Reflections on the provision of community palliative care for terminally ill children in Ireland

Claire Quinn presents a case study on the end of life care of a child and discusses the importance of new guidance

Abstract

In many areas of Ireland, children dying at home still have inadequate access to specialist palliative care. This causes unnecessary emotional and physical distress to the child, family, caregivers and healthcare professionals. Irish health policies aimed at improving the situation need to be fully resourced, structured, implemented, supported and evaluated. Timely referral of the child, advance care planning, patient advocacy and, finally, management of symptoms at the end of life by palliative care children’s nurse specialists can transform the experience of all involved. The author reflects on caring for a child with a life-limiting condition using the McNeilly (2006) reflection model.

Keywords

Children’s palliative care, continuous subcutaneous infusion, reflective practice

CHILDREN’S PALLIATIVE care is frequently supported with national agreements to underpin care practices (International Children’s Palliative Care Network 2012). In Ireland, the publication of A Palliative Care Needs Assessment for Children (Department of Health and Children (DHC)/Irish Hospice Foundation (IHF) 2005) and subsequent national policy for children’s palliative care (DHC 2010) has prompted discussion at community and tertiary levels in relation to governance structures and the needs of life-limited children. Adult community palliative care teams are often asked to collaborate in the care of a child and family (O’Leary et al 2006, O’Brien and Duffy 2010) but this has its problems (DHC/IHF 2005, Hannan and Gibson 2005, Quinn and Bailey 2011). Interventions such as the use of a syringe driver or continuous subcutaneous infusion, can hold the key to symptom relief and family reassurance. This reflective article will highlight and critically discuss some the challenges often faced by Irish families who wish to care for their life-limited child at home.

Children’s palliative care in Ireland

The internationally evolving specialty of children’s palliative care (Davis and Connaughty 2003, Liben et al 2008) focuses on ‘enhancement of quality of life for the child, support for the family and includes the management of distressing symptoms’ (Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT)/Royal College of Paediatrics and Child Health 2012). However, palliative care services for children in Ireland have been described as ‘often adhoc, lacking planning and frequently provided by adult palliative care teams’ (DHC/IHF 2005, O’Leary et al 2006, Quinn and Bailey 2011).

The aspirations of Irish parents for home-based end of life care (DHC/IHF 2005) are not always fulfilled. Recent anecdotal evidence indicates that the place of death for many children continues to be hospital although there is ambivalence around how this decision is made (Quinn and Bailey 2011). Some of this may be addressed by Irish policy recommendations (DHC 2010) and financial support for new nursing outreach posts funded by the IHF and the Health Service Executive (O’Brien and Duffy 2010).

Therapeutic interventions Barnett (2002) suggested that ‘a problem-based assessment of possible
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therapeutic interventions available’ is a necessary precursor to care planning for the palliative phase of illness. The care of a child with terminal illness who experiences complex symptoms at the end of life is challenging for parents and caregivers alike (Davies and Connaughty 2003, Clark and Quin 2007, Liben et al 2008, Monterosso and Kristjanson 2008). It is recognised that timely referral to palliative care and adequate therapeutic interventions can maintain the child comfortably at home (O’Leary et al 2006, Liben et al 2008, Monterosso and Kristjanson 2008) and minimise hospital admissions.

Syringe drivers The use of syringe drivers or continuous subcutaneous infusion to control difficult symptoms with medication is detailed in the literature (McNeill et al 2006, Costello et al 2008) and can enable effective children’s terminal care at home. Medications commonly administered by subcutaneous infusion include analgesics, anti-emetics, antipyretics, sedatives and anti-secretory drugs (Watson et al 2006), possibly as combinations of some 28 different compounds. Meticulous planning and monitoring are vital. Most infusions take place over a minimum of 24 hours, allowing symptoms then to be reassessed (Costello et al 2008). Towards the end of life, many people are unable to swallow medication and the use of syringe drivers is specially advocated at this stage (Ellershaw and Ward 2003).

The use of a syringe driver can, in some situations, promote patient independence (Lee 2006) and may be quite inconspicuous on the person. The need for intramuscular injections and other difficult routes can be negated (McNeill et al 2004) which is helpful with children. Costello et al (2008) emphasised the importance of patient and family participation in care planning particularly when managing complex symptoms. McNeill et al (2006) conceded the lack of research about drug combinations and their effectiveness specifically in children’s care, and this might be a subject of study in the future.

Reflective practice

Structured reflection when caring for a dying child can help nurses to maintain their equilibrium while coping with the clinical situation and also preparing for the next ill child. The reflective framework proposed by McNeill et al (2006) for use in children’s palliative care is helpful when trying to face, accept and understand events and experiences. A reflective framework can also assist nurses with closer analysis of their own practice (Hannigan 2001). An example is shown in Box 1, and four of the main items are expanded under the following four subheadings.

What happened? Where did it happen? How did I feel? What was the experience of the child and family? How did they feel about it? The case history of ‘Kate’, outlined later in this article, exemplifies many of these issues, and the associated stresses have been explored in the literature (Hannan and Gibson 2005, Clark and Quin 2007, Liben et al 2008, Monterosso and Kristjanson 2008, Quinn and Bailey 2011). Monterosso and Kristjanson (2008) observed that the palliative phase may not be comprehended by families and an ‘honest therapeutic relationship’ is crucial; early and appropriate referral to palliative care, and shared management of symptoms, are then understood and appreciated by all (DHC/IHF 2005, Hannan and Gibson 2005, Monterosso and Kristjanson 2008, Quinn and Bailey 2011).

‘Normality’ is urgently sought by families, corresponding with recognition that ‘home’ is central to the child’s and the family’s security (Hannan and Gibson 2005). However, this need to be ‘at home and normal’ is frequently and sadly exchanged for the absence of specialist and non-specialist outreach staff to assist (DHC/IHF 2005). Isolation is a central stressor for the family lacking community services and needing advice while trying to manage the complex symptoms of the child (Hannan and Gibson 2005). Parental anxiety while caring for a dying child was highlighted by Clark and Quin (2007) who acknowledged that the stress and burden of care are often left to parents because Irish services are commonly underfunded and unstructured. Consequently, anxieties that families experienced while the child was alive may still require attention after the child has died.

To what extent was the ethos of the partnership upheld? Parental and family involvement in a collaborative partnership, with mutual respect, early referral and advanced care planning, is key to the provision of effective therapeutic strategy (Hannan and Gibson 2005, DHC 2010, Quinn and Bailey 2011). Monterosso and Kristjanson (2008) recorded the views of parents, who described ‘inclusiveness’ and being involved at every step of decision making as paramount. Parents felt hugely
challenged in caring for their dying child and even ‘powerless’ to understand or influence the situation or to make any choices.

Conversely, Clark and Quin (2007) found that in Ireland the overall ‘burden of care’ was often left to parents, even when the child’s needs are complex and symptoms are significant. Therefore, in spite of parental feelings of ‘uncertainty’ and ‘lack of knowledge’; inclusiveness and partnership were in fact ironical concepts. Healthcare respondents did suggest that collaboration between parents and professionals was important in ‘getting it right’ but might be hampered by issues around collusion (not mutually sharing truths around prognosis or diagnosis), access to the child for assessment and care giving and advanced planning for decisions about location of care and care wishes.

Reflecting on the overall outcome, is there anything that needs to change? There are now requirements for the Irish government and Department of Health and Children to fund service development in response to the assessment of need and national policy (DHC 2010). Although this development is beginning, it is unfortunate that the economic climate prevails, as inequality in services for community palliative care for children remains and depends on several factors, such as geographical isolation, local palliative care service provision and staff availability. According to policy directives, in the future local collaborative structures will be addressed, further outreach nursing posts supported, implementation of a national paediatric hospice at home model explored, and guidelines formatted and education provided for those involved in the care of life-limited children (DHC 2010, IHF 2012).

What have I learned? Have my values changed? Is there anything I should do now? The central issues in children’s palliative care should be voiced by those who have the ability and experience to advocate for this minority group of children and parents. The general culture of Irish palliative care services must increasingly foster inclusiveness and equitable, resourced and established protocols (DHC/IHF 2005, O’Leary et al 2006, Clark and Quin 2007, DHC 2010). Supportive and effective palliative management of symptoms for children as well as for adults can then be achieved.

Kate’s story
I was recently introduced to a family with a baby diagnosed with a life-limiting condition. This was the first baby of a young couple living in southern Ireland. Following discharge from the local maternity hospital, follow up was conducted at a national children’s hospital and the family were sent home to care for the child as ‘best you can’, without education or support. A voluntary agency assisted the family and provided a nurse for a few hours a week. Kate (her name has been changed to maintain anonymity) was under the care of a GP and a ‘local’ paediatrician who was two hours’ drive away.

Kate, who had the neurological condition lissencephaly - an abnormality of the cerebral cortex - had many symptoms. The most difficult were 20–30 severe seizures each day, which added to her cerebral pain. She was very irritable, her sleep patterns were disturbed and bottle feeding was extremely difficult. Kate was subsequently very ‘chesty’ and frequently required suctioning. Intermittently she would travel for two hours to the hospital for insertion of a nasogastric tube when her body weight dropped or for intravenous antibiotics.

As the illness progressed, it was apparent that the parents were struggling and that Kate required referral to children’s palliative care, but no referral process or service was available at the time.

Although I was a community palliative care nurse with a hospice team, I felt helpless because children’s palliative care was unavailable. Kate’s parents felt she had no quality of life. They have told me retrospectively that she suffered a great deal. As her condition worsened, they made a last frightening and solitary journey to hospital with their dying child. There was no help locally. They were not upset that she finally died in hospital, as they had nursing support at last. The fact that she was resuscitated before she

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**Box 1 A model of reflection for children’s palliative care**

- What happened? Where did it happen? How did I feel?
- What was the experience of the child and family? How did they feel about it?
- To what extent was care family-centred?
- Who else was involved?
- To what extent was the ethos of the partnership upheld?
- Did the child and the family feel that they were given autonomy and choice in the situation? Were there any cultural, spiritual and ethical issues?
- Was a key worker appointed? If yes, how did this facilitate communication, if not, why not? Were there any sociopolitical constraints?
- What was the overall outcome – is there anything that needs to change?
- How can I make sense of this on a personal and professional level?
- What are my personal values in relation to caring for this child and family?
- What personal knowledge did I bring to this situation – empirical and experiential?
- Overall conclusion: what have I learned? Have my values changed? Is there anything I should do now?

(McNeilly et al 2006)

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was finally allowed to die did not seem to add to their distress; they viewed it as part of the process of dying, saying: ‘She tried to go three times.’

Conclusion

A referral to palliative care can enable therapeutic intervention and symptom management, particularly by the subcutaneous infusion of medications, and will enhance patient comfort, support choice for home as the place for end of life care and may reassure family members and caregivers. In Ireland, there has been no structure to facilitate terminal care available to children at home. The publication of Irish policy recommendations is welcome but requires careful implementation.

Further work might include comparisons with services available elsewhere, studies of parental preferences and, crucially, research on drug combinations that may be effective in the community care of the dying child.

Points for practice

■ More terminally ill children are being cared for at home.
■ Access to specialist community children’s palliative care is lacking in Ireland.
■ Irish government policies to improve the situation should be fully implemented, supported and evaluated.
■ Timely referral of the child, advance care planning, patient advocacy and community children’s nurse specialist management of symptoms are required.

References


Conflict of interest

None declared