7th International Conference on Ageing and Spirituality

‘The spiritual needs of caregivers who relinquish their primary caring role’

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What will be covered here?

- Introduction to where I am from - Flinders University
- Background literature to the research
- Study design
- Outcomes from the research
- Leading to the need for spiritual care and tools for its implementation
Background to study Spirituality

• Over four decades ‘spirituality’ has become a popular topic for discussion.
• Once the exclusive domain of theology and philosophy found in literature from a variety of disciplines.
• In health – psychology, nursing and medicine all agree for spiritual care
Background to the study (2) Carers

• Within the United Kingdom (UK) New Zealand and Australia the term ‘carer’ is used

• Within the United States (US) and Canada the term ‘caregiver’ is used

• This paper ‘family caregiver’ is used to define: those who provide care in response to illness or functional impairment that exceeds the ‘normal’ care or help provided with in families’ (Schumacher & Marren 2006 p.40)
Background to the study (3)

• Within the US > 65 million people - 29% of population (2012) are caregivers
• Within the UK 12% of people aged over 16 are caregivers
• Within Australia 12.5% (3,166,941.4 people) are caregivers
  – (SA population 1.7M Australia 25M)
Background to the study (4)

• Medical intervention have increased longevity – leading to an increase in number of people who will live with chronic conditions

• One of the largest surveys on caregivers health’ of any population group, they have lowest level of well-being (Cummins et al 2007)
Background to the study (5)

- There is recognition of value of the caregiver role in decreasing hospitalisation and institutionalisation.
- When caregiving of dying patients is considered – death of a family member increases vulnerability to pre-mature illness and death for those surviving.

(Street, Love and Blackford 2004)
Background to the study (6)

• WHO (2010) in its definition of palliative care affirms such care intends to improve the quality of life of patients and their families and includes effective pain management, assessment of psychosocial, physical and spiritual needs.

• Illness and hospitalisation evoke a spiritual quest for patients and families (Harrington 2006)
The case for implementing spiritual care

• Growing body of literature documents the positive effects of both religiousness and spirituality on human health (Brennan & Heiser 2012: Daaleman, Cobb & Frey 2001)

• Positive relationship exists between spirituality and wellbeing, even in times of distress and suffering (Baldacchino et al 2012).
Definition of Spirituality

- Spirituality is the way we seek and express meaning and purpose; the way we experience our connection to the moment, self, others, our world and the significant or sacred (from Meaningful Ageing Australia…Adapted from California Lutheran Homes Centre for Spirituality and Ageing)
Aim of the study

Part of a larger study to determine the issues faced by caregivers when they ‘hand over’ their primary caring role to health care providers – specifically ‘what were ‘spiritual’ or ‘religious’ issues for caregivers during this time
Design of the study

• Qualitative interviews (valuing people in the context of their lives where research questions involve human consciousness and subjectivity)

• Ethics application approved
  – Interview 15 people
  – Transcribed verbatim
  – Systematic search for common, recurring themes and relational patterns
Results

• Although the words ‘church’ and ‘religion’ were used during some interviews, no attempt was made on behalf of the researcher to define ‘spirituality’ preferring to allow respondents to comment from their own viewpoint, and whether this domain was beneficial to them
Results (2)

• Spirituality viewed positively - 8

• Spirituality viewed negatively - 5

• Spirituality viewed both negative and positive - 2
Results (3)

• Spirituality viewed Positively (a)-
  – (Interviewer) *in terms of the spiritual domain – any of that in your life*…?
  – *Always in my life…*I don’t tend to regularly go now but I can go into any church and get a peace* (P.13)
  – *I have Christian friend to talk to…*I think [spirituality] *is 90% of my support…*if I didn’t believe in Christ I think I would’ve gone under* (P.14)
Results (4)

• Spirituality viewed positively (b)
  – *I’m not a zealot….I do believe in God….and like the rest of parishioners… they have been wonderful, they supported me and prayed for [wife] and that was a big help* P.15
  – [in response to the question…do you derive comfort] *oh yes, oh yes, definitely* [P.5]
Results (5)

- Spirituality viewed negatively –
  - [in response to do you need spiritual support] no, I don’t know. I haven’t really thought of that area, no [P.10]
  - We haven’t thought about that part…a very hard question…at the moment I’ve tended to think there is nothing because of the way my son suffers [P.12]
Results (6)

• Spirituality viewed both negatively and positively –
  – [do you need support] *no I don’t think so…I was brought up a Presbyterian…I’d feel comfortable going back if I felt that was going to be of benefit* [P.6]
  – [dad] *used to go to church…I go to church…I guess I’m not really deeply religious* [P.11].
Spiritual care??

• I offer a model for spiritual care

- *Journal of Religion Spirituality & Ageing* 18 2/3
Conclusion and recommendations

• What could be classed as ‘negative’ might in fact represent a lack of interest rather than an negative view.

• As spirituality and religion may be seen as ‘personal’ beliefs and practices followed by one person may be rejected by another.
Conclusion and recommendations

• Whether caregiver or patient, important to consider how each person defines their spiritual needs…may not mean providing answers but rather listening..(Vivat 2008)

• Consist of entering into a dialogue with others taking cues from them
## Tools to assist in the implementation of spiritual care

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<tr>
<th>Author and Source</th>
<th>Tool</th>
<th>Components</th>
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<tbody>
<tr>
<td>Stoll (1979) Guidelines for spiritual assessment</td>
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<td>Concept of God or deity: sources of hope and strength: religious practices: relations between spiritual beliefs and health:</td>
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<td>MacKinlay (2006) Spiritual Growth and Care in the Fourth Age of Life</td>
<td><em>Assessment of the Spiritual needs of Older Adults Level 1 Level 2</em></td>
<td>Initial screening questions to identify any current and urgent spiritual needs Ultimate meaning in life Response to ultimate meaning Transcendence of loss and disabilities etc.</td>
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<td>Puchalski &amp; Romer (2000) Taking a spiritual history allows clinicians to understand patients more fully</td>
<td>FICA Spiritual History</td>
<td>Faith and belief Importance and influence Community Addressed in care</td>
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<td>Anandarajah and Hight (2001)</td>
<td>Spirituality and Medical practice: using the HOPE questions as a practical tool for spiritual assessment</td>
<td>H- sources of hope, meaning comfort and strength, peace, love and connection O-Organised religion P-Personal spiritual beliefs and practices independent for organised religion E-Effects of medical care on spiritual practices.</td>
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Some examples of questions:

- Spiritual history taking:
  - H = sources of hope, meaning, comfort, strength, peace, love and connection
  - O = organised religion
  - P = personal spirituality and practice
  - E = effects on medical care and end of life issues

(Spiritual care in nursing practice Mauk & Schmidt 2004 Lippincott Williams & Wilkins)
In conclusion

- Spirituality important aspect for patients and their families
- Relationship between spirituality and health
- May or may not include issues of religion
- Needs to be considered when offering ‘care’ to both patients and caregivers
References

Thank you

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