin.
- Johnson G (2004) Social death: the impact of protracted dying. In *Palliative Care Nursing: Principles and Evidence for Practice* (Payne S, Seymour J & Ingleton C eds). Open University Press, Maidenhead, Berkshire, pp. 351–363.
- Katz JS (2005) Palliative care in residential care facilities: a brief review International. *International Journal of Pallia*tive Nursing 11, 130–131.
- Komaromy C (2000) The sight and sound of death: the management of dead bodies in residential and nursing homes for older people. *Mortality* 5, 299–315.
- Lincoln YS & Guba EG (1985) *Naturalistic Inquiry*. Sage, Newbury Park, CA.

- Ling J (2005) Palliative care in Irish nursing homes: the work of community clinical nurse specialists. *International Journal* of Palliative Nursing 11, 314–321.
- NICE (2004) National Institute of Clinical Excellence (2004) Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer. National Institute of Clinical Excellence, London.
- O'Shea E, Larkin P, Payne S, Froggatt K, Murphy K, Casey D & Ni Leime A (2008) A Study of the Provision of Care for Older People Dying in Acute and Community Hospitals and Nursing Homes in Ireland: Towards a Quality of Life Focus. National Council for Aging and Older People, Dublin.
- Palan-Lopez R (2007) Suffering and dying nursing home residents: nurses perceptions of the role of family members. *Journal of Hospice & Palliative Nursing* 9, 141–149.
- Parish K, Glaetzer K, Grbich C, Hammond L, Hegarty M & McHugh A (2006) Dying for attention: palliative care in the acute setting. *The Australian Journal of Advanced Nursing* 24, 21–25.
- Payne SA, Langley-Evans A & Hiller R (1996) Perceptions of a 'good death': a comparative study of the views of hospice staff and patients. *Palliative Medicine* 10, 307–312.
- Phillips J, Davidson P, Jackson D, Kristjanson L, Daly J & Curran J (2006) Residential aged care: the last frontier for palliative care. *Journal of Advanced Nursing* 55, 416–424.

- Phillips J, Davidson P, Ollerton R, Jackson D & Kristjanson L (2007) A survey of commitment and compassion among nurses in residential aged care. *International Journal of Palliative Nursing* 13, 282–290.
- Renzenbrink I (2004) Relentless self-care. In Living with Dying: A Handbook for End-of-life Healthcare Practitioners (Berzoff J & P Silverman R eds). Columbia University Press, New York, pp. 848–867.
- Smith K & Biley F (1997) Understanding grounded theory: principles and evaluation. *Nurse Researcher* 4, 17–30.
- Steinhauser K, Christakis N, Clipp E, McNeilly M, McIntyre L & Tulsky J (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284, 2476–2482.
- Strauss A & Corbin J (1998) Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 2nd edn. Sage, Thousand Oaks, CA.
- Watson J, Hockley J & Dewar B (2006) Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal* of *Palliative Nursing* 12, 234–240.
- World Health Organization (2002) Definition of Palliative Care. Available at: http://www.who.int/cancer/palliative/definition/en (accessed 14 July 2010).

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