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‘We’ve Had Our Sex Life Way Back’: Older Care Home Residents, Sexuality and Intimacy

Abstract

Older care home residents are excluded from the sexual imaginary. Based on a consultative study involving interviews with three residents, three female spouses of residents and two focus groups of care home staff (n=16), making an overall sample of 22 study participants, we address the neglected subject of older residents and sexuality and intimacy needs. Using thematic analysis, we highlight how residents’ and spouses’ accounts of sexuality and intimacy can reflect an ageist erotophobia occurring within conditions of panoptical control that help construct residents as post-sexual. However, not all accounts contributed to making older residents’ sexuality appear invisible or pathological. Some stories indicated recuperation of identities and the normalization of relationships with radically changed individuals e.g. because of a dementia. We also examine care home staff accounts of the discursive obstacles that frustrate meeting residents’ needs connected with sexuality and intimacy. Simultaneously, we explore staffs’ creative responses to dilemmas which indicate approaches to sexuality driven more by observed needs than erotophobic anxiety and governance as well as panoptical surveillance.

Introduction

Sex and intimacy are, apparently, for the young. Older people rarely feature in the media as sexual or intimate beings and attempts to represent themselves as such are often ridiculed (Bytheway, 1995). Stereotypically, older people are understood as prudish or past it - sexually 'inhibited or inactive' (Mahieu et al, 2014: 1). Academic theorizing too has largely neglected sex, sexuality and intimacy in later life (Bauer, 1999; Doll, 2012; Gott, 2005; Villar et al, 2014a). In the context of care homes, older residents' sexuality can be considered a challenge because it is thought unusual or else is associated with the disinhibition that can accompany a dementia (Doll, 2012).

Nevertheless, people do not necessarily cease desiring or needing sex or intimacy when pronounced old or when they need to live in a care home (Gott, 2005). For instance, a recent survey of online dating across the lifespan has noted a slight drop in the importance placed on sexual attraction after the age of 60, but that erotic interest did not decrease much further after that age (Menkin et al, 2015). Indeed, sexuality and intimacy can remain important until the end of life (Kuhn, 2002) and older care home residents exhibit diverse responses towards sexuality and intimacy, which include denial, nostalgia and continuity (Bauer et al, 2012).

In light of the prejudices and stereotypes just described, we report on a consultative, feasibility study with a seldom-heard social group, which was conducted in 2014 in Northwest England, concerned with expression of sexuality and intimacy by residents. The study comprised interviews with care home residents, residents' spouses (living outside the care home) and two focus groups of care staff. We focus on care home residents because their opportunities to

express themselves as sexual and or intimate beings are more restricted compared with peer-aged others still living in their own homes (Bauer et al, 2014; Doll, 2012; Villar et al, 2014a).

Essentially, this article examines the discursive obstacles that frustrate residents' sexual and or intimate self-expression. Central to our thinking is our concept of ageist erotophobia (Simpson et al, 2015) in the context of panoptical control (Foucault, 1977). If erotophobia entails anxiety (often unconscious) concerning sexual activity (Ince, 2005), we use the term ageist erotophobia to describe anxieties concerning older people as sexual beings. Such anxieties are manifest in the widespread failure to imagine residents and older people generally as sexual beings or denial of their sexual capacities or rights in principle (as well as in practice) to sexual expression. Such thinking can be internalized by residents (and older people) themselves. By panoptical control we refer to thinking developed by Foucault (1977), but see also Simon (2002) that concerns how the organization of environments can encourage internalization of order and compliance (here resulting in exclusion of residents' sexuality). Just as importantly, our discussion highlights the counter-narratives of participants that can recuperate ageing identities. In addressing the issues just described, we contribute to emerging debate on the value of and problems associated with meeting intimacy and sexuality needs as registered in this journal (Villar et al, 2014b) and elsewhere (Villar et al, 2014a; Bauer et al, 2014). In particular, we seek to add to extant knowledge in identifying the diverse accounts of sexual and intimate citizenship being told in care homes from different perspectives.

Context: individuals and homes

As people are living longer, they face higher risks of failing health in the last few years of life (Dunnell/Office of National Statistics, 2008) when they are more likely to need care home accommodation. Nevertheless, longevity reflects prevalent forms of social inequality concerning gender, ethnicity and social class. Official statistics in Britain indicate that later life is influenced by gender combined with ethnic difference – white and black-British women are outliving white men by an average of around four to five years and black-British men by an average of five to six years (Wohland et al, 2015). Also, the ratio of men to women aged 65 or over in the UK in 2010 is currently around 100: 154 (Office for National Statistics (ONS), 2011a). Among those aged 85 and over, women outnumber men by 2:1 (ONS, 2011b).

Of the 10.3 million people aged 65 or over in the UK, 4.5 per cent (still over 500,000 people) were in 2011 accommodated in a communal home (ONS, 2014). The care sector accommodating older people is largely privatized, with 70 per cent (350,000) of the 500,000 beds available in the UK being situated in for-profit homes (Laing, 2014). Individuals aged 85 or over represent 58 per cent of the population in care homes for older people (ONS, 2014). Further, nearly one in ten men and one in five women aged 85 or over live in a communal establishment (ONS, 2011b), where women residents outnumber men by nearly 3:1 (ONS, 2014) and approximately two-thirds of care home residents experience some degree of dementia (ONS, 2011b).

Care homes constitute a distinct space in various ways. For instance, privacy can be more often compromised here (Bauer et al, 2012), and necessarily so in cases of urgency or emergencies. The idea of ‘privacy’ is more problematic, and takes on a different hue, in the context of adult

care homes. For instance, although residents' rooms are understood as private/personal space, staff may feel they have a legitimate right to access this space for routine care delivery, resulting in difficulties for residents in maintaining choice and autonomy (Eyers et al, 2012). Equally, there are communal areas where privacy in relation to sexuality and other matters might be further compromised. Furthermore, care staff and residents have different orientations to the spaces of care. For the former, they are workplaces that require professional negotiation of empathy and avoiding over-involvement (Green et al, 2006). For the latter, entry into a care home requires adjustment to changes in personal capacities, support structures, relationships and connections with kin and community (Eyers et al, 2012). Residents are obliged to renegotiate meanings, identities and relationships in these new contexts (Cook et al, 2014): in other words, the whole basis of their ontological security i.e. the ability to be oneself with familiar others (Wiles et al, 2012). This is particularly important for lesbian, gay, bisexual and trans (LGB&T) individuals who often feel obliged to go back 'into the closet' to protect themselves from hostility from fellow residents and staff, on whom their welfare heavily depends (Willis et al, 2013).

Sexuality, intimacy and sexual citizenship

This section discusses key terms used in this article: sexuality, intimacy and sexual citizenship. 'Sexuality' has been defined as a multidimensional process, referring both to the capacity to be sexual and to sexual self-identification e.g. as gay, straight, bisexual and ambiguous (Jackson and Scott, 1996). It is co-constituted by biological (bodily sensations), psychological (emotions and cognition) and cultural and social influences (Doll, 2012). The latter encompasses how we feel and think about and inhabit our bodies e.g. going to the hairdressers, dressing up, and flirting, as well as needs for touch and emotional connection. Expression of sexuality is heavily

influenced by gender combined with influences of generation and social class (Simpson, 2015b). For instance, loss of sexual capacity in later life is thought to be more difficult for men to manage in light of fears of diminution of masculinity and loss of assumed dominance within a relationship, which can be exacerbated by a greater reluctance than women to talk through sexual and relationship problems (O'Brien et al, 2012). In contrast, the sexuality of older women may have been constrained by moral imperatives of being a good wife and mother (Rowbotham, 1999), though those now in middle-age, born during or since the post-war baby booms, will have encountered the influences of feminism and gay liberation (Rowbotham, 1999). If older women are excluded from the category of beauty by youthful criteria (Doll, 2012), sexually assertive ones are generally seen as, at best, ambivalent and, commonly, a threat: breaching a legitimate ageing femininity that demands decorum and passivity (Kaklamanidou, 2012).

Essentially, intimacy refers to involvement in closer personal relationships which, in turn, involves physical, emotional and social elements (Brown, 2006). It is not just about feelings but involves sets of social practices (Cronin, 2015). As a multiform social process, it is affected by the mutually-influencing differences of age, generation and gender. If men tend to define intimacy in physical terms, women tend to emphasize its emotional content (O'Brien et al, 2012). Further, Ehrenfeld et al (1997) have argued that intimacy covers a spectrum of emotions, needs and activities ranging from feelings of caring, closeness and affection that go with companionship (that may or not involve sexual feelings or activity) through to 'romance', where we mark out, or 'idealize', individuals. In this formulation, at the other end of the spectrum lies 'eroticism,' which involves sexual desire and activity (Ehrenfeld et al, 1997). It has been suggested that older people are redefining sexuality as intimacy (Doll, 2012). This could reflect pragmatism in the face of loss of capacity, or else agency through a resignification

of sex and sexuality. Whatever the case, any adequate theorization of intimacy should attend to the nuances in-between tenderness and sexual activity and the distinctions and overlaps between them.

‘Sexual citizenship’ has been described as constituted by intersecting moral (discursive) and socio-economic (structural/class) dimensions (Evans, 1993). Whilst this baseline definition is useful, Plummer’s (1995) definition is more germane to our argument because it indicates how claims to a valid sexuality articulated by minoritized groups (including care home residents) could seek some control over their ‘body, feelings, relationships’, and how one is represented as a sexual and/or intimate being (Plummer, 1995: 151). Such thinking usefully regards sexual and/or intimate citizenship as part of a plurality of possibilities worthy of equal rights, recognition and respect. However, the hegemonic status of reproductive heterosexuality might compromise legitimate sexual citizenship later in life (Bauer et al, 2012).

Sexuality in care homes: current scholarship

This section evaluates extant work on sexuality and intimacy in relation to healthcare services aimed at older people and in particular the oldest in society needing dedicated nursing care. We identify key themes in an emerging though still rather limited body of scholarship. We have provided a thorough review of the literature bearing on the issues in question elsewhere (see Simpson et al., 2015) though briefly reprise the main concerns here.

There are various attempts at criticism of care services and homes accommodating older people concerning marginalization and consequent deprivation of autonomy. One strand of criticism is that older people and residents are not just seldom-heard (of) but also seldom seen: there

being a sequestering of frail older people away from the quotidian public sphere (Drakeford, 2006). Consequently, care homes have been thought to serve as warehousing for older people who can be viewed as a problem to be managed, and thus who are denied opportunities for autonomy over everyday decisions (Drakeford, 2006). The setting apart of old people in general, and older care home residents in particular, could be attributed to the idea that they represent social death and the widespread fear of mortality (Froggatt, 2001). It also been argued that the process of control may operate more covertly given that residents can be subjected to panoptical surveillance i.e. internalized self-control in response to technological and human surveillance integral to the care environment (see volume by Domènech and Schillmeier, 2012).

Whilst there is longstanding evidence of increasing sequestration of the oldest in society and care towards the end of life in sociology (Giddens, 1991; Elias 1995) and social work literatures (McDermott, 2010; Preston-Shoot and Wigley, 2002), it would be unfair to overstate the case. The kinds of disempowering practice just described no doubt exist, but they are by no means generic or representative. Indeed, and as manifest in our data and conclusions drawn from them, thinking in such a way would occlude the many innovative strategies deployed by care homes to promote independence, involvement in decision-making and inclusion in a de facto residential community. For instance, Haslam and Haslam (2014) have noted the considerable political, therapeutic and cognitive benefits resulting from including residents in decisions about the structure and presentation of care homes in terms of the refurbishment and redecoration of communal areas.

However, there is stronger evidence that panoptical control applies more to considerations of sexuality and intimacy (commonly understood as more private) as distinct from other more

routine aspects of care and welfare. Indeed, when issues of sex, intimacy and sexuality of older residents are not considered too personal for discussion (Bauer, 1999), they are commonly seen as irrelevant to ageing identities and citizenship (Bauer et al, 2014; Doll, 2012; Gott, 2005; Hafford-Letchfield 2008; Villar, et al 2014a). It appears that sex, sexuality and intimacy are occluded by concern with maintaining biological and psychological functioning (Bauer, 1999). Whilst these factors are important, the exclusion of sex, intimacy and sexuality falls short of a holistic approach to meeting needs. Further, one US survey noted that nearly one in five residents objected to sexual relationships between married couples in long-term care facilities (Yelland and Hosier, 2015). Yet, the denial of needs relating to sex and intimacy risks infringing human rights law as it concerns liberty, self-expression, respect for private life and freedom from discrimination. Addressing such issues, moreover, could meet criteria concerning holism, whilst helping to maintain older residents' and older people's self-esteem, and thus reduce or help prevent mental health difficulties (Royal College of Nursing, 2011), though we also signal below dangers of over-focus on constraint and denial.

Further, the small body of extant scholarship on older people and sex appears dominated by sexological, genitocentric paradigms concerned with ongoing engagement in heterosexual penetrative sex to orgasm in physically changed circumstances (Gott, 2005). For example, an article by Trudel et al (2000) typifies this heteronormative, sexual book-keeping approach and ignores older people's capacities as adaptive sexual agents (Mahieu et al, 2014).

If sexual citizenship is largely denied to heterosexual residents, the situation is doubly complicated for residents identifying or identifiable as LGB&T, whose distinct care needs can be neglected or made problematic (Willis et al, 2013). Approaches to delivering equality in care settings, professing to 'treat them all the same', commonly entail the presupposition of

heterosexuality (National Council for Palliative Care and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organizations, 2012). Research by Willis et al, (2013), based on surveys, focus groups with professionals and older LGB individuals, and in-depth interviews with LGB people aged 50-70, indicates that professionals commonly fail to recognize LGB individuals, or do not have the awareness to gather this information sensitively. LGB individuals fear surrendering their identity and related sense of sexual citizenship on entering a care home and thus being forced to endure isolation. Whilst important in raising issues of equality and diversity, this emerging body of work also largely neglects older LGB&T people as sexual or intimate citizens (Simpson et al, 2015).

Despite the above-identified limitations, a more critical body of work with clear policy and practice implications is emerging, to which we hope to contribute and which resonates in our discussion (see Gott, 2005, Hafford-Letchfield 2008, Villar et al, 2014a). Such work highlights the workings of erotophobic ageism that can combine with other forms of disadvantage related to class, race, sexuality and gender. Whilst we acknowledge the powerful effects of the diverse constraints identified in this scholarship, we seek to extend knowledge by recognizing the contradictions around and forms of resistance to ageist erotophobia that ensue from the resources that come with ageing (Simpson, 2015a) and the reflexivity of professional carers (van Loon and Zuiderent-Jerak, 2012). We would therefore argue that a more balanced evaluation of diverse experiences is required, which we aim to achieve in our analysis.

Research design

The consultation exercise on which this article is based reflects contributions from 22 participants. The consultation was designed to elicit care home residents' and care workers'

views on the feasibility of addressing sexuality and intimacy needs in aged care facilities. Not only is this a neglected issue, but it is also integral to providing person-centred care. The consultation process involved semi-structured interviews with three residents (two male and one female) and three spouses (all female) and two focus groups with 16 staff across two care homes. Although residents constitute a minority within a small sample, to avoid reinforcing exclusion and minoritizing residents, we have foregrounded their stories, as they are commonly lacking in a field of research where the views of care staff have been taken as proxy (Simpson et al, 2015). The consultation was conducted between May and August 2014 in one medium-sized and one larger-sized privately-owned care home (with accommodation for up to 65 and up to 102 residents respectively) in two urban areas of Northwest England. Whilst there are limits to the value of small-scale, feasibility studies (e.g. generalizability), they are useful methodologically to help test the adequacy of research methods and sampling frame as well as identifying key themes (van Teijlingen and Hundley, 2001). Although we would not claim that the stories produced in our study are representative of what is happening in British care homes, we are aware that participants will have drawn on common narratives to construct their accounts (Roberts, 2002).

On request from the research team, managers in the first home, care home 1 (CH1), approached a range of staff who they considered to have the appropriate expertise and nine staff volunteered to take part. At the time of the study, there were no residents with capacity to consent living at this home. The care home manager did, however, identify two spouses of residents who agreed to take part. In the second care home, (CH2), managers identified three residents with capacity to consent, and one of these residents asked to be interviewed with his wife who was visiting him. A care home manager also convened a group of seven staff with appropriate expertise. A plain-English participant information sheet (PIS) was provided to enable prospective

participants to make an informed decision about whether to take part. The sampling strategy had to be pragmatic given difficulties of finding residents with capacity to consent.

In the resulting sample, all residents and spouses identified as white British. Two of the female spouses of male residents with a dementia (accommodated in CH1) were interviewed singly. All three spouses lived outside of the care home and visited their husbands almost daily. One spouse was in her early 60s, another aged between 50 and 65 and the third spouse, an older woman, did not volunteer an age-bracket. The spread of ages within the sub-sample of residents and spouses (from sixties to eighties) can be regarded as a strength of the study and, as will be seen, this diversity has resulted in the telling of different generationally-inflected stories (see Edmunds and Turner, 2002).

In focus group 1 (FG1, CH1), staff participants ranged in age from their 20s to their early 60s. All but one identified as white British, with one female member of staff identifying as ‘British Asian.’ All but two staff participants were female. The composition of both focus groups largely mirrored the national profile of care staff in terms of gender and age but less so in terms of ethnicity. According to the Independent Longevity Centre UK (2014), 84 per cent of non-managerial care staff are female and 64 per cent of care staff are aged between 35 and ‘retirement age’ (currently 63 for women and 65 for men in the UK). Minority ethnic community and non-British (migrant) workers each account for 18 per cent of the care workforce. Each focus group reflected different levels of training and/or education. The focus group in care home 2 (FG2) consisted of seven individuals who, in terms of age, spanned the early twenties to early fifties and comprised care assistants, a registered nurse, a receptionist and a non-managerial administrator. Each group involved at least one member of staff with specific expertise in care of individuals affected by a dementia.

Semi-structured interviews were used with residents and spouses because they lend coherence to the encounter whilst allowing for exploration of unexpected themes or leads (Maxwell, 1996). Due to the sensitive nature of the subject, interviews were gender-matched (with a male researcher interviewing the couple). Gender matching was done because it was considered to be more difficult for older female interviewees to feel comfortable being asked about the principle of addressing sex, sexuality and intimacy with a male academic. Given that care homes can function as communities, focus groups were not used with interviewees to avoid breaches of confidentiality or disclosures that might be regretted. Further, vignette-style questions were used to discourage disclosures of personal sexual experience, as the focus of this consultation was on the feasibility of discussing intimate subjects. In one US survey, vignettes appeared to avoid over-disclosure without unduly affecting participants' own views (Yelland and Hosier, 2015). The questions in interviews and focus groups asked participants to imagine various forms of intimacy (same- and opposite-sex) in a fictitious care home (supported by suitable images, of two men, two women and a man and a woman holding hands). Specifically, participants were asked to consider whether and, if so how, all these forms of intimacy could be accommodated in the life of the home. Interviewees were reminded, when needed, that our study was not enquiring into sexual histories or preferences. Focus groups, which asked about the same themes using the images and vignettes interviews used in interviews, were deployed with staff as an economical way of accessing a range of opinions. They represent a dialogic method that affords participants a higher degree of control over the content of discussion and can encourage creative thinking about collective concerns (Frankland et al, 1997).

All interviews and focus groups were audio-recorded, fully transcribed, and uploaded into NVivo10 analysis software to organize data coding, cross-referencing, storage and retrieval. Open coding, consisting of simple descriptive codes, was used to develop themes. Three members of the research team independently read the transcripts and assigned initial codes inductively through engagement with narratives (which involved two complete ‘passes’ through the dataset). Consensus on themes and an overall coding frame were negotiated within the research team and differences in opinion were resolved by a fourth team member. Thematic analysis was undertaken that focused mainly on the content of stories, or what is said, but also attended to strategic points in how accounts were assembled. Attention was also paid to constraints of, and opportunities for, resistance to ageist erotophobia identified in extant scholarship that arise from biographical experience, the cognitive and emotional resources that come with ageing, and reflexivity that can come with professional positioning. The frequency and generality of the stories told largely determined the accounts that have been foregrounded in the discussion but we also highlight less frequent though no less consequential reports such as spousal concerns about quality of care that illuminate the working of power relations.

In terms of the politics of research, whilst the researchers set the overall agenda, study participants’ accounts went beyond our concerns to indicate how needs for intimacy accompany or can be eclipsed by other needs, such as privacy and individualized care. Moreover, consulting with stakeholders is consistent with good ethical practice (Lothian and Philp, 2001). Because the study involved care home residents, ethical clearance was sought from the National Social Care Research Ethics Committee (SCREC), which falls under the aegis of the Health Research Authority (allied to the National Health Service), and exists to promote the interests of patients and the public in health research. The findings from this

consultation are reported according to the main concerns identified by the stories told by the two groups of participants: residents and spouses, and staff.

Significance of sexuality and intimacy: residents' and spouses' stories

This section explores the varied meanings that residents and spouses attributed to sexuality and intimacy. When asked about their perceptions of the term sexuality, study participants most commonly distinguished between sex, (often assumed as genitocentric) and 'intimacy'. For example, one spouse, Marjorie (aged between 50 and 65), (all names and homes anonymized), queried: 'Are you talking about full sex or touching?' Nonetheless, by far the dominant narrative among participants was one that positions residents (and older people) outside sexual citizenship and post-sexual if not post-intimate:

Researcher: What do you think sexuality means to residents?

William (78): Negative... Nobody talks about it... Nobody practices it. We just live as we are - We've had our sex life way back.

Researcher: Do you think that applies to all residents?

William: Yes I think yer wastin' yer bloody time. I think you should leave it [researching sex and intimacy] alone. It's people's personal life - Have you had a look around at some of these? They're that bloody old, they've got cobwebs on 'em.

This narrative was also recognised by staff where a male care worker in FG1 recognized that the dominant view of sex and older people was one of incredulity – ‘a joke’ – and that only a minority of residents appear to maintain an interest in sexual activity, which was then framed as a problem to be managed. Another female care worker in FG2 remarked on how residents themselves might contribute to surveillance when censoring displays of affection, again, suggesting the internalization of thinking of residents as post-intimate. However, there was variety in responses of all groups, which transcended the denial of sexuality. For instance, when asked what she thought sexuality means to residents, Emily, (aged 80) explained:

Not a lot - with older people, they might've forgotten what it were like or can't be bothered - I suppose if you became friendly with someone, things might change [our emphasis]. But, as far as I'm aware, there's no double rooms here - You've got to remember with this generation - you had your husband and then you stopped. For our generation, it was like taboo - They've got children and grandchildren; they've got enough on their plate - Some women are glad when it's finished; other women aren't.

In short, residents may be considered ‘past it’ but one should never say never. Whilst Emily draws on generational thinking of old people as largely post-sexual, which would constrain sexual expression and gendered notions of sexuality (where sex is eclipsed by maintaining family relationships), contradictorily, the possibilities for intimacy are not completely ruled out here. Emily recognizes that becoming friendly with another resident could mean that ‘things might change’. She also invokes environmental barriers to intimacy given the lack of double-berth accommodation and generational expectations imposing constraints on the sexual self-expression of old female residents and older women.

Moreover, intimacy more than sex registered as particularly significant for spouses of residents affected by a dementia or other degenerative conditions. As spousal interviewee Marjorie 1, aged 50-65 years, declared: ‘...if they’ve got someone to care for them, that’s a lovely situation... as for sex, I don’t think people [i.e. residents] are looking for that.’ Nonetheless, intimacy signified in other ways:

Olivia (spouse): Do you still have appetites - with your Parkinson’s?

John (resident): Do bears shit in the woods?

Cuddling, touching and kissing is very important. For me it is anyhow - just so he knows that I still love him. As for sex itself, I don’t think that’s important. Well - not to us because my husband could not participate. (**Marjorie**, spouse, 50-65).

I couldn’t express enough to you what it means for these patients to be hugged (**Joan**, spouse, age not provided).

Well it’s [intimacy] just togetherness - If you’ve been married for a long time, you need each other, even if it’s to hold hands and have a cuddle - It’s just support isn’t it? It’s just knowing that somebody’s there for you - I’ll always be his wife and he’ll always be my husband. (**Olivia**, spouse, 61).

In the first section of dialogue, John’s humorous riposte constitutes a claim to ongoing sexual citizenship, though operating more at a psychological level. Further, intimacy is articulated by Joan as an essential human need given her perception of residents’ responses to affectionate contact. Similarly, Joan declared that, ‘It would be lovely to snuggle into him in bed.’ Such

narratives help normalize a loving relationship with a radically changed partner in conditions of greater uncertainty. For Marjorie (spouse 1), cuddling and kissing her husband was a way of showing him (and others) that: ‘we’re still together - a loving couple.’ Whilst Marjorie recognizes that the partner she knew has changed considerably, her love for him remains. This might offer Marjorie reassurance that she is still part of her husband’s life and that it is important that the rounded human being she married is not occluded by, or reduced to, a medical condition overly associated with age. Indeed, Marjorie went even further to counter panoptical surveillance in asserting her right to an intimate identity worthy of display when she stated: ‘We’re husband and wife and if I want to sit on his knee, I’ll sit on his knee.’

A similar story of continuity appears in the above statement with Olivia (spouse 3) declaring that she and John would ‘always be husband and wife.’ Olivia’s account of intimacy also invokes the enduring nature of the relationship involving mutual support between her and a partner (affected by a life-limiting condition, Parkinson’s disease), which was stated as a matter of fact as if it hardly required explanation. Olivia’s words and situation resonate with Youell et al’s (2016) findings concerning the ongoing importance of intimacy in the face of dementia. Indeed, Olivia’s distinction of intimacy, which was commonplace among our participants, is suggestive of relational longevity and mutual knowledge built up over time and appeared to be told regardless of any differences in age within the sample. On this account, intimacy is not simply essential to a relationship, but also implies a claim to intimate citizenship (Plummer, 1995) for Olivia and her husband.

However, needs relating to sexuality and intimacy sit alongside, or are even eclipsed by, other needs. For example, these concerned maintaining and developing relationships with family, (as echoed in Emily’s account earlier), avoiding isolation, and maintaining independence

through driving to the shops or using public transport to visit seaside resorts. The positive management of a dementia appeared paramount in spousal interviews, as was the need for privacy, which is vital to practicing intimacy. Besides, one spouse was particularly concerned about the needs of residents with a dementia for reassurance and continuity:

Well, that [sexual activity] comes secondary to looking after the patient - all they want is a hug and a love and someone to be kind to them and reassure them and that that's the most important thing. [Later] - when the hairdresser comes, I asked her 'just to trim it.' He always hated it dead short. And she's done it again today - and I just go mad - I know the way he likes his hair (**Joan**, spouse 2).

Although it could be argued that subconsciously, Joan's concerns could help maintain her husband's sexuality, considerations of overt sexuality appear less important in her account than physical affection, emotional reassurance and the personalization of care. Her statement also highlights a concern that intimate knowledge of her partner, built up over many years, is being disregarded by those contributing to her husband's appearance and well-being. This frustration is understandable when we consider that it signifies a loss of control over the care provided and failure to meet individual needs (connected to grooming practices) that are vital to maintaining a valid identity and the memory of a spouse who was once more independent.

Challenges and responses: care workers' stories

It's not really talked about on our unit - any sexual needs (**Care worker 5, female, FG2**).

This stark declaration above highlights the urgency for staff training and development opportunities concerning how to enable residents to meet their own needs relating to sexuality and intimacy. Staff in both focus groups highlighted various grey areas of consent within long-term relationships where one or both partners showed declining capacity to consent. Whilst residents tended to de-emphasize their sexuality, care workers in both groups were acutely aware of how forms of sexualized expression could pose ethical and legal dilemmas:

There used to be a resident - who had been known to ring up prostitutes - That could be a bit tricky - Because you might be encouraging somebody to break the law. (**Care worker 5, female, FG2**).

- they've obviously got that need and want to express it but can't because of the capacity [signifying both lack of ability to consent and duty to safeguard] and does that lady know what he's doing? Does she actually want him to do that? It's mind-boggling, really. (**Care worker, male 2, FG1**).

The first instance (based on a past event) could have been more complicated if the resident in question had limited dexterity and might rely on others to telephone to hire a sex-worker on his behalf, though this invites consideration of why older or disabled people should be criminalized for seeking sexual opportunity. The second instance (an imagined scenario) indicates the difficulties involved in balancing autonomy and self-expression with legal and professional duties to safeguard well-being. Circumstances can become even more complicated when sexual feelings are expressed by a resident with a dementia towards a person who is not a partner or spouse, or if staff suspect that residents were being subjected to sexual (or possibly other) experiences with spouses or others that they did not wish for or that may make them feel

uncomfortable or invaded. Nevertheless, staff considered ‘safeguarding’ paramount but also that this process had become overly regulatory, though, as discussed later, care workers were more than capable of innovating solutions to such problems.

Discursive obstacles

As intimated, the main obstacles to meeting needs relating to sexuality and intimacy were norms governing how residents should be and behave, which, again, largely reflect the workings of an ageism that divides people of different generations and an erotophobia that constructs residents as post-sexual. For instance, a male care worker, (FG1), supported by a female care worker (FG1), acknowledged that practically ‘every activity for daily living’, appeared on the home’s ‘pre-admission assessment form’ but ‘people avoid it [item relating to sexuality needs] like the plague’.

Sex and intimacy can be difficult subjects to approach anyway but this situation is complicated by generational differences between residents and younger or middle-aged carers. As female care worker 1, (FG2) explained: ‘It’s just something you don’t approach with an older person.’ Several other staff spoke of the difficulties of discussing such matters with individuals of their ‘parents’ or ‘grandparents’ age, though female care worker 1 (FG1) reflected thinking at a more strategic level when she spoke about how residents could puncture the silence around their sexuality by being encouraged to be peer educators. Further, a female manager (FG1) expressed concern about reducing a personal issue to a bureaucratic procedure indicative of control when she declared: ‘I’d hate the thought that somebody would write a care plan for me and my husband on how we can be intimate.’ Nevertheless, focus group participants were concerned to enable rather than contain or problematize and control residents’ sexual and

intimate needs, and felt that such issues were missing from staff development opportunities and plans. Indeed, one female care worker in FG2 suggested that any such training should aim to educate staff to confront their own assumptions and anxieties that accrete around ageing sexuality and intimacy.

Residents, spouses (regardless of age differences) and care staff appeared empathetic towards historic prejudice, discrimination and hostility towards lesbian and gay people, including experiences of stigma and criminalization that could prevent disclosure and discussion. Study participants emphasized the everyday nature of differences in sexual identification, and drew on an inclusive narrative that lesbian and gay and couples were just like any other individual or couple, but registered that they would need specific support to maintain self-esteem in care homes.

Despite the favourable responses towards sexual difference just described, it was acknowledged by staff that establishing sexual or intimate citizenship could be even more complicated for residents who might identify or be identifiable as LGB&T:

I think - men of this generation especially - straight men, married with children are not as open to it [sexual difference] as women. [Later] It's not really talked about in healthcare - It's like: 'where did you marry?' Not: 'What are your specific needs?' [Later] If you've got Miss Jones who's a spinster with ten cats, it's unlikely she's, I don't know you - you can't make that assumption. (**Female care worker 5, FG2**).

The first part of the statement shows awareness of the limits to tolerance, and how homophobia can be inflected by combined influences of age and gender. The second part reflects

understanding of the heteronormative character of the care system itself where heterosexuality operates as a gold-standard and how the distinct care and intimacy needs of LGB&T residents could be overlooked. Again, this resonates with scholarship addressing the erasure of sex and sexual difference from everyday practice (Hafford-Letchfield, 2008; Willis et al, 2013). Even in more tolerant times, another female care worker 5, FG2 noted the persistence of heteronormativity in the shape of ‘sexuality care plans’, which routinely failed to record LGB&T identification or anything about sex and intimacy needs. Interestingly, participants in both focus groups expected that sexual difference would be easier to address in future given the positive effects of more recent equality law and given the likely future effects of the present ethos of tolerance towards sexual difference.

Moreover, care staff in both focus groups described how the bureaucratic demands of care work, and myriad legal responsibilities in relation to safeguarding, could prevent appropriate tactility and displays of affection towards residents (such as giving a hug in times of distress) and developing relationships of trust with residents, which are vital to opening up discussions concerning sexuality and intimacy. The female manager in FG1 described how such circumstances helped create a climate of uncertainty whilst supplying an implicit critique of over-protective approaches to securing welfare: ‘Unfortunately, we are in an industry where you’re tied up by a lot of legislation and any kind of sexual behaviour nine times out of ten has to be reported as a safeguarding incident’. Another environmental obstacle indicative of an over-protective approach to safeguarding concerned the operation in one care home of a ‘no locked door’ policy (a decision of senior management), which effectively precluded any real privacy. Frustration with this policy was a constant refrain during interview with John and Olivia, and was echoed by several care staff in FG2 (the same care home). Indeed, Olivia likened this constant state of surveillance to ‘living in a goldfish bowl.’

Discursive barriers to meeting sex and intimacy needs were also structured into the design and furnishing of care environments and were materialized in care practices that regulate and constrain possibilities for intimacy. As one middle-aged female manager, (FG1), declared:

‘- care homes don’t lend themselves to any kind of intimacy. You might have a couple who’ve been married forever and a day and, all of a sudden, if one partner has to go into care and they’re in a single room with a single bed even trying to fit a little two-seater settee in is difficult - Residents might not sleep because they’ve suddenly gone from being cuddled up beside another human being for 45 to 60 years and they’re now in a single bed.

It is noteworthy that care workers did not simply describe the complexities of meeting sexual and intimate needs, they could also innovate solutions to problems they identified. Indeed, care workers ‘war stories’ were leavened by recognition that not all forms of expression of sexuality or intimacy were problematic. Critical incidents could be met with everyday creativity. For residents to satisfy their own sexual needs, care workers were required not just to exercise discretion, but to make adjustments to the environment and address staff attitudes (latent expressions of ageist erotophobia). As the manager in CH1 suggested, discrete spaces for intimacy could even be used by care homes as a marketing tool. She also described how her staff had improvised in placing curtains behind the frosted glass in one room for the benefit of one couple and how she had confronted staff to ask them to reflect on their attitudes towards residents that had involved mocking the latter’s sexuality. The incidents just described indicate possibilities for a more measured approach to safeguarding and enabling intimacy, determined

more by the observed needs and reactions of residents than anxiety about the sexuality of residents/older people.

Discussion

This consultative study demonstrates the varied meanings that residents and spouses attribute to sexuality and intimacy, and highlights how the combined demographic differences of age, gender, and sexuality may influence the stories told. For example, William's idea of sex and intimacy as intrinsically personal (a perception of residents also shared by staff within the second focus group) suggests the deployment of generational discourse that constrains talk about sex and intimacy (Gott, 2005). Such accounts resonate with scholarship that has remarked on how sex and older people are considered, 'rare, astonishing and ridiculous' (Hodson and Skeen, 1994: 223). Assumptions of this kind indicate the workings of an endemic ageist erotophobia that prevents the imagining of older people as sexual and intimate beings and can even involve a visceral sense of disgust at such a thought. In William's account we also get a sense of how this discourse is produced by residents themselves, and how it undergirds the construction of older care home residents as synonymous with decrepitude and overly associated with death, as symbolized in the reference to 'cobwebs.' This viewpoint also demonstrates how residents themselves might contribute to panoptical surveillance when censoring displays of affection, again, suggesting the internalization of thinking of residents as post-intimate. However, staff appeared more enthusiastic than spouses and residents about addressing such needs (see, also Villar et al, 2014b) and, unlike residents and spouses, there appeared very little difference between age and the stories told. In this case, differences of age may have been eclipsed by requirements of professional practice that call for residents to be treated with dignity (Chadwick, 2012). This augurs well for avoiding panoptical surveillance

and enabling the self-empowerment of residents and such enthusiasm is less surprising when we consider that care workers have to meet a range of legal, institutional and professional demands, and negotiate diverse relationships and various obstacles that can deny satisfaction of intimacy needs.

The alternative discourse, of John and Olivia, told a story of a continuing sexual relationship. This couple could be described as part of the post-war, 'baby-boomer' generation that asserted the right to sexual autonomy (Rowbotham, 1999). In this case, John described himself as a touchable self, which is important when we consider that older, sicker bodies, often taken as synonymous with decay, can be spoken of as if unworthy of touch, or else become touchable only through the protective barrier of plastic gloves (Twigg, 2000). Further, Olivia's reference to mutual care (much in evidence in their shared humour and emotional support throughout the interview) recuperates a valid identity for older, physically frail individuals. Indeed, the interaction between Olivia and John challenges the stereotype of older, disabled people as pitiful objects of care, and instead shows how the latter can reciprocate in emotional caring. This suggests support for the view that sexuality and intimacy continue to signify until the end of life (Kuhn, 2002) with residents' stories about sexuality and intimacy reflecting a plurality of views, including not just denial but also continuity (Bauer et al 2012).

Contrary to extant scholarship (see Willis et al, 2013) lesbian and gay residents generally figured in study participants' accounts as legitimate sexual citizens. Staff stories in particular were reflexive in looking beyond an age-inflected lesbian stereotype, and simultaneously encapsulated the difficulties of broaching a sensitive issue with a generation whose consciousness will have been shaped by stigmatizing, criminalizing and pathologizing discourses concerning non-normative sexual and gender identities (Dickinson, 2015).

However, the staff discourse was unequivocal that care homes have designed out possibilities for intimacy, which supports Hafford-Letchfield's (2008) argument concerning how, panoptically, sexuality and intimacy are erased from or designed out of policy, care systems and everyday practice indicating age-inflected erotophobia. The sudden change from living in one's own home to living in a care home means that residents may have to adapt to a loss of or change in status and can pose challenges in the longer-term to maintaining relationships that contribute to the basic sense of security and emotional well-being of residents.

Within this paper, concerns were also expressed about training to support residents in maintaining sexual and intimate relationships that reflect, not just a sense of professionalism and fairness, but were also informed by staff observations about how staff lack of knowledge could lead to denial of such needs, thus affecting residents' mental health. Whilst such reflexive awareness augurs well, we have noted elsewhere how existing guidance from governmental, nursing and voluntary sector sources has generally failed to percolate into care practice (Simpson et al, 2015). This issue requires further investigation, but we suggest that this state of affairs is attributable to a confluence of discursive (cultural) and structural (socio-economic) influences. Notably, this involves institutionalization of ageist erotophobia (see Hafford-Letchfield, 2008) combined with economic pressures within a largely privatized sub-sector of the healthcare. Currently, only a few corporate care home owners are making a profit (Laing, 2014), which encourages a sector-wide need to make efficiencies and which can contribute to under-investment in staff training.

Concluding thoughts

In analysing the diverse stories of different residents, spouses and care home staff, (sometimes inflected by differences in age, gender and class) we have contributed new knowledge in a UK context to a highly neglected topic of inquiry. We have not only highlighted the workings of erotophobia in care homes as distinct spaces, which can operate panoptically to constrain thought and behaviour, but also how, creatively and more agentially, spousal narratives of intimacy could normalize the identities of and relationships with radically altered individuals. We have also illuminated how needs concerning sexuality can relate to other needs and the discursive obstacles (largely identified by care workers) to meeting resident needs concerning sex, sexual identification and intimacy, as well as reflexive responses by care staff to surveillance and the difficulties and dilemmas involved in meeting needs.

The modest sample size means that our conclusions are necessarily tentative, though are still indicative of wider thought and practice. As scholars championing small-scale, biographically focused research have argued, individual and social experiences are overlapping if not co-constitutive. Indeed, following Roberts (2002), we consider that broader social trends are likely reflected in our interview and focus group stories, which provide insights into how social patterns are reflected in fragments of experience. At the least, the stories appearing in this article could be articulated in, and be indicative of, those occurring in comparable contexts. Besides, the stories shared by our participants highlight an urgent need for a larger study that could examine how the social differences of residents, (including generational differences between pre-war and first spike baby-boomer residents), their significant others and staff shape the stories told, and thus influence how sexual citizenship is approached in a larger sample of care homes. The narratives resulting from such an approach might help care staff to take their

cue from the individual concerned in the context of relationships in which they are embedded when supporting residents to meet their sexuality and intimacy needs.

We also hope to have made an important step in opening up in a UK context a critical exploration of a neglected yet important human rights issue that could ramify beyond the context in which accounts were produced. In particular, our discussion of the discursive and practical complexities of intimacy and sexuality as they operate in care homes indicates a retheorization of the sexuality of older people in general and older care home residents specifically. In this respect, the stories examined highlight an emerging politics of sexuality and intimacy that extend understanding of the various ways in which such individuals reclaim (or not) intimate and/or sexual citizenship and challenge panoptical control. Such narratives transcend and contest understandings of the oldest in society as an ‘abject’ category lacking in agency (Gilleard and Higgs, 2011). Indeed, such accounts recuperate older people from stereotypes that construct them as post-intimate or post-sexual and help us to recast them as individuals needing, desiring and worthy of intimacy. We have also uncovered the complex recuperative work that accounts of intimacy do in helping spouses remember and recover radically changed life-partners affected by a dementia or other life-limiting condition.

Furthermore, we have contributed to a growing body of sociologically informed practitioner work that goes beyond reductive thinking about vulnerability in later life as a largely medical matter, and of deficit models of the ageing body. In doing so, we have extended thinking concerning the socially constructed character of vulnerability in old age and have challenged dominant forms of thinking that overly associate the latter with decline, decrepitude and (emotional) dependency or lack of autonomy. Participant stories provide insight into how

vulnerability is co-produced by a complex of physical, psychological, social and environmental processes (Schröder-Butterfill and Marianti 2006).

Finally, the stories of professional carers themselves not only provide particular insights into the social construction of capacity and vulnerability but also how these issues can be sensitively addressed in ways that resist stereotypes of residents as thoroughly dependent and overly vulnerable, and thus needing protection from their desires. Indeed, these stories, which transcend the bed-and-body model of care, show how carers' reflexivity concerning constraints on intimacy that they might have a role in maintaining, can prompt critical thinking. Such thought could avoid panoptical, erotophobic governance and thus contribute towards more holistic care practices that do not erase sexuality and intimacy, but could help meet the discernible needs and wishes of residents regardless of gender, sexuality or other difference.

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