Sexuality, ageing and dementia

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Abstract

Background: Sexuality in later life and its relationship to dementia is a neglected topic: greater understanding of the area has the potential to contribute to the quality of life of people with dementia, their family members and formal carers. We review current knowledge about sexuality, ageing and dementia .

Method: review of the following areas: what is known about sexuality and ageing, and about attitudes to sexuality and ageing; what is known about the relevance of sexuality and ageing to people living with a dementia and their care; and the management of sexual behaviours causing concern to others.

Results: Sexual activity decreases in frequency with increasing age but many older people remain sexually active, there is no age limit to sexual responsiveness, and sexuality is becoming more important to successive cohorts of older people, including people living with a dementia and gay, lesbian, bisexual and transgendered elders. Attitudes and beliefs towards sexuality and ageing are strongly influenced by stereotypes and myths, not only amongst the general public but also amongst those working in health and social care.

Conclusions: Professional bodies should include sexuality, ageing and dementia on their training curricula. More work is needed on the impact of environmental issues, particularly in group living situations, on older adults' sexuality, and on consent issues. Ethical decision making frameworks can be useful in practice. Organisations should investigate how to support staff in avoiding a problem orientated approach and focus on providing holistic person centred care.

Keywords

Attitudes; decision making frameworks; dementia workforce; education; intimacy; relationships; residential/ nursing care; sex; training.

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In teaching, training, service provision and research sexuality and dementia remains a neglected topic but we believe that attention to sexuality and intimacy has the potential to contribute to the quality of life of people with dementia and of their family and formal carers. In this paper we focus on recent literature on what is known about sexuality, ageing and dementia, and draw some conclusions which have broad implications for the education and training of staff working in health and social care and for those providing services for families living with a dementia (for earlier literature see Benbow and Jagus (2002) and Jagus and Benbow (2002)).

What is known about sexuality and ageing?

In February 2011 SAGA Health surveyed sexual activity amongst people aged over 50 asking their panellists to compare their sex life today with their sex life in their 20s and 30s. 85% described a decrease in the frequency of sexual activity but 61% said it was more fulfilling and almost half (42%) of sexually active Saga panellists described themselves as sexually active at least once a week (SAGA Health, 2011). This is not surprising, given existing research findings, but attracted some interesting headlines (eg The over-50s having the time of their (love) lives, Daily Mail, 7/2/2011).

A study in the United States (Lindau *et al.*, 2007) reported on 3005 community dwelling adults who were asked about "any mutually voluntary activity with another person that involves sexual contact whether or not intercourse or orgasm occurs". They found the following figures for reported sexual activity: age 57-64 years 73%; age 65-74 years 53%; age 75-85 years 26%. With regard to women they noted that age impacts on the availability of a partner: at age 75-85 78% of men had a partner, compared with only 40% of women. In those women who had a partner the most common reason reported for sexual inactivity was the male partner's physical health.

A Swedish study on ageing also looked at attitudes to sexuality, frequency of intercourse during the previous 12 months, satisfaction with intercourse, sexual dysfunction, and reasons for cessation of intercourse amongst 70 year olds in 1971-2, 1976-7, 1992-3, and 2000-2001 (Beckman *et al.*, 2008). Table 1 presents some data from that study. The researchers found that later birth cohorts reported a higher level of satisfaction with their sexuality, fewer sexual dysfunctions and more positive attitudes. They concluded that the quantity and quality of sexual experiences amongst Swedish 70 year olds has increased over a 30 year period. The study can be criticised on several grounds. Sexual activity was defined as intercourse and limited to heterosexual activity. Findings were based on self-report and reports of increased sexual activity might reflect increased openness rather than a change in behaviour.

Some authors suggest that it may be appropriate to take a broader view of sexuality in older adults, including touching and holding hands, embracing and hugging, and kissing as sexual experiences rather than focussing solely on intercourse. Another possibility is to focus on intimacy rather than sexuality. A confounder here is that the terms intimacy and sexuality are sometimes used interchangeably (Rheaume and Mitty, 2008). A World Health Organisation document suggests the following working definition of sexuality:

"Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours,

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practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors." (World Health Organisation, 2006, page 5)

This definition includes intimacy as an aspect of sexuality. Intimacy can be regarded as having five components: commitment; interdependence; emotional intimacy (including positive regard); cognitive intimacy (including thinking about the intimate); and physical intimacy (ranging from closeness to sexual intercourse) (Rheaume and Mitty, 2008). Another distinction can be drawn between sexual and non-sexual intimacy (Waite *et al.*, 2009). A study which investigated the sexual behaviours and preferences of older adults living in the community found that most wanted a sexual relationship which included touching and kissing: masturbation and intercourse were not regarded as essential (Ginsberg *et al.*, 2005). This research would suggest that a broader view of sexuality would fit better with the experiences of older adults but there is currently no consensus on this.

The relationship between sexuality and quality of life in older adults has been explored (Robinson and Molzahn, 2007): older adults living in the community who reported higher levels of satisfaction with interpersonal relationships achieved higher scores on a quality of life measure and sexual activity contributed to this. The authors noted that there is a distinct lack of literature on the links between intimacy, sexuality and the quality of life of older adults.

Sexuality and sexual expression in Care Homes is an area which has been reviewed recently (Elias and Ryan, 2011). The review found that interest in sex does not necessarily decrease on admission to care, but opportunities to engage in sexual behaviour do, and that privacy and staff attitudes are major influences on this. They also noted that the model of care in Homes, which is predominantly medical with a focus on ensuring safety and providing physical care, is not conducive to residents' sexual expression. In addition they commented that the wishes of family members are often privileged over the wishes of their older relatives.

Given that older adults are typically perceived to be heterosexual, it comes as no surprise that older gay, lesbian, bisexual and transgendered people constitute an 'invisible' population in society (Department of Health, 2007). Several studies report that sexual intimacy is highly valued in older gay men's lives (Berger, 1982; Gray and Dressel, 1985; Pope and Schulz, 1990). Likewise two studies by Kehoe (Kehoe, 1986; Kehoe, 1988) confirm that older lesbians continue to value sexual expression and sexual intimacy in later life, and where sexual intimacy is absent it is frequently through lack of opportunity rather than through choice. A particular challenge for health services is that many providers report never having encountered gay, lesbian, bisexual or transgendered older clients (Age Concern, 2006), and only 14% of gay, lesbian and bisexual older people report being open about their sexuality with their healthcare providers (Heaphy *et al.*, 2003). It is estimated that in the United Kingdom 5% of the population are gay, lesbian or bisexual (NHS Inclusion Project, 2006) and, given that homophobic attitudes are often encountered in health professionals and health services appear to operate from a default assumption of heterosexuality (Fish, 2006), older gay, lesbian and bisexual people may face considerable barriers in their need for sexual expression. This may be especially true for those living in Care Homes (Ward *et al.*, 2005).

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We can draw some broad conclusions about sexuality and ageing from the literature. Sexual activity decreases in frequency with increasing age but older people remain sexually active, and there is no age limit to sexual responsiveness. In addition evidence suggests that sexuality is becoming more important to successive cohorts of older people and sexual life impacts on well-being. Gay, lesbian, bisexual and transgendered elders constitute a significant 'invisible minority' whose need for sexual expression is not abolished by ageing.

There is an important caveat to add to this, that, although sexuality is important to older adults, care must be taken in two areas: not to over-sexualise older adulthood and not to over-medicalise the changes in sexual function that accompany ageing (Taylor and Gosney, 2011).

What is known about attitudes to sexuality and ageing?

The media portrayal of sexual activity in later life tends to give messages to the public that it is not to be spoken of; may be the subject of humour, embarrassing or unacceptable; and/ or that older adults are unattractive or not interested in sex.

Health and social care professionals are not immune to these messages and the associated myths about sexuality and ageing. In England, sexual health has been absent from policy related to older people's health (Department of Health/ Care Services Improvement Partnership, 2005) and older people are absent from sexual health policy (Department of Health, 2001). Scotland acknowledges the need to define and address the sexual health needs of older people (The Scottish Executive Health Department, 2005) and Wales notes the need to take a lifelong learning approach (Welsh Assembly Government, 2010). In this context it is perhaps not surprising that a study which purported to look at sexual behaviour in Britain looked only at people aged from 16 to 44 years of age (Johnson *et al*., 2001).

Myths and stereotypes about sexuality influence all aspects of older people's care. Gott and colleagues carried out a qualitative study in primary care and found that general practitioners (GPs) regard sexual health as not being a legitimate topic to raise with older adults: they equate it with younger people (Gott *et al.*, 2004). Their beliefs were based on stereotypical views and myths regarding sexuality and ageing and GPs felt uncomfortable and untrained in addressing this area of health.

Residential and nursing home staff members' attitudes towards the sexuality of residents have also been investigated using the Aging Sexual Knowledge and Attitudes Scale (Bouman *et al.*, 2007). Members of care staff were found to be moderately permissive and positive, whereas nursing home staff members were more negative and restrictive than residential home staff. Managers in all homes were more positive and permissive than nursing or care staff. Members of staff who had been working in the area for less than 5 years were more negative than those with greater work experience. Staff perceptions and responses to nursing home residents' sexual behaviours have been shown to relate to both staff members' own levels of comfort with sexuality and organisational ethos (Roach, 2004), and some writers note that sexuality is not regarded as within the scope of the caregiving provided by homes (Nagaratnam and Gayagay, 2002). Allen and colleagues have argued that attention to young adults' attitudes toward late-life sexuality may help lead to interventions to decrease the stigma associated with sexuality and ageing (Allen *et al.*, 2009).

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Negative attitudes toward the sexuality of older residents of nursing and care homes may be further compounded if the resident is gay, lesbian or bisexual. One American survey found that 67% of doctors and nurses stated that homosexual patients were receiving substandard care or were being denied care (Age Concern, 2002). Beehler reported that 25% of health care staff express negative or homophobic attitudes, and it is very unlikely that any in depth assessment is made of an individual's sexual orientation and needs on admission to a nursing or residential home (Beehler, 2001).

It is now well established that survival rates for individuals with HIV in the United Kingdom are such they are able in many instances to live well into old age. A recent national study of people over 50 living with HIV (Power *et al.*, 2010) found that many of those surveyed reported poor experiences of primary care, and feared that social care providers, care homes and sheltered housing might be HIV prejudiced and/or homophobic. Of particular significance in this study was the finding that 20% of those over 50 living with HIV had experienced HIV discrimination in the previous year and that some of the worst experiences of discrimination had been in healthcare settings.

Again we can draw some broad conclusions from these and other studies. Attitudes and beliefs towards sexuality and ageing are often strongly influenced by stereotypes and myths. This is true both amongst the general public and also amongst those working in health and social care. One significant challenge for services is to meet the health care needs of increasing numbers of people over 50 with HIV both now and in the future.

What is known about the relevance of sexuality and ageing to people living with a dementia and their care?

If attitudes towards the sexuality of older adults are influenced by myths, it is likely that attitudes towards the sexuality of people living with a dementia will be even more influenced, and that this might affect aspects of their care.

Spouse carers of people living with a dementia have been interviewed to investigate their perceptions of how the dementia has influenced their marriage including their sexual relationship (Eloniemi-Sulkava *et al*., 2002). Sixty percent reported at least one negative sexual behaviour change (most commonly an increasing inability to pay attention to the partner's feelings and needs) and ten percent reported at least one positive sexual behaviour change. The changes reported, however, had little impact on whether or not the couple continued to have intercourse.

For those older adults who live in institutional care there are a number of important issues including loss of their partner; the relative lack of men; physical health problems; lack of environmental privacy; lack of informational privacy; and the attitudes of other family members, notably adult children. These may be highly relevant to the literature on what is often called 'sexually inappropriate behaviours'. A recent systematic review of argument-based ethics literature (Mahieu and Gastmans, 2011) has highlighted the prominence of the principle of respect for autonomy in ethical debate about sexuality of institutionalised older adults, this principle being privileged over others.

There is little consensus on the terminology or classification to employ for 'sexually inappropriate behaviours'. One classification lists verbal behaviours, physical behaviours and both (Alagiakrishnan

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et al., 2005) with some behaviour labelled as 'sexually ambiguous'. One difficulty here is who decides what is appropriate as people involved may hold different views. An alternative classification refers to 'hypersexual behaviour' (sex talk; sex acts; implied sexual acts eg requesting unnecessary genital care) (Prakash *et al.*, 2009; Wallace and Safer, 2009). Another uses the rather quaint term 'improper sexual behaviours' (de Medeiros *et al.*, 2008) but uses categories of intimacy seeking (eg misdirected affection when someone with dementia misidentified another person as a significant other); disinhibited behaviour (which the authors relate to non-Alzheimer dementias and regard as opportunistic and prompted by closeness); and non-sexual behaviours (which may be mistakenly regarded as sexual by others eg taking off ones clothes in severe dementia). This latter classification draws on interpretations of the behaviours (eg misidentifying someone as a partner; misinterpreting personal care; longing for closeness/ intimacy) and a more descriptive classification would seem more appropriate. The categories of sex talk, sex acts (which might involve self or others) and implied sexual acts are probably simplest to use in practice and avoid interpretations.

Now we come the 'elephants' in the room; capacity and consent. The law on capacity and consent needs to be considered in the context of a particular country. In the United Kingdom the Sexual Offences Act 2003 states that sexual intercourse without consent may be Rape, and any non consensual sexual behaviour may be Sexual Assault (Stevenson *et al*., 2004). In addition the Mental Capacity Act 2005 (which applies in England and Wales) specifically identifies consent to sexual relations as a decision that cannot be made on behalf of a person lacking capacity. Whilst this creates clarity in the law it raises some very difficult ethical and social questions. For example, how will a 'well carer' who has been in a loving and caring relationship for many decades make judgements about what is appropriate or inappropriate sexual behaviour in relation to a partner who may lack capacity? This issue is problematic for carers who are unlikely to know the finer points of sexual offences legislation or engage in formal ethical reasoning about their situation. Whilst the major ethical theories are *normative* in nature, in everyday life people operate to a large degree using heuristics or 'rules of thumb.' A carer might therefore believe that because a partner (who lacks capacity) seems to respond positively to intimate advances that means it is alright to continue. Given that sexual intimacy often occurs in an informal and spontaneous way, between loving partners, in private, deciding what is acceptable must be extremely difficult for the carer, further contributing to the stresses and burdens associated with the role. The International Longevity Centre (ILC-UK, 2011) referred to sexual intimacy in dementia in a recent paper as *The Last Taboo* particularly in relation to the care home setting. Given that the numbers of people with dementia are set to rise in the coming years there is a greater need than ever to establish some clarity in this sensitive area. There is also a pressing need to ensure that such discussions are balanced with the need to protect people with dementia who lack capacity from sexual abuse and exploitation.

Management of sexual behaviours causing concern to others

Tucker wrote a useful review of treatment approaches for 'inappropriate sexual behaviours' in dementia (Tucker, 2010) and divides them into non-pharmacological and pharmacological. She found no randomised controlled trials of treatment and that the literature is based largely on case reports. A wide variety of drug treatments have been used in management but with remarkably little evidence to support their use. Table 2 sets out some of the treatments and techniques found to be employed by Tucker with the addition of suggestions for organisational management.

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Roach looked at staff perceptions of the sexual behaviours of nursing home residents and how they responded (Roach, 2004). She described some staff as 'standing guard' against their personal discomfort, and disregarding residents' sexual needs. However she also describes 'proactive protection' in a setting of a responsive organisation which provides staff education and support; gives residents choice and social stimulation; and facilitates independence and dignity. Figure 1 sets out how Roach's construct of 'proactive protection' might lead to positive outcomes for residents.

Protection can be an important issue as some residents are vulnerable to the intrusive sexual behaviours of others which can be problematic during the night when homes have low staffing levels. Indeed, for staff providing long term care for people with dementia, the main source of tension in respect of sexuality is often the conflict between the need to protect people who lack capacity to consent to sexual activity whilst allowing autonomy of residents who do have capacity (Ehrenfeld et al, 1997; de Medeiros et al, 2008; Elias and Ryan, 2011). Archibald (1998) has pointed out that staff are likely to respond differently to residents of differing genders, with a protective stance likely towards women. There may also be 'protection' issues for the organisation: providers may be concerned about liability should residents be inadequately protected by staff from unwelcome or coercive sexual approaches (Loue, 2005; Wallace and Safer, 2009)

A helpful approach to dealing with these dilemmas has been demonstrated by Ehrenfeld and colleagues who have drawn attention to the sexual needs of older adults with dementia and to the ethical issues involved (Ehrenfeld *et al.*, 1999; Ehrenfeld *et al.*, 1997). They assert that the main dilemma in institutional care is the tension between staff members' desire to protect their elderly residents and maintain their dignity and the residents' desire to fulfil their sexual needs. They describe working with institutional staff on problems they identified using a decision-making worksheet which requires identification of the problem, consideration of personal beliefs and professional issues, and listing a number of possible responses to the problem before selecting a course of action. Their approach can be commended for highlighting the influence of beliefs, the importance of openness, sharing and discussion within the staff team and with other relevant people including relatives, and a recognition that there is no single clear approach to management.

A similar approach is set out in a recent report called The last taboo (ILC-UK, 2011) which is aimed at staff working in care homes. This document sets out lots of ideas about how to improve practice in the area and contains case studies, suggestions, links to useful material and a 12 item quiz designed to get people thinking about the subject and their own beliefs. Its approach is essentially similar to that of Ehrenfeld's group.

Conclusions

Older adults, whether straight, gay, lesbian or bisexual, (just like younger adults) are sexual beings, and their sexuality is important to their health and well-being. This is equally true of older adults living with a dementia. Unfortunately many people are still influenced by inaccurate out-of-date myths about sexuality and ageing: this is equally true of staff working in health and social care.

Sometimes the sexual behaviour of people with dementia causes concern for other people – particularly in institutional care. These behaviours can be classified as sex talk, sex acts (involving self

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or others) and implied sexual acts. There is no single answer to dealing with sexual behaviours causing concern to others and there is little evidence to support the prescription of drug treatments: the best strategy to adopt is one of openness, thoughtfulness, inclusion and discussion. The overall aim is to find a person centred way forward tailored to the individual involved.

Action is needed to improve sexual health in older people with dementia across a range of settings in education/ training and service provision and this should be acknowledged in policy documents. Professional bodies should routinely include sexuality, ageing and dementia on their training curricula, and education and training programmes should include knowledge, attitudes and practice relevant to sexuality, ageing and dementia. More work is needed on the impact of environmental issues, particularly in group living situations. A helpful first step in terms of future research would be to agree operational definitions of sexuality and intimacy applicable to later life. Consent issues are another area where focussed work is needed, including attention to the balance between autonomy and protection, the previous attitudes of people living with a dementia in relation to present attitudes, and family and staff attitudes in relation to the attitudes of people living with a dementia. Ethical decision making frameworks are available in the literature and their use in practice could be investigated and developed. In relation to institutional care settings there is a need to investigate how organisations can support staff in avoiding a problem orientated approach and instead focus on providing holistic person centred care to older adults using health and social services.

We might think that in the 21st century attitudes have changed, but the evidence is that sexuality in later life continues to be a neglected area. As people graduate into later life with greater expectations of remaining sexually active this is an area which urgently needs to be addressed.

Conflict of interest declaration

None.

Description of authors' roles

Susan Mary Benbow carried out the original review and presentation on which this paper is based.

Derek Beeston assisted in writing the paper and added additional review material.

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Table 1: Data from Beckman *et al.*'s 2008 study of Swedish 70 year olds

70 year olds reporting intercourse	**1971-1972**	**2000-2001**
Married men	52%	68%
Married women	38%	56%
Unmarried men	30%	54%
Unmarried women	0.8%	12%
Happy relationships	**1971-1972**	**2000-2001**
Men	40%	57%
Women	35%	52%

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Table 2: Examples of management of 'sexually inappropriate behaviours' in dementia modified from Tucker (2010)

Non-pharmacological treatments	Pharmacological treatments	Organisational management (for institutional care)
Redirecting behaviour	Anti-psychotics	Policies
Education	Anti-depressants	Staff education and support
Counselling	Anti-cholinesterase s	Open communication and discussion
Reorientation	Anti-convulsants	Clear communication with and involvement of relatives
Environmental manipulation	Beta blockers	
Same sex care-givers	Anti-androgens	

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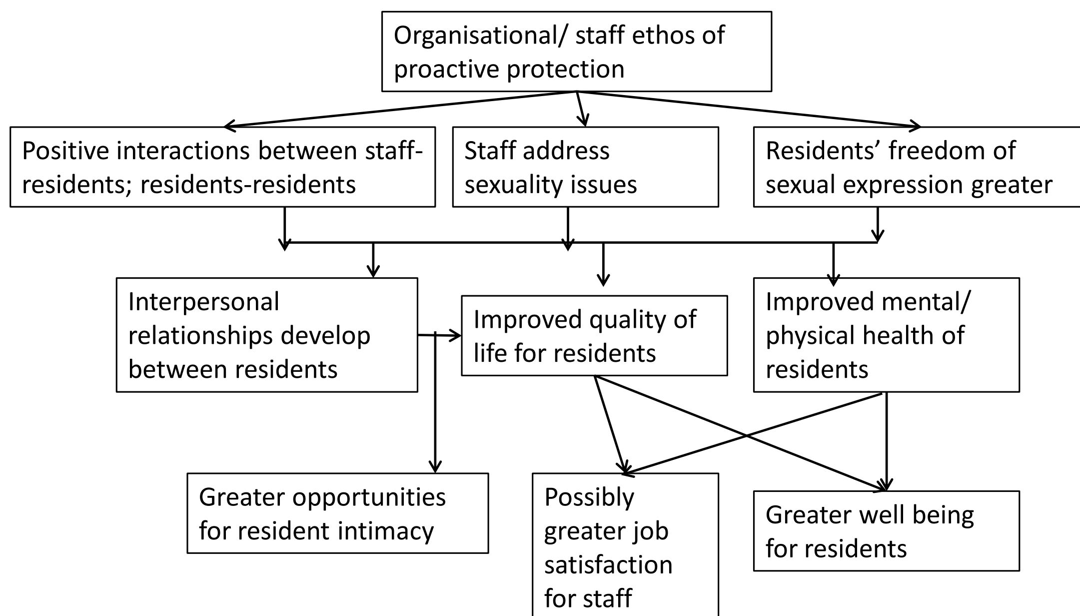
Figure 1: Proposed mechanism for proactive protection leading to positive outcomes for nursing home residents (modified from Roach, 2004)

Note: if staff are aware of the positive outcomes for residents this may increase their job satisfaction and lead to positive reinforcement of the cycle of proactive protection.



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