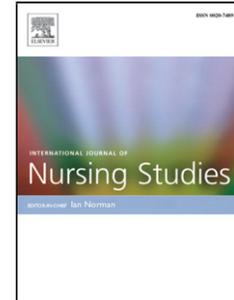


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“Behind Closed Doors with open minds?”: A qualitative study exploring nursing home staff’s narratives towards their roles and duties within the context of sexuality in dementia

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Abstract

Background: Despite sexual expression being recognised as a fundamental human need, sexuality in old age is often ignored and frequently misunderstood, with residents with dementia in a nursing home often viewed as asexual or incapable of being sexually active.

Objectives: The current study aims to understand the views held by nursing care home staff towards dementia and sexuality and explore the roles they may adopt whilst responding and managing sexual needs and expression for residents with dementia.

Methods: Face to face, in-depth, semi structured interviews were conducted with eight staff members working in two nursing homes in Greater London, United Kingdom. Data were analysed using Interpretative Phenomenological Analysis.

Results: The findings suggest that representations of sexuality in dementia held by nursing home staff ranged from the perception that sexual expression in old age was part of human nature and a basic human right to others that proposed that with the loss of memory, people with dementia may also experience loss of interest in sexuality and intimacy. Based on the representation of sexuality held (personhood versus biomedical model), nursing home staff adopted a role or a combination of roles (a facilitator, an informant, a distractor, an empathiser, a safeguarder) that legitimised past and anticipated responses in managing sexual expression in the nursing home setting. Nursing home staff's responses varied depending on the severity of the condition, level of involvement of the resident's family and their own personal views on their duty of care, old age, sexuality and dementia.

Conclusion: The simplified binary labelling and classification of sexual behaviour in dementia as appropriate or inappropriate often applied in institutional settings, fails to account for complex factors that may influence staff's decisions on the ethical dilemmas raised by dementia. A role based continuum approach could help staff move away from rigid binary judgments and train them to adopt formal carer roles that promote a more contextualised rights based approach in the provision of dementia care.

Keywords: Dementia; ; ; ; , Older people, Long-term Care, Nursing Ethics, Nursing Homes, Sexuality

1. Introduction

Sexuality is viewed as a core need and a right throughout the life span of an individual that takes into account their gender roles, identities, sexual orientation, activity, pleasure, eroticism and feelings of intimacy (World Health Organisation, 2006). Although the right to be sexually 'alive' is recognised as a fundamental human need, sexuality in old age is often ignored, neglected and frequently misunderstood (Walker, 1997), with older people often viewed as asexual or incapable of being sexually active in society and its institutions (Hajjar & Kamel, 2003). In care home settings, there is variation in how the sexual needs of older people are perceived and managed and often limited discussions about their sexual needs and desires of older people take place (Mahieu & Gastmans, 2015). More recent studies have suggested that nursing staff appeared moderately knowledgeable about aged sexuality and displayed positive attitude toward sexuality in older people (Mahieu et al, 2016).

There are no universally accepted definitions for long-term care facilities. Nursing home provides room and board and 24 hours day assistance with activities of daily living, personal and psychosocial care. The availability of services varies from facility to facility and from country to country. Nursing homes mainly serve frail elders with chronic diseases, disabilities, either physical or mental (mainly dementia) or both (Ribbe et al., 1997). Nursing homes are complex bureaucratic, adaptive systems with a number of diverse agents with various cognitive schemas, skill sets and agendas interacting with each other to deliver care (Anderson, Issel, & McDaniel, 2003). In the context of sexuality, participation in decision-making involves the negotiation of different and often, conflicting positions held by manager, family and colleagues (Joseph Rowntree Foundation, 2008) and therefore, these decisions are made in a non-discrete manner and in a relational context where the needs of multiple residents, workplace demands, and the general context are considered simultaneously.

In institutional care, when the resident has dementia and sexuality is being considered, there are further taboos at play (Kessel, 2001). The onset of old age, admission to a care home and

increasing cognitive dysfunction do not necessarily diminish sexual desires and needs (Higgins et al., 2004). For residents with dementia, the double jeopardy of being old and cognitively impaired compounds the problem further (International Longevity Centre United Kingdom, ILCUK, 2011). While residents may want their sexual desires to be acknowledged (Aizenberg, Weizman & Barak, 2002; Casta-Kaufteil, 2004; Lemieux et al., 2004), care home staff often report difficulties when encountering sexual situations for residents with dementia, due to their communication difficulties, declining decision making capacity and staff's own desire to protect and maintain the resident's dignity (Ehrenfeld et al., 1997; Tarzia et al., 2012). Resident and staff safety, risk of abuse, aggression and inappropriate sexual behaviours (ISB) are some of the key concerns of care home staff when responding to sexual relationships involving residents with dementia (ILCUK, 2011; Villar et al., 2014). On the other hand, the benefits of sexual expression and intimacy for older people with dementia, such as the enhancement of self-esteem, general health and wellbeing are well documented (Kuhn, 2002).

Some studies suggest the prevalence of inappropriate sexual behaviours (ISB) amongst residents with dementia is relatively low (Alagiakrishnan et al., 2005; ILCUK, 2011; Series & Degano, 2005), but others claim that their prevalence and impact are substantial (Cubit et al., 2007; Lonergan et al., 2002; Scott et al., 2002). ISB is often seen as a part of the symptom cluster of behavioral and psychiatric disturbances associated with dementia, which is often disruptive and distressing for both patient and their carers (Johnson, Knight & Alderman, 2006). ISB has been described as a disruptive behavior characterised by a verbal or physical act of an explicit or perceived sexual nature, which is unacceptable or misplaced within the social context in which it is carried out (Johnson, Knight & Alderman, 2006). This definition of ISB means that judgments made by care home staff concerning what constitutes appropriate and acceptable in any given time and context may vary and be informed by the culture and policy of the institution and staff's own attitudes, beliefs and values about dementia and ageing (Higgins et al., 2004, Johnson, Knight & Alderman, 2006). For example, in more hospitalised environments and in nursing homes where

there is relatively less privacy and a more medicalised/pharmacological approach to dementia care, there may be a different approach to the management of ISB dementia related behaviours (Joller et al, 2013). Lester, Kohen, Stefanacci and Feuerman (2016) found that the rates of policies related to sexual activity in nursing homes were low and the policies and restrictions were not uniform. Guidelines on sexuality in a care home environment have recommended changes in practice to promote a right-based approach to sexuality, privacy and dignity in dementia (Heath, 2011; ILCUK, 2011).

Given the variation in how sexual relationships and dementia related ISB are managed and evaluated in institutional care (Johnson et al. 2009), there is a need to move away from a simplified binary labelling and classification of a sexual behaviour as appropriate or inappropriate and develop a more contextualised and in-depth understanding of care home staff responses to ethical dilemmas of this nature. This study therefore aims to understand the views held by nursing care home staff towards dementia and sexuality. It will explore the challenges and dilemmas they may experience and the roles they may adopt whilst responding and managing sexual needs and expression of/for nursing home residents with dementia.

2. Method

Design

Face-to-face individual in-depth interviews were selected due to the sensitive nature of the topic.

Participants and recruitment

Nine nursing homes in Greater London providing care for people with and without dementia were invited to participate in the study and only two allowed access to their staff. Nursing homes rather than residential care homes were selected as previous research has highlighted that nursing staff demonstrate more restrictive attitudes towards sexual expression involving residents with dementia (Benbow & Beeston, 2012). Of the 9 nursing homes approached, 4 homes provided for elderly care and 5 for specialist dementia

care and had a range of occupancy (4 homes with under 50 bed capacity, 2 with a capacity of 50-75 beds and 3 with a capacity of between 75-100). The two nursing homes recruited were from the mid capacity range (50-75 bed capacity) and one nursing home specialised in dementia care. There were differences noted in the participating and non-participating nursing homes.

The manager of each care home was sent an invitation letter and information sheet explained the purpose of the study. Managers were also contacted by a telephone call in order to assess their interest in participation and to arrange a meeting to discuss the project. 6 care home managers declined participation at this stage citing a variety of reasons: too busy (n=3), failed to respond to multiple requests (n=2) and uncomfortable with the topic (n=1). Following the managers' approval for the care homes to be involved, nursing home staff were provided with a letter and information sheet inviting them to take part in the study. In total eight nursing staff, two men and six women participated in this study. Details of their demographic and relevant background information are presented in Table 1 below, which are broadly representative of the care home workforce in England (Hussein & Manthorpe 2012), apart from their educational attainment. The time and place of the interview were arranged directly with nursing home staff.

[Table 1 about here]

Data collection

Prior to the interview, participants were given a study information sheet to read, detailing what participation in the study would involve, and were asked to sign a consent form. Interviews lasted approximately 45 minutes. Prompts were used to gather as much relevant information as possible. Data were collected using a semi-structured interview guide. The interview schedule was not prescriptive but was used to facilitate an in-depth discussion on their wider role in a nursing home, views on sexuality in old age, views on sexuality in dementia and sexuality in a care home setting. Participants were also asked to recall events where they themselves or another colleague were uncomfortable and comfortable with sexuality being displayed by someone with dementia in a care home. Face-to-face interviews were conducted at participants' workplaces during their working hours.

Ethical requirements

It was emphasised to all participants that participation was voluntary and that their responses would remain anonymous. Confidentiality was assured but participants were informed that confidentiality would be broken if risk of harm emerged. Ethical permission was received from (INSERT AFTER REVIEW) Ethics Committee. No personal details of residents were collected. Interviews were recorded and transcribed verbatim with permission.

Data analysis

Following Interpretative Phenomenological Analysis (IPA) procedures, the transcripts were analysed for recurring themes (Smith, Osborn, & Jarman, 1999). IPA was the preferred method of data analysis as it allows the in-depth exploration of personal lived experiences, the meaning and sense making of these experiences. The transcripts were read and a number of emerging themes were identified. If these emergent themes were repeatedly found across and within interviews, they were noted as recurrent themes. Researchers discussed and agreed upon emergent themes, and examined the transcripts for connections amongst them. Groups of related recurrent themes were organised under a number of subthemes and two main master themes. Interpretations of the themes are illustrated by extracts in text from the transcripts. For reliability purposes all three authors coded the data independently to agree on the emerging themes. Discrepancies and interpretations were discussed within the research team.

In the extracts, (...) indicates that material has been omitted, material in brackets () was added for clarification by the authors and pseudonyms are used to protect the anonymity of participants involved in the study.

3. Results

Analysis resulted in two main master themes, each with constituent sub-themes: (1) Representation of Sexuality in Dementia and (2) Perceived roles and responsibilities relating to duty of care (see Table 2 below).

[Table 2 about here]

3.1. Representations of sexuality in dementia

In this first theme, nursing staff's systems of beliefs, representations of and responses to the needs and expressions of sexuality for people with dementia living in nursing care settings are explored. Nursing staff acknowledged that dementia initiates changes in the person and plays a role in their expression of sexuality and intimacy. Depending on representations of personhood in dementia, and perceptions on the ability and right to express sexuality, participants expressed two views: (1) sexuality as a fundamental component of ageing process, quality of life and wellbeing, where personhood prevails over the illness (dementia) (Sub-theme 1: Importance of sexuality across the life span) and (2) dementia becomes a defining characteristic of the individual that impinges upon their rights and sexual needs (Sub-theme 2: Sexuality and intimacy "forgotten" in dementia). Staff who held the former view challenged its taboo status advocating that the person with dementia had agency and the ability to exercise autonomy. In contrast, some staff believed that as dementia progressed, the quality and nature of sexual relationships changed and had little place in nursing home settings. These participants felt that memory decline and cognitive dysfunction in dementia affected the ability to express sexuality and intimacy as the residents become passive participants in care, in need of protection and no longer capable of making decisions for themselves. The belief held was that residents with dementia progressively 'forget' elements of their past life, lose their physical and mental function including their sexual expression and desires.

"I'm guessing some people just, because they got the dementia they can't communicate, so a lot of people may see it as an inappropriate conversation and don't realize that they are actually frustrated or having those kind of feelings and with dementia some people think they are going to be confused constantly, but just like, some people have good days and bad days, some people may want to talk about it one day, but not the other day. They might just see it as dementia rather than the person behind the dementia and the feelings they are having." (Johanna)

3.1.1 Importance of sexuality across the life span

Some nursing home staff perceived sexual expression in old age as part of human nature and

as a basic human right, important to all individuals regardless of their age, gender, sexual orientation, or cognitive ability. Staff here believed that sexual expression was permissible in a nursing home setting and residents with dementia had sexual urges like other (older) adults and they should be allowed to freely express these desires. For staff, the resident's own health and safety of other residents' was their primary concern with sexual expression only permissible under a controlled environment.

"Yes, because they should be able to express any concerns, wishes or views they have. They are still, a person who is going to have feelings and they should be able to express the ways they want to. But in a controlled safe and environment, where they are not going to cause harm to themselves or other people." (Johanna)

Staff who held these more liberal views towards sexual expression in this group tended to consider dementia as a normal part of ageing, an illness that does not "make the world stop". They acknowledged the declines in cognition but simultaneously celebrated individuality, challenging the myths, stereotypes and social stigma associated with dementia and ageing.

"They are small minded (laughs). Yeah just because you got an illness doesn't mean to say that suddenly the whole world stops. You still got to live your life, some of them will have dementia for ten or twenty years so it doesn't mean the whole world got to stop because you got dementia (mhm). I feel, you still got, even though it is not about having sex or whatever it is still the kissing, the cuddling, the affection and holding hands it is still you know, that's the whole circle of it, it is not just getting our, it is the whole run up and build up to it the actually feeling. It is nice laying in bed with somebody and close to somebody you know, it is yeah, just because you got dementia that doesn't just stop." (Violet)

"I'm guessing like stereotypes got a lot to play in it as well, people seems to think a soon as you hit a certain age, those feelings go and should't be discussed and things like that." (Johanna)

Staff also discussed in-depth the myths and stereotypes in dementia calling attention to the dehumanising way people with dementia are viewed and treated by the society.

“Some people think that with dementia, usually people attribute to dementia to madness. They think they are mad, they called them zombie, so they think they are mad.” (Sara)

Participants trajectory suggested that regardless of capacity and age, people with dementia have an agency to construct, restore and sustain a sense of personhood through personal and intimate relationships.

“As I’m concerned, just because they got dementia they still got those feelings, it is just other parts of the brain that are not connecting really well, but you know you still got, feelings are feelings you know... It is a feeling it something that you know, if you had all your life or most of your life adult life, then I don't think those feelings goes away, well hopefully they don't go away (laughs).” (Violet)

“You wouldn't not say because someone has dementia, you always put dementia in the front and deny them with anything they are saying because, dementia doesn't stop ... But many people have that belief “oh he has dementia what she is saying it is not right” but that is not true. You always make sure you give them a chance and an opportunity to express their views and listen and see.” (Jacob)

3.1.2 *Sexuality and intimacy “forgotten” in dementia*

The contrasting perspective expressed in the interviews was that in order to identify oneself as the same person over time requires memory and therefore, a person with advanced dementia could experience a ‘loss of self’ and become a different person. This contrasts with the earlier views that the person with dementia is the same person through the course of the illness. These varying views on personhood may in some ways explain the different views towards sexuality in dementia and old age.

“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. It is really difficult.” (Katie)

3.2 *Perceived roles and responsibilities relating to duty of care*

This theme describes how participants may seek to construct and verify their roles as formal carers in their interaction with the residents with dementia, their families and other residents in expression of sexuality at the nursing home setting. For most of our participants engaging in behaviours to encompass the expression of sexuality and intimacy of residents with dementia was a new and additional role that they do not readily acknowledge, but negotiate the role depending on their representations of dementia (discussed in previous theme). Staff felt that their job description and role mainly included assisting with personal care, assisting with day-to-day activities, facilitating interactions and treating residents with dignity, respect and compassion and many felt uncomfortable and embarrassed when the topic of sexuality was broached.

“As part of our role we should treat everybody equally and try to maintain their independence and dignity. If they wanted to do something that they used to, we shouldn't stop them, we should encourage and promote it. But when it comes to sexuality, in my option I believe if they wanted to do it then that's up to them, but I wouldn't encouraged it, I wouldn't say it is a part of my role to let them do that.” (Susan)

Staff adopted a role or a combination of roles as a response to managing sexual expression in nursing homes. These roles were not mutually exclusive or static but evolved with time (i.e. depending on the severity of dementia or level of cognitive decline) and context (i.e. sanctity of marriage). Staff members with liberal views tended to be more flexible and receptive to the needs and rights of the residents and to the changing demands of their own roles. On the contrary, staff whose perception of dementia was more informed by the biomedical model tended to focus more on the progressive loss of abilities of the person with dementia and adopted roles that were informed by their own attitudes and views of the resident's

family with sexuality and dementia considered often as mutually exclusive, inappropriate or morally permissible (see Figure 1).

3.2.1 *The facilitator*

Nursing home staff that held more permissive/permissible and liberal views regarding the individuality of those with dementia and the expression of sexuality in these settings perceived themselves as facilitators. This role encompassed adhering to resident wishes and needs by normalising sexual expression and intimate relationships in nursing homes. It was highly salient to their accounts that such a role was in line with guidelines in place that support individual rights, dignity, privacy, choice and control.

“You play a role in like if, somebody says “I want to put on that dress and I want to look sexy”, you will say yes put on that dress and look sexy (laughs). Because, if it is going to make them happy I will put that dress on and the shoes and the bag.” (Sara)

‘Behind closed doors’ was a popular answer given by staff when discussing ways to respond to sexual expressions involving residents with dementia. Promoting a culture of acceptance that older people with dementia may need for intimacy, wanting to protect a resident’s privacy and dignity, and considerations to safeguarding were factors influencing staff’s perceptions about whether redirecting a resident’s sexual expression behind closed doors was an appropriate or an inappropriate solution. Provision of a private space, the option of double bed if possible and ‘do not disturb’ signs may protect residents with dementia to express sexual behaviour in an overt fashion and in an inappropriate place, such as being nude, inappropriate touching and masturbating in communal areas of the nursing home.

“They (two residents with dementia) will go and sleep on the lady’s bed (...) it becomes a big problem (...) Therefore, the doors are to be locked, you know.” (Sara)

“... he got dementia as well and he comes out from the room naked and masturbating in the corridor. So generally take him back to his room then he can do in his room what he wants, but he can’t do it a public place because, that (...) he is doing in front of everybody.” (John)

One nursing home staff member described how a male resident with mild dementia at a certain time of the day would always have his door shut. Additionally, some nursing home staff explained how members of staff knew that the resident was communicating that he wanted privacy in order to express his sexual desires and needs, which made it easier for nursing home staff to respect and even facilitate this behaviour.

“He’s got slightly dementia (...) so about two o’clock you know he got some (pause), porn movies, dvd or videos in his room (...) when the door is shut you don’t go in there, you know. You just let him do whatever he wants to do and when he finishes, he just press the call bell. If, he wants another one (porn movie or dvd) you put another one and that’s it his privacy and then the door is always locked, so we know that.” (Katie)

In everyday nursing home practice, balancing the need for care, observation and safety with an individual resident’s right to privacy and empowerment to live their lives was a delicate issue. Encouragement of sexually intimate relationships behind closed doors was also perceived as an inappropriate and risky solution. Respecting the need to remain undisturbed behind shut and locked doors were perceived as barriers for nursing home staff to assess the residents’ safety.

“... in an environment where it can be contained (...) instead of just two people in their own room discussing it (...) so you can be able to assess the situation and also the risk and factors about it. Making sure everybody is safe.” (Johanna)

3.2.2 *The empathiser*

In this role, staff discussed the ethics of caring focusing on the importance of being respectful and empathetic to the sexual needs of the resident with dementia. Staff identified with the predicament of the resident and understood how it felt to be in another person’s situation. Many empathized beyond their current role as caregivers and anticipated that in the future they may be in a similar position as care recipients. Asking the “right” questions, listening and learning in a non-judgmental, selfless manner and being open to ongoing interpersonal engagement offered them a sense of emotional fulfilment in their role

as carers. It is possible that an empathetic nursing home staff member considered the relational elements of care as more important than the professionalized and formal tasks. Sexuality throughout the life span was not restricted to the suitability of the environment but to a basic human need for connection and a psychological need for intimacy.

“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)

“I won’t just dismiss it, that is not right, I won’t like it if someone said to me “oh you can’t have a relationship with that person because (...)”. You stand up for yourself don’t you, so in a way you need to stand up for them [...] Just because it is in a nursing home doesn’t mean to say it shouldn’t be accepted (...) people shouldn’t think it is just about sex, sometimes two major people have a relationship because, it is about companionship, holding someone’s hands and getting a hug now and then and a kiss on the cheek and it is okay if there is a little bit of playfulness.” (Vanessa)

Endorsement of such a role does not however necessarily mean that their care would entail a set of actions to facilitate sexual expression. The empathizer could also act as a facilitator (described above) but also solely adopt a non-assistive inactive position as an observer (see below).

3.2.3 *The observer*

It is not uncommon for staff to see a resident’s expression of sexuality as a personal matter not requiring intervention and assistance. Staff who adopted the role of the observer may either be embarrassed or feel ill equipped due to lack of experience or training to address issues of sexuality in their practice. Avoidance of such incidents and dissociation from this key aspect of their role as a carer may be a way for managing stress and discomfort. Embracing the observer role reflected a level of ambivalence towards not only their duties of care but also a fixed representation of the importance of sexuality in dementia. Thus, staff adopted a “sitting on the fence” mentality with ambivalent attitudes leading to inaction, where staff considered themselves as bystanders rather than active providers of care.

“As part of our role we should treat everybody equally and try to maintain their independence and

dignity by not you know. If they wanted to do something that they used to we shouldn't stop them to do that we should encourage and promote it. But when it comes to sexuality, in my opinion I believe if, they wanted to do it then that's up to them but I wouldn't encourage it, I wouldn't say it is a part of my role to let them do that." (Susan)

"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." (Vanessa)

3.2.4 *The informant*

The present role focused on the controversy around family involvement in the decision-making about resident's sexual expression in the nursing home setting. Some staff adopt the role of the informant looking for affirmation of their decisions from the residents' families or other staff members exploring an effective team approach. Depending on family demands and mental capacity of the resident such role may evolve to the role of the informant and custodian of relatives' wishes and needs. Many staff members explained that endorsement of the role was mainly guided by the need to avoid conflict with families. Families were perceived as omniscient, in the sense that staff believed that the families knew everything about the residents. Families provided useful information about the resident's personal values and wishes prior to having dementia. Staff believed that obtaining information about residents' family history and values could contribute to nursing homes responding more effectively to sexual expression, often at the expense of individual autonomy.

"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)

"I don't think we should have the actual right to say, yes or no, I think it has to go through family members you know, next of kin or daughter or whoever (...) because they are not my mom and dad (...) I didn't know them before so, because, they are completely different people now than there were before." (Violet)

In contrast to the rest of the nursing home staff, one female health care assistant felt that involving the families while discussing residents' sexual behaviour with staff was not appropriate. She believed that in other similar cases, where the children are the next of kin, the daughter or the son of the resident might not want to be involved due to their own discomfort.

"I'm not being funny, but you're not going to want to listen to your mom talking about her sexual feelings and things like this, or your dad (...) you might get quite embarrassed yourself." (Johanna)

3.2.5 *The distractor*

Similar to the previous role, when situations arise that sexuality in dementia is seen as a behavioural issue or as something that takes place in the wrong place and time and staff chose to turn attention to irrelevant distractors. Although staff did demonstrate awareness of the signals the resident expressed, they did not consider it appropriate and feasible to address the need for intimacy in care.

"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)

Additionally, staff felt that they often opposed sexual expressions in dementia due to families' apprehension and objections to intimate relations arising in nursing homes. In these instances, staff distracted the resident from their sexual urges, which consequently lead to a loss of autonomy for the resident with dementia.

"... she was licking her breast, especially nipples. (...) and when we ask her what is the matter with you or why are you doing this, she then said that, it gives me pleasure (...) anyways (...) she is in her room she can do what she wants. (...) When her daughter saw she was doing these things she got shocked (...) her daughter also said that, if you try to divert her into some other activities (...) So yeah that is the reason why we are trying to divert." (John)

3.2.6 *The safeguarder*

Nursing home staff adopted the regulatory role of a safeguarder to mitigate perceived risk of abuse or nonconsensual sexual activity irrespective of whether they viewed sexuality as a basic human right and attended to residents' sexual needs or viewed dementia as a defining characteristic

The duty of care takes precedence over their own representations and views. While undertaking this role, nursing home staff held salient two values (1) in the best interest of the residents and (2) protecting the sanctity of marriage. Protecting the resident's personal autonomy was an important consideration that nursing home workers took into account when responding to sexuality in dementia. However, the severity of dementia and capacity to consent influenced the extent to which importance was placed on personal autonomy versus safeguarding. In the instance of mild dementia, staff acknowledged that the person with dementia was able to make decisions about their life and therefore, staff should respect the resident's point of view. Perhaps what one member of staff was referring to when she said "it hasn't gone far yet", was that residents with mild dementia are still able to verbally communicate their wishes and interests and, therefore, it is easier for nursing home staff to trust that they are not physically or mentally vulnerable, so their decision to participate in sexually intimate relationships were indeed in their best interest.

"Oh yeah that one definitely you can ask them, they can make a decision. Because, it is mild it hasn't gone far yet." (Katie)

On the contrary, in cases of severe dementia, nursing home staff tended to view the expression of sexuality as a more complicated issue, since one or both residents with dementia may not have capacity to consent to sexual relations. Staff were concerned that residents with advance dementia are likely to be open to abuse and become "passive recipients" unable to communicate verbally or non-verbally their refusal. It was therefore considered important for staff to monitor continuously the mental capacity of those vulnerable residents and act as custodians to protect and support their choices and needs.

"We got to the last stage (...) sometimes they haven't got a clue, what you said, they don't understand the question or they just agree with you (mhm). They just, do you want chips, yes, do you want potatoes, yes, they just says yes (...) if, somebody else is telling them what they want, they

are just going to say yes anyways (...) If it goes too far, you know, how do we know that one is not taking advantage of the other.” (Violet)

Concerns about mental capacity made staff that held positive views on sexual expression and intimacy in dementia apprehensive about residents’ ability to recognise and respect each other’s boundaries needs and expectations from the relationship. Holding hands and cuddling did not usually provoke strong reactions but for some residents even this level of contact may be seen as problematic causing confusion and anxiety.

“Because a person (a resident with dementia) may feel like instead of talking about it, they might feel they want to be more hands on but the other person might not want that, but only talk about it (...) making sure everybody is safe.” (Johanna)

Staff’s sense making of the appropriateness or inappropriateness of sexual expression in dementia was also influenced by protecting and respecting the sanctity of marriage and partnership between the resident with dementia and their pre-existing partners. Staff believed that they had a duty to respect that sexual expression and a level of intimacy within a marriage or relationship, particularly if the relationship existed prior to admission into a nursing home or prior to the diagnosis of dementia. Sexual expression in the context of recognized relationship has the capacity to bring a source of comfort, closeness and intimacy to all partners involved. However, staff were conscious that their role as safe guarder involved assessing capacity and ensuring that no exploitation or abuse took place.

“... It is not like I have a wife and my wife will say because, I have dementia she will no longer sleep with me, no that is not fair. It is not right for somebody to say that. (...) because, if you have dementia and you have a wife or a partner, nothing will stop you for doing that.” (Jacob).

“... if you are in a nursing home and you are a couple (pause), fine. (...) That (sexual needs) continues that is your relationship (...) you can put it in a box and say that is value to them, because that is, that is a closeness, that is an intimate thing (...) you are still a partnership aren’t you and I have no problem with it at all.” (Vanessa).

Whilst sexual expressions within pre-existing relationships were seen as acceptable, some nursing home workers objected to any type of sexual expressions or relationships involving a resident with dementia and another person who was not the resident's partner. This was perceived as an act of disloyalty to the resident's partner who does not live in a nursing home. Staff felt that they had a sense of personal responsibility and duty towards protecting the sanctity of that marriage. The deeply held belief that people with dementia *"might no longer know that they are being disloyal"* made staff feel more accountable to the family.

" Holding hands - obviously fine, but if you kissing another person other than your partner it is cheating." (Johanna).

"But again, they (the family) will say it cannot continue. Because this lady has a husband that comes and take her out." (Sara)

Nursing home staff with strong religious, moral and ethical worldviews, acknowledged that their own personal values, such as religious or cultural beliefs framed their judgment and reasoning about sexual expression in dementia. Taking on the role of a safeguarder was a preferred and safe role for those nursing home staff who were not prepared to challenge their own religious, moral and ethical values at the expense of adhering to the resident's own value systems.

"Yeah because if you are Christian, they (staff) don't believe in sex before marriage (...) if they see a resident maybe showing their sexual nature towards someone else than their partner or towards them, they might think oh no that is wrong." (Susan)

4 Discussion

The aim of this study was to understand the views held by nursing care home staff towards dementia and sexuality and to explore the challenges and dilemmas they may experience whilst responding and managing sexual needs and expression for residents with dementia. The findings make an important contribution to the nursing evidence base on working with people with dementia. The findings highlight the

importance of moving away from describing, labelling and classifying sexual behaviours as appropriate and inappropriate. The decision-making process of responding and managing sexuality in dementia in an institutional setting is a far more complex process that depends mainly on the individual and social constructions of dementia, sexuality and ageing held by the nursing staff. The findings of this study propose a role based continuum model based on which the nursing home staff may identify with a range of distinct non-mutually exclusive roles when faced with the complexity of responding to sexuality in dementia. On the one end of this continuum, staff may adopt roles that facilitate and encourage sexual expression in dementia ('Facilitator', 'Empathiser'), while on the other end they may obstruct sexual interaction and intimacy to protect the resident and safeguard the dignity of resident and the moral norms of the institution and caregivers involved in their care ('Informant', 'Distractor'). To understand the positioning of each participant in this continuum, one needs to understand the interplay of their own personal views on sexuality in later life and dementia, residents' rights and duty of care. Consistent with recent evidence, the study suggested that some nursing home staff held positive attitudes towards aged sexuality and balancing residents' right to sexual freedom against staff's duty to safeguard all patients from harm and abuse play important role (Mahiue et al., 2016). Care home staff that viewed sexuality in dementia as a basic human right and those who prioritised the illness as a salient feature both were cautious and mindful of the complexity associated with balancing rights and duties.

Working so far with the biomedical model, much of the communication and practices surrounding care home staff are in relation to biological issues, resulted in the upheld belief that biological issues and pharmacological treatments supersede psychosocial issues and needs (Elias & Ryan, 2011). Higgs and Gilliard (2016) have highlighted that viewing dementia as 'the loss of self' or 'loss of the person' compromises the individual's agency, awareness, communication, judgments and reasoning. For some staff the reductionist biomedical view of dementia seems to influence their approach to dementia care leading to the objectification of people with dementia with their personhood and sexual needs undermined. Such staff often could only see the dementia rather than the person who may have dementia. Focus was therefore given to the biomedical aspect of illness, such as the degree of neurological impairment and their physical health rather than the social and psychological factors, such as their personal histories, needs,

desires and day-to-day interaction with other people. Nursing home staff in our study, who gave precedence to the medical discourse of dementia, tend to bring attention to the frailty, severity of the disease, objectification, othering and marginalisation of the person with dementia. They often underestimate the agency of the resident and use vulnerability (consent capacity) to justify their over involvement or safeguarding behaviour. Villar et al. (2014) drew attention to the issue that there is a fine line between safe guarding and violating the resident's basic human rights when responding to sexual relationships involving residents with dementia.

Privileging the person-centered model of care (Kitwood, 1997, McCormak, 2004, Edvardsson, 2008), nursing home staff in the current study challenged the views of ageing without agency and took into account the residents' individual autonomy and dignity to adopt the role of a facilitator or empathizer to encourage sexual expression in dementia within these settings. Operating within a relationship centered framework (Talbot & Brewer, 2015) is likely to enhance communication with residents with dementia, helping prevent situations where care home staff feel morally compromised, reduce staff burnout and sub-optimal care (Hayward et al., 2012; Mahieu et al., 2011), which has been reported to be associated with dealing with inappropriate sexual behaviours.

Diversity in what it means to be a 'carer' in a nursing home setting, role conflict and ambiguity seemed to be exacerbated by the lack of training or shared organisational policies and unclear policy guidelines of how to behave and manage this sensitive topic. This may result in the creation of a number of role-identities that each reflect the 'ought' and 'ideal' standards of each of the occupants of that position. Potential conflict and tensions may also arise from the difference between the 'perceived responsibilities' and 'actual responsibilities' or the formal versus informal roles and duties relating to their roles. The variety of roles described by our participants reflected the multidimensionality of caring and echoed the growing tension between the professionalised versus the more intimate and relational forms of care between the carer and residents in nursing settings. What was striking in the narratives of our participants was that making a decision to support or prohibit sexual expression and arriving at a judgment about the 'appropriateness' of the act was far more complex than policy allows space for. The guidelines on sexuality

and dementia that exist (e.g. Heath, 2011; International Longevity Centre United Kingdom, 2011) are non-prescriptive in nature but a list of aspirations with a focus on changing the care home environment. With the current emphasis on a PANEL (participation, accountability, non-discrimination, equality and legality) human rights based approach to dementia practice, there is an increased need to establish clear and concise guidelines and a policy in care homes in relation to sexual expression that would actively involve residents with dementia and their families in decision making (Lester, Kohen, Stefanacci and Feuerman, 2016; World Health Organisation, 2015).

More importantly, there is a need for more open discussions on the topic and additional training for staff as they report confusion or embarrassment when faced with such dilemmas, with some not readily responding to sexual expression as part of their work remit. The use of such a role based continuum approach could initiate discussions about attitude formation, enactment and levels of self-identification with the role(s) and the strengths and weaknesses associated with each role. Moving away from viewing management of sexual expression in dementia as a binary judgment (appropriateness versus inappropriateness) but adopting a role based approach may help care home staff understand the rigidity and/or flexibility of their own cognitions and actions, manage intrapersonal and intragroup conflict and be receptive to change.

Although this study makes an important contribution to the evidence base on sexuality and dementia, there are some methodological issues that should be considered when interpreting the results. The care homes approached were receptive to research, and the study took place in one area of England, which may influence the generalisability of the findings. The self-selecting nature of participation may have also biased the sample, perhaps participants with stronger views on the topic agreed to participate in the study. Considering the sensitive nature of the topic, it is possible that nursing home staff with a more cautious or prudent views towards sexuality did not participate in the study. With a small sample size, it is not possible to draw conclusion on how various SES factors, such as gender, ethnicity and religion may influence care home staff's beliefs and views on sexuality or whether the organisational culture influenced staff's views regarding sexuality in dementia. Future research with a large sample is required to investigate

further the rigidity of those roles and how conflict and movement within the roles are managed.

Furthermore, the potential impact of a theory and practice based educational tool designed to change or challenge decision-making processes of care home staff raised by ethical concerns in the context of sexual expression in dementia warrants further investigation.

Conflict of interest

None declared

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None

Contribution of the Paper

What is already known about the topic?

- Sexuality in old age is often ignored and frequently misunderstood, with residents with dementia in a nursing home often viewed as asexual or incapable of being sexually active.
- Nursing home staff find it difficult or inappropriate to consent to the formation of sexual relationships for residents with dementia, due to their communication difficulties and declining decision making capacity and the conflict between their desire to protect residents and maintain their dignity.
- Much of the evidence in the field has concentrated to how staff may classify sexual behaviour in Dementia as appropriate or inappropriate, failing to take into account the contextual factors that may inform their responses to ethical dilemmas of this nature.

What this paper adds?

- This qualitative study considers how representations of sexuality in dementia held by nursing home staff – personhood versus biomedical model may influence the role they adopt in responding and managing sexual expression in these settings.
- The findings suggest that a role based continuum approach could help staff move away from

rigid binary judgments and promote a rights based approach in the provision optimal dementia care.

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Figure Caption

Figure 1: Perceived roles and responsibilities relating to duty of care



Table 1: Participant characteristics (n=8)

| | | |
|--------------------------------------|------------------------|------------|
| Gender | Male | 2 (25%) |
| | Female | 6 (75%) |
| Age | 20 – 30 | 3 (37.5 %) |
| | 31 - 40 | 3 (37.5 %) |
| | 41 – 50 | 2 (25 %) |
| Ethnicity | White | 4 (50 %) |
| | Asian | 1 (12.5%) |
| | Black African/American | 3 (37.5 %) |
| Length of time as care worker | Under 1 year | 2 (25%) |
| | 1-5 years | 5 (62.5 %) |
| | 11-15 years | 1 (12.5%) |
| Religion | No religion | 3 (37.5%) |
| | Muslim | 1 (12.5%) |
| | Christian | 4 (50%) |
| Education | Less than High school | 1 (12.5%) |
| | High school | 3 (37.5%) |
| | Some college | 2 (25%) |
| | Undergraduate | 1 (12.5%) |
| | Prefer not to say | 1 (12.5%) |
| Position | Health care assistant | 7 (87.5%) |
| | Unit manager | 1 (12.5%) |

Table 2: Summary of the master themes, themes and sub-themes

| Master Themes | Subthemes |
|---|--|
| Representation of Sexuality in Dementia | Importance of sexuality across the life span |
| | Sexuality and intimacy “forgotten” in Dementia |
| Perceived roles and responsibilities relating to duty of care | The facilitator |
| | The empathizer |
| | The observer |
| | The distractor |
| | The informant |
| | The safeguarder |