Giving hope to families in palliative care and implications for practice

While parents of children with life-limiting may not be in denial, Helen Smith suggests they will need time to come to terms with the inevitable, and nurses are crucial to conveying information sensitively and involving them in decisions.

Abstract

Caring for a dying child and the family is one of the greatest nursing challenges. The way in which care is delivered will shape the experience they are about to face. Hope plays a crucial role in helping people cope, and healthcare professionals can foster appropriate hopes ethically, while maintaining open and honest communication. If palliative care is discussed with clients and families from the time of diagnosis, they can face realistic decisions better and not feel that they are ‘giving up’. They need to know that everything possible is being done to improve the quality of the time left to them.

Keywords
Children's palliative care, communication, dying, ethics, legal issues, hope, psychology

DEATH IN OUR society is viewed generally with anxiety and discomfort, and is a subject many feel reluctant to talk about or plan for. It is a taboo topic: one that even healthcare professionals are reluctant to broach. The primary goal of the current medical model of care is to maintain or restore the patient’s health, and death is often seen as failure (Gazelle 2003).

Despite this, children's palliative care has developed as an emerging medical specialty in the past two decades, aiming to affirm life and regard dying as a normal process; it intends neither to hasten nor to prolong death (World Health Organization (WHO) 2002). The aim is to help children with life-limiting illnesses be able to live as well as they can until they die. It is estimated that annually more than 40,000 children in England may require access to palliative care services - and the number is steadily rising, as advances in medical technology increase the life expectancy of children with complex medical needs (Together for Short Lives 2013a).

The death of a child in Western society is experienced as an unnatural event; no parent ever expects to outlive their offspring. Traditional medical care views death as a phenomenon to fight, with life at all costs being the primary motivation (Costello and Trinder-Brook 2000). It is therefore not easy to broach the subject of death with any parent and difficult to gauge when it is the right time to approach the topic of palliative care with families. Should it be done at diagnosis? During an acute episode? Or only when all other options have been exhausted?

Avoiding these conversations can lead the family to develop false hope that their child will survive or to the assumption by staff that the family knows what the outcome will be without it ever being discussed openly.

This article explores the concept and role of hope in children’s palliative care, the ethical and legal issues that affect the reality of giving hope to families and the implications for practice.

Palliative care

The best children's palliative care is defined as 'an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements, and focuses on the enhancement of quality of life for the child and support for the family' (Together for Short Lives 2013b). It includes the management of distressing symptoms, provision of respite and care, end of life care and bereavement support.
As the definition suggests, children’s palliative care is concerned not simply with the physical needs of the child, but also with the psychosocial, emotional and spiritual needs of the family as a whole. This is supported by WHO’s definition of palliative care for children as the ‘active and total care of the child’s body, mind and spirit... also involves giving support to the family’ (WHO 2002). The WHO definition emphasises an ‘active and total’ approach to care. Families often view it as ‘giving up’ on their child when, in reality, palliative care is not simply the cessation of curative treatments, but the active introduction of other approaches (Hain and Jassal 2010). The ‘total’ approach emphasises the need to recognise all the dimensions of the experience: physical, emotional, psychosocial and spiritual.

What is hope?
Hope is defined as a feeling of expectation and desire for a particular thing to happen (Oxford Dictionary 2013). It is recognised as an essential component of life. ‘Hope springs eternal in the human breast’ is a well-known quotation from Alexander Pope, which observes that it is human nature and a human need to hope that something better may be coming.

Hope is often linked to a person’s spirituality – those with a faith are often referred to as putting their hope in a higher being (case study 1). It is also frequently described using light metaphors, such as a ray or beam of hope, or light at the end of the tunnel.

In health care, it has been shown that there is a strong link between hope and quality of life in adults with cancer (Feuz 2012) - and hope is considered an effective coping strategy in dealing with serious illness. This can be in the form of hoping for a cure, hoping for the treatment to be painless, hoping for a quick recovery or hoping for a peaceful death.

In children’s palliative care, when there is no hope of a cure, there is often a tension for practitioners between, on one hand, promoting open and honest communication with clients and family and, on the other, fostering hope that may be unrealistic (case study 2). As healthcare professionals, we are encouraged to promote good communication. The National Institute for Health and Care Excellence (NICE) (2011) quality standards for end of life care services state that people approaching the end of life and their families must be communicated with and offered information in a sensitive way, at a time when it is helpful, and with respect for their needs and preferences.

In a study looking at caregivers’, patients’ and healthcare professionals’ attitudes towards fostering hope, Clayton et al (2005) found that, when discussing the future with terminally ill people with cancer, all participants emphasised the need to maintain hope. At the same time, several practitioners commented that it was important not to offer unrealistic hope or collude with unrealistic expectations.

Among the healthcare workers in the study, whether or not to discourage people who hoped for a miracle cure was a contentious issue, with a few concluding that they would not discourage it if it helped individuals cope. The medical staff in the group, however, stated that they would discourage service users from investing time and energy in futile treatments and from hoping for something that would ultimately not occur. In the same study, none of the service users or caregivers indicated that they did not want healthcare professionals to be honest or give false hope, but they did say it was important that any positive aspects were emphasised to them (Clayton et al 2005).

Truth telling in health care is a basic moral guideline in today’s society. However, when telling the truth can cause distress, it can be in conflict with the fundamental ethics of health care ‘to do no harm’, or the precedence of beneficence. There are several ethical frameworks that can be applied to this situation when deciding how much to tell clients and families.

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**Case study 1**

TOM (NOT his real name) is a nine-year-old boy diagnosed with a brain tumour just over a year previously. Despite chemotherapy and radiotherapy, the tumour has recurred and he now has spinal involvement as well. He has been admitted to the local hospice for end of life care. He is very weak and in a lot of pain, and it is clear that Tom does not have long to live. Over the next few weeks, he slowly deteriorates, becoming increasingly drowsy and taking only a few sips of water a day.

His family are devoted Christians and are open with staff that they are praying for healing. Some of the professionals are uncomfortable with this. It is clear that Tom is dying and his parents appear to have accepted this, but at the same time they are praying for a miracle.

This family’s faith gives them hope that, even when medical science cannot help their son, there is still the chance of a miracle of some kind right up to the end.
Ethical and legal issues

Consequentialism This approach takes the view that the correct moral response is related to the outcome or consequence of the act. The central aim is the premise of maximising the greatest good for the greatest number. Within this framework, there is always an outcome and a correct moral response.

Applying this to truth telling in palliative care may mean that staff are conservative with the truth because they wish to avoid causing undue distress. This may lead to neglecting the parents’ legal right to accurate information about their child’s condition. It may also mean that, when making any decisions about their child’s care, families are not necessarily in receipt of all the facts about their child’s condition.

Protecting people from emotional distress may, in effect, cause harm if the child is then subjected to treatment that is futile or painful. It also means that the family is kept in the dark until the child’s prognosis has worsened, and it may be an even greater shock when the news is eventually broken. The paternalistic side of the healthcare professions may lead them to decide, on behalf of the clients, what is best when, in reality, it is family members who ultimately should decide, because they will have to live with the consequences for the rest of their lives (Bracegirdle 1994).

Deontology This approach, on the other hand, is an ethical framework based on the duties and rights of individuals; it places value on the intentions of the individual, rather than the outcomes of any action, focusing on rules, obligations and duties. In palliative care, this would mean telling the client/parent the truth regardless of how upsetting or difficult it may be for them to hear it.

When a child is born, his or her parents have hopes and dreams for the child's future: education, career, marriage and grandchildren. But, when the child is diagnosed with a terminal condition, their hopes are shattered, and the parents may be left feeling hopeless.

Kirk et al (2004) described the presence of hope as one of the most important elements that palliative service users and their families want to be present in all healthcare communications. The authors noted a continuing need for hope, even when it was known and accepted that the condition was terminal and life expectancy was limited. Even in the end stages of disease, people still wanted the door to be left open for the possibility of a miracle.

Some family members have described it as living parallel realities - to acknowledge the terminal stage of the illness and yet still hope for a miracle cure. To have their hope dashed by a rushed or insensitive professional was experienced as extremely negative.
Denial can be a powerful coping mechanism, allowing parents and families the emotional energy to support their child

The way in which staff communicate with families will undoubtedly affect whether they allow the preservation of hope. If a doctor communicates even a sliver of hope, parents may hang on to that remote chance, no matter how small.

Hope is central to life, and specifically is an essential dimension for successfully dealing with illness as well as preparing for death (Kubler-Ross 1983). Adults who are aware of their impending death may maintain hope by shifting from hope for a cure to hope for what they define as a good death (pain free and as comfortable as possible).

Hopelessness is the opposite of hope and is highly correlated with depression. In adults nearing death, hopelessness is not thought to be due to knowledge of their condition but more to loss of meaning and purpose in their life (Liben et al 2008). Parents who know that their child will die soon face the loss of the hope they had in the child, as well as a loss of meaning and purpose in their own lives.

Barriers to open communication

Uncertain progress Davies et al (2008) looked at barriers to introducing the idea of palliative care for children to families; they administered a questionnaire to nurses and doctors about what they perceived as barriers. The most common obstacle identified was uncertain prognosis.

The types of illnesses seen in children requiring palliative care tend to vary greatly compared with those in adults. The trajectory of these illnesses can also vary greatly, with palliative care often spanning years before the child enters the end of life stage. The terminal conditions seen in children include congenital abnormalities, chromosomal disorders and neurodegenerative conditions, as well as malignancies. This uncertainty can lead to staff feeling torn between cure versus palliative care, rather than encouraging the two types of care to coexist or to be explored at the same time.

The difficulty in predicting the exact trajectory or overall prognosis of many of the conditions can lead to uncertainty when discussing goals of care with families. This uncertainty was also found by Contro et al (2002) who reported parental dissatisfaction with staff as a result of confusing, inadequate or uncaring communications about treatment or prognosis. Confusing messages may encourage parents’ pursuit of curative treatments, because they are likely to grasp at any glimmer of hope presented to them, no matter how small.

Family not ready to acknowledge incurable condition The second most common barrier identified was staff sensing that the family members were not ready to acknowledge that their child might have an incurable condition. There is a difference between parents knowing the facts presented to them, and understanding and accepting them. Strong et al (2004) described parents’ difficulty in accepting a grave prognosis when their instincts and moral obligations as parents were to protect the life of their child. It is not surprising parents may take longer than professionals to accept the inevitability of their child’s demise.

Denial can be a powerful coping mechanism, allowing parents and families the emotional energy to support their child. Their hopes for recovery are often boosted by the fact their child may have survived against the odds previously, and by the difficulty in accurately predicting how long the child may survive. In malignancies this tends to be easier, but with neurodegenerative and genetic conditions it may not be so obvious.

The fact that practitioners perceive that parents may not be ready to acknowledge that their child is going to die should not, however, detract from their duty to be honest as far as possible. Research has shown that parents feel it is important that they receive sensitive and caring communication, including frank discussions to prepare them for the dying process. In addition to this, as parents see changes in their child’s condition and appearance they are more likely to believe that their child may be dying (Davies et al 2008).

Implications for practice

Having looked at the vital role hope plays in people’s lives, but particularly in the lives of parents facing the death of a child, questions remain. How can we maintain open and honest communication with families, while at the same time allowing them to foster hope in a way that may help them cope with the reality of their child’s illness?

Parents and families want and require open and honest communication from healthcare professionals from the moment their child is diagnosed or becomes unwell. There is, however, a subtle difference between being honest with families and always telling them the whole truth. If the prognosis is unclear, then the healthcare professionals can only tell them what they know right now. If that turns out to be wrong, then the family has not been misled or lied to – professionals can only tell them honestly
what they know of the truth facts as they are at that time (Draper 2005). In this connection, Gillon (1985) stated: ‘It is meaningless to speak of the truth, the whole truth and nothing but the truth to a patient. It is meaningless because it is impossible.’

When practitioners fail to inform the clients about the facts truthfully – whether it be about prognosis, or the risks and benefits of a particular treatment – they are, in effect, taking away the client’s or parents’ autonomy and their right to make informed decisions about future care. Parents may continue to be optimistic and do not want to be seen as ‘giving up’ on their child when they may already have accepted the realities of terminal illness and are not necessarily in denial (Liben et al 2008).

Palliative care can be delivered in its totality, while positively supporting a family who may be wishing for a miracle cure.

There are ways in which, even when faced with the impending death of their child, nurses can help parents to foster hope. The primary goal must be to work towards integrating palliative and curative or life-prolonging care, so that they work together.

This will help on two levels. If palliative care is discussed with families from the time of diagnosis and throughout the child’s illness, they will be better informed when it comes to making decisions about palliative options and it may improve their ability to make crucial decisions. It will also help reduce the perception that palliative care means ‘giving up’ on the child and that nothing will be done, when in fact palliative care is active and involves looking at the child as a whole, and may actually improve quality of life.

Healthcare professionals can also help parents and caregivers maintain hope by asking about what their hopes and goals are for their child.

For example, for many families their hopes will be that pain is well controlled and that the child will not suffer; these are realistic hopes that practitioners can help them achieve.

Clayton et al (2005) identified that there is a change in the focus of hope over time as a child’s illness progresses and the family comes to terms with this deterioration. This is referred to as a spectrum of hope – it may start as a hope for a miracle cure, leading to the hope for good pain and symptom control, to eventually hoping for a peaceful death (Clayton et al 2005).

Children’s nurses by definition are committed to promoting the health and wellbeing of patients but, unfortunately, this is not always possible. The role of the child’s nurse in this situation should be to help parents and families focus their hopes on the quality of the time they still have with their child, the hope of making this time as pain and symptom free as possible, and the hope for a peaceful death.

Conclusion
Hope is an important coping factor for parents facing the death of a child. Hope may change over the course of the child’s illness, but should not be discouraged by nurses because it does not mean that the child or family are in denial of the inevitable prognosis.

On a daily basis, hope may be what they need to deal with the overwhelming reality facing them. Very rarely is a situation completely hopeless; there is usually an intervention, whether medical or psychosocial or spiritual, that may improve their quality of life. Where a situation is perceived as hopeless, families need to know that everything that can be done is being done and that the door is always open should a miracle cure become available.

References

Conflict of interest
None declared

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NURSING CHILDREN AND YOUNG PEOPLE
June 2014 | Volume 26 | Number 5

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