Paediatric Palliative Care

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> "Paediatric palliative care is not about dying"

Palliative care for children is a current, dynamic topic in society. At present, there are many changes happening in the area of paediatric palliative care, affecting issues such as the role of the nurse, the development of national policies and recommendations for the future of paediatric palliative care[1]. This article will discuss palliative care for children with life-limiting conditions, highlight national and international developments in this area of health care, describe current services provided and make recommendations for future development of paediatric palliative care in Ireland. It will also make reference to clinical nursing practice, the role of the children's nurse and outline the provision of care for children and families.

Paediatric palliative care

Paediatric palliative care is not about dying; the emphasis is on providing comfort and enhancing the quality of life for the child, while helping children and their families deal with their medical conditions and enable them to live life to the fullest[2]. Palliative care aims to make a child's end-of-life experience more dignified and should be accessible in any setting; home, hospital or hospice[3]. The World Health Organization (WHO) describes palliative care (see Table 1) as encompassing the physical, emotional, social and spiritual elements of the individual.

According to the DoHC[4] a life-limiting condition is "any illness in a child where there is no reasonable hope of cure and from which children or young people will die". Life-limiting conditions are divided into four categories (see Appendix 1) and children in each of these categories can have palliative care needs. Currently, there is no national database in any country which identifies children with life-limiting conditions; government publications and needs assessments are therefore based on estimates and actual figures are likely to be underestimated[4]. There are approximately 1,400 children living with a life-limiting condition in Ireland, and life-limiting conditions account for approximately 350 of the 490 childhood deaths that occur per year[4]. These statistics emphasise the need for adequate palliative care services for children and their families and the nurse has a fundamental role in providing this care.

Palliative care should run alongside curative treatment, beginning at the diagnosis of illness. However, Brandon *et al*[5] state that "offering palliative care to infants and children who are continuing to receive curative therapy is a challenge for the healthcare provider team and family because it is perceived as 'giving up hope' for recovery or cure".

Palliative Care Principles

Fundamental principles of children's palliative care include providing family-centred care, alleviating suffering and enhancing quality of life and maintaining good symptom control[2]. Palliative care adopts a holistic approach and should be multidisciplinary, available to all children regardless of diagnosis and documented correctly to ensure continuity of care. Every healthcare professional should act as an advocate for and in the best interest of the child. Respite care and support should be readily available when necessary and bereavement care should be provided throughout the whole process of palliative care[2].

Palliative Care Developments

The United Kingdom has led many developments in paediatric palliative care[6]. The need for paediatric palliative care was first highlighted in the 1980s when Sister Frances Dominica discovered that families with dying children needed support, assistance and respite breaks from daily routines[7]. In 1982, she opened Helen House Hospice which started an international drive to develop palliative care services for children. Palliative care was initially

Table 1: The WHO (1998) Definition of Palliative Care for Children

[as cited by the Department of Health and Children (DoHC) 20094]:

- "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Healthcare providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes."

associated with oncology services but has recently been developed to focus on all life-limiting conditions[4]. However, there are more resources and supports available for children with cancer and society must adapt to create better resources for children suffering from other life-limiting conditions.

Following on from the developments in the UK, palliative medicine became recognised as a medical specialty in Ireland in 1995; however, children's palliative care is a more recent development[4]. Benini *et al*[8] credit medical and technological progress for allowing children with life-limiting illnesses to survive longer than in the past, but not necessarily to recover. These children will require long-term support and appropriate palliative care.

Children's palliative care is unique[9]. The needs of children are different to those of adults (see Appendix 2) and therefore palliative care for children is significantly different to that for adults[4]. Children should be included in decision-making where possible, as emphasised in The National Children's Strategy[10]: "Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity." Where appropriate, the child should be consulted about their treatment plans and given a choice about where they receive their care. The nurse must be mindful of this and allow time for the child to express their concerns, fears and wishes surrounding death and dying[11].

Adolescents have different needs to children, including the desire for independence and the need to create a social identity, and they are more influenced by their peer groups[12]. The nurse must be aware that adolescents require a greater level of privacy and more involvement with decision-making. The nurse should always consider the best interests of the child when planning and implementing care[13].

In Ireland, palliative care services are structured into three levels of specialisation (see Table 2), which are important for establishing roles and responsibilities in palliative care.

In 2001, the DoHC highlighted the need for policy development regarding palliative care for children and published the '*Report of the National Advisory Committee on Palliative Care*'[14]. This illustrated the needs of children who required palliative care and the need for a review of palliative care services for children. This document is regarded as "the blueprint for the development of palliative care in Ireland and has been adopted as a national policy"[4]. The major findings of the report included the need to maintain the best possible quality of life and to incorporate palliative care as early as possible and highlighted that all three levels of palliative care specialisation should be available to each child and family.

Following on from this report, the DoHC published '*A Palliative Care Needs Assessment for Children*'[15], which symbolised the foundations and began the development of a nationwide paediatric palliative care service. The findings obtained from this study were consistent with results found in other countries. The key findings included the need for equity in service provision, co-ordination of services, development of home care and community services and accurate data collection regarding prevalence of life-limiting conditions and mortality. An identified 'key worker' for each family should be established to ensure consistency of care. Other recommendations included increased education, training and development for healthcare professionals regarding symptom management and control, information on local services and how to access them, improving counselling and bereavement skills and increased access to local respite facilities. The report provided guidance and direction for further policy development.

The evidence gathered during the compilation of the report illustrated that there is no data available regarding the number of children living with and dying from life-limiting conditions in Ireland. Current services are inequitable and vary according to diagnosis and geographical location and there is an inadequate availability of respite at present. There is a lack of children's palliative care services within the health system, with some children receiving care by adult specialist palliative care services. Further resources, education and funding are needed to create an appropriate service provision for children in Ireland.

Hospital versus Community Care

The number of children living with life-limiting conditions being nursed at home and in the community is increasing[17]. It is widely documented in the literature, both nationally

Table 2: Levels of Palliative Care Specialisation[1,4,14,16]

Level One – Palliative Care Approach

This approach is informed by principles of palliative care and should be incorporated into all practice. At this level, many patients will have their care needs met without the necessity of referral to specialist palliative care. This approach is an integral part of all clinical practice and should be a fundamental skill of every healthcare professional, particularly nurses, both in the hospital and the community. The aim is to promote both physical and psychological well-being.

Level Two – General Palliative Care

At this level of practice, those providing palliative care will have additional training, knowledge, experience and expertise in this area. This is viewed as an intermediate level, where engagement in palliative care is part of the health professional's caring role but does not define it.

Level 1 and 2 can be referred to as non-specialist palliative care and can be delivered by all healthcare professionals in hospital and community settings. The main focus is on quality of life and providing holistic care, which includes effective symptom control, open and sensitive communication and family-centred care.

Level Three – Specialist Palliative Care

This level refers to those professionals whose core activity is limited to the provision of palliative care. Caring for patients with complex and demanding palliative care needs requires a greater degree of training, knowledge and other resources. This support is available through primary care, acute hospital settings, specialist units and hospices.

and internationally, that in most circumstances, the home is the location of choice for end of life care; here, the patient is surrounded by loved ones with adequate professional support including the public health nurse[4,18,19]. The nurse has a fundamental role in working to achieve this wish for the families who express a desire to care for their child at home in the last few days, weeks or months. Home care allows the child to participate in routine family activities and offers social opportunities[1]. Rowse highlighted the importance of availing of community resources when providing palliative care and believes palliative care can be successfully implemented even if community resources are limited[20].

The role of the nurse is expanding from caring for children in a hospital setting to the advancement of community nursing roles. The nurse must help the child to live well and die peacefully when there is nothing more that can be done, whilst assisting the family and managing the issues surrounding death, dying and bereavement[21]. Davies *et al*[22] discovered barriers to the delivery of palliative care including limited access to speciality care, legal and ethical issues, uncertainties in prognosis and treatment outcomes and lack of communication. A partnership must be obtained between health professionals and the child's family to overcome these barriers and meet their needs in an individualised way[23].

Caring for a child at home can be challenging for the family and healthcare professionals. Willis states that "palliative care is about helping children to live before they die"[24]. When providing palliative care in the home, the nurse should encourage the family to focus mainly on spending quality time together and creating memories rather than on the child's illness. The care provided should be adaptable to meet the needs of the current family situation; through family-centred care, including negotiation with parents regarding their wishes to be involved and to what extent, holistic care can be provided. The importance of adequate communication between the nurse and family shouldn't be underestimated, and the benefits of a team-orientated approach are crucial to successful palliative care[25]. Effective communication is the cornerstone of paediatric palliative care[13].

Palliative care involves managing distressing symptoms, providing respite care and supporting the child and family through death and bereavement[26]. An initial comprehensive assessment of the child and their condition is necessary and the nurse needs to continuously reassess and monitor the child for deterioration. The nurse must assist the family while striving to maintain normality within the family unit and encourage hope where possible. Zelcer *et al*[27] found that parents face many struggles when a child is diagnosed with a life-limiting condition including competing responsibilities of other siblings, work and financial commitments and the need to become 'expert parents' and care-givers in order to meet the needs of their child.

Family-Centred Care

Pearson highlights that the nursing care provided should be holistic, incorporating the child's physical illness as well as their psychological, emotional and spiritual needs[28]. Pontin & Lewis emphasise the importance of 'knowing the family' and acquiring knowledge regarding the child, family members and available community resources in order to provide appropriate care and facilitate care delivery when the child moves into the end stage of palliative care[17]. The nurse must consider the needs of all members of the family when providing palliative care[29] and provide appropriate bereavement support which begins before death and continues after death[4]. Every family member will grieve differently and will require different levels of support at different times[1]. It is important that the nurse gives the family time and space to grieve and enlists further professional support when necessary.

The nurse must adapt to meet the changing needs of the family and be aware of the needs of the siblings[9]. The care provided needs to be tai-

Table 3: Future provision of palliative care[15]

1. Inclusiveness: All children regardless of diagnosis, location and age should be able to access appropriate care and specialist palliative care as required.

2. Partnership: The active participation of all participants in the child's care should be encouraged, including in areas such as decision-making and planning. Participants include the child, parents and healthcare professionals.

3. Comprehensiveness: Holistic care should be provided, focusing on the physical, psychological, emotional, spiritual, social and educational needs of the child and their family.

4. Flexibility: Care should be individualised, not specific to a particular location and be adaptable to fit the changing needs of the child and family.

lored to the needs of the individual family[30]. The nurse should include the family in care if possible, communicate openly, share information, listen to their wishes and work with the parents to ensure effective care[28]. O'Brien *et al* illustrate the impact of chronic illness on the child's siblings and the importance of strategies such as intervention programmes to provide information which allow them to express their emotions in a supportive environment[31]. Support groups may also prove beneficial to siblings[2].

Erichsen *et al* highlight the importance of nurses remaining honest and open surrounding issues of palliative care when caring for children and their families[32]. The nurse may face multiple challenges while caring for a child at end-of-life stage. The nurse should aim to create "an atmosphere of openness in a supportive environment that encourages truthfulness", advises Dunlop[33]. Brook & Hain support this and found families benefit from an honest, open environment in which they get to make informed choices[34]. A trusting relationship needs to be formed between the child, family and multidisciplinary team[28].

In 2009 the DoHC published '*Palliative Care for Children with Life Limiting Conditions*'[4] which aims to ensure coherent support and care is provided to children and their families. The policy focuses on addressing the findings and issues arising from the needs assessment[15] in order to build a responsive service and provide a framework for care for children with life-limiting conditions and their families[4]. This policy provides "a foundation upon which children's palliative care services can be developed in Ireland"[4]. The policy strives to ensure that all children will have the option to be cared for at home with the support of a multidisciplinary team.

Role of the Nurse

The nurse has a vital role in palliative care in providing support for the family throughout the illness, managing distressing symptoms, providing respite care and supporting through the bereavement process when the child passes away[35]. The nurse must maintain the privacy and dignity of the child when providing safe care, ensure confidentiality, provide comfort at the end of life, foster hope, assess, plan, implement and evaluate care which is tailored to meet the individual needs of the child while continuously monitoring and adapting the care given to suit the changing needs of the child[16]. For nurses and other healthcare professionals providing children's palliative care, appropriate education, knowledge, skills and competencies are required to provide holistic care (see Appendix 3).

Nurses must provide appropriate, sensitive care to children receiving palliative care and should recognise that they also need to continue to grow and develop[36]. The nurse must holistically view the child as part of the family unit and incorporate family into care. The nurse can enlist the help of voluntary organisations to allow children to make wishes to ease suffering[36]. An example of an organisation is the 'Make-A-Wish Foundation', who grant wishes of children living with a life-threatening condition, aiming to enrich life with strength, hope and joy[36]. Psychological support is paramount and must not be underestimated. The nurse should empower the parents and child to become active participants in care with open, honest communication and support.

Clarke & Quin highlight that due to the uncertain disease trajectory of life-limiting conditions in children, some children and their families may "move back and forth between boundaries of critical illness and management of chronic illness before reaching the final stage, when death is deemed to be imminent"[37]. The nurse should be aware of this and recognise the importance of providing adequate support and explanation to the child and family throughout these phases.

Keene *et al* illustrate the importance of bereavement care for healthcare professionals providing palliative care in order to deal with feelings of grief and loss, including the use of bereavement debriefing sessions[38]. Rushton discovered nurses can face many emotions including pain, stress and burnout when caring for dying children[39]. Hylton Rushton *et al* also found suffering and loss are inevitable dimensions when caring for a child with a life-limiting condition[40]. Particular emphasis was placed on the importance of increasing nurses' competence and confidence in providing paediatric palliative care and increasing their ability to manage and cope with grief responses, in order to restore and maintain a sense of personal and professional integrity.

According to Malcolm *et al*, "Children's hospices are one of the many fundamental palliative care services, and they provide much needed specialist care and support to children with life-limiting conditions and their families"[9]. They also provide a range of services including respite, play therapy, sibling support and activities, symptom control, end-of-life and bereavement care. Play is a key aspect of paediatric palliative care as it ensures emotional and sensory development. However, the DoHC did not see the development of a children's hospice as an immediate priority, as parents may not want to be separated from their children in their last few days and would rather care for them at home[15].

The DoHC[15] suggested four principles on which future service developments regarding palliative care should be based (Table 3). These must be incorporated into future care planning and the provision of services for children and their families.

The DoHC highlight recommendations for the future development of palliative care[4] (see Appendix 4). Palliative care is available in every county in Ireland; however, there is varied access to specialist inpatient units and multidisciplinary involvement and support. There have been many recent developments regarding palliative care for children in Ireland which are important steps in creating an effective, appropriate palliative care system for all who require it.

Ireland's first children's hospice, the 'LauraLynn House', is in the final stages of completion and aims to provide respite care, practical and emotional support and medical and emergency care, while providing families with a choice when death is approaching and providing ongoing support after the child has passed away. The vision of the hospice is about putting "life into a child's day, not days into a child's life"[41].

To enable children to die at home in familiar surroundings, a 'Children's Hospice Home Care' programme has been developed by government agencies. The aim is to provide appropriate care at home as a substitute for acute hospital care[4]. Developments in this programme included the appointment of Ireland's first Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine and the establishment of palliative care courses funded by the Irish Hospice Foundation for nurses and other healthcare professionals. A network of Children's Outreach Nurses will be developed throughout the country. These are important developments in paediatric palliative care, as O'Leary stressed the importance of children being cared for by appropriately trained staff[42].

In conclusion, paediatric palliative care is very topical in society at present. Romesberg states the function of palliative care is to add life to the child's time, not add time to the child's life[43]. Palliative care incorporates maintaining the best quality of life possible for the child and is the responsibility of all healthcare professionals. Morgan recognises that although palliative care is stressful for nurses, it can be rewarding and by providing holistic care "nurses have the power to create a brighter journey for patients and families" [44].

Although progress has been made in recent years regarding children's palliative care services in Ireland, further development needs to occur in order to continue providing holistic care. The recommendations for future practice include the creation of specialist palliative care teams incorporating paediatric consultants and community palliative care nursing positions, combined with further education and training in paediatric palliative care. These will assist with developing adequate children's palliative care services which should be provided by appropriately trained and educated paediatric healthcare professionals. The development of community palliative care roles will assist with achieving one of the ultimate goals of palliative care: allowing the child to spend their last few days in their own home, surrounded by loved ones and supported by healthcare professionals.

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Appendix 1

Categories of life-limiting conditions in children:

(Source: DoHC 2009[4])

Group 1: 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).

Group 2: 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).

Group 3: Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over years. (Example: Batten disease, mucopolysaccharidoses, muscular dystrophy.)

Group 4: 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.)
Appendix 2

Children's palliative care differs from adult palliative care as:

(Source: DoHC 2009[4])

- The number of children dying is small.
- The conditions are extremely rare with diagnoses specific to childhood.
- Predicting a prognosis can be difficult.
- The palliative phase is often much longer and can be episodic and unpredictable.
- Children may experience several apparently terminal phases.
- Care embraces the whole family and uses a model of family-centred care.
- Parents requiring adequate resources to support them with the heavy responsibility for personal and nursing care.
- Siblings are vulnerable and parents must continue to provide care for them while often providing 24-hour care to a sick child.
- Conditions are sometimes familial – other children in the family may be living with, or have died from, the same condition.
- Children's ability to communicate and understand varies according to their age or stage of development.
- The provision of education and play when a child is sick is essential.

Appendix 3

Competencies required for nurses to work with children with life-limiting conditions:

(Source: ACT UK adapted for use from DOHC 2009[4])

The ability to:

- Comprehensively assess and recognise the needs of the child and the family and actively monitor the child's condition.
- Listen to and respect the parents' choices, wishes and beliefs.
- Deal with specific problems and symptoms associated with the life-limiting illness.
- Communicate effectively and age appropriately with children and families to allow for shared decision making regarding care choices.
- Provide family-centred care and support throughout illness and beyond death to all family members, particularly siblings.
- Act as an advocate for the patient and family to secure additional services, funding and resources.
- Maximise the child's developmental potential, both physical and emotional, and enhance quality of life.
- Anticipate future problems associated with the life-limiting condition.
- Assess and manage symptoms throughout the duration of the illness including pain, dyspnoea, nausea, vomiting, constipation, anorexia, pruritis, fatigue, urinary retention and seizures[2]. Treatments include analgesia, anti-emetics, oxygen, laxatives and small frequent meals[45].
- Assess and manage the psychosocial needs of the child and their family.
- Meet the spiritual needs of the child and family whilst respecting cultural and religious beliefs.
- Have the knowledge of the available facilities and resources and make referrals to these when necessary.
- Work efficiently as a member of the multi-disciplinary team to provide holistic care and co-ordinate services for the child and family.
- Deliver information in a timely, appropriate fashion regarding prognosis, treatments and side effects of same[5] which will allow for informed decision-making[37].

Appendix 4

Recommendations for future practice in relation to paediatric palliative care:

(Adapted from DoHC 2009[4])

- The creation of a hospital-based specialist palliative care team is necessary, including consultants, clinical nurse specialists, nurses and social workers.
- A Consultant Paediatrician with a Special Interest in Palliative Care should be appointed who will have access to inpatient beds in a hospital setting.
- Paediatric Palliative Care services should be based in the proposed new national paediatric hospital when it is

operational.

- 8 regionally based Outreach Nursing posts should be created to facilitate integration of care across multidisciplinary services including occupational therapy and physiotherapy and provide support in the community.
- Respite care and supports should become more readily available for children and their families, both in the home and outside the home.
- Children's Hospice-At-Home teams will be developed by the HSE.
- Palliative care should be provided by paediatric-trained medical and nursing staff with the support of specialist palliative care services.
- Paediatric services should work closely with specialist adult palliative care services to provide appropriate care.
- Primary care teams and multidisciplinary network services should be created and should be available at community level.
- Further developments are needed regarding education and training for healthcare professionals in order to be able to adequately address the needs of children requiring palliative care.
- Further developments of bereavement services are recommended.
- Education and play should be incorporated into the delivery of palliative care.
- The development of standard protocols and guidelines are needed to ensure a standardised level of care given across all settings.
- A National Development Committee should be created to provide a national forum for the development of services and ensure these are available to all.
- The development of a National Database of children with life-limiting conditions is necessary to assess the need for palliative care and continuously improve the delivery of care.

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- Irish Association for Palliative Care (IAPC) www.palliativecare.ie
- The Irish Hospice Foundation www.hospice-foundation.ie
- The Jack & Jill Children's Foundation www.jackandjill.ie
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