

# Death, dying and emotional labour: still relevant after all these years

by Daniel Kelly (FRCN 2016)



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**T**he paper I have chosen to underpin this article is now 20 years old and was written following a clinical career in acute oncology, hospice care, as well as supporting young people with AIDS/HIV. In each setting I had witnessed how challenging it was to introduce palliative care when active treatment and cure were the main focus.

As a result, I developed an interest in what happens when (usually younger) people are

dying in places we would think of as high-tech settings. This influenced other research that I undertook with children and young people undergoing cancer treatment, most of whom were seriously ill and some of whom faced the transition to end of life care. Some of this work is referred to below.

The paper also acquired renewed relevance in 2020 in the context of the COVID-19 pandemic and the high mortality rates in people admitted for intensive care.

## Death, dying and emotional labour: problematic dimensions of the bone marrow transplant nursing role?

### Abstract

Bone marrow transplantation (BMT) is an established intervention for a range of conditions, including those of a serious, life-threatening nature such as leukaemias. The experience of those who fail to respond to such aggressive treatment, however, or those who die as a result of treatment-induced complications, remains under-researched. In this paper, we argue that despite the relatively high mortality associated with BMT, cultural, biological and professional factors contributed to a lack of attention to issues of death and dying and emotional labour in BMT settings.

Technological, biomedical and quality of life discourses that characterise much of the BMT literature are problematic and, we argued, serve to disadvantage those who will not survive such procedures. In addition, the provision of effective palliative care in BMT settings remains open to review through further research and development. As a first step, we argued that the role of nursing needs to be reconceptualised in BMT to allow key humane concerns such as suffering and the emotional labour of care to be explored and better understood.

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### Introduction and background

The way death and dying are managed in hospital settings has interested me since my earliest days of working in oncology as a newly registered nurse in Edinburgh. I had witnessed many patients undergoing aggressive cancer treatment only to succumb to their disease

eventually, and I became aware of the impact that this situation could have on the clinical staff around me, hence the link with emotional labour. At the time, I had read about this as a concept developed by the sociologist Arlie Hochschild in her book *The Managed Heart* (1983). In daily practice, I was struck by the

### Acknowledgement

The publication that started this career-long interest has been cited well and has stood the test of time. I must also acknowledge my colleagues Pam Smith, Sharon Ross and Ben Grey who contributed to the original paper and helped to shape its content

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emphasis placed on effective communication by all members of the oncology team. I had also seen this approach espoused in other clinical areas, of course, but in oncology this seemed to be more overt and it had a powerful impact on me and probably shaped my whole career.

The culture of oncology seemed less hierarchical and nurses were valued and their views about patients were heeded. This was not always the case in other clinical areas where I had worked. I can still recall conversations with certain patients, often young, who were referred to our unit having already undergone extensive cancer surgery. They were being admitted to our medical oncology unit to receive aggressive chemotherapy and radiotherapy, sometimes high dose with bone marrow rescue. There were several complex treatment regimens that we administered intravenously which could last for several weeks and most, to varying degrees, were associated with side effects that affected all aspects of life: hair loss, severe mucositis, debilitating nausea and vomiting, unrelenting diarrhoea, as well as neutropenia and the associated life-threatening risk of sepsis.

I began working with Pam Smith in 1999, who was then based at London South Bank University, when I was appointed to lead nursing research at University College London NHS Trust. She had a long-standing interest in emotional labour, and we agreed to join forces with colleagues who were also interested in the unmet support needs of patients undergoing BMT for leukaemia. We sat down and shared data from a study that she was working on concerning the emotional demands of nursing, which had included nurses working in BMT settings (Smith and Grey 2000).

The result was a partly polemical paper that sought to argue against focusing only on the technical aspects of disease and treatments (such as the emphasis placed on daily blood counts) to the detriment of emotional support. The main argument was that nursing in such high-tech environments should be reconceptualised to acknowledge more openly, the impact of high patient mortality rates on the emotional needs of patients and families, and also the impact on nurses, who must present a face that all is well (Kelly and Smith 2016). As the one group of professionals who work most closely with such patients over prolonged periods of time, nurses witness death and loss on a regular basis. We argued that the focus on technical skills alone risked

overshadowing the need to focus on humane or empathic dimensions of care, but we also emphasised the centrality of nursing overall (Kirby et al 2014).

If emotional support remained an unrecognised dimension of the nursing role, we suggested that the nursing role had become 'problematic' and the culture of high-tech settings should be questioned to allow new insights and ways of working to be developed.

### Influence and impact

I remember that the paper caused quite a stir at the time as some thought we were criticising expert colleagues. I sent copies of the paper to the haemato-oncology unit and offered to present it at seminars, and could quickly see by the reaction of some colleagues that there were issues they recognised as relevant.

Over the years, the paper has continued to be cited and I have been invited to address the topic on several occasions with haemato-oncology professionals, most recently in Adelaide in 2015. I believe this paper did strike a chord and the questions we raised have not gone away. This is despite the improvement in cancer treatments over the past 20 years with stem cell transplants, haematopoietic growth factors and a growing range of new, targeted agents improving clinical outcomes. However, some cancer diagnoses, such as pancreatic cancer or acute myeloid leukaemia, remain challenging in terms of cure, and mortality rates remain high. In this context, the central message of the paper remains pertinent.

Empathy and relational approaches to end of life care, wherever such care is provided, are fundamental to patient-centredness. A recent systematic review and meta-analysis demonstrated that empathic consultations can have positive clinical benefits, including the reduction of pain and anxiety levels and the enhancement of patient satisfaction (Howick et al 2018). Therefore, our argument for better awareness of these aspects of nursing care has endured and there now is a more solid evidence base on which to develop innovative practice.

In the paper, we also referred to the work of Isabel Menzies-Lyth (a social scientist and psychoanalyst) who focused on nursing in her research, and described the instincts evoked through close contact with seriously ill or dying people with what she called 'primitive' anxieties: 'Nurses are confronted with the threat and the reality of suffering

and death as few lay people are. Their work involves carrying out tasks which, by ordinary standards, are distasteful, disgusting and frightening' (Menzies-Lyth 1988).

One of the arguments we made was that increasing detachment from such anxiety-provoking events can lead to decreased levels of empathy (Haque and Waytz 2012). This has implications for the quality of a patient's experience and suggests that healthcare professionals may need to adapt and balance some degree of emotional detachment with empathy to benefit themselves and their patients. There is known to be a link between levels of emotional burnout and empathy in health professionals (Wilkinson et al 2017). For nurses who care for the acutely ill people and do not 'regulate' their emotional distance from patients, too much empathy is also a key risk factor for emotional burnout (Firth-Cozens and Cornwell 2009).

Our main call at the time was for more attention to be paid to these issues in high-tech environments, and for more awareness and research to be devoted to them by nurses. It is pleasing to see the evidence that has been added to what was a limited evidence base.

The original 2000 Journal of Advanced Nursing paper led to other research on end of life topics that I have returned to over the years, including one that explored the transition to end of life for children undergoing treatment for leukaemia (Nelson et al 2017). This project attracted particular attention and was featured in Nursing Standard, emphasising the emotional aspects of the process for children, families and healthcare professionals (Trueland 2017).

I have also written more about the needs of adolescents and young adults facing the end of life (Kelly et al 2012). Other projects have focused on children with leukaemia and how to carry out research into their communication and emotional support issues in clinical settings (Bryan et al 2019). I have also conducted systematic reviews (Edwards et al 2014) and was invited to join other teams doing similar work (Williams et al 2011). I produced additional papers on different aspects of the same issue, including treatment futility in intensive care (Kelly 2005) and the emerging culture of specialist oncology services for young people (Cable and Kelly 2019).

In 2004, I published an ethnographic evaluation of the first specialist unit that had been established for adolescents with cancer in the UK (Kelly et al 2004). We set out to

describe the emotional component of care carried out in what was then, a unique age-appropriate setting. This work was cited by the Teenage Cancer Trust in their Blueprint of Care to guide future service developments, including end of life care standards (Teenage Cancer Trust 2012). I also produced an editorial on the controversial topic of euthanasia for young people as a result of the law being changed in different countries of Europe (Kelly 2014).

### **Current and future relevance**

The original Journal of Advanced Nursing paper that examined the link between death, dying and emotional labour captured the situation as I saw it in 2000. It built on my own clinical experience as well as those colleagues I had heard talking about their workplace, where patients died but the provision of emotional support could be less than optimal. This was not because people did not care about what was happening, but often because the culture of where they worked was difficult to change.

In the intervening years there have been ongoing calls for better integration of supportive and palliative care into intensive cancer treatment services. In haematological cancers especially, there are still challenges to be overcome and medical specialists continue to call for more service innovations that can actually work successfully in the clinic (Niscola et al 2018). The way people with cancer are treated (in an emotional sense) is now considered a key component of healthcare quality, alongside patient safety and clinical effectiveness. This provides us with new ways to 'problematise' the everyday work of cancer nursing and to question whether and how the emotional needs of patients can be met in services that are increasingly under strain. The voice of nursing must be central to shaping future developments.

Fast forward to the pandemic situation of 2020 where COVID-19 has meant that deaths in hospitals have had to be managed on a massive scale in intensive care settings around the world. The challenge from our original paper to recognise the emotional labour and supportive dimensions of nursing when caring for people who are severely ill has not diminished, but has instead become even more pertinent.

We have witnessed unrelenting pressures on nurses and healthcare teams working with COVID-19 patients that have magnified the need for humane support, especially when

families had to be excluded from the final hours of a loved one's life. The images on our TV screens of clinical staff covered from head to foot in personal protective equipment serves to emphasise the need for the human touch, and there were many accounts of this provided by nursing colleagues. In this, the International Year of the Nurse and the Midwife, we can

take considerable pride in the accounts of colleagues who have actively engaged in the emotional labour of end of life care by supporting each other, as well as patients and their families, regardless of where they work. It is our responsibility to ensure that they, in turn, receive the recognition and support that they deserve.

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