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Institutional geographies in dying: Nurses' actions and observations on dying spaces inside and outside intensive care units

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ABSTRACT

This paper articulates the geographies associated with intensive care nursing work with dying patients and their families. Six focus groups were conducted with 27 registered critical care nurses who practice in hospitals in a mid-western city in the United States. The analysis is structured by three emerging themes (i) the importance of a 'good' and 'sacred' place, (ii) the body as mapped by medical specialties, and (iii) problems with procedurally driven suspension of 'do not resuscitate' orders beyond intensive care units (ICUs). Recommendations describe the need for institutional recognition of the moral importance of strong relationships between nurses, clients, and their families, and nurses' wide-ranging roles in bridging the various spatial domains of intensive care.

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1. Introduction

Previous decades have witnessed many changes in the care of dying patients in the United States: the development of advance directives, durable power of attorney, a heightened sensitivity to issues of informed consent, the development of palliative care, and ethical guidelines (Trough et al., 2001, American Association of Critical Care Nurses, 1999). Innumerable studies (Critical Care Medicine: Improving the Quality of End-of-Life Care in the ICU, 2006; SUPPORT Principal Investigators, 1995) costing millions of private and government dollars have been spent to examine different models of care. In particular, the last decade has seen an increasing concern for the care of dying patients specifically in intensive care units (ICUs). This is reflected in the increasing body of literature and professional society guidelines on dying in intensive care. (see for example, Mularski et al., 2006; American Association of Critical Care Nurses, 1999, www.AACN.org). A major reason for this interest has been the high and increasing number of deaths in ICUs. More than 5 million patients are admitted annually to ICUs in the United States (Society of Critical Care Medicine, 2006). Mortality rates have

increased in the last 12 years from a low of 12% in 2000 (Young and Birkmeyer, 2000) to 10–20% in most hospitals in 2010 (Frontline, 2010, 'Facing Death', November 10, 2010).

Dying in ICU poses challenges to staff because ICUs were specifically designed with an opposite objective in mind; to avoid death (Fairman and Lynaugh, 1998). Avoiding death in ICU today is increasingly difficult since those admitted are more often seniors with multiple co-morbidities (Kaufman, 2006). Life sustaining treatments such as cardiac and renal interventions are routinely initiated in ICUs. Paradoxically, whereas death used to occur in these spaces as the result of failing to do cardiopulmonary resuscitation (CPR), death now occurs in them as a result of actively withdrawing interventions (Prendergast and Luce, 1997; Prendergast et al., 1998).

The purpose of the study was to increase understanding of the ways in which intensive care nurses (in many countries also named 'critical care nurses') work with dying patients and their families. The major finding is an illustration of the three ways in which space was central to the dying body and the dying process in ICU. First, is the way in which imminent death signals a change in the purpose of space from ICU (where the goals are directed at life saving measures) to a 'sacred space' deemed more appropriate for dying a 'good death.' Second is the mapping of the body onto medical spaces that reflect medical knowledge and practice on body systems. The division of medical work makes specific physicians in specific spaces responsible for specific body parts

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while no one is responsible for the embodied whole patient. Third, space is tied to medical practices that interfere with patient requests to not initiate resuscitation. As a result, desired trajectories of dying are potentially altered.

2. Connections and contributions to geographical literatures

2.1. Geographies in death and dying

Death and dying have been longstanding concerns across a number of sub-disciplines and empirical fields of human geography. Studies in population geography at cross-national, national, and regional levels have described distributional patterns and inequalities in mortality. They have also explained the factors which contribute variously to these patterns including disease, deprivation, and population movement (Brimblecombe et al., 1999; Smallman-Raynor et al., 2002; Boyle, 2004; Garrett and Ried, 1995; Root, 1999; Gupta and Baghel, 2000; Kuate-Defo and Diallo, 2002). Although understanding these trends and responding to them effectively is critical to health service planners and policy makers (who arguably 'care' about them), in this research death and dying is merely a statistical event; each death being a data point potentially locatable somewhere on a map. This is not a criticism but more inevitable with this form and scale of analysis.

Social and health geographers have explored death and dying processes in greater depth, and the various roles that space and place plays in these. In social geography, geographies of aging have for example, explored the places where the oldest old spend their last years including hospitals, nursing homes, residential, and assisted living environments and homes/houses (see Cutchin, 2003; Andrews et al., 2007, 2009). Although not always explicitly concerned with dying, this research focuses on a range of factors – including designs, choices, and caring practices – that might make one's final place as positive an experience as possible. In health geography, the work of a number of scholars has focused on places of death (Brown and Colton, 2001) and more specifically palliative care in a range of settings including homes, hospices, and hospitals (Williams et al., 2001; Castleden et al., 2010). Structural issues with regard to this particular specialty are a common consideration in research including local needs and demands (Williams, 1999), service initiatives and roles of not-for-profit agencies (Williams et al., 2001), centers for training and expert delivery (Cinnamon et al., 2009), and local barriers and opportunities to services, and support benefits (Crooks et al., 2007; Giesbrecht et al., 2009, 2010). Although many valuable insights into dying have been provided in health geography, there are two notable gaps in the existing literature that are, at least in part, addressed by the current study. First, few studies have focused on places and services which are not designed specifically for dying, that is, dying in non-palliative institutional settings, including ICUs. These sites of dying require further research. Second, despite a focus on death and dying, most studies are focused on structures and, unlike this study, few are focused intimately on peoples' place—experiences, practices, and identities (see Andrews and Evans, 2008).

2.2. Geographies in nursing

In addition to making contributions to the geographical literatures outlined above, the study adds to an emerging body of research conducted and published predominantly by nurse researchers on their own profession, known as 'geographies of nursing.' (see Andrews, 2006; Carolan et al., 2006; Andrews and Evans, 2008). Re-focusing the core professional practice concept

of 'nursing environment' (Thorne et al., 1998; Andrews and Moon, 2005), studies have provided an understanding of how nursing relates dynamically to spaces and places, particularly as socially and culturally defined (see Kearns, 1993). Geographies of nursing constitute an important allied development to mainstream sub-disciplinary health geography illustrating how critical, qualitative research can include, not only a focus on health, but also a focus on the finer details in the production of health care (Andrews, 2006; Andrews and Shaw, 2008).

Five broad interrelated categories of geographical studies of nursing have been identified by recent reviews (see Andrews, 2006; Andrews and Evans, 2008; Andrews and Shaw, 2008). First, there are those studies that, without engaging directly with clinical practice itself, map important spatial contexts to practice such as the challenges of physical environment, urbanicity, and rurality (Hodgins and Wuest, 2007; Skelly et al., 2002; Moss and Schell, 2004). This research produces geographical 'evidences' on the periphery of clinical practice, yet can still inform the advancement of clinical practice at a planning, service level (Andrews and Shaw, 2008). A second group of studies considers place as a key factor in the production and translation of clinical evidence (Hodnett et al., 2005; McKeever et al., 2002; Sidani and Braden, 1998; Andrews et al., 2005; Andrews and Shaw, 2008), whilst a third and very specific empirical focus of attention has been on the nursing workforce and specifically on nurses' career movements at local, national, cross-national, and international scales (Brodie et al., 2005; Radcliffe, 1999; Pratt, 1999; Kingma, 2006). A fourth group of studies describes the ways in which places reflect and impact upon nurse–patient and professional relationships (Liaschenko, 1994, 1996, 1997, 2001, 2003; Peter, 2002; Peter and Liaschenko 2004; Cheek, 2004; Gilmour, 2006; Purkis, 1996; Malone, 2003; Halford and Leonard, 2003; West and Barron, 2005). A fifth group of studies describes how places both characterize and impact upon nursing and broader clinical specialties (Andes and Shattell, 2006; Duke and Street, 2003; Roush and Cox, 2000; Cheek, 2004; Andrews et al., 2005; Montgomery, 2001; Bender et al., 2007; Lock and Gibb, 2003). The current study contributes particularly here, extending the breadth of research to geographies of intensive care and intensive care nursing.

The current study also contributes to a body of place-sensitive nursing and health professional literature that has examined what makes for a good death in ICU and the barriers to providing end-of-life care in this particular context. Places have figured in important ways: a key finding being how making environmental changes allows for the creation of places for meditation, prayer, peace, and quiet and family gatherings (Beckstrand et al., 2006; Kring, 2006; Kongsuwan and Locsin, 2010; Wingate and Wiegand, 2008). In this literature, places also figure prominently in how a death is remembered. For example, studies show how in pediatric ICU, specific places remembered included the child's room and the waiting area. Also important are places for the family to go to for respite (Meert et al., 2008) and culturally specific places, such as homes for the place of death (Wingate and Wiegand, 2008; Beckstrand et al., 2006; Espinoza et al., 2008; Hughes et al., 2008; Meert et al., 2008).

Also recognized in the literature as important to a good death include being treated as a whole person, resolved relational conflict, good communication with staff, family involvement in care plans, and honoring both their and the patient's wishes (Beckstrand et al., 2006; Kring, 2006; Thacker, 2008; Wingate and Wiegand, 2008; Espinoza et al., 2008; Bergman-Evans et al., 2008). A key finding has been that environments that facilitated autonomy and control, a spiritual preparation for death, allowed for an acceptance and awareness of death, strengthened bonds between patient, family, friends, and pets, and managed symptoms and pain well, were superior (Hughes et al., 2008; Thacker, 2008;

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