Workshop 1B: Caring for People living with Advanced Dementia and Dying Well

Chair: Professor Claire Surr, Professor of Dementia Studies, National Teaching Fellow, Leeds Beckett University
aqueduct

Achieving Quality and Effectiveness in Dementia Using Crisis Teams

Dr Dons Coleston-Shields

Research Excellence for Innovation

Nottinghamshire Healthcare NHS Foundation Trust
• Increasing numbers of people with dementia live in their own homes
• Crises for people with dementia often lead to hospital admissions
• Crisis Resolution Teams and Home Treatment Teams seek to avoid hospital admissions and treat the service user in their own homes
• Little is known about the service offered to people with dementia
AQUEDUCT programme:

• Aim: To improve the quality and effectiveness of care for people with dementia experiencing a crisis, associated with a reduction in hospital admissions, better experiences for people with dementia and carers, and a reduction in care costs with the use of a resource kit (RK) which can be used by teams managing crisis in people with dementia (TMCDs)

• 3 work packages over 5 years
Services exist across the country that manage mental health crises in people with dementia, but are varied.

We conducted a scoping survey of 200 Trusts in England, receiving responses from 62 managers.

Variety of names for the teams: Dementia and Intensive Support Team, Dementia Crisis Support Team, Dementia Rapid Response Team.

We grouped the teams into three models to look at them in more detail.
Work Package 1

• WP1.1 Understanding Current TMCD Practice and Process
  • WP1.1.1 - Interviews With TMCD Staff Members About Current Practice
  • WP1.1.2 - Interviews With TMCD Staff Members, Service Users and Carers About the Experience of Giving and Receiving Current Practice
  • WP1.1.3 – Focus Groups on Positive TMCD Practice
  • WP1.1.4 – Briefing of TMCD Staff Members With the Home Treatment Package (HTP)

• WP 1.2: Development of the Best Practice Model and Fidelity Measure (FM)
  • WP1.2.1 – Stakeholder Consensus Conference
  • WP1.2.2 – FMv3 Field Testing

• WP1.3: Development of the Resource Kit (RK)
  • WP 1.3.1 – Field Testing the RK
Work Package 2

• WP2.1: Feasibility study of RK for TMCDs
• WP2.2: Economic evaluation of RK
• WP2.3: Focus groups on RK
• WP2.4: PPI Reality Check
The Plan

Work package 3

• RCT to assess the effectiveness of the Resource Kit for TMCDs
Engagement

- Keep people interested in taking part
- Give back to participants
- Generate discussion and ideas
- Disseminate our findings and information about our methodology
Twitter

- Provide updates of progress
- Link to interesting and relevant articles
- Disseminate links to publications arising from AQUEDUCT
- Create interest and maintain engagement amongst NHS staff, academics and public
- Follow other relevant and interesting Twitter users to keep up to date with new information, methods and findings
- Network with other researchers and link to organisations such as The Alzheimer’s Society
- Engage with PPI representatives
Thank you!

For any further information:
Dr Dons Coleston-Shields: dons.coleston-shields@nottshc.co.uk
@AqueductIMH

http://www.institutemh.org.uk/x-research/-/aqueduct
The Continuing Self
Biography, narrative, personhood and the spiritual journey for the person with dementia. A pilot project

Prof Margaret Holloway¹ Dr Mary Laurenson¹ Dr Claire Sloan¹ Dr Dan Harman² Wayne Morrow² Dr Peter Kevern³
1University of Hull  2Hull Royal Infirmary  3Staffordshire University
THE SPIRITUALITY DILEMMA

If we cannot find an understanding of spirituality that is relevant in the case of people with late-stage dementia, either:

(a) spirituality is not, in fact, “part and parcel of what it is to be a person…” or
(b) a person with dementia is not a person
THE PERSON-CENTRED PRACTICE DILEMMA

If we cannot incorporate spiritual needs and resources into person-centred practice with people with late-stage dementia, either

(a) Our practice is not holistic, or

(b) a person with dementia is not a whole person
Refuting notion that personhood contingent upon autonomous decision-making capacity in favour of emotional, social and spiritual aspects of personality

- Regards personhood as having transcendent continuity (Dewing 2008)
- PWD experiences life within complex web of relationships past and present
- Identity linked to own and others’ memories
- Fundamental human needs may become more critical in dementia (Kitwood 1997)
Narrative and biography

- Personal stories as counter to meta-narrative of dementia

- Telling own story is enjoyable and/or therapeutic

- Enables interact with others on own terms/how wish to present self
  - For anyone, personal story is mix of fact and fiction (Baldwin 2005)
  - For PWD may be greater role for others in constructing that narrative

- For professionals, understanding biography enables more accurate assessment and meeting of needs
Spiritual reminiscence

- Spiritual reminiscence = ways of telling a life story which emphasise meaning
- Scant attention given even within ageing research to assessing spiritual needs of PWD, particularly the spiritual journey
  - MacKinlay & Trevitt (2010) used focus groups which took present as starting point
  - Narrative approaches focusing on meanings in everyday (Baldwin 2005) not related to spiritual frameworks
- Practice interventions barely addressed
How can we capture the ‘continuing self’ in the assessment and meeting of spiritual need for the person with dementia?
Project Aims

- To explore the use of biography and narrative to uncover the spiritual journey of the person with dementia.
- To explore the understandings of spirituality, spiritual need and spiritual care held by care workers in this field.
- To compare the care worker’s perceptions with the self-narrative presented by the person with dementia.
- To determine the applicability of this method at all stages of dementia and consider any adaptations required between early and later stages.
- To refine a robust method to inform a wider study which will encompass implications for dementia care.
Project Research Questions

- How does the person with dementia reflect on their spirituality and spiritual journey when recalling their personal biography and telling their story?
- What is the effect of using non-verbal prompts - music, photographs and other mementos – on the process of representing and elucidating meaning?
- What informs the perspective of the care workers and how do they apply this to understanding the spiritual needs and resources of the person with dementia?
- To what extent do the care worker’s assessments (formal and informal) of spiritual needs and resources mirror the spirituality of the person with dementia as conveyed through their personal life story?
Sample of 3 groups of PWD at early, mid and late stage dementia; for each:

a. A conversational interview with the person with dementia and a family member where appropriate, using biographical, narrative and reminiscence tools, use of photo triggers, mementos etc. The purpose is to explore sources of meaning including in relation to life events and changing circumstances over time

b. Semi-structured interviews with their key worker/paid carer exploring her/his understandings of the concepts of personhood and spirituality and how they apply in their work and the extent to which and how they seek to address spiritual needs with this individual person with dementia
Discussion Session

15 Minutes
Yorkshire and the Humber Dementia Clinical Network

Time for a break?

15 minutes only please!

www.england.nhs.uk
Workshop 2B: Whole Pathway

Chair: Dr Kathryn Lord, Research Fellow, University of Bradford
Providing effectively for ethnic diversity in dementia

Jan Oyebode and Sahdia Parveen
University of Bradford
In this talk - focus on ethnicity and culture

1. Set the scene
2. Ethnicity influences every part of the ‘dementia journey’ or ‘well pathway’
3. Diagnosing well
4. Supporting well
5. Living well
6. Conclusions
The context

- Estimated 25,000 people living with dementia from ME communities (APPG, 2013)
- Double to 50,000 by 2026 (Wohland et al, 2010)
- Steepest increase expected in South Asian communities (DoH, 2009)
- By 2051 30% African–Caribbean population will be >65 years
- Irish community has the oldest age profile of all ME groups in UK

% 65yrs+ in BAME populations 2001–2051

2 of 7 recommendations:

• Raise awareness for people in BME communities and challenge the stigma
• Improve access to high quality services for people with dementia from BME communities

BUT is it not as easy as it sounds
Issues of ethnicity are complicated ...

- Ethnic communities are many and varied
- Culture changes over time and generations
- Individual stances vary regarding cultural values and beliefs
- Intersection with other issues (class, education, occupation, income)
ME access to dementia services

• Systematic review, Cooper et al., 2010
• ME populations in US and Australia –
  – Later access
  – Less likely to be prescribed anti–dementia drugs
  – Less likely to use 24 hour care
  – Less likely to take part in research
• UK – less information but Manchester (Purandare et al., 2009) and B’ham (Chadha, unpublished), lower and later uptake of health services than expected
Improving provision

Diagnosing well
- Raising awareness in diverse communities
- Improving diagnosis

Supporting well
- Understanding reasons for low uptake of services

Living well
- Culturally adapted carers’ groups
Diagnosing well – the issues

Issues for BAME populations

• Less awareness of dementia, less knowledge of services:
  – different explanations different solutions
• More stigma

Issues in diagnosis

• Lack of cultural competence
• GPs less likely to refer on
• Culturally biased assessments
Raising community awareness: Dementia roadshows

- Explain terminology and language
- Improve understanding of dementia
- Raise possible benefits of early diagnosis
- Improve awareness of how to access services
- Reduce fear and misunderstanding
- Showcase available support

Parveen, Peltier, Powell & Oyebode, 2015; Parveen, Peltier, Oyebode, 2016
Practical lessons

• Facilitators:
  – familiar with community and able to speak languages AND others of different backgrounds – builds trust and understanding
  – used to managing large events and responding sensitively to emotional issues
• Plenty of time for translation – there maybe several languages within one roadshow
• Ensure representativeness during planning – given complexity of inter-community relationships
• Be sure to co-design posters and materials
• Who’s the prime minister?

Move beyond culture bound cognitive tests
The potential of careful culturally aware accounts
Supporting well – the issues

• Later access to services

• Higher drop out rates by South Asian people

Bradford District Care Foundation Trust Memory Assessment and Treatment Services:

– Bradford city, 51% SA referrals, 40% DNA cf 9% of ‘white’ population

• Low uptake of non-domiciliary services

– Family orientation
– Community values and norms
– Lack of appropriate out of–home provision
Facilitators and barriers to attending memory clinics

- Interviews with 8 families

**Facilitators:**
- Value placed on early diagnosis/importance of attending appointments/positive experiences of men clinic staff/Alz Soc staff/social workers

**Barriers:**
- Perceived lack of information (about diagnosis/dementia/services/memory clinics)
- Views of medication
- Communication issues (around follow-ups/primary care and secondary care, lack of trust in HCPs)
- Setting of and travel to memory clinics
- Language barriers (or not)/dislike of culture-bound assessments

Shubra Singh, Chris North, Ambreen Kauser, Sahdia Parveen, Jan Oyebode
Living well: Information Programme for South Asian Families (IPSAF)

• Alzheimer’s Society in partnership with ME organisations

• Piloted in 2 phases with 200 people between 2013–15

• Aims to improve knowledge, skills and understanding

• Culturally tailored

• Developed in consultation
The IPSAF programme

Session 1: Understanding dementia
Session 2: Legal and financial aspects
Session 3: Looking after others
Session 4: Looking after yourself
Information Programme for south Asian Families (IPSAF)

- Improved knowledge of dementia and services
- Carers more confident in their role
- The person with dementia was given more choice.
- Families promoted independence and empowerment in the person with dementia.
- Provided carers an opportunity to connect with each other

“When you experience something which devastates you emotionally, you know, big time, it’s so important to find people in the same boat as you”
Living well – issues from IPSAF

• Raise awareness in tandem with developing culturally specific services
• Engage and empower local organisations
• Co-design acceptable social support

“Of course awareness-raising is the key to it, unless people understand what dementia is or what effect it could have in their life, it’s very hard for them to embrace this kind of a course (IPSAF)”
Ethnicity and dementia: conclusions

Diagnosis  Use of services  Move?  End of life

Family care

Majority pathway  South Asian pathway
Narrowing the gap: evidence-based recommendations for provision

• Need to work in close partnership
• Provision needs to build on existing values
• Culturally specific initiatives to raise awareness of dementia
• Develop awareness and services in parallel
• Assessment MUST use appropriate instruments but should also move beyond this to harness the potential of careful culturally aware accounts
• Be prepared to re–design, e.g. change from dyadic model to family based model, as appropriate
Recruitment of BAME communities in research is a challenge?

How do we overcome barriers to involving BAME communities in research?
Thank you for listening

j.oyebode@bradford.ac.uk
s.parveen27@bradford.ac.uk
Evaluating support for carers of people with dementia

Bridging the Gap to Evidence-based Dementia Care, Bradford
Kate Gridley
Professor Gillian Parker
7th December 2016
Specialist nursing support for carers

Current SPRU project:
- Evaluating specialist nursing support for carers of people with dementia: Nov 2015 – July 2017
- Funded by NIHR HS&DR

Focus is Admiral Nursing:
- 65 schemes across UK
- Hosted by NHS, local authorities and voluntary organisations

Vs ‘usual care’:
- Different in different areas
Aims

Explore:

- Processes
  - how services like Admiral Nursing work, what they do, with whom etc.

- Outcomes
  - what they achieve, for individual carers, as well as for other professionals and services

- Costs
  - how much it costs the NHS or other organisations to fund these services, against any savings their work might lead to
Methods

Six work packages:

1) Examine Admiral Nursing database
2) Explore outcomes with carers in focus groups and interviews
3) Conduct survey of carers in 30 areas of the country
4) Further case study work in 4 areas
5) Pilot the new data collection system with one Admiral Nursing team
6) Hold a full day stakeholder workshop to collaboratively produce evidence based guidance
The plan:

- Recruit carers from four areas (two with Admiral Nursing, two without)
- Run 4 focus groups (6-8 participants in each)
- Offer interviews to carers who can’t get to a focus group
- Speak to around 30 carers in total

Simple!
Recruitment was slow and 4 large focus groups was unrealistic. Instead we ran:

- 6 small focus groups
- 13 individual interviews

35 carers recruited in total:

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<th>Two areas with Admiral Nursing</th>
<th>Two areas without Admiral Nursing</th>
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<tr>
<td>• 3 x focus group with 2 to 4 participants</td>
<td>• 3 x focus group with 3 to 5 participants</td>
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<td>• 9 x individual interviews</td>
<td>• 4 x individual interviews</td>
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18 carers in total from AN sites                                    17 carers in total from non-AN sites
Recruitment in non-AN areas was challenging.

In addition to TIDE (national network of dementia carers):

- Carers Centres, forums and trusts
- Dementia Action Alliance
- Dementia specific and older people’s voluntary sector organisations
- Local carer led peer support groups (most successful)
- Local papers (unsuccessful)
- Twitter (unsuccessful)
- Facebook (unsuccessful)
Carer health
- mental and physical

Carer quality of life
- social isolation, reduced time doing things carers value/enjoy vs time off from caring, feeling supported, etc.

Confidence in caring
- not feeling able to carry on caring vs having the strategies and confidence to manage
Qualitative findings used to

Design a survey to capture

◆ Outcomes for carers
◆ Costs to carers (money and time spent caring)
◆ Costs to the wider health and social care system

Send this out in January 2017 to carers in:

15 Admiral Nursing areas
15 areas without an Admiral Nursing service

Compare findings
Next challenge:

Recruiting 590 carers to take the survey!

Going through

- Admiral Nursing services
- TIDE
- Join Dementia Research
- Alzheimer’s Society

Suggestions???

kate.gridley@york.ac.uk
Acknowledgements and disclaimer

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What Works in dementia training and education?

Professor Claire Surr – Leeds Beckett University
on behalf of the What Works study team
Aim and Methods

Aim
To gain an understanding of what constitutes an effective approach to education/training for the dementia workforce

Three inter-related work packages
WP1: Evidence review of dementia education and training across all health and social care settings

WP2: National surveys (on-line)
   Survey 1: Care and training providers
   Survey 2: Staff who have completed dementia training programmes reported in survey 1

WP3: In-depth case studies in up to 12 sites spanning health and social care settings
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Achievements

• Literature review completed and used to inform later phases
• Survey 1 completed and closed – analysis underway
• Survey 2 underway and due to close Dec 2016
• 9 of the 12 case study sites consented and 3 further sites under discussion
• Data collection underway in 6 sites
Survey 1 responses

- Total of 420 responses
  - 237 care providers
  - 134 education/training providers
  - 49 commissioners or networks

- Total of 718 training/education packages reported
  - 387 did not meet any Framework learning outcomes
  - 128 stated covered topics but did not meet any of learning outcomes
  - 204 met at least 1 learning outcome in the framework
Recruitment/participation challenges: Survey 1

- Getting a good response to on-line surveys can be difficult
- Unclear who to target in an organisation with survey 1
- Contact details often not available or incorrect – required hand searching and identification and significant use of social media
- Significant effort and time to promote the survey to organisations
Recruitment/participation challenges: Survey 2

- Survey distribution challenging
- Data protection burdens organisation
- Response rates low for many sites
- Lack of e-mail and internet access for some staff
- Ability to send reminders difficult
Recruitment challenges: case studies

- Move to HRA for R&D approvals caused delays in being able to commence recruitment
- Identifying primary care sites challenging
- Staff availability hampers participation and data collection
- Extensive waits for initial meetings and confirmation of capacity
Summary and discussion question

- Conducting survey and case study research across health and social care is challenging and takes time;
- Identifying the right people and getting surveys to them can be difficult and time consuming;
- Good survey response rates are difficult to achieve;

How can survey research be conducted more effectively across health and social care?
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Contact
Web-site:
www.leedsbeckett.ac.uk/pages/what-works/

@whatworksstudy

www.facebook.com/WhatworksStudy

whatworks@leedsbeckett.ac.uk
Discussion Session

15 Minutes
Yorkshire and the Humber Dementia Clinical Network

Thank you for Attending!

Link to evaluation form and certificate will be sent via email, any problems please email: Sarah.Wood1@nhs.net