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Nurses engagement with the dying and dead body: the influence of early encounters in End of Life Care

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EoLC policy agenda

- ▶ End of life care is a priority on policy and political agendas both in the UK (DH 2016) and internationally (WHO/WPCA 2014) and in interdisciplinary academic and practice debates globally (Higginson 2016).
- ▶ Healthcare policy has consistently highlighted deficiencies in the quality of end of life healthcare
- ▶ A range of strategies - across disciplines and settings - to improve the experience of care for patients and their families (NP&EoLCP 2015).

At the forefront of care

- ▶ Nurses are at the forefront of this care, caring for dying patients ‘managing’ the dead body, and dealing with the corporeal, emotional and relational dimensions of death.
- ▶ Whilst nurses are ‘taught’ the theory and practice of end of life care, little is known about their prior or early professional experiences of and reactions to death and how these shape their understandings and influence their practice.

Exploring nurses and student nurses experiences with the imminently dying

- ▶ How this informs our teaching of death, dying in the UK and internationally
- ▶ The review set out to identify gaps in research
- ▶ Arksey and O'Malley's (2005) five stage approach to conducting a scoping review
- ▶ Five main themes: different philosophies of care, relationships, knowledge, impact of death and giving care
- ▶ Also organisational factors such as mentoring and support, team working and professional relationships.
- ▶ 23 papers identified from international sources

Attitude to death

- ▶ Nurses' commitment to deliver such care depends on their own attitudes towards death, dying and the dead body (Hench *et al.* 2017) which can be established early in their career (Parry 2011).
- ▶ Early experience, influences attitudes to death, dying and the dead, and these early encounters can have a lasting effect (Terry & Carroll 2008; Anderson *et al.* 2015).
- ▶ Death and dying and post mortem care are major sources of stress for students (Osterland *et al.* 2016)
- ▶ Cooper and Barnett (2005) call 'death anxiety'.
- ▶ Student nurses (particularly in hospital settings) are often the ones delivering such care including post mortem increasing their anxiety (Cooper & Barnett 2005)

Knowledge

- ▶ Evidence that nurses' knowledge of end of life care and palliative care is poor (Andersson *et al.* 2016) and superficial (Watts 2014).
- ▶ A recurrent theme - feeling unprepared to deliver care at the end of life (McDonnell *et al.*, 2002; Anderson *et al.*, 2015; Andersson *et al.*, 2016; Heise & Gilpin, 2016).
- ▶ Anderson *et al.*'s (2015) New Zealand study on the earliest memorable death, nurses reported a lack of skills and knowledge about death and dying.
- ▶ Frustrated by this lack of knowledge and felt it influenced their ability to deliver high quality end of life care.

- ▶ Students 'caught between doing the "best" for the patient within the limitations of his/her role and knowledge' (Cooper & Barnett, 2005, p.428).
- ▶ Grubb and Arthur (2016) in their UK FATCOD study of students' (n=567) attitudes towards care of the dying.
- ▶ 'being at a later point in their course of study and having experience of death and dying were independently associated with more positive attitudes' (p.86).

Inadequacy and powerlessness

- ▶ Students in Cooper and Barnett's (2005) UK study of first year student nurses
- ▶ inadequacy and powerlessness with the physical suffering of patients
- ▶ preparing to sever the relationship with the patient
- ▶ not knowing what to do or say and dealing with unexpected death.
- ▶ Other gaps - symptom control (Irvin, 2000; Watts, 2014) and last offices (Edo-Gual et al, 2014)
- ▶ Lack of knowledge of psychosocial skills and communication skills (McDonnell et al, 2002)
- ▶ A key barrier to the delivery of high-quality end of life care (McDonnell et al, p.2002).

Impact of death

- ▶ Memory of this first death - vivid, re-living the encounter, complete with emotions they experienced at the time' (Anderson et al, 2015, p.698).
- ▶ Impact worse when the patient is younger (Espinosa *et al.* 2010) or when sudden (Heise & Gilpin, 2016) and if the patient has been known for a long time (Espinosa *et al.* 2010) when relationships have become well established.
- ▶ A lasting effect (Edo-Gual et al, 2014; Anderson et al, 2015) influencing future attitudes (Arslan et al, 2018) and care (Charalambous & Kaite, 2013).
- ▶ Fear of being present at future deaths (Charalambous & Kaite, 2013) and of it happening on their shift (Hove et al, 2009),
- ▶ Avoidance tactics (Anderson et al, 2015), focussing on the physical tasks of end of life care and not the emotional aspects (Anderson et al, 2015).
- ▶ Distress (Holms et al, 2014; Heise & Gilpin, 2016), sickness and absence (Hov et al, 2009) and which could ultimately result in 'crusty nurses' who are emotionally disengaged (Espinosa et al, 2010).

Care of the dead body

- ▶ Role in last offices, transforming the patient into a corpse (Quested & Rudge, 2003)
- ▶ Caring does not end when the patient is dead (Quested & Rudge, 2003),
- ▶ Impact of first seeing a dead body (Cooper & Barnett, 2005)
- ▶ Nurses recollection first time seeing face of a dead body (Edo-Gual et al, 2014)
- ▶ Shocked by rapid changes, discolouration, leakages (Edo-Gual et al, 2014), in particular the colour of the lips and tongue (Anderson et al, 2015).
- ▶ Ill-prepared for last offices in particular, packing orifices, wrapping the body, covering the head and face, closing the bag (Cooper & Barnett, 2005, Edo-Gual et al, 2014).
- ▶ 'enact the transition between life and death, and from person to corpse' (Rudge, 2003 p.553).
- ▶ Troubling boundary segregating the dying and the dead.

Education

- ▶ Educationalists ‘have a duty to explore other means of support to enable students to cope more effectively’ (Cooper & Barnett, 2005, p.430).
- ▶ Simulation, drama, effective integration of theory and practice, reflection, cinemaeducation (Andersson, 2016; Heise & Gilpin, 2016; Parry, 2011)
- ▶ Use of cadavers (McGarvey et al, 2015)
- ▶ Opportunities for students to talk about emotional aspects of death and dying (Costello 2004; Arslan et al, 2014).
- ▶ Positive role models, clinical supervision (Charalambous & Kaite, 2013; Irvin, 2000).

Education and training pre and post registration

- ▶ Poor education as a major issue (Parry 2011; Gillan *et al.* 2014a).
- ▶ Students concern with lack of experience after qualification, when they may well be in positions of leadership and in charge of a shift.
- ▶ Key aspect of influencing students' attitudes towards end of life (Gillan *et al.* 2014a)
- ▶ Promoting consistent high-quality care (DH 2016).

Teaching end of life care: purpose

- ▶ Create opportunities for students to experience death in a ‘stress free’ environment
- ▶ Not to encounter death for the first time in a hospital setting in the presence of relatives (McGarvey *et al.* 2015:249)
- ▶ This will enhance preparation and reduce fear (Osterland *et al.* 2016).

Mentorship and support

- ▶ Provision of support for patients and families
- ▶ Influenced by support by colleagues, mentors, good role models, clinical supervision.
- ▶ Lack of support mechanisms leads to isolation and inability to support others (Irvin, 2000; McDonnell et al, 2002; Holms et al, 2014).
- ▶ Nurses vulnerable if senior colleagues did not understand the emotional impact of the death of a patient (Anderson et al, 2015).
- ▶ When nurses part of a team and were able to discuss a patient's death this enhanced their ability to cope (Andersson et al, 2016).

Discussion

- ▶ Privileged to be providing care for dying patients
- ▶ Knowledge of palliative care was lacking
- ▶ A dearth of education and training and, consequently, nurses felt unprepared to deliver optimal care to dying patients (Irvin, 2000; Hov et al, 2009).
- ▶ How best to prepare students and registered nurses for work with the dying?
- ▶ Education should focus on:
- ▶ Recognising the signs of imminent death
- ▶ Emotional preparation and how to break bad news (Costello, 2004; Espinosa et al, 2010).
- ▶ Positive role models and mentors (Charalambous & Kaite, 2013; Andersson et al, 2016)
- ▶ While studies suggest such training can reduce 'death anxiety' - a lack of empirical research demonstrating effectiveness (Watts, 2014).

- ▶ Student nurses and experienced nursing staff are impacted both positively and negatively by early encounters with the dying and dead body
- ▶ Support helps to shape a more positive attitude
- ▶ Leading to provision of high-quality care
- ▶ Lack of support associated with death anxiety and death avoidance
- ▶ Emotional contagion, distress and even burn out
- ▶ Educationalists and senior nursing managers responsibility
- ▶ Staff to be fully informed, communicated with and supported to prepare their selves, the patient and their families of imminent death

To that end...the RCN on care of the dying

- ▶ “Although challenging and emotionally demanding, when you are supported to have the right skills, knowledge and attitude, end of life care can be very rewarding.”
- ▶ “A key part of the nurse’s role is being able to come alongside the person who is dying and those close to them and to support them throughout what is a natural process.”

(Royal College of Nursing, 2019, <http://rcnendoflife.org.uk/my-role/>).







