



## The experiences of providing children's palliative care education in undergraduate nursing programmes – A discussion of some practical issues

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### ABSTRACT

Despite recent proliferation of palliative care services for children, and the fact that the needs of these children and their families are enshrined in current policy directives, the challenges of providing education for nurses within this area of practice is largely underexplored. This paper examines some of the key issues facing nurse educators who are involved in the delivery of palliative care content in undergraduate children's nursing programmes. Drawing on the extensive experiences of two nurse educators in children's palliative care education, research and practice, key issues which should be considered by those involved in curriculum development and delivery will be outlined. Such issues include ambiguity in terminology and resultant lack of conceptual clarity, the limited evidence base to underpin practice and education, the complexities of teaching sensitive topics to large groups and limited teaching expertise to deliver the content. Suggestions for addressing such issues will be outlined.

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### Introduction

Palliative care for children, young people and their families has evolved as a small yet distinct area of practice (Price and McFarlane, 2009), as the number of children increase and the challenges experienced by families and practitioners become even more complex (Liben et al., 2008). As a continuum of care and not purely end of life care, palliative care for children in Ireland, in keeping with international developments, has undergone considerable change in recent years in terms of care and service provision for children and families. These changes have been greatly influenced by the uncertain and progressive/protracted nature of illness trajectories and associated complex care required by children particularly with non-malignant conditions (DHSSPS, 2007; DoH&C, 2010). Further although children are usually nursed across multiple care settings during the course of their illness trajectory, parental desire to care for their child at home necessitates more substantial community care services from nurses and others within the interdisciplinary team (Clarke and Quin, 2007). As such, this approach to care provision can pose challenges in relation to sustained resources and team working (McNeilly and Price, 2007). Wide recognition exists that nurses are at the

forefront of interdisciplinary care delivery regularly spending more time with children and families than any other health care professional (Schreiner et al., 2009) and as such nurses are often in the position of meeting new challenges first hand with the family (Costello and Tinder-Brook, 2000).

As a consequence the need for appropriately trained and skilled staff to address the complexities of partnership caring is now recognised as fundamental across all levels of palliative care service provision, care locations and range of agencies involved in caring for children and families (ACT, 2009). The need for relevant and evidence based education to underpin safe and competent practice through specific educational programmes for health and social care professionals is identified (DoH&C, 2010; ACT, 2009) and many programmes have been developed locally, nationally and internationally. The specific need for undergraduate programmes across disciplines to provide firm educational foundations have been highlighted (Ferguson et al., 2006) thus it is essential to recognise education within the field of children's palliative care is broad ranging and not only includes specialist education but also includes ensuring staffs are skilled in the application of the principles and philosophy of palliative care from early in a professional career.

Whilst the centrality of education to underpinning the nursing care for children and their families is clear, the challenges this can place on those who provide these educational programmes is underexplored. Explicit advice on how to deliver this content is not readily available, nor is there evidence of the realities of providing palliative care principles and practices as a foundation for

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professional practice within undergraduate curricula. Throughout this paper the authors, themselves experienced nurse educators/researchers will explore their perspectives of delivering palliative care theory, and skills to undergraduate children's nursing students and offer suggestions as to how the challenges that educators can face might be overcome.

### What to teach?

When considering specific content for undergraduate children's nursing curricula, a fundamental issue is to clarify competencies and content that is required by all nurses at the point of professional registration and those competencies that require specialist post-registration education. In clinical practice differentiation between generalist and specialist practice also remains unclear and may be compounded by the difficulty in defining palliative care for children, who requires it and when palliative care should be instigated. The application of the principles of palliative care can also vary across the clinical environment for many reasons. This lack of clarity may be related to the newness of the specialism of children's palliative care which has a short history. However there is no doubt that children's nurses require education to prepare them to address the complex issues that can emerge when caring for a child who is dying and during the palliative disease trajectory (ACT, 2009). There remains limited clarity regarding those skills which all nurses require to care for life-limited children, many of whom may have long term complex needs and disabilities, and those required to provide specialist palliative care, particularly at end of life.

Given the key role that nurses play in caring for children the authors believe therefore that the principles of palliative care should be included in all undergraduate nursing and midwifery programmes especially in the disciplines of children's and learning disability nursing. However there is inconsistency and considerable debate what exactly constitutes the principles of children's palliative care. Since many children who require palliative care will receive care in a variety of care settings, have complex and rare diseases with often unknown disease trajectories, identifying the specific content required to address the nurses' educational requirements for education in children's palliative care can be challenging. The nursing skills and knowledge required to address the often complex physical, psychosocial, ethical, legal and spiritual issues experienced by children and their families, are significant and without these a definite barrier to quality palliative care provision is created (Schreiner et al., 2009). This requires that psychomotor, interpersonal and management skills are taught and practiced. Time should be available for skills learning and practice which requires appropriate practice clinical learning environments, teaching resources, time and skilled supervisory staff. Not only do the physical care needs of the child who requires palliative care need to be included but self care and stress management skills need to be developed in students. Providing nursing care and working with families within a partnership approach can cause significant professional anxiety and stress (Wooley et al., 1989) as does the perceived powerlessness and frustration experienced by nurses caused by their consequent inability to provide a comfortable death to children (Papadatou et al., 2002; Clarke and Quin, 2007; Mack et al., 2008). Students consequently need to address their personal coping mechanisms when managing very sensitive issues and care practices (Contro et al., 2004). Additionally the authors suggest that delivering all aspects of palliative care raises significant, and complicated ethical, moral, legal spiritual issues for inexperienced nursing students to manage during undergraduate practice experiences in many clinical sites. These can include decision making in withdrawing support/treatment and communication with children (Bennett, 2009). The principles of children's

palliative care should be embedded in undergraduate nursing programmes to ensure the development of these skills is promoted from the outset. An additional factor requiring consideration in curriculum planning and delivery relates to the cutoff point between children's and adult service provision. The increased numbers of children with life-limiting conditions who are surviving beyond the age of eighteen (ACT, 2007), have led to challenges in addressing the care needs of young people as well as infants and children in the nursing curricula. Again the evidence specifically examining the palliative care needs of young people is limited. This creates an educational tension for children's nurse educators, who usually include care needs up to age 18, leaving young adult care for those providing adult programmes to cover, yet in reality these young people often continue within children's services as transitional care services are fragmented.

Managing the complex issues that can emerge when caring for children and young people with life-limiting conditions needs consideration in the development and delivery of palliative care education programmes at undergraduate level and this cannot be viewed as a post-graduate specialism. It is also necessary for all those interested in children's palliative care to discuss, develop and agree nationally competencies which can be obtained at undergraduate level and those that require post-graduate specialist experience attained at specialist level. It is recognised that there are efforts within Europe to develop a core curriculum in children's palliative care but more work needs to be done on developing competencies at undergraduate children's nursing level.

### Managing ambiguities in children's palliative care

In the delivery of palliative care education a key issue that needs to be addressed includes a lack of clear terminology and clarity in palliative care principles for children. The lack of clear terminology in children's palliative care and the inconsistent interchangeable use of terms that are applied to children with life-limiting diseases (Nicholl, 2007a) can pose particular challenges to nurse educators and students alike. There is widespread ambiguity in the terms used within policy and service developments (Himelstein, 2005) which can impact on service delivery including referral to palliative care providers. The terms life-limiting, life-shortening, complex needs or life-threatening are often used interchangeably within this area of practice and within literature. For curriculum developers and students ambiguity raises concerns.

In addition to ambiguity in terminology, lack of clarity can causes uncertainty in clinical practice for students as to when it is appropriate to implement palliative care within the child's disease trajectory. As a result inexperienced students, given their potentially limited clinical experience, may find it difficult to understand the conflicts and tensions that can arise when palliative care principles are promoted. This lack of clear cut principles may cause the student to grapple with complex conceptual issues of which they may have minimal experience. In the delivery of curriculum content this ambiguity requires the nurse educator to pay attention in planning teaching sessions to developing an understanding of these issues in students by using teaching strategies that encourage debate and discussion. The simple application of the terminology and principles used in adult care is inappropriate, given the different conditions, illness trajectory duration and family needs that require the children's nurses' attention. Complex concepts, terminology and underpinning philosophies in children's palliative care need to be introduced to students early in their programme and time needs to be given to the exploration of these issues and their implications for practice, especially if students have been taught adult palliative care principles before they undertake children's palliative care education. It is recognised that the principles

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