



## A REVIEW ON ROLE OF NURSES IN PALLIATIVE CARE

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### ABSTRACT

Nurses and healthcare support workers should be involved in the care of children and young people requiring palliative care. Experienced nurse with detailed theoretical and practical knowledge of palliative care and responsibility for leadership and management. Ageing populations are characteristic of many countries. The pattern of disease at the end of life is changing and more people are living with serious chronic circulatory and respiratory diseases as well as with cancer. More people will need help at the end of life, in a social context of changing family structure and wider migration, employment and ageing of potential care-givers. Evidence for the effectiveness of simple measures in these areas and for the role of coordinated team care, home nursing, and specialist palliative care is based mostly on studies of people with cancer. There are gaps in the evidence base for palliative care for older people with other serious chronic illness. But in many cases the needs and solutions are likely to be similar to those for people living with cancer.

### Key Words:

### INTRODUCTION

Palliative care in children's nursing is an active and holistic approach to caring for children with life-limiting conditions, Irene O'Brien, Anita Duffy 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[1].

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.

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 [2].

The home is considered by many to be the ideal environment for the deliverance of familycentred palliative care, free from the constraints of hospital routines, with less disruption to family life and better outcomes for parents and siblings [3]. Conversely, for others the security and support offered in the hospital environment relieves parents of the burden of care and decisionmaking dilemmas that home care presents, therefore enhancing the valuable time that they spend with their children [4]. 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 [5]. 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 [6].

Familycentred care plans addressing the needs of the ill child and family members are multifaceted, involving partnerships in decisionmaking between family members and professionals, and should be reviewed and readjusted according to the child's medical condition [7]. 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 [8].

Many countries have experienced dramatic improvements in population life expectancy. The proportion of elderly people, and particularly those over 80, has increased significantly in recent decades [9,10].

As populations age, people die in greater numbers after long illnesses from heart disease, cerebrovascular disease including stroke, chronic respiratory disease and respiratory infections, and cancer. Predictions suggest that these will be the five main global causes of death in twenty years [11]. Palliative care offers a support system to help patients live as actively as possible until death. It affirms life and regards dying as a normal process, but intends neither to hasten or prolong it. Using a team approach, palliative care addresses the needs of patients and their families, including bereavement counselling if necessary. It should be offered as needs develop, before they become unmanageable, and must not be something that only specialized palliative care teams, palliative care services or hospices offer when other treatment has been withdrawn [12,13].

## **PALLIATIVE CARE NEEDS**

### **Pain and symptom control:**

Observational studies show that when clinical guidelines on pain control are followed 70% to 97% of patients with advanced cancer gain adequate pain relief. Although research on implementation has been relatively neglected, educational interventions can improve the knowledge and attitudes of staff about pain though not necessarily patients' pain levels [14].

### **Communication skills:**

Allowing a better knowledge and recall of information and improved satisfaction [15] without causing psychological problems [16]. However, for patients with a poor prognosis, account must be taken of their preference to know the full facts or not [17]. In general, decision-making aids can help professionals explain treatments, clarify patient concerns and improve their satisfaction [18].

### **Specialist palliative care teams:**

A common model for delivering palliative care has been to concentrate expertise in multi-professional teams working in inpatient units, hospitals or the

community. These teams usually deal with a selected group of patients with the most complex needs, who have been referred by other teams of professionals. Despite conflicting findings in initial reviews [19-25], meta-analysis now shows small but significant benefits as measured by pain control and other symptoms and expressed care satisfaction by patients and their families [26-29].

### **Palliative day care:**

There is evidence that patients value attendance at palliative day care units where they can meet other patients, talk to staff and become involved in activities. There is no evidence as yet that attendance affects other outcomes such as quality of life or symptom control [30].

### **Role of nurses:**

- Communicating effectively with children and young people with palliative care needs.
- Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, and children's home or other community setting).
- Sustaining self and others' wellbeing, when caring and supporting children, young people and families with their grief, loss and bereavement.
- Working with primary carers and healthcare professionals to identify and manage symptoms.
- The importance of ensuring the child's participation in their care planning, utilizing tools/ communication aids as necessary.
- The boundaries when working with the child and their family [31].
- Use various tools to communicate with children eg ., Makaton or British Sign Language, switches or symbols.
- Seek and use interpretation services for children and families from differing ethnic backgrounds.
- Multidisciplinary care pathways utilized within the clinical setting.
- counseling techniques and how to use them.
- Legislation, policies and procedures relating to communication and record keeping.
- For children and families with palliative care needs including psychological issues such as anticipatory grief.
- Sensitively break news of diagnosis, and assist child and family with commencing their palliative care journey.
- Access resources both statutory and voluntary that support the family.
- Hold difficult conversations, ensuring the setting is safe and confidential.
- Document important conversations and communicate important facts to appropriate colleagues in confidential format that will contribute to the multidisciplinary planning and decision making [32]. Supports children, young people and their families through times of uncertainty, applying their specialist palliative care knowledge to the child or young person and



Communicates confidently and effectively with children and young people. Discusses treatment, care options and

- Appropriate cognitive level. They support the child/young person and their family in their choices. They utilise integrated multidisciplinary care pathways to guide child, family and professionals in effective communication and care planning. They provide constructive feedback to other staff or team members on their communication style or delivery at appropriate times. They create an empowering and affirming environment for families. They analyze complex child/young person/ family situations and shares experiences and insights with others. They communicate complex concepts clearly and effectively through the spoken and written word. They guide and support others to improve communication skills among the team. They teach communication skills and child specific modes of communication, in formal settings to specialist and non-specialist staff[33]. They debate with clarity and competence, while showing due respect for the perspectives of others. They create an environment that enables junior staff to share their views of patient/family issues within a multidisciplinary setting. They establish a therapeutic relationship in which they are able to utilise counselling skills to assist the child, young person or family member to explore their feelings about their illness or care. They deliver delegated nursing care, within defined guidelines and protocols following the prescribed care plan. They collect reliable information that informs nursing care which contributes to changes in the symptom management plan. They maintain activities of daily living for a child with palliative care needs. They relay simple information to other members of the multidisciplinary team[34]. They assess child's and family's needs and recognises when to report to supervising nurse. They provide basic palliative care for children in the home, hospice, school or other community setting. They advocate on behalf of the child's and family's needs, reporting to the supervising nurse[35-38].

They monitor the quality of work in own area and alerts others to quality issues. They apply appropriate clinical judgement, in consultation with others, to provide nursing care that meets the complexity of the child/young person's palliative care needs. They involve in partnership working with other agencies including education, social services and voluntary sector. They lead a discussion with support on specific topics associated with children/young people and their families with palliative care needs[39-44].

They develop therapeutic relationships with children, young people and their families to assist their informed choices for care and treatment. They Lead discussions of the multidisciplinary team that draws on members' knowledge and understanding of the child/young person and their palliative care needs, participating actively and collaboratively as a member of the team. They provide the child/young person choice

coping strategies in an appropriate manner and at an

where possible, recognising the impact these choices can have on quality of life ie remaining at home at end of life. They interpret basic clinical data to inform decision making. They support junior staff to develop skills in organising, prioritising and delegating. They ensure an appropriate induction or development programme is in place. They evaluate outcomes of care and makes alterations appropriate to the ever- changing clinical situation. They participate in the unit's recognised role in providing specialist advice and support. They develop individual learning outcomes for clinicians. They provide specialist learning and development around children's palliative care issues, nursing and care staff and also educational establishments. They are able to support others in discussions and can act as an advocate to children, young people, and families with palliative care needs[45]. Advanced care plan, evaluating this in partnership with the child/young person and their family with support of an experienced palliative care nurse.

- Uses listening skills to support individual family members/carers.
- Reports accurately to senior staff and is aware of the boundaries of support offered.
- Gives advice to families and carers on practical issues following death, seeking support from more senior staff where necessary.
- Recognises own supervision needs and accesses clinical supervision.
- Uses reflection to develop practice and shares knowledge with peers and others. [46-48].

## **CONCLUSION**

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 competency and consistency in children's palliative care.

Furthermore, health professionals require debriefing and bereavement support. Until then, gaps in the present children's palliative care system will remain controversial. There is evidence of unmet need for pain relief, good communication, and meeting preferences for place of care for older people. Evidence for the effectiveness of simple measures in these areas, and for the role of coordinated team care, home nursing and specialist palliative care, is based mostly from studies of people with various diseases.



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