

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

The Research Team

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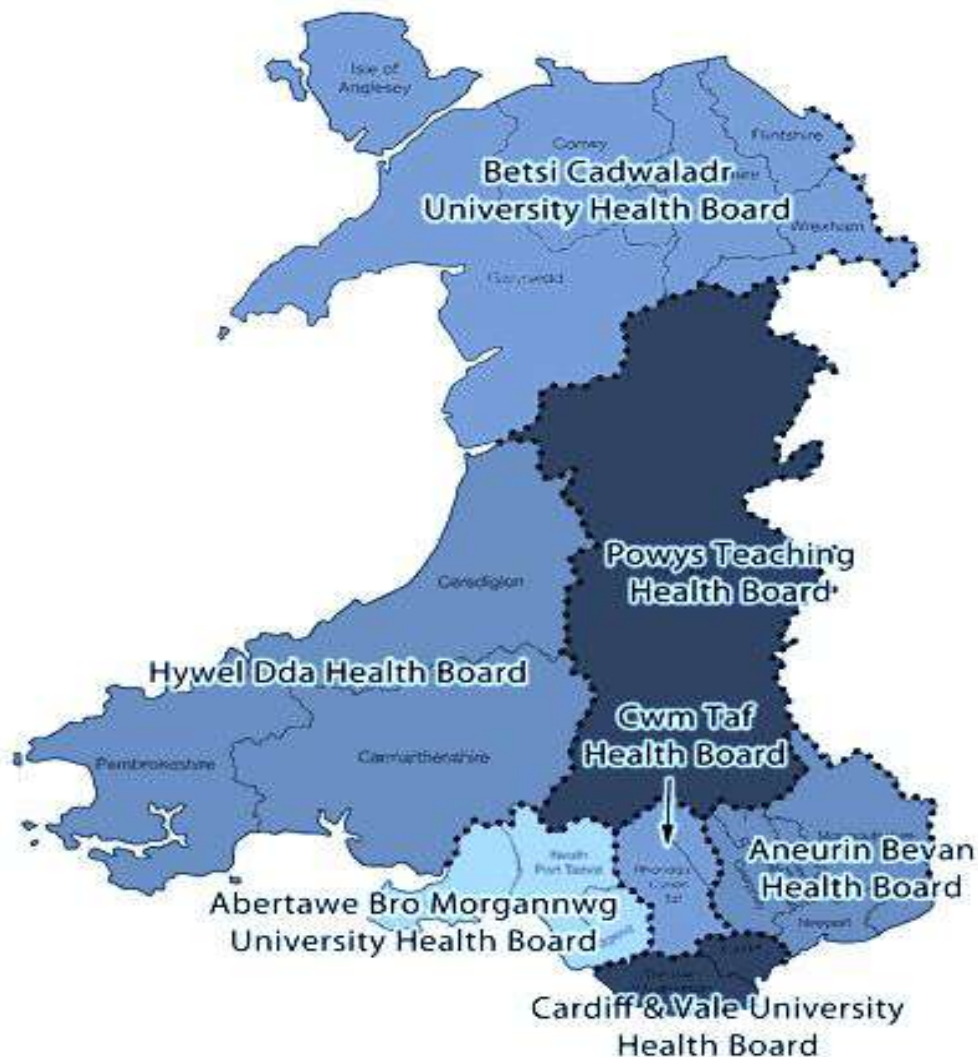
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- Research Assistants:

Abigail Loveitt, Glen Carney & Janine Thomas

Research centres



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 planned

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, 2015)
- Research evidence

Care and Treatment Plan (CTP)

	Outcome to be achieved	What services are to be provided ,or actions taken	When	Who by
e) parenting or caring responsibilities				
f) personal care and physical well-being				
g) social, cultural and spiritual				
h) work and occupation				
Outcomes to be achieved may also be agreed in relation to other areas				

3

Aims

- How are the spiritual needs of patients living with dementia addressed within the 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 of spiritual care in dementia
- Scoping exercise (how many CTP's for people with dementia? Where? how many have Domain 7 completed) – WISERD funded.

Method (cont.)

Phase 2 (Jan-July 2016)

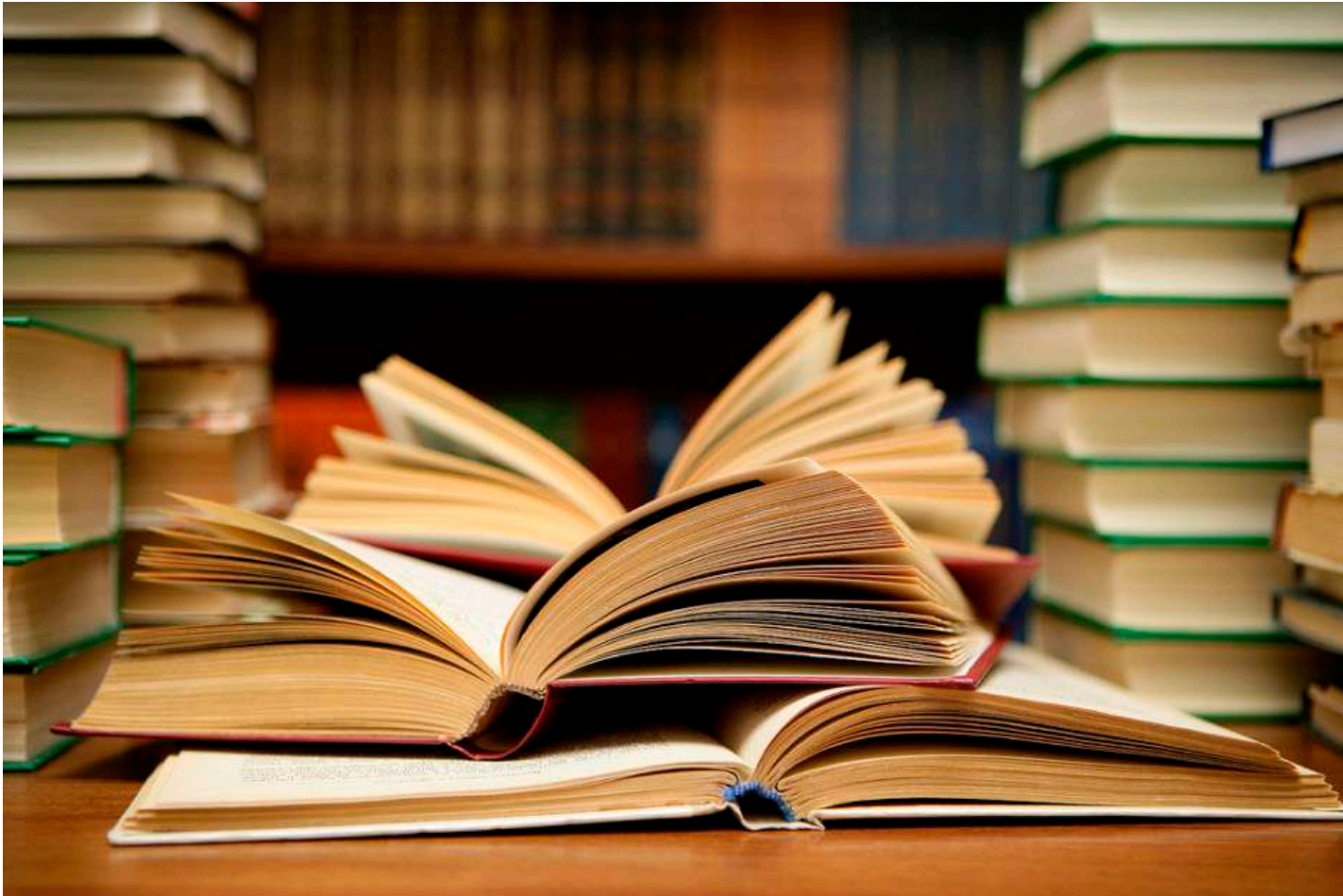
- Sample of 150 CTP's (50 from each Health Board, mix of community & in-patient)
- Thematic analysis of content
- Who completes them?
- How often are they updated?
- How does Domain 7 compare with other domains?

Method (cont.)

Phase 3 (Oct 2016)

- Focus groups (x2) with staff to explore their experience of completing Domain 7

Phase 1 results: Literature review



Dearth of literature

Search terms 'dement*' and 'spiritual*' and
'professional' across 5 databases



104 articles



Refined

(removed: main focus not spirituality, insufficient focus on
staff/carers/PWD, reviews/commentaries)



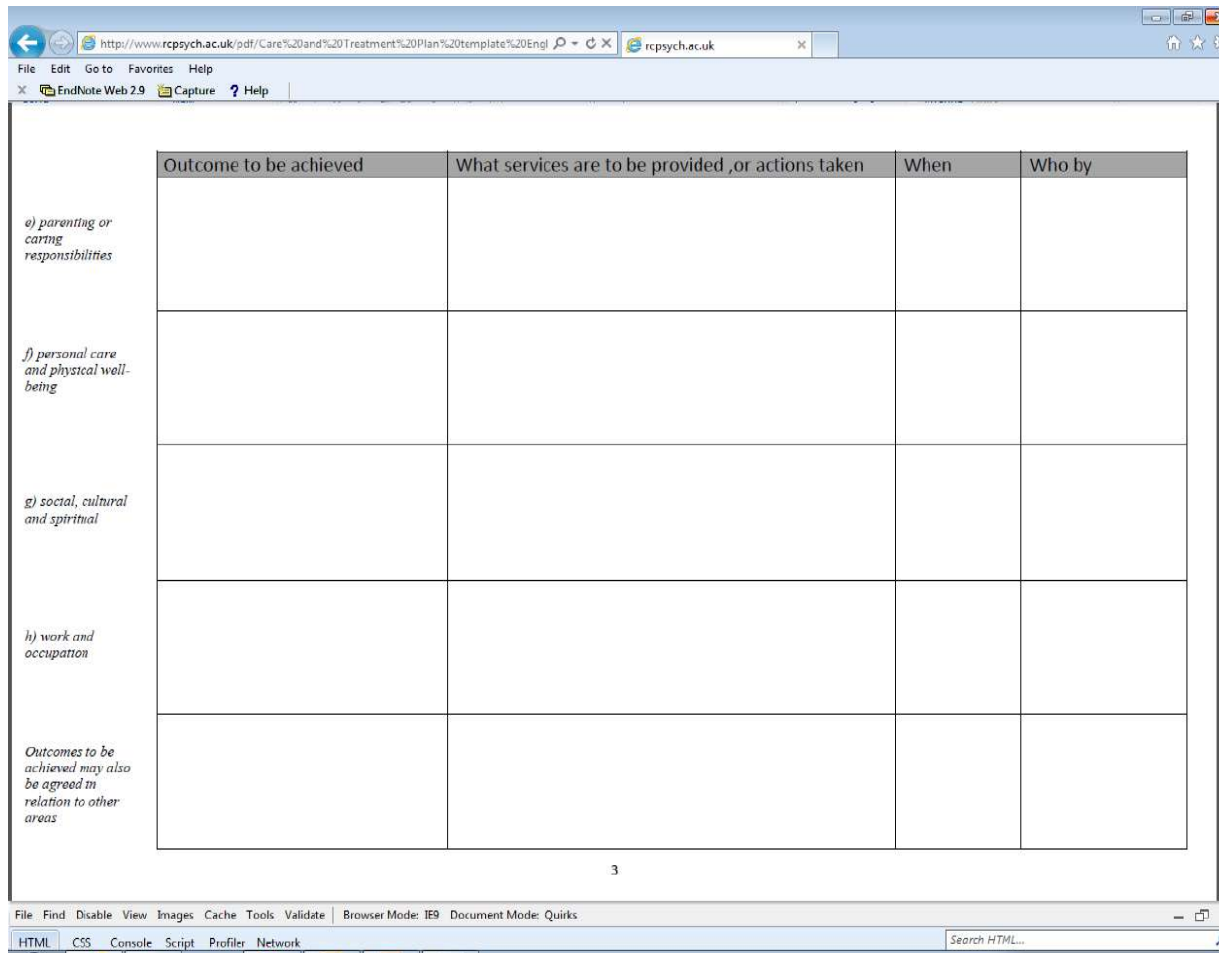
23 (mainly qualitative from USA)

Main points

- Focus: -end of life care (HCP's views) x9
-caregiver perspective x8
- Spiritual care highly valued by caregivers but lack knowledge & skills for assessing/ giving it
- Spiritual care (caregiver view): 'comfort care', focus on religion, referral
- Spiritual care (PWD view): religion, relational, reminiscence

- Difficult to separate spiritual from religious and cultural
 - Important for connecting in ways beyond physical care: meaning, fulfilment, hope, resilience
 - Challenges:
 - assessing spiritual needs (it's complex)
 - responding in ways that are meaningful & appropriate
-
- more education

Phase 2 results: Thematic analysis of CTPs



	Outcome to be achieved	What services are to be provided, or actions taken	When	Who by
e) parenting or caring responsibilities				
f) personal care and physical well-being				
g) social, cultural and spiritual				
h) work and occupation				
Outcomes to be achieved may also be agreed in relation to other areas				

3

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

	Location			
Health Board	Community	Hospital Continuing Care	Hospital Assessment	Total
Aneurin Bevan	11	0	39	50
Cwm Taf	25	4	21	50
Abertawe BroMorgannwg	25	4	21	50
Total	61	8	81	150

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)

	Number (N=)	Percentage (%)
Activities	85	56.7%
Social connections family	73	48.7%
Social connections staff	59	39.3%
Religion	44	29.3%
Supporting family and carers	19	12.7%
Person centred care	13	8.7%
Considered	13	8.7%
Culture	11	7.3%

Frequency of Completion of Other Domains (1-6 & 8)

	Number (N=)	Percentage (%)
Social, cultural, spiritual	150	100%
Medical and other treatments	148	98.7%
Personal care	142	94.7%
Accommodation	140	93.3%
Finance/money	123	82%
Education and training	62	41.3%
Parenting and caring	59	39.3%
Work and occupation	42	28%

Examples: Religious Quotes

- “Mr X 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 Y’s social, cultural and spiritual needs to be considered in the provision of care and recovery of mental health”

Religious Quotes (2)

“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 A’s love of music and weekly singing of hymns is respected and nursing staff are to facilitate these activities for Mr A’s enjoyment”

Person Centred Care Quotes

“Mr C lived with his wife prior to admission and received social, cultural and spiritual support from her. Mr C 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”

Person Centred Quotes (2)

“Staff to build up a therapeutic trusting relationship and to understand likes and dislikes. Carer to be male worker. Carer to discuss with family and Mr C what his likes and dislikes are. Carer to respect Mr C’s dignity at all times”

Person Centred Care Quotes (3)

“To allow Ms C to maintain her individuality. For family to complete the ‘This is Me’ document and following its completion communicate to all members of staff that wherever possible to maintain previous routines”

Phase 3: Focus groups with staff

Focus Groups



The focus groups

- 2 focus groups held in Oct/Nov 2016 (CTUHB, ABMUHB)
- 7 staff attended the first and 4 staff attended the second
- Staff: care co-ordinators, experienced and newly qualified nurses, hospital and community
- 1 hour, tape recorded, tapes transcribed and themes identified

Topics for the focus groups

- 1. Experiences of completing the Care and Treatment Plan in particular focusing on Domain 7.
- 2. Content of the CTP
- 3. Spiritual needs (an aspect of domain 7)

Main themes

- CTP in general
- Hospital/community differences
- Domain 7: social, cultural, spiritual

CTP in general

- **CTP general**
- • All domains seen as important, but not all are completed.
- • Different interpretations of the domains.
- • Differences in the community and hospital and across the health boards.
- • Not always useful; tick box format does not help with relationship building.
- • Who completes it i.e. nurse, MDT, only care coordinator?
- • Who owns the CTP. Few written in 1st person and few signed by the person with dementia.
- • Legal requirement and for audit. Thus, high completion. Content and quality vs quantity.
- • Multiple copies: hard and E copies, which one is most up-to-date.

Hospital/community differences

Community

- More time to complete CTP and usually more input from the family.

Hospital

- Time consuming – due to “firefighting”. 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 used when there are lots of clinical changes. Thus, CTP not seen as a live document.

Domain 7: social, cultural, spiritual

- Least completed of the 8 domains on the CTP
- Most difficult domain to complete
- Not all staff receive training. Training needed in completing CTP in general and Domain 7 especially.
- Spiritual needs seen as broader than the person's religious affiliation/beliefs but more difficult to pin down.

- ‘Spirituality’ is about:
 - The ‘essence’ of who they are
 - Being at peace.
 - The focus of your life
 - Meaning
 - Their spirit
 - Connection: to self, others, transcendent

- Spiritual care
 - Identifying what gives meaning and peace/contentment
 - Identifying what makes them 'at one'
 - It takes time to get to know them

- Lifting their spirits: happy, enjoyment, 'smile on face'

E.g. relaxation, nature, walks, gardening, coffee mornings, arts and crafts, music, pets, hobbies, sport

- Should be appropriate

Not making judgements & respecting beliefs

‘Spiritual’ quotes

- ‘Whatever their focus is in life, like nature...walks....that gives them peace of mind’
- ‘It’s about what brings a smile to their face, what makes it a meaningful day...it’s not just about church or praying’

Literature Review: Relevance of Findings to Study

1. Uncertainty about meaning of spirituality and spiritual care
 - Spiritual care was considered by HCPs to be important to PWD but unsure what is involved in providing it (Bursell & Mayers 2010)
(our focus group themes)

- It's about religion (Powers & Watson 2011).
 - Connection to the sacred or transcendent
 - Religious rituals such as bedtime prayers/religious practices; and non-religious rituals such as listening to music, fishing, holidays, and bridge, as ways to obtain spiritual fulfilment.

- It's about connections with others: relationships with staff and family/friends/neighbours (social connection)
- It's about what gives their life meaning and engaging in meaningful activities

(Powers and Watson 2011, Gardiner 2009)

Strong themes in study

- Connectedness with others (family, staff etc. themes 2, 3) 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)

Literature Review

- *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.

Definition

- Many definitions of spirituality in the literature
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).

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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

- Spiritual needs were mainly documented with references to the persons' religious affiliation and associated religious rituals/practice.
- It was acknowledged that the spiritual is broader but difficult to pin down, assess and document
- The focus in Domain 7 was on social needs

Conclusions (cont)

- The whole CTP needs to be analysed to give a true picture of the care being given
- Staff want training in completing the CTP in general and in completing Domain 7 in particular

Acknowledgments

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- We would like to thank the Research Assistants for their role in collecting the CTPs and staff for their time in participating in the focus groups.
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Training/education

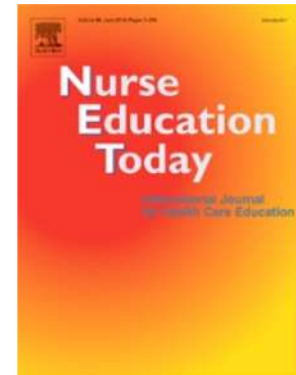


‘Nursing and midwifery students’ perceptions of spirituality, spiritual care, and spiritual care competency: a prospective, longitudinal, correlational European study’

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Thank you