

Sexuality in Dementia

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INTRODUCTION

SEXUALITY IS OFTEN the subject of mirth. Part of the humour around sex and sexuality stems from its status as a taboo. Humour often arises in the context of incongruity. Sexuality is an ever-present aspect of our lives, but one which, for the most part, we keep private. When sex does, then, intrude into our public lives it can make us laugh; but, by the same token, it can be shocking. Sexual humour is readily apparent in connection with age, but so too is the tendency to be shocked when the private becomes public. If we move into the arena of dementia, sexuality becomes more shocking than funny: there is a tendency for it not to be tolerated.

In a nursing home for people with dementia, staff were often physically assaulted. They took this in their stride: it came with the job; it was usually no worse than scratches, slaps and squeezes of the arm during personal interventions with residents. But when Jim started squeezing the breasts of the nursing assistants and tried to put his hand on a nurse's crotch, which was accompanied by an overtly lewd suggestion, it was difficult for the home to tolerate the behaviour. It was also difficult for the staff even to describe, because it was too rude to speak of it.

Attitudes, both to physical and sexual aggression in care homes, are changing. In order fully to understand ethical issues around sexuality and dementia we would need to understand attitudes to sexuality in older people generally. We should also be clear about our own views around sexuality at any age, in particular in connection with older age and dementia. Even the short account of Jim's apparent sexual disinhibition in the nursing home helps to highlight a key feature, which is that these issues tend to elicit quite different reactions or intuitions, reflecting different values.

The approach to ethical issues around sexuality in dementia which we wish to commend is that of values-based practice. We shall start by setting the scene in the context of the literature around sexuality in older age generally and in connection with dementia in particular. We shall then give an (albeit adumbrative) account of values-based practice and show how it might be used to approach fictitious cases, which are nonetheless based on reality.

SETTING THE SCENE

It is by now well established that sexual activity does not cease with ageing (Bouman, 2008; Stratford and Warner, 2010). It is true that the proportion of people

engaged in regular sexual activity decreases with age; and it may become increasingly appropriate to talk of ‘intimacy’ rather than ‘sexuality’ (Benbow and Beeston, 2012). Nonetheless, there is a cohort effect because sexual activity has seemingly become more important to older people over time. In a Swedish study, which included questions on sexual intercourse in 70-year-olds, in 1971–72 the study found that 52% of married men and 38% of married women had had intercourse in the previous year; but by 2000–01 the figures were 68% and 56% (Beckman et al, 2008).

Sexuality in care homes has been called ‘the last taboo’ in a publication that provides a rich source of advice and discussion of attitudes, policies and approaches (ILC-UK, 2011). Holmes et al (1997), in a postal survey of care homes in the US, found generally positive attitudes amongst staff towards sexuality and sexual expression in residents. Respondents to the survey agreed that more staff training was required. Nevertheless, attitudes and values amongst staff and residents and their families can act as barriers to sexuality and intimacy in older people, especially in nursing and residential homes. With reference to residents of care homes, Rheume and Mitty comment:

Some of the barriers to sexuality and intimacy in this age group are likely to be rooted in notions of body image, beliefs, and values regarding sexual expression (eg, outside marriage), and lack of knowledge about or, especially for women, comfort with their sexuality (Rheume and Mitty, 2008: 344).

One such barrier in care homes is the loss of privacy—loss of physical privacy and loss of privacy of information—both of which undermine the person’s autonomy (Rheume and Mitty, 2008: 345).

Undoubtedly, another barrier to a fulfilled sexual life in old age is illness. A variety of age-related changes can affect our expressions of sexuality, from loss of libido, to erectile dysfunction, to any form of pain, as well as depression and a host of chronic diseases (Rheume and Mitty, 2008: 346–47; Bouman, 2008: 696). Dementia itself can affect sexuality. It often reduces sexual interest; but concerns are usually raised when sexual activity is heightened. This sort of hypersexuality may have an organic basis: for instance, it may reflect the disinhibiting effects of frontotemporal dementias. So-called ‘sexual disinhibition’ is said to have a prevalence rate of anywhere between 2% and 25% (Stratford and Warner, 2010: 261). It is the management of such disinhibited sexual behaviour that leads to most ethical discussion.

SEXUALITY IN DEMENTIA AND ETHICAL ISSUES

Pace the rather positive attitudes found in Holmes et al (1997), staff in institutions for older people with dementia in Israel admitted to ‘difficulties, confusion, embarrassment and helplessness’ when they encountered erotic sexual situations involving patients (Ehrenfeld et al, 1997). The same team reported that ‘Behaviour at the level of eroticism aroused anger and objections. Staff reactions were particularly strong: rejection, disgust and anger’ (Ehrenfeld, et al, 1999). The central ethical dilemma for staff was the conflict between the need to protect and maintain the dignity of their patients and ‘the patients’ desire to fulfil their sexual needs’ (Ehrenfeld et al, 1997).

The study team used case histories to try to define the problems, to reflect on the beliefs of staff and to choose a desirable course of action.

There are a number of specific ethical issues that arise in connection with dementia and sexuality. We shall briefly mention just three. First, tensions often arise in connection with families. If, in a care home, a sexual liaison has formed and one or other of the people involved is still married, but has either forgotten this fact or is misidentifying the person in the home as his or her spouse, it can be difficult for staff to know whether or how to tell the family of what is occurring. Although many families can be supportive and accepting, some may object even if the spouse has died. A new relationship may be seen as disrespectful to the memory of the deceased parent; or, if the relationship were to involve another resident who was still married, it might be considered out of keeping with the parent's previously held beliefs about the sanctity of marriage. A variety of views can be found depending on the gender, marital status and relationship involved.

Bauer et al (2013) found that families, on the whole, were supportive of kissing, touching, hand-holding and hugging amongst people with dementia, but reacted less favourably to sexual intercourse. The families tended to think that they needed to know what was going on, partly so that they could offer some sort of protection if necessary. As the authors commented, 'There is a fine line, however, between needing to *know* what's going on and needing to *control* what's going on, particularly when it is couched as being in the resident's "best interests"' (Bauer et al, 2013: 9).

Second, it is increasingly recognized that there are particular issues in connection with gay and lesbian carers of people with dementia. Lesbian, gay, bisexual and transgender (LGBT) carers can meet a variety of reactions from acceptance to a disregard of their particular needs. Lesbian, gay and bisexual carers may have to accept that the dementia in their partner will lead to their sexual orientation being revealed in ways over which they have little control (Price, 2010). In an intolerant environment it can become even more difficult for any form of sexual expression to be revealed (Johnson et al, 2005). In a recent UK report, one care home manager described how, when staff found a female resident who was felt to prefer women to men trying to touch another women, this 'either provoked complete outrage or extreme amusement amongst the staff' (ILC-UK, 2011). Any form of discrimination is, of course, an ethical matter; but, for the LGBT community, discrimination in connection with their specific sexuality is superadded to the negative attitudes in relation to sexuality, older people and dementia in general (Peate, 2011).

Third, there is what Benbow and Beeston (2012) have called the 'elephants in the room': capacity and consent. The overwhelming concern here is that sexual intercourse without consent is rape. For our purposes, however, it is of note that so much of the literature on sexuality in institutionalized older people is concerned with the principle of autonomy and, therefore, with issues of consent and capacity (Mahieu and Gastmans, 2012). Of course, other issues also appear in the literature, such as the importance of privacy. But Mahieu and Gastmans found that arguments related to principles, not just respect for autonomy, but also the principles of beneficence, non-maleficence and justice, 'seem to play a prominent role in ethically evaluating the sexual behaviour of institutionalized elderly' (Mahieu and Gastmans, 2012: 353). They went on to comment that: 'Complex situations caused by having

dementia seem to warrant different ethical concepts such as care and dignity' (2012: 353). We shall return to their arguments later.

In their discussion of capacity and consent, Tarzia et al (2012) suggest that risks are inherent to any relationship and the person with dementia should not be protected from risks in a manner that is essentially paternalistic and undermining of the person's standing as someone in need of and able to benefit from intimacy and happiness. Thus:

A person-centred approach ... would take at face value the assumption that residents with dementia should have the freedom and indeed have the right to enjoy sexual expression, and from there, examine strategies and guidelines that would support resident autonomy and manage risk (Tarzia et al, 2012: 612).

They argue that the onus should not be on people with dementia to 'prove' they have capacity to decide on sexual relationships, but on professionals to prove 'incontrovertibly' that they do not (Tarzia et al, 2012: 611). They went on to suggest:

The only justification for interfering in a sexual relationship between two residents who appear happy ... is if one or both residents are not aware of the identity of the other person and believes the person to be someone else (2012: 612).

This argument is predicated on the worry that in an emotional moment old recollections might be stirred up which would induce shame at the recognition that their sexual behaviour was with someone who was essentially a stranger. This obviously is a concern, but it raises further problems. First, how do we know (incontrovertibly) that the relationship is based on misidentification? If a man with dementia refers to a woman as his wife when she is not, it could be that he is simply signalling, within the bounds of his language impairment, the closeness of their relationship. Second, it may seem harsh to intervene just in case a harm arises when we have no real idea how often this happens. Third, the suggestion (which comes from Mahieu and Gastmans, 2012) that the other person in the relationship will be 'a total stranger' will not always be true, if for instance they have been living together in the care home for some while. The realization that this is not the person you thought it was may be shocking, but it may not be a catastrophe!

Having made these points, it is not our intention to argue that the justification given by Tarzia et al (2012) for interfering is totally without foundation. Rather, our aim is simply to point to the difficulty in this area of setting down any hard and fast rules in anticipation of considering individual cases. The importance of casuistry—looking at things case by case—is, therefore, something we wish to emphasize (Murray, 1994).

CHEMICAL CASTRATION

The ethics of treatment seems worthy of specific mention. The management approach we would encourage for any form of behaviour in dementia which might be found challenging would be psychosocial and person-centred (Hughes and Beatty, 2013). This does not preclude the possibility of pharmacological management. We do not intend to review the management of sexually disinhibited behaviour, which is very adequately covered elsewhere (Series and Dégano, 2005; Bouman, 2008; Stratford and Warner, 2010; Tucker, 2010; Benbow and Beeston, 2012). Various different types

of medication have been used with varying degrees of success: there is no definitive drug treatment. Nevertheless, case reports on the use of both hormonal and non-hormonal anti-androgens, usually as a last resort, have often shown improvement of 'inappropriate sexual behaviors' (Tucker, 2010). This type of treatment is sometimes referred to as 'chemical castration' (Stratford and Warner, 2010).

This is an emotive term, for the idea of castration is repugnant. But why does it seem repugnant and might there be ethical grounds to justify such hormonal manipulation? After all, we might use an antidepressant with similar intentions (knowing that the selective serotonin re-uptake inhibitors can cause sexual dysfunction) and we do not feel so squeamish about manipulating chemicals in the body to try to change other behaviours.

An answer comes from the parallel case of someone with mania. If a person were just happy, we would not even entertain the diagnosis of mania and no medical intervention is justified. So, too, there would seem to be no grounds on which to intervene when a person is enjoying a perfectly normal and harmless relationship, even a sexual one. Where the person is in real danger of harm to self or others and the use of alternative interventions is either unlikely to be, or has not been, effective, then more draconian measures (for example, injecting antipsychotic medication in the case of mania and using hormonal manipulation in the case of someone with dementia and sexual disinhibition) become justifiable. The inclination neither to interfere with nor to stop (to castrate) a normal biological function (the sexual urge) is strong. But just as certain levels of exuberance become unacceptable, so too with sexual relations; and just as the manic woman may not recognize the risks she faces, so too the man with dementia who is sexually disinhibited.

In these sorts of cases it will always be a matter of judgement as to whether the more extreme type of behaviour has yet been reached. Even the distinction between normal and abnormal involves a value judgement. Hence, the real focus has to be on the evaluative nature of the judgements being made.

VALUES-BASED PRACTICE

Over the last ten years there has been growing interest in values-based practice (VBP) (Woodbridge and Fulford, 2004), which can be regarded as complementary to evidenced-based practice. Hence, just as the facts of each case must be carefully considered, so too do values; and the first step is to recognize that values are critically relevant. Thus, values-based practice has been defined as 'the theory and practice of effective healthcare decision-making for situations in which legitimately different (and hence potentially conflicting) value perspectives are in play' (Fulford, 2004: 205).

Recognizing facts and values can also be regarded as a necessary feature of clinical judgement: making judgements without knowledge of the facts is foolhardy; but even when the facts are known an evaluative judgement is usually required. Such judgements will often involve a framework of shared but nonetheless conflicting values, which will have to be worked out and balanced in a given context (Fulford et al, 2012). This process requires mutual respect for different values, even if some values, such as racism and ageism, are excluded. Fulford (2004) sets out ten key elements for the process of VBP, as shown in Table 1.

Table 1: The 10 key elements of values-based practice (adapted from Fulford, 2004)

Element	Description
1. The 'two-feet' principle	All clinical decisions require attention to both facts and values
2. The 'squeaky wheel' principle	We tend to notice diverse or conflicting values because they are problematic
3. The 'science-driven' principle	Progress in science increases complexity and choices and makes values more numerous and apparent
4. The 'patient-perspective' principle	For any given decision, the perspective of the patient should be centre-stage
5. The 'multi-perspective' principle	Where values conflict, the right outcome will generally follow from the right process which supports the legitimately held views of others
6. The 'values-blindness' principle	Awareness of values is encouraged by careful attention to language
7. The 'values-myopia' principle	We tend not to see the values of others, or to think they are the same as our own
8. The 'space of values' principle	Ethical reasoning explores differences in value judgements, recognizing their legitimacy
9. The 'how's it done' principle	Good communication, which will include skills in negotiation and compromise, must form part of the process of reaching decisions
10. The 'who decides' principle	The right decision is made in partnerships involving all concerned

In the cases that follow, we shall demonstrate how elements of VBP might be used in a way that supports decision-making in complex situations. In fact, elements of this process featured in the discussion of difficult cases described in Ehrenfeld et al (1997); and attention to values also featured in the ILC-UK (2011) document. The case-by-case approach (casuistry) is one that encourages reflection on the important values that emerge in any particular case and was commended in the Nuffield Council's report on ethical issues in dementia (Nuffield Council on Bioethics, 2009).

CASES

Vignette 1: Patrick and Faye

Patrick is 79 years old and lives in a nursing home. He has moderately severe Alzheimer's disease. He has been devotedly married to Maggie for 51 years. They

have rarely been apart. Although Patrick still recognizes Maggie as family, he is not sure about the nature of their relationship and often refers to her as his sister or mother.

Having moved into the home about six months ago, Patrick was initially reluctant to leave his room and was frequently irritable. However, he met another resident called Faye and they appeared instantly to be mutually attracted. They would stroll hand in hand, enjoying each other's company.

Faye's husband was recently admitted to hospital, which was one of the reasons for her admission to care. He had been her main carer. They, too, had been happily married for many years. Faye does not always remember that he is in hospital, sometimes forgets she is married, but still occasionally asks for him.

Staff in the home have been increasingly concerned about the closeness of the relationship. They feel Faye is very vulnerable, as she has been found in a bedroom with Patrick who had his hand down her blouse. She did not appear to be distressed by the incident at all. Staff do not, however, perceive Patrick as vulnerable; instead he is portrayed as the perpetrator.

Prior to this, Faye's family had asked the home staff to keep them apart as they were spending too much time together. They didn't feel it was appropriate, especially with their father being in hospital. They believed that Faye would be horrified if she had a better understanding of her situation. The current incident has left them angry and upset. They demand that Patrick is moved away from their mother. Patrick's wife, Maggie, was less upset—although still saddened and preoccupied—by their 'friendship' as she felt he was coming out of his room to socialize more and appeared generally more settled and content.

Discussion

It is quite clear in this case that there are both facts and values to be considered (element 1 from Table 1, hereafter VBP1). Awareness of values involves awareness of different values. In discussing this case the professionals must seek to encourage all those involved to express their views in order to understand the different values that underpin them. Key here, however, are the values of the protagonists (VBP4). Patrick and Faye can no longer give a coherent account of their prior values, which would undoubtedly have been offended by any form of adultery, but they are still valuers (Jaworska, 1999). As such, we should pay attention to their current actions, which demonstrate what is of value to them. Mutual understanding between all those involved must develop, which will require careful navigation and negotiation on the part of the professionals (VBP9). But they might start by exploring how it could be that Patrick and Faye still cherish their previous values despite their current relationship (VBP8). The value judgements of both families are legitimate, but they can perhaps be brought closer by a greater understanding of dementia and the effects it is having (for example, in terms of misidentification). There are undoubtedly issues of dignity and safety, so a plan needs to be established to maintain some boundaries. But it may be agreed, after appropriate meetings and consultation (VBP10), that this will not involve separating Patrick and Faye.

Vignette 2: Jack and Martin

Jack has been admitted to a long-stay ward because of moderate dementia and behavioural disturbance. He is 88 years old and has lived with Martin for many years. Martin visits Jack regularly and describes himself as his best friend. Staff suspect that Jack and Martin are partners, although Martin is conservative, from a generation less open about such matters. On account of his dementia, Jack is quite openly affectionate and sometimes overtly disinhibited in a sexual manner towards Martin, who can appear embarrassed by this. Martin occasionally reprimands Jack for his behaviour and can appear irritated, although staff sense this is mainly caused by embarrassment. Staff have observed them holding hands when they sit alone in the conservatory and try to give them privacy at this time. Some staff, however, are uncomfortable with the situation and have aired concerns about what they should do if Martin wants to take Jack to his room or out of the ward.

Discussion

We tend to notice conflicting values when they are problematic (VBP2). The possibility of latent homophobia might be an issue here: would staff feel similarly uncomfortable if the couple were heterosexual? The fact that staff give Jack and Martin privacy in the conservatory shows they recognize this as important, as something of value (VBP6). This needs to be squared with the objection to greater privacy (VBP8). All of this should be discussed in the multidisciplinary team and it will need to be acknowledged that the relationship of Jack and Martin may simply be more difficult for some staff than for others because of different values systems (VBP7). But through a transparent process of discussion (VBP5) and by recognizing the saliency of the values of Jack and Martin (VBP4) it should be possible to agree an appropriate plan amongst the team (VBP9).

Vignette 3: Hussain and Mahbubah

Mahbubah has been in an NHS assessment ward for three months. She has a diagnosis of young-onset Alzheimer's disease, which is now quite advanced. Prior to her admission, Mahbubah was cared for at home by her husband Hussain. As her condition deteriorated Hussain felt he could no longer cope and reluctantly agreed to the admission with a view to assessment for permanent care. Hussain visits Mahbubah every day. Although there are days when she doesn't seem to recognize him—times when she can rail against him—she generally seems most content when he is with her. The couple have been in a long and happy marriage and Hussain remains very loving towards Mahbubah: kissing, hugging and holding her hand. Recently, Hussain has asked to take Mahbubah home for overnight leave. Staff are reasonably sure that this is to facilitate intimate sexual activity but they are concerned that because of her advanced dementia Mahbubah no longer recognizes the nature of her relationship with Hussain and she lacks capacity to consent to sexual contact. Staff raised their concerns at a multidisciplinary team care review meeting and suggested that Hussain's request for overnight leave should be refused.

Discussion

It seems important in this case not just to recognize facts and values (VBP1), but to establish them. One fact that has not been questioned is that Hussain loves Mahbubah. But the reasons for Hussain's wish to take his wife home have not been established—staff are only 'reasonably sure'; so it may be important to go further than this and discuss concerns overtly with Hussain (VBP6). In doing so, staff need to be open to the values of Hussain (VBP7), but might also wish to explore with him the differences in terms of the value judgements being made (VBP8). There will, after all, be practical matters to be considered, but it may be that in part the possibility of going home is made more realistic by advances in assistive technologies (VBP3). Nevertheless, the perspective of Mahbubah must be considered: whether, for instance, the change of environment will do her good or be confusing and upsetting (VBP4).

In moving forwards, staff might also wish to consider the values that underpin their own concerns about lack of capacity (VBP8). In their review of the literature, Mahieu and Gastmans commented:

By referring to the concept of informed consent ..., the choice to engage in a sexual relationship is made within a framework of personal capabilities. Within this framework, mental and physical conditions are attached to human lovingness and sexual intimacy. Because elderly people suffering from mental and physical deterioration do not meet these pre-conditions, their need and desire for sexual fulfilment and human intimacy is being denied (2012: 355).

They are critical of an approach, seen in the literature, which reduces discussion of ethical issues around sexuality to standard principles (autonomy, beneficence, non-maleficence and justice) as if these issues can be discussed in a standardized way. They comment: 'The danger of standardization, however, is that ethicists will tend not to reflect on the fundamental values that underlie these basic principles' (Mahieu and Gastmans, 2012: 355). Their own inclination, therefore, is to enrich the discussion by using notions from the ethics of care, 'empathy, responsibility, respect, and vulnerability might provide us with a new orientation for dealing with the sexual needs and desires of institutionalized residents with dementia' (Mahieu and Gastmans, 2012: 355). The underlying values attached to the undisputed love of Hussain for Mahbubah need to be brought into play rather than allowing a prohibition on overnight leave to hold sway on the basis of concerns about legal concepts, which may have limited applicability in the context of love and intimacy.

Vignette 4: Hugo

Hugo is 74 years old and has lived in a care home for the past two years. He has a probable diagnosis of frontotemporal dementia. Hugo's family report that the condition has affected his personality—he has become increasingly inconsiderate and obstinate—but his memory and functioning abilities remain reasonably intact. On two occasions staff have found Hugo masturbating in the bedroom of a more vulnerable female resident whose outer clothing he had removed. It is also a daily occurrence that staff find Hugo masturbating in his own room. Whilst

acknowledging that in the privacy of his bedroom he is at liberty to do as he wishes, staff get upset that he continues to masturbate after they have entered his room, having always knocked and been invited in by him beforehand. The incidents involving the vulnerable female resident raised a safeguarding alert and in preparation for the strategy meeting Hugo was approached by the home's deputy manager to discuss the safeguarding process and the potential outcomes, which include the possibility that he will be moved to an all-male environment. During the discussion Hugo appeared totally unconcerned about his behaviour, but he was worried about the possibility of having to move. He said he was happy living in the home.

At the strategy meeting it was agreed to implement a number of measures to try and contain Hugo's behaviour and minimize the risks posed to others. However, it was also agreed that should these measures fail the only option would be to move Hugo to an all-male environment. Towards the end of the meeting Hugo was invited in to hear the outcomes. At this point Hugo revealed he could only achieve complete sexual satisfaction if he masturbated into women's underwear. He said that not having the garments readily accessible meant he needed to masturbate more often to try and achieve satisfaction. He also gave this as the reason for removing the outer clothing of the female resident.

Discussion

Again, in this case, there may well be some conflicting values at play (VBP2). There may, after all, be slightly different views about masturbation under any circumstances. Different perspectives will need to be acknowledged and accepted (VBP5). Perhaps some staff will regard Hugo as no worse than a young boy, whilst others will see him as a 'dirty old man' (VBP6 and VBP7). The possibility that he could be given medication to decrease his libido should also be considered (VBP3), along with the underpinning values of such an approach. In the end, part of the concern was lessened by the knowledge that Hugo enjoyed women's underwear (VBP4), which provided a controlled strategy for the home to adopt. By providing him with the means to his sexual satisfaction, they were more able to set other boundaries to his behaviour (VBP9 and VBP10).

CONCLUSION

Ethical issues around sexuality in the context of dementia are difficult because of the conflicting values that emerge. Our own attitudes towards sexuality and to sexual relations are often at issue and, given that these are frequently intensely private, confronting conflicting values in an overt manner presents problems. Nevertheless, it seems important that sex and sexuality should be regarded and dealt with at the level of underpinning values given the centrality of these issues to our lives. Little is said here or in the literature about ethical issues in connection with sexual relationships in the privacy of the person's own home. The literature focuses on institutional care. This should be a cause of concern for two possible reasons: either it suggests that there is the possibility of unethical practices in the privacy of people's own homes on a scale that is undetermined; or it suggests that sexual

intimacy only becomes routinely ethically problematic once a person with dementia is institutionalized. The latter seems to us more likely and more disturbing. It suggests, for instance, that deep friendships are problematic in care homes, despite the benefits of social interaction for people with dementia (Sabat and Lee, 2011). A values-based practice approach is a way to bring into the open the values that support or inhibit intimacy. Sexual intimacy may be unwanted or inappropriate for a variety of reasons, but it should not be regarded as routinely problematic when it otherwise provides the possibility of authentic human flourishing.

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