Supporting patients' and families' religious and spiritual needs in ICU – can we do more?

ICU PATIENT EXPERIENCE

For both families and patients, admission to the hospital environment can be frightening. This sense of fear is magnified in the intensive care unit (ICU) by the severe conditions and an intensive technological environment. While nurses grow accustomed to this, we know from first-hand experience that patients and families experience the ICU as a daunting and dehumanizing environment. In the ICU, patients' identities change as they lose emotional intimacy (Plakas *et al.*, 2009). ICU is also the place where many, perhaps for the first time, face their own mortality. Death, pain and suffering, loss and isolation permeate the environment of an ICU. Fear, terror and a heightened sense of vulnerability are common for those who find themselves in the ICU. This experience often affects the remainder of their lives. The sense of loneliness, abandonment, disempowerment and total dependency that grips ICU patients should never be underestimated. Having an intensive care survivor on our team makes us very much aware of the life-changing experience that comes from being so close to death and surrounded by death. It can be a lonely and desolate place to be; words uttered about the patient's condition around the patient but never spoken to directly; a reluctance to speak of the unspeakable possibility of death.

While modern approaches to care espouse a holistic approach, there is a tendency within the ICU environment to focus primarily on illness, treatment and recovery. The author who survived the ICU felt more like a number than

a person – an intensely dehumanizing experience. Recognizing potential for this dehumanizing, in this paper we seek to speak for the many voiceless patients and their families who have spent time in an ICU. We will also make a case for the importance of religious and spiritual support for those who must endure the ICU journey.

FAMILY COPING AND SPIRITUAL AND RELIGIOUS NEEDS

Studies reveal the vulnerability, isolation and intense emotions that families experience in ICU (Plakas, 2007). The family often adopts a heightened vigilance by visiting long hours at the ICU (up to 10 h/day). However, during this time, families are often out on a limb, left to their own devices, searching and seeking hope (Plakas, 2007). Religiosity and religious rituals become important supportive elements (Plakas *et al.*, 2009; Plakas *et al.*, 2011; Fouka *et al.*, 2012). Prayer and rituals can serve to turn negative emotions into positive ones (Fouka *et al.*, 2012). Our experience is that relatives (for example in Plakas, 2007) often turn to religion as a coping mechanism even when they had not been previously religious.

The importance of spiritual and religious care for families is supported within the literature. In long-term care settings, families report receiving spiritual care as crucial for coping with the illness and death of their loved ones (Daaleman, 2012). Indeed, receiving spiritual care in the last month of life was positively correlated with

satisfaction with overall care received (Daaleman, 2012).

INABILITY OF HEALTH CARE WORKERS TO MEET PATIENT'S SPIRITUAL AND RELIGIOUS NEEDS

Despite the importance of religion and spirituality to patients and families, we have a concern about the extent to which patients' and families' spiritual and religious needs are being met in contemporary ICUs. Part of the challenge is that in some cases health care staff simply do not see religion or spirituality as relevant. During data collection in the ICU for a study on spirituality, one author had an ICU charge nurse reply 'oh the patients have no need for that [spirituality] here' and 'isn't religion a bit outdated now'. However, at the same time, studies have indicated that internationally many nurses are attending to patients' spiritual care needs and believe them to be important (Cockell and McSherry, 2012). Nurses are often ill equipped to do so having received little or no formalized training for this (Lundmark, 2006; McSherry and Jamieson, 2011). Identified barriers to providing spiritual care include lack of sufficient time, social, religious or cultural discordance between patients and staff (Daaleman, 2012) and a lack of understanding of its relevance to patients' and families' lives. Despite these barriers, spiritual and religious care of patients are increasingly being recognized as necessary components of holistic care. Evidence suggests that attending to the spiritual needs

of patients improves health outcomes (Koenig, 2013) and indeed not addressing spiritual aspects of care can have adverse effects (Radford, 1998).

Spirituality concerns aspects of human existence that provide meaning and purpose to life (Coyle, 2002). Spiritual care is usually given in a one-to-one relationship; it is completely person-centred and makes no assumptions about personal conviction or life orientation (NHS Education for Scotland, 2012). While spirituality and religiosity are often considered interchangeably, religion refers to the outward practice of a spiritual understanding through the use of frameworks for a system of beliefs, values, codes of conduct and rituals (King *et al.*, 2001). Spiritual care is not necessarily religious care; however, religious care should always be spiritual (NHS Education for Scotland, 2012). In European contexts, many nurses see chaplains as a key resource and make referrals when necessary (McSherry and Jamieson, 2011).

The important role of chaplains as part of the multidisciplinary team in ICU

Societal trends suggest that the chaplaincy role may be re-emerging as an important concept in modern health care (Pesut *et al.*, 2012). Declining religious affiliation among populations means that individuals do not always have formal religious resources to fall back in time of illness. In this situation, the chaplain may help to construct a meaningful story of experiences and help patients and families to cope with serious illness and death (Pesut *et al.*, 2012). Chaplains are individuals employed or engaged formally by the health service to provide spiritual care to those in need. Chaplains respond to the spiritual and religious needs of individuals and families (NHS Education for Scotland, 2012). Hospital chaplaincy departments usually maintain contacts and resources for many religions other than those represented within the chaplaincy team (Health

Services Executive (HSE), 2009). However, chaplaincy service provision is not consistent internationally. Reliable figures for exact service provision are not available, although it is estimated that just over half of hospital services in the USA have access to chaplaincy services (Cadge *et al.*, 2008). In Greece, the Republic of Ireland and the UK, these figures are probably higher with considerable national commitment evident in the UK (NHS England, 2002; NHS Education for Scotland, 2007; Healthcare Chaplaincy Services, 2009; NHS Wales, 2010).

Populations are also increasingly diverse, with significant growth in religions such as Islam and Evangelicalism in some areas. Health care workers are not often well equipped to meet these diverse religious needs which can impact health care (Radford, 2008). Chaplains are one of the few health care providers with professional preparation for supporting diverse religious traditions and can be a great support to both patient/family and staff in these situations (Pesut *et al.*, 2012). Increasingly, population diversity requires chaplains to broker diversity, which many do successfully (Pesut and Reimer-Kirkham, 2012), and the requirement for this skill is increasingly a component of national approaches to chaplaincy (NHS England, 2002; NHS Education for Scotland, 2007; Healthcare Chaplaincy Services, 2009; Health Services Executive (HSE), 2009; NHS Wales, 2010). As such, the role of chaplaincy provision is increasingly seen as multi-faith (NAHC, 2006). Indeed, there are multiplicities of roles associated with the work of a chaplain (religious, sacramental, spiritual and pastoral) and given the diversity of faiths, cultures and creeds in contemporary society, chaplains need to be discerning when they minister to a patient/family member within the confines of a traumatic environment such as an ICU.

Dykstra (2005, p.124) states that the hours or minutes spent by the chaplain with people in time of crisis, tragedy

or fear are 'among the most critical of their lives in terms of at least charting the course for future integration of, or failure to integrate, this crisis into the fabric of meaning in their lives'. We believe from both personal experience and from working with ICU survivors this to be particularly true. We believe that there is a great need for the presence of chaplains in an ICU, and for nurses to assess, refer and support patient and family spiritual care needs at this particularly challenging juncture of peoples' lives. At the same time, we are also mindful that chaplaincy and health care services ought to be sufficiently developed to be able to provide support to those with faith or those with none.

Furthermore, nurses need to understand that chaplains are not just for those who are religious. People of all faiths, and no faith, can benefit from a supportive presence who can take the time to help them find meaning and purpose in their suffering. Indeed, chaplains have the potential to provide the humanizing effect that so often gets neglected in the ICU environment. There is a recognized need in the ICU for holistic, patient-centred and family-centred care which incorporates mind, body and soul, and chaplains have the potential to be key partners in that care.

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