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Citation

Jones, Kerry (2018). Advance care planning and dementia: whose decision? In: Advance Care Planning, decision making and agency, 16 May 2018, Centre for Death and Society, University of Bath, UK.

URL

<https://oro.open.ac.uk/55745/>

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Advance care planning and dementia: whose decision?

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GW4

- Universities of Exeter – Medical School
- University of Bristol – Centre for Ethics & Medicine
- University of Bath – Centre for Death & Society
- University of Cardiff- Coma and Disorders of Consciousness Research Centre
- Sandpit events– conference
- 2 reviews – dementia, decision making & EoLC,
- Dementia, frailty and brain injury

Background

- Focus on trajectory of malignant disease
- PWD - complex physical and psychological needs
- Not recognised as terminal
- Consequence PWD receive undignified treatment (tests, ANH) & unrecognised pain (Anquinet et al, 2013; Sampson et al, 2011).
- Admission to hospital

Review

- Review of 25 papers
- Studies - retrospective, surveys, documentary analysis of patient records and interviews with families, clinicians or those directly involved in a patient's end of life care.
- Synthesis generated 4 main themes
- Decision making, who decides, systemic factors and quality of death including the withdrawal of treatment.
- Role of families, health care professionals, PWD in decision making
- Discussions took place in dyad's (between carers and professionals or between professionals and families).

Decision making factors

- Legal issues and ACP and AD which are complex and vary internationally
- Future preferences and how and when to initiate these conversations i.e. in the early stages
- But who does this? Is it distressing to imagine a future self
- HP identification with a lack of training and responsibility for this
- Lack of co-ordinated care and out of hours services.

Legal issues

- Assumption that directives reduce the burden of making decision in the event of a crisis
- What we know - legally binding, a record of decisions about treatment and care
- Set a precedent, protect, preserve autonomy.
- However, advance statements as we know it are verbal and not written or legally binding.

No Advance directive? proxies

- Aim to encourage discussion
- Spouses informed to infer preferences in hypothetical futures ?
- Attitudes & to ascertain a person's needs
- Not always congruent between Dr's, spouse, person with dementia (Caresse et al, 2002; Kaufman, 2005)
- ACP idea to ameliorate consequences
- Justifying decisions – demanding and distressing, anticipatory grief
- HP – no record OOH A & E – treat intensively

Family involvement in ACP: proxies

- ANH, antibiotics, analgesics, diagnostic tests
- Difficulties in making decisions (Ayalon, 2012; Livingston et al, 2010)
- RCT carers of nursing home residents – structured face to face baseline, 3 and 6 months about EoLC options vs telephone
- Face to face - higher levels of satisfaction and make proxy treatment decisions (Reinhardt et al, 2014)

Sampson et al's (2010) UK randomised controlled trial

- Of 33 – 22 assigned to intervention following admission - 11 assigned usual care
- 7 carers [intervention group] wrote an ACP despite intensive support
- Difficulty in recruiting carers
- Potential distress during admission
- Carer reluctance to write ACP needs exploration
- Timing – Sampson et al, persist issue of carer's

Health professionals

- EoLC clinical and ethical considerations
- Complex and challenging for HP
- Robinson et al (2012) study views and experience of HP (n=96) clinical and non – clinical roles in palliative and dementia care
- Challenges – legal status, usefulness, how to implement ACP
- GP's & ambulance staff – uncertainty

Good in theory..... (Robinson et al, 2012)

- Reluctant to broach the subject
- Uncertainty about who is responsible
- Confusion about legal status of AD & ACP
- Bespoke forms [Tep]
- Patient preferences – unable to deliver due to lack of integrated care and dementia specialist support
- ACP – a tick box audit

Joint decision making

- Netherlands (Rurup et al, 2006) nurse/DR/carer response to EoL decisions
- 15 statements – ANH, AD, hastening death, self determination & euthanasia
- Nurses & spouse more likely than Dr's for refusal ANH to be upheld
- Nurses [63%], spouse [64%], doctor's [34%] euthanasia via AD permissible
- Conflict – varying levels of responsibility

Including the person with dementia

- Cognitive decline deteriorates impact on decisions
- Triplett & Black (2008) US – AD 81 PWD
- 40% did not document comfort care, pain relief or ANH
- Invasiveness of ANH only 20 refused, none re: A& E
- Treatment options not fully explained or realised
- Turn to health care agents to make decisions
- Hard to imagine future selves (Denning et al, 2012) UK

UK: Memory clinic (Dening et al, 2012)

- How PWD and spouse make decisions at assessment
- Discussion of preferences challenging
- Spouse preferences predominated
- Spouse choices framed by current experiences of care
- No reference to future i.e. Emergency admission
- PWD & hypothetical scenarios difficult
- Hard to imagine their future selves.

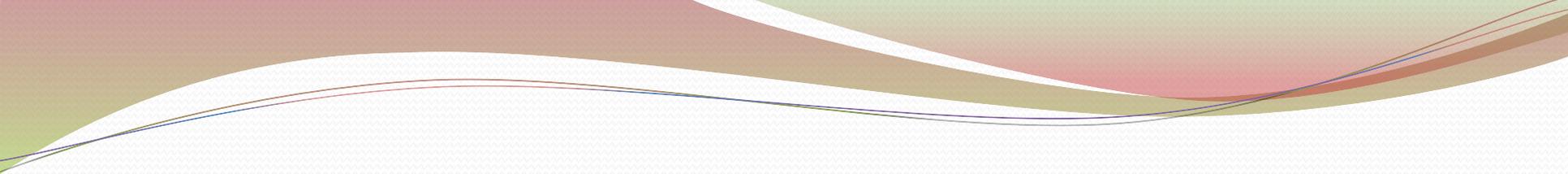
Systemic barriers

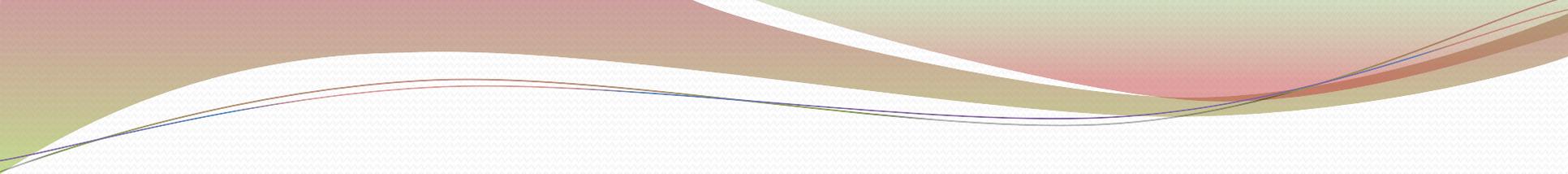
(Dening et al, 2012)

- Barriers to EoLC - whole system approach
- Pathways of care
- The impact of hospitalisation
- ACP – pressure to make decisions for spouse
- Impact on carers – Having to push for services
- Staff skills and training- lacked confidence
- Lack of integrated care – ‘not my job’
- OOH – so admit to hospital
- Admiral nurse and specialist support – good examples

Facilitating a good death

- Free from distress, pain according to patient wishes and ethical standards
- Studies – treatment intensity [resuscitation, ANH, sedation] (Parsons, 2009; van der Steen, 2011)
- N. Ireland & ROI (n=622) variation among HP in limiting/continuing treatment
- Half to prescribe antibiotics at EoL [UI] if community or care home under GP
- Less likely to prescribe if in hospital
- Evidence base for antibiotics at EoLC unclear

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- Dutch nursing home residents with pneumonia (van der Steen, 2005)
 - Treatment withheld in 23% of cases
 - Sedate to manage symptoms
 - Insufficient to control breathlessness, pain, anxiety (Anquinet, 2013; Vandervoort et al, 2014).
 - Comfort care and when to withdraw discussions needed

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- Decision making not one off decision
 - Different individuals at different points of time & various sites of care
 - Few examples of good death – limiting treatment intensity
 - EoLC decisions are not always congruent between spouse and person or with HCP
 - Implications for proxy decision making

Conclusion

- EoLC considered in context of current experience not hypothetical futures
- Defer responsibility to HCP
- Interagency communication
- Training needs in different settings – review annually
- Surrounded by people important to the dying
- Supported by vigilant well supported staff – communicating and coordinating care (Sampson et al, 2011)

Finally.....

- Decision making not one off event but necessitates adjustment along with a dementia pathway that is unpredictable..

Thanks