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Improving Palliative and End-of-Life Care for Older People in Ireland: A new model and framework for institutional care

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INTRODUCTION

In the Republic of Ireland, just over 27,000 people die each year. Just over three-quarters of them are more than 65 years old (1). This is comparable to the situation in the United Kingdom, where almost two-thirds of total deaths occur among those older than 75 (2). International demographic patterns indicate that in most parts of the world, people are living longer, and dying typically occurs in later life (3); these demographic trends are predicted to continue in this century. Epidemiological changes in Ireland are reflective of those in other European countries, where, increasingly, older people live with one or more chronic conditions — including cancer, organ failure, and dementia — for some years before they die (1, 3). Hence, a significant number of older people must now cope with one or more chronic conditions — and some an awareness of prolonged and uncertain dying — for a considerable period before death.

In Ireland, 40 percent of older people die in acute care hospitals, 15 percent in nursing homes, 25 percent in publicly funded long-stay institutions, and 20 percent at home (4). Previous reports have examined end-of-life care in hospitals and through specialist palliative care services — care that is largely funded by voluntary organizations — and its relationship with community medical and nursing services (5-7). The extension of palliative care services to meet the needs and preferences of those with cancer or other long-term conditions has been adopted as a government policy aim, without reference to time scale or definitions. In the Irish and British context, palliative and end-of-life care are seen as services that are offered over an extended period of time — up to two years — during which patients and their families

have an increasing awareness of approaching death (2). Unlike in other countries, in Ireland and Britain, end-of-life care and hospice care are not considered to be services that are required exclusively in the last few days of life. This more extended definition of palliative and end-of-life care will be used in this paper. It is reflected in the adoption of an end-of-life care standard in the draft National Quality Standards for Residential Care Settings for Older People, which links end-of-life care to palliative care services (8). Institutions providing nursing, residential, and long-term care for older people are increasingly recognized as places where older people can live their final years; they are also often seen as places that will provide care to older people as they are dying, although standards of care may vary (9). Overall, the evidence indicates that there is a diversity of provision, with geographical inequity in the distribution of services and lack of access to specialist palliative care for part of the population. Particular concerns have been raised about the coordination of services, especially in relation to community care services (9).

In this paper, end-of-life care is taken to mean care that lasts for an extended period — for the time in which an awareness of approaching death can be measured in days, weeks, months, and years. It is not confined to the hours immediately before death (2). Our focus is on the care provided to older people dying in hospitals and long-stay institutions. In the Irish context, this includes the following statutory, for-profit, and charitable facilities: acute care, community, and psychiatric hospitals; private nursing homes; and Health Services Executive (HSE) extended care units, as well as HSE welfare homes, voluntary homes, and voluntary welfare homes (4).

The process of dying is often hard work. It holds many emotional ups and downs for patients and their family members, but there is evidence that it is particularly problematic for older people for whom the nature of dying is often protracted, complex, and uncertain (10, 11). Moreover, an older patient's "dying" status may be ambiguous, and this may lead to over-treatment or under-treatment, which will delay referral to palliative care. Evidence from Ireland and the UK suggests that older people may be disadvantaged in terms of their access to appropriate and acceptable services that meet their wishes and preferences and those of their family carers, who may also be older people (2, 5-8). There are problems in recognizing the process of dying, and assigning an entry point to the end-of-life phase is always going to be somewhat arbitrary (12). Hypothesized models of typical dying trajectories linked to cancer, organ failure, and frailty have not always been supported by empirical data (13, 14). Earlier models have assumed a linear trajectory of decline (15) or have focused on psychosocial transitions alone (16). More recently, a new model, "the wave," has been proposed to capture the fluctuations in palliative care input relative to other health care interventions, including curative treatment (17).

At present, there is a lack of understanding about the experiences of older people dying in acute and institutional care environments, where the majority of people receive end-of-life care, and about appropriate models of care for these people. Typically, hospice and specialist palliative care has been developed for middle-aged patients following a terminal cancer trajectory, as in these cases it is easier to predict the course of dying. There remain concerns, however, about this model's applicability to older people, to hospitals, and to nursing homes, which have fewer staff; the staff they do have possess less end-of-life care expertise and often have competing priorities. Our paper seeks to explicate a framework to help develop end-of-life care that explicitly addresses these dilemmas.

METHOD

This paper draws upon a mixed methods study conducted in Ireland between September 2006 and August 2007. The study aimed to examine the end-of-life care experiences of older people in acute care hospitals and long-stay institutions in Ireland, and it had three specific objectives: first, to undertake a survey of all known Irish acute care hospitals and long-stay institutions in relation to contextual epidemiology of death and dying, facilities, staffing levels, access, and liaison with services and training and education needs of staff;

second, to describe key stakeholders' and direct care managers' perspectives on the current provision of end-of-life care for older people; and third, to explore the experiences of older persons in receipt of end-of-life care.

For the purposes of this research, older people are defined as those aged 65 years and over. Ethical approval was obtained from the National University of Ireland (NUI) Galway research ethics committee. Data collection involved a survey of 592 hospitals and long-stay facilities and interviews with 35 health care workers and 30 older patients nearing the end of life. For the analysis, we used quantitative and qualitative methods and focused on describing the end-of-life care facilities and services in the hospitals and long-stay facilities; the experiences of health care providers in delivering care; and the experiences, expectations, and preferences of older patients being cared for in the different institutional settings. A full account of our methodology and findings is published elsewhere (4). The model (Figure 1) and framework (Table 1) presented here drew upon these findings and upon an extensive review of the legal context and the empirical and policy literature (4). Over the course of a number of meetings, the research team used evidence from the quantitative data to identify the many barriers to the development of new conceptual approaches. Such approaches would seek holistic, person-centred solutions with longer time horizons than the typical reactive approaches would have. For example, a lack of physical space in the care facility meant that patients and their families had little privacy at the time of death. There were reported to be few single rooms, and those that were available were prioritized for infection control, not dying patients. These and similar insights were further illuminated and checked against the qualitative interview data. Both sets of data indicated resource constraints, capacity problems, infrastructure weaknesses, education deficiencies, and poor attitudes and expectations in relation to the quality of life for older people requiring palliative and end-of-life care. Our model and framework were initially developed and refined in this context, and we therefore claim that it is grounded in the experiences of older patients.

DEVELOPMENT OF A NEW FRAMEWORK FOR END-OF-LIFE CARE FOR OLDER PEOPLE IN INSTITUTIONS

This paper proposes a new model and framework for an approach to developing good practice in end-of-life care for older people living and dying in acute care hospitals and long-stay institutions

in Ireland. We will introduce the premises upon which the framework is based, suggest a conceptual model to map the transition of older people from life to death, and indicate the focus for, and dimensions of, the new framework. Four dimensions are identified: knowing and revealing needs; expressing values and preferences; interacting with others; and developing knowledge. All of this occurs at five levels: the older person, the family, the hospital and institutional staff, the organization, and society. We offer an example of how the model might be operationalized in practice to deliver good end-of-life care to older people and outline roles and responsibilities at each of the five levels. We then describe a number of elements of this new approach that take into account the individual older person's changing and unpredictable experiences as he or she moves from life to death, and we look at that person's situation in a wider family, organizational, and societal context. Finally, we illustrate this approach using a hypothetical case example to demonstrate how the new framework may be operationalized and how it can contribute to the development of good practice and care at the end of life.

The new framework is underpinned by some basic premises and links to our study data: older people dying in hospitals and long-stay institutions have care and support needs (9); there is often great uncertainty about the transition from life to death among older people (3, 13, 15); during the end-of-life period, many domains are encompassed in ensuring a good quality of life and

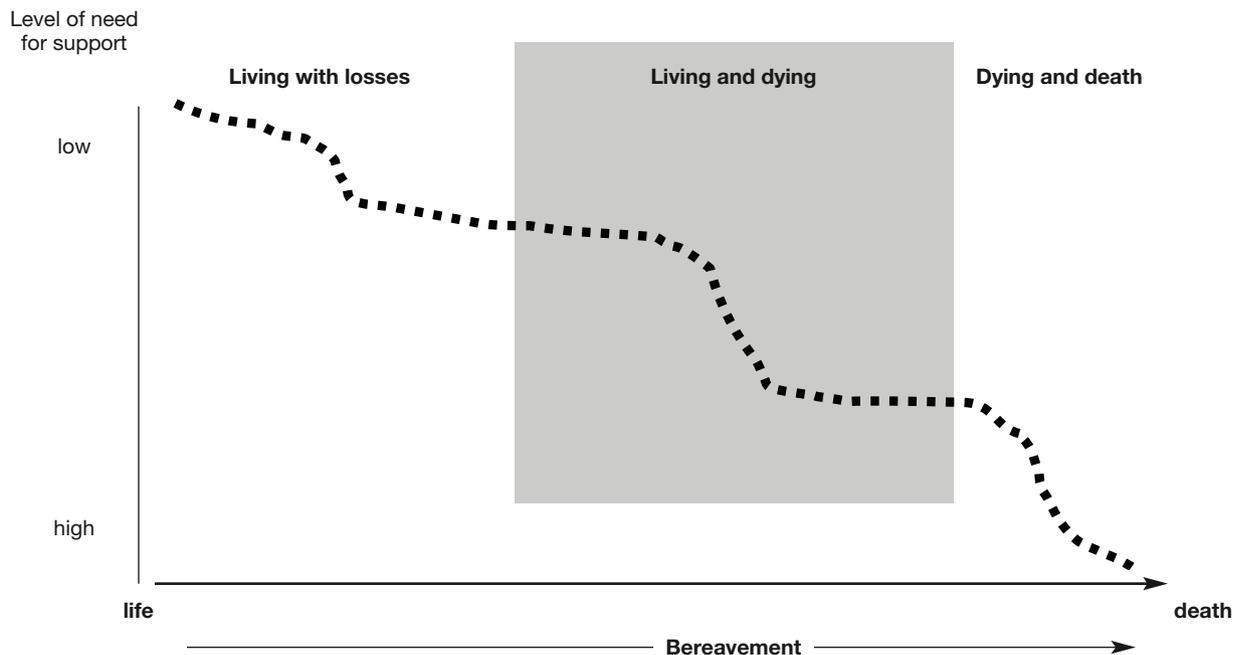
death, including the physical, psychological, cognitive, spiritual, social, and economic domains (2, 5); older people and their families live in complex social networks of mutual interdependency (3).

A Conceptual Approach to Mapping Four Transitional Zones from Life to Death

We identified four transitional zones that are encountered by older people and their families in hospitals and long-stay care settings (see Figure 1). Building upon previous work (9), we propose the following conceptual model for understanding older people's experience of transitions near the end of life.

- *Living with losses*: There must be an enduring emphasis on living and life if the quality of life of long-stay residents is to be preserved. However, there must also be an awareness that the older person is living with many changes — including the loss of function (physical, psychological, and/or cognitive), status, and identity — which may foretell his or her end of life. Some may be more aware of these transitions than others, and some will recognize admission to long-term care as a major life event (8).
- *Living and dying*: This zone is a transitional period for many older people. In it, their future appears uncertain. A change in a person's physical functioning and a decline in cognitive ability may raise questions about the nature of future support and care. A lack of recognition of the potential meaning of this zone can lead to too little or too much care intervention,

Figure 1 / Hypothetical Model of an Individual's Life — Death Trajectory Indicating Four Transitional Zones



depending upon how the future is perceived. Will the main focus be on living or dying?

- *Dying and death*: The awareness of an older person, the family, and/or the care workers that the person is actively dying is associated with an implicit or explicit acknowledgement of the dying status of that person. Entry into this stage may be gradual — those concerned must first pass through the zone of living and dying — or it may be clear-cut (for example, after an acute illness episode such as a stroke).
- *Bereavement*: For older people, their families, and their care workers, anticipated and actual losses may be experienced concurrently within the living with losses zone. These losses will become more prominent during the living and dying and dying and death zones. Following the death of the older person, bereavement may be experienced by family members, friends, co-residents, co-patients, and staff.

While these zones are regarded as predominantly sequential, the uncertainty of dying trajectories in late old age — and, in particular, the phenomenon of “bounce back,” which was evident in this study and elsewhere (18) — means that individuals may experience a number of episodes that would place them in the living and dying zone (Figure 1). There may well be fuzzy boundaries between the living with losses, living and dying, and dying and death zones. For example, acute, life-threatening events, like stroke or acute respiratory infection, in a person with heart failure may well mean that the person moves into the living and dying zone, as there is considerable uncertainty about outcomes. Likewise, with the bounce-back phenomenon, sometimes seen in late old age, there is uncertainty that may be resolved either by the patient’s death or return to health, and the person will reoccupy the living with losses zone. There are also situations in which older people require an increased level of support and care for reasons that are not life-threatening — for example, as changes in cognitive function lead to behavioural disturbances and a need for input from mental health specialists. In the bereavement zone, anticipated losses and feelings of grief may be experienced by an older person, family members, and staff (19), especially since the reality of his or her mortality has become more apparent in the dying and death zone. In the bereavement zone, it is also acknowledged that staff, as well as family members and peers, will be bereaved. Care for older people’s families needs to continue after the death, as these people face the future without the deceased. This period is typically considered to be the bereavement period.

Focus for, and Dimensions of, the New Framework

In our conceptualization of the complexity of older people’s experiences, we have already begun to allude to the service responses required to meet the various needs that may arise. In order to develop the framework further, we have identified five premises about end-of-life care for older people living and dying in hospitals and long-stay institutions. Drawing upon our study findings, we argue that end-of-life care provision should be respectful to older dying persons and promote their dignity; it should be supportive of families (the term also includes friends and significant others), who are central to the experience of the older dying person and who have their own needs; it should be supportive of staff and acknowledge that they too may experience loss and bereavement; it should be facilitated by coordination among providers as older people move between care settings; and it should promote the communication that underpins the process by which older people and their families explore issues and arrive at decisions through discussion with health and social care professionals. This communication is most effective where there is mutual understanding, respect, and an awareness of individual roles and functions. It involves verbal and non-verbal behaviours that convey meaning, and those involved in the discussion need to take account of the dying person’s difficulties with cognition and speech.

We have determined that although this framework is focused on the care of older people in specific institutional health and social care settings, the wider social and cultural context also shapes values and practices in such organizations. We therefore present a framework to ensure the development of good end-of-life care for older people that meets their needs and aspirations (Table 1). The framework addresses five levels: the older person, the family, the hospital and institutional staff, the organization, and society. The focus of good end-of-life care for older people incorporates both individual-level and social-level responses and reveals the rights and responsibilities of all parties. In the context of our data, this focus is delineated in four dimensions: knowing and revealing needs, expressing values and preferences, interacting with others, and developing knowledge. Table 1 illustrates how these dimensions may be expressed in relation to each of the framework’s five levels and complements the descriptive account we will now provide.

While it may be obvious that older persons facing the end of life should be the focus of care and support, these people have largely been

Table 1 / Proposed Framework Required for the Development of Good End-of-Life Care for Older People

Dimensions				
Focus	Knowing and revealing needs	Expressing values and preferences	Interacting with others	Developing knowledge
Older person	Recognition of bodily, emotional, social, and spiritual changes in self Willingness to reveal these changes to others	Ability to express important values and decisions to others	Helping others to understand what they need to feel safe, comfortable, and supported in their distress Expressing respect for staff providing support and care	Confidence and language to express things like physical, emotional and social concerns and changes.
Family	Recognition of bodily, emotional, social, and spiritual changes in self and older family members Willingness to reveal these changes to others	Ability to understand and express own values and decisions Recognition of the values of the older person and other family members, even if they differ	Assisting older people to obtain competent care/support that is compatible with their wishes Helping others to understand what they need to feel safe, comfortable, and supported in their own distress	Confidence, knowledge, and ability to engage with the health and social care system on behalf of themselves and in partnership with the older person
Staff	Recognition of changes and losses for older people and their families Recognition of own needs in the context of dying and bereavement work	Recognition of the need to understand the values and preferences of older people and their families Awareness of own values and beliefs	Eliciting the experiences and views of older people and their families Expecting respect from older people and their families	Listening skills Confidence to engage in difficult conversations Ability to create models of loss and change, ageing and dying
Organization	Recognition that older people and their families are facing losses and life changes Recognition that staff are impacted by loss, the deaths of older people, and the distress of family members	Recognition of the need for a mission statement expressing the organizational values and culture Recognition of the need for written protocols for end-of-life care, including support systems for staff	Facilitating communication and information provision that is respectful of the styles and preferences of older people and their families Acknowledging support needs of staff at all levels	Supportive organizational culture Leadership ability and knowledge necessary to improve end-of-life care Willingness to facilitate change, innovation, and excellence
Society	Recognition of the value of societal death talk Willingness to value and listen to older people and their advocates	Willingness to articulate differing cultural values related to end-of-life issues and care	Identifying places where interactions can occur (schools, libraries, lifelong learning centres) Preventing ageism and other forms of discrimination	Willingness to address dying, death, and society; the role of dying in the ageing process; and loss and change

absent from the literature, and too often they are silenced or ignored; their views and presence are passively acknowledged rather than actively sought. In Table 1, we identify ways in which their voices can be heard at all stages of end-of-life care. Families have two roles within our framework: first, they are participants with their own needs, views, and preferences; second, they are proxies for the older person who has become unable to articulate his or her own views. Health and social care workers at all organizational levels need to be able to recognize when patients enter the end-of-life period, and they must seek to improve the quality of care provided; they also have the right

to expect respect and freedom as they provide the necessary care. Organizations need to take responsibility for providing high-quality end-of-life care and facilitate their staff in providing this service. Ageism within organizations — especially health and social care systems — and within society generally makes it difficult to leverage the necessary resources and sanction investment in palliative and end-of-life care for older people.

Finally, individuals and organizations are embedded within, and shaped by, their wider societies and cultural groups. There is a need to engage with broader issues: how different social groups regard death and dying; what the avail-

able discourses are; and what the cultural practices and values are that define and shape attitudes toward ageing, death, dying, and bereavement. Only at this macro level will it be possible to understand and deal with ageism, discrimination, resource allocation, and priority setting, all of which can impact adversely on end-of-life care for older people (10).

At each level of focus, we have discussed the four cross-cutting requirements that are fundamental to good care toward the end of life. Knowing and revealing needs requires an explicit recognition of the bodily, emotional, social, and spiritual changes experienced by patients, families, and staff. Organizations must be able to recognize and respond to the fact that older people and their families are facing losses and life changes. At the level of society, greater public engagement in discussions about end-of-life care and death in older age must be undertaken, and these discussions must include reference to cultural and religious norms and values. Older people must also be allowed to express important values and communicate their decisions to others. For that to happen, health and social care workers must recognize the primacy of patient and family values and preferences and not fall back upon stereotypical assumptions and judgments. They must also be aware of their own values and the impact they can have on the caring process. Organizations have values too, and they must be explicitly stated so that there is no ambiguity with respect to a given organization's approach to care at the end of life. For example, the religious ethos of the organization may be incompatible with certain end-of-life preferences. At a practical level, this could be resolved by issuing written protocols for end-of-life care, including support systems for staff.

Interaction and communication about end-of-life care are required at all levels — between patients and staff, between families and staff, and within families and organizations. While the elements presented in Table 1 appear reliant upon the ability of people to verbally articulate their needs, we recognize that in the case of those with dementia or other conditions that affect the ability to communicate, responsibility for conveying the patient's wishes devolves to the people around the patient (20). The development of a lifelong, intergenerational understanding of dying and death is also necessary if good-quality care is to emerge at the end of life. Ageism needs to be tackled at the level of society to ensure that there is no discrimination against older people at the end of life (10).

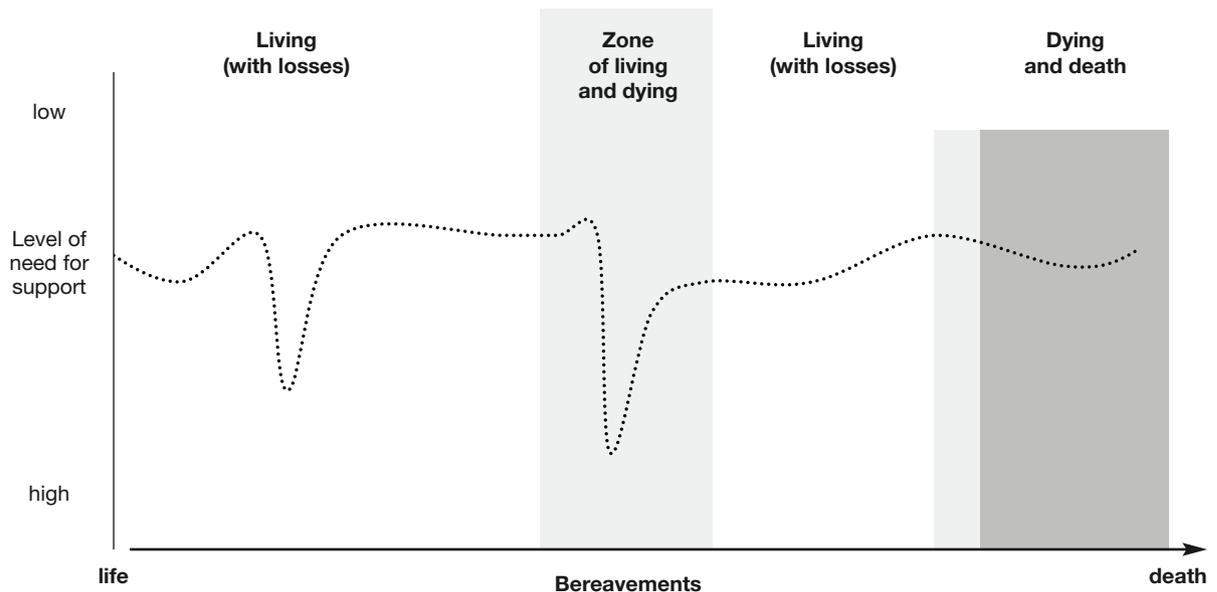
Without individual and professional recognition of the changing needs of older people in hospitals and long-stay settings, it is difficult for older people and their family members to have their needs met. That is why developing knowledge is so important. Patients require confidence and an appropriate language to express their preferences. Likewise, families require knowledge and assertiveness to engage with the health and social care system on their own behalf and in partnership with the older person. Health and social care workers require listening skills and the confidence to engage in difficult conversations with people who are dying (2). A supportive organizational culture is needed to facilitate open communication about dying and death between staff and patients.

This framework of service provision is based upon complexity of need rather than a diagnostic category such as cancer or heart failure (21). It is also not dependent upon a prognostication of dying that is unreliable and difficult for professionals (12) and widely resisted by patients themselves. It is a framework based upon the recognition of need, which is defined as distress, or an aspect of their experience that patients or their family members report as distressing, for whatever reason. The framework is predicated on the ability of patients and families to report or display distress and/or of staff to recognize it. For example, an older man with some experience of pain does not find his pain distressing, and so he does not require an intervention, such as medication; perhaps this is because minor pain indicates to him that he is alive, or because he counters the pain with his values — his stoicism, his fortitude, and/or his religious beliefs. Alternatively, an older woman with dementia is in pain, but she is unable to tell anyone about it — where it is, how severe it is. In this instance, family members and staff need to work together to identify and use patterns of communication — behaviours or movements that indicate discomfort — that are familiar to the woman.

A Hypothetical Case Example

Figure 2 demonstrates a hypothetical trajectory of an older man with heart failure who is admitted to a nursing home. Over time, he begins to live with losses; he knows that he may even lose his home. The lines shows that his condition fluctuates and two acute episodes, after which he requires additional care. Such episodes as these may be precipitated by acute exacerbations of the main illness, acute infections, a fall, or a psychological crisis such as bereavement or dementia. There may be a rapid decline in function, as shown in the shaded zone, leading to uncertainty

Figure 2 / Illustration of zones of living and dying in the context of levels of care required: hypothetical case example



about the status of the older person as he or she moves into the living and dying zone. At this time, levels of care need to be increased to deal with the distress, and this is ideally provided within the nursing home; if this care is unavailable, then the older person may need to be transferred to a hospice or hospital, but when the person starts to recover, discharge from the hospice should be planned. In this case, we have shown that there are two periods of rapid decline and subsequent recovery. The older man finally dies unexpectedly without requiring complex care. Alternatively, some older persons may die while complex care is being provided in a hospice or hospital. The actual trajectory of dying does not really matter. Rather, what is important is that end-of-life care is reactive, reflective, and responsive to the immediate needs of patients in the most appropriate setting. While the distinction between gerontological care and end-of-life care can become blurred in such circumstances, this may enhance care rather than diminish it, as providers integrate end-of-life philosophies into normal patterns of care and quality of life into dying and death.

DISCUSSION

This conceptual analysis offers a new framework to guide the delivery of palliative and end-of-life care to older people in institutions. It suggests that preparing for the final phase of life and recognizing approaching death can be a very positive and life-affirming exercise. The older people and

health professionals we interviewed in various hospitals, long-stay institutions, and nursing homes in Ireland provided us with some examples of good-quality palliative and end-of-life care. However, they also indicated that, overall, there is a serious lack of understanding of the principles of palliative care, a failure to recognize approaching death until it is too late to implement care, and an uncertainty about how to deal with older people as they are dying. These findings accord with evidence from research on palliative and end-of-life care for older people in community hospitals and care homes in the UK (22, 18).

The framework draws upon a number of principles, including respect for the older person, support for families, coordination of care, and good communication. These principles are not new in themselves; they are arguably the foundation for all good clinical care, not just palliative care. Moreover, there is debate about the extent to which communication underpins the process of delivering high-quality palliative care (23). For example, evidence suggests that ineffective communication about end-of-life care may be attributed both to the medical practitioner's failure to engage in discussion and the family's difficulty with hearing bad news (23). This suggests that merely improving professionals' communication skills may not be sufficient.

The new framework provides clear suggestions for how to improve palliative and end-of-life care for older people by engaging with these people and their families; it also suggests areas of professional focus in the realms of death preparation

and living with losses. However, one must keep in mind that the framework needs to be tested in a number of institutional environments. The framework is based on the experiences of a small number of older patients who were open to discussing their preparations for death (4); others in our sample were unaware that they were dying or declined to discuss the topic with us. Unfortunately, limited resources meant that we were unable to interview family members, so we could not benefit from their valuable experience and insight. Further research that elicits family carers' experiences during the process of caring and after the patients have died is urgently required to validate the framework. We attempted to capture a range of health professionals' views, but, once again, there may have been bias, as those most willing to discuss the end-of-life experience were likely those with greater awareness of, and more skills in, palliative care. Further research is required to test the framework in practice.

The framework outlined here is based on the view that while older people should be at the heart of decision making with respect to their palliative and end-of-life care, institutional structures and processes and social relationships also matter. Thus, while autonomy and independence for older people are important, so too are understanding, empathy, information, and communication. The proposed framework outlines the interconnected levels of people's experiences of care and the ways in which care is provided. It attempts to provide a more complex level of understanding of how older people can be helped to negotiate their way through changing circumstances as they approach the end of life, drawing upon models developed in care homes in the UK (24, 9). Palliative and end-of-life care must be flexible, contemplative, and responsive to need if it is to address the uncertainty associated with dying and death. Trajectories of dying are not always linear, as older people move in and out of the zone of living and dying. Current models fail to reflect this dynamic (13, 15). Furthermore, older people have to come to terms with many kinds of loss within long-stay care, and bereavement is a constant feature of life in such settings (18, 19). Therefore, it is not realistic to view the end-of-life experience as neatly confined to a defined period during which palliative care services can be mobilized and administered (9, 20). The need for palliative and end-of-life care can arise some time before death becomes imminent; it depends upon the physical, mental, and emotional state of the patient and the family. Meeting that need when and where it arises is the essence of good-quality care. We recommend strengthening the link

between good person-centred gerontological care and good palliative and end-of-life care. All levels of society need to be involved before an individual's experience of dying can be considered good — it is not just a matter for health and social care services (2, 10).

Currently, the Irish Hospice Foundation is engaged in developing a new approach to changing the culture of palliative and end-of-life care through an initiative called the Hospice Friendly Hospitals Programme (7). It focuses on four key themes: integrated care, communication, design and dignity, and patient autonomy. Clearly, there are potential overlaps between these four themes and the dimensions we propose, and this warrants further research. Building upon work undertaken in the UK (9), we will explicate the service and workforce requirements for providing practice development for the new framework. Practice development through resource allocation, staffing, training, and education is needed in order to bring about real change to the care process in Ireland. While our focus has been on institutions, we believe that this model and framework have implications for all older people requiring care toward the end of life.

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