Creating a ‘wish list’ to prompt conversations on end-of-life care

E veryone has wishes about how they would like to be cared for towards the end of their lives and how they would like to die. However, death and dying are still sensitive subjects – and even more so when they are discussed with people who have been diagnosed with a terminal illness (Tagney, 2014).

We are a group of third-year students in adult nursing at London South Bank University. In our second year, we undertook a module on end-of-life and palliative care; this included information on advance care planning (ACP). To encourage conversations around end-of-life care (EOLC) wishes and ACP – both between patients and relatives and patients and health professionals – we came up with the idea of a ‘wish list’. In this article we explore this idea and explain our work around it.

Why a wish list?

Everyone has different ideas on death and dying based on their life experiences (Graham et al, 2013). People’s views on both of these issues vary depending on whether they have been exposed to death and what their life expectancy is (Faull et al, 2012). We were interested in how death is viewed by patients, as we wanted to better understand the emotions and thoughts of those who are dying.

Patients near the end of life may find it difficult to broach the subject of how they would like to be cared for and die. Nurses have a role to play in eliciting and discussing patients’ end-of-life care (EOLC) wishes through advance care planning (ACP).

Patients at the end of life and their families need to have hope, receive compassionate care and be empowered. EOLC must be sensitive to patients’ cultural, religious and spiritual beliefs and needs.

A group of student nurses has developed an EOLC ‘wish list’ that can be used in ACP.

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We have spent time on hospital wards with registered nurses who are caring for patients at the end of life, and have seen how the presence of nurses at the bedside can enable the development of positive relationships with patients and families, as outlined by Reinke et al (2010). Having accumulated some clinical experience of EOLC, we met to discuss what death, dying and EOLC meant to us, both from a personal and a student nurse’s perspective.

The idea of an EOLC wish list to support discussions between patients, families and health professionals emerged. We determined areas that we wanted to research; each of us was assigned one area to explore, and we met on a regular basis throughout the semester to develop our
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wish list. During our meetings we realised that we all had different views on which element of the wish list was the most important. These views stemmed from our experiences of care on the wards, our own personal experiences, and our cultural backgrounds.

The wish list is composed of key words (Fig 1). Some of the evidence supporting its elements are discussed below. Box 2 tells more about our experience of EOLC.

Wishes
A good death has been described as: “the best death that can be achieved in the context of the individual’s clinical diagnosis and symptoms, as well as the specific social, cultural and spiritual circumstances, taking into consideration patient and carer wishes and professional expertise” (Bit.ly/EOLCGoodDeath).

What makes a ‘good death’ will obviously be different for each person. To express their wishes, patients need ongoing communication with clinical staff (Nursing and Midwifery Council, 2015). Staff need to be aware that patients’ wishes can change from one month, one week or one day to the next – or even from one hour to the next – as their condition deteriorates (Sleeman, 2013). This means their EOLC needs can change quickly and ACP should be viewed as a dynamic process.

Hope
Hope is important at the end of life (Kirby et al, 2014), both as a coping strategy and as a determinant of quality of life (Mok et al, 2010). Matzoo and Hill (2015) emphasise hope as a key component in the emotional journey towards death. Henry and Wilson (2012), likewise, identify it as a factor that helps patients and families through the difficult times leading up to death.

Kinghorn and Gaines (2007) have outlined a conceptual model of hope based on:
- Comfort – patients need to know that their personal and environmental comfort is ensured and their symptoms are well managed;
- Attachment – this can be achieved by maintaining a caring and welcoming environment, and recognising and addressing patients’ and families’ needs (Timmermann et al, 2015);
- Worth – this can be enhanced by ensuring that patients are cared for with dignity and respect.

For someone approaching the end of life, hope will likely be linked to having a good quality of life (Bit.ly/CareSearchHope).

Hope can come from reassurance that:
- Their relatives are prepared, supported and cared for;
- Their symptoms will be well managed;
- They will be able to die in their preferred place (Mendes, 2014).

Compassion
Compassion is expected of all nurses and should be reflected in the care they give at all times (Bloomfield and Pegram, 2015). By showing compassion, nurses can improve EOLC (rcnendoflife.org.uk) and enhance patients’ and families’ experiences (Bit.ly/NIA_EOLC).

Compassion can be demonstrated by communicating with respect, actively listening, regularly checking that patients are comfortable, giving regular mouth care, asking relatives and friends if there is anything they want the nurse to do, offering a hot drink – or simply being there (Westwood, 2010). Being present for patients and families is a key role of nurses in EOLC.

Empowerment
Another key role of nurses in EOLC is to ensure patients’ needs are met and their preferences respected, in accordance with the NMC Code (NMC, 2015). This states that: “We should encourage and empower people to share decisions about their treatment and care”.

This promotes autonomy and empowers patients to make decisions about their care. ACP is key in this regard, as it ensures patients’ wishes are elicited, heard and respected.

Family and friends
Support from family and friends is often extremely important to a dying patient, but most important of all is to respect the patient’s wishes about how much input they want from their family. Byock (2014) explains that patients who are dying often...
Spirituality
The thought of dying can be distressing and frightening. When patients are told they are near the end of life, various questions may go through their minds – “Why am I dying?”, “Why is this happening to me?”, “What will happen after I die?” – and they may look for answers or comfort in their religious and/or spiritual beliefs.

The National Council for Palliative Care highlights the importance of pastoral care (Bit.ly/NCPCSSpiritualSupport). Spiritual or religious beliefs can help patients make sense of their lives and find answers to their religious and/or spiritual beliefs.

In their role as patient advocates, nurses should assess and address patients’ spiritual needs and preferences (Sartori, 2010), giving them opportunities to prepare for death. Nurses should treat patients as unique individuals and be willing to learn about different traditions, religions and cultures. Discussions should be conducted in a sensitive manner, taking into account culture, spirituality and religion. Bereaved families will be comforted by the fact that their relative’s spiritual and religious wishes have been upheld.

Poster
We made the wish list into a poster that was presented at Queen’s Hospital in Romford (where we did our placement) during Dying Matters’ Awareness week in May 2016 (Bit.ly/DyingMattersMay). To embody the spirit of our wish list, we chose the image of a dandelion (Fig 1) to illustrate the poster.

The wish list poster was one of a number of posters picked by Jane Crussell, senior lecturer in adult nursing at London South Bank University, to feature on the stand. The EOLC team manned the stand in the hospital’s atrium so they could provide the public, patients and health workers with information about ACP and EOLC.

We spoke to the public, patients and health professionals about our poster, our reasons for designing it and our hopes of what it could achieve. Feedback was positive, professional healthcare workers and the public appeared open to the idea of talking about EOLC and saw the poster as a way of initiating these conversations.

Conclusion
Delivering good EOLC involves having sensitive and thoughtful conversations with patients and families about their wishes and preferences. Nurses need to be able to initiate, facilitate and be part of these conversations. They have a role to play in empowering patients, as well as in ensuring families have positive experiences of the last months and weeks of their relatives’ lives. As Dame Cicely Saunders et al (1995) explained: “how people die remains in the memory of those who live on”.

Our EOLC wish list can take the form of leaflets given to staff, patients, carers and relatives, or of posters up in wards to raise people’s awareness. We hope it can contribute in spreading the word about the importance of conducting ACP and encouraging open discussions, which is essential if we want to help patients at the end of life achieve a good death.

References
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