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How do patients and family in MND interrelate in the decision-making process? Reconfiguring the supportive relationship between patients and family caregivers in palliative care

Geraldine Foley, PhD
Assistant Professor
Discipline of Occupational Therapy
School of Medicine
Trinity College Dublin
Email: foleyg3@tcd.ie
@foleyg31

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Aims of presentation

- Overview of systematic review of MND patient & family caregiver relationship in the decision-making process
- Findings together with literature/evidence in the wider field of palliative care
- Help reconfigure the 'supportive' relationship between patients and family caregivers

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Systematic review

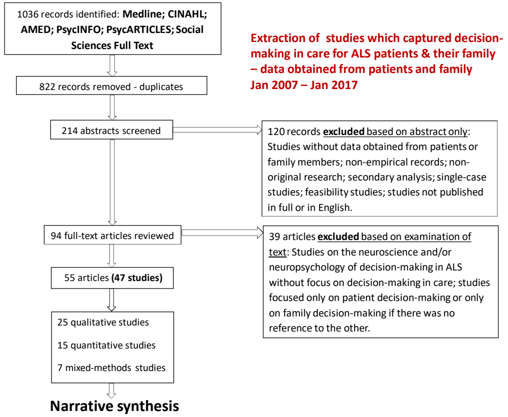
To examine the ALS patient/family relationship in the decision-making process

To ascertain how ALS patients and their family can shape one another's decisions pertaining to care

REVIEW ARTICLE

Decision-making among patients and their family in ALS care: a review

GERALDINE FOLEY[1] & GERALYN HYNES[2]



1036 records identified: **Medline; CINAHL; AMED; PsycINFO; PsycARTICLES; Social Sciences Full Text**

822 records removed - duplicates

214 abstracts screened

120 records **excluded** based on abstract only: Studies without data obtained from patients or family members; non-empirical records; non-original research; secondary analysis; single-case studies; feasibility studies; studies not published in full or in English.

94 full-text articles reviewed

39 articles **excluded** based on examination of text: Studies on the neuroscience and/or neuropsychology of decision-making in ALS without focus on decision-making in care; studies focused only on patient decision-making or only on family decision-making if there was no reference to the other.

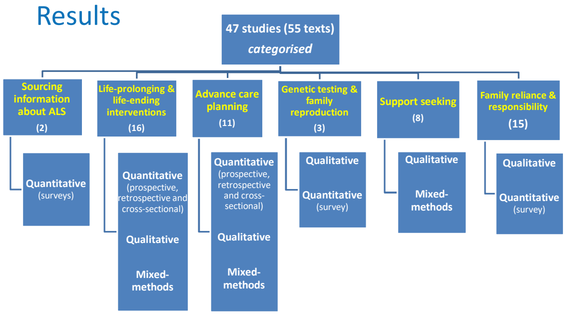
55 articles **(47 studies)**

25 qualitative studies
15 quantitative studies
7 mixed-methods studies

Narrative synthesis

Extraction of studies which captured decision-making in care for ALS patients & their family – data obtained from patients and family Jan 2007 – Jan 2017

Results



47 studies (55 texts) ***categorised***

Sourcing information about ALS (2)
- **Quantitative** (surveys)

Life-prolonging & life-ending interventions (16)
- **Quantitative** (prospective, retrospective and cross-sectional)
- **Qualitative**
- **Mixed-methods**

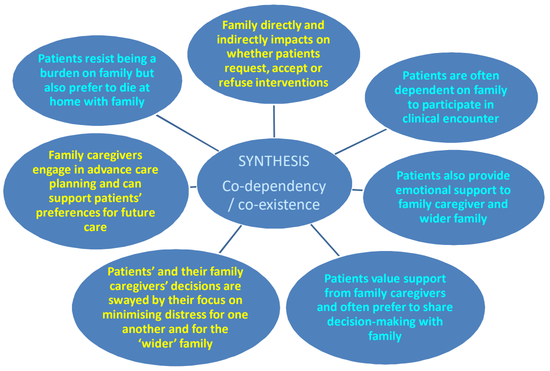
Advance care planning (11)
- **Quantitative** (prospective, retrospective and cross-sectional)
- **Qualitative**
- **Mixed-methods**

Genetic testing & family reproduction (3)
- **Qualitative**
- **Quantitative** (survey)

Support seeking (8)
- **Qualitative**
- **Mixed-methods**

Family reliance & responsibility (15)
- **Qualitative**
- **Quantitative** (survey)

Findings – *complexity* of decision-making



SYNTHESIS
Co-dependency / co-existence

Family directly and indirectly impacts on whether patients request, accept or refuse interventions

Patients are often dependent on family to participate in clinical encounter

Patients also provide emotional support to family caregiver and wider family

Patients value support from family caregivers and often prefer to share decision-making with family

Patients' and their family caregivers' decisions are swayed by their focus on minimising distress for one another and for the 'wider' family

Family caregivers engage in advance care planning and can support patients' preferences for future care

Patients resist being a burden on family but also prefer to die at home with family

Prompts us to think more about support exchange between patients and family caregivers in palliative care

How have we traditionally constructed the dying person in palliative care?

- The patient as a ***recipient*** of support (physical, psychological, emotional, social, existential, financial, etc)?
  - – From family caregivers

    de Wit et al. 2015, Hudson et al. 2013
  - From healthcare providers

    Temel et al. 2010, McIlfatrick 2006

How have we traditionally constructed the family caregiver in palliative care?

- The family caregiver as a ***provider*** of support (physical, psychological, social, emotional, existential, financial, etc) to the patient?
  - Clemmer at al. 2008, Lee et al. 2013, Grande et al. 2017, Pivodic et al. 2014, Hudson & Payne 2011

Why?

Have researchers (in palliative care research) conceptualised the patient essentially as a recipient of family support?

Are questions asked within studies focused on the patient-family caregiving relationship, shaped fundamentally by the pre-assumption that patients are recipients of support?

Reciprocity (palliative care)

- Concern can be bidirectional - patients concerned about family caregivers' burden; family caregivers concerned about patient distress (Hauser et al. 2006)

- Reciprocity in the supportive relationship (in the form of mutual empathy) between patients with heart failure and their family caregiver associated with patient confidence in self care (Sebern & Riegel, 2009)

- Positive dyadic coping strategies (e.g. sharing feelings, supportive listening) among patients and family caregivers in metastatic cancer resulted in greater dyadic adjustment (Badr et al. 2010)

Palliative care literature – patient can also render support (*directly* and *indirectly*)

- Patients can steer direction of their own care to alleviate family caregiver distress and advise family caregivers on matters that relate to the family caregiver wellbeing (Proot et al. 2004)

- Dying patients' preference for hospice care explained by their desire to alleviate family caregiver burden and reduce distress for family (Broom & Kirby 2013; MacArtney et al. 2016)

- Patients may decide to conceal their own needs to alleviate family caregiver distress and actively encourage family caregiver to engage in activities that offer them respite (McPherson et al. 2007)

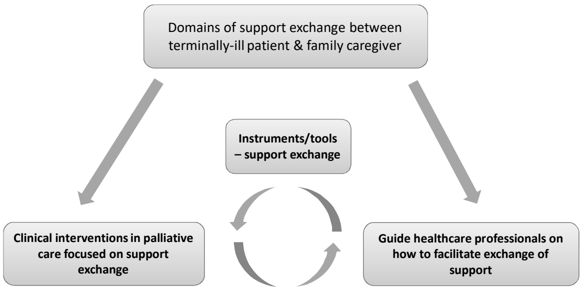
Bi-directional nature of support (palliative care)

- *Sociological-based* examination captured how mutual obligation to remain stoical in the face of adversity is a dimension of caring (Broom & Cavenagh, 2010)
- How remaining positive for one another can help both accommodate to advanced illness (Gardner, 2008)

The **'what'**, **'how'** and **'why'** of bidirectional support (Foley, 2018)

- What forms does support exchange take?
- In what contexts does it work and why?
- How might awareness (i.e. impending death) hinder or facilitate support exchange?
- Delineation between 'protecting' Vs 'supporting' – (e.g. buffering vs open/explicit/constructive support & open communication?)
- The role of the wider family on support exchange
- How might severity of illness or intensity of palliative care intervention shape how patients and family caregivers support one another?
- How do terminally-ill patients' and their family caregivers' *experiences* of formal services impact on how they support one another?

Relevance for the practice setting



Domains of support exchange between terminally-ill patient & family caregiver

Instruments/tools – support exchange

Clinical interventions in palliative care focused on support exchange

Guide healthcare professionals on how to facilitate exchange of support

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Palliative care

In line with underpinning principles of palliative care services

- Health promoting palliative care
- Rehabilitation in palliative care
- Bereavement
- Clinical effectiveness
- Person-centred care

Shifting assumptions about …..

Recognising the terminally-ill patient as ***both*** a recipient and provider of support –

Helps shift assumptions which have underpinned research on informal caregiving in palliative care

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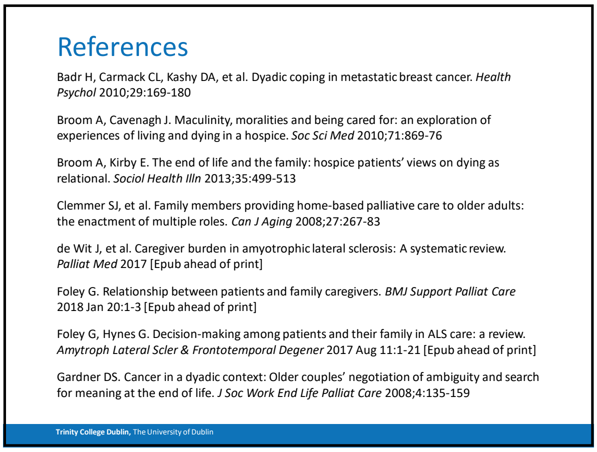
Thank You



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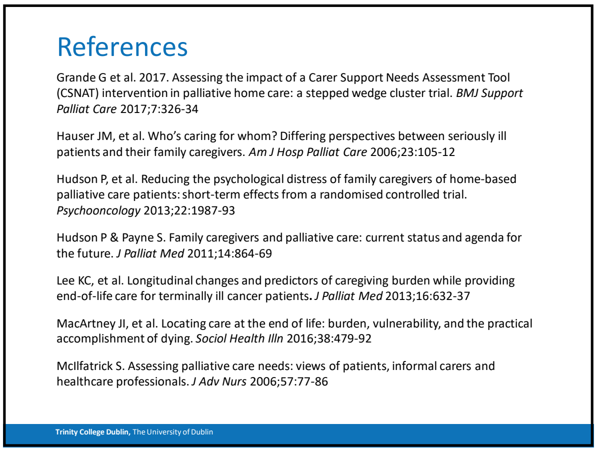

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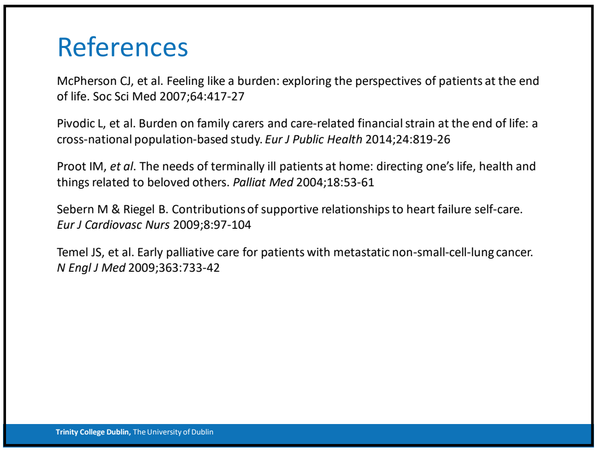

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