Dr Anne Fothergill, Principal Lecturer, Mental Health Research
Mental Health & Learning Disabilities: Improving Dementia Care Conference
1000 Lives/Public Health Wales
16th November 2017, All Nations Centre, Cardiff
Title and Aim of the Study

• Title: Exploring how the spiritual needs of dementia patients are addressed within Care and Treatment Plans (CTPs) in three Health Boards (HBs) in Wales

• Aim: To ascertain how the spiritual needs of patients living with Dementia are addressed within the CTPs
The Research Team

• Principal Investigators:
  • Anne Fothergill & Linda Ross (University of South Wales (USW))

• Co-A’s:
  • Ian Stevenson, Sara Collier (ABMUHB)
  • Sue Bale (ABUHB)
  • Wilf McSherry (Staffordshire University)
  • Paul Davies (CTUHB)

• Research Assistants: Abigail Loveitt, Glen Carney & Janine Thomas
Research Centres

- Aneurin Bevan University Health Board (ABUHB)
- Cwm Taf University Health Board (CTUHB)
- Abertawe Bro Morgannwg University Health Board (ABMUHB)
Funding

• Science & Health Research Institute (USW)

• Cwm Taf UHB

• Some matched funding from ABUHB

• Wales Institute of Social & Economic Research, Data & Methods (WISERD)
Timescale

• January 2015. Applied for internal funding from Science & Health Research Institute. Funding awarded February 2015
• Mar-July 2015. Preparation of ethics’ forms (University and IRAS) and supporting documents
• May-July 2015. Scoping exercise conducted. Funder WISERD
• June 2015. Additional funding from local HBs
• Sept 2016. Research Ethics Approval
• Dec 2015. NHS Research & Development Approval.
• Jan-July 2016. CTPs collected by Research Assistants and data recorded
• Aug 2016. Data analysis CTPs
• Oct 2016. Focus groups with staff
• Nov-Dec 2016. Focus group data analysis
• Jan 2017 onwards. Dissemination
• Jan 2018. Final report to IRAS (external research ethics)
Why? Background

- Mental Health Measure (WG 2010)
  - Requirement for CTP
- Francis (2013) and Andrews (2014) reports (compassion, dignity, respect, person centred)
- NHS Constitution (2013)
- Dementia Challenge (belonging, connection, end of life wishes)
- Health & Care Standards (WG, 2014)
- Research evidence
# Care and Treatment Plan (CTP)

<table>
<thead>
<tr>
<th>Outcome to be achieved</th>
<th>What services are to be provided, or actions taken</th>
<th>When</th>
<th>Who by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenting or caring responsibilities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care and physical well-being</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social, cultural and spiritual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work and occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcomes to be achieved may also be agreed in relation to other areas</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
What?

- How are the spiritual needs of dementia patients addressed within the new CTPs.

Objectives:

- 1. To analyse dementia patients’ CTPs, from both Community Mental Health Teams (CMHTs) and in-patient wards.
- 2. To compare Domain 7 with the other domains of the CTP.
- 3. To conduct focus groups with staff to explore their views on completing Domain 7 of the CTP; this will be compared with the written CTP.
Method

Phase 1

• Literature review

• Scoping exercise (how many CTP’s for people with dementia? Where? how many have Domain 7 completed) – WISERD funded.
Method (2)

- Phase 2
- Sample of 150 CTP’s (50 from each Health Board, mix of community & in-patient)
- Thematic analysis of content
- Who completes them?
- How often are they updated?
- How does Domain 7 compare with other domains?
Method (3)

• Analysis of the CTPs and focus groups with staff
• Study finished end Dec 2016
Actual Sample

- Collected 150 CTPs: 50 from each Health Board

Breakdown:
- CTUHB 25 Community, 25 Hospital
- ABMUHB 25 Community, 25 Hospital
- ABUHB 11 community, 39 Hospital
<table>
<thead>
<tr>
<th>Location</th>
<th>Community</th>
<th>Hospital Continuing Care</th>
<th>Hospital Assessment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Board</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aneurin Bevan</td>
<td>11</td>
<td>0</td>
<td>39</td>
<td>50</td>
</tr>
<tr>
<td>Cwm Taf</td>
<td>25</td>
<td>4</td>
<td>21</td>
<td>50</td>
</tr>
<tr>
<td>Abertawe BroMorgannwg</td>
<td>25</td>
<td>4</td>
<td>21</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td>8</td>
<td>81</td>
<td>150</td>
</tr>
</tbody>
</table>
Data Analysis: Content Domain 7 (Social/Cultural/Spiritual)

Initial themes 11 in total

• 1. Dignity
• 2. Compassion
• 3. Personhood
• 4. Religion/religious beliefs
Themes (Cont’d)

• 5. Social connections with family, friends, neighbours
• 6. Social connections with staff.
• 7. Activities and Interests (e.g. photos, memory books, watching TV, hobbies, work related activities)
Themes (Cont’d)

• 8. Support of family and carers.
• 9. Culture
• 10. Person centred care
• 11. Considered but no detail (to have social, cultural, spiritual needs met)
Themes Reduced to 8

1. Dignity was merged into person centred care

2. Compassion and personhood were removed. However these themes occurred in other parts of the CTP but not specifically in Domain 7

3. Revisited categories on social connections to distinguish social connection(s) between family and paid carers
**Themes: Domain 7 (Social, Cultural, Spiritual)**

<table>
<thead>
<tr>
<th>Activities</th>
<th>Number (N=)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social connections family</td>
<td>73</td>
<td>48.7%</td>
</tr>
<tr>
<td>Social connections staff</td>
<td>59</td>
<td>39.3%</td>
</tr>
<tr>
<td>Religion</td>
<td>44</td>
<td>29.3%</td>
</tr>
<tr>
<td>Supporting family and carers</td>
<td>19</td>
<td>39.3%</td>
</tr>
<tr>
<td>Person centred care</td>
<td>13</td>
<td>8.7%</td>
</tr>
<tr>
<td>Considered</td>
<td>13</td>
<td>8.7%</td>
</tr>
<tr>
<td>Culture</td>
<td>11</td>
<td>7.3%</td>
</tr>
</tbody>
</table>
## Frequency of Completion of Other Domains (1-6 & 8)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Number (N=)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social, cultural, spiritual</td>
<td>150</td>
<td>100%</td>
</tr>
<tr>
<td>Medical and other treatments</td>
<td>148</td>
<td>98.7%</td>
</tr>
<tr>
<td>Personal care</td>
<td>142</td>
<td>94.7%</td>
</tr>
<tr>
<td>Accommodation</td>
<td>140</td>
<td>93.3%</td>
</tr>
<tr>
<td>Finance/money</td>
<td>123</td>
<td>82%</td>
</tr>
<tr>
<td>Education and training</td>
<td>62</td>
<td>41.3%</td>
</tr>
<tr>
<td>Parenting and caring</td>
<td>59</td>
<td>39.3%</td>
</tr>
<tr>
<td>Work and occupation</td>
<td>42</td>
<td>28%</td>
</tr>
</tbody>
</table>
Example: Religion Quotes

• “Mr A. requires support to maintain his faith (not specified), which is very important to him. To be supported to pursue his faith and attend any spiritual meetings he wishes to within his capabilities”

• “Mr B’s social, cultural and spiritual needs to be considered in the provision of care and recovery of mental health”
"Has not signified that she has any spiritual needs. (Update 22.07.15). Family may be asked later regarding prior spiritual interests, with a view to offering visits to the hospital chapel in future"

“He seems to enjoy the church service and the hymns that are sung. He has enjoyed classical music for many years. Ensure that Mr C’s love of music and weekly singing of hymns is respected and nursing staff are to facilitate these activities for Mr C’s enjoyment”
Person Centred Care

“Mr D. lived with his wife prior to admission and received social, cultural and spiritual support from her. Mr D. is a young and physically fit man; it would be detrimental to him and his family/friends if he didn’t have access to an environment that would be able to maintain and support his person centred needs”
Staff Focus Groups Findings

• CTP in General
  • All domains seen as important, but not all completed
  • Different interpretations of the domains
  • Differences in the community and hospital and across the health boards
  • Not always useful as it is a tick box and does not help with relationship building
• Who owns the CTP? Few written in the 1st person and few signed by the person with dementia
• High completion rate as a legal requirement and for audit
• Multiple copies: hard and e copies, which one is the most up-to-date
Staff Focus Groups
Findings (2)

• Domain 7
Of the 8 domains on the CTP, Domain 7 (Social, Cultural, Spiritual) was the least completed
Supports outcomes from the written CTP
Spiritual needs seen as more than the person’s religious affiliation/beliefs
• It’s the essence of the person i.e. who they are. Its about engaging patients in meaningful activities that gives them peace, contentment, fulfilment and enjoyment. Some patients even if not religious enjoyed singing hymns.
Staff Focus Groups (3)

Community
• More time to complete the CTP and usually more input from the family

Hospital
• Time consuming – due to “fire fighting”. Thus, mental health crisis/patient’s condition takes priority
• Family often not available to help complete the CTP/staff do not always have the information
• Frequent reviews. Intervention plan used in one of the HBs to supplement the CTP as more up-to-date and when there are lots of clinical changes. Thus, CTP not seen as a live document.
Literature Review: Relevance of Findings to Study

• Spiritual care was considered by Health Care Professionals (HCPs) to be of importance to Persons with Dementia (PWD). However a basic difficulty with providing spiritual care is knowing what is involved in providing it (Bursell & Mayers 2010)

• Many definitions of spirituality in the literature
Definition

• Definition that fits with our study/themes

• “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009, p. 887).
Literature Review

• Association between strong religious affiliation and importance of spiritual care. (Powers & Watson 2011). Fits with our theme on Religion

• PWD have a need for spiritual connectedness with others through various rituals such as bedtime prayers/religious practices; and listening to classical music, fishing, holidays, and bridge, as ways to obtain spiritual fulfilment.

(Powers and Watson 2011, Gardiner 2009)
Literature Review

• Connectedness with others (family, staff etc.) and engagement in activities were strong themes within our study. The social in the domain was more dominant as staff encourage social interaction and activities around the PWD’s personal likes and dislikes such as contact with nature (walks, gardening etc) and creative activities (art, craft work, music etc.) (Powers and Watson 2011, Gardiner 2009)
• *Personhood* seen as a fundamental component of spirituality (Kevern, 2015).

• This was an original theme in our analysis as strongly occurring throughout the whole CTP but not specific to Domain 7.
Literature Review

• HCPs lack confidence and skills in assessing and making sense of spiritual needs (Keast, Leskovar, & Brohm, 2010)

• Lack of preparedness of staff was also a key finding in the RCN national survey of over 400 nurses in the UK (RCN 2010)
Conclusions

• We identified that spiritual needs were mainly documented with references to the person’s religious affiliation and associated religious rituals/practices.
Conclusions (2)

- The focus in Domain 7 was on social needs e.g. engaging in meaningful / purposeful activities and helping maintain social connections – “broader aspects of spiritual care”
Conclusions (3)

- Staff recognised that spirituality was broader than a person’s religious affiliations, but capturing this on the CTP was difficult.

- Staff agreed that training in completing the CTP would be beneficial, but especially to complete domain 7 as this was the least completed of all the 8 domains.
Conclusions (4)

- The entire CTP needs to be analysed because this documented what person centred care is, and was not specific to one domain.
Acknowledgments

• We would like to acknowledge the support/funding from our 3 participating Health Boards

• We would like to thank the Research Assistants for their role in collecting the CTPs.

• This presentation is based on research supported by the Wales Institute of Social & Economic Research, Data & Methods (WISERD). WISERD is a collaborative venture between the Universities of Aberystwyth, Bangor, Cardiff, South Wales and Swansea.
References and Suggested Reading


References and Suggested Reading


References and Suggested Reading


Thank you

anne.fothergill@southwales.ac.uk