The developing role of children’s nurses in community palliative care

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This article explores the evolving role of children’s nursing in palliative care in the community, following an identification of the deficiency of nursing services available to support families caring for children with life-limiting illnesses in the home. According to the recent policy from the Irish Department of Health and Children (DoHC) relating to palliative care for children with life-limiting conditions (DoHC, 2009):

‘there are approximately 1400 children living with a life-limiting condition and in the region of 490 childhood deaths per year. Of childhood deaths due to life-limiting conditions, the majority occur in the first year of life, with approximately 350 deaths per year from life-limiting conditions.’ (DoHC, 2009)

This short life-expectancy means that family time together, at home rather than in a hospital, is precious. Community nursing support in Ireland for children’s palliative care is limited; hence, families are often challenged when caring for children with life-limiting illnesses in the home, with carers reporting both physical and emotional exhaustion (Clarke and Quin, 2007). Consequently, the need to embrace change and develop paediatric community services in Ireland is apparent.

An assessment of the palliative needs of children in Ireland (DoHC and Irish Hospice Foundation (IHF), 2005) identified inefficiencies in children’s palliative care services, and subsequently a new national policy, Palliative care for children with life-limiting conditions in Ireland, has been published (DoHC, 2009). The policy is divided into three sections, with the first two defining children’s palliative care needs and describing the existing provision in Ireland, while the third section sets out guidelines for the development of the future provision of services. Among the numerous recommendations, the policy calls for the initial appointment of eight regionally based children’s outreach nurses, to facilitate service delivery in the community and integration between hospital, community services and specialist palliative care (DoHC, 2009). Furthermore, following the implementation of the Primary Care Strategy (DoHC, 2001a) and the National Children’s Strategy (Government of Ireland (GoI), 2000), children’s nurses are now ideally situated to lead the required change.

Palliative care in children’s nursing

Palliative care in children’s nursing is an active and holistic approach to caring for children with life-limiting conditions, focusing on improving the child’s quality of life and wellbeing through embracing the physical, emotional, social and spiritual needs of the child and family (World Health Organization (WHO), 1998). The WHO (1998) further advocates the early provision of palliative care to children at the time of diagnosis, henceforth initiating a collaborative approach to care, involving the parents and multidisciplinary teams in hospitals and in the community.

Currently, worldwide there are excellent palliative care resources available for children with malignant illnesses (Clarke and Quin, 2007). Nevertheless, excluding children...
been classified into four different categories, including conditions where treatment is prolonged and intensive, fails to cure or is not a curative option, and conditions of non-progressive neurological disability (ACT and RCPCH, 2003) (Table 1). Although the life-expectancy for many of the children rarely extends past 18 years, in more recent years some children have lived into adolescent life, presenting vast challenges in providing holistic, age-appropriate palliative care determined by the individual needs of the children and their families (DoHC and IHF, 2005). Statistically, the overall number of childhood deaths in Ireland decreased in recent years (CSO, 2008). However, children dying from life-limiting same category illness determined in healthcare policy documents (DoHC and IHF, 2005) remains relatively unchanged, despite slight adjustments in statistical age categories. In the year ending 2008, 332 children aged 15 years or under died from a life-limiting illness, with 79% of children being less than 1 year of age (CSO, 2008).

In order to establish an all-inclusive palliative care service in Ireland, an assessment of the needs of children with life-limiting conditions and an evaluation of current services and practices is essential to the development of future policy (DoHC and IHF, 2005). The home is considered by many to be the ideal environment for the deliverance of family-centred palliative care, free from the constraints of hospital routines, with less disruption to family life and better outcomes for parents and siblings (Cavaliere, 2007). Conversely, for others the security and support offered in the hospital environment relieves parents of the burden of care and decision-making dilemmas that home care presents, therefore encouraging the valuable time that they spend with their children (Howe, 2007).

Interestingly, an Australian study by Siden et al (2008) found that among families who had equal access to care in hospital, hospice or home, the choice of environment for children's end-of-life care was evenly divided between the three locations. However, the findings of an Irish needs assessment concluded that most families would prefer to have children with life-limiting conditions cared for and eventually die in the familiar home environment. At present, a lack of access to palliative care services and support unfortunately prevents the realization of these wishes (DoHC and IHF, 2005).

### Barriers to children’s palliative care provision

The complexity and rarity of many life-limiting childhood conditions, uncertain prognosis and the difficulty in predicting the disease trajectory have been identified as a barrier to professionals introducing palliative care services into the community (Davies et al, 2008). Many paediatricians liken palliative care to hospice care services, and fail to refer children to palliative care programmes until curative treatment is no longer considered possible (Thompson et al, 2009). Although the services of both hospice and palliative care may overlap for some children, confusion regarding the service provision of the evolving specialty of palliative care often presents as a major barrier to programme use, and deprives children with life-limiting illnesses of the quality of life and comfort that the service can provide and children and their families deserve (Morstad Boldt, 2006).

### Table 1. Four groups of children who are most likely to have palliative care needs (DoHC, 2010)

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Life-threatening conditions for which curative treatment may be feasible, but can fail. Where access to palliative care services may be necessary when treatment fails children in long-term remission or following successful curative treatment are not included. (Examples: cancer, irreversible organ failures of heart, liver, kidney.)</th>
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<tr>
<td>Group 2</td>
<td>Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. (Example: cystic fibrosis.)</td>
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<tr>
<td>Group 3</td>
<td>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Examples: Batten disease, mucopolysaccharidoses, and muscular dystrophy.)</td>
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<tr>
<td>Group 4</td>
<td>Irreversible, but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. (Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord insult.)</td>
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Following the devastating and unexpected diagnosis of a child’s life-limiting illness, heightened emotions, poor medical explanations and sometimes unreasonable hopes, compounded with uncertain prognosis can impede the ability of parents to make decisions considered to be in the best interests of the child (Baergen, 2006; O’Brien et al, 2010). Furthermore, for some families, the information received is often inadequate, incomprehensible, or given too soon to enable informed decision-making (Wilkes et al, 2000). The challenges parents sometimes face when caring for palliative children in the home are complex and often exacerbated by poor communication between professionals (Price et al, 2005).

Children with life-limiting conditions cared for in the home can become invisible members of the community, with respite care frequently considered as an emergency intervention as opposed to a personal right (Thurgate, 2005). Access to palliative care services in Ireland is inadequate and dependent on the child’s geographic location, with a lack of community and home services presenting a major barrier to caring for children with life-limiting conditions at home (DoHC and IHF, 2005). Many Irish parents find the availability of support services is dependent on prognosis, with community or home care restricted to crisis or end-of-life interventions (Clarke and Quin, 2007).

Despite receiving appropriate education and training prior to discharge, the challenges that caring for the child with a life-limiting condition present are often overwhelming for the families concerned. Adapting to new roles as caregivers, readjusting family routines and coping with stress related to strain on personal and financial resources can have a profound effect on the confidence and coping abilities of parents (Mazurek Melnyk et al, 2001). Nevertheless, for most families, home is where they want to be. Parents become expert carers and advocates for their sick child, and strive towards regaining control and maintaining normality in family life insofar as the child’s condition permits (Clarke and Quin, 2007). However, in reality few families can actually cope without the support offered by qualified and experienced nurses (DoHC and IHF, 2005).

**Children’s palliative care needs**

Children’s palliative care nurses aspire to provide ‘symptom control, emotional support and practical help for children and their families’ (Lenton et al, 2004:192). Currently in Ireland, nurses who may not be registered children’s nurses or understand the specific needs of critically or chronically ill children and their families provide nursing support for children with life-limiting conditions and their families in the community (DoHC and IHF 2005). Limited home care and respite services are provided by both voluntary and statutory organizations, with adult palliative care teams providing services for a small number of children (O’Leary et al, 2006).

However, as outlined in the National Children’s Strategy (GoI, 2000), children are valued members of society and have a right to receive quality health care and support appropriate to the specific needs of their illness. The palliative care needs of children differ greatly from those of adults, and some experts in adult palliative care specialties are concerned that the lack of children-specific nursing skills and competence in children’s care raises questions as to whether children’s palliative care is ‘the best available’, or if it is ‘good enough’ (O’Leary et al, 2006:435). In essence, education is central to excellence in children’s palliative care, particularly in relation to nurses caring for children with life-limiting illnesses (Clarke and Quin, 2007), irrespective of whether or not they have a qualification in children’s nursing. As community children’s palliative care services in Ireland are in the early stages of development, direct specialist paediatric services will not be available to many children with life-limiting conditions for some time. This makes it all the more urgent that the identified weaknesses of current services in Ireland are addressed (O’Leary et al, 2006).

**Recommendations to improve palliative care for children**

**Palliative care outreach nurses in the community**

Having identified that nursing care of sick children should ideally be carried out by trained paediatric staff (DoHC, 2001b), the formation of specialist paediatric palliative care nursing posts supported by a national paediatric palliative care consultant is seen as essential to bridge the gap in the present services available to children with life-limiting illnesses in the community (DoHC, 2005). As part of the Children’s Hospice Home Care Programme, and in an effort to establish equity to palliative care services for children, eight clinical outreach nurse specialist posts have been approved, including two for the Dublin area and a further six regional posts based in children’s units (IHF, 2009).

Children’s palliative care focuses on providing holistic care for children with life-limiting illness, and the role of the outreach nurse is to plan care that aims to achieve the best quality of life possible for all family members (Himmelstein, 2006). Clinical outreach nurses can help overcome many of the difficulties experienced by families, especially if the nurse is involved from the time of diagnosis. Establishing trust and honesty through caring and empathic communication can enable outreach nurses to build therapeutic relationships with families and thus improve the standard of care provided (McGrath, 2005).

Education regarding potential disease progression, anticipatory guidance towards recognizing and treating symptoms, and appropriate discussions with families in relation to choices and personal wishes for end-of-life care should ideally take place in conjunction with the outreach nurse prior to discharge (Himmelstein, 2006). Empowering families through information and education and facilitating an understanding of children’s care can improve families’ belief in self-efficacy and help them regain control over their lives (Longden and Mayer, 2007). Family-centred care plans addressing the needs of the ill child and family members are multifaceted, involving partnerships in decision-making between family members and professionals, and should be reviewed and readjusted according to the child’s medical condition (Lewis and Noyes, 2007).

In an effort to combat barriers to home care, including access to essential equipment and home care support, the government’s National Policy on palliative care for children...
with life-limiting conditions recommends that outreach nurses serve as ‘key workers’ in the community to ensure the coordination and efficiency of services, and act as the family’s link to other health professionals (DoHC, 2009). Despite these recommendations, there is currently only one outreach palliative care nurse in the whole of Ireland, based in Temple Street Hospital, Dublin.

A central bank of registered nurses or carers experienced in providing palliative care is to be established in each Health Service Executive (HSE) region, and respite services are to be provided by the primary care team, directly by the HSE or supported by HSE funds (DoHC, 2009). However, with the current curtailment of nursing recruitment in Ireland, regrettably, the needs of children with life-limiting conditions will remain unmet for some time.

Respite and home care nursing support services
The nursing support needs of each family can vary greatly depending on the severity and rate of progression of their children’s illnesses, home situations, available family support, acute periods of illness and children’s terminal care (Olsen and Maslin-Prothero, 2001). As a result, the care that community paediatric nursing services can offer ranges from home respite care, intensive support during acute illness, and/or end-of-life care. Not surprisingly, the identified gaps in the provision of home care for children with life-limiting illnesses highlights the need for the extension of the role of paediatric nurses into community services.

The new national guidelines for the delivery of paediatric palliative care services in Ireland recommend working within the ‘Hospice at Home’ model of care. This model primarily entails a community children’s nursing service, with appropriate input from interdisciplinary teams (DoHC, 2009). The development of GP-led multidisciplinary primary care teams, along with future sanctioning of community paediatrician and community children nurses’ posts, were further recommended by the Primary Care Strategy (DoHC, 2001a). Advances in community paediatric palliative nursing services should follow the key principles of inclusiveness, partnership, comprehensiveness and flexibility, thereby developing a service that ensures equity of access to holistic nursing care, working within the primary care model and in partnership with existing statutory and voluntary organizations. The intended outcome of this approach is to provide a service flexible to the needs of children requiring palliative care and their families (DoHC and IHF, 2005).

The development of an improved respite service for the parents of children with life-limiting conditions is another requirement (DoHC and IHF, 2005). Many parents are emotionally and physically exhausted and value respite care as time away from their caring responsibilities. Valuable time for self or family can help strengthen the coping abilities of carers (Olsen and Maslin-Prothero, 2001). Attention to the wellbeing of siblings is also paramount, as siblings’ adjustment to having a chronically-ill brother or sister can be dependent on the efficiency of family functioning; their family’s coping and stress levels, limitations and restrictions to personal and family activities, and responsibilities related to helping care for a sick child at home (O’Brien et al, 2009). Respite nursing services can help and enable parents to spend time with their other children in recreational activities, and reassure siblings with regard to feelings of security and love within the family unit.

Palliative care education
In recognition of the need for varied levels of education to suit professionals’ degree of involvement in providing palliative care to children, guidelines for European nurse education in palliative care were devised by the European Association for Palliative Care (EAPC) task force (DeVlieger et al, 2004). In essence, due to the absence of specific educational programmes in children’s palliative care, an Educational Framework to Support Excellence in Practice was developed in Ireland using the guidelines of the EAPC (Phelan et al, 2006). As a result, a programme, ‘Caring for the child with a life-limiting condition’, commenced in 2007 in the Centre of Children’s Nurse Education in Our Lady’s Children’s Hospital, Dublin. The programme provided multidisciplinary education on palliative care, management and control of symptoms, providing information regarding available services, and access to bereavement and counselling services (Phelan et al, 2006).

Participation in such education programmes is essential for all paediatric palliative care nurses to maintain and update clinical competence in order to provide best practice, especially when offering palliative care to children (DoHC, 2009). Furthermore, in Ireland, there are currently no postgraduate or higher diploma educational programmes specific to children’s palliative care. The introduction of children’s palliative care education into undergraduate programmes and promoting e-learning in educational nursing programmes is consequently recommended, in order to improve competency in palliative care nursing practice (DoHC, 2009).

Furthermore, suffering and loss are inherent elements of palliative care, and the emotional cost of experiencing multiple losses without professional and bereavement support can result in high levels of stress and burnout among palliative care nurses (Hylton Rushton et al, 2006). Staff support systems need to be developed which incorporate debriefing for nurses following the death of a child (DoHC, 2009). With these systems in place, nurses caring for children requiring palliative care must to be encouraged to access the available counselling and debriefing support services.

Conclusions
Children’s palliative care focuses on promoting the wellbeing of children with life-limiting conditions, and supporting children and families to live life to the maximum through the help and care that the service provides. Although some advances have been made in recent years, children’s community palliative care services in Ireland currently remain limited.

The development of clinical outreach palliative care nursing posts envisages the improvement of prompt initiation of palliative care, the continuity and coordination of community
support services, and the empowerment of families to care for palliative children in the home. However, few families can cope alone and the identified lack of appropriate support services causes significant hardship on parents and carers of palliative care children in the community. Respite care in the home offers some relief, albeit temporary, to families’ burden of care and should therefore be adapted to individual needs. Moreover, the current lack of nursing support services for ill children requiring palliative care in the community deprivates families of the choice of location for the death of their child.

Experienced children’s nurses in palliative care are needed in the community, particularly in rural areas where services are limited. Parents and families have a right to expect that nurses caring for their children have the expertise and knowledge required to provide holistic care for their child. Subsequently, education programmes have been developed to maintain indefinite. Until then, gaps in the present children’s palliative care system will remain controversial.

The Irish Minister for Health and Children, Mary Hanney, states in the foreword to the national policy: ‘It seems so unnatural to think about, or have to plan for, the death of infants and children but hundreds of parents and families go through this tragic experience every year’ (DoHC, 2009). Nevertheless, while children’s nurses welcome the policy, there is some way to go before the care provided to children and families requiring palliative care will be met. It will only be through discourse, research and debate that the agenda will move forward and the provision of palliative care for children will meet the needs of those that genuinely require it.

Conflict of interest: none

Association for Children’s Palliative Care (ACT), Royal College of Paediatrics and Child Health (2003) A Guide to the Development of Children’s Palliative Care Services. 2nd edn, ACT, Bristol


**KEY POINTS**

- Children’s nurses who provide end of life care for children and their families welcome the publication of Palliative Care for Children with Life-limiting Conditions in Ireland: a National Policy (DoHC, 2009).

- Children with life-limiting illnesses and their families deserve expert care provided by registered children’s nurses with the specific knowledge required to manage the critical challenges of providing symptom control, emotional and practical support in children’s palliative care.

- There is scope for educational institutes to develop specific palliative care educational programmes to develop expert practitioners in children’s palliative care nursing.

- Palliative care outreach nurses are fundamental to bridge the gap in the present services available to children and their families with life-limiting illnesses in the community.