‘On the edge of life’: caring for the dying and the dead

Jan Draper and Kerry Jones
Overview

Why this topic?

Literature search process

Literature search findings

Overview of themes

What next?
Why this topic?

Personal interest

Policy and practice in end of life care

Implications for curricula and practice

Platform for a bid
Literature search process

**Aim** – registered nurses’ and student nurses’ experiences of and attitudes towards the care of people who are imminently dying, including the dead body

**Inclusion criteria** – registered/student nurses, hospital/hospice/care home/community, 1990 to date, English speaking, exclusion

**Search terms**

**Sources** – MEDLINE, Pub med, Psychinfo, Cinahl
Literature search findings (1)

Initial search n=2616
After application of inclusion criteria n=183
After abstracts assessed for relevance n=121
A further 28 excluded (not available, non-English, theses) n=93
After second review excluding:
• All that were education focussed
• All with specialist niche/focus
• Methodological papers/tool testing
• Pre-2000

70 further papers excluded leaving n=23
Diverse geographical locations: Australia (4), Cyprus (1), New Zealand (1), Norway (1), Spain (1), Sweden (3), Turkey (1), USA (4), UK (7)

Settings: hospital, hospice, nursing home, residential care

The majority are relatively small scale qualitative studies (eg ethnography and phenomenology) using interviews, focus groups and reflective diaries

Some larger quantitative studies and cross-sectional surveys using validated tools

Independent and detailed reading of all 23 papers

Independent thematic analysis of key issues
Lack of knowledge and skills
Communication
Professional relationships
Concealing death
The dead body
Type of death
Concealing death
Time
Emotional challenges
Relationships with patients
Wanting to provide good care
Lack of knowledge and skills
Place
Different philosophies of care
Support
Education
Communication
Professional relationships
The dead body
Impact of death
Emotional challenges
Relationships with patients
Overview of themes

- Relationships
- Knowledge
- Impact of death
- Commitment to care
‘I’ll never forget that – you know – the blue colour – because his lips and tongue were hanging out, and I never expected it to look like that’ (Anderson et al 2015: 700)

‘The transformation from patient to corpse occurs before the nurse’s eyes and by the nurse’s actions’ (Quested and Rudge 2003: 558)

‘To do it properly. It’s part of being a good nurse, that end bit…’ (McCallum and McConigley 2013: 27)
‘The division of medical work makes specific physicians in specific spaces responsible for specific body parts while no one is responsible for the embodied whole patient’ (Liashenko et al 2011: 815)

‘The doctors keep pushing, they are trying to be God and they push just another day, another day of aggressive management’ (McCallum and McConigley 2013: 28)
Making places good spaces for dying

‘Taking attention away from institutional ICU markers changes the focus from the survival functions of the machines to the person and their loved ones’ (Liashenko et al 2011:817)

When cure and care occupy the same place

Death in between spaces
Temporal

Trying to control time of death
Moving the body too quickly
When does end of life care start?
What next?

Two papers:
- Literature review
- A more theoretical paper drawing on van Manen’s four lifeworld existentials

Potential research bid
Feedback from you all!
THANK YOU