

In this article...

- Cicely Saunders' concept of 'being with' patients at the end of life
- Reflections of a respiratory nurse on caring for a patient with terminal illness
- Support and training needs of nurses in 'being present' for patients

Challenges of 'being with' patients nearing the end of life

Talking points

'Being with' means being deeply involved in accompanying someone in their journey towards the end of life

If we overlook patients' psychological needs, we are not caring for them holistically

'Being with' patients at the end of life is challenging and nurses may avoid becoming overly engaged

Barriers include outcome-driven environments, time pressures, lack of confidence, fear of confronting oneself with death and nurses' tendency to want to 'fix things'

To be present for their patients, nurses need clinical supervision and communication skills training

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Abstract Cicely Saunders revolutionised the care of patients at the end of life by ensuring their psychological and emotional needs were met and by putting 'being with' them at the heart of their care. Applying this concept in practice is often a challenge for nurses, for reasons ranging from lack of time and outcome-focused environments to lack of training, lack of clinical supervision and reluctance to give too much of themselves. In this article, the author uses her experience of caring for a patient with end-stage interstitial lung disease and intractable breathlessness to reflect on the challenges of 'being with' patients at the end of life, and how this can have benefits for nurse and patient alike.

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'Being with' has been defined as being deeply involved in accompanying someone in their journey towards the end of life (Saunders, 1976), and as a moment of engagement between a health professional and a patient "whereby the patient has the opportunity to examine and express their thoughts and feelings relating to their imminent death" (Haraldsdottir, 2011). It has also been described as "presence" (Patterson and Zderad, 1976) and as "bearing witness" (Arman, 2007).

This article examines what it means for nurses to 'be with' patients at the end of life, with the aim of improving nurses' understanding of that notion and helping them deliver good end-of-life care.

A patient with severe breathlessness

As a respiratory nurse, I cared for John Richardson, a 74-year-old man who had end-stage interstitial lung disease. There were no curative treatment options available to him and he was being cared for at

home. I supported him and his wife Faye during the last 18 months of his life, regularly visiting them at home. Several pharmacological and non-pharmacological interventions could not alleviate Mr Richardson's severe breathlessness, which constantly reminded him of his disease and impending death.

At the time, I felt that the purpose of my visits was to 'fix things' – for example, reduce Mr Richardson's symptoms by adjusting his medication, organise access to the local hospice or answer his questions. As his anxiety and breathlessness increased, I felt a growing sense of helplessness and failure. I struggled with the fact that I could not fix things and began to share the pain Mr and Mrs Richardson were feeling. This was deeply uncomfortable and made me question whether I had become too close to them.

At the time, I was not conscious of what 'being with' might mean for Mr Richardson. I felt that, unless outcomes measurably improved, my visits were somewhat futile. However, during my visits, I was

Clinical Practice Discussion

allowing Mr Richardson to share with me his thoughts and fears about death and dying. He told me – and so did his wife after he had died – that my visits were of tremendous value to him.

Caring for Mr Richardson was incredibly hard, but it also taught me a lot about myself, my role and the needs of patients at the end of life. It made me want to explore the concept of ‘being with’ so I could better understand it in the context of my nursing role.

New concept

In the late 1950s and early 1960s, the medical profession still considered death as a failure, and patients often died in immense physical, emotional and spiritual pain. Cicely Saunders, the founder of the modern hospice movement, revolutionised the care of people approaching death by providing them with adequate analgesia and holistic spiritual care, which transformed their experience.

Saunders was driven by a personal desire for being with patients at the end of life. During the Second World War, she had observed nurses who, faced with drug shortages, had little to give but themselves when caring for dying soldiers (Saunders, 1976). She put the nursing presence at the heart of end-of-life care.

Saunders’ model of care involves staff ‘being with’ patients and bearing witness to their ‘total pain’ (Saunders, 1976), facing potentially uncomfortable feelings and painful thoughts reminding them of their own mortality. Through ‘being with’, Saunders challenges health professionals to get more deeply involved with patients while accompanying them in their journey towards death (Saunders, 1996; 1984; 1976).

Avoiding behaviours

There is clearly a case in favour of ‘being with’ patients at the end of life, but it is challenging to do so in practice. Nurses may, consciously or not, avoid difficult conversations, opportunities to engage and situations perceived as stressful in a variety of ways; for example, by denying the seriousness of a patient’s illness (Kruijver et al, 2000), ‘hiding’ behind charts (Ersser, 1997), creating an overly cheerful environment (Haraldsdottir, 2011) or not asking difficult questions (Jarrett and Payne, 2000).

Haraldsdottir (2011) observed nurses caring for patients at the end of life in a Scottish hospice. She found that priority was given to maintaining efficiency, especially in the mornings, when practical tasks such as washing and dressing were

Box 1. Reflecting on practice

- How do you prioritise your patients’ needs? Do you tend to ‘fix the fixable’ first?
- When patients express negative thoughts, do you try to cheer them up or change the subject?
- Do you prioritise your practical skills over your communication skills?
- Do you feel adequately skilled to ‘be there’ for your patients? If not, what are your learning needs?
- Do you prioritise clinical supervision?
- Do you take time to reflect on how you are (or a colleague is) feeling when a patient dies?

prioritised over responding to patients’ psychological or emotional needs. If a patient expressed negative thoughts, nurses often changed the subject or put a positive spin on the situation. In the afternoon, patients were left either alone or with their loved ones, to give them quiet time and respect their privacy, so again no time was spent ‘being with’ them. Providing a light, cheery atmosphere protected nurses and patients from addressing the anxieties caused by death and dying. The nurses ensured patients were not left alone to die or were not socially isolated, but did not create opportunities for ‘being with’ them.

A similar task-oriented focus was observed by Dalgaard and Delmar (2008) among palliative care nurses caring for patients at home, in hospital and in hospices. However, nurses were able to respond to individual patients’ needs for a

friendly ear when they were less busy; shifting from ‘doing for’ to ‘being with’.

Nursing presence

Being present is a vital component of nursing care. Fahlberg and Rousch (2016) co-wrote an unusual article – Fahlberg being a cancer nurse and Rousch a patient – about the key qualities of nursing care at the end of life. Rousch explained: “It’s not what they do, it’s who ‘they are’ with me. It is the nursing presence that makes a difference [...] At 3am when scared and anxious about impending mortality, a nurse who just sits and listens and has presence can be the difference that won’t show up in any reports but may be the turning point” (Fahlberg and Rousch, 2016).

The nursing presence is intangible and difficult to measure, yet it is clearly of great significance to patients in such vulnerable moments. Fahlberg and Rousch (2016) allude to Saunders’ view that nurses need to understand that, even if they cannot take away the reasons for a person’s distress, they still need to acknowledge that distress and try to alleviate it: “We cannot take away the hard thing that is happening but we can help to bring the burden into manageable proportions” (Saunders, 1963).

As a nurse, I find this challenging, as there is always a strong temptation to only address what is ‘fixable’.

Out on the boundaries

Nurses who are willing to achieve presence and develop true therapeutic relationships are “being courageous” (Arman, 2007) and “out on the boundaries of professional practice” (Wright, 1998). Benner (1984) suggests that viewing a patient holistically,



rather than as a set of tasks, is what differentiates proficient or expert nurses from novices or advanced beginners. So, rather than being a soft skill, 'being with' patients is in fact an expert nursing skill.

'Being present' can be transformative for the nurse as well as the patient. Arman's (2007) ontological study concludes that the giving of self may enrich the inner life of both parties and bring a new understanding of life in the face of death and suffering.

This is supported by Figley (2002), who assumes the presence of vicarious trauma ("All of us who attempt to heal the wounds of others will ourselves be wounded") in vicarious transformation, whereby nurturing positive relationships strengthens our professional reserve. Saunders (1973) suggests our very feeling of helplessness may be what enables us to meet the patient on an equal level and come together.

"As his anxiety and breathlessness increased, I felt a growing sense of hopelessness and failure"

Barriers to 'being with'

There are many barriers to achieving presence in nursing. In today's pressurised health-care environments driven by measurable outcomes, 'being with' can be dismissed as a soft skill. Technological advances limiting physical contacts, lack of staff and time pressures can all contribute to reduce nursing care to a series of tasks (Robinson, 2014). Nurses want to offer solutions and are often more comfortable 'doing for' patients (that is, carrying out tasks for them) than 'being with' them.

Nurses may find the provision of emotional and psychological support a challenging part of their role, and lack confidence or competence in dealing with patients' expressions of emotional distress. 'Being with' can be painful and involves emotional labour (James, 1989). To be able to work unaffected by excess emotion and insecurity, nurses may resort to the armoury of bedside manners (Jourard, 1971). They may also feel that they lack the support they need – particularly through clinical supervision – to achieve presence.

Hospices remain sanctuaries where holistic care is central and relationships with patients are valued. However, even in these environments, there is evidence that nurses still avoid opportunities for 'being with' patients (Haraldsdottir, 2011). Not all nurses are willing or able to make themselves vulnerable by giving something of themselves in that way.

Nurses' needs

If we overlook the psychological care of our patients, we are not caring for them holistically. So what do we need to be able to apply Saunders' vision of 'being with' patients to our practice?

To gain new understandings and learn lessons from their difficulties, nurses need opportunities for reflection and peer support, ideally through clinical supervision, which ensures support mechanisms are in place. Clinical supervision might have provided more clarity on what I did well and what I could have done differently; helped me take new learning to new situations; and encouraged me to form meaningful therapeutic relationships with patients.

I intend to raise the importance of clinical supervision in our team, highlighting its value for reflection and consequent learning opportunities, facilitating an improvement in practice. We could increase the frequency of supervision, offer a combination of group or single supervision as well as use skills of colleagues in other teams for support (for example chaplains, psychologists or the hospice team).

Communication skills training can give nurses the confidence to be present for patients – moving away from task-oriented, 'safe' encounters. The SAGE & THYME communication skills model (Griffiths et al, 2015) provides a good framework for such training. Teaching nurses how to deal with emotional distress can help them gain confidence in dealing with their own emotions (Bailey and Wilkinson, 1998).

Enriched understanding

During the 18-month period of my visits to Mr and Mrs Richardson, I did not consciously think about the value of my relationship with them and how, over time, it had become therapeutic in its own right. I never considered that, merely by being present, I would bring comfort and peace. Likewise, I did not realise that, beyond the emotional cost for myself, there was also a potential for transformation.

Without unpicking the situation, all you experience is the emotional cost. After personal reflection, I realised why I felt so uncomfortable, and I can see that my presence had great therapeutic value and how the relationship was beneficial to the three of us. Me bearing witness to their suffering gave them existential meaning, and enriched my understanding of this incredibly important part of end-of-life care. **NT**

● The names have been changed to protect the patient's confidentiality.

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