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Specialist palliative care nursing and the philosophy of palliative care: a critical discussion

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Introduction

Historically, palliative care nursing has been informed by a strong philosophy of care (Matzo et al., 2015) which is soundly articulated in palliative care policy, research and practice. However, over the past decade there has been a change in the way in which palliative care is provided in developed countries (Clark et al., 2015). These changes have included the increasing medicalisation and specialisation of palliative care (ibid), as well as the integration of palliative care into 'mainstream' health care services with a broadening of how, where and to whom palliative care is provided (Llamas et al., 2001, Buck, 2012).

Mainstream health care is arguably still dominated by a biomedical model which assumes that all illness is caused by a single pathology and removal or management of the pathology will result in an individual's return to health (Wade and Halligan, 2004). Embedding palliative care into this model may lead to a fractional approach to patient care that fails to address the wider ramifications of health and illness, namely the psychological, emotional and spiritual aspects of a person (ibid). At the same time, definitional changes in terms of what constitutes 'palliative care' (Pastrana et al., 2008) have resulted in a re-definition of the cohort of patients considered to have 'palliative care needs', from those with a 'terminal' cancer who may be in the last few weeks of life, to those with life limiting illnesses (including those with a non-cancer diagnosis) with a range of prognoses (Seymour, 2012). Furthermore, changing patterns of disease and dying relating to improved treatment modalities and ageing populations (Gott and Ingleton, 2011) are presenting new challenges not only to the technical aspects of palliative care nursing, but also to the organisational aspects of care provision (van der Steen et al., 2017). For example, expanding the remit of palliative care to include all life limiting illnesses has required services to be flexible and responsive to different illness trajectories, identifying new models of palliative care that will better meet the needs of patients with a non-malignant illness (Lewin and Schaefer, 2017). In addition, research has demonstrated the value of introducing palliative care earlier in the illness trajectory with significant improvements seen in patient's quality of life compared with patients receiving standard care (Temel et al., 2010, 2014a). All of these recent changes have resulted in a significant broadened focus of activity in the practice of palliative care leading to a disconnect between policy and practice (Gott et al., 2012) and confusion about the scope of palliative care internationally (Pastrana et al., 2008).

To understand contemporary trends, it is helpful to consider the history of palliative care development. Palliative care initially positioned itself as an alternative to the highly technological approach to dying that predominated acute hospital care (Clark, 2008a). In response, through the work of Cicely Saunders and the modern hospice movement, a unique philosophy of care for the dying outside the hospital setting was developed (Clark, 2008b). However, in more recent times it has been argued that the dominance of the biomedical model has led to the overmedicalisation of death and dying and an erosion of this unique palliative care philosophy. (Clark, 2002) In order to be accepted as an authentic area of medicine in mainstream healthcare, the development of 'specialisation' in palliative medicine was inevitable, and this specialisation has been underpinned by a biomedical approach to health and illness (Clark, 2002). In a similar fashion, palliative care nursing has embraced a model of specialist practice and knowledge which has become distinct from other areas of nursing (*A national professional development framework for palliative care nursing in Aotearoa New Zealand*, 2014; Canning et al., 2005). However, only a minority of people worldwide are in a position to access palliative care provided by a dedicated, specialist service (Rosenwax et al., 2016). Therefore many resource rich countries have adopted the World Health Organisation (2002) focus on the integration of palliative care principles into mainstream health care into their health policies (*Global Atlas of Palliative Care*, 2014), advocating that both medical and nursing clinicians should have the required skills and knowledge to provide a palliative care approach.

This has focused attention onto developing skills and knowledge in palliative care through undergraduate and post graduate programs, although there is global variation in terms of palliative care content in these programs (Wallace et al., 2009, Dickinson et al., 2008). However, in addition to formal education, guiding nurses in their practice is the strong philosophical framework which articulates the assumptions and values that underpin the discipline. Moreover, in practice, nurses work within a professional hierarchy of disciplines and are challenged by the professional boundaries inherent in many clinical settings which impacts on patient care (Powell and Davies, 2012, Gott et al., 2011)

It is within this context that the aim of this paper is to explore the challenges for nursing as a result of the evolving model of palliative care. By highlighting these challenges, this theoretical critique will enable nurses to reflect on opportunities to provide care that best meets the needs of patients with a life limiting illness.

Data Sources

This discussion paper is based on a critical reflection of the authors own experiences working in palliative care and is supported by literature and theory from seminal texts and contemporary academic, policy and clinical literature. An overview of both the philosophical influences on nursing knowledge and theory and the practice philosophy of palliative care will be provided. Finally, a discussion on how these two philosophical frameworks intersect will be provided in order to highlight the role of nursing and its contribution to patient care within a palliative care context.

Nursing knowledge and theory

The development of nursing knowledge has been influenced by a number of different philosophical frameworks (Cull-Wilby and Pepin, 1987). Through the early part of the 20th century nursing borrowed from the mechanistic biomedical model of knowledge development. However some have argued that scientific knowledge which focuses on ascertaining an “objective reality” is insufficient to support the complexity of nursing practice (Rutty, 1998). In an attempt to move away from a nursing model based of bio-medically derived reductionist principles, nursing theorists conceptualised what is referred to as the ‘aesthetics’ or art of nursing.(Carper, 1978) The use of intuition, personal knowing and ‘tacit’ knowledge provided a foundation to understand the meaning of the illness for an individual patient in a social context (Kennedy, 1998). Nursing began to place value on the human experience of illness and the unique meaning placed on that experience by an individual. Furthermore, the acquisition of skills and knowledge integrating these concepts (Benner, 1984) also influenced the development of nursing.

Carper’s theory: “Fundamental Patterns of Knowing in Nursing” aligns well to palliative care which some may argue requires practitioners to encompass both the art and science of practice (Costello, 2015). Carper describes four ways of knowing in nursing: empirics, ethics, personal and aesthetics (Carper, 1978). The pattern of empirical knowing includes verifiable knowledge derived from subjective and objective data and is considered to be the science of nursing. Ethical knowing describes the moral obligations and values of the discipline and personal knowing the interpersonal connection between nurse and patient. Finally, the aesthetics of knowing is the nurse’s perceptions of what is considered significant in a person's behaviour, also known as the art of nursing. Carper's work places equal importance on theoretical knowledge (science) and knowledge which is gained through clinical experience (art).

The philosophical framework in Carper's work acknowledges the acquisition of knowledge as being both theoretical and experiential. In addition, value is placed on learning that occurs as a result of the patient-nurse relationship adopting a more holistic view of knowledge development. This combination of evidence based care and values based practice provides a philosophical framework that guides nursing practice (Cody, 2013).

Palliative care philosophy

The philosophy of palliative care has been largely defined by the modern hospice movement and more recently articulated in the World Health Organisation (2015) definition of palliative care. Palliative care adopts an holistic approach to care that is attentive to the "the suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles" p576 (Ong, 2005). The overall aim of this approach to care is to achieve what has been described as the 'good death'.

A good death in Western society is considered to be a death with dignity, awareness, peace, adjustment and acceptance (Kehl, 2006, Holdsworth, 2015). However, the conceptualisation of what constitutes a good or bad death is obviously influenced by a person's beliefs and values. For health professionals, these values and beliefs and their relationship to patient care are also influenced by the culture in which they work, which varies between care settings (Clark, 2012). For example, a study by Costello in 2006 found that nurses' working in a hospital setting constructed good and bad death experiences around the death event itself rather than the dying process. For example, death which was unexpected or where there was a perceived lack of time for preparation and connection with family were considered 'bad deaths'. By contrast, a 'good death' was one which was expected, families were aware and distressing symptoms were absent (Costello, 2006). In contrast, a 'good death' in a hospice context is said to focus more on the 'journey of dying' integrating an open awareness of dying, open communication, and eventually an acceptance of death and settling of "personal business". In order for these to occur a person's pain and suffering must be relieved (McNamara, 2004). Whilst the construction of a good or bad death continue to be used in healthcare and throughout society, the way in which death is viewed has been dominated by a Western model of health care which is dominated by individualism, secularism and medical sciences (Bradbury, 2000). This is not the case in many non-Western societies where faith, religion and a community based approach to decision-making at the end of life may dominate (McLaughlin and Braun, 1998). Indeed, these sociological and cultural factors are likely to influence not only the perception of a good death, but also the way in which patients are cared for at the end of their life as we see an increasing diversity of ethnicity in the nursing workforce.

A strong philosophy of care which is embedded in the concept of a "good death" continues to inform the development and practice of palliative care nursing. However, nursing comes to this area of clinical practice with an equally strong discipline based philosophy of care.

Nursing and palliative care: a critical reflection

Nursing had a pivotal role in caring for dying patients in the early days of the modern hospice movement and was influential in supporting the development of a unique philosophy of care. (Clark, 2008b) Unlike medicine, nursing responded enthusiastically to the early work of Cicely Saunders, expressing concerns about dying patients being ‘abandoned’ by doctors and ‘ignored by society’ (ibid). The response to Saunders work was thought to be as a result of nurses’ perceptions of the ‘over medicalisation’ of death in the hospital setting and the use of ‘futile’ medical interventions to prolong life (Zimmerman and Rodin, 2004). Indeed, the medicalisation of death and dying proved a key driver for the development of modern hospices, which enabled patients to be taken out of mainstream health care in order to place them in an environment which maximised the likelihood of a good end of life experience (Clark, 2008a). The less medicalised environment of the hospice, with a focus on ‘care’ rather than ‘cure’, led hospice nurses to became central to the provision of hospice care. The notion of caring features strongly within a nursing philosophy and is considered by some to be the essence of nursing practice (Watson, 2003). A meta-synthesis on the process of caring concluded that caring is a “…context specific interpersonal process that is characterised by expert nursing practice, interpersonal sensitivity and intimate relationships” p202 (Finfgeld-Connett, 2007). Some have suggested that this core value within nursing fits easily with the philosophy of palliative care (Floriani and Rolland, 2012) and is the reason why nursing has made such a significant contribution to the development of a strong practice philosophy in palliative care.

The ‘holistic’ approach to care that hospices adopted early on in their development, focusing on ‘integrating the psychological and spiritual aspects of patient care’ has become a key component to their practice philosophy (Clark, 1998). Indeed, addressing issues such as hope, meaning and spirituality are now considered to be essential in caring for those facing the end of their life (Edwards et al., 2010). Literature suggests that a relationship based on trust provides a foundation to address sensitively existential issues (Boston et al., 2011). This requires a therapeutic relationship between the patient and nurse which is based on values such as compassion, respect, empathy and self-awareness. This philosophical approach to the caring relationship fits well with Watson's theory of human caring(Watson, 1988). Watson describes the "transpersonal caring relationship" which exists between the patient and the nurse. This relationship is used to foster faith and hope based on the patient's belief systems. Furthermore, it facilitates the patient's expression of emotion through authenticity, empathy and warmth (Watson, 1988).

However, the routinization and medicalization of hospice care has arguably resulted n a "surveillance and control of the process of dying" (Floriani and Rolland, 2012) which compromises the principles of holistic palliative care. A number of factors have influenced this paradigmatic shift. Firstly there have been increasing technological advances in medicine with more interventions available to relieve pain and suffering related to an end of life illness (Lagman et al., 2007). Secondly, with an expansion of palliative care to include all those with a life limiting illness (not just those with cancer) there is an increasing complexity of the illness trajectory (Murray et al., 2005). Finally, integrating palliative care early in the illness trajectory and extending it beyond just 'terminal care' has required more integration with mainstream health services, many of whom remain embedded in the biomedical model of service delivery (Floriani and Rolland, 2012). This integration into mainstream services may create some challenges. For example, in the hospital setting where a biomedical model dominates, maintaining an approach to care that recognises the value of nursing is known to be problematic (Gott et al., 2011). Secondly, the philosophy of care in hospital tends to focus on cure and prolonging life which can result in tension between a more "care based" approach seen in nursing and palliative care. Finally, the philosophical principles that underpin the medical model may not always align well with a nursing framework. For example, the reductionist approach to patient care which is inherent within the medical model (Beresford, 2010) has the potential to create tension between what has been described as the art and science of nursing (Costello, 2015). It could be argued that the art and science of palliative care nursing is particularly vulnerable to being eroded by this reductionist approach to patient care. For example, it has been suggested that whilst the 'science' of symptom control has advanced significantly over the years, the 'art' of nursing, such as communication skills based on compassion, empathy and genuine kindness, are less well developed in palliative care nursing (Costello, 2015). These skills are an essential component in the care relationship, however a recent report into complaints about end of life care in UK highlighted failings in communication in almost all cases (*Dying without dignity*, 2015).

With increasing integration into mainstream healthcare, palliative care is now considered to be integral to all clinicians practice regardless of their clinical setting (2014b). However, the split between generalist and specialist palliative care can be problematic, with continuing debate about remit, roles and boundaries (Firn et al., 2016) (Gardiner et al., 2012). Although specialists in palliative care may be well positioned to manage patients with the most complex needs, there is a risk in specialists being called upon to see all patients with palliative care needs. This risk includes the potential deskilling of the non-specialist workforce (Gott et al., 2011), inability to meet patient need as demand outstrips resources, and ultimately to fragmented care as yet another provider becomes involved in the patient's care (Quill and Abernethy, 2013).

Specialisation in palliative care has also been influential in the development of specialist palliative care nursing roles which require a different set of skills and knowledge. For example, advanced clinical skills, diagnostic reasoning and prescribing skills are required for advance practice roles such as the nurse specialist and the nurse practitioner. These roles have become embedded into the delivery of palliative care in many countries (Sheer and Wong, 2008). For example in the United Kingdom the Macmillan nurse role has been well established as a nurse specialist in palliative care having clinical, consultative, educational and research responsibilities (Ingleton and Larkin, 2015). A review of these roles in 2002 found that as a result of changing models of cancer care and the rapid introduction of new nursing roles, there was a need to clarify the scope of the role in order to use their expertise most effectively (Seymour et al., 2002). Over recent years there has been an increasing interest in developing advance practice roles that focus more on clinical assessment, diagnostic reasoning and prescribing, traditionally the domain of medicine. Evidence has shown that advanced practice roles such as nurse practitioners have improved patient outcomes with greater satisfaction in care, improved patient health and better access to health care services.(Horrocks et al., 2002, Charlton et al., 2008) However, some have suggested that advanced practice roles in nursing are developing in such a way that they are more aligned with the biomedical model and are criticised by some as being a medicalization of the nursing profession (Mantzoukas and Watkinson, 2006). Furthermore, one could argue that advance practice nursing roles contribute to the criticism that palliative care is suffering from an 'over specialisation' and 'over medicalisation' approach to death and dying (ibid).

This reductionist approach to nursing practice suggests an ongoing focus on knowledge development that is still based largely on a biomedical framework. Reductionism is said to be the opposite of holism and can be defined as a "deconstruction of a complex process in to component parts to enable better comprehension" (Beresford, 2010). Whilst acknowledged as a useful approach at times, reductionism has its risks. Beresford argues that reductionism oversimplifies a process reducing a phenomenon to its parts resulting in a disassociation from the phenomenon. Although the context of his argument is in the biological treatment of disease, the same could be true in palliative care. For example, ignoring emotional and psychosocial aspects of pain is known to cause a barrier to the treatment of physical pain and this is outlined well in Cicely Saunder's concept of "total pain". (Mehta and Chan, 2008)

Whilst the over-emphasis on knowledge which is informed by a biomedical model does not always sit easily within the palliative care philosophy, the empirical knowledge required to understand the pathology of illness, while at the same time understand the impact of the illness on an individual person, their family and society addressing the emotional, spiritual and psychological aspects of care, in many ways reflects the true philosophy of palliative care. As Cicely Saunders stated “You matter because you are you. You matter until the end of your life” suggesting an emphasis on recognising the uniqueness of every individual. However, she also acknowledges the dichotomy of caring stating “In the hospice movement we continue to be concerned both with the sophisticated science of our treatments and with the art of our caring, bringing competence alongside compassion”. (Saunders et al., 1981) p4

Nursing theory which is embedded in a discipline specific practice philosophy integrates well both the art and science of nursing. However, this creates a level of epistemological uncertainty and is thought by some to be a threat to the integrity of nursing knowledge (Pitre and Myrick, 2007). However, the division of polarised discourses such as qualitative and quantitative, art and science, positivism and constructionism fails to reflect the epistemological reality of nursing practise. Indeed, managing the science or certainty of death whilst responding to the multiple realities of patients and their families as they perceive, experience and interact with their own illness and death, requires clinicians to engage with multiple paradigms within their practice.

We would therefore argue that, in order to integrate both the “art and science” of nursing, an approach that embraces multiple paradigms is needed. “Reciprocal interdependence” is thought to be an alternative way of knowing in nursing that is able to integrate differing world views into a comprehensive whole (Pitre and Myrick, 2007). Pitrie and Myrick (2007) state that “the parts comprising the whole and the whole composed of parts interrelate to create growth and transformation within the realms of nursing practice, science, and philosophy rather than the division of polarized discourses “ (p81). Differing world views existing together through a reciprocal process of understanding contributes to a greater truth than each one alone (Pitre and Myrick, 2007). This is the challenge moving forward for palliative care nursing.

Conclusion

This critical discussion paper has explored nursing philosophy and discussed how this can align or conflict with a palliative care philosophy. The 'art' of palliative care nursing can be seen in the value placed on the unique illness experience which is clearly supported by nursing theory. Equally the 'science' of nursing is evident in the required knowledge of pathophysiology and the skills required to critically assess patient needs across all domains of care: physical, psychosocial, emotional and spiritual. Nursing theory supports this mix of art and science in nursing knowledge and practice.

However, it could be argued that at times specialist palliative care nursing is in direct conflict with the changing environment of contemporary palliative and end of life care which is now integrated into mainstream health care in many developed countries. Indeed, the philosophy of palliative care which considers the person as a unique individual within a social context requiring a 'total care' approach, may be at risk of being eroded by the over medicalization and specialisation of palliative care. With increasing medical technology available to manage distressing symptoms, it could be argued that clinicians are at risk of becoming overly focused on the physical response of the body to the disease, to the detriment of psychosocial, emotional and spiritual aspects of care.

Nurses are in a pivotal position to strengthen partnership working between providers across range of care settings, with positive outcomes for patients (Firn et al., 2016). However, nursing needs to continue to adapt and respond to the changing needs of the patients and their families in a rapidly changing healthcare environment. Nursing is in a unique position to apply new advanced clinical skills and knowledge originating from a biomedical model of health and illness, within a holistic model of care. The challenge is to not view these as polarising practice paradigms, but as complementary approaches that when used together can achieve better outcomes for patients and families. Understanding how this may occur will ensure that nurses remain responsive to the changing environment of palliative care.

Conflict of Interest

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