Focus on dying at home

Introduction

In July 2014, the Joint Committee on Health and Children in the Republic of Ireland (ROI) issued its report *End of Life and Palliative Care in Ireland*. The Committee found that while the majority of people (67%) express a preference to die at home, only 26% of people in ROI actually die at home (Joint Committee on Health and Children, 2014).

A survey of public awareness and attitudes toward palliative care in Northern Ireland (NI) published in 2013 showed a similar attitude – the preferred place of palliative care was the family home (McIlfatrick, et al., 2013).

The All-Ireland Institute of Hospice and Palliative Care designated 6-11 October 2014 as the first Palliative Care week across the island of Ireland. With the topic of palliative care featuring in the news, this edition of the CARDI Focus on series examines the issues behind dying at home and what steps could be taken to better fulfil the wishes of patients who have expressed a desire to die at home.
Palliative and end of life care

Dying at home requires access to what are called “palliative” care services. Palliative care is defined by the World Health Organization (WHO) as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems” (World Health Organization, 2002).

Key findings

- There is evidence that a significant number of people wish to die at home (67% in ROI and 61% in NI). However, just 26% of people die at home in ROI while in NI 30% die outside of a hospital, hospice or nursing home\(^1\). (DHSSPS, 2010) (Joint Committee on Health and Children, 2014).

- One in four of deaths that occurred in acute hospitals could have taken place at home if the necessary supports were in place (Irish Hospice Foundation, 2013).

- Hospice home care teams enable people to die at home when available - only 26% of people in ROI die at home but this figure rises to 40% of all patients who are cared for by hospice home care teams (Joint Committee on Health and Children, 2014).

- For dying at home to be possible, patients require access to medication (particularly out of hours), necessary equipment, nursing care and psychological and spiritual support (Gregan, 2014), as well as a family member or friend who is able and willing to provide care (Payne, 2012).

- There is a government palliative care strategy in NI (published in 2010) but none in ROI.

- There is a lack of awareness of palliative care and what it can achieve – a 2013 survey in NI showed that 75% of respondents had little or no knowledge of palliative care (McIlfatrick, et al., 2013).

\(^1\) NISRA statistics do not quantify the numbers of people who die at home in NI, but 30% die outside of a hospital, hospice or nursing home.
End of life care is the final stage of palliative care. It concerns all aspects of care relating to dying, death and bereavement. End of life can be from the point of receiving a life-limiting diagnosis through the months before death, up to and including the final hours (Irish Hospice Foundation, 2014). The NI strategy on palliative care notes that end of life care is “care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die” (DHSSPS, 2010).

Figure 1: The continuum of palliative and end of life care

Source: (Lynn, 2005)

Palliative care has historically focused on cancer patients. In ROI, 80% of people in receipt of specialist palliative care services are cancer patients (Gregan, 2014). However, as palliative care aims to provide relief from the pain, symptoms and stress of any life-limiting illness, there have been moves to extend the care to patients with other illnesses such as:

- Dementia
- Heart failure
- Advanced respiratory disease such as COPD, pulmonary fibrosis and cystic fibrosis
- Chronic kidney disease
- Scleroderma
- Motor neurone disease
- Cardio-vascular accident
- Multiple sclerosis (The Irish Hospice Foundation, 2009).

In NI, a 2013 survey showed there is a lack of awareness of palliative care and what it achieves, which may account for the gap in numbers who wish to die at home and those who actually do so. It found that while 83% of respondents had heard the term palliative care, 75% said that they had little or no knowledge of what the term actually meant (McIlfatrick, et al., 2013).
Death and dying in Ireland (ROI and NI)

Republic of Ireland
According to the Central Statistics Office Vital Statistics publication, there were 30,000 total deaths in ROI in 2013, of which almost 14,000 were people aged 65-84 and 10,000 were people aged 85 and over (Central Statistics Office, 2014). The biggest cause of death among the over 65s was heart disease (35%), followed by cancer (28%) and respiratory diseases (14%).

Figure 2: Causes of death among the over 65s in ROI in 2013

(Central Statistics Office, 2014)

In ROI, 40% of people who die at home are supported by specialist palliative care home care teams. 22% of deaths take place in nursing homes or other long-stay facilities.
According to the Irish Hospice Foundation, 67% of people in ROI have expressed a preference to die at home (Irish Hospice Foundation, 2013). As people age they are less likely to die at home and more likely to die in private nursing homes and public HSE residential care (O'Shea, et al., 2008).

**Northern Ireland**
Approximately 15,000 people die in NI each year. As in ROI the main causes of death are heart disease (35%), cancer (26%) and respiratory diseases (14%) (DHSSPS, 2010). As can be seen from Figure 3 the percentages of people dying in hospital, nursing homes, hospices and at home in NI are similar to those in ROI. In NI slightly more people die in hospital – 50% compared to 43% in ROI. In addition slightly fewer people die in a nursing home – 16% compared to 22% in ROI.
McIlfatrick et al. (2013) in a survey of public attitudes toward and awareness of palliative care in NI, found 61% of respondents noted that the family home was the preferred place of care. This was followed by a hospice (7%), hospital (2%) and nursing home (1%). A further 18% of people preferred a combination of hospital, hospice and home as their preferred place of care (McIlfatrick, et al., 2013).

In Scotland, the number of people wishing to die at home who do so increased from 31% in 2006 to 71% in 2013 (Oxenham et al., 2013). In terms of actual location of death in the US, 25% of people die in hospital and 34% die at home (Teno, et al., 2013). In England, 25% of all deaths from cancer occur in the home, compared to 48% in hospital (The National Council for Palliative Care, 2013). 51% of people in the Netherlands die at home, and this is strongly associated with the provision of palliative care by GPs (DeRoo, et al., 2014).
Dying in the home

As noted there appears to be a significant gap between the number of people expressing a preference to die at home (67% in ROI and 61% in NI) and the numbers actually dying at home (26% of people in ROI).

There are many possible reasons for this including: people changing their minds as illness progresses, the intensification of care needs and the likely or perceived burden on family carers (Irish Hospice Foundation, 2013). However, evidence collated from ROI and the UK suggests that between 22% and 40% of deaths in hospitals could have taken place in the home (Irish Hospice Foundation, 2013). In addition, a literature review of dying at home preferences from 33 countries indicates that most people prefer to die at home and around four fifths of patients did not change preference as their illness progressed (Gomes et al., 2013).

An assessment of evidence from cancer patients on factors associated with dying at home found that people were more likely to die at home if:

- There was a longer time between diagnosis and death.
- They had higher levels of education or came from higher socio-economic backgrounds.
- They were married, lived with relatives or had family support.
- There was home care support available.
- Caregivers and patients had agreed a preference to die at home and had expressed that preference (Gomes & Higginson, 2006).

If dying in the home is an opportunity to be made available to more people at the end of their lives, essential services and supports must be in place. Having a person who is able and willing to provide care (usually a family member but sometimes a friend) is essential if a person wishes to die at home (Payne, 2012).

The predominant responsibility for the care of people with life-limiting disease lies with GPs and community nurses, along with appropriate support from a specialist palliative care service and allied health professionals. Community or public health nurses and GPs must be equipped to provide necessary services in the home, particularly as 90% of care in the last year of life is provided by the primary care team (Irish Hospice Foundation, 2011). Gregan (2014) states that GPs and community nurses also need access to supports in order to facilitate the wishes of patients who wish to die at home. These supports include out-of-hours palliative medicines (especially those not routinely available in pharmacies), out-of-hours advice from a specialist in palliative care (available only when there is a hospice close by) and in ROI medical cards for terminally ill patients that give them access to therapies and specialised equipment for their homes.
For the patient, access to medication (particularly out of hours), necessary equipment and nursing care in the home is essential. Psychological and spiritual supports are important as is access to respite care and nursing support for families and caregivers (Gregan, 2014).

It is important for all patients who wish to die at home to ensure that decisions are made in advance and families, caregivers and medical professionals are aware of wishes. This is particularly true for dementia patients – research shows that 40% of people with no dementia are asked about end of life care practices, compared to 8% of people with dementia (McLoughlin, 2014). One way of achieving this is through an advance directive or “living will” which is a written document giving direction and guidance for healthcare decisions at a time of future incompetence (Medical Council, 2012).

**Palliative care in ROI**

Only 26% of people in ROI die at home but 40% of all patients who are cared for by hospice home care teams die at home. Providing access to specialised teams for all palliative care patients is therefore important (Joint Committee on Health and Children, 2014). Research shows that there is a geographic disparity in access to hospice home care teams in ROI - only 7% of home care patients in the better-resourced hospice services of the Mid-West die in acute hospitals, in contrast with 32% in the North East (Joint Committee on Health and Children, 2014).

An audit conducted in 2008/2009 found that one in four of these deaths could have taken place in the community if the necessary supports were in place (Irish Hospice Foundation, 2013).

There is currently no national strategy in the area of palliative care. The findings of the Joint Committee on Health and Children report on *End of Life and Palliative Care in Ireland* support the development of a *National Strategy on Palliative Care, End of Life and Bereavement*, including a dedicated budget for specialist palliative care (Joint Committee on Health and Children, 2014). At present, there is no formal framework to support community based staff (Irish Hospice Foundation, 2011). A Primary Palliative Care National Steering Committee was established in 2012 with the aim of encouraging innovation and sharing best practice on palliative care in the community as well as improving policy and services for people who wish to die at home (Irish Hospice Foundation, 2014).

Currently there are nine hospice units in ROI; three in Dublin and one each in counties Limerick, Cork, Galway, Sligo and Donegal. Specialist palliative care teams tend to be based in hospice units even when providing palliative care in the home. Referral to a specialist palliative care team for non-cancer patients is usually made by a GP or hospital consultant (Citizens Information Board, 2014).
The Alzheimer Society of Ireland provide home care services to people with dementia up to the time of death, although it has been noted that the current service is underdeveloped. The Irish Hospice Foundation and Irish Cancer Society provide night nurses for people who are dying of cancer and other illnesses, and these are currently the only free out-of-hours night nurse services available for the terminally ill (Joint Committee on Health and Children, 2014).

Palliative care in NI

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and NI. Research published by the council shows that approximately two thirds (9,570) of people dying in NI every year would benefit from a level of palliative care during the last year of life but for reasons of diagnosis are excluded.

A palliative and end of life care strategy for adults in NI Living matters, Dying matters was published in 2010. It defines good palliative care in terms of eight principles, whereby it:

- affirms life and regards dying as a normal process.
- intends neither to hasten nor to postpone death.
- provides relief from pain and other distressing symptoms.
- integrates the psychological, emotional and spiritual aspects of patient care.
- offers a support system to help patients live as actively as possible until death.
- offers a support system to help the family cope during the patient’s illness and into bereavement.
- uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated.
- will enhance quality of life, and may also positively influence the course of illness (DHSSPS, 2010).

Palliative care for people in their homes is provided in NI by community teams which provide specialist advice and work alongside a patient’s own GP practice teams enabling specialist care to be provided in the patient’s home or care home. Northern Ireland Hospice nurses provide a hospice at home nursing service while Marie Curie Cancer Care provided 144 nurses to offer end of life care in the community in NI in 2012-13, available for free to patients with all terminal illnesses and not just cancer (Marie Curie Cancer Care, 2014). Macmillan Cancer Support nurses in NI are trained in palliative care for cancer patients, and provide support and information (not direct nursing care) to people with cancer, and their families, friends and carers. They can also provide palliative care advice to professionals dealing with non-cancer patients (MacMillan Cancer Support, 2014).
The NI Hospice is the main provider of support for patients and carers in terms of advice and support programmes. In addition, the NI Cancer Network has a Supportive and Palliative Care Network which brings together professionals involved in the care with a view to improving services, engaging in research, and providing education and training (Northern Ireland Cancer Network, 2014).

Conclusion

There is a significant gap in the numbers of people in Ireland, North and South, who express a wish to die at home and those who actually do so. In order to close this gap a change in service provision is necessary to create the conditions to make dying at home possible. A patient wishing to die at home needs someone such as a family member or friend to provide care. They need services provided both by GPs and community nurses as well as a specialist palliative care team. In turn, GPs and nurses need access to particular services. Finally, families, friends and caregivers need communication and access to information at all stages of the process. With these services and structures in place, closing the gap between numbers of people in NI and ROI who wish to die at home and those who do die at home could be made possible.

Bibliography


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