

EXPLODING THE CULTURE OF CENSORSHIP, REPRESSION AND SILENCE: A  
CRITICAL ETHNOGRAPHIC STUDY OF RESPONSE TO SEXUAL BEHAVIOUR  
IN PERSONS WITH DEMENTIA LIVING IN LONG TERM CARE

By

LORI SCHINDEL MARTIN, B.A., B.Sc.N., M.S. (NURSING)

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Doctorate of Philosophy

McMaster University

© Copyright by Lori Schindel Martin, May 2004

REPRESSION OF SEXUAL BEHAVIOUR IN PERSONS WITH DEMENTIA

DOCTOR OF PHILOSOPHY (2004)  
(Clinical Health Sciences, Nursing)

McMaster University  
Hamilton, Ontario

TITLE: Exploding the Culture of Censorship, Repression and Silence: A Critical  
Ethnographic Study of Response to Sexual Behaviour in Persons with  
Dementia Living in Long Term Care

AUTHOR: Lori Schindel Martin, B.A.(University of Guelph); B.Sc.N. (McMaster  
University; M.S. (Nursing) (D'Youville College)

SUPERVISOR: Dr. Jennifer Skelly

NUMBER OF PAGES: xvi, 242

## ABSTRACT

This dissertation was undertaken to scrutinize the positions of professional and family care givers in response to the sexual behaviours of persons living with dementia in three long term care facilities. In keeping with the tenets of critical ethnography and critical social theory, the intent was to identify response patterns that might need to be altered to reflect a person-centred dementia care philosophy (Kitwood, 1997, 1998).

Semi-structured interviews, focus groups, and document review provided the material through which the rules, moral codes and actions in response to sexual behaviours were explicated. Ethnographic data transformation was undertaken through a process of description, analysis and interpretation.

The most striking findings of this research were: a) the response patterns were conservative, protectionist and linear, ultimately leading to sexual expression being forbidden or admonished; b) There was a lack of organizational support so that study participants were operating within a vacuum. Consequently, participants relied upon their own value and belief systems when responding to sexual behaviour, leading to practice inconsistencies; and c) There was an overwhelming culture of silence in regard to the sexual behaviour of persons with dementia. The reluctance and discomfort, with which both staff and families approached sexual expression of residents with dementia, resulted in collusion that ensured sexual expression remained closeted and repressed.

Study findings suggest that the culture of censorship and silence surrounding sexuality in persons with dementia remains similar to the centuries-old viewpoint

requiring strict moral controls (Foucault, 1978). Evolving from the participants' accounts, an alternative approach involving collective dialogue is suggested.

Implications of these findings extend to the need to expand organizational cultural perspectives through practice guideline development, educational initiatives and further research so that they come into alignment with the person-centred approaches that acknowledge the humanity, value and worth of those living with a dementia.

## ACKNOWLEDGEMENTS

I would like to express my sincere appreciation to my thesis supervisor, Dr. Jennifer Skelly (McMaster University, School of Nursing) for generous sharing of her time, ideas and advice, encouraging my independent thought, and helping me forge a more direct path through the forest than I would most certainly have taken on my own. I would also like to extend my thanks to the other members of my thesis committee: Dr. Susan French (McGill University, School of Nursing) for her wonderful wisdom and reflective questions and comments, and Dr. Catherine Tompkins (McMaster University, School of Nursing) for her invaluable advice and support regarding issues related to methodology, critical theory and data interpretation. I would also like to thank Dr. Christopher Justice (McMaster University, Gerontological Studies) for his thoughtful suggestions regarding how I might approach the anthropological study of culture and its relationship to critical theory.

I would like to extend my sincere thanks to the wonderful participants of this study for sharing with me their thoughts, ideas, beliefs and values related to a topic of a very sensitive nature. Their part in this endeavour cannot be underestimated. Their insights gave me direction in explicating additional knowledge to contribute to the field of gerontological nursing.

The Alzheimer Society of Hamilton and Halton supported this project financially. For this I am extremely grateful. In addition, I would like to express my absolute gratefulness and admiration to my family, friends, and work colleagues. I would like to

acknowledge that my work colleagues, in particular, Pat Morden, Chief Executive Officer of Shalom Village, enabled and encouraged me every step of the way in my pursuit of academic scholarship. Vicky Bach deserves special thanks for her generosity in assisting with the initial stages of data interpretation. Finally, I would like to express my thankfulness to my husband David, my children Fraser and Parker, my father Rudy Schindel, and my sister Vicki Schindel for their understanding, support and tolerance. They always knew just how to help me find balance between work and play. Now it is time to celebrate, because this achievement is ours to savour together.

## TABLE OF CONTENTS

	PAGE
ABSTRACT .....	iii
ACKNOWLEDGEMENTS .....	v
TABLE OF CONTENTS .....	vii
LIST OF FIGURES .....	xiv
LIST OF APPENDICES .....	xv
LIST OF ABBREVIATIONS .....	xvi
<b>CHAPTER ONE</b> .....	<b>1</b>
Introduction .....	1
The Problem of Sexual Behaviour in Dementia .....	3
Study Context .....	5
Underlying Assumptions .....	7
<b>CHAPTER TWO</b> .....	<b>10</b>
Literature Review .....	10
General Synopsis .....	11
Conceptual Papers .....	12
Research Papers .....	17
<b>CHAPTER THREE</b> .....	<b>27</b>
Methods .....	27
Research Paradigm .....	27



<b>TABLE OF CONTENTS ... cont'd</b>	<b>PAGE</b>
Formative Theory .....	28
Research Questions .....	29
Study Design .....	31
Setting .....	32
Sample .....	33
Data Collection .....	33
Data Analysis and Interpretation .....	36
Rigor .....	37
Ethics .....	40
Limitations of the Study .....	42
<b>CHAPTER FOUR</b> .....	<b>45</b>
Sex and the City: Description of Key Informants Across Three Sites .....	45
Recruitment of Subjects .....	45
Response to the Interviews .....	47
Family Participants .....	47
Demographic Profile .....	48
The Facilities .....	48
Individual Interviews .....	49
Focus Groups .....	51
Educational Background Regarding Sexuality and Dementia .....	54

TABLE OF CONTENTS ... cont'd	PAGE
Overall Management Response to Sexual Behaviour .....	55
Promotion of Sexual Health .....	56
<b>CHAPTER FIVE</b> .....	<b>58</b>
Adam Lay Abounden: A De-construction of Response Patterns to Sexual	
Behaviours .....	58
Sex Is Bad .....	60
Everything is Sex .....	61
Sex is Wrong .....	64
Being a Personal Target is a No-No .....	67
Males are Dirty Old Men, Women are Innocent Victims .....	69
Self-pleasuring is Disgusting .....	73
The Whisper Zone .....	75
To Serve and Protect .....	79
Surveillance .....	80
Forbidding .....	87
Reporting .....	90
Documenting .....	96
Pairing .....	98
Reassigning .....	99
Never the Twain Shall Meet .....	99

TABLE OF CONTENTS ... cont'd	PAGE
Redirecting .....	100
Separating .....	102
Isolating .....	104
Ignoring .....	104
Medicating .....	106
Behind Closed Doors .....	107
Ignorance Is Bliss .....	110
Experience .....	110
Knowledge .....	112
The Disapproving Family .....	113
The Unwritten Moral Code .....	116
Sexual Behaviours Must be Within the Context of a Relationship .....	116
Present Sexual Behaviour Cannot Contradict the Perceived Previous Sexual Persona .....	117
Sexual Behaviour Cannot be Intentional .....	119
The Rule Book .....	120
Meagre Policy or “Please sir, can I have more?” .....	121
A Few Good (Wo)men .....	130
Coaching .....	130
Understanding .....	133

TABLE OF CONTENTS ... cont'd	PAGE
Looking for Benefits .....	134
Providing .....	135
Counselling .....	138
Humouring .....	139
<b>CHAPTER SIX</b> .....	<b>141</b>
Toward a Critical Communicative Ethic: Getting to the Bottom of Clinical	
Ambiguity .....	141
Relationship of Study Findings to Research Questions .....	142
Research Question 1 (What do study participants mean by sexual behaviour associated with dementia?) .....	142
Research Question 2 (What is the basic description of what participants reveal to be the ways they respond to behavioural episodes they define to be of a sexual nature in dementia?) .....	143
Research Question 3 (What do participants identify to be the factors underlying their responses to sexual behaviour in dementia?) .....	144
Research Question 4 (What is the cultural/social context within which individuals respond to episodes of sexual behaviour in dementia? What are the explicit, implicit, and unspoken rules that influence decision-making and practice responses?) .....	145
Research Question 5 (How do individual accounts differ from group accounts	

TABLE OF CONTENTS ... cont'd	PAGE
regarding episodes of sexual behaviour in dementia?) . . . . .	145
Research Question 6 (How do individual and group responses compare and/or contrast with management responses to episodes of sexual behaviour in dementia?) . . . . .	146
Research Question 7 (What are the consequences of selected actions for the persons involved in the clinical situation?) . . . . .	146
Research Question 8 (What practice change initiatives can be identified?) . . .	147
A Second Look: Excavating More Layers of Assumption and Belief . . . . .	147
The Person With Dementia as Powerless, Asexual Being . . . . .	147
The Person With Dementia as Incompetent to Consent to Sex or “We don’t know!?” . . . . .	153
The Sacredness of the Genitals . . . . .	165
The Impact of the Community Case . . . . .	167
Relationship of Study Findings to Previous Research . . . . .	170
Relationship of Study Findings to Critical Social Theory . . . . .	173
Beginning to Question . . . . .	177
Decision-making and Sexual Behaviour in Dementia . . . . .	179
Toward a Nonlinear, Dialogical Decision-making Schema . . . . .	193
<b>CHAPTER SEVEN . . . . .</b>	<b>198</b>
From Pillow Talk to Professional Practice: Implications for Practice Guidelines,	

<b>TABLE OF CONTENTS ... cont'd</b>	<b>PAGE</b>
Education, and Further Research .....	199
Implications for the Development of Practice Guidelines .....	199
Micro-level Clinical Practice Recommendations .....	201
Practice Implications for the Broader Community .....	202
Implications for Education .....	203
Implications for Further Research .....	206
<b>CHAPTER EIGHT</b> .....	<b>209</b>
Conclusions .....	209
<b>REFERENCES</b> .....	<b>212</b>

## LIST OF FIGURES

	PAGE
<i>Figure 1.</i> Decision-making schema (Formative theory) . . . . .	30
<i>Figure 2.</i> Context of power and protectionism related to sexuality and dementia . . . .	175
<i>Figure 3.</i> Linear decision-making schema (present state of literature) . . . . .	181
<i>Figure 4.</i> Linear decision-making schema - Version 1 (present state of study sites) . .	183
<i>Figure 5.</i> Linear decision-making schema - Version 2 (present state of study sites) . .	192
<i>Figure 6.</i> Nonlinear decision-making map/schema (alternative) . . . . .	194

## LIST OF APPENDICES

- APPENDIX A. Summary of Conceptual Papers on Sexuality and Dementia
- APPENDIX B. Facility Information/Recruitment Letter
- APPENDIX C. Letter of Introduction and Focus Group Notice
- APPENDIX D. Semi-Directed Interview Guides
- APPENDIX E. Demographic Questionnaire for Interview/Focus Group  
Participants
- APPENDIX F. Focus Group Guide
- APPENDIX G. Ethics Approval
- APPENDIX H. Consent to Participate in Sexual Behaviour in Residents with  
Dementia Study
- APPENDIX I. Consent to Review Documents
- APPENDIX J. Document Review Sheet



## LIST OF ABBREVIATIONS

HCA(s)	Health Care Aide(s)
IP	Inclusive Personhood
LTC	Long Term Care
MMSE	Mini Mental Status Examination
MOH/LTC	Ministry of Health/Long Term Care
RNs	Registered Nurse(s)
RPNs	Registered Practical Nurse(s)
STD	Sexually Transmitted Disease

## CHAPTER ONE

### *Live With Me on Earth*

*Live with me on Earth among red berries and the bluebirds  
And leafy young twigs whispering  
Within such little spaces, between such floors of green,  
Such figures in the clouds  
That two of us could fill our lives with delicate wanting:*

*Where the stars past the spruce copse mingle with the fireflies  
Or the dayscape flings a thousand tones of light back at the sun -  
Be any of the colours of an Earth lover;  
Walk with me and sometimes cover your shadow with mine ....  
(Acorn, 1972)*

### Introduction

Delicate wanting, that state of being where sensuality, sexual expression, sexual awareness and sexual desire exists, appears to be far removed from the experience of and what is considered acceptable for those persons with dementia who reside in long term care (LTC) facilities. Sexuality for persons with dementia is something that is forbidden, ignored, relegated to whispered discussions in back rooms and pushed underground.

There is a tendency on the part of clinicians and families to disregard the sexual persona of persons with dementia. As an educational topic, sexual expression associated with dementia is glaringly absent from the curriculum of training programs. As a clinical topic, sexual expression by persons with dementia in LTC is seen as something problematic and difficult. It is not discussed openly amongst clinical teams in the

practice setting. Consequently, sexual expression for persons with dementia has become medicalized and pathologized, something to be managed, to be controlled, and to be eliminated. Sexuality, sensuality, intimacy, stroking, caressing, holding and tender touch, are, unfortunately not part of the everyday life of the person with dementia living in a LTC facility.

As I was preparing to undertake the research component of my dissertation, it occurred to me that this was the last horizon where care approaches do not match the philosophy intended in what is often referred to as “the new culture” of dementia care. The underlying tenet of this care approach is that the very essence of the person with dementia; their hopes, dreams, desires, aspirations, past goals, and hobbies; form the basis of all health related interventions. Really, these are seen as “life care” interventions, not those “health care” interventions typically associated with the medical model. An example of such a person-centred model of care is the Inclusive Personhood (IP) Model, which defines dementia-related behaviours such as agitation, sexual expression and aggression, as the result of a lack of recognition, acknowledgement and enablement of the “spirit” of the person (Kitwood, 1997, 1998; Kitwood & Bredin, 1992). The IP Model proposes that the person with dementia has five overlapping needs that culminate in the central need for love. These needs include comfort, attachment, inclusion, occupation and identity. The IP Model suggests that dementia-related behaviours result when the resident’s central need for love is ignored because the

interpersonal relationship between care provider and the resident occurs within an environment of Malignant Social Psychology.

An assumption that I brought with me into this research was that while organizational cultures were becoming more creative and forward thinking with regard to other types of dementia related behaviours such as wandering, noisemaking and physical aggression (Bell & Troxel, 1997; Cohen-Mansfield, 2000; Cohen-Mansfield & Taylor, 1998; Dawson, Wells, & Kline, 1993; Hellen, 1998; Hoffman, 1998; Kitwood, 1995; Misiorski, 2001; Rader, 1995), they were virtually malignant in terms of their attitudes and practice behaviours related to sexuality. In fact, references to the sexual health and needs of persons with dementia were difficult to find in the literature describing this “new culture” of dementia care. There had been little recognition that persons with dementia have sexual needs, therefore no thought given as to why this might be. This study was born of the need to expose beliefs about the sexual behaviours of elder persons with dementia living in LTC to scholarly scrutiny.

### The Problem of Sexual Behaviour in Dementia

For the most part, when persons with dementia make sexual overtures within an institutional setting, it is considered to be “inappropriate” and is often immediately subjected to clinical investigation. This suggests that sexual expression associated with dementia is seen as a pathological manifestation of the disease itself. In the medical

literature, sexual behaviour in dementia is reported within the context of the prevalence of rather noxious behaviours that are considered to be of risk, for example, physical aggression. Sometimes labelled as hypersexuality, sexual behaviour is reported to be displayed by between 2.9% to 8% of those elders diagnosed with Alzheimer's Disease (Burns, Jacoby, & Levy, 1990; Cummings & Victoroff, 1990; Devanand et al., 1992). Although the observed incidence of episodes of a true sexual nature are actually quite low, sexual expression of institutionalized elderly people with dementia is discomforting for co-residents, staff and families (Lichtenberg, 1997). Post (2001) suggests that the problem behaviours of persons with dementia are often interpreted through the lens of what he refers to as "universal hypercognitive arrogance". In the case of sexual behaviour, the pervasive myth is that persons with dementia are not capable of "controlling" sexual feeling and should therefore be thwarted from its expression. Similarly, Harris and Wier (1998) propose that because the demented person's sexual behaviour does not occur in a social vacuum, there are significant repercussions from any observers who find the behaviour to be offensive. This viewpoint is supported by my own clinical experiences whereby professional and family caregivers become fretful and anxious when residents with dementia expose their sexuality to the public eye.

### Study Context

This study was born as a result of an episode that took place in an Ontario LTC facility during the month of February 2000. The LTC community responded with shock and dismay when a front-page newspaper report described the case of two elderly residents with dementia who were discovered by their professional caregivers engaging in behaviour that was interpreted to be sexual. I can remember feeling shocked and dismayed when I read the headline that stared up at me from the newspaper before work that morning. Within hours of the story hitting the front page, urgent telephone calls were reverberating through the clinical “grapevine” in response to the episode. Upon closer scrutiny, the article revealed that the nature of the sexual behaviour actually involved relatively benign acts, such as caressing and touching, and some clothing had been removed. In other words, the actual incident did not likely involve genital contact, most certainly not penile vaginal penetration, but the headline had suggested otherwise. There was no evidence to suggest that the female resident was objecting to the circumstances in which she found herself. There was no report of physical injury. So, why was there such a negative response? Why was it that the first newspaper story and each subsequent story published during that whole week, were so very negative in that shocking portrayal of “demented sex”? The front-line staff members caring for the residents involved were uncomfortable with the situation, and after deliberations with their union representatives, contacted the local newspaper to report the incident. Despite

lack of evidence that sexual assault had occurred, the police launched an investigation and the male resident was treated with psychotropic medications and removed from the LTC facility. The newspaper report epitomized the male resident as a dangerous predator, while the female co-resident was portrayed as a helpless victim. The families of both individuals were placed in a distressing position.

The incident sparked apprehensive discussion among the LTC providers within the region. At that time, none of these LTC facilities had clinical practice guidelines in place that would assist staff to determine the best response when relationships of a sexual nature developed between their cognitively impaired residents. In addition, discussion revealed that in most LTC facilities in the region, little if any education had taken place to prepare staff to respond to episodes of a sexual nature.

As a result of this situation, I was very interested in finding out what I could about how the beliefs, values, practice philosophies, and organizational viewpoints related to sexuality fit with the person-centred care philosophies inherent in what has been coined the “new culture” of dementia care. I had my suspicions that the commonly held viewpoints about sexuality in dementia would not be akin to the tenets of person-centred care. Nonetheless, I was very hopeful that when I talked with representatives from each of the three LTC facilities that were invited to participate in the study, that I would uncover many stories of great sensitivity, evidence that open-mindedness in this practice area was the lay of the land. In fact, the administrators of each of the settings

were gracious and encouraging, suggesting to me that there was a very strong possibility that many positive ideas about sexuality in the face of dementia were just waiting to be given voice.

### Underlying Assumptions

It was the purpose of this study to uncover the nature of current beliefs and practices of front-line workers, front-line managers, and administrators working in LTC in response to sexual behaviour exhibited by residents with dementia. The study was undertaken to assist me to explicate and deeply understand how clinicians, both individually and in groups, achieve consensus and make decisions about how to manage displays of sexual behaviour. It was an attempt to expand knowledge concerning practice situations and decision-making related to sexual behaviour in dementia, and whether and how identified practice patterns might be reconsidered and redesigned. It was my desire to examine the necessity of the constraints built into LTC organizations in their response to sexual behaviours of residents with dementia. I wanted to explicate the norms that represent power in language use and the evolution of management strategies. In addition, I wanted to explicate the elements that might possibly exclude persons with dementia from full expression of their sexual desires.

My gut intuition and clinical experience was that generally, the sexual behaviours of persons with dementia were strictly controlled, and most often seen within the context



of risk management. My hunch was that formal caregivers approach sexual behaviour from the perspective of nebulous risk, predicated on personal value and belief systems, and not based upon any real assessment of true risk that the sexual behaviour might represent. In other words, staff selected response patterns on the basis of their worst imaginings of what “could happen,” rather than what was most likely to happen. My own clinical experience in such cases was that the greatest fear held by staff was the possibility of genital contact between two persons with dementia. My instincts also told me that families wanted to protect their older members with cognitive impairment from something that was so terrible as to be unspeakable. I wondered if families approached sexual expression associated with dementia with the same dread, choosing to react on the basis of their own worst imaginings, exaggerating the negative aspects.

My goal as an ethnographer was to determine the extent to which this awkwardness existed in several clinical settings, and to expose notions of constraint and repression as they relate to sexual expression of persons with dementia. While I was approaching the project with my assumptions “on the table”, I was prepared to discover that upon careful analysis, these assumptions might change (Kincheloe & McLaren 2000; Thomas, 1993). I thought that perhaps, as a result of uncovering these beliefs, values and ideas, the players involved in the study might begin to think differently about the sexuality of persons with dementia. Perhaps they would begin to construct with me

through a dialogue, a culture within which sexual relationships for persons with dementia would be seen in a new light, with greater tolerance and acceptance.

## CHAPTER TWO

### Literature Review

This research project was undertaken in order to render visible those values, beliefs and attitudes about the sexual behaviour of persons with dementia that could be modified, a transformative endeavour (Holstein, 1998; Kincheloe & McLaren, 2000; Thomas, 1993). Therefore, a review of the literature was carried out in order to understand the possible ideologies behind the interpretation and management of the sexual behaviours of persons with dementia living in LTC facilities. The literature review was conducted in order to subject the rhetoric, value claims and metaphorical images of the sexual behaviour of persons with dementia reflected in previously published articles and research to empirical scrutiny. I saw the literature review as a starting point through which to explicate and begin to understand current approaches, the “what is” of sexual behaviour associated with dementia, in order to go further and raise what Thomas identifies as the “ought” questions.

A search of the Health and Social Sciences literature (MEDLINE, Ageline, CINAHL, HealthSTAR and PsychINFO) was conducted from the year 1985 through 2004. In addition, the tables of content of the International Journal of Geriatric Psychiatry, Alzheimer’s Care Quarterly, and American Journal of Alzheimer Disease and Related Disorders were reviewed by hand for relevant articles on sexuality and dementia.

Only those articles published in peer-reviewed journals or edited book chapters were included in the critical review of the literature for this project.

### General Synopsis

The literature revealed several important points: a) Sexual expression is frequently interpreted to be the pathological manifestation of the dementia itself (Ballard, 1995, 1998; Feil, 1995; Hellen, 1995; Kuhn, 1994; Kuhn, Greiner, & Arseneau, 1998; Mattiasson & Hemberg, 1998; Philo, Richie, & Kaas, 1996; Rothman & Sebastian, 1990); b) true prevalence rates are suggested to be low, however distinctions between subtypes of sexual behaviour associated with persons with dementia living in LTC are difficult to establish due to ambiguous definitions and absence of data as compared to prevalence rates of other dementia-related behavioural syndromes (Fisher, Fink, & Loomis, 1993; Haddad & Benbow, 1993; Hallberg, Norberg, & Erikson, 1989; Hope et al., 1997; Jagger & Lindesay, 1997; Kolanowski, Garr, Evans, & Strumpf, 1998; Reisberg et al., 1987); c) professional caregivers react with discomfort when witnessing sexual expression in persons with dementia living in LTC (Ballard, 1998; Dupras & Poissant, 1987; Ehrenfeld, Tabak, Bronner, & Bergman, 1997; Kuhn, 2002; Philo et al., 1996; and d) management approaches most often focus on the pharmacological interventions that serve to “control” or eliminate its occurrence, rather than creative,

supportive interpersonal or environmental interventions (Cooper, 1987; Kyomen, Nobel, & Wei, 1991; Kyomen, Satlin, Henne, & Wei, 1999; Nadal & Allgulander, 1993).

### Conceptual Papers

Several conceptual papers, articles and book chapters focused on attempting to explain sexual behaviours and describe possible response strategies that should be selected by staff that could be described as operating from within the humanistic, caring paradigm. These are summarized in Appendix A. Still, the majority of articles focussed on explaining the etiology of sexual expression associated with dementia as a manifestation of pathology. Several articles suggested that sexual expression is a disinhibited behaviour resulting from loss of impulse control due to damage in the frontal-temporal areas of the brain (Ballard, 1995, 1998; Feil, 1995; Hellen, 1995; Kuhn, 1994; Kuhn et al., 1998; Mattiasson & Hemberg, 1998; Philo et al., 1996; Rothman & Sebastian, 1990). Some clinicians suggested that physiological need states such as undiagnosed urinary tract infection could manifest as sexual expression in the face of dementia (Ballard, 1998; Kuhn et al.; Harris & Weir, 1998; Hellen, 1995; Philo et al.). Of significance however, was that in most of the literature reviewed, sexual expression in the face of dementia was represented as a bi-product of a disease state, not necessarily as something that is a normal human behaviour. This interpretation may contribute to the

viewpoint, commonly held in LTC, that the sexual expression of persons with dementia should be considered a medical pathology that requires treatment.

Other clinicians reported that sexual expression in dementia is a manifestation of the psychological need for intimacy, touch and companionship. This need becomes sexualized because of disruption in neural pathways (Ballard, 1995, 1998; Feil, 1995; Kaplan, 1996; Kuhn et al., 1998; Mattiasson & Hemberg, 1998; Philo et al., 1996; Rothman & Sebastian, 1990). Kuhn (1994) suggested that inappropriate sexual expression is the result of misidentification of a potential partner as a spouse or significant other from the past. In addition, sexual behaviour can occur when typical rules about what is acceptable between partners in a married couple, are no longer evident within the context of the nursing home (Kaplan). The environment therefore perpetuates inappropriate sexual expression because the cues for appropriate conduct are missing. The literature also suggested that an insufficient social environment leads to inappropriate sexual behaviour that becomes an attempt on the resident's part to escape from boredom through self-stimulation (Hellen, 1995; Philo et al.). This body of work suggests that, in general, life in the nursing home is not conducive to the sexual and intimacy needs of persons with dementia.

The literature review also identified a number of conceptual papers and references to sexual expression in dementia in book chapters that stated staff feelings, attitudes, values and beliefs influence how they will interpret and respond to displays of sexual

behaviour. These writings reported that staff and students react to sexual behaviour with embarrassment and anxiety resulting in a cycle of rejection and isolation that contributes further to sexual acting out behaviours on the part of the resident (Ballard, 1998; Ehrenfeld et al., 1997; Kuhn, 2002; Mayers, 2000; Philo et al., 1996). Staff members varied in the degree of tolerance with which they responded to sexual behaviour, some overreacting by viewing it as pathology (Kaplan, 1996; Lichtenberg, 1997; Lichtenberg & Strzepek, 1990; Mattiasson & Hemberg, 1998; Mayers, 1998). Of significance is that most of the conceptual papers summarized in this section portrayed staff attitudes about sexual behaviour in dementia from the perspective of the clinical experiences of the authors, not from the results of any systematic, scholarly inquiry as was proposed with the present study.

Several articles included case vignettes in which the sexual behaviours of persons with dementia were viewed with anxiety by administrative and caregiving staff within LTC facilities. In some cases, well-meaning professional staff became concerned about sexual exploitation, and therefore separated residents with dementia from each other when it was perceived that a relationship of a sexual and intimate nature was developing (Lichtenberg & Strzepek, 1990; Lichtenberg, 1997; McCartney, Izeman, Rogers, & Cohen 1987). Indeed, the literature also suggested that the sexual relationships between older adults living in LTC who do not have a diagnosis of dementia are also considered

inappropriate and subjected to terminations by professional caregivers and family members (Collopy, 1988; Dupras & Poissant, 1987).

A case cited by Post (2000a) reflects this negative interpretation and response to the sexual behaviours of persons with dementia. Post describes a case involving an intimate relationship that developed between two residents with dementia in a LTC facility. The clinical team of the nursing home interpreted that the female resident misidentified the male resident as her beloved husband. She would bring gifts to this gentleman, and he did not discourage her advances to him. In fact, in one of his more lucid moments, he asked the administrator of the LTC facility if he could co-habit with the woman. The administrator made this request of the daughter of the female resident, who was shocked and immediately forbid the relationship to continue on the basis that it would dishonour her father's memory. The gentleman became depressed and withdrawn and refused to eat. He was given a feeding tube and moved to another facility. Post (2000a) did not comment further on the case other than to imply that this outcome was unsatisfactory and did not support the quality of life of either resident. Later in his book Post discussed what he called the key features of an ethics of dementia. While he identified one key feature as the right to an esthetic well-being and self-expression, sexual expression was not explicated as a part of this right.

In addition, the literature review revealed an additional anecdotal case report describing the romantic relationship that developed between two residents of a skilled



nursing facility (Berger, 2000). The woman of the couple was a 76 year old female resident diagnosed with a mild cognitive impairment. The man was a 79 year old male resident, cogent, but wheelchair bound due to a failed hip replacement surgery two years prior to the relationship. Both residents were widowed. The article described the struggle that staff experienced when the residents developed a close companionship, sharing meals and spending a great deal of private time together. The male resident eventually approached the social worker of the facility to request that he and the female resident share a room to live in. It is implied that this request was not accommodated. The article explicated the many and varied concerns held by the staff such as potential exploitation and risk of psychological trauma to the female resident. Berger suggested that clinical teams should develop assessment and practice guidelines to help make difficult decisions regarding cases such as this one. He recommended that private rooms should be provided; relationships between residents of the same sex should be tolerated; equipment such as erotic material, dildos and vibrators should be provided; and that pharmacological interventions that promote sexual vitality should be prescribed, for example, Viagra. While the recommendations are the most liberal of any of the articles reviewed, Berger made no suggestions about the process through which an organization could develop and implement policy that would support such freethinking viewpoints.

## Research Papers

Search strategies also focussed on identifying any articles that explored sexual expression from a research perspective. Using the search terms of sexual expression, intimacy, dementia, LTC and research, a limited number of studies were identified related to sexual expression in cases of dementia. These results reflect the current state of the topic of sexuality and dementia in relation to clinical practice. This is a relatively challenging area of inquiry, and we are only beginning to understand it as a behavioural phenomenon. One study was an intervention study directed toward evaluating the impact of a treatment regimen on a resident who was displaying sexual behaviours (Alexopoulous, 1994). Several studies were prevalence studies that related to frequency with which particular types of sexual behaviours are displayed within LTC (Archibald, 1998; Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999; Mayers, 1998; Zeiss, Davies, & Tinklenberg, 1996). One study was a postal survey that investigated the attitudes of staff working in 114 randomly selected nursing homes in the eastern United States (Holmes, Reingold, & Teresi, 1997). Two articles reported the results of studies that used descriptive, qualitative methodologies to explore responses to sexual expression by residents in LTC (Archibald, 2002, 2003). These studies all reflect the conventional nature and repressive conceptions about the sexual world of persons with dementia and are suggestive of what Thomas (1993) calls a “maximum security society”. The results

of the studies and the implications for the need for additional knowledge development are summarized below.

Alexopoulos (1994) published an anecdotal case report, describing a trial of a spaced retrieval intervention implemented over a three day period in response to a male resident's sexual behaviour in a LTC setting. The intervention employed a classical conditioning approach that consisted of repetitions of a response statement, "What are the ward rules? No touching," after every witnessed episode of inappropriate touching. The sample was a single, 87 year old male resident displaying sexual behaviour. All the staff members were trained to respond with the same verbal reminder of the ward rules after each witnessed episode of inappropriate touching. All behaviours extinguished by day four. At six months there was no recurrence of attempts at inappropriate touching. Limitations of this study include the absence of a clear description of what constituted inappropriate touching. As a result it is possible to infer that the contextual milieu within which this gentleman lived was built upon the professional belief that touching of any kind should be considered inappropriate. The study did not include an account of the care providers' beliefs and values and how these might have contributed to the construction of an environment within which touching was not allowed. Sadly, what is glaringly absent from this work is any exploration of alternate assessment or intervention approaches that might acknowledge and satisfy the sexual needs of the male resident.

Archibald (1998) conducted a descriptive, cross-sectional postal survey using a structured postal questionnaire. The objective of the study was to determine the incidence and management strategies associated with sexual behaviours displayed by residents. The study sample was administrators of residential care facilities in Scotland (n=23). The response rate was 85%. Most frequently reported behaviours were holding hands, fondling breasts, public masturbation and private masturbation. Sexual behaviours such as male residents attempting to fondle the breasts of female staff, public masturbation, and genital contact between co-residents were the behaviours most likely to result in derision or controlling responses from professional caregivers. Although not classified as a management problem, hand-holding was discouraged when it occurred in public, a somewhat disconcerting finding. This study did not include front-line workers accounts of how they responded to behaviours, the assessment process used to classify sexual behaviours, or the decision-making process they used to select a response. In addition, the study results suggest that there are indeed “ought” questions to be raised.

Ehrenfeld et al. (1999) completed a descriptive, qualitative, observational study with the goal to observe and categorize manifestations of sexuality among institutionalized elderly people with dementia. Their goal was also to analyse reactions of other patients, staff and families. Forty-eight psychogeriatric residents living in 8 LTC facilities in Israel were observed over a period of 14 weeks. An observation checklist was used to categorize observations. Thematic content analysis resulted in emergence of

three levels of sexual behaviour, love and caring, romance, and eroticism. Staff responses indicated greatest support when sexual behaviour of the love and caring type was observed. Behaviours at the level of eroticism, such as masturbation or attempts at sexual intercourse were most likely to result in reactions on the part of staff that were interpreted by the researchers to be rejection, disgust and anger. Interestingly, staff appeared to ignore any sexual behaviours that were initiated by female residents, rather choosing to “protect” female residents from the perceived sexual advances of male residents. A major limitation of this study was that there was no mention of the number of staff observed or their professional preparation or training. In addition, no interviews of staff were conducted, therefore, their personal accounts of their interpretation and responses to sexual behaviour witnessed in the residents in their care were absent from this study.

Mayers (1998) conducted a descriptive survey of direct care staff including registered nurses (RNs), licensed practical nurses and mental health therapists (n=33) working in a state hospital on an undisclosed number of psychogeriatric units. Many incidents of sexual behaviour were reported with not all episodes viewed as a management problem. Of the 69 residents whose behaviour was reported in the survey, 35 reported to be female had initiated sexual activity. None of the staff permitted sexual activity, including sexual touching of breasts, sexual touching of buttocks, sexual touching of genitals, kissing, attempted intercourse, mouthing of breasts and attempted

oral sex. Staff used physical restraint, restrictive clothing and separation of partners as interventions. Twenty-nine of the 33 staff participants indicated that staff members had been victimized by sexual verbalization. Twenty-six of the participants reported that staff persons had been the victims of sexual touching. In this study, staff members were portrayed as “victims” of the sexual advances of male residents, with sexual overtures constituting staff abuse. As in previous studies, the definition of sexual behaviour was clouded with references to normal social behaviours such as public displays of affection, for example hand holding, sitting in proximity, eating meals together and cuddling. Sex was seen as an exploitation of a vulnerable partner by another partner who was seen as the sexual aggressor. Consequently, all episodes of touching behaviour were interpreted with great inconsistency. Again, this study suggests that sexual behaviours of persons with dementia are repressed within the LTC environment. A major limitation of this study was that individual respondents were not interviewed, therefore, there were no accounts of staff interpretation of observed behaviour or the reasoning that led to the selection of a particular intervention.

Zeiss et al. (1996) completed a descriptive, observational study with the goal to investigate the prevalence of sexual behaviour in institutional dwelling demented elderly. Forty male residents in a Veterans’ Administration LTC hospital were observed by trained research assistants on nine separate occasions, three in the morning, three in the afternoon and three in the late evening. Each observation period was five minutes in

length, coded for behaviours across one minute time intervals. The behaviour was coded for three categories of sexual behaviour: appropriate, ambiguous, and inappropriate sexual behaviour. Most behaviours observed fell into the ambiguous category. Twenty percent of the sample displayed sexual behaviour considered to be appropriate. In comparison, only 18% of the sample ever displayed sexually inappropriate behaviour and when this occurred it was brief and minor. Most inappropriate sexual behaviour was observed in only 1.6% of observed one-minute time segments. The observed responses of staff to sexual behaviours were coded as positive, neutral, negative or ignoring. No staff member responded to inappropriate behavioural displays such as disrobing and masturbating in a public area. Study limitations include small sample size, and the absence of female residents living in the environment. The same-sex sample of this study might not be representative of the sexual behaviours typical within co-ed LTC units. That the largest category of reported behaviours fell into the ambiguous category, would suggest that definitions are unclear. Another limitation is that there is no description of the overall behavioural profiles of the sample. It is unclear as to whether the sample consists of residents whose behavioural profiles also include expressions of overt physical aggression such as hitting, biting, or kicking. Consequently, it is impossible to determine if the sample in the study is representative of residents who engage in the typical behavioural displays associated with dementia, other than those of a sexual nature. Of greatest significance is that sexual behaviours defined as inappropriate

were time-limited and episodic in nature, however when they did occur, staff did not respond even when it was blatant and upsetting to other residents. Again, there were no personal accounts included in this study that might explain why staff consistently ignored public displays of sexual behaviour.

Holmes et al. (1997) conducted a postal survey, the main objective of which was to measure the attitudes of health professionals in nursing homes toward sexuality and sexual expression in cognitively impaired residents. The staff members of 300 randomly selected nursing homes in the eastern United States were asked to complete a measure of attitudes toward residents with cognitive impairment. One hundred and fourteen representatives of the 300 facilities canvassed responded to the survey. The results suggested a primarily positive attitude and supportive orientation toward the sexual expression of residents with dementia. However, some respondents had a restrictive orientation to resident sexuality. Fifty-nine percent of clinical staff that responded felt that sexual behaviours were difficult to deal with. In addition, administrators tended to hold the most conservative viewpoints, possibly related to their fears about litigation. All respondents felt strongly that nursing home staff should receive special training relating specifically to resident sexuality. The main methodological limitation of this study is that the attitudes of staff members who might hold more conservative philosophies were likely absent. It is possible that those with more conservative viewpoints may not have even completed the survey as a result of their discomfort with the topic. Therefore, it is



difficult to make a statement regarding how representative the reported positive viewpoint was for the entire culture of each participating organization. It is highly possible that the results can be explained by a systematic bias among respondents, whereby recipients who responded were those who had a set of tolerant attitudes and values associated with resident sexuality. Of greatest significance, however, is that the study does not contribute toward an understanding of why staff struggle with how to respond to sexual behaviour in persons with dementia or the process through which clinical teams could develop a plan of care.

Archibald (2002, 2003) conducted a participant observational study that included in-depth semi-structured interviews with 17 care workers and managerial staff in a 48 bed residential care home in Scotland over a 12-month period. Archibald identified that the staff used a controlling and nihilistic approach to care, particularly in the area of the sexual behaviour of residents with dementia. Staff tended to operate from a conservative and protectionist position, particularly if the residents engaged in a sexual activity were female. They tended to separate any co-residents engaging in acts of intimacy, usually reprimanding the male resident involved. In addition, staff reported that they felt shocked, astonished, angry and embarrassed when a resident made either physical or verbal sexual overtures toward them during the provision of care. When faced with such behaviours their response was to withdraw and report it to senior management. The viewpoint of the care workers was not congruent with those of the senior managers in the

facility who tended to be more tolerant. However, of significance was that the senior management team did not provide emotional or educational support to staff so that they could deliver care in comfort. A limitation of this study was that the research was conducted in only one facility, therefore, it is difficult to make any generalizations or statements about how this organization's practice would compare to that of another facility. In addition, there were no direct interviews with family members, there was no explication of the decision-making pathways used by staff or families to determine a response, and no accounts that would help explain why staff, management or families behaved the way they do within a broader societal context. While Archibald outlined an educational initiative to help enhance care worker knowledge in the area of sexual behaviour and dementia, there were no alternatives suggested in regard to decision-making patterns that clinical teams could utilize to expand their reasoning or practice.

The articles reporting the results of the participant observation study conducted by Archibald (2002, 2003) were perhaps the closest in intent to the goals of this research project, however, the results do not stem from multiple sites, nor do they explain why a LTC organization may struggle with sexual expression in the face of dementia. In addition, the results do not contribute to our understanding of how residents, family and staff might make decisions together about how to respond to episodes of sexual behaviour in persons with dementia.

In summary, the literature review revealed that while there is a sense that staff members and families are uncomfortable about sexual expression in dementia, there is no understanding of why this is. The majority of the literature focuses on the organic and social etiologies of and pharmacological methods to extinguish sexual expression in persons with dementia. The literature suggests a preoccupation with the need to control sexual behaviour. The predominate rhetorical statements, value claims and metaphorical images of the literature pertaining to sexual expression of persons with dementia living in LTC were pervasively negative. The literature review identified a gap in knowledge related to the personal, cultural, and sociopolitical factors that may influence perception and response to the sexual expressions of persons with dementia. Therefore, the literature review revealed the need for additional scholarly inquiry into the values, beliefs and practice patterns of formal and family caregivers of persons with dementia living in LTC, by way of exposing ideologies behind decision-making in response to sexual behaviour, so as to take first steps toward liberating persons with dementia from any possible “sexual injustices”.

## CHAPTER THREE

### Methods

#### Research Paradigm

Critical theory provides the contextual fabric through which the cultural environment and the sociopolitical influences that shape our practices, and what is accepted as legitimate action in everyday clinical situations, can be discovered (Browne, 2000; Holmes & Warelow, 1997). In critical social theory, the concept of truth is linked to the idea that rational consensus is attained through discourse and critical debate (Braaten, 1991; Higgs & Titchen, 2000). Critical theory provides an integrative framework for the development of emancipatory knowledge where the central theme of societal experience is oppression, domination and power imbalance (Mill, Allen, & Morrow, 2001). The interpretation of clinical problems in health care and the determination of a response are socially constructed through human interaction. Critical theory can deepen understanding of the mechanisms and values that influence practice (Mill et al., 2001).

In keeping with the philosophical roots of critical theory, the major goal of this study was to raise the level of awareness and deepen understanding of the phenomenon of the sexual behaviours of persons with dementia. The study was intended to explicate the organizational conditions that constrain quality of life with regard to sexual expression for persons with dementia. The study was designed to explicate how personal

values and organizational interests shape practice policies within the LTC facilities that were studied. The study was also intended to assist study participants to question and negotiate issues, and to reach mutual understanding concerning social/cultural needs, interests, and norms related to sexual behaviour in dementia through conversation and discussion. In keeping with the nature of critical theory, this study was designed to uncover the nature of enabling and/or restrictive practices, and thereby identify any need for practice improvements, generate an opportunity for potential change, and ultimately, the enhanced sexual health of residents with dementia (Campbell & Bunting, 1991; Kincheloe & McLaren, 2000; Wells, 1995).

### Formative Theory

Many philosophers and scientists espouse the epistemological viewpoint that all research methods are theory-driven and all knowledge is theory-laden (Mitchell & Cody, 1993). Theory is used in ethnography as a means to guide data collection and analysis thereby limiting the influence of the researcher's own cultural experiences and perspectives. It is important that researchers clearly identify formative theory and assumptions held as the study begins in order that they can be examined, modified and expanded through research (Hughes, 1992). The assumption underlying this research project was that although individuals have their own value and belief systems that impact upon their responses to observed episodes of sexual behaviour in residents with

dementia, decisions about responses to be made are influenced by the social/cultural context within which that individual operates. This study was an attempt to explicate the social/cultural influences that impact upon individuals and groups who observe episodes of sexual behaviour exhibited by residents in LTC facilities. The relationship between the witness to observed behaviour, the social/cultural environment, and action taken in response are represented in Figure 1.

#### Research Questions

1. What do study participants mean by sexual behaviour associated with dementia?
2. What is the basic description of what participants reveal to be the ways they respond to behavioural episodes they define to be of a sexual nature in dementia?
3. What do participants identify to be the factors underlying their responses to episodes of sexual behaviour in dementia (reasons, purposes, motives, origins)?
4. What is the cultural/social context within which individuals respond to episodes of sexual behaviour in dementia? How do LTC facilities in which clinicians work influence the response to sexual behaviours that are witnessed? (What are the explicit, implicit, and unspoken rules that influence decision-making and practice responses?)
5. How do individual accounts differ from group accounts regarding episodes of sexual behaviour in dementia?

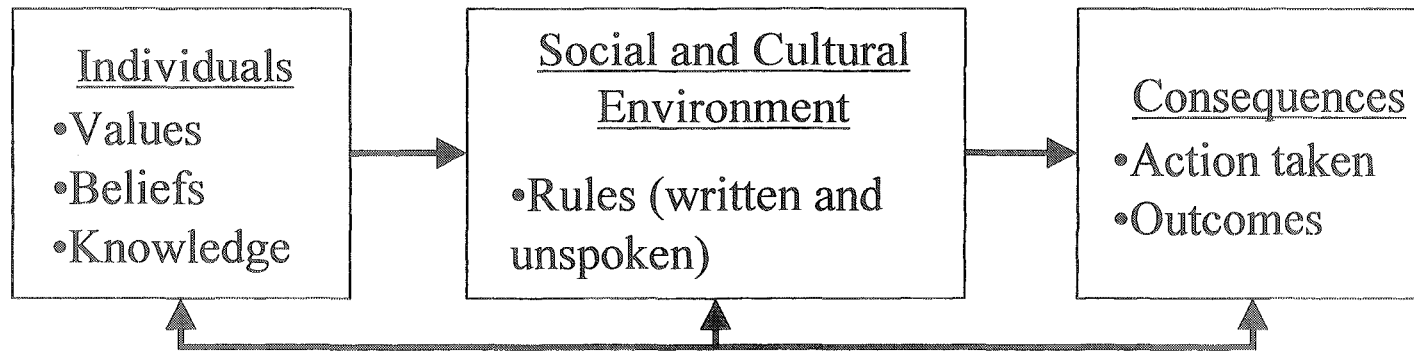


Figure 1. Decision-making schema (Formative theory).

6. How do individual and group responses compare and/or contrast with management responses to episodes of sexual behaviour in dementia?
7. What are the consequences of selected actions for the persons involved in the clinical situation - for families, for residents, for teams, for individual clinicians?
8. What practice change initiatives can be identified?

### Study Design

A descriptive, qualitative design using critical ethnographic methodology was selected for this study. The literature review revealed that there was a dearth of research information available regarding the processes through which clinicians make clinical decisions regarding the management of sexual behaviour displayed by residents with dementia. Consequently an exploratory study using ethnographic methods such as the one proposed here was appropriate (Krefting & Krefting, 1991).

Creswell (1998) identifies ethnography as the description and interpretation of a culture, group or system. The investigator studies the meanings of behaviour and language through a detailed account of customs, patterns of behaviour and rules (Brandriet, 1994; Lowenberg, 1993). In this way, ethnography can yield types of information that can be helpful for decision-making in health care, and can provide accounts of clinical experiences that will assist with informed policy decisions (Braithwaite, Bianchi, & Taylor, 1994; Krefting & Krefting, 1991). Creswell supports



that ethnography is an approach that matches the methodological and substantive intent of critical social theory. In addition, Thomas (1993) identified that critical ethnography opens to scrutiny otherwise hidden agendas, power centers and assumptions that inhibit, repress and constrain, whereby commonsense assumptions are questioned. According to Thomas, critical ethnography has a political purpose, with a focus on social change. In the taken-for-granted clinical world, it is that persons with dementia are asexual beings. Consequently, it is surprising and shocking when a relationship of a sexual nature develops.

### Setting

The study involved three nursing homes in the Central South region of Ontario. The investigator interviewed three to four staff members, one to two family members, and two to three members of the senior management team, for example, the Director of Resident Care, the Medical Director or the Administrator, within each of the three participating facilities. A focus group involving invited participants was conducted at each of the three facilities after the individual interviews had been completed. A letter of introduction that described the study and requesting a meeting to discuss possible participation as well as acceptable avenues to acquire participants was sent to Administrators of LTC facilities within the Central South region (Appendix B).

### Sample

A combination of sampling approaches was used for this study. Criterion sampling lead to the identification of the three LTC facilities that were approached to participate in the study. Inclusion criteria for initial approach was that the LTC facility offered care for persons with dementia, and at least one of the senior management team, such as the Director of Resident Care, Medical Director and/or Administrator, agreed to be interviewed. Invitation to potential participants to take part in individual interviews and focus groups was made using a purposive sampling approach (MacDougall & Fudge, 2001). Inclusion criteria included, fluency in English, a declared comfort level with the sensitive nature of the topic, a declared interest in the topic, a willingness to be approached by the researcher to discuss participation in the study, and provision of signed consent.

### Data Collection

The data collection process involved engaging individual practitioners and groups of clinicians in practical discourse about sexual behaviours in dementia using reasoned communicative action and consensus-building as a means to improving the character of decision-making (Ray, 1992). In keeping with the substantive intent of this project, individual interviews, focus groups, participant observation, field notes, and document review were utilized as the data collection methods. In-depth interviews provided an

opportunity for key informants within each organization to give an individual account of how they responded to episodes of sexual behaviour in dementia. Focus groups resulted in the identification of cultural values and group norms as a result of conversation between participants whereby individual ideas are considered in relation to the opinions of others (Robinson, 1999). The focus groups assisted the investigator to identify the values, ideologies, patterns, rules, characteristics, contradictions, oppositions, tensions or ethical dilemmas that form the basis of response to sexual behaviours in persons with dementia within the context of the LTC facility (Ray, 1992). Field notes of the investigator's perspective of observations made during encounters with informants were recorded in the form of a research journal. Any documents that referred to sexual behaviour such as site policies or practice guidelines that were revealed to the researcher through senior management staff attached to each facility were reviewed to identify practice patterns.

In total, 24 interviews were conducted, with participants representing non-regulated front-line staff, registered staff, senior management, and families from each of three LTC facilities. A variety of strategies were used to recruit participants for the in-depth interviews, for example, making an announcement at staff meetings, sending letters of introduction to staff and family members, and posting notices about the study (Morgan, 1995). Samples of letters of introduction and focus group notices can be found in Appendix C. Each interview was approximately one-hour in length and was taped

using a digital voice recorder. The investigator conducted all interviews using a semi-directed interview guide. The guide was intended as a prompt for the researcher, since true ethnography uses an open-ended approach to data collection, whereby questions stem from observed behaviour and the language used by the participants (Hughes, 1992). The interview guides can be found in Appendix D. Demographic data was also collected for interview participants (Appendix E).

A single focus group was held at each of the research sites using additional participants from within the ranks of front-line staff members. The investigator used a general invitation to acquire participants for the focus group through posting signs announcing the meeting to notify staff members. Each focus group was approximately one-hour in length and was taped using a digital voice recorder. The investigator conducted all three focus groups using a semi-structured guide that included three possible case studies to generate discussion between participants. The cases were introduced at the discretion of the investigator who acted as moderator during the sessions (Morgan, 1995). The focus group guide is found in Appendix F. In addition, demographic data was collected for focus group participants (Appendix E).

To acknowledge the time given by the organization to the study, the investigator conducted a workshop at each site on sexual behaviour associated with dementia for interested staff and families within the first month after completing data collection. The workshop discussion was recorded by the investigator in the form of observational field

notes, taking stock of participants' reactions, comments and questions. This data set was used to confirm the description of each culture that was being constructed through data analysis.

### Data Analysis and Interpretation

The data set collected as a result of individual interviews, focus groups, observational field notes, and document review involved three aspects, description, analysis and interpretation (Atkinson, 1992). The data were initially described, wherein the accounts given by participants, observations made by the investigator and document review was recorded in narrative form. Secondly, the data were analyzed by comparing and contrasting the descriptions given by individual participants and by the focus groups, observations made and documents reviewed from within each unique LTC facility. This step involved the building of taxonomies that represent the systems within which participants operate in response to episodes of sexual behaviour (Aamodt, 1989). Thirdly, the data were interpreted by the investigator through a process of reflection as to potential impact of explicated rules and patterns of behaviour on clinical practice. In this phase, data analysis elucidated the cultural/social themes that influence decision-making in the research settings (Aamodt; Atkinson). The data set was coded, overall themes and trends were identified, and comparative relationships within the data set elucidated. The data were integrated into an illustrative framework for how decisions about how to

respond to episodes of sexual behaviour are made within the research sites (Cahill & Fonteyn, 2000). The qualitative software program NVivo Revision 1.1 (Qualitative Solutions and Research, 1999) was used for data management and to assist with data analysis, for coding and retrieving data and to assist with the construction of the framework. Lastly, the data were reconsidered with respect to the identification of power relationships and the need for practice change. As a result of this reflection, an alternative clinical reasoning process was then constructed that would promote a considered and enlightened approach to sexual behaviours in persons with dementia.

### Rigor

Standards of quality during the data collection, analysis and interpretation phases of this research project were addressed by using several processes. In preparation for the investigation, I laid bare my assumptions, thereby setting the ground work for proving those assumptions wrong (Kincheloe & McLaren, 2000; Thomas, 1993). A series of actions were taken in order to ensure that I was able to verify the results and to maintain my capacity to reflect upon the findings in order to achieve deep understanding of the informants' words and stories (Creswell, 1998; Maxwell, 2002; Thomas, 1993; Wolcott, 2001). Verification was addressed in this study by ensuring ethnographic validity through multiple data sources, thereby increasing my capacity to draw inferences about the nature of response to sexual behaviour from potentially diverse voices. In addition,

interview and focus group questions were pre-tested with three individuals who worked in a LTC setting other than the research settings selected for the formal data collection process. This was undertaken in order to fashion a list of questions that were elegant, sensitive and I could ask with comfort and familiarity (Morgan, 1995). Once data were collected, I sought informant feedback from the interview participants. Each informant was given a written summary of preliminary data with the instruction to contact me to discuss any discrepancies and concerns or further expand upon a key point (Creswell, 1998). None of the participants contacted me after receiving the summary letters. The focus groups were used as a forum within which data from individual interviews could be authenticated by way of comparative analysis (Kidd & Parshall, 2000). In addition, at the end of each focus group, I gave participants a brief summary of key points elucidated through group process, a procedure known as member-checking. This gave group participants opportunity to clarify major points made during group discussion, since confirmation of data through reassembling exact groups at a later date was problematic due to work scheduling (Kidd & Parshall).

As the data were analyzed, I used the writing process itself to engage in constant reflection. I generated NVivo Revision 1.1 (Qualitative Solutions and Research, 1999) coding reports to assist with the refinement of the coding schema. As analysis progressed, I continually referred back to the original text of each transcript before the coding schema was finalized. As the illustrative quotes were extracted from transcripts

and embedded into the text of the dissertation, I inserted the participant number, page number and text line directly after the quote so that the context of the statement could be traced, thereby ensuring descriptive validity (Maxwell, 2002). As the text of the dissertation was edited, I would refer back to the original transcript source, re-reading the entire section to ensure that the account of each participant was portrayed in such a way as to be given voice without distortion, thereby ensuring interpretive validity. This was undertaken so that the inferences I was drawing were grounded in the words of those on whose accounts my perceptions were based, not solely from my imagination (Maxwell). In addition, as the text of the dissertation was under construction, I shared samples of sections of Chapters 5 and 6 with colleagues in addition to members of the dissertation committee. This was undertaken to discuss the use of language, the illustrative quotes and the developing conceptual schema in order to establish theoretical validity (Maxwell). I wanted to ensure that the final report achieved balance, by way of capturing the essence of the struggles experienced by the participants, but not doing so in a way that would sensationalize the results.

Lastly, I continually reflected upon the interpretive process and the connections between critical ethnography and critical social theory. I read and re-read each draft to ensure that the final report stayed true to the critical intent of explicating potential practice reforms (Kincheloe & McLaren, 2000).



## Ethics

Ethics approval was obtained from the McMaster University Ethics Review Board, Hamilton Health Sciences Division, prior to commencing the study (Appendix G).

Informed written consent was obtained from potential participants prior to undertaking any interviews or participating in the focus groups. To ensure confidentiality, the participants were not identified in any way in the research report, through ensuring that a numerical identity was assigned and that any identifying information regarding site of practice was removed. The written consent also assured participants that they could withdraw from the study at any time during the data collection and analysis process, and that they could refuse to answer questions or be excused from making comments during the interview and/or focus group sessions. A copy of the consent to participate is found in Appendix H.

Informed consent (Appendix I) was also sought from the Administrator of each research site prior to review of documents that pertain to sexual behaviour in dementia and to record the data on a worksheet (Appendix J). The written consent assured that information related to the documents would not be shared other than in the context of verbal and written reports of the study and that the data would be presented in such a manner as to not identify the facility.

All voice recordings and manuscripts were safely secured in a locked credenza for the duration of the study. The voice recordings, burned to a compact disc, and

manuscripts will continue to be stored in a secure location after completion of data analysis and report writing, for a period of two years, after which the compact disc voice recordings will be destroyed and the manuscripts shredded.

There were potential benefits and risks associated with participation in the study. One of the possible benefits of the study was that families, formal care providers and senior managers had an opportunity to reflect upon the ways in which episodes of sexual behaviour are interpreted and managed. This may have led to the identification of those aspects of clinical practice that could be improved upon, for example, educational initiatives that might expand the practice repertoire of front-line care providers or the development of practice guidelines where none exist. The focus groups might result in a forum wherein consensus on team approach to episodes of sexual behaviour might be reached. There were aspects of this study that represented some degree of risk to study participants. The topic itself was emotionally charged and responses had the potential to be deeply seated in individual beliefs and values. As a result, it may be that individuals participating in interviews or focus groups might have felt vulnerable to the judgement of those who were listening to comments made. Vulnerability was protected against by stating clearly at the beginning of each session that there were no incorrect answers/ comments to questions/points of discussion. In addition, participants were assured that they had the right to withhold comments on any of the points of discussion during the

study, and they had the right to withdraw from the study at any time during the data collection or data analysis phases.

### Limitations of the Study

The study findings and subsequently, their implications for practice, research and education were limited by the number of participants who were able to be interviewed. The interview process was affected by time and may not have elicited a full description of the phenomenon within the context of the unique culture of each facility. In addition, the small number of total participants, particularly family members interviewed, limits the degree to which their stories are representative of the total culture within each facility. Although there are accounts within the participants' stories that describe the attitudes and actions of others, these are possible conjectures that cannot be validated. The study participants may also have hesitated to share freely with the researcher, limiting the extent to which the cultural field of each setting was explicated. It is significant to note, however, that it might be likely that participants with less liberal and open-minded viewpoints were not made available to me. I suspect that those who struggle terribly with sexual expression in the context of residents with dementia were much less likely to come forward to give an account of their viewpoints. Therefore, it may actually be that the full cultural field is much different than the stories within these pages have suggested.

In addition, there was only one focus group conducted at each site. Although the focus groups were typically held with other practitioners other than those who participated in individual interviews, the additional viewpoints of five to ten others within each facility does not address the limitations as described above.

Perhaps of greatest significance is that despite attention to methodological rigor, my experiences as a clinician may have introduced a researcher bias that made its presence known throughout the data collection and analysis process. Although I was ever hopeful that there would be many positive accounts about sexual expression in persons with dementia, I could sense my own disappointment that participants were not more forward thinking. I may therefore not have been as persistent in uncovering positive accounts in later interviews, despite diligence in covering all topic areas outlined in the semi-directed interview guide. In other words, as the interviews were coming to an end, I may have been more vigilant to stories related to restrictive practices, rather than persisting in uncovering stories of exemplary practice. I may have incorrectly assumed that positive examples were not there to be discovered.

Lastly, the accounts that were elicited by me as a researcher were impacted upon by my own feelings of discomfort with the topic. Some of the participants indicated to me through their body language, facial expressions and speech patterns that they did not want to explore a certain topic any further. Consequently, there may be many stories and accounts left unsaid. However, there were several situations in which my instincts told

me that, although difficult for the participant being interviewed, if I gently probed, there would be more information forthcoming. During some interviews, however, my energy level and interruptions from outside of the room disturbed the ebb and flow, and I suspect that some significant, sensitive things were withheld.

## CHAPTER FOUR

### *XII*

*Full woman, fleshly apple, hot moon,  
Thick smell of seaweed, crushed mud and light,  
What obscure brilliance opens between your columns?  
What ancient night does a man touch with his senses?  
(Neruda, 1997)*

#### Sex and the City:

##### Description of Key Informants Across Three Sites

There were a total of 25 individual participants representing three long term care facilities in the Central South region of the province of Ontario. Each site also arranged for a single interdisciplinary focus group involving a mean of 10 people.

##### Recruitment of Subjects

Participants for individual interviews were recruited with the assistance of the senior management team of each of the three study sites. I first met with a representative of the administrative team at each site who acted as a gatekeeper, assisting me with gaining access to potential participants. During this meeting we discussed together the numbers of recruits I was looking for at each site. In addition, we talked about those staff members who would meet eligibility criteria for inclusion in the sample for both individual interviews and focus groups. The eligibility criteria included those persons

who were fluent in English, had the capacity to be articulate and reflective about this potentially difficult topic and were willing to be contacted by me to discuss the possibility of being interviewed. In the end, all participants interviewed for this study were the ones most likely to have direct personal contact with elderly residents and their families, such as health care aides, registered practical nurses and registered nurses. In addition, the sample included a social worker and a therapeutic recreation specialist. Other members of support services such as housekeepers and dietary aides were included in the focus groups. After representatives of the senior management team approached them individually, potential subjects gave their permission to be contacted by me by way of a formal letter of introduction (Appendix C). I then telephoned potential recruits and for those who were willing to be interviewed, set up appointments that were convenient for their schedules. Of potential recruits, only one person, a family member, declined to participate in an individual interview after I made telephone contact.

Focus group participants were recruited by a general invitation that was posted in the common areas for professional staff, such as the staff lounge (Appendix C). I made the signs announcing the focus group purpose, location, date and time and brought them to each of the sites to be posted. A telephone call was made to the designated organizational contact person, a representative of the senior management team, at two weeks and then four days prior to the scheduled date to issue a reminder in order to

reduce the likelihood of competing priorities. There were no family members included in the focus groups.

### Response to the Interviews

In general, participants who took part in individual interviews appeared to be comfortable with the topic and questions, and were willing to discuss their experiences in some detail. Participants all identified that in principle they had no difficulty with the concept that people with dementia were sexual beings with sexual feelings, even those with significantly advanced cognitive impairment. Nonetheless, most participants identified that although they didn't have a specific problem with sexual expression per se, they still found it discomfoting when observing frank public displays.

### Family Participants

From a family perspective, participants were a challenge to recruit. Several family members who were approached to participate refused to do so, stating that they found the topic difficult. One potential recruit flatly refused, stating she had nothing to say to me on the topic. She then proceeded to tell me that she had observed one male resident approaching another demented resident to try to touch her several times, and that she found the behaviour "disgusting". Her response and tone of voice would suggest to me that she did not approve.



A total of four families were interviewed. Only one family participant was a spouse, while the other three were daughters. The single spouse, a husband, was himself the target of negative speculation on the part of staff in the facility within which his wife was living. Staff regarded the witnessed intimacy behaviours he directed toward his wife as suspicious, distasteful and exhibitionist. The daughters tended to share the conservative viewpoints held by the staff. In particular, the daughters felt strongly that as advocates for the best interests of the parent, that they would not feel comfortable should any relationship of a sexual nature develop. Their inclination would be to forbid it, believing that sexual behaviours such as kissing, cuddling or fondling were out of character with how the parent had conducted themselves prior to the onset of their cognitive impairment, and therefore would require strict controls and supervision.

## Demographic Profile

### The Facilities

There were three long term care facilities involved in this study. Two facilities were located in residential areas in the central hub of a large metropolitan city in Central South Ontario. A third facility was located in a suburban residential area on the outskirts of the same metropolitan city of Central South Ontario. Two facilities were for-profit organizations. A third facility was a not-for-profit organization. Two facilities were of

small size, that is between 60 and 100 beds. One facility was a large organization, that is between 250 and 300 beds.

### Individual Interviews

There were 25 participants interviewed during 24 interviews over a period of four months during the late fall of 2002 and the early winter of 2003. Two participants, colleagues on a clinical team at the same facility, were interviewed together at their request. Of the total number of individual participants, 19 were female and six were male. In addition, four of the participants were family members, three were daughters of residents with dementia, and the single male family member was the spouse of a resident with dementia. The interviews were conducted at all three sites during the same time period, moving back and forth between sites to accommodate the schedules of individual participants. The majority of interviews were completed by the end of January 2003. The administrators of each site were interviewed during the middle of March 2003, after most of the earlier interviews had been transcribed and preliminary data analysis had begun. I transcribed all of the individual interviews personally in order to immerse myself in the words, speech patterns, terminology, and vocal nuances of the participants, given the sensitive and difficult nature of the topic. Transcription was completed before interviewing the administrators in order to identify if there were additional questions that

needed to be asked in order to explicate the full extent of each community's response to sexual expression in dementia.

There were seven participants from site 001, five of whom were professional clinicians, and two who were family members. Of the seven participants, six were female, and one was male. Of the professional staff interviewed, two were HCAs, one was a RPN team leader, one was a RN senior manager, and one was the administrator. The medical director of this facility was in semi-retirement and unavailable to participate in the study. All were full-time employees. None had educational preparation beyond a college diploma or program certificate. The length of service of staff participants within the facility ranged from 1 to 10 or more years. The mean length of service of staff participants at the site was 6.8 years. The length of stay of the residents of family members who participated was between 1 and 3.5 years.

There were 10 participants from site 002, nine of whom were professional clinicians, and one who was a family member. Of the professional staff interviewed, two were HCAs, one was a RN senior manager, one was a registered charge nurse, one was a RPN team leader, one was a social worker, one was a recreationist, one was the medical director, and one was the administrator. All staff members were full-time employees, other than the medical director who served in a consultant role. None had educational preparation beyond a college diploma or program certificate, other than the social worker who had a baccalaureate degree, one of the front-line workers who had a baccalaureate

degree in another subject area, and the medical director who had a medical degree. The length of service of staff participants within the facility ranged from 6 months to 10 or more years. The mean length of service of staff participants at the site was 5.9 years. The length of stay of the resident of the family member who participated from this site was between 2 and 5 years.

There were eight participants from site 003, seven of which were professional clinicians, and one who was a family member. Of the professional staff interviewed, one was a HCA, one was a RN senior manager, two were RN team leaders, one was a RPN team leader, one was the medical director, and one was the administrator. All staff members were full-time employees, other than one RN team leader and one RN team leader who both had part-time status, and the medical director who served in a consultant role. None had educational preparation beyond a college diploma or program certificate, other than the medical director who had a medical degree. The length of service of staff participants within the facility ranged from 3 months to 10 or more years. The mean length of service of staff participants at the site was 7.3 years. The length of stay of the resident of the family member who participated from this site was between 5 and 8 years.

### Focus Groups

The focus groups were conducted at each site after the individual interviews had been completed and transcribed, and the preliminary data analysis had begun. This was

done in order to identify if there were additional question areas or issues that needed clarifying during discussion with participants in the focus groups. The focus groups were completed by the middle of February 2003. All of the focus group participants at each of the three sites were female.

There were seven participants in the focus group at site 001. Four of these participants had been part of the individual interviews. This included the two HCAs, administrator and a RN senior manager. In addition to these people, there was one RN team leader, one RPN team leader and a food services supervisor in attendance. This focus group was held in the afternoon just before change of shift to accommodate work schedules. It was 45 minutes in length. Focus group participants at this site were all full-time employees of the organization. None had educational preparation beyond the level of a college diploma or professional certificate. The length of service of focus group participants at site 001 ranged from 1 to 10 or more years. The mean length of service of focus group participants at this site was 5.2 years.

There were eight participants in the focus group at site 002. None of the participants had taken part in an individual interview. The focus group was held in the afternoon to accommodate work schedules. It was approximately 55 minutes in length. In attendance were two recreationists, two housekeepers, one dietary aide, one social worker, one HCA, and one RN senior manager. Focus group participants at this site were all full-time employees of the organization. None had educational preparation beyond

the level of a college diploma or professional certificate, other than the social worker in attendance, who had a baccalaureate degree. The length of service of focus group participants at site 002 ranged from 1 to 10 plus years. The mean length of service of focus group participants at this site was 6.8 years.

There were five participants in the focus group at site 003. None of the participants had taken part in an individual interview. In attendance were two RN team leaders, one HCA, one recreationist, and one nutritional services supervisor. The focus group was held in the morning to accommodate work schedules. It was approximately 50 minutes in length. One of the team leaders and the nutritional services supervisor were part-time. The other participants were full-time employees. None of the participants in attendance had educational preparation beyond the level of college diploma or professional certificate, other than the recreationist who had a baccalaureate degree. The length of service of the participants at site 003 ranged from 1 to 10 or more years. The mean length of service of focus group participants at this site was 8.2 years.

In general most participants in the focus groups were actively engaged in the discussion around how they would respond to sample cases involving sexual behaviour of residents with dementia. Those employed in their organization as front-line caregivers or managers were more likely to give comments related to the cases or their own experiences. Those employed in support services such as housekeeping and dietary services were less likely to make comments. Although they admitted to having been in

situations where they had witnessed or been the target of sexual overtures made by persons with dementia, those employed in support services were less likely to give an opinion as to how these should be responded to.

### Educational Background Regarding Sexuality and Dementia

Educational initiatives were provided inconsistently. Site 002 offered two or three hour long educational events related to sexual expression associated with dementia shortly after the media publicized episode had occurred in February 2000. Only one of the nine participants from that site had attended the in-services. Site 003 had offered a single educational event that was implemented by an outside educational consultant provided through the Ontario Ministry of Health's Alzheimer Initiative Strategy #1 (Ontario Seniors' Secretariat, 1999). This in-service was a resident-specific strategy session. Only three of the seven participants from that site had attended the session, all three being registered professional nurses who closely involved in the supervision of the specific case. The front-line worker from site 003 had not attended the in-service because she had not been made aware. Site 001 had not offered any in-services on the topic related to sexual expression associated with dementia. None of the participants from all three sites had ever received any training in the area of sexual behaviour in dementia during their formal education. Only one of the participants from all three sites had read any articles on the topic. None of the three facilities had an in-house champion

or coach who was knowledgeable in or comfortable with this topic area. This was interesting, given that there were recognized experts in other practice areas, for example, skin, nutrition, falls and/or risk management.

#### Overall Management Response to Sexual Behaviour

The overall guiding principle in response to episodes of sexual expression was that residents with dementia should be protected from exploitation of any kind. The primary belief was that sexual expression, if allowed, represented an exploitation that would be dangerous and embarrassing, but in terms of the staff and family experience, not necessarily from the perspective of the residents themselves. As a result, most staff members were likely to separate individuals who were involved in behaviours that involved touching or being touched by another resident.

The most frequently mentioned response strategies implemented by staff were to separate co-residents with dementia who were engaging in sexual or intimacy behaviours, and then to report this behaviour to someone superior to them in the organization. Participants of either focus groups or individual interviews who were employed in such support service roles as food or housekeeping services were inclined to report these behaviours immediately to nursing personnel who would then move in and separate, or offer a lecture if the employee had been the target of the sexual overture.



Participants indicated that in most instances episodes of sexual behaviour would then be documented and a larger pool of persons would be informed of the event, for example, the administrator or the family of one or both of those residents involved. In the case of sexual overtures made by residents with dementia that were directed toward staff, the overwhelming response was to forbid it, firmly ending the behaviour with a verbal reprimand. Most participants stated that such sexual displays were embarrassing and difficult, but that they had eventually overcome such discomfort because of evolving life and work experiences.

#### Promotion of Sexual Health

None of the facilities involved in the study had made any provisions to meet the sexual needs of persons with dementia other than to acknowledge that, at times, privacy should be provided so that such persons could either engage in self-pleasuring behaviours or acts of intimacy with a partner to whom they were already married. None of the facilities had purposefully collected written or videotape erotic materials or equipment such as vibrators or dolls for use by their residents. None of the facilities had discussed the use of a paid escort service for their residents except one. This discussion occurred as a result of a recommendation made by an external consultant during an educational session, but the facility did not pursue anything beyond the very brief initial discussion. When the key informants who mentioned this during their individual interviews were

asked why this had not been actively pursued upon the advice of the consultant, they all responded that they did not know why it had not been implemented as an intervention.

## CHAPTER FIVE

*An Ode to Demented Sex*

We caught them, .... Smacking bums and stuff .... One man mauling another lady ... taking advantage. There he goes again. Perpetrator. If he knows nothing else, he knows how to prey ... the problem is he seems to want to make a show of it .... So, you worry and worry, protecting the innocent ones. Victims. You have to be very, very careful.  
Shhhhhhh.

Discount desire, it's like what babies feel, that feeling, that urge, that whatever it is, just so inbred, an animal instinct.

You little Madam you. Perpetual aggressor and victim.  
They don't want no part of their nonsense! They've seen some masturbating and they've freaked out! And when you saw that, it was like, "Oh, dirty. Don't do that. That's dirty." Shhhhhhhhhhhhhhh.

So: Here's the answer: It's nice to pass the buck. But lastly and always, keep them under the mattress! And Dance around the issue. In silence. Alone.  
Shhh!

(Schindel Martin, 2004)

Adam Lay Abounden:

#### A De-construction of Response Patterns to Sexual Behaviours

In essence, the organizational culture created by response patterns of staff and families to the sexual expressions of residents living in LTC facilities was that this must either be deeply buried and hidden from view or subjugated to stringent regulatory supervision. There was fear and discomfort associated with sensuality. The sexual being at the core of the person with dementia was considered base and dangerous. The beauty

and elegance of sexual expression evoked by the imagery and metaphor in Neruda's (1997) poem introducing the previous chapter was far, far removed from the words used to describe sexuality in the LTC experience. As an "Ode to Demented Sex" introducing this chapter illustrates, sexuality was referred to in fairly negative terms using derisive language and slang terminology. The stories of participants that are recorded here illustrate a culture of secrecy, of great discomfort, of staff and families who are in many cases disgusted by touch, kissing, touching and caressing.

Transcripts of the individual interviews and focus groups, archival information, document reviews, and observational field notes were all subjected to thematic content analysis. I approached the data set by first reading all materials through several times. After selecting a sampling of six of the interviews and focus groups, I acquired the assistance of a fellow graduate student who had completed a graduate level qualitative data analysis course who then read the sampling independently. Preliminary data categories were identified as a result of a consensus discussion I held with my colleague. The preliminary categories identified were: a) types of behaviours; b) descriptors used by the participants; c) emotional responses; d) common myths and beliefs; e) variables that impacted upon response; f) management strategies; and g) barriers to compassionate practice. These categories were used to code the data set using the NVivo Revision 1.1 qualitative data analysis software (1999). Further categories were identified and existing categories refined as the data analysis proceeded.

After a discussion with my dissertation committee and much deliberation, I set out to review the categories for emergent themes related to the overall sense of a culture of silence, repression and censorship. The ten emergent thematic categories identified were: a) Sex is Bad; b) The Whisper Zone; c) To Serve and Protect; d) Never the Twain Shall Meet; e) Behind Closed Doors; f) Ignorance is Bliss; g) The Disapproving Family; h) The Unwritten Moral Code; i) The Rule Book; and j) A Few Good (Wo)Men. Each category will be elucidated with illustrative examples.

### Sex Is Bad

One of the goals of this study was to uncover the types of behaviours that participants were likely to witness during their daily work with residents with dementia, and the beliefs, values and feelings the participants held in response. Since the sexual expression of persons with dementia was presented in such a negative light by the original media coverage that inspired this study, it was my intent to explicate all the types of behaviour witnessed, and how the participants within each research setting interpreted these behaviours. I was interested in trying to understand all those behaviours that participants would include in their conversations with me, which might help me work toward pin-pointing those behaviours of low risk that could be differentiated from those sexual behaviours that might represent a true risk. I was curious to discover the degree to which behaviours of a serious nature were described to me. I suspected that sexual

behaviours such as intercourse would be reported rarely, if at all. Despite this rarity of occurrence, it was my observation in clinical practice, that sexual behaviours were often interpreted and managed in a fashion that would suggest that genital contact, specifically sexual intercourse, was highly probable, represented a serious risk, and should be avoided at all costs.

The sexual behaviours described by participants across all three sites covered a broad range of categories. There were five over-riding beliefs and feelings that emerged from the data set about sexual behaviours associated with dementia: a) everything is sex; b) sex is wrong; c) being a personal target is a no-no; d) males are dirty old men, women are victims; and e) self-pleasuring is disgusting.

### Everything is Sex

In all three facilities there were no clearly identified parameters of sexual expression. Consequently, sexual behaviours as defined by the participants covered a broad range of behaviours, some relatively benign or at the very least ambiguous. Behaviours such as hand-holding, cuddling, kissing, touching, masturbating in public, removing clothing, fondling, and intercourse were all considered sexual acts with the same amount of inherent risk by most the participants. There were clearly limits to what would be considered appropriate by the majority of participants. Nothing beyond hand-holding between female residents was universally acceptable, and public displays of

anything between residents of the opposite sex were not considered acceptable by most key informants. In fact, there was disagreement between focus group participants on what was considered acceptable behaviour. Consequently, the beliefs of most participants, including families, was that staff should behave as vigilant protectors of human dignity, with sexual expression to be closely monitored and extinguished.

Sexual behaviours observed between two residents with dementia usually involved relatively benign behaviours such as holding hands, cuddling, and kissing. These behaviours were not universally acceptable or interpreted as benign by key informants. Ambiguous behaviours that involved body contact between two residents were often interpreted to be sexual in nature. Therefore they required some sort of supervision or protective vigilance. The pervasive message evident in each site was that touch itself is dangerous and could possibly progress to something that could get “out-of-control”. Any touch that might actually represent an attempt to offer comfort, could be incorrectly interpreted as a sexual act.

And a lot of times they'll sit on the couch together. And if one is in a ... like a low situation or looking like they've had something wrong, or feeling bad about something, the other will sit there and comfort them, put their arm around them. It doesn't mean really a sexual thing. But some people would look at it like that.

Other observed intimacy behaviours that were identified by participants as having a sexual nature were those that could be interpreted as more intrusive, including genital contact. “They do kiss, they hold, he caresses her breasts.”

Sometimes these were reported with cautious hesitancy, evoking an image of a spider that is slowly trying to get to a secret place that is out of bounds.

I've only dealt with men touching other women .... He has, uh, like, put his hand under her, under her dress .... And try and touch her in the perineum area .... When they're sleeping, he'd go in and touch their breast, or try to put his hands in their panties, panties .... Automatically, I just want to say, like, just scream at him and say "don't do it." I don't, we, (grins and squirms), really, I just think that it's part of his dementia, I really do. I don't feel any negative thoughts towards him.

This participant appeared to have some conflicted feelings about the male resident's behaviour. While her gut emotional response in reaction to his behaviour was extremely negative, she struggled to explain it away or rationalize it as the result of his cognitive impairment. However, her attempt to portray herself as a tolerant practitioner was somewhat unconvincing.

Families described their interpretation of touching behaviours using derogatory language. One daughter described the behaviour of a male resident directed toward a female resident other than her parent, observed while she was visiting. "I guess what I've seen here is the one man mauling another lady. Mauling her, trying to kiss her, you know, touch her."

The use of the term "mauling" would suggest that this particular participant believed that one resident's attempt to kiss and touch another resident constituted an attack. The imagery here suggests that the sexual overtures of the male resident



represented some base sexual urge, rather than painting a portrait of a loving and tender caress.

Many participants described public displays of sexuality using terms that were without joy. This suggests that witnessed episodes of sexual expression involving residents with dementia in the nursing home would not be celebrated as evidence of good quality of life. For example, another daughter described her mother's behaviour in a tone of voice that suggested disapproval and distaste.

And I really don't know why, because she had always [liked men], even when she was at another facility and she was at this point deteriorating, I would walk in, and she'd be walking up the hall, kissy, kissy, kissy, holding some guy's hand. She seemed to always like the guys, gravitate to men.

### Sex is Wrong

From an overall perspective, the response patterns of all three LTC facilities can be described as primitive and emotion-laden. When interviewed individually, participants indicated that when faced with sexual behaviours displayed by the residents in their care, that they responded in ways that they themselves thought best, admitting that these were often based upon their own value and belief systems.

Some staff key informants declared their own personal values and how they impacted upon their practice responses. For example, one participant clearly stated that she would always separate two residents with dementia who were engaging in kissing or

cuddling because she believed this behaviour was disrespectful. She stated, “Well, for me, if they’re, if they’re, if they’re married, but if they’re not married, and they’re not going to stay partners, I feel that’s not right, because of my value.”.

Another focus group discussion explained it this way,

S - ... Some people are just so ... you know, their behaviour or their morals or something are so strong that they can’t help themselves. And if they see that I think that they will probably ...

S - Their personality would step in and they wouldn’t allow it to happen.

S - Yah.

S - I think so.

Key informants acknowledged how upbringing may influence response patterns in the clinical setting. For example,

I mean so many things it could be, it could be their own background, it could be their, it could be their you know, the way they were raised, you know, their religious beliefs, their, um, country of origin, it could be anything like that, like where they come from. I don’t know why some people are like that. Well, I think a lot of it could be you know, from their own personal situations. A lot, you don’t know people, what they, what’s going on in their own lives, cause um, they may come from a situation at home where they uh, you know, they might be in a position where they’re not comfortable either, you see, because some get very, very upset.

Another stated,

I think the whole thing for me is the whole sexuality thing. It’s not something we’ve been brought up to think about, sexuality in the elderly. Like as kids growing up you couldn’t ever think of your parents doing that kind of thing, you know, so it’s always been kind of a taboo thing. My father was a minister, so we were pretty square in the do’s and don’ts and for that reason, sexuality wasn’t an

open topic in the house, because it wasn't, and that's the way it was .... I think in that, I'm maybe not as open minded as I could be, possibly.

Another participant, a senior manager in a facility, stated,

I think some people have belief systems, that are sort of, and they come from a different culture, they may also have a different level of education, and they have not, and they are not used to overt, uh, sexual behaviour, and they're too uptight. And, uh, and so they see it as wrong, they're interpretation of it is that it's wrong. And they want to medicalize it, or they want it to stop, they want it to go away.

Some behaviours were looked at in a more positive light, like a benign flirtation that could be overlooked and wouldn't be interpreted as offensive. However, the language that one participant used to describe the resident's behaviour was somewhat derogatory and parentalistic.

We have a male RN that worked here for a while, and one little lady we kept losing off the program, every time he was around, and he kept bringing her back. And I finally said, I finally looked and said, you little madam you, and she says, "In know, I just like walking behind him and watching his butt (giggles)", And I just looked at her and said, "well, there's stuff on fire in there!", and she said, "Oh, yeah!!".

By using descriptors like "little lady" and "little madam", the participant places the sexual behaviour of the female resident within the context of both childishness and wanton abandon. Seeking out opportunities such as watching a male from behind is relegated to something that should be made fun of and belittled.

## Being a Personal Target is a No-No

Sexual behaviour directed toward staff involved both verbal and physical advances, something that they were invariably uncomfortable with. Verbal advances included residents uttering graphic sexual stories or propositions to staff. Many of the practice responses were predicated on their need as staff to shield themselves from something that resulted in discomfort, to restore order, and to protect their own wounded sensibilities. For example, one participant stated during a focus group that a resident in her care often bragged about the size of her husband's penis and suggested that the staff person would enjoy measuring it. Another participant stated, "He would say stuff like, uh, "You know what you need, and you know that I could, like really have good sex with you." And he would say stuff like. "You know, you really want it." And,

This one fella said, uh, to the nurse the other day, he said, uh, he said, well, what are you going to do, and she said, well, I'm going to help you get washed and we'll wash your bottom, and he says, "Oh, can I wash yours?"

And,

Just about wanting to see the staff naked, or I don't know .... talking about the young hotties, and that type of thing. You know, going into various details, graphic details about you know, when they were young, their sexual exploits .... which I do not need to hear about in detail for extended periods of time.

Physical advances described by staff included grabbing and touching.

Like if I am washing him in bed and I'm washing his face and I turn around and you speak to him and, and he understands you, and I say, "Okay, roll over and let me wash", and whatever, and as I'm washing he might have a tendency where he may grab my arm, or he's, if I'm putting socks on he's rubbing my back. ... And

then he just kind of moans and groans, or .... he laughs because he knows he's being washed, he's being touched.

And,

I have a female resident, (laughs) .... Hooooo (laughs), you know what I mean (laughs), and she, um, she's veeerrrryy sexual, like extremely sexual, she definitely has that need. She's 94 years old, um, and ah, she, .... (begins to speak very quickly here) I was doing exercises the other day, had my hands up in the air, and she went like that to my breast (cups her own breast).

And, "He grabs breasts, he grabs any part of your anatomy that he can get his hands on".

In addition, racial slurs might be tied into the sexual expressions of residents with dementia that were directed toward staff. This was described as being very upsetting. It was suggested by one key informant that the ethnic background of staff was a variable that may put them in a greater position of receiving sexual advances of innuendo from residents. Front-line workers of colour were perceived to be the target of sexual overtures from male residents. As one participant stated,

I would say that with one fella the front-line staff don't handle him well. It's taken a lot of work over many years to try to manage him. He is aggressively sexually mouthy. It's just plain abusive, sexually. It's scary. And it's racially motivated. If they have a black voice, or even, an accent of the South, Jamaica or India, so he's more of a racist than anything.

Overall, staff described these experiences as very distasteful, upsetting, discomfoting and to be avoided. Staff response would be to ignore the behaviours and pretend they hadn't happened, or strictly and punitively forbid the behaviour to continue.

## Males are Dirty Old Men, Women are Innocent Victims

Episodes of sexual behaviour were more likely to be portrayed in a negative light when they involved male residents than if they involved female residents. In general, female residents were portrayed as victims who were sexually exploited by male residents. In addition, participants from each of the three facilities all tended to make statements that reinforced the gender biases implicit in the newspaper reports of the original case that triggered this study. Most participants believed that male residents with dementia were most likely to be the instigators of sexual behaviours, and that female residents were vulnerable to their unwanted advances, and therefore, required protection.

As one focus group discussion indicated,

S - Because it was usually the women who felt intimidated from the males that were ...

S - And men only want one thing (laughing) ...

Another participant shared this observation:

But I've found some staff frown more on males than on females. I think maybe because they're female themselves .... and for them to see um, an old man doing things like that, that that's totally gross, that's awful, why is he even doing that. If it's a lady or a female, they're females themselves, you know, they don't think nothing of it, because they know themselves, well, you know, it's common, we do it ourselves, or, whatever, but they don't frown on that.

The double standard evident in this account is reflected in the descriptions given by family members. Family participants also noted a difference in the viewpoints between men and women. One participant in particular noted that her opinion of her

mother's relationship was different than that of her brother's, explaining it based on gender.

My brother and I both have attorney over her health, and he used to just laugh and say, oh, you know, let them be, you know. But, then that's a man's point of view, and I think it's different than a woman's.

Key informants acknowledged that intimacy behaviours between women were viewed within the context of platonic friendship, mothering, nurturing or comfort behaviours. In direct contrast, if a man and woman were engaging in similar behaviours, typically the interpretation was sexual. As one participant stated,

I guess when we see women walking up and down the hallway holding hands, then we see that as okay, .... but when a man and a woman are walking up and down the hallway holding hands, um, or even linked arm and arm, we sort of ... ooooouuuuuuwww .... when a man's involved in it, whether it's with a woman or with a man, then yeah, um .... always sexual thoughts jump into it.

Relationships between women appeared to be considered acceptable, perhaps because the perceived level of risk associated with this type of relationship may have been considered to be negligible. There were two implied references to intimate relationships developing between female residents, but no specific references to relationships between male residents. The references to lesbian relationships were referred to only fleetingly, with participants suggesting that while they themselves had no difficulty with this, they imagined that their colleagues would find this challenging. One participant identified how her cultural background impacted upon her accepting views of relationships of the same sex. She stated,

No matter what colour we are, old, young, male/female, you go with female to female, or whatever, it doesn't bother me, it doesn't bother me at all. I mean, maybe some others it bothers them, but, no .... It's normal in our country, I mean, there's a lot of them. So, it's kind of normal to me. Because the way I see it, hey, it's yourself, whatever you're happy with, go for it. You know, you only live once, enjoy it, but not to the point that somebody's going to get hurt, or, then I will not leave it.

Of special note is that the participant still had to qualify the reference to relationships between residents of the same gender by saying that she would still ensure that they were safe. Risk seems to be associated with potential exploitation around intercourse and penile penetration. As one participant stated,

S - In fact we have a couple like that, right? Two women, no problem, and they are touching, they are kissing, they are um, and the staff really have no problem with it. There have been a few comments made, but nothing, and again, I think it's come down to potential exploitation, by a male.

I - This whole issue of the act of penetration business?

S - That's it.

I - And so they may not be as alarmed about two women, because they know that's not going to happen?

S - That's right.

It is significant to note that sexual relationships between men were not mentioned in any of the individual interviews or focus groups. Heterosexual men with dementia who make sexual overtures toward women are viewed as predators. Within the context of the organizations participating in this study, homosexual relationships don't even exist. Given that the resident population under investigation in this study were persons



with dementia who are represent a broad cross-section of the general population, this seems highly unlikely. Presumably there have been relationships between homosexual men in these LTC facilities. It may be possible that this type of relationship is unspeakable because it would represent significant risk because the possibility of penile penetration and this is an issue of great discomfort for many clinicians.

Front-line staff included male visitors in with those who should be carefully watched. This was the case despite the fact that the male visitor might be married to the resident who was the object of affection. Several participants described the sexual behaviours they observed between a male spouse and his wife.

There on the first floor we have a husband and wife, the husband visits daily. And, um, they do, have problems and the problem is not that he's um, that he's sexually, that he goes beyond kissing, um, but the problem isn't that he does it, the problem is that he seems to want to make a show of it to the staff. I mean, he will, he will, take off her diaper and stimulate her with his tongue and that sort of thing.

A focus group participant described how the general organizational viewpoint of the sexual activity between the same married couple was very negative.

We had this case of a husband and wife that was there, and he was kissing his wife, and half the staff were just crazy, he was a dirty old man, and this should be put to a stop, and this was brought up in a conference, and the staff and it started up, it was disgusting. And some people said, well, how do you know she didn't want him kissing her anymore. And I said, but they were married all those years. But it's not like he's doing something harmful to her, all we did was pull the curtains around to give some privacy, because sometimes he wouldn't do that, but that's what we do. But there was staff, it was disgusting, and this should not be allowed.

There was a single report of a participant who had observed a male visitor touching another resident in a manner considered inappropriate.

I had about eighteen months ago or so I had a bad experience on our unit when a visitor came in. And I saw him touching one of our ladies. And I tell ya, I was mortified .... We had the police and everything here and whatever. I was just mortified. And he denied everything. And I caught him. I thought, “You know what? Just get out of my face!!!” I was so upset. How do you deal with stuff like that?! Like, that’s something unspeakable.

In addition there was a single report of a male visitor making sexual advances toward staff.

Well, we had a resident whose wife was living here, who he was living in the retirement home, and he was taking a shine to the nurses in here, and he’s not really a resident but it was this situation where the husband of the resident, I mean he was close to dementia too, you know, but .... He was busy with chasing the pretty nurses, and would try to touch them and stuff like that. Not really bad, but just, uh, it was, alert.

That this participant described the situation as “not *really* bad” was telling. In essence, this account reinforces the organizational mind set that most incidents of sexual expression in these LTC settings were, in fact, considered “bad”.

### Self-pleasuring is Disgusting

Participants also reported observing residents engaging in self-pleasuring behaviours, portraying this behaviour as child-like and self-injurious.

Because look at little kids, three and four years old, they’ve got their fingers down their pants, and things like that. And they do that. I’ve seen some residents do that. I’ve seen some residents, when in the bathroom, they’re fondling

themselves, or you know, that kind of stuff .... We've had some residents in the past where they've used their cane, as a, as a device, like [one of my] female residents, she used, the end of a brush, those kind of things, we've had to remove them, because of, injury .... And lots of times she would have her hands in her pants.

And, "He'd come out. Without his pants, and fondling himself, and ....". And,

Well, I did have a lady with dementia and Down's who was admitted and she would not keep her clothes on, absolutely refused to keep her clothes on. She was masturbating, she was walking into places, she was all over the place stark naked, sitting on the floor masturbating.

Again, most incidents of self-pleasuring behaviours were reported in a tone of voice and language that would suggest something distasteful and base, something that staff would prefer not to witness.

While hand holding and kissing might be considered relatively acceptable under certain terms and conditions, other sexual behaviours were not. For example, self-stimulation was a behaviour that caused some degree of upset in the clinical setting.

I work with people who have seen someone masturbating and they're freaked out, and they're not, "just take that person and take them to their room". Um, and I've also worked with people who have walked into a room and saw someone masturbating and freaked out, and I've said, that's a private thing and you just walked into his room and so that's none of your business.

Overall, the responses of participants would suggest that sexual behaviours associated with dementia are dark, unmentionable behaviours that should be controlled, tamed, extinguished. These are portrayed as unwanted advances, creating an image of deviant behaviour to be acted upon (i.e., to be eliminated, or at the very least ignored).

The language typically used to describe behaviours suggest distaste, the behaviours are dark secrets, things to be hidden, things that should remain unseen, and unspoken.

### The Whisper Zone

A pervasive characteristic of the research sites was that sexuality and sexual behaviour was something unspeakable. This put professional practice into the “whisper zone” - people quietly discussing an issue, but never bringing it out into the open, relegating management options into a realm of secrecy and silence. Practice patterns were informal and inconsistent at best. Most participants stated that incidents of sexual behaviour were addressed informally amongst colleagues. As one participant explained,

We really don't have a team when it comes to [sexual behaviour]. We basically just talk amongst ourselves in the staff room, or, during our break, or as we're working, working with a particular girl, and you know, we talk amongst ourselves.

Another participant stated,

We've never sat down with a big [meeting] about how to handle residents like this. It's kind of the two girls that I work with, when we're getting report, I mean, we will kind of have sessions, where we say “Oh, my God, such and such, done this a couple days ago, like, how do you deal with it.” And they just sit around the table, like they were getting report here this evening, and we'll just kind of talk things back and forth .... Because it just kind of cleans the air a bit too. Gets your frustrations out, you know. And sometimes “A” will say, “Well, I don't this, or I say this, and he kind of backed off”, right? So, we kind of get feed off from each other like that. But, things have kind of a way of not being discussed teamly. We'll take it to the administrator or D of C and they make the final decision.

Overall, the informal talk seems to be the major way that staff members support each other. This gives the impression that this admittedly difficult topic is not open for discussion within the context of team. This lends itself to the picture of an organizational culture that leaves staff alone with the burden of this type of care. For front-line staff the state of affairs is that it is largely not discussed. As one participant stated,

But, I find that a lot of the seniors health care aides, it's like they deal with it everyday and a lot of times, it's never brought to me, and it's just, they're handling it, but then, it's like we're not documenting on it and it's not an issue, but it is an issue, but it's kind of, a "not said" issue.

One participant believed that it would be difficult to get all staff reading off the same page because views would be so disparate. She stated,

People's personalities will come into play with that, if you're conservative yourself, you're not going to want to talk about this, if you're, if you're shy yourself, you're not going, you know there's all these things that would be a barrier to, and I find that it's not something that people are open about, like oh, by the way, here's our policy about sex, you know (laughter) .... I mean, we'll never get to that point. If we had a liberal policy, we would never have everyone here thinking that that was a good idea. Ever.

Overall the sense is that cases that involve sexual behaviour were handled informally and out of the context of a team approach. This is unfortunate, because in the case of the older family member who while visiting his wife was reported to engage in sexual acts with her, the viewpoint of staff members was inconsistent. Some staff members were tolerant, others were revolted. Despite knowing the variation of staff opinion in this matter, the organization had not set about to encourage dialogue either

between staff or involving families about the case. Therefore, there was no forum in which to hammer out a consistent practice response. As the administrator involved in this particular case stated,

We haven't had a team meeting. A lot of times, the way that we operate is that we do a lot of things informally. Um, so we certainly have talked, so maybe we have stood around the med cart, and talked with people, you know, what do you think's going on, what should we do, or, you know, that type of thing, but as far as sitting down with him, with her, you know, his children or anything like that, we have not done that.

While most cases of sexual disinhibition were handled individually, more extreme cases might involve sitting down as a group and having a discussion about how to proceed. One front-line manager indicated that a group discussion could be helpful.

If it was something that is maybe escalating or continuing on, becoming more of an issue, then she [the senior manager] would either call myself, or we would maybe sit down as a team and look at, okay, what else are we doing, what are we missing, is there something else going on, are there some other physical issues that are going on .... We always try to go in with any difficult, not difficult, but any unusual situation or anything that's a little different with a team approach, rather than just one person going in and being very, you know, but working like that can easily help talking as a team.

It was interesting to discover the circumstances under which team discussion would be used to develop a care plan to respond to sexual behaviour. A team approach to management of sexual behaviour was more likely to happen if there was a situation that involved disagreement between the formal care providers and the family. This would suggest that open dialogue would not happen except in cases of great adversity.

Dialogue then became a necessity. As one staff participant stated,

It's just because the family doesn't want it that way, so we kind of sat down and the whole team, that was a few years back, so the whole team agrees to this, and then after awhile the family agrees with us. So, it all depends on the family and the team, the whole team, like we sat down and you know, we decide what's best and type of thing like that.

Sometimes formal meetings would be used to reinforce a practice response that might not necessarily be supported by the resident's family. As one participant described,

We had a lady admitted a couple of years ago, and she, unbeknownst to her family, had a gentleman friend who used to visit her. And, that was, and she was living in her own home, and no one could surprise them. However, when she was admitted to our place, her gentleman friend still came to visit, and everything was fine, except her daughter walked in on them (laughs), .... and she was shocked, her daughter was shocked, and the staff had no problem, in fact, we had a meeting, and the daughter was just horrified, however, with several meetings with the resident's council, we decided that the residents should place a "Do Not Disturb" sign on the outside of the door when the gentleman friend was visiting.

Overall, open dialogue was not encouraged, but would be utilized as a last resort in certain cases where there might be disagreement between the clinical team and/or family members. Open dialogue within the context of formal planning and education meetings was not part of the normal everyday approach to sexual expression associated with dementia. Despite this lack of open dialogue, however, most participants clearly understood that the unwritten rule was that they were obligated to keep their residents "safe".

## To Serve and Protect

The theme of protection was also a pervasive characteristic of the overriding culture of silence, driving practice responses and resulting in conservatism. Frequently individual participants contradicted themselves, initially stating as the interview began that they considered themselves liberal minded and viewed sexual expression in their residents with dementia positively. However, as each interview progressed, it became more apparent that in the unique practice world of their units that typical practice was very conservative. My hunch regarding the self-reported liberals, was that faced with incidents in the real clinical realm, they would err on the side of caution and be protectionist and cautious. I had a hard time believing they would behave in a more tolerant fashion. Most participants also believed that their work colleagues also had difficulty with this area of practice and there was no agreement about how to respond.

Overall, key informants believed that they were in a special position to protect their residents from what they perceived to be unwanted sexual advances. This was often in the context of female professional care providers protecting their vulnerable, demented female residents from the unwanted predatorial advances of demented, dangerous men. Protectionism was evident in six themes. Protectionism was directly linked to behaviours associated with residents: a) surveillance, b) forbidding, c) reporting, and d) documenting. Protectionism was also related to staff, in that the culture supported that they should be protecting themselves as well. This included e) pairing and f) reassigning.



All these protectionist behaviours reinforce the cultural belief system that portrays sexuality as negative and dangerous.

Overall, participants indicated that many members of the clinical team would bring their own values and belief systems to their direct clinical practice, and that the majority of clinical staff operated from a protectionist, risk-averse viewpoint. Values and beliefs seem to be tied up with a need to protect. As one participant stated, “We can’t get around our own parents sexuality let alone somebody we are looking after. And we also want to protect our residents. The staff feel that they need to protect them.”.

### Surveillance

There seemed to be an over-riding need to survey the landscape for evidence of sexual behaviour, so that any sexual behaviour that required action could be identified. The protectionist culture drove staff members to behave for all intents and purposes as “spies”. For example, “So we just walk around and make sure .... peek in a little bit. Don’t let them see you doing it. Peek in a bit, take a look.”. And, “We’d just have to watch, watch them closely and make sure it doesn’t get to the next level, I mean, if it’s kissing and holding hands or just keeping each other company.”.

One participant explained that it was critical to maintain surveillance even if both residents appeared to be consenting to a sexual encounter.

Just keep an eye to make sure that they are safe, you know, because maybe half way one of them would say well, no, and be needing help, or halfway, you know, just keep an eye on what's going on, well, not really, see what they are doing, but kind of making sure that they are safe or something like that .... I would just sort of do my regular routine, I would not stay behind the door, but, I would just go, kind of walk around and keep my ears or keep my eye on what's going on, because you can still hear what's going on or whatever, or, once in a while, you can peek inside, and .... I know it's not right to peek but, for their own safety.

Sometimes surveillance would mean assigning a one-on-one supervisor to ensure that the resident in question would have no opportunity to engage in behaviour toward another resident. For example,

If it required a one-on-one we would initiate that right away. Like if it was something that, someone, like if it was maybe that fella that was going around looking at all the ladies or whatever, then we would maybe put one-on-one with him until we could get PMAC [psychiatric consultation] in.

Staff participants felt some pressure that surveillance was also an expectation from a family perspective. As one participant stated,

... We would end up getting the brunt of it from the family members. Like, "Can't you keep them away from each other?" "Can't you move him into another floor?". Things like that, eh? And like you try to explain to them that you do the best you can. But you can't be there every five minutes, keeping an eye on their family member.

Surveillance also included observing for specific signs and symptoms that would require intervention, therefore, staff were always watching from a distance for evidence that no person involved was being exploited. Key informants identified that the relationship would only be allowed to continue if both residents appeared to be willing participants. As one key informant described,

If both of them are willing, then, and it's in the right place, then I would say, nobody's refusing anything, then, I would say, it's fine, and that's alright with me ... they are both willing to do it, then, .... I'm okay with that.

Willingness was inferred by the absence of typical behaviours that would indicate refusal. Staff indicated that they would be vigilant observers in order to determine if any behaviours that would indicate rejection were present. In that case they would step in and end the episode. As key informants involved in a focus group discussion explained,

S - See, you often know the signs of don't touch me, don't look at me, and we have on a regular basis and we intervene. But if they're sitting there holding hands, it's neither one of them is saying no to it, there's nothing wrong with it.

S - If they're crying or whimpering, sure you separate.

S - Any signs of distress.

S - Or even if they're just sitting there and doing nothing, they're not responding in any way. I would take that as they're not interested.

S - Really?

S - Well, they're not touching back, they're just sitting there, just sat there, I would intervene, because they're not saying anything, but they're not responding, so I take that as a no.

The landscape was also surveyed for evidence that an intimacy or sexual behaviour represented a significant risk to the residents involved, the staff person, or the organization itself. My general sense was that most staff did not discuss their feelings about the sexual behaviours they encountered unless they believed there was an element of significant risk of either physical or psychological trauma to the residents in their care.

Thus, most discussions centered on those behaviours that were considered pathological. If the behaviour was perceived to be of extreme risk, then staff members were more likely to identify it as something requiring action. These reports included the front-line staff members' sense of powerlessness. As one key informant explained,

I don't know if that's crazy or what, but when I looked at him, he, he used to make me like, really uncomfortable, cause it was just like his power over me, he was, and I just knew I had no control. Once he was in that mode there was no controlling him, and it's not that you want this control yourself, it's just that I felt so powerless.

The level of risk assigned to a particular sexual behaviour also had to do with the extent or degree of invasiveness of a particular act. Cuddling and kissing were described as a low level of risk. Ultimately the level assigned with this benign behaviour had to do with the chance that an unknowing family member may come across such a display and react with shock and dismay. Higher risk was associated with behaviours that involved removal of clothing or exposure and touching of the genitals, particularly in public. Sexual expression under the cover of darkness, meaning during a night shift were also likely to be assigned a higher level of risk and be responded to with alarm by staff who witnessed such behaviour. As one participant, a senior manager of a facility stated,

I think a lot depends upon the extent of that touching, um. It appears that simple hand holding and sitting together doesn't seem to upset anyone. However, if it goes beyond that, then people see it as a problem, and act, try to medicalize it.

The need for and level of surveillance also depended upon the overall health, medical status and ambulatory capabilities of the resident. This related to their capacity

to invoke harm. The more ambulatory a male resident was, the more likely he was to be assigned the label of predator. If a resident were medically ill and non-mobile, the less likely that any sexual behaviour would be perceived as a risk. In this instance, the staff could relax their vigilance and surveillance could be withdrawn. Response tended to be less urgent. However, those who worked evening and night shifts stated that their discomfort with sexual behaviours rose exponentially when staff-to-resident ratios were higher. This appeared to be related to lack of ability to supervise with any reasonable frequency. As one participant stated,

It's more ambulatory residents that would walk around. And this resident, he's in a wheelchair and so it's very hard for him to, to move around and to get around, but, before we had other residents that were ambulatory that used to walk around and they were, they were the ones that um, were harder to, to watch because, you know, you can be at one end of the room doing one resident, and sometimes you might not see, what's going to happen at the other end of the hallway, at the other end of the room so you kinda have to have eyes in the back of your head.

Residents with severe limitations to mobility were sometimes thought to be in a medical state where the fear of vaginal penetration was virtually eliminated. If that were the case, staff virtually discounted this type of resident as a risk.

I don't know if it's the fact that he's in a wheelchair, this guy we have now, and I know physically he can't get in that position, that he probably wants, and I've never seen him with an erection, and none of the health care aides have ever told me that they've, he's had an erection, or if he has they probably don't care or anything, so that kind of makes me look at it differently.

Another key informant explained, “He has been so unwell in the last few months, he isn’t really able anymore. We don’t really know what’s wrong. So, it seems that these problems do go away. But, you worry and worry.”.

Surveillance was also necessary in order to protect the vulnerable, severely regressed residents from sexual exploitation. Key informants also indicated that the level of cognition or disease regression had to be fairly similar in order for them to feel comfortable with a developing relationship. If one of the residents was at a much earlier stage of the disease process, then staff members were more likely to intervene because the possibility of sexual exploitation was higher. As one informant explained,

Well, there has been somebody, that um, they’re not, what’s the word I’m looking for, they’re not a vegetable, but they are just laying in the bed and they can’t answer or respond, and sometimes there’s a physical reason why they couldn’t object, no, either in a verbal or you know, they’re physically not able to get in touch with us. That would be a difference, a different story.

And,

But if it’s a resident who has no clue what is going, what the other resident wants from them, and can’t imply consent, that’s when I would redirect the situation to be, to .... something else, because if they can’t give consent, then I don’t consider that consent. And, but if they don’t know what’s going on, then that’s when I would say, okay, they can’t do anything this cannot follow on.

Yet another explained,

When it is so apparent, you have a person with two different levels if you want. One can be dementia where you can still be pretty active, bouncing around pretty good, if the other person has really been deployed as defenceless then I, I think it’s appropriate to stop it ....

Because, what I'm saying is, I'm saying this person is defenceless. So, I'm going to protect you, but it's because I believe that that person couldn't show yes or no.

The need for surveillance also relates to staff perception that they must protect the public from sexual advances, and even protect the resident from his own past history.

This protectionist act seems warranted given the circumstances of exploitation. As a senior manager in one facility stated,

But this person involved actually, um, was making advances, and he had kids coming to visit him and so we had to have that stopped, because he was advancing to kids. Which was pretty difficult when it involved children. He was arrested in the past for this. But I never put it on his chart, it was only on a form in my office. So that he was not labelled. He would say, "oh, yeah," to the kids, "I have a quarter in my pocket," and make them go in and find it.

Administrators are more inclined to operate from the perspective or risk management in terms of protecting the organization from bad publicity. As another administrator stated,

Things start to get at the risk management end of things, and all of a sudden you start seeing headlines, in your mind, and in the papers of stuff and the families hear about this and stuff, and uh, um, you didn't have any discussion with the family nor did you intervene and going to the paper and that's been a problem before, and that's I think a big fear that I think a lot of us have.

This example would suggest that risk aversion and the need to protect the organization from negative media coverage contributes to the practice of surveillance.

The need for surveillance was related to the presence of other disinhibited behaviours. If the resident's behavioural profile included physically catastrophic behaviours in addition to sexual disinhibition, the resident's behaviour was almost

always portrayed in a negative light and the surveillance level was high. This type of resident was almost invariably transferred out of the facility because all behaviours were considered to be unacceptable. As one key informant explained,

So at that time of course, the best way the administrator dealt with it, was to ship him out. We couldn't deal with him. He was physically aggressive also. ... It was the amount of physical aggression too. Like, he'd pull fire extinguishers off the wall, throw them at the doors, he'd barricaded like, girls into the rooms, staff members. And, he was a young, 65 year old man, with a history of alcohol abuse. He was very aggressive.

Overall, the organizational culture of all three sites that participated in this study perpetuated the viewpoint that the essential practice belief is to protect the residents by providing supervision to ensure that residents would be kept "safe". For the most part, the over-arching belief was that sexual behaviour represents potential harm, not only to the residents and the families involved, but to the organization itself, therefore surveillance is a necessary behaviour.

### Forbidding

It was clear that for the most part, certain behaviours, particularly public masturbation, were considered so highly unacceptable as to be forbidden. The protectionist culture creates staff that behaved as "censors". As one participant in a focus group stated,



You get a great big hammer .... You take them away and you put them in their own room, and telling them that they're not allowed .... We have one that you supervise, we take him into his room, and then he can play with himself [there].

Participants in all three facilities were highly likely to register strong objection for sexual behaviours directed toward them personally. The response brought to mind a personal emotional reaction, not a professional one. One participant of a focus group stated,

If that certain person touched me or tried to grab my leg, I would turn to the resident and say, "No, I do not like that," and of course, I would report it to the charge nurse, for me when I was in a situation like that, you have to make sure, and take that resident and bring him to the side and just sit down with him and say, "you know, this is not right. You know, you can't do this. No one likes to be touched".

While most staff participants stated that they tried to be professional about their response, none-the-less, descriptions of their dialogue sounded punitive in nature. For example,

I will not snap at them, but I will tell them off, like, "keep your hands to yourself!", or "That's not the right thing to do", and "that's not very nice", type of thing, explain it to them in a nice way, in a way that they will understand that I am not happy with what they did.

Family members also described the behaviours of staff in response to witnessed sexual overtures made toward them.

I think it was that same fella, yes it was, who touched the rear end of the nurse, and uh, she just turned, and I didn't actually see him do it, I just heard, turned around and heard, and she sort of slapped his hand a little bit, and she said, "Don't you do that, you've been told not to do that!".

A third family member stated,

I've seen it, I've seen it, but they (staff), I've also seen them (residents) put in their place in a hurry .... And there's one of them (resident) has a habit of, reaching up, and taking hold of the nurse's shoulder and what have you, and they're soon put in their place.

Family members were also inclined to forbid relationships of a sexual nature from developing between residents with dementia. As one daughter stated,

Once he asked to go, if he could take her into her room, the staff asked me could they go in her room, and I said, definitely not, because mother was starting to go at the time, and I don't know if he carried it any farther, would mother have known to stop it, or would she have just gotten upset, I didn't know that, so I didn't want it to go any farther.

Another family member described how her brother intervened to end a relationship between their mother and a gentleman caller. Their mother was beginning to experience significant problems as a result of a dementia and moved into a LTC facility. The gentleman caller also had an early stage dementia but was still living in the community and it was his habit to visit on a regular basis. Both children persisted in their desire to see the relationship end, despite the protests of their mother. The language used to describe the situation would suggest that the family members assumed they had the right to intervene on their mother's behalf because they believed her to be incapable, so they could disregard her personal feelings. Their response implied that they believed that the sexual relationship would represent potential danger to their mother, which they must protect her from.

And my brother was fit to be tied. And he called him up and told him, “My mother does not know what’s going on, get lost”, kind of thing. I remember that very clearly. But, but, but, that bothered my mom .... She told somebody. That, that, and that same sort of thing, “What right do you have to tell me, if I want to do this”, but we are so very much out to try to protect her, and, and, and, what the heck is this guy up to, you know, because my mom doesn’t know really what’s going on.

On occasion, forbidding behaviours were reported to include lecturing or bringing in the “big guns” to reason with the resident. This might involve bringing the family in, or a physician, or in one instance the seniors police constable, this done despite the fact that most participants reported that they believed that police have no role to play in these situations. For example,

I can think of one resident who was told outright. His behaviour, by the doctor, because we needed a strong male figure, that his behaviour was unacceptable, and it was discomfoting to many of the nurses. And, he did tone that down for a while.

And,

We report it to the charge nurse, then if the charge nurse with the Director of Care, the head nurse, usually together, and let the family know, and usually the son will come in and he’ll sit down and he’ll talk to his dad and explain to him, “You know, you can’t do that, these ladies have their rights”.

## Reporting

The protectionist culture results in a behavioural response that evokes an image of staff behaving as “informants”. Punishment of the resident will result in many cases.

Reporting was seen as an avenue to controlling the situation and absolving themselves of

any responsibility. Once an informant had delivered the message, the management team would now have the responsibility of any unpleasant task such as notifying families. As one participant stated,

Well, that's their decision how far this goes. Because they either talk to the family who want to press charges or whatever, you know, I think it's up to the management to make that decision, what's going to happen. Your job is to document what you saw, chart appropriately, notify, whatever, notify management, and you know that is THEIR JOB (laughs). They get the big job (laughs).

In other words, the management component of sexual behaviour is a distasteful, difficult task to be avoided if at all possible.

Reporting also included giving an account to the family, again with view to controlling the situation with the hope that the behaviour would cease, at least for a time.

As one participant of a focus group stated,

I would close the door and definitely report it, and go the charge nurse, and of course the family have to know, and maybe one of the family members could come in and maybe sit down, even though he might not be able to understand, explain to them, "This, this is, that opposite person, says no, or screams or hollers, that means she doesn't like that done".

Participants all voiced uncertainty about when an incident required reporting to either senior management or families. This reluctance to inform families was often related to discomfort around the topic. As one focus group participant stated, "But, "Oh, by the way. So-and-so is touching your mother's breasts." No, we don't. You know (chuckles). You don't necessarily ....".

A reporting chain appears to exist. Front-line staff reported sexual behaviour to their front-line manager, who reported to the Director of Resident Care, who reported to the administrator, who had an obligation to report to the Ministry of Health/Long Term Care (MOH/LTC), under the “Unusual Occurrence” clause in the Long Term Care Facility Program Manual (Ontario Ministry of Health/Long Term Care [MOH/LTC], 1993, amended 1995). This is somewhat ironic, because, indeed, sexual expression is to a certain extent viewed as “unusual”. However, in the context of the act it has a negative connotation. The chain of command was illustrated by the following descriptions, “So I just walked by, and I called the charge nurse and she came, and, and, of course, the administrator followed, because I guess she called her, and I explained what I had seen.”. And, “It goes from the observer to your team leader, and everything is dealt with by the director of care.”.

The bottom line, however, is that staff response patterns to sexual displays involving persons with dementia were highly influenced by staff perceptions of the position of management. The senior management team therefore had a high degree of influence over how sexual behaviour was interpreted and managed in the organization. As one focus group participant stated, “I’d probably just follow the direction of the Director of Nursing. She’d be the one that would say whether she thought that it was okay or not, like for everyone to accept. And if she could, we’ll accept it.”.

For the most part, reporting the incident was a primary response strategy. Creative, innovative or person-centred approaches were generally absent from any discussion about care planning initiatives. For example, “It’s part of the care plan, let the Director of Care know.”.

These images reinforce the sense that when it comes to sexual behaviours associated with dementia there was an overall culture of silence. One envisions people coming in sequence to “witness” the event for themselves. The participant accounts that portray reporting strategies lack images of team members talking about a situation together so that management techniques could be discovered through collegial dialogue.

A subtheme of reporting behaviours related to notification of the authorities, specifically the police. While prosecution was perceived to be highly unlikely, police contact was pursued in some cases. As the interviews progressed, I became very interested in what participants were saying about the role they thought the police should play when a resident with dementia made sexual overtures toward another resident. In the initial case that was reported in the newspaper, the police were involved. For the most part it seemed that only those situations that involved clear exploitation from non-demented family members should involve the police. As one staff participant stated, “If you’ve got a family member who comes in and visits Mr. “A”, and you find him up the hall molesting Mrs. “C”, then, you know, that’s uh, that’s a situation for the police.”.

Although protectionist and conservative in other areas of sexual expression, it would appear that there was a consistent message amongst participants, including families, that the police only have a role to play in cases that involve clear sexual abuse, such as a visitor molesting a resident, or if there was severe injury. As one family participant stated, "I can't see involving the police. Unless there was any violence in it. You know that would be different, there you would have to."

Another family member stated, "The only reason the police should be called in a place like this is if somebody really starting cutting up, and bothering other patients. Then they should be called to straighten them up, but other than that no."

A staff participant explained that it would not be advisable to involve the police.

I mean, demented people, you're gonna, you're gonna arrest someone for doing something in this state!?? Ahhh, I could see somebody that's really on the rampage and really being aggressive sexually, I guess, and you just can't calm them down, using something like Emergency Psychiatric Services at the hospital, but no, what!!! The police, .... I mean, I could see elderly conservative families thinking the police should be involved because someone has made a mistake and somebody has been in a room where they should not have been, or worse, but everyone's demented and to me they can't be held accountable, not by the police that's for sure.

One of the senior managers who participated stated,

To me the police should be involved when .... and if, there is .... injury, and outright, .... ah, .... and that is only to, only for the purpose of, .... really to document I suppose, I don't know why, because the police, the police can't take these people to, into the justice system, into imprisonment, because they do not know what they're doing .... They can't just put these, put these kind of, put these people in jails and so forth or incarcerate them, because these behaviours relate to dementia, and we have to find ways of dealing with them. They're not criminals.

To me criminality is an intent, and it's a deliberate intent, but these people are not capable of that.

A second senior manager explained it this way,

I think if someone is demented, um, they're disinhibited, their ability to understand, or understand the consequences of their action is diminished, and I don't see the role, the police is punitive, I don't see the role for that. It certainly would, I think that person might act out more aggressively sexually, toward another resident, it might worsen their dementia, or develop an acute delirium on top of that, I don't see any role for the police involvement in it at all.

Some senior managers who were interviewed stated that if a family were to ask for the police to be called so that charges could be laid in the instance of sexual behaviours between residents that they would counsel families not to do this. As one manager explained,

If you take the example of the gentleman who maybe went around to different women and then was encountered in bed with another female resident and there was some discrepancy from staff as to whether or not intercourse had taken place, or whether the female resident was resisting, or if something, um, you know .... and that's where the concern starts to come up as to whether or not the police need to be involved. And I think in most occasions too, if the families are notified, about the incident, and the family are explained it to them, and that you have a resident who is cognitively impaired as well, and you have some discussions about whether or not they want the police to be involved, nine times out of ten, they will say no, so we're not going to involve the police.

Most participants felt reporting should include informing the family, although it was unclear to what end. There was some suggestion that this was dealt with inconsistently.

Um, well, I suppose if you start keeping things from the family, like generally speaking, like, personally that doesn't really bother me, but in the population as a



whole you have to sort of look at that. So I suppose that they do, probably should inform the family. Just in, to keep it legally, you know, so that they don't get uh ... like what would happen if say the daughter were to suddenly walk in on them, and went "oh, my god, this has been going on, and you didn't tell me ... dah, dah, dah, dah." ... and you're going to get a person whose definitely going to, going to, react like that. So, I guess, I guess you would have to say that yes you would have to inform the family. I think, um, I'm sure a blind eye could be turned here now and again (laughter).

It is evident that in each of the three research sites, that contacting the family and the police is a consideration that is within the discretionary judgement of the administrator. The language and behaviour of all three administrators suggested to me that they were uncomfortable with the uncertainty and practice ambiguity in this area.

### Documenting

One of the professional strategies that staff used in response to episodes of sexual behaviour included formalizing the incident using a document. Filing a formal report, and committing it to paper constitutes "writing it up". The reason this was done was so that it would have attention drawn to it, so that it would be taken seriously and medical help would be sought. As one participant stated,

I just do no matter what, no matter what. You just, it should be documented. Whether, I mean, it's just something that happened, I guess. Whether I get hit or I get grabbed, or touched, it's just something I document, I guess. Because then, it can't help her if, because if it's not documented, it didn't happen, right?

One participant identified that she used some discretion about whether or not to document on a behaviour. If it was considered benign, it was not likely to be recorded,

but if it the behaviour was a severe enough incident, it would warrant completing a specific incident report. She stated,

I guess if there was a person who approaches and talks and gives a leery-eyed look I wouldn't bother with that. But if it's uh, actually, uh, sexual touching like touching of the breast or the genitalia, in bed with the person, I would feel that, I would think a hazardous analysis report would be completed.

It is quite interesting to note that touching of the breast or genitalia would be considered a behaviour worthy of being labelled a hazardous incident that required analysis. Again, this type of response and interpretation pattern seems out of keeping with Kitwood's Model of Person-centred Care (Kitwood, 1997, 1998). It seems symptomatic of an organizational culture heavily weighted with a hyper-vigilant and protectionist mentality. One senior management staff member stated that incident forms specific to sexual behaviours are rarely filled out however. She stated,

I try to explain to them it needs to be documented exactly what he's doing, not that he was sexually inappropriate, because there could be confusion about that. Our form is called a "sexual abuse form", it's an incident report, but they don't fill those out I can assure you. I would think that that's probably because you hate to label some guy with .... you know.

Even the documenting approaches appear to be underground and inconsistent. Discretionary judgement also appeared to play a role. And as one front-line nurse manager explained, the process of submitting a written document to the MOH/LTC is quite involved,

You would certainly have to inform the families and see how the families saw that. You would report it to the supervisor, and then the administrator, and you

know, depending on this is a behaviour that has happened in the past, they would go and talk to him .... But we would have to, like we report it. That has to also, like in any long term care facility, it has to be reported to the Ministry of Health . The physician has to be notified, and has to examine, our medical director has to come and examine to make sure the resident's okay. And families notified, all those issues.

This image suggests that once sexual behaviour is considered risky, rather than continuing to be shrouded in secrecy, it suddenly becomes very, very public, with everyone involved up to and including a physical examination by a physician. Again, this is evidence that the sexual behaviour of residents with dementia is controlled in the strictest sense. But it is hidden from public scrutiny until it can no longer be ignored.

### Pairing

When staff members feel particularly vulnerable to the advances of male residents, it was typical that they would approach the resident in pairs. The protectionist culture results in staff responding to predicted episodes of a sexual nature by "calling in the troops". For example, "We always make sure when someone is washing him or whatever, that there's two staff always there. Just as if it really upsets them there are two staff in the room at the one time."

This included bolstering the capacity of team members from other practice disciplines. For example,

If it's some of the staff members from other departments, i.e., dietary feel uncomfortable, we will, nursing, will intervene and say, okay, if you have to serve

him, when it's time to serve his meal, nursing will walk, one of the nursing staff will walk over with you, and so, so, you're not facing this, or if you don't want to, we'll deal with it.

### Reassigning

Closely related to pairing, is a protectionist strategy that involved modifying work assignments. "Redeploying the troops" often involved reassign male residents out of the case load for female staff, and permanently assigning the resident to a male care provider.

I think that, well, if there, if there are any male staff on, you would provide male staff, uh, yeah, we have one guy who regularly does this with the female staff and they have to tell him that it's inappropriate and they don't appreciate being touched.

And, "I will step in, and say, okay, you know, you go do someone else and I'll take over." And, "So, what'll happen, is someone who's more comfortable with that person and that type of behaviour, we'll just switch them."

### Never the Twain Shall Meet

The over-riding message in the LTC facilities involved in this research project was that relationships developing between residents that were perceived to be of a deeply intimate or sexual nature were not likely to continue. In addition, it was highly likely that intact sexual relationships between married couples were not likely to be

encouraged, particularly if the visitor was a male spouse and the female resident suffered from dementia. As a clinician, this was quite discouraging to me. The themes that emerged in this category were: a) redirecting, b) separating, c) isolating, d) ignoring, and e) medicating.

### Redirecting

It was highly likely that residents who were engaging in intimate acts would be redirected from continuing that sexual expression. In some cases this would be done creatively and with compassion. None-the-less, the residents were very highly likely to be interrupted and offered an alternative activity that was considered more acceptable. Several participants identified that it was important not to over-react. For example, as one focus group discussion revealed.

S - You go and separate obviously. Not drag them apart, you don't go in shouting.

S - You distract them.

S - I mean, there's ways of doing it, even though the one that's pursuing it, they're just trying to show affection, so you have to be, understanding their feelings, so you say, listen, I need you, or come here for a minute.

S - You go in with the tea and cookies.

S - You don't go in with the fire hoses. OKAY, THAT'S IT, EVERYBODY OUT!!!!

Staff made observations that at times, family members could also offer verbal redirection and affirmation. For example,

S - We have now someone who comes in on a daily basis to visit her husband, and one of the ladies is telling her, "This is my husband", and she says, "Oh, isn't that nice, how long have you been married?". And she feels just to go along with the, she understands that these people are cognitively impaired and they're not speaking of a right mind, so she just sort of lets it go.

S - Although she is very territorial if they get too close and there's sort of holding hands if she's there. I mean, she's not nasty to them, but she sort a ...

S - Redirects them.

S - Yeah, yeah, she does.

S - Or she'll come and get one of us.

S - Then take them apart, or help one person to come out of the room, and uh, kind of have them stop for a little while. Take them off the floor or offer them something to drink, or, get them to interact with another resident, or take them to an activity for a while.

Distraction was a technique employed in several situations in order to protect families from witnessing sexual expressions between two residents. Arrangements were made so that immediately prior to a scheduled visit, two residents with a special interest in one another would be separated.

We asked them to call ahead of time. When she was coming. The wife was very upset if there was a woman sitting holding hands or whatever, so, the solution to the problem was, listen if you call us in advance, we'll make sure that he's ready, and, he's by himself .... We would make sure he was on his own. You know, there's ways of working around things if they can't handle it.

This comment suggests an organizational culture that is capable of accommodating the sexual behaviours of residents in a supportive way, although ultimately, separating residents who were engaging in acts of intimacy remained the predominant response theme.

### Separating

Participants also acknowledged that for the most part, they felt that sexual behaviours between two residents with dementia should be stopped. They described intervening by separating the residents and removing them from each other's presence.

As one key informant stated,

When you see a situation like that (two residents together kissing), you kind of just have to get them apart, and like I said, provide them with a book or give them something to drink or, or, take one down to another floor, and maybe uh, interact with other residents.

Sometimes separating involved removing the resident from the vicinity of other residents by putting them to bed early. As one participant stated,

So, what the girls try and do is, make him one of the earlier ones that, like, before they start doing HS care, that he's one of the first ones they kind of wash and dress and put him to bed. And keep him out of, from wandering up when they can't watch him. And that, that works .... Isolating is the best, not isolating him totally, but separating him from getting at the female residents works best.

Separating also involved permanently moving the resident to another floor or alternate facility. As one participant explained,

It got to the point where they said well, no I don't want my mother to be with that person, could you move them, could you move my mother to the other side of the unit. I actually think one case ended up going to another facility.

Transferring a resident to another facility was more likely to happen if the ethnic background of the resident of concern presented a communication barrier for staff.

Inability to understand the verbal communication of a resident with dementia who was making sexual overtures appeared to be related to the interpretation that staff would put upon a particular behaviour. In this context, sexual expression was more likely to be interpreted in a negative light, particularly if the resident was not fluent in English. As one participant described,

There was a huge language barrier, so you couldn't really understand what he was saying, and his family would say, why don't you just separate him, and so it was very difficult. So I had to finally send him to a hospital because we just couldn't.

Families were very aware when certain sexual behaviours were dealt with by removing the residents from a particular location. These moves were handled quickly and quietly. "The nurses, of course, they took him away. And then he was moved to another floor right after that."

One senior manager described how difficult the moving patterns could become.

I moved people up to the third floor, I just kept removing people, so that was pretty tough, because, Hmmmm, .... but anyway, what happened was the man was bothering alert residents on the second floor, wandering into rooms, not being sexual, but just bothering, and so then second floor people wanted him off the floor, but I couldn't because I'd already removed all these people who he was sexually attracted to. And we only have two floors.



What is striking in this passage, is the degree to which sexual behaviours become intertwined with other dementia-related behaviours of inconvenience such as wandering. Again, this may have a relationship to gender. If a man wanders into a woman's room, he could only want one thing: sex. A woman who wanders is much less likely to be banished to another floor, because the behaviour will be interpreted for what it is: exploring the neighbourhood.

### Isolating

Closely related to separating, is the practice strategy that involves removing someone to a private space. This took place in response to public self-pleasuring such as masturbation, or private moments between couples. For example,

On the one occasion I found them, I just pulled the curtain and walked away. But, I know it didn't always go to that, I mean, the sons were called, and then the husband was spoken to, because the staff thought he was a dirty old man.

And, "I think if anything, all we've done is redirect that person if they want some private time, draw the curtain, go to the washroom, masturbate there, more for self-stimulation."

### Ignoring

In some instances key informants reported that either they or their colleagues would choose to ignore a behaviour. As one participant stated, "I just open the curtain,

and open the door, and I'll say "Oh, I'll come back in five minutes", let them continue what they're doing, and just go back, and pretend nothing happened."

Another participant stated that some of her colleagues purposefully ignored the sexual behaviours of their residents. "Some of them just, you know, play ostrich, stick your head in the sand, ignore it, and it'll go away."

Ignoring sometimes meant turning a blind eye, and choosing to pretend that the sexual behaviours between co-residents were not happening. One participant described how she and a colleague silently agreed to do nothing, but chose not to discuss it together or with their colleagues. This clinical decision therefore seemed duplicitous, the practice decision unspoken between them, a collusion that keeps the secret deeply buried.

Me and my partner, had seen, just happened to be there are the same time, and we just looked at each other, and kind of eye contact each other, and we just left. We talked about it after, but not at that moment.

In addition, families sometimes chose to ignore a developing relationship, hoping and assuming that the clinical team would handle things.

We knew, but I think we just kind of assumed that they would deal with it. You know, like she's there, you're the ones that are there all the time, um, you know, I assume they are keeping an eye on things, because they, they had told us, you know.

Overall, when staff and families chose to ignore the sexual behaviours displayed by residents with dementia, it served to drive their management practices underground, shrouding it in secrecy, concealing it from scrutiny.

## Medicating

In some instances, residents displaying sexual behaviour were given prescribed medications to control their sexual drive. As one participant stated, “And this one particular guy, he was, because this was an ongoing issue with him, we got [the psychiatrist] involved, you know him, and he was medicated because of it.”. And, “The doctor, medically, gave him Androcur or something I think, the point was to drop down that sex drive.”. And, “Whenever there’s a problem, a common reaction is to medicate them.”.

Some participants expressed concern that medicating residents with sexual disinhibition in order to suppress libido was not an appropriate measure to take. Some questioned how necessary this was. For example,

I have fought for not having people put on those drugs. Um, I have felt that, felt very strongly that that’s not our call. And, if that’s still something that they feel, then we shouldn’t be crushing that, that we should be trying to accommodate it in some way.

And,

I don’t care if you’re demented or not demented, why should, why should somebody else have the right to suppress your libido .... He would masturbate in front of the elevator at two o’clock in the afternoon. You know with visitors coming, and he was demented and he was also mentally challenged, .... but if you would have put him into his room he would have stayed there, instead of, um, chemically restraining his libido.

In this case, the use of a libido suppressant seemed to be an extreme measure, or form of punishment and control that the participant felt unnecessary.

There was the acknowledgement that medications themselves might be the root cause of sexual disinhibition in some cases, but despite this, the treatment response might still include medication to suppress libido. For example, one senior manager stated,

The other example was a male who, um, who was put on Aricept, and became sexually active. Apparently, this has happened before on Aricept. But anyway, he was really inappropriate, would fondle people's breasts, would pull his penis out and put it in somebody's face. So we stopped the Aricept. Put him on Androcur. And called [the psychiatrist].

Overall, the cultural narrative evident within each organization was one of restriction and control. Despite this, there was evidence of an enlightened approach, although I had the sense that this was not the over-riding belief system. There were pockets of person-centered practice behaviours on the part of staff but I had the overwhelming sense that these people were making decisions and operating alone and in isolation of each other. I had no sense that these people even knew each other's viewpoints. No sense that there was a critical mass of different thinkers who would join forces in an attempt to change the predominant culture of repression, censorship, fear and control.

#### Behind Closed Doors

Of critical importance for most participants appeared to be a variable related to privacy. Therefore, if a sexual display was stumbled upon that was taking place in a private area, it was more likely to be responded to with greater sensitivity and positive

feeling. Staff members were more inclined to tiptoe away. If, however, the sexual display occurred in a public area, the staff members were more inclined to respond by separating the residents. As one participant of a focus group stated,

Because one, with it being an open area, .... to go walking down the hall, and you've got other, outside family members coming in, and other families coming across this. Me, personally, I'd feel embarrassed.

Another participant explained,

It's always something that's done behind doors, and um, all of a sudden when you have dementia patients, that's not doing it behind doors, or not doing it in privacy, um, I think it's harder to say it's okay .... I think that's the part where, yeah, it's seen as wrong, that they're doing it in front of other people, or in the open.

Another key informant explained it this way.

Obviously the staff members were sensing that um, this display of behaviour in a public place was not appropriate and that was obviously based more on life experiences and these things are not necessarily to be done in public. However, other residents may react to it, and chances are that in some of our secured units, who would be quite oblivious to it, and it's hard to say more and maybe how people, well, families would react to it, if they came in and saw these two residents like that, who would whether those residents families or the families of others, and so maybe that's what, they thought about the need to, to intervene in some way. Um, I think it's a relationship that's been happening and um, when we know, I don't see any problem with redirecting them and taking them back to their own rooms.

A family member also indicated that sexual behaviour should be private, although his take was this should happen because it would offend the sensibilities of the nurses, rather than for the purpose of any broader social mores.

S - Providing they can do more or less in privacy.

I - Privacy is an important thing?

S - Yeah, that's right, as long as you can do it in private.

I - Why should it be in private?

S - Cause the nurses don't want to see that sort of stuff. The nurses don't want to see any nonsense going on in here. They'd just as soon turn their back and walk the other way.

Sometimes care plan directives included either ignoring a behaviour or ensuring privacy.

For example, "So we sort of came up with a plan, like if this was to happen again, what should we do, and, I mean, we could almost say, close the door and let it go, let it happen."

The language used to describe this care plan directive, "we could *almost* say, close the door and let it go ..." suggests some uncertainty on the part of the participant. It would suggest that letting it go was something that was not quite embraced by the clinical team, or perhaps although embraced hypothetically, in the real practice situation the couple would still be separated. It appears that the participant did not have any great confidence that "letting it go" was the right thing to do, and implied that in the real clinical world the couple involved would most likely be separated. And,

Develop a plan, what are we going to do with this person, what can we do with this person that works to, um, to make it better for this person, steering so and so, let's stick, let's take this person back to his room, let's see if we can get him back there, um, if he's um, masturbating, pull the curtains, it's fine, it's okay.

Again, the language used by this particular participant is almost derogatory and, perhaps, reflective of an organizational culture that is restrictive and punitive, as evidenced by the use of the term “stick” this person back in his room.

### Ignorance Is Bliss

It became evident that in most cases participants in this project were very unprepared and had no information base from which to deliver an educated response to episodes of sexual behaviour associated with persons with dementia. Themes emerging in this category were: a) experience and b) knowledge.

#### Experience

Key informants stated that they thought degree of experience contributed to how episodes of sexual behaviour were responded to in general. There was a general sense that professional and life experiences of some duration and richness would contribute to a tolerant attitude toward sexual displays in the work place. As one informant stated,

Maybe because I've worked with this resident for such a long period of time, I know how to control the situation. So, but um, some girls are young. I find the young girls, and they're just fresh out of school and in their twenties. Those are the ones, I found, really timid. Um, people, my age, I'm 38, and we've been doing this job way, for a long period of time, um .... you get used to that resident, so that you know what are the good times and what are the bad times. I think that helps too. What the younger girls learn to accept his behaviour, and know what he's doing. Or you give them little hints um, then they will continue and you can work with them a little bit longer.

Another key informant explained, "But I mean, they've never said but it seems like the younger ones are not as, like as used to dealing with them in this capacity, that they're more affected by it than we are."

Another key informant, herself a self-identified novice practitioner stated,

It made me feel very uncomfortable, probably because of my age more than anything. And, ah, my schooling, I hadn't been, ah, through, maybe I was in my first year beginning college. If it was to happen to me now, I would probably feel different.

Another explained it this way,

I think earlier in my career, um, lack of personal knowledge, lack of personal experience, um, and I was uncomfortable with it because I didn't know how to handle it or actually deal with it, or do something about it, even what was the right way to do something about it. How do you feel with something like that. So, yeah, I might not like it, but, I can look at it more professionally and say there's a problem here.

Still another participant, a senior manager, stated,

A lot of our staff they've been comfortable for years, this is nothing new, comments have been made, most of the staff, you know, it's like water off a camel's back, they, they just intuitively know, right, this is human nature, this is, you know, that's just mister so-and-so being mister so-and-so, and they are able to go ahead, it's not an issue .... And it seems, maybe I'm wrong, it seems almost as if it's the younger staff, rather than the older, more mature, experienced staff who have a problem .... Which surprises me. I thought they would be more enlightened. Well, I think they are more enlightened with their own peer group, but not somehow, to the older generation. It's like older people should not have sex period (laughs). It's like what my kids sort of say to me, (laughs) .... Uuuuuwwwww!!

The description here would suggest that the belief system of young staff is that sexual expression is not only for the cognitively intact, but for those who are also



chronologically young. Sexual expression becomes a commodity that is to be experienced by a small, elite group, exclusively owned by those persons who are in a position of societal power because of their youth and beauty.

### Knowledge

Key informants identified that they felt particularly unprepared for encounters with residents during which sexual expression was displayed. All stated that sexual expression was missing in their formal training. As one participant stated, “And I think many people don’t know how to handle it either. Including me, I mean, it’s something that I haven’t been educated on, you know what I mean”.

Key informants also indicated that despite having great difficulty with this during clinical experiences, there was very little continuing education or professional development offered. As one dietary staff person who participated in a focus group stated,

I think more education should be in all departments too, because I know from my end, dietary doesn’t see half the things the nurses see. And like I said the one’s that I walked in on, I was shocked. I didn’t know how to handle it.

Staff gave accounts that suggested that families also had little knowledge about the process of dementia, leading to protectionist behaviour. As one participant stated,

They don’t understand dementia. They don’t understand the process. They think that their parent is okay, and they’re you know, they’re not making good

decisions, well (laughs), they're not making, well, I mean, they're not maybe as far as they're concerned.

A family member spoke about her lack of understanding regarding sexuality and aging in general, describing her attempts to educate herself. She stated,

I read a really good article in McLean's. It was an excellent article on the aging and dating and uh, talked about you know, a ninety year old lady, her, her, granddaughter, which I thought was fantastic. I remember (lots of laughter) her granddaughter gave her a vibrator for her ninetieth birthday (laughter). And I thought, way to go!! I thought I hope I'm that, I hope I'm like that at ninety years of age. I do .... I just watched a program the other night, I taped it actually. My husband and I have been watching it on Sigmund Freud (laughter). I wonder what he would have thought of this!? .... And this has all been, been very new to me and it's, and it's been an education.

### The Disapproving Family

Family viewpoint and level of involvement had a great impact on whether or not a relationship of an intimate nature would be allowed to continue. If a resident had a family member such as a spouse, sibling or child who visited regularly, it would more likely be the case that staff members would put an end to such a relationship. Family members approval was a variable that would dictate staff response.

Yeah, if the families was okay with it, yes, I agree with it. But there are some families that are not going to agree with it, so when you see a situation like that, sometimes, you kind of just have to get them apart, and like I said, provide them with a book or give them something to drink or, or, take one down to another floor, and maybe uh, interact with other residents.

Many participants recognized the difficulty that family members experienced when they were faced with witnessing intimate behaviour between their spouse and another resident with dementia.

Especially if another spouse is involved. Now, we've got someone with Alzheimer's here and her husband is still living in the community and then we have another demented resident who wants to be friendly with this, you know, Alzheimer's woman whose husband is still in the picture, you know. I don't think that's right, I don't think the poor man should have to accept the fact that his wife has gone and some other man has her. You know, the fact that it's hard enough to deal with the fact that his wife is now gone. You know, her body's there, but she's gone from him, and I don't think we should be adding in another factor to it, by allowing that type of relationship to develop.

To a certain extent, staff reaction to intimacy between two residents with dementia was determined by the nature of the staff relationship with the family members. When the family-staff relationship was good, and the family member was upset with sexual behaviour on the part of their relative, staff members were more likely to engage in protective behaviour such as separating residents from each other. For example, "I would feel very badly if she didn't approve of it. Her husband having companionship or whatever. And it would be very awkward, I think, if she came into the facility and found them together." Another stated,

We had a female resident whose daughter was in quite often, and she had attached herself to one of the male residents. Now this lady was a widow, but her family could not accept the fact she had a boyfriend on the floor. And they got very upset every time they saw her with him. If her daughter didn't come by, and you tried to break them apart just in case you thought she might be coming, that was very hard to do.

Children were in a slightly different position, and if they didn't visit often, the staff felt they weren't obligated to either notify them or give heed to their opinions. As one participant stated,

I'm talking from experience, they have, they have maybe a son or a daughter, a child, um, the child does not visit on a regular basis, the family member may visit once a year, um, or maybe at Christmas time, they basically drop the person here, drop them off, and that's the end of that story. So for me to call that family member up and say, "Well, look at what your mom's doing now". You know, they've already shown me that you know, they're really not interested in what, you know, we're looking after their money, um, you know, the money's just coming in on a regular basis, kind of thing but there isn't any involvement so why should I go to that person and say, well, this is what your mom's doing, do you think it's acceptable.

Participants often expressed frustration that family members had unrealistic expectations regarding their ability to keep residents separated if they were developing an interest in each other. For example,

We would end up getting the brunt of it from the family members. Like "Can't you keep them away from each other?!" "Can't you move him to another floor?!" Things like that, eh? And like you try and explain to them that you do the best you can. But you can't be there every five minutes, keeping an eye on their family member.

Obeying the family takes priority over the wishes of the resident with dementia.

As one participant stated, "If the family has a problem with sexual intimacy, then we can't, we have to abide by them."

### The Unwritten Moral Code

The enforcers or censors within the system often worked toward maintaining the status quo by following some strict, unwritten, and often unspoken moral codes that heavily influenced the culture of silence and protectionism. Censorship could come from either family or professional staff. The themes in this category emerged as: a) relationship context, b) previous sexual persona, and c) perceived intent.

#### Sexual Behaviours Must be Within the Context of a Relationship

Sexual behaviours were more likely to be interpreted in a positive light and not subjected to censorship if they occurred within the context of a developing relationship. If the relationship had a history to it, and the resident couple was perceived to be engaging in courtship behaviours, then the relationship was more likely to be viewed with a positive spin. The relationship also had to be exclusionary and discriminate. As one participant stated, “[It’s okay] if it’s just the two people who are developing a relationship and it’s just with each other.”

As a senior manager explained,

I think there are relationships that do develop that are between two residents and staff know this and um, .... and um, .... we have to give, not necessarily if there is any damage involved in it or not, but if there is a sense that the couple have been together for awhile and they have developed a good positive loving relationship, and, and both of them are very content with this, um, then it makes it, then it makes it somehow easier for people to deal with. I think all of us. As opposed to um, a brand new budding relationship, like for some reason that’s probably a little

little more difficult when you may want to support it, but on the other hand, that protective mechanism is coming in and you are kind of wanting to see if anyone is getting hurt in this. Um .... and I mean, you may be more reluctant in regard to, take them somewhere private and let them be together for fear that some harm would come to them. Um, yeah, maybe as time goes on you, you would see that relationship forming and there is no harm, and there is just a higher degree of comfort in allowing the two of them to be on their own.

A second senior manager concurred, stating, "If you could see a relationship building between "A" and "B", then you know, my direction to the staff would be okay, you know."

This is quite an interesting point. It would suggest that sex for the sake of sexual release alone, is not acceptable. Sex should only be "allowed" if it is between two people who have formed an exclusive relationship of some duration, with an evident history.

#### Present Sexual Behaviour Cannot Contradict the Perceived Previous Sexual Persona

One consideration that would be brought to bear on how relationships of a sexual nature were interpreted had to do with perceptions of the past sexual conduct, values and behaviours of a resident. As one focus group informant stated,

Because most family members, the way they approach it is: "What would my mother have wanted if she were herself, alert, the kind of person?" .... you look at the person's values and ethics and the way they carried on in their life. And they may not look at it in terms of what my mother needs now. They look at in terms of who my mother was.

A family member stated,

S - Well, I just, knowing my mother, she would never have done anything like that. Never in her life. Mother was very affectionate with we children and my hus ... , her husband, but not, you know, for a stranger to be touching her and kissing her, if she had been in her correct and, it would never, ever have happened. Before, no.

I - So, how do you feel about that then, when your mother engaging in behaviour, when the mother that was wouldn't have done that. What, what, what was your thought about that.

S - Well, I think it kind of hurts to think that she was in that state that she would allow it, you know. I think it was her state of mind that bothered me as much as anything, you know, because she would never, never have allowed that to happen before. She was a very hard working woman in her church, and didn't like, wouldn't have stood for anything like that.

These comments suggest important implications for grief counselling and family education. How much do children really know about their parents' sexual preferences and past practices? As one participant stated,

... How do you know, like how do you know that, just because they were a proper woman, that she wasn't, as far as going to the whore in the bedroom, a maid in the living room, and a cook in the kitchen, you know what I mean? Just because she was proper, .... she probably still had some sort of libido, and, we don't know what Mr. X did for her when she was 22, maybe that was coming back to her, so I, you know, I, I can't answer that. And I certainly wouldn't want to be the one to say, oh, she would never have done that .... when she was younger. Because, if her daughter said that, my mother would have never done that, well, most kids don't think their mother has sex anyways, so ....

Another participant had an interesting take on considering the person's behaviour and how it was in the past. He stated,

I'm not the person I used to be when I was 20, I'm not the same person as I was at 30, I'm not the same person I was at 40, and I'm showing you my age (laughs). My circumstances, my environment, um, my abilities, dictate and determine how I react to my environment, okay? So, if I've become demented and disinhibited. Okay? And, ... now another example for you, we had a lady who was happily married for 70 years, she's demented, alzheimer's, she's been admitted to our facility, husband has passed on, and she misidentifies one of the other male residents, that's my husband, yes, okay? I think it would be more harmful to tell her that's not her husband and to tell her to stay away, I think it would cause her more distress.

### Sexual Behaviour Cannot be Intentional

A related thematic category emerged that suggested key informants were more likely to view sexual overtures by residents with dementia in negative terms if they felt that male residents were aware of their desire to touch them. This suggests that if the resident's behaviour appeared volitional with intent to create a reaction, staff were more likely to pathologize such behaviour and react negatively using punitive language. For example as the following conversation between the researcher and a key informant illustrates,

I - So they're kind of teasing you?

S - Of course they are. Most of them play those games, even the most demented.

I - Do they?

S - Yeah.

I - What is that, flirting or something?



S - Yeah, or trying to pretend they're more demented than they appear, then they are.

As another key informant stated,

There are some residents that you know, kind of do that on purpose and they know what they are doing. They'll kind of pretend that they're doing something else, and then they started laughing, and for you, for me, you know they're doing it on purpose because they already have that record. Like, I mean, they are known for that.

This suggests that despite their dementia, residents, particularly male residents are capable of forming plans, and taking deliberate action against other residents, trying to get away with things that they should know better not to do. This suggested to me that residents with dementia were perceived by staff to be engaging in forbidden behaviours that had the same moral code and negative label attached to them as adolescent sexual and drinking behaviours are often portrayed in society. The behaviours were portrayed as adolescents knowingly pushing the limits. As one informant stated,

We had a discussion about this concerning one of the residents who wasn't cognitively intact who continually sought out this one resident who um, you know, was unable to verbalize, was bound to a wheelchair, and he kept searching her out, because he knew she wouldn't do anything.

### The Rule Book

The rule books in the participating LTC facilities were meagre, insubstantial, weak, punitive, and conservative documents.

Meagre Policy or “Please sir, can I have more?”

Overall there was not convincing evidence that any of the sites had well-developed policy. By way of comparison, one site had no policy or clinical practice guidelines in the area of sexual behaviour and dementia. They were able to provide a single document that addressed resident abuse in general. However, the focus of this policy was to forbid formal caregivers from committing any act toward a resident in their care that resulted in physical or mental harm, neglect or violation of the human rights of the resident. Acts of harm were defined as physical abuse, psychological abuse, financial abuse, sexual abuse or neglect. Sexual abuse was defined as “sexual intercourse or other forms of physical sexual relations between staff and resident”. It is highly possible that this document with its negative language and heavy censorship might sway the organizational viewpoint in response to sexual behaviour associated with dementia in the same conservative direction.

A second site had developed a preliminary policy to ensure that married couples had access to private visiting space. The senior management team of this facility realized that the existing policy would not help guide the team’s response in the event that a situation such as the one reported in the newspaper story should occur. Therefore, they were considering revising the policy, however, no time or effort had been devoted to this initiative to date, the policy having been shelved for three years by the time this study commenced. The senior management team of this site was extremely hesitant to share

the original policy with me. Upon several attempts to acquire the policy for document review it was eventually stated that it just wasn't able to find among all the written records.

The third site quickly developed a sexual behaviour response decision tree as the result of an incident that occurred that they were unprepared to handle. The administrator of the site freely shared the document with me. This document focussed primarily on how incidents should be reported and documented. The decision tree was developed by a small number of key members of the senior nursing team in isolation of the larger organization and front-line staff. The document explicitly states that if a resident is "deemed incompetent and actions impact on another, then interventions must occur". This would suggest that within the context of dementia, sexual expression is not going to be allowed to happen. The policy itself reinforces the pervasive cultural viewpoint of sexual repression and censorship. In fact, the logical sequence of the document would suggest that if one has a dementia, one is no longer party to the rights, freedoms, privacy, confidentiality, dignity and choices that are the stated Bill of Rights of cognitively intact residents (Bell & Troxel, 1994). It is interesting to note that the decision-tree itself categorizes residents with dementia who become involved in sexual relationships as either "incompetent victims" or "incompetent aggressors". If these "parties" are seen together they are to be "immediately separated", the "seriousness" of the situation is to be assessed, and "follow-up notification" of the appropriate senior staff

and families is to occur. Clearly the policy itself would suggest that in most circumstances sexual expression occurs within the context of an unequal power base: There is always a perpetrator and a victim. This document does not support the philosophical tenets of person-centred care in any way. Admittedly, the administrator of the site stated that while the guidelines were somewhat helpful, the document needed further work. Unfortunately, there had been no efforts made to enhance it within the two years immediately prior to the study. The senior management staff of all three facilities acknowledged that the status of practice guidelines in place in their sites was deficient.

Team members from other disciplines displayed little understanding of the phenomenon if they had not experienced it themselves. However, several participants reported that they thought that guidelines of some kind would be helpful, particularly in the area of notifying families. As one participant in a focus group stated,

Where someone has an inappropriate sexual advance towards another resident, and that person is cognitively impaired, whether it happens once or has happened a couple of times, inform the family of that. You know, we sort of “Let’s make sure that doesn’t happen again”. But, you know, how do you approach it? How do you go about it? .... At what point do you tell the family?

Most participants were unaware if there was a policy or any practice guidelines in their place of employment. “I don’t know if we have a written policy, I imagine we must. Have I read it? No (giggles).” And,

No, that’s probably, but you know what, we may have, but I haven’t come across it yet. Because it really hasn’t been that much of an issue, but we might have um,

just because it became such a major issue, and when I was employed at another place it was a major issue.

And,

I don't think a formal one, I think we started into it. Well, I don't know, the D of C has a, uh, formal committee set up on it, I don't know, but I mean it's certainly there in thought.

And,

I think we're working on it .... Um, I don't think we actually do...I think once the parameters are clearly defined, we can, we can just, you know, it takes the decision-making off our shoulders, I guess, how, how, do we react. I mean, we react as individuals and our own reactions as an individual may be different from our reactions as a professional.

If there was policy, it was obvious that most participants were not aware of it.

My sense upon meeting with informants who were front-line workers, was that most front-line workers such as HCAs, therapeutic recreationists and nutritional services staff, were particularly marginal, disenfranchised individuals who were often unaware if any clinical practice guidelines were available within their own organization. The part they played within the organization was limited to direct care, and they had little voice or role to play in any other care initiatives. My perception was that they were doing things their own way, and in isolation of the rest of the team. As a result there was no single, conscious, organizational viewpoint for this specific area of behaviour. One participant was dismayed to discover that there were practice guidelines at her site. Having been

recently employed there, this information had not been included in her orientation. She stated,

I think if there is a policy, I think I probably won't like it. I think it'll probably be restrictive. Uh .... I find that, hhhhhmmph (disdain), those things for which there are policies, we are kind of making policies based on what's best for staff, and what's best for appearances, and families and not necessarily the resident. And especially at times like this, people get really up in arms about things appearing "respectful" enough (exaggerated voice, sounds sarcastic in tone).

She continued,

I'm sure if we have a policy but I'm sure it's very restrictive. Sure, you kind of say, this is what I would like to do, but I'll probably get in shit if I do it. So .... I guess, I won't. So I guess I'll just distract them and too bad that they're kind of having a lot of fun. But if there was a policy, you think I might know about it or have been handed it at some point or .... No one's ever said, oh, by the way if this ever comes up here's a policy.

Two participants of the same site, the single site that did have a policy document in place, stated they were aware of the content of their policy. Both participants were front-line RN team leaders. One described the policy this way.

It kind of differentiates what, uh, like say it's hand holding, uh, and sexual intercourse, and if it's a problem. Uh, like it actually says like if a resident, uh, can give consent or, what do you call it, has capacity, and one is the aggressor, and one is the victim, I think you call it a victim, and they're both uh, they both can give consent, then it tells you the steps of what to do. And then, if the aggressor, uh, .... say, has dementia, and the victim has dementia, it gives you the steps as to what to do. And, uh, basically you have to redirect them and separate them if both have dementia. And call the families and you know, have a care conference.

This participant's description of the policy would suggest that staff members are to interpret sexual relationships within the context of predator versus victim. Indeed, this

participant did accurately summarize the essence of the actual policy described above.

The policy could be titled, “How to identify the sexual predator and respond to avoid litigation by protecting the victim, then informing the families of those involved”. The policy creates an environment in which sexual relationships are viewed as pathological.

The second participant from the same facility described the policy in different terms. She stated that the policy was of assistance should her liberal viewpoints be questioned by colleagues particularly those within other practice disciplines,

I could probably find it if I went looking in the nursing practice manual. But, primarily, it's, if consent's there, let them go, you know, redirect them to a private area, um, document any behaviour, any overt behaviours that impact on you or other residents, and uh, consult with the supervisors is the main, you know. It gives us guidelines, it gives me guidelines if I've got somebody coming up to me and I've got somebody, especially from another department, nattering, I can say, look, this is what the policy says, yes, I will refer to my supervisors, but don't go getting too uptight if what you perceive is being done, needn't be done, isn't done, it might be what our facility has decided. And that way, it backs us up.

It is interesting to note that despite the fact that both these participants work in the same facility, their interpretations of the existing policy were different. While the first participant interpreted the policy to state “separate and inform families and have a care conference”, the second participant's interpretation was that “if consent is present, let them go, but ensure privacy”. This would suggest that DESPITE policy, a practitioner might interpret it based on personal values and belief systems.

In addition, most participants were skeptical about the degree to which policy or practice guidelines would help them. Front-line staff members in particular were likely

to be sceptical that such practice guidelines would prove helpful to them in the real-life situations they might encounter, therefore, even if such practice guidelines existed, they would be unlikely to refer to them. For example,

It's just that policies, sort of, .... pigeon-hole, and don't allow for flexibility. And the use of common sense. And, um, you know, I think we need to have a, I think we generally need to have a, policies, or general statements about how we approach things, but it should not be a .... recipe.

And,

I read something in the policy and procedure manual, but I can't remember what it was I read, I remember reading something on that .... But then again, when you work on a demented unit, you have to pretty much forget what's in the policy and procedure manual, and go by what the situation is. Like, nothing is in black and white, like, you know, it would be a perfect world if everybody was to just, you know, come out into the hallways, masturbate in front of the elevator at two o'clock in the afternoon, and you know, you would know how to deal with that because it was in the policy and procedure manual .... But you might find somebody who takes the urge to do that in the middle of lunch, you know, and you question whether the policy really helps you to decide how to respond to that kind of a behaviour that happens in the dining room with thirty other people around.

These participants were suggesting that no policy could ever allow for all the practice situations one could come up against.

From an administrative perspective, it became apparent that practice guidelines would be helpful. Study participants who were in management positions were stymied as to how to proceed. They felt that practice guidelines needed to be explicit enough to help avoid litigation from angry families, to identify when to notify families, and to outline when to allow relationships involving persons with dementia to continue. One



participant, a senior manager, stated, “We had a policy but it was really vague. And basically it was very benevolent. Our medical director felt it was a need, that we should acknowledge it [sexual needs], and accommodate a resident.”.

A senior manager of another site described the necessity of, but the difficulty associated with developing policy.

You have to look at it all, it's so hard, I mean you can't put, and this is where we are going to have to go back and look at our whole policy and our guidelines and remembering that they are only guidelines and there cannot be any overall clear cut 'thou shalt in this instance do this', and 'thou shalt in that instance do this', because there are soooooo many variables that you have to take into account .... I think as an administrator you want to be able to put policy in place, I mean I prefer to call them guidelines, um, in the end which promotes openness, awareness, um, discussion, um, which does give some guidelines for people who are impaired and who aren't impaired because we have some incidents obviously involving someone who is cognitively well involved with somebody who is cognitively impaired, and that kind of muddies the water sometimes for people. Um, I think that I would, my expectations would be that recognize that, um love and belonging is a need and that there is a need for companionship and you want to be able to support that. Um, and I think that at the bottom line we want to make sure that, that people are sort of demented, so that the guidelines to have some discussion about this, whether it involves the family or not, and that's what we would have to discuss whether we bring the family into it or not, or do we need to. But it needs to have an atmosphere here, where it's not left just up to an individual health care aide who might walk into a room and encounter and being left to try and make that decision on their own, to try and support it without having any one to turn to and have some kind of discussion about it. Um, I mean together as a team, with all the staff on the floor, social worker, try to sit down and have some discussions about it, about what it means, what's happening, we try and find, have some discussions about it, um, can make people comfortable with it. Because certainly if we don't promote that kind of environment and people are left to their own devices, there's certainly greater risk in terms of harm to residents, risk of harm to the institution itself, um, if people don't feel that they're being heard, then they're going to go somewhere to be heard, and that could be outside of the facility.

A senior manager at another site was relying on the clinical team to develop policy, and that from a management perspective it needed to spell out when residents with behavioural problems of a sexual nature needed to be transferred out to another site to be managed. The manager stated,

There isn't really a formal protocol, except that I would be involved in any discharge of a person. So, you know, and then before you discharge a person, you would ensure that you followed all the processes to make sure that you'd actually gone to every road that you can before you possibly want to seek an alternate site. Really with, the policies, with so many of these new facilities, like this is an inappropriate facility for some situations, and so, when it really comes to, for certain, people, or instances where a better facility with better, whatever, where space and privacy would be appropriate, is where they should be. Where they could be sent to. That's it from a management point of view. You know when you have real problems. But the policies, we haven't really sat down, I haven't with the other managers, and they would be doing that with their people, and I more or less rubber stamp whatever they come up with.

Another senior manager stated,

We have a little bit of a policy. I know that we started .... It's probably sitting in that pile right there. Right there, in my pile of things to do. Um, but as far as having a formalized whatever, no we don't. And I think there was something that came out of the ministry as well um, from that group that was meeting. And we have that information, but as far as having a formal policy, no, we do not. We have a little bit on sexuality um, resident abuse, sexual abuse, that type of thing. But you know, it's probably a one pager and it would be under resident abuse.

Overall, policy was something that administrators and front-line managers felt was important, but none of the facilities had invested a lot of energy into their development, felt the task was overwhelming, and were clearly unable to circulate policy in a format that was helpful to front-line staff such as HCAs. It is strikingly apparent that

the organizational culture of all three sites with respect to sexual expression in dementia was inconsistent, with ill-defined support mechanisms. Where policy did exist, it served to reinforce the culture of sexual repression, not open the organization to a management approach akin to the philosophical tenets of exemplary dementia care.

### A Few Good (Wo)men

Despite the presence of repressive, unwritten and often unspoken rules, an overwhelming culture of silence and protectionism, and conservative moral codes, there were a few pockets of compassionate, liberal minded practitioners identified, shining weakly in the darkness. I had the overwhelming sense, however, that these practitioners were few and far between, were operating in isolation of each other, and were not supported by their colleagues or administrators. Practitioners were practicing in a vacuum, and in some instances, operating outside of the directives of the in-house practice guidelines. The behaviours that emerged within this thematic category were: a) coaching, b) understanding, c) looking for benefits, d) providing, e) counselling, and f) humouring.

### Coaching

Most of the professional behaviour related to coaching was informal verbal support offered by colleagues to one another. Typically this would be those with more

enlightened viewpoints offering advice to their team mates. The very nature of this behaviour was that it was inconsistent. Few of the key informants spoke in a way that would indicate that they were obligated to do this, it just happened on the spur of the moment and was selective. In other words, if you were struggling with a particular resident's sexual behaviour, it would not be guaranteed that an on-site informal coach would be available to assist. This also had the feeling of being "secretive". There would not be a meeting called for experts to share their successful response strategies. Instead, a private and secret conversation would take place to offer the support. My overall perception of support and coaching was that it was underground. While reassurance was part of coaching styles evident in the stories told by participants, there was little evidence that staff members taught each other about the etiology of or meaning behind sexual behaviours. Response strategies were not carefully constructed, rather advice was limited to issues of "be wary and watchful, and set them straight". This tended to reinforce the overall culture of protectionism. The concerns of staff were negated, the staff coached each other to "forget about it - get used to it". As illustrated by the comments of one participant,

I do talk to some of the girls if I'm working with them, one on one. It depends on the situation. Or I'll say to them, "You know, you know, they're not going to hurt you, don't worry about it".

Another participant indicated that she had received advice from a colleague that sounded like a directive to set limits on the sexual behaviour. I did not get the idea that

the support offered included helping the participant to examine why the behaviour in question was upsetting to her in the first place. She stated,

She suggested that I, um, tell him that was uncomfortable and that after dinner hours he should probably leave the, the area and to be stern with him if I had to, but NOT to be MEAN. Um, but that, that was, that was mainly it, just to let him know that it does upset me.

Another key informant referred to her role as a coach for the front-line workers.

She indicated that her colleagues needed to know the management plan, and be reassured that if medications were part of the treatment regimen, that patience would be required until they took effect. She stated,

I would answer them, well, this person really doesn't know what they're doing, and you guys have to separate them, and there are certain things that we had to do now, and these plans require action, we do have this person, like if it's sometimes the case that we've already contacted geriatric outreach, and I'll say they've had some medications started but it takes time, the medications take time to work, it takes time to find the right one. You have to acknowledge that those problems are there, and it takes time to be able to deal with them.

A front-line worker explained that coaching was delivered to colleagues in a sensitive fashion. He stated, "... If I see something that I don't think is correct, then I will bring it up .... Usually I don't come across, you know, I can get the point across without hurting anybody's feelings."

Coaching also pertained to helping younger staff respond to residents who were making sexual overtures toward them. "Some of the younger female staff, who are

obviously discomfoted, we let them know that they can always back off, and ask somebody else to step in.”

Again, even the coaching was done in a fashion that would suggest that the sexual behaviour was abnormal. If you had not yet been desensitized to it, and hadn't learned to either extinguish the behaviour or ignore it, then one should pass the situation over to someone else who had. The more seasoned worker could tolerate the pathology better. This would often take the form of uttering a warning for those who would not necessarily be aware what the resident was capable of. As one participant stated, “We don't send young ladies there, we send middle aged ladies who are taking the HCA course and we will say, okay, J will probably get a little frisky with you.”

Warning also included issuing a communication that would let people know that a resident should not be disturbed because they were involved in behaviour that was considered sexual and private. However, even these warnings were often spoken in code. For example,

But generally we try to warn the .... like on the old B wing that could have happened quite easily, but by the same token, um, but if they, if you can kind of give them a hint, like, “oh, I wouldn't go in there just now!”

### Understanding

The responses of several participants indicated their attempts to be tolerant and accepting despite the general negative responses associated with the behaviours. As one

person stated, "I was never hard on him because .... (sighs) .... I guess just respecting him, that was my one thing, to respect your elders.". Another stated,

When it's done during personal care it's because, um, the person feels uncomfortable or they feel embarrassed .... They may not even so much embarrassment, just .... they're not seen as sexual beings, and they want somebody to recognize their sexuality, I think.

### Looking for Benefits

Staff accounts suggested that a relationship would be allowed to continue if there was a perception that there were clear benefits. As one participant of a focus group stated,

I think part of it goes back to where the family's level of acceptance is at that particular point. Like I had a very similar situation to this in one of the homes I worked in. In discussion with the family, they were comfortable with a situation like this because it gave each of their parents some companionship and some at that particular point in life, some quality to their life.

Another focus group participant stated,

When you lose everything else that's still one thing that you remember and you need, some people need. And if you put yourself in that position - say how many years down the road you're cognitively impaired - you don't know your name and you can't put a sentence together, but something happens and it feels good. That's all you know. That this is feeling good. Who are we to stop that? That that's one thing that's giving them pleasure. So, I don't know. That's another way of looking at it.

## Providing

A few participants were open-minded in their viewpoints to the degree that they believed that it was important to accommodate a resident's need for touch. For example, a single participant stated that she did not refuse it when a resident, who was referred to in a derogatory manner by most of the informants, touched her body. Rather, she acknowledged his need to touch and be touched, and normalized it, despite the insistence of her colleagues that the behaviours should be discouraged because they perceived them to be "sexual".

I have a tendency where I'll go up if they're standing there and I will give them a big hug. And this one particular resident, that, you know that everybody's the big sexual blah .... I will go up to him and if he's sitting by himself, I will say, "What's the matter X?". And he'll say something in his language, which I don't understand. "Oh, you come here you need a big hug today." I have a tendency where if he's rubbing my arm I'll say "Isn't that smooth?", and he laughs. Or if I get that back rub I say "Okay, don't stop, keep going, I like that back rub." .... Where a lot of girls, like I said, just frown and say "Oh, that's a sexual thing!"

One participant felt strongly that rooms should be provided for the purposes of intimacy. The informant stated,

I think that generally speaking people are pretty conservative and anything that is kind of sexy or kinda catering to sex drives is seen as disrespectful and inappropriate for a health care setting .... I think that's bullshit. I think we'd better get with the times. And that we should, um .... should try and put ourselves in their shoes, um .... Personally I think that it would be great if we had here a place that we could escort people to, but we don't. So .... that's a problem.

Another participant described how an external consultant had suggested that the facility contact an escort for a gentleman with early dementia who was expressing the



need for sexual activity. She explained that although they had discussed the suggestion it hadn't been acted upon.

She suggested that one of the options could have been to bring in an escort if that had been agreeable to his family, or .... allow his expressions of affection with another resident who was, uh, able to express satisfaction in the relationship .... We talked about it. And staff reaction varied greatly depending on um, their own values, I guess toward sexuality. "No, we can't do that, this is an institution!" "That's not appropriate!" And other people said, "That would be great, that would be perfect, for helping, preventing him from targeting other residents, but still allow him to, um, express his sexuality in an appropriate ...." We talked about it a little bit. Particularly after the in-service that we had, um, .... But I don't think we've explored it to the degree that, we could have and we should have. I think in those situations it was kind of an unusual situation, and it could have been meeting his needs.

This would suggest that any creative ideas, such as sexual toys, designated private areas for intimacy and sexual release, use of escorts, erotic material would not likely be implemented. I did not hear any of the participants seize ownership of these ideas. They were not empowered to follow these ideas up and investigate the possibility of implementing them. These interventions would likely be seen as negative within the organization. Of all the participants interviewed, I saw no single person on the horizon, even a family member, who would likely step forward and advocate for the sexual needs of residents with dementia. Individual participants who were more open-minded and forward thinking might continue to practice with compassion themselves, but my sense was that this would be shrouded in secrecy. I was not impressed with the idea that they would take it upon themselves to move forward and change the repressive culture. For

front-line workers, I suspect this might be because they don't see themselves as empowered to change the practice of others. For front-line managers such as RNs, I suspect it might be because they do not have a conscious vision of themselves as organizational leaders. For administrators, medical directors and members of the senior management teams who tend to operate from a risk management perspective, conservatism might exist because more libertine practices would mean going out on a limb. This might be problematic from a perceived public image and potential litigation perspective. Despite the fact that there were unique individuals who held more expansive beliefs about the possibilities for sexual expression of persons with dementia, again, the overriding organizational culture was to suppress anything related to sexuality. In particular this applied to the role of staff in facilitating relationships or providing equipment. As one focus group discussion revealed, "No, we wouldn't set up the room, and light the candles and that. No .... We're not a dating service."

In general participants believed that although it might be a creative thing to do, providing equipment to promote sexual release such as printed or video erotic material, dolls or vibrators would be beyond what the public could tolerate. As a senior manager of one facility stated,

I can see that, people would get their dander up, I mean, oooooo, pornography. I mean that would be a slippery slope, and I think it's easier to perhaps dance around the issue and still see it as a private matter, as opposed to um, actively supporting that person's sexual desires. You know what I mean? I think perhaps what the message might be if we were to get pornographic literature or magazines

or dolls or those sorts of things, that would be actively promoting something that perhaps people would find disagreeable. And I think it's easier to just, you know, Resident X, this is what would be appropriate for you, go to your room, or go private, and meet your needs privately.

### Counselling

Some of the participants identified the need to offer counseling, particularly to family members. Although this wasn't a pervasive message throughout the interviews, it was brought to light in one of the focus groups and bears mentioning.

We had a female whose daughter was in quite often, and she had attached herself to one of the male residents. Now this lady was a widow, but her family could not accept the fact she had a boyfriend on the floor. And they got very upset every time they saw her with him. If her daughter didn't come by, and you tried to break them apart just in case you thought she might be coming, that was very hard to do. I remember getting slapped in the face for trying to. So, I thought, you know what? .... Just leave, and if the daughter comes and she's really upset about it, we'll sit and talk or whatever.

Another participant explained,

There's another way of looking at it too. So you take one gentleman. He may take a fancy to a woman. So you keep an eye on them to see how far it goes. A week, two weeks tops, and then he's not interested any more. And he may not be interested in anybody else again for the longest time. So I think when a case like that comes up, I don't think you should call the family right away. Keep an eye on them, and see how far, you know .... And then bring it out if you figure it's not going to stop. And then try to educate the family on what's what.

That this theme was absent from the majority of the interviews supports the unrelenting sense of a culture of silence in response to sexual behaviour in the face of dementia.

## Humouring

Two staff members made reference to the fact that they used humour to help lighten up the situation when a resident made sexual advances toward them. As one explained,

I'm sorry but my humour is what gets me through, like we have one fellow who as soon as he sees me is like "HHHHEEEEEEEYYYYY  
BBBAAAABBBYYY!", just like that. And I go, "HHHEEEYYY there, my buddy", and I give him a pat and he's happy as a clam. Tell me why shouldn't I?!! Like other people might read something else into that, but it's not, that's all he wants, that's his style, it's served his whole life. And it's not going to offend me. Because it's not meant to offend.

Other staff members were likely to interpret this type of behaviour as unnecessarily flirtatious and unprofessional. As one participant stated, "Some kind of joke around and play along with it, but engaging in a flirtatious comment with the resident .... Um, I don't feel that that is appropriate, as a health care professional."

Overall, despite some evidence of small steps toward a culture of tolerance, the organizational culture of all three facilities involved in this study was seen as sexually repressive and controlling. Those who were more tolerant and open-minded would quietly go about their business, operating in the way they saw fit. In some instances this would mean turning a blind eye. No single participant felt that they had a moral obligation to split this practice conundrum wide open, and stop the needless "dancing around the issue". Rather, most of those interviewed acknowledged that something different should be done but weren't sure how to go about it. Most seemed to hope that

the development of a new policy might shed some light as to what actions they should take in the clinical setting. In the eyes of some participants, particularly administrators, this meant developing clear-cut policy that would “take the responsibility” for practice decisions off their shoulders. My sense was that the participants who were yearning for a policy, were looking for a written document that would unequivocally tell them what to do, and absolve them of any doubt as to their practice decisions. Yet none of the LTC facilities involved in the study had moved toward developing compassionate policy, and if they had done any work in this area at all, it had been completed in isolation of the broader organizational culture, again perpetuating the underground, buried and hidden nature of this clinical practice issue.

## CHAPTER SIX

### *Piece by Piece*

*Piece by piece your ship is drifting,  
Day by day across the blue.  
Like a bird your wings are lifting.  
Piece by piece and day by day I'm losing you.*

*Kiss by kiss your lips are colder.  
Remember when our love was new?  
Memories are getting older.  
Piece by piece and day by day I'm losing you.  
(Smith, 1995)*

### Toward a Critical Communicative Ethic:

#### Getting to the Bottom of Clinical Ambiguity

This study was conducted with the goal of explicating the viewpoints and practice patterns of professional and family care givers in response to the intimacy and sexual behaviours of persons living with dementia in three LTC facilities. The results paint a picture of an overwhelming, crushing culture of censorship, repression and silence regarding the sexuality and intimacy behaviours of persons with dementia. But perhaps, most significantly, the study findings point to the fact that persons with dementia in facility-based care were living within a culture that discounted the very existence of their sexuality, and certainly sought to deny its expression. The residents with dementia were no longer considered to be or recognized as sexual beings, period. They were spoken of

as persons who had not only lost themselves and their relationships, as the above song about lost love in the face of dementia describes, “piece by piece”, but had also lost their fundamental sexual essence as well.

### Relationship of Study Findings to Research Questions

Overall, the findings in relation to the study questions can be summarized as follows:

Research Question 1 (What do study participants mean by sexual behaviour associated with dementia?)

In the accounts shared by study participants, the language used to describe the sexual expressions of persons with dementia made no distinctions between social behaviours such as hand-holding; intimacy behaviours such as kissing, stroking, caressing, or touching; and flagrant sexual behaviours such as sexual intercourse. Most study participants found all of these behaviours to be equally unacceptable. Study participants responded to each of these behaviours in virtually the same way, as though each represented an equal risk because by definition, they made no distinctions between them.

Research Question 2 (What is the basic description of what participants reveal to be the ways they respond to behavioural episodes they define to be of a sexual nature in dementia?)

Staff within the LTC facilities did not formally discuss the sexual needs or behaviours of the residents with dementia in their care. There was no consensus about how to interpret or respond to episodes of sexual behaviour that involve persons with dementia. Because there was no formal vehicle for dialogue in any of the facilities involved in the study, practice decisions were predicated on the value and belief systems of individual players in each situation. Therefore, there was a wide range of responses given as to how participants would manage episodes of sexual behaviour within their own practice setting. Consequently, it became apparent that there were no consistent approaches to the management of sexual behaviour in persons with dementia. The majority viewpoint appeared to be one of conservative protectionism. The common response pattern was either to forbid the behaviour by separating or reprimanding the resident(s) involved or to ignore it by pretending it did not happen. Because there was no open dialogue between team members, including family, there were many assumptions made about the best way to proceed. Staff assumed that they should not support or encourage the sexual expression of residents with dementia because there were no consistent written guidelines that directed them to do so. Therefore, the unspoken moral codes guided practice.



Research Question 3 (What do participants identify to be the factors underlying their responses to sexual behaviour in dementia?)

Study participants shared stories that revealed several factors that played a role in their typical response patterns to sexual behaviour in dementia. Overriding societal values about the sacredness of sex and the vulnerability of women to sexual exploitation by men greatly influenced participants' practice responses to the sexual behaviours of those residents with dementia living in their care. Ageism and a belief that cognitively impaired individuals are incapable of participating in sexual relationships also induced participants to repress any evidence of sexuality in their residents. The few family members who participated in the study were very concerned about the absolute need to protect loved ones with dementia from potential exploitation by other residents. They would most likely forbid a developing relationship of a sexual nature between their parent and another resident. Because there was no open dialogue, families made assumptions that the clinical team had managed the behaviour in some acceptable fashion. However, family participants rarely made direct inquiries about the sexual behaviours of their relatives. In addition, the three LTC facilities that participated in this study had poorly developed and insufficient practice guidelines to assist staff to know how to respond. There had been few educational sessions offered to staff and no forum within which to discuss the varying value and belief systems that each partner in the interdisciplinary team might have.

Research Question 4 (What is the cultural/social context within which individuals respond to episodes of sexual behaviour in dementia? What are the explicit, implicit, and unspoken rules that influence decision-making and practice responses?)

There was an overwhelming culture of silence in regard to the sexual behaviour of persons with dementia. Sexual needs were not explored, not evaluated and consequently sexual health and expression remained closeted and repressed. The silence of staff and families served as a collusion that ensured that the topic was not discussed, so that the residents' sexual "secrets" would continue to be kept hidden and buried. There were exaggerated fears amongst participants about what just could be possible. An unreasonable fear of genital contact, sexual intercourse in particular, drove the conservative practice responses because the unspoken rule was that this behaviour was strictly forbidden. Without open dialogue, there was no way for staff to critically examine their worst imaginings and put them into proper perspective.

Research Question 5 (How do individual accounts differ from group accounts regarding episodes of sexual behaviour in dementia?)

The accounts of individual participants were very similar to the stories and viewpoints expressed by focus group participants. Both data sources revealed a practice culture that was uncomfortable with the sexual behaviours of older adults living with dementia and sought to repress them. The dialogue between participants in the focus

group sessions revealed the extent to which sexual behaviour were frowned upon and the degree to which response was inconsistent but controlling.

Research Question 6 (How do individual and group responses compare and/or contrast with management responses to episodes of sexual behaviour in dementia?)

The viewpoints of those participants who were members of the senior management teams of each of the three sites were akin to the stories and accounts of front-line care workers and families. Managers were particularly sensitive to the risk potential inherent in the sexual expression of persons with dementia. This risk aversion served to further reinforce the culture of censure, repression and silence, thereby virtually paralyzing each organization in any attempts to either develop or revise existing practice guidelines and policy.

Research Question 7 (What are the consequences of selected actions for the persons involved in the clinical situation?)

The absence of open dialogue resulted in clinicians, teams and families continuing to operate within a vacuum of ambiguity and uncertainty. This caused a discomfort and anxiety that reinforced the overall culture of repression and censorship. Because there was no open dialogue from an organizational perspective, the appropriate use of community resources such as external psychiatric consulting services and the

police was inconsistent. There were no parameters outlined with which LTC facilities could appropriately identify the need for these services and use them with confidence.

#### Research Question 8 (What practice change initiatives can be identified?)

The results of this study suggest the need for vast change in several areas related to the sexual behaviours of persons with dementia: policy development, education, and further research. These will be further explicated in the next sections of this chapter and in chapter seven.

#### A Second Look: Excavating More Layers of Assumption and Belief

While the results of this study can be simply inventoried as has been done in the list above, they can be more profoundly understood by re-examining them in the context of broader societal values and beliefs about what it is to be an aged person living with dementia. This deep exploration will further serve to elucidate why the participants in this study believe what they do, laying bare those constructed beliefs that need to be torn down.

#### The Person With Dementia as Powerless, Asexual Being

The theme of protectionism and repression is closely linked to the theme that persons with dementia can give no account of themselves. Relegated to a position in

society that is similar to other groups who are marginalized with respect to power and decision-making capacity, it appears that the broader viewpoint is that these persons must be protected from their own feelings and emotional expressions. Because their emotional expressions can appear “primitive” and raw, they are threatening to both staff and family members who operate within a cultural, organizational and societal milieu in which reason and logic are revered (Post, 2000b, 2001). This reflects broader societal themes that sexuality in general is considered base, unnatural, and is subjected to societal rules of conduct that are legislated. This reflects the writings of Foucault (1978), whose work exploring the history and nature of sexuality, reveals that sexuality, as a product of emotion and not of reason must be considered with distrust, and therefore strictly controlled (Foucault). Foucault states that some of the principal features of the relationship between societal, political and economic power and sexual expression include negativity and the insistence on rules. He explains,

.... [There is] never .... any connection between power and sex that is not negative: rejection, exclusion, refusal, blockage, concealment, or mask. Where sex and pleasure are concerned, power can “do” nothing but say no to them; what it produces, if anything, is absences and gaps; it overlooks elements, introduces discontinuities, separates what is joined, and marks off boundaries. Its effects take the general form of limit and lack .... Power is essentially what dictates its law to sex. Which means first of all that sex is placed by power in a binary system: licit and illicit, permitted and forbidden. Secondly, power prescribes an “order” for sex that operates at the same time as a form of intelligibility: sex is to be deciphered on the basis of its relation to the law. And finally, power acts by laying down the rule: power’s hold on sex is maintained through language, or rather through the act of discourse that creates, from the very fact that it is articulated, a rule of law. It speaks, and that is the rule. (p. 83)

As Foucault (1978) described in the last half of the 20th century, sexual expression was seen and responded to within the boundaries of its relationship to power, not as an essence that reflects what it is to be human. It would appear that even now, at the beginning of the 21st century, sexuality, at least for older persons in general, and persons with dementia in particular, is highly linked to societal power, is subjected to many constraints, and has been disconnected from their humanity (Davidson & Fennell, 2002).

In addition, within the broader social context, sexuality attached to elderly persons living in LTC facilities, whether demented or not, is considered repellent and disgusting (Collopy, 1988; Dupras & Poissant, 1987). Consequently, the sexual needs of elderly residents are largely ignored. Perhaps of greatest significance is that in the context of institutional living, LTC administrations take their duty to protect residents from abuse, injury and neglect to an extreme. Unfortunately, it is highly possible that the drive behind this rampant protectionism, are the liability issues (Hajjar & Kamel, 2003). Again, part of this might be related to the fact that administrators, staff and families of persons in LTC are not cognizant of how their own biases may influence management decisions. In addition, from a power base perspective, aged persons, particularly those with cognitive impairments have little economic value, have little power that they can harness, and therefore their sexual needs are not considered important.

Another variable stemming from the findings of this study exists beyond societal values and sexuality related to the attitudes and reactions of the staff members to relationships between residents. All of the participants indicated discomfort in response to witnessed episodes of sexual behaviour, but in particular their discomfort was raised when they found themselves to be the target of sexual overtures from residents with dementia. These findings are similar to those identified by Mayers (1998) and by Lawler (1993) in her work "Behind the Screens: Nursing, Somology and the Problem of the Body". Lawler identified that nurses were very likely to exert controls over patients who made sexual overtures toward them during body care. Staff members who participated in her study were also shocked, dismayed and upset when patients made remarks that sexualized the context of any technical procedures that were being done. These remarks were considered inappropriate, unacceptable and were censored. Sexual behaviour on the part of patients was viewed as an attempt to break the rules, rules that were unspoken, but "understood". Although Lawler's work explicitly did not include patients with cognitive impairments, some of the clinical examples given by nurse participants would suggest that they were particularly upset by sexual behaviours that were exhibited by elderly patients.

Perhaps the most significant finding of this study is the notion that the person with dementia is perceived largely as asexual. It would appear that the older person with dementia has lost his/her humanity, particularly in the realm of sexuality and sexual

expression. This lack of humanity also suggests that the sexual needs of persons with dementia are not important. This is supported by the fact that although all three facilities perceived their practice guidelines to be insufficient, none had taken any steps to improve upon them, despite the considerable passage of time. Sexual needs were certainly not considered, and sexual expression would most likely be censored and repressed, either with environmental or pharmacological interventions. This fits with the overall milieu of care evident in the asylum as described in the sociological literature (Goffman, 1961). In his descriptions of the life of a mental patient, Goffman states,

In the mental hospital, the setting and the house rules press home to the patient that he is, after all, a mental case who has suffered some kind of social collapse on the outside, having failed in some over-all way, and that here he is of little social weight, being hardly capable of acting like a full-fledged person at all. (p. 151).

Goffman's (1961) descriptions are not at all dissimilar to the everyday experience of the person with dementia living in the LTC setting. The person with dementia has suffered a "collapse" of self so pervasive as to be "hardly capable of acting as a full-fledged person", and certainly not at all in the ways of sensuality, sexuality and love. This state of affairs is also reflective of the present day cultural milieu associated with sexual expression of persons with mental illnesses living in psychiatric facilities and of those persons with developmental disabilities living in residential facilities. There is a body of literature surrounding sexual expression and sexual needs of persons with chronic mental illness and developmental disabilities such as Down Syndrome. This



literature is also fraught with protectionism and risk management approaches since health care professionals and families who care for such persons have concerns that the cognitive deficits associated with these conditions make them especially vulnerable to unwanted pregnancy, sexual exploitation and abuse, and sexually transmitted disease (Buckley & Hyde, 1997; Mossman, Perlin, & Dorfman, 1997; Park Dorsay & Forchuk, 1994; Timmers, DuCharme, & Jacob, 1981; Van Dyke, McBrien, & Sherbondy, 1995).

The management of sexual behaviour is not related to the clinical team's altruistic desire to identify and satisfy the sexual needs of the person with dementia as they would look after their nutritional needs. Rather, most management strategies are predicated on the need to "control" and "tame" something that is considered wild and dangerous. Perhaps this is a reflection of the general viewpoint of custodial care so pervasive in many LTC facilities. Certainly, the picture that emerges from the stories and accounts of this study's participants would suggest that, particularly in the area of sexual expression and sexuality, the person with dementia is in fact, cared for using all of the principles of Malignant Social Psychology, as described by Kitwood (1997, 1998). These include such response behaviours as treachery, mockery, derision and isolation, to name a few. At any rate, it is critical that one ask the reason for this pervasive need to protect the resident with dementia from their perceived "baser" instincts. This can be found in interview passages relating to consent.

## The Person With Dementia as Incompetent to Consent to Sex or “We don’t know!?”

So why is it that the sexual needs and desires of persons with dementia living in LTC are so flagrantly disregarded, controlled and extinguished. One of the main clinical conundrums associated with sexual behaviour in the face of dementia appears to be the issue of competence and consent. In the pure legal sense, the person with dementia is considered incapacitated to the degree that they need someone to speak on their behalf in regard to negotiating their instrumental and personal activities of daily living.

Unfortunately, this means that in many instances the preferences of the person with dementia are disregarded, and their opinions are not canvassed (Kitwood 1997, 1998). They are discounted and undervalued. Their behaviour is constantly supervised not in order to see what is right about it, but only to wait for the mistakes (Holstein, 1998). Their emotional needs and wants are rationed and restricted, and delivered only at the convenience of the staff. Where they are able to seek out companionship, this is strictly forbidden, and pathologized, particularly if the relationship involves intimacy behaviours that include genital contact. This relegates the person with dementia to a position of being someone else’s property. The person with dementia is treated more like a pet than a person. This would fit with the families need to advocate and restrict their loved one’s relationships. It has been suggested that some families are actually most concerned about relationships of a sexual nature between co-residents with dementia that risk being consummated because the very act of consummation would threaten inheritance (Dick

Young Productions, 2002). This begs the question as to whose needs are actually being served when a clinical team, in collaboration with families, restricts the intimacy behaviours that develop between two residents with dementia.

Participants had some interesting things to say in general about the capacity of a person with dementia to engage in acts of intimacy. Overall, participants indicated that while not capable of consenting in the legal sense, agreement to participate in intimate acts was inferred when protests were absent, at least for those who were capable of registering a protest. Consensual sex, therefore, was determined by the absence of non-consent, as manifested by the absence of such behaviours as scratching, crying, screaming, pushing away, or any form of agitation. For example,

S - As long as nobody's in distress.

S - As long as nobody's showing any signs of not wanting it.

S - See, you often know the signs of don't touch me, don't look at me, and we have on a regular basis and we intervene. But, if they're sitting there holding hands, it's neither one of them is saying no to it, there's nothing wrong with it .

S - I would say that instead of consenting to it, they don't consent. Like how would we know they are consenting to it, we know when they're not consenting to it.

S - Yeah.

S - But we don't know that they are consenting to it.

S - No, not, yeah, no. Definitely, it's not consensual as far as right minds going okay. It eh, but both at the same time have the need for comfort, but, that's all.

S - But nobody's saying no.

S - But that's not the definition of consensual.

S - You're right, it's not, but just from being in this profession and just seeing sometimes, like, get lost, or there's not.

Some participants believed that persons with dementia are capable of implying consent by not exhibiting their typical refusal behaviours. As one participant explained,

I - So you used the term implied consent. What do you mean by that?

P - If I see the resident not fighting back, like he's reaching out, and he or she is reaching out and willingly allowing this to go on, I would take this as consent. Or, if, but if I see them attempting to move away from the situation, that's not consent to me.

This proviso still left staff somewhat uncomfortable, as one participant stated, "I think if she was significantly more impaired than him, then it would be an issue because you'd be thinking: "Is he taking advantage because she's willing?". Another participant stated,

It's hard to know if they're both .... agreeing to it, because they have dementia. So, I, I, it's a really hard .... situation. I don't know. I don't know. I don't know what I would do, I don't know what .... As far as what's right, I guess, if, if it was my mother and someone else, or my father and someone else, and um, had dementia, I think I would prefer for them to be separated until I talked to them, I think. That's, that's for me I guess. That's how I just see it. They're their own person, yes, so that's the hard part. They are their own person, they still have sexual feelings involved, but the dementia makes it .... I don't know. They don't always do things that are beneficial to them, like eating things.

Despite these assertions that the person with dementia can imply consent by behaviour or absence of typical refusing behaviours, this almost "folk" belief had not

made it into the written rule book of any of the three organizations. Therefore, uncertainty clouded the whole issue of consent, creating great discomfort, and resulted in an inconsistent practice. Ambiguity reigned and staff members were ultimately left “wondering” and “worrying” if they had done the right thing in most cases. Nothing was clear. But, of course, nothing was discussed and nothing was debated, so clinical ambiguity could not be clarified through open dialogue. Everything was underground.

As one staff participant stated,

You wonder if, like he's not in his right mind, so does he actually, does he know what he's doing? No. Or does she know what she's doing, kind of thing. Um, they, you know, they, they've lost their ability to consent anyhow .... These people have dementia, so some people may look at them, as, you know, that they're children almost, needing to be protected. Um, so I think that is the issue. Because if they were elderly people who had all their faculties, and could give consent, then it wouldn't be an issue.

Another participant shared a similar sentiment. She stated, “Um, I don't know, I don't know, these are the ethical problems we face everyday, it's very difficult to decide what is right, what is ethically right for people who are demented. I don't know.”.

A senior nurse manager also stated that the issue of consent was problematic.

I - Do you think people with dementia can consent to whether they want to engage in sexual acts like hand holding, embracing ....?

P - I find that difficult, because we feel that they cannot consent to um, .... other things, like, um, with other decision-making, they're not .... it, it may be a relationship that feels comfortable to them, and reassuring, and, .... whatever, but I find that, like, part of our mandate is to promote their dignity, and um, ....

No one was ever able to give an answer to this question that was definite or appeared to be satisfactory. Most participants indicated that they “did not know” if the person with dementia could be “allowed” to participate in relationships of a sexual nature. The issue here appears to be that care providers believe that when persons with dementia living in LTC facilities engage in acts of intimacy with each other it is like eating something potentially poisonous. While participants all agreed that persons with dementia retain their adult feelings around sexual desire, these feelings were identified as something akin to poisoning. The language used to describe consent seemed to be associated with “knowing what is going on”, being aware of, and able to avoid exploitation, being able to stop an activity if it proceeded to include genital contact, but again this was only spoken about “in code”. As one family member stated,

I certainly wouldn't want to walk in his room and find him doing anything like that, or even touching her where he shouldn't have been. No, that would have bothered me terribly. If mother was as well as he was, and knew what they were doing, behind closed doors, go for it.

Another family member shared this same feeling of terrible worry over exploitation.

I mean, if they had all their wits about them, well, that wouldn't even be an issue, because then they can bloody well do what they want. But, I guess I just feel very protective of them. Like if this was happening to my mom, it would have definitely been, because she can't, you know, she can't defend herself.

Defend herself from what, one wonders? Another participant believed that residents with dementia who engage in sexual acts need to be kept safe. She stated,

P - I feel it's my responsibility to keep them safe. And that's maybe .... I'm not doing my job by allowing together demented residents who could maybe interact in a sexual way. Are they making a good decision when they don't have all their faculties?

I - So, um, would you be comfortable if there were two residents with dementia about the same level of cognitive impairment being together and having intercourse if they're not married?

P - No. And my whole reasoning would be the dementia. The dementia level, in they're not really making an informed choice. I, you know, I don't feel they can process that.

Just what is it that one needs to be able to process in order to make an informed choice related to sexual expression in the face of dementia? Should the expression of sexual desire be restricted and forbidden if the persons involved cannot give an account of the risk of sexually transmitted disease? Is it the inability to acknowledge the risk of hurting the sensibilities of a living spouse, of committing "adultery"? Is it inability of the person with dementia to describe the potential risk of being shunned by other residents and family visitors in the environment? The risk of being exploited for the pure sake of the sexual release of another resident with dementia, with no pleasure to be gained for oneself? All of these things? Another participant explained it this way,

Well, if they're carrying on like sweethearts, or girlfriend and boyfriend, or, husband and wife, or, um, if they're both consenting and know what they're doing and there's no, .... embarrassment for them, why should there be for me, so I would just put them into a private setting, because socially I don't think that they would know that um, that they need to be private if they're carrying on in the middle of the dining room. So, like they haven't lost the urge, it's loss of social skills that go with it. If they don't object, like, I mean, if, if, ah, um .... if one is objecting, then obviously they don't want it done, and they're capable of saying

“stop, don’t”, you know, then, maybe the other doesn’t understand what stop means, and that’s why we’re there. If they don’t look like they’re enjoying it, then they’re not enjoying it. If they are enjoying it, then they are. And I don’t care if you’re demented or not, like you know when you’re happy and you know when you’re not.

One of the senior managers who participated in the study also believed that consent was to be implied by the absence of protestations on the part of either party in a coupling. The manager thought that staff were very protectionist and saw their role to ensure safety at all costs. The manager suggested they often over-reacted.

The staff are always worrying about, um, is there some perceived manipulation, or perceived um, uh, intimidation by one. Someone is being exploited. And that seems to be a major hang up for them. And the way I ask them to look at it is, was, was there anything to indicate that was the case. I mean, it is plain in individuals with dementia who cannot communicate to us verbally, and so we use nonverbal communication, and I think there are lots of nonverbal cues, one can use, from observing the behaviour. I mean, I, we have a particularly enlightened RN on the secured unit, and she happened to see, um, two individuals who, were kind of in an embrace and he had his hand up her blouse, and um, .... like she described the female resident had no sign of distress, but was actually giggling and laughing, and he certainly didn’t show any signs of distress, right? He was quite happy with what he was doing, right? Um, so point being, who’s it harming. Okay? And, maybe it might not be appropriate in the lounge, okay?

The manager proposed that it would be unethical to intervene and separate residents with dementia who were engaging in acts of intimacy because it would cause distress. The manager explained,

I think it would be more harmful to tell a female resident, that’s not her husband, and to tell her to stay away, I think it would cause her more distress, I think it would cause more angst, um, and as long as she’s not overbearing, and he’s responding to her, and doesn’t feel threatened in any way, or doesn’t feel exploited, and seems to be enjoying the relationship, my question is, yes, this is a



person, who loved one man, now she has a delusion, right? Secondary to her dementia. Should we correct it? No. Because I think you'll do more harm then, I think we'll go back to basic ethical principles. Do no harm, beneficence, and nonmalficence, and so forth, and I think this would be sort of nonmalficence.

Another senior manager stated,

When you think of people with dementia, is we can't necessarily ascertain whether there is specific consent or not to behaviours, and certainly, you know, we can't be the police and make sure people can have healthy sexual lives, but I think that it's important that we get a sense that there is, there is um, again, consent, agreement on both parties, and again, you know, in a situation with a different resident perhaps who may be a little bit more, less cognitively impaired. I certainly have given this some thought, and I believe that, .... um, even if .... people can't verbally consent, um, just by their actions, obviously if someone's face looks as though he or she is content, happy, and they're holding hands with another man or another woman, um, through, that is consent, we're comfortable with each other, and this makes me feel good, and I don't have any qualms about that whatsoever. So the consent part is kind of tough .... It's very difficult to get an informed consent. Because what is it they are consenting to, it could be simple hand holding, but to go beyond that, um, and I think, with the sexual behaviour, there has to be an out at any point for a partner to say, no, I'm not comfortable with, and to leave that environment. But I'm not sure again, we can't be policing, we should not be policing people's private behaviours, and I don't know how to safeguard that.

One senior manager expressed concern that the issue of consent resulted in such a level of uncertainty as to result in conflict. Lack of clear MOH/LTC guidelines made decision-making even more difficult. The manager stated,

And it's hard to know the exact requirement, and I just keep reading that clause in the ministry manual over and over again about unusual occurrences and talking about the direct willful infliction of harm. And kind of emphasize the word willful, and then try to attach willful to someone who has dementia, and are they actually .... intending on causing someone harm, or are they just simply expressing a need for physical and emotional contact. And as nurses, we learn about supporting people's needs and so then you're caught in the middle there.

You don't know the intent, in that instance the intent of the male resident, in that regard, is it more for emotional and physical contact, and not looking to cause a co-resident harm? But I think in most cases, the staff do know the residents really well, and I think, you know, a health care aide is able to make a decision about how she would intervene based on her knowledge of the individuals.

Another senior manager stated,

I would think in their own, their own frame of mind that they're in, that they could certainly suggest, I think if you asked them, would you, would you, if you asked them, would you give consent, to being sexually involved with this person, they wouldn't even know what you were talking about, so again, it would be the signs whether they were smiling, whether they were yelling or screaming, or they were telling the person to get away or anything, going away, looking, or not seeming themselves. Whether they could actually give consent, I would say not, but certainly, you know, if it's allowed, that you could take their feelings, or take their, their what? (pondering) ... . Their actions, their facial expressions and things like that. Again, I think it's iffy as well, because I could come up to somebody and say, I really think that that person is enjoying themselves and there are not signs of distress and it would be quite enjoying that, and yet you could get somebody else who would say, well, I really don't think so. Really they're, I don't know .... It's a difficult situation, and I think a lot depends on the people or the person looking at the situation.

Treating the person with dementia as a non-person also appears to objectify them.

Therefore it is possible that staff become over-protective of their residents, as they would an object or piece of property. This even goes to the extent that they regard their residents' living spouses as base or abusive when they demonstrate apparent interest in maintaining some sort of semblance of a sexual relationship. The inherent animosity of many of the staff participants at this site toward a husband who visited his wife at the facility is evidence of the rule of property related to sexual expression in dementia. The staff language used to describe the nature of the behaviour of this particular male visitor

who was reported to engage in oral sex with his wife was extremely negative, derogatory and debasing. As one participant stated,

We came into an instant where, well I was in it, I walked in on it, and they were, they were married. And he comes to visit, everyday. Faithfully he visits. And she's still here. And they kiss and he comes to visit, and she's asking for him, and he calls her "lovey", and they've been married almost fifty years. And they hug and kiss. And it's so nice to see them hold hands, but this one incident, just, I was like, I was, out in the hall, but I was shocked, because I, they came in and I was going around checking everybody and make sure everyone is okay, and one of the cleaning ladies had walked by the room, and she said to me "Come here," and I said, "What" .... and she said, "I want you to see something because I'm not sure if I seen something correctly." So I said, "Oh." And she said "Walk by so and so's room but walk by slowly." So I said, "Okay", so I was walking down the hallway, and I just turned my head to the left and goes walking, and I look in the room and I just kept walking and she said, "Are they doing what I think they're doing?" And I go, "Yes." I was, sho .... I wouldn't say I was embarrassed, I think, my reaction, was "Oh, my God, I don't believe that." They were having, he was having oral sex with her. She .... and there was you know, it happens, but I was totally shocked and I said, "You know I have to phone, I have to call the charge nurse and let her know what is going on".

It is horrifying to think that one's most private moments with one's spouse are to be censored by others. This goes back to the issue of power, ownership and property. Just whom does the person with dementia belong to? Themselves? The family? The facility? Of course, checks and balances to prevent exploitation and protect the vulnerable and frail need to exist. However, it appears that the unspoken rule here is that outside of the context of a sentient being, any sexual overtures, including from one's spouse, represent exploitation. However, in striving to protect the person with dementia from potential sexual exploitation, in some cases, the very essence of their lives have

been removed from them. A member of the senior management team described the same relationship this way.

We have a husband and wife, where the husband has been known to, you know, have his head under the covers, um, that there was slurping noises going on, but as far as anybody, like, it's kind of been, like nobody has walked in to that area to actually see what's happening or what's going on.

This team all identified that nobody had ever discussed his sexual feelings or their intimacy relationship with the male spouse in question, even when they were concerned about the resident's personal welfare. Again, because of the silence surrounding this case, those in a position of power and authority have reinforced a cultural milieu in which no one is exactly comfortable with this relationship, and are not celebrating it for what it is: A wonderful connection between two human beings who still have each other at a time in their lives where there may otherwise be great joylessness, isolation and loss. How tragic, because when interviewed as a participant of this study, and asked to give an account of his relationship with his wife, he spoke with deep feeling about their intimate relationship and what it meant to him. He explained,

I can tell by the way she acts and the way she feels and every now and again she'll feel herself down in the crotch, and you know she still has the feelings. She always has been good that way, so, uh, I don't think there's anything unusual about it. She may be in old age, but she still remembers the fun we used to have, let's put it that way. She raised five sons and I raised five sons, so we had lots of fun in between. She had five sons with her first marriage, and I had five sons with my first marriage. We didn't have any together because apparently our blood didn't mix. Not that we didn't try, but our blood didn't mix. Yeah, I love that gal. So, I still come up here, every day of the week, except Saturday, which is market day. So, we get along alright. I kiss her. I still hug her and kiss her,

but that's it. I haven't been able to do anything in, what, over four years now, and the good lord has taken all that away from me. So I'm sterile as far as that goes. But hugging and kissing. Oh, yeah. Let's her know I'm still here and still love her.

This participant's description put his sexual expressions toward his wife within the context of a relationship with a deep, rich history. It embedded his sexual behaviour within the context of a healthy, normal, loving relationship. This was a gentleman who was respectful and dignified, whose intimacy behaviours with his wife were honouring a relationship that had survived through many challenges over 50 years. The staff's viewpoint that this man was an exhibitionist, interested in satisfying his own base sexual urges through exploiting his poor, demented, unknowing wife did not match either this participant's take on his relationship, or the female resident's reported lack of negative response to his overtures. This again, reflects the inconsistency of practice on the part of staff. With no open dialogue, and no practice guidelines, staff returned to their own value and belief systems, damaging the professional relationship between the clinical team and the family. Any acts of intimacy he engaged in with her, reported to be oral sex as observed by the staff participants, were inextricably connected in his mind's eye to raising ten children, having fun, and a prior relationship that was deeply satisfying and playful. Their present-day intimacy behaviour was not self-gratification on the part of the husband, rather it was his attempt to ensure that this part of their long-standing relationship was sustained. Unfortunately, because this was an unspoken thing, and

interpreted to be nasty and deviant by the staff, some members of the team had constructed their own social meaning, and they viewed the man with disgust. They saw him as an exhibitionist.

### The Sacredness of the Genitals

Overall, it seemed to be the case from the accounts given by the participants of this study that genital contact was the thing to be feared most of all. Intercourse, and its related fear of litigation due to assault seemed to make sexual relationships between residents with dementia impossible to contemplate. Over and over staff and family members referred to their concern about the possibility that two residents with dementia might “go too far”. This fear was in direct conflict with the belief held by some participants that the possibility of penile vaginal penetration was actually not very high.

Participants indicated that observing actual incidents of sexual intercourse between two residents with dementia was rare. In fact, most reported that this had not been their typical clinical experience. The following was a discussion about the possibility of intercourse happening that occurred during a focus group.

S - I mean, some men, they get very hard during care, but I don't know how long it would stay that way for penetration, but, I don't know ....

S - Naw.

S - Doesn't happen.

S - Couldn't happen.

S - I think it varies, but I really don't think so.

S - I don't think the full thing would happen.

S - They get a "chubby" that doesn't stay.

S - I don't think they really go for that. I think they really go more for the touching.

S - Yeah.

S - I've only seen that, either touching the body, or the hugging or the kissing. But I've never seen that.

Another participant stated:

I don't think in the past 18 years here, I have actually come across a situation where there was actually penetrative sex. I've not seen it. Okay? I've seen touching, I've seen breasts being touched, dresses being lifted, one person on top of another, but I don't think, that, that's, no one's ever reported that they've witnessed um, actual physical, penetrative intercourse. I have not seen that. In fact, I would almost venture that that doesn't surprise me. Because I doubt very much, that any of the males that I come across at this age with the co-morbidities they have and the medications they have that they would even be capable of an erection, secondly if they do have an erection of sufficient strength to penetrate an atrophied vaginal orifice. I mean, I just can't see it happening.

None of the participants reported an incident where sexual intercourse between two residents with dementia had actually taken place. The lack of reported incidents that involved sexual intercourse did not fit the general cultural response that in real life practice, sexual relationships should be controlled with view to the fact that intercourse would be possible and dangerous. This supports that although participants didn't think it

would be possible in most instances, unconscious practice ideologies were predicated on the notion that intercourse and genital contact was quite possible and should be avoided at all costs. But once again, because this practice issue existed within a culture of silence, no forum for shared clinical discussion could help practitioners and family members examine their unreasonable fears in order to reshape conservative practice ideologies. Therefore, no practice strategies were identified that might assist with reducing participants' fears of potential negative outcomes. The risk of the possibility of pregnancy would be nonexistent in this population of older adults. However, sexually transmitted disease (STD) could be a distinct possibility for residents engaging in sexual intercourse. Since there were no considered conversations about these relationships between reflective members of a clinical team, putting risk into perspective by testing for STDs was never identified as an option.

#### The Impact of the Community Case

It is important in the broader scheme of things to explore other variables that may impact on practice response and how the organizations involved in this study might respond to individual cases of sexual behaviour in dementia.

It was my sense that an ostrich approach had been taken to the practice issue despite the fact that most of the key informants made some reference to the front page newspaper story that I myself had seen two year earlier. Subversive, metaphorical



language was used, with informants referring to it as “the thing that happened that was in the newspaper”, or “that horrible thing that happened”. Interestingly, despite deep awareness that this incident had occurred, the negative publicity associated with it, and the fear generated as a result, there was little movement in all three facilities to formulate explicit practice guidelines. The administrators of all three sites stated that they supposed that if something were to happen, they would have to back-peddle and quickly put something in place. Though they felt concerned about it, there was little action. This inertia seems puzzling, but may be explained by the fact that the topic area is so sensitive and associated with societal taboo to the extent that it was perceived to be an overwhelming task.

Many of the participants referred to the case reported in the newspaper that drove this study in the first place in a fearful fashion. The impact of this case on the LTC community cannot be underestimated. One participant acknowledged that practice behaviours were quite different since the case was reported in the newspaper. She stated,

Because of all that stuff that went on a couple of years ago, with all the stuff in the paper (laughs). You know, we're all paranoid about it now. They would probably move, they would probably separate the residents. That's what I would see. Because, I would think, the families would not be agreeable to this happening, right? And the administration would be paranoid about the ramifications, you know, because of what happened a couple of years ago. It being in the newspaper and stuff. You know, we'd want to protect the residents.

Actually, what this participant is saying, reading between the lines is, “we would want to protect the facility from a similar instance of poor public relations and negative

media exposure". The participant continued expressing dismay at the degree to which sexual expression between elders with dementia is sensationalized.

These issues are not really that significant, however, because of their very nature, when it, when they do surface and people misconstrue what's happened, right, it tends to be sensationalized, right? And really they just blow it totally out of proportion. And we saw that with our wonderful newspaper, um, because their business is to sell newspapers, and sex sells, right? So, if they can have a headline of sex in nursing homes, and exploit it, because I felt that what the newspaper did then was exploit our residents, okay?

Another participant referred to the same situation, acknowledging how the case was influencing practice.

We are all concerned about how the patient appears, you know, and I think there's more of that than there should be, I think that this is a really high profile place, and things like that (the newspaper case) makes it even worse.

Yet another participant referred to the case. "I think that there was much ado about very little. And it's very unfortunate that it hit the papers."

A senior manager mentioned that fear of bad publicity might lead to protectionist, conservative decision-making.

We get to different levels of the decision-makers and things start to get at the risk management end of things, and all of a sudden you start seeing headlines, in your mind, and in the papers of stuff and the families hear about this and stuff, and uh, um, you didn't have any discussion with the family nor did you intervene and going to the paper and that's been a problem before, and that's I think a big fear that I think a lot of us do have.

A focus group participant made indirect mention of the case, again illustrating how pervasive the fear of poor publicity serves to reinforce the over-riding culture of silence and repression. She stated,

I find that what we feel is appropriate not everybody thinks is appropriate, and things could get out of hand, especially when the media get it. And the sad part is that it makes it look bad for everybody.

This variable may in fact be paralyzing the community in the writing of practice guidelines. A part of this may be fear of repercussions from the public.

#### Relationship of Study Findings to Previous Research

The work of Alexopoulos (1994) focussed on extinguishing the sexual behaviour of a male resident with dementia, predicated on the assumption that the only intervention approach to his sexual behaviour should be its elimination and control. The study did not explore how to help redirect or meet the study subject's sexual needs. This approach suggests that previous research literature reinforces the overall societal viewpoint that sexual behaviour is pathological in persons with dementia, and should be censored and repressed.

The focus on prevalence research also seems to suggest that the clinical world is obsessed with quantifying risk. The prevalence literature makes no reference to explicating those sexual relationships whereby persons with dementia gain strength, nurturance and quality of life. The treatment literature does not investigate the toys,

dolls, equipment or erotic material that could help sustain the sexual essence of persons with dementia as has been suggested by Berger (2000). Rather, much of the treatment literature explores the efficacy with which certain pharmacological agents can successfully suppress libido (Amadeo, 1996; Kamm, 1965; Levitsky & Owens, 1999; Schiavi & White, 1976; Stewart & Shin, 1997; Velez & Peggs, 2001). By its very nature the prevalence literature reinforces the idea that sexual expression is a problem behaviour that is pathological.

In some ways the study findings reflect the results of other studies but with some differences. For example, the results of the postal survey conducted by Holmes et al. (1997), suggested that within 300 LTC facilities across the Eastern Continental United States, respondents were quite positive about their viewpoints related to sexual expression and behaviour associated with dementia. The administrators were found to be slightly more conservative than front-line workers. The limitation of this postal survey was likely a bias toward eliciting a response from those who tended to be more open-minded and positive about sexual behaviour and this cannot be minimized. The results of the present study would suggest that professional response to sexual behaviours manifested by persons with dementia in LTC settings might actually be more oppressive than originally thought.

In addition, the findings of the present study support that care providers are often conflicted about how to respond when relationships of a sexual nature develop between

two residents with dementia. As a result, without a considered organizational approach, practice responses will be conservative with a tendency toward suppression. For example, the protectionist viewpoints of the care providers involved in the case scenarios and the anecdotal case reports described by Berger (2000), Lichtenberg (1997) and McCartney et al. (1987) are not unlike those of the participants in this study.

In particular, the findings of the present study show striking similarities to the results reported by Archibald (2002, 2003). Archibald reported that care workers did not have a clear understanding of the impact of dementia on the capacity of persons with dementia to consent to sexual relationships. Therefore, there was a tendency to disallow developing relationships because care workers felt their duty was to protect residents vulnerable to exploitation who were usually women. Separating residents was also a strategy used by staff to protect themselves and the organization for which they worked. In addition, Archibald reported that there was a general lack of ongoing managerial support for the practice decisions made by staff and the feelings they had regarding sexual expression of persons with dementia.

The results from the present study support the worry that the practices of staff caring for persons with dementia living in LTC facilities may be pervasively negative, repressive and controlling.

## Relationship of Study Findings to Critical Social Theory

In keeping with the underpinnings of critical theory, this study was designed to explicate how personal values and organizational interests shape practice policies related to sexual behaviour in dementia. In addition, this study was designed to uncover the nature of enabling and/or restrictive practices, and thereby identify the necessity for practice changes that might enhance the quality of the sexual and interpersonal lives of residents living in institutional settings (Kincheloe & McLaren, 2000).

The findings of this study have identified the oppressive nature of the treatment of persons with dementia specifically in relation to their sexual feelings and behaviours. Dialogue with each of the study participants suggested to me that there is a pervasive core belief amongst formal and family care providers that persons with dementia are less than human and therefore should be protected from any base self-expressions and exploitation as one would protect a piece of property or a valued object. This core value constrained quality of life for persons with dementia, and is in direct contradiction to some of the value statements inherent in the Alzheimer Disease Bill of Rights (Bell & Troxel, 1994), namely that all persons with dementia have the right to have physical contact including hugging, caressing and hand-holding (Bell & Troxel).

Unfortunately, especially when it comes to persons with dementia, the general societal values that shape the beliefs and response patterns of staff persons and families, have not changed significantly as compared to the culture of censorship and repression

described in the work of Foucault (1978). Consequently, the essence of sexuality for persons with dementia has been taken custody by “stakeholders” or powerbrokers that have made a guarantee to protect these persons from their sexual feelings at all costs, even if it impacts negatively on overall quality of life. There were six stakeholder groups that emerged from this data set: a) family care providers; b) formal care providers; c) the administrative management of the organization; d) police representatives of the legal system; e) MOH/LTC; and f) the community as represented by voices reported in the media. The relationship between these powerful stakeholder groups is represented in Figure 2. Each of these stakeholder groups operated in isolation of one another, with a slightly different agenda and despite no shared dialogue, with a common purpose: prohibiting the sexuality of older adults with dementia.

The family stakeholder group operated from the position of protecting the resident from exploitation and preventing certain life “pleasures”. The staff stakeholder group operated from the position of acting as enforcers to keep the residents safe, at the same time protecting themselves from the threat of professional censorship and the judgement of their peers. The police stakeholder group operated from the position of serving and protecting from within the boundaries of the legal system using rationality and logic, despite the fact that the presence of cognitive impairment precludes the possibility of intentioned criminal acts. The institutional stakeholders operated from the position of risk management, protecting themselves from the threat of litigation. The

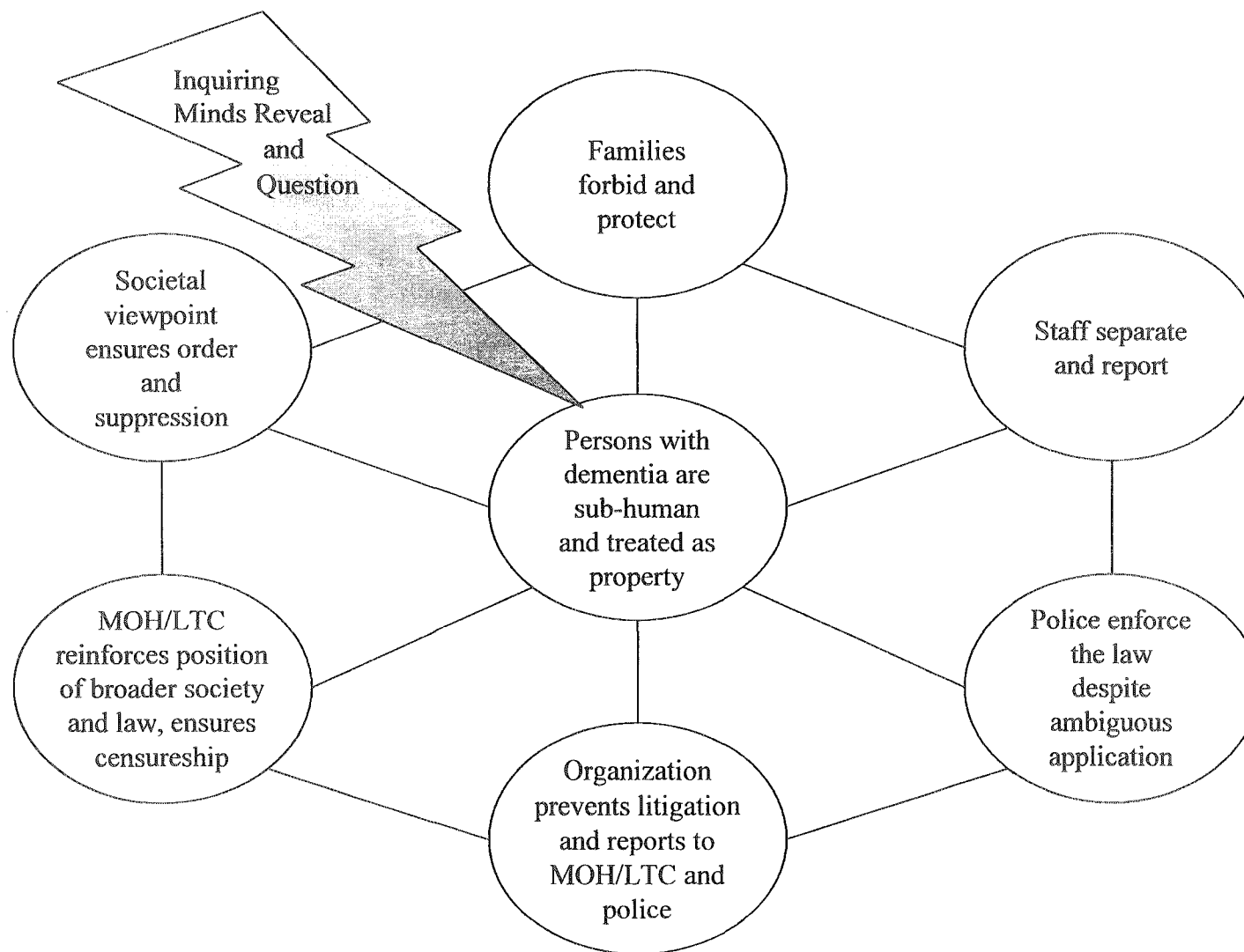


Figure 2. Context of power and protectionism related to sexuality and dementia.



societal stakeholders operated from the position of maintaining the status quo that requires control, licensure and insistence on certain rules to ensure order rather than chaos. The MOH/LTC operated from a position of rule bound reporting structures, supporting the general societal viewpoint of censorship and repression. That the process of reporting behaviour of a sexual nature to the MOH/LTC is done by way of completing an “Unusual Occurrence” document (Ontario MOH/LTC, 1993, amended 1995) reinforces that sexuality among older adults with dementia is seen as pathological. What was striking is the extent to the actions of each group serves to collude with all the others, serving to keep the secret of the sexuality of persons with dementia deeply buried.

My position as a researcher cannot be underestimated in relation to the findings of this project. Therefore, Figure 2 includes an additional element that represents the role of the “inquiring mind” that serves to explode the silence surrounding sexual behaviour by identifying those beliefs and actions that should be adjusted. By entering each unique culture as an outsider and asking questions that might give participants pause to ponder their practice decisions, I assisted participants to look at the issue of sexual behaviour with fresh eyes (Kincheloe & McLaren, 2000; Thomas, 1993). In addition, my role as researcher facilitated the identification of the few participants for this study who viewed themselves as libertines, acting on behalf of their residents by turning a blind eye when witness to developing relationships. However, by virtue of their silence, they were rebels without a home and revolutionaries with no partners. They were going out on a limb and

acting in isolation, but not taking action that would promote practice change. As a result of participating in this project, these persons were now in a position to have had their views put into the record thereby gaining courage to speak about their viewpoints with their colleagues. It is important to note here that because the questions were asked at all may have served to begin a process of change that may start the reflection and team dialogue that will be necessary to assemble the critical mass for widespread practice change.

#### Beginning to Question

One of the goals of critical ethnography within the context of critical social theory is to assist participants, through conversation with the investigator to consider new possibilities, to identify new ways of interpreting and reacting to life experiences (Thomas, 1993). Indeed, one of the goals of this study was to assist participants to begin to question and reflect upon their beliefs, values and actions related to sexual behaviour in dementia through conversation and discussion. Several participants, as a result of the interview process, began to contemplate how difficult the topic of sexuality associated with dementia actually was, yearning for a practice world that would be more expansive, liberal and tolerant. One participant was hopeful that practice in this area would indeed become more creative and open, because she had already seen movement forward in this

area comparing present practices to the “old days” when the environment was extremely intolerant of intimacy and sexual behaviour on the part of residents. She stated,

If person A thinks person B is their spouse, and the, the feelings are reciprocated or it's just somebody that they loved and were comfortable being around who's to say that somewhere in their dementia, that's not what makes them comfortable ... that isn't clicking for them, and I just figure that, dealing with dementia is hard enough without looking out, going out of your way to look for problems. If you can, .... If you can kind of work around it, rather than, .... it's hard to phrase. That, that seeing over the years, like there was that, it's harder sometimes to break, I go back to the real old days sometimes, when people have gone in and pulled residents apart because “Oh, that's just not right, yack, yack, yack, yack”, and excuse me, there wasn't a problem, the residents have gone ballistic, they've upset the entire unit, and I'm thinking, “Well, it was nice and quiet, those two residents were off minding their own business, and they weren't disturbing anybody, you come on and impose your morals and now we have a very agitated wing to deal with!”. That to me just doesn't make sense. You .... do it the way you, you do it to, to me it's more of a control thing in an institution, it's who controls what, then, um more than anything else. And, they, they, can control, and they lose so much, if they can control who they feel comfortable with, and who they want to express this part of their being to, who are we to say no to that.

One of the senior managers explained it this way,

How far do you really want to try and start being Big Brother, if you want. Because in other areas of dementia, you do take steps to protect people, because they no longer know that the stove is hot, or whatever, so you put in controls to keep that person from, from burning themselves or hurting themselves. But, it, it, you know, that's really a very sensitive, tough, question and you don't start. Because the whole idea in today's society is respect people for who they are, what they are and, and try and, and our whole goal here is to stop, uh, managing people from our perspective, trying to keep people, and keep their quality in their eyes as best as possible in really, some pretty tough living conditions. And I mean, we, if you step back and you walk down the halls and you watch how tough you have to be to get old, and what you give up. You know .... it is, it is really, really awful. You give EVERYTHING up. Including your sexuality.

One participant acknowledged that the process of participating in the interview helped her identify contradictions and discrepancies in her practice beliefs. She also saw the interview as an opportunity to clarify her thinking on the topic. She stated,

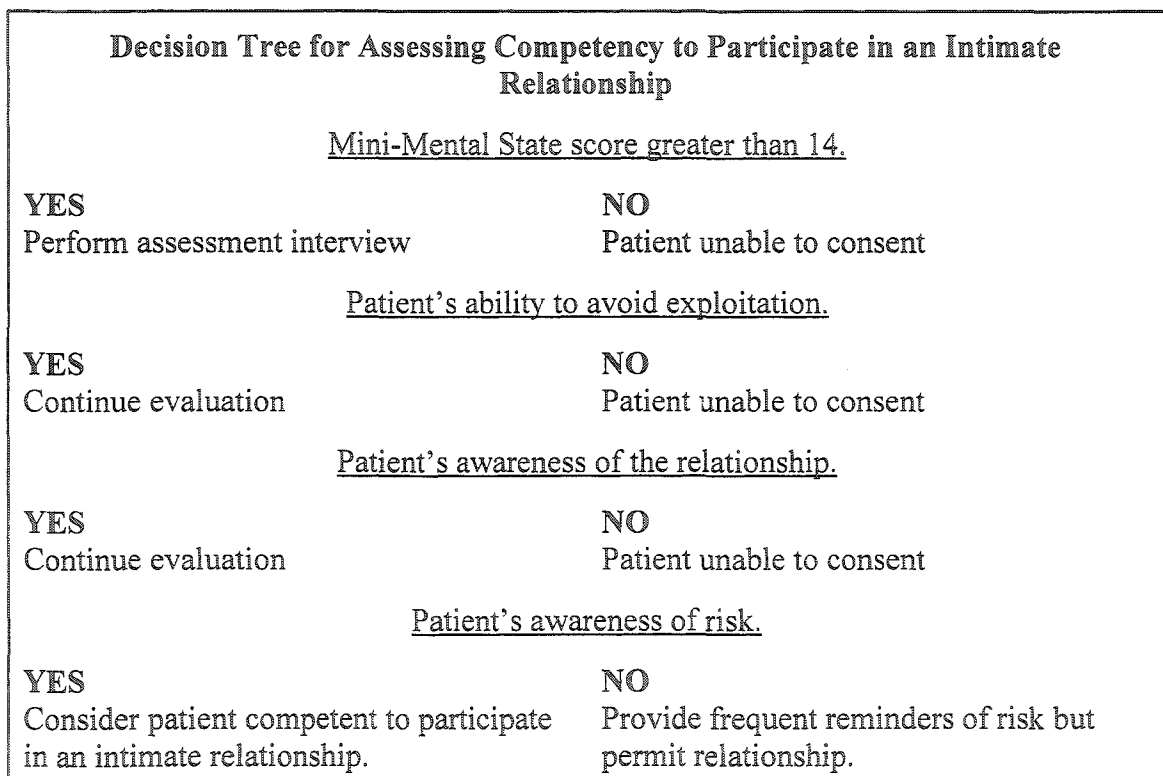
I find it interesting because my role as a professional, and how I view this for other people is very different from um, how I as an individual um, see the topic as a Christian, single, female, and um .... so it's been interesting talking to you and just, all of a sudden I would say something, and I would just think, why did I say that, where did that come from, that makes absolutely no sense, or I haven't even thought of it that way before.

#### Decision-making and Sexual Behaviour in Dementia

Overall, decision-making about how to interpret and respond to sexual behaviours between residents was fraught with uncertainty, difficulty, and ambiguity. If the person with dementia is “not a person”, then how are we to treat and respond to their sexual displays? The participants of this study were conflicted about the natural tendency to try to eradicate these behaviours as one would control the unruly behaviour of a pet. However, the correct way, the right answer was not clearly apparent. Therefore, clinical dialogue seems to be the necessary element that is missing here. If clinical dialogue were encouraged about this hidden topic, clinical teams would likely feel more comfortable with practice decisions that they made together. Because it has been driven underground, the participants of this study described feeling so very vulnerable. In this kind of decision-making environment, of course front-line staff will protect themselves from

malpractice litigation by being conservative with the residents in their care. Without dialogue there will be no massaging of the practice environment so that the common ground can be defined, expanded, understood and embraced.

Overall, the stories of participants revealed a response pattern that was a linear and reductionist approach to decision-making. Interestingly enough, although protectionist, the decision-making of the participants involved in this study was somewhat more expansive than the reasoning format suggested by the work of Lichtenberg (1997). In his decision-tree outlining clinical response to dementia, Lichtenberg reinforced the assumption that the sexual desires of the person who was severely regressed in the disease state should be forbidden and restricted primarily on the basis of competence (Figure 3). If the person with dementia scored below 14 on a Folstein Mini Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975; Cockrell & Folstein, 1988), the person should be considered “incompetent” and the relationship should be terminated, and no other assessments need be undertaken, because they are irrelevant. In this instance, cognitive capacity serves as a kind of “moral trump”. While Lichtenberg’s format is a preliminary foundation upon which clinicians can begin to reflect more carefully on the sexual relationships of persons with dementia, it reinforces the pervasive societal value of “hypercognitive arrogance” (Post, 2001). Two people with dementia cannot be allowed to relate because they cannot “think”. The person with dementia is portrayed as a sexual incompetent, therefore feelings and needs



*Figure 3.* Linear decision-making schema (present state of literature) (Lichtenberg, 1997).

can be disregarded and negated. This conservative decision tree was based on an arbitrary cognitive level, the validity of which has not been empirically established in the real world of clinical practice (P. Lichtenberg, personal e-mail communication, Friday, April 20, 2001).

In other words, the relationship between the MMSE score and the capacity to give an account of one's sexual behaviour has not been "tested". From a critical theory perspective, Lichtenberg's (1997) model delimits questions to "how to" instead of "why should". It is obsessed with issues of technique, procedure and correctness, forgetting the humanistic purpose of the assessment (Kincheloe & McLaren, 2000). The model's over-riding focus on capacity is a comfortable position, a handy, over-simplified choice that serves to reduce the anxiety and discomfort experienced by professional staff and families. Unfortunately, the sexual rights and freedoms of the person with dementia are forfeited in the process.

The reasonableness of using the MMSE score as an absolute criterion is beginning to be questioned by some of the participants of this study. In comparing the state of decision-making patterns in the research sites with those represented in the literature, it is apparent that the practice decisions of clinical staff at the three facilities were more complex, albeit still parentalistic and restrictive, as represented in Figure 4. However, in the case of study participants, more questions were likely to be considered, some of which were absent from Lichtenberg's (1997) framework, as represented in

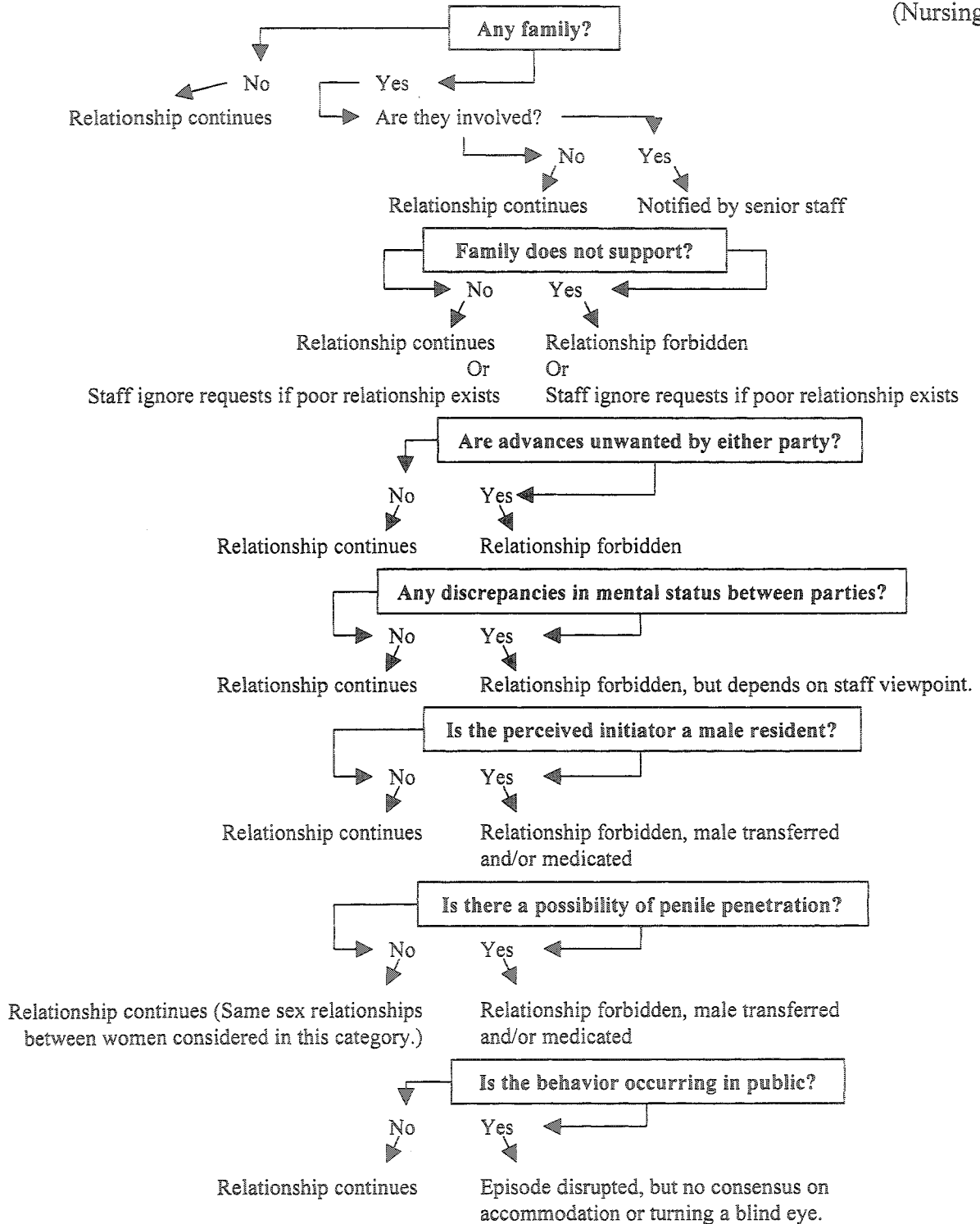


Figure 4. Linear decision-making schema – Version 1 (present state of study sites).



Figure 3. For example, Lichtenberg (1997) has not explicated the full extent to which the values of individual players, the beliefs of the family, or the environmental context within which behaviour is displayed could play a part within a clinical decision-making framework.

Perhaps the most significant finding of this study could be identification of a pervasive myth: PERSONS WITH DEMENTIA ARE INCOMPETENT WHEN IT COMES TO THEIR ABILITY TO AGREE TO PARTICIPATE IN SEXUAL RELATIONSHIPS. The common societal interpretation of this, the implications of this, is that front-line workers, front-line managers, senior managers and families all operate from a power base whereby persons with dementia are non-persons with no rights realized except this extremist manifesto that they should be protected from exploitation. The very nature of this desire has resulted in a pervasive OVER-PROTECTIONISM, that is in direct conflict with the typical rights of humanity espoused by the Alzheimer Society. For example, the person with Alzheimer disease has the right to love and to be loved; to feel successful; to feel connected; to have physical contact including hugging, caressing and hand-holding; and engage in behaviour that has meaning for them (Bell & Troxel, 1994, 1997). The rampant over-protectionism upon which many of the practice responses of most participants are built actually precludes the achievement of most of these goals, particularly when it comes to sexual expression. This has led to a subtle

domination over the rights of persons with dementia to participate in relationships as they choose.

In direct contrast, recent literature states that persons with dementia are adults capable of adult feelings that will allow them to engage in significant relationships (Kitwood, 1997). Clearly this is not allowed when it comes to relationships that involve sexual intimacy. Staff and families hide from the potential beauty of these relationships behind the shroud of “we must serve and protect”. Unfortunately, in at least two instances this need to protect, this unnecessary overprotection, resulted in relationships being highly censored or forbidden. For example, the children of one female resident interfered with her developing relationship with a gentleman caller and ended it for her, despite her protests. Unfortunately, her will was not considered and she was treated as a non-person. The family member who told this story was not even certain if she had a conversation about this with her mother, the relationship was terminated by an action of her brother, and her mother expressed her concerns about this to somebody else. This is most certainly an example of powerlessness. The husband of one female resident was also censored and spied upon by staff in order to ensure that his intentions were honourable. He was gossiped about, judged, and found to be wanting. He was considered an exhibitionist. His opinion or his viewpoint was not even actively canvassed. There was no attempt by care providers to deeply understand his position or

even his relationship with his wife. He was also subjugated to domination within the culture where his wife lived.

The power source driving practice in these instances appears to be uncertain, but appears to be related to the concepts of ownership or property. Who owns the resident and who holds the power? Is it the MOH? This doesn't appear to be so, because the Ontario MOH/LTC "Unusual Occurrence" (Ontario MOH/LTC, 1993, amended 1995) document is clear, but nobody follows it to the letter. Is it the Police? Is it the Board of Directors of each LTC facility? Is it the family members? Perhaps the ambiguity that has stymied clinical decision-making, has also infected inter-personal relationships. Because it is unclear who is actually spearheading the domination, and who "owns" the resident (and certainly residents don't hold their own power), it becomes an even bigger challenge to clarify and it is hard to know where to begin.

Perhaps one of the reasons that restrictive and linear clinical reasoning surrounding the topic of sexuality and dementia is so very difficult relates to the degree of emotional response that comes with the territory of something as sensitive as sex. Traditionally, clinical reasoning has been viewed as a thinking strategy that is distinct and superior to emotion. As MacMurray (1935) states,

We associate reason with a state of mind which is cold, detached and unemotional. When our emotions are stirred we feel that reason is left behind and we enter another world - more colourful, more full of warmth and delight, but also more dangerous. (p.16)

It is clear from the words of participants in this study, that clinicians do not feel comfortable with the sexual expressions of persons with dementia because they feel they are treading in dangerous territory. This would suggest that a negative emotional response to uncertainty is part of the clinical reaction that drives staff to censor relationships so heavily. As one participant stated,

First of all I would separate them, but I will not encourage them and bring them to their own rooms, together, like once I get them separated, then it's up to them if they want to continue somewhere else, and then I will just keep an eye on them. It is not my job to encourage them, because for me it's kind of, .... uh .... shaky ground.

Wurzbach (1991) suggests that clinicians often approach ambiguous clinical situations with the fixed belief that a specific result will occur as the outcome of a chosen intervention. This restricts the capacity of the clinician to consider with serious intent all possible treatment and response options. Wurzbach suggests that it is important that clinicians develop the capacity to recruit and weigh contradictory evidence so that they can take into account the unique variable associated with each clinical situation. This will not happen without open dialogue between clinicians, and it is already apparent that no forum for open dialogue about sexual behaviour in dementia exists within any of the three LTC facilities in this study.

Higgs and Jones (2000) define clinical reasoning as complex, multidimensional thinking and decision-making processes essential for autonomous professional practice. Reasoning is a thinking process that enables the clinician to select judicious and

perceptive action within a specific clinical context. They suggest that in order to be effective in the post modern world, reasoning must take place within the broader context of community, informed by the social ecology of the large work environment, yet maintaining a client-centred focus. They perceive that the rule bound, linear thinking pathways of the scientific process used to illustrate causal laws in the natural sciences are insufficient to describe the cognitive, interpretive and reflective processes necessary for reasoning in the human context. Unfortunately, from the accounts pieced together through investigations of this study, each of the three work environments encourage that staff follow pedantic, rule-bound reasoning patterns.

Higgs and Titchen (2000) perceive clinical reasoning to be the vehicle for knowledge use in clinical practice as well as knowledge generation. To reason effectively, clinicians need different forms of knowledge, including theoretical/prepositional knowledge, procedural craft knowledge and personal knowledge. Unfortunately, it would appear that in the area of sexuality and dementia, the necessary ingredients for effective and compassionate clinical reasoning that maintains a client-centred focus are all missing. The participants in this study, reflective to a certain degree of the state of the art of decision-making across three facilities, lack theoretical knowledge, procedural craft knowledge and personal knowledge. They have not been educated in the topic of sexuality and dementia. They have not reflected upon their own personal values and belief systems, consequently their practice decisions are often

predicated on knowledge that runs deep, but is not necessarily conscious. In addition, their practice responses are awkward and out of step with the philosophical tenets of person-centred care.

It may be that some aspects of clinical decision-making in situations that involve the sexual behaviours of persons with dementia must ultimately rely heavily on the intuitive capacity of clinical teams. It is highly possible that the “right” answer in many of the clinical situations surrounding sexual expression will not be readily apparent. Carnevali (2000) suggests that the thinking, reasoning clinician must have the capacity to engage in self-dialogue, reflection and questioning so that over time, with repeated use of thinking skills in a variety of clinical situations, the clinician develops artistry and expertise of practice. The thinking, reasoning clinician is seen as flexible and innovative.

Jones and Brown (1993) share this viewpoint, suggesting that the thinking, reasoning clinician is one who can evaluate perspectives that differ from one’s own so that important ideas, complicating factors, other plausible interpretations, and new insights can be identified. The critical thinker therefore strives to practice beyond the boundaries of rules and formulas. Again, without a supportive and nurturing forum wherein open dialogue about sexual behaviour in dementia can occur, clinical decision-making patterns will remain linear and formulaic. Consequently, management strategies will continue to be repressive and restrictive.

Benner and Tanner (1987) propose that the reasoning clinician has an expansive capacity to be flexible in the face of clinical ambiguity, because of an inherent ability to gain deep understanding of any given clinical situation based on a rich integration of knowledge, skills and expert know-how. The reasoning clinician can think far beyond the limitations of standard assessment forms, checklists and decision trees.

Lubart (1994) suggests that there are five attributes that result in a capacity to engage in creative reasoning. They include having tolerance for ambiguity, perseverance, an openness to new experiences, a willingness to take risks, and the courage of one's convictions and beliefs. Clearly, fundamental to the process of multidimensional and expansive thinking are the qualities of the thinker. The clinician must have not only a capacity to engage in reasoned reflection, but must also possess certain qualities that are beyond reason and are themselves "value-laden" such as courage, honesty and passion.

Upon further reflection on the phenomenon of sexual behaviour in dementia, it would seem that there is a fundamental tension between dichotomous philosophical positions. The person with dementia lives within a cultural milieu that supports being treated with the utmost respect and compassion, someone of inherent value despite the existence of a disease that will steal the very essence of "self". In the philosophical tenet of person-centred care (Kitwood, 1997), the essence of the person is to be celebrated and honoured. However, when it comes to the sexual essence of the person with dementia, a

conundrum exists. The person with dementia must be protected from the sexual core of the self. It is to be controlled, repressed and extinguished. The results from this study point to the need to resolve the tension that exists between these two opposing paradigms.

Silva (1999) suggests that integration of opposing paradigms may come about when clinicians cease to cling to the traditional process of making sense of clinical issues using logic and linear reasoning. She suggests that retroductive reasoning and fuzzy logic should be used to explore clinical phenomena where logical reasoning cannot occur or be exact. It may be that fully understanding the sexual expression of persons with dementia will always be to some extent elusive. This would support the need for clinical dialogue to an even greater extent.

Decision-making in the area of sexual behaviour and dementia should at the very least involve a reasoning strategy that mediates the flow of care from ambiguity through to narrative image and finally to clinical action. In terms of the discomfort that clinicians and families feel regarding ambiguity of clinical outcome, clearly this is deeply rooted in the reductionist and parentalistic thinking of the empirico-analytical scientific paradigm represented in Figures 3, 4 and 5. However, in the case of sexual behaviour, the thinking that must be used to deeply understand the full range of disinhibition must be far beyond linear patterns. It is critical that clinical teams use a nonlinear decision-making approach



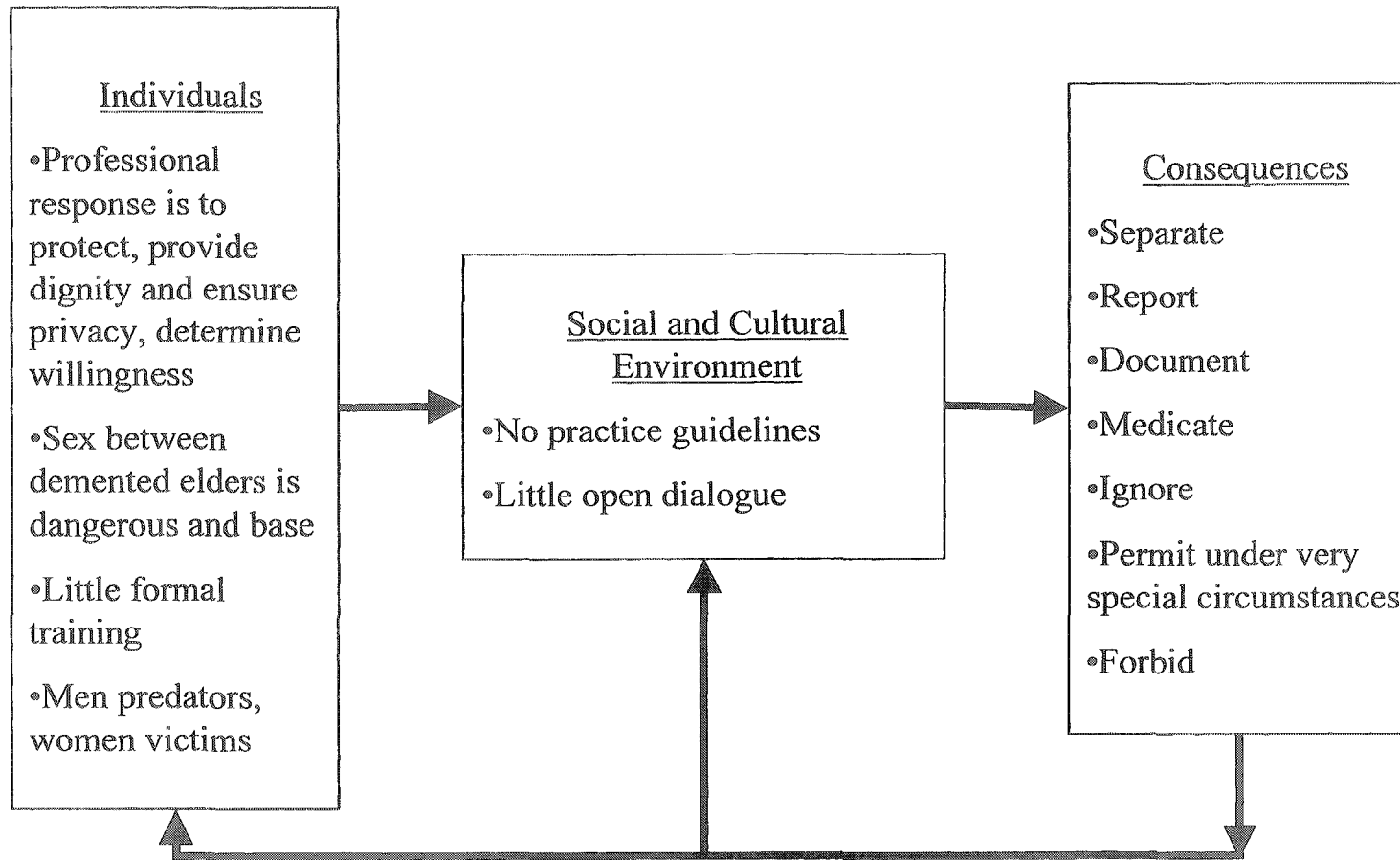


Figure 5. Linear decision-making schema – Version 2 (present state of study sites).

more akin to the complexity of sexual behaviour as is represented in the schematic diagram in Figure 6.

#### Toward a Nonlinear, Dialogical Decision-making Schema

The decision-making model represented in Figure 6 evolved from analysis of the anecdotes and accounts of the participants of this study as compared with the review of the literature. I was struck with the fact that if many of the participants in this study were to operate within an organizational culture that was not “risk-averse” and thrived on innovative thinking, that those “few good (wo)men” would actually operate quite differently. Decisions would not be made in isolation of each other. There would be a culture of openness, acceptance and tolerance where the meaning behind any one behaviour would be actively sought out, clearly identified, communicated with everyone, understood and therefore accommodated in the most respectful fashion possible.

The first circle at the top of Figure 6 supports that whatever decision-making takes place is grounded in the organization’s Vision and Mission Statements. The statements found within the Vision and Mission of most LTC facilities suggest that they support the rights, needs and personhood of all those who come under their care, including those residents suffering from cognitive impairment. Any practice guidelines related to the assessment and management of sexual behaviour must therefore be predicated on the basis of such compassionate organizational foundational beliefs. With

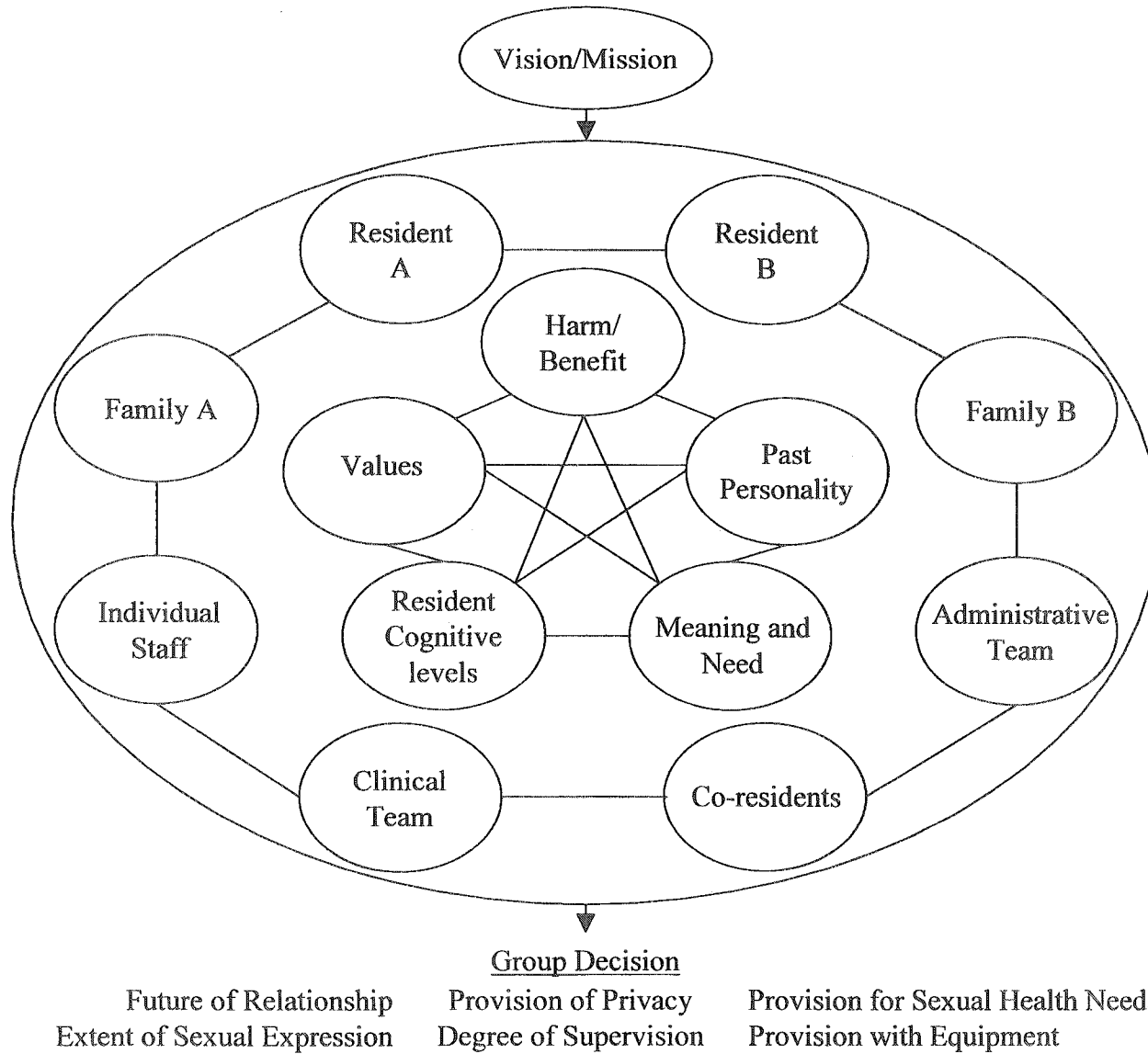


Figure 6. Nonlinear decision-making map/schema (alternative)

the Vision and Mission in mind, the clinical team and family will gather to discuss the case at hand in terms of each of the concepts within the inner circle at the center of the diagram. They will first identify how the sexual behaviour of the resident(s) relates to their own value and belief systems. They will discuss the presence and absence of indicators that support whether or not this is a behaviour that is mutually acceptable to the residents involved in the relationship, is discriminate and exclusive, identifying the possibility of implied consent. They will discuss how emotional responses to the observed sexual behaviours must be separated from the appropriate professional, mature responses that should be based on what is in the “best interest” of the residents concerned, rather than based on protecting the sensibilities and moral consciences of the team. They will identify and discuss the possible meanings behind the sexual behaviour, for example, the unmet needs that are the root cause of the behaviour, and then explicate the corresponding interventions to address them in creative, compassionate and acceptable ways. They will discuss the past preferences, practices and personality of the resident(s), including relationships of the same gender. The team should recognize that the person who “is now” and their expressed needs should be considered the paramount resident of concern, not the person who “was before”. That being said, the team should understand that the person who “was before”, needs to be symbolically present in the room, and be engaged in an imaginary dialogue so that reasonable interventions that honour their past preferences and practices can be taken. For example, in the case of a

highly religious woman who was very private, never dated within a span of 20 years of widowhood, and is now disinhibited and engaging in kissing and caressing in public, the team and family may agree that they will do everything they can to honour the privacy that this woman always relished, and protect her dignity by directing her to a private place rather than simply forbid the relationship because it clashes with her prior moral values, a restrictive practice recommended by Collopy (1988). As Berger (2000) states, “contemporaneous comforts and pleasures may be the only relevant concerns in considerations of quality of life” (p. 311).

Continuing with Figure 6, the team will also engage in a dialogue to explicate the harm-to-benefit ratio. For example, if the likelihood of sexual intercourse is high, the team should discuss with the family the reasonableness of testing both potential partners for STDs. In all, the considered dialogue should always address each of these issues, and in collaboration with the family result in the identification of a number of interventions, that may include the provision of erotic material, an escort service, a private room, or other equipment. These interventions are then discussed with each and every staff person so that practice response is consistent, respectful and innovative. Consideration will also be given to the potential impact of co-residents within the social milieu. The special considerations necessary to maintain everyone’s dignity will therefore be identified. The most important piece here is that there must be active dialogue. The lines connecting each of the elements within Figure 6 represent the need for continued considered

conversation. If any one of the lines connecting the circles within the figure are missing, the outcome for the resident(s) will not be satisfactory or based on a complete review of all the issues involved. This illustrates a much more complex process than what the present models seen in Figures 1, 3, 4 and 5 would suggest, leading to the identification of strategies that might serve to relax the stringent controls that care environments apply to the sexual behaviour of residents with dementia. The key point here is that the humane course is to admit the dilemma and ethical bind, admit the tension between the proposed and pre-existing models of decision-making, and struggle through the decision using all the elements in a considered dialogue.

## CHAPTER SEVEN

### *My Flower, My Valentine*

*A long time ago  
Twenty years or more,  
Red roses for my birthday  
From my friend.  
He used to call me "my flower".  
Surprised and happy,  
I stripped off the leaves  
And put them in my diary.  
They lasted a long time.*

*Rich red roses,  
When we were married.  
Violets and roses  
Little pink and yellow rosebuds  
Smelling like lemon cream pie  
With a shine on the top!  
I put them in a special vase  
All to themselves.  
Used slightly warm water,  
Put an aspirin in  
To make them last!*

*One beautiful Valentine card  
To Charles  
And to me.*

*He puts it away in his file,  
And when it is February 14th*

*He puts it in a fresh envelope,  
Lays it on the breakfast table.  
I have a Valentine with a heart on it.  
I take it out,  
And look at it ... Often.*

*(Foreman, Wilkinson, Aaron, Graham, & Watt, 1992)*

### From Pillow Talk to Professional Practice:

#### Implications for Practice Guidelines, Education, and Further Research

The results of this study paint a portrait of persons with dementia who are repressed sexually and considered non-persons with no right to express any sexual essence. This non-sexual status persists despite the fact that sexual feelings most definitely exist as evidenced by the words of longing in the poem created by persons with dementia that introduces this chapter. The practice guidelines related to sexual behaviour in dementia were either non-existent or insufficient in ways that supported the continuation of a predominant culture of control and censorship. In addition, families and staff members were uneducated about sexual behaviour in dementia, following decision-making patterns that were formulaic and linear, and based on their own belief and value systems. The implications of these findings related to the development of practice guidelines, education, and further research will be discussed in this section.

#### Implications for the Development of Practice Guidelines

One of the major findings of this study was that clinical teams in LTC facilities are operating in the context of ambiguity and uncertainty in the area of sexual expression and dementia. Practice guidelines in the three facilities for this study were either non-existent or insufficient to address the complex issues surrounding sexuality and dementia. As a consequence, front-line care workers and families made judgements based on



personal value and belief systems. Therefore, it is essential that families and all levels of staff become directly involved in the development of practice guidelines. Since practice response appears to be highly influenced by personal value and belief systems, it is essential that as many front-line staff and families as possible are involved with the development of guidelines and the evaluation of their implementation. One strategy to operationalize this would be to identify “care unit” champions who would be able to act as liaison between their colleagues and the team assembled to develop guidelines. Guidelines need to be comprehensive to the degree that they explicate the process through which clinical dialogue will assist a team to achieve consensus with the family as to how to proceed in each unique clinical situation. In addition, guidelines need to be reflective of the potential for relationships developing between residents of the same gender, and need to acknowledge the sexual needs of transgendered individuals. There were few references or mention made of this group of older adults, despite the fact that these individuals might be present in each of the sites. The guidelines should encourage a culture of tolerance, understanding, inquiry and dialogue, not one of surveillance, judgement and censorship.

Clearly, an open culture of inquiry cannot be shaped without the vision and leadership from representatives of the senior management teams in LTC facilities. Therefore, it is critical that those within organizational cultures who might spearhead a visionary change in this clinical practice area, be supported and encouraged to be

innovative. Presenting the results of this study at a local LTC Administrator's meeting might be one such venue. The recommendations related to clinical practice are as follows.

#### Micro-level Clinical Practice Recommendations

1. Practice guidelines should be developed with direct collaboration from all levels of staff, and include families and volunteers.
2. Practice guidelines should include a more complex approach to sexual assessment and consent capacity that carefully considers all the variables involved in sexual relationships, as suggested in Figure 6.
3. Organizations should encourage and model open dialogue between clinical team members and families. Senior managers are in a position to model this behaviour, thus creating a culture of considered conversation. In addition, front-line care workers must be given permission to talk about the sexual behaviours of the residents in their care, both with each other and with families.
4. Clinical case discussions should take place when it is noted that relationships are developing between co-residents. A dialogue using the schema suggested in Figure 6 will assist teams to make practice decisions on the basis of reasoned reflection rather than personal values.

5. Sexuality, sexual history, relationship history, sexual preferences, and intimacy needs should all be discussed with families at the time of admission to a LTC facility.
6. Care communities should review the availability of resources and equipment to meet the sexual needs of persons with dementia. For example, privacy rooms, dolls, toys, erotic material, escort services, and “Do Not Disturb” signs should all be discussed and made available when appropriate within the context of each resident’s situation.

#### Practice Implications for the Broader Community

1. The results of this study should be presented at the Regional LTC Administrators meeting. This will promote discussion between administrators and senior management team representatives within the broader community so that implications for social and community policy change can be identified.
2. Local resource agencies such as the Continuing Gerontological Education Cooperative could host practice guidelines clinics so that local LTC facilities could build resident-friendly approaches to sexuality together. This way practice guidelines would be consistent across facilities. A collaborative initiative might prove more fruitful since creating practice guidelines in isolation with few resources is not likely to succeed. In addition, a collaborative effort would help

to overcome the inertia experienced by the participants of this project as they struggled with developing practice guidelines in isolation.

3. The results of this study should be presented to the police services for seniors within the central region of the province of Ontario. This might lead to the development of a community education strategy to enhance knowledge of police constables who work with vulnerable older adults.
4. Provincial Alzheimer Societies should come out strongly in support of dialogue and tolerance regarding sexual expression in dementia. Local Societies should encourage family support groups on this topic and engage in a public awareness strategy. In addition, Alzheimer Canada should amend its Quality Care Guidelines documents to include sexuality as an explicit need and quality of life indicator.
5. Alzheimer Canada should host a review of Ethical Guidelines so that care providers recognize sexual expression to be an inherent part of the right of the person with dementia to experience an esthetic well-being and freedom of self-expression.

#### Implications for Education

There was no evidence that staff had had adequate opportunity to explore their own value and belief systems related to sexual expression. Since these were only

partially conscious, huge inconsistencies of practice responses were evident in the study sample. Values clarification exercises would be helpful to assist both staff members and families to explore their own value and belief systems, within the context of the philosophical tenets of person-centred care. In the process of identifying these, it may be possible to assist staff and families to separate their own value and belief systems from what is considered ethically and morally correct for the compassionate care of persons with dementia. In addition, topics related to sexual expression in the face of dementia need to be included in ongoing continuing education programs for all front-line staff. For example, staff should be assisted through case study and role play to anticipate clinical situations that might cause discomfort without adequate preparation, and they should be informed about the incidence/prevalence of the likelihood of sexual intercourse and genital contact so that they can confront their “worst fears” and put them into perspective.

Sexuality and dementia should also be included in the orientation programs for all new staff, and should also be on the agenda of family council meetings. In addition, the topic of relationships of intimacy, their potential to enrich quality of life, and provisions that would be made by staff to ensure dignity should be added to the orientation package for families as their relatives are admitted to the LTC facility. Social work staff should be coached so that they can help educate the families and understand such relationships in a positive context. In addition, LTC facilities would do well to develop an in-house

“sexpert”, one who can keep abreast of the literature in this area, assist with staff development, and provide clinical consultation and guide team discussion around difficult clinical cases. Lastly, but most importantly, sexual expression in the face of dementia should be included as a topic for review in the curricula of personal support workers, health care aides and front-line clinical managers in basic educational preparation programs.

The following recommendations are made regarding education:

1. Implement values clarification exercises for staff and families that focus not only on sexuality and sexual expression in dementia, but also on personhood.
2. Conduct regular educational in servicing on topics related to intimacy, sexual expression and dementia for both professional caregivers and family.
3. In larger facilities with greater human resources, develop an in-house “sexpert” to deal with issues related to intimacy and sexuality for all residents, not just those with dementia. For smaller facilities with fewer resources, ensure the availability of local Psychogeriatric Resource Consultants who could provide consultation regarding behaviours of a sexual nature.
4. Expand preparatory curricula for front-line personal support workers, dietary aides, and front-line clinical supervisors to include sexuality associated with dementia.

## Implications for Further Research

One of the major limitations of this study was the number of participants involved, particularly in the area of family members. Four family members was an insufficient number on which to base findings that could at all be considered representative of the majority of families. It is therefore highly recommended that further research be conducted with large groups of family members. In addition, it is very important that persons in the early stages of Alzheimer Disease be given a voice in this sensitive topic area. The Alzheimer Societies in Ontario and Canada are beginning to offer wonderful and important support groups to those persons in the very early stages of the disease. These persons should be invited to be involved in research studies that would allow them to influence practice related to sexual expression in dementia. It might also help clinicians to better understand the conflict that can exist between the sexual behaviour of the person who “was” versus the person who is “is” (Post, 1995).

In addition, to further examine and resolve the tension between opposing paradigms represented by the “old” and “new” cultures of dementia care, it would be helpful to conduct research that would explicate the positions of the MOH/LTC and the police/legal systems. It would be very interesting to canvass community police constables who specialize in responding to the needs of older adults. These are the law enforcers who respond to calls from LTC facilities. How do Ministry guidelines and

Police codes of professional conduct influence the decision-making mechanisms that were evident from these study results?

In addition, it would be interesting to conduct further research in the area of educational preparation for staff. One focus of research could be on explicating the most effective type of educational intervention that would support the critical thinking capacity necessary for front-line supervisors and front-line staff members to be innovative in this sensitive area of practice.

The implications for further research are summarized as follows:

1. Conduct a study evaluating an educational intervention to change widespread cultural protectionism and sexual repression, using a before/after design with true randomization procedures.
2. Conduct a study examining the impact of values clarification exercises on the attitudes and approaches of front-line care workers to the sexual behaviours of persons with dementia.
3. Interview MOH/LTC Personnel and discuss with them what they think about the findings of this study. Would they see a need to modify their “Unusual Occurrence” document? What guides the advice that MOH/LTC Compliance Advisors issue to a LTC facility should a family member register a complaint about sexual relationships between persons with dementia? What about the viewpoints of police officers and Crown Attorneys?



Further practice policy, educational and research initiatives are essential for topics related to sexual behaviour and dementia. The lack of information available in the literature exemplifies the very nature of this problem: It is the last horizon that requires building an expert, evidence-based body of knowledge so that persons with dementia live out their lives within the context of positive and affirming relationships, even those that might help maintain them as sexual beings.

## CHAPTER EIGHT

### Conclusions

The findings from this research study have served to explicate some of the response patterns of professional care providers and family members to the sexual behaviours of persons with dementia living in LTC. All three sites had limited in-house resources, poorly developed or nonexistent practice guidelines, and management strategies based on highly conservative and restrictive risk management philosophies. As a result, sexual expression for persons with dementia exists in these facilities within a vacuum that would preclude formal exploration of ways to promote their sexual health.

When making decisions on how to respond to episodes of sexual behaviour or intimate relationships developing between two persons with dementia, staff were inclined to use linear, reductionist frameworks that would invariably lead to the same outcome: censorship. These patterns of decision-making were reinforced in all three settings by either the non-existence of policy and practice guidelines, or the existence of very restrictive ones. The clinical reasoning blueprint related to sexual behaviour in dementia existing within each facility was discovered to be in direct conflict with the philosophical tenets of person-centred care. In fact, within the context of this study, persons with dementia had been relegated to the realm of non-person status, powerless to act upon their own desires, particularly where it related to sexuality. Thinking processes attached

to episodes of sexual behaviour were reflective of the empirico-analytical paradigm, in direct opposition to the goals and ideals behind person-centred care.

Factors that may have influenced the existence of the overall cultural milieu of repression and silence, similar in all three facilities, include the lack of open collegial dialogue through which sexual behaviour associated with dementia can be deeply understood and sensitively responded to within the context of each unique clinical situation. The tension between the opposing philosophical positions of protectionism can only be resolved through the development of practice guidelines and decision-making patterns that are innovative, involve multiple cognitive processes, and reflective of the humanistic-interpretive paradigm. In other words, clinicians and families must work together to develop guidelines that reflect the complex nature of what it is to be a human being with intact sexual feelings in the face of cognitive losses.

As a clinician, I was sobered to discover the degree to which the beliefs about and practices in response to sexual behaviour of persons with dementia were negative, controlling and out of sync with the philosophical tenets of the “new” culture of dementia care. It was my intent to uncover the hidden personal and political agendas of the unique cultural settings being investigated in this study. By doing so, I have experienced an ever stronger desire to effect practice change in the topic area. It is my hope that any reader of this document or any publications that it generates will not only be stimulated, but will be

incited to a level of personal awareness that they will take fervent action in the direction of positive change.

This dissertation comes to a close with the first stanza from a song written by Harry Warren and Mack Gordon (1960), entitled “At Last”, wherein the yearnings, and heart’s desire of an isolated someone, have been realized.

*At last, my love has come along.*

*My lonely days are over, and life is like a song.*

One can only hope that this would be the case for all persons with dementia. I envision a future in which it is possible for persons with dementia to openly enjoy relationships of deep personal satisfaction and meaning because these are encouraged and celebrated, not fleetingly stolen moments because sexual behaviours are extinguished and censored.

## REFERENCES

- Acorn, M. (1972). *More poems for people*. Toronto: New Canada Publications.
- Aamodt, A. (1989). Ethnography and epistemology: Generating nursing knowledge. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 29-40). Rockville, MD: Aspen.
- Alexopoulous, P. (1994). Management of sexually disinhibited behavior by a dementia patient. *Australian Journal on Ageing*, 13, 119.
- Amadeo, M. (1996). Antiandrogen treatment of aggressivity in men suffering from dementia. *Journal of Geriatric Psychiatry Neurology*, 9(3), 142-145.
- Archibald, C. (1998). Sexuality, dementia and residential care: Managers report and response. *Health and Social Care Community*, 6, 95-101.
- Archibald, C. (2002). Sexuality and dementia in residential care - Whose responsibility? *Sex Relationship Therapy*, 17(3), 301-309.
- Archibald, C. (2003). Sexuality and dementia: The role dementia plays when sexual expression becomes a component of residential care work. *Alzheimer's Care Quarterly*, 4(2), 137-148.
- Atkinson, P. (1992). The ethnography of a medical setting: Reading, writing, and rhetoric. *Qualitative Health Research*, 2, 451-474.
- Ballard, E. L. (1995). Attitudes, myths, and realities: Helping family and professional caregivers cope with sexuality in the Alzheimer's patient. *Sexuality and Disability*, 13, 255-270.
- Ballard, E. L. (1997, Summer). Another side of caregiving: Addressing the intimacy needs of the nursing home resident with dementia. *The Caregiver*, 14-16.
- Ballard, E. L. (1998). Sexuality, intimacy, and meaningful relationships in the nursing facility. In M. Kaplan & S. Hoffman (Eds.), *Behaviors in dementia: Best practices for successful management* (pp. 239-253). Winnipeg: Health Professions Press.

Bell, V., & Troxel, D. (1994, Summer/October). An Alzheimer's disease bill of rights. *The American Journal of Alzheimer's Care and Related Disorders and Research*, 3-6.

Bell, V., & Troxel, D. (1997). *The best friends approach to Alzheimer's care*. Toronto: Health Professions Press.

Benner, P., & Tanner, C. (1987, January). Clinical judgment: How expert nurses use intuition. *American Journal of Nursing*, 23-31.

Berger, J. (2000). Sexuality and intimacy in the nursing home: A romantic couple of mixed cognitive capacities. *Journal of Clinical Ethics*, 11(4), 309-313.

Braaten, J. (1991). *Habermas's critical theory of society*. Albany: State University of New York Press.

Braithwaite, R., Bianchi, C., & Taylor, S. (1994). Ethnographic approach to community organization and health empowerment. *Health Education Quarterly*, 12, 407-416.

Brandriet, L. (1994). Gerontological nursing: Application of ethnography and grounded theory. *Journal of Gerontological Nursing*, 20, 33-40.

Browne, J. (2000). Potential contributions of critical social theory to nursing science. *Canadian Journal of Nursing Research*, 32, 35-55.

Buckley, P., & Hyde, J. (1997). State hospitals' response to the sexual behavior of psychiatric inpatients. *Psychiatric Services*, 48(3), 398-399.

Burns, A., Jacoby, R., & Levy, R. (1990). Psychiatric phenomena in Alzheimer's disease. *British Journal of Psychiatry*, 157, 86-94.

Cahill, M., & Fonteyn, M. (2000). Using mind mapping to improve students' metacognition. In J. Higgs & M. Jones (Eds.), *Clinical reasoning in the health professions* (pp. 214-221). Boston: Butterworth Heinemann.

Campbell, J., & Bunting, S. (1991). Voices and paradigms: Perspectives on critical and feminist theory in nursing. *Advances in Nursing Science*, 13, 1-15.

Carnevali, D. (2000). Self-monitoring in clinical reasoning. In J. Higgs and M. Jones (Eds). *Clinical reasoning in the health professions* (pp. 166-173). Boston: Butterworth Heinemen.

Cockrell, J. R., & Folstein, M. F. (1988). Mini-mental state examination. *Psychopharmacology Bulletin*, 24(4), 689-692.

Cohen-Mansfield, J. (2000). Theoretical frameworks for behavioral problems in dementia. *Alzheimer's Care Quarterly*, 1, 8-21.

Cohen-Mansfield, J., & Taylor, L. (1998). Assessing and understanding agitated behaviors in older adults. In M. Kaplan & S. Hoffman (Eds.), *Behaviors in dementia: Best practices for successful management* (pp. 25-41). Winnipeg: Health Professions Press.

Collopy, B. J. (1988). Autonomy in long term care: Some crucial distinctions. *Gerontologist*, 28(Suppl.), 10-17.

Cooper, A. (1987). Medoxyprogesterone acetate (MPA) treatment of sexual acting out in men suffering from dementia. *Journal of Clinical Psychiatry*, 48(9), 368-370.

Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage.

Cummings, J., & Victoroff, J. (1990). Noncognitive neuropsychiatric syndromes in Alzheimer's disease. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, 3, 140-158.

Davidson, K., & Fennell, G. (2002). New intimate relationships in later life. *Ageing International*, 27(4), 3-10.

Dawson, P., Wells, D., & Kline, K. (1993). *Enhancing the abilities of persons with Alzheimer and related dementia: A nursing perspective*. New York: Springer.

Devanand, D. P., Brockington, C. D., Moody, B. J., Brown, R. P., Mayeux, R., Endicott, J., & Sakeim, H. (1992). Behavioral syndromes in Alzheimer's disease. *International Psychogeriatrics*, 4, 161-184.

Dick Young Productions. (2002). Freedom of sexual expression: Dementia and resident rights in long-term care facilities [Review of the film *Freedom of Sexual Expression*], Terra Nova Films. Chicago: Author.

Dupras, A., & Poissant, M.-S. (1987). The fear of sexuality in residents of a long-term care hospital. *Sexuality and Disability*, 8, 203-215.

Ehrenfeld, M., Bronner, G., Tabak, N., Alpert, R., & Bergman, R. (1999). Sexuality among institutionalized elderly patients with dementia. *Nursing Ethics*, 6, 144-149.

Ehrenfeld, M., Tabak, N., Bronner, G., & Bergman, R. (1997). Ethical dilemmas concerning sexuality of elderly patients suffering from dementia. *International Journal of Nursing Practice*, 3, 255-259.

Feil, N. (1995). When feelings become incontinent: Sexual behaviors in the resolution phase of life. *Sexuality and Disability*, 13, 271-282.

Fisher, J., Fink, C., & Loomis, C. (1993). Frequency and management difficulty of behavioural problems among dementia patients in long-term care facilities. *Clinical Gerontologist*, 13(1), 3-12.

Folstein M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 196-198.

Foreman, R., Wilkinson, M., Aaron, B., Graham, J., & Watt, M. (1992, February). *My flower, my valentine*. Unpublished poem, Creative Writing Group, Shalom Village, Hamilton, Ontario, Canada.

Foucault, M. (1978). *The history of sexuality: Vol. 1. An introduction*. New York: Vintage.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. Chicago: Aldine.

Haddad, P., & Benbow, S. (1993). Sexual problems associated with dementia: Part 1. Problems and their consequences. *International Journal of Geriatric Psychiatry*, 8, 547-551.



Hajjar, R., & Kamel, H. (2003). Sex and the nursing home. *Clinics in Geriatric Medicine*, 19(3), 575-586.

Hallberg, I., Norberg, A., & Erikson, S. (1990). Functional impairment and behavioural disturbances in vocally disruptive patients in psychogeriatric wards compared with controls. *International Journal of Geriatric Psychiatry*, 5, 53-61.

Harris, L., & Wier, M. (1998). Inappropriate sexual behavior in dementia: A review of the treatment literature. *Sexuality and Disability*, 16, 205-217.

Hellen, C. R. (1995, March/April). Intimacy: Nursing home resident issues and staff training. *American Journal of Alzheimer's Disease*, 12-17.

Hellen, C. (1998). *Alzheimer's disease: Activity-focused care* (2nd Ed.). Woburn, MA: Butterworth-Heinemann.

Higgs, J., & Jones, M. (2000) Clinical reasoning in the health professions. In J. Higgs and M. Jones (Eds.), *Clinical reasoning in the health professions* (pp. 3-14). Boston: Butterworth Heinemen.

Higgs, J., & Titchen, A. (2000). Knowledge and reasoning. In J. Higgs and M. Jones (Eds.), *Clinical reasoning in the health professions* (pp. 23-32). Boston: Butterworth Heinemen.

Hoffman, S. (1998). Innovations in behavior management. In M. Kaplan & S. Hoffman (Eds.), *Behaviours in dementia: Best practices for successful management* (pp. 13-24.). Winnipeg: Health Professions Press.

Holmes, C., & Warelow, P. (1997). Culture, needs and nursing: A critical theory approach. *Journal of Advanced Nursing*, 25, 463-470.

Holmes, D., Reingold, J., & Teresi, J. (1997). Sexual expression and dementia, Views of caregivers: A pilot study. *International Journal of Geriatric Psychiatry*, 12, 695-701.

Holstein, M. (1998). Ethics and Alzheimer's disease: Widening the lens. *Journal of Clinical Ethics*, 9(1), 13-22.

Hope, T., Gedling, K., Cooper, S., Fairburn, C., & Jacoby, R. (1997). Behaviour changes in dementia 1: Point of entry data prospective study. *International Journal of Geriatric Psychiatry, 12*, 1062-1073.

Hughes, C. (1992). Ethnography: What's in a word- process? Product? Promise? *Qualitative Health Research, 2*, 439-450.

Jagger, C., & Lindesay, J. (1997). Residential care for elderly people: The prevalence of cognitive impairment and behavioural problems. *Age and Ageing, 26*, 475-480.

Jones, S., & Brown, L. (1993). Alternative views on defining critical thinking through the nursing process. *Holistic Nurse Practice, 7*(3), 71-76.

Kamm, I. (1965). Control of sexual hyperactivity with thioridazine. *American Journal of Psychiatry, 121*, 922-923.

Kaplan, L. (1996). Sexual and institutional issues when one spouse resides in the community and the other lives in a nursing home. *Sexuality and Disability, 14*, 281-293.

Kidd, P., & Parshall, M. (2000). Getting the focus and the group: Enhancing analytical rigor in focus group research. *Qualitative Health Research, 10*, 293-308.

Kincheloe, J., & McLaren, P. (2000). Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 279-313). London: Sage.

Kitwood, T. (1995). Positive long-term changes in dementia: Some preliminary observations. *Journal of Mental Health, 4*, 133-144.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia: Open University Press.

Kitwood, T. (1998). Toward a theory of dementia care: Ethics and interaction. *Journal of Clinical Ethics, 9*, 23-34.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society, 12*, 269-287.

- Kolanowski, A., Garr, M., Evans, L., & Strumpf, N. (1998, September/October). Behavioural syndromes in institutionalized elders. *American Journal of Alzheimer's Disease*, 245-256.
- Krefting, L., & Krefting, D. (1991). Leisure activities after a stroke: An ethnographic approach. *The American Journal of Occupational Health*, 45, 429-436.
- Kuhn, D. (1994, September/October). The changing face of sexual intimacy in Alzheimer's disease. *The American Journal of Alzheimer's Care and Related Disorders and Research*, 7-14.
- Kuhn, D. (2002). Intimacy, sexuality and residents with dementia. *Alzheimer's Care Quarterly*, 3(2), 165-176.
- Kuhn, D., Greiner, D., & Arseneau, L. (1998, April). Addressing hypersexuality in Alzheimer's disease. *Journal of Gerontological Nursing*, 44-50.
- Kyomen, H., Nobel, K., & Wei, J. (1991). The use of estrogen to decrease aggressive physical behaviour in elderly men with dementia. *Journal of the American Geriatrics Society*, 39, 1110-1112.
- Kyomen, H., Satlin, A., Henne, J., & Wei, J. (1999). Estrogen therapy and aggressive behaviour in elderly patients with moderate-to-severe dementia. *American Journal of Geriatric Psychiatry*, 7(4), 339-348.
- Lawler, J. (1993). *Behind the screens: Nursing, somology, and the problem of the body* (North American Edition). Don Mills, Ontario: Benjamin/Cummings Publishing Company, Inc.
- Levitsky, A. M., & Owens, N. J. (1999). Pharmacologic treatment of hypersexuality and paraphilias in nursing home residents. *Journal of the American Geriatrics Society*, 47, 231-234.
- Lichtenberg, P. A. (1997). Clinical perspectives on sexual issues in nursing homes. *Topics in Geriatric Rehabilitation*, 12, 1-10.
- Lichtenberg, P., & Strzepek, D. (1990). Assessments of institutionalized dementia patients' competencies to participate in intimate relationships. *Gerontologist*, 30, 117-120.

Lowenberg, J. (1993). Interpretive research methodology: Broadening the dialogue. *Advances in Nursing Science, 16*, 57-69.

Lubart, T. (1994). Creativity. In R. Sternberg (Ed.), *Thinking and problem solving* (pp. 289-332). Toronto: Academic Press.

MacDougall, C., & Fudge, E. (2001). Planning and recruiting the sample for focus groups and in-depth interviews. *Qualitative Health Research, 11*, 117-126.

MacMurray, J. (1935). *Reason and emotion*. London: Faber and Faber Limited.

Mattiasson, A., & Hemberg, M. (1998). Intimacy - Meeting needs and respecting privacy in the care of elderly people: What is a good moral attitude on the part of the nurse/carer? *Nursing Ethics, 5*, 527-534.

Mayers, K. (1998). Sexuality and the demented patient. *Sexuality and Disability, 16*, 219-225.

Mayers, K. (2000). Inappropriate social and sexual responses to a female student by male patients with dementia and organic brain disorder. *Sexuality and Disability, 18*, 143-147.

Maxwell, J. A. (2002). Understanding and validity in qualitative research. In A. M. Huberman & M. B. Miles (Eds.), *The qualitative researcher's companion* (pp. 37-64). Thousand Oaks: Sage.

McCartney, J., Izeman, H., Rogers, D., & Cohen, N. (1987). Sexuality and the institutionalized elderly. *Journal of the American Geriatrics Society, 35*, 331-333.

Mill, J., Allen, M., & Morrow, R. (2001). Critical theory: Critical methodology to disciplinary foundations in nursing. *Canadian Journal of Nursing Research, 33*(2), 109-127.

Misiorski, S. (2001). Building a better life: Transforming institutional culture. *Alzheimer's Care Quarterly, 2*(3), 5-9.

Mitchell, G., & Cody, W. (1993). The role of theory in qualitative research. *Nursing Science Quarterly, 6*, 170-178.

Morgan, D. (1995). Why things (sometimes) go wrong in focus groups. *Qualitative Health Research*, 5, 516-523.

Mossman, D., Perlin, M., & Dorfman, D. (1997). Sex on the wards: Conundra for clinicians. *Journal of the American Academy of Psychiatry Law*, 25(4), 441-460.

Nadal, M., & Allgulander, S. (1993). Normalization of sexual behaviour in a female with dementia after treatment with cyproterone. *International Journal of Geriatric Psychiatry*, 8, 265-267.

Neruda, P. (1997). *Full woman, fleshly apple, hot moon*. (S. Mitchell, Trans.). New York: Harper Perennial.

Qualitative Solutions and Research. (1999). *NVivo revision 1.1* [Computer software]. London: Scolari, Sage Publications Inc.

Ontario Ministry of Health/Long Term Care. (1993, December 20; amended 1995, November 30). *Long-term care facility program manual*. (Unusual Occurrence Report, form #2309-69). Ontario Ministry of Community and Social Services, Toronto ON: Queens' Printer of Ontario.

Ontario Seniors' Secretariat. (1999). *Ontario's strategy for Alzheimer disease and related dementias: Preparing for our future* (20M/10/99 Cat. #7610-2231687). Toronto, ON: Queen's Printer for Ontario.

Park Dorsay, J., & Forchuk, C. (1994). Assessment of the sexuality needs of individuals with psychiatric disability. *Journal of Psychiatric and Mental Health Nursing*, 1, 93-97.

Philo, S. W., Richie, M. F., & Kaas, M. J. (1996). Inappropriate sexual behavior. *Journal of Gerontological Nursing*, 22, 17-22.

Post, S. G. (1995). Alzheimer disease and the "then" self. *Kennedy Institute of Ethics Journal*, 5(4), 307-321.

Post, S. G. (2000a). *The moral challenge of Alzheimer disease*. Baltimore: Johns Hopkins.

Post, S. G. (2000b). Commentary on "sexuality and intimacy in the nursing home". *Journal of Clinical Ethics*, 11(4), 314-317.

- Post, S. G. (2001). An ethics of love for persons with Alzheimer's disease. *Alzheimer's Care Quarterly*, 2, 23-30.
- Rader, J. (1995). Moving away from the hospital model to an individualized resident-centered model. In J. Rader, & E. Tornquist (Eds.), *Individualized dementia care: Creative, compassionate approaches* (pp. 3-9). New York: Springer.
- Ray, M. (1992). Critical theory as a framework to enhance nursing science. *Nursing Science Quarterly*, 5, 98-101.
- Reisberg, B., Borenstein, J., Salob, S., Ferris, S., Franssen, E., & Georgotas, A. (1987). Behavioural symptoms in Alzheimer's disease: Phenomenology and treatment. *Journal of Clinical Psychiatry*, 48(5, Suppl.), 9-15.
- Robinson, N. (1999). The use of focus group methodology with selected examples from sexual health research. *Journal of Advanced Nursing*, 29, 905-913.
- Rothman, B., & Sebastian, H. (1990). Intimacy and cognitively impaired elders. *Canadian Nurse*, 86, 32-34.
- Schiavi, R. C., & White, D. (1976). Androgens and male sexual function: A review of human studies. *Journal of Sex Marital Therapy*, 2, 214-228.
- Schindel Martin, L. (2004, January). *An ode to demented sex*. [Accounts of study participants]. Unpublished raw data.
- Silva, M. C. (1999). The state of nursing science: Reconceptualizing for the 21st century. *Nursing Science Quarterly*, 12(3), 221-226.
- Smith, L. (1995). Piece by piece [Recorded by Quartette]. On *Work of the heart* [CD]. Markham: Denon.
- Stewart, J. T., & Shin, K. J. (1997). Paroxetine treatment of sexual disinhibition in dementia. *American Journal of Psychiatry*, 154, 61-63.
- Timmers, R., DuCharme, P., & Jacob, G. (1981). Sexual knowledge, attitudes and behaviors of developmentally disabled adults living in a normalized apartment setting. *Sexuality and Disability*, 4(1), 27-39.

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park: Sage.

Van Dyke, D., McBrien, D., & Sherbondy, A. (1995). Issues of sexuality in down syndrome [Electronic version]. *Down Syndrome Research and Practice*, 3(2).

Velez, L., & Peggs, J. (2001). Managing behavioral problems in long term care. *Clinics in Family Practice*, 3, 3.

Warren, H., & Gordon, M. (1960). *At last* [Recorded by E. James]. On *Etta James: Her best* [CD]. New York: Chess.

Wells, D. (1995). The importance of critical theory to nursing: Description using research concerning discharge decision-making. *Canadian Journal of Nursing Research*, 27, 45-58.

Wolcott, H. (2001). *Writing up qualitative research* (2nd Ed.). Thousand Oaks: Sage.

Wurzbach, M. (1991). Judgment under conditions of uncertainty. *Nursing Forum*, 26(3), 27-34.

Zeiss, A., Davies, H. D., & Tinklenberg, J. R. (1996). An observational study of sexual behavior in demented male patients. *Journal of Gerontology: Medical Sciences*, 51A, M325-M329.

## APPENDIX A

## Summary of Conceptual Papers on Sexuality and Dementia

Author	Parameters of Sexual Behavior
Ballard (1998)	<ul style="list-style-type: none"> <li>· Sexual behaviour related to diminished capacity to control impulses.</li> <li>· Sexual behaviour result of feeling threatened and abandoned.</li> <li>· Staff attitudes and values impacts on how sexual behavior is interpreted and responded to.</li> <li>· Staff may reinforce inappropriate behaviors by overreacting or by the manner in which they communicate with residents.</li> </ul>
Ballard (1995)	<ul style="list-style-type: none"> <li>· Sexual behaviour could be result of poor impulse control and poor memory, i.e socially appropriate rules are forgotten.</li> <li>· Sexual behaviour has environmental context.</li> <li>· Suggests that sexual behavior could be expression of a need for human touch; Sexual behavior related to fear of abandonment.</li> <li>· Some sexual behaviors could be expression of physiological need such as too hot, urinary tract infection, pain, agitation.</li> <li>· Behaviour is problematic because of the negative attitudes and misinformation about sexuality held by staff.</li> </ul>
Ehrenfeld et al. (1997)	<ul style="list-style-type: none"> <li>· Sexual behaviours in dementia occur as residents attempt to have their intimacy/sexuality needs met.</li> </ul>
Feil (1995)	<ul style="list-style-type: none"> <li>· Sexual behaviours are suppressed secondary to action of inhibitions. As the person demented, sexual expression may occur as result of erosion of behavioral controls secondary to neurological damage.</li> <li>· Implied that sexual behaviors are an expression of need for intimacy and human touch.</li> </ul>
Harris & Wier (1998)	<ul style="list-style-type: none"> <li>· Sexual expression in dementia occurs because disease process results in poor memory for previously learned social controls. The clinician applies stimulus control techniques that reinforce sexual expression at an appropriate time and circumstance. Staff can extinguish sexual advances by giving a neutral response.</li> </ul>



Author	Parameters of Sexual Behavior
Hellen (1995)	<ul style="list-style-type: none"> <li>· Issues involving sexual expression are complex because each resident is unique. Sexuality seen as a continuing human need. Intimacy and sexuality inextricably bound. Masturbation viewed as self-expressed intimacy.</li> <li>· Sexual behaviours occur when the dementia experienced by the person results in a misunderstanding of socially acceptable boundaries.</li> <li>· Sexual behaviours could also be urinary tract infection, skin rash, must therefore rule out sexual behavior as a manifestation of a medical illness.</li> </ul>
Kaplan (1996)	<ul style="list-style-type: none"> <li>· Kaplan suggests that the environment itself perpetuates need for sexual behaviors, because need for touch and affection is not met.</li> </ul>
Kuhn (1994)	<ul style="list-style-type: none"> <li>· Sexuality viewed as a complex intrapsychic and interpersonal phenomenon. Sexually inappropriate behaviors occur as result of disease process that impacts on perceptions, social skills and other abilities that become distorted and forgotten.</li> <li>· Sexuality also result of misidentification that results in resident belief that a potential partner is actually a spouse or significant other from the past.</li> </ul>
Kuhn (2002)	<ul style="list-style-type: none"> <li>· Staff response to episodes of sexual behaviour in persons with dementia largely a function of personal values and belief systems.</li> <li>· Values clarification important to help them reflect upon how personal beliefs impact upon practice.</li> <li>· Clinical practice guidelines necessary, but little in literature.</li> <li>· Sexual behaviours of older adults with dementia needs to be “normalized”.</li> <li>· Families should be involved in discussions with clinical teams to determine the parameters and conditions under which relationships will continue.</li> <li>· Sexual expression between older adults with dementia living in the nursing home should be permitted if both parties and relevant family members consent and the risks are not judged to exceed benefits.</li> </ul>

Author	Parameters of Sexual Behavior
Kuhn et al. (1998)	<ul style="list-style-type: none"> <li>· Sexual behaviours hypothesized as being related to the resident to the environmental context in which they occur, may simply be inappropriate because they occur in the wrong place, i.e. in public under the scrutiny of others. Consequently, cause of behaviour is a disease process that renders the resident unaware of the surrounding in which he/she is behaving. Sexual expression a highly complex brain function and many biological and psychological factors may account for changes in a person's normal ways of sexual expression.</li> <li>· Hyper-sexuality may relate to a psychological need for intimacy that becomes sexualized. Physical closeness sought to reduce anxiety loneliness or fear may take form of sexual expression. Sexuality is result of unmet need for human connectedness.</li> <li>· Sexual behaviour can also be manifestation of an adverse reaction to medication or an acute medical condition.</li> </ul>
Lichtenberg (1997)	<ul style="list-style-type: none"> <li>· Sexuality a multifaceted experience in the nursing home setting. Nursing staff hold widely disparate views regarding which sexual behaviours to allow in the nursing home.</li> </ul>
Lichtenberg & Strzepek (1990)	<ul style="list-style-type: none"> <li>· Staff perceive residents to be non-sexual beings. Therefore staff respond to sexual behaviour negatively.</li> </ul>
Mattiasson & Hemberg (1998)	<ul style="list-style-type: none"> <li>· Sexual expression in dementia viewed as social, spiritual, psychological and physical components. Sexual behaviour in nursing home is an expression of a desire for recognition and an attempt to uphold one's identity. Situations of sexual behaviour are often innocent and should be handled generously.</li> <li>· Sexual behaviour as result of deteriorating cerebral functions that affects control of impulses.</li> </ul>
Mayers (1998)	<ul style="list-style-type: none"> <li>· Staff receive little or no specialized training to help them deal with sexual behaviours displayed by residents with dementia.</li> <li>· Staff frequently respond with embarrassment or disgust, which can prevent them from seeking assistance to management interventions</li> </ul>

Author	Parameters of Sexual Behavior
Philo et al. (1996)	<ul style="list-style-type: none"> <li>· Sexual behaviours occur because resident experiences memory loss, which may lead to sexual behaviours being acted out in socially inappropriate ways.</li> <li>· Could be physical, for example, illness such as colorectal cancer, urinary tract infection, scabies, vaginitis, prolapsed uterus, labial cancer.</li> <li>· Residents may also behave in a sexual way as a result of fatigue, sense of fear, perceived threat, frustration at functional losses.</li> <li>· External causes may be insufficient interpersonal approaches by staff. Sexual behaviour seen as reaction to the emotional of fear and anxiety displayed by the care providers. Sexual behaviour may be a call for attention, reassurance or closeness as a response to isolation.</li> </ul>
Rothman & Sebastian (1990)	<ul style="list-style-type: none"> <li>· Sexual behaviour may be related to loneliness and isolation.</li> <li>· Sexual expression also related to loss, and impact of institutionalization, eg., lack of privacy, lack of control</li> <li>· Behaviour triggered by lack of human contact and touch.</li> <li>· Sexual behaviour related to brain damage, i.e. deeper emotions, drives and impulses are no longer inhibited.</li> <li>· Most difficult thing that sexually expressive elders with dementia must face is the negative attitudes of staff.</li> </ul>

## APPENDIX B

### Facility Information/Recruitment Letter

Investigator's Address

Potential Participant Address

October 2002

Dear \_\_\_\_\_ (Administrator of Long Term Care Facility):

I am a graduate nursing student at McMaster University. As part of the requirements for completion of my Doctoral Degree, I am conducting a research study to investigate possible factors that influence the clinical reasoning and practice decisions made by health care providers in response to episodes of sexual behavior displayed by residents with dementia living in long term care.

Sexual behaviour is reported by health care providers to be an occurrence that challenges clinical management strategies and creates discomfort. I am proposing to interview approximately 10 staff and family members from three different facilities who agree to meet and talk to me about their experiences with episodes of sexual behavior in residents with dementia. In addition, I would like to interview two members of your senior management team, for example, the Director of Care, the Medical Director, or you, the Administrator. After the interviews have been completed, I would like to conduct a focus group with between 5 to 8 additional participants, who are front-line staff members. The interviews and focus groups are anticipated to take about 1 hour each and will be audio-taped. I am also interested in reviewing any documents that your facility has developed that relate to sexual behavior associated with dementia, for example, policy or practice guidelines.

Compensation for the time your organization will be contributing toward this study will be offered in the form of a two hour workshop on sexual behavior associated with dementia to be conducted by the researcher within six months after completion of data collection. I am requesting permission to conduct my study at your facility. I will be contacting you by telephone within the next week. I look forward to meeting with you to discuss the possibility that you and your facility will be willing to participate in this research project.

Sincerely,

Lori Schindel Martin

**APPENDIX C**

Letter of Introduction

Focus Group Notice

Focus Group Notice

**Attention All Staff**

**Interested in sharing your experiences and beliefs about the intimacy and sexuality needs of resident with dementia living in Long Term Care?**

I am a doctoral student in nursing doing a research project on the experiences of staff providing care to residents with dementia. I am hosting a meeting here at your facility to discuss your viewpoints about sexual behaviour in dementia. All information will be confidential.

Interested in participating in this important research project?

**Meeting will be held on Date, Year, Time  
Location, Facility.**

Any questions, please see Facility Contact or call Lori Schindel Martin at phone number.

## **APPENDIX D**

### **Semi-Directed Interview Guides**

Semi-directed Interview Guide for Formal Care Staff

1. When you hear or use the term sexual behaviour associated with dementia, what do you think is meant by this?
2. Can you tell me if you have ever had a clinical case involving one of your residents with dementia whose behavioural profile included sexual behaviour?
3. Could you describe for me what it was like to witness and respond to this sexual behaviour?
4. What was your “take” on this sexual behaviour? (Prompts: feelings, thoughts, etiology, why was it happening, how it should be viewed) How did your “take” compare to those around you? (Prompts: colleagues, family members)
5. What did you decide to do in response to episodes of this sexual behaviour? What happened as a result? How was this response viewed by others?
6. What resources were available to you to help you to decide how to respond? Which did you use? (Prompts: educator, clinical consultant, literature, policy, director of resident care, family members)
7. Overall, how do you think this particular case was managed? (Prompts: Was consensus on how to approach this case reached?)
8. If you were to change any aspect of this case, what would it be? (Prompts: resources available, interpretations that were made, approaches taken, practice change of any kind)
9. Are there other examples of such cases of sexual behaviour?
10. Is there anything else about sexual behaviour in dementia that you would like to share with me?



Semi-directed Interview Guide for Family Members

1. Have you encountered or witnessed sexual behaviour being displayed by residents with dementia living in this long term care facility?
2. When you use or hear the term sexual behaviour associated with dementia, what do you think is meant by this?
3. Can you describe for me what it is like to witness this sexual behaviour?
4. What is your “take” on this sexual behaviour? (Prompts: feelings, thoughts, etiology, why was it happening, how it should be viewed) How did your “take” compare to those around you? (Prompts: staff members, other family members)
5. What did you decide to do in response to episodes of this sexual behaviour? What happened as a result? How was this response viewed by others?
6. What resources were available to you to help you to decide how to respond? Which did you use? (Prompts: staff, other family members, family council, educator, clinical consultant, literature, policy, director of resident care)
7. Overall, how do you think cases of this nature are managed? (Prompts: were your wishes, opinions, values listened to? Honoured?)
8. If you were to change any aspect of this case, what would it be? (Prompts: resources available, interpretations that were made, approaches taken, practice change of any kind)
9. Are there other examples of such cases of sexual behaviour?
10. Is there anything else about sexual behaviour in dementia that you would like to share with me?

Semi-directed Interview Guide for Senior Management Team Members

1. When you hear or use the term sexual behaviour associated with dementia, what do you think is meant by this?
2. Have you encountered or witnessed sexual behaviour being displayed by residents with dementia living in this long term care facility?
3. Can you describe for me what it is like (for you, for your staff, for your families) to witness this sexual behaviour?
4. What is your “take” on this sexual behaviour? (Prompts: feelings, thoughts, etiology, why was it happening, how it should be viewed) How did your “take” compare to those around you? (Prompts: staff members, other members of your administrative team, family members)
5. What did you decide to do to manage the behaviour and what happened as a result?
6. What resources were available to you to help your clinical team to decide how to respond? Which were used? (Prompts: staff, other family members, family council, educator, clinical consultant, literature, policy, director of resident care)
7. Overall, how do you think cases of this nature are managed?
8. If you were to change any aspect of how your clinical team approach cases of sexual behaviour, what would it be? (Prompts: resources available, interpretations that were made, approaches taken, practice change,, capacity for consensus)
9. Are there other examples of such cases of sexual behaviour?
10. Is there anything else about sexual behaviour in dementia that you would like to share with me?

**APPENDIX E**

Demographic Questionnaire for Interview/Focus Group Participants

Participant #: \_\_\_\_\_

Date: \_\_\_\_\_

Facility Code: \_\_\_\_\_

Please complete the following:

**For both staff and families:**

How long have you been associated with this long term care facility? (either as staff or family member)

- 1-2 years     2-5 years     5-8 years     8-10 years     10 plus years

**For staff only:**

What is your role within your facility (check one)?

- health care aide                       personal support worker  
 registered nurse                       dietary aide  
 housekeeping                       registered practical nurse

What is your employment status?

- part-time                       full-time

What is your basic educational preparation?

- high school                       certificate  
 college diploma                       baccalaureate degree

## APPENDIX F

Focus Group Guide

Thank you very much for agreeing to come and talk together about sexual behaviours displayed by residents with dementia and cognitive impairment. I am going to read a case to you (Moderator will begin with Case Study Number 1 ). I would then like us to discuss together your thoughts and ideas about this case and how it relates to your own practice. (Subsequent cases will be introduced at the discretion of the moderator, where it is appropriate within the context of the discussion. For example, should the group participants appear to have reached consensus with the case under discussion, the next case will be introduced so that its impact on dialogue and consensus-making can be evaluated).

Case Study Number 1: An 82 year old female resident and a 78 year old male resident have become very “taken” with each other. Both are cognitively impaired. They enjoy each other’s company very much. The woman is a widow. Her daughter is the substitute decision-maker. The gentleman is married. His wife is still living and comes to visit him everyday. The couple is spending more and more time together. They hold hands while sitting together on the couch, while walking up and down the hallway together. Sometimes they kiss. Sometimes they kiss passionately.

Case Study Number 2: A 95 year old female resident and a 65 year old male resident have become very “taken” with each other. Both are cognitively impaired. They enjoy each other’s company very much. The female resident is a widow. Her son is the substitute decision-maker. The gentleman is single, having never been married. Their private rooms are right next door to each other. The male resident spends most of his time in his room listening to his radio. The female resident seeks him out, entering his room. The couple spends more and more time together. They hold hands while sitting together in his room. Sometimes they kiss. Sometimes they kiss passionately. Sometimes they touch each other in private areas.

Case Study Number 3: An 86 year old male resident and an 82 year old female resident live in the same dementia care unit. Both are cognitively impaired, both are married with their spouses living. They are frequently seen in each other’s company, but each spends time with the other residents in the unit. When they are together they hold hands as they walk up and down the hallway or sit on the

couch. Just before lunch one day they are found in a corner of the parlor, sitting together. The female resident has her shirt off and the male resident has his trousers undone with his penis exposed.

Discussion Guide Questions

1. Have any of you ever experienced a case(s) such as this?
2. How do you think you would react to this one? Why?
3. What do you think your clinical team should do to determine a management plan for this case?
4. What resources would you utilize to understand the parameters of this case? (Prompts: clinical consultant, literature, policy, educator, director of resident care, family members, ethicist, family council)
5. What would you do if no agreement is reached about how to approach/respond to the behaviors described in this case?
6. Do you think agreement is possible? Why or why not?
7. What would you like to see done differently in the management of cases of this type in your facility?

**APPENDIX G**

Ethics Approval

**APPENDIX J**

Document Review Sheet

Facility Identification Number: \_\_\_\_\_

Date(s): \_\_\_\_\_

Number of Staff: \_\_\_\_\_ Number of Residents: \_\_\_\_\_

Document Type and Source	Findings
Practice Guidelines Document Number: _____	
Policy Statement Policy Number: _____	
Critical Incident Sheets Title of Incident Form: _____	
Educational Sessions particular to sexual behaviour in past year:	