

## 11. Frailty, care, deep old age.

### Overview

As discussed in earlier lectures, older people are not a homogeneous group, and there are vast differences between people at the age of 60 years and those at 90 years. Many people become more frail as they age, others become disabled and require support or care. While sexual needs may diminish with age or disability, the human need for social contact, intimacy and sexual satisfaction do not disappear. Despite this, many people in caring or support roles treat older people who are frail or disabled as if they are asexual. In this lecture we will explore some of the implications of this for older people who require support or care.

### Objectives

By the end of this topic you will have:

- Considered the effects of loss of social power experienced by older people in supported accommodation and nursing homes.
- Examined the effect on people in care, of being denied fulfilment of their need for intimacy and sexual expression.
- Considered how support workers and carers can respond to the intimacy and sexual needs of older people
- Reflected on the implications of these for professional practice.

### Key Concepts

Role of carers, loss of social power, the body in deep old age, fourth age

### Required reading

Twigg, J. (2004). The body, gender, and age: Feminist insights in social gerontology. *Journal of Aging Studies* (18 ), 59-73.

Davies, H. D., Zeiss, A. M., Shea, E. A., & Tinklenberg, J. R. (1998). Sexuality and Intimacy in Alzheimer's Patients and Their Partners. *Sexuality and Disability*, 16(3), 193-203.

### Further reading

Johnson, B. K. (1996). Older Adults and Sexuality: A Multidimensional Perspective *Journal Of Gerontological Nursing* 22(2), 6-15

### Lecture Notes

The time of life between the ages of 60 and 75 is sometimes referred to as the 'third age'. Heralded as 'the time of your life', when one is free from child rearing responsibilities and able to explore personal interests, the third age is almost always produced as a positive time of life. Twigg (2004) argued that literature on this time of life is often "often passionate, subjective and written from the inside".

It can be argued that individuals are aged not by their bodies, but by social and cultural expectations. Popular culture, advertising and the media urges us to feel bad about ageing and to start this early. Consumer culture shapes the body as something to be worked on, fashioned and controlled, a site of self identity and reflexivity as well as of consumption (Twigg, 2004)

Unlike the time of the third age, when individuals are urged to work against ageing, and judged harshly if they fail by showing signs of age, after about the age of 75, people enter what some theorists call the fourth age. This has been described as a time when individuals are likely to become more dependent on others; they may be frail and require assistance with personal care or to live in aged care facilities. The third and fourth ages can be described in chronological terms – the distinction is actually qualitative. In other words, the main characteristic of those in the Fourth age is their need for assistance with daily tasks. Twigg describes the literature concerning this time of life as very different from that relating to the younger aged: it is “written from the outside, it is about them – the old – not us. The very old remain eternally Other”. She argues that literature about people in the Fourth Age becomes very different than that about or directed towards those in the Third Age. It is more likely to be couched in the language of ‘officialese’ or that of policy makers, and directed towards others, not old people themselves. Rather than age, it is the onset of infirmity that marks this transition. Bodily difficulties such as mobility, incontinence, dementia or bed sores, are often seen as more important than factors such as morale and wellbeing which may become subsumed.

### ***The Body in Deep Old Age***

Partly because women experience greater longevity and partly because they tend to experience more disability, gender is a relevant issue in deep old age. Women tend to spend longer in this time of life than men, which means that they consume support and care more frequently than men. According to Twigg (2004) this means that misogynist discourses, which have long focused on the bodies of women, are extended and amplified in relation to old women.

It is in deep old age that we may start to need greater support and assistance with our daily lives. When this cannot be provided at home, it is a time when many people require residential care. Life in residential care for those who are disabled or infirm is all about the body and its management. Day to day routines centre on the care of the bodies of those who cannot care for themselves.

... indeed, this is what makes the places and regimes so grim. The day to day routines of the institution turns around bodies – their cleanliness, orderliness and health. Bodies are monitored and surveyed for signs of dirtiness, sickness and decline. They are got up, dressed, washed, moved, fed, toileted, arranged in chairs to produce ... the ‘lounge standard resident’ (Twigg, 2004, p. 65).

### **Reflection**

In her article (required reading) Twigg refers to the ways in which ‘care work’ is concerned with the body in aged care facilities. Reflect on the section in Twigg’s article about the body in deep old age (section 4) and write in your journal about the ways she identifies that old people are regulated and disciplined (in Foucauldian terms).

- Write about the implications of this for working with old people with support needs, who live with family.
- Write about the implications of this for old people with support needs who are in care.

### Activity

The following is an excerpt from a conference paper *Old age, sickness, death and immortality: A cultural gerontological critique of bio-medical models of old age and their fantasies of immortality*. By John A. VINCENT, available from <http://www.people.ex.ac.uk/JVincent/Conference%20papers/Tampere%20Symposium/Old%20Age,%20Sickness,%20Death%20and%20Immortality.doc>

According to Vincent:

*In an academic paper on ‘Aging and the biochemistry of life’ leading researcher Robin Holliday (2001) explains the history and basic theories of ageing and some of his part in it. The paper is largely concerned with the bio-chemical processes within cells which are identified with ageing. The cultural understanding of old age – how people think about older people – is embedded in how ‘older’ molecules, proteins, cells, organs, soma, organisms are described.*

*They are contrasted as*

adult,[proteins, cells, organs, bodies]	aging [proteins, cells, organs, bodies]
young	senescent
integrated	disordered
development	failure, loss, decline
normal	abnormal
maintain	altered
invest	run down
accurate	incorrect, damaged, mistakes, mutant, defective, errors, unstable,
fitter	disposable, diminished, unwanted,
healing, repair, detoxified	breakdown, dangerous, harmful, deleterious.

*Holliday’s concluding argument is that ‘natural aging’ and disease in old age are not actually different. He suggests that “The paradox of evolution is that those forces which gave rise to animals with all their adaptations for successful life also gave rise to aging and the ending of that life.”*

Vincent suggests that an analysis of the discourses about aging in Holliday’s paper compares *ageing to success* in the same way as *death* does to *life*, and that the logic of this reading is

that ageing is the opposite of success, that is to say it is a failure, not a normal, but a pathological process. An alternative reading of the same sentence might be:

successful life = successful ageing = successful death.

i.e. ageing is not contrasted with life, it *is* life, and thus evolution makes sure all parts of life are successful. However, this reading is clearly not the author's intention as he refers to a paradox. The paradox is only present if the first reading – that ageing is failure - is intended.

If you find this difficult, read the article (which you can find by following the link above).

Think about what Vincent's suggests concerning the construction of successful ageing, and the similarities between biomedical discourse about ageing cells suggested by Holliday and social discourses about aging.

Write in your journal about the implications of this for your own attitudes, and for your work.

### ***The Family and Old Age***

For many people, expectations of caring in old age centre on the family. The phrase 'the family' almost always conjures an image of the nuclear family. In relation to the care needs of the aged, images dominate of either a nuclear family burdened by a frail aged or disabled relative, or of a woman in her third age burdened by an aged parent. However, this focus on family as monogamous, didactic, living together and primarily heterosexual is increasingly not the norm in society. Roseneil (2004) argued that post modern living arrangements are 'diverse, fluid and unresolved' – for example influenced by divorce rates, lone parents, childlessness, sexual orientation and gender identity – which means that the normative ideal of 'the family' is changing.

In this changing social scene, care and support for others as they age may not be familial, and in this setting, friendship networks become more important. In thinking about the care and support of those who are frail aged it is important to rethink what constitutes a family, and to respond to the people that the individual who are in care define as family, regardless of genetic ties. Increasingly people are defining family in different ways, and many now think of their family beyond blood ties, as family of choice. For many, definitions of family are expanding beyond family of origin to include friendships.

The concept of family of choice is particularly relevant for those in gay, lesbian and transgender communities, where family of origin may disown or reject an individual because of their sexuality or gender identity. In these communities, friendship, both as a practice and as an ethic is particularly important. Non-normative intimacies are more frequent, for example, friends, lovers and ex-lovers are often seen as family. This reconfiguring of the family is likely to become more prevalent as individuals who are part of the generation in which issues such as divorce, childlessness and single parenting age themselves.

### **Activity: What is intimacy?**

The Oxford English Dictionary defines intimacy as:

*The state of being personally intimate; intimate friendship or acquaintance; familiar intercourse; close familiarity; an instance of this;*

*A euphemism for sexual intercourse.*

Think about how you understand the concept of intimacy. Do you most commonly assume to it as the former or the latter definition given above? Do you think about it in other ways?

Write about your reflections, and about the ways intimacy needs for old people in care might be fulfilled. What changes might need to be made to ensure these changes happen?

### ***Intimacy and care***

Kinsey's research into sexual behaviour found that 80% of people over the age of 60 were sexually active. While some physical difficulties may emerge for the frail aged people to have satisfying sexual lives, the desire for sexual satisfaction and/or intimacy do not disappear. As we have seen in previous lectures, friendship, not merely acquaintance, is an important factor for intimacy. Friendship occupies a central role in people's lives, and satisfies people's need for pleasure, emotional and affective satisfaction.

Sexual intimacy in care settings may be difficult. The lack of availability of sexual partners may present a problem, as may space. Without private, appropriate space, intimacy and sexual liaisons may be impossible. Health professionals and care workers often assume that once a person is in care, they are no longer sexual. Many workers' cultural values, personal beliefs and lack of training can present obstacles to addressing patient's sexual needs. Regardless of this, it is not necessary for workers to become sex therapists, or to have extensive training. Structural changes to space in care settings, and policies regarding respecting privacy and safety needs can give permission to people in care to pursue relations with others.

### **Activity: what does it mean to be sexually active?**

Being sexually active involves a great deal more than having heterosexual intercourse. Even heterosexual intercourse is often seen in limited ways, as penis/vagina penetration. Review the list below and think about whether engaging in the activities listed would constitute being sexually active.

- Kissing another person passionately (same sex/opposite sex)
- Kissing and cuddling with another person (same sex/opposite sex)
- Caressing or massaging another person (same sex/opposite sex)
- Private masturbation
- Mutual masturbation
- Using sex toys alone
- Using sex toys with another person (same sex/opposite sex)

- Oral sex (same sex/opposite sex)
- Genital sex within an established relationship (same sex/opposite sex)
- Genital sex with a surrogate
- Genital sex with a sex worker

Did you think any of these activities were not a way of being sexually active? In your journal write about your views about old people engaging in any or all of these activities.

**Activity: Sexual Permission Systems**

Each of us has a set of unspoken rules about what is acceptable or unacceptable about having sex. This activity provides an opportunity for you to think about what dos and don'ts are included in your 'rules'. The examples in the first row are suggestions to get you started.

1. Draw up your own table like the one below. First complete it for yourself.

Questions	OK	Not OK
WITH WHOM is it OK to have sex?	Eg your spouse, someone you are in love with, yourself, someone you like etc	Eg your friends spouse, age differences etc
WHERE is it OK and not OK to have sex		
WHEN is it OK and not OK to have sex?		
WHAT is OK and Not Ok to do when you have sex?		
WHY is it Ok and not OK to have sex.		

2. Now, based on your knowledge or experience, complete a second one for old people in care.

Questions	OK	Not OK
WITH WHOM is it OK for old people in care to have sex?	Eg your spouse, someone you are in love with, yourself, someone you like etc	Eg your friends spouse, age differences etc
WHERE is it OK for old people in care to and not OK to have sex		
WHEN is it OK and not OK for old people in care to have sex?		

WHAT is OK and Not Ok for old people in care to do when they have sex?		
WHY is it Ok and not OK for old people in care to have sex.		

Reflect on your responses, which will remain private. Write in your journal about ways in which old people's need for sexual expression and intimacy might be better addressed in practice and the role of workers in this.

*This activity is suggested by Davies (1998)*

How can support workers respond? Old people with dementia

### **Dementia - sexuality and intimacy**

*This information is provided from the Alzheimer's Association Australia Helpsheets, downloaded from*

[http://www.disability.vic.gov.au/dsonline/dsarticles.nsf/pages/Dementia\\_sexuality\\_and\\_intimacy?OpenDocument](http://www.disability.vic.gov.au/dsonline/dsarticles.nsf/pages/Dementia_sexuality_and_intimacy?OpenDocument)

#### **Intimacy and sexuality**

The need for closeness is a very important and natural part of people's lives. Intimacy is the giving and receiving of love and affection. It involves caring touch, empathic understanding, comfort in times of need and a feeling of safety in relationships. Sexuality is the feeling of sexual desire and its expression through sexual activity. Like intimacy, it is a natural expression of human need. For many people, however, sexuality goes beyond the narrow concept of sexual intercourse. It is often bound up with many of the broader expressions of intimacy, including physical closeness, kissing and hugging.

#### **How are intimacy and sexuality affected by dementia**

People with dementia continue to need caring, safe relationships and touch. However, they will vary in their individual ways of giving and receiving affection, and the way in which their dementia affects that capacity. As a result of the disease, some people with dementia may become demanding and insensitive to the needs of others, and less able to provide caring support for their family and partners. They may also experience changes in their expression of sexuality. Some people continue to desire sexual contact while others may lose interest in sexual activity. Others may display inappropriate sexual behaviours.

Carers may experience a range of feelings about continuing a sexual relationship with a partner who has dementia. These may include feelings of rejection, distaste and guilt. It can be helpful to discuss these with a counsellor.

#### **Changed sexual behaviours**

It is important to remember that any strange or uncharacteristic behaviour is part of the illness and not directed in a personal way. The person may no longer know what to do with the sexual desire, or when or where to exercise the desire.

### **Increased sexual demands**

Some partners find that a person's desire for sexual activity increases as a result of dementia. This can result in unreasonable and exhausting demands, often at odd times or in inappropriate places. Occasionally aggression may be shown if those needs are not met. A carer may have to keep safely out of the way until there is a mood change. Some carers complain of feeling like an object. Once the person with dementia has had sex, they may immediately forget what has occurred.

### **Diminishing sexual interest**

Many people with dementia lose interest in a physical relationship and may become very withdrawn. They may accept physical contact from others, but not initiate affection. Carers may feel hurt and bewildered by the loss of interest.

### **Loss of inhibitions**

People with dementia sometimes lose inhibitions and make advances to others, or undress or fondle themselves in public. Sexual advances are sometimes made because the person with dementia mistakes another person for their partner. Sometimes, an action which appears sexual - for example, a woman lifting her skirt - may be an indication of something else, such as the need to go to the toilet.

## **Managing inappropriate sexual behaviours**

### **Things you can try**

- Consider all possible reasons for the inappropriate behaviour. These could include needing to go to the toilet, discomfort or boredom.
- Gently discourage inappropriate behaviour.
- Try to remain focused on the person, not the behaviour.
- Aim to distract the person if possible or redirect them to another activity.
- Find ways to include different forms of touch in the everyday routine, so that the person gets some physical contact. Massage, holding hands and embracing are ways of continuing to provide loving touch.

### **Support for carers**

Like all the other problems carers face, this one can be helped by discussing it with an understanding person. Support and affection from friends and family can help many carers to cope with the situation. Talking about problems in a carer support group can help. Knowing that others have been through the same experience may assist you to feel that you are not alone or abnormal. It is healthy to have a laugh or a cry about things.

For some, a good friend is enough, while others find that their doctor or social worker is able to give them the time and understanding needed. There are many qualified counsellors who are used to talking with families about sexuality. Your doctor should be able to refer you to

an appropriate counsellor. The Alzheimer's Association also provides confidential counselling which many carers find helpful.

### **Reflection**

How helpful do you think this form is for frail aged people?

Think about ways it might be changed or improved and write a critique of it in your journal.

### **References**

- Davies, H. D., Zeiss, A. M., Shea, E. A., & Tinklenberg, J. R. (1998). Sexuality and Intimacy in Alzheimer's Patients and Their Partners. *Sexuality and Disability, 16*(3), 193-203.
- Roseneil, S., & Budgeon, S. (2004). Cultures of Intimacy and Care beyond 'the Family': Personal Life and Social Change in the Early 21st Century. *Current Sociology, 52*(2), 135-159.
- Twigg, J. (2004). The body, gender, and age: Feminist insights in social gerontology. *Journal of Aging Studies (18)*, 59-73.