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TITLE PAGE

Title of Paper:

SEXUALITY & DEMENTIA: AN E-LEARNING RESOURCE TO IMPROVE KNOWLEDGE AND ATTITUDES OF AGED CARE STAFF

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Abstract

Expression of sexuality by older people, particularly those with dementia, can be challenging and confronting for aged care staff. Education on this topic is often a low priority area for aged care organisations and there appears to be limited training programs available. Results from our study highlighted the value of an eLearning education intervention that significantly increased aged care staff and nursing students' level of knowledge relating to older people's sexuality. It also improved their attitudes and permissiveness towards late life sexuality and the expression of sexuality by people with dementia. Furthermore, respondents reported the importance of existing workplace policy (if any) on the expression of sexuality, the overall signs of wellbeing and ill-being exhibited by people with dementia, and the need for guided discussions with family members. Significant improvements in staff understanding and response towards the expression of sexuality by people with dementia may enable the facilitation of a care environment that is supportive of the verbalisation and expression of sexual preference, need and desire by people with dementia. This can, in turn, improve quality of life, health and wellbeing for people with dementia as well as reduce potential tensions between staff-resident-family when sexual expression is considered to be inappropriate.

Introduction

Fundamental to being human, no matter one's age, is expression of sexuality that embodies "*sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction*" (p.9) (World Health Organisation, 2002). Older people's ability to express their sexuality is important to both their physical health (Zeiss & Kasl-Godley, 2001) and psychosocial well-being (Nusbaum, Singh, & Pyles, 2004; Roach, 2004; Robinson & Molzahn, 2007; Zanni, Wick, & Walker, 2003). Older people can continue to engage in sexual activity (Beckman, Waern, Gustafson, & Skoog, 2008; Ferris et al., 2008; Hyde et al., 2010; Lindau et al., 2007; Palacios-Ceña et al., 2012), and those with dementia can go on to develop new and meaningful relationships (Everett, 2007) and partake in sexual expression (Archibald, 2003).

The range of sexual expression by people living in residential aged care facilities (RACFs) includes the maintenance of physical appearance; passing compliments; having close proximity and physical contact (e.g. holding hands, hugging/cuddling and kissing); display of affection; flirting; reading or watching sexually explicit materials; masturbation; as well as sexual intercourse (Nay, 2004). However, sexual expression by residents can cause unease, embarrassment and distress in care staff, especially when people with dementia are involved (Tzeng, Lin, Shyr, & Wen, 2009; Villar, Celdrán, Fabà, & Serrat, 2014), or when staff are confronted with lesbian, gay, bisexual, transgender or intersex (LGBTI) activity (Di Napoli, Breland, & Allen, 2013; Hayward, Robertson, & Knight, 2012). Differentiating between what care staff view as normal and abnormal sexual activity as well as consensual and non-consensual sexual relationships may be difficult for staff to interpret, leading them to be overly cautious or restrictive when people with dementia are involved (Mahieu, Anckaert, & Gastmans, 2014). Furthermore, while there is a growing acceptance of the LGBTI community, concerns over discrimination and lack of sensitivity by care staff toward this population persists (Stein, Beckerman, & Sherman, 2010). Moreover, overtly sexual activity is often deemed to be disruptive and problematic (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005) and rarely seen as beneficial or something to be encouraged (Archibald, 2003) by care staff.

There is increased acknowledgement regarding the importance of sexuality for older people and the need to address sexuality within holistic care (Katz & Marshall, 2004). However, neither sexuality nor sexual health is routinely discussed with older people and

sexual health assessments of older people are not customarily conducted by RACF staff (McAuliffe, Bauer, Fetherstonhaugh, & Chenco, 2015). A possible explanation may be that the majority of health care professionals are reportedly untrained for either a discussion or assessment of sexual health (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005).

Knowledge is important as a higher level of knowledge is indicative of a more positive attitude towards late life sexuality (Mahieu et al., 2015). While doctors and nurses generally possess positive attitudes toward late life sexuality, their knowledge is limited (Di Napoli et al., 2013; Dogan, Demir, Eker, & Karim, 2008; Mahieu et al., 2015). Specifically, younger and less experienced nurses hold more negative and restrictive attitudes toward later life sexuality (Bouman, Arcelus, & Benbow, 2007). Conservative attitudes toward sexuality for older people in RACFs are found in nurses whose responses to residents' sexual expression are influenced by their level of comfort to that expression (Mahieu, Van Elsen, & Gastmans, 2011). A desire for education and training in late life sexuality particularly in the context of people with dementia has also been reported by nurses (Di Napoli et al., 2013). However, education on sexuality and older people is often a low priority area for aged care organisations, and research suggests that there are limited training programs available (Shuttleworth, Russell, Weerakoon, & Dune, 2010).

Improvement in care staff understanding and response towards the expression of sexuality by people with dementia can improve quality of life, health and well-being as well as reduce potential tensions between staff-resident-family when sexual expression is considered to be inappropriate. To date, the limited research on educational interventions has demonstrated that education of sexuality and ageing can improve both knowledge and attitudes of staff in RACFs (Bauer, McAuliffe, Nay, & Chenco, 2013). Currently, no study has looked at the efficacy of an eLearning education intervention that can support self-directed learning and access to training materials by aged care staff. This study aimed to address this gap by evaluating the ease of use, quality and effectiveness of an eLearning education intervention to increase knowledge and improve attitudes of staff toward the expression of sexuality by people with dementia living in RACFs.

Methodology

Design

This study was a sequential mixed-methods design utilising an online self-directed eLearning education intervention, and an online questionnaire followed by an individual semi-structured interview that included a think-aloud protocol.

Participants

Participants were undergraduate nursing students, registered nurses, enrolled nurses, personal care workers and diversional therapists recruited from Griffith University, Queensland and Australian government approved and accredited RACFs providing low and high care to older people with dementia in both Brisbane and Northern New South Wales, Australia.

Educational Intervention

The education intervention was based on the ***Sexualities and Dementia: Education Resource for Health Professionals*** (Jones & Moyle, 2014) developed for the Dementia Training and Study Centre (Queensland - DTSC). Content in the education resource was based on both national and international literature. An Expert Advisory Group consisting of representatives from academia, industry, government, peak bodies and advocacy groups guided the development process. The final education resource was reviewed and approved by the Expert Advisory Group and the Australian Department of Health and Ageing prior to its release in 2013. The initial print version soon ran out and an updated version was released in the following year, as well as an eLearning resource.

The education resource is built around four learning modules: (A) Intimacy, sexuality and sexual behaviour; (B) Dementia and the expression of sexuality; (C) Ethical considerations: policy guidelines development for *sexualities** and dementia in care settings; and (D) Developing *sexualities* and dementia policy guidelines for care practice. Case studies, activities and resources are provided to facilitate and consolidate learning about the various content focus areas. The purposes of the education resource are to:

- increase understanding of the concepts of intimacy, sexuality, sexual behaviours and expression of various types of sexuality (including the benefits of and barriers to expression of sexuality);

- identify dementia-related sexual expression;
- discuss the roles of health professionals and approaches to the expression of sexuality by people with dementia;
- consider the cognitive capacity of people with dementia to have intimate and sexual relationships;
- provide a framework for developing policies / guidelines on sexualities for people with dementia; and
- identify strategies to transfer knowledge of sexualities and dementia into care practices.

This study used the education resource placed on the National DTSC eLearning platform to support self-directed learning.

Procedures

Ethical approval for the study was obtained from the University Human Research Ethics Committee (Ref: NRS/60/13/HREC). Participants were recruited via information flyers displayed in participating RACFs and distributed at information sessions held during staff meetings. Staff who consented to participate in the study received an email containing a URL (i.e. website address) to access the eLearning education resource, online questionnaires and a user name, password and instructions. Prior to completion of the education intervention, participants completed an online questionnaire that consisted of questions seeking demographic information as well as their knowledge and attitudes toward the expression of sexuality by older people in RACFs. Participants had up to four weeks to complete the self-directed resource. Upon completion of the eLearning education resource, they completed the post-intervention online questionnaire (without demographic questions). The online questionnaires and learning modules each took approximately one hour to complete. Participants could complete each module either in one or more sittings. Finally, a purposive sub-sample of the participants was interviewed. As an incentive, participants who completed the eLearning education resource as well as the pre and post-intervention online questionnaires were entered into a draw for one of five \$200 retail vouchers.

Outcome Measures

Demographic information such as age, gender, ethnicity as well as location and length of RACF employment were sought from participants. Knowledge and attitudes of participants toward the expression of sexuality by older people in RACFs were assessed using:

- A. *The Aging Sexual Knowledge and Attitudes Scale (ASKAS)*. The 61-item scale is designed to measure two realms of sexuality: (a) 35 true/false/don't know items assessing knowledge about sexual changes and non-changes related to advanced age in males and females; and (b) 26 items assessing respondents' attitudes toward sexual behaviour in older people on a seven-point Likert scale (i.e. 1 = strongly disagree to 7 = strongly agree) (White, 2004). The ASKAS is appropriate for use in those working with older people. It was also developed for use in assessing the impact of group or individual interventions on sexual functioning in older people such as pre-test and post-test procedures (White, 2004). The ASKAS has been found to be a psychometrically sound and valid tool with a reliability of .85 to .87 in nursing home staff (White, 2004).
- B. *The Staff Attitudes about Intimacy and Dementia (SAID) Survey*. The 20-item survey, using a four-point Likert-type scale, was developed to assist staff members to identify personal attitudes about ageing, intimacy, sexuality and dementia (Kuhn, 2002). While psychometric properties have yet to be determined, the SAID has previously been used in another similar study by Bauer et al. (2013).

A group of participants were interviewed using the think-aloud technique (McAllister, Billett, Moyle, & Zimmer-Gembeck, 2009) where they were presented with two case scenarios of intimate and/or sexual relationships involving an older person with dementia in RACFs (refer to Figure 1). Participants' views of and their approach and response to the scenarios were sought. They verbalised their decision-making process by stating directly what they thought. If participants were silent for more than a set length of time (i.e. five seconds), a prearranged prompt was used to get them talking again (e.g. "Could you tell me what you're thinking about now?"). In addition, the ease of use, quality and effectiveness of the eLearning education resource were evaluated during the interview.

<Insert Figure 1>

Results

A total of 42 participants consisting of 16 nursing students and 26 registered nurses, enrolled nurses, personal care workers and diversional therapists completed the education intervention. Participants' demographics are presented in Table 1.

<Insert Table 1>

Similar with previously reported reliability coefficients for the ASKAS when administered to aged care staff (Bauer et al., 2013; White, 1982), a satisfactory Cronbach's alpha of .93 (i.e. .91 at pretest and .94 at posttest) was found in the study sample. Responses to both ASKAS and SAID items are shown in Table 2 for those items for which a statistically significant change in knowledge and attitude was observed.

<Insert Table 2>

Knowledge of Late Life Sexuality

Total ASKAS knowledge pretest and posttest scores were computed where lower scores indicated higher knowledge level. A Wilcoxon signed-rank test revealed a statistically significant change between participants' pre and post ASKAS knowledge scores ($Z=-2.82$, $p=.005$). Participants scored lower for the ASKAS knowledge items in the posttest ($M=51.0$; $SD=8.56$) than pretest ($M=57.57$; $SD=15.06$). No significant associations were found between demographic characteristics and ASKAS knowledge scores.

Attitudes Toward Late Life Sexuality

Total ASKAS and SAID attitude pretest and posttest scores were computed where lower scores indicated higher permissiveness. Comparison between participants' pre and post ASKAS and SAID attitudes scores were conducted using Wilcoxon signed-rank test. Significant differences were found for both ASKAS ($Z=-2.57$, $p=.01$) and SAID ($Z=-3.14$, $p=.002$) attitudes scores. The total score for the ASKAS attitude items at posttest ($M=41.10$; $SD=11.97$) was lower than at pretest ($M=48.76$; $SD=16.51$). Similarly, the total score for the SAID attitude items at posttest ($M=37.38$; $SD=7.48$) was lower than at pretest ($M=41.90$; $SD=10.88$). No significant associations were found between demographic characteristics and ASKAS and SAID attitude scores.

Think-Aloud Case Scenario

Nine participants were interviewed and presented with the two case scenarios (refer to Figure 1). Analysis of the think-aloud qualitative data was undertaken via a three-step process of referring phrase analysis, assertional analysis and script analysis (Ericsson, 1980; M. Fonteyn & Fisher, 1995; M. E. Fonteyn, Kuipers, & Grobe, 1993). Findings reflect the following three themes (relevant to the case scenarios) and representative participant quotations provide support.

Being Happy and Well

Participants demonstrated that following completion of the education resource, they stopped focusing on cognitive capacity for consent *“Before, I would say no since she [Mrs. Antoine] has severe dementia, now it’s different...”* (#3). Positive consideration was given to people with dementia following their involvement in intimate and/or sexual relationships. Participants also acknowledged that people with dementia can assent to be involved in intimate and/or sexual relationships and they viewed sexual activity resulted in overall happiness and signs of well-being in people with dementia but remained a concern for families *“Seems like they [Mr. Green & Mrs. French] are seeking each other out and happy. Maybe the daughter is only picking on the negative sides of the relationship. Of course, I would check if her concerns are valid but look out for other positive signs of happiness and well-being and point them out to her too.”* (#27).

Conferring with Family

All participants raised the need for discussion with family regarding both family and staff concerns *“It’s important that we don’t have a knee jerk reaction but talk to him [Mr. Antoine] and discuss what has been observed and our concerns for his wife.”* (#3). Several participants also highlighted using the P-LI-SS-IT model of care approach to guide discussion with family regarding intimate and/or sexual relationships involving people with dementia *“I will use the P-LI-SS-IT to talk to the daughter regarding her concerns about her mother’s [Mrs. French] relationship.”* (#14).

Workplace Policy

Participants appeared uncertain if family have the right to make decisions for people with dementia when it comes to allowing or the continuation of a new intimate and/or sexual relationship. Several participants highlighted the need for them to be aware of existing workplace's policy (if any) on residents' expression of sexuality in order to respond appropriately to both residents and their family *"I would need to know if my organisation got anything on it, need to find out cos that will help."* (#7).

Evaluation of Self-directed eLearning Resource

The overwhelming sentiment from participants was that the education intervention was beneficial in increasing their understanding: *"It was easy to read. It helped to understand more on this topic. I learned and got something out of it."* (#34); changing their views: *"It did make me think about other areas I didn't even think about..."* (#6); and providing new ways of responding to intimate and sexual expression by older people including people with dementia in care homes: *"I can try to use some of those strategies in my work."* (#9). However, a number of participants indicated that the delivery of the education intervention via the self-directed eLearning mode, while convenient, did not allow for discussion with others: *"It was quite long to get through alone without anyone else."* (#3) and *"It's great I can do it from home... There's times I thought of examples and would be good to talk about it given the topic but can't do that."* (#34).

Discussion

Overall, results from this study showed that staff knowledge was significantly improved and attitudes were significantly more permissive toward the expression of sexuality by people with dementia living in RACFs following their completion of the self-directed eLearning education intervention. Further analysis showed that (a) knowledge improved most significantly for four ASKAS items relating to sexual desire, responsiveness, satisfaction and ability; and (b) increased permissiveness for three ASKAS and SAID attitude items relating to sexual interest in older people, supporting sexual activity in nursing home and in particular, married couples when one has dementia and residing in a care facility. Staff also appeared to be less reliant on cognitive capacity assessment but focused instead on the overall

happiness and well-being of residents and strategies to respond to intimate and/or sexual relationships of people with dementia. For staff to appropriately respond to expression of sexuality by people with dementia living in RACFs, discussion with family and support from the organisation in the form of relevant guidelines and policy are needed.

Unlike Bouman et al. (2007), who found that older staff or staff with more years of work experience reported more positive attitudes toward later life sexuality than younger staff and staff with fewer than five years of work experience, our results coincide with those of Bauer et al. (2013) where no difference based on demographic characteristics were found. This may be explained by the average age and work experience of staff in both studies being over 30 years of age and 5 years respectively. If the sample had been more representative of the younger and less experienced subgroups, disparities based on age or work experience may have been detected

The education resource included content relating to LGBTI groups and other areas such as sexually transmitted disease (STD) infection. As the study utilised pre-existing scales that did not relate to these areas, knowledge and attitudes of these areas were not assessed. In addition, because of a recent increase in migrant staff from different cultural and ethnic groups in aged care (King & Martin, 2007), cultural effects on attitudes needs to be examined given recent research that demonstrated an association between cultural factors and attitudes toward sexuality (Ahrold, 2010). An all-inclusive survey that encapsulates the scope of these areas is needed.

The validation of the influence of education and knowledge on staff attitudes toward the expression of sexuality by people with dementia living in RACFs in our study is in line with other research (Bauer et al., 2013; Saunamäki, 2010). However, while the education intervention was effective in improving knowledge and nurturing more permissive attitudes in staff, to what degree (if any) this change impacted on practice was not examined in this study or earlier studies. To our knowledge, the impact of these changes on care delivery and resident outcomes remains unknown and requires further investigation.

Lastly, a significant drawback in the chosen method for the education intervention (i.e. self-directed eLearning resource) has been identified. Given the nature of the topic of education, this mode of education delivery lacks the power to engage discussion and,

interaction, and support for practice change. Other education initiatives that incorporate contemporary technology and take into account travel resource limited and time-poor health professionals should be considered. One such example is an interactive live webinar (i.e. seminar via the internet). This method eliminates the need for travel time and expenses. It also provides the opportunity to reach, engage and interact in real time with healthcare professionals located in urban, rural, regional and remote areas of Australia. Importantly, webinar enables the presenter to utilise polls, chats and calls to action, or to show the healthcare professionals PowerPoint slides or videos. Webinar can also be recorded and watched by those who wish to recap the content or those unable to attend (Nurani, 2012).

Overall, the study reported in this paper shows the importance of delivering education to staff and improving knowledge and attitudes on sexuality and older people. Research outcomes reflected significant improvements in staff understanding and response towards the expression of sexuality by people with dementia living in RACFs that may enable the facilitation of a care environment that is supportive of the verbalisation and expression of sexual preference, need and desire by people with dementia. This can, in turn, improve quality of life, health and wellbeing for people with dementia as well as reduce potential tensions between staff-resident-family when sexual expression is considered to be inappropriate.

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Figures

Figure 1. Think-Aloud Case Scenarios (Kuhn, 2002)

Case Scenario 1:

Upon entering the nursing home, the widowed Mrs. French met Mr. Green and they became inseparable, even at bedtime on most nights. Both had a diagnosis of dementia. Mr. Green treated Mrs. French with utmost respect and became very protective of her. Mrs. French clearly enjoyed the attention. Mrs. French's daughter objected to this relationship because Mr. Green often refused to let the staff assist her mother with bathing and her hygiene was becoming poor. The daughter also complained that her mother seemed more confused after the nights spent with Mr. Green. The daughter insisted that they be kept apart at night to enable Mrs. French to receive personal care as well as proper rest.

Care Scenario 2:

Mrs. Antoine was admitted to the nursing home a month ago as her husband no longer felt capable of caring for her at home. Mr. Antoine visits her often and generally appears protective of his wife. Yesterday he was seen taking his wife into her room in spite of her apparent resistance to him. Staff strongly believes that Mr. Antoine initiated sexual contact but wonder if Mrs. Antoine could understand what was happening due to her severe dementia.

Tables

Table 1. Demographic Characteristics of Participants

	Total % (<i>n</i> = 42)
Age⁺ (ranging from 16 to 67 years of age)	38.0(17.2)
Gender:	
Female	90.5
Male	9.5
Nationality:	
Australian	64.3
Overseas	35.7
Most Spoken Language:	
English	92.9
Others	7.1
Level of Education:	
Year 10 and/or below	7.1
Year 12	28.6
TAFE Certificate I-IV	19.0
TAFE Diploma	16.7
Bachelor Degree	11.9
Graduate Certificate/Diploma	9.5
Masters	7.1
Profession:	
Nursing Students	38.1
Diversional Therapist	4.8
Registered Nurse	21.4
Enrolled Nurse	7.1
Personal Care Workers	28.6
Years Worked in Aged Care⁺ (ranging from 0 to 25 years)	5.4(7.2)
Prior Education/Training in Sexuality & Dementia:	
Yes	23.8
No	76.2

⁺ Reported in mean(standard deviation) years

Table 2. Items with Statistically Significant Change following Education Intervention

	<i>p</i> -value
ASKA Knowledge:	
There is a greater decrease in male sexuality with age than there is in female sexuality (<i>improve</i>)	.04
An important factor in the maintenance of sexual responsiveness in the ageing male is the consistency of sexual activity throughout his life (<i>improve</i>)	.02
There is an inevitable loss of sexual satisfaction in postmenopausal women (<i>improve</i>)	.04
Secondary impotence (non-physiologically caused) increases in males over the age of 60 relative to younger males (<i>improve</i>)	.03
ASKA Attitude:	
Aged people have little interest in sexuality (aged = 65+ years of age (<i>more permissive</i>))	.04
If I knew that a particular nursing home permitted and supported sexual activity in residents who desired such, I would not place a relative in that nursing home (<i>more permissive</i>)	.00
SAID	
A married couple, with one spouse living at home and one with dementia residing in a care facility, is entitled to be sexually intimate even though the one with dementia appears unable to give consent. (<i>more permissive</i>)	.03

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