“Dementia has got nothing to do with sexuality, when you have dementia that sexual side is gone”: Understanding nursing home staff’s narratives on their roles and duties about sexuality in dementia

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Sexuality in Old Age

- Human sexuality in old age neglected and misunderstood

- Sexual needs within care home settings seen as not relevant, denied, ignored or stigmatised (Shakespear, 2000; International Longevity Centre United Kingdom, ILCUK, 2011; Tarzia et al., 2013)

- Evidence equivocal on whether care home staff have positive or restrictive attitudes towards sexual expression in care homes (Bouman et al., 2007; Glass et al., 1986; Luketich, 1991; Mahieu et al., 2015; Walker & Harrington, 2002).
Sexual Expression in Dementia

• For residents with dementia, the double jeopardy of being old and cognitively impaired compounds the problem (ILCUK, 2011)

• ‘Inappropriate’ sexual behaviors considered as a challenging behavior and psychological symptoms of dementia (Gomes-Pinto & Sikdar, 2014; NICE, 2006)

• Limited studies focused on views of spouses, caregivers & health professionals on what constitutes inappropriate or appropriate sexual behaviors in the context of dementia (Burns et al., 1990; Miller et al., 1995; Mayers, 1998; Svetlif et al., 2005).

• Taboo, subjective and controversial topic

• Variations in attitudes and beliefs result in differential treatment of residents
Guidelines on sexuality and dementia in a care home setting

Older people in care homes: sex, sexuality and intimate relationships
An RCN discussion and guidance document for the nursing workforce

The last taboo
A guide to dementia, sexuality, intimacy and sexual behaviour in care homes

www.ilcuk.org.uk
Aims of the study

1. Understand the social representations held by nursing home staff’s towards dementia and sexuality within the context of institutional care

2. Explore the challenges and dilemmas they may experience and the roles they may adopt whilst responding and managing sexual needs and expression for residents with dementia
Research Methodology

**Design:** Qualitative Study

**Participants and Recruitment:**
Two nursing homes in Greater London, U.K.
8 nursing staff (2 men & 6 women)

**Data collection**
Using a semi-structured interview guide

**Data analysis**
Interpretative Phenomenological Analysis (Smith, Osborn & Jarman, 1999)
<table>
<thead>
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<th>Demographic Characteristics</th>
<th>20 - 30</th>
<th>3 (37.5 %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>31 - 40</td>
<td>3 (37.5 %)</td>
</tr>
<tr>
<td></td>
<td>41 - 50</td>
<td>2 (25 %)</td>
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<tr>
<td>Ethnicity</td>
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<tr>
<td></td>
<td>BAME</td>
<td>4 (150%)</td>
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<tr>
<td>Length of time as carer</td>
<td>Under 1 year</td>
<td>2 (25%)</td>
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<tr>
<td></td>
<td>1-5 years</td>
<td>5 (62.5 %)</td>
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<td></td>
<td>11-15 years</td>
<td>1 (12.5%)</td>
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<tr>
<td></td>
<td>Muslim</td>
<td>1 (12.5%)</td>
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<tr>
<td></td>
<td>Christian</td>
<td>4 (50%)</td>
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<tr>
<td>Education</td>
<td>Less than High school</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td></td>
<td>High school</td>
<td>3 (37.5%)</td>
</tr>
<tr>
<td></td>
<td>College/ Undergraduate</td>
<td>3 (37.5%)</td>
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</tbody>
</table>
Findings

1. Representation of Sexuality in Dementia
2. Perceived roles and responsibilities relating to duty of care
Representation of Sexuality in Dementia

Importance of Sexuality across the lifespan

Sexuality and Intimacy forgotten in Dementia
Importance of sexuality across the life span

- PWD continue to have the same rights as everyone else.

- Sexuality key component of ageing process, quality of life and wellbeing, where personhood prevails over the illness.

- PWD allowed to freely express these desires. However, resident’s own health and safety of others residents’, remains a primary concern.

“Sexuality is a big part of life, even though they have dementia they still feel sexually, they still express their sexuality then yeah (pause), they can as long as it is safeguarding other people, as long as it is not harming any other people, then that’s fine.” (Joanna, health care assistant)
Sexuality and intimacy forgotten in Dementia

- Dementia becomes a defining characteristic of the individual
- Reductionist biomedical view of dementia
  - Objectification of people with dementia with their personhood undermined
  - Focus on the degree of neurological impairment and their physical health rather than the social and psychological needs

“I don't really know because, dementia got nothing to do with sexuality (laughs) because, when you have dementia that sexual side is gone. So it is not there, the desire is going, the feelings is gone, so it is difficult really (mhm). It is really difficult (okay).” (Katie, healthcare assistant)
Perceived roles and responsibilities relating to duty of care

- Adopted a role or a combination of roles
- Roles were not mutually exclusive or static but evolve with time and context
- Depended on severity of the condition, perceived or actual involvement of family and own personal views on their duty of care, old age, sexuality and dementia.
Facilitator

- Adhering to resident wishes and needs by normalising sexual expression and intimate relationships in the care home setting

- “Behind closed door” – Promoting a culture of acceptance that older people with dementia have a need for intimacy, wanting to protect a resident’s privacy, dignity, choice and control

“...you are working in an environment where you are suppose to support people, so that support should given with no bias at all. Because, that is in their care plan, that is what you said you would adhere to, so get on with it basically. It is their choice, so that is what it is (yeah)… You are there to meet their needs, it is not about you, it is about them so you should (yeah).” (Vanessa, health care assistant)
Empathiser

- Identified with the predicament of the resident

- Asking the “right” questions, listening and learning in a non-judgmental, selfless manner and being open to ongoing interpersonal engagement

- Relational elements of care more important than professionalised and formal tasks

““Why because, they are human like you and tomorrow it is your turn (pause). You imagine yourself if I get to that that stage what will I tell my people to do.” (Sara, duty manager)
Observer

• Expression of sexuality as a personal matter - does not require intervention and assistance

• Embarrassed or feel ill equipped due to lack of experience as a way for managing stress and discomfort

• “Sitting on the fence” mentality with ambivalent attitudes leads to inaction, with staff bystanders rather than active providers of care

“It is a very personal thing isn’t it!? So maybe people might think, oh because it is very personal, I don’t want to get involved in that.” (Jane, health care assistant)
Informant

- Seeking for affirmation of their decisions from the residents’ families
- Need to avoid conflict with families (they know best mentality)
- Families perceived as omniscient

“Because, the families know what they want, the families will know what they want, they know what is good for them, they are the ones to told us, I want this for mother, I want this for my father, you understand ...” (Jacob, nurse)
Distractor

- Sexuality in dementia seen as a behavioral issue, or as something that takes place in the wrong place and time

- Staff choose to tune attention to irrelevant distractors to stop any activity

“Yeah I don’t think so because, when they express themselves, we try to divert them and try to not get into that sexuality. We understand their feelings but we generally avoid them because, we can’t do anything anyways.” (John health care assistant)
Safeguarder

- Emphasis on the severity of dementia and capacity to make informed decisions
- Preserving the sanctity of marriage
- Fine line between safeguarding and violating the resident’s basic human rights
- Not prepared to challenge their own religious, moral and ethical values at the expense of adhering to the resident’s own value systems
Discussion

• Move away from describing sexual behaviors as appropriate and inappropriate

• Medical model still prevails in care homes with biological issues supersede psychological issues

• Clearly a need to focus on personal centered dementia care

  • Extreme cautionary stance, which emphasizes the risk of abuse to the resident and thus, aims to stop and avoid sexual relationships
  • Person-centered model of care, takes into consideration the residents’ individual autonomy and dignity and thus, aims to encourage sexual expression in a safe way
Implications for practice and policy

• Is there a need for policy?
  – In the absence of clear guidelines and policies the judgment about what may be considered appropriate behavior regarding sexual expression was based on their own values, attitudes and a case by case assessment
  – to reduce variations in practice, which acknowledged the subjective nature of the issues

• Is there a need for training?
  – Training could get people to identify with a role or a combination of roles depending context and time
  – Identify the strengths and weaknesses associated with each role
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