

Thesis

'Half of them are dying on their feet but they still have strength for that'

Sexuality, dementia and residential care work: a disregarded and neglected area of study

The Thesis is submitted in the form prescribed by the Academic Council and as published in the University Calendar, for the degree of Doctor of Philosophy at the University of Stirling 2002

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4/03

Declaration

I have composed the thesis and the work it embodies has been done by me and has not been included in another thesis.

Signed Caribald

Date 27/9/02

Acknowledgements

Firstly I need to acknowledge all the participants who gave of their time, thoughts and ideas on what is generally acknowledged to be a difficult and sensitive area of work. Particular thanks are given to the staff of Glenevis Home with whom I worked for almost a year observing, questioning and generally causing them to consider much more than they would normally be inclined to do, the subject of sexuality and dementia.

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Thank you to all.

**If things were always what they seemed
how impoverished would be the imagination
of (wo)men**

**Durrell L (1958: 19) *Balthazar*
The Alexandrian Quartet**

Contents of the Thesis

Introduction to the Thesisi - xii

Abstract of thesis.....1

Chapter 1 Dementia as a construct and the ambiguities inherent

1.1	Introduction.....	16
1.2	Medicalisation and the disciplining of dementia.....	17
1.3	Ambiguities and uncertainties apparent in the medicalisation of the illness.....	20
1.4	The ‘mask(s) of dementia’.....	23
1.5	The social construction of dementia.....	24
1.6	The person-centred paradigm	26
1.7	The disability role of dementia and the implications for sexual expression.....	27
1.8	Ethics and decision-making in sexual expression for people with dementia in care situations.....	31
1.9	The sociological body	34
1.10	Older bodies	35
1.11	The ageing body and gender differences	36
1.12	Ageism.....	37
1.13	Conclusions.....	39

Chapter 2 Debates and Discussions Around Sexuality

2.1	Introduction.....	43
2.2	Constructs of sexuality	45
2.3	Researching socially sensitive topics	46
2.4	Histories of sexuality	48
2.5	The construction of women’s sexual identities	51
2.6	Sex talk	55
2.7	Sexuality and older people	57
2.8	Sexuality and people with dementia.....	60
2.9	Sexuality – older lesbians, bisexuals and gays.....	62
2.10	Conclusions	64

Chapter 3 Sexuality - Dementia and Residential Care

3.1	Introduction.....	67
3.2	Residential homes and their history	68
3.3	The home/institution debates.....	71
3.4	How power is enacted in residential homes	73
	3.4.1 Residents, sexuality, power and gender differences.....	73
	3.4.2 Staff enactment of power, ambiguity and gender implications.....	75
3.5	The culture of organisations	77
3.6	Care work and gender expectations.....	79
3.7	Spatiality and bodywork	82

3.7.1	Metaphorical and physical closeness and the emotion work involved	83
3.7.2	Touch	88
3.7.3	The management of intimacy.....	90
3.8	Sexuality in organisations	94
3.8.1	Sexual harassment	96
3.8.2	Sexuality and long-term care organisations	97
3.9	Sexual stories	99
3.10	Concluding the literature review.....	99

Chapter 4 Theoretical Voices and Research Parameters

4.1	Introduction	106
4.2	A toolbox approach.....	107
4.3	Feminist enquiry	108
4.3.1	Difficulties and tensions in the collection and interpretation of the data	110
4.3.2	The collection of the data - hearing the voice of the research Participants.....	111
4.3.3	Challenges in the interpretation of the data	114
4.4	Feminist theories and Positivism/Normative research methods – a false dichotomy?	117
4.5	The diversity of postmodern approaches.....	119
4.6	Feminist ethnographic approaches	120
4.7	A partial grounded theory approach	122
4.8	A selective use of Foucault and Goffman.....	124
4.8.1	Foucault	124
4.8.2	Goffman	125
4.9	Conclusions	126

Chapter 5 The Different Methods Used to Obtain the Data

5.1	Introduction	128
5.2	A reflexive account – from practitioner to researcher	129
5.3	Methods timetable.....	133
5.4	The postal survey	134
5.5	Key concepts arising from the analysis of the postal survey.....	135
5.6	Glenevis Home – a case study	138
5.7	A reflexive account of access.....	139
5.8	Observations – the process.....	145
5.9	Observations – the emotions and difficulties of not being ‘one of them’	147
5.10	Participant observation and diaries	150
5.11	Semi-structured interviews	155
5.12	Documents	158
5.13	Sexuality training workshop for care workers	159
5.14	Triangulation and its application in analysis of the data	164
5.15	The delimiting, disentangling and ordering of the data	165
5.16	Conclusions.....	170

Chapter 6 The Postal Survey

6.1	Introduction.....	173
6.2	The piloting of the Holmes et al (1994) questionnaire.....	175
6.3	The process of piloting of the Holmes et al (1994) questionnaire.....	176
6.4	Home five – the first pilot focus group	177
6.5	Home six – the second pilot focus group.....	181
6.6	The piloting and acceptance of my questionnaire.....	182
6.7	The postal survey, design and process	183
6.8	My questionnaire design	184
6.9	The findings from the postal survey.....	186
6.9.1	Demographic data and gender issues.....	186
6.9.2	The main types of sexual expression by people with dementia reported by managers.....	187
6.9.3	A view of the field and the types of sexual expression causing most concern	192
6.9.4	The management of sexual behaviours causing concern and the role dementia plays	193
6.10	Discussion and conclusions	195
6.11	Findings from the survey, addressing the research questions	196
6.12	Research questions and themes to have emerged from the findings.....	199
6.12.1	Ambiguity	199
6.12.2	Gender.....	200
6.12.3	Spatiality	201

Chapter 7 Spatiality and Sexual Expression

7.1	Introduction.....	202
7.2	The public face (space) of Glenevis	204
7.3	Inner space – spatial structures	208
7.3.1	The sitting rooms.....	208
7.3.2	Corridors	210
7.3.3	Residents' rooms	210
7.3.4	The staff quarters.....	211
7.3.5	The forum	212
7.4	Institution versus home – ambiguity at bar night	213
7.5	Small scale living units – a homely and intimate space	219
7.6	Privacy and surveillance difficulties.....	224
7.7	Sexual observation of staff by residents.....	226
7.8	Privacy and some of the (sexual) dangers associated	229
7.9	Conclusions.....	235

Chapter 8 Sexuality and the Social Organisation of the Home

8.1	Introduction.....	240
8.2	Work and the routine in the Home	242
8.3	Sexual disruption of the routine	248
8.4	How the care workers perceive the residents	255
8.5	Dementia as a construct in Glenevis Home	257
8.6	Dementia and extenuating circumstances - the 'halo' effect	263

8.7	Care workers and family discourses	265
8.8	Professional discourses	273
8.9	Pivotal people - the 'toughies'	275
8.10	Conclusions.....	280

Chapter 9 Sexuality and the Key Worker Relationship

9.1	Introduction.....	283
9.2	The key worker relationship and its different constructs	284
9.3	Expectations of the key worker relationship.....	286
9.4	Thwarted expectations of the key worker relationship	288
9.5	Vulnerability as a factor in the key worker/key resident relationship ...	301
9.6	The key worker as sexual confidant.....	308
9.7	Conclusions.....	314

Chapter 10 Sexual Stories Told by Care Workers

10.1	Introduction.....	318
10.2	What common form do the sexual stories take?	322
10.3	Sexuality and its meaning for staff.....	323
10.4	General incidents stories including masturbation	327
	10.4.1 Private parts – the issue of masturbation	328
10.5	Resident-to-resident sexual expression	333
	10.5.1 The story of Margaret and Michael – a hard lesson learned.....	334
10.6	Resident-to-staff sexual expression	337
	10.6.1 The story of Christine and the patrolling of moral boundaries ...	339
10.7	Conclusions.....	345

Chapter 11 Talking About and Managing Emotions in the Context of Residents' Expressed Sexuality

11.1	Introduction.....	349
11.2	Emotions, emotion work and emotional labour	353
11.3	Jenny's 'stories' of sexual harassment and the emotional impact this entailed	355
11.4	Fred's story of gay sexual harassment and the continuing emotional disturbance that has resulted	367
11.5	The unbelievable story of Will and Wilma	373
11.6	Conclusions.....	379

Chapter 12 Conclusions drawn from the thesis

12.1	Introduction.....	384
12.2	The limitations and the key contributions of the study	384
	12.2.1 The limitations of the study.....	384
	12.2.2 Key contributions to the study.....	386
12.3	Conclusions of the literature review.....	387
12.4	Conclusions from the empirical work.....	389
12.5	What staff said about sex	390
12.6	The types of sexual expression that staff found most difficult.....	392

12.7	The role dementia plays in staff response.....	394
12.8	How context influenced staff response.....	397
12.9	Omission - why the subject has been so neglected	400
12.10	The implications of the findings for policy and practice.....	401
12.10.1	Policy	402
12.10.2	Practice issues.....	404
12.11	Further research	405
12.12	To conclude.....	407

Bibliography	409
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Appendices

Appendix 1	Final Questionnaire
Appendix 2	Matrices/Tables of Sexual Stories Told by Staff
Appendix 3	Examples of Levels of Coding
Appendix 4	Holmes et al (1994) Questionnaire
Appendix 5	Architectural Plan of Glenevis Home
Appendix 6	Managers and Staff Interview Questionnaires
Appendix 7	'Diagnosis' of Dementia in Staff Documents
Appendix 8	Feedback from Sexuality Training Day
Appendix 9	Further data analysis of postal questionnaire
Appendix 10	Table of Staff Details
Appendix 11	What the Incident Register is and Some Notes from the Register from 'Jenny's case'
Appendix 12	Relevant Scientific Seminars and Conferences Attended

Introduction to the Thesis

Often research questions and topics come from the world of professional practice, with the researcher (him, or) herself being a practitioner (Punch 1998). This knowledge can be used as a starting point for developing research questions as the researcher often has a considerable experiential knowledge about the topic. This reflects my own situation. The impetus for this thesis was primarily based on contextual knowledge acquired during the course of my work for several years as senior fieldworker at the Dementia Services Development Centre (DSDC). Talking with staff in a development capacity, the subject of sexuality and dementia appeared to be an issue. The facilitating of workshops on the subject, writing training materials and assisting in the production of two videos, was how I responded to perceived staff need. In practice this is a difficult area for staff yet when undertaking an initial literature search apparent was the dearth of research undertaken. The literature was mainly North American with sexual expression by people with dementia pathologised and contained within the context of problematic behaviour. This stimulated questions as to why this was the case. Why has this problematic area not been more widely researched? It seemed timely both from an academic and practice perspective to embark on a doctoral research programme. Working within a university environment, in a centre that was now established and valued by practitioners would perhaps provide the necessary credibility and legitimacy for an exploration of this sensitive subject.

If writing a PhD is analogous to telling a story, then this is a detective story with the primary aim of exploring the hitherto marginalised and moralised domains of sexuality and dementia within residential settings. The overarching research question is about neglect. Discussing heterosexuality Rubin (1989), argues that the imagining of certain acts as morally acceptable

or, unacceptable is crucial to defining heteronormality. Borrowing from Rubin and applying these ideas to sexual expression by people with dementia, I will argue that by situating certain acts as immoral or on the margins of acceptability, the centre or norm is defined. Sexual identities then become defined with reference to moral values. My thesis is that the sexual identities of people with dementia, as with other people with disabilities, are constructed on what is seen as the margins of acceptability. The literature, primarily by omission, lends support to this argument. Whilst there is an increasing literature that points to many older people continuing to be sexually active and interested, sexuality and people with dementia remains a neglected area of study.

Whilst the thesis generally is about neglect of the subject area, I also explore other specific research questions both in the literature and empirically. They include:

- ❖ What did staff say about sex?
- ❖ How did care workers respond to sexual expression by residents?
- ❖ What were the types of sexual expression staff found most difficult?
- ❖ How did a diagnosis of dementia affect the response of staff to sexual expression?
- ❖ How did the context influence staff response?

These research questions are conceptualised through the social as opposed to the biomedical model of disability. Using disability as an analytical conceptual tool, I am interested in exploring how the various constructions of dementia influence how care workers respond to sexual expression by residents with dementia. Acknowledging that prior to the last 10 years, dementia has been set firmly within a biomedical framework, in chapter one I use the literature to gain insights into what role dementia plays in staff response to sexual expression.

To address this question I critique the assumption that there is a shared understanding of what is meant by the construct of dementia and explore the ambiguities inherent in the different constructs, looking specifically at the identities that emerge. Social control is an important concept in sociology and in chapter one I discuss the concept of medicalisation of dementia and the medical surveillance or ‘medical gaze’ that often ensues. For example, (sexual) behaviour is conceptualised as a medical problem requiring a medical response.

Medicalisation as a concept is often used as a critique but I note that the apparent certainties afforded by the biomedical framework may have benefits for both family and professional carers. The ‘role of dementia’, an allusion to Parson’s (1951) ‘sick role’, can provide legitimacy to the deviance termed as illness, in this case, dementia. This has certain benefits but also disadvantages in residents’ sexual autonomy. The theme of ambiguity becomes central when considering the different types of dementia such as Lewy body dementia where the different presentations, the fluctuations of impairment, make the understanding of sexual behaviour problematic. I have used the concept of the ‘masks’ of dementia to explore the difference between the internal and external appearances of people with dementia and explore how this will impact on staff response to residents’ sexual expression.

The person-centred paradigm suggests that dementia be considered as a disability. This argument is critiqued and explored with reference to sexual expression by those so labelled as ‘disabled’. I explore how the response of care workers to sexual expression by people with dementia may be influenced by ethical considerations with the theme of responsibility emerging. I argue that ageism may be a feature in care workers’ responses to sexual expression by residents. I note that there has been a neglect of the body in sociology until

relatively recently. This will be examined with the main emphasis given to gendered older bodies including ageism in the discussion.

I conclude this chapter by noting that there has been little theorising about dementia with debates mainly centred around the medicalization of the disability. Ambiguity is a key theme to emerge. I argue, based on the literature, that dementia is an ambiguous and inchoate illness that perplexes even those who claim considerable medical/scientific knowledge of it. If this argument is accepted, then theoretically it may be proposed that care workers, whose understanding of dementia is often lay as opposed to medical, will have difficulty in the construction and understanding of dementia. In the context of sexuality, the identity constructed is asexual, or challenging behaviour, or it is ignored. I suggest that whilst the social disability model has been useful in helping to improve the care of people with dementia, it has not furthered the debates about sexuality and dementia. Many of the issues around people with dementia expressing sexuality are about decision-making. The literature points to the many (ethical) difficulties involved for staff when these residents express sexuality. The theme of responsibility in terms of deciding whether to allow a sexual relationship between people with dementia to continue appears important.

This first chapter has focussed on dementia. In the second chapter I will focus on the care workers. My research questions include what staff say about sex and what types of sexual expression they find most difficult. The themes that have emerged in chapter one when discussing dementia, those of ambiguity, identities, responsibility, ageism and gender, are also to the fore when considering sexuality. In chapter two I argue that there are influences other than dementia, such as historical and late modernity debates on sexuality, that may

influence the interactive process and thus staff responses, when residents with dementia express sexuality.

Responsibility as a theme comes to the fore and here it is within the context of class and gender. I was interested in exploring some of the secondary research questions that address how care workers respond to sexual expression and what they say about sex. The insights offered in the historical and specifically the late modernity constructs of sexuality, and how these may inform staff attitudes towards older people (with dementia) expressing sexuality, are of interest. Dual standards for men and women expressing sexuality emerge, and using Skegg's (1997) work to inform my arguments, I note that 'reputation' and responsibility for this remains a concern for working-class women. Decorous behaviour and avoidance of appearing too sexually available appears important. I theorise that these considerations may impact on situations when male residents make sexual advances to women workers

In this chapter I also return to the theme of neglect. Supported by the literature, I argue that the neglect of the subject may be as a result of the potential adverse effect that researching such a subject may have on the career of academics. Neglect is also apparent when looking at older lesbians, gays and bisexuals (lgbs). If older lgbs with dementia are neglected in the literature generally, they are particularly neglected in the literature on long-term care. In the third chapter, I bring together the issues of dementia, sexuality and long-term-care. One of my research questions asks how context influences how staff respond to sexual expression by residents with dementia. In chapter three this question is addressed by exploring issues around care work and how sexual expression by residents may impact. The definition of care work and the expectations of the workers and the organisation are discursively explored in the literature.

At the end of this chapter I draw together the issues from the literature and note the work previously carried out in the area of sexuality, dementia and long-term care situations. I note the gaps in the literature and then I detail where my empirical work sets out to address the gaps and also the questions stimulated by the literature review. These questions parallel my initial secondary research questions, with lgbs emerging as an issue to be explored further.

How care workers respond to sexual expression by residents with dementia is of concern. Central to my research therefore is an attempt to understand the ‘meanings’ that the different ‘social actors’ (care workers and other staff) construct around residents expressing sexuality. I draw upon Goffman’s (1959, 1961, 1978) social theory on dramaturgy and Foucault’s (1979) ideas on power to inform my work. My epistemological position involves the use of mainly interpretivist methodologies so that later in the research process I can theorise around the relationships revealed between the different social actors. Edwards and Ribbens (1998:2) note that feminist social researchers concerned with intimate and ‘domestic’ issues are involved in the social construction and material production of knowledge within the domain of public and academic discourses. There is potential for tensions and ambiguity when trying to serve both audiences whilst remaining faithful to the intimate forms of knowledge gained. In chapter four I set out my methodological arguments and note that epistemologically, I am interested in hearing the voice of mainly women care workers. Throughout the thesis I have endeavoured to retain these voices whilst undertaking an academic analysis of the data.

The central argument of my thesis is that the area of sexuality and people with dementia in care situations has been neglected. In chapter four I explore several theoretical perspectives including feminist methodologies, and argue that using this ‘tool box’ approach will help to address and break down the silences surrounding this subject area. Feminist and postmodern

approaches allow a theoretical opportunity to create a new understanding and a space to explore ambiguities apparent in both the literature and in my empirical work.

In chapter five I explore my use of multiple methods to obtain the data. I noted in chapter four my use of feminist methodology and the consequent need for reflexivity. There is always a danger in being self-reflexive of making the self too central. In chapter five I begin by acknowledging myself within the research process and provide a reflexive account of access to Glenevis Home. Whilst I acknowledge that I remain the prism through which the data are analysed and constructed, following this section I place myself on the periphery of the thesis.

I have compared my thesis to some kind of a detective story with the consequent need for an exploratory approach. I have employed a postal survey to provide an overview. Whilst this method was useful in providing this, helping in the selection of a residential home in which to undertake the main part of my research and providing themes and concepts that informed the development of my interview schedules, it did not address in depth, my secondary research questions. I use a case study approach to address these and other questions generated from the literature and the empirical data.

The location of the case study, where my fieldwork was undertaken, I named Glenevis, a social work residential home for older people. I used observation, participant observation and semi-structured in-depth interviews, in obtaining the data. I also accessed staff working documents such as the Kardex and the incident book. Included in this chapter are the findings from the training workshop that I provided for staff following the completion of my fieldwork. Grounded in the data, in the conclusions of this chapter I set out a route map of the

thesis indicating the reasons why the empirical chapters have been structured in this specific way.

The development and use of my postal questionnaire is chronologically first in the data collection and is therefore included in the first of my empirical chapters (chapter six). The process of developing the questionnaire and the data from the pilot groups is discussed. I detail the discomfiture of staff taking part in the two pilot groups when discussing this subject and discuss the themes of ambiguity and also space that emerge. The final questionnaire (Appendix 1), used in the postal survey, was sent to all the managers of social work residential homes in one region in Scotland. The findings point to a dissonance between what is expected of workers professionally in terms of their attitude to sexual expression by residents including those with dementia, and what they feel privately. The tension between this public and private metaphorical space appeared pertinent when addressing the response of care workers to sexual expression by residents with dementia.

This relates to Hochschild's (1983, 1998) work and the concept of emotional labour but also has resonances with the work of Goffman (1963) and impression management. Both concepts are explored in greater depth in the last chapter on emotions. Gender is also an issue with male residents to the fore. The findings from the postal survey plus the themes and research questions generated from the literature have helped to inform the sequence of the subsequent chapters in the thesis.

The theme of spatiality and the research question of how context may influence staff response to sexual expression by residents is explored in chapter seven. I argue that Goffman's (1959) dramaturgical concepts of 'front stage and back stage' are relevant and note in this chapter how geographical space may influence staff responses. When addressing the area of sexuality

and dementia there is a need to theorise and map how sexual and gender identities and socio-spatial relations are shaped in the home. One of my research questions is how sexual expression is constructed as moral or immoral in particular spatial contexts. The exploration of space in chapter seven begins to address this question. I provide a descriptive context in which to site this ethnographic-type case study. Ambiguity, as I note in the literature, is a component of both sexuality and dementia so how boundaries and distance are negotiated and how space is used, is pertinent. The themes of gender, ambiguity and space are explored and in this chapter I begin to theorise about how sexuality and dementia is talked about in Glenevis.

As my research is mainly contextualised within a residential care home and is primarily about exploring the 'sexual culture' (Herdt 1999) therein, in chapter eight I address what both staff and residents 'do' in the home. Chapter seven provided a 'stage', a spatial context, in chapter eight the way the various 'actors' behave on and off stage is addressed. What it means to be a 'sexed subject' (Hubbard 2000) in the home is explored. I look at the routine of the home and explore how this appears to be a component that helps to contain disturbance in what seem to be for staff, 'scary' forms of sexuality. Infantilisation, ageism, reputations and identities are emergent themes as is space once more. Care workers report that becoming close to residents is a major aspect of their work and one that provides job satisfaction. This appears to be exemplified in the key worker relationship that I explore in chapter nine.

The care workers report that mainly, each worker is allocated four 'key' residents for whom they are responsible for providing extra aspects of care including bathing, taking the resident out and working with their family. Again, I use grounded theory in developing theoretical concepts and I begin to question how sexual expression by key residents impacts on what

seems to be a mock-kin relationship. How care workers manage the complex ambiguities inherent in caring within the key worker relationship when sexual expression becomes part of that association is addressed. Central are the tensions that arise when familial discussions converge on sexuality. My concern was to explore the research questions of care workers' response and also the relationship context of the key worker/key resident relationship. I argue that this can help in contributing a better understanding of space and the emotions generated.

The exchange of stories and/or gossip is part of the fabric of communities. Of particular interest in chapter ten is how sexual stories circulate in terms of which stories are told and when. I draw on the work of Plummer (1995) who argues that society itself may be seen as a 'textured but seamless web of stories emerging everywhere through interaction: holding people together, pulling people apart, making societies work'. Following on from Plummer, the nature of the sexual stories in Glenevis Home is explored. Methodologically I am interested in hearing the voices of mainly women care workers. One of my research questions is what staff said about sex. This exploration is important, I argue, as it is part of the political processes of the home that may reflect the debates about sexuality generally in society. The social role of the stories, the way they are produced and the work they perform within these processes, is analysed. Being reflexive is an important part of feminist methodology and here, as in the thesis generally, I ask, as Plummer (1996) asked, 'What are these stories told to curious sex researchers all about and in doing, I acknowledge that there will be different 'truths' told.

Pritchard and Morgan (2000) argue that space and place are increasingly being critically analysed as sociocultural constructions rather than simply physical locations. Any examination of space must accordingly explore its 'emotional' geography with gender critical

to the construction. In chapter eleven, I refer back to the initial argument of the thesis that highlights the absence of sexual expression by people with dementia in the literature. I apply the substantive theories of emotional labour (Hochschild 1983, James 1989), bodywork and feeling rules (Lawler 1991) and the exploration of environmental regulation of emotion; the emotions of control (Fineman and Sturdy 1999), in the analysis. I address some of the reasons why the subject of sexual expression by residents may be marginalised and undisclosed.

The literature is concerned with the processes involved in emotional labour. In this chapter I address the processes but also use the theme of space to explore some of the main emotions expressed by some care workers when sexual expression is a component of their work. I use care workers' storytelling as a conceptual tool to explore some of the emotional geography of the home.

I began the empirical chapters by discussing general aspects and so providing an overview of the subject. I conclude these chapters by focussing in on the specific, the space in the care workers' heads looking at the emotions generated when sexual expression by residents with dementia becomes a component of care work. This chapter concludes the empirical chapters and addresses some of the complex issues associated with residents with dementia expressing sexuality. In the chapter I consider the response of care workers in managing such situations. How a diagnosis of dementia may have affected this response, is explored. The thesis has as a major focus residents with dementia yet dementia, like sexuality, is highly ambiguous, contested and situated, so throughout all the chapters I take into account the talk of dementia and where it occurs.

Ambiguity, private and public, gender and spatiality are major themes that have emerged from the data. Each chapter builds incrementally on these themes in exploring why sexual expression by people with dementia has been such a neglected and marginalised area of research. In the conclusions to the thesis I explore the findings and address how these may inform policy and practice and suggest several areas that need further research. The latter I suggest needs to include ‘hearing the voice’ of people with dementia with regard to sexuality and intimacy, and issues around older gays and lesbians who have dementia. A further area of neglect is men in the caring professions, particularly in residential care work with regard to resident expressed sexuality.

My aim in this thesis has been to explore why sexuality and dementia has been marginalised in the literature and practice. I have argued that the contribution of the thesis is to both theory and practice. The thesis brings together the study of sexuality, older people with dementia and residential living and examines them in the context of an ethnographic-type study of home life. The thesis makes connections between ideas, theories and practice. It also provides insights into issues around sexual expression by people with dementia reaching the ‘interior’ of social life that has been hitherto neglected. The central contribution and concern of the thesis is to peel back the layers of residential life and allow an examination of this sensitive area.

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'Half of them are dying on their feet but they still have strength for that'

Sexuality, dementia and residential care work: a disregarded and neglected area of study

Sexual expression by people with dementia has tended to be pathologised in biomedical debates or ignored in person-centred discussions. The thesis therefore brings together the study of sexuality, older people with dementia and residential living and makes connections between ideas, theories and practice reaching the 'interior' of social life that has hitherto been neglected. A postmodern feminist approach was used to explore this subject, which is 'seen' primarily through the lens of (mainly) female care workers' experience with ethnographic and grounded theory methods used to obtain the data. A postal survey involving 28 social work residential homes was undertaken followed by a period of fieldwork using observation, participant observation and in-depth interviews in one social work residential home.

The overall research question addressed the neglect of the topic, others looked at what staff said about sex, how they responded to residents' expressed sexuality, what they found most difficult, the part dementia played and how context affected response. Resident-to-resident sexual expression was more widely discussed than resident-to-staff

expression. The latter was reported to be the most difficult area for staff to manage and one that appeared to carry emotional costs. There was also a tension between what staff said and how they responded in practice. Ambiguity was a key constituent with the defining of dementia sometimes a contested area between care workers. Where the resident was very advanced in their dementia, the extenuating circumstances of the illness seemed to engender more forbearance. The difficulties arose when the diagnosis was not so apparent. The data point to the subject being a difficult area with staff sometimes choosing to ignore or remaining silent about resident sexual expression. Researchers' neglect may in part be due to difficulties in obtaining research funding or the possibility of their career prospects being compromised.

Chapter 1 Dementia as a Construct and the Ambiguities

Inherent

1.1 Introduction

There appears to be a neglect of the subject of dementia and sexuality within the context of residential care. In undertaking a literature review I explore possible reasons for this omission. I begin in chapter one to address both the medical and social constructs of dementia. One of my research questions addresses the role dementia plays in care workers' response to sexual expression by people with dementia. I use the literature to gain insights into how dementia is perceived. I counter the assumption that there is a shared understanding of what is meant by the construct of dementia and explore the ambiguities inherent in both the medical and the social care models. The social care model suggests that dementia be considered as a disability. This argument is critiqued and explored with reference to sexual expression by those so labelled as 'disabled'.

I explore how the response of care workers to residents' with dementia sexual expression may be influenced by ethical considerations with the theme of responsibility emerging. Returning to the theme of neglect, I note that the body, particularly gendered older bodies, has been ignored in sociology until relatively recently with ageism implicated.

I conclude that there has been little theorising on dementia reflecting the marginal position held by those with the illness. The debates have mainly centred around the

medicalisation of dementia and it is apparent that dementia is an ambiguous and inchoate illness that may perplex even those who claim considerable medical/scientific knowledge of the condition. If this argument is accepted, then theoretically it may be proposed that care workers, whose understanding is lay as opposed to medical, may also have difficulty in the construction and understanding of dementia. I theorise that this will impact on the identity of people with dementia and as a consequence sexual expression by them may be seen within the construct of challenging behaviour. Ageism is also implicit and it may be theorised that a contributory factor in the neglect of the subject is that sexual expression by those with dementia in residential care may not be interpreted as such.

Many of the issues around people with dementia expressing sexuality towards other residents appear to involve decision-making. The literature points to the many (ethical) difficulties involved for staff when these residents express sexuality. I argue that this will influence and impact on care workers' response. Ambiguity is a key theme to emerge in the literature with responsibility, ageism, neglect and identities also apparent.

1.2 Medicalisation and the disciplining of dementia

Medicalisation means to make medical but as Conrad (1992) notes the concept has now wider and more subtle meanings and is often used as a critique. Conrad (1992:211) notes that medicalisation consists of defining a problem in medical terms using medical language to describe a problem or using medical intervention to 'treat' it. The medical definition or construct of dementia is encompassed within the two important systems for classifying dementia and known psychiatric illnesses. The International

Classification of Diseases (ICD) and a US system known as American Psychiatric Association Diagnostic and Statistical Manual (DSM) are used to help with diagnosis. The two systems vary slightly and therefore the diagnostic practice will vary (Chesterton and Bender 1999). The DSM IV classification of dementia has five elements including impairment of abstract thinking, impaired judgement, other disturbances of higher cortical functioning and personality change.

There are different kinds of dementia. The two most important are Alzheimer's disease and multi-infarct dementia. Clinically, the temporal and parietal lobes of the brain are most often affected in Alzheimer's disease. The temporal lobes are involved particularly in memory; damage in these areas can cause profound memory loss (Chapman, Graham and McDonald 1999). The authors note damage of the parietal lobes may result in people possibly not being able to recognise family members, their belongings or who they themselves are when they look in the mirror. There are also visual-spatial difficulties when the parietal areas are affected. The other main areas of the brain that can be affected are the frontal lobes. The frontal lobes are where we process information to make judgements and to communicate. Damage in this area can result in disinhibited behaviour, where the person speaks and behaves in a way that they would not have acted pre-morbidly. The main inference from the literature is that the person's behaviour and responses are the result of tangible physical damage to the brain caused by the illness.

The medical model has remained intact and powerful and it is hard not to conclude that ostensibly it offers benefits, certainty and a framework when considering this ambiguous illness. Bond (1992) argues that one of the most important perceived

benefits of the biomedical model of dementia is the bringing of order to dementia care. Bond (1992:401) discusses this in relation to family carers who, when given a medical diagnosis of dementia for their relative, are then able to accept that their loved one is ill, not crazy. Bond argues that medical labels and authority can ease the stress of dementia care by increasing the sense of predictability and control of family caregivers, and also professional carers. The label of dementia can legitimate an individual's bizarre behaviour and absolve him or her of responsibility (Bond 1992).

Responsibility is a theme taken up by Golander and Raz (2000:366) in their study of people with dementia in a ward setting. They report that having dementia can produce certain side benefits or 'halo effects' for the person. The authors used the concept of the demented 'role', an allusion to Parson's (1951) sick role, as both roles have aspects in common. In their study, those residents on the ward who did not have dementia reported that the 'demented role' had a beneficial end product in that it exempted its owners from social responsibilities. The 'role' of dementia', as noted by Golander and Raz (2000) can provide legitimacy to deviance termed as illness, in this case, dementia. This has certain benefits but may have disadvantages in terms of the control exerted on residents' sexual expression. Social control is an important part of medicalisation first conceptualised by Parsons (1951) who noted the way that the 'sick role' could conditionally legitimate the deviance termed illness.

Based on the work of Foucault (1977) this medical and social control suggests that certain behaviours become perceived through the 'medical gaze' and that medics may lay claim legitimacy for all activities pertaining to that condition including sexual expression by residents. Medicalisation has occurred in both 'deviant' and natural

aspects of life. Conrad (1992) however provides a review of the literature and points to how classification systems, including the Diagnostic and Statistical Manual classification system (DSM), have appeared to change because of social factors.

1.3 Ambiguities and uncertainties apparent in the medicalisation of the illness

As noted medicalisation has occurred for both deviant and natural life processes and this is particularly true of sexuality. In the late 19th century masturbation was considered a disease and was the object of many medical interventions (Conrad 1992). This is no longer the case. Classically the American Psychiatric Association, in response to the Gay Liberation Movement in 1973, would vote to no longer include homosexuality in the DSM classification system. Now homosexuality is considered a lifestyle rather than an illness (Conrad 1992:225).

Conrad's work is useful in highlighting the ambiguities present in the medical classification systems and the need for social factors to be taken into account. Foucault's (1977) concept of power/knowledge is pertinent here. He challenges the existence of neutrality or absence of ambiguity in science, and suggests a contextual reading of scientific knowledge. Gastaldo and Holmes (1999: 234) reviewing some of the literature based on Foucault, argue that the analysis of medical knowledge indicates that over short periods of time, medicine not only changed what was accepted as true or false propositions, but also changed the ways of practising and interpreting evidence to support practice. This supports Conrad's (1992) findings. Following on from this Manias and Street (2000) noting the literature, argue that a particular view of 'truth'

will depend on the history, cultural context and power relations that operate in society and this includes biomedicine.

The literature indicates that the old biomedical certainties, whilst remaining influential, are being steadily eroded not least from within medicine. Whilst classification systems such as the DSM are useful in aiding diagnosis, McDonald (1999) argues that these classifications can fossilise the meaning of syndromes. A syndrome is a collection of signs and symptoms. They are based on carefully defined symptoms created by consensus amongst a small and select group of experts in the field in an attempt to systemise ignorance. McDonald (1999) and others argue that boundaries of knowledge are all subject to change over time leaving little room for complacency. The concepts of dementia have changed in the past and continue to do so.

The literature indicates that whilst knowledges and technologies in dementia care are increasing, paradoxically this new knowledge has also created ambiguities (Harding and Palfrey 1997). These authors remind us of the pseudodementias such as depression that can mimic dementia and Kitwood (1989) argues that the phenomena of 'rementia', a reversal and repairing of the damage to the brain, can occur when person-centred care is provided. Lewy body type dementia also provides a useful example of the ambiguities inherent in dementia. It has been acknowledged for some time that there are different kinds of dementia with the two most important being Alzheimer's and multi-infarct dementia with Lewy body dementia only recently established as another subtype. Lewy body type dementia is characterised by fluctuating cognitive impairment affecting both memory and higher cognitive functions. The fluctuation of impairment is pronounced with both episodic confusion and lucid intervals evident in, for example, the variable

performance of everyday living skills (SIGN 1998). The fluctuations of cognitive impairment that characterise Lewy body type dementia arguably can only add to the difficulties in caring for people with this kind of dementia. Until recently this type of dementia was unknown. There may be others. It would appear that any certainties in dementia are being constantly challenged (Chesterton and Bender 1999).

In a meta analysis of Alzheimer's type dementia by Gilleard (2000) the one constant in terms of risk was increasing age, with gender and ethnicity found only to moderate the effects of both genetic and environmental risk factors. This meta analysis of the most recent epidemiological research once more is indicative of ongoing ambiguities and uncertainties in medical knowledge about dementia. Yet other professions have accepted the biomedical model of dementia, arguably reinforcing 'the medicalisation of dementia through professionalising care' (Bond 1992:15). This model has become in effect the 'universal truth'. This has allowed medicine to treat the problems of the body with little reference to psychological or social influences that Kitwood and Bredin (1993) and Kitwood (1997) have cogently argued be included in the debates. The biomedicalisation of both ageing and specifically dementia, has resulted in the illness being viewed as a process of inevitable decline and irreversible decay (McColgan et al 2000).

The theme of ambiguity is central when considering my research question about the role dementia plays in care workers' response to sexual expression by people with dementia. Before going on to discuss the social model of care I want to develop the discussion on the ambiguity implicit in the construct of dementia by using the metaphor of a mask.

1.4 The 'mask(s) of dementia'

Gubrium and Holstein's work (1999) in their discussion of how and where the nursing home serves as a discursive anchor for embodiment is useful in exploring further the ambiguities of dementia. They note that having dementia does not necessarily result in visible bodily signs. Using data from a carer's support group they report how some spouses spoke of how the person with dementia 'looks' despite his or her cognitive deficits - they look 'so good' 'so healthy'. One wife spoke of how "If you looked at him you'd think he was really fit, just like a guy enjoying retirement...that's the way it is with this thing (dementia). You just never would think it really." (Gubrium and Holstein 1999:524)

There are certain similarities between these ideas and those of Featherstone and Hepworth (1993). Both sets of authors suggest a masking of the difference between the external and internal realities. The latter authors posited the concept of 'the mask of ageing' where there is a perceived difference between the ageing visible body and the perception of the ageless self on the inside. In Gubrium and Holstein's (1999) work the authors suggest an apparently 'normal healthy' body masking the mental disintegration. The mask metaphor is a useful construct in thinking about dementia. It suggests something hidden, unknown and ambiguous. People with dementia may not show visible signs of disability that register on the body.

In people with visible and corporeal disabilities the body is 'transformed into a spectacle in which "abnormality" becomes a visual feast through which the "truth" and "order" of the body is iterated and reiterated' (Hughes 1998:11). According to this

argument it may be said that in people with dementia the 'gaze' might be less able to penetrate and classify. Bartlett (2000), however, points out that a body that is marked by intellectual damage, even though the damage may be unseen, will often be spoken about and thought about in terms of what that body can and cannot do. There seem to be resonances here with Becker's (1963) Labelling Theory. Although as noted there are many uncertainties and ambiguities around the diagnosis and thus the construction of dementia, a theme that emerges is that the person labelled with this disability, tends to be negatively perceived. This point will be explored now under the social construction of care and specifically in the discussion of dementia within the construct of disability.

1.5 The social construction of dementia

There appears some consensus from the medical literature that something tangible and potentially catastrophic is happening to the person's brain. Although medically this is accepted through the use of such technologies as Magnetic Resonance Imaging (MRI), as indicated earlier there are challenges to this conclusion (Harding and Palfrey 1997). These authors note that a diagnosis of dementia is arrived at based on the flimsy nature of medical evidence. There appear to be many ambiguities created by the lack of knowledge about how precisely dementia affects behaviour and the imprecise nature of diagnostic tools. Harding and Palfrey (1997) also challenge the cultural imperialism of language used in psychological testing. They note that the language used in much cognitive testing, is one many people with dementia may not be familiar with and so may 'fail' in their assessment.

If any discussion is to take place about the construction of dementia, it is important to address the theoretical grounding. Neglect emerges as a key theme, with little theorising of dementia apparent until recently with any conceptualising mainly occurring within the social constructionist perspective (Kitwood 1997). The theoretical gaps are arguably consistent with the power relations and the lack of influence associated with people with dementia (Harding and Palfrey 1997). They have not as a group been 'seen' as significant by sociologists. In place of theory there is a considerable body of folklore and an abundance of tacit knowledge with the person with dementia becoming primarily a body with physical care needs (Kitwood and Bredin 1992). As noted earlier, the dominant metaphor of biomedicine, the body as a biochemical machine, has predominated in the discussions.

Whilst Harding and Palfrey (1997) have contributed to the theorising of dementia and have challenged assumptions made within the biomedical model there are difficulties with their ideas. The inference from their work is that dementia is mainly a social construct. This does not accord fully with the narratives of people with dementia (Davis 1989, McGowin 1993) or their carers (Bayley 1998) who note fundamental changes that are occurring to the person over a period of time to which they succumb and from which they die. Harding and Palfrey's (1997) work is useful in deconstructing and challenging the malign image of older people with cognitive impairment. There are resonances here with disability writers in general. Harding and Palfrey (1997) are also important in that they highlight the discrepancies, ambiguities and uncertainties of this illness. They alert us to the differences and contradictions that can occur between the internal and inscribed external body, alert us to the 'masks' of dementia.

In the medical construction of dementia, the illness has become institutionalised in the DSM classification system. Dementia has become defined as a result of a specific disease process. In this definition there has been a failure to recognise the extent to which cognitive decline may be socially produced (Lyman 1989). Kitwood furthers this debate in the discussion of person-centredness.

1.6 The person-centred paradigm

Kitwood (1997) and Kitwood and Bredin (1993) have been central in the UK in offering an alternative paradigm to the dominance of biomedicine. Kitwood's work on person-centred care where the self is retrieved allows for the construction of dementia as a disability. The person here is seen as unique and valued as an individual. Their biography, their health status, their previous response to stress and their personality are all factors that will influence how they respond to dementia. Kitwood (1997) is very specific also about what he terms malignant social psychology. By this he means the negative and damaging treatment meted out, unwittingly and sometimes wittingly, by more powerful others to people with dementia.

This he argues can have a deleterious effect similar to the brain damage that results from the organic disease. This malignant social psychology occurs almost immediately a person is diagnosed as having dementia. Staff and carers start to behave in a different way towards them. They are often no longer trusted or seen as responsible. This negative response by others to those labelled as having dementia counters the more positive 'halo' effect posited by Golanter and Raz (2000). These authors describe some of the positive effects the role of dementia plays in terms of absolving the person of

responsibility. Kitwood argues that people with a label of dementia may, as a consequence, be subjected both internally and often externally to a debilitating onslaught that erodes their sense of personhood. They can be disempowered, infantilised and intimidated (Chesterton and Bender 1999). If this model is accepted it will influence how care workers respond to sexual expression by people with dementia in their care.

Kitwood (1997) suggests the illness needs to be seen for what it is, a disability. The disability model is useful in that it specifies what is missing/damaged and how people with dementia can be helped and the environment made more user-friendly (Chesterton and Bender 1999). Using the concept of disability is of interest in addressing my research question of the role that dementia plays in care workers' response. The literature suggests that whilst disabilities studies can and have contributed to the debates by opening the doors to the cultural politics of dementia (Bartlett 2000) there are difficulties specifically when sexuality becomes a component.

1.7 The disability role of dementia and its implications for sexual expression

The debates within disability studies have had a profound impact in transforming the reactionary view where impairment is 'seen' as a negative category denoting invalidation, to the emancipatory concept of disability. Hughes (1998), discussing the work of Foucault (1979) and Goffman (1978), suggests that the 'stranger' or person with a disability is produced by categorising and normalising propensities of knowledge or as Goffman (1961) argues, condemned to wither away in institutions.

Since the 1970s there has been a refusal of people with disabilities to be invalidated by the 'gaze', by the professional disciplines. The gaze has been deflected from the disabled body to the social body. Kitwood and Bredin (1993) and Kitwood (1997) have furthered these ideas in dementia care but as Bartlett (2000), in her review of the disabilities literature and people with dementia, argues applying some of the ideas wholesale from the disabilities literature to the area of dementia is problematic.

Oliver (1996: 15), discussing the concept of empowerment, suggests that 'empowerment is something that people do for themselves collectively'. Bartlett (2000) notes that these ideas could paradoxically exclude people with dementia further. The concept of empowerment reveals the extent to which the disability movement comprises articulate, young, physically disabled people, with older people with cognitive impairment not only excluded, but also ignored. Bartlett makes the point that if people with dementia were to articulate their anger and dissent about their situation it would be seen as symptomatic of dementia and treated with medication. Another point worthy of note is that many people with dementia are over 85 years. Bartlett (2000) reviewing the literature, argues that this group, unlike younger people, may need more 'permission giving' before they become empowered to take up their basic human rights and this is particularly the case with older women. Ageism and sexism then can be significant social barriers with dementia a further discriminatory factor as well as the attendant stigma attached to 'mental' illness.

Mulvany (2000:596) argues that a major challenge facing the sociology of mental health is how to deal with the concept of mental impairment and how to link this with the study of the social production of disability. There are the similar tensions around

applying the concept of cognitive impairment and the social production of disability. Quoting the work of Shakespeare (1996) Bartlett (2000) notes that whilst ideas have a role when combating discrimination against vulnerable groups, action is what matters. This is particularly the case in terms of the concepts around person-centred care espoused by Kitwood and Bredin (1992). Packer (2000), in a series of articles discussing person-centred care, notes the difficulties for many staff in transferring theory into practice. This may be the case when applying a person-centred approach when a person with dementia expresses sexuality (Archibald 1997). Sexual expression not only involves the needs of the person with dementia but it can and often does involve others whose needs also have to be considered, for example, the spouse or partner or care staff working in a residential home where residents with dementia make sexual demands (Archibald 1997).

There seem to be gaps or contradictions apparent in the person-centred philosophy. If there is recognition that a person with the disability of dementia is an adult being with adult status then this adult may have sexual needs. Adult status includes an acceptance of a person as a sexual being and is symbolised by autonomy, self-determination and choice (Hockey and James 1993). Promoting and maintaining these aspects of a person's life are central to the disabilities movement. These factors are often missing in the life of a person with dementia. But adult status should confer responsibility, responsibility for one's own actions, which can be absent in people with dementia as the illness progresses. This produces tensions and difficulties particularly for staff in long term-care situations (Sherman 1999). People with dementia are adults but may be deemed 'incompetent' in terms of decision-making in the area of sexuality.

Bartlett (2000) argues that the impact of the label of 'dementia' is not dissimilar to the experience of the person with a label of learning disabilities when sexual expression is a component. Brown et al (1994), reviewing the literature on people with learning difficulties, reports that implicit in the role of services is the regulation of sexuality and the creation of sexual boundaries (disciplining and surveillance). She questions the ways in which people with learning difficulties are really free to express sexuality and the penalties they incur in breaking out of the roles prescribed for them. Expressing sexuality for example, can heighten their visibility as opposed to increasing their chances of acceptance and integration. These arguments may also apply to people with dementia in residential care. Brown suggests that far from a homogenous set of values, sexuality reveals a complex set of social rules. Following on from this one can theorise that people with dementia like people with learning difficulties, may be seen as 'breaking these rules' for their 'kind' with a double jeopardy for those who choose to be gay or lesbian. These issues have not generally been addressed in person-centred debates in dementia care. The 'person-centred' discussions with a few exceptions (Archibald 1997,1995), may as a consequence be seen as yet another debate that has marginalised sexuality as opposed to empowering and facilitating people in this area as suggested by McLean (1994).

The literature seems to suggest that a focus on mental impairment poses a greater challenge for sociologists than a focus on physical impairment (Mulvany 2000). The portrayal of mental disorders as a social construction whilst providing a much-needed challenge to the essentialist or biomedical view of the body, has as Mulvany notes, placed major limitations on sociological inquiry. This is true of sexual expression and people with dementia. There appear to be complex reasons that need to be considered

when looking at the general omission of sexuality and dementia in both research and practice including the ethical implications involved.

1.8 Ethics and decision-making in sexual expression for people with dementia in care situations

The classical issues in medical ethics are those of addressing the limits to paternalism and respect for the individual and this is particularly pertinent in dementia care. Hillan (1993) discussing ethics in nursing argues that 'care' implies assurances of safety for the person where, for example, the person may be too confused to understand the risks that are involved. There is a need to clarify therefore exactly what the risky situation is, as most situations involve some kind of risk. Hillan (1993) notes when addressing the ethics and rights of a person, account must be taken of other clients, particularly she argues in long-term care homes. Here the interests of one person may conflict with those of another, raising the issue of justice. This may be factor in decision-making when residents with dementia express sexual intent towards staff or other residents.

Ethical issues are raised when a person with dementia either in the community or more pertinently to my study in long-term care, has a sexual relationship with another. Central are whether the family carer should be informed and whether the relationship should be allowed to continue. Reviewing the literature it becomes apparent that there are few practice guidelines for staff. For example, Parkin (1989) points to sexuality being an ever-present issue for workers and residents yet noticeably absent from staff meetings, agendas, training programmes policies, rules and guidelines. Lichtenberg and Strzpek

(1990) are rare exceptions who detail how staff may assess competency in people with dementia to participate in a sexual relationship.

Sherman (1999) discusses aspects around the concept of the 'duty to care' and notes the difficulties inherent in this area and the fine dividing line between care and control. She argues that if sexuality is considered at all when a resident is admitted to care, then it is dependent on the values and policy of the organisation and not necessarily on those of the resident. Punishment can be meted out to those residents who behave in what are seen as sexually unacceptable ways. She infers that the morality of residents is often under constant surveillance in long term-care homes.

When discussing ethics in dementia a discussion of the 'self' becomes central in the debates. The critique of biomedicine and the way it constructs dementia has led to an interest in the subjective experiences of the person with dementia, the nature of personhood and the self (Holstein 1998). In the recent debates in dementia there has been a preoccupation with the 'self'. The 'loss of self' has been a key characteristic for some (Cohen and Eisdorfer 1986) but not others (Sabat and Harre 1992). The latter argue that with regard to construction and deconstruction of self in people with Alzheimer's disease, the self is manifest in any one of its repertoires of personae. The 'selves' are in clusters of behaviour and it is all-important that the persona be the 'right one', the socially appropriate one at that time (Harding and Palfrey 1997). The difficulties for the person with dementia surround the presentation of the 'appropriate' self. This lies not in the disease process, rather in the social interactions and their interpretation of the symptoms shown. This resonates with Kitwood and Bredin's (1993) ideas.

These ideas of the 'self' are discussed by Post (1995) and explored further. Of relevance to my study are the issues raised about the self that underscore the complex and ethical dilemmas sometimes posed for staff in dementia care with regard to sexual expression. Post (1995: 5), asks for example, whether the 'then' self should control the destiny of the 'now' or 'demented self'? This seems an important issue for professional carers who have to reach a decision on whether to allow a sexual relationship to continue (Post 1995). Post notes that people with dementia have heterogeneous disabilities that confer on them a preferential moral significance based on their needs. They are, because of their disabilities, open to abuse and can be deemed defenceless and easily victimised. In these situations the 'gaze' of professionals may be legitimised.

Discussing people with learning difficulties Post (1995) argues that their capacity and agency are easily underestimated but this is also applicable to people with dementia. Accessing the literature, Post notes that people with cognitive impairment or 'retardation' can receive oppressive care, a kind of care based on the assumption that the 'retarded' are so disabled that they must be protected from the dangers and risks of life. Mayers (1998:224) affirms this and notes that people with dementia who respond to 'primitive impulses in non-selective manner must be protected' and argues also that other patients must be protected from this sexually active patient (Mayers 1998:224). If these arguments about risks are applied to people with dementia expressing sexuality then the sexual needs of residents may not be a consideration. The situations involving such sexual 'risks' will possibly be dealt with efficiently by separating the couple or through medication (Sherman 1999, Harris and Wier 1998, Cooper 1987) as opposed to any in-depth discussion and involvement of the residents as advocated by Lichtenberg

and Strzpek (1990). Whether people with dementia expressing sexual intent towards staff are responsible for their actions is another consideration.

Whilst the ethics of a person with dementia having a sexual relationship with another person are now coming to the fore, there are other theoretical gaps that need to be explored. The 'self' or selves discussed above have bodies, often older bodies, the discussion of which has until recently been neglected. The role of dementia and care workers' response needs to be seen within the context of how older bodies generally are perceived. In the following three sections I explore the theoretical neglect and the ageism inherent.

1.9 The sociological body

Whilst there has been an absence of ethical debate with regard to sexuality and dementia and a reluctance to acknowledge the sexual self or selves of people with dementia, Turner (1984) suggests that there has also been (a theoretical) prudery with respect to the body, with the formal recognition of the body's pivotal role taking a long time to emerge (Shilling 1993). There may be a number of possible reasons why the body has now emerged, including the increase and thus visibility of the ageing population. The emergence of postmodernism, which has resulted in the decoding and deconstruction of the body, has made visible the taken-for-granted and peripheral. Whilst there has been an increasing sociological literature of the body Turner (1996) and Shilling (1993) argue that the ageing body has been neglected.

Harper (1997) referring to the sociological literature on theoretical approaches to the body argues that the external body is inscribed by social law, morality and values and, as such is a public body, signed to be disciplined. The internal body is the lived-in and experienced body as defined in the work of Freud and Lacan. This, Harper suggests, is a useful conceptualisation in helping to critique some of the major binary categories for example male/female, active/passive, young/old, private/public. In each pair one is more dominant. This is a major theme in feminist debates, the embodiment of the 'other'. In terms of sexuality 'queers' are defined by their sexuality whilst heterosexuals are not. Those who are on the periphery who are not male, not white and not young are not generally acknowledged to have lived-in sexual bodies. Certain written knowledges about the body are rendered invisible and unacknowledged. Pertinent here would be those dealing with older, sexual bodies and the theoretical constructs involved.

1.10 Older bodies

Fleming (1999) with some validity argues that social gerontologists, through their positive ageing agenda, have taken up the challenge to rectify the stereotyping and discriminating of older people on the basis of age. A casualty of this however is that the realities of age-related degeneration and decline have been minimised. Fleming, discussing the literature, argues that this lack of acknowledgement of the bodily decline of older people presents certain tensions for social constructionists who assert that age is simply a social construct. Reviewing the Australian literature on disability and ageing, Fleming concludes that like gender, disability has remained in the background and has remained underdeveloped.

The postmodern body, without organs and the associated theoretical prudery in respect of human corporeality, may be seen as a refusal to acknowledge the awkward reality of bodily functions (Harding and Palfrey 1997). These authors postulate that as we age, our bodies tend to wrinkle, sag, we tend to go grey, lose teeth, slow down, cease to perform as well and that ultimately we die. Our physical condition is changing, at times unpredictably, so as we age there is potential as Hazan (1986) notes for constant ambiguities and cultural paradoxes. When loss of bodily and mental control occurs in extreme old age there is stigmatisation and exclusion (Harper 1997). It is not too surprising therefore that many older people would choose to avoid the negative stereotyping and loss of independent identity that accompanies the label 'old' but there are also gender differences that need to be considered.

1.11 The ageing body and gender differences

Fleming (1999) presents an interesting argument with regard to gender differences in older people as they age. He argues that contemporary discourses on ageing are essentially 'feminised'. Using the work of authors such as Arber and Ginn (1995) to support his argument, Fleming acknowledges that older women are a disadvantaged group both socially and economically, and more likely to be institutionalised than older men. For these reasons older women have had a higher profile than older men in gerontological research though this has not been without difficulties. Gender generally has been under-developed in ageing studies and even when included in the sociology of old age has not been treated as a key element in social life (Ginn and Arber 1995). Fleming, accessing the literature, argues that whilst this emphasis on older women has

been an important corrective, it has been at the expense of older men creating an academic 'blind spot' in gerontological studies.

This is not however simply as a result of the 'feminisation' of old age but as a result of ageism. Life course analysis in the roles of men has privileged those of younger and midlife men. Reviewing the literature Fleming (1999:4) does acknowledge that mainstream masculinity literature and media give little, if any, attention to the intersection of ageing and masculinity. The images of older men and women tend to be shaped through the pervasive effect of ageism and consequently their image is encumbered with negativity from the onset.

1.12 Ageism

Ageism appears implicit in the literature with gender implicated. Fleming (1999), following on from Harding (1991) has argued that ageism is a form of oppression like sexism but unlike sexism, it is something potentially everyone will encounter if they live long enough. Yet feminists are implicated in ageism. As in mainstream masculinity literature, where the emphasis has been on younger men, feminists have tended to focus on issues related to younger women. It is only from the 1980s on that feminist writers start to explore how and why ageing is different for men and women (Arber and Ginn 1995, Harding 1991, Harding 1988, Peace 1986). From the literature it is apparent that ageism not only shapes the perceptions of people both young and old who hold these ideas, but it also limits and negatively shapes, people who are the object of that 'oppression' (Laws 1995). Ageism is, as a result, central to the identity of people (Laws 1995). For older people, this is manifest in the emphasis on youth and vitality which

undermines the positive contributions (and possible sexual attractiveness) of older people. Judgements tend to be made at the first encounter based on the corporeal appearance of a person.

Featherstone and Hepworth's (1993:306) work offers useful insights. In their discussions of the 'mask' (of ageing), it is about ageing generally that they seem most concerned. Here ageing per se is 'seen' as almost akin to disfigurement, with the 'real' person hidden behind the disfiguring (wrinkled, greying) mask of age. The 'datedness' of body image, for example, clothes worn and vocabularies used, can, the authors note, further add to the negative stereotype. Stereotypes here are seen as being a symbolic stigmatisation which finds its way into everyday action and gives negative meaning to the experience of growing old (Featherstone and Hepworth 1993). Within these stereotypes are gender differences as Fleming (1999) has noted with regard to men. But Sontag (1978) argues that ageing is particularly oppressive toward women.

The images portrayed of old age are important in the construction of old age and dementia, but so too is the power and political use of words (Ashley 1980). The power of negative stereotypes of ageing which stigmatise old people is substantial. The work of Hockey and James (1993) and their use of infantilisation as social discourse is pertinent. They note that the figurative, for example referring to older women as 'girls', often becomes literal. Hockey and James (1993:11) argue that this seemingly trivial example is symptomatic of more damaging and embedded practices of infantilisation which are being played out in a diversity of social situations, including residential homes, with the cumulative effect being far from trivial.

Metaphors shape individuals' understanding of reality and the way that a particular discussion of old age is sustained which maintains older people in marginal places in society (Hockey and James 1993). The authors suggest that when the language of ageing is subjected to the same scrutiny as gender or race issues, parallels are observed which highlight similar subtle discriminatory practices that operate conceptually to diminish the social status of, and marginalise, older people.

Ageism is, however, not a gender-free zone. Evers' (1981) work discusses how the stereotyping of old women in geriatric wards by nurses powerfully influences their 'careers' on the ward negatively. Her work will be returned to later. Harper (1997) from a feminist perspective suggests that as we age, control, as defined through male experience, lessens when such conditions as incontinence and paralysis intervene. Men as they age lose their control over bodily emissions and share similarities with the portrayed leaking and draining representations of women's bodies. It is precisely the omission of these male images in the mainstream masculinity literature that Fleming (1999) takes issue with. Following from this, Harper (1997) argues that if the overarching notion of adulthood was not defined through the perceived male control of his body and mind, then the natural lack of control which exists in different ways in different people, as they age, would not be so stigmatised.

1.13 Conclusions

Following on from the last section and concluding this chapter, it is hard to ignore the theme of ageism when addressing the research questions of why dementia and sexuality has been neglected. The inference from the literature is that there has been little

theorising about dementia and even feminist researchers who, until relatively recently, have generally focused on younger women's issues. The sexual bodies of older people and people with dementia have tended to be omitted from sociological analysis. The debates around dementia have tended to be centred primarily around the biomedical aspects of the illness with the social construction of dementia a relatively recent addition.

When addressing my research question about the role dementia plays in staffs' response, ambiguity appears central. The construction of the label of dementia appears problematic. I have argued that the apparent solid biomedical construction that seems to provide some certainty in this inchoate illness is increasingly being challenged. Apparent are the difficulties inherent in both defining and diagnosing dementia. The literature points to Lewy body dementia, for example, typically showing a fluctuating course. It can be theorised that these ambiguities may make the caring for people with dementia in residential care difficult particularly when these residents express sexual intent. There may be difficulties in knowing if the sexual behaviour is a result of disinhibition due to the illness or whether it is the resident simply expressing sexual need.

If there are difficulties for the 'medical experts' in understanding and recognising dementia, prior to the more obvious and later manifestations of the illness, the implications for staff who have received little training or education with regard to dementia are many when considering sexual expression by residents. The question arises if staff have not received any training then how will they construct dementia? I theorise that regardless of lack of training, the medical model will remain dominant and the (deviant) role dementia plays in staff's response is that of mental illness. When

residents with dementia express sexuality, blaming the illness may be a way of constructing and pathologising this sexual behaviour and thus legitimately dealing with it by chemical restraint or separating couples. This may be a way of protecting the reputation of the person, staff and the organisation. This will be explored in more depth later in the thesis.

The social model of dementia has enhanced the care of people with dementia but has been limited when the model is applied to people with dementia expressing sexuality. Kitwood (1997) has argued for dementia to be seen as a disability but when the construct of disability is examined, the disabilities movement has tended to be for, and by younger, articulate people. Older people and people with dementia have been absent and singularly underrepresented. When sexuality is introduced into the disabilities debate, it becomes apparent that far from a set of homogenous values, a more complex set of social rules is needed. The person-centred debates have been another area where sexuality has been marginalised.

Having dementia may confer certain benefits for people with the disability. They may not be held responsible for their actions when their behaviour is constructed as a result of dementia but there are insidious and negative aspects to this absolving of responsibility. People with dementia may be infantilised in that they may not be considered sexual beings and they may be excluded from decision-making. Responsibility is also a concern for staff in whether to allow a sexual relationship involving a person with dementia to continue. There are many ethical concerns including whether or not to include the person's family, and whether it is the past or present 'self' that should be considered, when arriving at a decision.

There appears to be little guidance for staff so it is easy to speculate that rather than exploring complex and difficult options, it may be easier to either ignore the problem or treat everyone with dementia as if they were incompetent and prevent or disallow a sexual relationship between residents. There are however other issues that need to be considered further. Chapter one has been about exploring the role of dementia and how the various constructs of the illness may influence care workers' response to the expression of sexuality by people with dementia. In the next chapter I explore other aspects that may influence care workers' response such as the historical and late modern debates on sexuality in UK society.

Chapter 2 Debates and Discussions Around Sexuality

2.1 Introduction

In chapter one my aim was to explore the various constructs of dementia and to explore the role of dementia in care workers' response. I also began to address the question of why the subject of sexuality and dementia has been so neglected. To develop my research questions further I noted that it was important to begin to look at context, particularly the historical and modern debates on sexuality that may influence how care workers respond to, and also what they say about, sex. This I do in chapter two.

I begin in chapter two by exploring the various constructions of sexuality. Next the subject of neglect is addressed by looking at some reasons why researchers have not explored this subject area. As a feminist researcher, and as the majority of care workers are women, I am interested in gender and how this has influenced the historical and modern debates on sexuality. How the historical and late modernity constructs of sexuality and gender intersect, will be examined. One of my research questions asks how does context influence staff response? I argue that an exploration of the cultural context of UK society in the late nineteenth and twentieth centuries will help to increase the understanding of contextual influences. The literature is explored to gain insights into how staff attitudes towards older people and people with dementia may be influenced by these debates. I explore how gender may be a factor in care workers' response to sexuality.

Following this, I begin to address how sex is talked about, the language that is used to express ideas and feelings about the subject. To explore the question of how staff talk about sex, I look at the difficulties for people generally when discussing sexual matters. Sexuality and older people, and sexuality and people with dementia and the difference in how each group is perceived, are addressed. Lastly, the issues around gay and lesbian older people are considered.

I conclude by noting that there are marked parallels between the constructs of dementia and those of sexuality. As with dementia, the literature on sexuality points to this being a complex and ill defined subject. Also the themes of neglect, ambiguity, responsibility, identities, ageism and gender are apparent with class and respectability also emerging. I note that the topic area may have been neglected for a number of reasons. The literature suggests, for example, that researching sensitive subjects may compromise the researcher's career development. Continuing the theme of neglect, there are interesting gaps in the literature. Whilst there is a dearth of literature on sexuality and dementia, there is an increasing literature on sexuality and older people. Sexuality and dementia is largely constructed as problematic and as noted in chapter one, is often situated within biomedical discourses. Older people generally expressing sexuality are seen in a much more benign way. Gay and lesbian issues with regard to older people have been largely invisible, particularly when sexuality and dementia are considered. Ageism is once more of note in that sexual activity is perceived as being the preserve of the young.

2.2 Constructs of sexuality

In this section I want to explore the nebulous and ambiguous nature of sexuality. Resonating with dementia, there are difficulties in trying to define what is understood by the terms sex and sexuality. Hawkes (1996:1) argues that sex ‘occupies a position parallel to death’. Each is a source of a deep and powerful emotions both negative and positive. She notes the contradictory nature of the feelings and ideas associated with sex: pleasure and fear, freedom and restriction, control and abandon. She posits that the ‘specialness’ of sex that combines anxiety and fascination is perpetuated through a collection of shared ideas. The conflation of morality with *sexual* morality in that an ‘immoral’ act usually pertains to a sexual act, is of note. In many ways sexual desire has been seen as potentially problematic and uncontrollable in Western traditions. This argument is supportable in terms of the extent to which sexuality is subjected to regulation and prohibition. It is scrutinised in a way that would not be tolerated in other areas of life (Hawkes 1996).

Hawkes (1996: 8) discussing the literature on sexuality suggests that ‘sexuality’ is a 19th century production. Sexuality is what one does with one’s genitals or is an ascribed identity defined through such aspects as dress and mannerisms. Sex or sexuality in this construction indicated something that was fixed within certain boundaries. Caplan (1987) suggests that shifts in the meaning of sexuality have occurred over time, which has been noted by historians. Sexual behaviour, practice and morality, for example, have been and are in a constant state of flux. Sexuality is mysterious, contradictory and ambiguous. It is at once private and yet public and it is teeming with inconsistencies,

tensions and conflicts. In short it is many faceted and nebulous when attempts are made to define it.

Sexuality does not conform to a single definition or social standard (Rubin 1990). Instead of referring to a singular sexuality some are considering it more productive to consider the notion of 'sexualities' (Mac An Ghail 1996). This makes sense if it is accepted that sexuality is influenced and shaped by many different factors, including gender, needs, desires and fantasies (Weeks 1985) and also power, and consequently will be different in both women and men. Sexuality therefore is neither (totally) the property of the (individual) body nor simply a natural tendency; rather it is formed, and informed, by the society in which we live (Bell 1993). The above academics have attempted a definition of sexuality but what has been less considered is how researching such a sensitive subject of sexuality may impact on an academic's career, and thus possibly influence the sociological research undertaken of the topic. This issue needs to be explored as it may contribute to the understanding of why the subject area has been so neglected in the literature.

2.3 Researching socially sensitive topics

Often the main focus when discussing sensitive research topics is the need for researchers to be alert to the responsibilities towards those being studied and although slow in developing in the social sciences, this is now well established (Lee-Treweek and Linkogle 2000, Lee and Renzetti 1990). In this section, I want to look at the literature that addresses how the sensitive nature of the research topic can impact on the researcher's career and other aspects of their life. Lee-Treweek and Linkogle (2000:20-

23) refer to this as 'professional danger'. The authors note that all academics who threaten academic convention may find themselves in danger of compromising their careers. Those who undertake controversial research may encounter risk and this can constrain what social scientists feel able to study.

Lee and Renzetti (1990) suggests that research into sensitive areas of research can present dangers and be threatening to the researcher as well as to those being researched. Organisational research funding tends to exclude support for research topics that may be considered sensitive or detrimental to organisational interests (Trolden 1987). Trolden (1987) discussing research into sexuality and using Goffman's (1978) work on stigma, suggests that researchers are in some way marked when working in the field of sexuality. They become somehow sexually suspect and personally stigmatised (Seiber and Stanley 1988). Trolden (1987) accessing the literature, notes that researchers in the area of sexuality are viewed as psychologically disturbed and can be considered either over-or under-sexed. Younger unmarried women researchers appeared to be more stigmatised than male researchers or older women researchers. The subject area is seen as somehow immoral or unnatural and by extension the researcher becomes similarly tainted. Trolden notes that in a study carried out for the Scientific Study of Sex, 32% of researchers had experienced occupational related discrimination including jokes, ostracism and loss of promotion (Seiber and Stanley 1988). The discomfiture, the personal and career difficulties that can occur when researching sensitive topics may offer explanations as to why the sensitive subject of sexuality and dementia has been previously marginalised in academic debates.

2.4 Histories of sexuality

Following on from the above discussion to the area of sexuality generally, there is a need to explore and contextualise sexuality within an UK 19th and 20th century historical framework to seek possible explanations as to why sexual expression by people with dementia is generally absent from the research. As with the regimes of truth in biomedicine, the particular views of truth with regard to sexuality depend on the history, culture, context and power relations that operate in society (Foucault 1979).

There seems to be a general consensus amongst historians and other writers (Weeks 1989, Hawkes 1996,) about sexuality and the 19th century. It was a time of great change. Urbanisation, a rapid rise in population and rapid technological development characterised this period and were inherently unsettling, uneven and unpredictable. The ascendant power of the bourgeois, a powerful, if numerically small, and wealthy section of the population, who was sandwiched between the old aristocracy and the rapidly expanding working class, were central in the drive to create new predictabilities and new moral imperatives in a time of change (Hawkes 1996). Bell (1993) noting the literature, argues that there emerged in response a veritable explosion of multiple and particular discourses around and about sexuality. These discourses included institutionalised campaigns and statute law responding to anxieties about 'unregulated sexual desire, the characteristics and manifestations of women's sexuality, and the consequences of non-productive erotic practices for example, masturbation and same-sex desire' (Hawkes 1996:10).

Whilst there were anxieties about unregulated sexual desire and the manifestations men and women's sexuality and same sex-desire, there appeared to be a virulent anti-masturbation hysteria which reached its peak in Edwardian times. Anxieties of parents were manifest early in children's lives encouraged by child rearing manuals (Hall (1992). The manuals and books, which disseminated the (Grimm) stories about masturbation, were widespread and were harnessed to the discipline and control of men's sexuality. This resulted in a surveillance system directed at children. Whole sets of regulatory systems and controls were employed. The anxieties and guilt associated with masturbation have remained embedded. Hall (1992), noting the work of Lee (1983), found looking at sex education in the 1980s that boys still believed that masturbation could cause impotence and that shame was still attached. From this it may be theorised that if people with dementia are constructed as child-like as the literature suggests they may be, then it can be speculated that similar surveillance and moralisation may be directed towards them if they are found masturbating in a residential 'home'. Alternatively the 'halo' effect of dementia may be present where the behaviour is simply constructed as part of the illness. This needs to be explored further empirically.

Foucault (1979) addresses the influence of context with regard to sexual expression. He traces the disciplining of bodies and the operations of discipline within institutions. The privileged place of (and obsession with) sexuality was part of the operation of power making control possible and invisible. He notes that the disciplining operates through various techniques including separating individuals from each other, the imposition of timetables and organising the passing of time into successive stages through which individuals' progress. Power essentially for Foucault is productive producing domains

and objects and rituals of truth. Foucault's argument was that people understood (and understand) sexuality through the discourses or sets of knowledges that society makes available to them. Out of these strategies of normalisation emerge a sense of what sexuality is, and what it should be.

The tensions and ambiguities surrounding sexuality are nevertheless apparent. Hypocrisy and general anxieties surrounded sexuality alongside discourses of prudery and sexual repression (Hall 1992, Hawkes 1996). But Foucault (1979) and others challenged the notion of a linear development from prudery and sexual repression in the Victorian era to enlightenment and liberation in the late 20th century. Foucault argued that repression could not silence discourses about sex because sex was everywhere. The restrictions placed on the discussion of sex was a necessary part of discourses in so much that it allowed the 'other' discourses, the 'knowers' and the 'experts' to be heard. Sexuality was brought into the realm of knowledge, 'scientia sexualis' where it was seen as harbouring a fundamental secret, a secret to be exposed and examined for what it tells of the person, by those with expertise (Bell 1993).

It was the discourses which evolved from the 'psy' professionals, psychiatrists, psychologists and sexologists to which Foucault referred (Bell 1993:10). Discourses and practices evolved (Sawicki 1991) which formed divisions between healthy/ill, normal/perverse, legal/criminal and were utilised as a means of social control, These 'experts' include Krafft-Ebing (1899), Ellis (1899) Freud (1912-49, 1986) and Kinsey et al (1948) through to Masters and Johnson (1966). Sex in Foucault's analysis became a means of policing society via techniques of normalisation. Throughout the 20th

century gender-specific heterosexual coitus was not only retained, but its position was strengthened at the apex of the constructions of sexuality (Hawkes 1996: 69).

Society then in the 19th and 20th centuries made sexuality highly visible on different levels and the messages seemed unequivocal. The essentialist argument of sex seen in biological terms: part of nature with individual men almost caricatured as aggressive and promiscuous with innate sexual desires in need of sexual release, remained unquestioned. In this schema, men were in control and dominant. The notion of the male as crudely potent and needing control has been taken up by feminist writers where the argument levelled is that the discourses of sexuality are more ambiguous and a site of conflict. For example, the 'ripping yarns' discourses about the rampagous male have resulted in a silence surrounding the less 'successful' images of men. The sexual difficulties experienced by men including difficulties involving impotence and premature ejaculation described by Hall (1991) with its attendant despair and anxieties are at odds with the 'man-on-top' sexual identity. It is important to discuss gender as there are marked differences in the literature with regard to the construction of sexual identities for men and women. These differences are prevalent and may influence what care workers say about sex, how they respond to sexual expression by residents and which sexual behaviours are problematic.

2.5 The construction of women's sexual identities

As the majority of care workers are women it is important when considering context and response to sexual expression by residents, to explore the construction of the sexual identities of women, particularly working class women.

A constant theme that has emerged from the literature over the years is that sexuality has been defined mainly by men and has been experienced by many women as coercive and objectifying (Few 1997). Historically, from the beginning of this century the medical understanding of female sexuality has been constructed as natural, as that of the female succumbing to male advances. Any resistance by women was part of the game to excite men. Noting the literature, Few (1997) argues that female participation in sexuality was not ignored but was seen as complementary to male sexuality. Women have been poorly represented in the debates and seen as somehow less important. Yet in terms of biological 'performance' Kinsey et al (1948), noted that women were able to experience multiple orgasms (Few 1997). Although Kinsey et al reported this finding there were gaps evident in the sexual surveys undertaken. In the influential reports on sexuality (Kinsey et al 1948, Masters and Johnson 1966 and later Hite 1976), few older women or older people of either sex were included.

A dual identity has tended to be ascribed to women with regard to sexuality. The 'Eve' construction typified one aspect. Women, essentially working class and/or black women, were (and are), continually informed by this discursive legacy (Hawkes 1996). In this construction women are seen as analogous to the animal kingdom (with association of serpents), and therefore unable to resist sensual temptation. The opposite and competing image was that of the pure 'Madonna' construction of women's sexual identity where women were seen as more sensitive but this was dependent on sexual desires being suppressed and hidden (Hawkes 1996). The reputation most valued was the asexual woman, demurely dressed, essentially white and non-working class. Within these constructs are a range of contradictory and ambiguous identities. Women are seen as sexual agents but also as asexual and as such, sexually anaesthetised (Hawkes 1996).

They are seen as powerful and as powerless, victims in need of protection. The difficulty and unease for men lay in the tension between the two images, women as more biddable than men but potentially corrupting.

The 19th century judgement of respectability for women was based on, and embedded in, their visual representation. Moral judgement was based on appearance (Nead 1988). The importance of examining why and how these sexual identities are constructed becomes apparent when it is seen that they are not simply a historical construct, rather they persist and impact adversely in the 1990s on women's sexual choices and behaviours (Few 1997). The theme of respectability emerges here and may be a component in how care workers feel about and how they ought to respond to, for example, residents' sexual advances towards them.

Holloway and Jefferson (2000) note that respectability connotes differently for men and women. For men what appears important is the respect aspect. Being looked up to and well regarded is important. For women, sexual status is crucial for their sense of respectability. Respectability for women means sexual respectability with their identities invested in this concept (Holloway and Jefferson: 73-4)

Skeggs' (1997) work is useful in providing a cultural context for working class women and furthering the discussion on respectability. She notes how the Foucauldian concept of pleasure was used as a form of productive power in the attempts to teach working class women the pleasure derived from bourgeois domesticity and so reduce the need for obvious direct control. If made pleasurable then the oppressive features of the work are rendered less noticeable. Domestic ideology, the promulgation of home and family

values became part of the discourses around female respectability, polarising domesticity and sexuality. Respectability became a marker and burden of class, a standard to which to aspire. The cult of domesticity was central to the 'self defining of the middle classes' (Skeggs 1997: 5). The discourses about respectability were created by those who were seen to be capable of being moral, the middle classes, for those who were seen to be in need of control, the working class. Finch (1993:10) defines as the 'classing gaze' the middle class's use of for example, social surveys, observation and ethnography looking at drinking habits, language which were about moral references. This classification achieved a recognisable measurable entity - the working class. It was this '(middle) classing gaze' that was focused on working class women's sexuality. The importance of this was the positioning of women at the centre of this construction, as it was primarily women who were observed (Finch 1993).

Skeggs (1997) posits that an attempt was made to codify female sexuality through the domestic-feminine ideal through working-class women's education. This domestic ideal was able to provide a way to respectability and status and ideal that can be applied to the context of working in a residential home. Although Skeggs acknowledges shifts in class relations in late twentieth century UK, what is evident is that certain themes remain constant and how historical constructs can and are, recycled. She argues that the working class is still seen as the 'other' as somehow pathological. Issues around single (welfare) mothers are a case in point used by both recent governments. Magazine articles, she cites *Marie Claire* 'Council Estate Slags' - imply that working class women are still represented through what is seen as their 'deviant' sexuality.

In terms of neglect and gaps in the literature, class has almost disappeared from feminist analysis and Skeggs questions the reasons for this. Whilst there are difficulties in understanding what is meant by class structure and how it should be defined, Skeggs asks whether it remains invisible because it is no longer experienced as strongly as gender? Or is it because it has not been recognised as a problem for those ‘who have the privilege to ignore it’ (Skeggs 1997: 6).

Jackson (1982) argues that naturalist theories remain powerful in the discourses about sexuality. This means that embedded is the idea that ‘boys need to sow their wild oats’ (boys will be boys) and nice girls do not have, or enjoy, or ask for, sex (Few 1997: 619). This thinking persists amongst young and older women. Recent research testifies to the persistence of sexual ‘reputation’ as a concern for women (Holland, et al 1990). This may be pertinent when considering how care workers respond to residents’ sexual expression towards them, the workers. How care workers talk about sex and the language used is also relevant in addressing my research questions.

2.6 Sex talk

In the preceding sections the historical debates around sexuality have been explored. This has helped to provide a context and inform how (women) staff may respond to sexual expression by residents with dementia. In the next section, before proceeding to explore the debates around sexuality and older people, I address sex-talk, the tensions around the vocabulary used to discuss sex. What care workers say about sex is one of my research questions. I want to explore some of the tensions and difficulties in talking about the

subject. If people have difficulty in talking about sex then this may impact whether or not, and how, practitioners discuss sexuality.

Ruth (1987:151-154) argues that the discussion of sexual language might be funny if it were not so serious. It would be funny if it were not for the fact that sex-talk is a map of sex-thought with sex-thought in this society being schizoid. She speaks of the dualism of two opposed realities, which function to manage society's relationship to sex. "But how" Ruth (1987:151) asks in reference to sexuality, "can one communicate with precision about a set of events for which there are no accurate words?" Lawler (1991) argues that the language used about sexuality shares a similar space to the privatised body in that it is hidden away and talked of in sanitised, or vulgar words.

Sexuality, Lawler argues, does not fit into socially acceptable language and so we have generally succumbed to this social prohibition against talking about 'it', The biological terminology -penis, vagina, sexual intercourse -is sanitised. The slang used is frequently masculine, single mindedly genital and exclusively heterosexual, often violent and contemptuous (Ruth 1987:151). Ruth speaks of the dualism of two opposed realities which function to manage society's relationship to sex. To the fore and up-front are nice people behaving nicely in an antiseptic realm of non-sexuality and non-sex. Here the person is modest, covered, in control and unbothered by fantasy and dark confusions - a fantasy world itself. In the backstage area is a shameful, (sin)ister, troublesome area in which dwell pleasure, pain, intensity of feeling and 'experience of carnality' (Ruth 1987:155) in its widest sense. These two incompatible but simultaneously operative realms of consciousness Ruth argues, have to be balanced precariously with people learning early in life, the 'intricacies of the dance'.

Following from this it may be theorised that if there is no comfortable language in which to discuss issues around sexuality, then how to discuss sexuality becomes problematic and may influence staffs' ability to talk about sexuality to older people in their care.

2.7 Sexuality and older people

When reviewing the literature on sexuality and older people there are gaps apparent with the themes of neglect, ageism, homophobia and gender pertinent.

Fleming (1999) accessing the literature, argues that older men in contemporary society have become relatively redundant, even invisible in terms of life itself. Fleming argues that older men are stereotyped as genderless and deemed not really men at all. Whilst there is some credence in Fleming's arguments in terms of the invisibility of older men in the mainstream debates on masculinity, this argument is problematic when sexuality enters the discussions. White (1982), for example, found that older men are more frequently studied than older women, which is interesting given the greater proportion of older women in the population as a whole (Archibald and Baikie 1998). This emphasis on older men may be explained because older men are more sexually active than older women. Alternatively, a key consideration might be, as other researchers (Masters and Johnson 1966, Starr and Weiner 1981), have indicated, that the sexual interest and sexual competence of the male is the key factor in sexual activity in older couples. An erect penis serving is an obvious signal and determinant of sexual activity (Archibald and Baikie 1998).

Social gerontological research on sexuality has for the most part been concerned with white middle class, non-institutionalised old people (Harding 1988), that is 'younger' and fitter older people. There is an assumption in the literature of heterosexuality (Laner 1978) with older gay men and older lesbians generally invisible (Berger 1982, McDonald and Rich 1984). Chater (1999) argues that the dominant debates on sexuality include glaring omissions. She notes that not only are different groups classed as the 'other' but also there is a lack of the acknowledgement of the specificity of the dominant culture (Chater 1999:132). The 'norm', the 'universal truth' for older people is an asexual identity unless they are 'younger', healthier, heterosexual, wealthier, white, old people living in the community (Solnick 1978, Sviland 1978). Harding and Palfrey (1997) argue that we live in a time and in a society where the quintessentially modern individual is young and never dies.

Whilst there is a growing literature on the subject of sexuality and older people, the cultural construction of sexuality and the ageism which permeates some of the sociological literature and society generally, confines many old people of whatever gender, to an asexual identity (Archibald and Baikie 1998). Omission, as Starr and Weiner (1981) note, is a powerful statement. It can be seen as an indicator of how society disregards older people as sexual beings. Harding (1988:42) argues that the mainstream discourses on ageing 'have been genderless or androcentric'. Harding (1988) notes the fairly limited vision of feminist debates on ageing and sexuality. Asexuality is, and has been, one representation of specifically ageing women in feminist discussions. Older people then, like other marginalised groups, have become the 'other' with regard to sexuality.

The power of the 'norm' and how it can be used to discipline and control subjects is pertinent. How this combines with surveillance to become an instrument of power producing 'docile' bodies by the normalising power of the judgmental gaze (Foucault 1979) has resonance here. Disciplinary power in the context of older people and sexuality is exercised through its invisibility. Spence (1991: 249-250), for example, reviewing research findings on sexuality and older people found that although there were physiological changes in sexual response due to age these are insufficient to explain the decrease in sexual activity found in older people. A major determinant of sexuality in old age seems to be surveillance or how others view such activity. Normalising judgement allows only degrees of difference from the norm (Brush 1998). The norm with regard to the expression of sexuality is by those with 'desirable bodies'- the young, lithe and beautiful while those with older bodies, by implication, are rendered asexual. Balsamo (1992: 210) argues older women's faces and bodies in particular are 'sites of multiple defects and deformities'.

Bernard and Harding Davies (2000) in their exploratory study asked participants at a major conference on nursing and older people to complete a questionnaire titled 'Reflections on ageing'. One of the aims of the study was to explore what might be problematic about ageing for a particular group of professional women. Their findings resonate with those of Featherstone and Hepworth (1993) who use the metaphor of the 'mask of ageing'. One of the most important factors for these women was the change to their physical appearance. The external reality for example, wrinkles and looking ugly, losing their hair and becoming invisible and being seen as an asexual being were problematic for these respondents. Their view of ageing could impact on how they perceive older people for whom they care.

Ageism, sexism and neglect are apparent in the literature on older people and sexuality. Ageism is not only the prerogative of the younger heterosexual or homosexual population. Adelman (1986) in her study of older lesbians found the taboo of discussing ageing and old age as strong in the lesbian community as in mainstream society. There are positives in that the literature on sexuality and ageing has now become a growth area. Within these debates there has been a certain biomedicalisation of sexuality and older people. For example, sexual dysfunction in menopausal women (Hofland and Powers 1996), concern with erectile difficulties (Helgason et al 1996) and sexually transmitted diseases (Letvak and Schoder 1996), but there has also been a positive and encouraging component. A good sex-life for older people has been seen as part of healthy ageing (Meston 1997, Laflin 1996, Gibson 1992, Solnick 1978). These ideas contrast sharply with the discussions of sexuality and dementia.

2.8 Sexuality and people with dementia

The difference that emerges between the literature on sexuality and older people and sexuality and people with dementia, is that the latter is generally sited in the biomedical debates and largely framed as problematic (Kuhn D R, Greiner D and Arseneau L 1998, Amadeo M 1996, Derosne C, Guigot J and Chermat V 1996, Cooper 1987, Zeiss et al 1990, Nadal and Allugulander 1993, Haddad and Benbow 1993a and b, Alexopoulos 1994). The role of dementia here appears to be the (deviant) 'sick role' as noted in chapter one with social control intrinsic. The literature on care giving, intimacy and dementia (Kuhn D R, Greiner D and Arseneau L 1998, Litz et al 1990, Shapira and Cummings 1989), again focuses on the problematic with discussion of how to manage

such behaviours as opposed to any discussion about the facilitation of sexuality (Archibald 1997).

The empirical studies cited above point to the disciplining of dementia that Katz (1996) referred to in his work. This disciplining of people with dementia as noted earlier has resonances with the discourses around people with learning difficulties expressing sexuality. There is a need to access the literature on learning disabilities and sexuality for at least two reasons. The first is that there remains a dearth of literature on sexuality and dementia. The second is that within the field of learning disabilities there is a considerable literature on sexuality where parallels can be drawn with dementia.

Brown (1994) discusses the normalisation philosophy with adult status as a central concept, and the social value implicit in this, and notes that it is also value laden with normative properties. The philosophy, which encourages culturally normative experiences no matter how handicapped and disabled the person, has been problematic when applied to sexuality. Beneath the normalisation debates that mirrors in some respect person-centred debates in dementia, the sexual role for people with learning difficulties can be 'off limits', particularly non-heterosexual expression. While the concern of procreation is not an issue with people with dementia, but HIV and AIDS may be, the generic prohibitions such as (economic) dependence and cognitive functioning which form barriers to them assuming adult roles, are pertinent.

Referring to the work of Weeks (1989) Brown suggests that sexuality varies according to social position, resources and ideology and is a property which is largely ascribed. It is created and constructed and what is accepted, and acceptable, is highly dependent on a

person's status and social position. The role of dementia, may as the literature suggests, impact on the person's sexual identity and how they are perceived and responded to by others. Extrapolating from the literature on learning disabilities, if lesbian or gay is added to the label of dementia, the person may be in 'triple jeopardy' in terms of being accepted and allowed to participate in sexual relationships.

2.9 Sexuality – older lesbians, bisexuals and gays

The themes of neglect, ageism, class and gender are to the fore when exploring the literature on older gays and lesbians(lbgs), and specifically older gays and lesbians with dementia. If there has been a failure to acknowledge people with dementia and older people generally in the various debates on sexuality, older homosexual people particularly older lesbians, have suffered further marginalisation (Berger 1982) and have become almost invisible (McDonald and Rich 1984). As noted earlier being gay/lesbian was considered a mental illness until fairly recently. It was illegal. Lesbian sexual expression was unthinkable and certainly marginalised for most of this century with the exception perhaps of the avant-garde groups on the Left Bank of Paris in the 1920s and 1930s. Some argue that whilst now there is increasing attention being paid to older people, and to homosexuals as a group, this has not extended to older homosexuals (Berger 1982). Because of the 'invisibility' of older lbgs few empirical studies have been undertaken (D'Augelli et al 2001).

Gabbay (1997) looking at lbg gerontology found only 58 papers with the studies of men and they were almost invariably conducted on white, middle class well-educated city-dwelling men. Most of these studies focussed on dispelling myths and stereotypes of

older gay men. Gabby points to that of the 58 papers on glb, 43 included women with only five studies focussing only on older lesbians. Recent findings according to D'Augelli et al (2001) suggest that there may be an increasing number of older lgb people who disclose their sexual orientation for the first time in later life. This may be important for older gays and lesbians who are admitted to residential accommodation in terms of staff response. The limited literature on the subject points to a negative staff response (Szasz 1983)

Berger (1982) argues that as a group, older homosexuals (in the US) are short-changed politically with regard to publicly funded social services. There is a presumption that all older people are heterosexual which leaves agencies ill prepared to deal with what he regards as the unique situation of older homosexuals. In the UK, Humberstone (1997) notes that when an older gay man or lesbian woman is admitted to hospital there is a reluctance to see partners as next of kin and she argues for the development of policies to address this anomaly. This is an area that has been addressed to an extent in practice for patients generally but not specifically for older people, by RCN (1998 a, 1998b, 1994). Yet often when a partner dies, there can be a failure to recognise the depth of feeling suffered by the remaining partner and consequently support and grief counselling can be missing. Humberstone (1997) in the UK and Slusher et al (1996) in the US report that there are now support groups being established for older gay men and lesbians.

There have been no studies to date which have focused only on lesbian and gay sexuality within nursing homes (Fairchild et al 1996) and few on sexuality and long-term care generally. Szasz's (1983) study where nursing home staff's view of what was appropriate

sexual behaviour included only a hug or a kiss on the cheek has parallels with a child-like and asexual construction of residents. Fairchild et al (1996) ask if resident sexuality is assumed by nursing staff to manifest itself as only heterosexual expression, how will staff react to homosexual expression in a nursing home or residential home?

2.10 Conclusions

There are main themes that have emerged from this review of the literature on sexuality which are similar to those that have emerged when looking at the literature on dementia. These include neglect, ambiguity, ageism, gender, and identities with respectability and class also appearing.

Sexuality, like dementia, has been subjected to changes in definition over time and like dementia has, at various points in history, been medicalised. The 'psy'- professionals (and religious) have been influential in defining what was 'normal' and acceptable with regard to sexuality. The main messages from the literature appear to be that it is a complex and ambiguous area; a subject potentially unsettling and one deemed to be essentially, the property of young people. There appear to be double standards apparent for men and women that have remained constant over time. There have been various constructions of male sexuality and one that remains pervasive is the idea that 'boys will be boys' with a certain leniency and understanding given to the biological urges of men. These gender stereotypes have been challenged by feminists and male academics but they have remained remarkably intact. Working class women's sexuality was and is, linked to discussions around respectability. Recent research bears testimony to the persistence of sexual reputation as a concern for women.

Women's, and particularly working class women's sexuality, has to an extent, been codified through the domestic-feminine ideal. This appears to have been used as a marker in providing respectability and status and these ideas have proved remarkably resistant to change. The literature suggests that the argument that society has moved from a Victorian sexually repressive society to that of sexual enlightenment in late modernity is difficult to sustain. Rather, the legacy from the past, including the negative attitudes associated with working class female sexual expression, remain powerful and influential. Respectability therefore appears to warrant further empirical exploration with regard to what staff say about sex, the types of sexual expression they find difficult to manage and their responses. Female care workers' reputation may be at risk if they are seen as encouraging, however unwittingly, sexual attention from (male) residents. This may result in the under-reporting of sexual incidents directed at staff. These and other issues will be explored further in chapter three.

Ageism is manifest both in practice and academia and the resultant childlike qualities often ascribed to older people mean that they are often credited with an asexual identity. If, as Foucault (1979) argues, power through discourses produces domains of truth, then it can be speculated that the discussions around sexuality that have evolved historically, will probably impact on care workers attitudes as in society in general. This may as a consequence influence how care workers respond to sexual expression by residents. For example, the literature points to sexuality being constructed as heterosexual and enacted by young and fit people. Following on from this it can be theorised that older people, particularly those with disabilities, will be disqualified from being considered as sexual. It may be anticipated that when older people and people with dementia do express sexual feelings this will be met with disbelief and repugnance. The ethical

considerations addressed in the previous chapters will also impact and add to the reluctance of staff to discuss or facilitate sexual expression in residents of a nursing or residential home.

In both chapters one and two the findings from the literature point to dementia and sexuality separately, being difficult areas to define, discuss and manage. In chapter three I want to explore the issues that arise when the two areas of dementia and sexuality intersect.

Chapter 3 Sexuality - Dementia and Residential Care

3.1 Introduction

In the last two chapters, dementia and sexuality have been explored. How these two substantive areas intersect in residential care will be addressed in chapter three. I have noted that context is an important consideration in addressing my research questions. Following on from this, in chapter three I begin with a brief history of the policy and practice of social work residential care. The culture of organisations, the construction of care work and how power is enacted in long- term care is explored. Space is critically analysed addressing not only the public versus the private aspects of residential 'homes', but also how care workers manage the intimate spaces and the maintain boundaries when carrying out bodywork. The impact of sexuality on these institutions, including sexual harassment, is discussed and the emotional 'disturbance' that results from sexual expression by residents, particularly during these intimate care sessions, is considered. The sexual stories that are part of the culture of organisations are discussed. My conclusions are drawn from the three chapters of the literature review. I conclude that both the medical and social constructs of dementia are characterised by ambiguities yet the apparent solid construction offered by biomedicine remains influential. The findings in chapter one suggest that sexuality in dementia care has either been marginalised or pathologised. I argue that there are gaps in the literature that point to the need to address empirically the role that dementia plays when someone with the illness expresses sexuality.

A conclusion I draw from chapter two is that the theme of sexual respectability and working class women appears important and may be a factor in how care workers respond to resident sexual expression directed at staff. There are gaps in the literature with regard to this theme and I argue that this area warrants further empirical study.

In chapter three it is the theme of neglect and/or gaps in the literature that are to the fore. The literature on bodywork whilst providing useful insights stops at exploring sexuality, and sexuality and people with dementia. The main literature on sexuality and dementia is North American and is set within a nursing home setting. Following on from the literature the aims of my research are to explore empirically why sexuality and dementia have occupied such a marginalised space. I want to explore the role dementia plays when sexuality becomes a component of residential care work and address what staff say about sex in these settings.

3.2 Residential homes and their history

The history of residential care homes is important in the contextualising of sexuality and dementia. The history of the homes and societal perception of those who are admitted for long-term care today is important in furthering the understanding of care workers' response and interaction with residents.

Residential homes that originated from the 19th century Poor Law asylums had a somewhat tainted legacy of dependency and punishment from their inception. Historically residential homes were noted for their harsh regimes of custodial care that were designed to deter and stigmatise people seeking such help (Bland 1999: 542).

Booth (1985) reports that what characterised these institutions was the batch treatment, regimentation, depersonalisation and segregation of residents, characteristics well documented by Goffman's (1961) concept of the total institution. Residential homes have moved on in their development from the Goffmanesque 'total' institution but for many older people who live in, and possibly staff, who work in residential care, there may still be resonances with the historical construct of the Poor Law asylum. For example, as in previous times, older people now need to have multiple complex needs to be admitted to residential care and become as a consequence defined as 'socially incompetent' and dependent (Bland 1999). The expert 'gaze' as a result intensifies when these ageing bodies require admission to residential care (Powell 1998). The demographic changes and the ageing of the residential population have resulted in residential homes becoming de facto, a major arm of the dementia service (Butler 1990: 90).

Bland notes that as early as the 1960s Townsend (1962) spoke of the need for a different kind of relationship between staff and residents from that of 'master' and 'inmate' to more of a 'hotel relationship' in which people would choose to enter residential homes. However, the low income of many old people and the public subsidy required, meant that 'need' remained the determinant of admission and standards and staff attitudes to residents remained generally unchanged (Bland 1999: 542). Bland's (1999) work is of interest to my study on at least two counts. Firstly she explores two contrasting approaches to residential care, the 'social care' model and the 'hotel' model. She critiques the 'social care' model of care that tends to be unchallenged in practice and which predominates in social work residential care homes. This critique is about challenging the very concept of 'home' and the inherent core values. The tentative

findings are that there is less ambiguity and uncertainty of purpose with the hotel model. She notes paradoxically that the hotel appears more successful in realising the core values of privacy, independence, dignity and choice espoused by the social model of care. I will return to this argument later.

Secondly, Bland explores the analysis of risk in social work homes. Risk assessment is at the heart of how care is organised in social work residential care homes and this can have a restrictive influence on residents' autonomy (Bland 1999:545). She notes that as the social care approach assumes overall responsibility for residents safety and welfare, and lies primarily with the local authority and its staff, there is a tendency to try and avoid risk rather than manage it. Fears of adverse publicity and potential litigation are cited as reasons that militate against policies that encourage responsible risk-taking. If these arguments are accepted then this must have particular relevance to sexual risk-taking such as allowing sexual relationships by residents to form and continue.

Sumner's (2001) work is also useful when reviewing social work policy and practice. He notes the philosophies of empowerment; involvement and consultation embedded in local authority policies nationwide as in the 1998 Better Government for Older People Programme and Best Value and National Service Framework 2001. He argues that perhaps never has the (older) individual held such a strong hand in terms of exerting influence on service provision; but this has not necessarily been reflected in residential care. In this area for example, Bland et al (1992) and Willcocks et al (1987) found a culture of dependency and lack of control for residents. An important point made by Sumner is that it is essential to note the effect that the succession of negative research findings has had on policy formation. He argues that for many, residential forms of care

are an anachronism. and the antithesis of the current ethos in terms of promoting independence and the promotion of ‘community care’ options. Residential care has been largely discounted and thus marginalised as an option in the continuum of care (Sumner 2001: 233). Using the work of Peace et al (1997) Sumner notes that though resident disability has increased, staffing levels have not, with poor skill levels apparent in staff. The Scottish *Regulation of Care Act (2001)* aspires to address such aspects as training levels and care standards, but whether there will be recourse to additional funding so that the issues of cost do not override issues of quality remains to be evaluated.

The inference from the literature is that there are a number of paradoxes implicit in social work residential homes. They purport to be a ‘home’, yet remain very institutional in terms of the facilitation of residents’ autonomy and privacy. In the next section I will discuss the tensions and how this may impact on residents sexual expression.

3.3 The home/institution debates

The domestic or social model of care is part of the discussion around constructing residential homes as the resident’s home and so moving away from the institutional model of care. As Bland has argued the debate between home and institution has been well documented but remains unresolved with many ambiguities apparent (Peace et al 1997, Willcocks et al 1987). Whilst many residential homes, as Lee (1993:2) notes, do resemble some people’s homes through the choice of homely decor and the creation of

small units within homes, the space does not belong to the residents. The residents remain 'consumers of someone else's construction of home.

Douglas (1991) highlights some of the difficulties in defining what we mean by home and argues that the sociological construct of home as an embryonic community has allowed a certain mystique and idyllic construct to gather around the notion of 'home'. Following on from this Lee's (1993) point is pertinent. Rather than the 'safe' and idyllic construct that is often associated with the term 'home', it is increasingly acknowledged that for some, home may not be the haven of security as constructed in the past. For some, 'home' can be an abusive place in terms of sexual abuse and domestic violence.

There are other aspects of the construct of home that need to be examined in terms of neglect and gaps in the literature, specifically its partial application with regard to sexual expression. Sexuality has for the most part been omitted in the constructs of 'home' yet paradoxically until recently was considered as belonging to the private realm of the family and presumably thus situated in the home. The acknowledgement that organisations are arenas of powerful sexual and emotional politics has only emerged fairly recently, through feminist studies of sexual harassment in organisations (Hearn and Parkin 1995, Parkin 1993).

Other aspects of 'family home' life appear to cause tensions when considering sexual expression by residents in an institution such as a residential home. In residential care where staff implement a social care approach described and critiqued by Bland (1999), staff attitudes to such aspects of care as privacy tend to be governed by how the resident is constructed. They may be seen as 'patient', 'family member' or 'child' (Bland 1999:553)

or as noted in chapter one as ‘disabled with dementia’ without any of these roles guaranteeing a right to privacy. Bland (1999) notes that the primary function of staff is ‘to care’ with normal conventions surrounding privacy seen as inappropriate, impractical or even dangerous. I argue that this will be particularly the case for some people with dementia.

Whilst the social care approach emphasises privacy as a core value this, as Bland argues, is in conflict with the overriding need of staff to minimise risk by keeping the resident under surveillance, setting up, for example, a domestic model of parenting and care in the organisation. The boundaries between care and control are often blurred with power enacted in many subtle ways. Foucault’s (1979) concept of power is relevant here in terms of the disciplining of bodies within institutions. He notes that the disciplining operates through various techniques including separating individuals from each other, the imposition of timetables and organising the passing of time into successive stages through which individuals progress. This may adequately describe some forms of residential care. Foucault was interested in how power was enacted in micro situations such as institutions. In the next section I explore how power is enacted in residential homes.

3.4 How power is enacted in residential homes

3.4.1 Residents, sexuality, power and gender differences

The literature that addresses institutional care often focuses on dependency. Booth (1985) concludes that institutional living has a detrimental effect on functioning of individuals

and increased dependency occurs as a result. There appear to be gender differences within these caring environments. Evers (1981), for example, notes dependency and subordination is a part of being a patient (and arguably a resident) with caring and control features of the social relations within which these are experienced. She offers some interesting insights into gender differences with regard to how long-stay care is experienced differently by women and men in the geriatric wards studied. She remarks on the double incompetence experienced by women compared to men.

Evers (1981) notes that women who are generally preparers of food and providers of family care have to surrender part, or all, of this care work to other women. They then lose their central life role as caregiver particularly for their spouses, as they lose independence and suffer increased disability. For men generally, dependency on nurses or care workers tends to be seen as an extension of their relationship with the women in their family. Thus dependency for many older men means less of an assault on the self and self-esteem, compared to that experienced by many older women (Evers 1981). Evers argues that gender differences extend to how nurses view old men and women. In her study, Evers reports that men have subtly different experiences from the women patients on geriatric wards. Both men and women patients had various typifications accorded them but a common difference was that all the men retained more of their identity and individuality in the face of institutionalisation. Evers theorises that nursing men does not pose a challenge to the nurse's 'ownership' of caring work, but rather it reinforces it.

Evers' work is useful in exploring power, gender issues and context. Lindesay and Skea (1997) in their study of elderly nursing home residents further the discussion on gender.

One of my research questions looks at the role that dementia plays in terms of staff response. Evers (1981) and also Lindesay and Skea (1997) alert us to the importance of gender when looking at staff's response. The latter authors noted that male residents with dementia initiated more interactions with staff than female residents. Also both female and male staff initiated a higher proportion of interactions with male residents than female residents did. Whether this is as a result of men retaining more of their identity and individuality or being more interesting, or whether they are seen as having more status and importance, is open to speculation.

The theme of neglect is evident in the literature specifically in relation to gender. The above literature would appear to counter Fleming's (1999) argument that older men have become invisible in the debates. It may be the case in mainstream masculinity discussions but in the literature on sexuality and long stay care, men appear to the fore with older women rendered invisible or perceived less favourably by staff (Bullard-Poe et al 1994, Mulligan and Palguta 1991, Szasz 1983). In an unusual study looking at women and sexuality in nursing homes, Nay (1992) reported that staff believed women in a nursing home setting to be asexual. Harding (1988), in addressing this commonly held view of older women, questions the power relations at work with regard to silences around older woman's sexuality. How staff in long-stay care enact power will now be explored.

3.4.2 Staff enactment of power, ambiguity and gender implications

Residential homes are organisations where essentially women work and mainly older women are cared for, with both groups of people not usually associated with power.

Atherton (1989) argues that power is pervasive and unequal in residential homes, and rests primarily with staff. He notes that staff and residents represent two different groupings. For example, staff are paid, whereas residents are paid for, or pay, to be there. Staff are employed on a basis of their strengths, residents are there on the basis of need. Staff are there only part of the time, whilst residents are there continuously. Atherton notes that in no other occupation other than nursing or parenting, is power in terms of surveillance (*le regard*) so pervasive with regard to the intimate aspects of a person's life. His arguments that staff incorporate elements of family life while incorporating elements of totality, as people are processed, controlled and observed, concur with those of Bland (1999) and Parkin (1993). The home model has become blurred with the total institution model. Once more the ambiguity of how terminology of the family or home can distract from the recognition of the totality of control and surveillance, is raised. It is noted that this can simply be a way of avoiding questions of how power is enacted in these units (Parkin 1989).

Stannard (1978), discussing work in US nursing homes, notes that how power is enacted is not quite so well defined. It is more subtle and ambiguous in that hands-on staff and residents share similar characteristics. Both have low status and suffer marginality. He notes, as Peace et al (1997) note twenty years later, that staff groups working in nursing homes tend to occupy marginal positions in the labour market. He argues, because of their low levels of education, staff do not entertain sophisticated and complex ideas of human motivation and mental illness (Stannard 1978:178). Their interpretations of patient actions are based on lay rather than medical knowledges. Clarke's (1978) work echoes some of these ideas. She explores nursing against a background of work experience particularly family and domestic commitments. She

asks how much does family experience, looking after children for example, contribute to the management of dependency in adult patients? She notes, as others have noted (Goldthorpe et al 1968), that people's work behaviour is related to expectations which are formed outside the work situation (Clarke 1978:70). The intersection of familial and work experience within the culture and context of residential homes may have important implications for addressing staffs' response to residents with dementia expressing sexuality, and therefore needs further exploration.

3.5 The culture of organisations

It is important for the purposes of my study to look at the culture of organisations that produces 'models of care' and constructs of residents. I need to develop the discussion about context and how this may influence staffs' response.

Citing the literature, Alvesson and Due Billing (1997:104-5) point to culture being characterised by 'a set of meanings, ideas and symbols that are shared by the members of a collective'. Culture here means the importance of symbolism manifest in myths, stories, the interpretation of events and experiences that are influenced and shaped by the groups in which they live. Peace et al (1997) borrow from Foucault (1979) and apply his ideas to residential establishments for older people. Here the setting would be construed as manifestations of certain power relations and the care provided seen as forms of control. Peace et al look at deviance and how this is used as a form of construction of symbols used in settings to maintain the norms of groups. They argue that residents can be seen as representing some of the most marginalised and deviant of groups. They have failed a range of assessments and because of differing kinds of frailty require admission to care.

Following this the inescapable construct of residents is old, needy and possibly child-like, the very opposite of the young and healthy construct associated with sexuality noted in chapter two.

Lorentzon (1990), discussing social work and nursing staff, notes the power of labelling within these caring situations. The construction of 'bad' patients and 'difficult' residents leads to them being the object of intervention. The professional, not the resident, defines the problem with the solution arrived at by the professional. Goffman (1978) posited the notion of spoiled identities that accrued from 'deviant' behaviour. Stannard (1978) in his work describes that when patients violated institutional expectations of proper patient behaviour, the norms prohibiting abuse of patients, were suspended. If Stannard's ideas are accepted and following on from the discussions previously on sexuality and dementia, it can be theorised that older people with dementia, gay or lesbian older people, expressing sexual intent may be seen as violating institutional norms with possible negative repercussions.

Although his work is based a single case study Stannard cites other literature in support and argues that all the institutions mentioned in the studies cared for people of low status who are relatively powerless and whose credibility is tarnished. There are 'resistances' within these constraints. For example, whilst residents are under constant surveillance and constantly assessed, there are difficulties for staff in determining what goes on in residential care all of the time. No one knows the whole story in spite of record systems and changeover meetings. Atherton (1989) argues that even in establishments where only limited privacy exists, many staff do not know what goes on at first hand. This is important with regard to sexual expression by residents. I return to

Bland's (1999) work where the minimising of risk was seen as imperative in the social care model. If staff, regardless of the constant surveillance of residents, are unable to know what is going on all the time, then sexual expression between residents, particularly those with dementia, may represent intolerable risk taking and when discovered, disallowed.

This section has shown how power may be enacted in long-term care situations. In the next sections I explore the 'care' work that is undertaken, how gender is implicit and question how familial and work knowledges intersect to gain further understanding of care workers' response. I am interested in exploring the workers expectations of care work and how they manage intimate caring situations.

3.6 Care work and gender expectations

Feminists have made explicit the many ways in which the definitions of work are fundamentally gendered with men's labour used as a general standard for understanding all work activities (Mirchandani 1998). Mirchandani (1998: 168) also notes that this 'masculine' work norm ensures that many of the activities that women and some men are involved in on a day-to-day basis, are labelled less important than the 'real work' done by men. Harding (1991) argues that women's lives should be taken as the starting point of inquiry for developing theoretical insights. This is an important point as there appears a consensus in the literature that care work is mainly associated with women (Finch and Grove 1983), with caring relationships involving what women do in both the public and private domain (Graham 1983). Within this construction of care work there are societal assumptions that women have an 'inherent propensity and natural

responsibility for these activities (Aronson 1992). 'Home life' and 'work life' has been organised around the notion that these are defined as female and male roles respectively (Halford et al 1997). How much domestic care merges with cultural expectations of private family life (James 1992) has been poorly documented and scrutinised. If a care worker's experience is that of raising children, for example, will this impact in how she responds to child-like residents with dementia expressing sexuality?

I use the term 'she' as there seems little exploration of how men 'fit' into a feminised workplace such as nursing or residential care work. The theme of neglect is apparent with men working in these settings often rendered invisible in the literature. Most of the references, and these are meagre, are in the sociology of nursing literature (Halford et al 1997, Savage 1995, Lawler 1991 Abbott and Wallace 1990, Christman 1989 and Gray 1985). It is hard to ascertain if the invisibility is due to the 'logic' underlying the often-presumed association between male nurses and homosexuality (Savage 1987). The male nurse is sometimes seen as someone who has failed in a man's (work) world, and is further emasculated by taking on women's work. If his masculinity is in question so too is his sexuality-a correlation being evident between gender role and sexual preference (Savage 1987: 76). Gipson and Hoffman (1996) note that male nurses previously sought after for 'heavy duty' work are now being sought to work as care assistants in nursing homes. They are seen to provide women residents (in an almost totally female environment) with more opportunities for social interaction with men, and for the men residents, another male figure with whom to relate. But there are difficulties. Hegemonic constructs of men as sexually predatory means that limits are placed on male access to bodies (Connell 1995). These boundaries, however, can become blurred in both nursing and care work situations.

Gender is an important consideration but how care work is constructed is valuable in addressing the question of context. The studies of Lee-Treweek (1994) and Clarke (1978) provide insights into how work is constructed by mainly female residential and nursing staff and what properly constitutes work. The expending of physical energy, doing something during the time they were paid for, was paramount. It was on this type of work that staff thought they would 'be judged and sanctioned' (Clarke 1978: 77). In Clarke's study looking at staff on a long-stay ward and echoed in Lee-Treweek's (1994) work, the main aims were getting through the work. Work was defined as physical tasks. Metaphors such as 'pulling your weight', 'mucking in' were used. Hockey (1990) in her study found staff work styles constituted a distinct social group with characteristics such as being good-natured and a willingness to undertake hard work, viewed positively.

Lee (1993) notes that the standard to aspire to in the worker's discourse (discourse used here as sets of knowledges) was that of the 'good worker' which encompassed quite broad skills, including offering to do the dirty jobs. The discourses were about 'the workers to do womanhood well' (Lee 1993:6). Work was symbolised in one nursing home by the presentation of well-ordered bodies. Here personal hardship with regard to the work (avoiding the use of hoists and other aides) and tough behaviour towards the residents, was central to the workers concepts of what their work entailed (Lee-Treweek 1994). Work in the above studies appeared to be about impressing colleagues as opposed to addressing the psychological needs of residents. Work is seen as doing bodywork well.

3.7 Spatiality and bodywork

The above section points to work being constructed as mainly physical hard bodywork. In this section I want to explore how workers within this construct of work manage the intimate bodywork tasks. Space emerges as an important theme in terms of how workers manage the intimate space between themselves and the residents when undertaking bodywork but first I will look at geographic space.

I have already started to explore some of the debates on the public versus the private space in residential care and noted the ambiguities and tensions. Here space is considered in terms of gender and identities. Feminists have highlighted that within geography, gender relations vary over space and that the symbolic meanings of space/places, and the messages they transmit, are gendered (Ardener 1981). An example here would be residential homes where the majority of the workforce and the majority of the residents are women. Peace et al (1997) drawing on the work of Willocks et al (1987), describe a residential home as a community for living, having to provide for private lives in public places. In line with the quality-of-life movement being espoused in the gerontological professions, social policy gerontologists have also begun to espouse a more multidimensional and dynamic approach to understanding the environmental experiences of older people (Parmalee and Lawton 1990).

In terms of spatiality the work of Goffman (1961) is useful. He drew attention to the importance of distinguishing between front and back regions in total institutions. Bodywork is potentially demeaning work and careworkers and nurses go off-stage to perform it in back-stage areas such as bedrooms and bathrooms (Lee-Treweek 1994).

Bodywork often involves dirty work that is hidden and is delegated to lower staff. Trained nurses move away from shit and vomit with such dirty work transferred down the occupational hierarchy (Lee- Treweek 1994). It is within these 'back-stage' regions that intimate bodywork is carried out and here the nursing literature is helpful.

3.7.1 Metaphorical and physical closeness and the emotion work involved

Hancock in her introduction to Savage's (1995) work notes that the construct of closeness plays an important part in the structuring of relationships across a number of domains. Experienced nurses used a range of strategies to promote and manage their 'closeness' with patients. Savage found that closeness came to be identified by some nurses as how well they knew the patient and consequently the ease that was experienced in the relationship-they could talk about anything without embarrassment. That closeness developed as a result of carrying out intimate physical or unpleasant procedures; a conflation of emotional and physical closeness occurred. This is what nurses learned on the wards that countered the notion of body and mind dualism.

Intimacy can be viewed as a process and a state involving static and dynamic elements. At issue is how the participants see the level of intimacy as appropriate, or not, in a given situation or occasion (Acitelli and Duck 1987). Nursing, and by extension care work, entails a level of intimacy not usually encountered outside sexual contexts. Nurses experience sexual harassment from male patients, as women do elsewhere from men in society and this would include male nurses (Lawler 1991). Sexual harassment will be discussed more fully in a later section. Nurses unlike perhaps other workers with the exception of perhaps care workers, have to continue on-going physical and nursing

care for the harasser (Savage and Witz 1992) with all the attendant emotional labour/work involved.

Hochschild (1983: 7) defines emotional management as management of feelings to create a publicly observable facial and body display. Emotional labour comprises those activities involved in emotional management when they are carried out for a wage in the public sphere. Hochschild's work is centred primarily on the airline industry. She argues that jobs that involve emotional labour share three characteristics. They require the worker to produce an emotional state in another, for example, gratitude or fear. The employer is allowed, through training and supervision, to exercise a degree of control over the emotional activities of the employee. Thirdly, emotional labour is the occupational equivalent to work carried out in private but it is commodified and sold for a wage. Those jobs, which have a high emotional labour component, are usually female occupations where gender stereotypes and expectations are reproduced in the workplace (Smith 1992). Hochschild's work will be returned to later in chapter eleven.

The difficulties identified in the literature with regard to emotion work appears to be that many of the activities that are part of the person's job are not recognised as 'work' and this would include emotional labour and emotion management. James's (1989 and 1992) seminal work has been crucial in applying these concepts of emotional labour to care work in the UK. She notes that emotional labour underpins domestic care work and that care work then makes emotional demands which are equally hard as the physical components of work but are not so readily recognised. The skills of emotional regulation are learned at home predominantly by women and transferred to the workplace and care work (James 1992). Emotional labour is about action and reaction,

doing and being. It is demanding and skilled work involving personal exchange and it means caring about people before it can be effective (James 1989,1992). Hochschild (1983) argues as noted that it can be appropriated for commercial purposes. The response may not be genuine but may appear so.

There appears to be a 'right' time and place for most feelings (in Parkin 1993). Emotions like sexuality are seen to be located within the private sphere, which as Parkin argues, leads to forms of social control over emotions. Keeping control of emotions is then seen as a strength in the organisational setting, with those showing emotion seen as emotionally weak. Men who are seen to express emotion are seen to be even weaker 'like women' (Parkin 1993:184). Lack of control is a central feature that is managed by emotions being confined to the private or dealt with in the public domain by counselling. Parkin (1993:185) argues that in this way emotions are controlled by those in power defining what is meant by emotionality and then pathologising those emotions which do not fit the criteria of organisational strength, 'the norm'. These are important points when considering how care workers respond, what they say about sex and to whom they talk.

In our society where dominant white masculinity constructs prevail, emotions have to be suppressed and silenced as boys grow up. Masculinity is identified with being independent and self-sufficient and without emotional needs. Emotions are gendered as 'feminine' and linked to vulnerability and so to 'weakness and femininity' (Seidler 1998). Using these arguments, it would seem that women are the best people to deal with others emotions. Gubrium (1989), however, characterises emotion work as a craft and constructs emotion work as an integral part of both women's and men's work. Yet whilst emotions appear legitimate in the domestic domain they are an anathema in the workplace (James 1992). James notes that knowledge, skills and techniques of

emotional labour require training in the same way that physical labour does, but this apprenticeship takes place in the home rather than workplace education. Home appears to be the ideological base for emotions

Graham (1983) and others argue that caring wherever it is undertaken is very hard work under the emotional rhetoric of 'caring'. Savage (1995) citing the literature argues that there needs to be more attention given to work and emotion and that a distinction has to be made between the private and the public expressed feelings of the care worker which links with Goffman's (1959, 1963) work. When carrying out intimate tasks for patients nurses (and care workers) have to negotiate a 'socially delicate territory' (Lawler 1991: 151) of invading another's personal space in intimate ways, and this Lawler argues, requires taken-for-granted rules. This is helpful when addressing how care workers' respond to sexual expression by residents as most problems articulated by nurses interviewed by Lawler (1991:150) were in relation to sexually explicit or sexually suggestive behaviour by the patient where the rule governing modesty had been transgressed.

Lawler, addressing the norms and values, taboos, beliefs and learned ways of behaving in respect of the potentially embarrassing aspects of bodywork, posits four main rules which form the taken-for-granted social environment in which nursing is practised. The first involves the compliance and control rule. Here the patient will be obedient and compliant as a result of the power differential between the powerful nurse and dependent patient. Rule two is that of dependency where the patient is so ill or sedated that it is physically impossible to be other than dependent, and so requires intimate tasks to be undertaken. The third is the modesty rule where the patient is expected to be neither too modest, nor too free, to expose her/himself. The nurse may define the

unwarranted exposure of parts of the body, normally kept covered in public, and/or accompanied by sexual suggestive remarks, as sexual harassment. The fourth is the protection rule. This acknowledges the patient's potential for feeling embarrassed. This occurs where help is needed when the patient is unable to maintain total control the body or unable to ensure their privacy for bodily functions. This rule is about assisting both the nurse and the patient by making various aspects of nursing care private (Lawler 1991:165).

Returning to the literature on dementia and to the research question about the role dementia plays in care workers' response and how they responded, Lawler's rules may be of value. A person with dementia may not be able to comply with rule one but may fulfil the expectations of rule two, that of dependency. The modesty rule may not be adhered to but then there would be mitigating circumstances, for example, the 'halo' effect of dementia. Rule four would possibly apply to people with dementia.

Savage (1995) found that intimate procedures were easier for nurses when they felt close to the patient. Whilst supporting Lawler's ideas that nurses tend to focus on the fusion of the lived body and the object body, she notes there were difficulties experienced by the nurse regardless of social rules. For example, when the patient was of a similar age and the opposite sex. These were aspects that proved difficult for nurses in managing intimate work situations (Savage 1995). The wearing of uniform appeared to make nursing acts permissible and less ambiguous (Lawler 1991). Lawler (1991) argues that uniforms transfer nurses into representations (actors) rather than specific individuals, which seems somewhat at odds with the idea of closeness and knowing the patient. Savage (1995) does address this apparent contradiction. She notes that if the context in which the nurse/patient

relationship is transformed too completely from institutional to private sphere, the definition of the reality that nurses and patients usually abide by, becomes unhelpful and ambiguous. In other words the nurse patient relationship is complex and highly fragile and needs markers which the uniform can be said to supply.

This has significance in residential homes where staff do not wear uniforms and residents for example, have dementia. The situation then becomes highly ambiguous particularly in the area of intimate care tasks, meeting basic needs such as washing, toileting, dressing and feeding. Twigg (1999) notes that care workers are drawn into intimacy in their work situations and report that physical intimacy can be overpowering. Here care workers have little or no symbolic protection against the polluting nature of their work unlike nurses who are invested with special purity in managing the body and who are reinforced by their uniform (Twigg 1999). Yet nurses' uniforms represent a highly ambiguous area. Whilst providing a 'barrier' and legitimacy to carry out intimate care tasks, they have been depicted in media representations as highly erotic and thus sexualising the wearer. Such films as the *Carry on Nurse/Doctor* series provide examples.

Regardless of uniform, the conflation of emotional and physical closeness is less clear in studies centred on old people's homes where the theme of neglect once more emerges.

3.7.2 Touch

The literature on touch lays emphasis on the ambiguities and the inherent potential for misinterpretation. Yet touch is an integral part of bodywork and caring generally and needs to be included in the discussion of spatiality and context.

People are touched in different ways: physically, spiritually and psychologically. Savage (1995) differentiates between expressive touch that suggests caring, and instrumental touch defined as task-orientated. There appears to be a taken-for-grantedness by nurses (and possibly care workers) that high amount of touch has a positive implications for patients (Estabrooks and Morse 1992). Rather than touch being viewed in positive terms it might also be constructed as a means by which nurses exercise control (Mulaik et al 1991). It is unclear whether it increases or decreases patient anxiety. Touch seems to be context and person specific. For example, it depends on the relationship of nurse/patient/ age/culture /part of body touched and the context (Weiss 1988: 5).

Savage (1995) found that expressive touch was used in different ways by different people with junior nurses more spontaneous in the use of expressive touch and experienced nurses using it in a more considered way. Most nurses, male and female, commented how rarely they touched young men because of possible sexual connotations. The reluctance to touch patients of any age was overcome when the patient was distressed and when there was no (sexual) ambiguity in a given situation. Savage describes how one nurse caring for a old person with a mental age of two (with dementia), used almost total body contact hugs. The role dementia plays in staffs' response here would be that the person presenting a safe and child-like (asexual) persona was a person sexually safe to touch.

Touch remains highly ambiguous in institutional settings. It can be interpreted sexually and can be seen by staff as harassment. There are issues around men who have erections, who flirt or touch up female staff and men who wanted particular staff to attend to bodily

needs. Because of the intimacy surrounding such tasks as incontinence, sexuality is an ever-present issue (Parkins 1989). A considerable number of nurses use touch spontaneously but the general consensus is that nurses are nonetheless selective in the way they use this form of touch. Interestingly, many nurses are at a loss to describe this aspect of care. Some say they know from experience in that they receive 'vibes' and know by a patient's body language (Young 1987) when touch would be appropriate. Lawler (1991) notes the inability of nurses to articulate what they do (and why) when they practice. The same may be applied to care workers and how they speak about sex.

In the provision of physical care, for example, 'context and intent, are all that differentiate some nursing actions from sexual ones' (Savage 1995: 74) and so the management of ambiguity becomes a central task of caring, particularly when sexuality becomes a component of managing intimate caring situations.

3.7.3 The management of intimacy

In the literature it is apparent that both nurses and care workers feel tensions between becoming close in different respects to patients or residents, whilst at the same time maintaining some kind of professional distance. How this space is negotiated and managed is of interest specifically with regard to sexual expression. Increasingly it is being acknowledged that in residential homes the private and personal (sexual) experience enters the public domain (Archibald 1998). What has not been acknowledged until relatively recently is the need to examine and provide theoretical space to look at bodywork carried out by 'care' workers (Smith 1992, Lawler 1991). Smith, exploring intimacy in nursing uses spatiality, in its many aspects, as an analytical tool, which is useful for my study.

The work of Smith (1992), Lawler (1991) and Twigg (1999) will be addressed in this section to explore how care workers manage physical intimacy and sexual expression in the work situation. Lawler (1991) notes in her study that overt sexual behaviour by patients directed at nurses was invariably by male patients and it tended not to be tolerated by nurses unless there were extenuating circumstances and here the four 'rules' came into effect. These circumstances often were around issues of responsibility. If the patient was viewed as not being able to help or be responsible for actions (rule two), for example, or where the patient had suffered brain damage, the behaviour was treated tolerantly and with understanding (Lawler 1991).

Although Smith (1992) and Lawler (1991) have as their focus nurses, their work arguably has a wider application to other forms of bodywork. There are evident gaps in the literature. Both authors stopped short of any in-depth analysis of sexuality with Lawler noting that this was an area needing further research. Reviewing the literature on the history of sexuality, Lawler points to the nursing literature veering heavily towards boundary keeping, deciding what is normal and what is deviant with the bias in favour of heterosexuality. Lawler notes that sexual bodies and body products never come without a great deal of cultural baggage attached in the caring situation where there is touching of bodies involved. The most problematic areas of the body, for both nurse and patient, are those associated with sexuality and genitalia.

Twigg (1999) discussing how care workers manage bodywork, points to the gaps in the literature and notes the lack of sociological analysis and theorising in this area. She points to how the private nature of the 'home' has acted as a barrier to ethnographically informed work. Community care has been dominated by managerial debates about

(financial) efficiency and effectiveness with little place for bodywork in this analysis. Twigg argues that the lack of analysis on bodywork reflects the desire of social gerontologist to move away from the excessive focus on the body and its decline that characterises the biomedical model. It is seen as good practice to move from this negative imagery to that of stressing the person behind the mask of age. Twigg, viewing the literature, notes that the subject of the body is uncomfortable and an unwelcome one with the topic lacking decorum. These ideas become even more pertinent when addressing the gaps evident in the debates about the older sexual body that is marked with dementia. There are tensions when debates of the 'good' body, that is young and beautiful, are faced with dirt, decay and death associated with older bodies. These are bodies with which workers work and it is possible to theorise that this will impact on care workers response when faced with these older bodies disabled with dementia, express sexuality.

Twigg (1999: 4) notes that 'care' has a warm loving aspect to it that produces a kind of halo effect. The conceptualisation of care is often embedded in interpersonal family relationships that are often complex and conflictual. She argues that bodywork is often not part of this caring when for example, caring for older family members whereas but bodywork and childcare is central. Yet as noted earlier 'caring' from the perspective of employment situations, has been presented in harsher accounts where work is often shaped by dirt, physically hard, poorly regarded and rewarded (Lee-Treweek 1994). Care work involves dealing with dirt, vomit and other wastes and is about managing dirt and disgust (Twigg 1999: 5). Twigg, discussing the work of Miller (1997), argues that disgust as an emotion is rooted in fear of contamination, whether physical or moral pollution. Disgust is rooted in the organic and above all it is related to the body. It is

other people's (older) bodies and by-products that disgust in residential care work. If these arguments are accepted then it can be speculated that this will have major implications when residents express sexual feelings with all the taboo and pollution issues evident around the area of sexuality as noted in chapter two.

Twigg (1999) reported in her study, that some care workers found old bodies a bit of a shock as they had seen few images of ageing bodies. Older people were expected to keep covered up, with the ageing naked body taboo. For young care workers the ageing body was novel and to a degree, a shocking experience, that brought the workers face-to-face with realities of ageing. One careworker who discussed sexual attractiveness in the study was at a loss to imagine how the ageing person they worked with now could ever have been like them, that is young and (sexually) attractive. Care workers tended to emphasise the social touch of cuddles and kisses, echoing the work of Fairchild et al (1996), rather than intimate bathing help, as a route to emotional closeness.

The literature points to workers receiving little help in managing bodywork from employers. Bodywork borders on the taboo (Lawler 1991) with little or no public debates of the body. As with sexuality it is a territory where language itself is problematic, awkwardly polarised between the medical and clinical and vulgar which makes it a difficult area for staff to discuss. This reflects the privatisation of these aspects of life in that it is rarely spoken about other than in childhood or intense intimacy or crude jokes. According to Lawler (1991) nursing is coy about what bodywork entails and so it is glossed over enabling the body and its embarrassments to be rendered safe, abstract, subdivided and scientific. Language is used as a distancing technique so that terms such as personal hygiene are used and also humour. The body

and humour are closely linked in dirty jokes; sexual innuendo and lavatory humour where the body is the focus. The more formal the occasion the more embarrassing and/or humorous the body lapse. Often these relate to sexual incidents (Twigg 1999) and provide ways of distancing or accelerating closeness with the resident or patient in organisations.

3.8 Sexuality in organisations

To provide a contextual framework in which to site sexuality in residential care, it is necessary to explore organisational theory briefly. Omission is an obvious theme to emerge in the literature with sexuality having remained strangely absent from organisational theory until recently (Hearn and Parkin 1987). Hearn and Parkin (1987, 1995) reviewing the literature, note that this omission is best read as ideology which looks at how sexuality could possibly be avoided. When sexuality within organisations is explored, another theme to emerge is that of gender. Hearn and Parkin (1987) for example using Classical Theory look at how this approach is still influential with its deeply embedded assumptions of how organisational leadership is performed by men and how maleness carries the inherent qualities of leadership that women lack. The authors argue that sexuality is ignored and that the conflation of maleness and sexuality creates the possibility of femaleness and sexuality.

Hearn et al (1989) note the compelling paradoxes which have emerged in the study of sexuality and organisations. For example, it is men who deploy or use their sexuality at work far more than women, yet it is women's workplace identity that is often saturated with sexuality (Gutek 1989). It becomes more obvious and less of a paradox when it is

seen that heterosexuality structures organisations within which men establish both their difference from women and their power over them (Savage and Witz 1992). The latter authors note that whilst there is an increasing literature on sexuality and organisations now, there is a necessity also to investigate how gender is embedded within different power relations when considering sexuality in organisations.

Gender is also an issue in residential organisations. As discussed earlier, the designation of 'home' can lead to people falsely assuming that personal issues such as sexuality can remain private. In residential homes, for example, the protection and condoning of men's (oppressive) sexuality is all the more powerful because of the ambiguous organisational position and the vulnerability of residents and many staff (Burrell and Hearn 1989). In these 'intermediate zones' men can exercise power over women as they would in a family setting. In the private world of the family, rules and procedures about sexuality are not usually drawn up. Sexuality has then to be reframed as unprofessional conduct in order to fit. Gutek and Cohen (1987) use the term sex role spillover to denote the carry-over of gender based expectations in the workplace some being rooted in the stereotypes about men and women. Lawler (1991) particularly highlights sexuality as being problematic and argues forcibly that the theory of the body cannot ignore sexuality because almost any human interaction is fundamentally sexual and genderised.

Sexuality is private, intensely felt and often kept secret in organisations as elsewhere (Hearn and Parkin 1995). They note that organisations are places of emotion ranging from anger to joy to sorrow illustrated in sexual attraction and liaisons between members of organisation and in sexual harassment. The authors note that in response to the need for control, emotions are centred around discourses about professionalism.

Disclosures about personal feelings of distress about stressful situations, such as sexual harassment, may legitimately occur in supervision sessions.

In organisations such behaviour can be defined as friendly or seen as normal. It is difficult to define and so the person internalises it and remains silent. If women are unable to define or communicate the existence of such a problem they can be prevented from sharing the experience with others. As a result they can be left silent in an isolated and vulnerable position (this can also apply to men in some caring situations). Girls and women often remain silent about their experiences. Some girls believe they are guilty and have 'asked for it' therefore deserved 'it'. Another reason is that they fear that they will be open to further abuse and attack. Following on from Skeggs' (1997) work, a good reputation is also a factor. A further reason is to protect the assailant in that the woman may feel sorry for the attacker. Fear of not being believed is central. Sexual harassment is often seen as a trivial matter and this is reflected in the silences that surround the issue.

3.8.1 Sexual harassment

In this section I want to explore sexual harassment further as a component of organisational life. As noted sexuality until recently was considered as belonging to the private realm of the family with only recent acknowledgement that organisations are arenas of powerful sexual and emotional politics. The feminist literature on sexual harassment of the 1970s and 1980s was set against the broader concerns of male violence, which has served to contribute empirically to the study of organisations. Hearn and Parkin (1995:37) argue that these studies have highlighted the complex form and process of

sexuality within organisations with women's subordination at work either 'erotised' or 'sexualised' (Halford et al 1997). The latter authors are keen to argue that if women's bodies are sexualised or objectified at work, this can also apply to men in certain work situations and this warrants further investigation. Following on from this it is possible to theorise that male care workers like women care workers may be the recipients of male residents' sexual expression and that this may be a type of expression care workers find difficult.

The above studies have in effect made sexuality visible in organisations. Staff working in residential organisations are often omitted however within these studies. Most studies are mainly concerned with young employed people. Sexual harassment has been studied in total institutions such as prisons or schools but there are few if, any, mentions of residential homes for older people. Sexual harassment is not usually associated with older people (with dementia) in residential homes sexually harassing staff. Staff themselves would probably not conceive of it as 'sexual harassment'. This may be as a result of how old people are constructed as asexual with ageism to the fore.

3.8.2 Sexuality and long-term care organisations

If most institutions bring into play organisational controls over (sexual) time and space and (sexual) bodies then this arguably applies to residential settings. Private life and sexuality are inevitably important features in residential homes, which spill over into the public domain of organisational life. Parkin (1989) argues that in these homes there is an assumption that sex and work are separate. She notes that there is 'a combination of overt sexual need and expression, yet only an implicit recognition of sexuality through

allocation of space, rotation of duties and informal supervision. There tends to be 'no explicit laid down rules of conduct' (Parkin 1989:113). She notes too the ambivalence amongst staff and managers.

The specific literature on sexuality and long-stay care is mainly North American (Trudel and Dejardins 1992). Most of the studies consist of general articles or non-experimental survey research (Steinke 1997) and many are about staff attitudes and difficulties in addressing issues of sexuality. Sexuality appears marked by staff discomfort with sexuality considered very disturbing for staff (McCartney et al 1987). Ageism and the construction of older people as asexual is also an important factor with management of these issues a concern (Murgatroyd 1998, Litchenberg 1997, Sloane 1993)

The literature notes that whilst staff appear discomforted or dismissive about the sexuality of residents, sexuality appears to be of importance to a considerable number of older residents. Long stay care can mark the end of sexual freedom for older people and people with disability (Aylott 2000, Brown 1989). Many of the issues are around the lack of privacy but also stereotyping. Forming sexual relations can be seen as 'bad behaviour' with tranquillisers often a ready solution.

When addressing the question of what staff say about sex and what types of sexual expression staff find difficult, Kautz et al (1990), reviewing the literature, found a number of reasons why nurses do not meet (sexuality) nursing care standards. These included common myths about older people being asexual with masturbation constructed as harmful and homosexuality seen as abhorrent. Importantly they found that nurses in one study perceived most sexual problems to be too complex to be dealt

with within the realms of nursing practice. This pertains to nurses but may well apply to care workers. Kautz et al (1990:70) from their own study reported that nurses felt they needed written information to help with talking to their patients about sexuality. They argued that this might help to initiate discussion. Staff also needed a role model to help them to overcome their own anxieties and embarrassment. Fineman (1993) argues that embarrassment avoidance can sometimes take on an institutional quality with the discussion of sexual incidents and stories not permitted.

3.9 Sexual stories

One of my research questions is about what staff say about sex. I am interested not only in how they talk about sex but the sexual stories they tell. According to Plummer (1995), stories have provided a means of passing on culture, a means of transmitting values and ideas, 'with gender as a key organising metaphor' (Plummer 1995: 157). Some stories are told and made explicit whilst others remain untold. Following on from Plummer, I am interested in exploring what allows some stories to be told and sanctioned and what negotiations and shifts occur in both the public and personal sphere over time, which facilitates this process. These issues will be addressed further in chapter ten.

3.10 Concluding the literature review

The literature review and the substantive conclusions drawn provide a means of supplying a conceptual background to my research. I argue that the main contribution my research makes to both theory and practice is that it brings together the study of

dementia, sexuality and residential care. The conclusions arrived at from the literature review begin this process.

In chapter one and in the other two chapters, ambiguity is the key theme in the literature. The medicalisation of dementia and the social care constructs of dementia are characterised by ambiguities. The apparently solid construction offered by biomedicine is increasingly being challenged yet it remains influential. I have argued that a reason for this may be the apparent certainties the model offers to both family and professional carers in the understanding of what is an inchoate illness. Other advantages that accrue to professional carers when applying this model are that sexual behaviours may be either dismissed as child-like behaviour occurring in someone old and mentally incompetent and as such not constructed as sexual. Conversely, the behaviour is pathologised and treated with anti-libidinal drugs and constructed as challenging behaviour.

The role that people with dementia appear to play in this biomedical model is that of a 'sick role' with the resultant social control that ensues. The person is seen as vulnerable and thus in need of protection and/or needs treatment. Ethical issues are to the fore but there are difficulties apparent for the person with dementia. Whilst there is an acknowledgement of their vulnerabilities often their competencies are underestimated. This leads to the person not being involved in any decision-making with regard to sexual relationships.

The social care model that includes a person-centred approach emphasises the need to see dementia as a disability. This has limitations when sexuality is a component. In this

model where dementia is seen as a disability, this may paradoxically exclude further people with dementia. Whilst apparently more liberal in terms of taking into account the different aspects that make up a person with dementia, the debates have further marginalised sexuality. Omission is a powerful factor with ageism implicit. The person-centred debates are about seeing the person as an individual adult but according to the literature with only few exceptions, this has not included the construction of the person with dementia as an adult *sexual* being. Sexuality appears not to have been an issue in the person-centred debates, with neglect a main theme to emerge.

From chapter one I conclude that sexuality in dementia care has either been marginalised or pathologised. There are gaps in the literature that suggest there is a need empirically to address the role dementia plays when sexuality is expressed by someone with the illness.

In chapter two where sexuality is explored, the theme of *ambiguity, as with dementia, is* also apparent. Sexuality is a difficult, complex and ambiguous area with definitions and constructions differing over time. Sexuality is not an emotionally free zone. From the literature there appear to be powerful and contradictory emotions involved that are reflected in the polarised language used to talk about sexuality. These factors will, I argue, influence how care workers talk about sex as will the historical social/sexual legacies from the 19th century. The latter appear to retain an influence, particularly in terms of societal gender expectations. There seem to be double standards apparent for men and women. Although both male and female academics have challenged the stereotype of the 'man-on-top' image of the sexually driven man who needs to relieve

his sexual desires, the construct remains powerful, with a more tolerant understanding towards male sexuality often apparent.

This is in contrast to the sexual construction of working class women. Respectability and reputation emerge as key themes with sexual respectability coded in the domestic-feminine ideal. Following on from this I argue that women care workers' sexual reputations may be seen to be at risk if they are viewed to be encouraging sexual attention from male residents in any way. I noted in chapter two that this sexual expression by male residents, even those with a disability of dementia who might not be held sexually responsible, may mean an underreporting of sexual incidents and may be a contributory factor in the neglect of the subject. I contend that this area warrants further empirical study.

Omissions occur throughout the literature on sexuality. The literature appears to be youth focussed. When older people are included it tends to be the younger and fitter of the older age group living in the community and most of the literature is from the US. The literature tends to focus on the potential difficulties for older people continuing to be sexually active with suggestions about how to overcome these problems. Again the medical model is prominent but overall, there is an increasing literature on sexuality and (younger) older people, and the theme that emerges is that continuing to have a sexual relationship is beneficial. The literature on sexuality and dementia, in contrast, is sparser and the debates are focused on the problematic nature of sexual expression. Sexual expression is often constructed as challenging behaviour. The positives and the beneficial aspects that are manifest in the literature on older people and sexuality are omitted. People with dementia appear to be the 'other', mad and child-like, with the

role of dementia seen as a disability that possibly precludes sexuality as a component of their life.

In chapter three when the two substantive areas of sexuality and dementia intersect in long-term care, the themes of ambiguity, gender and omission become more sharply focused, as does the emotional cost for staff in managing this aspect of their work. It is apparent from a mainly North American literature, that staff attitudes, staff lack of training and the overall culture that constructs older people as asexual, acts as a deterrent to a sexual life continuing for older people when they are admitted to long-term care. Sexual needs are seen as less important by staff, but this is not the case from resident reports. It appears easier in residential care to ignore this subject, not to discuss it, than have to deal with it and produce guidelines for staff in what is seen as a problematic and fraught area of work.

The work of Lawler (1991) and Smith (1992) has been focused on nursing and whilst these authors have provided useful insights they have stopped short of an in-depth analysis of sexuality, particularly of older people and dementia. Twigg's (1999) study on bodywork and residential care does not explore sexuality. She argues that there is a need for further theorising in this area of bodywork and this is my intention. By reviewing the literature on the three substantive areas of dementia, sexuality and residential care (see Table 1 and 2) my aim has been to provide insights into an area hitherto little explored. The tables below indicate the data bases searched.

Table 1 Data bases searched
Ageinfo
Medline
Cinahl
British Nursing Index
ASSIA
Psychinfo
Cambridge Journals online
SOSIG
DSDC
Stirling University library

Table 2 Key terms used:
<ul style="list-style-type: none"> ❖ Sex* and, Intimacy and, ❖ Residential/nursing home/dependent living situations/nursing/staff attitudes/harassment/problems ❖ Dementia/Alzheimer's/learning disabilities ❖ Masturbation/abuse/behaviour/history ❖ Sex* and Older/ elderly/- men/women/gay/lesbian/identities

Table 3	Literature reviewed		
	Pre-fieldwork	Fieldwork	Data analysis – writing up
Dates	1980's-1995	1995-1997	1997-2001
Priority	Some priority	Some priority	Main priority

Whilst the review includes current knowledge, the literature drawn upon to inform the research questions was confined to that available at the time (see Table 3) when the empirical component of the research began. This literature was a key component in developing themes and questions to be asked in the postal survey and later in the main study in Glenevis Home. Following on from the literature review, therefore, the aims of my research are to explore empirically why sexuality and dementia has occupied such a marginalised space and to provide some (theoretical) explanations. I want to understand

further the role that dementia plays when sexuality becomes a component of residential care and how this influences care workers' responses. I am interested in exploring empirically what care workers say about sex, the types of sexual expression they find most difficult and how the context of a social work home influences their responses. The major themes of ambiguity, space, gender, ageism and emotions will be used as analytical concepts to assist in this process. The types of sexual expression by people with dementia and the prevalence of such occurrences within the social work residential homes in one area in Scotland will be addressed through a postal survey. Following this, the main part of my study, the analysis of the 'sexual culture' within one social work residential home in Scotland will help in providing useful insights into this neglected area of study and further addressing my research questions.

Chapter 4 Theoretical Voices and Research Parameters

4.1 Introduction

Following on from the literature review, in chapter four I will explore the methodological tools that will enable me to address my research questions. In the literature review I have highlighted the gaps and the ambiguities present in this topic area. Central to my research therefore is a search for an understanding of the ‘meanings’ that the different ‘social actors’ (care workers and other staff) construct around residents expressing sexuality. My epistemological position consequently involves the use of mainly interpretivist methodologies so that later in the research process, I can theorise around the relationships revealed between the different social actors. I explore several theoretical perspectives including postmodern feminist approaches, and (partial) ethnographic and grounded theory methods. I examine each in the light of their traditions and note some of the tensions. I use Goffman (1959, 1961, 1978) and Foucault (1979, 1977) to inform my work. I argue that using this ‘toolbox’ approach helps to address some of the theoretical and methodological challenges when researching the sensitive and ambiguous areas of sexuality, dementia and residential care.

I conclude that the above theoretical frameworks would be limited if used individually, and whilst there are tensions in this eclectic methodological approach, the advantages appear to outweigh the disadvantages and so warrants its use.

4.2 A toolbox approach

Jennifer Mason (1996:14) suggests that one of the initial questions that should be asked in the preliminary research process is ‘What is the intellectual puzzle? What needs to be explained?’ I will add to this, what are the methodological tools needed to ‘break’ the silences surrounding this topic area of dementia and sexuality? In addressing these questions my emphasis, as a feminist, is about listening to the voices of, mainly women, care workers and using them as a fundamental source of knowledge. I use a postmodern feminist approach in data collection and in the analysis of the data.

Feminism is not a single unified approach (Bernard et al 2000). Postmodern feminists, particularly, see no universal category of ‘woman’ rather, there is more a commitment to trying to understand the experiences of different groups. The constructed and gendered nature of sexuality particularly of older women is pertinent. Whilst I theorise about the interactions between the actors involved, reflexively, I attempt to account for ways that I may have imposed my values when interpreting the data. I acknowledge that as a woman, I am also represented in the data. In the next chapter I provide a reflexive account of access, how I influenced and was influenced in turn, by the research process. The notion of reflexivity is useful in exploring vulnerabilities, ambiguity and doubts and is one feminists of all persuasions would support.

The literature review has highlighted the limited research that has been undertaken on the subject of sexuality and dementia necessitating an exploratory approach with the need, I argue, for the use of diverse theoretical approaches. Ethnography, in providing a framework to examine methods and procedures employed by people to construct,

account for, give meaning to and make sense of their world, appears useful when exploring the subject of sexuality. This framework allows an examination of the codes of interaction and the rule systems to which these actors adhere and respond within the residential home (Glenevis) where my research was undertaken.

I borrow some of the concepts from grounded theory whose theoretical underpinnings are those of pragmatism. This allows a generating of inductively based theoretical explanations of processes. Glaser and Strauss (1967) as Agar (1986) notes, show the importance of the emergence and revision of analytical categories in ethnographic work as part of a grounded theory approach. I argue that using a (partial) grounded theory approach allows theoretical space for what has not previously been explored and allows the field to inform the course of theoretical outcomes-the inductive building of theory, which is particularly important in this under-researched area of sexuality and dementia. In the next section I start to explore what discursive frames influence the way workers speak about residents with dementia expressing sexuality.

4.3 Feminist enquiry

My research questions involve the listening to the voices of care workers and hearing what they say about sex. Issues around this area have generally been pushed out of research agendas including those of feminist researchers as noted in my literature review. Feminists, however, with their emphasis on making private knowledges public and seeking to understand these privately based knowledges and personal understandings of women (Edwards and Ribbens 1998) appear pertinent in addressing the silences around the subject area of sexuality and dementia.

There is no distinct feminist methodology so that there are different feminisms with consequent multiple feminist approaches to research methods (Punch 1998). Punch notes the labile nature of the feminist research field but acknowledges a central theme apparent through all feminist approaches. This is to make central women's diverse circumstances and the institutions and frames that influence these situations. The aim is that of realising social justice for women (Punch 1998:141).

There are a number of feminist views on research methodology. Sandra Harding (1991) classically identifies three common categories: feminist empiricism, feminist standpoint and postmodern feminism. Feminist empiricism follows more closely the existing rules and principles of science. Eichler (1988) notes that there are a number of steps that feminist empiricists should avoid in order not to fall into the trap of malestream research. These include androcentric practices, over-generalisation of research solely based on men's experiences, an absence of the explanations of the social and economic influences of gender relations and the use of language double standards, for example, instead of man and wife to use man and woman. The criticisms of Positivist or Normative research methodologies by feminist empiricists May (1993) concludes, are not aimed at the foundations of science but on its practice. Other feminist epistemologies argue that feminist empiricism simply replicates the male norms of scientific enquiry and should equally be challenged.

The basis of standpoint feminism is that of taking the disadvantage of women's exclusion from the public realm by men and turning it into a research advantage. Accessing the literature May states that this argument suggests that the researcher is able to operate from an oppressed position as a woman and a privileged position of a

scholar. A woman's experience thus provides a starting point on which to base research being a 'stranger' in a new social scene. A critique of this feminist standpoint epistemology would be that there are remarkable parallels with realism as the ideas of science have been maintained (May 1993).

Postmodern feminism is the third category of feminist research methodology. All three have at their core the central theme of providing a platform for women's voices. Of the three it is perhaps the latter that I argue offers the most rounded approach. This perspective argues from the position that there is not one single truth yet nevertheless acknowledges bias within this position. Women's experience from a postmodern perspective is influenced by such factors as class, education and sexual orientation. Denzin and Lincoln (1994: 15) note that postmodernism can be described as an intellectual perspective, movement or 'mood' and has different versions and aspects including cultural and aesthetic ones. Essentially the value of postmodern feminist inquiry is in questioning and analysing existing truths. Here there is a challenge to the accepted constructions of power, truth, knowledge and gender that influence and are part of our social arrangements (Wuest 1995:126). A postmodern feminist approach (es) is not however without inherent difficulties and tensions.

4.3.1 Difficulties and tensions in the collection of and interpretation of the data

Whilst a postmodern feminist approach appears to be suited to my research in that it privileges the voices of women care workers, makes public issues around sexuality and care work and acknowledges that there are multiple 'truths' involved, the approach is not without difficulties.

The challenge when carrying out feminist qualitative research is not only retaining research participants voices in the research accounts but in knowing whether the voice being heard is the true or authentic voice (Edwards and Ribbens 1998). There may be different influences that will shape the spoken voice. Ribbens (1998) for example, whilst acknowledging numerous moral voices present in her head with regards to mothering, argues that she does not believe in an internal hegemony that shapes feelings accordingly and represents an internalisation of an external surveillance emanating from powerful bodies of knowledge as Foucault (1981) suggests. In the context of sexuality I would tend to argue otherwise. Whilst Foucault does not allow for agency of the self or gender, class or race to be considered, in the literature review I have argued that the legacy of historical debates on sexuality remains influential. It may influence how care workers respond to residents expressing sexuality, but also how they speak about sex and may include how they speak about sex to me the researcher. The feeling voice being spoken may be an example of deep acting.

4.3.2 The collection of the data - hearing the voices of the research participants

Catania (1999) discussing interviews and human sexuality, notes that the self-presentation that occurs during interviews is presented as an image of the self for others. He suggests that people may do their best to answer truthfully but there may be recall difficulties or coping psychological mechanisms that inhibit or distort presentation. These ideas are taken up by Holloway and Jefferson (2000:3) in their research interviewing respondents about fear of crime. They argue that treating people's own accounts as unproblematic flies in the face of what is known about interaction between people where accounts are less clear-cut and confused. There will be a

contradictory relationship between knowing and telling about themselves. They note that we deal in the interview situation with ambiguous representations of talk, texts, interaction and interpretation. The authors also note that interviewing and the interpretation of the data generally leaves no room for the defended subject, their work echoing Catania's (1999) ideas. Here they refer to the effects of psychological defences against anxieties on people's stories and how these are told (Holloway and Jefferson 2000:3). They note their theoretical starting point constructs both the researched and the researcher as anxious defended subjects. The emphasis of my research is that culture and social rules influence interactions but there seems value presented in the arguments of the above authors. Later in my work I acknowledge reflexively my own anxieties that influenced my responses to some care workers and consequently my interpretation of the data.

Holloway and Jefferson (2000) note that often researchers assume shared meanings to words and that the question asked will be one that is understood by respondents. I made this assumption initially when interviewing the care workers in my study. I asked them to tell me their stories about sexual incidents that had occurred in the residential home. The ambiguity became apparent to me as I checked randomly with several respondents how they had experienced the interview situation in an attempt to monitor the emotions and power relations therein. One care worker reported that she was unsure whether I wanted her to talk about sexual incidents concerning residents or talk about sexual incidents involving staff.

This ambiguity and difficulty was only mentioned by one respondent who was not unduly concerned but reported this as a means of helping me with the research process;

perhaps helping me to clarify my meaning. I duly took note of her comments and thanked her but I did not change my question. She helped to alert me to how this ambiguity could be used to analyse what the care workers prioritised in their story telling. When staff told their stories there were many general stories told with no mention of the names of people involved (see Appendix 2). I argued that this 'vacillation' was used possibly as a need to stay safe through comfortable well-rehearsed stories that 'everybody' knew and talked about. The particular story told, the details of its telling, the points emphasised and the morals drawn, all represent choices made by the storyteller. Such choices are revealing, often more so than the teller of the story suspects (Holloway and Jefferson:35) and may be helpful in broadening understanding of the subject area.

There may be resistance to talking about the potentially embarrassing and difficult subject of sexuality. Care workers may not want their voices heard. Skeggs (1995) found that the young women she researched had a pragmatic approach to feminism and in many cases it was found by these young women to be detrimental to their lives. The same may be the case of providing a platform for care workers in discussing sexuality. As Skeggs (1995:87) notes this is not to say that feminist awareness should be abandoned and, noting the work of Bhavani, argues that the crucial question for all (feminist) researchers to ask is 'does the analysis reinscribe the researched into powerlessness, pathologised, without agency?'

The above discussion highlights some of the tensions for feminist researchers in retaining the integrity of a (postmodern) feminist approach in the data collection process. There are other challenges in the interpretation of the data.

4.3.3 Challenges in the interpretation of the data

Edwards and Ribbens (1998) note the difficulties for researchers in hearing, interpreting and representing the voices of participants, and they include in this the reflexive voice of the researcher. They note the dilemmas in seeking to explore these privately based knowledges, reconstituting them into publicly based knowledge and expertise and by so doing extending the dominance of academic based knowledges intruding into the everyday working lives of, in my research, care workers (Edwards and Ribbens 1998:13). I am very aware of this dilemma in my research on sexuality and dementia. The literature points to the subject being emotionally laden with staff having difficulties in discussing such issues. The above authors address this by arguing that without some kind of collective representation, private knowledges are likely to be more vulnerable and difficult to sustain (Edwards and Ribben 1998:13). Dissemination in practice journals and feedback to staff are also ways of addressing these issues and I did this.

Miller (1998) argues that the data analysis stage remains deeply disempowering to respondents who have little or no control over which particular issues receive the main focus. Mauthner and Doucet (1998) rightly note that whilst we start from the bottom-up, we end by speaking for and about them. It has to be acknowledged that the research process is one of unequals. Rather than simply listening to the voices of respondents the authors suggest that research is a more complex process and what is needed is a balancing act between different standpoints. The standpoints include the participant's voice, the researcher and the theoretical perspectives

There is a need to be aware of the researcher as a moral audience and this is particularly the case in my research involving sexuality. Miller (1998) argues that we can attempt to address the above issues by reflecting on the feminist principles of reflexivity, power relationships, participants' voices and emotions in the research process. Emotions are particularly relevant in my study on sexuality. Mauthner and Doucet (1998) note also that the stories told may contradict feminist understandings and create emotional difficulties. In my study the stories of how some women care workers spoke about and treated other (older) women were sometimes difficult to reconcile with feminist understandings.

As noted earlier, feminism has at its core the emancipatory notion of providing a voice for women. I argue that there needs to be a more pragmatic approach in exploring how power is enacted. Feminism is concerned with women's oppression yet there seems to be a gap in addressing how women themselves may be instrumental in the oppression of other women. Bloom (1996) notes that women's subjectivity is thought to be constantly fragmenting in a patriarchal system where women learn to internalise negative and conflicted ideas about what it is to live as a woman. In the literature, as I note in earlier chapters, feminists have been implicated in ageism by virtue of their avoidance, until recently, of issues concerning older women. The literature also points to how in some circumstances, women workers can oppress older women in their care (Lee-Treweek 1994 and Evers 1981). It is entirely plausible that this may be as a result of the values inherent in our malestream society. But as Kelly (1996) notes, in reference to developing feminist perspectives on abuse and violence by women on women and children, silence on these issues means that we will continue to fail (older) women who

have suffered at the hands of other women. Unless these issues are heeded, the voice of all women, young and old, will not be heard.

Reflexivity is the heart of feminist research. There is a need to reflect on our understanding of our own personal, political and intellectual autobiographies as researchers and make explicit where we are located in relation to our respondents (Mauthner and Doucet: 121). The authors note how little attention has been given by feminists to the issues of reflexivity and power specifically in the data analysis stage of the research. The reason why we choose some ideas rather than others is not always immediately obvious and not easy to articulate in a logical sequential fashion. It is important therefore to locate the researcher's social location and emotional responses to the research participant as this will impact on both the collection of and interpretation of the data. The research process does not end in the fieldwork but power relations continue into the analysis and writing (Mauthner and Doucet 1998). I have endeavoured to be aware of these issues and dilemmas in the analysis of my data.

Following the discussion around the tensions about the use of a postmodern feminist approach, I want to now move on to discuss the methodological tensions that are apparent between my epistemological position and one of the methods used in obtaining my data, specifically the use of a postal survey.

4.4 Feminist theories versus Positivism/Normative research methods – a false dichotomy?

Mason (1996:29) suggests that the researcher when planning and designing the research should consider the purposes of the research and this I have done as detailed in previous chapters. An important consideration that emerged due to the neglect of the subject was that I needed to obtain a ‘view’ of the field. A postal survey seemed a useful way to address some of the ‘what’ questions but there are philosophical tensions that emerge in the use of quantitative methods in feminist research.

Qualitative methods are those usually associated with feminist research. These methods include semi-structured interviewing, ethnography and participant observation. Methods that involve actively listening to what people say are important (Oakley 1999: 155). The face-to-face interview has become in essence the paradigmatic ‘feminist method’ (Kelly et al 1994:34). This route, as the latter authors argue, is seen as one through which inter-subjectivity and non-hierarchical relationships between women researchers and participants can be developed. There are a number of questions raised by this assumption not least of which, and pertinent to my study, is whether all women want to share their experiences with another woman. I argue that the initial ‘distancing’ of a survey may be useful in addressing some the research questions but also allowing participants privacy to explore what some people find a difficult and sensitive area.

Yet some feminists contrast quantitative methods, that is surveys and structured observations, negatively with qualitative methods. Quantitative or Normative research methods are often perceived antagonistically as a paradigm clash with the term

'positivist' often appearing as a 'term of abuse' (Oakley 1999:156). Oakley, discussing the work of Bryman (1988), notes that Positivism as a philosophical position came under attack in the 1950s when Marxism came to the fore. Grounded theory (Glaser and Strauss 1967) developed in the 1960s pointed to the potential mismatch of 'academic' theory and the lives of those being researched, also impacted. Postmodernists have expanded the repertoire of arguments in favour of qualitative approaches. Their scepticism that there is any real world out there waiting to be discovered, has been well-documented (Oakley 1999:160). But as Oakley and others (Kelly et al 1996) note the real war against Positivism was waged by feminist social scientists who observed a pervasive masculine bias across different disciplinary traditions. Feminist social scientists have as a result, since the 1970s, argued for the usefulness of qualitative methods in prioritising the voices of socially disadvantaged groups such as women.

There are difficulties with most orthodoxies and this applies also to feminist orthodoxies. Oakley (1999) for example, takes issue with the dualistic thinking between qualitative and quantitative research methods where one set of dualisms is privileged over another. There can be hegemony inherent in both with, for example, qualitative methods as a dominant epistemological assumption for feminists whose main interest is in hearing the 'silent' (Oakley 1999:161). She argues that the early optimism of using a qualitative paradigm that includes a more reflexive and possibly a less exploitative approach, has not achieved its democratising potential with class imposing its own dimension of inequality, as I noted earlier. Oakley's main point is that criticisms of bad practice should be disentangled from criticisms of methods per se. It is interesting that Oakley, as one of the early feminists, raises the question of how it is possible to know whether the data obtained is what women know rather than what people know? She

notes that ways of knowing are more affected by social position with gender only one aspect.

Kelly et al (1996) argue that women's accounts cannot provide us with everything we need to know. Male dominance and masculinity and men are always part of the research so feminists need to map out these connections. Kelly et al (1996) point out that most of the methods endorsed as 'feminist' that is interviews, ethnography, grounded theory, all have non-feminist origins and histories. The authors suggest that what makes research feminist is not the methods as such but the framework in which they are located and the particular ways in which they are deployed (Kelly et al 1996:46). Kelly et al have increasingly used self-report questionnaires. They note the problem for feminists is not necessarily the use of surveys but the ways in which participants are treated and the care with which we as the researchers represent the lived experience of those participants. So rather than assert the primacy of any method what becomes important is to delineate the topic and scale of the study (Kelly et al 1996). Postmodernism whilst not a method but an approach parallels this thinking.

4.5 The diversity of postmodern approaches

Postmodernism, I argue, contributes to a wider understanding of my subject area. Cheek (1999) discussing postmodern approaches suggests that these should be more than simply esoteric positionings where meanings are understood by a select few. Postmodernism is more characterised by diversities of theories and the value of including these approaches is that of acknowledging reality is plural. The usefulness of postmodernism is that as an approach, it challenges the way that reality has come to be

represented. It has helped me to question ‘what are the taken-for-granted assumptions and understandings in the residential home under study that have shaped practices and the way people work with regard to sexual expression? Also why are some truths excluded and marginalised?’

One of the criticisms levelled at postmodernism’s inherent plurality is its overlapping of other approaches. This has provoked feelings of exasperation but there is value I would argue in examining, as Cheek (1999:385) notes, the incoherences and excavating layers of understanding ‘that make up reality at any point in time’. Cheek discussing the literature argues that postmodernist approaches are not a research method but rather they are about discussing strategies or struggles around different truths. Whilst some have argued that postmodernism can result in a nihilistic approach (Reason 1994), the advantage in using this method has resulted in the making visible the taken-for-granted, the peripheral and the hidden, such as sexuality and dementia.

As I have argued earlier, context is important in addressing my research questions. A (partial) ethnographic approach will be useful as a way of contextualising sexuality and dementia within the culture, customs and social rules of one residential home.

4.6 Feminist ethnographic approaches

Bradley (1999:26) in her ethnography of death notes that it is a topic in which every action appears to be invested with layers of meaning and it is particularly helpful therefore to have an open-ended approach. This is arguably true when studying sexuality. Hammersley and Atkinson (1995:1-10) suggest that ethnography is where

the researcher participates overtly or covertly in people's daily lives for an extended period of time. The primary aim is to describe how the people involved see their own and others' actions, within the context of the particular setting under study. Intrinsic in this approach is the use of participant observation with the concept of culture central. Shared understandings of cultural meanings of the group are important to the understanding of behaviour with the feminist ethnographer set to uncover that meaning.

Within ethnography, Burgess (1984:80) reviewing the literature, observes how there have been major distinctions made with regard to active and passive roles, open and closed roles, and known and unknown participant observers. He notes that whatever the distinctions, the basic typology is that devised by Gold (1958 cited in Burgess 1984) who identifies four ideal typical field roles: the complete participant, the participant-as-observer, the observer-as-participant and the complete observer. My 'roles' moved between those of observer-as-participant and participant-as-observer although as Burgess (1984:85) argues, research roles are constantly negotiated and renegotiated with different informants throughout the research project. For example, in my role as observer-as-participant whilst undertaking fieldwork, particularly with the staff or in the back stage area of the home, I had to negotiate and renegotiate my role. It was only when I began the participant-as-observer role and began interviewing, that there occurred a gradual winning of staff confidence and acceptance of my role as researcher.

In my study I use only a partial ethnographic approach in that the time I spent in the residential home was under a year and was therefore not prolonged and repetitive. Also whether I truly became part of the setting as suggested in the literature (Punch 1998), is

open to speculation. At the end of my fieldwork I became more a marginal member than fully integrated as ethnographers such as Whyte (1955) reported to have become.

Eclectic methods characterise ethnography. They also characterise my overall research methodological design. I have argued for the use of postmodern feminist ethnographic approach as relevant to my obtaining data that will help to address my research questions. I go on now to explore my use of grounded theory as another method used.

4.7 A partial grounded theory approach

Grounded theory is a method, a research strategy, whose purpose is to generate theory from the data, with the word 'grounded' pertaining to theory being grounded in the data (Punch 1998: 163). It is suggested that a small amount of data be collected, then analysed and theories developed inductively from the data before moving on to the collection of the second set of data. This proceeds until theoretical saturation occurs. The reason for using grounded theory is that no satisfactory theory or theories are available on the topic. As noted in my literature review this resonates with the subject area dementia and sexuality which makes this method pertinent for my study as part of an eclectic methodological approach.

One of the difficulties is that whilst there has been little theorising on sexuality and dementia, and as such there is relevance in using this approach, there are difficulties. The approach seems to assume a 'blank sheet' approach where the researcher is urged to go into the field, gather data and theorise from the data and then look at the literature as another source of data. What this approach seems not to acknowledge as in my case,

is the experiential knowledge of years of working in the area of sexuality and dementia, that is brought to the research process.

Whilst I used aspects of this approach, I did not analyse and then theorise as I proceeded, rather I collected the data during my fieldwork and then, analysed and theorised from the data as a whole. I did use the literature in a grounded theory way, using the literature as a source of data but whilst I identified emergent themes from the literature these were not used as an a-priori framework for analysis. Appendix 3 provides an example of how the analysis of the raw data was undertaken. The findings were grounded in the data and then comparisons made with the literature. This has continued throughout the research process.

I use therefore a partial grounded theory approach (Glaser and Stauss 1967). This theoretical approach, while not developed to give a voice to, or to gain further knowledge for women, addresses the person's subjective interpretation of their social experience as a source of knowledge. There are certain parallels with feminist epistemological positions. For example, feminists mainly argue that women are experts about their experience and so subjective experience can be used as a source of knowledge. In grounded theory and similarly in feminism, the context of knowledge formation is the social processes that occur within social structures. These are fundamental. Other similarities occur between grounded theory and feminist positions. Whilst the searching for the meaning of the lived experience is important, it is the exploring what participants *construct as their own reality* that is prioritised. Feminists consider that the boundaries between the public, the political and the personal are artificial constructs. Equally in grounded theory, the very nature of the development of

theory from field studies suggests that any theory so grounded in the personal and practical experience of participants cannot be dichotomous with it (Wuest 1995).

4.8 A selective use of Foucault and Goffman

4.8.1 Foucault

It is not my intention to undertake a Foucauldian analysis of the data but I argue that some of his ideas in terms of power are useful in informing my work. Foucault was anarchic, a loose sociological canon, claiming no adherence to any sociological positioning. He noted that all his books were little tool boxes open to people to use this or that idea as a screwdriver or spanner, to short-circuit systems of power (Patton 1979: 115 cited in Mathias and Street 1999). It is this disruption of truths that allows for ambiguity and doubt to be acknowledged and explored and it is these ideas, I argue, that align him with postmodernism.

Foucault's notion about the micropolitics of everyday life is pertinent. It can be argued that this focus on the micropolitics shifts the importance away from the larger patterns of power or domination (Manias and Street 2000). Foucault's ideas however are helpful in my work in examining the local power relations of individual's social and cultural practices in the residential home under study. Following on from Foucault, I theorise about the silence surrounding the issues of people with dementia expressing sexuality in residential care. This may be a result of malestream practices, but it may also be that of workers' expressed resistance. If I, as a feminist researcher, aim to provide a space for the marginalised voices of this predominantly working class group of women, I need to

consider that there may be resistances to this 'empowerment' and that there are discursive practices in different settings.

4.8.2 Goffman

An initial reading of Goffman (1978, 1961, 1959) may suggest a rejection of conventional hierarchies and if not an anarchist on the scale of Foucault, a rebel, rebelling against modern society. As noted by Gouldner (1970), in Goffman's theory of dramaturgy, professionals, that is psychiatrists, are manipulated by patients, doubt is cast between cynicism and sincerity and the stage becomes a model for understanding life. There are ambiguities however in Goffman's theory in that whilst apparently rebelling, there is an accommodation made by him to existing power arrangements. Goffman's is a sociology of co-presence, and it is what happens when people are in each other's presence that is important (Gouldner 1970: 379). Life is episodic and lived in narrow interpersonal circumferences. It is as Gouldner notes, ahistoric, coming alive only within the fluid transient encounter. Individuals are seen as less the products of the system than individuals working the system, but not rebels against this system (Gouldner 1970).

For Goffman (1959) social life is systematically regarded as an elaborate form of drama in which as in the theatre people are not viewed as trying to do something but trying to be something. There is a striving to project a convincing image of self to others. Critics of Goffman note that he does not explain why some selves rather than others are selected by the person and why the other images of the projected self are accepted or rejected. Which selves are more gratifying in their consequences to self and others and

whether this shapes their selection and acceptance, is not addressed. Nor does he clarify the manner in which power and wealth provide resources that affect the capacity to project a self successfully (Gouldner 1970).

There are ambiguities and tensions in Goffman's work but it is these ambiguities, Gouldner (1970) suggests, that lead to a selective use of Goffman's ideas, which has resonances with Foucault's toolbox approach discussed above. I am interested, following from on this, in Goffman's ideas of back stage and front stage regions and how behaviour is managed in these different areas by staff. I am interested in the ideas of impression management that follow from his theories, when observing, participating in discussions with and interviewing care workers in the residential home in my study.

4.9 Conclusions

I conclude this chapter by reiterating that the methodological tools I will be using to uncover and make visible areas of life in residential homes that have hitherto been left unexplored (ethnographically) in the UK. My approach is that of a postmodern feminist, using ethnographic and grounded theory methods in both the collection and in the analysis of the data. I have argued that the above theoretical frameworks would be limited used individually. Whilst there are tensions, there appear to be sufficient commonalities. I will conclude this section by noting the work of Mauthner and Doucet (1998) who ask how within the qualitative analysis process, the respondents' voices and perspectives are kept alive whilst at the same time recognising the researcher's role in shaping the research process and product. How I have transformed people's private

lives and stories into public categories, theories and texts, will now be discussed in the next chapter that addresses the methods I have used.

Chapter 5 The Different Methods Used to Obtain the Data

5.1 Introduction

In this chapter I discuss my use of multiple methods to obtain data based on the methodological arguments posited in the last chapter; that is a postmodern feminist approach using (partial) ethnographic and grounded theory methods. The methods used include a postal survey sent to 28 managers of social work residential homes in one region in Scotland. From this survey I chose one home that I have named Glenevis, as a case study and used semi-structured in-depth interviews, observation and participant observation to obtain the data. Documents written by staff, the incident book, case notes and the Kardex, were accessed and the data from the workshop that I facilitated for the workers from Glenevis was also included. This chapter therefore, developing the themes from the literature, addresses the methods of data collection, and provides a reflexive account of access. I conclude chapter five by discussing how the findings from the postal questionnaire, the literature and the research questions have influenced the way the following empirical chapters are structured. Often writing a PhD is seen as akin to writing a story. I use the analogy of Goffman's (1959) dramaturgy, conceptualising these chapters as a screenplay with the themes and research questions helping to inform the next act or chapter.

5.2 A reflexive account – from practitioner to researcher

Throughout my thesis I have used the personal pronoun. I argue as others (Seibold 2000:148) have argued, that the emphasis on exploring the research encounter and the research process as the lived experience, supports the use of the personal pronoun in feminist writings. It is part of being reflexive which entails not dividing (parts of the researcher) self from the whole (Rose and Webb 1998:556). It is necessary therefore to analyse the effect of (my) self within the research process as I am, as Webb (1992) notes, an integral aspect of the generation of knowledge. My epistemology needs therefore to be foregrounded. It needs to precede the discussion on data collection as it inevitably shapes and determines what I 'see'. However it is not a case of applying a superficial layer of self to the research process, the skill is to consider reflexively how this self impacts on how the data is seen, gathered and analysed (Behar 1996), and this I have attempted to do.

In the literature review I noted that the dearth of research on the subject of sexuality may be due in part to the negative effects that accrue from researching such a sensitive subject as sexuality on the researcher's career. In my case, being a member of staff at the University of Stirling undertaking a PhD part time, I could choose a topic area. Funding was not an issue.

This may change as I apply for research funding to undertake research in areas that have emerged from my PhD. I am also a middle-aged woman so according to the literature I am thus least likely to be stigmatised, but age has been of some significance.

A PhD is about learning how to do research, often embarked on when a person is young, following on from their first or second degree course. Scheurich (1997) discusses the term positionality which encompasses such factors such as class (which may or not change over the course of a lifetime), gender and race. All these interact, influence, constrain and limit productions of knowledge. My background was that of nursing and health visiting. I was embarking on this research as a middle-aged woman. I brought expertise gained over many years working in the field of dementia, working with people with dementia, their carers and staff. While endeavouring to be open to new ideas, being human I inevitably brought fixed ideas, biases and 'baggage' collected over years of practice. Working within an academic setting has been a relatively recent experience. Respectability is rarely recognised as an issue by those who 'are positioned with it, who are normalised by it and who do not have to prove it' (Skeggs 1997:1). As with the working class women in Skeggs' study, (academic) respectability has been an issue in my evolution from practitioner to researcher.

There has to an extent been in the earlier stages of this research, an element of the (naive) 'heroine' researcher. The idea of uncovering that which was being ignored or worse, hidden, was high on my research agenda. From a feminist perspective, I considered it important to give voice to (mainly) women care workers for whom the expression of sexuality by people with dementia seemed to be an issue. The occupational and cultural position of (mainly) women care workers is, and has remained, the central focus but what has evolved during the data collection is an increasing awareness of the subtleties and complexities involved in the issues around sexuality. Some care workers were reluctant to give voice to this subject and this was

their right. As the literature suggests this is for some, an embarrassing and difficult area to discuss.

Part of reflexive practice is considering how I may have influenced the data collection process. For example, when I reflected on some of the care workers' silences on this subject and their initial coolness towards my research, I considered my own situation. I have a number of good women friends and my work situation involves working with many women in the caring professions. I generally have a good rapport with these groups and individual women. But I do not continually observe or ask them what must at times be very difficult and awkward questions, about a subject that they do not generally want to discuss

In terms of being able to empathise with these women and their circumstances, I was helped by a situation that occurred outwith the research process, during the data analysis period. I was on holiday with my husband on a small island off the coast of Ireland where we became engaged in conversation with an old man, aged 75, waiting on the quayside. We spoke for some time then as the old man was taking his leave of us he said, "Well it's been lovely to talk with you" and as he said this he deftly but deliberately, touched my left breast with his hand, then took his leave. I experienced the same feelings of disbelief reported by several care workers when this had happened to them in Glenevis. The incident was out of context and inappropriate. The way I managed the situation was to laugh after my initial shock. It happened so swiftly that I had difficulty believing it had happened at all until my husband remarked "Did I see what I thought I saw?" I confirmed this and we walked along the beach shaking our heads at the practised way it had been accomplished and laughing at the sheer

effrontery of the man. It was good to have someone to share this experience with and to be able to laugh about it.

In some ways although I would not have chosen for it to have happened, it felt like serendipity. It was a very tangible way of being able to connect emotionally with the feelings being expressed by the care workers. Here was I, an experienced practitioner, with considerable knowledge in this area, who regularly provides training on the subject, experiencing many of the emotions reported by the care workers. I was fortunate to have someone to share this experience with and to defuse the situation by laughing and talking about it, but this is not necessarily the case for all care workers in their work situation. Many of the care workers have received little training on how to manage such situations.

So undertaking a doctoral study was for me both about foregrounding a subject which had remained hidden and about being part of what Robson (1993) refers to as *real world enquiry* which seeks to contribute to developing policy and practice. My interest was in exploring how the research could inform and add to the body of academic knowledge and how it could ultimately inform practice. It was also about my own professional development. As Hammersley and Atkinson (1983) suggest, most researchers have limited time and resources in which to carry out research. I was no exception, working full-time at the University. Where possible, I managed to take one day per week, when work allowed, and every Sunday to devote to the study. Annual leave and accumulative study days allowed concentrated periods of observation and time for analysis. The development, piloting, completion and analysis of the postal questionnaire took a year. The fieldwork occurred between July and April the following

two years. In total, the thesis undertaken on a part-time basis, has taken seven plus years to complete (see Table 1).

Time frame for study

1994-1995	Beginning of literature search, development of questionnaire
1995-1996	Questionnaire accepted, access granted and questionnaires sent to managers of 28 social work residential homes in one region in Scotland
1996-1997	Analysis of data and writing of chapter six of the thesis
1997-1998	Commencement of fieldwork in Glenevis home
1998-2001	Transcribing of interview tapes, analysis of data, writing of the remaining chapters of thesis
2002	Submission of thesis (February)

5.3 Methods timetable

Table 1

- | |
|--|
| 1. Postal survey |
| 2. Case study in Glenevis social work residential home using multiple methods including: |
| ❖ Observation |
| ❖ Participant observation |
| ❖ Semi-structured in-depth interviews |
| ❖ Accessing working documents in the home |
| ❖ Data from training workshop provided for staff in Glenevis |

Table 1 outlines the methods used in the data collection. Using a grounded theory approach in the analysis enabled the development of an increased understanding of the issues, addressing the research questions I posited and developing further research questions.

5.4 The postal survey

The compilation, piloting and analysis of the postal survey will be discussed in depth in the next chapter so only a brief outline will be given here. Of a sample of 28 residential homes in the survey, 24 of the managers from the homes responded. For the purpose of analysis these homes were then divided into traditional design and small-scale living homes. The small-scale living-type homes comprised several units with a population of eight residents to a unit and usually had a small sitting room and dining area with attempts made to provide a more domestic and homely environment. Some of these homes also have a large communal sitting area. The traditional homes were characterised by all the sitting areas being communal and usually large. Initially I intended to undertake research into both types of homes. Acknowledging the advice from my supervisors, I decided that the data from the postal questionnaire and those from Glenevis, a case study in one home and the data from a workshop on sexuality for care workers from the home, would be sufficient for my doctoral study.

My choice of Glenevis Home as a case study was therefore informed from data on the small-scale homes only. Of the small-scale homes (10), I discarded those homes that reported no sexual expression or those that reported only few incidents (4). In retrospect it might have been useful to have researched the one home that reported no sexual expression and the home that reported many incidents. My concern at that time was with choosing a home that occupied the 'middle ground'. Whilst Punch (1998) notes that generalisation should not necessarily be the objective of all research, choosing a home without either the extreme of no reported incidents or multiple cases, might, I hypothesised, provide a means of developing propositions. I would assess from the data whether concepts that emerge from this 'average' home might be applicable and

transferable to other residential homes. As Punch notes this does not mean that the one case study, for example, Glenevis, would prove generalisability. Rather, it might mean putting forward concepts that could be tested in further research where generalisability might be tentatively suggested. Punch (1998) refers to this as analytical or theory connected or, theory generalisation.

From the six remaining small-scale homes, one was discarded, as it had no male residents with dementia. Glenevis was chosen from the remaining five homes as it represented the average, having 14 male residents. Three of the male residents in the home were reported to have dementia. The home, at the time of report, had a female manager. In my original design of researching two homes, my intention was to have both a female and male manager to look at possible similarities and differences in management practice. If the staff in Glenevis chose not to take part in the research then a second home was identified that had 10 male residents and also a female manager.

5.5 Key concepts arising from the analysis of the postal survey

In the methodology chapter I noted that from a feminist perspective that the data analysis stage can be viewed as deeply disempowering to respondents (Miller 1998). I have where possible endeavoured to avoid this but inevitably at the data analysis stage the choice of which data will be used, is mine. These issues may be less apparent in the analysis of the postal survey (s) but care is still needed as I note when using the Holmes et al (1994) questionnaire, developed in the US and discussed in more depth later in chapter six, in my first pilot study.

In some ways the process of piloting of the Holmes et al (1994) questionnaire (see Appendix 4) by the use of focus groups, may be said to have been disempowering in that participants in the first group would have chosen not to have taken part (see chapter six). The points made by the mainly women participants however were helpful in guiding and informing the final questionnaire and if not empowering them, empowered me the researcher, to ask pertinent questions in the final draft of the questionnaire (see Appendix 1). I thanked the participants verbally after the focus group and then by letter so this may have helped to make the situation more empowering. I argue that research is seldom neutral and that it may be that by stimulated discussion in the focus group, issues around sexual expression by residents will be explored further in the homes where the piloting was undertaken.

Through data collection and the piloting of several versions of the questionnaire I developed the final questionnaire. I will discuss this process in more depth in the next chapter. In terms of analysis, I was also interested in narrative and the meanings of the sexual stories told by workers. I also wanted to know the types of sexual expression and which they found difficult. In the final questionnaire I began this process by providing a narrative, a vignette on which managers could comment. The analysis of narratives and meaning were further developed in the main study.

As noted earlier, the reason for my undertaking a postal survey was to attempt to gain a view of the field. The findings informed my conceptual thinking for the next stage of the research. Through my own experiential knowledge and particularly during the piloting of the questionnaire, and finally through the analysis of the findings, several important analytical concepts emerged and these included, space, gender, different

sexual identities, the impact of dementia and the emotion work involved when sexuality is expressed by residents. Ambiguity, as in the literature, emerged as a theme to develop.

In the questionnaire the issue of private and public space is explored. This includes not only geographic space and sexual expression, but also the inner space of the managers. Space I argue is a key concept and needs further exploration. I was interested in the difference between the managers' public and private feelings and response to sexual expression by residents (with dementia), and this was what I have explored in the main study with regard to staff. One of my research questions is 'what are the types of sexual expression that workers find difficult' so resident-to-resident sexual expression, but also resident-staff sexual expression was explored. Mainly the vignettes in the questionnaire concerned resident-to-resident sexual expression. The findings from the literature and also from the questionnaire point to resident-staff sexual expression being a type of sexual expression that staff found difficult and one that warrants further exploration in the main study. The questionnaire was a useful if limited way of exploring the field. I have discussed the limitations of survey use earlier but specifically, the questionnaire was about managers' views and not those of care workers. Managers' views add to the overall story but I needed to explore how care workers responded to sexual expression by residents with dementia and this I was able to do in the case study.

5.6 Glenevis Home as a case study

As noted above, my fieldwork was undertaken in Glenevis, a social work residential home for older people. Punch (1998:150-153) notes the value of using a case study is that of gaining an understanding of the case in-depth, in its natural setting by recognising its complexities. A case study uses context and multiple sources of evidence to provide a detailed account. Epistemologically, my purpose in using a case study approach has been to obtain a deeper understanding of the needs and feelings of the care workers who have participated in the study and to provide a means of hearing their voices.

There are limitations to the use of case study in that it occurs in a particular place, at a particular time, and under particular circumstances. Each case study is unique yet it is also in some respects similar to other cases. Although case studies have been a source of criticism, properly conducted, particularly in situations where knowledge is shallow, fragmentary and incomplete, they have a valuable contribution to make (Punch 1998: 155). Yin (1984:258) emphasises that a case study investigates, within a real-life context, a contemporary phenomenon where the boundaries between phenomenon and context are not clearly defined. The limitations of any survey approach as discussed earlier can arguably be addressed by the use of a case study and this combination will provide a greater depth to the subject. This is crucial when trying to gain an understanding of this sensitive area of sexuality and dementia. The sensitive nature of the subject was highlighted when obtaining initial access to the home.

5.7 A reflexive account of access

I was advised by influential friends in the social work department that it was essential that I apply for access as soon as possible as this was a time-consuming process and would probably take several months. In line with the protocol of the social work region in which the research was to take place, I submitted a research proposal to the senior research and development officer. The research proposal proved difficult as I had not completed a literature review or fully thought out my research questions. This was *real world research* as Robson (1993) continually refers to it. There was not ever going to be a 'right' time. There was need to be adaptable and flexible in the research process and this was a case in point. I submitted my proposal and quickly obtained an interview with the senior research officer for the department and there followed a nine-month process of discussions, interviews, the submitting of pilot questionnaires until finally access was granted. I discuss this process in some depth in chapter six.

Following the development of the postal survey questionnaire and the dissemination of the findings to staff and management (see chapter six), I was granted access. After nine months of experiencing frustration, anger and despair that I would ever be granted access, I was finally given permission to undertake the research. The choice of Glenevis as noted above, was informed by the findings from the questionnaire. It was intimated to me that staff had been informed and that they were expecting me to contact them soon

Whilst the formal agreement for access had been approved by social work management, access throughout the research process, as others have noted (Robson 1993), has to be

constantly negotiated. I therefore needed to persuade the unit manager and staff of Glenevis Home that my research was both legitimate and potentially helpful, and would not be too disruptive of their time. I have endeavoured throughout the research process to share information and this was how I began. I made arrangements to speak to the staff group about the research but prior to the meeting there was an opportunity for a talk with the managers. Corinne, one of the depute managers, asked, preceded by a nervous embarrassed laugh, "*Why are we the chosen ones?*" (*Fieldwork observations*). What I did not know at the time was that there had been issues around sexuality with regard to staff. As a result of this, one member of staff had left and there were still unresolved issues in the home. In retrospect the nervousness was understandable and my study must have seemed to be linked and thus associated with higher management concerns. I was able to an extent to offer some reassurance but it was uncanny that on two subsequent occasions when I had to contact the home following my fieldwork there had been highly charged issues around sexuality occurring in the home.

I explained about my research and how and in what way, I had chosen this home. The previous manager of Glenevis who had completed the questionnaire, had not it seemed involved the staff in any way. They were not aware of the initial research and the subsequent report of the findings sent out to all the managers in the study. I promised to send them a copy of the report (which I did) and reported that Glenevis had been chosen as a result of the findings of the questionnaire. The findings suggested that the home was somewhere in the middle of the homes involved in the survey in terms of reported sexual expression by residents. My explanation was aimed at reassuring them that the choice was based on my research findings and not for any other reasons. When I asked

how they felt about this the depute replied “*That’s okay we just wondered*” (*Fieldwork observations*).

Robson (1993) discussing access, notes how a researcher may be seen as a tool of management. Certainly despite a real attempt at friendliness and openness, my initial presence seemed to have a less than positive effect. Whilst acknowledging that research into sensitive subjects may involve particular kinds of costs including guilt, embarrassment and shame (Rezetti and Lee 1993), I found this cool reception slightly troubling. It contrasted sharply with the often warm reception I receive doing consultancy and development work. This coolness continued amongst some of the staff for the first few months. The term ‘emotional labour’ coined by Hochschild (1983) assumed a personal meaning. It was a hard transitional period. I had to accept a loss of status. I moved from being an experienced practitioner (although some of the skills remained useful) to an inexperienced researcher. It was all too easy in the early stages of the research to internalise many of the difficulties involved as my lack of experience.

Throughout the course of the research I have endeavoured to give as much information as possible to participants. The first meeting with the staff group I viewed as part of that process. I wanted to give them information and provide a forum for them to ask questions. The manager had informed the staff briefly of my research. He introduced me to the group and said he would leave it to me. When I began some stared, some avoided eye contact whilst others smiled. The atmosphere was generally friendly, if curious. I had prepared a handout outlining my name and contact address and telephone number. It described the aims of my research and how I hoped to work with them. It stressed confidentiality and anonymity. I suggested to staff that we might read through

the handout together and that they might want to ask questions. I felt quite nervous but so too I felt, did some of the staff, and this was later confirmed during some of the interviews.

In retrospect I should have informed staff that whilst confidentiality and anonymity would be respected, I would disseminate my research findings at conferences and ultimately in peer review and practice journals for the benefit of workers generally. Also I should have, as Seibold (2000) insisted with the participants of her study, ask them to sign the consent form after their interview.

Seibold offers some interesting comments discussing issues around informed consent. She asks whether asking participants to sign their consent before being interviewed is really ethical or is actually informed consent. She found, and this was reflected in my experience in Glenevis, that in some interviews highly personal information was revealed. I will discuss this later in the chapter. I did inform the staff that the data would be part of my PhD but at the time my preoccupation was with gaining acceptance and admission. Staff were informed that participation was voluntary and that anyone could withdraw at any time but I did not include this statement on the written sheet nor did I obtain written consent from individual staff. Hammersley and Atkinson (1983) note that there are positives in not always providing a full account of intentions at the beginning of the research. They argue that once people have learned to trust that the researcher is able to be discreet, maintain anonymity and confidentiality, permission is more likely to be given.

A difficulty experienced, particularly in the initial phases of the research process, was the difference in relationship between the 'me' the development worker and women workers, and 'me' the researcher. I was in their territory and there were times when they would decide when and if, they would talk and provide me with information. There were many 'resistances' apparent particularly whilst undertaking the observation part of the fieldwork. I made detailed memos throughout the fieldwork, in part to deal with the emotional labour inherent in the research process as noted by Lee-Treweek and Linkogle (2000) and others. I noted how I seemed to be typified by staff and residents and considered reflexively how my own feelings, biases, behaviour and approach influenced and impacted on these relationships. Towards the completion of the fieldwork observations, relations improved but Marion, a care worker, provided an indication of how I might have been viewed by some-that is as someone 'watching' and taking note. The tenor was jocular but barbed.

As we went into the sitting room she said to the residents "This is Carole she is here to check up on you (and her?) I'd better not shout at you" (Fieldwork observations)

I did not achieve the close relationship with many of the workers that I had hoped but this was perhaps an unrealistic aim. Later, the relationship between myself some of the careworkers became warm and friendly but I was never really accorded the status of 'the same'. My feelings of being an 'outsider' in the early stages of the fieldwork I took to be due to the sensitive nature of the research topic. Arguably my class and educational status also impacted as Skeggs (1995) and others have noted. Simply being a woman interviewing other women was not sufficient to gain an entry. I had to work

hard at gaining acceptance and winning confidences and this was achieved partly through the social intimacy achieved during some of the interviews but also by disengaging with the managers of the home.

My relationship with the managers of the home had evolved through a different pathway to that of the care workers. My work at the Dementia Services Development Centre (DSDC) involves working with management at unit level. I am at ease interacting with this group of mainly women managers. At the beginning of the fieldwork in Glenevis Home there was an initial apathy to my involvement but the second contact with management was different. I noted:

I had arranged with the unit manager to return this morning. He was in his office and seemed a bit more friendly. He made me a cup of coffee. My role today quickly became that of confidante-fellow manager. (Fieldwork observations)

I also noted that he had only recently come into post and that he was “*to all intents and purposes in not dissimilar position to me*”. It became all too easy for me to go into the manager’s office when I came to the home and I had to be continually aware that I was in a research role and not that of a development worker. I felt at ease and the managers were welcoming. I realised that if I wanted to enter the world of the care workers I needed to exit the world of the managers. The care workers went into the office for the report or for other formal purposes. Their world was out with the office. What emerged during the data collection was that there were a whole set of different ‘others’ from the care workers’ perspective, including the managers and the residents. At this early stage

I explained to several managers that I would not come into the office that I would spend my time with the care workers. The impact of this was eventually to lead to my being viewed as the 'other' by management as the data supports for example,

When I arrived Corinne the depute manager was on duty and was a bit short with me scarcely smiling, quite cool in fact... I thought well I have achieved what I set out to do by being accepted by the care workers but the price is that I can't be accepted by both sides. (Fieldwork Observations)

It might have been the case that Corinne was preoccupied with other matters and her 'coolness' had nothing to do with my presence. Her mood varied. In some situations when Corinne gave the report to staff, she addressed a lot of the comments to me, as a possible fellow-worker. But over a period of time, for example, when I was found sitting and talking with care workers in their backstage area by a manager as documented in my field notes, I began to feel a definite change in my relationship with them as I noted during the observation process.

5.8 Observations – the process of being the observer-participant

In ethnography, as Punch (1998) notes the primary aim in the least obtrusive way, is to find out what is happening and make cultural interpretations as the data evolves. I discussed in the last chapter that my research 'role' moved between that of the participant observer to that of the observer-participant role. My roles were known to the staff but nevertheless had to be negotiated and renegotiated over the research period.

My observations recorded over a period of four months were informed by the findings from the questionnaire, but also loosely followed the dramaturgy, the unsystematic observations described by Goffman (1959). This method is a means of observing how people interact, form relationships and particularly how they construct self-presentations and carry them off. I began using direct observation to observe the staff in the different units within the home. Robson (1993) notes the advantages and disadvantages of observation. The advantages include its directness as a technique with both linguistic and non-linguistic aspects to the data that serve to compliment information from other methods, for example surveys. Robson acknowledges that observation is not trouble free or an easy option. The Hawthorne effect is ever present so logically it is difficult to know what the behaviour might have been like if it had not been observed. Observation is also time-consuming. It can be daunting in its very openness.

Personal appearance is as Hammersley and Atkinson (1983) argues, a salient consideration. I dressed simply in a long skirt, jumper and waistcoat-informally and wore a 'bum-belt' to contain pen and small notepad. As with Liebow (1967: 255-56), I adopted the dress and some of the speech of the care workers without 'looking silly or feeling uncomfortable'. But as Sue Scott (personal communication 1997) notes 'no matter what you say or write to people, they will see you through their own prism and there is no control over that'. Several residents however asked if I was a social worker, a manager.

Ralph, a resident asked 'Was I from the office upstairs? Was I a social worker?' (Participant observation)

Following from this, I did not aspire to become exactly like the care workers, but rather as Hammersley and Atkinson (1983:79) noted, to give off the message that I sought to be accepted as a marginal member. Although my approach was ostensibly informal, I had different ideas that I wanted to pursue. This I did both by observation and cross-checking this with data from the questionnaire, care staff report during the interviews and during the periods of participant observation and later using the literature as data.

5.9 Observations – the emotions and difficulties of not being ‘one of them’

Armed with some sensitising concepts from my own practice, a short literature review and the findings from the questionnaire, I began the observational phase of the fieldwork. The rationale was that I would ‘immerse’ myself in the ‘field’ in true anthropological style. There were difficulties however that I did not anticipate in my research design. The first was that the home was on three floors with each floor divided into two units of eight residents with a long corridor dividing each area. The staffing ratio was for most of time 1:16 residents. This resulted in staff becoming ‘lost’. There were so many places for them to disappear, so many residents potentially for them to attend, and so many sitting rooms (6) for me to observe that observation became problematic. From these observations, I began to develop spatial issues, both geographic and metaphorical, as an important analytical concept. How, for example, staff distanced themselves or not from both me, as a researcher and the residents.

I learned later during interview situations, that a number of the staff felt distinctly uncomfortable being ‘observed’ and endeavoured to keep out of view. I decided that I

would mainly observe the (3) sitting rooms where staff tended to work because of the residents' dependencies. In some of the other sitting rooms, the residents, after finishing their afternoon tea would go down to the common sitting area (the forum) downstairs so in effect those sitting rooms were empty for several hours. I also attended the 'bar night', which occurred twice weekly and was held in the forum (see Appendix 5 for the plan of the home). This afforded a further opportunity to observe staff and resident interactions. I noted that what was imperative if I was going to achieve any detailed observations of staff, was that I would need to go into the staff room, the 'backstage' area during meal breaks so that I could be amongst, talk to, observe and get to know these workers. The staff room was a relatively new acquisition. Previously the care workers and domestics had sat in the forum at the front door where visitors could observe staff sitting and smoking. Staff reported that they had no privacy or time away from residents so this new staff room was seen as a great benefit. The staff room was on the top floor of the home (in the sleep-over flat) with a small kitchen available for staff use.

When I went into the staff sitting room initially some of the care workers were very friendly and we talked about different subjects. I noted "*Jenny had appeared quite quiet at the initial meeting(when I first met staff) but here backstage she was very chatty. There was no sense of shyness on either side. We talked woman-to-woman. It felt very comfortable*" (Fieldwork observations). Two other staff came into the room and again I deliberately refrained from talking about sexuality at this time so that I could try and establish a woman-to-woman relationship. There were some of the care workers whom I refer to later as the 'toughies', who were very cool at my being in the staff room and began to influence those who had initially been friendly towards me.

The coolness continued and to some extent it was understandable. This was their private space and I was there and however friendly I tried to be, I remained a researcher, someone listening and taking a mental note. Whilst I rationalised and could understand, I experienced great feelings of rejection of somehow not 'doing it' right. This emotional experience of the research process, was very threatening generally as others have noted (Lee-Treweek and Linkogle 2000) but specifically to my sense of (research) self. I learned however from the experience and to an extent, used it to an advantage.

Once I realised the situation, I tried several strategies. I found that if I was doing something, for example, eating, then this somehow legitimised my being there. So whether I had already eaten or not I endeavoured to take fruit or a sandwich. My tactics of not talking and patiently waiting to be included in the conversation, firstly by eye contact and then being verbally included, seemed to be the best approach. This probably put me 'in my place' in the pecking order-'speak when you are spoken to'. Paradoxically, although at first emotionally demanding in that I experienced feelings of failure, I persevered and gradually came to find the situation of benefit. By not talking I could listen, be on the periphery and be able mentally to take note. Difficulties occurred towards the middle of the fieldwork when the care workers became friendly and immediately involved me in the conversation at tea breaks. I had then a double act to perform. I had to take part in the conversation whilst at the same time make a mental note of issues. Hammersley and Atkinson (1983) note that a fieldworker's willingness to stay and learn can often overcome hostilities. To a large extent I found this to be the case.

The tea breaks were supposed to take half an hour but often extended to 45 minutes so provided a means of gathering rich data. I considered it essential following these

sessions, to make a mental note and then as quickly as possible go to the toilet and write headings and cryptic notes. I contracted (with myself) that after each visit and period of observation, I would write up these notes within 24 hours. I wrote memos and reflexive notes, with other possible areas to explore highlighted. I was in a crude way generating theory, using a grounded theory approach. I obtained some interesting data from observing staff in this 'backstage' area but it had costs and conditions attached. The observation period did provide some insights into how power is enacted within this home including resistances by care workers in their co-operation (or not) with my research. The care workers response to me changed when I began to interview them and undertake participant observation. In retrospect, although I have obtained useful data during the observational periods, it might have been less stressful for the care workers and myself if I had begun the fieldwork with interviewing and participant observation.

5.10 Participant observation and diaries

In terms of acceptance, my situation changed considerably when I began the participant observation and interview phase of the research following the four months of fieldwork observations described above. I began this phase by starting work at the home at 8am Monday which was hand-over time. I had wondered previously where staff put their coats and valuables. I had previously just put my coat over a chair in the staff room but where to place my belongings safely was now an issue as I had on my person a valuable portable tape recorder borrowed from a colleague. I asked Chris the manager where I could hang my coat.

He said in the locker room and that there was a locker and key for my use. This was interesting. Why I wondered had I not been given a key before? Was I seen as only now starting to 'work'? I felt that I had been admitted to the (another) back stage region and there I hung up my coat and used the locker. I was a worker. This feeling was further enhanced when I sat down to join the staff group in the forum where Chris asked if I wanted a drink if so, help myself. There was then a chorus from the three careworkers about not getting served here, that you have to get things yourself. It was said in a jocular, friendly manner-rather welcoming, different to how the situation had been in the backstage area. Why I wondered? What had changed? (Participant observation)

I felt that my identity and status had somehow changed. My aim was to be a mutant worker so that I might enter the world of the care workers. Did this small (spatial and identity) shift signify acceptance? In part yes, but throughout the process was fluid and one that had to be constantly negotiated. I had accrued study days and annual leave time so designed an intensive period of fieldwork. I met with staff at (2pm) the hand-over time, when most of the staff would be there in the back-stage area. The group was generally friendly and accepting of what I proposed. In line with what had been discussed at the initial meeting, I reiterated to the care workers that I would work with them for three-hour periods.

I tentatively proposed that on each of the three floors of the home, I would work with the different staff for the allotted time but the time periods would cover the 24 hours. For example, I would cover 8am-11am on one day and then 11am -2pm on the next day, and so on. Within the three-hour period I would interview that member of staff with whom I

would be working. I would work two nights to meet and work with the night staff. Hammersley and Atkinson (1983) warn that long periods of fieldwork are quite unmanageable and result in data of poor quality. The three-hour periods therefore suited the staff and allowed me to type up my notes and observations immediately but I did not manage to transcribe the tapes until the intensive part of the fieldwork was completed. I wrote to each member of staff in the first week reiterating the date and time agreed for me to work with them. I also sent each a small diary.

The idea of staff recording their thoughts and ideas in a diary that I proposed at the initial staff meeting, I took from Robson (1993). I asked staff to keep a note for a week prior to the interview and my working with them, of any (sexual) incidents that perhaps made them feel uncomfortable and any incidents of sexual expression with which they had been involved. I would not in any future application of diaries use the word 'uncomfortable' as it assumes a negative response to sexual expression. My idea was to prime staff to think and consider aspects of sexual expression so we could discuss these at the interview. I informed staff that I would not ask to see the diaries, that they would simply be an aide-memoir. It might be that I was not clear enough beforehand of what exactly I wanted. It might be that staff were simply not interested or they felt uncomfortable, but this method of data collection was not successful. Gladys, one of the older care workers who had been at the home over ten years when asked whether she had used the diary tapped the side of her forehead with her finger and said "*I dinnae need to do that*". In response I asked "*It's all in your head?*" and she replied "*Yeah*". Others felt that they had nothing to record. The only person to use the diary and write extensively on his thoughts and feelings was an activities worker who had an engineering degree. There may be

possible issues around literacy that affected the care workers' response to the use of diaries.

Whilst this three-hour work period with staff worked in general, what it did not allow for was that people would 'forget' I was to interview them. They would change shift with another worker, or they were off sick. As time was limited to undertake this research and I also had to travel a considerable distance to this home often through wintry conditions, I did use these factors to interview some care workers who were not scheduled for interview that day. It put some staff under pressure. They could have refused but no one did. This potentially negative situation proved advantageous. One care worker, Morag, who had been more than uncivil to me at times, was 'caught' in this situation as another care worker was off sick. The others in the staff group who had already participated, argued strongly (for me) that they had been interviewed and that it was 'her turn'.

Feminists, as noted earlier, place emphasis on power relations and also the emotions during the interview situation as this will influence the dynamic of the interview. I found Morag a very difficult, brittle and antagonistic woman. I needed to undertake emotional labour in her company and during the interview. She had been one of the care workers who had contributed to there being a rather negative atmosphere in the staff room. When we were left alone she said angrily "*What exactly do you want then?*" I had no time to get my tape recorder so I simply asked her questions and wrote her replies on my note pad. I intuitively knew that if I asked her to go the interviewing room she would have refused and I was interested to hear her views. Although very reluctant she appeared not to be too traumatised by the interview but said to the others afterwards "*I really got into that (the interview)*". She was certainly much friendlier towards me following the interview and

appeared easier in her manner. This caused me to consider that her behaviour may be due mainly to her feeling threatened by the subject and her participation in the research. Holloway and Jefferson's (2000) work and the defended subject had resonance here. I had to acknowledge that I too had been a 'defended' subject and due to the anxieties of the research situation, feeling a (research) novice, I had forgotten some of the skills I had learned through years of practice.

For example, I provide input into different staff groups in my practice work at the DSDC and teach that when family carers are aggressive and/or complaining it is usually because they are stressed and anxious. It is helpful if staff can try not to take this behaviour personally. Yet I failed to see Morag's hostile behaviour as due to (probable) anxiety about the topic area, instead I took it as personal. I worked with her for the remainder of the three-hour period and documented observations and looked at, as with all the workers, the difference and/or convergence, of what she said in interview and what she did in practice and cross referenced this with other care workers' reports. The interview situation had marked an improvement in our relationship with both of us possibly gaining insights about each other.

Participant observation involved working with each care worker in the home in carrying out such tasks as making beds, setting the tables, emptying commodes, tidying bedrooms, making cups of tea and helping at bar night, serving drinks to residents. Some staff were quite protective of me, for example the night staff. who insisted that they would empty the commodes. Other staff used me to go for towels or a glass. One care assistant asked me to give a resident her tablets. She gave me the tablets in the sitting room to take to the resident in her bed. Being a nurse I felt uncomfortable with

this as I did not see the medication chart nor did the care worker say the name of the tablets. I managed this situation by saying that there were two residents of that name and I was not sure which was to get the tablets. The care worker just sighed and came with me and together we woke the resident and gave her the tablets. I might have been reduced in the care worker's perception with regard to usefulness as a worker, but I felt easier in my own mind.

5.11 Semi-structured interviews

The interview schedule (Appendix 6) for care workers was designed to help address some of my research questions, for example, the role of dementia and what staff said about sex.

The work of Catania (1999) as noted earlier discusses impression management sometimes used by respondents who may distort their self-disclosures to maintain or enhance their social image. Whilst Catania's focus is that of how younger people talk about their own sexuality in an interview situation and the literature related to this issue, there may be useful points that could be applied to my study. Accessing the literature Catania notes that impression management was significantly correlated with reports of sexual behaviour. Following on from this, I needed to consider if impression management would be used by participants in my study when they spoke about how they managed incidents that involved sexual expression by residents. I argue later that this appeared to be the case with some care workers.

The semi-structured in-depth interviews varied in length from 30 minutes to 2 hours. All the careworkers (17), three domestics, the unit manager, three depute managers and the area manager were interviewed. Not included were residents although I did talk to them on an informal basis and also the family carers. The unit managers offered a room along the corridor from the staff room for the interviews. It was used occasionally by the managers but was generally free. It was small and quiet with a desk and two chairs. There was a small table lamp used to create an intimate and friendly atmosphere during the interviews. Returning to Seibold's (2000) work, with regard to participants revealing highly personal information, the interview setting needs some further comment. This intimate, friendly atmosphere thus created helped to put the participants at their ease, but there is the inherent risk of them becoming too relaxed and possibly disclosing too much. One worker discussed at some length his own sexuality. Although he stated at the close of the interview that the session had been interesting and had provided an opportunity to discuss issues, following the interview he appeared unable to meet my eye whenever I saw him at the home. Ethical and methodological issues raise the question of knowledge construction and control (Seibold 2000). I decided it was not appropriate to use his personal disclosures when writing about my findings.

I endeavoured to be as sensitive and non-hierarchical in approach as possible in the interview situations. It was not until I was to interview one of the managers that I realised that I automatically sat in what was the manager's chair and indicated the other chair to the care worker/domestic. It was only then that I realised how I had taken for granted the power relations. Consequently and following that interview with the manager, I offered either seat to the care workers but each time they did not take the

manager's chair. Perhaps it was not an issue for them but it did cause me to be more aware.

Some of the staff were initially apprehensive when they came into the room, for example, they sat very rigidly in the chair and looked nervous and uncomfortable. My approach with all the staff was to firstly ask if they objected to the interview being recorded. I explained that it was to help me remember and that they could at any time stop the interview. I also mentioned that once I had transcribed the tapes they could have a copy of their interview. No one so far has asked for a transcript. Not all staff agreed to having the interview taped so I made detailed notes in these situations. On one occasion I did not switch the microphone on and consequently did not record the interview. I always checked the tape following the interview so was able to make as detailed notes as possible. I noted staff's behaviour and comment before and after the interview and these notes and the participant observation notes were written up within 24 hours. I began by asking staff why and when they had started to work in the home. I asked them gently to talk about themselves for some time before broaching the subject of sexuality. Each situation varied. Some staff immediately raised the subject of sexuality, others spent a lot of time talking in what seemed to me an attempt to avoid the topic. In these situations I had to balance the time factor between how long staff could be away from their work situation and giving them time to feel comfortable.

Hammersley and Atkinson (1983) argue that the distinctiveness of the interview setting must not be exaggerated. It is a resource in that the 'artificiality' of the interview in taking people out of the settings in which they usually work allows for an understanding of how they may behave in other circumstances. For some staff in my study, the

interview allowed an exploration of issues pertaining to sexuality that they had never had chance to reflect on. Others reported it was an opportunity to share their feelings about the (sexual) situations in the home in which they had been involved with residents. One member of staff as noted above, used it as an opportunity to discuss aspects of his own sexuality. It offered privacy and time-out from the work situation. One point of interest that emerged was that often some care workers would imply that I would obtain better information from certain other care staff “ *Wait ‘til you speak to Gladys*”. This ‘tip’ proved to be disappointing in some respects, but fascinating in others. Some of the quieter members of staff appeared more reflective than the louder and ‘tougher’ care workers, producing valuable insights.

5.12 Documents

There are various documents that the staff use in the home to write about residents. At the end of each shift the care worker on each flat documents anything of significance in the Kardex. There was also the incident book where incidents out of the norm were documented. Of particular interest in exploring in the documents was how dementia was typified (see Appendix 7). It was apparent as the fieldwork progressed that dementia was constructed and to some extent defined by what was written in the case notes. How occurrences of sexual expression were documented, or not, was also of interest. Case notes, the Kardex and the critical incident book were accessed. I delayed seeking permission to access these documentary sources until late in the research process. The managers granted permission and I accessed these sources on night duty.

5.13 Sexuality training workshop for care workers

Two years after the completion of the data collection, I facilitated a workshop on sexuality for staff as a means of saying thank-you to them. Whilst I had given them boxes of chocolates, I felt I wanted to give more to thank them for their kindness. It was not until I had made the suggestion that I realised that the idea of a training workshop may please managers more than the care workers. To an extent this was the case. The managers were very enthusiastic about the idea but none of the managers attended the workshop. The data from the fieldwork suggested that an exploration of sexuality for both managers and the care workers might have been useful for all concerned. The whole tenor of the workshop pointed to the care workers appearing to have enjoyed the day and that they seemed to gain from attending (see Appendix 8).

Six care workers and one domestic attended the workshop. One of the care workers was new to the home. Anne, Cathy, Jenny, Fiona, Beth, the new care worker and Rhona attended. It seems that Gladys and Sheila and another two of the older care workers were reported as saying that they knew enough about sexuality without having to attend a workshop. Fred, the male care worker who had been subjected to verbal sexual expression by a male resident and who had been very distressed, did not attend. Morag reported that she had not realised the date of the workshop and so had made other arrangements. The night staff did not attend and several care workers had left since I had completed my data collection.

I was interested to see the care workers again. I had music playing and as I usually do in all the workshops I facilitate, endeavoured to put people at their ease. My work as

Senior Fieldworker at the DSDC involves a development role. I have facilitated numerous workshops on sexuality and dementia. The workshops are what are referred to here and in other parts of the thesis.

Jenny was immediately at ease and did a lot of talking, Cathy and Beth were more reticent throughout. I explained to them why I was facilitating this workshop and thanked them again for their input. I reiterated that I would provide anyone with a transcription of their own interview. I also asked if I could use any of the information that came out of the workshop for my research, reassuring them about anonymity. All readily agreed to this. I explained the course of my research that I had begun the analysis but this was now interrupted by a literature review.

The training programme for the day was about looking at what was meant by sexuality. It was also about exploring sexuality and old age, using visualisation. The latter involved first getting the care workers to relax and then asking them gently to visualise themselves as old and when they had done this what kind of sexual intimate relationship they would envisage and like for themselves. I then went on to explore with them what was different about dementia. They were then asked to cartoon case studies we looked at the impact on family carers and how this might affect their sexual relationship with the person. Their comments were noted on a flip chart.

For this group the definition of sexuality included: comfort and company, attraction, feelings, liking each other, chemistry in that *'someone you could look at and go wow!'* with alcohol playing a part in the relaxing of inhibitions. *'An alright body'* was a

component. One young care worker particularly, saw this as important in order to feel attractive and to engender these feelings in others. *'A nice bum', 'hormones'* in terms of how this might influence how you feel sexually during the menstrual cycle. One care worker noted that she would like *'more sex at certain times of the month'*. *'Smell, like a man's aftershave', 'the style the clothes you wore'*, were important. This led on to a discussion about *'kinky boots'* and some reminiscence *'remember we used to call them shagging boots'*. Personality and humour were seen as crucial. Sexuality might mean that between women and men or between women and women or men and men. Of interest here was the informal and colloquial terms used for sex for example, *'shagging boots'* which reflects Ruth's (1987) work on language and sexuality. For me it was gratifying that these workers felt at ease enough to discuss sexuality so frankly and openly. I acknowledge that this was a day 'away' for the women and possibly afforded them the freedom to speak openly. They were also a group, and groups have a different dynamic from a one-to-one interview situation. They also knew me.

The opening exercise of the workshop was useful and interesting on several counts. Away from the work situation and even though it was two years since we had last met, there remained a sense of friendliness and ease apparent in most of these women care workers. They were thoughtful, humorous and appeared not very inhibited by this sensitive subject of sexuality. But this was a discussion about sexuality in general. There was also group support and they had chosen to be at the workshop.

In the discussion about imagining themselves as old and sexual, some reported that they could not imagine being old, and although in their fifties, still felt as if they were eighteen which resonates with Featherstone and Hepworth's (1993) work and the mask

of ageing. Some who were young, could only assume that inside you would feel the same person, whether you were eighteen or eighty. The ageing body was discussed. A younger care worker expressed disgust at the idea of the ageing body taking clothes off in front of a partner if your body was old and sagging. She said she herself would stop sexual relations when her body became unattractive. She said *'The idea of taking your clothes off with someone new at 60!'* The care workers reported that *'If you had the same partner, then they would be used to your body'* (some of the care workers spoke with regret of how even at this time of their life they did not have a partner).

They discussed how physically being old, they probably would not be able to have a sex life. There would not be the same amount of energy *'I suppose you could take your time more'* reported one worker. Sexuality was, they perceived, more about looking for comfort, *'More a kiss and a cuddle'*. *'All the feelings would be there in terms of the need to feel good about yourself'*, one reported. There was a consensus that the idea of being touched and loved rather than the sexual act was the important thing. One reiterated what one of the residents had said - *'You're better with a fish supper' (than having sex)*. The idea of sexuality and older people being associated more with a kiss and a cuddle than sexual intercourse or other aspects of sexual expression has been a theme noted throughout my data. Sexual behaviour and the needs associated with old age, as constructed by care workers, had parallels with the needs of children which has implications in how they respond to residents who express sexual intent.

It was generally assumed that sexual needs would diminish and disappear with age. Also discussed was how it was difficult for some workers to accept different sexualities with some feeling threatened by same sex approaches. The care workers tended to agree

when one worker reported that she '*...felt sick if a lesbian touched me, nothing against them, but it is unnatural. Just kenning makes me uncomfortable*'. Only one worker disagreed and reported that she did not feel threatened as she did not feel attracted to them (lesbians) which was interesting. An interpretation of this comment suggests that other care workers might feel threatened as they felt an attraction and thus might be tempted.

For these workers, dementia was about loss of memory and residents being disorientated. The workers also reported that residents with dementia lose their inhibitions and their thinking becomes distorted so that they lose their ability to make a judgement. Their personality can change also. Some further discussion revealed that residents speak to staff about sexual issues but some staff do not tend speak to residents about these issues. They all agreed that there was a certain amount of humour and banter involved in the care of residents. When asked to discuss case studies, the stories that were told were those that had already been told to me in the interview situations. Both case studies discussed had happened a number of years previously and thus were safely located in the past. Both were about resident-to-resident sexual expression. This was arguably a safe area to discuss, and once again gender was implicated. In each story told it was a male resident taking the sexual initiative.

This data has been included because it adds incrementally to the data gathered. The triangulation of data will now be discussed further.

5.14 Triangulation and its application in analysis of the data

In chapter four I noted that a single theoretical framework was insufficient to address the complexities of my research. In the section following on from this, I argue the need for mixed methods; a need to triangulate the data to allow for a necessary rigorous interpretation.

Denzin (1970) has advocated triangulation, or multiple measures, in the analysis of the same empirical events. It has been advocated as a means of allowing this integration to be achieved. It is seen as a means of reducing bias and increasing ‘validity’ or perhaps more realistically, producing a fuller picture not necessarily a more objective one (Fielding and Fielding 1986). While multiple data sources reduce the risk of reliance on a single data source and provide a basis for triangulation (Silverman 1993), this approach is not unproblematic. It is time-consuming and there is a risk of conflicting results adding confusion and uncertainty. Different methods are likely to produce different accounts. Both Silverman (1985) and Blaikie (1991) argue forcibly against using triangulation to adjudicate between accounts. Rather the value of using triangulation in my study is how it contributes to an incremental understanding and providing answers to my research questions.

There is value in Blaikie’s argument of using different methods sequentially so that each in turn provides a basis for the development of succeeding stages of the research process. This is how triangulation has been defined and used in my study. This is what Robson (1993:290-1) refers to as ‘the Complimentary Purposes’ model. Here the methods are deliberately interactive and used to help enhance interpretability. Rather

than being a 'prisoner to a particular method or technique' a multi-method enquiry provides scope to explore, as in this study, unknown territory (Robson 1993: 291).

But to read this chapter linearly as a journey, or story unfolding, is a simulacrum - an imitation of something that never existed (Scheurich 1997: 3). It has been more a patchwork quilt of reading, thinking, rejecting, grabbing, considering and piecing together, in essence it has been an ongoing dynamic. The notion of a narrative structure, a pre-set pattern, belies the contradictory, heterological nature of this research. There is a story but there are plots and sub-plots that have influenced the process, including that of the methodology and methods adopted.

5.15 The delimiting, disentangling and ordering of the data

In chapter four I noted that my epistemological position involves the use of mainly interpretivist methodologies so that later in the research process, I can theorise around relationships. I also needed within this process to address my research questions and yet where possible retain the voices of the (mainly) women care workers.

As noted the main principle of grounded theory is that theory is grounded in the data and that the literature should be a later addition to the process and seen as additional data for analysis (Punch 1998). Rather than a strict adherence to grounded theory principles, I did not undertake an in-depth literature review initially due to the pressure by social work management for me to begin the study in Glenevis. As I began analysing the data the literature was a later source of data and help in the analysis. Coding of the observational data, the interview data and the participant observation data began

following the completion of fieldwork. I later added the data from the workshop provided for the care workers.

The analysis and writing activity was a fragmentary process. The delaying of the analysis until after the collection of the data does not adhere to a grounded theory approach but this was the reality for me in terms of time available. I did develop the semi-structured questionnaire in situ as new concepts presented, but the idea of data collection, analysis, data collection until saturation occurred was not a possibility. But I was guided by grounded theory concepts in the data analysis. The codes derived from each interview, such as dress and routine, in the early coding were mainly descriptive but were compared between participants. In Appendix 3, I provide in a diagrammatic example of some of the data beginning with the analysis of staff profiles, including gender, age, and whether they have cared for relatives. I was interested in the intersection of family and professional sets of knowledges. My findings pointed to care workers having little training in dementia care but probably most had experience in caring for relatives young and/or old. I wanted to explore whether these knowledges would impact on how care workers responded to (child-like) people with dementia expressing sexuality.

Following on from this in the analysis (see Appendix 3) in level 2 and level 3 coding, I developed the concept of space further in terms of boundaries. Care workers spoke of becoming close to residents and this was a key theme to emerge in providing job satisfaction for the care workers. I then began coding how care workers used touch or not, comparing observational data and staff interview reports. The concept of key worker in a mini-family relationship was explored and the tensions that arose in this

familial discourse when sexual expression towards the care worker was manifested, were analysed.

Ethnography sets out to understand how within a culture and its rules and procedures, people make sense of their lives. I was interested in exploring the structure and the routine within the home and how this might impact on the expression of sexuality by residents. During the observation and participant periods of fieldwork I looked at such factors as how care workers related to management and again I used the concept of closeness in the analysis. In the staff questionnaire I asked workers who they would share their (sexual) stories with, and would this include managers? I explored who is in authority and how this is invested and subverted. This became an interesting issue in terms of how power was enacted. Managers on the whole, reported being liberal in their thinking in terms of resident sexual expression compared to some care workers. In the analysis I again looked at space and observed that managers often due to administrative work only leave the office occasionally during a shift. The care workers in contrast, spend most of the shift out of the office doing bodywork and as a consequence having contact with family carers who may complain if their relative is found to be involved sexually with another resident. The managers and care workers seem at times to inhabit different (spatial) worlds.

From a feminist perspective gender was an issue. If care work is seen as 'women's work' and emotions/emotion work is gendered according to the literature, the position/identity of men care workers is worthy of attention. The main inference from the literature is that sexual expression by residents is reported to be mainly enacted by male residents. I wanted to explore this in the analysis looking at how care workers

responded to both male and female residents' with dementia sexual expression, by analysing the staffs' sexual stories.

A key concept that emerged was how people were typified in this process, including women residents with dementia. I was interested in how staff perceive residents' sexual identities but also the identities that staff project of themselves. I wanted to pursue issues of conformity and group membership. What others have reported (Hockey 1990, Lee Treweek 1994) is that various categories emerge amongst staff groups. This became apparent both in the 'backstage' area and during the interview situation in Glenevis. A group to emerge were those I referred to as the 'toughies'. These were the women care workers who tended to be loud-spoken and brash in their statements and who often 'held court' in the backstage area that was the staff sitting room. I was interested in the stories told by the 'toughies' and their response to the interview situation, and how this compared and contrasted with the other quieter care workers' responses. My interest was in what helps to define and express cultural group identity. Which of the care staff was admitted or excluded, in this process and what were the rules for membership (of different groups), was of interest.

I wanted to look at the interpretative work that occurred when staff labelled behaviour as sexual and the role dementia plays in this process. As the analysis continued in earnest, patterns began to emerge, helped by the compilation of matrices (see Appendix 2 on the categorisation of sexual stories). I returned to the concept of space once more and noted that physical closeness is not usually found outside marital or sexual relationship yet it exists between care staff and residents. Following on from the literature I was interested

in how staff share intimate contact in the bedroom and bathroom and in terms of boundaries, how this is managed.

The literature pointed to dementia being an ambiguous and fluid concept so how staff constructed dementia and how they accessed the information that would help in this construction, was pertinent. Punch (1998) discussing the Miles and Huberman's (1994) framework for data analysis, outlines the need for data reduction through editing, segmenting and summarising.. This is the process I developed in ordering the issues listed above. In terms of editing, although I had considerable data on family carers, I made a decision earlier on in the analysis, that my focus would be that of care workers. I had considerable data on my talks with residents when I spent long periods initially sitting with them during the observational periods. This too I discarded. I made numerous diagrams of the data to display my thinking, for example, the development of space as a key analytical concept and also ambiguity, with the eventual emergence of level 3 coding of themes. Numerous drafts of each chapter were written that helped in making links between categories and this was aided by continued communication with the literature.

The quotes used in the empirical chapters were those chosen as a result of systematic analysis, that is, coding and selection of the data. They were used as a typical example or because they were unusual.

5.16 Conclusions

In chapters four and five, developing the themes from the literature, I have explored the theoretical basis of and the methods of data collection and provided a reflexive account of access. These chapters provide the methodological underpinnings for the next chapter where I explore the findings from both the pilot and those of the final questionnaire, using the literature by interpreting the findings with reference to other work. In the last section of this chapter I address how I have endeavoured to obtain some order from the data and point to the complexities and difficulties involved in the process. Important themes have emerged that have helped to guide how the empirical chapters have been structured.

The empirical chapters begin in chapter six with the first stage of work undertaken and provide an analysis of the findings of the postal questionnaire with this providing a view of the field, albeit from the managers' perspective. I was interested to find out the types of sexual expression that occur in residential homes and the types of sexual expression by residents that staff find difficult. Specifically, the role dementia plays begins to be addressed in this chapter. Major themes to emerge, ones where further exploration was indicated, were those of ambiguity, gender and space. The theme of spatiality is taken up and explored further in the next chapter (chapter seven). The findings from the postal survey have been useful in providing indicators of themes that warrant further study.

The private and public spaces in Glenevis are explored with regard to sexual expression by residents with dementia. Spatiality, that is the social space that the home occupies in

the community and the physical spaces within the home, are considered, noting the ambiguities. Earlier I use the analogy and liken the thesis to a story that has a beginning and end but with various sub plots. It may also, using the dramaturgy of Goffman, be seen as a drama or stage play. Using the latter analogy, in chapter seven I set the scene where the sexual interactions take place. One of my research questions looks at how context influences staff response and this is explored further. Following on from this, in the next chapter (chapter eight) the social actors are brought onto the stage and I look at how they interact within the home, the social organisation and how sexual expression by residents with dementia impacts. In this chapter I begin to address my research question of how care workers respond to sexual expression by residents and add to the discussion of how context influences staff response.

Space and ambiguity are once more important in chapter nine. Care workers report that becoming close to residents (chapter eight) is an important component of job satisfaction. This is explored further in chapter nine allowing a more in-depth focus on this particular area. I note the difficulties for staff between the key worker and key resident when resident-to-staff sexual expression becomes a component of these mock-kin situations, when boundaries become blurred.. How care workers manage these sexual situations is analysed and explored, as is the research question that addresses the types of sexual expression that staff found most difficult. In chapter ten I analyse the other sexual stories told and explore further the themes that include gender, ambiguity, homosexuality and ageism. I address here as in other chapters, the role that dementia plays in staff response and what staff say about sex. Following on from this in the final empirical chapter (chapter eleven), I conclude by exploring the emotions, the emotion work and labour for staff when resident sexual expression becomes a component of care

work. The emphasis in the first of the empirical chapters (chapter six) was that of obtaining an overall view of the field. In the final chapter, moving full circle, I conclude with the particular, that of exploring the space in the care workers' heads and addressing the emotions and emotion work involved when sexual expression becomes part of care work.

Referring back to Goffman's ideas of dramaturgy, I argue that throughout the empirical chapters, dementia in effect becomes one of the 'actors' in the screenplay. Sometimes dementia is centre stage whereas at other times it becomes more peripheral. The latter is particularly the case when there is resident-to-staff sexual expression. In these situations, unless the person is profoundly affected by dementia, dementia appears not to play a key role in care workers' response. Dementia therefore appears highly ambiguous and situated. I will throughout note the talk of dementia wherever it occurs. I begin to explore these and other issues in the next chapter using the findings from the postal questionnaire.

Chapter 6 The Postal Survey

6.1 Introduction

In chapters four and five, I discussed in some detail the theoretical arguments in support of a multi-method approach to obtain my data. Following on from this in chapter six, I discuss the first stage of the empirical work undertaken, the postal survey. The purpose of the survey is to obtain a 'view of the field', to find out the types of sexual expression by residents and how staff manage these. I explore the findings from the piloting of the Holmes et al (1994) questionnaire (Appendix 4) and note how this was used to inform the development of my own questionnaire (see Appendix 1) used in the postal survey carried out in one region in Scotland. I note that the findings not only provided a 'view of the field' but also allowed me to locate a residential home in which to undertake the main part of my research. The findings also led to the development of themes that informed the next stage of the empirical work. I discuss how the findings from the survey begin to address some of my research questions including the kind of sexual expression staff find difficult, how they respond to sexual expression by residents, and the role dementia plays in staff's response. Further research questions were also generated from the findings for consideration in the main study.

As noted the reason for undertaking a postal survey was to obtain a view of the field so I was interested in exploring the main types of sexual expression and the ones that staff find difficult. The two most difficult types of behaviour reported by the managers appear to be resident-to-staff sexual expression, so this is discussed in some depth.

I conclude that the role dementia plays is not always clear from the findings but appears to be less ambiguous when the resident who has dementia is a woman. The emphasis then in terms of the managers' response is around care and protection. There appears to be some 'halo' effect reported by managers with regard to taking a liberal view of sexual expression by this group of residents, but this needs further exploration. Whether care workers share this view of people with dementia requires additional work. Key emergent themes are ambiguity, gender and space.

Gender from a feminist perspective is central to the discussion. The data from my postal survey suggests that gender permeates the data and is a major theme to emerge regardless of whether dementia is present or not. Men residents appear to be the main actors both in resident-to-staff and resident-to-resident sexual expression, and also in solo sexual expression. Sexual expression by women residents is poorly represented in the data. This resonates with the findings from the literature. I note what the realities of gender really are, or appear to be for staff, based on the managers' reports.

There is ambiguity apparent in the findings when the question of how context may affect managers' response is addressed. Whilst the public expression of sexuality by residents is seen as inappropriate, sexual expression in private although reported to be more suitable by most managers, particularly with regard to masturbation, can be viewed as unsafe in certain circumstances. The theme of space consequently appears to warrant further exploration and this is undertaken in chapter seven.

6.2 The piloting of the Holmes et al (1994) questionnaire

Douglas Holmes, administrator (Research and Development) of the Hebrew Home for the Aged, Riverdale, New York was involved in a workshop with me on sexuality and dementia at the Alzheimer's Disease International Conference in Toronto 1993. Holmes and his colleagues had undertaken a large study on the subject of sexuality with regard to residents in nursing homes in the United States that involved the use of their postal questionnaire (see Appendix 4). Following the workshop, Douglas Holmes kindly gave permission for me to use their questionnaire in my preliminary research. Whilst it did not fully address my research questions, I found it useful as a basis on which to develop my own questionnaire later piloted and then used in the postal survey. Table 1 outlines the process involved in piloting the Holmes et al (1994) questionnaire.

Table 1 Piloting the Holmes et al questionnaire
1. Six social work residential homes recruited outwith the main research area
2. The managers of four of the homes sent the questionnaire for comment
3. Met with a mixed group of staff and a depute manager from home five
4. Met with a mixed group of mainly managers in home six

As noted in table 1 there were six homes involved in the pilot of Holmes et al questionnaire. I used the managers of six residential homes as an easily accessed and convenient sample group. Managers from four of the homes involved were sent the questionnaire for comment. I met with staff from the other two participating homes to go through the questionnaire with them on a face-face basis. The latter two homes provided a richer source data than the sparse details obtained from the other four managers who for the most part simply completed the questionnaire with little comment. This made me aware of some of the limitations of using a postal survey during this initial piloting. Useful data would be obtained, but the postal survey would simply be a platform to lead on to a

more in-depth look at the issues, using qualitative methods. The Holmes et al questionnaire was very structured and allowed little space for open questions to be asked. I noted this and both provided space and asked open questions in my own questionnaire to give a greater opportunity for respondents to have their voice heard.

6.3 The process of piloting the Holmes et al (1994) questionnaire

Before beginning to pilot the Holmes et al questionnaire permission was sought from the relevant social work service managers who readily granted access. This ease of access was due to good personal and inter-departmental relations between the managers and the DSDC. All six managers of the chosen residential homes were contacted by phone prior to sending out the questionnaire. Two were completely taken aback by the request and a little embarrassed, but agreed to participate. The other four agreed, reporting that sexuality and dementia was an issue in their particular home.

As noted above, following the initial telephone call, the managers from homes one to four were sent a questionnaire with an accompanying letter. Managers from the other two homes involved agreed to meet and, together with their staff group, to complete the questionnaire. The postal questionnaires from the four homes involved were returned within six weeks. I asked two of the managers to complete the questionnaire personally, and two to complete the questionnaire with their staff group. I asked this to obtain the widest possible information including both the managers' and some care staffs' perspectives. In fact, all four completed the questionnaires with their staff group. This highlighted the lack of control the researcher has as to who completes the questionnaire

once it is sent to a participant. The report from this group of four was minimal. These managers reported a sense of frustration as to the lack of subtlety of the Holmes et al questionnaire in eliciting complex issues. Also some of the questions in the questionnaire were ambiguous and it did not address issues around gender. This was noted also by the two staff groups from the remaining two participating homes.

The richest source of data was the discussions with the two remaining managers and their staff groups. It became apparent from the discussions that not only was the Holmes et al (1994) questionnaire flawed, it was also limited in its scope for my purposes. Meeting with these two staff groups enabled the eliciting of information with regard to the development of my final questionnaire. It also provided invaluable experience for the later part of the research in helping to sensitise me to the variation in staff response to the research situation.

6.4 Home five - the first pilot focus group

I give an account of the two focus pilot groups as this provides a reflexive view of the fieldwork process.

The staff group from home five was a mix in terms of sex and age. The manager had agreed to participate when contacted by phone but on the arranged day was unable to attend. A rather vague excuse was given by the depute manager, who also stated that she too was unable to attend. I speculated whether her initial reluctance was due to her discomfort around the area of sexuality or whether she had indeed another pressing

appointment. However after some discussion with the depute manager describing what would be entailed, she began to be interested and stated that perhaps her appointment could be delayed. This raised the question 'If this is how the managers react how will the staff respond?'

The group of staff (10) comprising two men and eight women care workers, convened for the purpose of this research, seemed both embarrassed and awkward when I went into the room. They were, according to the depute manager, given a choice to attend the session but the atmosphere in the room spoke more of coercion than voluntary attendance. There was no setting of the scene with cups of tea to help to facilitate the proceedings; rather a group of uncomfortable looking staff waiting to begin. I gave them information about my background and the reasons for the study and then asked their permission to go through the questionnaire with them.

I gave consideration to putting the group at ease. Prior to the meeting I carefully considered how I would dress. I decided that dress would be informal with skirt and blouse and colourful cardigan. During the group I tried to be conscious of my tone of voice and body language but the group was not relaxed nor did it become so. Some staff in the group were very embarrassed and there was little eye contact. Others watched and listened intently but did not participate. Two older women often dominated the discussion in spite of others being encouraged to participate. Staff tended to wait for the response of the depute manager before responding to the question from the questionnaire. She reported later that she soon became aware of this and consequently did not proffer an opinion until other staff expressed a view.

Robson (1993) notes the importance of making the initial questions easy and interesting in a questionnaire and this is what Holmes et al (1994) did. The first question related to the seemingly innocuous question of residents holding hands. Assumptions can be erroneous in that this was not an innocuous question for this staff group. A heated discussion occurred between a small number of staff over this question with issues such as gender and difficulties that arose when spouses particularly, saw their partner holding hands with another resident. Obtaining a consensus with staff was difficult as opinions varied so it was decided after some negotiation, that the majority view would prevail.

The issue of gender permeated the discussion. Whilst it was felt acceptable for women to hold hands this was not so for men. Staff reported that it was a routine occurrence for men to touch their genitals, but staff needed to consider before agreeing that this was the case for women. Staff assumed here that it was the resident's own genitalia that they were touching as opposed to the genitalia of other residents. The question was ambiguous. This was true of a number of other questions. Of interest were staff attitudes that were voiced with regard to different aspects of sexual expression. Hugging was acceptable but the suggestion of any more intimate contact challenged the liberal views held by staff, for example, with regard to homosexuality. In some staff there appeared a dissonance between their personal abhorrence of homosexuality and what was expected of them professionally.

On ending the group session, staff were asked about their views with regard to the questionnaire. Comments from the younger female staff members included:

I felt really uncomfortable

The whole subject was horrible

The older female staff responded with “*The questionnaire was very limiting*” and “*But it makes you think*”.

Staff reported that the main acts of sexual expression were those of male residents towards (young) staff. “*The old men don’t fancy the old women residents but staff are a different matter!*”. One (female) staff member said, “*I didn’t come into this line of work to have my chest felt*” and shuddered as she spoke. Others nodded in assent. Men residents appear to be the main ‘actors’ in incidents involving sexual expression and often, it is staff who are the target.

Following this group discussion I spoke with the depute manager to obtain her views as to how she had viewed the session. One of her main comments focused on the illiberal attitudes expressed by staff in the group. She reported a lot of the (sexual) harassment that occurred was as a result of staff placing themselves in positions to render it more likely. There appeared to be have been little training for staff on the subject or any proactive measures taken with regard to sexuality, yet the depute showed scant sympathy for staff in terms of any difficulties that they might experience. I take up this point later in the thesis and discuss some of the differences between the responses of managers and those of care

workers and note the different worlds each group seems to inhabit. This disparity between care workers and managers was not so apparent in the second pilot focus group.

6.5 Home six - the second pilot focus group

The second group was different in composition. It comprised the unit manager, two depute managers and two senior care workers. We met in the unit manager's office where the unit manager spent the first ten minutes of the group session on the telephone and then only stayed for a further half an hour. During the time he was at the meeting he seemed ill at ease shifting in his seat, and not contributing to the discussion. He left saying he had another appointment yet when asked previously, he seemed to readily agree to participate in this group. Ostensibly he was very interested in the research, in practice he was possibly using avoidance techniques to

allow others to answer potentially awkward questions. Interestingly once he left, the group seemed to relax visibly. In this group, the younger staff appeared more at ease and articulate than the older staff. There was one male member of staff in the group.

Here, staff did not mention, unprompted, the harassment of staff by residents but when I mentioned it following the discussion of the Holmes et al questionnaire (1994), staff reported that it did occur. Male residents sought out female members of staff and incidents often occurred when carrying out bodywork. Again the body language and the facial expressions of some of the group pointed to the distaste felt when considering this type of sexual expression. The comments from this interview included "*It makes you think*" and

“The questionnaire needs to differentiate between those that do, and those that do not have dementia”. The staff group suggested that an important line of inquiry should involve what is and what is not, acceptable to staff with regard to resident sexual expression. This staff group appeared stimulated as opposed to the somewhat traumatised appearance of some in the other group.

The two group sessions were extremely useful in identifying issues and highlighting problems in questionnaire design. The data from the groups indicated that sexual harassment of staff by residents was a necessary line of enquiry. The Holmes et al (1994) questionnaire, following the findings of the pilot, was discarded. Based on the findings from the pilot, the literature and my own experiential work, I compiled my own questionnaire (see Appendix 1), that after some revisions was used in the postal survey.

6.6 The piloting and acceptance of my questionnaire

Table 2 outlines the process involved in the development of my final questionnaire. I piloted the final draft of my questionnaire in another region in Scotland and this involved the unit managers of six homes. Table 2 outlines the process involved.

Table 2 My questionnaire - the process
1.Piloting of my postal questionnaire in six social work residential homes
2.Revisions based on participants' comments
3.Submission and acceptance of questionnaire to District Management Group
4.Access granted
5.Contactd by telephone 28 managers of social work homes in one region
6.Postal questionnaire with accompanying letter sent to all 28 managers

On completion of the piloting I provided a report of my findings to those who participated, and their managers, and a letter of thanks. One manager in receipt of the report noted that *“the responses from staff were positive even though they did have uncomfortable feelings when carrying out the task”*. From a feminist perspective the process appeared to be disempowering for some, but for others stimulating and interesting. I note in chapter five that empowerment may only be achieved for some staff through an opening up of the subject area so that they may be helped to address situations involving sexual expression by residents in their work place.

My final questionnaire (Appendix 1) was submitted to the senior research officer in the area where I was to undertake the survey. She expressed approval and facilitated my research proposal through the District Management Group, who approved and granted access to managers in 28 social work residential homes in the region. Access was granted on condition that manager participation was on a voluntary basis. On reflection I chose managers as a group to survey as these were usually the work group with whom I generally worked in a development capacity. I was interested in their views before going on to address those of the care workers.

6.7 The postal survey, design and process

Following the acceptance of my research proposal by the District Management Group, each manager was contacted individually by phone. I spent considerable time on the phone with most of the participants, which I deemed time well spent. I was able to provide information about my research, but importantly, listen to some of their experiences with

regard to resident sexual expression. All those contacted agreed to complete the questionnaire. Some were interested and intrigued, some were concerned about the time involved in completing the questionnaire, some needed some persuasion, whilst some spoke at length about the issue of sexuality in their residential home.

Once their agreement to participate was obtained, the questionnaire and a covering letter were sent to each. Assurance was given in respect of confidentiality and anonymity. Of the 28 managers, 24 returned the questionnaire, a good response rate of 85%. Of those questionnaires returned, one was discarded, as large parts of the questionnaire had not been completed. This manager had been late in completing and returning her questionnaire so there was no time to ask her to complete it fully. Consequently 23 were incorporated in the analysis.

6.8 My questionnaire design

My questionnaire was designed to explore the types and prevalence of sexual expression by people with dementia in residential care and the managers' responses to this. It was designed as a structured postal questionnaire for use in a cross sectional survey. The questionnaire (Appendix 1) was divided into four sections. Demographic data, such as gender, was first elicited. Addressing the research question of what types of sexual expression staff found most difficult, the second section provided a checklist of behaviours usually described as sexual and staff were asked which behaviours they found acceptable, or not. In the pilot focus groups staff had used the word 'acceptable' when discussing the type of sexual behaviour that was acceptable or not to them and so I used

this terminology. The third and largest section focused on the expression of sexuality by residents with dementia using vignettes and began to address the research questions of the role dementia plays in staff responses and how context might influence staff.

Vignettes provide an artificial or fictionalised account, which comes contextually closer to the 'real' situation than perhaps general questions in a questionnaire. In vignettes, details can be varied and a wider range of possible situations can be examined than could be directly observed (Holland 1996). Generally there has not been widespread use of vignettes in ageing research (Holland 1996) but where they have been used with some success is when studying attitudes, for example, to death and illness (Williams 1990). Alexander and Becker (1978) advocate the use of vignettes in questionnaires as a means of giving respondents a concrete example; they provide a means of analysing people's judgement by varying the characteristics.

Vignettes in this study were used to obtain information specific to residents with dementia. Each vignette consists of a short case study based on material gathered from the workshops on sexuality and dementia that I had facilitated in the course of my full-time work at the DSDC and what staff had reported during the piloting stage of the questionnaire. The managers were asked to comment on whether they had found the situation outlined acceptable and whether a similar incident had occurred. I was interested whether managers using vignettes would be able to check these stories against their own experience. The response rate and detailed information given suggests that managers were able to relate to the vignettes.

6.9 The findings from the postal survey

As the postal survey is only a small, but important, part of my overall research I have been selective in the data I have used in this chapter. The data on the development of my questionnaire using the two focus groups (6.4 and 6.5) have provided informative material that adds incrementally to the findings in the next stage of the research, and so have been included. The data from these groups for example, suggest that family carer involvement is an important issue to explore. The effect of family carer involvement on managers' response was noted and appeared, supported by the data from my main study, to exert an effect on staffs' response. This will be discussed in the ensuing chapters but not in great detail. I made a decision early in my study not to interview family carers as my main interest was that of care workers and their response, but the data suggests that it would be an area worthy of further research. A full analysis of the questionnaire data can be found in Appendix 9.

6.9.1 Demographic data and Gender issues

Most studies on residential care have addressed the resident profile (Booth 1985, Bland et al 1992) rather than any in-depth look at staff characteristics, particularly with regard to staff sex ratios. Most managers of residential homes are women. In this survey 18 of managers were female and five were male. In terms of the care staff and residents, the majority were female. The literature highlighted that care work is essentially seen as women's work with the majority of residents in long term care, being women. The

findings from this postal survey point to this being the case for the 23 homes involved. The homes represent, for the most part, feminised work places.

6.9.2 The main types of sexual expression by people with dementia reported by managers

One of the purposes of undertaking a postal survey was, as noted, to obtain a ‘view of the field’. I was interested in exploring the types of sexual expression that occurred in these residential homes and then addressing the research question that looks at the type of sexual expression by residents that staff found most difficult to manage. Table 3 outlines the main types of sexual expression reported by managers.

Table 3 The main types of sexual expression by residents with dementia reported by managers (n =23)

Gender	Types of sexual expression	Managers report
1. Male/female residents with dementia	Holding hands	15
2. Male residents/dementia	Fondling breasts of staff	11
3. Male residents/dementia	Public masturbation	9
4. Male residents/dementia	Private masturbation	9
5. Female residents /dementia	Public masturbation	4
6. Female residents/dementia	Private masturbation	1
7. Male residents/dementia	Having sexual relationship with female resident with dementia	5

From Table 3 it appears that gender is to the fore with five of the most reported types of sexual expression involving male residents. The most commonly reported form of sexual expression is that of male and female residents holding hands. This is also the type of sexual expression managers reported feeling most comfortable with, the one reported to be

most acceptable and the one they reported they had no difficulty managing. Men and women holding hands is 'seen' as 'normal' and reflects the wider cultural acceptability of heterosexual expression. Holding hands is seen in many ways as a safe expression of sexuality and it is easy to disclose. Holding hands is an easy story to tell and an easier form of sexual behaviour to explain. Holding hands becomes less innocuous and less acceptable to managers if there is family carer involvement, or the two residents holding hands are male and there is family carer involvement. (Table 4)

The findings from the piloting of the Holmes et al (1994) questionnaire suggest that family carer involvement may affect how staff respond to sexual expression by residents with dementia. The findings shown in Table 4 point to how the ostensibly innocuous sexual expression of residents holding hands may affect staff response when there is a carer involved. I checked the data to look at what staff found acceptable and also the prevalence of this type of sexual expression.

Table 4 The effect of carer involvement on managers' response (n =23)

Situation	Carer involvement	Acceptable	Prevalence
Men and Women holding hands	No carer Involved	23	15
	Carer involved	15	4
Men and men holding hands	No carer Involved	21	3
	Carer involved	17	0

The findings in Table 4 indicate that when a family carer is involved not only is holding hands by residents less acceptable, but it happens less, particularly when it is men residents holding hands. This seems to suggest that staff may prevent or discourage such sexual expression if a family carer is involved.

One can speculate that holding hands is discouraged either to protect the feelings of the carer or to prevent any possible altercation with them. This expression which was seen in private as innocuous and possibly seen as a comfort and constructed as a result as asexual, in public where there is a possibility of discovery by the carer, the behaviour is interpreted as sexual and so discouraged. There are gender issues apparent with regard to what might be interpreted as homosexual behaviour. In British culture, it is not acceptable for men to hold hands in public. Gay men holding hands in public is a relatively rare phenomenon and would probably invite derision and hostility. Women holding hands, however, would attract little comment (Archibald 1998).

Gender comes to the fore again in the second most commonly reported sexual expression, that of male residents attempting to fondle the breasts of female care staff.

Table 5 Homes (12) where managers reported male residents attempting to fondle the breasts of female care staff

	Mean number of male residents (12 homes)	Range of male residents (12 homes)
Mean total and range of men	41	20-50
Male residents touching breasts of female staff	11	7-19
Male residents with dementia touching Breasts of female staff	4	1-8

In Table 5 out of the 23 homes involved in the survey, 12 managers reported that male residents fondling the breasts of female staff had occurred, that is just over half. The number of males to females in these homes is approximately 1:3. There are far fewer men than women residents but men appear the key players, as noted earlier. In terms of the role dementia plays it can be speculated that because dementia may result in misrecognition and disinhibited sexual behaviour, this is possibly a factor with regard to the number of incidents in this category or conversely, it may not be a reason. This is something that can be explored in the main part of the research.

When the data are explored to look at the difficulties managers have with male residents with dementia touching the breasts of female care workers and how they feel about this kind of sexual expression, some interesting points emerge (see Table 6).

Table 6 Managers reporting of difficulty and feeling uncomfortable with the different types of sexual expression (n =23)

Types of sexual expression	Difficulty		Uncomfortable	
	Yes	No	Yes	No
Male residents attempting to Fondle breasts of female Members of Staff				
Numbers	9	14	19	4
Male residents attempting to fondle male members of Staff				
Numbers	11	12	21	2

The findings indicate that whilst 14 managers reported no difficulty with managing this form of sexual expression compared to only nine who did find difficulty, most found it uncomfortable compared to only four who did not. The feelings of discomfort rise

markedly when male resident-to-male staff sexual expression occurs, reflecting possible difficulties with male homosexual expression between residents. One can speculate that male residents attempting to fondle female members of staff, however distasteful, is seen as a risk which is part of the job, whereas male residents attempting to fondle male staff runs counter to social norms (Archibald 1998). This is explored later in the thesis.

Men are to the fore and out-number women in the third most commonly reported sexual expression, that of public and private masturbation (see Table 1). In the case of masturbation in private, there is more data on men compared to women. However it can be argued that the situation may prove to be subtler than the findings indicate if gender expectations are taken into account. The ability to recognise in the same way, or whether staff even acknowledge that female residents may masturbate, is a moot point and will influence what staff report. What surprised and disconcerted Nay (1992) was that staff did not expect female residents to be sexual.

I have noted in chapter one that the role that often seems to be assigned to women with dementia is that of being vulnerable, childlike and in need of protection. The data from the postal survey seem to support this to an extent. An example is found in managers' response to question 12 in the questionnaire. The findings show that the acceptability of this woman having a liaison with a male resident in her bedroom is reduced from 20 acceptability (where there was no hint of distress) to 6 acceptability where some distress was evidenced. Although I stated in the vignette only slight distress was observed, the acceptability of this continued liaison was reported to be largely unacceptable by managers. I discuss these findings further in the next section.

6.9.3 A view of the field and the types of sexual expression causing most concern

Of managers who completed the questionnaire, 17 reported that the questionnaire had covered the types of sexual expression that had occurred in their residential homes. The additional types of sexual expression not mentioned in the questionnaire were as follows: masturbation by a resident in a shared room, soliciting in public, masturbating whilst being bathed, male resident stealing and wearing women's underwear, rape and sexual attack by a male resident on a female staff member.

One of my research questions addresses the types of sexual expression staff found most difficult. Using the terminology that staff used in the focus groups I phrased this question by asking the managers the kind of sexual expression that had caused most concern regardless or not whether the resident had dementia. There were five respondents who did not complete this section, and of the five, three had not reported any occurrence of sexual expression in their home. There was one manager who had completed this section and who had reported no concerns. In this home the only instances of sexual expression reported were those of holding hands and masturbation in private by a male resident.

In all but three instances, the remaining managers report that the sexual expression which managers reported as giving most cause for concern had actually occurred in their residential home. So concerns seemed to be based on the experience of having to cope with the sexual expression. Of the 18 managers who did express concern, the main concerns reported were those sexual expressions directed towards staff, particularly male residents attempting to fondle the breasts of female staff and residents making sexually suggestive remarks to staff. Exploitation and coercion of vulnerable residents was the second most

common concern, followed by public sexual expression, for example, masturbating in public or one resident touching another's genitals in public. These were the sexual behaviours that were of most concern to staff. How these behaviours are managed when dementia is a feature, is of interest as it addresses my research question of the role dementia plays in staffs' response.

6.9.4 The management of sexual behaviours causing concern and the role dementia plays

Addressing the theme of gender, managers were asked about cases specifically involving people with dementia. There was little difference in response with regard to male or female residents attempting to fondle the breasts of female staff. The accent was on discussing with staff and explaining to the residents that the behaviour was inappropriate and unacceptable. There appeared to be a certain amount of tolerance shown towards people with dementia that has echoes of the 'halo' effect described by Golaner and Raz (2000). There was symmetry in the response of managers whether it was men or women residents masturbating in private. Responses included: *"Leave and close door"*, *"Staff should not have entered room"*.

Where public masturbation occurred there was a small but interesting difference. The manager's response, regardless of whether the resident was male or female, was to remove the resident from the public area and take them to their room. When it was a male resident however, two managers reported that they had sought the help of a psychogeriatrician and a GP respectively. Medical authority was invoked in these cases to help with the management of this male sexual expression (Archibald 1998).

Different approaches emerged when managers were asked to comment on situations involving sexual intimacy between residents. In situations that involved two residents, where the woman had dementia and man did not and there was a hint of exploitation; (Question 12 in the questionnaire), 17 managers reported finding this situation unacceptable. Of the 17, only six of the managers reported that this had occurred in their own home and two of these had reported that they had responded by stopping the relationship. Two managers who reported its occurrence were more tentative in response. One tried to find out what had happened or simply observed, while one tried to find out what had happened to the woman to understand what had caused this distress.

Where this type of sexual expression had *not* occurred in their residential home managers were asked if it were to happen, how would they respond. Table 7 details this response.

Table 7 –Managers’ response to Q 12 (d) where this had *not* happened (n = 16)

Response	Numbers
Observe	2
Observe and intervene	7
Intervene immediately	2
Other	1 - staff to be vigilant and if behaviour persists police to be called 4 data missing

There is a sense of disquiet reported by managers when commenting on the situation described in this vignette. In homes where this type of sexual expression had not occurred, the managers’ main response was that of intervening and/or stopping the relationship. This reflects similar issues raised in the literature with regard to the ethics of such situations and gender issues where women with dementia take on the role, in some staffs’ perception, of vulnerable and childlike and in need of protection.

Gender is of note in Question 13 that documents the relationship where the man had dementia and the woman did not. Managers reported a general acceptance of this situation. However, in two cases managers reported that their response was to seek permission from the families for the relationship to continue although the woman resident was mentally competent (Archibald 1998). As noted earlier, heterosexual activity with the associated risk of loss of reputation has always been difficult for women.

6.10 Discussion and conclusions

The purpose of this survey was to obtain reports from managers on the frequency and types of sexual expression in residential care by people with dementia. From a feminist perspective this has provided a means of giving voice to a mainly female group of managers whose participation was voluntary. I spent considerable time on the phone with many of the respondents discussing my research and listening to their experiences endeavouring to give something back whilst taking from them. To this effect I also provided written feedback to staff participating. I noted in chapter four, that women and men working in residential care may not want their voices heard when sexuality is the focus of discussion. The data from the survey and the data from the two focus groups point to the subject being difficult and embarrassing for a number of staff. This echoes the literature, yet paradoxically, there was a good response rate from the participating managers.

Some (Kelly et al 1996 and Renzetti 1992) suggest that using a self-report questionnaire has advantages for respondents when the subject is sensitive. A sensitive subject

according to Lee and Renzetti (1990: 512) is one which “potentially poses for those involved a substantial threat...”. It is a topic often seen as threatening, one fraught with conflicting emotions, attitudes and responses. This is one of the advantages of using a postal questionnaire in that it can provide space and privacy for managers to answer the questions. The good response rate I achieved would lend some support to this being a useful initial approach in obtaining a ‘view of the field’. Whilst a small study and so not generalisable, the findings do add incrementally to the themes and concepts elicited from the literature and have helped consequently to inform the next and main part of my study.

There are however, disadvantages in using a postal survey as noted earlier. The information obtained is limited to the questions asked. It is not possible to explore in any depth the issues that emerge. Also in terms of my research, the questionnaire only explores managers’ views so I need now to go on and address the views of care workers. Acknowledging these limitations, the findings from the survey have helped to begin the process of addressing the research questions and providing indicators of the questions for exploration in the next and main phase of my research.

6.11 Findings from the survey – addressing the research questions

Omission and neglect of sexuality and dementia is evident in the literature. The findings from the focus groups in the initial piloting of the Holmes et al (1994) questionnaire and the initial responses I received when phoning participants, suggest that this may be due to the difficult and embarrassing nature of the subject, which resonates with the literature.

Yet throughout as I have documented, although the area has been neglected by researchers the issue appears salient and is of concern to practitioners.

The findings from the survey have helped to address the question of the types of sexual expression that occur in these residential homes and the types that staff find most difficult. These appeared to be resident-to-staff sexual expression in terms of men residents touching the breasts of women staff and men residents making sexual remarks towards staff. I only provided two vignettes in the questionnaire that involved resident with dementia to staff sexual expression, the rest I concentrated on resident-to-resident or solo sexual expression. Also I did not give a great deal of emphasis to resident gay and lesbian sexual expression yet both areas appear difficult for staff. The findings suggested that further work is needed in these areas and this I addressed in the next and qualitative part of my research in Glenevis.

The question of the role dementia plays is not always clear from the findings. Although the vignettes in the questionnaire were scenarios specifically about dementia, managers were not asked whether they would manage the situation differently if the residents did not have dementia. There does appear to be some kind of 'halo effect' produced by dementia in terms of managers' response in theory at least, but this is something that needs to be explored further and this I do later in my research. Dementia here, as in the literature, appears ambiguous. There is more apparent clarity when staff discuss women residents with dementia. When women residents with dementia are seen by staff as slightly distressed as in the vignette in question 12, then the role of women with dementia as vulnerable, childlike and in need of protection, is hard to ignore. The theme of dementia and gender will be explored in subsequent chapters.

As with any sensitive topic, disclosure is an issue. In my postal survey where managers were asked to report on sexual expression, the possibility remains that they may not have been fully aware of all the sexual expression that had occurred. Staff may manage a situation themselves with no difficulty, or may feel too shamed to mention the incident. This is one of the limitations of a survey but the arguments of only being able to obtain some of the available data may equally apply to qualitative methods. In interview situations the data obtained, in terms of the stories told, are only those that the staff wish to impart.

The question of how context influences staff response is addressed in part by the survey. Where sexual expression by residents takes place, the spatial aspects appear significant. An issue to emerge is that whilst sexual expression by residents in public is seen as inappropriate, some managers report that sexual expression in private can be 'unsafe'. As in the literature, my findings suggest there also appear to be tensions between the privacy of the resident and risk taking in the participating homes, particularly if the resident is a woman and has dementia. Bland's (1999) work is useful here where she critiques the 'social care' model of care that tends to be unchallenged in practice and which predominates in social work residential care homes. The model, whilst ostensibly espousing the core values of choice, privacy and independence, the duty to care and a reluctance to risk-take can be to the detriment of their core values. The findings also point to the ethical dilemmas for staff in these situations. Equally they resonate with Post's (1995) assertion that there is a tendency by staff to underestimate the competency of those disabled by dementia to be involved in decision making.

The public and private and the ambiguity inherent, emerges again in terms of how managers are able professionally to manage a situation, and what they privately feel about incidents involving sexual expression. The response of managers in this study points to most of them having a liberal view of residents' sexual expression, particularly, if the resident does not have dementia. This appears somewhat at odds with the findings in the literature where sexuality appears marked by staff discomfiture. I am interested to explore further the difference between the findings between the managers' response reported here and the response of care workers in Glenevis who are undertaking bodywork with residents.

6.12 Research questions and themes to have emerged from the findings

The main point from the survey is that the findings are those based on managers' report as opposed to care workers. The findings are useful in providing a view of the field and useful to compare with the report from care workers. Managers are often one step removed from the care situations. I have argued earlier that this may make it easier to affect a more liberal view towards residents' sexual expression. This is something that needs to be explored further.

6.12.1 Ambiguity

The literature points to dementia being an ambiguous illness to define and that its presentation can fluctuate and how people affected respond to the illness is idiosyncratic. The role of dementia I noted in chapter five appears at times to have a

major role to play whereas at other times, it has a 'bit' part in the drama. It is ambiguous and becomes more so when the resident with dementia moves from playing the role of an old dependent person with a disability in need of care, to that of an adult male expressing sexual intent and the difficulties that ensue for staff. This is a theme that will be explored further in subsequent chapters as it is key.

6.12.2 Gender

Gender permeates the data from this postal survey with men in the residential homes, as noted in the literature, the main actors, whether it is resident-to-staff sexual expression, resident-to-resident sexual expression or solo sexual expression. It is useful here to refer to other studies concerning sexuality generally, in terms of gender perceptions. Abbey (1982) for example, looked at gender differences in the perception of non-verbal cues and sexual intent. Where cues were more ambiguous, men tended to impute more sexual meaning than women did. Gutek and Cohen (1987) suggest that women prefer not to relate to men at work in a sexual manner, preferring to leave sexuality out of the work place and this might be the case for care workers working in residential care. Women residents and sexual expression is a not an area well represented in the managers' report which resonates with the literature (Nay 1992). This is something that needs to be explored further in the main study. Also resident-to-resident and resident-to-staff homosexual expression appears to warrant further exploration.

6.12.3 Spatiality

Space is important in terms of the how context may influence staff response. The spatial aspects such as the blurring of boundaries between public and private spaces within the home are important and will be explored in the next chapter (chapter seven). When addressing the area of sexuality and dementia there is arguably a need to theorise and map how sexual and gender identities and socio-spatial relations are shaped in the home. This I do in the next chapter that is informed by the findings of the literature, the findings from the postal survey (see Appendix 9 for further data analysis on the postal survey), and by the data from the qualitative, (partial) ethnographic, study undertaken in Glenevis home.

Chapter 7 Spatiality and Sexual Expression

7.1 Introduction

In the previous chapters I have reviewed the relevant literature, discussed the methodology and explored the findings from the postal survey. Here (in chapter seven) the data from an ethnographic study carried out in Glenevis, a social work residential home in Scotland, begins to be examined. Following the findings of the postal survey, the theme of spatiality will be explored further, as will those of ambiguity and gender.

Space/position is important for several reasons including its centrality in the choice of Glenevis Home as an area of study. The home was chosen because it was seen to occupy the 'middle ground' in a number of ways, particularly in terms of the sexual expression by residents reported by staff. Whilst it cannot be representative of all residential homes, it appeared to be representative of the small-scale homes involved in the postal survey. This chapter consequently occupies an important space between the quantitative and the qualitative data. The theme of space provides a contextual framework in which to site the findings from the ethnographic study.

Referring back to Goffman's (1959) dramaturgy, space affords an important context for the actors involved, with dementia seen as another actor within the universe of interaction that takes place in Glenevis Home. When addressing the area of sexuality and dementia, there is a need to theorise and map how sexual and gender identities and socio-spatial relations are shaped in the home. This helps to address my research

question of how the context may influence the response of staff. How sexual expression is constructed as moral or immoral in particular spatial contexts is of concern. I address these issues (in chapter seven) firstly by providing an overview of the home. A description of the layout is given and then people are added looking at what they are doing and how they are behaving within the home. The large-scale social structures of the home and how these intersect with the personal sexual agency of the residents and staff within this given space, are examined.

I begin by looking at the public space occupied by the home and how this appears to influence the construction of residents' 'identities'. The 'inner space' of the home is then discussed, drawing on the work of Peace et al (1997), Willcocks et al (1987), Douglas (1991) and others. The construct of 'home' is often associated with safety and security with abuse until recently, often ignored. This will be discussed further within themes of private and public, and home and institution. For example, the small-scale living design has helped to create a more homely/family ambience but this intimacy may have sexual consequences. How the spatial aspects of the home appear to impact on sexual expression and how this is managed, is explored. I address, for example, how staff manage the moral work of protecting residents, particularly those women with dementia who are perceived as vulnerable. The home has large spaces separating each small living area and this, combined with low staffing levels in the home, complicates the sexual surveillance of residents. The 'home' is seen as a place of privacy but in a residential 'home' there are few places that are private to anyone, even the residents' bedrooms.

I conclude that space as a theme is important but the issues are complex and ambiguous. Whilst staff report that sexual expression by residents is best conducted in private, particularly solo sex, other situations involving residents with dementia enacting sexual expression in private bedroom areas appear to be problematic for staff. The role of dementia ascribed to women residents with dementia is that of vulnerable and needy. The role of dementia is less clear when male residents express sexual intent towards staff. The latter type of sexual expression appears most difficult for staff and I theorise that this difficulty may result in staff not discussing these situations with others.

7.2 The public face (space) of Glenevis

Space, as Diaz Moore (1999) notes, has been used as a concept of life care research since Goffman (1959, 1961) with the physical setting salient to the understanding of human experience. Goffman (1959) argues that architectural structures are merely props in a social drama and do not determine behaviour in a direct fashion. However, Diaz Moore expands on this, suggesting that place is important not only in terms of understanding human behaviour, but also with regard to the socially shared understanding of the purpose of places by which people define their situations. Ardener (1981) discusses wide variations in residential space throughout the world and notes that whilst physical distance between dwellings may not be great, social distance may be very great. Atherton (1989) argues forcibly that residential establishments have a great capacity for affecting the self-image of residents. Laws (1997:2) suggests that if spaces are constituted and constitutive of social relations then space will impact on 'identity formation'. In other words how we present ourselves to the world says a lot about who

we are and this pertains particularly to architecture, and in this case, the architecture of the home.

The external appearance of Glenevis, although pleasing, still retains a certain institutional feel. The home is one of several built at this time (1980s) in this large town. The design reflects the social policy being enacted then and now (Bland 1999). Residential homes were and are seen as communities for living (Willocks et al 1987). These homes provide space for private lives to be lived in public places. These lives are seen by those in control of resources, as best being lived out in a small domestic-type environment. The well-intentioned emphasis blurs the lines between home and residential care. It has been a move away from the large Goffmanesque-type institution to what is considered a more enlightened form of care surroundings.

The philosophy of creating a small, homely and domestic environment continues to be seen as the optimum environment particularly for people with dementia (see Marshall and Archibald 1998) and for old people generally. This concept has to an extent been treated unproblematically. The literature points to a general consensus of opinion as opposed to in-depth research findings. The design literature for people with dementia (Calkins 1988, Coons 1991), however, emphasises that design is simply one part of a complex system and pattern of interaction. This will be explored further in the next chapter with regard to the social organisation of the home.

Discussing the design of Glenevis with the architect, he reported that the architectural brief was that of group living and it was determined by a number of factors including economic considerations. The area designated was '*a small, 'tight', urban site*' which

resulted in the need to build up rather than out. The resulting three-storey home was ‘*shoehorned*’ into the site. The design brief addressed the limitations of the site and the fact that this is an architectural conservation area. The final design consequently reflects the characteristics of the vernacular architecture of the surrounding tenement buildings. Its pale blond cast stone frontage will in time become begrimed like the surrounding buildings. At present and nearly twenty years on, it stands out from its surroundings somewhat and it is difficult at first glance to establish whether it is some kind of sheltered housing or residential accommodation. There is no front garden but there is space between the pavement and the home for residents to sit outside when the weather permits.

The home is set back from the main road, on a slip road, so whilst the residents can be seen and see what is going on, traffic immediately outside the home is reduced. Whilst on one level the home is set back from the main thoroughfare, the architect noted, ‘*it is situated within the heart of the community*’. It overlooks the park and in theory it is within walking distance of shops, churches and the library. The few able residents walk to the pubs and shops. Some go to church. Sometimes a member of staff may take a key-resident out to shop but this seemed to occur very infrequently during my time at the home with low staffing ratios given as the reason.

As space is explored paradoxes become evident. The (almost) ideal situation of the home, in theory, makes it a focal point of the community and facilitates opportunities for interaction. Initially this was the case. According to the architect the building of the home was welcomed and was seen to be an asset for local people. At the opening ceremony of the home the community policeman and many others from the community

attended. The momentum of this initial process now seems to have petered out. The data point to an infrequent input from the community. Local singers or other groups present a 'one off' concert rather than sustained interaction taking place between community and the home. The home whilst central in its spatial situation seems to be peripheral. In a sense the home has become a 'conservation area' for older people. The design of the home and the space it occupies is important but so too is the metaphorical space that residential homes occupy in the collective and societal consciousness. Regardless of the almost ideal community-based setting of the home, as with other residential establishments, Glenevis represents arguably a place where some of the most marginalised groups in society are housed (Peace et al 1997).

Normally people live in their own homes. Many older people are reluctant to consider admission to residential care for a number of reasons but not least because of the negative image that accrues by becoming a resident. Residential homes are places where many people would choose not to be, including some residents in Glenevis. In common with residents in other social work residential homes, most people admitted to Glenevis have multiple complex needs and are unable to live in their own homes. People who enter residential homes are in need of care (and protection) and are perceived as vulnerable beings. They are often not 'seen' as having sexual needs with an ascribed asexual status implicit.

7.3 Inner space – spatial structures

In this section, the aim is to provide a description of the inner space of the home in which to site the different and deeper levels of analysis in the following sections and later chapters. The plan of the building (Appendix 5) indicates the overall areas but for the purposes of this chapter I will focus on the primary areas used by residents and care staff.

7.3.1 The sitting rooms

The home is on three floors (see Appendix 5) and on each floor there are two units catering for eight residents. The sitting rooms, like the main building, are L-shaped. They are small and tight for space. There is a small kitchen area within each of the six sitting rooms ostensibly to allow residents to make tea for themselves or make a small snack but, as Sheila, one of the older care workers noted:

They can make tea or coffee whatever, aye but the cookers are not really used in here. If you put the rings on they just give off smoke.

I seldom observed residents making tea for themselves and never observed any resident making a snack. These were tasks carried out by the care workers or the main kitchen more often supplied the food. Independence and maintenance of residents' skills in this area appeared not to be encouraged.

During my observations I noted that there was a shabbiness apparent in most of the sitting rooms, and they might be best described as 'well-lived' in. The carpets had stains on them, there were few interesting pictures on the walls and the television (on most times) in all the sitting rooms, was central. The curtains tended to be rather faded and in some of the sitting areas where residents smoked, the wallpaper was somewhat discoloured. On one level the sitting rooms were comfortable. They were informal places, back stage areas for residents to be, making few demands. These were the basic living areas that the domestics and care staff kept clean. They were the areas in which the routine of the home was enacted for most of the day for the many of the residents, particularly those with dementia.

The care staff remarked that each sitting room has a "different feel". What they referred to was the different resident composition as opposed to different design features and I found this to be the case the longer I worked in the home. There were a number of implications as a result of the little space available in the sitting rooms. A rule in the home was that if the care staff ate with the residents in the small sitting rooms, they, the staff, could obtain their meal free. This was to encourage interaction with residents. There were however only eight dining chairs available so this meant that staff could not sit at the table with the residents and facilitate conversation or interact. There were also only eight (slightly) more comfortable chairs for residents and each resident had his or her own chair in some of the sitting rooms. The space was for the 'family' of eight residents in effect and this did not include staff or other residents from different parts of the home.

The constraints of space meant that other residents from other units were discouraged from visiting. Two women residents who were very old and frail and who appeared very fond of each other were from different living areas. They seldom left their flats to go elsewhere in the home so finding ways of seeing each other was resolved by them by meeting and sitting in the corridor near the lift on the second floor. In a limited way they were able to watch people coming up on the lift and were able to walk in the corridor and have a change from their sitting area. Most people 'stayed in their place' or went to the large communal sitting area near the front entrance, referred to by staff as the "forum" (see Appendix 5), at different times of the day, usually in the late morning or afternoon.

7.3.2 Corridors

Whilst space was at a premium with regard to the site of the home and in the six sitting rooms and residents' bedrooms, there was a lot of space used for the corridors that separate each flat. There were long spaces between each of the six group living areas that distanced one group living area from another. I observed that this had implications for both surveillance and interaction particularly with the staff resident ratio of 1:16. I noted that there was often only one staff member for each flat so staff were literally lost to residents for long periods of time.

7.3.3 Residents' rooms

Along each corridor were the residents' bedrooms. These were small due to economic constraints. There was a sink in each room but not a toilet. I was invited into several

rooms by residents and helped to tidy several rooms during my period of participant observation. Residents colonised their rooms in different ways. Some, like Edna had lots of family photos and momentos. Some of the male residents had very little in the way of personal possessions. Where residents had children, particularly daughters, a great effort had been made to create a homely space for their parent. Most residents have their own room. There were however four double rooms, referred to as “*married quarters*” by Sheila a care worker when Jimmy and Madge, a couple in the home were married. Another worker Beth said that it was ‘*good to have a couple for the double room as it was so difficult to match pairs of people for these double rooms*’.

7.3.4 The staff quarters

The third floor of the home houses two group living areas but also the staff area. This was previously the manager’s flat. It has been refurbished and had a room and bathroom used by managers for their sleepover period. There is also a small office that managers use if they need to write without disturbance. This was the room that was allocated for my use to interview staff. The staff have a small sitting area and a kitchen area where they can make a snack or a hot drink. It is their own private space and here I noted they could feel well apart from the residents and management. This was their ‘back stage’ area that I refer to in my observations. During my period at the home, management did occasionally come to the staff’s sitting area, sometimes in the middle of a tea break, but none of the residents were observed in this space.

7.3.5 The forum

The forum, a large central public area on the ground floor, represented not only the immediate visual impression and introduction as people entered the home, but in many ways was a bridge between the 'public' and 'private' spaces of the home. It is the area that people see first when they enter the building and is the internal public face of the home. The space in the forum is used for different purposes throughout the 24-hour period by both staff and residents. It is a large space with lots of large easy chairs set out in a large rectangle with coffee tables on which to place cups and glasses. It has a television and music centre. There are plants and a parrot in a cage. It has a pleasant appearance and is a place where people are able to sit and watch the 'comings and goings' of the home. For residents it is an area where people can be together yet equally it is a place where they can be apart and anonymous.

It is an area of surveillance yet paradoxically it provides privacy. There are parallels with similar kinds of public spaces in hotels. As in a hotel, this large lounge space can have an impersonal feel yet it is place in which some people appear to feel more comfortable. The forum allows a distance between residents' small and rather cramped sitting rooms and provides a means of escaping people with whom they do not necessarily accord. Conversely they can meet with people from other group living areas. My observations pointed to very few residents visiting each other and sitting in the small sitting rooms. An exception might be if they called to accompany the other person down to the forum. The space in the forum was *'usually used by the more able residents but some people with dementia wandered from flat one on the ground floor to sit for a*

short while and then returned to their sitting area. It provided (some) residents with change of space (Fieldwork observations).

The easy chairs in the forum contrast with the small, and less comfortable, chairs in the small kitchen/dining/sitting areas of the six resident flats. The forum is a place where the more able residents sit and read and talk and where the activities worker provides the more able residents with activities. This is the area where the bar night and any entertainment is held. It is the place where, in the evening, the day staff sit with the oncoming night shift and over a cup of tea give the report. It is the place in the morning where the night staff give the day staff the report again over a cup of tea. I observed that whether by design or due to the fact that residents preferred their small sitting areas at these staff report times, the forum was rarely used by residents during these periods. At these times residents either used their own sitting rooms or were in bed. The night staff also used this area to sit in all night and to write their reports in the morning.

7.4 Institution versus home – ambiguity at bar night

Ambiguity as stated previously is an important theme in this, as in other chapters. How staff and residents use the forum and the implications in terms of how context may influence staffs' response to sexual expression, will now be explored. The role that dementia plays is also highlighted in terms of gender. I begin here to theorise that the role dementia plays particularly in resident-to-staff sexual expression is minimal. Gender, in terms of staff expectations of male sexuality, appears to supersede dementia in importance.

The forum appeared to have many different applications and uses. One pertinent to this study is that of its use as a bar. Twice weekly from about 7pm –10pm, the forum is used for the ‘bar night’ activity. Residents throughout the home are able to come to the forum and take part in the activity of social drinking. The rules are that each resident is allowed only three (alcoholic) drinks of their choice for which they pay a subsidised amount. They are rationed with regard to alcoholic intake as many of residents according to staff *‘have a drink problem’*. Kate the assistant manager, reported that over the last three months all the people admitted to the home had a diagnosis of Korsakoff’s, that is alcohol related dementia. Alcohol intake is a big issue for residents and staff and the bar night in some ways, was seen by staff as a way of rationing the use of alcohol albeit in very institutional way. This had resonance for me with nursing practices years ago in the old psychiatric hospitals. I noted at the time:

The staff were standing or dishing out drinks and again it all seemed a bit custodial. (Fieldwork Observations)

It is hard to ignore the Goffmanesque institutional aspects of this approach that are reflected in the account of Eileen, a resident with dementia. She reported when showing me her room that:

I could only have two drinks to begin with as the doctor said so. I hated this as it made me stand out and be different. People would ask why was I different. They wouldn’t be friends with me. I wanted to be like everyone else. After two months my doctor said I could have three drinks which made me happy. (Fieldwork Observations)

The following observation I made during a participant observation period gives a sense of how these rules were applied but also subverted by some residents. On this particular evening I was keen to 'participate' rather than simply observe so I asked if there was anyway in which I could help.

Beth told me that the bar once opened was not to be left unattended as a lot of the residents had drink problems. I pulled the bottles out and the glasses. Corinne, the assistant manager, came out and fussed on about the measure and tried the pub measure in the cupboard. It ended up with whisky spilled over the area and Corinne looking embarrassed. However we managed to get a glass and decide what the measure should roughly be. I tended to give a generous measure, which went down very well with the residents. They said "Are you new here? Never mind hen you'll soon learn." (Participant observation)

Although staff appeared to observe the rules about alcohol allocation strictly I observed that there were resistances. One scene I observed whilst there was a respite at the bar, was that several women residents who had dementia were sitting smiling pleasantly with their drinks at their side. They epitomised the role of women with dementia as noted in the literature, that is vulnerable and in need of protection. In this instance they were in need of protection with regard to their drinks. One of the male residents took advantage of their lack of awareness and *'went round siphoning up other women residents with dementia's drinks, drinking anything alcoholic (Participant observation)*. The staff appeared never to sit down with the residents, or have a singsong but rather stood around the bar and watched.

It was interesting to undertake participant observation on the bar nights and to observe both staff and residents' interaction, as there were a number of paradoxes. This was a residential 'home' yet attempts were made to simulate a bar atmosphere. The care workers on observation, often dressed casually in jeans or dressed more formally like Helen, an older care worker, who often dressed in what I described as her 'cocktail' clothes. They acted as bar maids, replenishing drinks as necessary up to the allowed total. Music was playing. There was an ambience of a pub created with the smell of drink and cigarette smoke adding to the overall effect, resulting in a blurring of boundaries between residential home and ostensibly a 'pub'.

Residents became 'merry' as the night wore on. Staff remained standing and generally on the alert with surveillance a theme. Surveillance was aimed at monitoring residents' alcohol consumption but also, as I learned later so as to be wary of male residents' sexual advances. Several staff reported that the disinhibiting effect of alcohol often lead to some male residents making sexual remarks and attempting to fondle the breasts of female staff. How context influences staff response to resident sexual expression was apparent at the bar night. They responded by being wary and keeping a distance.

There was arguably a dissonance between staff and residents shared understanding and expectations in regard to this bar space, and with regard to expectations of each other. Diaz-Moore (1999), notes the importance of the socially shared understanding of the purpose of places by which people define their situations with negotiations part of the social interaction structured by roles and rules. In Glenevis, the role expectation of staff was that of caring for residents. Whilst staff did continue to care for residents, male residents in particular often did not keep to the expected role of resident and a blurring

of roles and boundaries ensued. The interaction became as that between man to barmaid. Pat, one of the care workers who had worked at the home for over ten years, typified what other staff had reported with regard to resident-staff sexual expression at bar night. She reported

In the public area and especially at bar night that she had sexual remarks made to her...She had male residents put their arm round her with their hands slipping towards her breasts. (Interview (not taped) with Pat)

Jenny, an attractive younger care worker who had worked in the home two years and who had reported being sexually harassed by Jimmy a male resident, noted:

Michael, (a male resident with some cognitive impairment) sometimes but just at bar nights, usually makes comments.

CA Can you say what kind of comments?

Jenny - Sort of like - sort of "Do you want a wee bit?"

(Interview with Jenny)

Jenny to an extent here and in other parts of the interview, tends to regard drink as the reason why Michael and other residents step out of role. Rather than seeing cognitive impairment as a contributor to the resident's sexual behaviour, the issues appear to be more about gender. It is a male construct that she is familiar with-people and particularly men lose their inhibitions when they have consumed alcohol and became more sexually explicit. It appeared as a way of managing and thus coping with this behaviour, that is outwith the normal care worker/ resident interaction. This was the

“talk” of most of the care workers with regard to sexual expression by male residents on bar night. In a sense this “talk” suspended the usual identity of (asexual) resident to that of a (normal and thus sexual) male. Most of the staff appeared to be aware of how men behaved at bar night. It was seen as their own responsibility not to place themselves ‘at risk’ or in a position to be ‘groped’. If they did place themselves in such a position then what was implied by some care workers, was that it was their, the care workers’ own fault. This approach might result in care workers having difficulty in discussing such occurrences with others if they were possibly seen as encouraging such advances. The theme of sexual respectability highlighted in the literature appears pertinent here.

I noted in the postal survey that the sexual expression of women residents was poorly represented in the findings. This was often true in the report of staff in Glenevis. Women residents being flirtatious at bar night was only mentioned by Roger (assistant manager) and this seemed to be in a rather patronising and indulgent way as opposed to seeing this as a possible (normal for some) sexual response to the disinhibiting effects of alcohol. There are gender issues here and throughout, that permeate the data. Ardener (1981: 27) notes that we all have social maps in our heads with some selected populations receiving greater ‘marking’ and being ‘coloured in’ while others are overlooked. This appears to be the case with regard to older women residents expressing sexuality.

7.5 Small scale living units – a homely and intimate space

In terms of space, I was interested in the staffs' views on whether the small-scale design of six different units within the home provided a more homely context for residents to live. Whether they help to facilitate closeness between residents (and staff), was of interest. The general consensus obtained from the staff was favourable. The units did provide a more social and a more friendly and homely type of environment for residents. Some staff invoked the concepts of 'home' and 'family-like' when interviewed. According to the manager Chris small scale living is '*a wee bit closer to a natural home and.. It's more like a natural family*'. Helen, a care worker, also invoked the concept of 'home' in support of the smaller units.

Well it is more like their home. I think that it (small-scale living) is actually a good idea because it is their choice whether to be in a small group. It is more personal. It is not like an institution with one big area and that is it. (Interview with Helen)

Doris one of the older domestics reported, '*It gi'es them a more homely ...they're sort of they're like wee families*'

Doris noted however that this sense of family has its difficulties in that some male residents become too familiar. She infers that because the staff are seen as 'family', the male residents become familiar with them. These men in this setting, she reports, almost

see it as their right to attempt to fondle the care worker's breasts and that it is the care worker's responsibility to '*put them right*'.

Which again is why you get the likes of the elderly men, maybe if the care assistant is leaning over them pressing the button for the buzzer. Yes, yes, you wouldn't do it to a stranger.

CA So is what you are saying - that because it's an intimate small scale family setting it's almost giving them (male residents) permission, that it's okay?

Yeah I mean it's up to who ever the individual is (the worker) to put them in their place and they would probably then stay in their place. It is a very relaxed atmosphere. (Interview with Doris)

There are ambiguities apparent in terms of the concept and expectations of 'home' as a safe and caring place. Ardener (1981) suggests that women are vulnerable to molestation from strange men especially outside their home ground, yet the home can also be a place of vulnerability where men can abuse their position. 'Home' may not be the haven of security as constructed in the past. It is increasingly recognised that for some, 'home' can be an abusive place (Lee 1993) for both residents and I argue, for workers.

Evelyn, one of the older care workers, spoke with enthusiasm that the smallness of the units enabled staff to get to know the family carers better.

We also get to know the sons and daughters of the residents. You get to know things about them as well and they get to know you sort of thing.

It's a homely, more homely environment; it's the same people. They mightn't get on with them but it's the same people. (Interview with Evelyn)

Evelyn appeared to imply that in any family situation all members do not necessarily get on with each other, but it is the same and thus (comfortingly) known people in the group that offers certain advantages. Other staff, whilst acknowledging the positive aspects, were less sanguine about these small family situations. Some reported the claustrophobic aspect of life in these small units. Martha, an older care worker who had worked at the home for ten years, reported that:

Residents might want to get lost and not be put under a microscope. I have only ever heard it once but one lady did say, "It (the small sitting room) felt like a goldfish bowl" For her it did. It (small-scale living) doesn't suit everyone. (Interview with Martha)

Gladys, a care worker, when asked about the advantages of small group living talked about the conflictual aspects.

You'll never get eight people that get on together. All personalities clash, you always get one who wants to dominate and you'll always get one that winn'ae come forward. (Interview with Gladys)

To an extent these last statements matched what I had observed in flat one where I spent a considerable time. The conflict between the residents of this small group of eight was evident at times. Ethnography is about describing the habits, customs and points of reference of social groups. The quote that follows provides an account of the interaction between the social group of residents in flat one.

I talked to residents Edna, Bella, Harry and his wife Madge, and Andrew who appeared to be a rather disgruntled man. Christine, who is reported to have mental health problems, seemed the unpopular one. She kept going into everyone's room. She was an ex-nurse and has a sharp tongue. 'She is not an easy lady', according to Anne a care worker. Christine came to sit next to me and she talked without difficulty of her nursing background (mental handicap) at the same time she was giving commands to Andrew to button his top trouser button. Edna and Bella meantime spoke in whispers about Christine in an apparently disparaging way. Madge looked daggers at her and could scarce be pleasant to her. Bella later told me that her glasses had gone missing and when Christine with her zimmer came back into the room, Bella asked me to look in Christine's bag as she suspected Christine had stolen the glasses. (Fieldwork Observations flat 1)

During this observation period lasting over one hour I initially felt a sense of frustration as not one care worker came into the sitting room. I was sitting there to observe the interaction between staff and residents yet this was not possible. As I sat observing however, I became more and more drawn in to the world of the residents and their interactions. They were accepting of my presence and appeared to enjoy our conversations

or as often, my listening to them. In this early part of my research, although the original aims of my observation were not being immediately met, the observation periods in this and the other two flats were fascinating and enjoyable.

It could be argued that in some ways, how these residents interacted was like a family with their incipient jealousies, disagreements and alignments. Harry, one of the male residents with dementia in flat one, repeatedly comes to the fore in the sexual stories reported in later chapters of the thesis, as a resident who abuses his place in his 'home'. Staff reported that Harry repeatedly touched the breasts of care workers as they attended to his needs. Within this small homely setting he was found to have been going into the nearby bedroom of a female resident with dementia. This case study will be discussed later.

Fiona, a young and recently employed care worker, noted that low staffing meant that it was difficult to find time to talk to the residents. On observation, this was the case in the morning but often I noticed in the afternoon and evening that opportunities for communication and interaction were missed. Care workers had to give residents their meals, give out medicines and do bodywork like bathing. As Lee-Treweek (1994) and Clarke (1978) found, these tasks were prioritised and seen as real work. This busyness meant that not only was there little time for communication, but there was little time also for 'surveillance' of residents. Whilst the geography and low staffing levels on one level provided residents with a certain privacy, it raised issues about 'surveillance' and also issues of protection of vulnerable residents, particularly those with dementia as I discuss later. Whilst Sherman (1999) notes the morality of residents is often under constant surveillance in long term care homes, in Glenevis the geography of the home made this difficult to undertake.

7.6 Privacy and surveillance difficulties

Surveillance and how power is enacted in residential homes is a theme in the literature (Parkin 1989, Atherton 1989). Care and protection of particularly vulnerable women residents with dementia is an issue, as noted in the findings of my postal survey and in the findings of my qualitative work. Helen, a care worker, for example, spoke about the fright she felt and the sense of responsibility, at finding a woman resident who was reported to have advanced dementia, in a state of undress.

I remember going along to make tea in the other sitting room and she was there (a woman resident with advanced dementia). I popped along to the other sitting room to make their tea, came back and there she was sitting in her chair with her tights and pants off and I took her through to her room. The other (male) resident who was sitting there said "I'm just off to my bed now". (Interview with Helen)

The theme of ambiguity appears to the fore here as does dementia. Whilst this woman resident was advanced in her dementia and often could not undress, there were no witnesses as to what had happened. It might have been on this particular occasion that she had managed to take her clothes off, it was not possible to tell. Helen had her suspicions about the male resident present at the time and informed other care workers, but she did not report this to management, rather she and the care workers *'just kept an eye on the situation'*. This case will be explored in greater depth in the following chapters. Pertinent here as well as the ambiguity of the situation, was the geography of the home. The long

corridors and the very low staffing were considerable factors in staff's concern in keeping these vulnerable women residents safe.

Once again the theme of protection of vulnerable women residents was evident. In this case there appeared ample justification for concern but there were other times that Corinne reported that care workers tended to be over zealous in the 'duty to care' especially when it was residents with dementia, that resonates with the work of Post (1995).

'You know it's perhaps easier to say "Oh I think she is being exploited" because they have dementia they're automatically being exploited. The fact that although they have dementia they are as likely to have feelings, have feelings of pleasure whatever. (er) So I think that again that when somebody has dementia it was less easy (for staff) to accept as well because they (residents with dementia) are not seen as having the ability to control their lives.' (Interview with Corinne assistant manager.)

There appeared some basis for Corinne's comments. The data did point to staff wanting to protect residents, with little to suggest that in some cases pleasure might be a component of the relationship rather than exploitation. The emphasis tended to be on issues around exploitation, taking advantage of people who were incapable. The situation became complicated however in certain cases when asking staff to define who had dementia and to what degree, and who consequently was able to give informed consent. This will be explored in the next chapter. There appeared to be little role modelling by managers, staff involvement in decision-making and exploration of anxieties and attitudes in this and other cases. On observation, staff being controlling for example, separating residents in certain difficult and ambiguous sexual situations,

appeared to provide a sense of power in what seemed like very powerless situations for some care workers. Corinne (assistant manager), although having overall managerial responsibility for residents when on duty, did not have hands-on caring responsibility or the close relationship that occurs between care worker and resident. This may make it easier for her to be more liberal in stance. In terms of impression management (Goffman 1959) she may also have been trying to impress me during the interview.

7.7 Sexual observation of staff by residents

There has been little exploration in the literature about the difficulties of working and living in the small-scale environments when sexual expression is a component of life. Care workers in my study reported such difficulties. Observation cannot simply be applied only to residents. Staff also become objects of observation by residents. Mainly, male residents remarked on staffs' bodies at bar night and on other occasions. Staff came under scrutiny by the residents when they, the staff, were either the object of desire or were called upon to deal with expressions of sexuality by residents in the small sitting areas. One of the major emotions reported was that of embarrassment. These situations appeared difficult for staff to manage and also to talk about with others. The following two examples appeared to capture some of the care worker's difficulties when coping with situations involving sexual expression in these small sitting areas. The claustrophobic nature of the small sitting room emerges and paradoxically the 'goldfish bowl' aspect means there is less privacy available to residents than they would experience in a larger, more 'public' sitting area.

In the first quote Paul, a young male care worker, goes into the small sitting room and greets the residents.

Yeah and when I walked into the room I'm very sociable I said "Hello ladies" etc and hmm the client wanted to hug and kiss (me) which is fine. So I say "Hello" and (gave) a kiss on the cheek but it (she) was grabbing and hugging longer (than I wanted) and I was like trying to get away and what do you do? Hmm so I got myself out of the situation but she continued wanting more kisses and hugs....But I did feel uncomfortable. (Interview with Paul)

There was discomfort expressed by Paul but also a sense of revulsion revealed later in the interview. This woman, according to Paul, had overstepped certain boundaries that were difficult for him to cope with. The other residents observing what had occurred made the situation more difficult for Paul in this small, homely sitting area.

Again the smallness and immediacy of the sitting area proved embarrassing for Martha another care worker. Martha reported a situation involving Harry. Harry was feeling the breast of a woman resident in the sitting room in the presence of other residents including his wife, which was particularly difficult and embarrassing. Martha reported that his wife was sitting on one side of Harry so there was no disguising what was happening. It was difficult for Martha to tactfully intervene.

How can I put it - he was making passes, if you like, to other senior residents. One of the ladies concerned - like his wife was sitting at one side of him remonstrating at this lady and he was touching her (the other woman resident) all the time, touching her breast. (Interview with Martha)

Martha found that very difficult to manage. The situation was resolved by the woman resident telling Harry to stop what he was doing which he did.

Other difficulties for Martha were around men and women residents exposing themselves in the sitting room in the presence of other residents.

One lady with dementia, one night was trying to get out of her clothes. I couldn't leave, I thought what can I do? I gave her a bath and it worked and I got her into her nightie and dressing gown whether she felt freer..more comfy. That's how I got round it. I'll try that one again. But it's quite hard to deal with in the small sitting room if there's men there. It's embarrassing. (Interview with Martha)

The advantages in terms of the design of the sitting areas is that they are a small, domestic type environment for residents, yet it can appear difficult for staff to manage situations of residents exposing themselves or masturbating in these small 'tight' sitting areas. In these sitting areas as in other parts of the flats in Glenevis, staff often work singly.

7.8 Privacy and some of the (sexual) dangers associated

As others have noted (Willcock et al 1989), in residential care no one seems to have total privacy. The experience of residents is often of private lives in public places but conversely the staffs' experience is that of public lives in private places as discussed above.

My own observations initially which were added to throughout the fieldwork, was that there appeared to be a rather cursory approach to privacy of residents by some staff. For example, Pat, a care worker, showed me around the home on my initial visit. She knocked in a perfunctory way on the door and then entered the resident's bedroom.

We went into several rooms Pat knocked and hardly waited for a reply before going in. (Fieldwork observations)

It might have been that Pat was aware that the residents would not be in their rooms, but they might have been. It was apparent from my data that in some cases, residents' sexual expression was interrupted and compromised by this lack of privacy. Corinne, the assistant manager noted:

Masturbation in private is also an issue with staff knocking and walking into rooms or residents not answering and staff going in or, staff thinking the residents are not in their room and walking in. (Interview with Corinne)

Often this lack of (sexual) privacy appears to be because the staff tend not to see the residents as sexual beings. It can be the last thing they might consider when going into a resident's bedroom. Lee (1993) notes, the residents have single rooms but life is often still experienced as a collective experience acted out in a public space and this was true to an extent in Glenevis.

The findings from my postal survey point to managers viewing the resident's bedroom as the appropriate place for sexual expression. This tended to be for solo sex, that is, when the person wished to masturbate. Also the bedroom was seen appropriate for couples who did not have dementia and who wished to pursue a sexual relationship. Lee-Treweek (1994:2) notes that in Western Society the bedroom has been constructed as a place of privacy and has unique symbolism. There are difficulties, however, as noted by Bland (1999) in her study, with regard to privacy and risk taking. In my study sexual risk taking in terms of allowing some residents' privacy may be difficult for staff in practice. In several incidents reported in Glenevis, care workers regarded the bedroom as an unsafe place, a place where it was not possible to monitor what seemed to them very challenging and difficult sexual situations.

From a postmodern perspective there are many 'truths'. In Glenevis, in one situation involving sexual expression by residents, Corinne's version or construct was as follows:

Another couple, a year or so ago, became friendly and were often found at the lift bit of the home (this is a sitting area just near the lift.) Staff had a lot of difficulties with this and wanted it stopped. The couple were kissing and cuddling and the woman although confused seemed to be deriving pleasure. It

was the public nature of the relationship but when managers suggested that the couple should go to the bedroom the staff felt "it would be even worse in the bedroom." (Fieldwork Observations)

Corinne in describing the incident reduces it to a romantic episode with the couple, simply kissing and cuddling. Although Wilma the resident, was 'confused' and so too was Will, the situation, Corinne seemed to imply, was innocuous. The report from several care workers suggested that theirs was a different and experienced reality. There were tensions apparent between the account of the manager and those of the care workers. For example, Sheila a care worker reported that when she came out of the lift one time she found the couple in a more sexually explicit situation than the one described by Corinne.

Aye it was at the lift and I couldn't believe it one day and I'd come out the sitting room and thought "Oh my God he's (Will) standing at the lift he's telling her (Wilma) to rub it (his penis) harder (laughs) (Interview with Sheila)

The care workers, although Sheila laughed when reporting the incident, were by all accounts flabbergasted by what they had discovered. Although Corinne's report above suggested a liberal approach to this sexual expression, the management plan nevertheless was that of separating the two residents following discussions with the residents' carers. The care workers worked hard to keep the two residents apart by careful surveillance. Privacy, particularly privacy within the bedroom, was not an option for Wilma and Will.

In her work, Lee (1993) discusses protection of the residents by the workers over territorial boundaries with visitors having to show they could behave appropriately. In Glenevis similar dramas were being enacted. Sandra was a younger resident who had suffered a stroke, who appeared cognitively impaired as a consequence and who thus was considered vulnerable. Her daughters visited regularly and too did Sandra's boyfriend who was viewed by a number of staff with suspicion and some hostility. Others such as Sheila, a care worker, viewed him as a source of help.

Yeah Like a lot of folk (care workers) used to always moan about him (Sandra's boyfriend) but I've never had a problem wi' him. In fact I'm grateful because if it wasn't ae for him it would be a big load really because she is heavy work. So wi' him being there it's taking a wee bit pressure off you. (Interview with Sheila)

However when I started to inquire whether Sandra's boyfriend was able to do other aspects of care for her, such as putting Sandra to bed, it became evident that this posed difficulties for (some) staff.

CA So does he care for her in other ways? Does he put her to bed at night anything like that?

Sheila - No. I put her to bed. He was doing it. I don't know the views of the other staff but we felt that if he was putting her to bed she wasn't ae getting washed. Well I like ..But when he was doing that he was just putting her to bed with her vest underneath her nightdress.. So that wasn't ae nice.

Beth was more forthcoming about the reasons why staff now put Sandra to bed. She seemed to suggest possible abuse by the boyfriend, but there was ambiguity evident. They suspected abuse but they just did not know for sure.

Err not an easy man no but I always just try and keep on the right side of him He's had her out once up at the house..but he used to put her to bed at night when he first started coming here but we weren't very sure about it. I mean he done it for years granted em but I don't know if it were this that decided it but we did speak about it. I'm no saying we didn't speak about it but we decided that em yeah that we would put her to bed and that's the routine now.

CA You didn't feel comfortable him putting her to bed?

Beth Not particularly no. None of us felt particularly happy about it. I know a couple of times when I went in em she was upset and I couldn't understand why she was upset and I thought, 'God you just don't know' and this is the thing. Now we put her to bed and she's never upset. (Interview with Beth)

The decision that staff would put Sandra to bed was taken without any discussion with Sandra and her boyfriend. It was based on observations, surmises and intuition and was based on a real desire to protect this vulnerable woman from abuse. Yet I observed when her boyfriend walked into the sitting room, Sandra's face radiated pleasure and happiness. There was a lot of ambiguity present. Paul, a young male care worker, noted Sandra's poor quality of life and her (sexual) needs that related to her boyfriend.

I think the staff were very negative towards the boyfriend and have continued that. What I disagree with is that staff, not knocking the staff, but it's just that I feel that he's coming in and assisting Sandra to bed and Sandra is quite happy with this she's not distressed at all. My feelings are that I'm quite happy for that to happen... but the staff and er senior staff are very clear that we should stop it (allowing Sandra's boyfriend to put her to bed). I just feel that they shouldn't be doing that because it's obviously what Sandra wants. It's part of their relationship in the past. ..As long as Sandra needs are being met and one of her needs is to have him in her life... (Interview with Paul)

Corinne, when I interviewed her, pointed to the very fine dividing line between protection and control taken by staff. The above situation appeared very difficult but whether the difficulty was for staff or for Sandra is a moot point.

The dangerousness of bedrooms did not pertain only to the protection of cognitively impaired women residents. Staff were concerned about their own sexual reputation and safety. For example, Peter the arts worker in the home, because of a case that was currently being addressed by the social work department, reported that he seldom went into the bedrooms of male or female residents. The case he spoke about was that accusations of sexual abuse had been made against a male care worker and this had caused a furore. Peter was anxious never to place himself in a position where such accusations could be levelled at him. Also Gladys, an older care worker who had worked at the home for over ten years, reported that she refused to go into the bedroom of a women resident to help her with intimate tasks. This resident, Christine, who had

mental health problems, had accused the staff of being lesbians. Gladys did not want to be seen in any way to be associated with and labelled by, these accusations.

7.9 Conclusions

This chapter has provided a descriptive account and a stage setting or context in which to site the findings from the ethnographic study of Glenevis. Following on from the last chapter, several of the main themes to emerge such as gender, ambiguity and private and public space have been explored further. The findings from this chapter on spatiality, tentatively begin to address how these themes may be central in why sexual expression tends not to be more widely discussed, and in addressing the research questions I have posited.

Ambiguity, where there is uncertainty in situations involving sexual expression, for example, where there are no witnesses as to what actually occurred, appears a factor. This is noted in the situation described above involving the woman resident with advanced dementia. It may be that if staff feel uncertain and unsure, they do not want to be seen as overreacting. The 'talk' then becomes talk amongst themselves as opposed to discussion with the managers. This may be a valid response in situations where, as the data suggest, managers report that care workers often tend to overreact when sexual expression occurs. Yet as noted, managers tend not to leave their office other than for short forays, so they do not have to deal personally with these situations in practice. They may therefore be able to express more liberal ideas and in theory react in a more measured way.

One of my research questions addresses how context may influence staffs' response. The findings here point to the answer being complex. There are paradoxes inherent between the public and private space in the home that make the simple dichotomy of such concepts as public/private and home/institution unsupportable.

The postal survey findings pointed to managers approving of residents who did not have dementia expressing sexuality in the privacy of their own bedrooms. In this chapter the data indicates that staff find the bedroom area dangerous sites when some residents with 'confusion' express sexuality. Bedrooms are places of privacy but as noted they may also become places of potential (sexual) exploitation or places where surveillance is difficult and loss of control of the situation may be experienced by staff. Sexual risk taking was often not seen as an option. Yet there were few places in the home where sexual expression did not happen including the small sitting areas as noted above. Corridors and other public places in Glenevis, such as the forum, appeared to be places where the private act of sexual expression did occur. The private act was enacted in public but in some situations as discussed above, it was felt by staff to be a safer option. The residents could be seen and thus their actions controlled. Care workers, such as Martha, reported that it was only when residents publicly acted out sexual expression that staff were alerted to the sexuality of residents in their care.

Little research has been undertaken with regard to how sexual expression may impact in small-scale living situations. The design of small-scale and thus homely and domestic residential care living areas has been treated unproblematically yet my data points to these small sitting room areas possibly being challenging for some staff and residents with regard to sexual expression. Any sexual activity in these areas is amplified due to

the intimate nature of eight residents eating and spending most of the day within this rather cramped area. They are amplified for staff often working alone in these small sitting rooms. Embarrassment was voiced as a major concern, an emotion that staff possibly would not readily share with others. So in these situations the context may have an effect on how care workers' respond. Embarrassment may mean that they will not talk about and may possibly hide knowledge about these potentially embarrassing occurrences. It thus remains a hidden issue. This will be explored further in the chapter on emotions.

From a feminist perspective, gender is a main source of concern. It has emerged as a major theme of this chapter as in the previous chapter but with some differences apparent that have resonances with the findings from the literature. Emerging in this initial analysis is that the sexual identity of women residents appears as asexual or childlike or, if they have dementia, as vulnerable as potential victims of sexual exploitation, by sexually predatory male residents. What is also emerging in terms of gender is the sexual responsibility of the female care workers. It is another construction of women. Rather than victims, women are seen as the people who should be responsible and take a key role in controlling men as at the bar night situations described above and this impacts on how they respond to resident sexual expression.

Juliet Blair (1981: 211) talks in the context of actresses but it is of value here in terms of how women generally are 'seen'. A woman who can be observed in public by men not related to her in ties of kinship or marriage is considered in many cultures to be drawing attention to her sexuality. The image of women is tied up with the idea of stimulation to the heterosexual act. The visual stimulation of men is thought to be such

a basic biological fact that it is hardly questioned. Women are seen as agents for controlling and civilising the wayward energies of men. In Glenevis, the sexual reputation and moral conduct of residents and some family carers has emerged but so also has that of staff. Women care workers may be at risk if they are wittingly or unwittingly 'seen' to be encouraging the advances of male residents. Recent research testifies to the persistence of sexual 'reputation' as a concern for women (Holland, et al 1990). This may be a factor in possible under reporting of resident-to-staff sexual expression.

One of my research questions asked about the types of sexual expression that staff find most difficult. The findings from the postal survey point to resident-to-staff sexual expression being considered the most difficult. There may consequently be silences around the reporting of this type of sexual expression. This theory is explored later in the thesis.

The findings in this chapter are somewhat equivocal when addressing the role dementia plays in care workers' response. Where the person has advanced dementia and there is cause for concern about the woman being sexually exploited, then as noted above, care workers respond by watching and protecting the woman. In this case the role assigned by staff to women residents with dementia is once more that of a vulnerable woman in need of protection. Where the role of dementia is less apparent, and when male residents with dementia or cognitive impairment express sexual intent towards the care workers, gender appears a more prominent theme. Here (stereotypical) male sexual behaviour, as opposed to the 'halo' effect sometimes associated with dementia, is to the fore. The themes of ambiguity, space and gender will be explored further in the next

chapter, as will the research questions discussed earlier. The theme of spatiality is explored further addressing specifically the metaphorical closeness reported by care workers between workers and residents that is exemplified in the key worker/key resident relationship.

Chapter 8 Sexuality and the Social Organisation of the Home

8.1 Introduction

In the last chapter I began the analysis grounded in the data, providing a stage setting for the 'actors' who work in Glenevis. This chapter (chapter eight) addresses what both staff and residents do in the home and the culture that underpins their social interactions. How the 'actors' behave and what they say, both on and off stage with regard to sexual expression by residents, is explored. This is important in the way it provides a route map of sexual expression in the home building incrementally on the themes that have emerged in the previous chapters such as ambiguity, gender and space. The theme of gender is apparent in terms of resident sexual expression described but is mainly the themes of ambiguity and space that are explored further. Other themes such as infantilisation and ageism emerge in the analysis and are explored. How these themes help in addressing the research questions, is noted.

Following on from the discussion of spatiality in the last chapter, I begin this chapter with a description of the routine of the home. What care workers do within this context and what happens when there is sexual disruption of this routine, is considered. The roles that care workers assume, exploring both familial and 'professional' debates and how care workers access knowledge, are addressed. I note that the occupational culture of the home points to a movement towards 'disciplining' the work of care workers, for example, the introduction of Scottish Vocational Qualifications (SVQs) into the work place.

The social structures in Glenevis are considered, allowing sexuality to be contextualised and situated as something constituent in human relations within the home, rather than as something discrete and apart. Katz (1996) drawing on the work of Foucault, uses the word 'disciplinarity' to cover the process that legitimises and authorises the creation of disciplines. It involves power relations where people are regulated, classified and governed, in short, disciplined. Using some of Katz's idea I argue that whilst the routine in the home 'disciplines' the residents, it does not always manage to contain 'scary' acts of sexual expression. The task-orientated work routine appears to offer little sexual space but this can be deceptive. When sexual expression does occur it can, as a consequence, be amplified and constructed as 'shocking' by staff. The geography of the home, as noted in the last chapter, renders the total surveillance of residents difficult, which adds to the general disquiet particularly in the areas of risk and protection of perceived vulnerable women residents.

How care workers perceive residents is an important constituent in exploring how sexual expression is managed in Glenevis. I theorise that there is an implicit (and sometimes explicit) culture of both infantilisation and ageism within the home that militates against the needs of residents, particularly residents with dementia. This appears to influence how care workers respond to residents when the resident's sexual (adult) self comes to the fore. I use typologies as an analytical device both to look at staff identities in terms of how this influences the management of sexual expression by residents and to explore how resident identities are constructed. Residents are described by some as 'friends' but often depicted

as recalcitrant children. There are apparent difficulties for some workers in reconciling these 'child-like' identities with sexual expression.

I conclude that the apparent tight routine of the home does not contain sexual disturbance. Space as a theme is important in terms of the difficulty of surveillance, and the issues of private and public discussed in the last chapter, once again emerge. Implicit is ageism. Staff by not considering residents as sexual beings often have difficulty when confronted by resident sexual expression. I note that whilst both the professional and familial debates around sexuality influence care workers, neither necessarily provides guidance for staff when they have to address the expression of sexuality by residents in the home.

The findings from the data suggest that familial debates are more influential and are deeply embedded in the culture of the home. A recurrent theme to emerge in this chapter is that of space, specifically, metaphorical space. Care workers report that a major component of job satisfaction in caring for residents is that of forming close relationships and becoming close to at least some of them. But this closeness can be (sexually) problematic particularly within the key worker relationship. Lastly, and briefly, I will explore how pivotal individuals appear to influence how sexuality is constructed and acted on within the home.

8.2 Work and the routine in the home

Ethnographically, as with any organisation, the social organisation of Glenevis encompasses routines, rituals, the environment and how work is constructed. The batch

living described by Goffman (1961) and the depersonalisation of residents (Peace et al 1997; Booth 1985) was observed at times in Glenevis but also at other times, caring and kindness was shown. There appeared to be a dissonance between my observations, allowing to a degree residents' perspective, and how care workers perceived their (work) environment. This became apparent when looking at the temporal aspects of the environment; time passing and how for example, residents' lives were ordered and potentially restricted. Goffman (1961) notes that in (total) institutions, time itself becomes a punishment epitomized in the monotony of routinisation. In Glenevis I observed long periods of time in some flats, where literally nothing seemed to happen other than the flicker of the television screen. Whilst the care workers noted that for them, particularly in the mornings, there was never enough time- "*time flies*" (*Interview with Jenny*)-the monotony was evident for residents whose day seemed often only to be punctuated by mealtimes.

Ethnography provides a framework to examine methods and procedures employed by people to construct, account for, give meaning to and make sense of their world with the researcher often a stranger in their midst taking note. I was a stranger to residential care in terms of spending long periods observing the work process. Previously my world, when I had last carried out bodywork, had been that of nursing on busy acute hospital wards so I had to adjust to the workers' definition of being 'busy' and under pressure. I needed to enter their world.

When work started in the morning after the report, there was quiet in most flats. There was none of, for example, the bustle of a hospital ward. Most days, the staffing ratio was one care worker to sixteen residents and as each resident had their own room, the bulk of the initial morning work was carried out behind closed doors mostly closed to public view. There was only the muffled sound of a care worker's voice to be heard with sometimes a sleepy response from a resident. The 'sleepy' environment belied the rush behind the scenes, the rush to complete the productive body activities of the person (Lee Treweek (1995). Whilst ostensibly the atmosphere appeared to be relaxed, the care worker had to accomplish a variety of tasks ranging from housekeeping to heavy physical care particularly at this time when work appeared highly routinised with tasks needing to be completed by a certain time to meet the meal schedules.

Task orientated care, as opposed to a person-centred approach, (Kitwood and Bredin 1992) was evident. Anne a care worker previously reported that there were few rules in the home but on observation and in practice, implicit rules were in evidence.

Anne (care worker) then went to knock at the door to get the residents up. So much for them staying in their bed for as long as possible as she described to me earlier. Charlie, the new resident with very poor short-term memory, did not come through (for breakfast) until everyone had finished. Anne kept going through to get him to come to the dining room. Bella came through rubbing her eyes and she said she could have stayed in her bed. Anne said that she could "go back to bed after breakfast."

Bella did not (go back to bed) and later fell asleep in the chair. (Participant Observation)

Residents were 'encouraged' to get up for breakfast but once up, dressed and breakfasted, they were left sleeping in the chair or watching television until coffee was served later in the morning.

Grint (1998:3) talks of the 'enigmatic essence of work' and the social constructs that provide the framework as to how we 'read' work. When care workers started to work at Glenevis they reported that there was the expectation that they would have the time to talk, to take residents out and generally have a closer relationship with them than they had in previous work situations. This is what they aspired to and what seemed to be valued in their work situation. Morag, a care worker who had worked previously as a nursing auxiliary, for example, noted,

You get much closer to them and you're more acknowledged by residents and relatives than (working in) hospital. (Interview with Morag)

Becoming close to residents was reported to be a large component of care workers' job satisfaction and this was echoed by other care workers such as Martha and Gladys, two of the older care workers who had worked at the home for ten years.

However when the routine of the home was observed and care workers' report of the routine of the home was analysed, there appeared to be discrepancies that mirrored Bland's (1997) findings where most of the work time is allocated to physical tasks, with little available for psychological care of residents. The routine of the home is epitomised in Fiona's account. The almost 'stream of consciousness' narrative helps to provide an insight into the 'treadmill' aspects of the day in the home that leaves little time for reflective practice to occur.

CA So you come on at 8am can you just take me through a day?

You come on at 8am and then when we come up the stairs and tell the residents that their breakfasts are going to be up shortly and you put the stuff on the table and get the kettles all ready then we'll - some of them (care workers) will get residents up before breakfast fine if you've got time but if there's a busy (period) then you would just put their housecoat on and take them through to the sitting room and give them their breakfast and give out their drugs then we'll go back in and get the residents who aren't dressed and those that need a help we'll get them done and do the beds clean out the commodes and set the tables for like dinner time and if you've got some time to spare you'll go and sit in the sitting room and talk with the residents and that and if someone wants you to themselves you can go into their room and sometimes that happens - er put away the clothes sometimes in a morning if we've got time then we do the dinners and after dinner time we just sort of clear away and take a couple to the toilet if it needs to be done er then we go for our tea break and in the afternoon at 2pm we make all the beds cause there's a unit each day to give a

full bed change so we make up the beds then after we come up at 3pm we take up the trolleys again and put all the dishes away. (Interview with Fiona)

While Fiona did mention *if there is time to talk to residents* the whole tenor of what she said placed emphasis on the tasks to be done as opposed to person-centred care approach to care and becoming close to residents. Fiona's discussion later was more about the ordering of bodies and body management. The satisfaction derived from seeing shining clean bodies as evidence of work achieved is apparent.

Aye so it's different on each floor but it's different kind of busy sort of thing. At least on the ground flat and back (where residents are more disabled) you can look back and see your work sitting in front of you whereas on the other two floors you're running about mad like but you can't really see the work because you've not got the residents that you've just washed and dressed (laughs) sitting in front of you. (Interview with Fiona)

In Fiona's account something akin to the Taylorist model of organisational efficiency (Grint 1998) is apparent. This seems contrary to addressing the psychological needs of residents that was being espoused both by management and care workers. James (1984:131) notes with regard to nurses: 'Nurses do things as their work...If they are not doing something physical they are not working'. This appeared to be true of many of the care workers at Glenevis. Whilst there appeared many constraints on staff, what was also apparent was that there were many missed opportunities to spend time with residents and

so achieve the desired closeness. This was true of staff on both day and night duty. This task-oriented approach is important to acknowledge in terms of context and how this highly routinised situation will affect care workers' response when residents with dementia express sexual intent.

8.3 Sexual disruption of the routine

In this section I want to explore how, despite the apparent tightly organised routine within the home that regulates and disciplines residents, sexual expression can occur. Whilst this discussion helps to provide a context for sexual expression by residents, I want also to explore how within this context there are factors that may influence how and in what way sex is discussed with others.

In the previous chapter I noted how, as in other studies (Willcocks et al 1987), the care workers can appear somewhat cavalier in respect of residents' privacy and personal space. For example, some care workers gave a cursory knock and without waiting for an answer walked in. This was again highlighted by the story of Teresa, a care worker who had worked on night duty for several years in the home and who had cared for her own mother-in-law for a number of years. Part of the routine of the home was to wake some residents early with a cup of tea. From Teresa's and another care worker's report, this reveille call inadvertently appeared to reduce the residents' private (and sensuous) time in bed in the morning. Allowing them for instance to masturbate in the privacy of their room.

...in here there was a lady who was doing it (masturbating). So I sort of knocked and walked in but I think I was sort of quick and er she was quite flustered and actually managed to stop I think but I just acted as normal and said "I've just brought your coffee and tablets and left them at the side of the bed" and spoke about her teddy bear and said "it was nice" just to give her time to get herself together. (Interview with Teresa)

Firstly, the use of language is interesting. Teresa uses 'it' as shorthand for masturbation. 'It' is used often in when care workers describe issues pertaining to sexuality which seems to suggest the difficulty of finding a comfortable vocabulary with which to discuss sexual matters that resonates with the literature.

In the above scenario, Teresa quickly realising what was happening, helped to alleviate the situation by her sensitive approach. However, it was an example of the lack of privacy and consequently the lack of sexual space available to residents even within the supposedly private area of their own room. Teresa in this situation and with regard to another resident Michael expressing sexuality, was not only sensitive towards these residents, but was also very reticent about who she told. So whilst invading the privacy of the above resident she did not make public the sexual stories. A theme to emerge in the analysis in this and other report from care workers was the protection of the resident's reputation. Often in these situations as described above where the worker 'discovered' a resident expressing sexuality in their own room, or the resident disclosed something of a sexual nature to the care worker, some care workers reported that they would be circumspect with whom they would

discuss these issues. This would then impact on the general knowledge of staff in the home about sexual expression by residents. Confidentiality and respecting the resident's privacy on matters sexual is ethically sound but may limit the sharing and understanding of, sexual situations that other staff may encounter in their work situations. I will return to this in the conclusions of the thesis.

Returning to the discussion of the routine in the home, when the residents were up and dressed they either sat in the small sitting rooms or they went to the forum. Some sat in their bedrooms and the few who were able, went out to the shops or possibly to the pub. The routine as in similar organisations (see Parkin 1989, Lee-Treweek 1994) seemed immutable. Certain groups in residential care are seen to need order because they cannot 'control' themselves for example, children, older people and people with learning disabilities. Routine is often seen as necessary so that anarchy does not prevail. The routine might equally be considered as a means of containing (sexual) disturbance, where (residents) bodies are part of the physical disciplining of the organisation, though not always successfully. Bodies can become undisciplined and produce scary forms of sexuality as Molly, a domestic who had worked for many years in the home, reported.

...one man who came in for a day and he was sitting with one of the 'patients' and I just came in and he... (demonstrates with hand)

CA He had his penis out?

Yeah. 'It was quite a shock you know'. (Interview Molly with a domestic)

I noted here that Molly referred to residents as 'patients' which has connotations of institution rather than home. She used non-verbal actions to demonstrate what had happened as she appeared to find it embarrassing and/or may not have had the 'right' vocabulary to express what she was trying to communicate which resonates again with Ruth's (1987) work. I used the medical term 'penis' and whilst she did not use this word, she appeared to understand the meaning.

Molly was apparently very distressed at the discovery of this man masturbating in the sitting room, this very private sexual behaviour being enacted in a very public place. It may have been that the situation was made more scary because this man was an unknown quantity, he was on 'on trial' for long term placement and as such was unknown to staff. It seemed that it was the shock of the unexpected and not knowing how to manage the situation that caused the distress. Other care workers seemingly treated Molly in an unsympathetic way. She had to 'tough it' out and used humour to assist in this. There was not a lot of sympathy for her plight (still less for the resident's). This story told by Molly might be described as a 'headline' story in that all staff heard about it, but there were difficulties attached. The telling of these stories to other staff as Molly discovered can lead to that member of staff being gently ridiculed and certainly not treated with any kind of empathetic understanding. This response by other staff may consequently influence whom staff talk to about sexual expression by residents.

...when I seen that man I got a shock and I said to the girls (that she had seen this man masturbating in the sitting room) - (they said) "Was it out?" I said "Oh aye he

had it out but he whipped it in quicker - it wasn't a mars bar, ken?" (Interview with Molly)

The outsider (resident) involved in this incident failed his 'trial' and was not admitted for long term care. The manager said that the sexual incident was not the reason but failed to say why he was not admitted.

Although fixed into 'time packages' by the routine, some of the residents were able to use the routine to find (sexual) space. The two residents referred to in the previous chapter Will and Wilma, both of whom had dementia and who had begun an affair, provided one such example. Will was asking Wilma to masturbate him when Sheila a care worker, discovered them. The two residents were able to plan their affair around staff break time, apparently aware of the staff's routine. They would wait until staff went for their tea break and then become intimate in the corridor as Martha, another care worker noted:

CA Did he really know you were watching him?

Hmm at one stage he would watch and know when we were on tea breaks and that, so we would split our tea breaks so he would know we were around and really that's how we dealt with it until a room became available on another floor. (Interview with Martha)

Although he had dementia, Will appeared to use the routine to avoid the censure and discovery of staff. Yet both Will and Wilma failed to appreciate the inappropriateness of their

public sexual conversations and behaviour in the corridors of the home or perhaps they were not able to find any other place. Dementia is an intriguing and contested label that has many ambiguities inherent. Context here appeared to influence staff response as very public nature of the sexual expression, was shocking to staff and so they felt it necessary to do something about it. The public nature of the affair also resulted in many of the staff knowing about the situation. The role dementia appears to play here is that the residents are viewed as recalcitrant children who are placed under surveillance and ultimately separated as opposed to suggesting they use the more private bedroom space or discussing the matter with them.

As Stannard (1978) notes, whilst residents are 'subjects' under constant surveillance and constantly being assessed, there are difficulties for staff in determining what goes on at all times. I observed in Glenevis that as a result of the low staffing, and the geographical space that needed to be covered, care workers were not able to spend substantial amounts of time with residents. It was reported that the long periods that residents were left to their own devices meant that sometimes considerable time had elapsed before workers became aware of sexual activity occurring between residents. There is also implicit in this, ageism, in that the report from care workers suggests that they seemed never to consider residents and older people generally, as interested in sex. It was not perhaps until a resident informed them or they inadvertently discovered the situation, as with Will and Wilma, that staff were made aware. Martha, for example, reported how, although staff had been aware of Harry occasionally touching the breasts of women residents in the small sitting room, they had not appreciated the extent of this unwanted sexual attention on Cissie a women resident with dementia in the same area as Harry.

' was really quite taken aback at the extent of it and that it had been going on for so long and nobody had known. It was only when she said he (Harry) had been bothering her (Cissie) sexually for a long time... Nobody had picked up on it. We had seen him in the corridors but there was nothing for us to say, "Don't go along there". He was quite entitled to be in the corridor. (Interview with Martha) Gladys, another care worker, verified Martha's account later.

The role of dementia here as previously appears to be that of a woman needing care and protection. Martha appears to express distress that she had not been aware earlier and so offer protection to this woman. Yet there are ambiguities in this situation. Cissie, this vulnerable woman with dementia, emerges as capable and was able to assist Martha, in terms of helping her to feel at ease and comfortable when talking about the sexual incidents involving Harry. Martha reported that for her this was a very uncomfortable situation. It was difficult for her to talk to Cissie about sexual issues. It was difficult to broach the subject as she, Martha, found it embarrassing.

I think she was quite glad to talk about it but at the end of the day she made me feel more comfortable than I think I made her feel. (Interview with Martha)

In the case of Cissie and Harry, one can speculate that the care workers might have consciously or unconsciously, chosen not to see what was happening between the residents as this incurred a high emotional cost. Or, it might also be the case that sexuality was not even a consideration. Whether staff have to be or ought to be aware of residents' sexual

activity, is a contentious issue and depends on many factors and will impact on what gets spoken about in the home. Care workers, as Bland (1999) noted, appeared to place great emphasis on 'the duty to care' with the need to protect, particularly women with dementia, against predatory non-dementing male residents, a finding in my postal survey. Martha's distress was possibly in part due to the fact that she had failed in this aspect of her work.

8.4 How the care workers perceive the residents

The role that dementia plays is an important research question and within this is the identity construction by staff of those with the illness. How staff perceive residents is important when considering sexual identity. If staff do not consider their residents to be sexual beings then discussion about the sexual needs of residents would seem to be redundant. The findings from the observations undertaken in Glenevis, resonate with the work Hockey and James (1993), and point to an infantilisation process often both implicit and explicit, that frequently occurred as part of the care process. The use of infantilisation is useful in exploring the potential damage that the embedded practices of infantilisation can produce in terms of staff response to residents' expression of sexuality. Infantilisation means here treating residents as if they had returned to a childhood state and how this can erode the resident's sense of personhood and adult (sexual) self.

As part of this process older people, like children, are supposed to show affection but are not supposed to have sexual relations. The findings from the training workshop indicated this was how the care workers perceived their own sexual needs would be as they aged and

these would be met by *a kiss and a cuddle*. Older people, and particularly women with dementia, tend to be bounded by debates about vulnerability and an inability to steward their own bodies. In care situations where infantilisation occurs staff can be seen as surrogate parents. There are different kinds of parents and parenting methods (Hockey and James 1993) but what this parenting model should afford staff the authors note, is safety (and control). Without the safety of the parent-child model, there is the potential of being drawn into some kind of uncomfortable and unwanted sexual interaction. This model is not necessarily successful in preventing sexual expression as the later case studies indicate.

A theme to emerge from the data with regard to resident 'identity', was the difference between what staff reported during the interviews and what was observed in practice. In the interviews some care workers reported, for example, that they saw residents as *'friends'*, people on a par with themselves. Morag, a care worker when asked how she saw residents remarked as *"residents and friends"* (Interview with Morag). Anne, an older care worker also reported that she saw herself as a *"friend" to the residents you have to be don't you?"* (Interview with Anne). Gladys, an older care worker, felt that

Each one (resident) is an individual. Some are nicer than others are, some are difficult, and some are absolutely beautiful.

Rhona, a younger care worker, chose not to use the term *'friend'* rather she perceived residents as *'needy'* but also as people who might take advantage and thus needed to be 'put in their place'. *'I just see myself here for someone that needs me. Although when they*

snap their fingers I say “on you go” and make them do things for themselves.’ (Interview with Rhona)

The idea of wilful and manipulative residents taking advantage (of the good nature) of staff was noted both in the backstage area and in the office. It was often a source of mirth, with residents portrayed as recalcitrant children, children trying to get one over on the staff (parents). On observation, rather than an adult-adult friendship, often residents were spoken about, and to, as recalcitrant children. How care workers viewed residents with dementia will now be explored.

8.5 Dementia as a construct in Glenevis Home

In the documents of the home, that is the case notes, where care workers and managers record their assessments and ongoing work with residents, the construction of dementia was interesting. Appendix 7 gives an indication of the many classifications of dementia in the home. The descriptions ranged from a medical focus of, “Alzheimer’s” or “multi-infarct dementia”, to more lay terminology – “slightly forgetful” or “gets confused”. The many different constructs of dementia may have been due to a lack of a ‘dementia’ diagnosis by GPs when the person was admitted, or a reluctance to cite dementia for other reasons. The service manager gave one reason that might explain the GP’s reluctance to use the term dementia. For example, when I started to carry out my fieldwork in Glenevis there had been to date, four managers within the past three to four years with the fifth, Chris, in post during the time I was working in the home. The third acting manager was

reported to have had a very negative influence on the home. *She “wouldn’t have anyone with dementia over the door” and this at a time there were 14 empty beds! (Interview with Caitlin, service manager)*

This acting manager was in post only a short time but her legacy might have been an aspect in influencing how the care workers viewed the residents with dementia. The increasing number of residents with dementia or cognitive impairment was a theme reported by staff. This accords with other studies including Godlove Mozley et al (2000) and Netten (1998) who all report increases in the number of people with dementia in residential care. Sheila, for example, reported that on her flat approximately 11 out of 16 residents had dementia.

...I would say “lucky if there are five without dementia.” (Interview with Sheila)

Roger, one of the assistant manager’s reiterates what Sheila reported arguing that most residents in the home have some degree of dementia.

As I say I’m certain most of our residents have a bit dementia. There’s very few that come in who are totally free of it. (Interview with Roger)

The shared understanding of what dementia involves, was to a degree, evident amongst staff. As noted in chapter one, the literature on dementia has been mainly informed until recently by biomedical discourses. The findings from Glenevis pointed to the care workers’ knowledge of dementia having been acquired mainly through hands-on work with residents or by caring for a relative with dementia. The main construction of dementia by care workers however

appeared to parallel that of biomedicine, where loss, disintegration, and a rather nihilistic approach to care was evident.

There had been little training input for staff yet when I used the term 'dementia' all appeared aware of the meaning. Gubrium (1986) argues that Alzheimer's disease and dementia generally, is something that everyone knows about to some extent. Pertinent here, he notes that Alzheimer's is a "social disease" spread descriptively as much as it is contracted (Gubrium 1986:210). The care workers' descriptive construction of dementia tended toward pathos 'poor souls', the burden they represented in terms of extra work and also the different (sexual) identities they were ascribed. The constructions of dementia were for the most part negative with some exceptions. The exceptions tended to be those residents who were easy to like and where there was little ambiguity as to the diagnosis of dementia, as Beth notes.

There's one just now and she's a lovely wee lady. She's always laughing. She's got dementia there's no doubt about that. (Interview with Beth)

Marion reiterated the likeable qualities in Margaret a past resident but appeared amazed that having dementia and being likeable could coexist in one person. There appeared to be different levels of confusion with some residents seen as '*poor things*' and others seen in a more positive light.

'Margaret, she was in (present resident's room) but very nice, sweet you wouldn't think it (that) she had dementia. Aye amazing really nice.'

(Interview with Marion)

There was in some care workers' report a sense of some understanding and thus sympathy for the person, but the increase in workload that people with dementia represented was also acknowledged and seen as problematic for staff who were already under a lot of pressure to complete tasks. It was the emotional work required that appeared the most difficult.

Dementia can be quite hard cause you tend to have to repeat yourself a lot - all the time, the same questions all the time and it's a shame because some them that are in the early stages of dementia. They know something is happening and they can get quite upset and call themselves "stupid and thick" and it's a shame because it's no' in their control. (Interview with Fiona)

In Fiona's report she notes that residents with dementia are 'no in control'. It is not their fault; they are helpless in these circumstances. Evelyn also spoke about the pathos of the illness.

Poor soul it's a shame and you think what they were like years ago and poor soul she doesn't know what she doing. (Interview with Evelyn)

The domestic Doris reiterated the theme of the extra work that resulted from caring for people with dementia and the emotional labour that was required. Doris had previously cared for her mother who had dementia.

Er but I do think in particular the part (flat) I'm (working) in, like I think they're over-endowed with senile people. I've got five or six senile dementias and you've only got one staff to cater for them so it's hard going. Like, dementia people, they're not always aware of the mess they're making toilet-wise you know and things like that and that makes my work harder you know? And their eating habits is, er a lot of them don't know...how can I say where their mouth is hardly you know, they're spilling stuff, it's on the carpets. They dinn'ae bother me too much except those that are at the stage where they are moaning. .. Yeah, yeah and er if you're having a bad day yourself you know and I'm like everybody else - I serve lunches down the stairs and I've got one that talks all the time, one who's jealous of the one that talks all the time, and she's trying to stop her and the other one er making noises - whinnying you know, and that's all in one sitting room at dinner time. If you're in a room any length of time and it's going on and on at you, not moaning at you in particular, it can be wearing because you canna turn round and say really like if it were your family, your children "Will you shut up the now?" You know you cannae really say that you've got to be really (careful)... (Interview with Doris)

There are a number of issues here. Doris refers to residents as 'dementia people' and 'senile dementias', as somehow 'the other'. The negative construction of dementia for Doris arises from both her family and work experience of the illness. For her it seems to have come to be associated with chaos, disorder and disintegration. Becker (1963) argues that deviance is created by social groups. These groups create rules whose infraction constitutes deviance. Some residents with dementia infringed a number of rules in terms of how residents were supposed to behave.

For Doris those residents she described seemed to have become for her, little more than animals (or children!) with their 'whinnying' sounds and gross eating behaviours. She elicits more a scene from Bedlam than that of a 'home' yet the tension between public and private was apparent. Although Glenevis was reported by care workers to be a 'home' with almost a sense of family associated with (some) of the residents, Doris reported that she was not able to speak to the residents with dementia as she would her own family. She had to 'be careful' and watch what she said to residents. This was a work situation as opposed to home. There were parallels with her children in terms of the mess and disorder but she could not deal with situation as she would in her own home. She was required to 'do' some emotional labour. This will be explored further in the last chapter.

8.6 Dementia and extenuating circumstances - the 'halo' effect

Following on from the above discussion I wanted to explore whether the care workers' social construction of dementia would provide a similar 'halo effect' when people with dementia expressed sexual intent and what the costs were for both care workers and people with dementia. Marion reports

If somebody had their marbles and ken what they were doing..it's a wee bit different.

CA So you feel somebody that if they had their 'marbles', that they would be kind of responsible for their actions? It would put a different slant on it?

Aye. Somebody with dementia wouldn't know what they were doing. (Interview with Marion)

Andrea also reported the similar sentiments.

CA If a resident with dementia made sexual overtures to you would dementia make any difference?

It would. I would tend to make allowances. I wouldn't consider him (she assumed I meant a him) then to be just "a dirty old man" (and then hurriedly said) I mean he wouldn't be a dirty old man anyway. (Interview with Andrea)

There are several points from Andrea's quote that are important to explore. Once more the person who had dementia would be exempted from any (sexual) responsibility. The assumption that the person making sexual advances would necessarily be a man was interesting. This gendered interpretation of the sexually active male resident appeared to permeate the data with some exceptions. Christine's story discussed in chapter 10 for example, where she accused all the female staff of being lesbians, demonstrated this was not always the case. The second point is as Andrea implied in the above quote, that if the resident did not have dementia and made sexual advances he might well be seen as the proverbial 'dirty old man' as opposed to someone who might have sexual needs however inappropriate the context. He would be seen as breaking the behaviour/body rules (Lawler 1991) discussed earlier and treated censoriously as Andrea indicated.

The difficulties for staff were around whether the resident had dementia or not. This knowledge was to an extent based on what was reported in the Kardex, but the resident's dementia identity was also constructed based on how staff perceived their behaviour in practice. Ambiguity was ever present. Beth reported:

Hmm you see it where you'll get somebody who you think "have they got dementia, have they not, like Michael.. He's got a certain amount of dementia but not a lot, and you can sometimes think "he's not got any dementia". Another time you' think "Oh aye he has got a wee bit" And we have been told he has slightly - it doesn't come over a lot compared to someone else where you're very aware of it. And you

get someone else where they can hold a conversation with you 10 minutes and then it suddenly slides. (Interview with Beth)

Fiona was more emphatic in her assessment of Michael's cognitive status:

As I say if he (Michael) had dementia he had an excuse but he's not (suffering from dementia) so I dinn'ae find that acceptable of Michael. He knows everything he's doing. (Interview with Fiona)

The difficulty for care workers was that it was not always apparent whether the resident's behaviour was of a sexual nature or it was simply a result of dementia. Their knowledge was often based on their own observations and life experience.

8.7 Care workers and family discourses

Following from the last section I would now like to explore issues around family discourses, that is sets of knowledges that care workers hold about family roles and expectations. This is important, as there appeared to be a mirroring of caring family relationships that care workers brought to their work situation. Most of the care workers who came to work at Glenevis had little further education. They worked previously in shops or factories with some having worked as auxiliaries in nursing homes or hospitals, as home helps and one had worked in sheltered housing (see Appendix 10 for staff details). A strong theme to emerge was that most of the women care workers were involved in familial

caring whether caring for children and (or) older relatives who had dementia or other physical illness (see Appendix 10). This was not generally true of the male care workers.

While some care workers reported a high instrumental focus, for example, redundancy and living locally to the home being motivating factors in applying for work in the home, having family caring experience was cited as one of the main reasons why they applied for the job of care worker. Experience of caring for other groups was also seen as pertinent experience for caring in an old people's home. A large component of the work knowledge of care workers had as its basis family caring. I was interested in whether this 'family' knowledge would help workers manage situations involving sexual expression by residents.

As in any family relationship being close is a determinant of that relationship. Here the findings pointed to care workers experiencing job satisfaction primarily on being able to achieve closer relationships with residents. Care workers, such as Evelyn, Fiona, Cathy, Jenny and Martha, reported that compared to their previous work situations, working in Glenevis allowed time for workers to become close to residents. This however was relative as discussed. Also it becomes apparent that this metaphorical spatial closeness was partial, and could result in certain tensions that will be discussed in more detail under key residents in the next chapter. In this routinised environment the blurring of work and home experience was apparent. There were marked similarities in how Gladys described the routine of getting her residents up in a morning, and a mother getting her children ready for school

Eight out of 16 I have to wash and dress. In a morning you can't stagger the breakfast cause you're starting at 8am report until 8.30 and then breakfasts have to be over by 10am. So what I do to make sure that they all get a hot breakfast. I get a few of them up and put their housecoats on and bring them to the table. A couple I wash and dress although the couple in their housecoats have normally finished their breakfast by the time I get the couple who need help with washing and dressing to the table. So I take one of these away and wash and dress them. That way everyone's getting a hot breakfast. (Interview with Gladys)

Emergent from the data was the increase in the physical/bodywork that care workers were now undertaking with the implications this has with regard to sexuality. Beth, an older care worker, who cared for her mother, reported how she managed bathing and intimate care with certain residents. Often she and Fiona, a younger care worker, bathed a male resident together. *"Which you know just helps to make it sit light and it's company for him."*

What she implied was that working in twos reduced the awkwardness of the situation for all concerned. There are parallels in the data to Lawler's (1991) work in how the genital (and potentially sexual) areas of the body are managed. Lawler argues that body care work covers taboo areas and actions of the body not normally spoken about and thus remains hidden from view. Lawler notes that sexual bodies and body products never come without a great deal of cultural baggage attached in the caring situation-of touching bodies and being touched and practice veers heavily towards boundary keeping. Here Beth describes how she managed boundary keeping when bathing residents:

Likes as I was saying if you were washing some of the men er, you would ask them to wash themselves (their genitals) unless they were demented and couldn't do it. It's like the women if they've got dementia you wash them for them but if they've not, you say could you have a wee wash yourself. You wash their armpits; you wash back, front but....

CA But not in between their legs?

No I always say to them, even some of them (who are demented) as long as they know what to do the women especially know what to do. I just say "use the cloth just give yourself a wee wash and here's the towel". Because you've done everything else for them and the same for men.

CA But it's a way of keeping boundaries I guess as well

That's right and respecting them really as well you know it's not making them feel uncomfortable. I think maybe when you get older they just accept it. You know they don't seem to think anything of it because I mean with women in here if you're washing them you've to lift up their boobs and wash underneath, cause they get all red, you've got to do all that-.you just get on with the job it's just natural.

Beth had received little training, SVQs were in the early stage of implementation so that her management techniques were based on 'life experience' and caring for family members. She reported that it was 'natural' to bath and to see an adult man naked, it was part of care and women's work. Strategies have been adopted however to avoid potentially 'difficult' sexual situations occurring when washing the genital areas. Atherton (1989) notes with reference to nursing/care work, that in no other occupation except for parenting

is care so pervasive with regard to intimate aspects of the person's life. What makes the situation potentially difficult for workers is if the resident is uncomfortable during the process, again showing parallels with Lawler's (1991) work. What also matters to the intimate bodywork being successfully achieved, is that care workers themselves and also the resident are, or appear, comfortable in the situation. *'I think if they start, .. If she was uncomfortable it would make you feel (uncomfortable), but I've not come upon (that).'* (Interview with Beth).

Past experience of caring whether with relatives or in another caring situation often gave confidence and enabled care workers to feel qualified to do the work. However the familial (work) experience did not necessarily help in terms of addressing sexual expression by residents. Clarke (1978) notes as others have noted (Goldthorpe et al 1968: 70), that people's work behaviour is related to expectations which are formed outside the work situation rather than, or as well as, the organisation production in the workplace. Sexuality until recently was considered as belonging to the private realm of the family (but not necessarily talked about within the family). How staff talk about sex is one of my research questions. In families people do not tend to discuss sexuality intergenerationally and this was reflected in Marion's remarks.

Okay we all sit (herself and residents) sitting at the table somebody the same age as my mother.. I just feel it's not the thing (sexuality) to talk to the residents about. I dinn'ae ken it's a different, a different generation from us. They think differently

probably (we think they're) old fashioned. I mean a 26 year old talking to a 76 year old it's not the thing is it? You know what I mean?

CA You feel a bit uncomfortable?

I don't think it's nice to start talking to your granny about sex, it's not very nice.

CA It just wouldn't feel comfortable?

Definitely not!

(Interview with Marion)

The idea that it was not quite 'nice' to discuss sexuality with people akin to your grandmother was interesting. This care worker was very loud, swore a lot and appeared very strict with residents yet in terms of sexuality she appeared diffident. The difficulties of discussing sexuality with residents was not simply the domain of younger workers. For example, Martha a care worker in her fifties as noted earlier, felt very uncomfortable and it was the resident who put her at her ease.

Referring back to the theme of spatiality, there were spatial divisions in closeness for example, bedrooms and bathrooms that appeared to provide privacy and thus provide an opportunity to talk with residents in contrast to the lounge area. The closeness tended to concentrate around physical tasks.

You get a lot more satisfaction if a resident knows you and likes you and gets on with you, you know? I'm not saying that I feel like that with every resident that's in here doing my two nights. There's plenty I don't feel like that with and there's some

of them I do. The trouble is, is when you start having to deal with that resident like a physical illness like you're in their room quite a lot and you start to get to know them - some of them.. (Interview with Kimberley)

For Kimberley the emphasis seemed to be on the resident liking and getting on with her. The closeness with residents had positives but also negatives when she did not particularly like the resident and/or when the resident was sexually suggestive or exposed himself in the private space of his bedroom. Here context became important in how the care worker responded. The privacy of the resident's bedroom when carrying out physical/medical tasks, provided too intimate a space for Kimberley.

I was putting somebody's cream on and they used to sit up naked... at first, this is a man who used to have a cover over him, the downie, and then he wasn't doing that just sitting up and not having anything on him. He was just getting his cream over his back and arms (so there was no reason for him to be uncovered) and I said to the other night shift "When did he start doing this"? And they didn't seem to find anything wrong with that. (Interview with Kimberley)

Implicit in what she discussed was that the resident was receiving treatment and within that context this resident was unnecessarily exposing himself and thus breaking the modesty rule (Lawler's 1991). Other care workers did not consider this an issue, but it was for Kimberley, making her feel very uneasy. The response to Kimberly's story by other care workers appeared not very helpful. She reported. "*I don't know maybe I am quite prudish that sort of*

way but I think it's got to do with you being professional in your job as well not to encourage anything like that and I would never-I would be very aware of something like that."

The lack of shared understanding between Kimberley and the others might be a potential inhibiting factor in discussing sexual incidents amongst staff. If staff generally do not construct certain actions as sexual, and other members of staff do as in Kimberley's case, this might result in the one staff member feeling isolated and even doubting her own interpretation. As Kelly (1996:20) notes, there are a number of ways that women's experiential knowledge is denied, invalidated and forced underground. This may be one such way and will be explored in chapters ten and eleven.

Other workers appeared not to be aware of the potential (sexual) situation and did not construct the situation as sexual. The expression and interpretation of sexuality is an individual experience. It might have been that the care workers did not consider older people sexual or, that they had become enmeshed in routinised work and ceased to be reflective about their practice. The data appear to suggest that societal and familial debates around sexuality influence but do not necessarily provide guidance for staff when they have to address the expression of sexuality by residents in the home. Whether professional discourses have provided help in managing situations involving sexual expression by residents is now explored.

8.8 'Professional' discourses

Whilst the family 'caring' experience remains pertinent it is increasingly deemed insufficient to undertake care work as noted in the literature. Care workers (comprising the largest working group in the home and predominantly women) are expected to undergo SVQ training as part of the 'professionalisation' of care work. This accords with others (Howe 1992:30) who have noted that 'in the public mind, professionalism and qualifications go hand-in-hand' now legislated for in the (Scottish) Regulation of Care Act 2001. As Lee Treweek (1995:4) notes, these educational changes indicate a move to presenting care work as 'real' work with quantifiable and measurable skills. The official language used in social work quality standards documents is the need for care workers to take cognisance of residents' psychological needs, as part of the organisational belief system, with the care workers perhaps internalising and articulating these as key aspects of their work. My findings suggest there are difficulties inherent in practice.

Corinne, one of the assistant managers, noted care workers have '*moved from manual workers to profession practitioners in the course of three years.*' (*Interview with Corinne*). Responsibilities have increased as a result with little training input, and there has been the added disruption of a quick succession of managers in the home over the past four years. Marion discussing how the care worker's job had changed, noted that:

'Aye well to start with we were care assistants and now we are social care workers.

We've got a lot a mair to do now. We got to do SVQs.

CA Yes but not everybody?

No not everybody If you don't want to you don't have to but you get mair money there's that to it and we're professional people they (managers) keep telling us.'

(Interview with Marion)

There seems to be resonance between what Fournier (1999:302) argues and my data. She notes that “the meaning of professionalism, and the type of ‘moral conduct’ it invokes, is not fixed but is highly contestable”. On observation, there was often a dissonance with the managerial vocabularies of ‘professional’ approaches and how some care workers perceived their role. Marion, for example, was sometimes less than ‘professional’ in terms of how she spoke of and to, residents. Although Marion was undertaking the SVQ course, the notion of the psychological needs of the residents plus the sensitive handling of their physical needs was yet to be realised and may never be, as the strength of lay discourses may remain more powerful than that of the ‘official’ ones.

Fournier argues that professional practice not only constitutes the subjectivity of the other (resident) but positions ways in which workers should conduct themselves. This refers not only to how to perform the job but the type of person you need to be to do the job. Care workers in the home had been allocated tasks such as giving out medicines where previously this was a management responsibility. They were now expected to be more attuned and aware of the psychological needs of residents yet as noted earlier, the Tayloristic form of work persisted. This was contrary to the person-centred approach to care espoused in the literature. However, learning these (SVQ) ‘techniques’ was seen to

reconstruct care workers as 'real' professional carers and as such enhance their chances of promotion. This (subject) positioning of care workers as professionals was not straightforward however in the home. Whilst the care workers who had eight years or less experience in this work were encouraged to take SVQ qualifications, those who had worked as care workers for longer, did not. Their work experience sufficed. This will now change with the legislation. However, some of the older staff who had worked in the home for many years were availing themselves of the opportunity for study. Reviewing the SVQ materials I noted that whilst the psychological needs of residents were uppermost, the sexual needs were not. Sexuality and how to manage situations was not discussed. What appeared to inform and influence practice appeared not to be the SVQs but key people in the organisation.

8.9 Pivotal people - the 'toughies'

Identity construction in terms of residents with dementia appears a factor in how care workers respond to sexual expression. Analysing the data and using a grounded theory approach, I theorised that within the home the interactions and therefore the response of care workers will not only be influenced by resident identities, but also the identities of key actors. I draw on the arguments of Grint (1998:127) who reasons that rather than taking 'culture as the glue' holding the organisation together, it is more appropriate to regard this cohesive essence as the result of social action. It is social actions generated by pivotal individuals in organisations that are contingent to the generation of social action. In Glenevis there appeared to be one group that I have referred to as the 'toughies' who by their loud, at times abrasive, manner appeared

to influence the culture in the home and care workers' response to resident sexual expression, more than other groups. I have included in this group Gladys, Morag, Rhona and Marion.

Gladys appeared to be key and pivotal in influencing other workers with regard to sexuality and so I use her as a key informant. In her 50s, she was vociferous and loud and she was quick to state her opinion in both the 'back-stage' and 'front-stage' areas of the home. She was held in some respect and listened to by the younger workers. One motive appeared to be that of impressing fellow workers, (myself included) particularly the younger staff, with regard to her qualities of toughness, knowledge and experience and also her own (good) qualities. Gladys following on from the discussion on 'professionalisation', did not undertake SVQs or 'act up' in terms of management. Hers was a 'common sense approach' and several times she indicated her contempt for academic learning.

"Aye" said Gladys "she (the social worker) has a degree too" (This was the second time Gladys has mentioned someone having a degree and using this as a way of disparaging them. They maybe have a degree but they don't have a clue. (Participant observation)

Part of the tough approach by this group was their challenge not only to academic learning but to management. Rhona, for example, often spoke in a disparagingly way of management, particularly about Corinne, and both she and Gladys I observed subverted authority in their own way. When I first met with the staff group to explain about my research I inadvertently touched on a difficult subject. I asked whether staff worked on the

same flat or rotated and worked in different areas. There was an awkward silence then Chris, the new manager, explained that he had introduced a change in practice. Staff worked on the same flat unless they had to cover for staff working in other flats. During a period of participant observation I noticed however that Gladys and Rhona were continuing with the old practice.

My impression, confirmed later, was that Gladys and Rhona were going round the home in twos although they are supposed to work in their own area. When asked about staff rotation in the home Gladys reported that they no longer rotate. She did not agree with this ruling. During this observation session I observed that she and Rhona subverted the rules. They were doing it their way.

Whilst disparaging management, Gladys appeared influential and kindly in teaching the younger care workers about approaches to take when male residents expressed sexual intent. She also alerted the younger staff to the fact that male residents were sexual beings and that they needed to consider things like bending over the residents and exposing their breasts. Gladys' warnings were often about predatory male residents. This time it was not about vulnerable residents but (vulnerable) young staff. In the next chapter I discuss how Fred, following sexual remarks addressed to him by a male resident, sought the help of an older woman care worker. Gladys was that worker and appeared to listen sympathetically, but referred him immediately to management.

Whilst Gladys appeared to act in a parental way to the younger staff and appeared knowledgeable; a factor that seemed to characterise this group of toughies was the difference in their behaviour during the interview sessions compared to other situations, for example, in the backstage area. Assertive/aggressive loud behaviour was often evident when others were present. In the interview situation there was a distinct lack of enthusiasm and there was discomfort apparent in their body language during the sessions when discussing sexuality. Morag reported:

'If I walked into two old people's room and they were having sex I'd be quite disgusted. But I've never come across anything bad or embarrassing.' (Interview of Morag)

The use of the words '*bad*', '*embarrassing*' and '*disgusted*' gives an indication of a rather repressive attitude to older people expressing sexuality, more specifically, expressing sexuality within the context of the home.

Marion another toughie was also less than forthcoming in the interview situation but it is possible that on one level for her, as with the other toughies, I may have been seen to represent management. At one bar night session when I asked if I could help in any way Marion replied "Yes get the key from Corinne and open the bar." When I went to Corinne for the keys she had been listening to the exchange and said "Is that her (Marion) skiving, sending you for the key." Relations between Corinne and Marion appeared poor and this became more evident as the night wore on. Marion asked me to make a list of the names of

those residents at the bar night session so that we would know who had had their drink quota. She said “I will call out and you write”. At this Corinne stormed out of her office and said “There is a printed list” and that she (Marion) should know this and that I was a visitor and shouldn’t be asked to work. Following this Marion kept making ‘V’ signs behind Corinne’s back.

With regard to residents, Marion appeared quite unsentimental and stated firmly that they should do as much for themselves as possible. For example the bar night session Beth was going to take across two residents’ drink to them when Marion said “leave them (the drinks) they can both come to the bar and get their own drinks. They are quite capable.”

When Marion swore loudly in the back stage area other care workers appeared unfazed by her outbursts but appeared wary of her. Unlike Gladys who listened to Fred, when Marion was approached by Jenny a care worker who was distressed following an incident where a male resident had grabbed her hard by the chin and kissed her forcibly on the lips, she simply laughed.

Whilst some of the care workers (the ‘toughies’) appeared to have undue influence on attitudes to sexuality and how situations were managed in the home and these will be discussed later in the thesis, there were ‘resistances’ from the other care workers. The latter sometimes expressed different views in the privacy of the interview session, from those expressed by the toughies. One of the difficulties of the prevailing ‘tough’ culture within the home was that it sometimes did not allow space for care workers to explore and share

feelings and ideas or to tell their stories. This will be discussed further in the last chapter on emotions.

8.10 Conclusions

In the previous two chapters I concluded that the findings pointed to the themes of gender, private and public and ambiguity emerging as issues and implicated in why sexuality in the homes was either disregarded or tended not to be spoken about. The findings of this chapter add to the previous findings with ageism and infantilisation, reputations and identities and the vocabularies of sex, emergent themes in the literature, being developed here. I have argued in this chapter that whilst the routine in the home appeared immutable in disciplining residents, there were resistances. I have also argued that neither the familial debates nor the professional discourses have totally prepared the care workers to manage sexual expression by residents.

In the last chapter, it was noted that at bar night alcohol helped in allowing care staff to make the transition of resident identity from resident-child to adult-male sexual being. The findings here suggests also ageism and infantilisation may play a part in the ascribing an asexual identity to residents and thus how staff respond. I note that the geographical space of the home and the low staffing ratios do not facilitate observation of residents. Staff therefore may not be alert to sexual expression by residents until confronted by situations, for example, the case of Will and Wilma. But there are tensions within these situations that emerge in this chapter. Care workers have been described by managers in the last chapter

and in the piloting of the postal survey as overreacting to sexual situations, particularly where predatory men are seen to be exploiting vulnerable women with dementia. Yet the situation described by Martha in this chapter, of Cissie being sexually exploited by Harry, a male resident, a situation that had been continuing for some time before the care staff became aware, arguably reinforces staffs' views about the need for control. Staff had noticed Harry in the corridor but had never 'thought' of 'that' happening so this was a particularly frightening, out of control, situation.

Both Martha and Molly, the domestic, in their different ways indicated the difficulties that some staff have in talking about sexuality. Molly had possible difficulties with vocabulary and was embarrassed, as was Martha. As Marion noted, it is not commonplace for discussion about sexuality to take place intergenerationally in families. In residential homes there is a 'mock' family situation so talking about sexuality with people seen as old and from the previous generation appears to be difficult for some care workers. It is similar to the way some people have difficulty in talking to children about sex. It is not an easy subject to discuss and seemed to be made worse for Molly by the lack of sympathy afforded by the care workers. For Martha, it was the sensitivity of the older woman resident with dementia who took control of the situation and helped Martha to discuss the issue.

Identities and reputations came to the fore in the data. Why care workers may not discuss sexual expression by residents that occur in residents' bedrooms, may be due to staff wanting to preserve the (sexual) reputation of the resident. The staff may intrude on the resident's privacy but may not always make public sexual expression by residents.

How residents were constructed by staff appears important in what is discussed in the home, but staff identities also appear to be important and is a theme that will be explored in later chapters. There seemed to be a culture of 'toughness' in the home and I have typified some care workers as 'toughies'. These workers appeared loud but also influential in terms of what topics were discussed and how care workers should deal with them. This culture of how power is enacted, I theorise, made it difficult for some care workers to discuss issues around sexuality and this theme will be developed in later chapters. There seemed to be an underlying concern about possible derision from the toughies about the right way to manage (sexual) situations. Yet these apparent toughies during the interview situation particularly had some difficulty in discussing sexuality with some seeming to use avoidance or delaying tactics.

Residential homes contain elements of both the private world of the family and public world of work and it is to this intermediate zone I now want to turn. Care workers have reported that one of the major components of job satisfaction is the close relationship that can be achieved with residents. Specifically there appeared to be a common currency reported by care workers of the close and valued relationship that accrued between the care worker and their key residents, that could best be described as a mock-kin relationship. Grounded in the data I was interested in how this key worker relationship, that encompasses the private family and public world of work, is affected when residents express sexuality. The tensions that occurred between the 'familial' and 'professional' discourses and how neither fully provided a means to assist care workers to manage incidents of sexual expression, will now be explored further within the context of the key worker relationship.

Chapter 9 Sexuality and the Key Worker Relationship

9.1 Introduction

Following on from the previous chapters, the theme of space is explicitly employed again in this chapter (chapter nine), but mainly in a metaphoric sense. Metaphors convey meanings that are easily understood because it is assumed that they are shared. In the last chapter care workers reported that becoming close to the resident was a component of job satisfaction. This was the ‘talk’ with the key worker/key resident relationship epitomising this rapport. Using grounded theory in analysing the metaphorical closeness of staff and residents, and addressing my research question of how context influences staff response, the question I asked is how does the expression of sexuality impact on these close quasi-family relationships? The ‘emotional geography’ of these situations is explored and deconstructed and it is noted that whilst this ‘key’ relationship can provide aspects of job satisfaction in terms of emotional closeness with the resident, it has certain (emotional) costs.

The key relationship appeared to provide a site not only to explore these potentially close relationships within the context of sexuality, but also allow further exploration of previous themes that converged on this (relationship) site. These include, ambiguity in terms of the blurring of professional and familial roles, the infantilisation of residents and the ‘tough’ culture apparent within the home. Boundaries and the transgression of boundaries will be addressed in this chapter. The parallels with childcare within the family will be considered

exploring the sense of specialness and 'mini-family' status afforded to some of the key residents.

The chapter begins with a discussion of the different constructs of the key worker and the expectations staff have of this role. Grounded in the data, I was interested in exploring what would happen when these expectations were thwarted, when the almost idealised relationship was compromised by a resident expressing sexual intent towards their key worker. Other aspects of the key worker/key resident relationship are then discussed and these include vulnerability and the key worker as sexual confidant.

I conclude that the data support the argument that the key worker/key resident relationship *ought* in some way to be special. The thwarted expectations of the relationship when residents express sexual intent to their key worker is only one component in influencing staffs' response. Other factors appear more important with dementia playing only a peripheral role. The tough culture of the home appears to influence how sex is spoken about and influences who is told what and how. Men residents resist infantilisation and the ascribing of asexual identities. For them, sexuality remains a live issue with boundaries constantly being broached.

9.2 The key worker relationship and its different constructs

I noted in the introduction to the thesis that the care workers reported that as a rule each worker is allocated four 'key' residents for whom they are responsible for providing extra

aspects of care including bathing, taking the resident out and working with their family. The literature suggests that the role of key worker has often been treated unproblematically both in policy and practice. Bland (1997) provides a useful exploration of the key worker concept. She exposes to scrutiny the rather idealised view and expectation of the key worker role that has been of central importance in both practice and in social science for the last twenty years. Bland's (1997) study challenges the intended psychological benefits that were to accrue to key residents noting that the time spent on the psychological welfare of residents by staff, in all residential care settings, was minimal.

Bland's (1997) findings concur with what I had observed in Glenevis where low staffing levels, large geographical areas covered by care workers, the considerable time taken for meal breaks and report giving, were factors that greatly eroded the time available for staff/resident interaction. In Glenevis, care workers reported that for some residents a great deal of time was allocated for physical care tasks. This emphasis on physical care however did not preclude workers from taking time for psychological care. I was not able to observe care workers providing intimate physical care but what they reported was that it was during this time, for example, bathing or putting a resident to bed that time was found to develop the key relationship. Gladys, a care worker noted:

Obviously on a one-to-one basis you have a better relationship with your key worker (resident)... in a bath, in their bedroom, when you're having a conversation, giving them a bit of your time. That happens with every social care worker. (Interview with Gladys)

Significantly for this study, Lawler (1991) amongst others, has noted that it is often at these times and in these intimate spaces that sexual expression occurs. Whilst the key worker/key resident relationship has been seen as 'manifestly appropriate' (Barclay 1982:69) what has not been confronted in the various discussions is what happens when the key relationship becomes 'manifestly inappropriate' for the *key worker* (Archibald 2001). The policy documents (Mallinson 1989) did not, nor do they, address the lived reality when sexuality becomes a component of the key relationship. Using this data from the literature, I was interested in exploring whether the concept of the key worker married with those of the care workers in Glenevis. How within this framework they responded to resident-staff sexual expression was important as was the part dementia played.

9.3 Expectations of the key worker relationship

Of the 17 care workers interviewed; eight made reference to their key worker/resident relationship as important and spoke of the relationship in positive terms (see the table below). Of the eight, five care workers discussed incidents involving sexuality within the key worker/key resident relationship and seven spoke positively about the relationship with only one care worker being non-committal.

Key worker	Positive comments	Neg/comments	Sexual expression
Anne	Yes	No	No
Martha	Yes	No	Sexual confidant
Gladys	Yes	No	(Wanted)sexual confidences
Evelyn	Neutral	Neutral	Male resident exposing himself
Jenny	Yes	No	No
Beth	Yes	No	Sexual innuendo
Marion	Yes	No	No
Fred	Yes	No	Sexual remarks

Most of these care workers reported that the key relationship was seen as somehow special. There appeared to be genuine feelings of warmth expressed when the key workers spoke of their key residents with few offering any critical comments. Generally these care workers reported a sense of difference between the key resident and other residents. Jenny's comments were typical.

I just always think of my own four (key residents) ...I like them a bit better than the rest. (Interview with Jenny)

One can argue that this positioning of key residents in a 'special' category and/or as 'family' is a continuation of the residential 'home' discussions and the blurring of boundaries between the two. It is worth noting here what Skeggs (1997) brings to the fore with regard to family (values). The debates around family values have historically become part of those around female respectability, polarising domesticity and sexuality. The constructions of 'family' and 'home' in the debates tend to signify safety and a domestic environment with sexuality not seemingly a part. Yet sexuality is often, if not necessarily

fore-grounded, a component of family life and sometimes, as the vast literature on child sexual abuse testifies, a traumatic and unsolicited component.

When the construction of key residents labelled as ‘special’ and ‘different’ and by some as a ‘mini-family’ is explored further, it becomes apparent that there are a number of difficulties inherent in these constructions. One is that the debates appear to provide little space for care workers to explore any difficult relationships within this ‘ideal family’ setting. This situation appeared to be further exacerbated by the ‘tough’ culture of the home. The ‘specialness’ accorded to (some) key residents whilst resulting in a sense of closeness between the resident/worker, also seemed at times to be more about a parent-to-child relationship. There appeared tensions between the concept of key worker/key resident being that of empowerment, doing *with* their resident as opposed to caring *for* their resident. The concept of empowerment suggests that of facilitating residents to be as independent as is possible within the constraints of their particular situation rather than that of infantilisation. How the construct of the key resident as ‘special’ may affect the care worker’s response when their key resident expresses sexuality, will be explored now.

9.4 Thwarted expectations of the key worker relationship

Grounded in the data, there appear to be a number of factors within the key worker/key resident relationship that may affect the care worker’s response, including those of thwarted expectations. My findings pointed to Fred, a young male care worker who had

worked in the home for only a short period of time and his relationship with Andrew, one of his key residents, providing a useful example to explore this aspect.

Fred appeared to have had a number of preconceptions of what a key worker/resident relationship should entail that resonates with some of the policy documents discussed earlier. For example, he reported that *“The aim of the key worker and the key resident is that they are supposed to have a (good) relationship together.”* (Interview with Fred) ‘Good’ here pertains to a close and at least friendly relationship with the resident. The basis for Fred’s key worker relationship with Andrew was not ideal. Andrew was already in receipt, in Goffmanesque terms (Goffman 1963), of a ‘spoiled’ identity (he was labelled as aggressive and a misogynist by other care workers). Initially their relationship was uneventful and seemed to be developing positively for both. Corinne, the assistant manager noted that

I think that Andrew had developed quite a good relationship with Fred. He (Andrew) was very isolated but he is now very settled and seems quiet. (Interview with Corrine)

Fred’s reaction at the time he was allocated Andrew as key resident was not clear, but during the interview (following the sexual incident described below), Fred appeared resentful-he *had* to accept Andrew because there were no other male care workers working on the flat.

I chose two residents but I had to take Andrew.

CA You had to take him why?

I had to take him because he didn't get on with female staff. (Interview with Fred)

Bland (1997) notes that there is a need for users to be involved in the debate and discussions about key workers with regard to expectations of the role and in the choice of key worker. In practice in Glenevis the key relationship seemed on both sides (for the key resident and for the key worker) sometimes to be based on chance or expediency as opposed to choice, as in the case of Fred and Andrew.

Fred, early in my interview with him, blurted out and spoke about Andrew, "*I don't think much of him. I treat him as distant as possible, I couldn't be doing with this man*" ... (Interview with Fred). Some of the care workers I had interviewed had been tentative and sometimes it was well into the interview before we were able to discuss sexual incidents, particularly those involving themselves. Fred was different. There was a sense that he wanted to talk. He needed little prompting to discuss his relationship with Andrew perhaps because three months following the incident, he still felt unable to discuss it with others in the home. Fred reported that whilst bathing Andrew, Andrew had addressed gay sexual remarks to him. I asked:

CA How did that feel?

Angry - I felt quite sick I mean I'm not homophobic or anything but in society as a group affair that sort of thing you don't mind them but when it is directed at you in an intimate situation like this. (Interview with Fred)

Fred appeared very disillusioned with this key worker/key resident relationship and implied that he had experienced a real sense of betrayal following Andrew's remarks. Andrew making sexual remarks was distressing but more distressing for Fred was that they were gay sexual remarks. The emotions experienced at the time of the incident resurfaced during the interview (three months after the event). I was so concerned with the intensity of his feelings that when I switched off the tape recorder I gave some time to explore these feelings further. I said that *"I can appreciate it must have been difficult for you going over all those quite painful memories"* or words to that effect. He expressed real anger and what he would like to do to the resident, unpleasant things. I provided time and used counselling skills in affording Fred an opportunity to discuss his feelings. The emotional intensity evident in Fred's story suggested a need for further exploration of emotions and emotional work when addressing resident-staff sexual expression. The findings from the postal survey pointed to resident-staff sexual expression being one of the most difficult types of sexual expression to manage. This was evident in Fred's story.

Whilst I provide time and space for Fred, I was left with a certain emotional fall-out from the situation. Whilst Fred appeared calmer after he had discussed the incident, the vehemence in how he spoke of the resident caused me to question whether I should break

confidentiality and speak to Corinne, his manager. Fred informed me that he had received help and supervision from Corinne but the residual feelings against the resident remained. As I was back in the home after the weekend, and his manager was aware of the situation, I decided against taking any further action but I experienced very real anxieties over the weekend. I later read the work of Lee-Treweek and Linkogle (2000) *Danger in the field* in which they discuss this type of situation that (novice) researchers may have to deal with and the difficulties involved. Their work was a source of help and made me aware that in retrospect I should possibly have sought help from my supervisors or from another source.

As noted, there was a great deal of emotion involved for Fred as a result of this incident. Whilst this emotion was recognised by the manager initially in that Corinne reported, “*I mean he (Fred) was really distressed and was in a dreadful state*” (Interview with Corinne), Fred was not allowed to change his key resident. The manager’s rationale to retain Fred as key worker was that it would be not in the resident’s best interest to change the key worker at this stage. The emphasis was on the resident’s needs.

Sometimes if a resident is very unhappy with a member of staff as a key worker then I would consider whether it was appropriate for this to be changed. I’m not keen on automatically changing

CA If it’s staff who want a change?

If you were to change key workers every time there was a problem, you know, it would be absolute chaos. Residents and staff have to work through problems rather

than push them aside... So I always believe that wherever possible to help the member of staff to work through the situation.

(Interview with Corinne)

As in family conflict situations, Corinne, who had worked for almost 20 years in a children's unit, reported a need to work through a situation. To change key worker each time there was a problem in the relationship would be insupportable but there seemed inconsistencies in Corinne's reasoning. Whilst she had allowed Anne, a care worker, to change Andrew for another resident, Fred was unable to change his key resident. Whilst Corinne had argued that it was not in the resident's best interests, it was also the case that there was no other male care worker available on the flat. When I interviewed Corinne later she appeared not to be aware of the residual feelings that Fred was still attempting to come to terms with and the negative impact the situation had on the key relationship. Whilst Fred had managed to inform Corinne of what had happened initially, he did not feel empowered to discuss the incident further with her. According to Corinne it had been dealt with and managed and there had been no further incidents but as Fred reported the relationship between himself and Andrew would never be the same again.

She (Corinne) said that "It's been sorted" and you know

CA ... It's been resolved?

Yeah sort of instantly and because it sort of isn't, okay it hasn't happened again, you know but it still has the potential to happen to them (other care workers) what happened to me. But the thing is, things will never be the same again and though

that I know ...I'm well aware that his personal care is going to go downhill.

(Interview with Fred)

In this example, the thwarted expectations of the key worker appeared to be simply one factor that impacted on the care worker/resident relation. Fred had to manage not only sexual remarks directed at him by Andrew but gay sexual remarks that proved to be intolerable. In her work Lawler (1991) found that patients touching and making and sexual remarks to staff, were viewed differently and more censoriously, as opposed to other forms of sexual expression, for example, patients exposing themselves. This concurs to a degree with my findings but I found some staff had considerable difficulty also with male residents exposing themselves and masturbating in the sitting area.

One can speculate that whilst Fred's thwarted expectations of the key worker relationship impacted on his response to the situation, these sexual remarks also posed a threat to his sexual identity in some way. Fineman (1993), with reference to nurses, notes that a complex of early-life anxieties concerning sexuality are triggered in the nurse's, and here the care worker's daily work. The emotional complexities involved when sexuality becomes a component of care-giving will be discussed later in the thesis. What did emerge here, a theme previously discussed, was the 'tough' culture of the home that did not provide a sympathetic and supportive environment for Fred to discuss his feelings. Whilst Corinne did provide some support, Fred's concern about how other care worker's viewed him appeared important.

CA So other staff, although they apparently don't know about this (incident), are still remarking on the fact that he (Andrew) is looking at you in a very sexual way; fancying you? And yet they didn't know about it?

Yeah. But it must be obvious. It's got to stick out like a sore thumb whatever he's doing. (Interview with Fred)

Fred found it *embarrassing* to talk to the other care workers about the incident. Initially he spoke to Gladys and he spoke to Paul, a young male care worker, both of whom may have discussed it with other care workers, as some appeared to be aware of the situation. Fred's construction of how the other care workers were aware of the situation was that the blame lay with the resident's lascivious looks and remarks directed at him. It was in some ways easy and safer to blame the resident towards whom he felt this huge anger. Corinne reported that she provided time to discuss the issue with Fred and to address ways of dealing with similar situations. Whether this occurred following Paul's advice to Fred to go back to Corrine and speak with her is not clear. Paul reported that he felt Corinne did not manage the situation particularly well.

The office insisted on him continuing to work with the man (Andrew) even though he (Fred) requested a move from being key worker. They said "It would be a learning situation for him". Paul thought this was not a good way to manage the situation. Fred came to Paul and Paul said to him that "You should go back to management and say that they need to give you strategies on how to manage the situation should it occur again" (Participant Observation)

On one level this was a learning situation for Fred but there had been no anticipatory guidance with regard to sexuality, and although support was initially provided, over the longer period, he had felt unsupported and remained adamant that he did not want to care for Andrew. This had apparently proved to be a traumatic experience for him. The key analytical points that emerge from this case suggest that staffs' private feelings and what is expected of them publicly, in their work situation, possibly needs further consideration and supportive input from managers. There appears to be a need to address not only the needs of the care worker but also to evaluate the impact that a continuing key worker/key resident relationship may have on the resident following a sexual incident (Archibald 2001).

The findings from this case and other care workers' responses, suggest that care workers have individualistic reactions to resident-to-staff expression of sexuality. For example, the same actor in a different context may act differently or different actors in a similar situation may respond in different ways. For example, Andrew also made sexual remarks to Peter the activities worker who, whilst uncomfortable with the situation, had no residual feelings of anger and reported that the tactics suggested by management enabled him to feel confident should a similar situation occur. He reported

Later I was really uncomfortable, and so I reported it to Corinne and she sat down with me and we talked about it for five or 10 minutes or so and that helped. But she did tell me in future to be careful about Andrew and that it's ok to say to Andrew "I'm really not happy talking about that"... and that helped a lot. The situation has never arisen since, but if it does I know now what to do. (Interview with Peter)

There were differences in each worker's work situation that may have impacted on the situation. Peter had a limited contact with Andrew and provided no intimate care and so probably felt under little threat. The situation for Peter was easily avoidable, as he tended to hold group sessions as opposed to providing one-one activities. Fred's position as key worker however resulted in him having to provide ongoing fairly intensive care for Andrew.

Cathy, who did provide intimate care for residents, unlike Peter reported that sexual remarks made to her by residents whether key residents or not, were of no import. *"I feel I could handle that because the talk never bothered me, remarks never frightened me."*(Interview with Cathy) Whilst it can be argued that (some) women deal with sexual innuendo from men on a regular basis, not all staff expressed such a tolerant response as Cathy as the findings from the postal survey indicate. The talk happened also to be 'heterosexual'. Cathy, however like Fred, reported some difficulty around sexual remarks being made by a person of the same sex which concurs with the findings from the pilot survey and the data from the training workshop.

CA How would you feel if it was a woman resident?

Obviously it would make you feel more awkward I think rather than a man doing it.

(Interview with Cathy)

Whilst Fred's thwarted expectations of the key worker/key resident relationship possibly have contributed to some of the intense emotions experienced, other care workers reported

a similar sense of betrayal and outrage when 'sexually harassed' by residents who were *not* their key resident. For example, Jenny cared for Jimmy a resident with alcohol-related dementia. Although not his key worker Jenny had, she reported, achieved a good rapport with Jimmy until he made sexual advances towards her. *"I was on my knees and he just grabbed my face and kissed me on the lips, and there was nothing I could do about it"*. Jenny rationalised that *"He (Jimmy) just had too much to drink that night, and it was just the situation and it never happened again after that."* (Interview with Jenny)

However, several months after the event, and here there are parallels with Fred, she still appeared to have very strong feelings about the event.

I felt "What a cheek! How dare you do that?" you know it was like- I felt like hitting him. Because it was violent in a way and I felt ugh! I felt that he just took it out of my hands by doing that. It was like going over a boundary. Until then you could have the banter but after that it was more... (Interview with Jenny)

Once again, as reported by Jenny, boundaries had been transgressed. In this case Jenny reasoned *"But I thought Jimmy could be ma granddad (laughs) you know. Not quite but... an old man (Interview with Jenny)*. As with Fred, Jenny implied that this old man was or should have been, beyond sexual feelings. There appeared to have been a challenge to the ascribed asexual resident identity.

Jenny reported that there were extenuating circumstances, that Jimmy had been inebriated, but there was nevertheless a real sense of hurt, anger and betrayal. As in Lawler's (1991) work, care workers reported that if there were extenuating circumstances such as dementia, then this made sexual comments and advances, if not acceptable then understandable, but attempting to unravel these circumstances in Glenevis proved challenging. Jimmy had cognitive impairment and a probable alcohol-related dementia. Andrew was cognitively impaired and had mental health problems. In each case these extenuating circumstances appeared not to influence how care workers reacted and how the care workers viewed the resident following the respective incidents. In the incident involving both Jenny and Fred ageism was an issue that contributed to the sense of shock and outrage.

The success or failure of the key worker/key resident relationship generally, seemed to depend on a number of factors. Being sexually 'harassed' by a resident whether a key worker or not, appeared to be a traumatic event, exacerbated for Fred, to a degree, by the thwarted expectations of the relationship. I have argued that becoming close to a resident was an emergent theme and although relative, this was enhanced in the key worker/key resident relationship. My findings suggest this closeness might negatively impact on the relationship particularly when sexual expression was directed at a care worker by their key resident. A particular difficulty appeared to be, as in Fred's case, when the worker was not able to change the key resident and had to continue to address the intimate care needs of that resident.

The 'tough' culture of the home appeared to include at least one manager's expectation of how care workers should respond to sexual expression by residents. After minimal input the expectation was that the care worker would then be able to cope. There appeared to be a lack of insight into the possibility of long-term implications for the care worker following these events. I theorised, grounded in the data in the last chapter, that the tough culture was not conducive to staff sharing the feelings and experiences with other care workers, other than with a selected and trusted few. Resident-to-staff sexual expression seldom became a 'headline' story in the home. This and other kinds of sexual stories told, to whom and why, will be discussed further in the next chapter. What seemed pertinent here, in parallel with the findings of the postal survey, are the tensions between the private/personal values and what is expected professionally of the worker. There were certain work expectations demanded of Fred that did not appear to take account of his private feelings and the emotional labour involved. This will be discussed further in the final chapter.

If sexual expression directed at the care worker was a factor negatively impacting on the key worker/key resident relationship, then a resident appearing vulnerable and in need seemed to have the opposite effect. Vulnerability, defined here as appearing helpless and defenceless in different ways, seemed to generate protective feelings particularly when the resident had dementia. Whether this accords with the key worker role of imparting power to residents is open to question. I will now explore how staffs' perception of resident's vulnerability as an ascribed identity is challenged, when sexuality intervenes.

9.5 Vulnerability as a factor in the key worker/key resident relationship

It is difficult to ignore the power (parent-to-child) relations involved in key relationships when addressing the issue of vulnerability. The care worker adopting the role of (powerful, parent) protector to the resident's powerless (vulnerable child) role appeared to the fore in some relationships. Vulnerability seemed a factor in terms of what motivated some care workers to give that extra input to their key resident. Anne talked about having a *soft spot* for Gerda, one of her key residents who has learning disabilities. In some ways Gerda might be said to be in double (or triple, if gender is included) jeopardy of losing her sexual self. She was old and had a learning disability. Interestingly Gerda (possibly because she had lived in an institution all her life before being admitted to Glenevis and so was familiar with the system) was able to choose Anne to be her key worker. She was very demonstrative and gave hugs readily to staff. She touched and was touched a great deal and demonstrated pleasure in this physical contact. On observation, she gave a lot of positive feedback in her interaction with staff.

*Gerda came in with a duster and Anne gave her a big hug and squeeze. Gerda came up to me and started touching and examining my bangles and asking if I had two of one of the bangles as she liked it. Anne said, "She's just like a child."
(Participant Observation)*

I discussed with Anne as with other care workers, the nature of touch, who does and does not receive touch. In terms of Gerda, Anne was adamant that the physicality of Gerda was

not sexual in intent and became quite defensive at the suggestion. However, Teresa, a care worker who works on night duty, and other care workers initially placed another (sexual) construction on aspects of Gerda's behaviour.

I've heard some of my colleagues talking about Gerda...Er...sometimes some staff can feel intimidated because we have to cream underneath her breasts under her thighs and sometimes her bottom gets red. I think it's just the way she is sometimes she acts quite keen - spreads her legs out and I do know it makes some people feel uncomfortable er...

CA It feels like what- sexual?

I think sometimes like the ones I have met (people with learning disabilities) are usually... it's when they first meet her when it first starts happening they (staff) can sometimes ..but then as they get to know her that's just Gerda that's her personality

CA But it appears sexual?

It can appear like that until they get to know her (Interview with Teresa)

It was interesting to note that Teresa initially implied that people with learning disabilities might be sexually disinhibited. Teresa to begin with interpreted Gerda's behaviour as potentially sexual so that she and other care workers felt discomfited. The situation was ambiguous. However once they 'got to know her' or possibly been informed by Anne and others of the 'right' ascribed (childlike and consequently asexual) identity, the situation was viewed and managed differently in that staff just considered that is how Gerda is and got on with the task in hand. Her behaviour was seen as both understandable and

acceptable. How care workers respond to sexual expression therefore may depend on whether the behaviour is interpreted as sexual or not.

Teresa's refusal to use the word sexual until pressed in this context is interesting. Whether she did not want to label or whether she simply had difficulty with the term is open to question. From this case it appears that how a (sexual) situation is constructed, as in the case discussed in the last chapter where Kimberley was the only care worker to construct the male resident unduly exposing himself as sexual, will influence how it is discussed and managed.

It can be assumed that Gerda, like most people had erogenous zones that when touched produce at the very least pleasurable, if not erotic feelings, most staff somehow had not acknowledged that. The ascribing of an asexual identity may have allowed staff to feel more comfortable but it may have had less positive outcomes for Gerda. Other than being denied an adult sexual status, Gerda was arguably more vulnerable to sexual abuse within the home. Rather than regarding this as '*that is how Gerda is*', perhaps more discussion with regard to needs of Gerda and the boundaries within which care workers need to work, would have been more helpful as the literature suggests (Brown et al 1994).

Beth, an older care worker, discussed vulnerability as an aspect of one of her key worker/key resident relationships. She acknowledged that it was not simply that she has an affinity for her own key residents, rather it was the neediness of the residents per se that was the attraction for her.

But there again I've got a soft spot for Sandra a younger resident who has had a stroke, and I'm not her key worker. As I say, I think it's the ones that, some of them are very independent they do their own thing and everything else ...but it's more the ones who are not capable of mixing that I feel sort of sorry for in a sense (Interview with Beth)

Beth reported feeling particularly sorry for Arthur who was by her own account, her favourite key resident.

I mean likes of em Arthur, I'm his key worker and he has absolutely nobody and.. I'm aware of it he relies on me... Sometimes he doesn't see me much for a couple of days if I'm on another floor. But sometimes if I'm on a backshift I try and spend even if it's a cup of tea with him, but he's aware of me... you know when I'm here and he hasn't got anyone else you know which is really quite sad. He's no mother, father, brothers or anything. Nobody comes to visit him. (Interview with Beth)

According to my data, it appeared possible that the perceived vulnerable and childlike qualities of some residents have helped to forge the relationship between them and their key workers. For Beth, who had worked for many years with children and who herself has had a family, this key worker/key resident relationship might be seen as an extension of that previous experience and as such familiar and possibly pleasurable and fulfilling. Beth reported that what she most enjoyed about the relationship was the fact that Arthur was dependent on her, that he had no one else in the world. It seemed that the relationship was

that of parent-to-child with both ostensibly seeming to derive some benefit from this kind of relationship. This was the case until Arthur became a man (child) expressing his romantic feelings. Arthur was reported by several of the care workers to be a 'nice' man and seen as *harmless* regardless of the sexual innuendo of his comments to staff as Jenny noted.

I like Arthur He says a few things but I sort of...because I like himI dinnae take it... as rude or anything.

CA - What kind of things did he say?

I said like "I had a hangover" and he said "Oh I'll take you through to your bed" That sort of thing. Yeah. But I just laugh at Arthur because (pauses)...I dinn'ae find it insulting (Interview with Jenny)

In Jenny's account Arthur's sexual/romantic remarks appeared to be treated more as compliments rather than threatening in any way. She just 'laughs' it seems at the (mere) idea. Arthur was not taken seriously in his attempts at flirting with staff. Initially, Beth also responded benignly to Arthur's romantic/sexual comments initially but as the (sexual) incidents continued, she developed a sense of unease about the situation and started to question whether she had in some way encouraged him in his advances. She later dismissed this idea but she was not the only member of staff to question and to feel guilty about possibly encouraging the advances of residents. These feelings expressed by care workers have been highlighted and will be explored further later in the thesis. Beth, during the interview, ruminating on the incidents involving Arthur, dismissed the idea that she

encouraged him reporting that she was simply being just '*being ordinary to him*'. Beth, with some difficulty, began to share her some of the problems she had experienced with Arthur with regard to sexual expression, during this interview.

Well that's an example right now with Arthur it's been quite difficult; it's not difficult. It's wrong to say that. I take it over quite lightly but it's just coming over a wee bit more... like a fortnight ago... I went to visit him in hospital, that was the first time I noticed it, and er he said to me "I wouldn't make a very good lover" I just sort of passed it over. I didn't laugh out I just sort of tried to make light of but it's just, it's not an endearment he does but

CA It's a bit loaded?

Yes it is loaded and he is just trying to be nice. He is just trying to be nice you know but I think "Oh dear" I mean it's not that I'm being, I'm just being ordinary to him as I would be to someone else, maybe that wee bit extra because he is my key resident. (Interview with Beth)

But the situation persisted with Arthur making further comments such as "*I wish you would love me*" to Beth. What appeared difficult for Beth was that the situation seemed to be intensifying, fuelled by the closer key worker/key resident relationship. The expected boundaries between key worker and key resident were not being observed. The relationship appeared to have shifted from in a sense parent-to-child, to an unwanted and unwarranted (in Beth's view) adult male-to-adult female romantic/sexual relationship.

Earlier in my fieldwork during an observation period, I observed on bar night, when I was serving drinks at the bar, Beth and Corinne the assistant manager. They were standing near the bar talking when Arthur came to the bar and indicated to me that he would like to buy Beth a drink.

Beth said "a lemonade". I said "I'll put it on your bill" and Arthur nodded sagely. Both Corinne who was listening and Beth turned away and laughed (Fieldwork observations).

Arthur's approach was that taken by any number of men interested in furthering their relationship with a woman and I treated his request seriously. Beth turned away and laughed which made me feel uncomfortable. Arthur on this occasion and on other later occasions did not appear to have been taken seriously by staff. Yet as with other residents, (Jimmy and Harry) sexuality appeared to remain a preoccupation regardless of whether staff preferred to ignore his (adult) sexual status or not. Gender is once more to the fore here with men residents once more the key actors.

Arthur also approached Peter, the activity worker.

There is another guy Arthur I think he has dementia. He has come up to me in the past, when I am on my own, and said "People say I am homosexual," He gets very uptight and you have to sit with him and say. (stops here) that's the problem for me because I don't know what to say. (whether) to validate if he is and that's fine or

say “You’re not Arthur” but that would be going against my own principle as there is nothing wrong with being homosexual ...He has approached me three or four times in the last two years, if he has seen me on my own in the office. (Interview with Peter)

Often, as in this case and the situation involving Fred, there is a sense of the worker’s own sexual identity and sexual values being challenged, also there is a sense that staff lack the skills to talk about sexual issues with residents. The role of dementia for both Beth and Peter appeared minimal. The workers seemed not to take account of Arthur’s cognitive impairment but rather focus on the sexual behaviour. How they responded was to listen and to try to respond appropriately, but they were left with feelings of uncertainty and doubt. This role of sexual confidant into which Peter was unwittingly drawn will now be explored within the context of the key worker/key resident relationship.

9.6 The key worker as sexual confidant

Sexuality was a feature of the key worker/key resident relationship that Fred neither courted nor enjoyed. The situation resulted in Fred reporting that he felt emotionally distanced from his key resident and the quality of care provided had been compromised. A role that Martha neither chose nor sought in the key worker/key resident relationship was that of sexual confidant. However in this situation, where the care worker was that of confidant rather than the object of desire, the key worker/key resident relationship appeared

to improve and be strengthened as a result of this intimacy between the resident and the care worker.

Whilst there was an awareness of some (male) residents' sexual identity and thus an increased awareness that extra vigilance was needed, the social construction of residents' asexual identity appeared a persistent theme. Martha, who was trusted by management to 'act up' or stand-in for managers, reported that becoming close to residents was important when for example, reminiscing and sharing their past.

I think the best part for me about the job is talking to them and just listening to them and the reminiscences that they have - I could sit there all day, fascinated. (Interview with Martha)

Reminiscing provides a therapeutic understanding of older people in the 20th century (see Butler 1963), but seldom does this include the subject of sexuality. Martha was at ease when discussing the past but, as was reported in the last chapter, she was less so when the resident wanted to discuss sexual concerns. Martha following the incident involving residents Cissie and Harry discussed earlier, was still 'taken aback' when Jimmy, one of her key residents, decided to use her as a sexual confidant.

As Jimmy's key worker I found it quite difficult just before they got married. I had a good relationship with Jimmy and he came to me - he had had a drink right enough but he did come to me and was quite worried about marrying Madge. I said to him

that I thought he was happy. He said "Yes I am quite happy to get married but it is the sex bit". Again I was quite taken aback. (Interview with Martha)

Martha reported that Jimmy then proceeded in a frank way to discuss his past and present sexual difficulties that might affect his relations with his wife-to-be. Martha reported that she experienced embarrassment and difficulties in having to respond to a conversational subject that was for her something unexpected and unwelcome. Once she had recovered from her shock she reported that she was able to act in response. A GP visit was arranged through the manager, but when the GP, accompanied by Martha visited, Jimmy denied that he had any problems.

There are a number of points worth discussing from the above case. Jimmy acted in an adult-to-adult capacity that Martha had some difficulty managing initially. He had developed a close relationship with Martha and appeared to be able to trust her. In a number of ways she fulfilled his trust in her. She presented as a capable, middle aged woman in her fifties and in Jimmy's case, invited trust. Whilst she appeared capable in many ways, she reported unease and embarrassment when confronted with issues around sexuality and initially did not feel capable of coping with the sexual (adult-to-adult) confidant role. By discussing the situation with her manager and arranging medical intervention for Jimmy, introducing a medical component, seemed to her a tangible way to help both Jimmy and herself. Jimmy's denial of any problem when the GP visited and a later refusal to attend a hospital outpatient clinic, caused Martha to feel somewhat annoyed following the effort and emotional costs involved.

Martha reported difficulties initially in having to discuss sexual issues with Jimmy but they were seen within the context of his imminent marriage to Madge and therefore appropriate, if embarrassing. Although Martha reported annoyance at Jimmy's refusal to receive medical help, she acknowledged that Jimmy, when sober, found the situation shaming. Jimmy evolved a way of apparently resolving both his and Martha's problem.

I said to him after they were married that if he wanted he "could broach the subject again" but he said "No". He had spoken to Madge and she was okay with that side of her life and it was more companionship....I felt more comfortable with that one
(Interview with Martha)

Whilst Martha appeared more comfortable with not having to discuss sexuality further, the situation, if resolved for Martha, was not it seemed resolved for Jimmy. Anne, another care worker, mentioned that the night staff had reported Jimmy coming out of the room he shared with his wife. He was stark naked and said to the night staff "*My wife wants sex but I can't give it to her.*" *(Interview with Anne)* His (frustrated) sexual needs were again manifested on another occasion, as Jenny so graphically described earlier, when he grabbed and kissed her on the lips. Jimmy's difficulties culminated in his becoming violent to his wife and discharging himself from the home. Alcohol abuse was a factor, but so too, arguably, were the unresolved sexual difficulties. The theme of boundaries being crossed could be constantly applied to Jimmy. For example, his expressed sexual intent towards Jenny and his later violent behaviour towards his wife following a bar night session were

deemed unacceptable by staff in the home. According to what I could deduce from staff report, his sexual difficulties did not seem to be seen as a component of his behaviour.

Paradoxically, Martha reported that she had felt the situation involving the discussion of Jimmy's sexual difficulties had helped to build a closer relationship between her and Jimmy. Consequently when the situation arose where he presented her with *a pack of three* (condoms) when she was about to go on holiday, she was amused and touched.

When I was going on holiday to Majorca and he gave me condoms. I don't even know where he got them.

CA Your pack of three?

Yes. He said "I've got something for you, it's in the drawer." I thought it was a bar of chocolate. I went to the drawer and there was this packet and he said, "That's for your holiday". I said "My holiday!" (laughter +++). He said "I was listening to something on the news, on the television" he said. "All women going abroad should have them". I said to him "Jimmy I'm going on HOLIDAY" (laughter++) Again it establishes a relationship. I didn't find that at all embarrassing,

CA It didn't affect your relationship?

No but some staff said, "Oh I don't know if I would like that." But he was looking after me he saw it on the tele. ... Yes he was looking after me because my husband was not there. I found that quite funny. (Interview with Martha)

It is worth quoting Martha in that she helps to illustrate several issues. The first is that it is difficult to ignore Jimmy's preoccupation with sexual matters. He had obtained condoms from outwith the home and presumably had intended to use them or, as he implied, bought them specifically for Martha. Martha used humour effectively to defuse what some care staff regarded as inappropriate sexual behaviour. Again there were different constructions placed on this story. Martha's construction was that it was inoffensive because it was a gesture of concern. Jimmy was taking care of her. This role reversal appeared to generate mirth rather than offence. Jimmy was seen, as somehow "cute"—arguably like a child offering care to an adult.

Other care workers present when Martha told the story, constructed Jimmy's offer of condoms as less than amusing and as sexual. Martha reported that other care workers when told said; *"Oh I don't know if I would like that."* There have been several examples in this chapter of the different constructions being made of the same situation. It is an important issue, as how stories are constructed may influence the response of care workers. Postmodernism is about acknowledging that reality is plural and also about questioning why some truths are excluded and marginalised. These issues will be discussed further in the next chapter.

I have used Martha as a key informant and used her stories throughout the thesis. Holloway and Jefferson (2000) use reflexivity to understand subjectively their (good) relationship with some of their respondents. Martha, when I reflect on our research relationship, was a source of interesting stories but she was also during the interview situation, willing to ponder, reflect and really question and explore how she felt in the sexual circumstances she describes. I liked

her easy and mature manner and her willingness to share her thoughts. As with any respondent she may have been selective in what she told or had forgotten, but for me, she appeared generous and thoughtful. She is nonetheless a paradox. She reports that she feels embarrassed talking to residents about sexuality, yet unlike the 'toughies' I interviewed who were ostensibly confident and telling other staff what to do with regard to sexuality, but were very uncomfortable in the interview situation, Martha appeared at ease when I interviewed her. Which stories are told and to whom will be discussed in the next chapter as this may help to address why sexuality and dementia has been so neglected.

9.7 Conclusions

The theme of spatiality, that of the metaphorical closeness achieved between care workers and residents, exemplified in the key worker/key resident relationship, has been explored in this chapter. The data seems to support my argument that the key worker/key resident relationship in Glenevis *ought* to be in some way special. This debate, combined with the 'tough' prevailing culture in the home, appeared to leave little space to discuss feelings of shame and anger particularly in situations where the resident had directed (his) sexual expression towards the care worker. Whether staff are able to share sexual stories, how they respond to them and what they say about them and the subject in general begins to address the question of why the subject suffers neglect. James (1989) argues that care work/labour makes emotional demands which are equally as hard as the physical components of work but are not so readily recognized. What my data suggests is that this is particularly the case when sexuality is a component of that work and will be explored further in the last

chapter. The intimacy and the expectations of the key worker/key resident relationship appear to influence how and when issues around sexuality are discussed. The need to respect the privacy of the resident, but also the desire to remain silent about the failed key worker/key resident relationship, is salient.

The theme of gay and lesbian sexual expression noted as a finding in the postal survey and in the literature has emerged as requiring further exploration particularly when gay sexual attention is levelled at the care worker. Grounded in the data I explored whether the thwarted expectations of the key worker/key resident relationship may be a factor in care workers' response. On further analysis, thwarted expectations appeared to be only small component in influencing care worker's response to resident expressed sexuality. Other factors seemed to have a greater impact. For example, in Fred's case, what appeared to cause distress was that the sexual remarks made to him by the residents were gay and to a lesser extent, were made by an old man. The remarks were seen as erosion of boundaries between young and old, resident and worker and gay and heterosexual identities. The inability to change the key resident after the resident had expressed sexual intent towards Fred appeared to create a sense of stress and seemed to influence the quality of care afforded to the resident. When the care worker chose not to change key resident, as in the case of Beth, here the key worker/key resident relationship was significant due to the prolonged time spent, particularly in intimate care tasks. This seemed to create and increase tensions. Of note, is that whilst all the residents discussed in the above cases had cognitive impairment, this appeared not to influence staff response. Dementia here had seemingly only a bit part to play. Gender was more to the fore as in each case discussed all the main actors were men residents.

Supported increasingly by the data, I have argued that ageism/infantilisation of residents by (some) care workers influenced how they responded to resident sexual expression. The key worker/key resident relationship appeared to provide a means for some care workers (and some residents) of furthering a parent/child relationship, with the vulnerability of some residents a key component. Following on from the last chapter the infantilisation and the ascribing of an asexual identity to residents appears to influence how (sexual) actions by residents are interpreted and managed. If the resident is ascribed a child-like status by the majority of the group of workers, it then becomes difficult to explore the resident's actions as sexual. The sexual needs/actions of the resident become assimilated into the caring task as in the case of Gerda. Paradoxically this may have the potential, I argue, to render residents more exposed to sexual abuse in the home.

There appears, however, to be resistances by some residents to this ascribed preferred asexual identity allocated to them. For example, Jimmy, Harry, Andrew and Daniel, again all men, appeared to resist staff attempts to deal with situations involving sexuality. For these men sexuality was and seemed to remain a live issue with boundaries being constantly broached. Gender issues are evident throughout the data in that the incidents involving sexuality reported by staff invariably (but not exclusively) involved men as the key actors. The ascribed sexual identity of women residents appeared often to be more that of victim.

The data appears permeated by the lack of preparedness of staff to address situations involving sexuality. This is not particular to Glenevis as Parkin (1989) as noted. The reaction of management to incidents involving sexual expression by residents in Glenevis

was generally responsive as opposed to a proactive response. There appeared to be little discussion and long term support was not considered. There is a strong sense analysing the data, that the greatest wish of both managers and (some) care workers is for the situations involving sexuality to be quickly resolved and residents 'put back into their asexual (toy) 'box'. The wish to evade issues around sexuality is not simply the prerogative of practitioners. Sexuality has remained strangely absent from Organisational Theory until for example, Hearn and Parkin's (1987) work , as I noted in the literature review.

In this chapter I have explored space and the disturbance of boundaries in some depth. The findings from the postal survey, particularly during the piloting process, and from the literature, point to the subject of sexuality being difficult for staff to manage in work situations, with the most difficult type of sexual expression being that of resident-staff. This chapter builds on the previous findings, lending support to the thesis that sexual expression by residents (with dementia) is constructed as on the margins of acceptability. In this chapter staff report suggests that sexual expression particularly resident-to-staff expression in the key worker/key resident relationship, is unexpected, unsolicited and has lasting emotional consequences for some staff. This chapter consequently provides a link with previous chapters building up the argument and generating more questions and issues to be addressed in the next chapter. These include an exploration of the types of sexual stories told and to whom these are told and why. From the data it appears that how these sexual stories are interpreted may influence staff response. This will now be addressed.

Chapter 10 Sexual Stories Told by Care workers

10.1 Introduction

The theme of spatiality was central in the last chapter, the exploration of which, using the context of the key worker/key resident relationship, allowed for the research questions to be addressed and additional ones to be generated. Space as a theme is once more employed but less centrally. Space in terms of stories being situated in the safe and distant past is noted. Following from the previous chapters, the themes of gender, homosexuality, (moral) boundaries and ambiguity are further explored to help address the research questions and add incrementally to an understanding of the overarching research question of why the subject has been so neglected.

Plummer (1995:5) notes that we live in a world of sexual stories and that sex has become the 'Big Story' with the domains of public and private merging. He argues that society itself may be seen as a 'textured but seamless web of stories emerging everywhere through interaction: holding people together, pulling people apart, making societies work'. He questions the idea that these sexual stories take us towards a sexual truth and argues that sexual stories can be seen as issues to be investigated in their own right. Following on from the arguments I have posited so far, the nature of the sexual stories in Glenevis Home is explored in this chapter. Ethnographically, this exploration is important as it is part of the political and cultural processes of the home and often reflects the debates about sexuality generally in society. The social role of the stories, the way they are produced and the work they perform within these processes, is

analysed. Noting the emotions that can be involved in disclosing some sexual stories, I have tried, as cautioned by Pujol (1991), to be sensitive to the network of textual and contextual connections in which the person telling the story is immersed.

One of my original research questions asked what staff say about sex. In this chapter (chapter ten) I explore this question but extend it to encompass what staff say about sex, to whom and why. There have been several examples in the last chapter of different (sexual or asexual) constructions being made of the same situation. This seems an important issue as how stories are constructed may influence the response of care workers. The sexual stories that staff tell appear important in addressing the question of why this subject has been neglected. For example, the data point to resident-to-staff sexual expression seldom becoming a 'headline' story in the home. Only selective staff appear to be party to the information, whereas often the sexual stories about resident-resident sexual expression appear to be general currency. The opportunity or not, to share sexual stories with others may well influence how staff respond to and what staff say about sex. This subsequently begins to address the question of why the subject suffers neglect.

Plummer (1995) notes that no stories are true for all time and space, rather there are multiple layers. The main concern here is that of excavating the layers of understanding that make up the 'reality' of these stories. Yet in this excavation process it needs to be acknowledged, as others have noted (Cheek 1999), that the writing and speaking can only ever be a partial view of that reality. What has been apparent interviewing staff is that their sexual stories are memory stories. Often they have been dredged from the (safe) past. They (and I) are working with memories that have constructed the events-constructions that have probably changed with time and reflection. The construction

then becomes as important as the story as it will reflect how the person relates to the social (Crawford et al 1992). Crawford et al suggest that overall what is important is the social context of the stories and the meaning the episode has for the person. I am interested particularly in the patterns and the degree of control/power that care workers experience in their work lives when sexual expression by residents intervenes.

Bell (1993:66) argues that disciplinary power operates through 'normalising judgement' which not so much relates to a breaking of rules as stepping outside 'acceptable behaviour'. In society generally and so in Glenevis there are well-rehearsed stories about what constitutes moral and immoral behaviour but within these stories ambiguities appear ever present. These stories include how residents, who are constructed as somehow 'deviant' by staff, are disciplined, categorised and marginalised as part of staff coping strategies. Stories can convey a stigmatising message and mark out identities. Identities can mark out difference and differences can help in constructing and defining some residents as the 'other'. This process arguably helps to structure the moral life of the home and that of the individual resident. How 'deviance' is constructed for example, gender roles and gay and lesbian issues, will be explored using the case material provided by the staff.

The chapter begins by exploring the common form the sexual stories take followed by a discussion of how sexuality is constructed, that is what staff say about sex. I argue that staff are constantly negotiating the construction of sexuality as it is an ambiguous and difficult concept to define. The second section provides a description and classification of the stories told. In the third section I will use case studies to explore the themes of gender, homosexuality, (moral) boundaries, ambiguity and space. I note most of the

stories that staff have told are 'memory' stories and as a consequence occupy a 'safe' space having occurred a number of years previously. Space as a theme is useful also in looking at the processes that create a space or not, for stories to be voiced in the home. Plummer (1995) notes for example, that to be able to tell a story or indeed not to tell a story under the conditions of one's own choosing, is part of the political process.

Reflexively, if the argument that sexual stories are part of not only a social but a political process is accepted, then as a researcher I am part of that political process. The understanding and interpretation of the data as noted previously needs to include an acknowledgement here of my own prejudices and preconceptions as well as those of the people I interviewed. I need to acknowledge that I did not interview residents and allow the stories of mainly women residents to be told from their perspective. My focus has been hearing the stories of staff in this study; even here it is only stories that they chose to tell with regard to the work settings. I did not explore staff's family /sexual background as this was not the remit of the study. Yet family history may have had a major impact on what people said and talked about (Holloway and Jefferson 2000) and how they responded to situations involving sexual expression by residents.

I conclude the chapter by noting that the exploration of the sexual stories told has built incrementally on the themes from the previous chapters and has provided a greater understanding of the research questions and the issues. Gender has been a key theme and also ambiguity. Resident-to-staff sexual expression is again noted as a difficult area for staff particularly when there is a homosexual component evident. Some stories reveal that there are high emotional costs and emotional labour involved for staff. This will be discussed further in chapter eleven.

10.2 What common form do sexual stories take?

For the purpose of analysis I have divided the stories staff have told into three categories. All the stories in an abbreviated form can be found in appendix 2. The first category includes the general incidents that staff have reported. The general incidents refer to the stories that staff tell about incidents in general where no residents are named. An example would include, '*men tend to make sexual comments and touch care workers' breasts at bar nights.*' The second category looks at resident-to-resident sexual expression, and in the third, resident-to-staff sexual expression is addressed. All the stories are classified into these category groups (Appendix 2 tables 1,3 and 5) and the ranking of the stories in terms of how many staff told the stories is summarised in tables 2,4 and 6.

Categorising the stories is a useful strategy in providing an overview of the kind of stories told. It offers some indicators as to which staff had access or not to the information and/or who chose to tell that particular story. There needs to be caution however in interpreting the data as for example, some staff had only worked at the home for a relatively short period. Some incidents occurred only after some staff had been interviewed. For example, the story of Michael (story 18) had not occurred when I interviewed Chris the manager of the home. Staff may have forgotten the stories or had decided not to tell. The story (5.4) of a male care worker making sexual remarks to another male care worker (in the presence of other care workers) is a story only the assistant principal officer chose to tell.

The quantification of the data helps to stimulate such questions as to why some care workers are in receipt of stories and others are not. Why do some stories hit the 'headlines' whilst others are supposed to be confidential but are somehow 'leaked' and become underground 'headline' stories. Fred's story (story 6) provides such an example. Appendix 2 provides an indication of the range and type of stories told by staff. For the purpose of this chapter my intention is to explore the three types of story which address the major themes of, for example, ambiguity, space and boundaries, homosexuality and gender that have occurred in the previous chapters and so add incrementally to the understanding. I will explore one of the general occurrences commonly reported by staff, that is masturbation as this addresses the research questions of how care workers respond to sexual expression, the influence of context on their response and the types of expression staff find difficult.

Resident-to-resident sexual expression and one story involving resident-to-staff sexual expression will then be explored. First, an exploration of how staff define and construct behaviour as sexual will be addressed.

10.3 Sexuality and its meaning for staff

The literature points to sexuality being mysterious, contradictory and ambiguous with shifts in meaning occurring over time, and sexual behaviour, practice and morality in a constant state of flux (Caplan 1987). Sexuality is difficult for anyone to define and based on the data, the care workers in Glenevis were no exception to this. Cathy, a care

worker, reported that for her it was natural and thus normal, particularly for men. Gender is apparent in most of the stories told with men the main actors.

To me it is only human nature. The moo-ing or rattling things or the man touching himself with page three, that to me is the man who still has sexual feelings. Just because he is on his own and is in a residential home doesn't mean to say these feelings go away. (Interview with Cathy)

Sylvia, an older care worker, when asked how she would define sexuality noted:

Well you know like a male resident starts to put their arm round you-a wee bit too friendly you know, more than you would like or maybe touch (her breasts) or something like that (Interview with Sylvia)

There is a sense in Sylvia's report of boundaries being eroded, of residents becoming too 'friendly' and their attempting to touch what are seen as sexual areas of the body, in this case breasts. But often the situation described by care workers are ambiguous and younger care workers or other care workers as noted in the last chapter, for example, may need help to construct the circumstance as sexual. This was the case with Fiona, a young care worker. She was not able to attend my initial meeting with the care workers so when I wrote to her asking if she would like to participate in my study, she spoke to Gladys, an older care worker, and reported that she had never experienced any sexual expression at work.

It was just one time when I was doing something and he skelped my bum but I didn't take that as anything I just took that as normal, but Gladys said "That is

it (sexual)” and I said “It was only a skelp” but talking to Gladys this was a regular thing and she says it was because I was sort of newish that he hasn’t really started yet (laughs) seemingly - but I never sort of thought of it as anything sexual at the time I just thought it was normal.’ (Interview with Fiona)

Younger care workers being helped to construct the situation as sexual has been noted in earlier chapters. Fiona’s remarks about the resident hitting her bottom she perceived as normal, that is not sexual, is interesting. It suggests that the construct of the resident as sexual in his actions was possibly deemed abnormal and thus her response may well have been affected. Amplification of a resident’s sexual reputation may be an effect with subsequent negative response from staff. Harry was a case in point as Sheila noted:

But when he first came in ken, he was a very nice person he was. He used to get his cuddle but when I experienced just wi’ how he kept touching at his self I thought “ Goodness it’s my imagination” like the rest of them. But I never got what they got.

CA and what did they get?

Well it’s just like when he used to, when he was in bed, he used to buzz and when they went to bend over (to turn off the buzzer) he would put his hand on their bust and that. (Interview with Sheila)

Teresa also noted the changes in Harry who changed from a nice cuddly (child) person where giving a cuddle appeared ‘natural’, to a man making sexual advances.

Harry who used to always be cuddly and touchy but at the end even his touch was getting ...(sexual) but that was happening to every one. It sort of changed and became more gropey.

CA More sexual?

Yea more sexual rather than the feeling it was just natural a cuddle which I did feel comfortable with. (Interview with Teresa)

The story of Harry was a headline story as Teresa indicates 'it was happening to everyone' so that when his actions became interpreted as (adult and) sexual, staffs' responses changed, in that they were wary and kept their distance, and no cuddles were offered. Dementia here appears to be peripheral, yet Harry as noted earlier had dementia but this appeared not to be taken account of in care workers' report.

Often care workers found it difficult to articulate what made a comment or action sexual. It was reported as something intuitive as Jenny describes.

I mean he's a nice man, he really is and he's been respectable but there's just something. I dunno really

CA But you feel that you have to be careful?

Yeah there's just something there I don't know what it is. (Interview with Jenny)

Jenny's report implies ambiguity, something uncertain and yet intuitively she knows that some male residents are sexually 'unsafe' and so care is needed.

As noted in the literature, the most problematic areas of the body, for both nurse and patient/resident, are those associated with sexuality. Masculinity for example, and male power over females generally, is enacted as Lawler (1991) argues, through the body and it centres on the penis. Following on from this, Marion reported that a male resident exposed himself when she entered his room.

I've had a resident, one man going into his room and he's standing there naked and pointing at his self - he's been incontinent. Pointing at his penis, standing naked.

CA How did that feel?

I just walked out again (Interview with Marion).

The man may have been in need of help. He had been incontinent and his penis may have been sore. Marion did not ask or wait to find out. The situation was constructed as sexual and threatening and Marion responded accordingly. In most of the report in this section ambiguity is to the fore but when, as Lawler (1991) notes, areas of the body associated with sexuality are involved, that is, breasts and the penis, the situation may be less ambiguous, but not always.

10.4 General incident stories including masturbation

Most of the stories told by staff were general stories. They exceed by 10 those specific reported stories about resident-to-staff and there are 13 more general stories than specific stories related to resident-to-resident sexual expression. It can be speculated

that general stories are easier to tell. There is no naming of names and ‘everybody’ knows about them. But whilst they are constructed, as ‘normal’ (male) sexual behaviour the behaviour is not necessarily accepted or welcomed. An example of this is story (2.4) the sexualised touching of female care workers at bar night.

Analysing the data there is a massive gender skew in these general stories. There are 15 stories reported in this section and out of 15, 10 involve male residents. One possible reason for this was that male residents were more overt in expressing sexuality. A second reason is that staff appeared to have some difficulty in constructing (most) older women residents as sexual beings. When I interviewed staff I often had to prompt them to consider women residents’ sexual expression. The top three ranking general stories involve male residents, including male residents masturbating.

10.4.1 Private parts – the issue of masturbation

As noted in the literature review the anxieties and guilt associated with masturbation have remained embedded in society. Grounded in the data, for example, issues around masturbation, it is male residents who are mainly represented, as in the findings of the postal survey. This may be explained by the fact that physically it is more obvious when men masturbate, or it may be explained in terms of staff attitude. Masturbation is what (all) men do but not all women.

Gladys reported two incidents of males masturbating in their bedrooms.

Two men, I just went into the room.(she shrugs her shoulders).

CA You seem to imply that that's expected

Yeah it's expected. I cannae answer why I think that.

(Interview with Gladys)

When I asked about women residents masturbating in their rooms, Gladys reported finding this more to difficult to manage but was unable to think through why this was. It is difficult to avoid the conclusion that care workers tend to ascribe an asexual identity to women residents, but ambiguity and issues of respectability were apparent also.

Kimberley, one of the care workers who worked on night duty, reported that she thought of older women as generally asexual '*I kind of sort of think that women kind of lose their sexual interest towards the end of life.* But then conceded that she did not really know. She noted:

You usually find that women tend to be 'prim and proper' you know likes of films or anything on late night anything sexual and they're watching the tele late they're shocked and horrified and mortified at what's on television.

(laughs) (Yet) They sit there watching to the bitter end and then they'll go on about it (laughs). (Interview with Kimberley)

Kimberley noted the prim and proper behaviour of the women residents but seemed critical about their 'performance'. It was difficult to avoid in her comments a certain censorious view of women residents' sexual expression as opposed to any kind of

understanding of the constraints and contingencies under which older women have to work with regard to sexuality. Whilst a postmodern feminist approach appears to be suited to my research in that it privileges the voices of women care workers, I have been more than aware in the analysis of the data that the voices of older women residents have not been represented. They have either been poorly represented in care workers' reports or at times been patronised or seen negatively.

Morag, one of the 'toughies', also appeared scathing of some women residents:

Oh yes when we took them (some residents) to the pub one of the women residents said she fancied a man in the bar and couldn't keep her eyes off him all night (laughed at this) They (women residents) become brazen after a drink.
(Interview with Morag)

Unlike the comments made by Roger, one of the assistant managers, who noted in chapter seven where women residents were spoken of in a patronising indulgent child-like way, Morag here acknowledges the sexuality of women residents but in a rather contemptuous way. Yet there was ambiguity in Morag's expressed attitudes. Whilst seeming to express disdain, she appeared tolerant of women residents found masturbating in their room, a subject that some other staff such as Gladys, had reported difficulty.

CA What about such things as masturbation?

Yeah well..all three were women (she had found masturbating) were their own bedrooms

CA So how did you manage the situation?

They all stopped when I went in their room so it wasn't an issue (she shrugged her shoulders. (Interview with Morag)

When addressing what types of sexual expression staff found difficult, the report from both Morag and Gladys point to an individualistic response with one reporting finding women masturbating difficult whilst the other did not.

Generally the 'talk' about masturbation involved male residents. Marion, one of the toughies, appeared to unfazed by discovering male residents masturbating when she went into their room. She reported that it was a common occurrence and commented on how attuned she was to this kind of male behaviour hinting that other staff however were not so aware as she was about matters sexual. In her 'talk' there are echoes of surveillance, disciplinary techniques and 'the gaze' being focussed on residents. Marion also noted that finding male residents in this compromising position was a '*bit of a laugh*'. She reported that :

'Oh yes, some men have constantly got their hands down there, everytime you go into their room or in the sitting room. Not everyone notices but I notice. I just walk out and forget about it. Have a laugh about it actually. There's quite a few of them done it'. One man, every time you went into his room his hands were in his trousers, he was touching himself all the time.... Like in the sitting room somebody else (member of staff) brought it up and I said "The same thing's happened to me" and we just started laughing. (Interview with Marion)

Humour can be a way of distancing a person from a situation or alternatively bringing people closer together and can be associated with private sphere – home (Savage 1995). The literature points to the highly complex nature of humour. Often the care workers would report feelings of being ‘in control’ of the sexual situations and this helped with managing these potentially difficult scenarios. Humour and, or ridicule appeared a feature. Marion reported, for example, being able to manage these situations by telling the story of this sexual, private behaviour of the male residents to other staff. The response then was to laugh about it thus making it less threatening by possibly demeaning the residents involved.

A story told exposed the lack of privacy about the residents’ sexual life. Speculation appeared rife amongst staff about Michael, a male resident. Michael’s is a specific story as opposed to a more general one but as it is not a resident-to-resident or resident-to-staff I have placed it in the general stories category (Appendix 2 table 2). It is useful in highlighting a number of issues. Jenny reported that a number of staff ‘*have a laugh*’ at Michael’s expense. He is seen by a number of staff as ‘*fair game*’. Jenny previously described him as ‘*sleazy*’ with a reputation of being sexually opportunistic and certainly sexually aware. Jenny reported:

CA Has masturbation has been an issue?

That’s more wi’ Michael not like in front of us. He locks his door (laughs)

CA Are all the staff aware that he does that?

Yeah they do but we .. he doesn’t know we know (laughs). That’s what I mean, there’s something about Michael that would take it further

CA But he locks the door staff don’t go in? He’s quite private about it?

Yeah

CA So how do people know about it?

We just ..we don't really..Because of comments he makes we say "Michael's away wi' his Daily Star" We don't really know, but because he talks about sex a lot... (Interview with Jenny)

This is one story that it is permissible to tell because all staff knew about Michael's sexual proclivities. He was labelled as 'sleazy'. As Lorentzon (1990) notes discussing social work and nursing staff how power is enacted in these groups, patients or residents may labelled as a 'bad' patient or a 'difficult' resident and can be targeted as the object of, as in Michael's case, jibes.

10.5 Resident-to-resident sexual expression

In this section addressing the second type of story to be told, that of resident-to-resident sexual expression, gender remains an issue with regard to the worker's expectation of certain gendered behaviours. (Table 3 provides an indication of which stories were told by which member of staff.) Some of the stories in this section, for example, stories 6.1, 6.2, 8.0, relate to the stereotypical predatory male taking advantage of the vulnerable women residents (often those with dementia) and these aroused a fierce, protective response in staff as the story of Margaret appeared to demonstrate. The story of Margaret and Michael is useful in that it furthers the discussion on one of the major themes of the thesis, that of ambiguity.

10.5.1 The story of Margaret and Michael - a hard lesson learned

The role of this story (Appendix 2 Table 4) might fall into that of a warning or a morality tale. In this story dementia is key, with a needy woman with dementia the main actor. Of the staff, six told this story and of the six, three were angry with Michael for taking sexual advantage of what was described by those staff, as '*this beautiful demented woman*'. Peter the art worker's response was typical:

She (Margaret) was a beautiful looking woman very attractive. I could imagine why he (Michael) found her attractive but she couldn't seem to defend herself. She couldn't quite stand up for herself she was quite confused. I felt I had to go to the office and report it and make sure they knew about it. (Interview with Peter)

As a result of care staff's concerns, Michael was brought into the office and reprimanded although he protested vehemently that Margaret did not object. Corinne, the assistant manager, was quite scathing about what she perceived as the care workers' overreaction to the situation. She attempted to reason with them and asked them to monitor and observe the situation.

'It was a real interesting one. We had a male resident (Michael) who was perfectly lucid and a female resident (Margaret) who was very attractive and suffered from quite severe dementia and she always put her makeup on in a morning.. she always looked very attractive very smart. This male resident would sit beside her in the sitting room in the same flat and horror of horrors

(ironic) he was seen kissing her and er the reaction was, you know, really absolutely horrendous "How could he kiss her? How could she let him kiss her" etc, etc "This was a beautiful woman". I asked them to monitor it and asked, "Does she seem distressed at all?" Again this comes out at change over er and this (story telling) went on for some time and really that there was I think, there was anxiety that perhaps the relatives would come in and they would be absolutely horrified at the resident being kissed by this man. But she was .. what would you say...she was giving 'the come on' so much but no one had actually taken notice of that. (Interview with Corinne)

Firstly, Corinne reports that Michael is perfectly lucid. In his case notes it was recorded that he had some cognitive impairment and Beth for example, questioned whether he had dementia or not as it was not always clear. Secondly, the message implied in Corinne's report was that staff were once more appearing to overreact. Ambiguity emerges here as a key theme. This story where it seemed obvious that Michael was the perpetrator due to his sexual reputation, proved to be wrong and called into question the construction that staff had placed on both Michael and Margaret. The apparent certainties of the situation were overturned and staff reported feeling somehow duped and foolish. The situation appeared to cause them to doubt themselves and their own knowledge. Some staff reported feeling angry. The protected 'child' became a sexual woman leading men 'on' with all the associated risks to reputation that this incurred for Margaret, as for women generally. From this, one can speculate that how the manager responds to staff in these situations, may impact on what staff disclose to management when future sexual incidents occur.

Corinne seemed to imply that staff were so busy and concerned protecting this woman that they had failed to notice that Margaret was the instigator. The debate between manager and staff appeared to be about whether firstly a woman with dementia could have sexual feelings and needs, and whether this was necessarily an exploitative situation. The second was concern about the reaction of the family carers. The findings from the postal survey indicated that when a resident had a family carer who visited, this appeared to greatly influence staff response to sexual expression by the resident. This finding was supported by other cases reported by staff, including this story of Margaret.

When Margaret's family were approached and involved, it was then that staff learned that *'she had always responded to men that way.'* (Interview with Sylvia) Staff on the basis of this information had to revise their views and some expressed a certain annoyance at being 'misled'. They had rushed to rescue Margaret with righteous anger only to find that rather than the victim, she was the initiator. Sylvia commented:

So I think that everybody has to be made aware of the situation. I, maybe we, could have let that go on further you know putting blame on Michael. It shouldn't, I mean you wouldn't blame Michael but maybe ... you know thinking that he was making the advances all the time and things like that. You know it was the other way round! (Interview with Sylvia)

There are many issues in this story about labelling and reputation that will be addressed further in the next section.

10.6 Resident-to-staff sexual expression

A number of reasons why stories are told have already emerged from the previous instances such as, the need to warn others and so protect vulnerable residents (and staff). In these situations there is almost an obligation to report and tell. A category I used in the analysis of the data asked who did the staff 'talk' and why? Staff appeared to tell their stories when distressed but not all felt there was (metaphorical) space within the home that was conducive to the disclosure of their story. Whereas Fred, distressed by sexual remarks made by a male resident to him, told his story to managers and several other care workers, Jenny also distressed did not report her story until four days later to management. Both these stories will be discussed more fully in the next chapter.

Cathy, a domestic who 'acted up' as a care worker when necessary, reported that the care workers discussed these situations amongst themselves and then went on to the office.

Well obviously us just talking together wouldn't be the proper way of handling things. But we would all say - well basically all the colleagues I have any dealings with - I think we would be under the same outcome, we would go to the office.

(Interview with Cathy)

But Cathy then went on to be more specific about whom she would discuss situations with and in whom she would confide.

Not every member of staff obviously but personally I have got colleagues I could talk to and trust and I know that I have got colleagues who could trust me.

Being able to trust colleagues was seen as very important in this difficult and uncertain area of work. Many of the stories like the story of Margaret and Michael were about warning other staff members and protecting vulnerable residents. But I was interested as to when staff would report matters to the office as noted earlier as this may influence how care workers respond to incidents involving sexual expression. Kimberley reports:

CA When would you inform anyone?

If someone (seriously) forced themselves on you, if the situation became out of control

CA Would that be something you would go to management about?

I'd probably mention it yeah. Sort of usual if you get maybe somebody doing that kind of thing they're doing it to a lot of different people sort of not singling one person-or maybe they are singling one person! and if so staff should be even more aware of that. (Interview with Kimberly)

Apparent also was that if the incident was a 'one-off' then staff might not report the incident to management or if they did just mention it casually, and so not make a fuss or 'lose face' as Sylvia and older care worker noted.

I wouldn't, I wouldn't report it in.. not unless, no not unless he or she tried to make it worse. I think then I would make a formal complaint but if it was just a

one off I would just casually mention it to the officer whoever was in charge whatever. (Interview with Sylvia)

10.6.1 The story of Christine and the patrolling of moral boundaries

Humorous stories can relieve tension in staff but also used sometimes to denigrate as noted above with Michael. Stories can be used to label and stigmatise. Stories are also told to make sense and check out and so provide a coherence and order in what is seen as a chaotic situation- the greater the sense of disorder, the greater need to tell stories to create stronger boundaries (Plummer 1995). The story of Christine (Appendix 2 Table 5), a resident with mental health problems and possible dementia, seemed to fall into the latter category. Her story appeared to carry a stigmatising message that marked the erosion of boundaries and to a degree structured the moral life of the home, in terms of staff's response to her situation. It was a story that served to mark her out as the 'other'. Gladys one of the toughies who told the story and who appeared to influence other staff's attitudes, implied the story was about self protection-hers. It was also, it seemed to me, a story of punishment where Christine was put in her place and marginalised. There appeared to be sexism implicit in the story and also homophobia.

As noted earlier most of the stories involved men residents with sexual expression by women if reported, treated either indulgently or rather scathingly. Christine ran counter to this construction by not only making sexual comments to staff, but homosexual comments. Christine, as the abbreviated version of the story in Appendix 2, Table 6 describes, made comments about the women care worker's hair and asked them for a kiss.

She (Christine) keeps asking men and women for a kiss and they don't like it"
(This is almost word for word what the other staff had said.) "She's psychotic",
the hospital said and "she was attention seeking." (Interview with Rhona)

Later during an acute psychotic episode Christine referred to all the women staff as lesbians. This resulted perversely in her, attracting the label of lesbian. She was a problematic character according to the care workers and appeared to overstep the (moral) boundaries.

Whereas previously women care workers had been happy to hug and touch her, once they had been labelled as 'lesbian', only the minimum of touch necessary to carry out care tasks, was provided. The labelling process affected even Beth, an older care worker, who was often generous in giving hugs and seemed very sensitive to the needs of residents.

She (Christine) used to say "Do you want a wee kiss" or "Give me a kiss" or something, and very, very, initially I used to give her a peck on the cheek. But then you found, you heard other things about her

CA Other things?

That er she was always asking .." I don't suppose you will give me a kiss?" But it was more into it. You drew back

CA It was more... sexual ?

Yes, you just drew back from it. (Interview with Beth)

This story was interesting. Beth, when telling the story, was in receipt of the knowledge of how to 'treat' Christine. Christine had become labelled as lesbian and as the 'other' and from this according to Gladys, a distancing had occurred in how Christine was to be cared for, particularly in terms of her intimate needs. Retrospectively therefore in constructing the events, Beth's story may well have changed with time and reflection. For example, Beth implies that she did not readily accede to Christine's demands for a kiss. Only '*very, very initially*' did she kiss her and then only a '*peck on the cheek*'. By telling the story thus Beth appeared to be '*keeping herself right*'. How care workers respond therefore may be due to peer pressure, particularly pressure from the 'toughies' in the home.

Gladys, one of the 'toughies' reported her thoughts and concerns about Christine:

This one particular lady (Christine) I can't give her all the attention she needs. I help her wash and help her dress but as I help her wash and dress there are certain areas I say "no, no, come on you do it" and I leave the room while she does it, even if I'm just outside the door. I say "put them on first" and then when certain parts of the body were covered, I come back but that's particular to myself. At the same time protecting myself

CA Is that how you feel?

Yeah. Oh I mean she's voiced it to a psychiatrist which was before she came in ..she's also told the psychiatrist at a meeting that she was'nae going back (to Glenevis) because we were all lesbians (laughs) I mean everything's no right. So on knowing the background you have to protect yourself because a resident has more rights than a social care worker. Far more rights than a social care

worker. So at all times I protect me. So if it came to the crunch and there were things that had to be done I would make sure there were two of us in the room rather than just me. (Interview with Gladys)

Here Gladys' response of distancing herself from Christine seemed about self-protection, protection of her own reputation and, as she also implies, potentially her job.

Gladys, as I learned from other staff, appeared to have greatly influenced the kind of care that Christine received. Goffman (1978) posited the notion of spoiled identities, which accrues from stigmatised behaviour and one that greatly influences the 'moral career' of the person thereafter. Gladys appeared to have exerted much power and influence yet her perception was that '*because a resident has more rights than a social care worker*' she felt the need to protect herself. What appeared missing in the stories about Christine, was any kind of understanding of her mental health needs. She was apparently psychotic and delusional but staff seemed to construct her comments literally. If she was '*attention seeking*' it was perhaps because she received so little. None of the managers told this story. According to what staff reported there appeared to be little managerial guidance yet the effects had considerable repercussions on Christine's end of life care.

I was also not immune from the pervasive nature of the labelling process. I had interviewed several staff including Gladys and was therefore in receipt of their feelings and attitudes. When I was involved in participant observation on the first flat one evening Christine asked me to accompany her to her bedroom. For a few seconds I hesitated and later recorded my internal monologue at that time. '*Was there some sexual aspect to this request as staff had said? But I then said to myself "come on" and*

just as quickly dismissed the potential sexual connotations. But I realised that I too was being caught up in the labelling of people, and how subtle and pervasive it can be.

I did go with her to her room and when she sat on the bed and started to take off her clothes I suggested that I should go. Again I'm not sure whether this suggestion was based on providing privacy for her or that of securing my own comfort. She insisted on my staying. I folded her clothes and found some paper and she used the commode in her room. She looked weary with the world. She got into bed and again I asked if she wanted me to leave as she had closed her eyes but she said no. She said "I would love to just go to sleep" and I said, "Go to sleep" and she said "To sleep and go over to the other side and meet my family". I asked who that would be and she said her husband's name, her two brothers and mother and dad and her auntie. (Participant observation)

There was a sense of a lonely and tired old woman whose quality of life in these later months had been compromised. I spent about 20 minutes with her and felt very sad when I left her particularly when she said on my leaving her room "*Thank you for talking to me*". She died a month later.

Following on from this how staff speak about sex is one of my research questions and pertinent here. Using language as a symbol, of interest was the use of 'gay' with reference to homosexuality and the complete absence of the use of the word 'lesbian' other than by Gladys, who was only reflecting Christine's terminology. In the home whilst there appeared a tacit, if awkward, acceptance of 'gays' there appeared little acknowledgement of lesbians. Some staff reported that they had '*no problems*' with

'gays'. Marion perhaps in her own direct way voiced what some other care workers may have felt but were not able to articulate.

We've got a few gay people it's allowed now eh? When I worked in hospital I never actually kent somebody who was gay ken what I mean? But initially ... (when she started working here and found out several staff members were gay) so it was quite a shock aye I never thought for a moment he (the chef) was like that. (Interview with Marion)

Marion notes that it is allowed now and people can talk about the subject. Staff are able to tap into the worldview that renders these stories and views allowable. This was true on certain levels. Helen reported that many people her age (50s) were anti gay, especially men but she was not. She said *'To me they are just people like anybody else'*. But she then went on to mark the 'difference' between gays and the 'straight' community. *'To me it's just like another religion. A different religion from everyone else.'* This was certainly an unusual construction and was open to the argument likening homosexuality to religion made it somehow more acceptable in her mind.

Morag, one of the toughies, referred more to staff than residents when making her statement. *"We do have one or two gay members of staff but I mean I have no problem with it at all"*. But there were subtleties and ambiguities in the staff's attitudes. Some of the staff as noted above had taken time to accept that other staff were gay (but not lesbian). They appeared fairly comfortable with the concept of 'gayness' when interviewed. It became a different issue when homosexuality became overt in the home

either through resident-to-staff sexual expression as in Fred's story, or between staff. This mirrors the findings from the staff training day and also from Christine's story.

When the situation arose where one male care worker was reported to have made sexual remarks to another male and gay member of staff, there was an outcry that resulted in the care worker who had made the remarks, leaving. In this case gay sexuality became overt and not something 'out there'. It was brought into the 'home' and severely tested some staff in their attitudes. None of the care workers told me this story, although it had only recently occurred in the home when I first arrived to carry out fieldwork. This was not a 'safe' story to tell. It was a difficult and embarrassing story and was only told to me by the assistant principal officer.

10.7 Conclusions

The sexual stories that have been explored in this chapter have built incrementally on the themes from the previous chapters. In the methods chapter I noted that the role of dementia appears to be almost akin to one of the actors taking part with stage appearances varying. I could use this analogy with the major themes that have emerged in the thesis. In the last chapter, space was a central theme. Here the main parts or themes have been those of gender and ambiguity with space taking a less prominent role.

Gender appeared as a theme throughout in many of the stories with male residents the main protagonists. Whilst the stories told here are about male resident sexual intent

towards either women residents or women staff, male care workers' bodies can also be sexualised/objectified in the work place as Fred's story and others have indicated. The gender issue is that whether it is women or male care workers that are targeted, it tends to be men who are the perpetrators. This appears the norm and this may be one of the reasons why the women care workers responded so negatively to Christine expressing lesbian sexual intent. The data point increasingly to gender and gender expectations playing a key role in care workers' response.

In the three stories related, ambiguity was a theme apparent throughout. The maintenance of boundaries appeared a constant tension and anxiety. Within the ambiguities present what appeared important for staff were feelings of control. This in some situations was achieved by the use of humour and denigrating some residents, or in other situations as with Christine, it was by withdrawing emotional care. Emotional care and emotional labour will be explored in the next chapter grounded in the data, many of the stories told indicate that certain emotional costs are involved when residents express sexual needs.

For the staff the feelings of control were offset by anxieties about the rights of residents being more important than those of staff. Consequently any staff being accused of abuse by residents would, in Gladys's view, be taken seriously and staff compromised as a result. These fears and anxieties appeared grounded in some reality for staff. Peter mentioned a similar situation reported in the last chapter. Ethel, the new manager of the home, when I visited three years following the original fieldwork, also told her story that of a male care worker reported by a woman care worker of kissing a woman resident on the lips. There was ambiguity in the situation but a huge internal

investigation had occurred. Ethel reported that following the internal inquiry '*the staff are still raw and divided about the situation*'. In many ways these stories epitomised the dangerousness of situations where staff could be accused of abusing residents and would as noted by Gladys, affect how staff respond to resident expressed sexuality.

Ambiguity as to how the care workers ought to respond to sexual situations appears to be affected by managers' responses. Some of the situations reported by care workers appear scary and exploitative. Their response, as in the case of Margaret and Michael, was to inform the office. If staff themselves are responded to in a less than supportive way or given little training, then this may possibly result in fewer staff reporting incidents or increased anxiety with emotional costs accruing for staff. In two situations involving Corinne, and one involving the manager of the home where I piloted the Holmes questionnaire, managers appeared to have less than a supportive approach towards staff.

In the stories told in this chapter dementia has played a rather ambiguous role. Although the male residents and Christine involved had some cognitive impairment, other than in the case of Margaret who had moderate to advanced dementia and who was consequently in need of protection, dementia has been peripheral.

Space as a theme has had a more peripheral yet important role in this chapter. Space has been important in terms of how space is provided for stories to be told. Once again it appears the case, based on the data, that the space for resident-staff sexual expression to be spoken about is limited. Cathy earlier spoke of the need to have someone she could trust with whom to discuss her stories. Although some care workers expressed some

ambivalence towards their managers, particularly towards Corinne, managers were seen as people care workers could talk to, to share their distress as in Fred's case or their anxiety, as in the case of Margaret and Michael. Some of the care workers also were able to share stories with each other.

Space with regard to the stories told from the safe and distant past was also a feature. Some of the stories told had happened many years ago in the home so that were spoken about almost as reminiscences. There were few recent stories told other than those of Jenny and Fred mentioned earlier. The story of the recent event of a male care worker making sexually explicit remarks to another male care worker in front of others, was not told by the staff in the home, only by the assistant principal officer. It may be that emotions were still raw as staff took varying positions in the case.

Emotions and emotional work that often needs to be undertaken is explored in the next and last chapter of the thesis as these appear important themes that have emerged from the data throughout. The analysis of the empirical chapters begins in chapter six with an exploration of the general and ends in chapter eleven, with the specific. In the first empirical chapter there was an exploration of the data from the quantitative postal survey that provided, amongst other aspects, a view of the field. The final empirical chapter (chapter eleven) concludes, based on the data and the development of themes discussed above. Here the focus is on emotions and how care workers feel and how this may influence how they respond to sexual expression by residents. How they feel may also address the question of why the subject has been neglected. The final chapter is also about the theme of space that is, getting into the heads of the actors and thus exploring their feelings and emotions.

Chapter 11 Talking About and Managing Emotions in the Context of Residents' Expressed Sexuality

11.1 Introduction

The theme of spatiality developed over preceding chapters is once more to the fore in this chapter (chapter eleven). Lee-Treweek (1996:115) speaks of the need to understand the world as an emotional space, becoming a key concern sociologically particularly with reference to the 'caring' professions. Following on from this, it is the space in the care workers' heads, their emotions and the emotional work they have to undertake when sexual expression by residents becomes a component of their work, that I will discuss in this chapter. The boundaries between what workers feel privately and how they have to behave publicly, is addressed.

From a feminist perspective making private knowledges public and seeking to understand these privately based knowledges and personal understandings of women (Edwards and Ribbens 1998) appear pertinent in addressing emotions associated with this subject area. Postmodern feminist approaches are about challenging the accepted constructions of power, truth, knowledge and gender that influence and are part of our social arrangements (Wuest 1995:126) and in this chapter as in the previous ones, this is what is intended.

Following on from the last chapter, I use the care workers' storytelling as an approach to explore some of the emotional geography of the home. I apply the substantive

theories of emotional labour (Hochschild 1983, James 1989), bodywork and feeling rules (Lawler 1991) and the exploration of the environmental regulation of emotion and also the emotions of control (Fineman and Sturdy 1999), in the analysis. I address some of the reasons why the subject of sexual expression by residents may be marginalised and undisclosed. Specifically I look at the attributes and experiences commonly associated with femaleness and underclass social status, emotions (Code 1993:21), when sexual expression by residents becomes a component of work.

Emergent from the sexual stories told by staff in the last chapter, was that although many staff appeared to be in control of certain (sexual) situations, there was nevertheless a real emotional price being paid by care workers. This appeared to be made worse by a lack of knowledge about strategies, a lack of being able to share with others who have experienced similar situations, and lack of sensitivity from other staff. Hearn and Parkin (1995) note that in response to the need for control, emotions are centred around discourses about professionalism. In the stories told by staff keeping control of emotions was often seen as strength. Control reflects and reproduces the wider social structures of power. These are contestable terrains shaped by 'different forms of actor resistance, co-operation and compliance to morally questionable means and/or ends' (Fineman and Sturdy 1999: 632). The authors argue that control is a characteristic of Modernity to create order. I applied this concept to the home where sexual expression by residents was often viewed as unpleasant, unwelcome and embarrassing. I suggest that control and the need for emotional labour is often created in Glenevis by the tough culture of the home and sometimes by organisational needs. The expression of emotions that follow incidents of sexual expression by a resident towards staff appeared to be discouraged. Staff were expected to be emotionally competent. Using

the case studies of Fred and Jenny, I look at possible reasons why some staff disclose their story.

I have noted in earlier chapters that there appeared a lack of openness in the discussion and recording of sexual incidents particularly those where residents showed sexual intent towards staff yet, as discussed, this type of sexual expression is the type staff find most difficult. In this chapter I will argue that there were difficulties for staff in acknowledging and managing their emotions when residents expressed sexuality. Managers, as noted, appeared to lack an appreciation of the long-lasting emotional impact on some care workers when residents expressed sexual intent. The potential for both residents and care workers to be negatively affected by what at times were very powerful emotions being expressed by care workers, appeared not to be fully dealt with, as in the case of Fred.

Gender has been throughout the previous chapters a main theme and is developed further in this chapter. Some argue (James 1992 and Hochschild 1998) that the emotional regulation and feeling rules are learned at home by women and that these are transferred to the workplace. Consequently it is argued that women are more able to do emotional labour. Emotions are consequently gendered as 'feminine' and linked to vulnerability and so to 'weakness and femininity (Seidler 1998). Men who are seen to express emotion are seen to be weak-'like women' (Parkin 1993:184).

In a residential home, body work and intimate care is a component of care as in nursing. Sociological analysis looking at emotions and bodywork in a residential context has been limited with a few exceptions, for example, Twigg (1999) and Lee-Treweek

(1994). In this chapter I will extend the analysis and include the emotional impact on workers when sexual expression is a factor of bodywork.

Sexual harassment (Drouet 1993, Thomas and Kitzinger 1997) is pertinent to the analysis and will be considered and discussed. In the previous chapters the themes of ageism, ambiguity and the tough culture of the home were evident and remain so when analysing how emotions were managed in the home. In her study Twigg (1999) notes that the subject of bodywork and intimate care is both uncertain and an unwelcome one. The same is true of this research on sexuality and perhaps further amplified because of the more sensitive nature of the subject.

Whilst the sharing of sexual stories in Glenevis was emotionally supportive for some care workers allowing for validation of their feelings and to confirm what they had witnessed, in other situations disclosure led to ridicule. What caused the care worker to disclose or breakdown and who the care worker chose to disclose her/his story to, is worthy of some exploration as this appeared to impact on the emotional well-being of the care worker involved and addresses the question of why and how care workers respond.

I begin the chapter with an exploration of Jenny's story and the emotional costs that accrued when Jimmy, a resident with possible Korsakoff's dementia, kissed her forcibly on the mouth. I then explore further Fred's story looking at the continuing emotional disturbance that followed the incident where Andrew, a resident, made sexual remarks to him. Lastly I return to the story of Will and Wilma. Of the three case studies chosen, two of the incidents discussed happened during and around the time I completed my

fieldwork in the home. The information was therefore immediate and I was able to observe the emotional impact of the sexual incidents on the care workers. The third case study involving the residents Will and Wilma, was chosen as several care workers told this story and vividly recounted the emotions they had experienced at the time. All the residents involved in the three case studies had dementia, yet in only one study, that of Wilma and Will, did it have a role of any consequence.

I conclude that emotions and emotion work appear an important consideration when sexual expression becomes a component of care work. The data supports the finding that context and also the individual appear crucial aspects to consider when looking at emotional work and labour that resonates with the work of Wharton (1993). How managers and other care workers respond to the sexual story of the care worker involved appears to affect response.

11.2 Emotions, emotion work and emotional labour

Part of the grounded theory method is using the literature as data so before going on to discuss emotions and emotion work within the context of Glenevis, I will return to the sociology of emotions and address the important theme of public and private.

There are many definitions of what is meant by emotions. Hepworth (1998) addressing the literature notes that there are two perspectives on human emotions, the subjective inner and social outer. The inner is conceptualised as an integral feature of the intensely personal structure of inner meaning and as such is at the heart of the person's sense of self. Subjective emotions are exposed to the social worlds in terms of culturally

determined points and modes of expression (Hepworth 1998:173). In Glenevis, the culturally determined points appear to be whatever the worker feels inwardly, the outward show needs to be that of emotional competence. But James and Gabe (1996) question whether emotions are amenable to sociological study in the same way other aspects of life. They suggest at best the sociology of emotions may be able to make connections between the observable and non-observable (James and Gabe 1996:5), the inner and outer and this is where I have based my analysis.

In terms of emotional work and labour, Lee-Treweek (1996:118) notes the literature on women and emotion at work is based on feminist perspectives on emotional labour, central to which is that women's emotional skills, as commodities, are bought and sold in the work situation. I note in my literature review Hochschild's (1983: 7) definition of emotional management, that is the management of feelings to create a publicly observable facial and body display. Emotional labour comprises those activities involved in emotional management when they are carried out for a wage in the public sphere. The difficulties identified in the literature with regard to emotion work appears to be that many of the activities that are part of the person's job are not recognised as 'work' and this would include emotional labour and emotion management. James (1989 and 1992)

According to Hochschild (1983) emotional labour intrinsic in some work situations (airhostesses) estranges the person from their feelings with consequent negative consequences. Wharton (1993) argues that the concept of emotional labour as suggested by Hochschild is more complex, and there needs to be an acknowledgement that this kind of labour does not have uniformly negative consequences. Lee-Treweek

(1996:118) uses the term, the autonomous use of emotion work, to differentiate it from the connotations of enforced emotional behaviour associated with emotional labour. Here the emotion work displayed by workers operates independently from formal training and management rules. This resonates with the findings in my work, an example, being the case involving Christine, the resident who labelled all the staff as lesbian. Here the emotional work involved control and coercion as opposed to the usual view of 'care' that is more associated with caring and nurturance. What Lee Treweek refers to as the hidden side of care.

Wharton (1993) argues the concept of emotional labour is complex. In Fred's case Hochschild's definition of emotional labour is appropriate albeit it is a man who is undertaking the labour. Emotional masks can rapidly switch when professional limits and identities are tested (Fineman and Sturdy 1999) as in Fred's case. In Jenny's case mentioned earlier and described below, the emotional labour she performs is in front of other care workers as opposed for the benefit of residents.

11.3 Jenny's 'stories' of sexual harassment and the emotional impact this entailed

Jenny's story as discussed in previously, was that bending down to get something from a cupboard in the sitting room, Jimmy grabbed her face and forcibly kissed her on her lips. Jenny did not report Jimmy's comments to me, but I learned later through her entry in the incident book that Jimmy had said to her "*I have been waiting to do that*", implying his was a premeditated action. In my interview with her several months later she expressed anger, a sense of revulsion and vulnerability. But her story was appeared

modified for the different audiences. It was during her supervision session with Corinne that Jenny disclosed what had occurred. Corinne appeared perplexed as to why Jenny had taken four days to report the incident and felt that as so much time had elapsed that she could do little about the situation.

It was talking through why she hadn't reported it earlier and you know it was really (Jenny's) embarrassment, and I think the thing which is always around is 'do people have any responsibility for this'? Obviously have they almost given permission for this to happen? Which wasn't the case at all but I think at the back of people's minds. Sometimes they don't want people to know about it.
(Interview with Corinne)

Corinne implied that Jenny was very upset about what had happened and embarrassed and as a consequence did not want people to know about it. Jenny did not say to Corinne that she had told another care worker about the incident nor did she mention this to me. Apparently distressed and disbelieving as to what had happened to her, Jenny ran from the room and the first person she met was Marion, one of the toughies. Marion reported to me that when Jenny told her what had happened, she, Marion, burst out laughing. As noted four days elapsed before Jenny told anyone else. She did report being made to feel in some way responsible for what had happened by Corinne. So Corinne here appeared to Jenny a reproving audience, sympathetic to a certain extent but perhaps lacking in understanding about the effort needed to disclose this story.

I felt that they (the managers) made me feel that I was responsible for it. She (Corinne) said "Well maybe you're just too friendly, giving off signals to him. (Interview with Jenny)

Although Jenny reported being made to feel responsible for what had happened, the act of disclosing appeared to enable her to seek out another care worker, someone with whom she had a good relationship. This builds on the data from the last chapter where the response, and here the emotional response, of the care worker is affected by the recipient of the story and their reaction. I will return to this later.

Well I spoke to Paul about it, cause I get on well, and he said "She's making you the wrong one in that, because she's not going to deal wi' it." So he said "Write out an incident form." (Interview with Jenny)

The telling of the story to Paul appeared to validate Jenny and allowed her to be more assertive with management, but this appeared to present difficulties for Corinne according to Jenny.

As soon as I did (say she wanted to fill an incident form) she (Corinne) said "Are you not happy with what I said?" It's too late to do anything about it. It's too late to say anything to Jimmy now. It's over but if you want to still keep the form ...then we'll.... (Interview with Jenny)

Corinne appeared reluctant to take the formal action of completing an incident form. It is interesting to note that Corinne during my interview with her spoke of the lack of formal reporting about incidents involving aggression.

When I went first into residential elderly care I remember a member of staff being absolutely horrified that someone had hit her with a walking stick but there were absolutely no records anywhere. Nobody had reported a violent incident at that time - this was 5 years ago in that particular unit. They didn't fill in incident reports. A lot of the aggression was actually hidden. (Interview with Corinne)

She appeared to see no contradictions in her stance on aggression and her own and others', reluctance to record sexual incidents. For her aggression was a 'safe' and a necessary subject to disclose, sexuality appeared not to be. On some levels there appeared to be a considerable symbolism attached to the incident book and this is indicated in Jenny's stance. Reporting and writing up incidents in the book seemed an indicator of the incident being officially acknowledged. Talking to staff, the perception held was that it was only incidents of a serious nature that were reported. It seemed to be used where there might have been legal repercussions following an incident. It was used in effect to 'cover the backs' of staff following a fall, for example. The care workers would be asked to write up the incident on the supplied form and sign it. The duty officer would deal with the form-sign it, keep a copy, and send the original to the assistant principal officer (APO). When asked about what gets reported and written in the incident book, the unit manager Chris replied that, *"It's only if there was a fire or if*

anyone was injured” When asked if anything of a sexual nature was sent to the APO he replied “*Er no*” but elaborated further.

I would imagine if there was something of a serious sexual nature.... It's a difficult one again for the individual (confidentiality). (Interview with Chris)

The relatively straightforward issues about physical injury were recorded but there appeared to be unwritten rules around sexual incidents being recorded. This addresses the question of what staff say about sex. In the official documents little appears to be said. The potential for amplification of the incident and confidentiality were cited as reasons. As a result little was recorded and little appeared to be discussed outwith supervision sessions in terms of resident-to-staff sexual expression. There were very real tensions apparent between the sensitive nature of the incident, the care workers' feelings and respect for privacy, and the sense of a conspiracy of silence being created as a result. The ambiguities in approach and a lack of openness whilst on one level the care worker's story remained confidential, the secrecy seemed instrumental in creating a sense of shame in care workers such as Jenny and a sense of not being able to cope emotionally in others.

When I accessed the incident registrar (see Appendix 11) Jenny's was the only resident-to-staff sexual incident reported with comments from both her and Corinne in the book. The majority of incidents recorded concerned those of residents falling or smoke alarms being activated. Yet there had been other recent incidents involving residents' sexual expression including that of Fred, yet this was not recorded.

Corinne implied that the reasons sexual incidents were not recorded were the legal implications and not being able to substantiate the accusations.

You have to be very aware of access and particularly when it's allegations, which have no witnesses. (Interview with Corinne)

Yet Jenny, urged on and supported by Paul, implied that the action of recording the incident involving herself and Jimmy placed an important marker down for officialdom to acknowledge. It had happened, and the process of this acknowledgement seemed to have vindicated and helped her. Corinne's response by downplaying sexual issues might be a way of keeping control of the situation for her own and for organisational needs. There may be structural reasons for not recording sexual incidents. It may be a balancing act enacted by managers with the reputation of the home a consideration. If too many incidents of sexual harassment are recorded then there could be potential repercussions. For example, if a care worker left the home they might complain and accuse management of not providing enough protection. Too many incidents might cause a spotlight to be focused on an unwelcome topic. It might be argued also that Corinne by her response de-legitimises Jenny's account. Here organisational imperatives appear to influence how feelings are managed and expressed.

The important point here to be noted is that Jenny's emotions have been sidelined with Corinne implicitly suggesting that Jenny is both overreacting and may be to blame for Jimmy's actions. Corinne, as I have noted in previous chapters, has reported that in her view staff overreact to situations involving sexuality. Yet she herself engages in emotional labour, by downplaying these sexual situations. I have argued previously that

how care workers' stories are received may influence how they respond. Corinne's response may be seen as instrumental, in that being possibly concerned about the contagion of these emotions within the staff group, by belittling the (person) telling these stories, she was attempting to make the telling of stories to others, less likely.

For Jenny, the first point to note is that the interaction that took place immediately following the sexual incident. Goffman (1956), discussing embarrassment, notes that a social encounter is a face-to-face interaction that has the potential for embarrassment for one or more participants and self control can be lost. To appear discomfited or flustered can be seen as evidence of weakness or moral guilt. There seems to be a critical point where the flustered person gives up trying to conceal embarrassment and flight or fight can occur. This appears to have been the case with Jenny where Marion's less than sensitive approach seemed to have exacerbated the distress in Jenny. Marion was one of the 'toughies' in the home and one who appeared to use humour '*have a laugh about it*' as a means of handling potentially embarrassing situations.

Embarrassment is a powerful means of social control. The consensus social rules of the group, what the group expects of social behaviour and response to situations, are fundamental to embarrassment. Embarrassment occurs when these rules are broken (Lawler 1991). But as Lawler notes little research has been carried out on establishing the rules that defines some things as embarrassing and this is particularly the case with regard to sexual expression. Jenny could be said to have broken the 'act tough' emotional rules of the home and was as a consequence made to feel embarrassed and shamed.

Jenny in her interview reported that she was '*getting things cleared*' in her mind. She appeared to be trying to sort out her thoughts and emotions. She was *shocked and disturbed* after the incident but other emotions became apparent following the interaction between Jenny and Corinne. These were those of guilt and again, shame. Some argue that guilt people feel is from a sense of hurting others or institutions (Resneck-Sannes 1991) of feeling that they have *done* something wrong. Jenny reported that she was made to feel guilty by the way she was questioned. Jenny speculated during my interview with her that perhaps her actions had influenced the situation in some way

*At the night out (staff and resident night out) I love everyone sort of thing when I'm drunk... but that's.. I don't... I just do that (laughs) (kisses and hugs).
(Interview with Jenny)*

Jimmy was present at this night out so there may have been mixed messages. Jimmy's comments pointed to a rather premeditated action, despite his reported cognitive impairment due to alcohol abuse. Jenny's difficulty in perceiving Jimmy as asexual may well have exacerbated the situation and made her unaware of possible warning signs. According to Lawler (1991) staff get little help in managing bodywork arguing that it borders on the taboo. The same applied in Glenevis in terms of sexual expression by residents. Guidance, sometimes perceived as unhelpful, seems to be provided after the event.

Applying Resneck-Sannes (1991) work, shame is an experience of *being* bad/wrong or disgusting, and is derived from a sense of weakness, inadequacy, loss of self-control

and esteem. It is the self that is at fault. Often guilt and shame can occur together but shame is not readily shared. The person wants to hide so as to cover their feelings to prevent further exposure of inadequacy. Sociological reasons would veer towards the culture impacting on how space is provided or not, for stories to be disclosed and here I argue that the tough culture of the home was implicated. Jenny apparently 'hid' for four days without telling anyone at work her story.

Thomas (1990) discussing anger notes that this emotion has seldom been explored empirically in nursing research. The reasons may be that it is deemed inappropriate to a predominantly female profession. In the psychology literature anger is seen to be gendered as male. In Jenny's case it would seem that she was able to express her anger only some time following the sexual incident. But when asked if a similar situation should happen again how would she manage, she replied:

That's the problem. I say to myself I would (be more assertive), but I'd probably wouldn't. I'd maybe want to, but wouldn't do it. But I can't see what I would have done that might cause... I never mentioned it. I probably would be the same. (Interview with Jenny)

Whilst the literature on emotional labour and the general theories of interaction provide some insight, the literature on sexual harassment allows a fuller analysis to be developed.

Drouet (1993) notes sexual harassment can take at least three forms including sexual comments and touching sexual areas of the body. Often it is girls and women who

suffer harassment and often they do not complain because they fear they will not be taken seriously. As a consequence men are rarely challenged about their behaviour. This perpetuates the men's perception that what they have done is normal behaviour and that it is acceptable or at least condoned. Girls and women often remain silent about their experiences. Some girls believe they are guilty and have 'asked for it' and therefore deserve what follows. Jenny reported that she was made to feel that she in some way might have 'asked for it'.

Another reason is fear that they will be open to further abuse and attack and a 'good' reputation is a factor. The latter point is pertinent to Glenevis where the onus is seen to be on the care worker to avoid such situations, particularly at bar night, and if she does not then she pays the penalty of derision and possible loss of her 'good' reputation.

James's (1989) work has been seminal in the area of emotional labour. She was the first British sociologist to look at emotions and care work using Hochschild's model. James notes that certain occupational groups undertake emotional management for example, hospice nurses, as part of their routine work practices. She points to the potential role of organisations in scripting emotions for their members. Managers in Glenevis could be said to have implicitly choreographed the emotional rules, implicitly, as there were no guidelines, little open discussion and little written and recorded information, but care workers, particularly the 'toughies' also played a part. The main message from the data appeared to be that emotions with regard to sexual expression needed to be dealt with preferably by the care worker himself or herself or with a trusted care worker. Or, if the care worker required help from management, it was expected that the situation would be quickly and discreetly managed, and that emotions would be dealt with accordingly.

Referring back to the research question of what staff say about sex, language, as noted in the literature, plays a part. In Glenevis Fred's case below is one example, where little was documented about resident expressed sexuality towards care workers. One of the difficulties is the use of language to describe sexual harassment in care settings. The absence of a label makes it difficult to discuss. This is one way that discussion about harassment is curtailed (Lawler 1991). If workers are unable to define or communicate the existence of such a problem they can be prevented from sharing the experience with others. As a result they can be left silent in an isolated and exposed position. This was Jenny's experience for a few days and even later she was unable to share her feelings with the larger group, as they did not in her view tend to discuss sexual incidents. *"But I don't know how the rest feel because you never sort of mention it."* (Interview with Jenny)

The point at which the behaviour is seen as sexual harassment, if it is seen as that at all, is difficult to establish, according to Lawler (1991:205). If it is defined as sexual harassment, then there is a need she argues, in relation to nursing, to subject nurses' work to scrutiny through a 'sexual lens'. The same could be argued for residential care homes. Lawler collected little data on sexual harassment where the term harassment was actually used. Yet much of what was reported by nurses could be described as such. The reasons she suggests are that sexual harassment is incorporated into working lives where it is institutionalised and seen as part of job. It is not a major problem but one that needs to be managed from time to time.

In residential care there is an ideology of home and the family that places a heavy burden on care workers to tolerate and, arguably, not to name this behaviour as sexual

harassment. I have discussed this in the literature review where the construction of home does not leave space for the discussion of sexually abusive behaviour within the 'home'. Here Corinne for example, remarked when discussing the case of Fred '*somebody very unhelpfully said that he had been sexual harassed*'. Following on from Lawler's (1991) work it might have been seen as unhelpful because the situation would need to be scrutinised using a 'sexual lens' rather than as problem behaviour.

Opening the debate on sexual harassment as Lawler (1991:21) notes, risks opening a debate which hovers uncomfortably close to the margins of respectability' where nurses in particular have tried to throw off a heavily sexualised public image. There are difficulties with this interpretation when applied to residential homes. The debates around sexuality involving older people in these homes are around how residents are labelled asexual and the consequent denial of (sexual) personhood. Society generally views older people as (sexual) innocents not capable of such actions. The discussions around sexuality have tended to centre around accusations of abuse of residents by care workers and have caused unwelcome publicity and damage to the reputation of social work, and care workers generally, as noted by Peter the art worker. This is another aspect, discussed earlier, that may affect care workers' response.

I would be afraid that hmm if someone did put a hand on me and I didn't even respond people could report us. They could report me and say he put a hand .. they could inflate it out of all proportion. So for that reason I don't go into the residents rooms. Again it's just to defend myself against the possibility.

CA But you'd mentioned you'd heard

Okay I'll be more explicit about that ... It's not really here but what I've heard from other homes, other social work homes. Apparently there is a case going on just now of a resident accusing a male member of staff of raping her. I hear similar stories, not so extreme but forms of sexual contact and I feel I have enough problems. There is no way I would get myself into that. The lesson's to avoid. (Interview with Peter)

But there are ambiguities here. The often-ascribed asexual status of residents appears at odds with the situation reported where there were accusations of rape directed at the care worker involved. Peter in response to this and other such alarming stories, is one of avoidance of any physical contact or, avoiding any compromising situations such as going into residents' rooms unaccompanied. This echoes the fears expressed by Gladys working with Christine a resident who referred to all staff as lesbian. The fear of these accusations being in some way validated, meant that Gladys did not go into the room of Christine to undertake intimate caring tasks unless accompanied by another care worker. But this was not an option open to Fred whose key worker tasks involved the bathing of Andrew, one of his key residents.

11.4 Fred's story of gay sexual harassment and the continuing emotional disturbance that has resulted

When I interviewed Fred he readily told his story about his experience involving sexual expression. Fred was giving Andrew a bath. During this process, Andrew made explicit sexual remarks to Fred. Fred immediately stopped bathing Andrew and ran from the

bathroom, stunned and distressed by what Andrew had said to him. Fred sought out another care worker who was on duty, Gladys, who advised Fred to go at once to the office. This he did where he told Corinne of what had happened. She took him upstairs to the staff room and gave him a cup of tea and listened empathetically, and gave advice in terms of how to manage a situation should it occur again. It seemed when interviewing Corinne that as far as she was concerned, the actions taken by her—discussion and advice—had resolved the situation but not according to Fred. Apart from the second assistant manager only Gladys was informed as to what had happened. When I asked if he had discussed the incident with other staff he replied with feeling:

No! No!

CA It's kind of private?

Yeah it's private and embarrassing. (Interview with Fred)

Yet several remarks made to me by other care workers suggested that many were aware of the situation.

There are a number of points that need consideration in Fred's case looking first at sexual expression in relation to bodywork. Discussing Miller's (1997) work Twigg notes that disgust as an emotion is rooted in a fear of contamination whether visual or moral. In Fred's case moral pollution appeared a pertinent factor with regard to homosexuality (as discussed in chapter nine). Twigg (1999) in her study noted that workers did not tend to associate bodywork with emotional closeness. That was achieved through kisses and cuddles for residents. However in Glenevis some care workers reported that doing bodywork such as bathing the resident appeared to provide

an opportunity for care workers to be both physically and emotionally close to the residents. This intimacy could however be an arena for unwanted sexual expression by residents towards staff and became an arena for emotional management and labour as in Fred's case. Fred found that having to continue to provide assistance in the intimate situation of bathing, within the context of a key worker/key resident relationship proved problematic.

Corinne's lack of appreciation of the long lasting deep emotions experienced by Fred following this incident appeared obvious. I described the organisational reasons reported by Corinne in chapter nine. Fred was obliged therefore to keep Andrew as his 'key' resident and was required as a consequence to 'do' emotional labour. Hochschild's idea that emotional labour as a gendered commodity mainly associated with the skills of women, needs some consideration in the context of my data. It seems that many of the studies on emotions and emotional management are gendered, in that they are mainly associated with the skills of women. In terms of body and care work generally, this is presented as an extension of domestic and family roles. Peisah (1991) for example, noted that the overriding experience of being a mother influenced care practice usually in the direction of fostering dependency. Gattuso and Bevan (2000) note the importance of mothering and being mothered as an important factor that is brought to the caring situation. It is only women involved in these situations who are considered, not men. If this argument is accepted it needs to be asked where do male care workers fit into the analysis of emotions and emotional management?

In Fred's situation the notion of emotional labour as socially empowering for care workers (Lee-Treweek 1994) would be difficult to support. He reported feeling

powerless in this situation. He had to continue caring for this resident yet he was forced to control his sense of anger and revulsion.

I've still got to be his carer (key worker). It's difficult to describe. It'll always be there, do you know what I mean?

CA So how do you feel each bath time then?

I don't like doing it Like every bath time...(pauses).

You can't say what you'll do it's a gut reaction

I mean you shouldn't have to defend yourself when you're giving a resident a bath It should be....a proper key worker relationship. (Interview with Fred)

As in Lee-Treweek's (1994) study, there appeared to be a lack of recognition of the (long lasting) emotion work involved for care workers. There appeared to be a dissonance between how Corinne perceived the situation and how it was managed, and Fred's experience. Corinne gave time and used counselling type skills with Fred. Her approach and emphasis was that of helping him to manage similar situations should they reoccur. To a degree she appeared helpful in this context and Fred acknowledged this. But there appeared to be mixed messages. There seemed to be a less than sympathetic approach in terms of emotional support. Corinne implied to Fred that women care workers have to deal with this sexual harassment (my terminology) by male residents all the time. The message was clear they seemed to manage, so why not he?

Rather than speaking to him (the resident Andrew) she would say female care workers get harassed all the time dirty old man stuff, but the thing is it's different with me. (Interview with Fred)

Fred argued that it was different for him because this was not heterosexual situation which was for him was 'normal', but a gay encounter and the implications of moral pollution were evident in Fred's arguments. Corinne, as in Jenny's case, appeared somewhat bemused at what she considered the over-reaction of Fred to a seemingly (to her) innocuous situation. She described to me what action Fred had taken immediately after the incident. *"he left (the resident), and sort of went to a colleague who was around at the time and said, "What do I do? What do I do? My notes transcribing the tape from the interview seemed to capture the rather contemptuous tenor of what Corinne said (Imitation of a rather wet member of staff running for help to colleague). (Interview with Corinne)*

Later in the interview Corinne pondered possible reasons for Fred's reaction. She appeared aware that emotionally he was very distressed at the time. She spoke of Fred being in a panic and in essence out of control emotionally.

Was he thinking he was gay in effect? It wasn't (the case) because he's engaged. That was a panic. It was well you know "what would other staff think?" So there was a panic element there. (Interview with Corrine)

Discussing the literature on emotions and organisations, Wharton (1993) commenting on Hochschild's and other studies, extends the discussion and broadens the scope,

meaning and potential effects of emotional labour and management. She notes that the effects of emotional labour depend on conditions under which it is performed. Fred was providing intimate bodywork and drawn as a consequence into a physical intimacy. It could be argued that Andrew perhaps because of his mental health problems was either disinhibited or chose not to observe the unwritten rules of bodywork described in Lawler's (1991) work. Andrew was Fred's key resident and as discussed in chapter nine, by making sexual remarks to Fred, Andrew had also transgressed the unwritten rules of the key worker and key resident relationship.

I identified various debates around masculinity noted in the literature review. One version is that men can experience deep feelings of shame around needs, vulnerability and helplessness. They are taught not to lose control with emotions gendered as feminine (Seidler 1998). Vulnerable feelings are experienced as threatening and need to be controlled. Noting these arguments, Corinne's reaction to Fred's emotional state could only have reinforced these ideas. Fred, as with Jenny, implied a sense of shame following the incident and its disclosure. Kaufman (1985:74) argues that rage is a more natural and spontaneous occurring reaction, often observed to follow shame. Underneath the shame men can feel rage. Fred reported to me that he had gone to Corinne because he was emotionally out of control, he was '*cracking up*'. He reported to me that he felt so angry at the time. Fred appeared aware that the feelings of anger might not be appropriate that it was "*not nice to feel angry*" (*Interview with Fred*). He deemed as others have commented on (Thomas 1990) that anger seemed inappropriate in the care setting. Yet three months following the incident when I interviewed him he remained angry, expressing the unpleasant things he would like to do to this resident given the chance.

In Fred's case as in Jenny's case, managing to cope emotionally with situations involving residents' sexual expression was only a part of the emotional management process. Both care workers had also to control and manage their emotions in the presence of the other 'tough' care workers. Others, (Peisah 1991), have noted relationships amongst staff as a source of stress. In Glenevis it can be argued that a lack of sympathetic and supportive environment for those care workers who were emotionally traumatised by sexual expression by residents, was a source of stress and (emotional) labour. Different emotions were reported to have been experienced by care workers in the case of Will and Wilma.

11.5 The unbelievable story of Will and Wilma

The reported story of Will and Wilma was that both these residents who had dementia, decided to begin a sexual relationship with one of the difficulties being that they seemed unable to discriminate in terms of the most appropriate place to conduct this. The question as to whether they were so incapacitated as to be unable to give informed consent to the sexual relationship was debatable and contested amongst staff. They had nevertheless broken the social 'rules' of the home by being both sexual and being so in public. The story was about the public nature of their affair and the sexual language used. The two respondents, Sheila and Martha, did not refer to Will being 'unfaithful' to his wife but rather to the public and shocking nature of this affair and the fact that it was older people saying and enacting sexual expression. Here the research question of how context influences care workers' response was evident.

Several times Will and Wilma were seen and overheard as to their sexual intentions. Will had a wife who visited and Wilma had daughters who visited regularly. When Will's wife and family heard about the relationship between Will and Wilma, they insisted that the relationship be ended. The couple were subsequently parted and Will was moved to a different floor of the home when a room became available. Neither Will nor Wilma appear to have been consulted. In terms of emotions and emotion work, of note in this case was the sense of disbelief of care workers when they encountered Will and Wilma having a sexual relationship in the corridor of the home.

In the literature on emotions and emotional management seldom is disbelief mentioned as an emotion to be managed. I have noted already that in Glenevis sexual expression could be argued to occur on at least two different levels. Cathy spoke about residents brushing past and touching her.

They (male residents) make sure that you have got to brush, touch them, pass them instead of maybe (them) moving to one side. Or just wee comments if you walk in. (Interview with Cathy).

This was an everyday occurrence she reported. On another level Anne reported that in terms of frequency of sexual expression

It varies. It tends to be one of the residents and then it can be a daily occurrence and when he leaves it may be that there is nothing further for ages. (Interview with Anne)

Corinne also spoke about specific individual cases that were discussed repeatedly and engaged the staff's attention. Then she reported, another situation would demand the headlines.

It is usually more the things that obviously hit the headlines sort of thing in terms of change over, it comes up over and over again the same sort of thing. (Interview with Corinne).

There appeared to be as noted above by Cathy, low level sexual expression occurring on a daily basis that some staff would perhaps not recognise or acknowledge as sexual expression, described by Lawler (1991) as becoming institutionalised in work practice. The other main type of sexual expression was the 'headline' cases that appeared only periodically. As they tended to be only sporadic, their impact was all the more dramatic when they did occur. This coupled with the very real difficulty of some staff to see residents as sexual beings, added to a sense of amazement and disbelief experienced by staff as in the case of Will and Wilma when their relationship was discovered.

It was generally acknowledged by the care workers that the relationship between Will and Wilma had been going on for some time before staff had appreciated the sexual nature of the interaction. Sheila reported feelings of disbelief and thought that she was 'dreaming' when she saw what Will and Wilma were doing. What happened next was interesting.

That night when I had went down the stairs I think they (other care workers) were doing bed change and I just spoke about what I had seen and what I had

heard. And I had thought they would be thinking, "It's all in my mind". But another care assistant she had experienced it that night too and I thought, "Thank goodness."

CA That you'd be believed?

Aye I thought they'd be just sitting there and saying she is just dreaming.

(Interview with Sheila)

An important part of story-telling is trying to be believed and taken seriously. Having other care workers to authenticate what Sheila had seen appeared to provide a sense of relief and helped to validate her experience.

The second time Sheila saw Will and Wilma involved in sexual expression she was with another care worker (Martha) in the sluice.

We were gob-smacked. I saw it wi' another care worker (Martha) the next time.

It was really funny because like you could see the sitting room you could see through the glass a reflection and you said "My goodness." (Interview with Sheila)

The impact and the responsibility, was reduced when it was shared with another care worker. They were able to have a laugh and giggle about the situation. It has been noted by others that joke-work can be a tactic for handling embarrassment where laughter provides a catharsis and relief and contributes to group cohesion (Meerabeau and Page 1996) particularly in situations involving sexual incidents (Twigg 1999) and this was how the two care workers responded.

In this case the care workers did not for most part, use a moralistic route for the story they reported to me. The story was about shock and the outrageous idea of old people having sex. The shocking aspect to the care workers seemed to be that this was happening in the home, in a public space and between two old people. In Twigg's (1999) study some care workers were shocked by the appearance of old bodies. To some workers the ageing naked body was novel and to a degree shocking. This might help to explain workers attitudes in Glenevis where there was a general sense of disbelief at older residents expressing sexuality. Hepworth's (1998:179) ideas that there is in society generally, the deeply rooted Christian belief in the impropriety of strong sexual feelings in old age and that older people should somehow have 'respectable elderly emotions' appeared evident in Glenevis. There is also the consideration that Will had a wife who still visited and as noted in the findings of the questionnaire, the involvement of family appeared a major influence on how staff manage sexual situations and relationships in the home. The case of Will and Wilma was no exception.

Sharing the experience appeared for some staff a way of managing their emotions. Fear is not an emotion often mentioned in terms of the literature on emotions other than perhaps in the psychoanalytical studies. Fear was an emotion that was expressed with regard to sexuality in terms of not being believed, false accusations and litigation. In the case of Will and Wilma, Martha reported that she had recorded the incident for fear of the family carers finding Will and Wilma in a compromising position.

CA Did you report that particular incident to the office?

Yes and I actually done a written report as well because well there was no evidence to... but staff had seen Will slipping out of her room. So eventually

one of the officers asked the staff did they think it was “bad enough to involve the families” and we said, “Yes it was”.

CA Bad enough in terms of?

Well bad enough in terms of, well what if the families walked in and found them? (Interview with Martha)

Inherent in this statement was the scepticism in the manager's remarks asking if it was (really) bad enough to involve carers minimising the situation. The 'halo' effect mentioned by Golander and Raz (2000) may be argued to pertain to some residents with dementia, but as discussed above the ambiguities involved in the construction by care workers of what is meant by dementia are complex and contested. If the resident is in receipt of an agreed dementia label/ ascribed identity, it is likely that this will absolve her/him potentially from sexual responsibility. However it is also likely that it will result in the person being excluded from the decision making process as to whether the relationship they have formed with another resident will be able to continue.

The data seemed to suggest that family carers had a considerable effect on how a case involving sexuality was managed. In Will and Wilma's case it had a drastic affect. Both residents had dementia and it may have been that because of this they were not consulted about ending and relinquishing their relationship. Yet the care staff noted that Will appeared mentally capable. He was aware when staff went for their tea break for example.

Like he (Will) looked demented but he knew when we were going off on tea breaks cause he said one time he says “ Wait till nine o’clock” “ Wait till seven o’clock. (Interview with Sheila)

After discussing the case of Will and Wilma Sheila said

You just have to laugh about it. Half of them are dying on their feet but they still have the strength for that (laughs). (Interview with Sheila)

There was a certain resignation about Sheila’s remarks, a head-shaking disbelief around that old people might even consider being sexually active. Sheila kept referring with disbelief to what her eyes were conveying. She spoke about ‘dreaming’. Metaphors shape individuals’ understanding of reality. Sheila was only able to explain what she saw through the metaphor of dreaming. It was too difficult initially to construct the sexual actions of Will and Wilma as ‘real’ until checked out with other care workers. This need to check with others, to validate what they have experienced, appears to be a response that is important for care workers in managing the emotionally challenging situations of sexuality.

11.6 Conclusions

Emotions, emotional work and emotional labour appear to be key when sexual expression by residents becomes a component of care work. Following on from the last chapter using the medium of storytelling, some of the reported expressed emotions of care workers have been explored and have furthered the understanding of why sexuality

and dementia has still to be discussed more widely. This analysis lends support to Wharton's (1993) work that suggests that the individual and also the context appear crucial aspects to consider when looking at how emotional labour and its impact on the worker and their response.

Staff bring a whole set of agendas to the caring role that will impact on how they respond emotionally to sexual expression by residents. The culture of the home in terms of providing support, sometimes long-term, and possibly counselling input, appeared important. Ambiguities and boundaries have been constant themes throughout this research. The exploration of emotions and their management by staff in Glenevis proved to be no exception. Whilst there appeared written instructions (SVQs) with regard to the physical care of residents, there was little guidance with regard to emotional work and how care workers might manage potentially difficult emotions connected to sexual expression by residents. In Jenny's case she was left with mixed messages. She perceived that management thought her too friendly with Jimmy and that this might have provoked the assault. Yet the debates around residential care are about home and getting close to the resident and all the emotions that that entails. Care workers in the home subscribed to this philosophy, particularly within the key worker/key resident relationship. The acceptable feelings of warmth, closeness and caring about residents appeared to be articulated but the darker emotions of fear and anger for example, that were in conflict with the presiding culture of home, were less examined, to the detriment of care workers and residents.

Emotional labour in Hochschild's (1983) work focused on airline stewardesses in managing their emotions under the public gaze. In Glenevis, care worker to resident

ratios were often 1:16 or, if they were better staffed, four staff for 48 residents. The managers were observed to leave the downstairs office only very infrequently and family carers visiting the home were an irregular occurrence for a number of residents, according to my observations. Care workers were, as a result, often free from the 'public' gaze. The literature on emotional labour and management has focused on the detrimental effect on workers that simulating emotions can have and this has been acknowledged in the data here. But there are wider implications to consider with regard to emotions and their management.

The lack of group and/or ongoing managerial support may mean that unresolved feelings of anger and fear can lead potentially to mistreatment of residents. For example, Gladys' behaviour in emotionally distancing herself from Christine and encouraging other care workers to emulate her actions, could be considered as being tantamount to emotional mistreatment. Older people with physical or mental impairment are at greatest risk (Aitken and Griffen 1996). There appears to be a lack of openness and debate that may as I have argued earlier be related to management and organisational needs.

There are paradoxes however, in that whilst sometimes there was an open debate, this could be detrimental to the residents, as in Will and Wilma's case. All the staff appeared to be aware of the situation and observed and monitored the couple. Both sets of family carers were involved. Will and Wilma were in effect under a microscope and their every sexual move observed. Whilst there appeared reasons for concern about people's dignity and ethical concerns about the ongoing marital relationship between Will and his wife, the case provided a smoke screen for other issues. Workers could

express their (righteous) concern but implicit was ageism and the shocking nature of these two older people indulging in open sex. This time it was not the case of having to protect a vulnerable woman resident with dementia from a predatory male. Wilma by all accounts was more than willing and happy to be involved and able to take care of herself as Martha reported.

Eventually they (the management) spoke to Wilma's family first because out of the two she was the more demented and she should be taken care of first. They (her family) were absolutely fantastic about it. They just laughed and said "Is this (sex) rearing its head again?" I think she was in hospital before and it has happened there. They said "so long it wasn't annoying anyone else and no one else was becoming upset by it". Wilma was quite a strong character as well, because if you said to her don't do this don't do that she would tell you to "fuck off, I'll do as I like". Will was certainly weaker of the two. In fact a lot of the time I used to think Will was quite frightened and went into her room anyway (Laughter). (Interview with Martha)

There appears to be room for debate as to whether their rights as a couple had been infringed or not. The staff, both managers and care workers, appeared to have difficulty emotionally managing their case, particularly when the emotions of the family carers were added to the situation. There are many ethical dilemmas concerning residents with dementia expressing sexual needs. Dementia presented one of the biggest ambiguities in how it was generally perceived by workers. The 'halo' effect mentioned by Golander and Raz (2000) may be argued to pertain to some residents with dementia, but as discussed above the ambiguities involved in the construction by care workers of what is

meant by dementia are complex and contested. If the resident is in receipt of an agreed dementia label/ ascribed identity, it is likely that this will absolve her/him potentially from sexual responsibility. However it is also likely that it will result in the person being excluded from the decision making process as to whether the relationship they have formed with another resident will be able to continue as with Will and Wilma.

These conclusions and the implications for policy and practice, will now be discussed in the next chapter (chapter 12).

Chapter 12 Conclusions Drawn from the Thesis

12.1 Introduction

In the conclusions I discuss the limitations and the key contributions of the study. I discuss the research questions and where possible, provide some answers, but note also that further research questions have emerged in the process. Some of the theoretical developments that have arisen from the findings are discussed and I argue that the findings support the thesis that sexual expression by people with dementia is situated on the margins of acceptability and is a difficult and embarrassing subject for some workers. I note that the situations involving sexual expression by residents are often complex and contested and following this I offer some explanations as to why the subject has been neglected. Finally, I will discuss the implications for policy and practice and the areas where further research is indicated.

12.2 The limitations and the key contributions of the study

12.2.1 The limitations of the study

I recognise the limitations of the study. It occurred in a particular place at a particular time and under particular circumstances and consequently certain factors render the study atypical. I need to acknowledge my impact on the data both in the collection phase and during the analysis. As Hammersley and Atkinson (1983) note, existentially, the researcher is part of the world that is studied. I have endeavoured to be reflexive to

how my gender, class position and educational status may have influenced the information provided by respondents but it is not possible to be aware and reflexive at all times.

My thesis, based on a postmodern feminist approach, has taken the field in new directions but reproducibility has not been the aim. The study has been exploratory and based on hearing the voices of (mainly) women care workers with the aim of obtaining the best possible grasp and understanding of the subject. I have addressed this through 'actor' or respondent 'validation' which does have its limitations as Hammersley and Atkinson (1983:196-7) note. There can be no assumption that the accounts of intentions, beliefs motives involved given by any actor are any guarantee of their truth. The meanings the actors provide are reconstructed on the basis of memory and, as noted earlier, many of the stories provided by care workers in this study are 'memory' stories. The value, as I noted previously in the thesis, is my interpretation of their interpretation of these stories; but this relies on the influences that I bring to the analysis and also the 'gloss' the care workers' chose to place on the story.

It can be argued that treating people's own accounts as unproblematic flies in the face about what is known about people's confused and contradictory relationship to knowing and telling about themselves (Holloway and Jefferson 2000). They may have misdescribed their story to counter my interpretation so that it can readily become a 'hall of mirrors' or a 'hermeneutical circle' where there is no end to the interpretative process (Denzin 1989:141). Although Holloway and Jefferson (2000:3) argue that there are other ways of interpreting these ambiguous representations such as, critical realism,

I have attempted as others have noted, to treat the process of 'validation' as yet another valuable source of data and insight (Hammersley and Atkinson 1983:198).

In chapter five I discuss how I used triangulation as a means to build up a body of evidence incrementally to support theory building and my arguments. Using multiple methods as Hammersley and Atkinson (1983) note lend weight to the idea of reflexive triangulation and this is what I have attempted to achieve. I need to acknowledge that ultimately my account is only an account of what the individual respondents chose to disclose.

The remit of my study has been the exploration of care workers' views. I did not set out to interview residents. One reason was at the time (1994) the voice of the person with dementia was not yet being heard. In retrospect the material I collected in unplanned discussions with residents point to this providing another dimension. I was unable to make use of the material as I did not apply for their or the management's permission to interview the residents. I will discuss this later in the section that addresses areas for further research. Similarly I did not interview family carers, the data from whom would have added further to the findings as noted earlier.

12.2.2 Key contributions of the study

Borrowing from Holstein (1998: 13), I argue that my research is about rendering visible the ideologies that support the desexualised construct of people with dementia with the intention of modifying them. The research undertaken has provided key insights into the way that dementia is perceived and the role the illness plays when sexual expression

by residents is a component of care work. Dementia is often to the fore in resident-resident sexual expression, but less so when the sexual expression is resident-to-staff. In theory the 'halo' effect suggested by Golander and Raz (2000) and present in staff report, is in practice, a contested site due to the ambiguities inherent in dementia. The most difficult type of sexual expression for staff is that of resident-staff sexual expression. In terms of neglect, it is the one less publicly spoken about, the one less discussed amongst care workers and the one less written about in the official documents. I will discuss these and other conclusions in more detail in the next sections and address the main conclusions from the systematic literature review undertaken.

To conclude this section, the strengths of the thesis are that the research has reached areas of the interior of home life that has hitherto remained, for the most part, unexplored and as such provides insights that would not have been possible if this study had not been undertaken.

12.3 Conclusions of the literature review

I have undertaken a systematic literature review on the three substantive areas of sexuality, dementia and residential care to look at the work that has already been carried out in these areas and to note the gaps and omissions. This literature review on the three linked and substantive topics contributes academically to an area that has been under-researched and theorised. I note that:

- ❖ The medicalisation of dementia and the social care constructs of dementia are characterised by ambiguities.

- ❖ The role that people with dementia play in this biomedical model is often a ‘sick role’ with the resultant social control that ensues. This may lead to the person not being involved in any decision-making with regard to sexual relationships.
- ❖ The social care model that includes a person-centred approach emphasises the need to see dementia as a disability. This has limitations when sexuality becomes a component of work.
- ❖ Respectability and reputation emerge as key themes with sexual respectability coded in the domestic-feminine ideal. Following on from this I argue that women care workers’ sexual reputations may be seen to be at risk if they are viewed to be encouraging in any way sexual attention from male residents. I note in chapter two that this may mean there is an underreporting of sexual incidents by care workers. This may be a contributory factor in the neglect of the subject.
- ❖ The literature on sexuality and dementia is sparse and the debates are focussed on the problematic nature of sexual expression. Sexual expression is often constructed as challenging behaviour. Omitted are the positives and the beneficial aspects that are manifest in the literature on older people and sexuality
- ❖ In chapter three when the two substantive areas of sexuality and dementia intersect in long-term care, the themes of ambiguity, gender and omission become more sharply focussed, as does the emotional cost for staff in managing this aspect of their work. It appears easier in residential care to omit this subject, not to discuss it,

than have to deal with and produce guidelines for staff in what is seen as a problematic and fraught area of work.

The findings from the academic literature, have helped to inform sociological discussion of the relevant areas in my empirical work.

12.4 Conclusions from the empirical work

My argument is that the area of dementia, sexuality and residential care is under-researched and the extensive literature review undertaken for this study underlines and supports this assertion. Whilst the literature has helped to inform this study there have been gaps and omissions that my empirical work has helped to address. The conclusions from the findings have provided some answers as to why the area has been so under developed. In support of the literature, my findings suggest that residents expressing sexuality is a difficult and problematic area for care staff. However, there are subtleties and complexities involved that influence discussion and documentation. These I will discuss by addressing the research questions within the major themes that have emerged:

- ❖ What did staff say about sex?
- ❖ What were the types of sexual expression staff found most difficult?
- ❖ How did care workers respond to sexual expression by residents?
- ❖ How did a diagnosis of dementia affect the response of staff to sexual expression?
- ❖ How did the context influence staff response?

12.5 What staff say about sex?

I have noted above that both officially and due to the prevailing tough culture of the home, talk about sexuality, particularly resident-to-staff sexual expression was difficult. I found resonances with the literature in terms of the language used to discuss sex. For example, staff in Glenevis often used the word 'it' to imply a penis or to denote 'having sex'. The word sexual harassment was seldom applied to situations involving resident-to-staff sexual expression. As Lawler (1991) notes if the situation is not defined in this way it may be treated as simply challenging behaviour as opposed to looking at the situation through the prism of sexuality.

What staff say about sex in Glenevis also suggests that ageism and infantilisation are a constant with staff reporting *'Half of them are dying on their feet..'* or *'he is old enough to be my grandad'*. What staff say about sex is that it is mainly men residents who are the main actors, with women residents expressing sexual need, seen as an aberration. There have been few studies to address issues around women with dementia's sexual needs and expression (Nay 1992). Following on from this, in my study I needed to prompt most respondents to talk about women residents' sexual expression as very few workers volunteered information on this topic. When they did there was evidence of an indulgent infantilisation process that seemed to deny older women residents' sexual needs. These women residents generally were not seen as a sexual threat unless their sexual advances were to women care workers or gay male care workers or where there was a possibility of staff being accused of sexual abuse. There appeared ambivalence in some women care workers' report towards women residents expressing sexual need. There seemed to be double standards with regard to men expressing sexual need and the

expressed needs of women residents. This emerges also in the general literature on sexuality. Gender is an issue.

There are ambiguities that find parallels in Evers' (1981) work. Evers spoke about how nurses typified patients with some, particularly the 'characters', finding merit with staff. In my empirical work, for example, in the case study of Will and Wilma, it was Wilma who was admired by some staff in the way she openly addressed methods of securing her sexual needs. She swore and spoke candidly about sex. Martha, one of the care workers, suggested it was she rather than Will, who was the more sexually demanding of the two. However women residents generally were constructed as asexual or as sexual victims in need of protection and it was this that epitomised their labelling formation.

A finding that emerged within the debates of the family and what staff say about sex and to whom, is the difficulty that occurs for some people when faced with talking about sex and sexuality between generations. For example, Marion, one of the care workers reports, "*talking to a resident about this topic. I just feel It's not the thing you talk to the residents about I dinn'ae ken it's a different, a different generation from us*". The embarrassment and difficulties reported by several care workers of talking to residents about sexuality in my study may be a further reason why this subject is not discussed in an adult-to-adult way. There were parallels with parents talking to their children about sex, and how some parents have a great difficulty talking intergenerationally about the subject. Talking about sex is often difficult for staff but there are some types of sexual expression that staff find more difficult than others to manage.

12.6 The types of sexual expression that staff found most difficult

The findings from both the postal survey, the literature review as well as the empirical findings point to resident-to-staff sexual expression being one of the most difficult for staff to manage and one that appears to carry high emotional costs for some staff. Grounded in the data, there are a number of reasons for this including the reputation of the care worker, the tough culture of the home, the silence about the subject in the written records and the silence with regard to sharing with other staff. In addressing the research questions, it is apparent that none of these are mutually exclusive rather, they overlap. When discussing the types of sexual expression that staff find difficult it is necessary not only to look at what they say about sex but what they say from an official perspective.

In the Incident Register in the home where ‘important’ incidents are recorded, there are few recorded incidents of sexual expression, particularly of those involving resident-to-staff. My findings point to little training or proactive work being provided for staff on how to manage incidents of sexual expression by residents, with managers tending to minimise the incidents reported by staff. It is implied that staff are overreacting or ‘asking for it’, and in the case of one male care worker, it was inferred that sexual harassment is what many women care workers have to deal with on a daily basis. There is a dearth of literature on how male care workers manage sexual expression by residents and little on the emotional labour that may ensue. I have argued that belittling the telling of their stories makes the recounting to others less likely. The tough culture of the home where the expectation is that care workers have to (emotionally) manage these situations, also play a part in some sexual stories not being told.

The reputation of the care workers appeared another key reason why sexual incidents involving resident-to-staff sexual expression were not widely discussed. As noted earlier, the concern was that they, the care workers, might have in some way 'asked for it'. In the nursing academic literature (Lawler 1991), it was the risk both for the nurse and the profession posed by an exploration of sexuality in the work place, that was given as a reason for neglect of the subject. Sexuality has consequently become somewhat institutionalised and seen as part of the job. These findings concur with what I found in Glenevis, but also pervasive was the 'tough' culture of the home that meant the onus was to a large extent, on the individual to manage and avoid such sexual situations.

As noted by Skeggs (1997) the sexual reputation of women was of issue and needed to be protected. In the case of Christine, who accused the staff of being lesbian, there appeared a real anxiety amongst some women care workers that this label might be conferred on them if they touched or carried out intimate tasks for her. When the resident-to-staff sexual expression was gay or lesbian, this was even more difficult to manage for many of care workers. These findings may explain why there is a dearth of literature on the subject. Grounded in the data, the findings point to the subject of gay sexuality being acceptable in theory but when gay or lesbian sexual expression occurs in practice, staff have difficulties. As in the case of Christine, the resident expressing sexuality in this way, was labelled, marginalised and given only the basic care.

Some staff reported that they had to behave professionally towards the gay or lesbian resident despite their private sense of abhorrence. An interesting finding was that whilst staff thought that in society generally gay or lesbian sexuality was acceptable-Marion a

care worker said, *"it's okay to talk about it now"* it proved to be more complicated when these issues were brought into the home and became explicit. This was true whether it was staff or resident sexual expression. I use the term 'public' in these situations to mean the 'liberal' debates on gay and lesbian sexual expression evident in society generally. I noted differences in terminology also. Whilst gay was often used, the term lesbian was only used by Gladys and even then she was simply quoting the language that Christine, the resident who had accused all the staff of being lesbian, had used. Gay was an acceptable term, lesbian seemed to have more difficult connotations for staff.

The public and private aspects of space have emerged as an important theme particularly in the area of gay and lesbian issues. How staff are supposed to feel and act professionally as opposed to how they feel about issues personally, emerged as important both in the findings from the postal survey and in the case study. Most of the women care workers expressed particular difficulties with the idea of women residents expressing sexuality towards them, the care workers. This was reported in the interviews with staff but also in the workshop report. Some male care workers expressed difficulties with male residents expressing sexual intent towards them but one gay male care worker found it easier to deal with male resident sexual expression than women residents expressing sexual intent whether or not the resident had dementia.

12.7 The role dementia plays in staff response

Epistemologically, obtaining the views of the mainly women care workers has provided a rich source of data. Ambiguity and uncertainty that has characterised the findings

suggests that the postmodern feminist approach that I have used has allowed space to explore these ambiguities. I theorise that ambiguity may be major component in why this subject area has been neglected. Ambiguity has emerged as a central theme both in the empirical work and in the literature. The diagnosis of and the defining of dementia is a contested area and is exacerbated in dementias such as Lewy body dementia where there can be marked fluctuations in its course. This has implications as noted in my study where staff have received little training or education about dementia. It has implications on a number of counts. The findings point to dementia in the staff documents having many different definitions ranging from Alzheimer's to a little confused. There is ambiguity in the documentation but as I have noted there is often ambiguity between care worker's verbal accounts. Some care workers define some residents as being advanced in their dementia whilst other staff, with regard to the same resident, would argue otherwise.

An implication that follows from the theme of ambiguity is the issue of responsibility in terms of resident-staff, resident-resident and solo resident, sexual expression. My findings point to care workers reporting that where they know a resident has dementia then they would not hold the resident responsible for their sexual actions. This appeared to be by no means an uncontested area. Staff differed in their opinion with regard to which resident had dementia and how badly they were affected, but there was also a dissonance between what they reported and their actions. For example, in certain situations where the resident was known to have dementia and or have mental health problems, the extenuating circumstances of dementia appeared not to influence the situation positively. This was particularly the case where there was resident-to-staff sexual expression. It was only in situations where there appeared little ambiguity, that

is, where the resident was very advanced in their dementia, that the extenuating circumstances seemed to engender more forbearance in the care staff.

Ambiguity is highlighted in incidents of male residents exposing their genitals. The staff are often unsure whether this is as a result of the person having dementia or whether they are deliberately exposing their body and their action thus being interpreted as sexual. It was often difficult for staff to know with any degree of certainty whether the action was to be interpreted as sexual and thus reported as such. This did not simply apply to residents exposing themselves but also to residents touching staffs' breasts and bottoms. If staff are unsure then it becomes difficult to report these issues to management and this may influence how staff respond. Staff may manage the situation by interpreting it as non-sexual.

I have discussed throughout the thesis that women residents, especially those with dementia, are seen as in need of protection from predatory male residents. There are other situations that I have discussed where the Foucauldian concepts of 'surveillance' and 'the gaze' can be successfully combined with the notion of pastoral care (Foucault 1988) to offer a broader explanation. Ethical issues around the area of consent appeared not to be to the fore in Glenevis.

A finding that has emerged in this study is that sometimes managers can appear to ridicule care workers by suggesting that theirs, the care workers' response, is an overreaction to a sexual situation. The managers also inferred that the care workers tend to be intolerant of residents expressing sexuality. This combined with the often ambiguous nature of many sexual situations may have led to an under-reporting and/or

discussion with managers of sexual incidents. I theorise that it can be easy for managers to express liberal ideas when the tendency is for them to remain in their office for most of the day undertaking administrative work. It is arguably less easy for care workers who are in receipt of residents' sexual advances or who might incur the wrath of family if the residents are found in an unambiguous sexual position when the family carers visit the home.

There does however, in my findings, appear to be some collusion between managers and care staff in terms of controlling the sexual expression by residents with dementia. There seems to be a fine dividing line between care and control. If the situation is controlled, that is the sexual relationship between residents is disallowed, sometimes for what are seen as the best intentions (pastoral care), then sexuality is no longer an issue, it does not exist. Managing a sexual situation this way avoids the need for meetings and discussions with the residents to look at competency. The argument that avoidance of such situations which might be fraught and difficult for staff particularly in the context of the resident's carers involvement, is plausible.

12.8 How context influenced staff response

My findings are that context was important in influencing how staff responded to resident sexual expression. I have used the theme of space as an analytical device, specifically public and private space. The data suggests the blurring of boundaries that occurs with regard to public and private that resonates with the literature.

Architecturally, I argue that there has been a largely uncritical acceptance of the small and homely concept in the design of homes particularly for people with dementia. From my findings I argue that there is a need to explore how this close, homely and intimate space may impact when a resident or residents express sexuality. I have explored the debates of 'home' both in the literature and with respondents in my study and what emerges is that for some there appears to be a certain mystique and an acceptable quality in the concept. There is little recognition that home may also be an abusive place for some people (Lee 1993). Home is often where the sexual and intimate relationships occur yet in residential 'homes' little attention has been given to this area. In my study I have noted that for some staff, having to manage incidents of sexual expression directed at them by residents in such small intimate situations, can prove difficult. Also the lack of supervision in these small units in Glenevis, meant that men residents were able as in a family home, to wander into the bedrooms of others in the 'family' and sexually *'interfere with'* some women residents. In my study it appears to be the intimate and small nature of these family units combined with the low staffing, that helped to facilitate this sexual and sometimes unwanted intimacy between residents.

I have argued that my findings point to neither familial nor professional debates adequately preparing workers to manage sexual expression when caring for this group of residents. Professional discussions appear to emphasise the need for staff to consider the psychological needs of residents in tandem with the resident's physical and medical needs. However, there are inherent difficulties that staff report. There is a need to become close to residents yet there is also a need for professional distance with the difficulty in practice of balancing the two. There are tensions also in the familial

debates that staff seem to value. Few of the care workers I noted had professional qualifications yet they had a wealth of experience in caring for their family members. It was this family caring experience that was brought to their work situation that was exemplified in the key worker/key resident relationship.

Yet it is in these key 'family' relationships where boundaries become eroded that sexual expression sometimes occurred. Lawler (1991) and Savage (1995) have furthered the discussion of intimacy and nursing practice and Twigg (1999) has explored bodywork within residential care work. My study has helped to further the exploration of this subject area within a residential setting and particularly within the key worker/key resident relationship, where mock-kin status is afforded to some key residents. As in any family situation, because of the prolonged and intimate nature of this relationship, the expression of sexuality by the resident to the key worker can become problematic. I argue that within a culture where this almost idealised relationship occurs, it can be difficult to discuss the issues when sexual expression becomes a component.

Context is also important in terms of how sex and sexual stories are spoken about in the home. When the sexual expression is in the privacy of the resident's bedroom, some staff may not disclose and tell the story. Earlier I spoke about the reputation of care workers being a key consideration. In terms of residents' reputation, some care workers reported that they were discreet in what they disclosed to other care workers. Teresa, one of the care workers for example, appeared very aware about the power of labelling and deviance amplification if she were to disclose sexual information about one of the residents.

When sexual expression however occurred in public, then it became public knowledge as in the case of Will and Wilma, and became a 'headline' story, with the residents almost forfeiting their rights to privacy. Equally when staff expressed sexuality, as in the case of a male care worker expressing sexual remarks to another male care worker in the presence of others, this too became public knowledge.

12.9 Omission - why the subject has been neglected

In addressing the research questions in the previous sections, some of the reasons why this subject has been neglected have emerged. I have suggested that the ambiguous nature of dementia might have resulted in an underreporting of sexual incidents. Ageism might be another reason for understating sexual expression. I argue, for example, that where a sexual incident is constructed as asexual, then the worker does not need to take further action. In such situations a denial of a resident's sexuality, a lack of acknowledgement of the person as a sexual being, may not be in the resident's best interest if person-centred care is the aim.

The data point to the subject being a difficult and uneasy area for many staff including managers, one that they would choose to ignore or remain silent about. The difficulties in talking about sexuality in terms of the language used and also intergenerational issues, made discussion of sex-talk between younger care staff and older residents problematic. The term 'sexual harassment' tended not to be used. Resident-to-staff sexual expression was not defined or discussed as such.

The issues around gay and lesbian sexuality were also omitted. I have noted that care workers appeared liberal in their ideas towards gay and lesbians in the wider community but less tolerant when this kind of sexual expression occurred in the residential home. For some workers gay/lesbian sexual expression appeared to be sexually threatening and whilst staff were able to discuss resident-staff lesbian sexual expression, that is the case of Christine, at the training workshop as a group, the story of staff-staff gay sexual expression was omitted both in the interview and back stage discussions.

Women residents expressing sexuality, as I have noted earlier, with few exceptions tended to be omitted from the discussions unless characterised as in need of protection from predatory male residents. I have argued that this as a result of sexism and ageism with older women residents typically seen as asexual, with a diagnosis of dementia further compounding the situation.

The potential difficulties in obtaining funding for research into this area of work and the possible negative repercussions on the researcher's career prospects, are all reasons why this area may have been neglected despite it being of concern in practice for staff.

12.10 The implications of the findings for policy and practice

On the basis of the findings of both the literature and of the empirical work I have undertaken I would like to explore the implications for both policy and practice.

12.10.1 Policy

If Sumner's (2001) argument that residential homes for older people have become an anachronism is to be challenged, then a more creative response to caring for older people in these situations is needed. I am aware reading Sumner's paper that following various well received pieces of research (Peace et al 1997, Willcocks et al 1987,) on residential care, that change has been slow yet meantime the lives of older people, people with dementia, and those who work in residential care homes, continues. Sumner notes that though resident disability has increased, staffing levels have not, with poor skill levels apparent in staff. The Scottish *Regulation of Care Act (2001)* aspires to effect changes but whether this will succeed where others have been less successful, remains to be seen.

At policy level, I would argue for an inclusion and acknowledgement of the sexual needs of older people and people with dementia in residential care homes in policy statements and guidelines. The debates of this Government are around issues of social inclusion. Often explicit in these are issues around religion, race and colour. Less explicit are issues around the sexual/intimacy needs and sexual orientation of older people, people with dementia and this is the case of the National Care Standards 2001 (Care Homes for Older People). Sexuality is not mentioned but it is implicit and as such is incorporated under the standards of choice, privacy and dignity.

Sexuality needs to be made more explicit in policy documents not only because of demographic changes and human rights issues, but also because the generation that is greying now, the 'baby boomers' may be more sexually assertive. If residential homes,

in whatever form, are going to continue and it would seem they are for the foreseeable future, policy in the area of sexuality needs to be proactive, for the reasons stated above and also because of issues around such areas as HIV and AIDS. This is again a neglected area but one that needs consideration in terms of policy.

The literature points to ageism and infantilisation being endemic in society. This will need a sustained offensive on all fronts but also at policy level. In terms of policy what has to be considered is the need to avoid an idealisation of older people when considering sexuality. This may seem paradoxical given the above arguments but I argue that idealisation in different forms does occur and it is an aspect of infantilisation and ageism. A majority of older people and people with dementia are heterogeneous. Some may have led full and active (sexual) lives whilst others have been abusive, violent and nasty at different times in their lives. This legacy of a lifetime, people carry with them into old age. This needs to be considered when addressing sexuality and related issues; when taking into account the person's needs but also those of others with whom they share a 'home' when they move into residential care.

I would argue that this has implications for policy in terms of sexual expression. Older people including people with dementia being admitted to residential may be helped, as would staff, with a policy document regarding sexual expression. The Jewish Home in New York has such a policy that has been found to help both residents and their carers. I suggest here that this might provide ground rules for all concerned and would be a basis for discussion when difficult situations arise. The silences surrounding the area of sexuality and dementia in residential care highlighted both in the literature and in my

empirical work, suggest that opening up the debates and including residents in a sensitive way, may be of benefit.

12.10.2 Practice issues

There is a need also to open the debates on sexuality and this I have done (see Appendix 12). Emergent from the literature and my findings is the need for training and education of staff with regard to this area. There are several points that need to be made that help to focus and address my findings more directly.

The first is that often training and education on the subject of sexuality, where it is provided, is directed at care worker level. My findings point to the need for managers also to be provided with training and education in this area together with other (multidisciplinary) staff. These ideas on training are supported in the literature (Murgatroyd 1998, Nolan and Keady 1996). Part of the education process needs to address the need for role-modelling by managers and the need to consider the potential for emotional distress that incidents involving sexual expression by residents generate in some care workers and also in managers.

The findings in my research point almost to an institutionalisation of aspects of sexual expression. I argue that the preventative measures discussed above would be useful but also that an open discussion and debate about the headline cases that occur could be used as teaching opportunities. In the US literature Rosenkoeter (1996) looks at guidelines for assessing the changing situation of couples when one of them is admitted into long term care. These address relationship issues as opposed to simply focussing on

sexuality. The questions elicit issues around intimacy in a sensitive way. Sexuality is not an easy area and requires sensitivity, good timing and discretion but it is an area that needs to be explored if a resident's needs are to be met. The literature I have found although limited, points to older people wanting to discuss sexuality and that it is important to them (Loehr et al 1997, Deacon et al 1995), but often staffs' discomfort deters. This has emerged in my study and has implications for practice.

12.11 Further research

There are several areas that seem to suggest that further research is needed. The first concerns people with dementia. I have noted earlier that there has been an increasing literature on hearing the voice of the person with dementia that was not evident when I began this thesis. In order that we can plan and devise policies that are person-centred and that person-centred planning can become a reality with regard to a resident's sexual life, we need to ask people with dementia about intimacy and their sexual needs.

There has been little research undertaken in this area, yet if we are to see people with dementia as adult people this is arguably a necessary step to undertake. This may include seeking the views of people living in the community and also people who are living in residential care. The limited literature on the subject suggests that sexuality is an important area for older people generally but is often not discussed in residential home. This is sometimes as a result of staffs' difficulties rather than residents' diffidence.

Acknowledging the above, there is a need to be more specific. There are substantial gaps in the literature with regard to older women, sexuality and dementia. In my work what was evident was the constant need to cue the care workers to discuss women residents with dementia expressing sexuality. There are greater numbers of older women with Alzheimer's yet few studies of their sexual/intimacy needs have been undertaken.

There appears to be a lack of empirical research on carers' response to sexuality and dementia when the person they cared for is admitted to residential care, in the UK. My research has had as a focus care workers' responses but throughout the data it was apparent that family carer involvement influenced how care workers responded to sexual expression by residents. Families were often involved in the decision making. Families who were involved varied, with some being tolerant if not indulgent towards their relative, others were less so insisting the relationship with the other resident be terminated. Families appeared in my research, to be less involved when the sexual expression was resident-to-staff. This might have been because there were no family carers who remained in contact with these residents.

Another area in need of further research that has emerged, both as a gap in the literature and as an issue in my empirical work, is that of gay and lesbian issues when people with dementia are admitted to residential care. These issues have been considered by the RCN (1998a, 1998b and 1994) but this work is not specific to older people or people with dementia. Di Augelli et al (2001) argue for further research about the support for partners of older lesbian, gay and bisexual (lgb) people, and I would add to this, research on lgb who are admitted to residential care. The issues of gay and lesbian older

people has been raised recently by Age Concern (2001) and so research into this area would be timely.

Emotions and emotional labour have been a major theme to emerge with regard to staff managing residents' sexual expression. As noted earlier it is an under-appreciated area of care work and one that has largely been neglected in terms of sexuality. This points to the area requiring further research. Equally, emotions, when discussed in the literature, have been essentially feminised. I would argue that given the increasing number of men in the caring services whether nursing or residential care, there is scope for research to be undertaken on the emotional impact of sexual expression by residents on these male workers and how they 'manage' with such situations.

12.12 To conclude

Researching this topic of sexuality has engendered in me a real sense of compassion, empathy and consideration for both residents and also care workers in this ambiguous and difficult area. It has helped me to be more reflexive in my own work practice and has helped to further my understanding of the subject. Seibold (2000: 152) argues that in feminist research and theory there are broadly three aims. First, women's experiences are the major object of investigation; second, the researcher always attempts to see the world from the vantage of a particular group of women, and thirdly, they are critical activists in efforts to improve the lot of women and all persons. I have made an attempt to address all three aims in my study.

**And at the end of all
Our exploring
Will be to arrive where
We started
And to know the place
For the first time**

TS Elliot

(The Four Quartets)

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DEMENTIA SERVICES DEVELOPMENT CENTRE

**A QUESTIONNAIRE ON
THE EXPRESSION OF SEXUALITY
BY PEOPLE WITH DEMENTIA
IN RESIDENTIAL CARE**

**Carole Archibald
Senior Fieldworker**



Rembrandt. 1638.

THE EXPRESSION OF SEXUALITY IN RESIDENTIAL CARE

Thank you for agreeing to complete this questionnaire on the subject of sexuality and dementia in residential care. Your input is most appreciated. The information will be used as part of a PhD research project and will be treated with the strictest confidence. When giving feedback the information will not be linked to you personally or to your home but will be presented in aggregate form.

The questionnaire should take 20-30 minutes to complete. I suspect, like most people, you are very busy but if you could find time within the next two weeks to complete the questionnaire and return it by I would be much obliged.

Would you please **PRINT** your answers

Section 1

First some information about you, your staff and your residential home. This is to provide a context in which to view the information on sexuality.

- | | | | |
|---|--|----------------------|---|
| 1 | What is your job title? | <input type="text"/> | |
| 2 | Are you male or female? | | <input type="checkbox"/> |
| 3 | Do you have: a) a nursing qualification | | Yes <input type="checkbox"/>
No <input type="checkbox"/> |
| | b) a social work qualification | | Yes <input type="checkbox"/>
No <input type="checkbox"/> |
| 4 | How many beds are in your residential home? | | <input type="text"/> |
| 5 | How many residents have single rooms | | <input type="text"/> |
| 6 | Is your residential home divided into small scale living units?. | | Yes <input type="checkbox"/>
No <input type="checkbox"/> |

There are an increasing number of people with dementia both being admitted with, and developing dementia whilst in residential care. Some may or may not have a diagnosis. In your opinion:

- | | | |
|----|--|----------------------|
| 7 | How many male residents do you have? | <input type="text"/> |
| | How many of these have dementia? | <input type="text"/> |
| 8 | How many female residents do you have? | <input type="text"/> |
| | How many of these have dementia? | <input type="text"/> |
| 9 | How many female staff do you have? | <input type="text"/> |
| 10 | How many male staff do you have? | <input type="text"/> |

Section 2

There are certain behaviours, within a spectrum of social behaviours, we tend to term as sexual. Of these some are seen as more difficult than others to manage. The following is a checklist of behaviours usually described as sexual.

Please tick those YOU find difficult (D) or not difficult (ND) to manage within the context of residential care.

In a public area - residents

1	Kissing	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
2	putting arms around each other	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
3	holding hands	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
4	masturbating	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
5	making sexually suggestive remarks	D	<input type="checkbox"/>	ND	<input type="checkbox"/>

In private between men and women

6	kissing	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
7	putting arms around each other	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
8	one resident touching another's genitals	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
9	one resident masturbating another	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
10	intercourse	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
11	sexual exploitation of one resident by another resident (ie a more dominant and powerful resident coercing a more powerless resident to have sexual contact)	D	<input type="checkbox"/>	ND	<input type="checkbox"/>

In private between people of the same sex

12	kissing	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
13	putting arms around each other	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
14	one resident touching another's genitals	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
15	one resident masturbating another	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
16	intercourse	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
17	sexual exploitation of one resident by another resident (ie a more dominant and powerful resident coercing a more powerless resident to have sexual contact)	D	<input type="checkbox"/>	ND	<input type="checkbox"/>

Sexual expression of residents towards staff

18	male residents attempting to fondle breasts of female staff	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
19	place hands up the skirts of female staff	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
20	male residents attempting to fondle male members of staff	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
21	female residents attempting to fondle male members of staff	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
22	female residents attempting to fondle female members of staff	D	<input type="checkbox"/>	ND	<input type="checkbox"/>
23	sexually suggestive remarks	D	<input type="checkbox"/>	ND	<input type="checkbox"/>

Please tick those YOU feel comfortable with (C) or uncomfortable with (U) within the context of residential care.

In a public area - residents

1	Kissing	C	<input type="checkbox"/>	U	<input type="checkbox"/>
2	putting arms around each other	C	<input type="checkbox"/>	U	<input type="checkbox"/>
3	holding hands	C	<input type="checkbox"/>	U	<input type="checkbox"/>
4	masturbating	C	<input type="checkbox"/>	U	<input type="checkbox"/>
5	making sexually suggestive remarks	C	<input type="checkbox"/>	U	<input type="checkbox"/>

In private between men and women

6	kissing	C	<input type="checkbox"/>	U	<input type="checkbox"/>
7	putting arms around each other	C	<input type="checkbox"/>	U	<input type="checkbox"/>
8	one resident touching another's genitals	C	<input type="checkbox"/>	U	<input type="checkbox"/>
9	one resident masturbating another	C	<input type="checkbox"/>	U	<input type="checkbox"/>
10	intercourse	C	<input type="checkbox"/>	U	<input type="checkbox"/>
11	sexual exploitation of one resident by another resident (ie a more dominant and powerful resident coercing a more powerless resident to have sexual contact)	C	<input type="checkbox"/>	U	<input type="checkbox"/>

In private between people of the same sex

12	kissing	C	<input type="checkbox"/>	U	<input type="checkbox"/>
13	putting arms around each other	C	<input type="checkbox"/>	U	<input type="checkbox"/>
14	one resident touching another's genitals	C	<input type="checkbox"/>	U	<input type="checkbox"/>
15	one resident masturbating another	C	<input type="checkbox"/>	U	<input type="checkbox"/>
16	intercourse	C	<input type="checkbox"/>	U	<input type="checkbox"/>
17	sexual exploitation of one resident by another resident (ie a more dominant and powerful resident coercing a more powerless resident to have sexual contact)	C	<input type="checkbox"/>	U	<input type="checkbox"/>

Sexual expression of residents towards staff

18	male residents attempting to fondle breasts of female staff	C	<input type="checkbox"/>	U	<input type="checkbox"/>
19	place hands up the skirts of female staff	C	<input type="checkbox"/>	U	<input type="checkbox"/>
20	male residents attempting to fondle male members of staff	C	<input type="checkbox"/>	U	<input type="checkbox"/>
21	female residents attempting to fondle male members of staff	C	<input type="checkbox"/>	U	<input type="checkbox"/>
22	female residents attempting to fondle female members of staff	C	<input type="checkbox"/>	U	<input type="checkbox"/>
23	sexually suggestive remarks	C	<input type="checkbox"/>	U	<input type="checkbox"/>

Have any of these behaviours occurred in your residential home?

Yes

No

If yes please say which one/s please give the number/s

FOR EXAMPLES

kissing in public = 1

kissing in private between men and women = 6

Please say approximately how often for each one (eg daily, weekly, monthly a year ago)

D	W	M	WLY	OY

Can you describe the behaviour/s you were/are concerned about

.....

.....

Have there been any other sexual behaviours not mentioned here

Yes

No

If yes which?

.....

.....

.....

Section 3

I would like now to look at the kind of sexual expression that occurs in your residential home involving people with dementia. Dementia is a complex disease adding another dimension to the expression of sexuality. It is not possible to cover all aspects of sexual expression in a questionnaire so a series of case studies, will be given to help explore some of the issues. For the purpose of this study it is assumed that **the early to middle stages of dementia would mean that there is a degree of insight, and with careful explanation and good communication skills, it is possible to obtain consent from the person with regard to sexual expression.** In all the case studies the residents are in the early to middle stages of dementia and have lived in the residential home for at least a year.

Please tick the box which represents the most appropriate answer for you

Key to Abbreviations used Table

D - Daily, W- Weekly, M - Monthly, WLY - Once or twice within the last year, OY - Once or twice within the previous year.

1 Jimmy and Florrie are residents in a residential home. Both have dementia. They are often seen holding hands in the corridor and appear to derive benefit from this activity. **Neither have spouses.**

- a) To you would this situation be acceptable unacceptable
- b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

2 Frankie and Jessie both have dementia. They have been resident in the home for a year and in that time they have formed a relationship and are often seen holding hands when walking around the corridor or in the sitting room. Other residents comment but the comments do not seem to effect the behaviour of the 'couple'. Jessie's husband visits regularly. He tends to be upset when he sees Jessie and Frankie holding hands.

a) To you would this situation be *acceptable* *unacceptable*

b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

3 James and John, both with dementia, are residents who have lived in the home for approximately a year. They are often seen walking hand in hand in the corridor or when in the sitting room. Both seem to derive some pleasure from the contact. Neither have spouses or close family who visit. Other residents comment but the two men seem not to notice.

a) To you would this situation be acceptable unacceptable

b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
- other (describe)

4 Sam and Henry, both with dementia, are residents who have lived in the home for approximately a year. They are often seen walking hand in hand in the corridor or when in the sitting room. Other residents comment but the two men seem not to notice. Both seem to derive some pleasure from the contact. Sam has a wife and family who visit on a regular basis.

a) To you would this situation be acceptable unacceptable

b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately

other (describe)

5 Ken who has lived in the home for a year has dementia. He is frequently found masturbating in the sitting room. There are several other residents of both sexes in the room who do not seem to be aware of Ken's behaviour.

a) To you would the resident's behaviour be acceptable unacceptable

b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many men with dementia have been involved in such an occurrence?
 How often in your experience has such an incident occurred?

No of men	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

6 Jessie has dementia. She has lived in the home for a year or so. She is often found masturbating in the sitting room. There are several other residents of both sexes in the room who do not seem to notice Jessie's behaviour.

a) To you would this resident's behaviour be *acceptable* *unacceptable*

b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many women with dementia have been involved in such an occurrence?
How often in your experience has such an incident occurred?

No of women	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

7 It is 8.00am and two care staff are starting to get residents up for breakfast. John has dementia. They knock on his bedroom door and on receiving no reply they enter. They find John masturbating. He continues to masturbate when the two staff enter the room.

- a) To you would the resident's behaviour acceptable unacceptable
- b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'men' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of men	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

8 On another day as care staff are starting to get residents up for breakfast, they knock on Jessie's bedroom door and on receiving no reply they enter. Jessie they find is masturbating and continues to do so in spite of their presence

- a) To you would this resident's behaviour be *acceptable* *unacceptable*
- b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'women' with dementia have been involved in such an occurrence?
How often in your experience has such an incident occurred?

No of women	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

9 A female care worker is assisting Ken, who has dementia, to take a bath. While she is helping him undress, he leans over and attempts to fondle her breasts and when her back is turned he tries to put his hands up her skirt.

- a) To you would this resident's behaviour be acceptable unacceptable
- b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'men' with dementia have been involved in such an occurrence?
How often in your experience has such an incident occurred?

No of men	D	W	M	WLY	OY

How did you respond the last time this happened?

.....
.....
.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

11 Maggie who has dementia has lived in the home since her husband died a year ago. She has started to go into Alan's room at different times of the day. The staff think that the couple may be having a sexual relationship. Maggie seems to be deriving some pleasure from this relationship. Alan does not have dementia.

- a) To you would this situation be acceptable unacceptable
- b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

12 Nan has dementia. Her husband died a year ago and it was then she was admitted to the home. She has been seen several times recently going into her bedroom with Bill, a resident who does not have dementia. They spend approximately an hour in the room. Usually Nan, a timid, anxious, woman does not appear to be concerned when she emerges, but on one occasion she was seen to be distressed.

- a) To you would this situation be *acceptable* *unacceptable*
- b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

- ignore
- observe
- observe then intervene
- intervene immediately
-
- other (describe)

13 Ken has dementia, while Agnes does not. What they do share in common is that they are both widowed. They have both been in the home for a year and in that time have formed a friendly relationship. On several occasions recently they are seen going into Nan's bedroom and spend some time there. It is assumed that their relationship has become more intimate. Neither of the 'couple' show signs of being distressed.

a) To you would this situation be *acceptable* *unacceptable*

b) Has a similar incident occurred in your residential home? yes no

If No, go to question d)

c) If yes:

How many 'couples' with dementia have been involved in such an occurrence?

How often in your experience has such an incident occurred?

No of couples	D	W	M	WLY	OY

How did you respond the last time this happened?

.....

.....

.....

d) If no:

if it were to happen, how would you respond?

ignore

observe

observe then intervene

intervene immediately

.....

other (describe)

SECTION 4

To conclude, just a few more facts about you and your staff

Would you please indicate the age group into which you fit?

- 21-30yrs 31-40yrs 41-50yrs 51-60yrs

How long have you worked in this unit as a manager?

- 1-5yrs 6-10yrs 11-15yrs 16-20yrs

Have the staff in your residential home had training (input) on the subject of sexuality?

- Yes
No

Have the staff had training (input) on the subject of sexuality and dementia?

- Yes
No

If there is anything you feel you would like to comment on or if there is a situation you feel has not been covered if you would briefly comment

.....
.....

Would you like an abstract of the findings to be sent to you?

- Yes
No

Could I ask you to quickly read over and check you have not accidentally omitted to answer any of the questions.

Any further comments, please write them on the next page.

Lastly could I ask you once again to return the questionnaire back by....

THANK YOU VERY MUCH FOR YOUR HELP AND COOPERATION

Appendix 2

Matrices/Tables of Sexual Stories Told by Staff

Table 1 General incidents including resident masturbation

Staff	1.1	1.2	1.3	1.4	1.5	2	2.1	2.2	2.3	2.4	3	4	5.1	5.2	5.3	5.4	6	7
Anne	*	-	-	*	-	-	-	-	-	-	*	-	*	-	-	-	-	-
Cathy	-	-	-	-	-	*	-	-	-	-	*	-	*	-	-	-	-	-
Morag	-	*	-	-	-	-	-	-	-	*	-	-	-	-	-	-	-	-
Sheila	-	*	-	-	-	-	-	*	-	-	-	-	-	-	-	-	-	-
Rhona	-	-	-	-	-	*	*	-	*	-	-	-	-	-	-	-	-	-
Fiona	-	-	-	*	-	-	-	-	-	-	-	*	*	-	-	-	-	-
Martha	-	-	-	*	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Gladys	-	-	-	-	-	*	-	-	-	*	-	-	-	-	-	-	-	*
Andrea	-	-	-	-	-	*	-	-	-	-	-	-	-	-	-	-	-	-
Kimb.	*	-	*	-	-	-	-	-	-	-	*	-	-	-	-	-	-	-
Evelyn	-	*	-	-	-	-	-	-	-	-	*	-	-	-	-	-	-	-
Pete	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Sylvia	-	-	-	-	-	-	-	-	-	-	-	-	*	-	-	-	-	*
Jenny	-	-	-	-	-	*	-	-	-	-	-	-	*	-	-	-	-	*
Paul	-	-	-	-	-	-	-	-	-	-	-	*	-	*	*	-	-	-
June	-	-	-	-	-	*	-	-	-	-	-	-	-	-	-	-	-	-
Molly	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Chris	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	*	-	-
Roger	*	-	-	-	-	-	-	-	-	-	*	-	-	*	-	-	-	-
Kate	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Beth	-	-	-	-	-	-	-	-	-	-	-	*	-	-	-	-	-	-
M	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Corinne	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Marion	*	-	-	-	-	*	-	-	-	-	-	*	*	-	-	-	-	-
Fred	-	-	-	-	-	-	-	-	-	-	*	-	-	-	-	-	-	-
Doris	-	-	-	*	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Teresa	-	-	-	-	*	-	-	-	-	*	-	-	-	-	-	-	-	-
M Cait	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	*	-	-
M Ethel	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Totals	4	3	1	3	1	7	1	1	1	3	9	4	6	2	1	2	2	1

*- had reported, - not reported ,

Table 2 Ranking in terms of reported - General Stories

Story 3 (9) care workers reported sexualised touching of female care staff by **male** residents at bar night where alcohol often implicated.

Story 2 (7) care workers reported **male** residents masturbating in their (resident's) bedroom.

Story 5.1 (6) care workers reported **male** residents making sexual remarks to female care staff.

Story 4 (4) male and female care workers reported prolonged hugging by **women** residents constructed as 'too touchy' and inappropriate.

Story 1.1 (3) care workers reported **male** residents coming out of their (resident's) room with no trousers on.

Story 1.2 (3) care workers reported **male** residents lying on their (resident's) bed with no trousers on.

Story 1.4 (3) care workers reported a **male** resident constantly removing his urinary sheath and asking staff to replace it.

Story 2.4 (3) care workers reported **women** residents masturbating in their (resident's) bedroom.

Story 5.2 (1) male care worker and (1) assistant male manager reported **women** residents making flirtatious remarks to male staff.

Story 5.4 (1) unit manager and (1) service manager reported a **male** care worker making sexual remarks to another male care worker.

Story 6 (1) female care worker and (1) art worker reported fear of being placed in a compromising position by residents and sexual accusations being made against them (the workers).

Story 1.5 (1) female care worker reported **woman** resident opening her legs rather too eagerly to have cream applied to groin area.

Story 2.1 (1) female care worker reported **male** resident continuing to masturbate when she entered his bedroom.

Story 2.3 (1) female care worker reported **male** residents constantly touching their genitals.

Story 5.3 (1) male care worker reported **male** residents making sexual remarks to male care workers.

Story 18.1(2) Jenny and Marion reported how resident Michael always took *The Sun* newspaper page three to his room as an aid to masturbate.

Table 3 Resident-to-Resident Sexual Expression

Staff	6	6.1	6.2	7	8	9	10	11	12	13	14
Anne	-	*	-	*	-	-	-	-	-	-	-
Cathy	-	-	-	-	*	-	-	-	-	-	-
Morag	-	-	-	-	*	*	-	-	-	*	-
Sheila	-	-	-	*	-	-	*	-	-	*	-
Rhona	-	-	-	-	*	-	-	-	-	-	-
Fiona	-	-	-	-	-	-	-	-	-	-	-
Martha	-	*	-	*	-	-	*	-	-	-	-
Gladys	-	*	*	*	-	-	-	*	-	-	-
Andrea	-	-	-	-	-	-	*	-	-	-	-
Kimberl.	-	-	-	-	-	-	*	-	*	-	-
Evelyn	-	-	-	-	*	*	-	-	-	-	-
Peter	-	-	-	-	-	*	-	-	-	-	-
Sylvia	-	-	-	-	-	*	*	-	-	-	-
Jenny	-	-	-	-	-	-	-	-	-	-	-
Paul	-	-	-	-	-	-	-	-	-	*	-
June	-	-	-	-	-	-	-	-	-	-	-
Molly	-	-	-	-	-	-	-	-	-	-	*
M Chris	-	-	-	-	-	-	-	-	-	-	-
MRoger	-	-	-	-	-	-	-	-	-	-	-
Kate	-	-	-	-	-	-	-	-	-	-	-
Beth	-	-	-	-	-	-	-	-	-	*	-
M	-	-	-	*	-	*	*	-	-	-	-
Corinne	-	-	-	-	-	-	-	-	-	-	-
Marion	-	-	-	-	-	-	*	-	-	-	-
Fred	-	-	-	-	-	-	*	-	-	*	-
Doris	-	-	-	-	-	-	-	-	-	-	-
Teresa	-	-	-	-	-	*	-	-	-	-	-
M	-	-	-	-	-	-	*	-	-	-	-
Caitlen	-	-	-	-	-	-	-	-	-	-	-
M Ethel	-	-	-	-	-	-	-	-	-	-	-
Totals	0	3	1	5	4	6	9	1	1	5	1

Table 4

Ranking of Resident in terms of reported-Resident Sexual Expression

- 1 **Story 10** - (8) care workers and (1) service manager reported the relationship and subsequent marriage of Jimmy and Madge.
- 2 **Story 9** (4) care workers (1) assistant manager and (1) art worker reported about Margaret, a very attractive resident with advanced dementia, who was kissed by Michael.
- 3 **Story 7** (4) care workers and (1) assistant manager reported the story of the sexual relationship that developed between Will and Wilma.
Story 13.0 (5) care workers reported the story of Sandra and her partner Steve who visited her on a regular basis.
- 4 **Story 8** (4) care workers reported the story of Richard who was suspected of taking the underwear of Pearl who was very advanced in her dementia.
- 5 **Story 6.1** (3) care workers reported the story of Harry placing his hands up Cissie's blouse and also going into her room.
- 6 **Story 6.2** (1) care worker reported that Harry appeared to be taking sexual advantage of his physically frail wife.
Story 11.0 (1) care worker reported about Ruby, a past resident with severe dementia, who was suspected of having been sexually abused by her father.
Story 12.0 (1) care worker reported that two past residents, a male and female resident both of whom had dementia who had formed a sexual relationship, absconded from the home for a day.
Story 14.0 (1) domestic reported the story of Hannah a resident with advanced dementia and her sister.

Table 5 Resident-to-Staff Sexual Expression

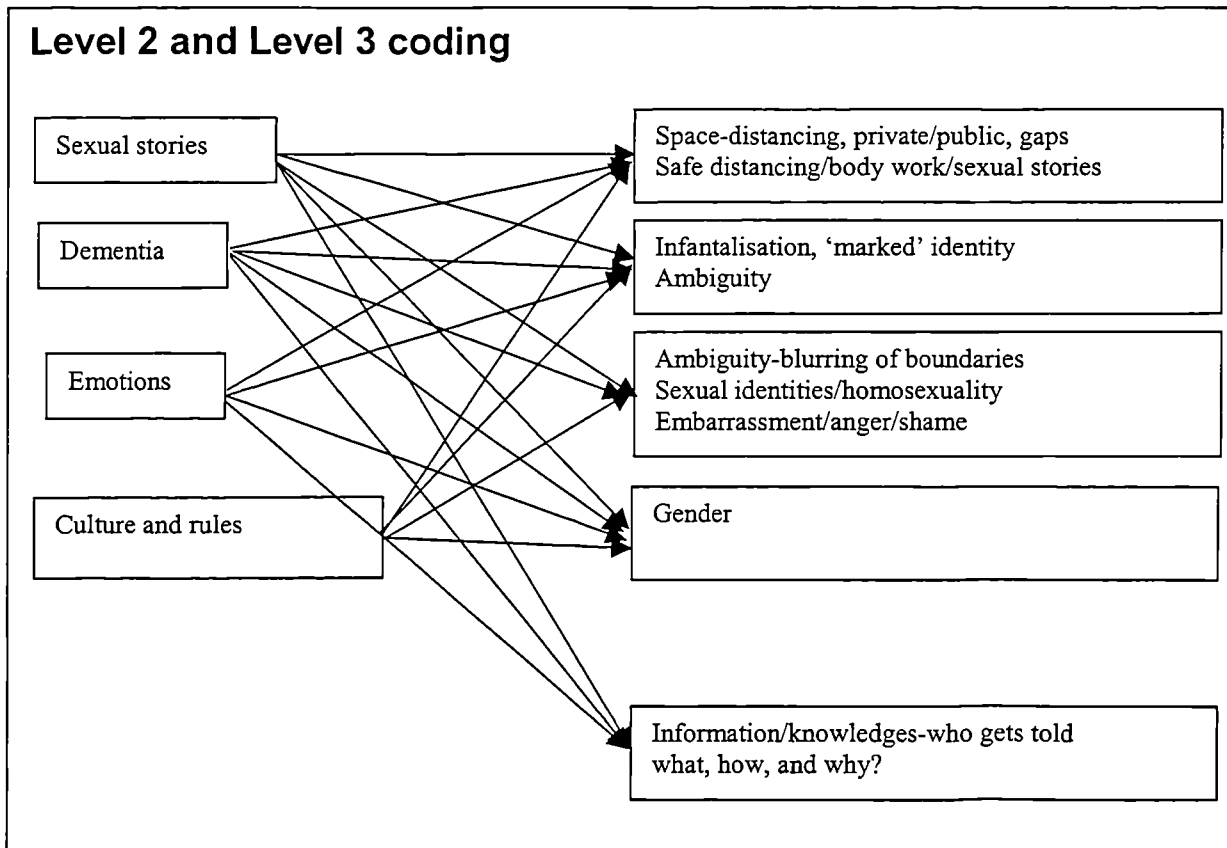
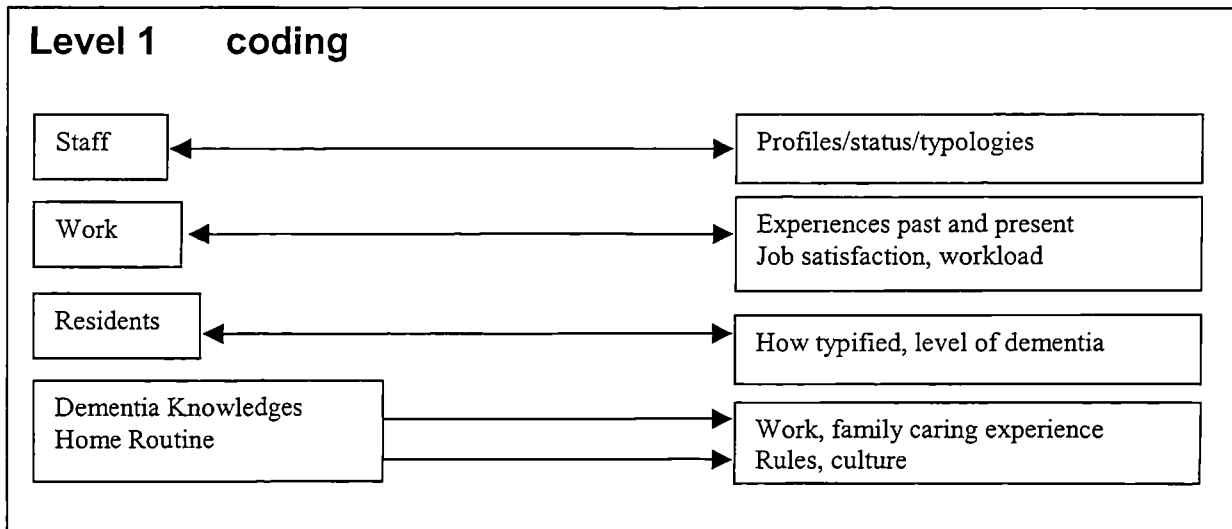
Staff	15	16	16.1	17	17.1	17.2	18	18.1	18.2	19	20	21	22	23	24
Anne	*	-	-	-	-	-	-	-	-	-	-	-	*	-	-
Cathy	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Morag	-	*	-	-	-	-	-	-	-	-	-	-	-	-	-
Sheila	*	-	-	-	-	-	-	-	-	-	-	-	*	-	-
Rhona	*	-	-	-	-	-	-	-	-	-	-	-	*	-	-
Fiona	*	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Martha	*	-	-	-	*	*	-	-	-	-	-	*	-	-	-
Gladys	*	-	-	-	-	-	-	-	-	-	-	-	*	-	-
Andrea	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Kimberly	*	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Evelyn	-	-	-	-	-	-	-	-	-	-	*	-	-	-	-
Peter	-	-	*	-	-	-	-	-	-	*	-	-	-	-	-
Sylvia	-	-	-	-	-	-	*	-	-	-	-	-	-	-	-
Jenny	-	-	-	*	-	-	-	*	-	-	-	-	*	-	-
Paul	-	-	-	*	-	-	-	-	-	-	-	-	-	-	-
June	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Molly	-	-	-	-	-	-	-	-	-	-	-	-	*	-	-
MChris	-	-	-	-	-	-	-	-	-	-	*	-	-	-	-
M Roger	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
M Kate	-	*	-	*	-	-	-	-	-	-	-	-	-	-	-
Beth	*	-	-	-	-	-	-	-	-	-	-	-	*	*	-
Corinne	-	*	-	*	-	-	-	-	-	-	-	-	-	-	-
Marion	-	-	-	*	-	-	-	*	-	-	-	-	-	-	-
Fred	-	*	-	-	-	-	-	-	-	-	-	-	-	-	-
Doris	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Teresa	*	-	-	-	-	-	-	-	-	-	-	-	*	-	-
M	-	-	-	-	-	-	*	-	-	-	-	-	-	-	-
Caitlen	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
M Ethel	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Totals	9	4	1	5	1	1	2	2	1	1	2	1	7	1	1

Table 6 Ranking in terms of reported - resident to staff sexual expression

- 1 **Story 15** (9) care workers reported Harry used every opportunity to grab female staffs' breasts and bottoms.
- 2 **Story 22** (6) care workers and (2) domestics reported the story of Christine who was labelled as lesbian by staff.
- 3 **Story 17** (3) care workers and (2) assistant managers reported the story of Jenny who was grabbed and kissed by resident Jimmy.
- 4 **Story 16** (2) care workers and (2) assistant managers reported how resident Andrew made sexual remarks to Fred.
- 5 **Story 18** (2) care workers reported how Michael, who was naked, had come up to Teresa and put his arms around her.
Story 20 (2) care workers reported the story of a new male admission who had been found masturbating in the sitting room and had shocked staff.
- 6 **Story 16.1** (1) Peter reported how Andrew had made explicit sexual remarks to him.
Story 17.1 (1) Martha reported that Jimmy her key resident was able to discuss intimate sexual matters with her.
Story 23 (1) Beth reported how Arthur one of her key residents had made sexual remarks to her.
Story 18.2 (1) Jenny, care worker reported how Michael, a resident had asked for a kiss and how she felt obliged to provide a kiss on a daily basis.
Story 21 (1) Martha reported how one young male care worker had constant sexual remarks made to him by a woman resident.
Story 17.2 (1) female care worker reported how her key resident Jimmy (R31) had given her a 'pack of three' to take on holiday.
Story 24 (1) manager reported how a male care worker had been accused of kissing a female resident with dementia in a sexualised manner.

Appendix 3

Examples of Levels of Coding



10. Residents should be allowed to obtain and/or retain pornographic materials.
- strongly disagree disagree agree agree strongly
11. Sexual expression (i.e., hugging, kissing, caressing) among residents with dementing illness is perfectly healthy, and could contribute to their positive quality of life.
- strongly disagree disagree agree agree strongly
12. "Solo sex" (e.g. masturbation) should be prohibited.
- strongly disagree disagree agree agree strongly
13. Families should be notified at the first episode of sexual expression between residents with dementing illness.
- strongly disagree disagree agree agree strongly
14. Sexual expression (i.e., hugging, kissing, caressing) among alert and orientated nursing home residents is perfectly health, and may contribute to their positive quality of life.
- strongly disagree disagree agree agree strongly
15. If resident's family/families is aware and currently accepting of the sexual activity occurring then staff should not interfere.
- strongly disagree disagree agree agree strongly
16. Vulnerable adult reporting regulations makes it necessary for nursing home staff to stop sexual behaviour between residents *with dementing illness*.
- strongly disagree disagree agree agree strongly

Please provide the following information:

Are you: Male
 Female

Marital Status: Single
 Married
 Divorced

Age: _____

Ethnicity: _____

Religion: _____

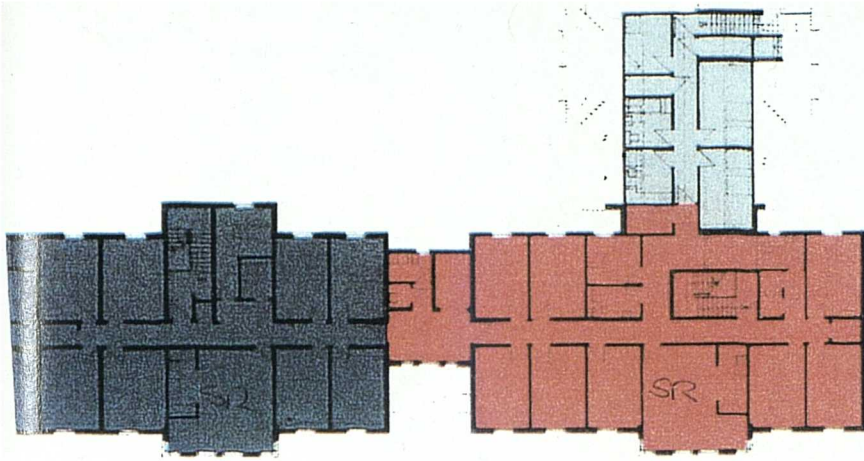
Your position:

- Administration Nursing
 Social Service Other
 Medicine Licensed Nursing Staff
 Other therapy

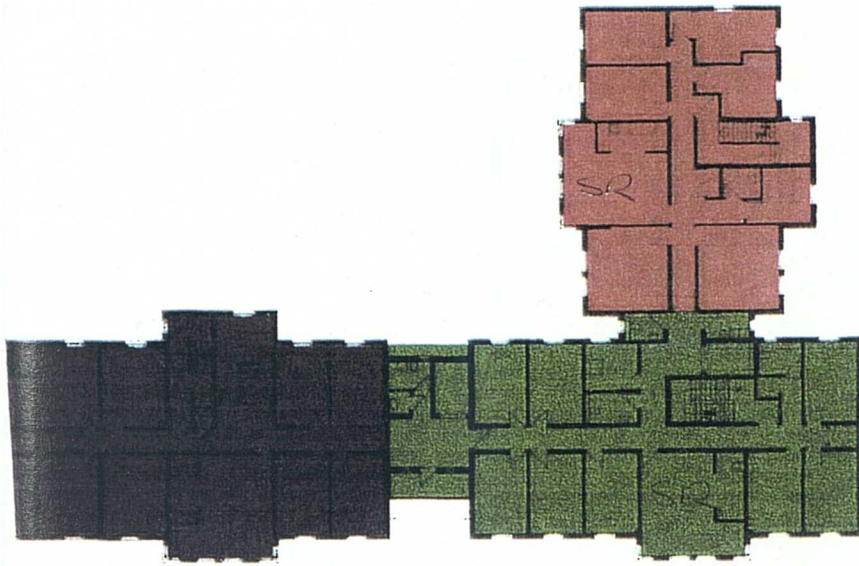
Appendix 5

Architectural Plan of Glenevis Home

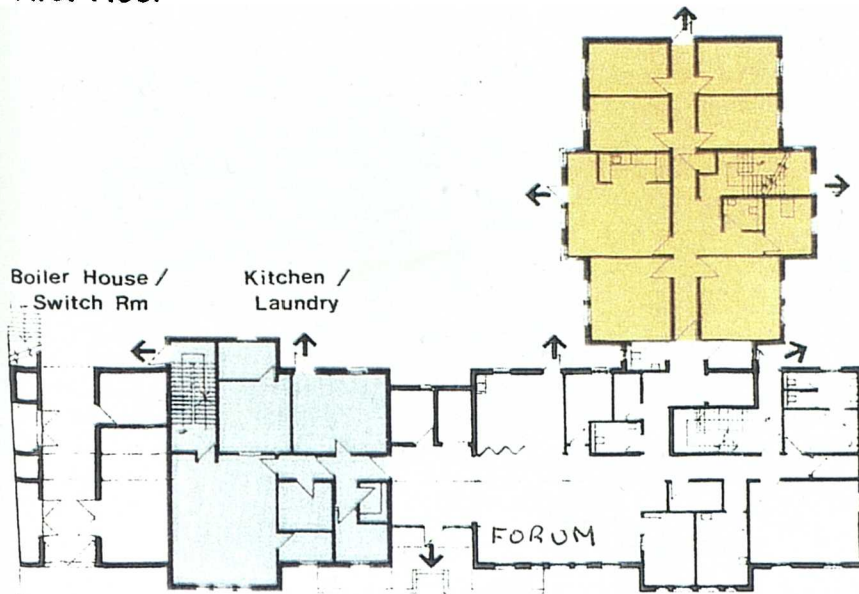
Staff Base



Second Floor



First Floor



Ground Floor

Appendix 6

Managers interview schedule

Can you tell me about yourself- information re work background etc.

I have been talking to staff about sexuality can you say what you would consider sexual

Can you describe any occurrences? recent? others?

How were these managed?

How comfortable did you feel?

How powerful do you think staff feel in these situations?

How easy do you think it is for staff to report incidents?

What kinds of things would you expect staff to report?

Would they know of these expectations?

How would this (how the staff responded to a situation of sexual expression) influence your perception of that member of staff?

How does dementia / carer involvement/drink/ (alcohol) gender, influence decision making with regard to sexual expression?

What are the differences in your opinion between how female staff respond and how male staff respond to expression so sexuality?

What are the differences re duties between the care and domestic staff?

Are there policies for sexual expression (and dementia) in the home?

Appendix 6

Staff interview schedule

Can you tell me about you – (age approximately, qualifications, how long in post, why did you choose this work marital status, children etc.?)

Have you cared for a parent/older person in your family?

Can you tell me about the home- (routine, rules, good/less good points- small scale units?

Residents- how do you see the residents? What are the good things about working with them

What about people with dementia- differences?

Family carers- how do you see them ?

How would you define sexual expression

Sexual incidents? how do/did you feel? how much control did you feel you had?

Who did you tell- who would you tell and why?

How easy is it for you to discuss issues of sexuality with –the residents? Other workers? With managers? With family carers?

Who do you find the easiest to talk to?

When would you go to management?

How did you (and they) manage the incidents

Were they well managed in your view?

How did you view the residents after? Did it make any difference to how you felt about the resident?

Are there worse behaviours than sexual expression in your view?

Are there differences in your view re male residents female residents expressing sexual needs?

(I tried to cover most of these questions in the interviews but it was not always possible due to time and also giving staff freedom to develop and speak about issues that I had considered)

Appendix 7

'Diagnosis' of Dementia in the Staff Documents

- ❖ Multi-infarct dementia
- ❖ Alzheimer's disease
- ❖ Senile dementia
- ❖ Dementia
- ❖ Short-term memory loss
- ❖ Some memory loss
- ❖ A little forgetful
- ❖ May have some dementia - difficult to say
- ❖ Slightly forgetful
- ❖ Mild memory impairment
- ❖ Short-term memory loss - gets confused
- ❖ Brain damage from alcohol abuse
- ❖ Problems with short-term memory
- ❖ Memory for recent events poor
- ❖ Forgetfulness leading to repetition

Appendix 8

Feedback from Sexuality Training Day

When asked to give their comments about the workshop the biggest difficulty was that there had not been enough time to fully discuss issues.

- ❖ Not enough time
- ❖ Too little time to discuss everything
- ❖ Time (too little)

On commenting on what two aspects of the day they had derived most benefit, they reported:

- ❖ More understanding and confidence in my approach on this issues
- ❖ More insight into relationships before residents come into residential care
- ❖ How sexuality might affect behaviour
- ❖ More insight into what it may be like for a married couple if one has to go into care
- ❖ Understanding that no matter what age, residents may have sexual desires
- ❖ More awareness of people's feelings and needs
- ❖ More awareness of their losses
- ❖ More awareness of their needs and how I would wish to be considered
- ❖ More knowledge and awareness
- ❖ Understanding
- ❖ (Awareness of) other people's emotions

When asked what they most enjoy about the course they replied:

- ❖ Explanations
- ❖ Making light of the situations faced
- ❖ It was easy to address the course as we all felt at ease
- ❖ Talking (discussions) and the videos
- ❖ Watching the videos
- ❖ Group discussions- listening to different experiences and opinions
- ❖ All!

What did you least like about the course?

- ❖ All very interesting

Are there any ways that the sessions might have been improved?

- ❖ No
- ❖ (More) time
- ❖ No
- ❖ More time to go more in-depth
- ❖ 3 said no comment

Appendix 9

Findings from the postal questionnaire

Section 1

1. Job title	6 Deputies 17 Unit Managers
2. Managers	16 were women and 7 were men
3. Qualifications	11 with nursing qualification 14 with social work qualification - (2 had dual qualification)
4. Beds in home	a range of 23-50 mean 41
5. Single rooms in home	a range of 5-45 mean 30
6. Small scale living units	10 small scale 13 traditional build
7. Number of male residents	a range of 3-19 mean 10
Male residents with dementia	a range of 0-11 mean 3
8. Number of female residents	a range of 15-36 mean 28
Female residents with dementia	a range of 6-30 mean 12
9. Number of female staff	a range of 9-43 mean 28
10. Number of male staff	a range of 1-9 mean 4

Section 2

In public area behaviour staff reported to find difficult or not difficult to manage n-23

Behaviour	Difficult	Not difficult
1. Kissing	-	23
2. Putting arms around each other	-	23
3. Holding hands	-	23
4. Masturbating	20	3
5. Making sexually Suggestive remarks	13	10

In private between men and women n-23

Behaviour	Difficult	Not difficult
6. Kissing	-	23
7. Putting arms around each other	-	23
8. One resident touching another resident's genitals	4	19
9. One resident masturbating another	6	17
10. Intercourse	4	19
11. Sexual exploitation of resident by another	19	3 (1 missing)

In private between the same sex n-23

Behaviour	Difficult	Not difficult
12. Kissing	2	21
13. Putting arms around each other	-	23
14. One resident touching another's genitals	7	16
15. One resident masturbating another	8	15
16. Intercourse	8	15
17. Sexual exploitation of another resident	20	3

4 Sexual expression of residents towards staff n-23

Behaviour	Difficulty	No difficulty
18. Male residents attempting to fondle breasts of female staff	9	14
19. Place hands up the skirt of female staff	10	13
20. Male residents attempting to fondle male members of staff	11	12
21. Female members attempting to fondle male members of staff	9	14
22. Female residents attempting to fondle female members of staff	10	13
23. Sexually suggestive remarks	9	14

5 Staff report on whether they feel comfortable or uncomfortable In a public area n-23

Behaviour	Comfortable	Uncomfortable
1. Kissing	21	2
2. Putting arms around each other	23	-
3. Holding hands	23	-
4. Masturbating	1	22
5. Making sexually suggestive remarks	9	14

In private between men and women n-23

Behaviour	Comfortable	Uncomfortable
6. Kissing	22	1
7. Putting arms around each other	23	-
8. One resident touching another's genitals	18	5
9. One resident masturbating another	18	5
10. Intercourse	19	4
11. Sexual exploitation	23	-

6 In private between people of the same sex n-23

Behaviour	Comfortable	Uncomfortable
12. Kissing	20	3
13. Putting arms around each other	22	1
14. One resident touching another's genitals	14	9
15. One resident masturbating another	14	9
16. Intercourse	14	9
17. Sexual exploitation of one resident by another	1	22

6. Explain to residents but accept
7. Sensitive but discrete monitoring

14 If it had not occurred

1 reported they would ignore, 4 would observe and 1 would intervene immediately

15 2 Frankie and Jessie holding hands – Jessie’s husband visits regularly n-23

Managers report	15 Acceptable 4 had occurred	4 unacceptable 19 had not occurred
-----------------	---------------------------------	---------------------------------------

Data for frequency missing

16 If this situation had occurred responses of managers included:

1. Acceptance and talk to spouse and explain
2. Discourage behaviour in front of spouse
3. Acceptance

17 If it had not occurred

2 reported they would ignore, 5 would observe, 3 would observe and intervene and 1 would intervene immediately. Other responses include 1 talk to husband and help him understand, 4 observe and 1 try make husband’s visit more comfortable- 2 missing data.

3. James and John both have dementia holding hands in corridor n-23

Managers report	21 Acceptable 3 had occurred	1 unacceptable 19 had not occurred
-----------------	---------------------------------	---------------------------------------

Frequencies missing

18 Response of managers where it had occurred included:

1. Accept
2. Counselling resident
3. Ignore

19 If it had not occurred

4 reported they would ignore, 12 would observe, 1 would observe and intervene and 1 would advise privacy and support and educate staff - 2 missing data.

4. Sam and Henry holding hands - Sam has a wife who visits n-23

Managers report	16 Acceptable 0 had occurred	6 unacceptable 23 had not occurred
-----------------	---------------------------------	---------------------------------------

20 If it had not occurred

2 reported they would ignore, 12 would observe, 2 would observe and intervene, 1 would intervene immediately, 1 observe. Other responses- 1 would explain to family, 2 would discuss with family, 1 would advise a discrete approach talk to wife if approached and 1 would provide support to family.

5. Ken had dementia found masturbating in sitting room

Managers report	1 Acceptable 9 had occurred	22 unacceptable 14 had not occurred
-----------------	--------------------------------	--

21 Response of managers where it had occurred included:

1. Ask him to go to room.
2. Ask him to go to room and say behaviour is unacceptable.
3. Ask for psychogeriatric input.
4. Remove from sitting room and ask GP for help and advice.
5. Explain that it is unacceptable to masturbate in public area.

22 If it had not occurred

1 would observe and intervene immediately, 6 would intervene immediately, 1 would explain behaviour natural but should be done in bedroom and 1 would distract- 5 missing data.

6. Jessie has dementia and is found masturbating in the sitting room n-23

Managers report	2 Acceptable 4 had occurred	21 unacceptable 18 had not occurred 1 missing data
-----------------	--------------------------------	---

23 Response of managers where it had occurred included:

1. Asked female staff to speak to her and asked her to go to her room
2. Asked to go to her room and explained that the behaviour was unacceptable in public
3. Asked her to go to her room where she could behave as she wished in private
4. Encourage her to do it (masturbate) in her own room

24 If it had not occurred:

4 would observe and intervene, 8 would intervene immediately and 2 would take her to her room and 1 would distract —4 missing

7. John has dementia and continues to masturbate in his room when staff enter n-23

Managers report	23 Acceptable 8 had occurred	0 unacceptable 12 had not occurred 3 missing data
-----------------	---------------------------------	--

25 Response of managers where it had occurred included:

1. Close the door and not entered
2. Ignore resident and counsel staff if they over-dramatise
3. Ignored and left the room immediately

26 If it had not occurred:

7 would ignore, 2 would observe and intervene 6 missing data

8. Jessie continues to masturbate in her room when staff enter n-23

Managers report	22 Acceptable 1 had occurred	1 unacceptable 22 had not occurred
-----------------	---------------------------------	---------------------------------------

27 Response of managers where it had occurred included:

Missing data

28 If it had not occurred:

1. 12 would ignore, 1 would observe, 1 would observe and intervene and 1 would intervene immediately. Of the other responses, 5 say that staff should not enter room unless asked, 1 would withdraw from room and 1 would leave and return later.

Managers report	6 Acceptable	17 unacceptable
	6 had occurred	16 had not occurred 1 missing

35 Response of managers where it had occurred included:

1. Stopped sexual relationship
2. Intervened
3. Observed
4. Coped with distress at the time
5. Spoke with resident and asked resident to withdraw his attention
6. Tried to find out what had happened

36 If it had not occurred:

2 would observe, 7 would observe then intervene and 2 would intervene immediately. Other responses include 1 would warn Bill if he persists that staff will call the police and 1 ask staff to be vigilant- 4 data missing

13. Ken has dementia and Agnes does not. The couple have begun a sexual relationship n-23

Managers report	20 Acceptable	2 unacceptable 1 missing
	4 had occurred	16 had not occurred 3 missing

37 Response of managers where it had occurred included:

1. Accepted
2. Discussed with staff and family
3. Ignored

38 If it had not occurred:

4 would ignore, 9 would observe, 1 would observe and intervene and 1 would intervene immediately. Other response include 1 would talk to the families as both families should be made aware of the situation- 3 missing data

Section 4

39 Age group of staff n-23

3	31-40years
9	41-50years
11	51-60years

10	1-5years
8	6-10years
1	11-15years
3	16-20years

Length of time working in home

40 Training input for staff dementia

14	Yes
9	No

8
16
1

Training input on sexuality and

Yes
No
Missing

Appendix 10

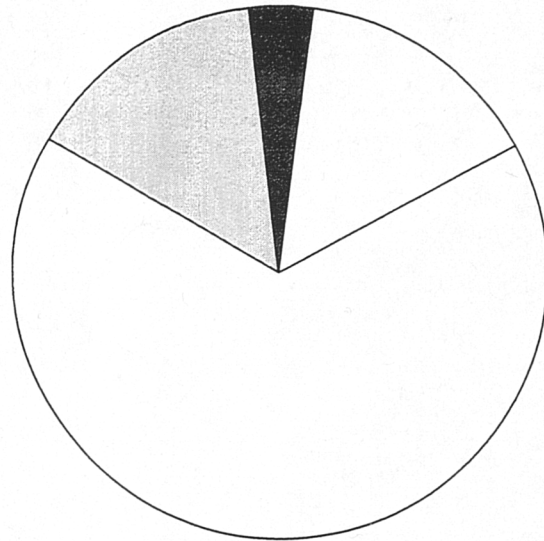
Table of Staff details

Staff	Approx. age	Prev work	Cared for reli	Job satisfact
Anne	50+	Shop	Yes	-
Cathy**	30+	Domestic	-	Yes
Morag	20+	Auxiliary	-	Yes
Sheila	50+	Nursing/ho	Yes	-
Shona	30+	Social care	Yes	-
Fiona	20+	Nursing/ho	Yes	Yes
Martha	50+	Domestic	-	Yes
Gladys	50+	Homehelp	Yes	Yes
Andrea	30+	Auxiliary	Yes	Yes
Kimberley	30+	Social care	Yes	Yes
Evelyn	50+	Shelt. hous.	-	Yes
Peter***	30+	Engineer	-	No
Sylvia	50+	Nursing.ho	Yes	Yes
Jenny	30+	Homehelp	Yes	Yes
Paul	20+	Student	-	Yes
June**	50+	ATC	-	Yes
Molly**	50+	Catering	Yes	Yes
Chris*	50+	Minister	Yes	-
Roger*	40+	Industry	-	Yes
Kate*	30+	PE teacher	-	-
Beth	50+	Shop	Yes	Yes
Corinne*	50+	Social Work	-	-
Marion	20+	Learn dis	Yes	-
Fred	20+	Student	-	Yes
Doris**	50+	Factory	Yes	Yes
Teresa	30+	Nursing.ho	Yes	Yes
Caitlen*	40+	Social work	-	-
Ethel *	50+	Social work	-	yes

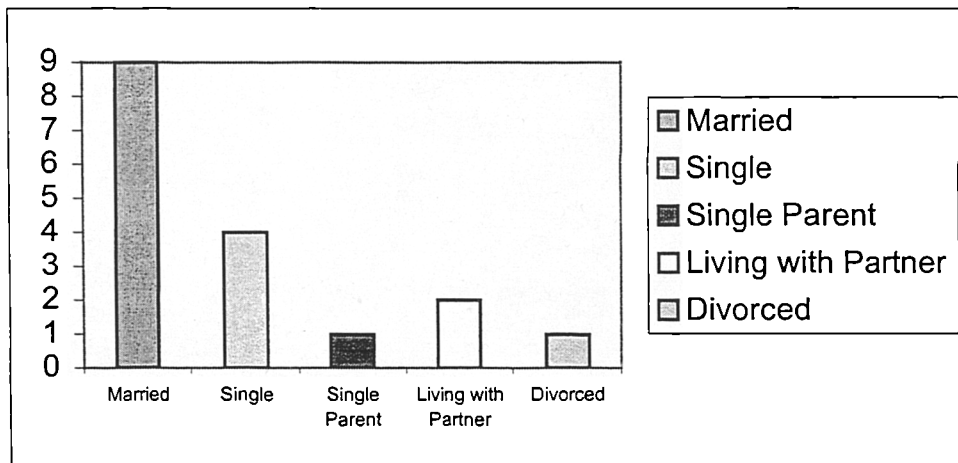
17 Care workers
 * 6 Managers
 ** 4 Domestics
 *** 1 Art worker

Profile of Staff Interviewed

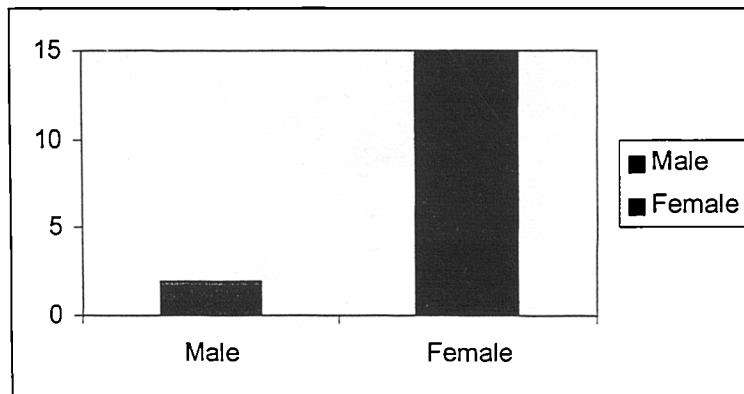
Staff



Marital Status



Gender – Social Care Staff



Appendix 11

Incident Register

An incident is written on an incident report form by the worker and a decision is taken by the manager whether to take the case further and report it to the assistant principal officer (APO).

There are incident procedure guidelines for residential and day care services.

All staff and residents must be aware of the existence of the register and how to use it.

Aims are:

To ensure all allegations, complaints, incidents or matters of importance that question the unit's professional credibility are recorded officially and dealt with in an efficient and open manner.

- To protect clients from abuse and malpractice.
- To protect staff from malicious allegations and complaints.
- To protect social work professional practice, policies and procedures.
- To ensure confidentiality is maintained at all times.
- Definition.
- An incident is an occurrence related to the running of a unit – residential or day care services, which could cast doubts on the integrity of the service.

For example:

- The potential or actual injury to staff and clients.
- Allegations and complaints of unprofessional conduct.
- Incidents requiring police involvement.

Appendix 11

What the Incident Register is and Some Notes from the Register from 'Jenny's Case'.

Of the 49 incidents noted, 32 involved resident falls, with other miscellaneous items noted as: resident involved in shoplifting, resident burned his leg with a cigarette, excessive drinking by resident, fire incident, fire alarm, resident accusing staff of poisoning her food and putting dope in her cigarette.

Jenny's account of the incident involving Jimmy read:

When I was bending down to gain access to a drug cupboard in the sitting room a client Jimmy (kissed me on the lips. There was (word crossed out) no witnesses to this incident. At the time I was shocked and disturbed by the incident. After getting things cleared up in my mind I reported the incident to the senior (manager) Corinne (at my supervision.

Corinne's response was:

Reported four days after the incident took place and all aspects discussed in supervision-reasons for not reporting earlier, ways of dealing with the situation, etc. Because of the time lapse both Jenny and myself did not feel it appropriate to confront client.

Appendix 12

Relevant Scientific Seminars and Conferences Attended

BSG Paper (1996) Researching sexuality and dementia in residential care: What managers report

BSG Poster (1997) Factors influencing staffs' tolerance of sexual expression by residents

BSG Paper (1998) Sexuality and dementia: exploring emotions and relationships in care work

Medical Sociology Paper (2000) 'Sexuality and the key worker relationship'

Publications from the thesis

Archibald C (2002) Sexuality and Dementia in residential care-whose responsibility *Sexual and Relationship therapy* 17(3) :301-9 (Forthcoming)

Archibald C (2001) Resident sexual expression and the key worker relationship *Practice* 13(1): 5-12

Archibald C (1998) Sexuality, Dementia and Residential Care: Managers Report and Response *Journal of Health and Social Care in the Community* 6(2): 95-101