

**"THIS IS NOT A WHOREHOUSE!"**

**SEXUAL ACTIVITY IN LONG-TERM CARE**

by

BETHAN JOAN EVERETT

B.A., York University, 1976

M.B.A., The University of British Columbia, 1982

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR IN PHILOSOPHY

in

THE FACULTY OF GRADUATE STUDIES

(INTERDISCIPLINARY STUDIES)

THE UNIVERSITY OF BRITISH COLUMBIA

November 2005

© Bethan Joan Everett, 2005

## ABSTRACT

A society's moral heart can be judged by how well it provides for its weakest and most vulnerable citizens. In recent years significant strides have been made to improve the quality of institutionalized persons' lives. However, because we have not yet fully developed a moral vision of long-term care living, residents do not always receive the basic care that they should. Particularly ignored and inadequately addressed is the complex moral and social issue of residents' sexual lives.

Currently there is little support for sexual activity or sexual care in long-term care settings. Society's moral rules are designed for independent people living in their own homes. Professional governance bodies have created moral rules regulating short-term professional interactions and responsibilities but rarely have ones that pertain to long-term care settings. The aim of the present research is to contribute to the development of a moral vision of how long-term care institutions should manage sexual activity and sexual care.

A qualitative study was designed to identify the factors that negatively influence sexual activity and sexual care, and the supports that residents and staff respectively need in order to have sexual lives and provide sexual care. Using an exploratory design the

investigator conducted in-depth interviews with twenty-four residents and staff and carried out twenty hours of participant observation with two community residents. Six negative influences on residents' sexual lives and nine negative influences on staff's provision of sexual care were identified.

The work also explores ethical and legal issues pertaining to the provision of sexual care. It is argued that residents have moral rights to sexual care which impose duties on institutions to provide that care. Legal barriers to providing such care are then considered, and found not to be insurmountable.

The above research and explorations led to three conclusions. First, unless sexual care is available residents cannot have sexual lives. Second, for sexual care to be available institutions must accept that it is their moral responsibility to provide it and ensure that staff are adequately supported. Third, institutions should develop a framework for the delivery of sexual care.

## TABLE OF CONTENTS

<b>ABSTRACT</b> -----	(ii)
<b>TABLE OF CONTENTS</b> -----	(iv)
<b>LIST OF TABLES</b> -----	(ix)
<b>ACKNOWLEDGEMENTS</b> -----	( x)
 <b>CHAPTER ONE: SITUATING THE STUDY</b> -----	<b>1</b>
Introduction-----	1
Conceiving the research project-----	2
Definition of sexual care-----	2
What should be provided-----	5
What is provided-----	6
Scope of research-----	6
Significance of research-----	7
Organization of thesis-----	7
 <b>CHAPTER TWO: DEVELOPING THE CONCEPTUAL FRAMEWORK – RATIONALE FOR THE STUDY</b> -----	<b>10</b>
Introduction-----	10
Personal and professional exposure to sexual activity and sexual care issues-----	11
Literature review-----	12
Negative attitudes of others-----	14
Psychological and physiological limitations-----	15
Lack of opportunity-----	16
Lack of privacy-----	17
Avoidance of instability and chaos in medical settings-----	18
Lack of education-----	18
Embarrassment, believing that sexuality is not relevant to the presenting medical problem, and inadequate training-----	19
The legal duty to prevent sexual abuse-----	19
Expert interviews-----	20
Identifying the specific parts of the conceptual framework that will be studied----	22
 <b>CHAPTER THREE: METHODOLOGY</b> -----	<b>24</b>
Introduction-----	24
Step 1: The conceptual framework and problem definition-----	26
Step 2: Development of the study design-----	26
Participation in legal forums-----	27
Participation in medical forums and workshops-----	28
Participant observation of sexual health clinics, client interviews,	



& staff meetings-----	29
Sexual health client interviews-----	29
Sexual health staff meetings-----	30
Sexual health policy development working group-----	30
Linking sexual health participant observations to the literature and expert interview findings-----	31
Study design-----	31
Subject selection - sampling strategy for residents and staff participants-----	32
Resident recruitment-----	32
Staff recruitment-----	33
Numbers-----	35
Instruments used to collect data at GPC-----	37
Participant observation of persons with disabilities living in the community-----	38
Subject selection- sampling strategy for community participants--	39
Instruments used to collect data in the community settings-----	39
The time frame-----	39
The primary setting-----	41
Description of GPC-----	42
Resident demographics-----	47
Staff demographics-----	49
The role of the investigator-----	51
Step 3: Fieldwork-----	53
Interviews with GPC residents and staff-----	53
Participant observation of persons with disabilities living in the community-----	54
Document analysis-----	55
Theoretical validity – issues of reliability & validity-----	55
Reliability-----	55
Validity-----	58
Cross-checks of interview "facts" -----	58
Member checks-----	58
Ethical Issues-----	61
Confidentiality-----	61
Researcher's role in the process and giving back to participants-----	62
Data Management-----	63
Data Analysis-----	63
Interviews with residents and staff-----	66
Thematic analysis-----	67
Participant observation of persons with disabilities living in the community-----	68
Document analysis-----	69
Data analysis conclusions-----	69

<b>CHAPTER FOUR: RESIDENT NARRATIVES-----</b>	<b>70</b>
Impressions of GPC-----	70
Resident demographics-----	72
Introduction-----	73
Resident stories-----	73
Deriving themes-----	85
Staff's negative attitudes to residents' sexual lives-----	85
Psychological limitations-----	87
Time spent in institutions-----	87
Lack of self-esteem-----	88
Negative past experiences related to sexual activity-----	90
Physiological limitations-----	91
Lack of opportunity-----	92
Lack of privacy-----	93
Sense of powerlessness to change the culture, values and attitudes of institutions against residents' sexual lives-----	96
Conclusion of thematic analysis-----	97
 <b>CHAPTER FIVE: STAFF STORIES-----</b>	 <b>98</b>
Introduction-----	98
Staff demographics-----	99
Staff interviews-----	100
Deriving themes-----	116
Duties to set professional boundaries-----	117
Client-Staff relationships must remain professional-----	117
Client-Staff sexual relationships are inappropriate -----	118
Sexual care must be therapeutic and professional-----	119
Legal duties to provide care-----	120
General duty of care-----	120
Duty of care with respect to residents who are cognitively impaired-----	121
Personal and religious values-----	122
Avoiding sexual harassment in the workplace-----	124
Inadequate training and education-----	126
Lack of time and resources-----	126
Lack of privacy-----	127
Lack of physical privacy-----	127
Lack of confidentiality with respect to residents' sexual information -----	129
Lack of sexual care guidelines-----	130
Sense of powerlessness to change the nature of long-term care	

living as it is practiced today-----	130
Conclusion of thematic analysis-----	131
<b>CHAPTER SIX: THE ETHICAL PERSPECTIVE-----</b>	<b>132</b>
Introduction-----	132
Prima facie arguments for rights to do-----	133
Prima facie arguments for rights to receive-----	136
Countervailing arguments for residents' rights to do and to receive-----	137
Harm to self (and participating others) re: rights to do-----	138
Reasonableness or unreasonableness of assuming the risk associated with a self-harming act or activity-----	138
Harm, capability and interference-----	139
Parameters of justified interference-----	142
Examples of harm to self (and participating others)-----	146
Harm to self (and participating others) re: rights to receive-----	147
Harm to others-----	151
Reasonableness of permitting actions that create harm-----	152
Justified interference-----	152
Examples of harm to others-----	155
Offense to others-----	160
Seriousness of offense-----	161
Justified interference-----	164
Examples of offence-----	168
Clinical example-----	170
Conclusion-----	176
<b>CHAPTER SEVEN: LEGAL ISSUES-----</b>	<b>177</b>
Introduction-----	177
Legal concerns-----	178
Legal rights of institutionalized persons to engage in sexual activity-----	178
Sexual rights-----	179
The right to marry-----	179
The right to physical integrity-----	180
The right to freedom of sexual expression-----	181
The right to sexual intimacy in a private and dignified setting-----	181
Trends supporting sexual activity rights-----	182
Legal duties of institutions-----	185
Prevention of foreseeable harm-----	186
Criminal responsibility-----	186
Civil responsibility-----	187
Negligence-----	187
Criminal law: negligence-----	187
Civil law: negligence-----	188

Waivers of liability-----	190
Ensure consensual sexual activity occurs in private-----	191
Uphold prostitution and bawdy-house laws-----	193
Ensure health care providers act in accordance with professional standards-----	195
Uphold the rights of health care providers-----	196
Uphold substitute decision-making laws-----	199
Power of Attorney Act-----	200
Patients Property Act-----	201
Representation Agreement Act-----	202
Health Care (Consent) and Care Facility (Admission) Act---	205
Adult Guardianship Act-----	205
Conclusion of substitute sexual decision-making-----	206
Conclusion-----	206
 <b>CHAPTER EIGHT: DEVELOPING A PRAGMATIC FRAMEWORK FOR THE DELIVERY OF SEXUAL CARE-----</b>	 <b>208</b>
Introduction-----	208
Principles of the pragmatic framework for sexual care-----	208
Recommendations for changes to management strategies-----	209
Autonomy and protectionism-----	209
Education curricula-----	212
Developing guidelines for sexual care-----	213
Principles for evaluating a pragmatic framework for sexual care-----	214
 <b>CHAPTER NINE: TOWARDS A MORAL VISION OF LONG-TERM LIVING -----</b>	 <b>215</b>
Introduction-----	215
Methodological review-----	215
Themes and conclusions-----	217
Research limitations-----	218
Directions for future research-----	220
Concluding reflections-----	221
 <b>BIBLIOGRAPHY-----</b>	 <b>223</b>
 <b>APPENDIXES-----</b>	 <b>241</b>
Questionnaires – A-----	241
Consent Form - B -----	249
Legal Cases Cited – C -----	251
Statutes and Regulations Cited – D -----	253

## LIST OF TABLES

Table 1.2 - The continuum of facilitated sex (Earle, 2001) -----	4
Table 2.1 - What is known in the literature -----	13
Table 2.2 - Expert Interviews – Summary of findings -----	21
Table 2.3 - The concepts and their relationships as understood at the beginning of the research project -----	23
Table 3.1 - Research steps and methods -----	25
Table 3.2 - The study's time frame -----	40
Table 3.3 - Resident's demographics -----	48
Table 3.4 - Staff's demographics -----	50
Table 3.5 - Examples of threats & controls to reliability -----	57
Table 3.6 - Examples of threats & controls to validity -----	60
Table 3.7 - Data organization and analysis -----	65
Table 4.1 - Resident's demographics (self-reported by participants) --	72
Table 5.1 - Staff's demographics (self-reported by participants) -----	99
Table 6.1 - Harm to self as valid rationale for interfering with rights to do -----	145
Table 6.2 - Rights to refuse assistance when harm to self is at issue ----	150
Table 6.3 - Harm to others as valid rationale for interfering with rights to do and to receive -----	154
Table 6.4 - Offense to others as valid rationale for interfering with rights to do and to receive -----	167

## ACKNOWLEDGMENTS

I would like to thank the following people for their significant contribution to this work

### The Committee

Prof. Dean Bobinski  
Dr. Alister Browne  
Dr. Martha Donnelly  
Prof. Stephen Salzberg (1954- 2004)  
Dr. Elvi Whittaker

### The Others

Dr. Carol Anderson  
Dr. Hal Brown  
Dr. John Christianson  
Dr. Lori D'Agincourt- Canning  
Dr. Stacy Elliott  
Dr. Patti Janssen  
Dr. William Maurice  
Dr. Kurt Presinspberg  
Dr. David Rabin  
Ms. Barb Rines  
Mr. Bill Sullivan (Q.C.)  
Ms. Jenny Young

### G.F. Strong/ George Pearson Centre

The participants  
The residents, staff and administration of George Pearson Centre  
The GFS Sexual Health Team

*For my children Kyle, Kirsten and Dominic who wish I had a different topic.*

## CHAPTER 1:

### Situating the Study

Nursing homes are frequently seen as places of exploitation (of staff as well as residents), places that stimulate either moral outrage or revulsion that is captured in what surely must be a latent cultural icon - a blabbering, incoherent, disheveled elder strapped into a geri-chair beckoning or threatening some unseen others for help or warning and invariably ignored by staff who, without emotion, expression, or enthusiasm, mechanically carry on with the onerous tasks of daily bed and body work that is made even more difficult by the niggling demands of residents. The image is coupled with the olfactory assault of urine, excrement, and myriad other unpleasant odors that suffuses inevitably drab corridors or insipid sitting rooms where residents sit transfixed, each in their own world. There are also disturbing sounds of people moaning from down the hall, crying out, one elder scolding another harshly, others weeping in protest. No wonder that the pall of long-term care is feared as much as the coffin it covers! Long-term care seems suffused with a terrifying absence, the absence of any sense of control, dignity, or identity. It is a perverse state of living death, somewhere just this side of madness.

--- George J. Agich, 1993:4

### Introduction

The quotation above reflects a familiar and ubiquitous image of long-term care living. Although in recent years significant strides have been made to improve the lives of institutionalized persons, there has been a distinct lack of attention to certain quality of life issues that raise complex moral and social issues (Berger, 2000; Collopy, Boyle & Jennings, 1991; Institute of Medicine, 2001; Richardson & Lazur, 1995). One such issue is residents' sexual lives.

This study aims to contribute to the development of a moral vision of how long-term care institutions should manage sexual activity and sexual care. Achieving this goal gives rise to the following questions. Why is residents' sexual activity so commonly eschewed by staff? What factors or actions curtail residents' sexual expression? What supports do residents need to have sexual lives? What types of sexual activity should and

should not be permitted in long-term care? Why is there so little support for the provision of sexual care? Are health care providers ethically obligated to tolerate residents' sexual lives and must they provide sexual assistance? Does the provision of sexual care conflict with staff's legal duties? What supports do health care providers need to provide adequate and appropriate sexual care? To accommodate sexual care, what management strategies should be in place? This dissertation attempts to answer these questions.

### **Conceiving the research project**

For several years I have been particularly interested in how people with disabilities cope in a world inexorably oriented to the able-bodied and able-minded. My interest stems partly from having a son with a severe mental disability, partly from my undergraduate years studying sociology, and partly in later years from my interest in management studies and medical ethics. I am aware of the many personal and professional demands placed on caregivers and understand the need to address their concerns. At the same time, I am cognizant that persons with disabilities<sup>1</sup> need support in their fight against marginalization and protection from the decisions of others that are not in their best interests.

### **Definition of sexual care**

Sexual care raises complex moral and social issues for those living and working in long-term care facilities. However, the precise meaning of sexual care is not always

---

<sup>1</sup> In accordance with common language I use the term "persons with disabilities". I am aware of the movement to use positive terms such as "persons of difference" or "persons with severely restricted physical or cognitive attributes". I support the use of these positive terms and in no way mean to be disrespectful by using language that may become antiquated and pejorative.



clear. For the purposes of this research study, sexual care is defined as the "continuum of facilitated sex" as described by Earle, 2001 (Table 1.2).

**Table 1.2 - The continuum of facilitated sex (Earle, 2001)**

<b>The continuum</b>	<b>The role of the nurse - examples</b>
Providing accessible information, advice and services	Arranging for information to be available in Braille, large print and audio-tape
Fostering an environment which allows intimacy	Acceptance and acknowledgement of patient's sexual needs
Offering and observing need for privacy	Closing doors, providing curtains
Encouraging and enabling social interaction	Arranging suitable transportation
The procurement of sexual goods	Purchasing or arranging the purchase of pornographic magazines
Arranging paid-for sexual services	Assistance with arranging, or information on how to arrange, paid-for-sex; willingness to discuss this as an option for the patient
Facilitation of sexual intercourse with another party	Undressing, or helping to undress, patient
Facilitation of masturbation	Assistance patient with positioning and technique
Sexual surrogacy	Assistance with arranging, or information on how to arrange a sexual surrogate <sup>2</sup>

<sup>2</sup> For information on the role of sexual surrogates see Noonan 1984; O'Brien, 1990; Society for Human Sexuality, 1999.

In defining sexual care as a gamut of services that respond to the individualized needs of clients, I do not mean to imply that all health care providers should be responsible for delivering all aspects of sexual care on the continuum. Certain types of sexual care require the services of specialized and trained clinicians.

### **What should be provided**

One purpose of long-term care is to help people live with their disabilities and improve the quality of their lives, including their sexual lives (Mulligan & Modigh, 1991; Spector & Fremeth, 1996). Institutions should therefore utilize philosophies of care which aim to achieve this goal. Holism and client-centered care are two such approaches. Holism ("whole person"), considered by contemporary nursing practice to be important, requires that caregivers come to know their patients as individual "whole" people (Earle, 2001; Fulton, 1996; Godfrey, 1999; Kolcaba, 1997; May, 1992; Williams, Cooke & May, 1998). According to McCann, 2000:134, "Patients are only given their full respect when nursing care has firm foundations in a truly holistic approach incorporating human sexuality as a vital component of humanity". This sentiment is echoed by the World Health Organization which states, "Every person has the right to receive sexual information and to consider accepting sexual relationships for pleasure as well as procreation" (Mace, Banneman & Burton, 1974). Client-centered care, which aims to customize care to the specific needs and circumstances of each individual, envisions that sexual care will be delivered in ways that are acceptable and meaningful to clients (Institute of Medicine, 2001).

## **What is provided**

Research shows that long-term care institutions neglect residents' sexual lives. According to Berger (2000:309), "Nursing homes actively create environments in which residents can have a satisfying rich lifestyle, although, commonly, attention to sexuality is absent". Earle (2001:436) makes a similar claim: "The professional neglect of disability and sexuality in nursing, and in other health and social care professions is well documented". This occurs despite the documented benefits of sexual activity on people's psychosocial well-being and the knowledge that having a severe disability or illness does not mean that people lose their ability to be sexual and experience sexual pleasure (Barrett, 1991; Breen & Rines, 1996; Brown, Carney, Cortis, Metz & Petrie, 1994; Cornelius, Chipouras & Daniels, 1982, 1982; Dressel & Avant, 1983; Mace et al., 1974; McCann, 2000; Nye, 1999; Reinisch & Beasely, 1990; Szasz, 1989; Weeks, 1986).

Resolving the dissonance between the sexual care that should be provided and that which currently exists provided the impetus for this dissertation research. To the best of my knowledge, there has been no previous work which develops a moral vision of how long-term care institutions should manage sexual activity and care based on an improved understanding of the obstacles to sexual activity and sexual care and their relationship to ethical, legal and administrative considerations.

## **Scope of research**

The focus of my research relates to persons living in long-term care. However, because many long-term care residents have physical and/or mental disabilities, I sometimes refer to the work as being relevant to persons with disabilities. While there is

overlap between these two populations, I recognize that the research does not address all the sexual issues that may concern persons with disabilities.

The ethical arguments presented in this thesis pertain to both capable and incapable residents. For reasons which will be discussed in Chapter 3, given that incapable residents did not participate in my study, the ethical arguments and proposed pragmatic framework for sexual care require testing in clinical settings which serve these people. This is particularly so because, unlike George Pearson Centre ("GPC") which was home to a younger population of persons with severe physical disabilities, the majority of residents living in long-term care facilities suffer from dementia or cognitive impairment.

Finally, although I believe that the ethical arguments and pragmatic sexual care framework advanced in this work are applicable to other types of institutions such as geriatric nursing homes, psychiatric in-patient hospitals and prisons, further research is required to verify this claim.

### **Significance of research**

This research offers to provide new insight into the practice and management of sexual care in long-term residential facilities. This is an important area of exploration because of its potential to contribute to both theory and practice. Theory is advanced by the delineation of an ethical case in support of sexual activity in long-term care. Practice is improved by the adoption of management strategies which better support residents' sexual lives and staff's ability to provide sexual care.

### **Organization of thesis**

The material in this thesis is arranged in nine chapters. Following this introductory chapter, Chapter 2 summarizes the current state of knowledge and practice regarding sexual activity in long-term care. It highlights unresolved areas of inquiry, and describes the process of developing the study's conceptual framework. The literature review is largely descriptive and focuses on studies that identified negative influences on the sexual lives of persons with disabilities, especially those residing in institutions. I also review research that offers insight into health care providers' reluctance to provide sexual care. Results from expert interviews, which aimed to help further refine the study's focus, are reported.

Chapter 3 details my methodological approach. This includes descriptions of the primary field of study (i.e., GPC), the fieldwork, and document analysis. Issues of reliability and validity are addressed, as are data management and analysis.

In Chapter 4, residents' stories provide a rich account of their sexual lives, what sexual choices they want to make or are making, the negative influences on their sexual activity, and what supports they need to have sexual lives. Using data analysis and interpretation I discuss six key influences that impact negatively residents' sexual lives.

In Chapter 5, I present staff's views of residents' sexual lives and examine nine negative influences on their provision of sexual care.

The ethical rationale that establishes moral obligations of long-term care institutions to provide sexual care is advanced in Chapter 6. *Prima facie* rights for residents to have their sexual lives tolerated and to receive assistance to carry out sexual activity that they cannot do for themselves because of their physical disabilities are proposed. These rights are then weighed against countervailing arguments of harm to self

(and participating others), harm to others, and offense to determine if they can be legitimately canceled.

In Chapter 7, seven legal issues regarding sexual activity and care are addressed. Residents' legal rights to engage in sexual activity, the legal responsibilities of institutions with respect to residents' sexual activity, the rights of substitute decision-makers, prostitution and bawdy-house legislation, professional duties of care, negligence, and staff's rights to work in a sexual harassment free environment are reviewed.

In Chapter 8, I begin developing a pragmatic framework for the delivery of sexual care. Three long-term care management strategies changes are proposed. Modifying autonomy and protectionist bioethical paradigms designed for acute care settings so that they resonate with the realities of long-term care living, changing attitudes through education curricula that promotes a sex-positive ethos, and developing sexual care guidelines are discussed.

In Chapter 9, I provide a summary of the research and highlight key themes that arise from the study. Methodological strengths and limitations of the research design, study sample, and data analysis are reflected upon. I end the chapter and dissertation with suggestions for future research and my own concluding thoughts.

## **CHAPTER 2:**

### **Developing the Conceptual Framework - Rationale for the Study**

A characteristic of humans – perhaps because of our large conceptualizing brain – is to adopt important life activities to a variety of functions. We eat, for example, not just for nutrition, but also for entertainment, socialization and relaxation. So it is with our sexuality.

---Michael Barrett, 1982:1

...sexuality has become an increasingly social and political as well as moral issue....in spite of the undisputed significance of sexuality, it remains taboo.

--- Sarah Earle, 2001:435

### **Introduction**

Institution administrators' long-standing struggle to balance residents' "sexual expression with concern about obligations to prevent assaults, harassment, the transmission of sexually transmitted disease and unplanned pregnancies" has resulted in a large variety of sexual activity policies (McSherry & Somerville, 1998:90-91). They range "from completely disallowing all forms of sexual activity, to allowing some forms but not others, to providing private suites for the use of individuals and their partners" (McSherry & Somerville, 1998:90). Within this context, social scientists continue to call for greater emphasis on improving the quality of life for institutionalized residents, more acknowledgement and understanding of sexuality in persons with disabilities, and an abatement of professional neglect of sexuality and disability (Barrett, 1991; Collopy et al., 1991; Earle, 1999, 2001; Koch, Kralik & Eastwood, 2001; McAlonan, 1996; Seymour, 1998; Shakespeare, Gillespie-Sells & Davies, 1996; Tepper, 1997).



Using Batey's (1977) schema for developing a conceptual framework, this chapter aims to describe the rationale for the study. According to Batey, the conceptual phase of a study includes identifying the problem/phenomenon to be addressed, the current state of knowledge about the problem, areas of ambiguity or incompleteness in the current level of knowledge, the framework of concepts and their relationships, and the specific part of the conceptual relationships that will be studied. Using these factors as a guide I now describe the conceptual framework developed for the present study.

I begin with a description of my early personal and professional exposure to sexual activity and sexual care issues. I show how these experiences led to the preliminary identification of the research problem and a basis from which I could explore current knowledge. I next present an overview of the empirical literature on sex and disability, sexual activity in long-term care, and some of the reasons why health care providers are reluctant to provide sexual care. The review is descriptive in nature and covers qualitative and quantitative studies with literature drawn from the fields of medicine, nursing, law, sociology, and psychology. The findings from fourteen expert interviews, which were conducted to help further decide what focus the study should take, are also summarized. I then discuss the relationships between the literature review, results of the expert interviews, and my goal to create knowledge that may improve residents' sexual lives and staff's provision of sexual care. I end with identifying the gap in knowledge that the present study will address.

### **Personal and professional exposure to sexual activity and sexual care issues**

The conceptual framework began with my question of why long-term care residents' sexual lives are curtailed. This question arose from three experiences. First,

over years of paying visits to friends and relatives living in long-term care I saw few opportunities for sexual expression. Single rooms with single beds were the norm, as was the separation of long-term partners. These medicalized “homes” discouraged even the most benign types of socializing. Intimate encounters seemed unimaginable. Second, case consultations held with the GFS/GPC Ethics Committee, of which I am a member, renewed my awareness of repressed sexual freedom. Discussions about residents' access to the private “visiting” suite, staff compliance with institutional “policy” regarding non-interference in residents' sexual activity, and the institution’s obligations to protect residents from sexual abuse added to my perception that the complex moral and social issues involved in sexual activity and care have not been adequately resolved. Third, in recent years it has become increasingly necessary for me as mother and co-guardian of my son to consider what sexual opportunities I want him to have. On what basis would it be moral to refuse him a sexual life? What supports will he need to have a safe sexual life and keep others safe? What obligations should be imposed on caregivers to help him have a sexual life?

When I looked to the literature for guidance I found little that helped answer my questions and concerns. Thus, for a variety of personal and professional reasons I decided to address our inadequate knowledge.

### **Literature review**

Table 2.1 summarizes the significant issues raised in the current literature on sex and disability, sexual activity in long-term care, and health care providers' attitudes to sex and sexual expression. These fall under two main categories: obstacles to resident’s sexual lives and obstacles to health care providers providing sexual care.

**Table 2.1 – What is known in the literature****Obstacles to residents' sexual lives**

Negative attitudes of others  
Psychological & physiological limitations  
Lack of opportunity  
Lack of privacy

**Obstacles to health care providers providing sexual care**

Avoidance of instability and chaos in medical settings  
Lack of education  
Embarrassment, believing that sexuality is not relevant to the presenting medical problem, and inadequate training  
The legal duty to prevent sexual abuse

Factors that deter persons with disabilities, including those who live in long-term care, from having sexual lives include: negative attitudes of others, psychological and physiological limitations, lack of opportunity and lack of privacy. Reasons for sexual care being inadequate or unavailable include: avoidance of instability and chaos in medical settings, lack of education, embarrassment, believing that sexuality is not relevant to the presenting medical problem, inadequate training, and care providers' perception of their legal duty to prevent sexual abuse. Literature from both categories of research are discussed in the following two sections.

### 1. Obstacles to residents' sexual lives

#### Negative attitudes of others

Lack of sexual freedom and negative attitudes to persons with disabilities' sexual lives remain prevalent (Earle, 2001; Kempton & Kah, 1991; Schrover & Jensen, 1988; Shakespeare et al., 1996). Historically, a strong negative mythology in western culture has discouraged sexual expression in persons with disabilities (Schrover & Jensen, 1988). Labels such as "crippled", "handicapped", and "disabled" remain and undermine the positive self-concept necessary to achieve a healthy intimacy with others (Becker, 1984). Even sexual activity among older adults without serious cognitive or physical disabilities is often labeled as abnormal or inappropriate (Aylott, 1998; Brown, 1994; Dolan, 1985; Kamel, 2001; Morris, 1993; Pollard & Barker, 1985; Szasz, 1983). Sex is often seen as only for the young, beautiful and able-bodied. Those who do not fit the criteria "should" be asexual (Becker, 1984; Brown, 1994; Cort, 1998; Evans, 1999; Pederson, 1993; Saretsky, 1987; Williams, 1999). As a result, persons with disabilities often come to believe that their sexual needs and desires should cease. They then commonly develop

feelings of guilt and anxiety around normal sexual urges (B.C. Coalition of the Disabled, 1990; Pederson, 1993; Schrover & Jensen, 1988; Tallmer, 1984).

#### Psychological and physiological limitations

Although psychological and physiological limitations may negatively impact persons with disabilities' sexual activity, several studies have shown that education and support can help these individuals have successful and rewarding sexual lives (Alexander, Sipski & Findley, 1993; Barrett, 1982; Basson, 1998; Courtois, Charvier, Leriche & Raymond, 1993; deMey, 1998; Sipski & Alexander, 1997a; Sipski, Alexander, Rosen & Raymond, 1995). The sexual development and behaviour of persons with disabilities is very similar to that of their able-bodied peers. Most disabilities do not reduce interest in sex or the capacity for sexual function (Reinisch & Beasley, 1990). In fact, some studies show that age and physical limitations may indeed increase the need for intimacy (Dressel & Avant, 1983; Reinisch & Beaseley, 1990; Starr & Weiner, 1981). Physical and psychological sexual dysfunctions or difficulties such as erectile dysfunction, lack of ejaculation, anorgasmia, impaired lubrication, dyspareunia, spasticity, fatigue, bowel and bladder incontinence, fears of pregnancy, negative impacts on self-image and body image, and problems with partner communication can be alleviated through various forms of psychological counseling and physiological therapies and treatments (Althof & Lavine, 1993; Barrett, 1991; Basson, 1998; Berard 1989; Bregman and Hadley, 1976; Courtois, Charvier, Leriche, Raymond & Eyssette, 1995; de Mey, 1998; Dianko, Brown & Herzog, 1990; Ekland, Griffin, Copeland, Elliott & Nigro, 1998; Elliott, 1998, 1999, 2002a, 2002b; Elliott & Krassioukov, in press; Forman, Gilmour-White & Forman, 1996; Fowler, 1999; Geiger, 1979; G.F. Strong 1991, 1999;

Gillan, 1980; Griffith & Trieschmann, 1977; Harison, Glass, Owens & Soni, 1995; Hennessey, Robertson, Swinger & Compston, 1999; Kettl et al., 1991; Kreuter, Sullivan & Siosteen, 1996; Krogh et al, 1997; Leo, Rao & Bernardin, 1991; Lundberg, 1978; Mattson, Petrie & Srivastava, 1995; Maurice, 1999; Metz 1998; Rines & Breen, 1991a, 1991b; Roe, 1999; Schuler, 1982; Shabsigh, 1997; Sipski & Alexander 1993a, 1993b, 1997b; Slater, 1999; Smith & Bodner, 1993; Sonkson & Biering-Sorenson, 1992; Stein, 1992; Stenager, Stenager & Jensen, 1994; Tepper, 1999; Vas, 1969; Westgren, Hulting, Levi, Seiger & Westgren, 1997; Whipple & Komisaruk, 1997; Willnuth, 1987; Yarkony, 1990; Zorzon et al., 1999).

#### Lack of opportunity

A major reason for long-term care residents' non-involvement in sexual activity is lack of opportunity (Wasow and Loeb, 1979). McCracken (1980) found that when older adults stop having sexual relations, it is not for the most part due to incapacity or lack of interest, but rather due to the loss of sexual partners. Despite the negative impact of lack of opportunity, some studies have documented interest in sexual activity among a substantial percentage of long-term care residents. White's (1982) study of United States nursing home residents concluded that seventeen percent of sexually inactive residents indicated a desire to have sexual lives. In another study seventy percent of males and sixty percent of females aged sixty-five years or more reported that they enjoyed sexual intercourse on a regular basis (Fielden, 1997). Mulligan and Palguta (1991) found that institutionalized geriatric males remain especially interested in coitus. Finally, Bretschneider & McCoy's (1988) study of sexual interest in healthy eighty to one-hundred-and-two-year olds found that sixty percent of men and thirty percent of women

had sexual intercourse at least sometimes. Twenty-six percent of the men and ten percent of the women were reported to have intercourse several times a month to several times a week.

### Lack of privacy

Privacy is "the ability to control the degree to which people and institutions encroach upon one's life" (Marshall, 1974:255). Control of one's private space is "the ability to control interaction, to have options, devices and mechanisms to prevent unwanted interaction and to achieve desired interaction" (Altman, 1975:17).<sup>3</sup> Without a commitment to protecting each individual's right to privacy, rights to accurate sexual information and sexual expression are "meaningless" (Brown et al., 1994:1).

People who have their homes in institutions rarely have access to and control over private space, as privacy needs in these settings are often not accepted (Altman, 1975; Bauer, 1999; Bermann, 2003; Depres, 1991; McCann, 2000).<sup>4</sup> This is despite the fact that staff's intrusions into the territory and personal space of hospitalized patients have been shown to produce anxiety and feelings of depersonalization (Glen & Jownally, 1995). Kaas' (1978) study found that nursing home residents and staff both cited lack of privacy as the most frequent reason for repressed sexual expression. Similarly, Spector & Fremeth (1996) found that the unavailability of properly equipped private rooms in nursing homes negatively impacts sexual activity.

## 2. Obstacles to health care providers providing sexual care

---

<sup>3</sup> Jean Brigg's (1970) description of how "Eskimo" people attain privacy while living with family in an isolated igloo provides an example of how standards of privacy are impacted by culture. A question of interest, not undertaken in the present study, is how does the culture of institutions impact concepts of privacy?

<sup>4</sup> For more information on privacy standards in health care settings see Anderson & Kitchin, 2000; Cahill, 2001; Margolin, 1988; Toronto Rehabilitation Institute, 1994.

### Avoidance of instability and chaos in medical settings

Irene Barnes (2001) describes caregivers' reluctance to accommodate sexual activity amongst cognitively impaired residents due to the resulting turmoil. To some degree, her story confirms Dupras and Poissant's (1987) finding that a major factor that explains sexual repression in hospital settings is staff's desire to maintain stability and avoid chaos. The authors found that altercations frequently occur when staff feel patients' sexual activity has disturbed the proper functioning of the hospital, whereas patients experience that they have been wrongfully watched and controlled.

### Lack of education

Research has shown that health care providers' lack of education and knowledge about sex and sexuality results in their trying to curtail residents' sexual activity (Dupras & Poissant, 1987). Some studies have suggested that nurses who have strong negative attitudes to, or inadequate knowledge about, sex and sexuality are unlikely to provide sexual care (Gamel, Davis & Hengeveld, 1993; Lewis & Bor, 1994; Payne, 1976; Webb, 1988). Without sex education programs, staff often have inconsistent attitudes to residents' sexual lives, experience uncertainty about how to redirect inappropriate sexual activity, and may be reluctant to embrace positive attitudes to residents' sexual lives because of lack of knowledge and fear of legal liability (Abramson, Parker & Weisberg, 1988; Doyle, Bisson, Janes, Lynch & Martin, 1999; Turnstull & Henry, 1996).

Although the literature supports a need for staff education, few programs exist (Daniels, Cornelius, Makas & Chipouras, 1981; Steinke, 1977). This is despite the fact that identifying effective methods to teach health care providers about sex and sexuality has been recommended as a way of addressing lack of sexual care (d'Ardenne, 1988;



Gamel, Hengeveld, Davis & Van Der Tweel, 1995; Gripton & Valentich, 1983; Hodge, 1995; Joseph, 1991; Latimer, 1981; Pollard & Barker, 1985; Schuler, 1982; Webb, 1985).

In addition, several studies have shown that education helps nurses develop positive attitudes to sexual care (Doyle et al., 1999; Lewis & Bor, 1994; Mayers & McBride, 1988; Turnstull & Henry, 1996; White & Catania, 1982). This is especially true when it focuses on helping care providers learn how to separate personal and professional values (Lewis & Bor, 1994).

Other studies have shown that staff education programs are quite effective in eliciting support for residents' sexual lives, and they help reduce the tension between residents and staff over issues of sex and sexuality (Mayers & McBride, 1988; Steinke, 1997; White & Catania, 1982).

Embarrassment, believing that sexuality is not relevant to the presenting medical problem, and inadequate training

Merrill & Thornby (1990) reported that physicians fail to take adequate sexual histories because of embarrassment, believing that sexuality is not relevant to the presenting medical problem, and inadequate training.

The legal duty to prevent sexual abuse

Institutions and health care providers are also reluctant to provide sexual care because they are concerned that it may interfere with their legal duty to prevent sexual abuse and exploitation (McSherry & Somerville, 1998). This is relevant given that disabled persons are at high risk of being physically, sexually, and emotionally abused, especially when they have significant dependency needs (Bernard, 1999; Ducharme & Gill, 1997; Marchant & Page, 1993; Westcott, 1994). In addition, severely disabled

persons sometimes find it difficult to articulate their abuse, may be less likely to be believed, and may lack the knowledge required to understand when abuse has taken place (Sant Angelo, 2000).

### **Expert interviews**

To further understand what focus the present study should take, expert interviews were conducted (Marshall & Rossman, 1999). This strategy allows for well-informed, experienced individuals with knowledge of the research area to identify problems perceived to be significant. Fourteen open-ended discussions took place with two sexual health nurses, one long-term care nurse, one community nurse, one psychiatrist, one geriatric psychiatrist, one social worker, two former long-term care residents, two lawyers, one ethicist, one long-term care policy author, and one prison assistant deputy warden. All of the consultants consented to their opinions being recorded as research data. Table 2.2 lists the titles of the fourteen interviewees, significant issues identified, and the contextual feature(s) to which their concern(s) relate. Ethical, legal and administrative considerations were dominant in these discussions.

**Table 2.2 Expert Interviews – Summary of findings**

<b>Position/Title</b>	<b>Main issue of concern</b>	<b>Contextual concern</b>
1. Sexual health nurse #1	Improvement of staff's attitudes to residents' sexual activity	Administrative
2. Sexual health nurse #2	Sexual assistance provided by front-line staff without adequate guidelines from institutions and professional ruling bodies	Legal
3. Long-term care nurse	Allowing residents' to have sexual lives while protecting them from possible harm	Ethical
4. Community nurse	Concerns about maintaining personal and professional boundaries when assisting clients with sexual activity	Legal
5. Psychiatrist	Balancing medical care with consideration for quality of life issues. Harm reduction when psychotic patients are sexually active.	Ethical/ Legal
6. Geriatric psychiatrist	Questioning the use of scarce resources for sexual care	Ethical/ Administrative
7. Social worker	Lack of opportunity for residents to have sexual lives due to social stigma, lack of social support and poverty. Concern about residents' ability to give informed consent for sexual activity when concerns about influence, manipulation and duress are present	Ethical
8. Former long-term care resident #1	Long-term care's focus on the needs of staff instead of clients	Administrative
9. Former long-term care resident #2	Lack of residents' power to voice concerns without fearing that their care will be compromised	Administrative
10. Lawyer	Impact of human rights legislation on residents' rights to have sexual lives in their homes versus rights of staff in their workplace	Legal
11. Lawyer	Implications of allegations of running a common bawdy-house and allowing prostitutes on site	Legal
12. Ethicist	Rights of residents to have sexual lives versus harm to self, harm to others and offense	Ethical
13. Policy writer	Conflicting rights of residents and staff	Ethical/Legal
14. Assistant deputy Warden	"Family" visits on prison sites and issues with privacy, security, safety and public opinion	Ethical/ Legal

**Identifying the specific parts of the conceptual framework that will be studied**

Although the literature identifies many of the negative influences on sexual activity and care, the recommendations to date have failed to ensure that long-term care residents are ubiquitously allowed to have sexual lives. Findings from my expert interviews suggested that contextual features such as ethical, legal and administrative considerations have not been adequately addressed. For example, the experts predicted that, even if private rooms for sexual activity were made available, sexual care would remain largely unavailable because of insufficient information about how their existence impacts such things as staff's professional and legal responsibilities.

Table 2.3 represents the concepts and their relationships as understood at the beginning of the research project, after the results of my literature search and expert interviews were evaluated. The final column identifies gaps in knowledge that need to be addressed in order to meet the goal of improving residents' sexual lives and staff's provision of sexual care. These gaps form the basis of my dissertation research.

**Table 2.3 - The concepts and their relationships as understood at the beginning of the research project**

<b>Residents' Obstacles</b>	<b>Literature Recommendations/ Expert interviews</b>	<b>Goal</b>	<b>Missing knowledge to reach goal</b>
Negative attitudes of others	Provide residents with various psychological/physiological treatments	Improve residents' sexual lives	Improved understanding about how sexual activity and care interact with each other and with ethical, legal and administrative considerations
Psychological and physiological limitations	Address biopsychosocial constraints		
<b>Health care providers' obstacles</b>	<b>Literature Recommendations/ Expert Interviews</b>	<b>Goal</b>	<b>Missing knowledge to reach goal</b>
Avoidance of instability and chaos in medical settings	Provide staff with education	Improve staff's provision of sexual care	Improved understanding about how sexual activity and care interact with each other and with ethical, legal and administrative considerations
Lack of education	Educate physicians to overcome embarrassment and become better informed about sex and sexuality		
Embarrassment, believing that sexuality is not relevant to the presenting medical problem, and inadequate training	Identify effective methods to teach nurses about sex and sexuality and the importance of separating personal and professional values		
The legal duty to prevent sexual assault	Address contextual features that negatively influence sexual care		
Strong negative personal attitudes to sex and sexuality			

## **CHAPTER 3:**

### **Methodology**

What to outsiders may seem to be an unacceptably restricted life is often, for those who live it, filled with meaning. Persons with physical and perceptual differences may daydream of a full physical range of activity—the weekend athlete dreams of being an Olympic medallist—but this does not mean they believe their existence is necessarily burdensome or lacking. To argue a necessary harm without reference to this experiential literature is to insist that one's own sense of normalcy should rule...

--- Tom Koch, 2001: 373

#### **Introduction**

This chapter describes the research steps and methods used in this study (Table 3.1). Step 1 summarizes the development of the conceptual framework and problem definition. Step 2 describes the further development of the study design. Step 3 describes the primary field of study (i.e., GPC), and provides an overview of the three distinct but interrelated sources of data (i.e., interviews, participant observation and document analysis). Reliability, validity, data management and data analysis are also discussed.

This work is grounded in four years of research. The overall research methodology may be described as qualitative, exploratory and embedded in a design that emanates from multiple sources. Situational ethics served as a guide to help resolve ethical dilemmas that arose throughout the research process (Noddings, 1984).

**Table 3.1 Research steps and methods****Step 1: The conceptual framework & problem definition**

Defining a problem in long-term care  
(Sexual activity is curtailed in long-term care)

Literature review  
(Obstacles to residents' sexual lives  
& staff's provision of sexual care)

Expert interviews  
(Identification of experts' opinions of significant  
issues with respect to sexual activity and sexual  
care)

Investigating the moral and social nature of residents' sexual lives and staff's provision of sexual care. Specifically, focusing the study on how the negative influences on sexual activity and sexual care interact with each other and with ethical, legal and administrative considerations. Contributing to the development of a moral vision of how long-term care institutions should manage sexual activity and sexual care.

**Step 2: Development of the study design**

Participation in legal & medical  
forums & workshops

Participant observation of  
sexual health clinics, client  
interviews & staff meetings

Linking the literature & expert  
interviews (i.e., step 1) to the other  
aspects in step 2 of the study  
design

Study design

Designing the study to (i) identify the factors that negatively influence sexual activity and sexual care, and (ii) identify the supports that residents and staff respectively need to have sexual lives and provide sexual care.

**Step 3: Fieldwork**

Semi-structured, in-depth  
interviews with GPC residents  
and staff

Participant observation  
of persons with disabilities  
living in the community

Document analysis

Data analysis

**Step 1: The conceptual framework and problem definition**

The research began with my question of why long-term care residents' sexual lives are curtailed. After reviewing the literature and conducting fourteen expert interviews, I concluded that before this question could be answered further investigation of the moral and social nature of residents' sexual lives and staff's provision of sexual care was required. Specifically, I believed that the study should focus on understanding how the negative influences on sexual activity and sexual care interact with each other and with ethical, legal and administrative considerations. This, I hoped, would help determine how long-term care facilities should manage sexual activity and sexual care. This work recognizes a failure in the practice of long-term care management to ensure that residents have opportunities to improve the quality of their lives in ways that are important to them, and illustrates a mismanagement of long-term care facilities due to inadequate information, understanding and knowledge about what is required to ensure residents can have sexual lives and staff will provide sexual care. It therefore has all the necessary elements to contribute to new knowledge and to improve long-term care management and localized care practice.

**Step 2: Development of the study design**

With the research question identified, further development of the study design was guided by my involvement in three activities: (i) participation in legal and medical forums and workshops, (ii) observing sexual health clinics, sexual health client interviews and sexual health staff meetings, and (iii) membership in a sexual health policy development working group. The process ended with the linking of the findings from the literature review and expert interviews to (i)- (iii).



I participated in the activities listed above as a result of suggestions made by the expert interviewees. On the experts' advice I identified specific clinics, conferences and documents that I thought would help answer the research question. For each activity I contacted a senior administrator, explained my research, described why the subject material was of interest to me, and asked if I could participate as an observer. With the exception of one clinic I was welcomed. The exception was the sperm retrieval clinic where the staff felt that the nature of their work was too sensitive to warrant observers.

#### Participation in legal forums

Two forums, *Meeting the Standards of Care: Challenging Issues in Patient Safety - Creating Fair and Effective Patient Sexuality Policies and Adult Guardianship Legislation*, presented by the Continuing Legal Education Society of British Columbia, helped me identify legal concerns that commonly arise when institutionalized residents have sexual lives. The seminars also helped to increase my awareness and understanding of institutions' legal duties and responsibilities regarding sexual care. For example, I learned that it was prudent of Riverview Hospital, an eight hundred bed tertiary care hospital, serving patients suffering from severe persistent mental illness, to develop a patient sexuality policy. Specifically, the policy helped abate administrators' concerns regarding the spread of sexually transmitted diseases, unwanted pregnancies, and possible damage to residents' self-esteem as a result of carrying out sexual activity behind garden bushes and in stairwells. The policy established a distribution system for complimentary condoms, provided education seminars for residents and staff, and set up a private suite that residents could access with minimal interference.

### Participation in medical forums and workshops

A variety of medical forums and workshops including Greater Vancouver Mental Health Services Society's seminar on *Sexuality and Mental Health*, G. F. Strong's, workshop for health care professionals on *The Assessment and Management of Changes to Sexuality in People with Chronic Illness or Physical Disability*, U.B.C. Hospital's Grand Rounds on *Sexual Issues with Psychiatric In-Patients*, an ethics forum on *Sexuality at GPC*, and Mainstream Society's *Residential Sex and Sexuality* seminar for community caregivers helped me to better understand providers' concerns. In one case, hospital staff wanted to know what were their legal duties to supervise the sexual activity between two psychiatric in-patients, one of whom was known to be HIV positive. In another case, a community care provider wanted to know if she had any moral or legal obligation to comply with a client's requests for her to watch pornographic videos with him. As the answers seemed obvious to me (i.e. there is a legal duty to prevent foreseeable harm and care providers are not obliged to necessarily meet all the demands of their charges) I understood the need to improve support to clinicians who must manage sexual activity.

Beyond participating in conferences and seminars, I gave several talks on sexual activity in long-term care. Presentations were made at Vancouver Hospital and Health Sciences Centre's Grand Rounds, Providence Health Care's ethics training seminar, Vancouver Richmond Health Board's Geriatric Mental Health team, four nursing homes, and the West Vancouver's adult day-care and long-term care planning day. Besides giving me the opportunity to practically work through issues with clinicians, I was once

again reminded of the importance of adequately supporting care providers who provide sexual care. In one nursing home, after I was able to assist staff in redirecting a resident's inappropriate sexual advances, instead of wanting to transfer him to another facility, they became eager to help him find more appropriate sexual outlets!

#### Participant observation of sexual health clinics, client interviews & staff meetings

Participant observation of sexual health teams operating at G. F. Strong and Vancouver Hospital and Health Sciences Centre helped deepen my understanding of the sexual concerns of persons with disabilities. I elaborate on each experience.

#### Sexual health clinics

Attending sexual health clinics, where nurses work with clients with disabilities to find practical ways of enhancing their sexual lives, gave me an opportunity to experience some of the frustrations that face long-term residents. In one clinic I observed a severely spastic male client learn how to insert medications into his urethra so that he could obtain an erection and masturbate. In the first session the nurse demonstrated the procedure. She removed the condom drainage, inserted the erection pellet into the urethra, stimulated blood flow to the penis by manual touch and then replaced the condom drainage. In the second session the client carried out the procedure on his own. After struggling for over forty-five minutes he succeeded. However, despite his achievement, he was unlikely to be able to use his newly acquired skills because to date his residential staff had always refused to deliver or administer any erection enhancement medications. The reason? - "Staff don't like me doing it." (Fieldnotes: April 18, 2000)

#### Sexual health client interviews

In observing several G. F. Strong sexual health nurses' interviews with in- and

out- patients I was reminded of the difficulties that face persons with disabilities when they want to have sexual lives. Erectile dysfunction, lack of money to purchase medications or sexual enhancement devices, emotional difficulties with intimate relationships, lack of opportunity, and lack of privacy were some of the issues discussed. Clinicians fielded a variety of questions, offered education in anatomy and physiology and gave practical advice, such as suggesting alternate positions for sexual activity to compensate for physical disabilities. During these sessions I repeatedly heard how clients' sexual concerns often emanate from, or are exacerbated by, lack of sexual care.

#### Sexual health staff meetings

As an observer at the Vancouver Hospital and Health Sciences Centre's Centre for Sexuality, Gender Identity and Reproductive Health staff meetings, I learned about some of the questionable reasons why sexual care is unavailable to persons with disabilities. When a client with severe physical disabilities was seeking approval for sex change surgery, clinicians' were concerned about the lack of guaranteed post-operative sexual care. To improve the probability of a positive outcome, it was necessary for caregivers to agree to regularly insert moulds into the client's newly formed vagina, so that it would keep its shape and remain supple. The Centre's staff believed that care providers would likely refuse to provide this service, even though they routinely deliver similar types of care (e.g. catheterization, condom drainage changes, genital washing and disimpacting bowels) because, in their experience, personal values commonly dictate the delivery of sexual care.

#### Sexual health policy development working group

From November 2000 to February 2002 I had the opportunity to sit as a member

of the Vancouver Hospital and Health Sciences Centre's Sexual Health Working Group. Our mandate was to "explore the sexual needs of patients/clients/residents with the objective of identifying potential alternative methods of supporting these health issues". The committee recognized and concluded that clients could not have sexual lives unless staff were willing to provide appropriate supports. We also realized that staff would not likely provide these supports unless the institution developed sexual care guidelines.

### **Linking sexual health participant observations to the literature and expert interview findings**

In order to finalize the study design, insights gained from my participation in the above activities were linked to the areas of missing knowledge identified in the literature and expert interviews. This led to the development of a study design which aimed to do the following: (i) identify the factors that negatively influence sexual activity and sexual care, and (ii) identify the supports that residents and staff respectively need to have sexual lives and provide sexual care. I believed that this information would offer insight to how sexual activity and care should be managed because it aimed to capture the contextual factors that institutions must attend to, in order to ensure that residents have opportunities to have sexual lives and that staff are adequately supported to provide sexual care.

### **Study design**

The study design chosen for this research was exploratory and one that emanates from multiple sources. Exploratory studies are particularly useful for "investigating the relationships between phenomena about which not much is known" (Woods & Catanzaro, 1988:150).

The following is a description of the four main aspects of the present study design including a description of participants and the methods used to select them, the study time frame, selection and descriptions of the settings, and the role of the investigator.

Two data sources, including interviews with GPC residents and staff and participant observation of two persons with disabilities living in the community, were used. I now describe these informants and the instruments used to collect data.

#### Subject selection - sampling strategy for residents and staff participants

Purposeful sampling and appropriateness, which were used to select residents and staff, aim to ensure that potential participants are chosen according to the extent that they meet the selection criteria (Sandelowski, 1995; Woods & Catanzaro, 1998). This sampling technique is useful when information is needed about particular kinds of populations, situations or experiences. Participants were chosen on the basis of my assessment regarding the extent to which they met the selection criteria, and the likelihood of their contributing to a better understanding of the negative influences on sexual activity and sexual care.

#### Resident recruitment

Criteria for residents' participation included having a desire to have a sexual life, an ability to communicate in English either verbally or through a communication device, the physical capability to endure the interview process, and the capability to consent to join the study. As GPC physicians were in the best position to evaluate these criteria, I asked them for referrals. In less than two weeks, I was provided with a list of candidates. I then approached these individuals to discuss the project further and to set an interview time.

Two biases were created by this sampling technique. First, because only those residents who had an interest in having sexual lives were referred, it may incorrectly appear that having a sexual life is important to all residents. There is no intention on my part to portray residents as having such a uniform attitude. Second, as incapable residents did not participate in the study their input remains an important area for future research. The decision not to include incapable residents was made partly to reasonably limit the scope of the research, and partly to avoid informed consent issues and inherent difficulties with substitute decision-makers being able to adequately convey their charges' personal sexual experiences.

#### Staff recruitment

Table 3.4 (page: 50) lists the titles of the GPC employees at the time initial data were collected. In recruiting staff, I interviewed only those individuals who had the most responsibility for providing sexual care. Missing are the perspectives of clerical or maintenance personnel who are sometimes responsible for managing such things as residents' sexual advances.

The primary criterion for staff's participation was their having a desire to discuss their personal and professional views about sexual activity and sexual care. This created the sampling bias that the opinions and attitudes of those who chose not to participate may not be the same as those who did.

Staff referrals were self-generated or came to my attention through other staff. Potential participants were given a letter of introduction, which was followed by a personal contact to discuss their questions and set an interview time. Recruitment was greatly facilitated by the administration's permission to conduct these interviews during

working hours.

With the exception of two groups of potential participants, all fourteen staff referred to the study readily agreed to join. Interestingly, two staff members, who refused to formally participate, were willing to spend several hours discussing the issues with me. They also requested that their views be included in my report. This emphasized the importance of flexibility in study design, and in particular, the ability within research to find ways that individuals can participate in a manner that is comfortable for them. The second group of potential participants who resisted joining the study were resident care aides. Although lowest on the clinical hierarchical scale, their input seemed critical because of their extensive knowledge of and exposure to residents' sexual activity. In order to try to reduce the aides' resistance, I attended several staff meetings to explain the importance of including their perspectives. I also recruited senior administrators and nurses to reassure them that their participation would not jeopardize their employment. Finally, after weeks of rejections, a nurse supervisor, who had a close rapport with some of the aides, convinced two, out of approximately thirty aides I contacted, to be interviewed. These two individuals agreed to participate but only on the basis that they be interviewed together. Although I had not contemplated doing group interviews, I promptly agreed and was again reminded of the need for design flexibility.

As I intuitively felt resident care aides' opinions were fundamental to understanding the research question I thought it necessary, without going too far beyond the scope of the present study, to try to discover why they were so reluctant to participate. To this end, I began the interview with the following leading question: "Tell me, what is it about residents' sexual activity that makes aides uneasy about this study?" In response,



both aides quickly insisted that there were no sexual issues on their wards but conceded that there might be "problems" on other wards. Since I already had information to the contrary, I took this resistance as further warning that they were frightened or uncomfortable with voicing their opinions. To reduce the tension and put them more at ease I chatted about some of the stories that I had heard. After a while, they opened up and offered one reason for their reticence. "We are blamed no matter what happens and with sexual activity it's worse. The higher ups never believe us." It was at this point that I first began to understand the role that feelings of powerlessness play in the availability of sexual care.

As it is impossible to say if the views of these two aides are representative of other resident care aides, I acknowledge that further exploration of their experience is an important area for future research.

### Numbers

A suitable sample size for qualitative research is that which allows the researcher to gain in-depth knowledge associated with the research topic (Sandelowski, 1995). The sample size did not need to be large or random because the goal of the enquiry was discovery and understanding, not generalization (Waxler-Morrison, 1995). The initial determination of study numbers was made on the basis of my wanting to hear multiple perspectives and to reach saturation (Strauss & Corbin, 1990; Woods & Catanzaro, 1988). Saturation means that new subjects are interviewed until no new major categories of data or themes emerge. Although I do not believe saturation can ever be fully achieved, because human stories can never be told or understood in their entirety, after twenty-four interviews I felt close to this ideal. In the end, I interviewed ten residents,

two resident care aides, five nurses, one recreation therapist, two social workers, two physicians, and two administrators.

Although family members were originally slated to participate, this idea was abandoned when I was unable to recruit any suitable candidates. Most residents interviewed refused to refer family members, because they were either no longer in contact with them, or they had no interest in having their sexual lives discussed by them. In retrospect, I felt embarrassed that I had not foreseen that residents would likely be humiliated or angry at the thought of family members discussing their sexual lives. Despite my extensive experience with working with persons with disabilities, I too had fallen into the trap of stereotyping their needs for sexual privacy to be less important than others.

For a variety of reasons, the three family member referrals that were made failed to produce an interview. First, as the ex-spouse of one resident had not had any substantial involvement or contact with the resident for over sixteen years, I felt that her input would have little or no relevance to answering the research question. Second, when a resident's spouse agreed to be interviewed, but "only on issues not pertaining to sexuality" (Fieldnotes: August 21, 1999), I decided to proceed with the hope that something that he would say would be relevant. However, none of my six messages to set an interview time was returned. Third, a resident's partner, who lived hundreds of miles away, was also never available for an interview.

Fortunately, my failure to recruit family members proved not crucial to answering the research question. This is because staff did not identify families' concerns as a significant negative influence on their provision of sexual care. Therefore, I tentatively

concluded that, at this stage of the development of a framework for sexual care, family concerns may not be a critical factor for initially determining how sexual activity and sexual care should be managed. This having been said, I acknowledge that families' concerns can create very difficult clinical situations. Therefore, future research that focuses on family perspectives and how to manage their concerns is required.

Despite the drawbacks and difficulties with recruiting resident care aides and family members, individuals who did join my study were enthusiastic participants. None of the interviews was truncated and all participants invited me to return with further questions. One participant's comments were encouraging.

It's crazy no one looks at residents' sexuality. Some have tried but it always gets closed down. We don't even blush when we've taken away one of the most basic aspects of life from these people. What possible moral grounds have we for taking sex away from them? Even prisoners now can have sex visits and here we are treating long-term care residents with less respect than criminals. How did we get to this place and why are we so slow to do something about it? We appreciate you trying. (Fieldnotes: May 29, 2001, social worker)

The success of participants' eager participation can be attributed to three factors:

(i) research questions were well developed with input from experts and stakeholders, (ii) participants could see the relevance of the research to their lives and work, and (iii) a sense of trust between participants and researcher that assured each person that their views were important.

#### Instruments used to collect data at GPC

In order to construct a robust account of the negative influences on sexual activity and sexual care, in-depth semi-structured interviews were used as the main methodological technique. As a qualitative data collection method, these types of interviews help uncover the participant's meaning and perspective and maintain a respect

for how the participant frames and structures responses (Kvale; 1996; Marshall & Rossman, 1999; Morse & Field 1995).

Questionnaires for each group of GPC participants (i.e., residents, staff, administrators and family members) (Appendix "A") were developed by the investigator and reviewed in final draft form by a rehabilitation social worker, a psychiatrist, several members of the G. F. Strong Sexual Health Team, two former long-term care residents, and one former sexual health client. The purpose was to ensure that salient issues were included and that the questions posed were sufficiently open-ended. In final form, the University of British Columbia's Research Ethics Board approved the questionnaires. My intention was never to follow the questionnaires in sequence or in their entirety. Rather, they were used to remind me of the relevant issues and to help maintain focus. Interviews were approached as conversations and participants were encouraged to raise topics and issues of personal importance.

#### Participant observation of persons with disabilities living in the community

The second source of data deemed important to meeting the study's objectives was participant observation of two persons with disabilities living in the community. These individuals' experiences served as a small but important preliminary comparison to the experiences of institutionalized residents. As I did not have sufficient time or resources to interview a greater number of community members, I acknowledge that my conclusions need further testing.

Participant observation was used to gather these data because it allows the researcher to focus on the context and reactions of individuals in their social settings (Marshall & Rossman, 1999; Morse & Field, 1995). Given that one of my primary

interests was to evaluate the impact of environment on sexual activity and sexual care, using this method was apt.

#### Subject selection - sampling strategy for community participants

Purposeful sampling and appropriateness were used to select the two community participants (Sandelowski, 1995; Woods & Catanzaro, 1988). Selection criteria included having a severe physical disability, living in the community, being willing to discuss one's sexual life, and being able to communicate in English, either verbally or with a communication device. A staff member at the Vancouver Hospital and Health Sciences Centre introduced me to the first participant. She was in her mid-forties, employed full time, and lived in a staffed, apartment style group home. A mutual friend introduced me to the second participant, a male in his fifties, who lived in his own home with his children and staff. Introductions to both these individuals were made with their consent and knowledge that I was interested in discussing their sexual lives and that our discussions would be reported in my data.

#### Instruments used to collect data in the community settings

For the community participant observation, extensive fieldnotes were recorded during and after every interview. As both participants knew that my focus was their sexual lives, at some point during each meeting conversation about the topic was initiated.

#### The time frame

Table 3.2 provides a visual representation of the study's time frame.

**Table 3.2 The study's time frame**

	Year 1	Year 2	Year 3	Year 4	Year 5
Expert interviews		*		*	
Literature review	*	*	*	*	
Med/Legal forums, clinics	*	*	*		
Community participant observation	*	*	*	*	
Interviews and follow-up with GPC residents and staff	*	*	*	*	
Document analyses		*	*	*	
Data analysis	*	*	*	*	
Write up	*	*	*	*	*

My initial interviews with residents and staff were carried out over approximately seven months. I wanted to be in the field long enough to reach saturation, frequently enough to experience daily life in the facility, but truant enough to avoid, as much as possible, disturbing regular clinic routines. According to my need for clarification of developing theory, over the subsequent two and one-half years participants were re-contacted on an informal basis.

Participant observation of the two community members took place over two and one-half years. Each person was interviewed ten times. These meetings were scheduled according to the participants' willingness to meet and my sense of when new information might be available.

Document collection and analysis were carried out throughout the project's life. I used this particular mode of data collection to clarify issues or questions that emerged in the research. For example, I referred to the sexual activity policies and guidelines of other types of institutions to determine current attitudes and trends.

#### The primary setting

GPC was chosen as the main field study because of its uniqueness as a long-term care facility. Unlike geriatric institutions, GPC houses a younger population of men and women with severe physical disabilities. Most GPC residents are deemed capable, even though many have cognitive impairments due to disease or injury. Working with a younger population allowed me to circumvent much of the cultural negativity attached to seniors having sexual lives. It also helped ensure that I would have sufficient numbers of capable individuals who could participate in the study. Finally, the site was chosen because of the administration's tremendous support for the project. I was offered copies

of pertinent policies, risk management documents, statistics, access to staff participants during working hours and the overwhelming assistance of the G. F. Strong Sexual Health team. Everyone involved could not have been more accommodating and for that I am very grateful.

### Description of GPC

At the time this research was conducted, GPC was affiliated with a cluster of health care institutions known as Vancouver Hospital and Health Sciences Centre. The group consisted of four individually operating sites including Vancouver General Hospital, The University of British Columbia Hospital, G. F. Strong and GPC. The cluster fell under the authority of the *Hospital Act* (1996).

GPC is situated in Vancouver, British Columbia in a park setting extending over 7.7 hectares. It was named after the Honourable George S. Pearson, Minister of Health and Welfare, 1946-1950. Six wards opened in 1952 as a tuberculosis hospital. In 1966, a seventh ward was added to accommodate patients with polio. In July, 1999 GPC was home to one hundred and fifty-six residents who lived on five separate wards, one of which was dedicated to persons who were ventilator dependent.

The majority of residents living at GPC were middle age (average fifty-five years old) adults who, as a result of a disability, required levels of care beyond that which could be accommodated in the community. Residents' disabilities resulted from spinal cord injuries, multiple sclerosis, traumatic brain injuries, cerebral palsy or a variety of other conditions. Referrals came from all over the province but mainly from the local Vancouver area. All residents were wheelchair dependent using either manual or electric wheelchairs for mobility. To increase independence many residents used assistive



communication devices and environmental controls.

The following excerpt from the GPC Mission Statement (1994) summarizes the institution's aims, goals and objectives.

The aim of George Pearson Centre is to provide comprehensive care and services to meet the long term needs of younger adults with severe physical disabilities. The goals and objectives are:

- to adopt a client centered framework for the delivery of services to residents and families.
- to focus our collective services upon resident quality of life, as defined by the individual resident.

This may include, but is not limited to, the following:

- maintaining current levels of ability
- adapting to limitations
- anticipating future needs
- to achieve the stated goals within the defined resources available

On the recommendation of a task force comprised of board members, residents, and employees in 1989, the term "client centered" came into use when it was incorporated into the Mission Statement.

Being client centered means that we will treat consumers as partners in the process of creating and delivering services. Our service must be responsive to the needs identified by consumers and provided in ways acceptable and meaningful to them. In any situation, the needs and preferences of the person with a disability will be the primary consideration in our design of service, education and research. (Adopted September 19, 1994 at the Residential Program Steering Committee)

Program services included chaplaincy/pastoral care, speech-language pathology, medicine, nursing, clinical nutrition, occupational therapy, physiotherapy, recreation services, music therapy, artworks, social work, a swimming pool and a resident computer room (Technology Independence Centre). Other available services included nutrition and food services, a cafeteria, a women's auxiliary, a special events room, a social centre/canteen, an activity wing, a kitchen, a hair salon, access to Handy-Dart

Transportation, parking, telephones on each ward, Mason's Manor (i.e., a room that could be booked for group activities and private gatherings), and ward "Quiet Rooms"<sup>5</sup> which could be used by residents either on their own or with family, friends, visitors or sexual partners.

In 1999, GPC supported a paid employee, who was a client advocate and advisor to the Resident Council. The Council was formed in July, 1992 to act as a channel for two-way communication between residents and administration. Council representatives helped with staff hiring and program and service planning. The Council, which met every two weeks, consisted of ten elected representatives. Minutes from these meetings were posted on each ward for everyone to read.

Alcohol (beer and wine only) was served in the canteen Saturday afternoons, Tuesday evenings and on special occasions. Residents were limited to three drinks per occasion and the cost was charged to their individual accounts. Consumption of alcoholic beverages was otherwise not permitted in the building or grounds. Smoking, in accordance with the City of Vancouver's Smoking By-law, was allowed only in designated areas. In 1999, housekeeping staff provided security. Confiscating alcohol from residents' rooms and telling residents that they must smoke in designated areas was the usual way of enforcing these rules. Residents were required to drive their wheelchairs in a responsible and safe manner according to the "Safe Wheelchair Driving Protocol". Failure to do so could result in a temporary loss of driving privileges.

Visiting hours were from 10:00 a.m. to 10:00 p.m. daily with management approval required for any extensions. Most often, residents were assigned to rooms with

---

<sup>5</sup> For a variety of reasons that are described in this thesis, these Quiet Rooms proved extremely inadequate for supporting residents' sexual lives.

three or four other people. Single or double rooms were available but only after lengthy waiting periods (sometimes years). Single beds were occasionally allocated in order to limit the number of clients with behavioural issues being on a single ward. In 1999, ventilator dependent residents were housed on an exclusive ward. Finally, rooms were allocated on the basis of gender to ensure that rooms, not wards, were single sex. A daily user fee was assessed for all residents.

The Residential Program considered itself to be a community and health care center. A team approach to individualized care focused on maintaining residents' functional ability and independence.

Although not listed in GPC's brochure, residents could access the G.F. Strong Sexual Health Service. Residents had the option of traveling thirty blocks to G. F. Strong or they could request to have the sexual health professionals come to them. The sexual health service provided an opportunity for individuals with a physical disability (and their partners or families), to voice their concerns and to receive information within a sensitive, supportive and confidential setting. The service also offered individual and group counseling, patient and family education, customized workshops and presentations, erection enhancement, and a sperm retrieval clinic (for persons with fertility concerns). The team consisted of five registered nurses who specialized in the area of sex and disability. There was also a sexual medicine consultant, a physician, with specialized training in sexual medicine.

Use of the Quiet Rooms at the end of each ward was governed by the following in-draft protocol:

The Residential Program recognizes the need for residents and their partners/significant others to have access to a private space. Thus, the Quiet

Room located off the wards is designed for the exclusive, private use of centre residents and their families/significant others. To use the room, all visitors must be accompanied by, or have consent of the designated resident. The Quiet Room is not for staff use. Residents and visitors who demonstrate inappropriate use of this room may have their privilege for use suspended.

The Quiet Room may be used in 3 ways:

- For casual visits for no more than 4 hours with friends and family
- For visits of more than 4 hours or overnight visits. For such visits, the "Application for Use/Waiver of Liability" form must be completed
- As an interview space between staff and resident only if the resident is in agreement

To reserve a Quiet Room, residents were required to be independent in self-care, or be able to direct their family/significant others to provide it, including taking full responsibility for medications while booked into the room.

Residents and their visitors using the room were required to follow the Centre's rules regarding a zero tolerance policy to smoking, alcohol, drugs and/or other illegal activities (not defined). Abuse of this protocol was grounds for immediate suspension of privileges, with the ward team being responsible for determining when reinstatement of privileges was appropriate.

Signing one's name on a calendar outside a Quiet Room reserved its use. The room was available on a first come, first served basis and could be booked for a twenty-four hour (maximum) time period. Based upon demonstrated need, the Residential Program manager or designate could extend the duration of stay. Everyone using the room (maximum two persons overnight) had to sign the application form and a waiver of liability. This meant that residents had to disclose the names of their sexual partners. At the time of data collection, Quiet Room occupancy statistics were not kept.

Resident Demographics as of July 14, 1999 (Source: Dept. of Clinical Records, G. F. Strong)

As of July 14, 1999 there were eighty-one male residents (53.6%) and seventy female residents (46.4%) for a total population of one hundred and fifty one. The average age of residents was fifty-five years, representing a range from twenty-three to eighty-five years. The average length of stay was four thousand and sixty four patient days, which translates to eleven years. Many residents lived at GPC until their death. The following represents a breakdown of residents by primary diagnosis (Table 3.3).

**Table 3.3 Residents' demographics**

Diagnosis	GPC total	%
Multiple Sclerosis	40	26.5
Cerebral Palsy	30	19.9
Spinal Cord Injury	26	17.2
Head Injury	25	16.6
Other	22	14.6
Post Polio	8	5.2
Total:	151	100%

The primary reason for residents remaining at GPC was lack of government or other funds to finance the intensive levels of care required for these people to live in the community. For example, without increasing the current budget, the funding of one-to-one workers for five to eight hours per day, for one GPC resident to live in the community, would result in the cutting of thirty-five to fifty-six hours currently allocated to others who receive only one hour of community care per day (Division of Community Geriatrics, Department of Family Practice, UBC: 2000).

Staff Demographics as of October, 1999 (Source: Dept. of Clinical Records, G. F. Strong)

As of October, 1999 the staff totaled five hundred and thirteen, with a staff/resident ratio of approximately two to one, when full-time equivalent estimates are used. Table 3.4 presents a breakdown of staff according to occupation and gender.

**Table 3.4 Staff's demographics**

Occupation	Female		Male		Total
Care Aides	129	(82.0%)	30	(18.0%)	159
Licensed Practical Nurses	17	(66.0%)	9	(34.0%)	26
Registered Nurses	50	(80.0%)	13	(20.0%)	63
Recreation Therapists	5	(72.0%)	2	(28.0%)	7
Social Workers	2	(67.0%)	1	(33.0%)	3
Other staff*	164	(62.0%)	91	(38.0%)	255
Total	367	(72.0%)	146	(28.0%)	513

\* Other staff included office & accounting, computer operators, bio-technicians, seating specialists, building maintenance, buyers, distribution attendants, laundry, inventory clerks, volunteer coordinators, cooks, food services, dieticians, aestheticians, pharmacists, lifeguards, music therapists, occupational and physiotherapists.

There were five physicians contracted by the institution and all were male. Specialist physicians' services such as physiatrists, psychiatrists and respirologists were sub-contracted. All physicians worked on a sessional basis.



### The role of the investigator

In qualitative interviewing, it is fundamentally important for the researcher not to impute personal views but rather to allow participants' perspectives to be fully heard (Marshall & Rossman, 1999; Morse & Field, 1985). However, recognizing that the researcher is not separate from but part of the interaction, I acknowledge that interface with participants, as well as my reading, informal conversations and personal experience, affected my decision to follow certain lines of inquiry over others. I now elaborate on my personal concerns and how I chose to resolve them.

I came to the research with three concerns. Specifically, I anticipated that there would be some strong resistance to the study, that personal values would play a key role in participants' attitudes and responses, and that there would be multiple and diverse perspectives on the subject matter.

First, resistance was anticipated because I had heard from the outset that people thought that my topic was "far too controversial" and "the issues too involved and difficult to unravel" (Fieldnotes: April 13, 1999; June 2, 1999). To reduce resistance and build participants' trust I decided that I should attend the institution frequently but always for relatively short periods of time. My hope was that people would become comfortable with my presence but not overly irritated by any disruption that I caused to their lives and routines. I also thought that the resistance might be reduced if participants were allowed to control, as much as possible, the structure and content of the interview process. For example, when I arrived on time for my interview with the resident care aides but was kept waiting for over thirty minutes, I sat quietly and as unobtrusively as possible at the nursing station until beckoned to our interview.

Second, anticipating that personal values would play a large role in my interactions with participants, I was concerned about the adequacy of my training and ability to elicit sensitive information. To overcome these weaknesses, a psychiatrist coached me in interview techniques and helped me learn how to be alert to participants' cues, deepen discussion on sensitive topics, and react if people became angry, sad or tearful. The psychiatrist also helped me to understand how my own biases or anxieties might cause me to deflect the conversation to more comfortable areas.

On the advice of one of my advisors, I practiced my new skills in an interview with an elderly woman who was willing to discuss her sexual life and critique my techniques. After describing her sexual past, fantasies and current sexual desires, I raised open-ended questions and tried to keep the interview focused. The woman's feedback was encouraging and her criticisms, such as my failure to regularly check whether she was comfortable with continuing our conversation, were incorporated into subsequent interviews.

Third, anticipating that there would be multiple and diverse perspectives encountered, I felt it important to assure participants that their input was important, even if it differed from others'. In each introductory meeting, I tried to make this point clear. I also endeavored to assure participants that I was not affiliated with administration. I felt that if interviewees saw me as being attached to management, they might either resist joining my study or feed me information that they thought would please their superiors.

Finally, although I was aware that writing could not capture people's full experience, and that my personal orientation would affect my attention and focus, I sought to describe the social phenomena as openly, respectfully and reflectively as

possible.

### **Step 3: Fieldwork**

The third stage of research, which can be characterized as immersion in the field of study, involved the following activities: (i) in-depth, semi-structured interviews with GPC residents and staff, (ii) participant observation of persons with disabilities living in the community, and (iii) document analysis.

#### Interviews with GPC residents and staff

Initial interviews took place in the institution over seven months in 1999. Each interview with residents, residents care aides, front-line nurses, administrative nurses, sexual health nurses, recreation staff, social workers, physicians and administrators took approximately one and one-half to three hours. The twenty-four meetings were conducted in residents' rooms or lounges, the Quiet Rooms, and staff's lounges or offices. The time and place for each interview were arranged to meet the needs and preferences of participants. Some took place in the late evening, others in the early morning or on weekends. Follow-up meetings were arranged when I needed to ask further questions or clarify developing theory. Some participants were seen up to six hours in total.

In the initial interview, participants were always given a clear explanation of the study. Specifically, I stated the following: (i) the objective of the study, (ii) the background and qualifications of the researcher, (iii) the names of professors and university involved, (iv) the importance of their collaboration to help answer the research question, (v) the reasons why they were selected as a potential participant, and (vi) the possible benefits that they may reap by agreeing to participate.

Interviews followed a questionnaire profile that included six elements: (i)

informal conversation with the participant to promote a relaxed bond, (ii) a few brief background information questions, (iii) identification of the issues to be addressed, (iv) the substantive questions, (v) a discussion of the issues of importance to the interviewee, and (vi) the researcher's thank you to the participant and reconfirmation of contact information to ease follow-up by either party.

The substantive questions followed the criteria developed by the conceptual framework and were structured into three main areas. The first area of questions elicited participants' opinions about sexual activity and sexual care. The second area targeted their views of the contextual features which negatively impact sexual activity and care. The third area identified what supports residents and staff respectively need to have sexual lives and provide sexual care.

#### Participant observation of persons with disabilities living in the community

Over the period of 1999 to 2002, two community members were observed. My discussions with the female participant centered on her many sexual liaisons. She "loved" to discuss how she met men and what she liked to do with them. She attributed her successful sexual life to "the control we residents have over employment descriptions and hiring staff. If our staff don't like us being sexual then we can let them go" (Fieldnotes: September 22, 2002). This stood in sharp contrast to GPC residents who have little or no authority regarding employee contracts or hiring.

My conversations with the male participant focused on his recent interest in pursuing a sexual life. He told me that the following factors contributed to his ability to have a sexual life.

Look, I can tell my staff not to come into my bedroom. I can also tell them to help me with condoms, changing sheets, or getting physically close to a lover. If they

don't like it I can fire them. Fieldnotes: April 22, 2002

### Document analysis

The gathering and analyzing of pertinent background documents helped to improve my understanding of issues and to identify trends in the management of sexual activity in geriatric, psychiatric and prison facilities. Specifically, I extensively used the University of British Columbia's library, Sunny Hill's Sexual Resource Network, G.F. Strong Sexual Health team's resources, G. F. Strong's library, and Internet to locate relevant materials. I also contacted several Canadian long-term care institutions and requested copies of their sexual care policies or guidelines. All documents were analyzed by content analysis, which is a systematic examination of pertinent documents by segmentation of the contents into topics (Marshall & Rossman, 1999; Morse & Field, 1985).

### Theoretical validity: issues of reliability & validity

Traditional standards or criteria for judging the legitimacy or authority of qualitative research have been called into question (Whittaker, 1999). Social scientists have claimed that a broader rendering of reliability and validity of research is needed. However, reaching agreement on what criteria to include is not always straightforward (Oakley, 2000; Yin 1994). I describe how I chose to approach these issues.

### Reliability

The reliability of qualitative research studies is judged by whether an independent researcher in a similar situation would generate the same abstract ways of describing the real world (Morse & Field, 1995; Woods & Catanzaro, 1988). Reliability, being the ability to replicate findings, is somewhat problematic in qualitative research because of

its reliance on a single truth. Some have argued that reliability in a qualitative context may be described as the researcher's attempts to ensure results are as dependable as possible (Lincoln & Guba, 1985; Yin, 1994).

Researchers have suggested that reliability can be enhanced by having and recording a research plan that identifies the problem of interest, the context or settings, specific field procedures, questions to be asked, field reports, transactions in which data were obtained and interpreted, and the results (Lincoln & Guba, 1985; Yin, 1994). These issues were first addressed in my dissertation proposal and modifications were made as necessary throughout the research process. Yin (1994:98) and Merriam (1998) also suggest documenting the life of the project through maintaining a "chain of evidence" or an *audit trail*. In this respect, I maintained original field notes, interview tapes, documentary and archival data, and the data analysis journal.

An important aspect of reliability is the researcher's ability to manage complex researcher-participant relationships and to constantly reflect upon one's performance as interviewer (Cresswell, 1998; Kvale, 1996). To this end, I carefully documented and regularly reviewed pre-conceived notions that I held about residents' sexual lives. "Critical-subjectivity" (Cresswell, 1998:196), a reflective tool that helps assess the interviewer's performance, was used. Specifically, before each interview I listened to the tape of the preceding interview.

Reliability is also influenced by the researcher's status or position, participant choice, social situation conditions, and the methods of procedure (Woods, 1988:137). Controls put into place to ensure reliability in these respects are reported in Table 3.5.

**Table 3.5 Examples of threats and controls to reliability**

<u>Threat to reliability</u>	<u>Example</u>	<u>Control</u>
Researcher's status or position	Investigator's status as academic, gender & comfort with discussing the sensitive topic may influence the sharing of information by participants	<p>Researcher's role in the research setting was clearly stated to participants</p> <p>Researcher received formal interviewing training</p>
Participant choice	Participants may possess characteristics that differ from non-participants	<p>Researcher was supported by physicians and other staff to recruit participants</p> <p>The characteristics of participants and the decision process involved in their choice to participate was documented</p>
Social situation conditions	Participants may judge the appropriateness of information in relation to the context	<p>Fieldnotes were recorded immediately after data collection to ensure accurate recall of the context</p> <p>For each interview the social, physical &amp; interpersonal contexts were described</p>
Methods of procedure	Replicability of research is not possible	<p>Strategies used to collect, analyze and report data were documented</p> <p>Interviews were transcribed verbatim</p> <p>Participants reviewed the transcripts and reaction to working analysis was obtained from several participants</p>

### Validity

Validity, which is the extent to which research findings represent reality, or the ability to make defensible knowledge claims by accounting for sources of invalidity, was addressed by a continuous cycle of checking, questioning and theorizing (Kvale, 1996). Cross-checks of the interview "facts" and member checks were two strategies used to promote validity (Woods & Catanzaro, 1988: 137).

#### Cross-checks of interview "facts"

Within each interview, in order to test the internal consistency of the stories, relevant facts were reviewed with participants. The aim was not to ascertain the "truth" of what informants had told me but to ensure accuracy of any interpretations. One example occurred when a resident made the following statement: "There are rules against residents having sex" (Fieldnotes: August 19, 1999). At the time, I took this to mean there were written rules regarding sexual activity. However, when I checked with administration I found out that I was mistaken.

#### Member checks

Member checks, which are a sharing of preliminary analyses with participants, were carried out during the initial interviews (Cresswell, 1998; Lincoln & Guba, 1985; Merriam, 1998). Segments of my notes were reviewed with participants. Although interviewees were free to alter what they had said, rarely did any one choose to do so.

As sexual activity is a personal and sensitive topic, and because I planned to present participants' interviews as direct quotations, I felt an ethical obligation to ensure that each person was completely comfortable with what would be published. To this end,



in October, 2001, approximately two years after the initial interviews, I re-contacted all but two participants. The interviewees were provided with a copy of what I proposed to report. Although I encouraged them to make any changes that they wanted, only two residents each requested the deletion of one or two words. With respect to the two staff members, who could not be contacted because of their having left GPC without forwarding addresses, I replayed the audio recordings of their interviews to reconfirm transcription accuracy.

Table 3.6 lays out my approach to ensuring validity.

**Table 3.6 Examples of threats and controls to validity**

<u>Threat to reliability</u>	<u>Example</u>	<u>Control</u>
History and maturation	Data is generated over time	Distinguished maturation from the effects of intervening phenomena by using constant comparative analysis
Observer effects	Participants may become dependent on researcher for status enhancement or satisfaction of psychological needs	Obtained independent corroboration from multiple participants  Used coding techniques likely to elicit contrived responses
	Participants may behave abnormally to promote self (e.g., omit relevant information, misrepresent their claims)	Compared data to themes found in the literature
	Researcher may see and report data as a function of their position	Presented data in relation to researcher's position and relationships
		Employed comparative analysis and participant validity checks
Participant selection	Possible distortion of data by selection of participants	Recruited participants who met the purposeful and appropriateness sampling criteria  Questioned commonly assumed meanings
Mortality	Lack of participants' commitment to remain involved with the study over time	Often reminded participants that they are experts in the research topic and that their input is highly valued
		Provided consistent follow-up to participants in the form of updates and information about the ongoing research
		Facilitated participants' access to the researcher by providing e-mail address and other relevant contact information

### Ethical issues

Ethics is embedded in the choices made in every step of the research process (Whittaker, 1999). Ethics encourages the researcher to be continually reflective and to always concern herself with the rights and well-being of each participant. The sensitive nature of the topic of sexual activity and the related need for confidentiality, the personal presence of a researcher in a field, and what is owed to participants were significant ethical issues in this work.

### Confidentiality

All participants signed an informed consent form (Appendix "B"), which had the approval of the University of British Columbia's Research Ethics Board. Part of the intent of obtaining informed consent is to delineate potential risks for participants. Risk of revealing participants' identities, particularly residents', was significant because of the small size of the institution and the uniqueness of each person's diagnosis or disability.

Confidentiality may be classified as internal and external and each type may be uniquely threatened (Phtiaka, 1994). Internal confidentiality refers to confidentiality within institutional settings, whereas external confidentiality refers to it in communities at large. In order to facilitate internal confidentiality, several safeguards were employed. First, transcripts were presented only to participants and were not shared by the researcher with anyone else. Second, participants were asked to help pinpoint identifying information so that it could be removed. Surprisingly, one resident refused to allow me to do this. When I first realized the problem I immediately spoke with the resident, voiced my concerns and expressed my wish not to publish the interview. At that time, and on four other occasions, the resident made the following or similar comment:

It's not important to me if people know who I am. I just want them to know how I feel and what it's like for us in here. You must tell it like it is. (Fieldnotes: September 1, 1999)

In the end, I reluctantly decided that the most respectful thing to do was adhere to the participant's wishes. To this day I am left wondering if I have done the right thing.

Externally, confidentiality was maintained by using pseudonyms and only general descriptions of settings and diagnoses.

### Researcher's role in the process and giving back to participants

A researcher's presence in fieldwork, whether extended or brief, often entails a process of entering other people's lives, extracting information of importance to them, raising expectations and leaving (Marshall & Rossman, 1999). Ethics is essential to, and very much a part of, every aspect of the researcher-participant relationship (Whittaker, 1999). As participants are vulnerable, it is important for the researcher to reflect on whether the research questions are causing them any emotional distress and to determine if their participation is respectful of their needs. In addition, as relationships develop in the field, it is necessary to build trust with participants and give back. In this regard, when participants showed an interest in a particular aspect of my work I was always willing to pay extra visits to discuss relevant issues or to provide them with pertinent documents. I was meticulous about arriving on time to all interviews, even when I "knew" participants were likely to be tardy or truant. As it is the researcher's duty to fit into the lives of participants, and not for them to fit into a previously defined research design, all interactions with participants were set up to meet their needs as much as possible.

So that results could be brought back to those who contributed, all participants

were offered summaries of the findings and a copy of the final thesis was promised to the institution.

### Data management

All resident and staff interviews and a number of my informal discussions were audio taped. A professional typist transcribed the formal interviews while I transcribed the informal interviews. The typist worked under an employer's confidentiality agreement, which further assured the safety and privacy of participants' data. It has been said that transcription is not an objective process but rather is an act of interpretation (Kvale, 1996; Mischler, 1991). Although data are not necessarily made invalid by transcription, regular reflection on the researcher's interpretations is necessary and was carried out.

Transcription verification was done by simultaneously reading the manuscripts against a replay of the audio recordings. The transcriptions were found to be accurate and required only minor correction. When the process was repeated a second time, I recorded notes about participants' intonation, timing and emotions. A comparison of these notes to my interview fieldnotes revealed no significant differences.

All tapes, transcripts and informed consent forms were stored in a locked filing cabinet in the researcher's office. No one else had access to these materials.

### Data analysis

The following section provides a detailed description of the steps taken in the organization and analysis of data (Table 3.7). Data analysis was an iterative process moving back and forth amongst interviews, analyses and pertinent document reviews. Content and thematic analyses were used to analyze each of the three data sources

(Marshall & Rossman, 1999; Morse & Field, 1995).

**Table 3.7 - Data organization and analysis****Interview data**Interviews of GPC residents & staff

- \* Tape recording interviews, making field notes and transcribing
- \* Editing: Correcting, expanding and revising fieldnotes
- \* Storage: Import data to *Ethnograph*
- \* Coding: Content analysis by identifying topics and coding each line of the interviews under these topics
- \* Description: Writing descriptions of each topic category
- \* Search & retrieval: Designating retrieval orders and coding so retrieval can be done by interview, subject, question or codes
- \* Data linking: Connecting relevant data segments and identifying possible relationships
- \* Flow charts: Drafting flow charts relating data to conceptual framework

Participant observation of persons with disabilities in the community

- \* Tape recording and/or making fieldnotes and transcribing
- \* Description: Writing descriptions for each visit indicating context, people present, issues discussed, personal dynamics, relationships and emotional content
- \* Storage: Journal of each visit containing transcriptions, fieldnotes and contextual descriptions
- \* Coding: Content analysis by identifying topics and coding transcriptions and fieldnotes under these topics
- \* Data linking: Connecting relevant data segments and identify possible relationships
- \* Flow charts: Drafting flow chart relating data to conceptual framework and resident and staff interviews

Document analysis

- \* Obtaining pertinent documents from libraries, sexual health units, long-term care institutions and the Internet
- \* Description: Reading and summarizing categories and topics discussed
- \* Storage: Indexed binder containing documents and description summaries
- \* Coding: Content analysis by identifying topics and coding relevant points under these topics

**Data analysis**

- \* Thematic analysis: Carried out on each of the three data sources
- \* Comparison of themes to those found in the literature and expert interview
- \* Isolating missing themes, identifying new themes and expanding on their relevance by revisiting selected participants and experts
- \* Gradually describing a set of generalizations consistently discerned in the database about negative influences on residents' sexual lives and staff's provision of sexual care
- \* Confronting these generalizations with principles and themes
- \* Explicating steps that should be taken to change long-term care management strategies for the provision of sexual care

### Interviews with residents and staff

In order to perform content and thematic analysis on my interviews with residents and staff, data were uploaded into a computer program (i.e., *Ethnograph*) for easier management. *Ethnograph* removed many of the mechanical tasks such as cutting, pasting and sorting. It also facilitated coding and allowed for the retrieval of data by interview, subject, question or codes.

Each interview was read and important topics were identified and given a code. Each line of interview data was also coded. Once saturation was reached (i.e., no new data topics emerged), descriptive paragraphs were written and relations between the topics were proposed (Strauss & Corbin, 1990; Woods & Catanzaro, 1988).

Some of the main topics identified in the residents' interviews were as follows: "residents' desires" included the sexual activities residents were either currently engaging in or had a desire to engage in, "obstacles" with the sub-categories of "residents' limitations" and "staff action" respectively described the reasons residents gave for not being able to have sexual lives and residents' experience of staff's actions which curtail their sexual lives, and "why not permitted" captured residents' beliefs about why staff curtail their sexual lives.

Staff's data fell under these topics: "why stop" with the sub-categories of "professional concerns" and "personal concerns" respectively detailing the professional and personal concerns staff had with residents' sexual lives, "options for residents" listed the various ways staff thought residents should carry out their sexual lives (e.g., some staff thought residents should leave the premises for sexual activity), and "how stop" included the ways staff reported that they curtailed residents' sexual activity.



Data from administrative personnel were categorized under the following topics: "legal risks" included staff's statements about legal issues and concerns, "administrators' attitudes" with the sub-categories of "personal concerns" and "professional concerns" captured administrators' personal and professional concerns with residents' sexual lives, and "administrators' actions" detailed administrators' responses to residents' sexual activity.

### Thematic analysis

Thematic analysis involves identifying themes in interviews that are not usually obtained from participants' direct descriptions but rather are derived from topics that extend throughout a set of interviews (Morse & Field, 1995). Interviews were read, reread and reflected upon in their entirety. A general summary of each interview was written.

Residents told stories about their being unable to get staff to bring them the medications, close doors or change sheets, wanting to date but feeling physically inadequate to attract sexual partners or too frightened to go out on their own, and being sexually limited due to the presence of roommates. Themes that emerged were the negative attitudes of staff, the psychological and physiological limitations of residents, the lack of opportunity to find sexual partners, the lack of privacy, and the sense of powerlessness to change the culture, values and attitudes of institutions against residents' sexual lives. The most notable conclusion that I made was that residents are virtually powerless to have sexual lives unless staff support them with sexual care.

Staff's descriptions contained stories of their being disciplined or dismissed for assisting with residents' sexual activity or failing to sufficiently protect residents from

sexual exploitation or abuse, wanting to uphold personal or religious values (e.g., not wanting to provide assistance with sexual activity between unmarried couples), having their breasts and buttocks grabbed by residents when they deliver daily care, having no time for coffee breaks let alone sexual care, having to endlessly protect roommates from unwanted exposure to sexual activity, and not knowing what sexual assistance is appropriate to provide. Themes identified were the duties to set professional boundaries, the legal duties to provide care, personal and religious values of staff, the wish to avoid sexual harassment in the workplace, inadequate training and education of the staff, the lack of staff time and resources, lack of privacy for residents and staff, the lack of guidelines to direct what assistance is appropriate, and a sense of powerlessness to change the nature of long-term care living as it is practiced today. The most notable conclusion made was that if we want staff to provide sexual care institutions must adequately support them to do so.

#### Participant observation of persons with disabilities living in the community

Content analysis of community participants' data identified the following topics: "Desires" detailed types of sexual activity these individuals want to pursue, "actual sexual activity" described sexual activity participants engaged in, "obstacles" included the barriers they encountered when trying to have sexual lives, and "opportunities" listed the factors which these individuals believe allow them to have sexual lives.

These participants' descriptions of their sexual lives contained stories about their sexual successes due to their ability to access privacy and sexual care. I concluded that these two key supports must be available to institutionalized persons if we want them to be able to have sexual lives.

### Document analysis

Pertinent documents were also reviewed with content and thematic analysis. Sexual activity policies developed for geriatric, psychiatric and penal facilities were analyzed. Also reviewed were a number of papers and documents pertaining to the legal responsibilities of institutions. The most notable theme identified in the document analysis was the growing trend of institutions to recognize the value of allowing residents to have sexual lives.

### Data analysis conclusions

The themes that emerged from this study for the most part replicate the negative influences on sexual activity and sexual care that have been identified in the literature. However, the present study puts a much greater emphasis on residents' and staff's feelings of powerlessness to change current approaches to sexual activity and sexual care. Residents repeatedly reported that they could not have sexual lives because of lack of staff support. Staff consistently conveyed that they are unable to change such things as the lack of private rooms or administration's failure to develop sexual care guidelines. This led to my final conclusion that in order to ensure that sexual care will be available, institutions must accept that it is their moral responsibility to provide it. This entails institutions adequately supporting staff's provision of sexual care by ensuring that they will be acting in accordance with the law, and by developing a pragmatic framework for the delivery of sexual care. Chapters 6, 7, and 8 elaborate on these requirements.

## CHAPTER 4:

### Resident Narratives

Now is the Winter of our Discontent,....But I, that am not shap'd  
for sportie trickes, Nor made to court an amorous Looking-glasse:  
I, that am Rudely stamp't, and want loues Maiesty, To strut before a  
wonton ambling Nymph: I, that am curtail'd of this faire Proportion,  
Cheated for Feature by dissembling Nature, Deform'd, unfinish'd,  
sent before my time Into this breathing World, scarce halfe made up,  
And that so lamely and unfashionable, That dogges barke at me, as I  
halt by them. Why I (in this weake piping time of Peace) Haue no  
delight to passe away the time, Unlesse to see my Shadow in the  
Sunne, And descant on mine owne Deformity.

--- William Shakespeare, 1597. *King Richard the Third*

Act 1. Scene 1.

You never really understand a person until you consider things from his  
point of view...until you climb into his skin and walk around in it.

--- Harper Lee. 1960:30 *To Kill A Mockingbird*

### Impressions of GPC

A walk down the interminable, sloped, windowless corridors of this rather ancient  
converted tuberculosis sanatorium, now known as GPC, left me wondering how anyone  
could call this place home.

At the institution's entrance there were a few residents slumped over in  
wheelchairs either smoking or waiting patiently to be picked up by their special needs  
transportation service. Their chrome and leather wheelchairs melded incongruently with  
heaps of soiled laundry that too waited pick up. Occasionally, residents' grunts or spastic

hand signals would startle a passer-by, who more often than not, would ignore their pleas to light a cigarette or retrieve an item from their backpacks.

Once inside the institution there was a large, drab, vacant lounge filled with second hand furniture and an ever-silent piano. Thick blue cigarette smoke billowed into the corridors from a small cafeteria that was filled with residents staring into space or mesmerized by daytime television. Residents who parked themselves in the hallways were in the same position when I left the building as when I arrived.

The livelier, brighter feel of the wards was constantly obliterated by the ubiquitous olfactory insult of bowel and bladder waste and the spectacle of residents being washed and dressed behind ill-tied hospital curtains.

I could not imagine a less intimate and romantic atmosphere for sexual activity.

Table 4.1 represents the resident demographics when my fieldwork began.

**Table 4.1: Residents' demographics (self-reported by participants)**

<b>Residents</b>	<b>Number</b>	<b>Average Age</b>	<b>Age range</b>	<b>Primary Diagnosis</b>
Male	7	43.3	23 - 52	Multiple Sclerosis, quadriplegia, brain injury
Female	3	53.6	44 - 61	

<b>Av. yrs at GPC</b>	<b>Range of yrs.</b>	<b>Yrs in other Institutions</b>	<b>Religious Affiliation</b>
8.15 yrs	2 mos – 33 yrs	0	3 Roman Catholic 1 Anglican 1 prays to "God" 5 non-affiliated

## **Introduction**

The desire and decision to have a sexual life emanates from a multiple of biopsychosocial factors and influences (Rines & Breen, 1991). I came to this work not to inquire as to why people want to have sexual lives, as this was simply a given. Rather, my aim was to deepen the understanding of the negative influences on residents' sexual activity so that support for their sexual lives can be improved. In this chapter, I seek to contextualize residents' experiences of having, or trying to have, sexual lives in long-term care.

This chapter is divided into three sections. The first section provides an account of each resident's experience of trying to have a sexual life. So that the reader can get a better sense of residents' perspectives, the interviews are presented as direct quotations. Section two examines how six factors that negatively influence residents' sexual lives were derived from the data. Section three presents my conclusions about what supports are needed to ensure residents can have sexual lives.

## **Resident stories**

### Resident #1- Joe

Joe was waiting in his bed when I arrived at the appointed time. As Joe had one of the few private rooms in the facility, we agreed that it was a suitable place for our interview. Despite extreme spasticity and weakness, using a pole that was anchored to the floor, Joe took about fifteen minutes to maneuver his way out of bed and sink into his wheelchair. Although Joe's ragged t-shirt was drenched in saliva, due to constant secretions from his mouth, he never tired of meticulously wiping his face.

With garbled words and various gestures, Joe asked if he should use his

communication board. Even with my significant experience communicating with people who have little verbal communication, I was hesitant to embark on our interview without this assistance. Unfortunately, Joe's attempts to start the board failed. A nurse then reported that no one had come to repair the board, despite the fact that the work order had been signed seven days earlier. This drawback aside, we continued our interview orally.

Sexual activity is the number one priority in my life. I couldn't get enough when I was younger and now that I'm older my desire is less but it's still there. Staff told me I should go to malls and coffee shops to try and meet women but so far that hasn't worked. Most people don't want to talk to me.

I don't think I'll find a woman to have a relationship with because everyone sees people who live at Pearson as lowlifes.

I want to masturbate a couple of times a week. I can do it on my own if I have injections but I really want to do it with a woman. The staff tease me about masturbating and most don't want to give me the injections. Some of the workers complain that I masturbate too often and that I shouldn't get meds (medicine) because I don't have a wife but I think that's between the doctor and me.

Towards the end of our interview, Joe asked if I would give him a "hand job". I politely refused, reiterated the purpose of my interview and research, and continued by asking him about his frustrations with lack of sexual outlets.

The government gives me eighty-two dollars a month for all my expenses above this room and my food. My erection meds cost twenty dollars a pill so I can't afford it, almost never. I can't find a woman so all I have left is to masturbate and they don't even want me doing that.

#### Resident #2 - Allen

Allen and I met at the nurses' station. He was young, slightly built and chatted easily as he drove his wheelchair to the Quiet Room at the end of the ward. Although the Quiet Rooms were ostensibly for residents use only, I recalled that staff had brought me here for their interviews. I wondered to myself what else "belonged" to residents in name



only.

The cramped room was filled to the brim with a table, chair and bed couch.

Maneuvering about in it with one person in a wheelchair was difficult enough. I could not imagine how two people in wheelchairs could possible fit.

I used to engage in one-night stands with sluts before I became ill, but now I prefer a long-term relationship because it gives me such a wonderful feeling. I have a fiancée and we like to cuddle and kiss and I bring her to orgasm. It's such a good feeling when you're with someone. I only wish I could get an erection so she could bring me to orgasm and then we could both make each other feel good.

I'd be satisfied with my sexual life if only I could get an erection that I could keep. I don't have the money to buy a pump which costs about five hundred dollars. I only get eighty-two dollars a month to spend. One of the health care aides gave me a list of herbs for erection enhancement but I only got one because they too cost a lot.

My girlfriend comes from out of town when she can to visit me. She rents us a motel and looks after me and all my needs when I'm with her. She comes in here, I say, "Hi honey", we kiss and then we're out of here. I'd never bring her into Pearson to stay because gossip and humiliation take over in this place. If you use the Private Room here everyone knows. The only option for us is to find a way to get out of Pearson to have sex.

### Resident #3 - Doug

Doug too suggested using the Quiet Room for our interview. As we made our way down the hall through a maze of residents, staff, wheelchairs, equipment, and miscellaneous visitors all staring at us, I was acutely aware of why residents were constantly telling me that a private sexual encounter was impossible at GPC.

Doug, a large, strong, intelligent man openly discussed his views about world affairs, religion and philosophy but was much more circumspect about talking about his sexual life. Just as I was beginning to think that the interview was a failure, Doug unexpectedly opened up.

Although I have many Catholic views on sex in that I fundamentally think that the purpose for sex is for procreation, I believe it's natural. You can go to the zoo and watch animals masturbate. They are not in the real world and can't naturally procreate. They're locked in a cage and life is so boring for them, masturbation is probably the most exciting thing they can do. Just watch them, they can do it all day long. My guess is that this also applies to people.

The problem for me is that I'm only half a man because I can't give sexually in a balanced way. In a relationship there's got to be a lot of giving and taking. When you don't have anything to give it's one-sided and that's not fair anymore. I have only eighty-two a month to spend and that's not enough to smoke. I also can't have sex so I can't give in an overall balanced way. I lost some family in the accident that put me here. It has some heavy psychological implications for my sex life and procreation. I have to resolve all that stuff in my mind before I can feel good about sex again. A while back I got involved with a woman and she took me to her home and we jumped in bed together but nothing would happen. I couldn't get it up. It was useless to me. Physically because of my spinal cord injury and lack of sensory ability I'm no longer able to take part. I can't do a damn thing with it. I can't really take advantage of what sex has to offer. If I could get much more involved in sex it would become a much higher priority, but right now it just isn't the way it is supposed to be. Sex makes me feel useless.

What I would like is to have someone massage the parts of my body I can feel such as my ears, hair and head. I miss having someone touch me because it's such a good sensual feeling.

I also want to feel useful to others because that increases my sense of self-worth. If I could get useful to the point where I could be truly independent I'd be happy. Pearson is where I've hung my hat but it isn't home. I do what I can to make it my home but my heart is elsewhere. I want to get enough money so I can hire my own staff to look after me and then I can move back closer to my family. I'd feel useful with them because I could give them some of my values and knowledge. I wouldn't last a week if it weren't for people, for the milk of human kindness that keeps us all alive. You want to feel you can pay that back, either that or give me the knife.

#### Resident #4 - Les

Les was adamant that our interview take place mid-morning after he was fed, cleaned and dressed. Despite setting specific meeting times, on several occasions when I arrived, he had already departed for the day. On my fifth attempt I finally caught him in. He asked me to conduct our interview in the bedroom that he shared with three other

men. One roommate had already left for the day, one was being washed and dressed in clear view of the rest of us, and one was lying in his bed blankly staring at me. I asked Les if his roommates would mind us talking in front of them, or if they ever objected to his blaring rock music or pictures of nude women, which were pasted all over the walls around his bed.

The other two guys in here can't talk. It doesn't matter what we talk about they don't pay much attention. They don't really understand us. They have to be taken care of all the time. One gets up at five thirty every morning and the lights go on and workers galore start coming and going. I can do what I want in here and I want to have a room with other people. I like to chat with the guys so I'm fine with the set up here. I go out every day with my friends and sometimes the Rec. Dept. When I'm around here I like to go on the computer.

I sometimes watch porno videos as an outlet but watching them frustrates me because it's not a real and whole relationship. I've made up my mind pornography is all crap. I don't need it. There's more to life than looking at some pictures or movie or stupid porno. I like the whole relationship and really getting to know a woman, her personality and just enjoying her company. I like the company of women. I really like hanging out with them.

I've no sensation in my body so I can't have intercourse. There is no other thing except kissing. I had one girlfriend who I knew for about four years when I first came here. She was on Ward Seven, the ventilator ward, so we couldn't do much but we were companions. Everyday we'd be together talking. Her Dad lived across the street and he'd come and visit everyday. We'd go out places all the time. When my Mom would come from out of town we'd all do something together. Then my girlfriend died. Now I've got another girlfriend who lives here too but I've kind of lost interest in her. There's also a health care worker I like. She's on my ward and about my age. I find her very attractive and nice. I know it's just a fantasy but it would be nice to go to a restaurant and take her out for dinner but it's inappropriate as she's married.

My dream is to meet someone like this staff person and have an intimate relationship at her place. It would be great if she would want to masturbate me. I've always worried about having a relationship with an able-bodied woman because I've thought if I had to depend on her to take care of my every single need, we couldn't have a normal relationship. I've thought a sexual relationship would be out of the question. However, recently I'm sort of coming around to the view that there may be a woman out there somewhere that I could get to know and like. I do go on lots of trips with the Rec. Department here. They can be fun but I don't think I'll meet a girlfriend on one of those outings.

This place is no good for relationships because staff know most of us guys are limited sexually so they joke about it, more in a form of gossiping. Everyone knows everyone's business. So little privacy here. There was one resident who did have a girlfriend who was a health care worker here. They tried to keep it private by going to private places in the building or to her place. There was a lot of gossip about it by other workers. She tried to avoid working with him but all the rumours kept going. Everything was known. Privacy doesn't exist here. I think the gossip was rampant and inappropriate.

One day I had a talk with a psychiatrist who came in once a week for three to four weeks. I talked to him each time he came but later I found out it went back to the so-called team. Just about every nurse on the ward and every health care worker already knew all about it. After that I was so ticked off I wouldn't talk to him again. I'm not part of the team. He should have told me he was going to tell everyone. He didn't mention he was going to tell anyone else. I assumed he had some kind of confidentiality where he can't tell anyone unless I gave him permission. Next thing I know I had the Social Worker calling me to her office asking me why I take all these drugs which I was doing at that time. I pretty quickly learned not to open up to anyone like that. The staff know so much about us already. It's best to keep whatever you can to yourself.

#### Resident #5 - Ellen

"You fucking idiots. I'm not listening to you!" screamed Ellen as her wheelchair careened down the corridor. Residents and staff poured into the hallway to see what the commotion was about but retreated as soon as Ellen left the ward. This was my first encounter with Ellen. Some weeks later, during our interview, she explained that the incident was "just one more example of staff telling residents what to do and never, ever, ever letting residents make their own decisions."

When I arrived for our interview, staff directed me to Ellen who was sitting in a washroom stall in the middle of the ward. The stall curtain was partly open so everyone in the vicinity could easily see that she was struggling to get off the toilet, pull up her underpants and get back into her wheelchair. I walked further down the hall to afford her greater privacy but could not help noticing that no one else bothered. After about fifteen minutes, Ellen called out and rang an emergency assistance bell. Another ten minutes

elapsed before staff finally arrived to help her.

When finally into her wheelchair, Ellen drove rapidly to the residents' lounge at the entrance to the ward. I breathed a sigh of relief when we found no one else in the lounge. I wondered why I seemed to have more issues about the privacy for interviews than residents. Perhaps, I mused, they are more inured to intrusions than I.

When I wasn't in a wheelchair and I'd be walking to the skytrain to go to work everyone would say oh, she's drunk, keep away from her, she's drunk. I'd stop and turn around and say I'm not drunk, I haven't been drinking. That was awful mean of people to say that. They treated me like dirt but when you're in a wheelchair they don't even talk to you. You are untouchable.

I've accepted that I can't have able-bodied partners but I like this guy in here. He's a quad and can't do much because he's paralyzed from the neck down. I get off on kissing so we asked if they'd put us in bed together but they wouldn't do it. We weren't even having sex. We just wanted to lie together. I think only married people can get double beds. They say it's too hard for them to work around. They have an absolute rule against a couple being in bed together and even if we could manage to get into bed on our own, staff would constantly invade our privacy.

They won't let you have any freedom here. They always spy because they have nothing better in their lives, so they have to go to someone else's life. I did have a boyfriend here before and staff always walked in so we could never have any privacy. Even if you're just kissing they're right there. They say, "I thought you rang the bell". They make it quite comical. They have their rules and stick to them. Sex is not allowed here.

I'd like a private room but I'll wait years to get one, if ever. I'd like to masturbate with my vibrator and watch some porno movies, but my roommate never ever goes out. I never use my vibrator because this roommate stays in bed all the time and she's always watching me. Snooping, so I can never do anything private or personal. She just watches me all day and always wants to know what I'm doing. When you room with three you can't do nothing. As for sexual freedom there is none. I feel like I'm under constant supervision from staff and roommates. They should make a room for people to be alone because that lounge down there (the Quiet Room) has nothing but a couch. How could you do anything in there?

#### Resident #6 - Mak

As Mak's illness kept him asleep most of the day, it was most difficult to find a

time for our interview. After seven attempts, one mid-morning I found him awake.

A slightly built, physically delicate, young man Mak came across as both intelligent and shy. Each question I asked was met with a bow of his head, a bemused grin and a long blink of his large dark eyes. Although his speech was garbled and almost incomprehensible, his expressive body language made it easier to understand.

Intermittently, Mak would pick up his communication board and methodically type with one finger.

I'm quite good at computers so I can make a small amount of money each month doing a few jobs for friends. Almost no one in here has any money and everything costs. That goes for dating and sex too. We can't let anyone know if we make money because they then want to take away some of the eighty-two dollars a month they give us for spending money.

I'm a virgin but I'd like to find a girlfriend and go out on a date with her. I like one health care worker here and asked her out but she turned me down nicely. My heart has stopped for dating. I've deceived myself and been led astray that women are attracted to me but I now know this is just a fantasy. Women don't want people like me that can't speak and are in a wheelchair. That's why I'd like to find a clean prostitute so I can try sex out but I don't know where to find one. I'm scared they won't be clean because they use drugs and needles. I'd like to try kissing, touching and intercourse. I had a girlfriend in high school and we would kiss and cuddle but that's all. It's so hard for me to meet a woman because I can't talk. However, I can ejaculate and I like to masturbate. I watch some pornography on videos and Internet chat lines but I still want to try being with a woman.

I don't think staff here would help me find a clean prostitute and even if I found a woman to be with I'd be scared in here that everyone would know. It would be so embarrassing and humiliating. Health care workers are like gods, they seem to know everything about you.

#### Resident #7- Gene

"I've missed lunch and I'm so hungry," declared Gene as he arrived in the ward where we had arranged to meet. A recreation worker offered to cook him a hamburger.

The three of us headed off to a small kitchen and chatted while lunch was prepared. Once

ready, the staff member placed the hamburger on Gene's forearm. With incredible dexterity, and without use of his hands due to quadriplegia, with minimal spillage he maneuvered the food into his mouth.

Gene, heavy set, with long blond hair, a smooth face and little hair on his forearms was in regular treatments preparing for sex change surgery. On the day of our interview his fingernails were brightly painted, some blush had been applied to his cheeks, and he wore a summer dress that fell slightly below his knees.

After the staff member left, we proceeded with our interview in hushed tones because a funeral was taking place in the adjoining room.

I'm comfortable at this particular point in time with my sexuality but I'm frustrated because I'm scared to go out to try to meet sexual partners. I'm afraid of being assaulted again. A while back I had this thing happen to me in Ontario. I was going out shopping and I was all dressed up. These two guys they knew about me and I guess they were watching me all the time. They knew I had nice stuff, stereo and everything and there was two of them. One guy wanted to kill me and the other guy wanted to steal my stereo. So they broke in one night into my apartment and they tore the chain right off the doorframe. Pulled the phone out of the wall and they made me undress in my bedroom and made me do crazy acts to myself. They had found my four-foot sword and they were poking me with it but not enough to hurt me, but they left marks. They had my hands tied behind my back and they took me out to the balcony and made me face flat down on the balcony and tied my feet onto the top rail of the balcony. They were kicking me in the side and then they went in and found my baseball bat and they used that on my head. I faked being knocked out and they went in and found a butcher knife and destroyed my red and black velvet couch and chairs and my dining room set. Then they came out and pissed on me. Before they urinated on me they tied the sword from the top of rail to the crack of my bum. Then they went in and started taking my stereo and stuff down the stairs. I did some heavy praying they were not going to make me dead. Somehow I got loose. I heard them going down the stairs and then I went down another set of stairs which goes right to the super's door. I told her to phone the police. The police got them as they were putting the stuff into the taxis. I went to court and they got one year a piece.

So that's why I'm scared to go out so I now hope the right person will find me. I want to have a relationship with another person and have sex with that person. I can't do the things I use to do like dance or just have normal sex but I'd like to go out to a bar or a dance with a man and just get to know them. I have a friend but

we don't have sexual relations. I guess I'm waiting for the right person. I just have to make my mind up to go out certain nights. There's a staff person here who likes me a lot. If I move out he wants to be my partner.

I get really to the point that I need to have somebody touch me. Since I've been on these hormones it's changing the inside of my groins. What a relief to be touched there. When staff wash me down there it gives me a good feeling. I like being washed in the middle. I need help to do sexual things and I would like a health care worker to help me but even more I'd like a sexual partner.

If I ever found a partner the trouble with any sex at Pearson is the walls are thin and people gossip. It would be better to move out with a partner than try to have them in here for sex.

Staff here are doing their best to accept me and even help me out. They even talk to me about their own personal and sexual relationships, like when they ask me for advice about how they should handle their own boyfriends or husbands. Should I go with him or should I go with another person? Mostly I feel very included however certain female staff, the health care workers, say I should stay the way God made me. They've seen a picture of me as a man, with a beard and moustache. Sometimes I think about religious views, then I wonder if what I'm doing is right or wrong. The Reverend here tells me, if you're happy in dresses and want to have the operation, God will be happy for you.

#### Resident #8 - Scott

Scott shared a room with three men who were all out when I arrived. Due to illness and profound weakness, Scott had to remain in bed for our interview. His voice was so quiet that I had to lean over his chest and mouth in order to hear him.

We residents should get assistance to have some sexual activities because sexuality is part of being human. I believe we should make changes around getting assistance for sex so that everyone receives complete and excellent health care.

I don't think I can find a partner outside Pearson because at my current level of disability I can no longer attain and maintain an erection, even though I can still orgasm with ejaculation. I'm only interested in a hand job. My preference is for a massage therapist to assist because they're trained in anatomy but the staff here won't touch genitalia.

For about two years, every Thursday night I had a little friend come in and give me a hand job. She was a single mother and a nurse and every month I would set



aside fifty dollars and give it to her. She had a hard time accepting the money because it wasn't sexual and she wasn't a hooker. Since she moved to Edmonton I haven't found it's worth the hassle to enter the negotiation of trying to find a health care worker who wants to do it and to get the money to pay for it.

Sex is frowned upon by management and staff. They don't understand that when you become disabled you don't automatically lose your desires for sex and sexuality. When a resident is trying to be sexual they are gossiped about and workers peek in on drawn curtains because they want to know what's going on. Privacy is very important to me and my interest in privacy has increased since I've come to Pearson. There sure isn't much privacy here.

Pearson is a unique home. It needs to change and offer more support to residents but it does provide good basic health care. I was one hundred and thirty pounds when I came in here and now I weigh one hundred and seventy. They give me proper care so they are the reason I'm still alive.

#### Resident #9 - Hannah

Hannah asked to be interviewed in her private room just before bedtime. Weak and unable to speak except in short, breathless phrases, her voice was scarcely audible. To compensate, I pulled my chair next to her bed and leaned about four inches over her face. I regularly stopped our discussion to check if she was comfortable with our physical proximity and to see that she had the strength to continue.

I go home with my partner every weekend. I'm not that interested in sex anymore but sex is a normal part of marriage. I don't need help positioning myself. I have a lot of spasticity, which has made intercourse difficult, but they pump medication into my blood stream and it relaxes my muscles a lot. I have moments of desire about being physically active and emotionally close to someone. The reality however is I'm often too tired and perhaps too old so a full sexual life isn't possible for me.

I would never bring my partner here for sex and intimacy because people are always walking in and out. Sexual life is a private thing and we can't do what we want here. This is not a holiday home. We only get basic care here. If it were ever to be different around here the attitudes of both the residents and staff would have to change to become more cooperative. There would also have to be more staff. They have too much to do.

Resident #10 - Sara

Sara asked to be interviewed about two in the afternoon, "after nap time".

Despite her youth, severe disability and weakness controlled her body.

I see this place as a jail. I need twenty-four hour care and I have nowhere else to live. They are so regimented and make everybody in here feel regimented. It's a prison and I'm a prisoner. I feel like a little kid. I can talk and I can express myself so who are they and what gives them the right to tell me what I should do? I had an argument just the other day over a health care worker that talked right through me as if I wasn't in the room. I shouldn't have to feel I've got to ask them about my personal and sexual life. I've learned not to talk or complain unless absolutely necessary. The health care workers talk about me and other patients. They even talk about my tattoos on my hips which I got when I was very young. This is private and they shouldn't be discussing it. I've gotten used to people walking into my room anytime to change my catheter, give me a bowel movement and tell me I've got my period, which I never know when it's here or not.

As far as talking about sex to people in here that's a no-no because staff don't have time. There is no one in here that has time to sit down with you to even talk, read a book or tell a dirty joke.

Sex is not allowed here. If I wanted to have my male friends over for the night staff would disagree. They wouldn't go along with it. When my former sexual partner did come and stay with me overnight in the Private Room it was no good. It was a couch and not a real bed. My partner was a very clean person and likes to look good when he goes to work in a suit. He gets up here and wants to have a shower but he's told he can't because he's public.

Now there's one fellow that comes to visit me a couple of times, every couple of months. He is in a wheelchair and he is a very nice person. He always comes in and talks to me and holds my hand. Even holding hands makes us emotionally close. I like to fantasize about holding hands with a man.

I would like to use my dildos but staff stole them. They just disappeared when I moved rooms and I know that somebody who works in here has taken them. I'd like to masturbate but it doesn't look like anyone is going to give my dildos back.

There's no opportunities to meet people here. Next month there is a barbecue in July and they call it a day for family and friends to get invited. The problem is for many of us our friends and families work so what do you do when they have entertainment on a weekday? That's crazy. They don't take into consideration that most people do have a job, at least most people I know. That's why I never have visitors.

When a nurse entered the room to tell Sara that another therapist was waiting for her appointment she exploded with rage.

Get out! This is the type of thing that goes on here all the time. You have to stick to their agenda. It's never about the residents. I specifically told them already that I didn't want to be disturbed and interrupted when you came to interview me but they don't care. It's always what the workers want.

### **Deriving themes**

Using data analysis techniques described in Chapter 3, six negative influences on residents' lives were identified in my study data. These were the staff's negative attitudes to residents' sexual lives, the psychological and physiological limitations of residents, the lack of opportunity to find potential sexual partners, the lack of privacy, and residents' sense of powerlessness to change the culture, values and attitudes of institutions against their sexual lives. Drawing from residents' interviews, fieldnotes and my own interpretations I now illustrate how these themes emerged.

#### Staff's negative attitudes to residents' sexual lives

All residents interviewed mentioned that the staff's negative attitudes to their sexual lives result in their receiving little or no support or assistance with their sexual activity. In most cases this meant that because of their severe disabilities, they could not engage in any sexual activity. Ellen's story is typical in this regard.

I get off on kissing so we asked if they'd (staff) put us in bed together but they wouldn't do it. We weren't even having sex. We just wanted to lie together...They have an absolute rule against a couple being in bed together and even if we could manage to get into bed on our own staff would constantly invade our privacy.

Sara reported a similar experience.

If I wanted to have my male friends over for the night staff would disagree. They wouldn't go along with it.

As these comments suggest, residents typically experience staff as having "rules against" (Fieldnotes: August 19, 1999) sexual activity. However, at the same time residents also experience positive feelings about staff's delivery of other forms of care. One resident reported that staff's care was mostly "excellent, respectful, and accommodating" (Fieldnotes: March 2, 2000). Also recall Scott's description of his experience of staff's typical care.

I was one hundred and thirty pounds when I came in here and now I weigh one hundred and twenty. They give me proper care so they are the reason I'm still alive.

Hannah too noted staff's diligence with care in every area but sexual care.

Staff do an excellent job of caring for us on the whole. There are so few of them and so few resources but our basic feeding, cleaning, and dressing needs are met pretty well. Sexual care isn't the same. It just isn't there and maybe there is no time for it but I suspect even if there were time and people it still wouldn't be available. (Fieldnotes: September 23, 1999)

One resident described her experience of sexual care as "dismissive, non-existent, and inhumane" (Fieldnotes: March 2, 2000).

A number of residents told me that staff's negative attitudes to their sexual activity made it virtually impossible for them to have sexual lives.

Joe: So long as staff hate me masturbating I'll never have a chance to do it on a regular basis. They have so many ways of stopping me. (Fieldnotes: March 10, 2000)

Doug: No one in this place can be sexual without staff's approval. If they are they get put down pretty fast. Some staff are good about it but they can't let other staff know or they too get stopped. Just the way it is. (Fieldnotes: March 10, 2000)

Mak: Staff control this place and easily control us residents having sex. We all need help in different ways but as long as staff don't want to help, we ain't doing much (Fieldnotes: March 12, 2000)

Some staff agreed with Joe, Doug, and Mak's sentiments.

Social Worker: It's true that unless staff want to help residents being able to express their sexuality there is no way residents can do it to any extent on their own. (Fieldnotes: March 12, 2000)

Physician: Staff have to be persuaded or told that they should support residents' appropriate sexual expressions. Unless that happens sex and sexuality will continue to be repressed in here. (Fieldnotes: March 14, 2000)

Staff's negative attitudes clearly curtail residents' sexual lives. However, the following two negative influences do not emanate from staff but from residents themselves.

#### Psychological limitations

Each resident participant alluded to, or outwardly described, a psychological difficulty that he or she had with having a sexual life. These limitations stemmed from a variety of factors including having a history of living in institutions, lack of self-esteem and past negative experiences related to sexual activity.

#### Time spent in institutions

Gene who had lived in institutions many years was forthright about his fears of his going into the community to try to meet sexual partners.

I've been living here for such a long time. I don't really know what it's like to be part of the community out there and although I'd like to I'm pretty scared. I'm waiting for the right person...I'd like to go to a dance and meet someone but I'm always thinking something bad will happen to me. Being like I am I can't stop guys from hurting me. That's why a lot of us look to staff for possible relationships. They are nice, they care about us, it's safer and where are we supposed to go to find someone else? (Fieldnotes: October 14, 1999)

Other residents, such as Les, also saw staff as a potential source of intimate company.

Many residents will never be able to leave this place so ya I think we should be able to have relationships with staff. I mean who else can we do it with? Really it would be better not to have to rely on staff and usually they won't do anything with us anyhow, but we need their help to find someone else. Like not help with everything but at least some things to get us started. Sexual Health staff try to help but they can only go so far before other staff stop them for this or that reason. The staff who work here with us all the time all get mad with us for being attracted to staff. Hell, even if we are attracted to another resident they figure a way of stopping that. Figure that one out. (Fieldnotes: April 8, 2000)

Staff also understood that when residents spend years living in institutions their confidence to seek sexual partners in the community is commonly undermined. Staff acknowledged that without appropriate supports residents are unlikely to overcome their psychological difficulties.

When folks have spent decades in institutions most can't even conceive what it's like to live and be part of the community. It's a completely foreign world to them out there. Sure they get taken out but it's all protected. It takes a lot of guts for them to ever go out on their own or even with a group that's not supervised by staff. Seems to me our past history of institutionalizing people has set us up for having residents look to staff for relationship possibilities. We have to develop programs or something that really helps these folks feel supported in looking for sexual outlets outside. If we don't we sure shouldn't be so surprised and angry when they ask staff for relationships. (Fieldnotes: January 8, 2002, Social Worker)

Most people who have lived in institutions for any amount of time have been sexually abused. Most of these folks are scared to death about sex and intimacy. Going out of the institution to face the world and try to find safe partners seems way worse to them than staying in the environment that in the past had been the source of their sexual abuse. Our programs to help residents are made difficult by staff not being in agreement about what needs to be done. (Fieldnotes: December 16, 2001, sexual health nurse)

### Lack of self-esteem

Some residents blamed their difficulties with having a sexual life on their lack of self-esteem, which commonly manifested in their believing that able-bodied people will never be sexually attracted to persons with disabilities. Les recounted his fantasy about a

relationship with an able-bodied woman in this way.

If I had to depend on her to take care of my every single need, we couldn't have a normal relationship. I've thought a sexual relationship would be out of the question.

Able-bodied women have so much going for them. It's hard, no make that very, very hard, for me to approach them. I think most of them are looking for more than a guy in a chair. (Fieldnotes: February 5, 2000)

Like Les, Ellen had no faith that able-bodied people would ever treat her as an equal, let alone be sexually attracted to her.

I've accepted that I can't have able-bodied partners because (people in the community) treated me like dirt...when you're in a wheelchair they don't even talk to you. You are untouchable.

I don't often even try to see able-bodied partners. I always think there is no way they'll even talk to me, even though I know I'm a good companion. (Fieldnotes: November 4, 1999)

Both Les and Ellen struggled to overcome their psychological difficulties. In a conversation with Ellen she told me that her view about the possibility of having a sexual relationship with able-bodied people was changing.

I'm interested in this friend of a friend. He comes to see me once in a while and we get off on each other. I'm hoping we can get into something more, like some sex. I really think he likes me. I find it really scary and like I can't almost believe it. Somebody who has a working body wants a cripple like me. Ha. I never thought it would happen but it sure is nice. (Fieldnotes: June 3, 2000)

One nurse remarked that staff wrongfully do not help residents with their psychological limitations because it acts as a "natural barrier" to residents being sexually active.

We all know that most of our residents have lots of psychological problems with their sexuality but in an unconscious way, I think we often don't help them enough to overcome them because it works as a natural barrier to controlling sexual activity. Staff are happy when they don't have to deal with residents'

sexuality and feel less guilty about not helping when it can be chalked up to something in residents. (Fieldnotes: March 15, 2000)

### Negative past experiences related to sexual activity

Some residents blamed their sexual difficulties on past negative experiences or loss related to sexual activity. Doug's experience was most profound in this regard.

I lost some family in the accident that put me here. It has some heavy psychological implications for my sex life and procreation. I have to resolve all that stuff in my mind before I can feel good about sex again.

As was the case with Les and Ellen, Doug who was adamant that "sex makes me feel useless" struggled to overcome his psychological limitations with having a sexual life.

What I would like is to have someone massage the parts of my body I can feel such as my ears, hair and head. I miss having someone touch me because it's such a good sensual feeling.

Most of the residents were trying hard to overcome their psychological barriers to having sexual lives. One resident described the process that he was going through.

I want to feel normal and be as much as I can like everyone else. Sex is an important part of being like others. It's not good to force people who don't want to give up sex for no reason that seems logical. It would be really nice if staff would help us help ourselves to be more normal and have sex, relationships and all the rest. (Fieldnotes: March 14, 2000)

Other residents told me that they cannot overcome their past sexual histories without receiving appropriate therapy. Allen's thoughts in this regard are notable.

Sometimes I think it would be best if I could talk with someone about my sexual hang-ups. Sexual health nurses are really good but staff give us so much grief about seeing them it's not usually worth it. And even if you do go, most likely whatever you decide to do sexually won't be allowed. There is no support here for us to get over our sexual hang-ups because they don't want us to be sexual anyhow. (Fieldnotes: Feb 20, 2000)



### Physiological limitations

In an institution that houses persons with severe physical disabilities, physiological limitations to having sexual lives were ubiquitous.

Joe: I can masturbate on my own (but only) if I have injections.

Allen: I only wish I could get an erection.

Doug: ...we jumped in bed together but nothing would happen. I couldn't get it up.

Les: I've no sensation in my body so I can't have intercourse.

Gene: I need help to do sexual things.

Hannah: ...I have a lot of spasticity, which has made intercourse difficult.

Like with psychological limitations, I found that residents were quite motivated to find ways to overcome their severe physiological limitations. Whether or not residents were aware, or took advantage, of therapies and treatments varied from person to person. For example, Joe focused his efforts on autoerotic activities. Others like Ellen and Hannah took medications to alleviate their physiological symptoms, which made sexual activity difficult. Les, Allen, Doug and Gene satisfied some of their sexual desires by experimenting with kissing and touching.

A sexual health nurse confirmed the literature which documents the many effective therapies and treatments available to help persons with disabilities overcome their physiological sexual dysfunctions and concerns. However, in order for residents to take advantage of these interventions, all staff, and not just sexual health clinicians, need to support them to do so.

We can help most residents have a productive sexual life if they want one. There is almost always something we can do to alleviate most sexual difficulties. One of the biggest hurdles we have is getting other staff to support our work. We try and try but if they aren't willing and the institution doesn't set policy on it, we can only do our best to do what we can on our own. It's not the proper thing for clients. (Fieldnotes: April 22, 2001, sexual health nurse)

The next two negative influences on residents' sexual lives primarily emanated from contextual features inherent in the medical model of service delivery used at GPC. These are lack of opportunity and lack of privacy.

#### Lack of opportunity

Joe who was so severely physically disabled he could not sit up properly or speak, reflected on his frustrations with trying to meet potential sexual partners.

Staff told me I should go to malls and coffee shops to try and meet women but so far that hasn't worked. Most people don't want to talk to me. ...Everyone sees people who live at Pearson as lowlives.

In another meeting at a later date Joe made the following comment.

I've tried everything staff have suggested but going out there by myself is useless. People aren't going to want to talk with me. I will keep trying but I know I don't have a chance. (Fieldnotes: January 2000)

Les also recognized that opportunities for Pearson residents to meet potential sexual partners were few and far between.

I'm out with the Rec. Department on tons of trips. Some are really good but none of them put us in a position where we are likely to meet any single people. If we want to do that staff basically tell us we're on our own. But we can't do it all on our own, and even if we managed to find a sex partner, don't think staff would let us carry on with sex in here. So in the end even if we try to do our part it's to no avail. We are told do things for yourself, be responsible for yourself. Fine, most of us want to be, but telling us to be completely independent in our sex lives is as crazy as telling a quad to get dressed and go for a walk. (Fieldnotes: February 8, 2000)

The inappropriateness of Recreation Department events for residents who partake with the hopes of meeting a sexual partner was also brought to my attention by a social worker.

We infantilize residents by taking them to baseball games and bus tours. Those are things we'd do with our kids. These folks are adults and we never think or are willing to take them to nightclubs or singles events. I think the Rec. Department should put on regular adult evenings. The folks living here can't do it on their own, and unless we are willing to help them, the vast majority of them won't be having any sex in their lives. (Fieldnotes: March 5, 2001)

Sara's story resonated with the social worker's evaluation.

There's no opportunities to meet people here. Next month there is a barbecue in July and they call it a day for family and friends to get invited. The problem is for many of us our friends and family work so what do you do when they have entertainment on a weekday.

It is also important to note that many residents lacked opportunities for sexual lives due to their very limited financial resources.

Joe: The government gives me eighty-two dollars a month for all my expenses my erection medications cost twenty dollars a pill so I can't afford it, almost never.

Alan: I don't have the money to buy a pump which costs about five hundred dollars. I only get eighty-two dollars a month to spend.

Doug: I have only eighty-two a month to spend and that's not enough to smoke.

Mak: Almost no one in here has any money and everything costs. That goes for dating and sex too.

### Lack of privacy

Privacy has different meanings in different contexts. In the present study I found that residents' privacy is breached in four ways, all of which negatively influence their sexual lives.

First, residents found their privacy violated by GPC's team approach to care. Joe explained a situation that irked him.

Some of the workers complain that I masturbate too often and that I shouldn't get meds because I don't have a wife but I think that's between the doctor and me.

Likewise, recall Les' story of his experience with lack of privacy.

One day I had a talk with a psychiatrist who came in once a week for three to four weeks. I talked to him each time he came but later I found out it went back to the so-called team. Just about every nurse on the ward and every health care worker already knew all about it. After that I was so ticked off I wouldn't talk to him again. I'm not part of the team. He should have told me he was going to tell everyone. He didn't mention he was going to tell anyone else. I assumed he had some kind of confidentiality where he can't tell anyone, unless I gave him permission. Next thing I know I had the Social Worker calling me to her office asking me why I take all these drugs which I was doing at that time. I pretty quickly learned not to open up to anyone like that. The staff know so much about us already. Its best to keep whatever you can to yourself.

Second, privacy was breached by staff's "typical" (Fieldnotes: October 21, 1999) physical intrusions on residents' sexual activity. Ellen's experience was cogent in this regard.

They (staff) always spy because they have nothing better in their lives, so they have to go to someone else's life...Even if you're just kissing, they're right there. They say, I thought you rang the bell.

On numerous occasions (Fieldnotes: June 3, 1999; September 9 1999; March 25 2001; June 21, 2001) I was told a story about a recently injured male resident who regularly brought prostitutes and girlfriends into the Quiet Room. Informants reported that not only was "the cafeteria rife with staff gossip" but that several disapproving staff were known to "constantly interrupt the liaisons by pretending they had to administer meds" (Fieldnotes: March 25, 2001).

Third, residents found their privacy compromised because of staff's "gossiping" about their sexual activity (Fieldnotes: July, 21, 1999).

Mak: Heath care workers are like gods. They seem to know everything about you.

Les: This place is no good for relationships because know most of us guys are limited sexually so they joke about it, more in a form of gossiping. Everyone knows everyone's business. So little privacy here.

Mark: ...even if I found a woman to be with I'd be scared in here that everyone would know. It would be so embarrassing and humiliating.

Ellen: The health care workers talk about me and other patients. They even talk about my tattoos on my hips which I got when I was very young. This is private and they shouldn't discuss it.

Allen: I'd never bring her (his girlfriend) into Pearson to stay because gossip and humiliation take over in this place. If you use the Private Room here everyone knows.

Hannah: I would never bring my partner here for sex and intimacy because people are always walking in and out.

Scott: Privacy is very important to me and my interest in privacy has increased since I've come to Pearson. There isn't much privacy here.

Fourth, because most residents are forced to live in bedrooms with two or three roommates, residents complained that physical privacy is virtually impossible to obtain.

Ellen's experience was indicative of residents' frustrations with living in these conditions.

I'd like to masturbate with my vibrator and watch some porno movies but my roommate never goes out...this roommate stays in bed all the time and she's always watching me.

Ellen's experience was buttressed by a story told to me by a former GPC resident.

Oh God I remember living with three others in a room. Not for a few nights or weeks but years. Try to imagine having three strangers in your bedroom for years. Bet you can't even fathom that. Sure sometimes you become friends with your roomies but not necessarily. And even if you are friends with all of them, everyone needs private time sometimes. At GPC there's no place for privacy and you go insane if you think about it too much. Quite cruel you know to put people in these living conditions. Privacy is essential for sex so for my years in there I couldn't do anything, not even masturbate because sure enough a roomie or a staff would come through the door. We shouldn't be housing people like this with no privacy and no space to have sex. In years from now society will be embarrassed about what we did to people. (Fieldnotes: October 2001)

Interestingly, staff also saw privacy as an issue that interferes with residents'

sexual lives.

Social Worker #1: I think there are issues however if a resident shares a bedroom with others and when the residents' sexual activities impact on the other roommates.

Social Worker #2: Residents don't feel the private lounges are accessible or safe. For instance they have regular sized doors that are hard to get wheelchairs through and the doors have to be opened by handles instead of electricity.

MD #1: Privacy is also a problem.

MD #2: Lack of privacy is a big, no a huge problem here

Sexual Health clinician: The second big issue at Pearson is lack of privacy. There is no place for people to have any kind of relationship with anybody. There is no private space for them and although there are a couple of private rooms residents have to book them and everybody knows they are there and what they are there for.

Nurse #3: Lack of privacy is a problem here. There are no secrets at all, people know what's happening even in the Quiet Room and it's not comfortable at all for residents or staff. On the wards there are often four to a bedroom and the rooms are small. Some of the residents can't speak for themselves so can't say they don't want to see a porno movie that is being played by a roommate.

Nurse #4: When we talk about privacy it's just not there. Most residents live in four to a bedroom wards which is not conducive to any form of intimacy. Even though we offer the Quiet Room everybody knows who is in it and who they are with. Everyone then talks about what they believe people are doing in there.

Sense of powerlessness to change the culture, values and attitudes of institutions against residents' sexual lives

Residents' sense of powerlessness to change the culture, values and attitudes of the institution against their sexual lives was felt by all participants. Ellen's thoughts reflect these sentiments.

We can't do a damn thing about staff not wanting us to do sexual things. Okay I get it that there are no official written rules against us having sex but you better believe rules still exist. The staff just don't go along with anything you want to do sexually. They are always against it for this or that reason. On and on they go. How can we change a damn thing? They have all the power. We try, but you

know, we are crippled and some of us are sick. They don't want to change anything and we have no way of doing anything about that. Some of the staff try sometimes but overall nothing changes. It's like sex is a sin. Well most of us don't think so but we don't have a choice about living here really. None of us can get staff to let us be normal human beings with sexual lives. They'd rather us be eunuchs. If they were in our position, I'll bet they'd want staff to drop the rules against sex. It's about power and it's simply inhumane. (Fieldnotes: June 21, 2000)

### **Conclusion of thematic analysis**

After reflecting on residents' stories, the negative influences on their sexual lives, and, in particular, their sense of powerlessness to change the institution's negative attitudes I was led to the conclusion that it is virtually impossible for residents to have sexual lives unless staff support them to do so. What supports staff need to provide sexual care remains to be determined. I begin this process in Chapter 5 by examining the experiences of staff and identifying nine negative influences on their provision of sexual care.

## **CHAPTER 5:**

### **Staff Stories**

...the needy...have a fundamental claim on the resources of the community and its more prosperous members. The weaker members of the community stand in a special status.

---Robert Veatch, 1986 The Foundations of Justice

#### **Introduction**

This chapter begins with staff's stories which I present as direct quotations. I follow this with an examination of how nine negative influences on staff's provision of sexual care were derived from the data. The chapter ends with an assessment of what supports are needed to ensure that staff will provide sexual care. Table 5.1 reports staff demographics when fieldwork began.

In order to protect confidentiality in such a small institution I refer to staff only by their titles.



**Table 5.1 : Staff demographics (self-reported by participants)**

<b>Occupation</b>	<b>Av. Age (each category)</b>	<b>Religious Affiliation (all categories)</b>	<b>Gender (all)</b>	<b>Av .Yrs @ GPC (all)</b>
Administrators	44.5			
Physicians	50.0	1 Anglican	5 males	9.98
Social Workers	45.5	3 non-affiliated	9 females	
Registered Nurses	39.4	1 Unitarian		
Recreation Workers	38.0	2 Jewish		
Resident Care Aides	42.0	7 Roman Catholic		

## Staff interviews

### Administrator #1

I think the institution has a responsibility to acknowledge the rights of residents to be sexually active and I believe we should make sexual activity a component of rehab. and continuing care. I haven't really gone out and championed my thoughts about how resident sexuality should be treated here because I may have a few staff that will raise their eyebrows. I need to communicate it but I've seen no need to globally communicate it. Should there be some future complaints and or instances that require that level of communication then, at that particular time, I think it would be appropriate to communicate my thoughts more broadly.

Pearson is primarily a home but because it is also an institution we have to uphold certain rules so people can live together. For example, we can't allow residents to smoke in their rooms, even though they would be able to in the privacy of their own home because it's a safety issue. The same sort of thing may apply to sexuality. When it does, we have to negotiate and make a sort of contractual arrangement with all the participants. I rely on the residents to communicate to administration if they feel that there is a concern.

We have had a couple of instances where staff have complained or refused to help residents and we've told staff they should leave their morals at the front door. If you have a problem then express your problem and you may be removed from a situation that you find uncomfortable, but my expectation is that as a professional, you know how to work at arms length and you are expected to work with residents' sexuality as part of the activities of daily living.

For the particular population we are talking about here at Pearson, as for sexual relationships, the residents are all adults and sexuality is part of an adult's well being in life. The staff should be assisting the residents to be able to maintain a level of sexuality. I don't see any boundaries. I see it as part of the ongoing care. We rely upon the Recreation Department to identify whether or not there are pairings that are or shouldn't be taking place, like if residents offer sexual favours to get an extra bath a week. One of the best ways for residents to meet people is the sort of mixers that our Recreation Department gets going.

My philosophy is that if a resident doesn't have the money to go on a date and it's deemed to be necessary to maintain an optimal level of quality for that resident then I might find the money. It's the cost of doing business. I'm not going to do it forever and ever but I can do it once or twice. I certainly can't fund one hundred and sixty-five residents on a continual basis, so I would much rather rely upon the professionals to be creative and find different ways of doing it without money and within their own departmental resources. We may arrange for a certain group to go out on an outing, say a pub night. You want to get a dynamic outing but at the same time you want to also get an outing where there is an expectation of enjoyment. We know there are a number of residents that have developed

friendships and intimacies in the organization and we encourage that.

When we have diverse viewpoints and need to negotiate between various parties we have some wonderful resources for that, like risk management, legal consultants and human rights and diversity. I'd sit down with the program people involved and say, ladies and gentlemen, this is sort of where we are going with this one. Let's work on it. We may have difficulty paying for it but let's look at it. For example, I know of one instance where a fellow in a nursing home drove the female staff crazy because he was extremely horny and forward in his sexuality. Staff started to fear what was going to happen to them if something wasn't done about it. Staff and administration got the resident a lady once or twice a year to satisfy his urges. He'd come back in three or four days with the biggest grin and smile on his face and he quit hitting on staff. People got together and solved a big issue there. That's the sort of creative problem solving we need to do here.

Behind closed doors individuals can do what they want. I don't have any concerns at all so long as it doesn't cross over and spill out into the public place such as with open displays of exhibitionism and masturbation.

I think one of the biggest issues is trying to respect the privacy of the individual that wishes to engage in sexual activities. Like, who is entitled to know a sexual relationship is going on?

#### Administrator #2

For residents at Pearson it's important that residents get to know what their sexual capabilities and limitations are, to accept their sexuality the way it is and to learn what they can do to enhance it. I think absolutely that sexuality is a vital part of the rehab. process, which means improving their lives. Sexuality doesn't die just because you have an illness or impairment. Sexual activities are very common at GPC. However, we do have government regulations and legal obligations that we must fulfill which, means we can't always have residents doing whatever they want to do. As a facility we have a responsibility to ensure the safety of the people involved. For instance, if the sexual activities involve sadomasochism or torture, whether or not it's pleasurable to the participants, if it inflicts harm I'd want to interfere. We have a vulnerable population here. These people can't walk at all so we always have to be concerned that sexual activity is consensual and not abuse. For example, one recent incident disturbed me. During the morning care routines two health care workers cleaning a female resident discovered a piece of a wooden back scratch inserted into her vagina. This particular resident is disabled to a point it is questionable whether or not she could have done this herself. The resident refused to have any interactions with any staff and said she liked it and it was none of anybody's business. This resident is cognitively intact and wanted us to leave her alone. We felt we had to try to make sure it wasn't a staff person who was involved but it was very difficult to investigate because there was no cooperation on the part of the resident.

We also have an obligation to ensure a safe work environment for the staff. Staff don't always let us know what's really going on. We've had reports where residents would inappropriately grab a female staff member's breast or crotch or accuse a male staff of sexually assaulting them. If it's an ongoing behaviour and the resident won't stop we may reassign the staff because that's not a happy work environment for that particular staff member. Staff shouldn't be forced to assist with residents' sexuality if they don't want to do it. I think I personally would feel comfortable positioning a vibrator or some kind of device but I wouldn't feel comfortable masturbating someone. That's very intimate and I think that relationships may form in the minds of some and not in others. I think that's dangerous ground. People have personal values and as professionals we should try not to bring our personal values to work but I think that's very difficult for some people, especially if they are religious and certain sexual practices are against their religion.

The problem with the Quiet Room is that our folks aren't independent in their care so if we leave them alone in there they could harm themselves. Even if a prostitute were willing to take over the daily care of a resident, the institution wouldn't condone prostitutes coming in because solicitation is against the law, the changing of money, the fact that we are knowingly allowing something like this to happen and staff may not be comfortable. If residents want to hire prostitutes it would be better if residents left the premises. The residents aren't prisoners, they can come and go as they please. If they wish to go out on an outing and Handy Dart is booked for them, they don't have to disclose where they are going. So quite honestly they can do what they want.

People living here are coming to terms with a whole lot of issues and often initially play down their sexuality but I think that it's always there at the back of their minds. It shouldn't be shoved down people's throats when they aren't ready for it but when residents are prepared to deal with their sexual needs it's vital that there be a group of people they can discuss it with. The sexual health team should be responsible for this.

### Resident Care Aides

Health care workers are shocked when residents make sexual approaches to them. It happens regularly and we get no help. The new and younger health care workers get it the worst. They really get used by residents because they don't know what to do and they don't know they have the right to tell residents to stop. Anything residents do is brushed under the table by the higher ups who just say, "don't worry about it, it won't happen again". That's bullshit. They tell us residents are brain damaged but we still know they know what they are doing. It's used as an excuse. They know exactly what they are doing. Higher ups tell us we're crazy and making it up when we complain about residents being sexual with us. When we complain to supervisors everything we say is swept under the carpet. A lot of people have left because they can't handle the contents and nude pictures in the rooms. We have to learn to ignore nude pictures on the walls because even the

people who run this place have seen it and don't do anything about it so what can we workers do? It's a hard job.

Some guys grab and pinch us when we bend over to get their bags, some make remarks and some masturbate which we know because their condoms are off in the morning. We have to put condoms on the males and some of them get excited just because a woman is touching them. If it won't stand up we have to get it to otherwise the condom will fall off. We put a tissue over and rub and stand there doing our job but we know when some of them are staring at us and getting off on it sexually. It's hard on us. We don't like it and we don't want to be taken for granted and seen as (sexual) objects. Sometimes you don't even want to go into the resident's room because you know something is going to happen and they'll do something sexual to you. It's unfair because if a resident goes to higher quarters and complains about staff saying something against us, people get suspended without them even coming to us to see what really happened. But when residents do it to staff they do nothing about it. We are always seen as the bad person. It's always poor resident but what about poor staff? We get abused and that's not what we're here to do.

We are told if we don't like it we know where the door is but the trouble is the job is our bread and butter. None of this is in our job description to have to experience residents' sexual lives. We aren't hired as anything else but health care workers. Nobody will help us. We've just got to try to not let it affect and offend us but it's all unfair.

We have one guy that pulls his condom off to masturbate but the guy in the next bed complains about it. We were told to just pull the curtains around him and let him have his privacy but he's still disturbing the guy in the next bed. We don't want to be caught in the middle of other people's sexuality so they should go to the experts.

The health care workers want to know what is our duty if residents make sexual demands and why don't they tell us in our job descriptions what they expect us to do?

### Social Worker #1

Some staff feel uncomfortable cleaning up after residents' sexual activities mostly because it goes against their religious views.

Everybody has a sexual part of them and everybody should be allowed to express that. I think residents should decide for themselves what they want to do and what are their values, choices and decisions around sexual activity. We should do everything possible to try and find a way for them to conduct their sexual lives themselves. There are opportunities for residents that can enhance the sexual part of their lives and the organization can assist them to meet this in certain ways.

The institution should assist in sexuality by providing private rooms, having videos on site and perhaps giving some consideration to allow the use of prostitutes on site.

Residents have physiological barriers because of disability. They may not be able to move, masturbate, touch or position themselves for sexual activity. Psychologically they have to deal with needing assistance which impinges on their privacy, negative institutional attitudes and values, a strong bias in society against folks with disabilities having sexual lives, difficulties in meeting people and lack of skills of how to be reciprocal in relationships due to their dependence on others.

Basically residents should do what the rest of us do. Decide how best to meet their sexual needs and then see how to do it or see if there is a way they can do it. I think they are more restricted than able-bodied people but I think they should consider their sexual lives in the same manner.

I would try to find a way of allowing residents to do what they want without harming themselves or others. I would look to get as much information and as many perspectives as I could. I also don't have any issue around self-stimulation with cognitive impaired or non-cognitive impaired as long as it doesn't impact on other people and is not done in public. Pearson has a hospital ambience but residents would benefit from having smaller settings and more control over daily decision-making.

There's a number of staff who don't support sexual activity by residents. Even though, to a certain extent, some sexual activities have been allowed, staff have indicated quite strongly they don't support such things as the private room, the sharing of rooms without being married and the provision of assistance for such things as changing the sheets after sexual activity.

I think that if staff are asked to assist in sexual activities with residents, unless it's a regular couple, I think they should run it by the doctor or team. I would have no issues at all to assist residents to go offsite and do whatever they want to sexually, nor do I have issues with a resident using the Quiet Room with a prostitute. I think there are issues, however, if a resident shares a bedroom with others and when the residents' sexual activities impact on the other roommates.

I think a lot of residents don't understand the societal norms around expressing sexuality be it from lack of experience or from brain injury. A resident making sexual overtures to a staff person isn't just a straightforward interest in sex. It's much more complicated than that.

Social Worker #2

I strongly think that all people, including those with disabilities, have sexual desires and are sexual individuals. When sexual urges are not relieved people become frustrated. With Pearson residents we are talking here years of frustration.

The majority of staff are against resident sexual activity. I am only against bestiality and necrophilia being permitted. Staff come from a lot of different religions and cultures and their beliefs get in the way of their duties here. People who live here live in a fish bowl. When somebody is having a relationship it gets all around. Everyone knows and it's often made fun of. It's treated the way you would look at little children. We can be very condescending. We take away the belief that residents are sexual beings because the residents know that staff don't feel positive about it and then residents try to hide their sexuality even further. The rules say residents must let staff know when they are using the private room so there's no privacy. Every ward has a lounge which is supposed to be strictly for the use of residents. It's now used for team meetings and by staff more than anything else. Residents don't feel the private lounges are accessible or safe. For instance they have regular sized doors that are hard to get wheelchairs through and the doors have to be opened by handles instead of electricity.

Unions play a big role and are disempowering because sexuality is about openness, flexibility and the human individual. Unions protect seniority so the people running them are the most entrenched in their ideas and aren't open to looking at new things like sexuality in institutions. They have their rigid structures that shouldn't be deviated from so, I believe, they will hinder the development of allowing people in institutions to have sexual lives.

Residents have their own barriers to sexuality because they often lack self-esteem and think they don't look good. They think they're disabled and therefore they couldn't find anyone to have sex with or at least with anyone who's not disabled. They live in this environment for so long that it becomes a self-fulfilling prophecy and they believe they are worthless, non-sexual, stupid and dependent on everyone to clean their bowels, brush their teeth and feed them. Their own physical disability probably accounts for eighty percent of any lack of sexual behaviour.

I think that every resident should have a private room with electric beds and grab bars so they don't need staff in their rooms most of the time. Residents should be able to hire outside staff to provide assistance when having sex. This is a home, with many young people here so we should set it up as a home and not as an institution, which is what we currently do. We have to stop making sex shameful, but who will educate the administrators? Look at this place we have four people to a bedroom. I can't imagine living with three other people. Some scream all night. I'd go crazy. We need to change the physical structure here and the deeper culture of how residents' sexual lives should be respected.

Sex with other residents is fine because institutions are often isolated and all residents have is other residents. Sex with staff is okay as long as they are working in accounts or a nurse on another ward that has nothing to do with care for the resident. Sex with prostitutes should be okay for residents. Masturbation of residents by staff who are comfortable doing it should be allowed. You just have to make sure the boundaries are well understood and that staff is supervised. I myself wouldn't masturbate residents because I'm in a monogamous relationship and I wouldn't feel comfortable. Since I'm in a position of power, if I was to provide a sexual service to somebody, it would have to be someone I don't know at all and would have no chance of ever meeting again even in the hallway. When assistance is required by staff it should not be ordered or mandated. Only staff who feel comfortable doing it should.

When residents are cognitively impaired it's a grey area to allow them to have sex if they can't be informed about the risks, such as people taking advantage of them. Even then however I still believe they ought to have the right to make decisions without input from staff because I think sexuality is instinctual and has nothing to do with competence.

#### Recreation Therapist

Our people are extremely dependent. Meeting people and having opportunities for sexual relationships is very difficult for people who are so severely disabled. Residents sometimes make inappropriate sexual comments and it's extremely difficult to deal with. I'm sure they are lonely and they don't get physical touch but grabbing staff only makes staff keep more distant. I don't think residents are really trying to manipulate staff sexually. I think they just are lonely and looking for companionship. But, in our department we want to keep a social atmosphere and make everyone feel comfortable. Sexual remarks and comments interfere with that. When residents' sexual lives become a problem that aspect should be dealt with by doctors, nurses and sexual health, not other departments. If residents need assistance they should only get it from staff, if staff are willing to do it and it wouldn't be hurting anyone.

I think sexuality is a personal decision and residents should do what they like. If they want to go out we should help them do that. Everybody needs to be loved and I guess everyone also needs physical contact. If it's two consenting people it's really nobody else's business. We have to be very careful about assisting people in making friends or intimate partners. We certainly can't go out and find someone a mate. It's inappropriate for residents to have sexual relationships with staff or volunteers if they are working directly with them. If a relationship starts up with a volunteer we don't discourage them, we just change the roles so they don't volunteer with that resident.

When residents have any kind of brain damage we have to set up boundaries because you don't want to give them the impression that you go around giving hugs all the time. We have to protect residents with mental challenges who could



be taken advantage of. I'd be a little concerned about them, but other than that it's really a personal decision.

One activity that I think helps residents to feel normal about their sexual lives is to have small evening drop-in groups, where residents and a facilitator can talk about sex. Also, private rooms would be a really nice thing. For myself it would be difficult to always have people around twenty-four hours a day.

### Medical Doctor #1

At Pearson there is a younger population age group, more people in the ages of thirty to sixty years old. I would say thirty to forty percent of the residents have significant interest in sexual activities. I think we spend more time looking at the issue of what to do with inappropriate sexual behaviour as opposed to healthy sexual behaviour and inappropriate demands. I think the institution should open up avenues for sexual expression in whatever form makes a resident physically and emotionally better. We should help residents make their own choices and be in charge of their own lives a bit more when it comes to sexual expression. I think the residents, just like everyone else, crave intimacy, but unlike the rest of us, they don't have families and most of their personal relationships have broken down as a result of their disability. There is very little opportunity for residents to be touched in an affectionate way because they spend their lives being handled by health care workers.

At Pearson we run a critical care type format. Staff are hardly able to cope as it is. Somehow when you come here to work you put on an institutional mask. We wear white lab coats around here yet I'm not even sure why we still do that. As ward physicians we aren't the residents' medical resource by choice so they may or may not feel comfortable discussing their sexuality with me. But it's interesting because the way we monitor residents interest in sexuality is by the amount of visual material the person starts having around him, his demand for pornographic videos, the reporting of inappropriate comments made to health care workers and requests for more frequent condom catheter changes. In my private practice, in a general exam, I would usually ask if the person is married, how they are relating to their wife sexually and ask if there is any concerns that they have. But I haven't done it in this kind of institutional setting. I guess I program myself as institutional staff and I avoid the more intimate discussions. You don't break the barriers down because when we work with people all the time day in and day out and year in and year out health care workers almost have to set up psychological boundaries so they can do that kind of work and not get intimately involved with residents.

Residents wind up looking for relationships inside the institution or get prostitutes because they live in an institution where the model doesn't allow them the opportunity to interact with the rest of society. We should look at prostitutes the same way people seem to know who the drug dealers are here. Residents should get to know who the prostitutes are.

We have to worry about some of the residents being cognitively impaired so they can't be taken advantage of sexually. For instance, I'd worry about those with poor impulse control and would they be taken advantage of financially when involved in sexual activities. I'd also worry about sexually transmitted diseases, their willingness to take preventative measures, their knowledge of contraception and pregnancies. There was a woman here in the past five years who did get pregnant.

Privacy is also a problem. An example is a patient on the ward who asked me to prescribe Viagra, which I did. He filled the prescription at an outside pharmacy so no one here would know. A nurse happened to see the medication in his drawer and reported it. I got a call saying I had to record the medication in case there were contraindications or dangerous drug interactions. So, even though he didn't want people to know he's getting Viagra, it's now on his permanent GPC record. It's like when we have the private room but everyone knows who is coming in.

### Medical Doctor #2

Residents who have severe disabilities can experience sexuality in a number of ways. Besides intercourse there is touching, fantasizing, pornography and so on. I think we have to provide an environment where sexuality is acceptable, and in a sense promoted, because from my perspective it currently isn't. Individual residents express their needs and we deal with it on a one to one basis but certainly the actual institutional structure is not supporting it. I think if residents see sexuality as important to them we should try to facilitate it, especially because we are just reaching a new era of dealing with sexual issues, because we now have Viagra and many more assistive devices. Staff should be more educated to be more accepting of the fact that sexuality is part of a normal human functioning and that when residents request it or want certain forms of sexual activity it should be available for them.

With folks at Pearson we do get some complicating factors that we have to consider. For instance, there are behavioural issues surrounding sexuality, such as when residents are disruptive by inappropriately touching staff, which is a big concern for health care workers.

Another concern to me are cognitive deficits and possible increasing deficits where we may need to assess residents to determine their degree of competency to ensure their sexual activities are done voluntarily.

Lack of privacy is a big, no a huge, problem here. Most of the information we have is written in the chart or documented in some way, which goes against residents who want their information kept private. Most residents live in bedroom wards with several other people and many residents aren't comfortable booking and using the private room because everyone knows what they are doing. Also since Pearson is also a hospital and not only a home residents need to be cared for

and given medications. Those routines need to be respected in a facility like this, so people can't just be off in rooms having sex when their care is compromised.

My basic philosophy is to try and facilitate and assist patients where we can to achieve their goals and needs. However, when people need assistance for their sexual activities it may take a certain level of expertise, such as when an injection of prostaglandins is required. Not everyone can or should be doing that so it's a question of who gets trained to do it. Also the boundary should be there to distinguish between what is clinical and what is a sexual act. Staff would need to be trained to provide the clinical assistance and then leave the room.

My private practice and my sessions here are totally different, but certainly in my private practice patients volunteer and talk about their sexual issues in a confidential setting. I feel very comfortable talking to people about sexual issues but I'm dealing with people who are mobile in the community and in their own homes. At Pearson we have privacy, institutional, and disability issues. I talk to them about their physical history but it's interesting, I'm just thinking right now, I actually don't routinely ask residents about their sexual lives. I've got to start to think it over because I haven't been doing that routinely. I deal with it on a one to one when residents bring it up to me.

### Sexual Health Clinician

Over the years residents have told me sexuality is important to them. Pearson residents are sexual in many different ways. Some like masturbation while others like touching another person, videos, pornography and sex toys. Residents need the benefit for taking responsibility for themselves in their sexual lives and we need to help them get there. If you think about how their bodies work they often can't engage in a sexual relationship without some kind of assistance from somebody else. Even in terms of masturbation they don't have a great deal of hand function so they are very limited in terms of how they can address their own sexuality by themselves. That's what sets residents up because staff have dilemmas about what assistance is appropriate.

For staff it's very frightening. They have fears that if they set somebody up for masturbation and clean up afterwards residents may later accuse staff of actually having helped them masturbate. There have been a number of instances of sexual abuse at Pearson where staff have lost their jobs. There is also the fear that some staff believe when they assist residents sexually they may get a lot of gratification and that their professional boundaries could be easily lost. Staff need to be very clear about what they're doing in assisting with sexuality. Some staff think it's quite legitimate to assist with actual masturbation but I don't because of the vulnerability to both clients and caregiver. Given the abuse that has occurred at Pearson direct assistance may not be the right thing. We can always come up with a vibrator that's got a switch so residents can use it on their own once it's set up.

For health care workers it's particularly difficult for them to assist because they have no distance from clients. They work with residents day in and day out for years. If I were a nurse at Pearson I would have to think long and hard about assisting in terms of my own license and protection as a nurse because the organization doesn't have a clear policy. I hear it all the time around here where staff say to residents if you can't do it yourself then tough luck. Why should we assist anyway? -It's not my job. We had a sexual health service of sorts since 1975 but we still don't have a clear policy around what's acceptable for health care professionals to assist with and what isn't. Nobody wants to go there.

Staff also have their own values and beliefs around sexuality. Health care workers are being asked to support residents even though, in many cases, they disapprove of the residents' sexual activities such as masturbation or having a sexual relationship outside marriage. We all come to our jobs with values around sexuality. Let's say for instance a client gets pregnant and wants an abortion and their health care worker is very anti-abortion. It's not going to work. You can tell her she needs to put her values away but it's probably not going to happen. In that case you are better for everyone involved to switch health care workers and as an organization we should be able to do this.

People at Pearson aren't able to have sexual relationships they way the rest of us are, especially if they make a mistake. If they get into a relationship that isn't great my God there are team meetings about it. If they have a relationship Sexual Health gets a call to come and assess if it's appropriate. We as able-bodied people don't have health care teams assessing whether every relationship we enter is appropriate.

There is the issue of cognitive ability. I think there is only one person in the whole building who is deemed incompetent but for staff it's difficult with cognitively impaired people to know if they should interfere with their sexual choices. My thing is to ask people and say I know you are in this relationship with somebody would you like some information? Give them the choice, and if they say no, I think we have to accept and live with that. I don't think we have the right to tell people they can't be in relationships. We all learn from being in relationships regardless of whether they are painful or hurtful, so who are we to judge what experiences benefit another person?

Sexual health used to have an office at Pearson but we abandoned it because the downside was the residents became very dependent, so the philosophy of supporting independence and taking responsibility for one's sexuality was getting hurt. We tried to limit our sessions to three but the same residents would come back all the time, even though we'd addressed their sexual issues at that point in time as much as was possible. Professionally it's hard not to become too involved if you are seeing people who are just hanging around.

Probably the number one problem for residents is meeting people, just by the very nature of living in a facility and not having much opportunities to get out because

of such things as no money. The second big issue at Pearson is lack of privacy. There is no place for people to have any kind of relationship with anybody. There is no private space for them and although there are a couple of private rooms, residents have to book them and everybody knows they are there and what they are there for. Even those rooms aren't amenable to relationships. There is no physical or emotional space to have a relationship in. Everybody knows everybody's business and everybody knows what's going on. Everything is charted and there's team meetings.

#### Nurse #1

I'm having a hard time envisioning sexual interest because I can only think of a few residents who have continued to be interested in sexuality. They have difficulties with sexuality because of their disability, no sensation, some of them are cognitively impaired and some have mobility issues. I think their own disability stops them more than staff reactions to it. I haven't gone around and asked them but I hear the majority have just abandoned it all together, so it's not a big deal. We don't know our residents well enough to see if sexuality is a need or something they'd like to explore. When a resident has been here a long time you tend to assume you know everything about that person. When they first arrived we may have asked questions about sexuality but it kind of gets forgotten and if the resident doesn't say anything then nobody is going to ask.

Some of our folks are cognitively impaired so I think it's our responsibility to explain about protection against sexually transmitted disease and pregnancy in a way they understand. I've seen people who are developmentally delayed and want to have a family but their own relatives are against it. I think in those circumstances I would be paternalistic and set limits.

The problem with sexual activity is that these people are sick and the people who care for them may not have the same values as those receiving the care. Sexuality should be allowable but it's a question of who is it impacting. Staff shouldn't necessarily have to look at pictures of nude women when they are working and time is a problem. We don't know the predictability of the time a sexual activity would need, so given staff look after four to six residents a piece, it's a problem to set aside time to discuss sexual needs.

#### Nurse #2

When the sexual acts of residents cause conflict I don't think they should be permitted. The residents we have here are younger and say, I am a human being and I need my needs met. Residents are lonely and they haven't got family or friends so staff become their friends and that is where sexuality comes in. Sexual counselors may open up avenues where residents can find a place to have their needs met but that does not mean it's a healthy approach to meet their needs on the ward. Residents are in wheelchairs and frustrated and ask staff to get them adult movies. Some staff say yes and some say no depending on how they feel

about going to get such a movie. When the movies are played here not all the residents have earplugs to control the sound so everyone hears noises and knows what is going on. That's uncomfortable for staff.

One resident was exposing himself and masturbating in front of staff. He's on Viagra, doesn't have a sexual partner and pulls off his condom drainage about three times a day so staff have to come and reapply it. After three times we put on a diaper. Staff also aren't clear why we'd have to give him his medication of Viagra because it just creates inappropriate work for staff. I know we aren't supposed to question what the resident wants but the staff do wonder. Staff suspect the resident is using the medication for the wrong reason so he can have a longer erection or masturbate or his condom will come off and then he will get the staffs' attention. The resident's intent is not to go meet a partner but inevitably to masturbate longer and use the staff as well.

Residents sometimes sexually harass staff, such as when one person told a staff member that her breasts were like watermelons. He told her this right in front of her which was derogatory. Some staff, often because of differences in culture, don't know how to reply back and they land up putting up with whatever is going on instead of telling the residents it's inappropriate and leaving the room. Resident care aides are always with the residents for an eight-hour period. They are closest to the residents and have the least amount of power. They should be expected only to provide health care. I know people want us to have the broader view of a holistic approach but when it gets complicated, like with sex, it's not fair to leave those with the least amount of power to deal with it.

Staff are here to care for residents basic needs like bathing, cleaning, grooming, dressing and feeding. Our job descriptions says nothing about dealing with residents' sexual natures. Basically it's personal care, very black and white. Like with smoking, staff have the right to say they won't light a cigarette for a resident. Same with sex they don't have to do it, although we don't have guidelines.

If staff help residents in their sexual nature the relationship between staff and residents will change. You can't maintain a professional relationship after that. In long-term care even when staff engage in conversations with residents friendships develop and it can land up in relationships. Residents may even offer staff sexual favours to get things they want from staff. Some residents ask staff to masturbate them and some staff do it because they think they are doing the resident a favour. Even though my understanding is they used a paper towel and did it under the covers it's not an appropriate expectation from a caregiver. Residents need to learn to seek their sexual needs in a more appropriate fashion.

Lack of privacy is a problem here. There are no secrets at all. People know what's happening even in the Quiet Room and it's not comfortable at all for residents or staff. On the wards there are often four to a bedroom and the rooms are small. Some of the residents can't speak for themselves so can't say they don't want to see a porno movie that is being played by a roommate. That leaves staff to say no

to the movie.

An alternative is for the resident to go out and do their sexual activity elsewhere. However, there is a problem with that too. My understanding is that we are responsible if some resident goes off site and his wheelchair tips over and they ask staff to go and help them. We have a duty of care to help that resident, even though the resident is making choices. So if a head injured resident chooses not to take birth control and gets pregnant, who is going to take responsibility for that child? If you've got residents wandering into rooms and feeling and touching other residents, again we don't have guidelines. What are we to do with that resident? Do we have a duty to intervene if residents are head injured and want to engage in risky sexual behaviours?

The residents are quadriplegics so they all require some assistance to do things sexually. It would be best if a friend could set it up for the residents but I suppose if there was a way staff could just set up a movie without having to hear or acknowledge what was going on and leave it might be okay because you're not having to really be exposed to the full movie itself. Staff were very concerned about two residents wanting to co-habit in a room because of fear of AIDS, cleaning up after them and looking after them after they've completed the act. Even when residents use the Quiet Room it creates too much work for staff.

### Nurse #3

Sexual activity isn't prevalent at Pearson because its fearsomely sublimated because of the institutional setting, lack of privacy and lack of dignity associated. In some cases the disease process itself presents so many psychological and emotional components to it it's difficult for residents to overcome them. So it's difficult to have personal relationships.

One of the big problems with sexual activities in long term-care settings is you can't wipe somebody's nose and butt all day and not develop some kind of relationship.

Competency is a very large stumbling block because I act as an advocate for my patients and if I think a potential partner is looking for a healthy intimate relationship then go for it. But if this person is looking to use my patient for an additional cigarette supply then I'd give them problems over that. One case was when a male volunteer around here was taking advantage of female residents would have them over to his place to have sex and then would dump them. When I got to work one day one of my residents was waiting for a bus ride to go visit this person but I looked and since there was no return trip booked I told her she can hate me tomorrow but I'm not letting her go. From a professional basis it's not whether she is happy with me or likes me, it's whether or not I look after her. Residents look to us to be their protector, sort of like a big sister or big brother.

Another resident's father was getting him a prostitute and using the Quiet Room.

Some very emotional discussions were occurring in the dining room over that. Some staff should have had their hands slapped about confidentiality because they were making their positions known in public. My way of dealing with it was to talk to the father who was encouraging this behaviour. I'd say to the father whether or not she is bought doesn't matter. Whether or not sonny gets his rocks off doesn't matter. What I'm saying is he's only been here for two months and look at the issues he's got on his plate. Now father, what are you going to do when your son is infatuated with a woman and for some reason he gets psychologically or emotionally hurt because it's a devastating affair or if he has a dystonic reflex and gets a brutal headache? Even if you tell the resident what the risks are, if they joke and laugh them off, I'd have to question how appropriate their judgment is.

A young guy and gal on this floor were in a room on the ward here with a do not disturb sign up. However, as a professional, I know the guy is a diabetic and hasn't had breakfast so I'm going in. If they want to get all snarky about it then I'm going to suggest something other than this place to have a relationship. You see it's a job for me, a profession, and I have to maintain standards of practice. Sure they'd like their do not disturb sign honoured but until what time? Is this guy actually interested in getting healthy? I'm worried about my professional association coming back to me and saying you knowingly walked away from a patient in distress.

Once there was a husband and wife couple here in a double bed. It was very difficult to deliver care in a double bed because you are restricted to working on one side of the bed. The man tried very hard to be his wife's protector and wanted to do her daily care. We said no and we put a curtain in between them so it fell down the middle of the bed and could be pulled across. He didn't like that much but we have to do our job.

If a resident wants to masturbate a lot and needs his sheets changed I'd say sorry you have to wait until next Tuesday which is your bath day. We don't have the budget, time or resources to clean you or your sheets.

The majority of my day is prioritizing crisis. If people don't breathe they don't have sex. Yesterday I had somebody with a bronchospasm for almost two and one-half hours. Normally I'm supposed to have my pills done and given a series of treatments so I finally can go to breakfast. At breakfast time I hadn't even started my pills. There's no way I could leave him. He was just coughing, discharging, refluxing and regurgitating. I was just continually suctioning. I didn't even get a chance to empty the bottle, somebody else had to do that for me. My time is tightly utilized so the priority of other components such as mental or spiritual health and getting involved in sexual activities is way down on my list and don't get factored in. With sexual assistance even on site you can't cram assistance down staffs' throats.

Sometime, as an alternative, residents go offsite and have some beers and catch



the table dancers. This is still problematic for staff. I get a phone call from one of these guys who says, "Hey I couldn't help it I had an erection, my condom fell off and now I've soiled my pants, please help". My priority in this situation is to people here, not to the people that went off site. Even if it's good for the guys from a spiritual and emotional component, there's not a lot of room there to provide them assistance. We don't have enough staff or money for any of that.

#### Nurse #4

A lot of our residents could never be really sexually physically active in terms of intercourse but they certainly can think. Sexually they can have the ideas of excitement, wanting their hair fixed up and to look and be attractive. A lot of the residents know there is no privacy here and everyone will know, tease them, and put up barriers if they want to engage in sexual activity. Residents don't want to be humiliated and embarrassed when they have to ask for help. One of the staff once paid for a stripper and prostitute to come for a resident's birthday. The resident still talks about it, and although he was embarrassed, he was also excited that people saw him as a sexual being. He still talks about it. We also had one guy in here recently who said, "I'm young, I've been sexually active my whole life, and you aren't going to stop me".

The problem is that a few residents trying to impose their values is not going to go anywhere with staff here. Everyone has to develop an empathy for understanding that in daily life people have boyfriends and girlfriends, and to see how difficult it is for people to even find a partner if they have a disability. Instead of encouraging residents to find another partner or find other sexual activities to do we shut the person down.

The main barriers to having sexual activities at Pearson is the layout of the institution itself, which offers no privacy. The values of staff, staff saying it's not my job, nurses feeling they have to look after more life threatening things like medications, and sex just not fitting into the mould of this long-term care residential setting.

When we talk about privacy it's just not there. Most residents live in four to a bedroom wards, which is not conducive to any form of intimacy. Even though we offer the Quiet Room, everybody knows who is in it and who they are with. Everyone then talks about what they believe people are doing in there. Staff aren't open to accepting residents as sexual beings. Instead of seeing residents' inappropriate comments as loneliness and wanting to meet someone or talk with someone about their sexuality, staff see it only as problem behaviours that need to be stopped. They don't believe residents need it. In defense of staff they have no training for it. Most of the RN's have been trained under a military model with a very strong Catholic background. When sex comes up they giggle and gossip about it because they are uncomfortable with sex and sexuality.

When residents are using the Quiet Room I've heard that staff have walked in during the middle of sexual activity, turned on the lights and then walked out leaving the door wide open. When another guy had his girlfriend in for the night one staff person yelled right in front of them, "This is not a whorehouse!"

Some staff are worried about abuse issues, which is reasonable, but often it comes down to who is going to do the work. In one case two residents from two different wards wanted to be together once a week but it became this huge debate on which staff from which ward would be responsible for coming and taking the guy back to his bedroom. I think staff use the excuse of workload to support their own values about sexuality.

I try to be open but I remember sometimes that I had to clean up after masturbation, and although it was body fluid, it seemed more messy being intimate body fluid. Also I wouldn't know how to give an injection into the penis. I would think I would hurt it so I would need training to provide that assistance. It's not our job to engage in sexual acts with residents but assisting would require a lot of education. We have to be careful that when we assist we don't encourage residents to see staff as sexual and the proper target for their sexual advances because it is easy for residents to get confused. The attitudes of staff will be hard to change and what happens on the wards most often depends on the attitudes of the nurse in charge. We should be saying let's figure out how we can work it best for everybody.

### **Deriving themes**

In this section, I endeavour to demonstrate how nine themes that negatively influence staff's provision of sexual care first emerged from my data. As was the case with residents, deriving these themes was not as simple a process as it may appear on paper. In reality, the process took years and I was particularly struck by the number of times I had to return to participants to clarify and confirm theoretical constructions. I felt that this lengthy process was mainly a reflection of my delicate subject matter.

As pointed out in Chapter 2 the literature reports several negative influences on care providers' provision of sexual care. Identified are the wish to avoid instability and chaos in medical settings, embarrassment, believing that sexuality is not relevant to the

presenting medical problem, inadequate training, and interference with care providers' legal duty to prevent sexual abuse. The present study confirms the literature and most notably adds to knowledge by identifying staff's sense of powerlessness to change the nature of long-term care living as it is practiced today. I now describe how each of the nine negative influences on staff's provision of sexual care was derived from my data.

#### Duties to set professional boundaries

The first negative influence on staff's provision of sexual care is their duty to set professional boundaries with residents. Their licensing bodies and the institution require staff to always act in the best interests of residents, which includes not engaging in sexual relationships with clients (Registered Nurses Association of British Columbia, 2002a). In trying to set appropriate sexual boundaries, staff are cognizant of three things. First, they are aware that in long-term care settings, because staff and residents work and live in close proximity with each other on a daily basis over years, relationships of some sort inevitably develop. Staff also are aware that they are responsible for ensuring that all relationships that do develop remain professional. Second, staff believe that client-staff sexual relationships are inappropriate because they see that there is significant risk that these relationships will prove, more often than not, detrimental to residents. Third, staff know that the provision of sexual care must always be therapeutic and professional.

#### 1. Client-staff relationships must remain professional

Nurse #3 was graphic in her description about why she thought staff-resident relationships develop in long-term care.

One of the big problems with sexual activities in long-term care settings is you can't wipe somebody's nose and butt all day and not develop some kind of relationships.

Nurse #2 echoed a similar sentiment and articulated the concern that long-term care staff-resident relationships easily slip into personal and sexual relationships.

In long-term care even when staff engage in conversations with residents friendships develop and it can land up in relationship. If staff help residents in their sexual nature the relationship between staff and residents will change. You can't maintain a professional relationship after that.

MD #1 explained the extraordinary lengths long-term staff have to go to ensure sexual relationships with residents do not occur.

...when we work with people all the time day in and day out and year in and year out, health care workers almost have to set up psychological boundaries so they can do that kind of work and not get intimately involved with residents.

## 2. Client-staff sexual relationships are inappropriate

All staff interviewed stated that it is inappropriate and unprofessional for caregivers, who work directly with residents, to engage in sexual relationships with them. Most commonly, staff feel that these types of relationships are not in the best interests of residents. A sexual health nurse described her view.

Look you have clients who are vulnerable in so many ways. As people with disabilities they usually struggle more than able-bodied people to find sexual partners. Staff know everything about residents including their financial positions, their family relationships, their past and present psychological profile. Residents know almost nothing about staff's personal circumstances but a staff person may know a person has a big ICBC settlement for being injured in a car. The staff person starts a personal relationship with the client and lands up using them for their money. Doesn't matter if it's conscious or not. At the end of the day the resident isn't better off. Sure the resident may get all sorts of good things out of it but you can never fully discount that the resident wasn't taken advantage of. If people coming to a doctor can't trust that when they take their clothes off the doc won't come onto them, our system of care would be chaotic and rife with inappropriate and abusive relationships. No matter how you cut it a client-professional relationship inherently involves power and within that relationship there is no way to ensure the power is not being used inappropriately. (Fieldnotes: April 15, 2002, sexual health nurse)

Staff-resident sexual relationships are not the only ones thought to be non-therapeutic. The recreation therapist, for example, believed that sexual relationships between volunteers and residents are also inappropriate, at least while volunteers are directly involved with care.

We have to be very careful about assisting people in making friends or intimate partners. It's inappropriate for residents to have sexual relationships with staff or volunteers if they are working directly with them.

### 3. Sexual care must be therapeutic and professional

Staff know that in order to uphold professional boundaries, when sexual care is provided, they need to be clear about how professional boundaries will be maintained.

The advice of one of the sexual health clinicians is poignant.

Staff need to be very clear about what they're doing in assisting with sexuality. Some staff think it's quite legitimate to assist with actual masturbation but I don't because of the vulnerability to both clients and caregiver. Given the abuse that has occurred at Pearson, direct assistance may not be the right thing. We can always come up with a vibrator that's got a switch so residents can use it on their own once it's set up.

Social Worker #2 felt that sexual care could be provided but at the same time emphasized the importance of staff being clear about how to maintain a professional relationship.

Masturbation of residents by staff who are comfortable doing it should be allowed. You just have to make sure the boundaries are well understood and that staff is supervised.

Several interviewees were aware of the many ways resident abuse could occur if staff were free to have sexual relationships with them.

Admin #1: We rely upon the Recreation Department to identify whether or not there are pairings that are or shouldn't be taking place, like if residents offer sexual favours to get an extra bath a week.

Sexual Health Clinician: Sexual health used to have an office at Pearson but we abandoned it ... Professionally it's hard not to become too involved if you are seeing people who are just hanging around.

Nurse #2: Residents are lonely and they haven't got family or friends, so staff become their friends...Residents may even offer staff sexual favours to get things they want from staff.

### Legal duties to provide care

The second negative influence on staff's provision of sexual care is its potential to interfere with their legal obligations to provide other forms of care. Staff differentiated between their general legal duties to provide care and their duties of care with respect to residents who are cognitively impaired. I take these up in order.

#### 1. General duty of care

Staff's primary concern regarding their general legal duty of care is their belief that sexual care inappropriately competes and interferes with the delivery of care that residents need to survive (e.g. feeding, bathing, dressing, toileting, medications). When residents are involved in sexual activity, staff feel obligated to ensure that residents comply with their daily care regimens. Finally, staff are concerned that their assistance with sexual activity could increase the risk of residents being harmed.

Participants made the following comments regarding their legal concerns about sexual care interfering with their duty to provide other types of care.

Nurse #3: If people don't breath they don't have sex.

The nurses and aides have so much do here so I'd be really afraid that daily care would be compromised if they were also responsible to look after residents' sexuality. (Fieldnotes: November 29, 2000, administrator)

One of the physicians expressed his concern about residents not receiving

essential care when they are engaged in sexual activity.

MD #2: ...since Pearson is also a hospital and not only a home residents need to be cared for and given medications. Those routines need to be respected in a facility like this so people can't just be off in rooms having sex when their care is compromised.

A nurse concurred with the physician.

Nurse #3: A young (diabetic) guy and gal ...were in a room...with a do not disturb sign up. I'm worried about my professional association coming back to me and saying you knowingly walked away from a patient in distress.

Staff also commented about their concerns regarding their legal responsible to prevent sexual assault.

We are legally liable to make sure residents remain safe, including safe from any sort of sexual abuse. (Fieldnotes: November 19, 2001, nurse)

Admin #2: As a facility we have a responsibility to ensure the safety of the people involved. For instance if the sexual activities...inflicts harm I'd want to interfere... We have a vulnerable population here...so we always have to be concerned that sexual activity is consensual and not abuse.

## 2. Duty of care with respect to residents who are cognitively impaired

Staff's duty to protect residents with cognitive impairments from harm negatively influences sexual care.

Nurse #3 felt staff have a duty to protect residents who are psychologically impaired from engaging in sexual relationships that could cause emotional harm.

... what I'm saying is he's only been here for two months and look at the issues he's got on his plate...what are you going to do when for some reason he gets psychologically or emotionally hurt because it's a devastating affair...I'd have to question how appropriate their judgment is.

MD #1 worried that cognitively impaired residents should be protected from sexual activity that might result in sexually transmitted diseases or unwanted pregnancies.

I'd also worry about sexually transmitted diseases, their willingness to take preventative measures, their knowledge of contraception and pregnancies.

A number of other staff were concerned with the vulnerability of cognitively impaired residents.

Social worker #2: When residents are cognitively impaired its a grey area to allow them to have sex if they can't be informed about the risks such as people taking advantage of them.

Recreation Therapist: We have to protect residents with mental challenges who could be taken advantage of.

MD #1: We have to worry about some of the residents being cognitively impaired so they can't be taken advantage of sexually.

MD #2: Another concern to me are cognitive deficits and possible increasing deficits where we may need to assess residents to determine their degree of competency to ensure their sexual activities are done voluntarily.

Sexual Health Clinician: There is the issue of cognitive ability. I think there is only one person in the whole building who is deemed incompetent but for staff it's difficult with cognitively impaired people to know if they should interfere with their sexual choices.

Nurse #1: Some of our folks are cognitively impaired...I've seen people who are developmentally delayed and want to have a family...I think in those circumstances I would be paternalistic and set limits.

Nurse #2: So if a head injured resident chooses not to take birth control and gets pregnant who is going to take responsibility for that child? Do we have a duty to intervene if residents are head injured and want to engage in risky sexual behaviours?

Nurse #3: Competency is a very large stumbling block because...if this person is looking to use my patient for an additional cigarette supply then I'd give them problems over that...Residents look to us to be their protector, sort of like a big sister or big brother.

### Personal and religious values

The third negative influence on staff's provision of sexual care is their desire to uphold personal and religious values. This issue is most significant with staff who work



directly with residents (i.e., nurses and resident care aides) and administrators who are ultimately responsible for all care delivered.

Nurse #4 felt that upholding personal and religious values was staff's main obstacle to providing sexual care.

The main barriers to having sexual activities at Pearson is ...the values of staff, staff saying it's not my job.

Nurse #2 described how the provision of sexual care depended on staff's personal and religious values. This illustrates one of the reasons why residents often receive unequal levels of sexual care.

Residents...ask staff to get them adult movies. Some staff say yes and some say no depending on how they feel about going to get such a movie. Even when residents use the Quiet Room some staff feel uncomfortable cleaning up after the fact, mostly because its goes against their religious views.

At a later date these two nurses made additional statements which echoed their original sentiments.

Nurse #2: Some of the staff would help a couple who was kissing in their bed by pulling the curtain around them but it really depends on who's working and the value system of the person who is on.

Nurse #4: ... what happens on the wards most often depends on the attitudes of the nurse in charge.

Most staff felt that they should not have to provide sexual care if it offends their personal and religious values.

Admin #2: Staff shouldn't be forced to assist with residents' sexuality if they don't want to do it. People have personal values and as professionals we should try not to bring out personal values to work but I think that's very difficult for some people, especially if they are religious and certain sexual practices are against their religion.

Nurse #1: The problem with sexual activity is that these people are sick and the

people who care for them may not have the same values as those receiving the care. I feel for the staff who has been asked to do something incongruent with that person's values and beliefs. I don't think we should impose that on staff because it infringes on caregivers' rights. We can't force staff to assist in sexual activities if its against their values and beliefs. We have a lot of people who are Catholic with a big Philippine population so assisting in sexual activities is against their usual way of life.

In contrast, one administrator felt that staff should be expected to provide sexual care regardless of personal or religious values. However, he conceded that, in certain cases, individual staff members could be relieved of their duties.

Admin #1: We have a couple of instances where staff have complained or refused to help residents and we've told staff they should leave their morals at the front door. If you have a problem then express your problem and you may be removed from a situation...but my expectation is that as a professional you know how to work at arms length and you are expected to work with residents' sexuality as part of the activities of daily living.

#### Avoiding sexual harassment in the workplace

The fourth negative influence on staff's provision of sexual care is their wish to avoid sexual harassment in the workplace. Specifically problematic is residents' sexual advances, which commonly occur during daily dressing, washing and toileting regimens. Staff stated that, "given residents see staff as sexual targets" providing sexual care is a mistake because it promotes "inappropriate sexual behaviours in residents" (Fieldnotes: October 16, 2001, nurse).

The trouble, you know, is that lots of the residents make sexual remarks and grab us. We may be able to deal with that but why would we ask for more? Imagine someone making a remark about your breasts and then your next job is to give the client a penile injection for erection enhancement. Even if you're trying to be super professional, he's madly relating the sexual thoughts to whatever the staff do. Puts us in an impossible situation .(Fieldnotes: November 22, 2000, nurse)

The following comments reflect staff's beliefs that they are entitled to have "safe"

work environment, which means having a work place free of sexual harassment.

Health care workers are shocked and angry when residents make sexual approaches to them and it's particularly awful when the bosses do absolutely nothing about it. We get abused and that's not what we're here to do. They're supposed to do something about that. (Fieldnotes: April 23, 2003, resident care aide)

MD #2: ...there are behavioural issues surrounding sexuality, such as when residents are disruptive by inappropriately touching staff, which is a big concern for health care workers.

Nurse #2: Residents sometimes sexually harass staff, such as when one person told a staff member that her breasts were like watermelons. I know people want us to have the broader view of a holistic approach but when it gets complicated like with sex. It's not fair to leave those with the least amount of power to deal with it.

Other staff understood the institution's obligation to ensure sexual harassment is not present in the workplace.

Admin 2: We also have an obligation to ensure a safe work environment for the staff.

The institution has a legal responsibility to protect us from sexual harassment. We don't have to put up with a lot of what goes on here. (Fieldnotes: August, 12, 2001, nurse)

We have a right not to be sexually harassed and the administration must ensure it doesn't happen. (Fieldnotes: January 10, 2003, nurse)

One of the social workers recognized the difficulties involved with ensuring a sexual harassment free workplace, especially when residents have been institutionalized for years or when they are cognitively impaired.

I think a lot of residents don't understand the societal norms around expressing sexuality be it from lack of experience or from brain injury. A resident making sexual overtures to a staff person isn't just a straightforward interest in sex. It's much more complicated than that.

### Inadequate training and education

The fifth negative influence on staff's provision of sexual care is inadequate training and education to deal with sexual activity.

MD #2: Staff should be more educated to be more accepting of the fact that sexuality is part of a normal human functioning and that when residents request it or want certain forms of sexual activity it should be available for them.

Nurse #4: In defense of staff they have no training for it...they are uncomfortable with sex and sexuality...assisting would require a lot of education.

However, the question of exactly what sexual care training staff should receive remains elusive. One MD commented on the problem this way.

MD #2: Not everyone can or should be doing that so it's a question of who gets trained to do it. Also the boundary should be there to distinguish between what is clinical and what is a sexual act. Staff would need to be trained to provide the clinical assistance and then leave the room.

Social Worker #2 pointed out that all staff, including administrators, need more education about sexual activity.

We have to stop making sex shameful but who will educate the administrators?

If administrators are to lead the way to change they first need to understand all the issues faced by staff when they work with residents' sexuality. It's very complicated and won't be solved if all the problems aren't addressed. (Fieldnotes: July 27, 2000, social worker)

### Lack of time and resources

The sixth negative influence on staff's provision of sexual care is lack of time and resources. This issue is primarily important to nurses whose skills are needed to meet many of the medical needs of residents. For example, all four nurses interviewed commented that providing sexual care to residents is problematic due to their already over-taxed workloads.

Nurse #1: We don't know the predictability of the time a sexual activity would need so given staff look after four to six residents a piece it's a problem to set aside time to discuss sexual needs.

Nurse #2: One resident was...masturbating...and pulls off his condom drainage about three times a day so staff have to come and reapply it. After three times we put on a diaper...it just creates inappropriate work for staff.

Nurse #3: If a resident wants to masturbate a lot and needs his sheets changed I'd say ...we don't have the budget, time or resources to clean you or your sheets. My time is tightly utilized so the priority of other components such as mental or spiritual health and getting involved in sexual activities is way down on my list and don't get factored in. We don't have enough staff or money for any of that.

Nurse #4 recognized the strain of providing sexual care puts on nurses' time and resources but also wondered if religious and personal values were the real reason that sexual care was not provided.

...often it comes down to who is going to do the work. In one case two residents from two different wards wanted to be together once a week but it became this huge debate on which staff from which ward would be responsible for coming and taking the guy back to his bedroom. I think staff use the excuse of workload to support their own values about sexuality.

### Lack of privacy

The seventh negative influence on staff's provision of sexual care is lack of privacy. First, the institution's physical structure does not provide adequate and appropriately equipped private space for residents' sexual activity. Second, staff sense that residents' sexual information is not treated as confidentially as is other personal information.

#### 1. Lack of physical privacy

Many staff voiced concerns about sexual activity occurring in public and the unavailability of properly equipped private facilities.

Admin #1: Pearson is primarily a home but because it is also an institution we have to uphold certain rules so people can live together. Behind closed doors individuals can do what they want. I don't have any concerns at all so long as it

doesn't cross over and spill into the public place such as with open displays of exhibitionism and masturbation.

Resident Care Aides: We have one guy that pulls his condom off to masturbate but the guy in the next bed complains about it. We were told to just pull the curtains around him and let him have his privacy but he's still disturbing the guy in the next bed.

Social Worker #1: I also don't have any issue around self-stimulation...as long as it doesn't impact on other people and is not done in public. I think there are issues however if a resident shares a bedroom with others and when the residents' sexual activities impact on the other roommates.

Nurse #2: Lack of privacy is a problem here. On the wards there are often four to a bedroom and the rooms are small. Some of the residents can't speak for themselves so can't say they don't want to see a porno movie that is being played by a roommate. That leaves staff to say no to the movie.

Staff also recognized that lack of appropriate and private physical accommodations for sexual activity curtails residents' sexual lives. As the institution was built as a medical facility most residents' rooms are shared and the usual amenities that make sexual activity conducive (e.g., locking doors, showers, soft light, music, etc.) are not readily available.

Social Worker #2: I think that every resident should have a private room with electric beds and grab bars so they don't need staff in their rooms most of the time...Look at this place we have four people to a bedroom. We need to change the physical structure here and the deeper culture of how residents' sexual lives should be respected.

Recreation Therapist: Also, private rooms would be a really nice thing. For myself it would be difficult to always have people around twenty-four hours a day.

MD #2: Most residents live in bedroom wards with several other people and many residents aren't comfortable booking and using the private room because everyone knows what they are doing.

Sexual Health Clinician: The second big issue at Pearson is lack of privacy. There is no place for people to have any kind of relationship with anybody. There is no

private space for them and although there are a couple of private rooms residents have to book them and everybody knows they are there and what they are there for. Even those rooms aren't amenable to relationships.

Nurse #4: The main barriers to having sexual activities at Pearson is the layout of the institution itself which offers no privacy. Most residents live in four to a bedroom wards, which is not conducive to any form of intimacy. Even though we offer the Quiet Room everybody knows who is in it and who they are with. Everyone then talks about what they believe people are doing in there.

## 2. Lack of confidentiality with respect to residents' sexual information

The lack of confidentiality with respect to residents' sexual information negatively impacts sexual care. A number of staff commented that because GPC uses a team approach to care, most staff are aware of intimate details about residents' sexual lives. A number of staff reported that this information was commonly inappropriately disseminated. Also, questions of how to control "gossip" and whether or not residents' sexual information needs to be shared with the whole team were repetitively asked.

Social Worker #2: The majority of staff are against resident sexual activity. People who live here live in a fish bowl. When somebody is having a relationship it gets all around, everyone knows and it's often made fun of. It's treated the way you would look at little children. We can be very condescending.

Sexual Health Clinician: People at Pearson aren't able to have sexual relationships they way the rest of us are, especially if they make a mistake. If they get into a relationship that isn't great my God there are team meetings about it. There is no physical or emotional space to have a relationship in. Everybody knows everybody's business and everybody knows what's going on. Everything is charted and there's team meetings.

MD #1: Privacy is also a problem. An example is a patient on the ward who asked me to prescribe Viagra which I did. I had to record the medication. So even though he didn't want people to know he's getting Viagra it's now on his permanent GPC record.

MD #2: Lack of privacy is a big, no a huge problem here. Most of the information we have is written in the chart or documented in some way which goes against residents who want their information kept private.

Nurse #4: A lot of the residents know there is no privacy here and everyone will know, tease them and put up barriers if they want to engage in sexual activity.

Why does everyone have to know all this personal information about residents' sexual lives? There must be some way only people who have to know can access that information. We just assume it's okay to let everyone in on it, even when we know many misuse their knowledge of that information. (Fieldnotes: December 12, 2001, physician)

### Lack of sexual care guidelines

The eighth negative influence on staff's provision of sexual care is lack of guidelines, which inform staff what is expected of them and is appropriate for them to provide. Without guidelines, many staff are reluctant to provide sexual care for fear that the institution, or their professional bodies, will discipline them.

Resident Care Aides: The health care workers want to know what is our duty if residents make sexual demands and why don't they tell us in our job descriptions what they expect us to do?

Sexual Health Clinician: If I were a nurse at Pearson I would have to think long and hard about assisting in terms of my own license and protection as a nurse because the organization doesn't have a clear policy. Why should we assist anyway? It's not my job.

It's completely unacceptable that the institution doesn't provide guidelines for staff to help them deal with sexual expression. (Fieldnotes: June 3, 2000)

Nurse #2: Our job descriptions says nothing about dealing with residents' sexual natures. Basically its personal care, very black and white. Like with smoking, staff have the right to say they won't light a cigarette for a resident, same with sex, they don't have to do it, although we don't have guidelines.

### Sense of powerlessness to change the nature of long-term care living as it is practiced today

The ninth negative influence on staff's provision of sexual care is the sense of powerlessness to overcome the nature of long-term care living as it is practiced today.



Staff made several comments that show how powerless they feel to change the long-term care system in which they operate. Specifically, a number of staff showed their frustration with trying to get the system to support their provision of sexual care.

We had a sexual health service of sorts since 1975 but we still don't have a clear policy around what's acceptable for health care professionals to assist with and what isn't.

If they want staff to provide sexual care the administration has to help them do that. For years we've asked for sexual care guidelines and a budget for education but it never comes. Nothing will happen unless some of these things happen. (Fieldnotes: October 23, 2003, sexual health nurse)

Listen, I'm not doing anything much to do with sex unless I have clear permission from my licensing association. It's too risky. We don't even get guidelines from this place, let alone hoping to get it out of our association. (Fieldnotes, November 20, 2002, nurse).

When it comes to providing sexual care we all have to know what we can and cannot do. Bottom line. The higher-ups just don't want to deal with this issue and we can't make them so sex gets thrown out the door. (Fieldnotes: November 18, 2002, social worker).

Our professional associations can take away our licenses for doing sexual care that they deem is inappropriate. The rules are clear about us not having sexual relationships with clients, but they don't tell us what is okay to do when we provide sexual care. On top of that we don't even have internal guidelines that tell us what we can and cannot do. That leaves us in an uncomfortable position. Individually we have to decide what's appropriate and if we decide wrong we can lose our jobs and licenses. And you wonder why no one is comfortable providing sexual care? (Fieldnotes: January 30, 2003, nurse)

### **Conclusion of thematic analysis**

The data presented in this chapter show that if we want sexual care to be Available, institutions must adequately support staff to provide it. First and foremost, facilities must accept that it is their moral responsibility to do this. The ethical rationale for the obligation to provide sexual care is developed in the next chapter.

## CHAPTER 6:

### The Ethical Perspective

No man is good enough to govern another man without that other's consent.

--- Abraham Lincoln. Speech, Peoria, Illinois October 16, 1854

#### Introduction

In this work I have shown that long-term care residents must have sexual care available to them if we want them to be able to have sexual lives. I have also argued that staff will generally be unwilling to provide such care unless the institutions they work for accept their moral responsibility to develop appropriate standards of care, provide adequate resources and educate staff accordingly. The purpose of this chapter is to delineate the ethical case in support of sexual activity in long-term care institutions.

In the following analysis I show that institutions have a moral obligation to tolerate residents' sexual lives and provide assistance with sexual activity they cannot do for themselves because of their physical disabilities. I argue that residents ought to have rights, not privileges, to have sexual lives. In this context, rights do not mean legal rights but moral rights, which society ought to confer on people to guarantee them that which the right dictates. Rights<sup>6</sup> in contrast to privileges entail correlative duties, which may be positive or negative (Feinberg, 1973:12, 58). Positive rights impose a duty on some other(s) to do something, whereas negative rights require some other(s) not to do something, such as not to interfere. Negative rights (rights "to do") ensure staff's

---

<sup>6</sup> For a useful collection of readings on the nature of rights, see J. Waldron (1984).

tolerance of residents' sexual activity and positive rights (rights "to receive") guarantee that residents will receive the assistance that they need.

My case for establishing residents' rights comes in two stages. First, I advance arguments in favour of presumptive ("prima facie") rights for residents to engage in sexual activity and to receive help to do so. Second, I consider potentially countervailing arguments based on harm to self (and participating others), harm to others, and offense to others and argue that they are insufficient to cancel these rights in most situations.

### **Prima facie arguments for rights to do**

Some GPC residents reported that they want to engage in the following sexual activities which they can carry out without staff's assistance: touching, fondling, lying in bed with partners, kissing, masturbating, viewing pornography in magazines or on wall-posters or videos, and mutually agreed upon sexual intercourse with spouses, partners, other residents, or prostitutes.

Four arguments provide a prima facie case for their right to be able to do so.

The first argument appeals to the value of liberty as outlined by J.S. Mill <sup>7</sup> who argued that, "...all restraint *qua* restraint, is an evil" (Mill, 1859/1965:Ch. 5: para. 4). Mill reasoned that "to be prevented from doing what one is inclined to do, or from acting according to one's own judgment of what is desirable, is not only always irksome, but always tends, *pro tanto*, to starve the development of some portion of the bodily or mental faculties..." (Mill, 1848/2004: Bk. V, Ch X1, Sec.2). Assuming such states of affairs to be undesirable this implies that people, including those living in institutions, ought to be allowed to do what they want unless there are sufficient countervailing

---

<sup>7</sup> My understanding of Mill was enhanced by the writings of D. G. Brown, 1972; P. Remnant, 1970; and A. Ryan, 1965.

considerations to warrant restrictions. Mill did not say interference is never appropriate, but rather that the onus of justification always lies with those wanting to interfere (Mill, 1848/2004: Bk. V, Ch X1, Sec.2). Freedom to do what one wants is the rule, interference the exception (Browne, Blake, Donnelly & Herbert, 2002).

The second argument appeals to the value of non-discrimination and equal rights for long-term care residents to use private areas of their homes as appropriate places to engage in sexual activity. Home is and should be a place of refuge from the outside world, "...a place of privacy and independence" (Depres, 1991:98). Both men and women view home as a place of personal control (Churchman and Sebba, 1995). As society demands that most sexual activity be carried out in private, public displays of it are rare without resulting social pressure or legal penalties. The public often frowns on and verbalizes objections to intimate touching in public, and the law expresses disapproval through nudity and public disturbance legislation. Because home traditionally has been the most acceptable place for consenting adults to engage in intimate sexual activity, long-term care residents should be able to use their homes as a place for sexual expression.

The third argument appeals to and acknowledges the importance of sexuality and having a sexual life as part of people's humanity (Ince, 2003; Johnson, 2004). Sexual activity is a natural human function, which often produces substantial benefits for people's well being (Mace et al., 1974; McCann, 2000; Weeks, 1986). It is an integral part of the development of a positive self-concept and high self-esteem (Brown et al., 1994; Cornelius et al., 1982; Nye, 1999). Reasons for wanting sexual contact are diverse and equally applicable to persons with disabilities as they are to able-bodied people

(Barrett, 1991). Despite these facts, there has been a lack of sexual freedom for persons with disabilities, who are rarely provided the support and assistance they need to have sexual lives (Doyle et al., 1999; Schrover & Jensen, 1988; Shakespeare et al, 1996). This occurs even though sexuality is considered to be an important part of patient care, and the World Health Organization promotes the inclusion of it within health care (Earle, 2001; Mace et al., 1974). Recognizing that persons with disabilities are sexual beings means accepting that having a sexual life can be equally meaningful for these people as it is for others.

The fourth argument appeals to what should be the focus of long-term care, namely to help residents live with their disabilities and improve the quality of their lives. By implementing holistic and client-centered philosophies of care, which aim to respect clients' entire humanity and provide care that meets their specific needs, these goals can be achieved. Both these approaches support the provision of sexual care. Holism (i.e., a philosophy that caters to the whole person) encourages clients to pursue health goals that are important to them (Goldstein & Krasner, 1987). Client-centered care aims to customize care "to the specific needs and circumstances of each individual, that is, to modify the care to respond to the person, not the person to the care" (Institute of Medicine, 2001). Contemporary nursing practice considers the notion of holism to be important (Earle, 2001; Fulton, 1996; Godfrey, 1999; Kolcaba, 1997; May, 1992; Williams et al., 1998). "Patients are only given their full respect when nursing care has firm foundations in a truly holistic approach incorporating human sexuality as a vital component of humanity" (McCann, 2000: 134).

Together, the value of liberty, residents' rights to use their homes for sexual activity, the importance of sexuality and having sexual lives, and preserving a focus on holistic and client-centered care provide a strong *prima facie* rationale for upholding residents' rights to do. Although rights to do suffice for the able-bodied to have sexual lives, they prove inadequate for many persons with disabilities. Without assistance these people often cannot carry out that which, I will argue, they have a right to do. Under these circumstances rights to receive are required.

### **Prima facie arguments for rights to receive**

Requests for professional sexual assistance range from the professionally unproblematic to the profoundly intimate. GPC residents requested assistance with getting into bed with a sexual partner, turning lights off, replacing blankets after sexual activity, injecting erection-enhancement medications, obtaining and starting pornographic videos, finding a "safe" prostitute, masturbating, maintaining privacy, enabling social interaction that augments sexual opportunities, and procuring sexual "toys". Not asked for by residents in this study but referred to in the literature is the need for assistance with positioning and enabling sexual intercourse (Earle, 2001). In addition to the importance of allowing people to express their sexuality and have sexual lives, a number of arguments support rights to receive help with these things. I shall discuss the primary one.

Assistance rights are supported by most people's desire to create and live in a just society. One of the fundamental principles of such a society is to ensure that the weakest and least powerful members have basic opportunities to achieve self-fulfillment and better themselves (Rawls, 1971). If we do not hone our practices so that our structures

and assumptions avoid banishing persons with disabilities from participation, we fail to meet one of our most basic moral obligations. To avoid this situation and level the playing field, we must recognize the particular characteristics that prevent individuals from participating and provide them with that which they need to do so. Given that disability is the most prevalent characteristic that prevents GPC residents from having sexual lives, the appropriate accommodation is to offer them the assistance that they need to overcome those aspects of their disabilities, which curtail sexual opportunities. This duty to accommodate is supported by GPC's self-imposed mandate, which obligates the institution to reduce the negative impact of residents' disabilities, and aims to help residents improve the quality of their lives (GPC 1994 Mission Statement).

#### **Countervailing arguments for residents' rights to do and rights to receive**

Rights to do and receive produce benefits for both the individuals concerned and society at large. For individuals, the importance of allowing people to do as they choose and improve their overall well-being is recognized. For society, both promoting freedom of expression by allowing sexual expression and justice by treating persons with disabilities equally to others helps achieve our common goals.

Given these benefits, I now consider the question of under what circumstances long-term care institutions can cancel these rights to do and receive. Three potential countervailing considerations challenge these rights: (i) harm to self (and other participants), (ii) harm to others, and (iii) offense. I will now examine each and discuss its impact on rights to do followed by rights to receive.

### **Harm to self (and participating others) re: rights to do**

Harm to self arguments seek to provide a valid rationale for interference in order to prevent physical, psychological or economic harm to the actor himself (Feinberg: 1986, xvii). In order to determine if and when harm to self arguments will successfully override residents' rights to do, guiding principles must be developed. This involves determining the following:

- (i) criteria that indicate the reasonableness or unreasonableness of assuming the risk associated with a self-harming act or activity,
- (ii) standards for differentiating between a person making a capable ("person capable") or incapable ("person incapable") choice, and
- (iii) parameters of justified interference.

In this section I will argue that interference in self-harming activity is only permissible when a person is incapable or has compromised capability, it is unreasonable for the individual to assume the associated risk, and the interference is effective, not generative of other and greater harm than it prevents, the mildest possible, not discriminatory, and thought justifiable, if at all possible, by those upon whom it is imposed.

#### Reasonableness or unreasonableness of assuming the risk associated with a self-harming act or activity

Harm exhibits various intensities. Harm can be mild, moderate, serious or fatal and within each of these categories the risks associated with a particular harm can be reasonable ("reasonable harm") or unreasonable ("unreasonable harm"). Although prudence usually dictates that we choose a less dangerous alternative over a greater one, it is not always reasonable to do so. For example, it may be reasonable for a coronary



patient to engage in sexual activity and risk a cardiac arrest and unreasonable for him to play it safe and forfeit something he values tremendously. Feinberg (1986:102) suggests that the following five factors should be used to determine the reasonableness of assuming risk associated with a self-harming act or activity:

- (i) the degree of probability that harm will result,
- (ii) the seriousness of the harm being risked (i.e., the value or importance of that which is exposed to risk),
- (iii) the degree of probability that one's goal will be reached by taking on the risk,
- (iv) the value, importance and worthwhileness of reaching that goal, and
- (v) the necessity of the risk and availability of less risky alternative courses of action.

In general, it is uncontroversial to say that the greater the (i) degree of probability that harm to self will result, and (ii) seriousness of harm one is exposed to, the less reasonable assuming the risk will be. Also that the greater the (iii) degree of probability that one's goal will be reached by taking on the risk, (iv) value, importance and worthwhileness of reaching that goal, and (v) necessity of the risk and the more less risky alternative courses of actions are not available, the more reasonable it is to assume the risk (Feinberg, 1986:103).

#### Harm, capability and interference

When all are agreed that harm is reasonable, an individual should be free to assume the associated risks in order to achieve her goals. Thus, interference would be inappropriate for both capable and incapable persons. When there is disagreement over whether harm is reasonable, the permissibility of interference in the interest of the

individual depends on whether weak paternalism or strong paternalism is used as the ethical standard.

Weak paternalism says that when individuals are capable they should be free to live at whatever risk to themselves they choose (Beauchamp & Childress, 2001; Buchanan, 1978). "Unencumbered individuals can refuse any treatment, however appropriate, and live with danger, neglect, self-neglect, abuse, and exploitation; all others can ever do is to explain and argue" (Browne et al., 2002:286). Weak paternalism only permits possible interference with rights to do in the individual's interest when a person is incapable.

Weak paternalism significantly differs from strong paternalism, which supports interference with capable people when it can be shown that they would benefit from it (Beauchamp & Childress, 2001). What it means to benefit varies according to two different philosophies of strong paternalism. One group of strong paternalists maintains that interference with a capable person's choice in their own interest is appropriate if and only if others have reason to believe that the individual would be subsequently appreciative of the intervention (Dworkin, 1971). The other group of strong paternalists says that interference with a capable person's actions in their own interest is justified if and only if there is reason to think the individual would be better off (Brock, 1983).

The debate between weak and strong paternalism has never been decisively settled and it is beyond the scope of this thesis to try to resolve it here. However, in recent times mainstream health care ethics and the law have come down on the side of weak paternalism (Browne et al., 2002:286). Due to weak paternalism's prevalence and wide acceptance in today's western health care standards, for the remainder of this work I will

assume that it is the appropriate one to use. Later, I will show that because most sexual activity is associated with reasonable harm, and since strong paternalism allows for such harm, there is little difference between sexual activity that can be interfered with regardless of which standard is used.

With weak paternalism, if a resident wants to do something that others deem an unreasonable risk, legitimate interference depends on whether a person is capable or incapable. Feinberg (1986) analyses capability in terms of the ability of making voluntary choices. For all practical purposes, a choice is voluntary, and thus a person is capable, if and only if a person can: (i) communicate verbally or non-verbally that she has a desire to do or not do something (i.e., indicate and thereby establish her preference to do something more than another thing or something over nothing at all), (ii) understand the information that is relevant for making the decision (i.e., demonstrate the cognitive ability to process, retain, and understand the relevant information), and (iii) appreciate the reasonably foreseeable consequences of a decision or lack thereof (i.e., have the ability to apply relevant information to her circumstances and be able to weigh the foreseeable risks and benefits of a decision or non-decision). When we evaluate a person's ability to make a voluntary choice, we do not have to agree with how the benefits and harms are weighed. Although many people would not choose to have unprotected sex, a person may do so because he values having "natural" sex more than he wants to avoid the potential harms. What is important is that there is an understanding and appreciation of the risks and benefits.

Thus, according to weak paternalism, when a resident is capable (i.e., has the ability to make voluntary choices), interference is not permissible. In the event a person

cannot make such choices interference is permissible, but only subject to qualifications to be added shortly, and only to the extent the elements of voluntariness that are lacking are addressed. For example, if a woman demonstrates a wish to be sexually active but is unable to understand and appreciate some of the aspects of the potential harm to which she may expose herself, interference is permissible but only to the point that the specific harms involved are addressed. Rarely, would stopping her sexual activity altogether be the appropriate interference. Finally, when the person's capability is compromised, i.e., the person is neither clearly capable nor incapable to make voluntary choices, it is reasonable to adopt a proportional rule to determine the appropriateness of interference. Specifically, as the person's capability diminishes, and the unreasonableness of the activity increases, interference becomes more apt (Feinberg, 1986:118-121).

#### Parameters of justified interference

Weak paternalism allows paternalistic interference with the liberty of an individual only if the person is incapable or has compromised capability and it is unreasonable to assume the associated risks. It does not, however, follow that we should interfere as soon as these conditions are satisfied. There are five further conditions that must be met before interference is appropriate (Browne et al., 2002:289). (These conditions would also have to be met before strong paternalism would sanction interference.) I illustrate each condition by using the example of a pre-menopausal woman with mild to moderate mental challenges who is sexually active with several other residents.

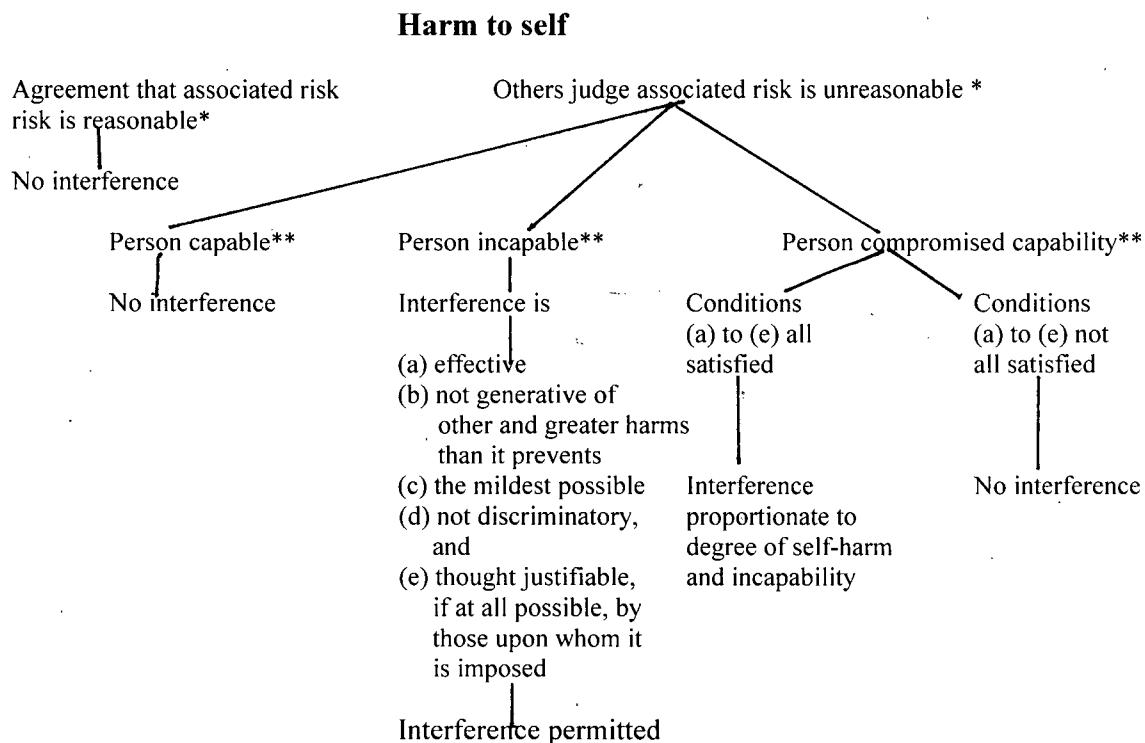
- (a) Interference should be effective. If there is valid reason to stop the resident from engaging in sexual intercourse we should only try to do so if the interference will actually stop or reduce the activity. It is no good preventing

her from carrying out the activity in her bedroom if she can equally easily take to the stairwells, bushes and washrooms to fulfill her desires.

- (b) Interference should not generate other and greater harm than it prevents. Not allowing the woman to engage in any form of sexual activity will certainly reduce some of the associated risks. Doing so, however, may cause her great distress, severe depression, loneliness, unsatisfied libido, discomfort, etc. If these latter harms are greater than the benefits of reducing the risks, interference is not permissible.
- (c) Interference should always be applied minimally and only to the point the associated risks become reasonable. Potential harms such as unwanted pregnancy, acquiring a sexually transmitted disease, and non-consensual "sex" can usually be mitigated in far less drastic ways than stopping the woman from having sexual intercourse. For example, consideration can be given to administering a long-term contraceptive, or in certain circumstances, limiting sexual partners (Kaeser, 1992).
- (d) Interference should not be discriminatory and hold people to a higher standard than similarly situated individuals. If a person with similar disabilities living in the community would not have her sexual activity interfered with, it is discriminatory not to treat long-term care residents in the same way.
- (e) Interference should be thought justifiable, if at all possible, by those upon whom it is imposed. It is a terrible thing to be prevented from doing what you think you are entitled to do, and Mill speaks of this as something that "partakes of the degradation of slavery" (Mill, 1848). One can be so

prevented, but only as a last resort. Despite the woman's cognitive disabilities, the onus remains on those wanting to interfere to explain or demonstrate to her, at a level that she can understand, why interference is necessary. The goal of this explanation should be to procure, if possible, her agreement with the interventions.

With the parameters of justified interference established in Table 6.1, I summarize the circumstances under which self-harm is a valid rationale for interfering with rights to do.

**Table 6.1: Harm to self as valid rationale for interfering with rights to do**

\* Reasonableness depends on the following:

- degree of probability that harm to oneself will result,
- seriousness of the harm being risked (i.e., the value or importance of that which is exposed to the risk),
- degree of probability that one's goal will be reached by taking on the risk,
- value, importance and worthwhileness of reaching that goal, and
- necessity of the risk and availability of less risky alternative courses of action.

\*\* Capable person = a person who has the ability to make voluntary enough choices, i.e., choices where the person can do the following:

- indicate verbally or non-verbally a preference to do something or to do nothing,
- understand the information and has the cognitive ability to process, retain and understand the relevant information, and
- appreciate the reasonably foreseeable consequences of a decision or lack thereof.

Examples of harm to self (and participating others)

Using this theory, I now return to address the question posed at the outset, which was whether interference is permissible when institutionalized residents engage in potentially self-harming sexual activity such as touching, fondling, lying in bed with partners, kissing, masturbating, viewing pornography in magazines or on wall-posters or videos, and having sexual intercourse with spouses, partners, other residents or prostitutes.

For most residents these activities will involve associated risks that are reasonable, because the degree of probability that those residents' goals will be reached, the value, importance and worthwhileness of reaching those goals, and the lack of available less risky alternatives will be greater than the probability and seriousness of harm. When this is so, interference is not permissible. In the event that the associated risks are unreasonable, interference is permissible but varies according to the standard of paternalism used. If weak paternalism is used, only incapable persons can be interfered with. If strong paternalism is used, both the incapable and capable can be interfered with if and only if there is reason to believe that they will subsequently be appreciative or better off for it. As it will be rare that capable persons will find themselves appreciative of or be better off for having their sexual lives interfered with when they do not wish this to occur, it is likely that strong paternalism, like weak paternalism, will result in interference being permissible only when incapable persons engage in sexual activity where associated risks are unreasonable. In either case, the interference must always be effective, not generative of other and greater harm than it prevents, the mildest possible,



not discriminatory, and thought justifiable, if at all possible, by those upon whom it is imposed. As these conditions can seldom be met, prohibiting sexual activity can only be done in the rarest of circumstances.

I now turn to discuss when rights to receive can be canceled by harm to self (and participating others).

### **Harm to self (and participating others) re: rights to receive**

The issues of paternalism related to self-harm differ from the professional autonomy issues that are relevant when residents ask for assistance with sexual activity. As rights to receive involve other people as active participants, due consideration must be given to their objections about what they are being asked to do. In this section, I discuss the circumstances in which care providers can refuse assistance with sexual activity that causes self-harm.

Refusals to assist based on the possibility of self-harm appeal to the principle of non-maleficence, according to which health care providers should do no harm. "Harm" here must be understood to mean harm that is associated with unreasonable risks, for harm that is associated with reasonable risks is by definition harm that can be beneficially risked to achieve some goal. As such, activities that are associated with reasonable risks should be facilitated. By contrast, activities that are associated with unreasonable risks cannot beneficially be risked. Therefore, as long as there is agreement on what are reasonable and unreasonable risks, there is no problem in knowing what activities should and should not be facilitated.

Problems only arise when there is disagreement over the classification of risk. In the case of the incapable person, these disagreements are fairly readily resolved, for there

is no presumption that incapable persons know their own interests best. Thus, while their evaluations of what something is worth are certainly relevant, their families and health care providers essentially make the determination of whether associated risks are reasonable or unreasonable.

Matters stand differently with respect to the capable resident, in which case, there is a presumption that they know their interests best (Feinberg, 1986:59). However, it does not follow that they should always have the final say of what risk is reasonable and unreasonable, for they can be mistaken in their judgments. As argued earlier, thanks to the triumph of weak paternalism, this does not matter as far as the right to do goes. But it does matter when others are asked to help facilitate the actions. Here, although it must be used with caution, the principle of non-maleficence has force.

There are two circumstances in which capable persons can confidently be presumed to be mistaken, and hence have requests for assistance refused. These are as follows:

- (i) When the request for assistance is “predicated on a factual belief that HCPs have firm evidence to suppose is mistaken” (Browne, 2003:85). For example, if a capable resident with quadriplegia does not believe that he is at risk of autonomic dysreflexia<sup>8</sup> if he engages in sexual

---

<sup>8</sup> Autonomic dysreflexia or hyperreflexia means an overactivity of the autonomic nervous system, specifically the sympathetic division. It can occur when an “irritating” stimulus is introduced to the body below the level of the spinal cord injury, such as prolonged genital stimulation. A reflex is activated and mobilizes the sympathetic portion of the autonomic nervous system, which results in a narrowing of the blood vessels and a rise in blood pressure. In normal circumstances the brain sends a message to the spinal cord to activate centers there to be responsible for inhibiting the overreaction. With autonomic dysreflexia, especially those with spinal cord injuries to T5, the impulse gets blocked at the level of the spinal cord injury and cannot reach the brain, so sympathetic stimulation goes unchecked. If not treated promptly the rise in blood pressure may result in seizures, stroke or death. Treatment for autonomic dysreflexia is removing the precipitating stimulus and taking actions to lower the blood pressure. Emergency treatment is required if these actions fail (Elliot & Krassioukov, in press; Sipski & Alexander, 1997a).

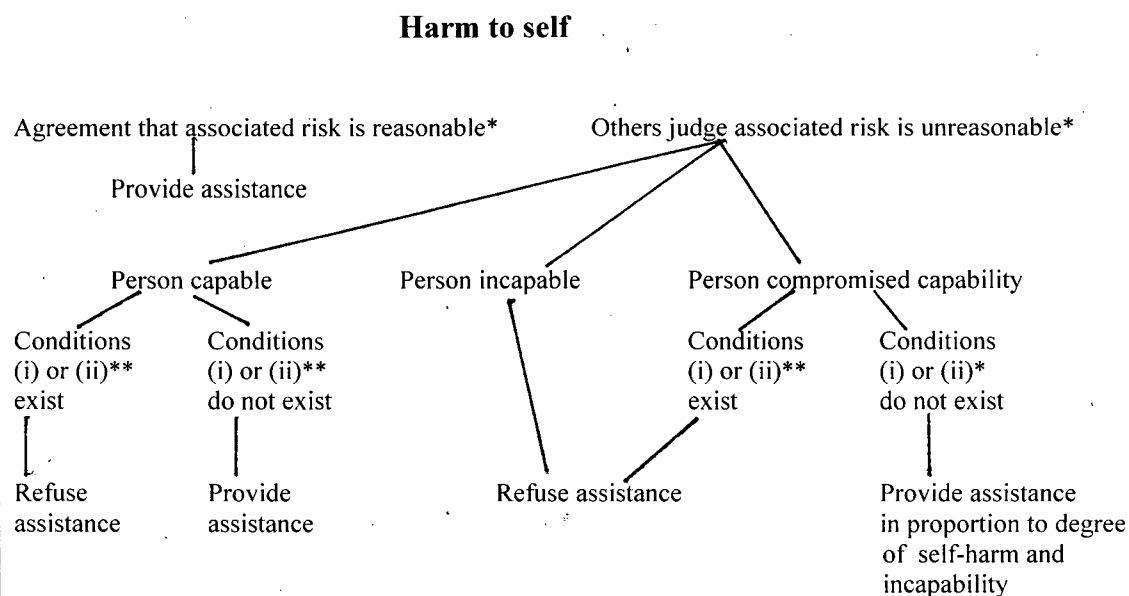
activity, when in fact he is, health care providers do not have to provide assistance. If we know that he would not engage in sexual activity if he thought he had autonomic dysreflexia, but simply does not believe he has it, refusals to help would be appropriate.

- (ii) When assistance will predictably result in harm that is “imminent, serious, and virtually certain” (Browne, 2003:85). Capable individuals often suffer from shortsightedness, infatuations, tunnel vision, etc. that prevent them from making appropriate evaluations of what something is worth. If there is no realistic chance that the benefits are worth the risks, as there would not be if the harm fell under the above description, then requests for assistance can again be refused. For example, assistance is not warranted if it is almost certain that sexual intercourse will result in the resident suffering a cerebral hemorrhage.

When sexual activity is at issue, it will be rare that either of these conditions will be met. Thus, invoking the principle of non-maleficence to cancel capable residents’ rights to receive will not often be permissible.

Table 6.2 provides a visual summary of when requests for assistance can be denied when self-harm is at issue.

---

**Table 6.2 Rights to refuse assistance when harm to self is at issue**

\* Reasonableness depends on the following:

- degree of probability that harm to oneself will result,
- seriousness of the harm being risked (i.e., the value or importance of that which is exposed to the risk),
- degree of probability that one's goals will be reached by taking on the risk,
- value, importance and worthwhileness of reaching that goal, and
- necessity of the risk and availability of less risky alternative courses of action.

\*\* Condition (i) = request for assistance is "predicted on a factual belief that HCP's have firm evidence to suppose is mistaken." (Browne, 2003:85)

Condition (ii) = assistance will predictably result in harm that is "imminent, serious, and virtually certain". (Browne, 2003:85)

I now turn to the second potentially countervailing argument against rights to do, and receive, harm to others.

### **Harm to others**

Study participants claimed that care providers, the institution, and families are potentially harmed by residents' sexual activity.

Care providers claimed that three things potentially harm them:

- (i) professional censure,
- (ii) the personal distress they may experience as a result of residents being injured by sexual activity or care, and
- (iii) the demands of delivering sexual care that result in increased workloads.

It was also claimed that the institution is potentially harmed in the following ways:

- (i) increased costs of having to hire staff to provide sexual care, and
- (ii) exposure to costly litigation and damaged reputation should residents be injured when engaging in sexual activity or receiving sexual care.

Finally, it was claimed that families are put at risk in the following way:

- (i) residents' sexual activity that threatens their potential inheritances or family reputation.

The *Harm Principle* tells us that harm to others can justify interference with the liberty of the individual (Feinberg, 1973: 33). But before this principle becomes useful, we must first understand what is meant by "harm".

### Reasonableness of permitting actions that create harm

Harm to others can be psychological/emotional (e.g., instilling feelings of shame about sexual orientation/performance) or physical (e.g., transmitting a sexually transmitted disease). It can be the result of action (e.g., sexual assault), or inaction (e.g., failure to practice safe sex techniques). It can fall anywhere on a continuum from negligible to fatal. Whatever its kind, Feinberg (1984: 189-191) suggests that the reasonableness of permitting actions that create a given degree of harm depends on the following two factors:

- (i) the magnitude (i.e., gravity) of harm, and
- (ii) the probability of harm.

Magnitude refers to the degree of harm that the negative outcomes produce. Probability is the likelihood of the harm occurring. Feinberg contends that, in general, the greater the gravity of a harm, the less probable its occurrence need be to justify interference. Conversely, the greater the probability of harm, the less grave it need be to justify interference. Thus the important concept for the *Harm Principle* is not the magnitude of harm alone, or the probability of harm alone, but risk, which is the product of the two (Feinberg, 1984:191).

### Justified interference

A significant risk of harm to others, however, does not automatically justify interference. As was the case with self-harm, interference must be effective, not generative of other and greater harm than it prevents, the mildest possible, not discriminatory, and thought justifiable, if at all possible, by those upon whom it is imposed. Condition two (i.e., interference must not be generative of others and greater

harm than it prevents) requires balancing the risk of harm against the social utility of the act or activity (Feinberg, 1984: 191). Social utility refers to the value of the risk creating conduct to the actor, to others directly affected by it, and to society in general (Feinberg, 1984: 192). The greater the social utility of the act or activity in question, the greater must be the risk for its prohibition to be justified (Feinberg, 1984: 191). For example, because there is great social utility in allowing ambulances to drive at high speeds, interference is only warranted if the risk of harm to others is extremely significant (e.g., if an ambulance's proposed route is through a busy pedestrian mall).

Table 6.3 provides a visual representation of when interference with rights to do is permissible when others are potentially harmed.

**Table 6.3 Harm to others as valid rationale for interfering with rights to do & receive**

**Harm to others**

Activity that harms others can be interfered with  
if and only if  
the activity carries a significant risk \* and the actual interference is

- (a) effective,
- (b) not generative of other and greater harm than it prevents,\*\*
- (c) the mildest possible,
- (d) not discriminatory, and
- (e) thought justifiable, if at all possible, by those upon whom it is imposed.

\* Risk depends on the following:

- magnitude (i.e., gravity) of harm, and
- probability of harm.

Condition (\*\*) is satisfied depending on an on balance judgment between the risk of harm and the social utility of the act or activity (i.e., the value of the risk creating conduct to the actor, to others directly affected by it, and to society in general).



### Examples of harm to others

In light of this, I now examine the claims made that care providers, the institution, and families are potentially harmed by residents' sexual activity. I will take them in the order in which they are presented at the beginning of this section, and argue that none is sufficient to cancel the case for allowing or facilitating sexual activity.

### Harm to care providers

Care providers maintain that they are wrongfully harmed when they are threatened with professional censure or when they experience personal distress if their charges are injured while engaged in sexual activity. Care providers also maintain that they are harmed by the increased workloads that occur as a result of their having to provide sexual care.

The first thing to be said in reply is that it is important that the alleged harms are not exaggerated. First, it is not clear that professional censure and liability will not be appreciably increased over that which care providers currently bear whenever they help someone out of bed, or wheel them in a wheelchair. Risks are inherent in health care and long-term living, and eliminating all risk is likely to create more harm than it prevents. Second, although I concede that it is difficult from an administrative point of view to do, it is possible that workloads may be able to be adjusted by reducing some duties and substituting those regarding sexual activity instead without augmenting the total workload. Third, again though not an easy task, it is conceivable that schedules can be manipulated so that those who have conscientious objection to helping can be exempted, while others who regard sexual activity as an important part of life in an institution can

carry them out. If certain team members are willing to provide sexual care while others are not, it is reasonable to reassign duties so that total workloads are not increased but specified team members are granted time to provide such care.

The above considerations can be used to mitigate staff's complaints about harm and perhaps will persuade them to facilitate sexual activity. But in the end, facilitating sexual activity should not expose any care provider to the slightest increase in risk of professional censure, liability, workload, or distress. It is ultimately up to the institution to indemnify and render them harmless in what they do, to provide time in their work schedules to allow them to do it, to hire new staff on the understanding that such duties will be part of the job and, most importantly, to provide ongoing education which supports staff's provision of sexual care.

#### Harm to the institution

The second set of objections raised the question as to why institutions should take on these extra burdens. More specifically, why should they allow costs to increase by altering work schedules and hiring new staff? Also, why should institutions expose themselves to costly litigation?

There are two objections to allowing institutions not to provide sexual care on the basis of increased costs. First, it is simply hard to believe that the limited numbers of residents in any long-term care institution could make so many sexual care demands that it would result in the entity's financial integrity being threatened. It is far more likely that the costs of sexual care will prove relatively insignificant. Also, institutions are unlikely to be successfully sued if they meet their moral and legal responsibilities to prevent foreseeable harm, which (as I have shown) can be easily done with respect to sexual

activity. But, even if we concede that institutions could possibly demonstrate that allowing sexual activity and providing sexual care puts them at significant risk, interference remains problematic because it runs afoul of three of the application conditions. Specifically, it does not meet condition (b) (i.e., not generative of greater harm than it prevents) in that the injustices created by society not allowing its most marginalized citizens to have sexual lives has to be greater than the harm of increased costs to institutions. Also, it does not meet condition (d) (i.e., not discriminatory) in that other institutionalized populations such as prisoners are allowed to have sexual lives when long-term care residents are not. Finally, it does not meet condition (e) (i.e., thought justifiable, if at all possible, by those upon whom it is imposed) in that given there is discrimination, residents are unlikely to think canceling their rights is justifiable.

The second objection to allowing institutions not to provide sexual care on the basis of increased costs and the possibility of litigation is that these factors are highly unlikely to ever outweigh the requirement that long-term care facilities meet their most fundamental obligation, which is to help its citizens live improved lives. Given sexual activity is an important, natural, human function that contributes to people's well being, it should only be denied in the rarest of circumstances. It is only by underestimating the institution's self-imposed mandate to help residents improve their lives, remove the impact of disabilities, to provide a home for the disabled, and to cater to the physical, psychological, and social needs of the people under their care, and regarding sexual activity as an unnecessary (and possibly salacious) frill that the institution can disregard it on the basis of harm to the institution.

### Harm to families

Families claimed that they are harmed by residents' sexual activity which threatens their potential inheritances or reputation. Reduced inheritances can occur in two ways. First, residents' expenditures on sexual activity can leave less money available for distribution to heirs. Second, if residents completely deplete their financial resources by spending on their sexual lives, family members could feel liable for the costs of institutionalization.

If relatives have been promised, or have come to reasonably expect, an inheritance there is a moral obligation for residents to live up to their promises. However, it is not the business of institutions to put restrictions on capable residents who are doing things that they could do if they were not in the institution. Thus, unless the family has evidence of a legal right to an inheritance (e.g., a promissory note), there is little the institution can do to compel capable residents to act morally. A reasonable degree of moral suasion can be applied, but because capable residents are entitled to decide how they should act, the use of more severe pressure tactics is inappropriate and not permissible.

Although it is true that substitute decision-makers will probably have the authority to restrict incapable residents' unreasonable financial expenditures, as they must always act in their clients' best interests, if financing sexual activity is beneficial, funds must be advanced.

Similarly, when families maintain that their reputations are damaged, which can occur when residents have extra- or post-marital sexual relationships, although relatives may suffer greatly, the institution is once again limited in the action it can take. Capable

residents are morally and legally entitled to make decisions for themselves, despite the fact that their choices may be contrary to what they have done in the past or what relatives believe ought to be done. As capable persons in institutions are generally allowed to do what capable persons living outside can do, institutions have no right or responsibility to place restrictions on these people's choices. With respect to incapable residents, as institutions always have a duty to act in the best interests of residents, and if sexual activity is in residents' best interests, restriction of their sexual lives is not permissible. However, it may not always be in incapable residents' best interest to permit them to have extra-marital relationships. This is especially true when family relationships are at stake as it is very difficult to go against the wishes of family. For example, if a demented resident is engaging in sexual contact with other residents and her spouse objects, the resident's interests may be best served by the institution finding ways for her to have more time with her spouse rather than allowing the extra-marital relationship.

As good family relationships contribute to improving many residents' quality of life, it is incumbent on institutions to attempt to help residents and relatives come to agreements or mutual understandings about residents' sexual lives. This is more likely to be achieved if families have an understanding of the rights of residents and obligations of institutions and know that, outside of the responsibility to prevent foreseeable harm, facilities have no legal authority to enforce settlements between the parties. It is only by underestimating and not appreciating the value of sexual activity that the harms alleged by families can be seen to be greater than the harm of not allowing residents to have sexual lives. As sexual health providers can attest, with education and open

discussion, many families will come to accept that their loved ones ought to be able to choose to have sexual lives in ways that are important to them.

I now consider the third and final potential countervailing argument against rights to do and receive, which is offense to others.

### **Offense to others**

Study participants advanced three offense arguments:

- (i) nurses and resident care aides claimed that pornography on residents' bedroom walls should not be allowed because they are entitled to a workplace free of "sexual harassment",
- (ii) these same staff maintained that they are offended when they are forced to tolerate or assist with sexual activity that is an affront to their personal and religious values (e.g., assisting with sexual activity between same sex couples), and
- (iii) other residents complained that they are offended when they are unwillingly forced into voyeurism by having to watch roommates' sexual activity.

The debate between whether or not offense is a morally relevant reason in support of canceling rights to do has not been decisively settled. Mill (1859/1965: Ch. 1, para. 9) argued that "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."

Although Mill contended that harm to others is the only valid liberty-limiting principle, according to Feinberg (1985: ix) offense has "won widespread support" as a "coercion-legitimizing principle". In view of the fact that detractors of Mill's thinking exist, I will accept that offense to others is a legitimate liberty-limiting rationale. I do this partly

because it is more plausible (without such a principle public nudity could not be prohibited), and partly because the ubiquitous offense arguments advanced in sexual activity debates can be met even on that assumption.

The *Offense Principle* tells us that serious offense can justify interference with the liberty of the individual. And, just as I had to explicate the key term in the *Harm Principle* before it could be applied, so we have to explicate the key term “serious offense” in this principle.

#### Seriousness of offense

Feinberg (1985:2) defines offense as conduct which affects people’s mind states and results in irritating sensations, disgust, revulsion, shocked moral sensibilities, and shameful embarrassment. Feinberg (1985: 34-35) goes on to state that the seriousness of the offense is determined by the following criteria:

- (i) the magnitude (i.e., intensity, duration and extent) of the offense,
- (ii) the reasonableness of avoiding the offense,
- (iii) the degree to which the person offended voluntarily agreed to be so,  
and
- (iv) the degree to which the person offended is abnormally susceptible to  
the offense.

The magnitude of offense refers to a combination of three things. First, the intensity or strength of the offense. Second, the duration or time over which the offended feelings are experienced. Third, the extent or how widespread the offense is. In general, the greater the intensity, duration and extent of the offense the more serious it will be.

The reasonableness of avoiding the offensive conduct refers to the degree to which the offended party can avoid exposure to the conduct without being unduly inconvenienced. The more difficult it is to reasonably avoid a given offense, the more serious it is. If people who are highly offended by pornographic pictures choose to enter a store and leaf through or pore over the pictures in an adult oriented magazine, they cannot claim the negative mind states they experience reach a level of seriousness that entitles them to cancel the storeowner's rights to sell the materials. The storeowner may rightly argue that she sells the material to consenting adults and that the offended parties could have reasonably avoided their sickened mind states by choosing not to peruse the materials. If, however, these people walked into a neighborhood drugstore and were unwillingly forced to see the magazine pictures openly displayed at the cash register, seriousness remains intact because it is impossible for these customers to make a purchase without being exposed to the offensive materials.

The degree to which the person offended voluntarily agreed to be refers to the actions of the offended party that contribute to or allow the offense to occur. Offense is less serious the more the offended party voluntarily agreed to the noisome conduct or its consequences. If a person voluntarily attends, pays for, and watches a pornographic movie in a theatre that advertises or regularly shows these types of films, the consumer cannot later maintain that she was wrongfully or seriously offended by what she saw. The patron may indeed suffer serious offense but because she willingly brought the negative mind states upon herself, the offense is not serious in the sense that consideration can be given to canceling rights to do or receive. Similarly, when a woman applies for employment as a nude dancer in a striptease club and is later offended by patrons' leering



or sexual remarks, she cannot claim that her offended mind state is so serious that consideration should be given to canceling the club owner's rights to operate the business. In applying and accepting employment, the woman voluntarily agreed to work in this environment and thereby waived her rights to take offense at the typical and normally acceptable behaviour of nightclub clientele. Her only recourse is to abandon employment, as she cannot dictate that the club be closed or demand customers change what they do.

The degree to which an offended party is not subject to "abnormal susceptibilities" (Feinberg, 1985:35) refers to the standard that should be used to evaluate the impact of the offensive conduct on offended parties. Feinberg (1985: 24) offers the following description of what is meant by this term.

It seems clear, however, that the more fragile our sensitive sufferer's psyche, the less protection he can expect from the criminal law. Provided that the conduct the very thought of which upsets him has any redeeming value at all, personal or social, his own claim to protection is likely to be overridden. If a mere sneeze causes a glass window to break, we should blame the weakness or brittleness of the glass and not the sneeze. Similarly, if "bare knowledge" that discreet and harmless "immoralities" are occurring in private leads to severe mental distress, we should attribute the distress to abnormal susceptibilities rather than to the precipitating cause. We don't punish persons when their normally harmless and independently valuable (at least to themselves) activities happen to startle a skittish horse whose presence was unsuspected. Rather we expect the owners of skittish horses to keep them away from "startling" activities and to take steps to cure them of their skittishness.

The point Feinberg makes is that when people have fragile psyches, the weakness exists in them and not in the actor's actions. Therefore, these people's offended feelings should not be used as the standard for evaluating whether rights can be canceled. One way to determine whether a person has an abnormal susceptibility to being offended is to

compare the sensitivity of that person to that of a reasonable person<sup>9</sup> in the same circumstances. If a reasonable person in the same circumstances finds the act offensive, seriousness remains static. However, if a reasonable person in the same circumstances does not find the act offensive, seriousness diminishes.

In summary, in general, an offense is more serious the greater its intensity, severity, and duration. Conversely, the more the offended party could have reasonably avoided the offense, agreed to be exposed to it, or has an abnormal susceptibility to being offended the less serious the offense.

### Justified interference

Even when an offense is serious, as was the case with self-harm and harm to others, interference is not justified unless it is effective, not generative of other and greater harm than it prevents, the mildest possible, not discriminatory, and thought justifiable, if at all possible, by those upon whom it is imposed.

Condition two (i.e., interference must not be generative of others and greater harm than it prevents) requires balancing the seriousness of the offense against the reasonableness of the offender's conduct. Feinberg (1985: 44-45) suggests that the following standards determine the reasonableness of conduct that may cause offense:

- (i) personal importance to the actor as measured by the person's own preferences,
- (ii) social value,
- (iii) the availability of reasonable alternatives,
- (iv) motivation of malice and spite, and
- (v) the locale where the activity is conducted.

---

<sup>9</sup> By a "reasonable person" is meant "the average person", the "person on the street". The reasonable person is, thus, not a Sunday school teacher or devotee of strip bars, but a fictional person who embodies those and only those attitudes that we would expect to be most widely shared in society (Devlin, 1965).

The importance of offensive conduct refers to the value the actor holds for it. This value is measured according to the actor's needs, goals, and individual preferences. As this is a subjective evaluation, the reasons for a particular conduct being important will likely vary greatly from person to person. One person may engage in prostitution in order to protect livelihood and provide for children, while another may wear garish or revealing clothing in order to increase self-esteem and overall happiness. In general, the greater the value to the actor the greater the reasonableness of the conduct that causes the offense.

Social utility refers to the benefit to society. "The greater the social utility of the kind of conduct of which the actor's is an instance, the more reasonable is the actor's conduct" (Feinberg, 1985: 44). For example, given that freedom of expression has such a high priority in our society, even lewd and obnoxious sexual public conversations may be deemed reasonable.

The availability of reasonable alternatives refers to other and less offensive conduct that an actor can partake in and still meet her goals. The less such alternative courses of action are available the more the offense is reasonable. If the only way a person with severe disabilities can watch pornographic videos is to have another person put it in the playing mechanism, the reasonableness of asking for this assistance is significant and likely to override any offense taken.

Malice and spite refer to the actor's motive for engaging in the offensive conduct. The more the motivation is based on malice and spite the more unreasonable the offense. Offensive conduct becomes totally unreasonable if it is done for no other purpose whatever except to cause offense (Feinberg, 1985: 44).

The locale refers to the suitability of the environment in which the offensive conduct takes place. Offensive conduct is more reasonable the more it takes place in settings where it regularly occurs and is expected to occur. Although it may be unreasonable to allow sex shops, prostitutes, and nude dancing clubs in a residential neighbourhood, it may be perfectly reasonable to allow them into warehouse districts known for providing adult entertainment.

In summary, in general, the more reasonable the offender's conduct and the less serious an offense is, the less interference is permissible. Conversely, interference is more permissible the less the offender's conduct is reasonable and the more offense is serious. Table 6.4 provides a visual representation of when offense can be used as valid rationale for interference with residents' rights.

**Table 6.4: Offense as valid rationale for interference with rights to do and receive****Offense**

Activity that offends others can be interfered with  
if and only if  
the offense is serious\* and actual interference is

- (a) effective,
- (b) not generative of other and greater harm than it prevents,\*\*
- (c) the mildest possible,
- (d) not discriminatory, and
- (e) thought justifiable, if at all possible, by those upon whom it is imposed.

\* Seriousness of offense depends on the following:

- the magnitude of the offense (i.e., intensity, duration and extent)
- degree to which the person could reasonably avoid the situation
- degree to which the person offended agrees to the offense
- degree to which the person offended possesses abnormal susceptibilities

Condition (\*\*) requires balancing the seriousness of the offense against the reasonableness of the conduct that causes the offense. Reasonableness of conduct is determined by the following:

- the personal importance to the actor,
- its social value,
- the availability of reasonable alternative(s),
- the degree it is motivated by malice and spite, and
- whether or not it is conducted in a locale where it is common, and widely known to be common.

### Examples of offense

I now return to the examples set out in the beginning of this section to determine whether the offense experienced by nurses, resident care aides, and other residents is valid rationale for interfering with residents' rights.

All complaints about offense should first be scrutinized for seriousness by the criteria articulated above. In health care institutions (like anywhere else) there are always people who are looking for opportunities to be offended, and there is reason to think that some will be overly sensitive and quick to take offense. So, we can reasonably think that the total number of complaints based on offense will be greater than the number of complaints based on serious offense. Even when the frivolous complaints are subtracted, the above criteria for applying the *Offense Principle* will whittle away at the number of those that call for restrictions or prohibitions.

When nurses and resident care aides experience serious offense at having to work in bedrooms with pornographic pictures on the walls, or being aware of or assisting with sexual activity that offends their personal or religious values (e.g., same sex liaisons), residents' rights are not cancelable because it is likely that the reasonableness of their conduct will outweigh the seriousness of staff's offense. Three reasons contribute to this being the case. First, there is significant social value in retaining the sanctity of people's homes and bedrooms as places of privacy and personal expression. Homes and bedrooms are accepted common locales for sexual activity. Residents, like others, should be able to use the private parts of their homes, and specifically their bedrooms, as places for sexual expression. Second, because residents have little or no choice about where they live when

they are placed in an institution, there are no other reasonable alternative places for them to have sexual lives. Third, justice is not upheld when offended staff are granted the authority to cancel residents' rights, but residents are not given equal power to forbid staff from engaging in conduct that is offensive to them. If staff can dictate that residents should not have pornography in their bedrooms, there is no clear rational reason why residents should not be able to tell staff not to wear certain clothing when in their rooms (e.g., forbid religious paraphernalia such as nun's habits, crosses on necklaces, kippit or turbans). Thus, to avoid this untenable position from either perspective, tolerance would be mutually beneficial.

With respect to roommates' offense at being forced into voyeurism, it is reasonable for the institution not to permit residents to engage in sexual activity when non-consenting roommates are present. This is so because roommates cannot reasonably avoid the offensive conduct. However, it may be possible for the institution to provide reasonable alternatives for residents who cannot use their bedrooms for sexual activity. For example, private, accessible and adequately equipped rooms could be made available. And if so, prohibiting sexual activity would not be justified; regulation will be sufficient to remove the problem.

By the above expedients, it should be possible to sufficiently overcome offense-objections so as to allow residents to have reasonable sexual lives. But in the end, as in the case of harm to others, the responsibility lies on the institution to ensure that qualified staff are available and willing to provide sexual care. One obvious solution is for institutions to hire in a way that employees know what is expected of them. Potential employees then have a duty to decline employment offers that involve responsibilities

that are offensive to them, and once hired, they are in no position to complain. A second solution is for the institution to help staff find ways to deal with their uncomfortable feelings. This may be achieved through supportive education, providing staff with a forum and process for dialogue, and, in certain circumstances allowing individual staff to opt out of providing sexual care that offends them.

Before ending this Chapter, I offer the following clinical example to illustrate how the theory of liberty proposed in this chapter illuminates what ought to be done.

### **Clinical example**

Twice a month, a seventy-five year-old male resident living in a long-term care facility hires a sixty year-old escort to dine with him at a restaurant and then return to his private room to have sex. Each visit the resident pays the escort two hundred dollars (the going rate) plus the cost of their dinner. The resident states he can well afford the cost for two evenings a month and that his sons' are angry about the expenses because "they are greedy and want a bigger inheritance". On one occasion the resident loaned the escort seven hundred dollars for her car repairs but says he made a mistake that will not be repeated. The resident says that he enjoys the escort's company, that sex is a natural function, and that they are "fond of each other". The resident believes his sexual activity is not disrespectful to his wife who died fifteen years ago, because "she would never want me to remain isolated for the rest of my life". Due to severe arthritis, the resident is unable to inject erection-enhancement prostaglandins into his penis, so regularly asks staff to do this for him.

The resident has multiple sclerosis involving some recent brain lesions. When assessed for evidence of capability by psychiatry he shows ability to reason out and



evaluate his sexual choices, but has some difficulty with abstraction, which is highlighted by his inability to draw the hands on a clock face indicating the time of ten past two.

The resident's adult children say that they believe the money being spent on the escort is excessive, may harm their father's long-term financial well-being, and is detrimental to their "rightful" inheritance. The family members have evidence that the escort fills in dollar amounts on the resident's cheques and that their father then signs them. They say their father is not meeting the escort two times a month as he claims, but at least twice a week. They also feel that their father's sexual "antics" are disrespectful to their deceased mother and to his own past morals and religion.

Staff worry that the escort may be a manipulative woman who is not intimately "fond" of the resident but "fond" of the money he spends on her. Nurses also maintain that because they believe the resident's relationship with the escort is abusive, they should not have to contribute to this harmful activity by injecting prostaglandins. Staff also claim that they are harmed by potentially subjecting themselves to professional discipline if the resident were to be harmed as a result of their assistance with injections. Finally, some staff claim that they should not have to assist with injections because it offends their religious values, which specify that sexual activity should only occur for procreation.

#### Harm to self

The residents' children maintain that their father's expenditures on the escort cause him harm because he is jeopardizing his financial well-being. According to the self-harm theory the first step is to determine if the risk associated with the resident's spending is reasonable or unreasonable. It is obvious from the resident's remarks that he

has a great value for his sexual life with the escort. To determine if his expenditures are a serious and probable risk to himself, staff or a consultant should establish whether the children's financial calculations reveal real financial peril or whether their worry is to protect their inheritance or family reputation. If it can be shown that the financial position of the father is in jeopardy because of his hiring the escort (i.e., his financial resources will prematurely expire given his current net worth), the next step is to determine the resident's capability status. A capability assessment looks at whether the resident's reasoning processes are sound.

Evidence that the resident is able to use a reasoned process to come to his conclusions derives from how he weighs up risks and benefits in the current situation. When the resident says he would not have sex with the escort unless he was fond of her shows that he is evaluating his sexual behaviours in relation to a value that is important to him. He is also evaluating what he is doing in regard to social standards, namely that sex is accepted as a normal human function. His reasoning with respect to his wife demonstrates how he interprets her values, even though it does not agree with his sons. However, with respect to the total money the resident spends on the escort, his calculation of long-term financial wherewithal appears unreasonable, subject to confirmation that he does not fully understand the implications of his running out of money. There is also evidence that the resident's memory is failing and that he has possible cognitive impairments regarding time concepts. In addition, it is worrisome that the resident gave the escort money for her vehicle repairs, a transaction outside of her professional relationship with him, because as far as we know, she is only interested in financial compensation. Although the resident is able to review his decisions and

behaviours and state that he is going to correct his actions, the fact that the prostitute fills in his cheques is not something a reasonable person would do in these circumstances. To completely determine capability in this area of the resident's life it needs to be explored with him why he does this.

If the resident is found capable he cannot be restricted in his own interest. He is entitled to give his money to the escort, for whatever reason, even if he ends up penniless and on the street. On the other hand, if there is evidence sufficient to show incapability in the area of understanding and managing his finances, although weak and strong paternalists may counsel different things, according to either standard spending restrictions can properly be put in place in the resident's interest. In this scenario, it is important to note that if the resident can find sexual opportunities that do not cost him money, restricting his sexual activity is not warranted because, thus far, he is not incapable of making sexual decisions. It is likely, however, that the resident will be found to have compromised capability in the area of financial decision-making. According to the theory this means that, provided the conditions for interference are met, restricting his financial expenditures on sexual activity is permissible so long as it is done in proportion to the degree of self-harm and incapability. One possible way to meet this criterion is to restrict the resident's sexual expenditures to a reasonable amount per week.

#### Assistance with self-harm

Staff argue that they should not have to assist with injecting prostaglandins because it encourages the resident to engage in what they believe to be an emotionally abusive relationship. This, they maintain, flies in the face of the principle of non-maleficence. To establish their case, care providers must first demonstrate that the

associated risks are unreasonable. This will prove difficult to do if the capability assessment shows no evidence that the resident cannot evaluate what constitutes for him excessive emotional harm. As long as this is so, the resident remains the final arbitrator for assessing risk in this area.

#### Harm to others

The family believes that they are harmed by their father's sexual activity because the money spent should be part of their rightful inheritance. If their father is found capable of handling his finances, the family has no enforceable claim on his money. Presuming that the father is found incapable of handling his finances, the family must demonstrate that there is a significant risk (i.e., the gravity and probability of harm) that his assets will be unreasonably depleted by his expenditures. Even if the family can do this, interference must be applied minimally, which means it is likely that some reasonable amount of money should be made available to the resident for his sexual liaisons.

Staff's claim that they are harmed by their possible exposure to professional discipline is also be difficult to prove. This is because if they act in accordance with their professional standards and reasonably reduce foreseeable harm they are unlikely to risk professional censure. In addition, appropriately reducing foreseeable harm can almost certainly be achieved by minimal interventions. For example, if staff believe that the resident is at risk of contracting a sexually transmitted disease, as there is nothing in the capability assessment that indicates the resident is not capable assessing these risks and appreciating the merits of using safe sex techniques, staff can simply inform him of the risks and encourage him to use these appropriate measures.

### Offense to others

The offense suffered by the family results from their negative feelings that the activity is an insult to their deceased mother. Although it is likely that the family can establish serious offense, it will be difficult for them to demonstrate that the seriousness of their negative mind states is greater than the reasonableness of the resident's actions. The resident, like anyone else, is entitled to try to improve the quality of his life in ways that are important to him in the context of present circumstances. It is problematic to argue that the resident's desire to have a sexual life and decrease his loneliness is unreasonable. This is especially true in light of the fact he lives alone in an institution and his wife has been dead for over a decade.

When staff claim that they should not have to provide assistance because they are offended that the resident's sexual activity is not for procreative purposes they must demonstrate that the reasonableness of the resident's sexual activity is less than the seriousness of their offense. Although the seriousness of the offense may be extensive for some staff it is likely that this seriousness will be significantly decreased by their abnormal susceptibility to being offended in these circumstances. The religious convictions of staff do not have a similar negative impact on the reasonableness of the actor's actions. In our pluralistic society tolerance of different perspectives and ways of life must be respected. Given there is little else in the facts of the case that indicate the resident is not acting reasonably, the institution remains responsible for ensuring that care providers help the resident with that which he has a right to do. The institution can allow offended staff to opt out of assisting but it still must ensure that other providers are available to deliver the care.

## **Conclusion**

When sexual activity is at issue, institutions will find it difficult to use harm to self (and participating others), harm to others, and offense to others as valid rationale for canceling rights to do or receive. In many cases the harm or offense will not reach a level that warrants interference. However, even if it does, interference can only be applied in limited ways. Thus, I conclude that, in most circumstances, when sexual activity is at issue institutions will be required to honour residents' rights to do and receive and find other ways of managing care providers who disagree with the institution's mandate and ethical obligations.

In Chapter 7, I discuss the legal implications of permitting sexual activity and providing sexual care in institutions.

## CHAPTER 7:

### Legal Issues

It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization

--- LaForest, J. *Eldridge v. British Columbia (Attorney General)*,  
[1997] 3 S.C.R. 624 para. 56

#### Introduction

The topic of legal liability as a result of long-term care institutions permitting or assisting with sexual activity covers a range of issues from residents' and caregivers' rights, duties of institutions and health care providers, and substitute sexual decision-making. Civil, criminal and administrative law affect these concerns. The primary tension involved in sexual activity and care in institutions is the balancing of residents' rights to have sexual lives with the responsibilities of institutions to prevent foreseeable harm. Other notable legal issues involve privacy, prostitution and bawdy-house legislation, professional standards and regulations, rights of health care providers, and substitute decision-making laws. The legal issues discussed in this chapter emanate from information accessed in my expert and staff interviews. As there may be other legal issues that were not identified from the information obtained, I acknowledge that this is an important area for future research. In the first section of this chapter, the rights of residents to have sexual lives are discussed. Common law and relevant Canadian and British Columbia legislation are considered. In the second section of the chapter, the legal duties of institutions and health care providers are examined. In the final section of the chapter, I conclude that although these common legal concerns allow some limitations to

be placed on sexual activity and sexual care, they do not prevent it from occurring altogether.

### **Legal concerns**

Seven legal issues emerged from information obtained from my data:

1. What legal rights do people living in institutions have to engage in sexual activity?
2. What are the legal responsibilities of institutions with respect to residents' sexual activity?
3. If staff provide sexual care, on what grounds can they be found negligent? Can waivers of liability remove the risk of negligence claims?
4. If residents are permitted to entertain prostitutes, is there a risk of a keeping a common bawdy-house charge being laid against the institution?
5. What professional standards must care providers uphold when it comes to sexual activity and care?
6. What rights do staff have to work in a sexual harassment-free environment?
7. Who, if anyone, has a legal right to make substitute sexual decisions for incapable residents?

### **Legal rights of institutionalized residents to engage in sexual activity**

In this section, I argue that although there is no specific Canadian legal right that explicitly upholds sexual activity ("sexual activity rights"), such rights are supported by existing "sexual rights" (i.e., the right to marry, the right to physical integrity, and the right to freedom of sexual expression), statutory and common laws that recognize a right of institutionalized persons to engage in sexual activity in a private and dignified setting,



and current trends in the management of sexual activity in institutions (e.g., prisons, psychiatric in-patient hospitals, geriatric facilities) that acknowledge the value of allowing institutionalized persons to have sexual lives.

The sexual activity rights that I aim to establish pertain to both capable and incapable persons. Restrictions on these legal rights, which seek to protect those in need, are discussed in section two of this chapter.

### Sexual rights

McSherry and Somerville (1998:102) maintain that three sexual rights support sexual activity rights for persons living in long-term care. They are the right to marry, the right to physical integrity (i.e., rights related to procreative choice), and the right to freedom of sexual expression (e.g., consensual sexual intercourse is a personal and private activity).

### The right to marry

All provinces across Canada, through *Marriage Acts*, recognize the rights of adults to marry. For example, in Ontario the *Marriage Act* (1990) s. 5(1) states the following:

Any person who is the age of majority may obtain a license or be married under the authority of the publications of banns, provided no lawful cause exists to hinder the solemnization.

In British Columbia, a licenser, issuer, or clergy who solemnizes a marriage is penalized if a mentally disordered or impaired person is allowed to be part of the proceedings. Section 35 of the *Marriage Act* (1996) articulates this restriction.

An issuer of marriage licences who issues a licence for a marriage, and a religious representative or marriage commissioner who solemnizes a marriage, knowing or having reason to believe that either of the parties to the intended

marriage or to the marriage is a mentally disordered person or is impaired by drugs or alcohol, commits an offence and is liable on conviction to a penalty of not more than \$500.

Although the *Marriage Act* does not specifically state this, it is implied under common law that if a mentally disabled person has capacity the individual has a right to marry. Park v. Park (1953), established that because a mental illness or intellectual disability does not necessary imply a lack of understanding, it is not full capacity that is the fundamental issue, but rather whether or not an individual can demonstrate understanding of the marriage contract. Therefore, institutionalized persons who have a mental illness or intellectual disability are entitled to marry provided that they can meet this criterion.

#### The right to physical integrity

Physical integrity rights or the rights to make procreative choices have been most significantly discussed by the Supreme Court of Canada in E. (Mrs.) v. Eve (1986) ("*Re Eve*"). In *Re Eve* at page 418 the Court discounted that eugenics (i.e., a theory "founded upon the rearticulation of the Mendelian theories of inheritance, developed from the premise that physical, mental and even moral deficiencies have a genetic basis" provides justification for compulsory sterilizations). The case dispelled the notion that "feeble-mindedness contaminates" normal people, and that lack of intelligence and hygiene (e.g., inability of women with intellectual disabilities to cope with menstruation, pregnancy or childbirth) proves people's inability to cope with parenthood (McSherry and Somerville, 1998:112-113). The result of *Re Eve* is that all rationalizations and decisions for involuntary or non-therapeutic sterilizations of anyone who does not have capacity to consent to the procedure are highly questionable and unlikely to be allowed. The case

establishes that in Canada there is a right not to have one's procreative capacity interfered with unless there is informed consent. This contrasts to the American approach which recognizes a positive right to procreate (McSherry and Somerville, 1998:105).

#### The right to freedom of sexual expression

Although there is no explicit right to freedom of sexual expression in Canada, the courts have upheld a reasonable expectation of privacy, R. v. Morgentaler (1988), R. v. Beare (1988), R.B. v. Children's Aid Society of Metropolitan Toronto (1995). According to McSherry and Somerville (1998:108) a legal right to sexual privacy in Canada might be derived from "the right to physical integrity identified in *Re Eve*. That is, if a right to physical integrity implies freedom from state interference with the privilege of giving life, it may also extend to freedom from state interference in relation to private sexual activity. Rights of and such interference could, in practice, translate into a right to sexual privacy". In addition, the authors make the following observation:

It is probably fair to say that many, if not most people in democratic societies would now agree that because consensual sexual intercourse is a personal and private activity, if it does not exist; a right to freedom of sexual expression should exist.

#### The right to sexual intimacy in a private and dignified setting

Welch & Clements (1996) argue that sexual activity rights for institutionalized persons, including those who are involuntarily placed and/or incapable, emanate from both the *Canadian Charter of Rights and Freedoms* (1982) ("*Charter*"), and common law. Specifically, they state that long-term care residents have a right to a private and dignified setting for sexual activity and that a failure to provide it "...amounts to denial of access to the right to sexual intimacy" (Welch & Clements, 1996: 276).

The authors first argue that although the *Charter* technically applies only to government institutions, the spirit of s. 7 (“Everyone has the right to life, liberty and security of the person and the right not be deprived thereof except in accordance with the principles of fundamental justice” and s. 15 (“Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, nationality or ethnic origin, colour, religion, sex, age or mental or physical disability”), is relevant to persons living in long-term care facilities, especially when hospitals are provincial resources (Welch & Clements, 1996: 276). Thus, because others can have sexual lives, it is discriminatory not to provide persons in long-term care with a private and dignified setting for sexual activity. It is notable that in the year following the publication of Welch & Clements’ article, the Supreme Court of Canada in Eldridge v. British Columbia (Attorney General) (1997) held that the *Charter* applies to private entities if they are implementing a specific governmental policy or program. Thus, it could be argued that as many long-term care facilities carry out government funded programs to provide homes for persons in need of specialized care, they are required to adhere to the *Charter*.

The authors’ common law argument emanates from the tenet that what the law does not specifically prohibit can be presumed to be permissible. For example, although the *Mental Health Act* (1996) constrains certain rights of involuntary patients, because it does not specifically remove the right to sexual activity, it is implied that involuntary patients can engage in sexual activity unless other laws interfere with this right (Welch and Clements, 1996:276).

#### Trends supporting sexual activity rights

Despite the lack of a definitive legal right that allows persons in institutions to engage in sexual activity, sexual rights are supported by a clear and growing trend in institutions to recognize the value of allowing residents to have sexual lives. Over the past thirty-five years in Canada, a remarkable change in attitude to sexual activity in institutions has occurred. Up until the 1970's, "masturbatory practices and sexual relations between inmates were forbidden, and in mental institutions repressed, because of fears that procreation would lead to social degeneracy and to beliefs that sexual behaviours were considered by many as a symptom and cause of mental illness" (Bourgeois, 1975: 555). Today, institutions commonly tolerate residents' masturbation provided that it is carried out in private. The trend to embrace sexual rights in institutions is also seen in the increased numbers of facilities that are developing sexual activity guidelines and policies (e.g. Riverview Hospital, 1993a, 1993 b, 1994, 1996, 1999; Shalom Village, 1997; etc.). Increasingly, the literature and various organizations, including government departments, have acknowledged that the sexual rights of persons with disabilities ought to be respected (Ames, 1991; Brown, 1994; Brown et al., 1994; Brown & Mirenda, 1997; Els, 2001; Kirkendall, 1976; Kroll & Klein, 1992; Lewis, 1993; Molloy et al., 1999; Perlin, 1993). Others have offered insight into health care providers' attitudes to sexual activity and some have suggested programs or models which support the provision of sexual care (Breen & Rines, 1996; Chubon, 1981; Cooper & Guillebaud, 1999; Dauw, 1988; Ekland & McBride, 1997; Evans, 1999; Giami, 1987; Gibson, Bol, Woodbury, Beaton & Janke, 1999; Hingsburger, 1993; Tepper, 1992, Turnstull & Henry, 1996; Wallace, 1992; White, 2000). In addition, sexual rights are increasingly acknowledged in the literature, which is becoming replete with studies that focus on

managing sexual activity in psychiatric hospitals and long-term care institutions (Bhui & Puffett, 1994; Brady & Carmen, 1990; Chase, 1988; Civic, Walsh & McBride, 1990; Cosgray, Hanna, Fawley & Money, 1991; Cournous, Empfield, Horwath & Kramer, 1989; Davidhizar, Boonstra, Lutz & Poston, 1991; Holbrook, 1989; Jacobs & Bobek, 1991; Keitner & Grof, 1981; McSherry & Somerville, 1996, 1998; Meyer, Cournos, Empfield, Agosin & Floyd, 1992; Seeman, Lang & Rector, 1990; Welch & Clements, 1996; Welch, Clements & Moreau, 1999; Welch, Magher, Soos & Bhopah, 1991).

Finally, the Correctional Service of Canada's adoption of an operating policy that allows conjugal visits on prison premises firmly abets sexual activity rights. The standard operating policy (SOPS 700-12: 2002-06-03) "provides eligible offenders and visitors with extended private visits within the institution to enable them to foster personal relationships in home-like surroundings" (para.1) for up to seventy-two hours per offender, once every two months, subject to the discretion of the institutional head (para. 6). The program is not only for conjugal visits but seeks "to enhance the offender's capacity to pursue his/her Correctional Plan..., to encourage offenders to develop and maintain family and community ties in preparation for their return to the community, and to lessen the negative impact of incarceration on family relationships" (paras. 1,2).

According to one of my expert interviewees (i.e. the Assistant Deputy Warden), "the majority of inmates are serving between two and ten years. Even the life sentenced are eligible for parole at some point, even it is ten to twenty-five years down the road. The Corrections Canada's policy has recently significantly changed. We used to only support existing or spousal relationships in private family visits. Now, the policy permits inmates

to have private family visits with people they have met while incarcerated, provided the relationship is assessed to be beneficial to the offender”.

Although these recent developments in correctional facilities illustrate a trend to accepting sexual activity in institutions, they do not address the concerns of most long-term care facilities regarding incapable residents engaging in sexual activity.

Management policy issues, therefore, remain unsettled by how sexual rights can be balanced with institutions’ legal responsibilities. I address these concerns and associated legal duties in the next section.

### **Legal duties of institutions**

While institutions have a legal responsibility to prevent foreseeable harm, ensure consensual sexual activity takes place in private, uphold prostitution and bawdy-house laws, ensure that health care professionals act in accordance with their professional standards, uphold the rights of health care providers, and adhere to substitute decision-making laws, it is important to understand that there is no legal responsibility to prevent consensual sexual activity or “sexual activity in general, unless to allow this would constitute a breach of the duty to provide reasonable care to the persons in the institution” (McSherry and Somerville, 1998:102).<sup>10</sup>

---

<sup>10</sup> My understanding of the legal duties and rights is enhanced by the writings of: Devlin, 1965; Fiesta, 1997; Lowman, 1990; Roberson, 1994; Picard & Robertson, 1996; Rocco & Haydon, 1999; Rozovsky, 1979, 1994; Rozovsky & Rozovsky, 1982; Sharpe, 1987; Sharpe & Sawyer, 1978; Winkler, 1992; Wolfenden 1957; Yalden, 1992.

### Prevention of foreseeable harm

First and foremost, institutions have a legal duty to prevent harm to residents and others that is reasonably foreseeable. This responsibility emanates from both criminal and civil law (McSherry & Somerville, 1998:99).

### Criminal responsibility

The *Criminal Code*, 1985 (“*Criminal Code*”), s. 27 ( “Use of force to prevent commission of offence”) allows caregivers to use as much force as is reasonably necessary to prevent the commission of serious offences such as sexual assault (McSherry & Somerville, 1998:100). Section 27 states the following:

- s. 27. Every one is justified in using as much force as is reasonably necessary
  - (a) to prevent the commission of an offence
    - (i) for which, if it were committed, the person who committed it might be arrested without warrant, and
    - (ii) that would be likely to cause immediate and serious injury to the person or property of anyone;

Section 215 (“Duties Tending to Preservation of Life”) of the *Criminal Code*, requires institutions to provide the necessities of life to persons in their care. Part of this section reads as follows:

#### s. 215 (1) Duties of persons to provide necessities

Every one is under a legal duty

- (c) to provide necessities of life to a person under his charge if that person
  - (i) is unable by reason of detention, age, illness, mental disorder, or other cause, to withdraw himself from that charge, and
  - (ii) is unable to provide himself with the necessities of life.

The court in R. v. Brooks (1902) defined the necessities of life to mean “such necessities as tend to preserve life”. For long-term care institutions, McSherry &



Somerville, 1998:100 contend that this means residents must be provided with a safe living environment, which is one that protects them from serious harm.

### Civil responsibility

The courts have held that institutions have a duty to protect those in their custody from harm, and to prevent them from doing harm to others, Home Office v. Dorset Yacht (1970), Lawson v. Wellesley Hospital (1975/1977). This duty applies to prisons, Howley v. R. (1973), Funk Estate v. Clapp (1988) hospitals, Lawson v. Wellesley Hospital, supra, Ferguson v. Hamilton Civic Hospitals (1983), Koerber v. Kitchener-Waterloo Hospital (1987), Frerotte v. Irwin (1986) and nursing homes, Stewart v. Extendicare Ltd. (1986). McSherry and Somerville, 1998:101 argue that institutions must therefore reasonably protect residents and others from assault, including sexual assault. It should be noted that although institutions have a clear legal duty to sufficiently supervise persons in their care to ensure that they are not harmed and that they do not harm others, this responsibility does not imply all harm must be prevented.

### Negligence

When there is a breach of a duty of care, negligence can be raised against the institution and/or health care providers under criminal or civil law.

### Criminal law: Negligence

The *Criminal Code* defines criminal negligence in the following sections:

- 219. (1) Every one is criminally negligent who
  - (a) in doing anything, or
  - (b) in omitting to do anything that it his duty to do, shows wanton or reckless disregard for the lives or safety of other persons.
- 220. Causing death by criminal negligence.

Every one who by criminal negligence causes death to another person is guilty of an indictable offence and is liable to imprisonment for life.

221. Causing bodily harm by criminal negligence.

Every one who by criminal negligence causes bodily harm to another person is guilty of an indictable offence and liable to imprisonment for a term not exceeding ten years.

If institutional staff demonstrate reckless disregard for the safety of residents or others and as a result someone is seriously injured or dies, criminal negligence charges may be laid. For example, if a health care provider is intoxicated and fails to adequately supervise a resident who is known to be sexually aggressive, if another resident is sexually assaulted, the authorities may contemplate charges of criminal negligence. Criminal negligence is an unlikely risk when sexual activity is consensual or when health care providers have taken reasonable precautions to avoid foreseeable serious harm.

Civil law: Negligence

Sharpe & Sawyer (1978:15) offer the following definition of civil negligence.

Negligence is the omission to do something which a reasonable man, guided upon those considerations which ordinarily regulate the conduct of human affairs, would do, or doing something which a prudent and reasonable man would not do.

Laskin, J. in Jordan House Ltd. v. Menow (1974) at p. 247 outlined the Canadian civil approach to negligence:

The common law assesses liability for negligence on the basis of breach of a duty of care arising from a foreseeable and unreasonable risk of harm to one person created by the act or omission of another.

Negligence claims will only succeed if the court finds that there is a duty of care between the parties, a breach of that duty has occurred, the complainant sustained an injury, and the injury was caused as a result of the breach of duty. By using the example

of a physician prescribing a sexual enhancement medication such as Sildenafil Citrate (i.e., "Viagra") to a patient who is taking nitrates, I illustrate the meaning of these duties. The patient makes a negligence claim after he suffers a severe cardiac arrest, which renders him incapable of gainful employment.

#### Duty of care

As a matter of law, a legal duty of care exists between a health facility and patients, between the physicians and patients, and between other health personnel and patients (Linden, 1982:304). In the example cited, because there is a physician-client relationship, a duty of care exists between these two parties.

#### Standard of Care/Breach of Duty

To establish that a breach of the standard of care has occurred the complainant must demonstrate that the health care provider failed to act according to the conduct that would be undertaken by a peer, in the same circumstances, acting reasonably, Crits v. Sylvester (1956/1956), Swanson v. Wilson (1955/1956). The Court of Appeal in *Crits v. Sylvester* at p. 508 made the following comment:

Every medical practitioner must bring to his task a reasonable degree of skill and knowledge and must exercise a reasonable degree of care. He is bound to exercise that degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing, and if he holds himself out as a specialist, a higher degree of skill is required of him than of one who does not profess to be so qualified by special training and ability.

In the example at hand, it is probable that a breach of duty of care can be established because the physician should reasonably have known that the medications are contraindicated (Compendium of Pharmaceuticals and Specialties, 2004).

### Injury

Legal actions citing negligence must show that the complainant suffered some actual loss or injury as a result of the breach of duty. This means that the loss or injury must be demonstrable. It is not sufficient to only show that a negligent act occurred, McKeachie v. Alvarez (1970). In the present example, the injury is not established by the mere fact the doctor wrote the prescription. Rather, the complainant must demonstrate that he suffered a tangible loss or injury as a result of ingesting the medications. Given that the patient suffered a severe cardiac arrest, which results in him being unemployable, injury will likely be proven.

### Causation

To demonstrate causation the complainant must show that the negligence of the physician caused the injury. The primary test is whether the person's injury would not have happened but for the negligence of the physician, Wilton v. Genik (1995). Mishaps, which could not be reasonably foreseen, are not subject to negligence actions, Stamos v. Davies (1985). The complainant must therefore demonstrate that the cause of his cardiac arrest was the ingestion of the two medications, and not some other unrelated reason such as obesity, high cholesterol or prior heart disease.

### Waivers of liability

Some participants asked that if the institution required residents to sign waivers of liability with respect to their sexual activity or care, would this reduce the risk of negligence claims being successful?

Waivers of liability form one piece of evidence that demonstrate the signor has been informed of the risks and benefits of an activity. The Supreme Court of Canada in

Crocker v. Sundance Northwest Resorts Ltd. (1988) found that people have a right to assert their will via a contractual waiver. Although not referred to in the case, the Court decision accords with the "volenti" principle, which entitles a person to assume risk, provided one is fully aware of the risks involved. For waivers to be recognized as valid by the Court they must be completed according to the principles found in Dyck v. Manitoba Snowmobile Association Inc. (1985). In this case the Court found that waivers are only valid under the following circumstances:

- (i) the parties clearly had a release in mind,
- (ii) the party signing the waiver did so without pressure,
- (iii) the difference between bargaining strength of the parties involved was one where the courts could not hold a transaction unconscionable, and therefore unenforceable because the stronger party has taken advantage of the other,
- (iv) the party signing the waiver knew and was aware of the inherent dangers, and was not participating as a result of being taken advantage of due to social or economic pressures, and
- (v) the waiver was fair, reasonable and applicable.

Capable residents who understand the risks involved in sexual activity and care can sign waivers of liability and agree that they are aware that they are giving up the right to sue. A waiver of liability signed by an incapable resident is not enforceable.

#### Ensure consensual sexual activity occurs in private

Institutions' responsibility to ensure that sexual activity occurs in private emanates from various sections of the *Criminal Code*. Sections of Part V (i.e., "Sexual offences, public morals and disorderly conduct") of the *Criminal Code* define what is meant by a public place, disorderly conduct, nudity, causing a disturbance, indecent exhibition and loitering.

150. Public place.

Any place to which the public have access by right or by invitation, express or implied;

#### 173(1) Disorderly Conduct

Every one who willfully does an indecent act

(a) in a public place in the presence of one or more persons...

is guilty of an offence punishable on summary conviction, and

#### 174 (1) Nudity.

Every one who, without lawful excuse,

(a) is nude in a public place, or

(b) is nude and exposed to public view while on private property, whether or not the property is his own,

is guilty of an offence punishable on summary conviction.

s. 175 (1) Causing disturbance, indecent exhibition, loitering, etc.

Everyone who

(a) not being in a dwelling-house, causes a disturbance in or near a public place,

(b) openly exposes or exhibits an indecent exhibition in a public place,

(c) loiters in a public place and in any way obstructs persons who are in that place, or

(d) disturbs the peace and quiet of the occupants of a dwelling-house by...disorderly conduct in any part of a building or structure to which, at the time of such conduct, the occupants of two or more dwelling-houses comprised in the buildings or structure have access as of right or by invitation, express or implied

is guilty of an offence punishable on summary conviction.

As many, if not all, long-term care institutions allow public visitors onto their premises most will fall under the *Criminal Code's* definition of a public place. Therefore, as public institutions that must adhere to the *Criminal Code*, McSherry and Somerville,

1998:100-101 argue that they have "the authority to restrict sexual activity, or at the very least, ensure that consensual sexual activity occurs in private".

### Uphold prostitution and bawdy-house laws

When sexual activity involves payments between the parties involved, prostitution and bawdy-house laws are of concern. Institutions have a legal duty to uphold the relevant *Criminal Code* laws.

#### Prostitution

213(1)(c) Every person who in a public place or in any place open to public view stops or attempts to stop any person or in any manner communicates or attempts to communicate with any person for the purpose of engaging in prostitution or of obtaining the sexual services of a prostitute is guilty of an offence punishable on summary conviction.

213(2) In this section, "public place" includes any place to which the public have access as of right or by invitation, express or implied, and any motor vehicle located in a public place or in any place open to public view.

Canadian law does not prohibit prostitution per se but does penalize the peripheral activities connected to it. These activities include communicating in public for the purposes of prostitution, soliciting and living off the avails of prostitution (Sturdy: 1997:1). The purpose of s. 213 of the *Criminal Code* is to eliminate street solicitation and the social nuisances it creates including traffic congestion, general street disorder, and activities related to prostitution such as trafficking of drugs, violence and pimping, and exposure of street solicitation to uninterested individuals, Reference Re: Criminal Code, ss.193, 195.1(1)(c) (1987).

Given institutions such as GPC meet the s. 213 (2) *Criminal Code* definition of a public place, at first glance, it appears that institutions should restrict prostitutes plying

their trade in the facility. However, in R. v. Tremblay (1993) Cory, J. at pp. 969-970 comments on the meaning of a public place:

It cannot be forgotten that the sexual activities were conducted behind closed doors out of the view of the general public. It is true that the public did have access to the Pussy Cat premises. Thus it came within the definition of a public place provided by s. 150 of the Criminal Code, R.S.C. 1985, c. C-46, which "includes any place to which the public have access as of right or by invitation, express or implied". Nonetheless, common sense indicates that there are great differences between locations which can come within the definition of public places. Obviously, the performance of an activity in a closed room in a house, where only two consenting adults are present is far different from carrying out the same activity in a school yard or a public park.

Therefore, provided that sexual liaisons between prostitutes and residents occur in private they are unlikely to offend.

#### Keeping a common bawdy-house

210(1) Every one who keeps a common bawdy-house is guilty of an indictable offence and liable to imprisonment for a term not exceeding two years.

210(2)(c) Every one who as owner, landlord, lessor, tenant, occupier, agent or otherwise having charge or control of any place, knowingly permits the place or any part thereof to be let or used for the purposes of a common bawdy-house is guilty of an offence punishable on summary conviction.

211. Every one who knowingly takes, transports, directs, or offers to take, transport or direct, any other person to a common bawdy-house is guilty of an offence punishable on summary conviction.

The definition of a bawdy-house was explored in R. v. Patterson (1968) at p. 162 where the Court found that "in cases where the Crown has failed to prove a habitual or frequent use of a place for the purposes of prostitution, the conviction has not been upheld." As there must be actual evidence of the continued and habitual use of the premises for prostitution, single events of prostitution being in a particular place have not been upheld as evidence that premises are habitually used for such a purpose, and



acquired a reputation in the community as such, R. v. Davidson (1917) Stewart J.A.

giving judgment for the majority of the Court at p. 54 made the following observation:

It might very well happen that a clerk in a hotel who had become friendly with a man, or guest or inmate or a regular customer of the hotel, might, on receiving a wink, shut his eyes to his friend's proposed escapade and allow him to take a woman to his room on one occasion without protest, and yet not be guilty at all of habitually allowing any casual guest to do so.

Given the focus of common bawdy-house charges rests on frequency of use and ambiance, unless prostitutes are using the institution as their business basis and it is common knowledge in the community that this is a place of ill repute, it is improbable that casual or even regular visits from prostitutes will attract a keeping a common bawdy house charge.

#### Ensure health care providers act in accordance with professional standards

In Canada, the growing complexity of society and government has increased the need for specialized knowledge and control in areas which are believed to affect the public interest. This involves a branch of law known as public regulation and administrative law. Government agencies, such as the Registered Nurses' Association of British Columbia ("RNABC") are empowered by statute to regulate the professional activities of its members. These agencies have legal licensing authority and can restrict or remove members' privileges to practice. The RNABC is empowered by a provincial statute, the *Nurses (Registered) Act* (1996), which entrusts the organization with the responsibility for establishing, monitoring and enforcing standards of education and qualification for registration, promoting high nursing practice standards, monitoring and enforcing professional ethics, and reducing incompetent, impaired or unethical nursing practice. I use the RNABC (Registered Nurses Association of British Columbia, 2002a,

2002b) regulations to analyze what professional standards nurses must uphold when it comes to sexual activity and sexual care.

Nurses have a clear responsibility to always act in the best interests of their clients and not to have romantic (sexual) relationships with them. The RNABC's 2002a policy statement Appendix 5, "Nurse-Client Relationships: Establishing Professional Relationships and Maintaining Appropriate Boundaries" establishes this rule:

It is always the nurse who is responsible for establishing and maintaining appropriate boundaries. Nurses assume responsibility for ensuring relationships with clients are therapeutic and professional. Where nurse-client relationships exist nurses must not enter into friendship, romantic, sexual or similar personal relationships. Nurses are responsible for initiating, maintaining and terminating a relationship with a client in a manner that ensures the client's needs are first and foremost...Nurses do not engage in social relationships with clients and need to be very cautious in socializing with former clients, especially those who are vulnerable or may require ongoing care.

Not being allowed to have sexual relationships with clients in no way prohibits nurses from providing sexual care. Just as psychiatrists and gynecologists can provide sexual care in accordance with their particular expertise, so too can nurses.

#### Uphold the rights of health care providers

The *Human Rights Code* (1996) ("*Code*"), which deals with discrimination occurring between private parties or individuals and the provincial government, gives employees a right to work in an environment free of sexual harassment (Hogg: 1992). Institutions have a duty to ensure that its employees are not sexually harassed when they provide sexual care. Sexual harassment complaints emanating from staff are against the employer (i.e. the institution), even if it is residents who are doing the harassment.

The *Code* aims to protect fundamental rights of dignity and equality and prohibits discriminatory practices. Its purpose is identified in s. 3(b) and 3(c) of the *Code*:

3(b) to promote a climate of understanding and mutual respect where all are equal

in dignity and rights

3(c) to prevent discrimination prohibited by this Code

In order to prove sexual harassment when, for example, staff are required to work in residents' rooms with pornography posted on the walls, they must produce the following evidence as outlined in Bouvier v. Metro Express (1992) at page 59:

- (i) the conduct was of a sexual nature,
- (ii) the conduct was unwanted, and
- (iii) the result of the conduct was humiliating and an affront to personal dignity.

The procedure to establish discrimination under the *Code* was established in Ontario (Human Rights Commission) v. Etobicoke (Borough) (1982) and involves three steps.

First, the complainant (i.e., staff) must prove *prima facie* evidence of discriminatory practice. To do this staff must first demonstrate that there is a service, facility or accommodation customarily available to the public which has been denied, and secondly, that the denial was based on discrimination forbidden by the *Code*. In the case of pornography being on residents' bedroom walls, staff need to demonstrate that the pictures are sexual in nature, that other nurses are not required to work in areas that display pornography, that they do not want to work in such conditions, and that it is humiliating and an affront to their personal dignity to do so.

Second, the employer (i.e., the institution) must justify the discriminatory behaviour and demonstrate that every necessary action to remedy the situation, on a balance of probabilities, was taken. The employer must establish that it exercised all due diligence to prevent the act or omission from being committed and that it subsequently acted to mitigate or avoid the affect thereof.

In British Columbia (Public Service Employee Relations Commission) v. British Columbia Government and Service Employees' Union (B.C.G.S.E.U.) (1999) ("*Meiorin*")

at p. 21 the Court set out the following three-step test for determining whether discrimination is justifiable. The employer must demonstrate on a balance of probabilities the following:

- (i) the employer adopted the standard for a purpose rationally connected to the performance of the job. The focus at the first step is not on the validity of the particular standard, but rather on the validity of its more general purpose,
- (ii) the employer adopted the particular standard in an honest and good faith belief that is necessary to the fulfillment of that legitimate work-related purpose, and
- (iii) the standard adopted is reasonably necessary to the accomplishment of the legitimate work-related purpose. To show that the standard is reasonably necessary it must be demonstrated that it is impossible to accommodate individual employees, sharing the characteristics of the claimant, without imposing undue hardship upon the employer.

In defending against a claim of sexual harassment, the employer must demonstrate why allowing pornography on the walls of residents' rooms is a reasonable standard and show why there are no other reasonable alternatives which would decrease the harm to staff. For example, the institution might have to demonstrate why the standard of requiring residents to keep their pornography in binders, instead of on the walls where staff cannot reasonably avoid the pictures, should not, or could not, be adopted.

Third, the complainant has the burden of proof to show the employer's explanation is a pretext and that the real action for basis is discrimination. If, for example, the institution could demonstrate that requiring residents to keep pornography in binders would somehow cause the institution undue financial hardship, staff would then have to

show why this explanation is a pretext for discrimination (e.g., the institution's real goal is not to employ Roman Catholic or Muslim health care providers).

Sexual harassment is most likely to be established when employers fail to prevent discriminatory behaviour from occurring or mitigate or avoid the affect thereof. If staff can demonstrate allowing long-term care residents to hang pornography on their walls is discriminatory, the employer must remove the offensive materials. However, because the legislation does not forbid such materials from being on the premises, the institution must only ensure that they be displayed so that staff can reasonably avoid them.

#### Uphold substitute decision-making laws

Institutions have a legal responsibility to ensure that proper authority is being used when family, friends, staff or others make substitute sexual decisions for residents. First, the law is definitive that capable residents can make their own sexual decisions within the confines of the law. Substitute decision-making is most commonly utilized when residents are incapable of making decisions in a particular area of their lives. The difficulty with substitute sexual decision-making is that it is not clear at law whether anyone has the right to make some sexual decisions for others. For example, can a substitute decision-maker choose a sexual partner for a charge?

In British Columbia, several laws empower appropriately appointed people to make substitute decisions for persons who are not capable of making decisions for themselves. The *Power of Attorney Act* (1996), the *Patients Property Act* (1996), the *Representation Agreement Act* (1996), the *Adult Guardianship Act* (1996), and the *Health care (Consent) and Care Facility (Admission) Act* (1996) give duly appointed substitute-makers powers to make financial placement and/or health care decisions for others.

For each of these pieces of legislation, I describe what authority substitute decision-makers can be granted and determine whether these powers allow for substitute sexual decisions. I conclude that substitute sexual decisions can only be made under a section 9 representation agreement if it can be successfully argued that a sexual decision is a health care decision and if the donor specifically gives a representative that authority, and under the *Patients Property Act, supra* when a committee makes a substitute sexual decision that is in the best interests of the person that they are making the decision for. A substitute sexual decision might also be viable, in a limited and negative sense, when a duly appointed person has authority under the *Power of Attorney Act, supra*, the *Patient's Property Act, supra*, and the *Representation Agreement Act, supra* to control another person's finances and decides that it is in the donor's best interest to refuse to release funds to pay for services related to sexual activity (e.g., hiring prostitutes, purchasing sexual devices).

#### Power of Attorney Act

The *Power of Attorney Act, supra* s. 9(2) allows capable individuals and corporations to confer "authority on more than one attorney acting separately or acting together, as the case may be, to do on behalf of the donor anything that the donor can lawfully do by an attorney, subject to conditions and restrictions, if any, that are contained in the power of attorney". The authority granted to a person with a power of attorney terminates if the donor becomes incapable unless, under section 8 of the *Power of Attorney Act*, an enduring power of attorney has been granted. If properly executed by a capable adult, an enduring power of attorney authorizes the authority of a power of attorney "... to continue despite any mental infirmity of the donor..." (*Power of Attorney*

*Act*, supra s. 8(1)(a)). Powers of attorney are enacted for legal and commercial matters. They are not used as instruments to confer authority on others to make decisions regarding health care or other personal matters. There is nothing in the scope of a power of attorney, or an enduring power of attorney, that authorizes duly appointed individuals to make substitute sexual decisions, except perhaps in the circumstance where an attorney has the power to refuse to release funds that will be used for sexual activity (e.g. hiring prostitutes, purchasing sexual devices).

### Patients Property Act

The *Patients Property Act*, supra allows a judge, usually of the Supreme Court of British Columbia, to appoint a committee to act on behalf of a person who may be incapable of making decisions relating to his or her personal or financial welfare and may therefore be in need of protection. Powers granted in an enduring power of attorney or representation agreement cease when a committee is appointed. If a person is incapable of making decisions regarding one's personal welfare, a committee of the person is appointed. A committee of Patient affairs is appointed when a person is incapable of making decisions regarding financial affairs. A committee can be appointed as either one of these things or both (*Patients Property Act*, supra s.3 (2)(d)(ii)(C)). A committee of Patient affairs does not have the power to make substitute sexual decisions unless it directly relates to financial matters (e.g., hiring prostitutes, purchasing gifts for a sexual partner).

The committee of the person and the committee of Patient's affairs may or may not be the same person and may be more than one in number. A relative often seeks to be committee. The Public Guardian and Trustee can act as committee. Financial institutions,

such as trust companies, can also be appointed as committee of a person's affairs, but only individuals can be appointed as committee of the person.

A committee has a duty to act in the best interests of the patient. The role of committee of the person includes determining where and with whom the patient lives, and making arrangements for the patient's care, food and clothing. As well, the committee of the person has authority to provide consent to health care for the patient, but the committee of the person does not have the authority to consent to medical treatment that is not in the patient's best interest *Re Eve*; *Re: K.* (1985).

There are some matters so personal to a patient that a committee of the person cannot do them on behalf of the patient. These matters include making a will, taking custody of a child, contracting a marriage, changing the designation of beneficiaries under an insurance policy, pension plan, or registered savings plan, distributing any part of an estate, voting in an election, and entering a plea or electing a mode of trial in a criminal proceeding (Robertson, 1994). It is likely that most sexual decisions are so personal that they too cannot be referred to a committee. However, a committee's interference with sexual activity is permissible if it is in the best interests of the incapable person to do so. It is likely that avoiding foreseeable harm will be in a person's best interest, but because sexual activity often has benefits attached to it, eliminating all harm will not (Mace et al.: 1974; McCann: 2000; Weeks: 1986).

#### Representation Agreement Act

The *Representation Agreement Act*, *supra*, allows adults "to arrange in advance how, when and by whom decisions about their health care, personal care or financial affairs or about other matters will be made if they become incapable of making decisions



independently..."(*Representation Agreement Act, supra*, s.2(c)). Appointing a representative avoids the court having to appoint someone to help adults make decisions, when they are incapable of making decisions independently.

Section 7 of the *Representation Agreement Act, supra* specifies the types of substitute decisions that can be made by a duly appointed representative.

s. 7(1)

- (a) the adult's personal care, for example, where and with whom the adult is to reside;
- (b) routine management of the adult's financial affairs, including subject to the regulations,
  - (i) payment of bills,
  - (ii) receipt and deposit of pension and other income,
  - (iii) purchase of food, accommodation and other services necessary for personal care, and
  - (iv) the making of investments;
- (c) major and minor health care decisions...but not including the kinds of health care prescribed under section 34(2)(f) of that *Act*;
- (d) obtaining legal services for the adult and instructing counsel to commence proceedings, except divorce proceedings, or to continue, compromise, defend or settle any legal proceedings on the adult's behalf.

(2) An adult may authorize a representative under subsection (1)(a) to accept a facility care proposal under the *Health Care (Consent) and Care Facility (Admission) Act* for the adult's admission to a care facility, but only if the facility is

- (a) a family care home,
- (b) a group home for the mentally handicapped, or
- (c) a mental health boarding home.

(2.1) A representative may not be authorized under this section to help make, or to make on the adult's behalf, a decision to refuse life-supporting care or treatment.

Representatives appointed under s. 7 of the *Act* have limited decision-making authority. As s. 7 does not address substitute sexual decision-making powers, representatives have no authority to make such decisions.

Under s. 9(1) of the *Act*, if an adult consults with a member of the Law Society of British Columbia (s. 9(2)(a)(i)), the donor may authorize his or her representative to do any or all of the following:

- (a) physically restrain, move or manage the adult, or have the adult physically restrained, moved or managed, when necessary and, despite the objections of the adult;
- (b) give consent, in the circumstances specified in the agreement, to specified kinds of health care, even though the adult is refusing to give consent at the time the health care is provided;
- (c) refuse consent to specified kinds of health care, including life-supporting care or treatment;
- (d) give consent to specified kinds of health care, including one or more of the kinds of health care prescribed under section 34(2)(f) of the *Health Care (Consent) and Care Facility (Admission) Act*;
- (e) accept a facility care proposal under the *Health Care (Consent) and Care Facility (Admission) Act* for the adult's admission to any kind of care facility;
- (f) make arrangements for the temporary care, education and financial support of
  - (i) the adult's minor children, and
  - (ii) any other persons who are cared for or supported by the adult;
- (g) do, on the adult's behalf, any thing that can be done by an attorney acting under a power of attorney and that is not mentioned in paragraphs (a) to (f) or in section 7(1).

Although the *Act* does not specifically empower s. 9 representatives to make substitute sexual decisions, it is possible, if one successfully argues that such decisions are health care decisions, that this power could be conferred. To do so, the donor would need to explicitly state in the agreement the scope of sexual decision-making power that the representative is to have.

If a s. 9 representative does not have the specific power to make substitute sexual decisions, it can be argued that s. 16 of the *Act* requires representatives to act in accordance with the individual's current wishes regarding sexual activity unless it is not reasonable to do so. Specifically, the section requires that representatives act in the following manner:

- consult and comply if it is reasonable to do so with the wishes of the adult (s. 16(2)(a)(b));
- comply with any instructions or wishes the adult expressed while capable, if consulting and complying with the adult's current wishes cannot be determined or it is not practicable to comply with them (s.16(3));
- act on the basis of the adult's known beliefs or values if the adult's instructions or expressed wishes are not known, or if unknown, act in the adult's best interests (s.16 (4)(a)(b)).

### Health Care (Consent) and Care Facility (Admission) Act

Under the *Health Care (Consent) and Care Facility (Admission) Act*, when an incapable adult requires non-emergency minor or major health care, and there is no designated substitute decision maker (e.g., committee of person appointed under the *Patients Property Act, supra* or representative appointed under the *Representation Agreement Act, supra*), a temporary substitute decision maker can give consent to treatment.

According to s. 16(1) of the *Health Care (Consent) and Care Facility (Admission) Act*, a health care provider in the following listed order must choose a qualified temporary substitute decision maker:

- (i) the adult's spouse;
- (ii) the adult's child;
- (iii) the adult's parent;
- (iv) the adult's brother or sister;
- (v) anyone else related by birth or adoption to the adult.

The authority of substitute decision makers is restricted to health care decisions so there is nothing in this *Act* that contemplates granting substitute sexual decision-making power to these individuals.

### Adult Guardianship Act

As of March, 2005 only Part 3 of the *Adult Guardianship Act* is in force. This part of the *Act* addresses support and assistance for abused and neglected adults and there is nothing in this section which is relevant to the making of substitute sexual decisions. Part 2 of the *Act*, which is not yet in force, contemplates the appointing of associate substitute decision makers, guardians, and monitors. Once in force, it will replace the *Patient's Property Act, supra*. There is no authority under the current *Act* for substitute sexual decisions. The new legislation is expected to confer the same decision-making authority that currently exists in the *Patients' Property Act*.

#### Conclusion of substitute sexual decision-making

With the exceptions of a representative under the *Representation Agreement Act, supra* being granted the specific authority to make substitute sexual decisions, or when a committee of person appointed under the *Patients Property Act, supra* authorizes the curtailment of sexual activity in order to avoid foreseeable harm, or when funds for sexual activity are withheld under either of these pieces of legislation or the *Power of Attorney Act, supra*, the law does not contemplate substitute sexual decision-making. The quandary this situation poses for institutions is that if no one else is empowered to make substitute sexual decisions, the responsibility may fall to these entities by virtue of the fact they are legally required to prevent foreseeable harm. At the same time, institutions are responsible to allow residents to engage in activities, including sexual activity, that are not legally prohibited.

#### **Conclusion**

The preceding analysis shows that nothing in current law prevents consensual sexual activity. However, in certain circumstances the law allows for some limitations

to be placed on sexual activity and sexual care. The law, whether criminal or civil, is most problematic in its failure to be explicit about what sexual care can be provided. The result is that the permissibility of any given sexual activity, or the delivery of any form of sexual care, is left to the discretion of individual health care providers, who may be subject to legal sanctions if he/she interprets the law incorrectly. It is therefore essential that institutions create guidelines that inform staff what sexual care is expected of and appropriate for them to provide. In the next chapter I address the development of sexual care guidelines and make other recommendations for changes to long-term care management strategies.

## **CHAPTER 8:**

### **Developing a Pragmatic Framework for the Delivery of Sexual Care**

Feeling the fullness of the presence of the world depends on feeling the fullness of another person, as a person; reality is given to us by the reality of people, reality is taken from us by the unreality of unpeople; our sense of reality, of trust, of security is critically dependent on a human relation....

--- Oliver Sacks, 1982:238 Encephalitis Lethargica

#### **Introduction**

In this chapter, I develop a pragmatic framework for the delivery of sexual care. The types of approaches I adopt (e.g., “autonomy rooted within community”, “supported decision-making”etc.) are not exhaustive but rather constitute a place to begin. It is my hope that others will build on this preliminary design.

#### **Principles of the pragmatic framework for sexual care**

Based on the ethical rationale advanced in Chapter 6, the following principles should underpin the development of a pragmatic framework for the delivery of sexual care:

- (i) Residents have the right to make sexual choices as circumscribed by ethics and the law.
- (ii) Residents are entitled to receive assistance with sexual activity that they cannot do for themselves because of their physical disabilities, and that are within the boundaries of professional practice standards, organization policies/standards and the law.
- (iii) Care providers are entitled to receive adequate and appropriate support to provide sexual care.

## **Recommendations for changes to management strategies**

Beginning to develop a pragmatic framework for the delivery of sexual care involves long-term care institutions making three changes to management strategies. First, management must adopt concepts of autonomy and protectionism that encourage staff to provide sexual care. Second, they should introduce education curricula that promote a sex-positive ethos throughout an institution. Third, sexual care guidelines should be created so that staff know what sexual care is appropriate for them to provide to capable and incapable residents. I now elaborate on each of these recommendations.

### Autonomy and protectionism

Autonomy and protectionism are bioethical concepts that originated in acute care settings. The basic tenets inherent in each of these concepts (i.e., the robust independent individual making informed choices, and the elimination of risk) are unhelpful in resolving moral dilemmas in long-term care settings. This is because the functions and goals of acute and long-term care hospitals are very different.

The mandate of most acute care hospitals is to cure, abate or slow the progress of medical illnesses and disease (Collopy, Boyle & Jennings, 1991). The acute care patient usually sees the disease state as external to her moral personality and only uses hospitals when she believes it will further personal goals (Collopy et al., 1991). In acute care settings, autonomy is held in high regard because it has been deemed ethical to value individual liberty, rational free choice, and independence (Beauchamp & Childress, 2001). According to the acute care view, autonomy conceptualizes patients as robust, rational, self-reliant, self-asserting, and capable adults (Agich, 1993; Collopy et al., 1991). Bioethics, aimed at upholding this particular view of autonomy, emphasizes the

importance of informed consent and monitors the medical settings and behaviours of health care providers to ensure that any restrictions placed on patients are minimal, and that the rights of patients, not service providers, are respected (Collopy et al., 1991).

Acute care protectionism seeks to minimize risk so that full attention can be given to patients' medical concerns. For this reason, acute care patients, or their substitute decision-makers, usually readily agree to vast restrictions on liberties. This includes their not making decisions about what to eat and drink, when to sleep, and what to wear and do all day. Most acute care patients voluntarily postpone sexual activity, which results in low demand for sexual care. Thus, only a few specialized health care practitioners are expected to or trained to provide such care.

In long-term care settings, little of the above applies. The mandate of most long-term care facilities is not to cure residents of illness or disease, but rather to be "homes and places to live" (Collopy et. al, 1991:12). Unlike acute care, where the primary issue is often life or death, the most common concern of long-term care residents is lack of personal control (Collopy et al., 1991). According to Agich 1993:9 "The dissonance between the image of the robust, strong and unencumbered individual making her own way competently in the world and even the most banal limitations that underlie the need for long-term care should be readily apparent."

Typically long-term care residents are physically and/or mentally impaired. These people commonly require assistance with the activities of daily living including eating, dressing, washing and toileting. They are also often unwilling to waive their liberties, including the right to be sexually active, because, unlike their acute care counterparts,



they are interested in improving the quality of their lives within the confines of the institution.

One problem with using traditional views of autonomy and protectionism in long-term care is that it allows staff to claim that sexual care is not required and that sexual activity should not be permitted. If staff see residents as robust, independent and capable, this allows them to refuse sexual assistance because most independent people do not need such help. Similarly, when staff accept the acute care concept of protectionism and set their goals on the maximum abatement of risk, they can legitimately curtail residents' sexual activity because, like all other activities (e.g., bathing, walking across a street, etc.), it is inherently risky. As eliminating sexual activity and care is antithetical to what I have argued is required, it is imperative that these concepts be redefined so that they resonate with the realities of long-term care. I therefore propose that acute care concepts of autonomy and protectionism should be replaced with concepts such as "autonomy rooted within community" (Collopy et al., 1991) and "supported decision-making" (Gordon, 2000). Together these concepts encourage residents to make choices or indicate preferences and allow staff to help them evaluate and manage risks.

Autonomy rooted within community views moral personhood as something that "is not abstracted from the individual's social context or state of physical or mental capacity" (Collopy et al., 1991:9). It recognizes that human beings develop and express their autonomy in a social world and that autonomy is attained through human relationships (Collopy et al., 1991). Rather than eschewing dependency, autonomy rooted in community embraces it (Collopy et al., 1991). Supported decision-making, which promotes interdependent (as opposed to independent) decision-making, upholds an

incapable adult's capacity to make choices but allow caregivers to assist in decisions that require both an understanding and an appreciation of the consequences (Gordon, 2000). These approaches are conducive to managing sexual activity in long-term care because they aim to respect the sexual choices of incapable residents but at the same time ensure that excessive or unnecessary risks are not taken.

### Education curricula

The overall aim of education curricula should be to change institutions' negative attitudes towards sexual activity and sexual care. Changing attitudes in a culture is a difficult proposition because moral behaviour is a habit formed by spending many years in families, schools, cultures and various environments, which shape how we look at things morally and how we believe we ought to behave morally (Dewey, 1920/ 1970). According to Dewey (1920/1970), when attitudes are firmly entrenched, moral habits can only be truly changed through a combination of internal reflection (e.g. education, moral suasion) and external pressure (e.g., laws, sanctions). To encourage internal reflection, the institution should provide staff with a process for dealing with their moral distress regarding sexual activity and care. D'Agincourt-Canning & Smye (2001) suggest one way to deal with morally contentious issues in health care settings is to build a framework for dialogue by providing the following:

- (i) ongoing critical incident debriefing,
- (ii) regular case reviews and discussions facilitated by an ethicist,
- (iii) regular education sessions,
- (iv) orientation sessions for potential staff which include a discussion of the philosophy and mandate of the services/program,
- (v) institutional care reviews and discussions supported by ethics committees<sup>11</sup>,

---

<sup>11</sup> As many long-term care facilities do not have an ethics committee or ethicist, I suggest that it would be valuable to allot time for staff, who normally work at the facility, to get together to have these discussions.

- (vi) time allocated for the ethics committee to discuss their varying perspectives on morally contentious issues.

External pressure can be brought to bear by instilling a sex-positive ethos throughout the institution. The rationale for adopting this view in long-term care is that it is most likely to promote the greatest overall happiness, respect patient autonomy, show the most caring toward the disabled, and come closest to doing justice (Preinsperg, 2002). Education curricula should therefore aim to help staff learn to be non-judgmental about residents' sexual lives and to be willing to facilitate sexual activity.

#### Developing guidelines for sexual care

My final recommendation is for institutions to develop guidelines detailing what sexual care is appropriate for staff to provide. What is appropriate for capable residents will be different than for incapable residents. These guidelines are necessary to ensure just care for two reasons. First, residents receive uneven levels of care when staff make individual decisions about what sexual care should be provided. Second, it is simply iniquitous to put staff in the position of having to determine how sexual activity and sexual care should be managed because they rarely have the information and knowledge to do this. I recommend that the following principles should be used to develop sexual care guidelines:

- (i) Care providers are entitled to be informed of the institution's sex-positive ethos and should know what sexual care they are expected to provide.

Employment descriptions and contracts should reflect these expectations.

- (ii) Care providers are entitled to receive education and training for the sexual care that is appropriate for them to provide.

- (iii) As sexual care should be the result of cohesive teamwork, there must be accountability between individual staff and disciplines.
- (iv) A stable environment of legal, administrative and professional support should support sexual care.

### **Principles for evaluating a pragmatic framework for sexual care**

Given that the above recommendations are meant to form the building blocks of a pragmatic framework for the delivery of sexual care, it is important to develop criteria that will help evaluate its ongoing development. To this end, I suggest that the following questions be regularly asked:

- (i) Have the residents' and staff's needs being appropriately met by the guiding principles in the pragmatic framework for sexual care?
- (ii) If not, what supports need to be incorporated into the framework?

In the next and final chapter of this thesis, I review the rationale for the study and summarize the results of all aspects of this work.

## **CHAPTER 9:**

### **Towards a Moral Vision of Long-Term Care Living**

Civilization...is the acceptance and the encouragement of differences.

--- Mahatma Gandhi

#### **Introduction**

With increasing populations and a corresponding increase in demand for long-term care, we have reached a pivotal point in time where there is a need to develop our moral vision of long-term care living. This includes making decisions about how long-term care institutions should manage sexual activity and care. The present study has contributed to these ends.

Guided by an exploratory design and situational ethics, this research offers a descriptive and critical analysis of how sexual activity and sexual care interact with each other and with ethical, legal and administrative considerations.

This final chapter provides a summary of the research and highlights key themes and conclusions arising from the study. I reflect on methodological strengths and limitations of the research design, study sample and analysis. My purpose is to solidify my claim that long-term care institutions are ethically obliged to support residents' sexual lives. I end the chapter and dissertation with suggestions for future research and some of my own concluding thoughts.

#### **Methodological review**

The aim of the present research was to contribute to the development of a moral vision of how long-term care institutions should manage sexual activity and sexual care. My hope and explicit intention was to try to improve the quality of institutionalized persons' lives by ensuring that they have opportunities to have sexual lives, and that staff

are adequately supported to provide sexual care.

This qualitative study was designed to identify the negative influences on sexual activity and sexual care, and the supports that residents and staff respectively need to have sexual lives and provide sexual care. The results of the investigation both confirmed and enhanced current knowledge. The most notable additions to the literature are the delineation of the ethical case in support of residents' sexual lives and the development of a pragmatic framework for the delivery of sexual care.

The research design primarily emanated from the results of fourteen expert interviews which were carried out at the beginning of the project in early 1999. Research data were collected from twenty-four interviews with residents, staff, and administrators from June, 1999 to December, 1999. In 2000-2003, most participants were revisited on a number of occasions to clarify information and findings and to enhance developing theory. In total, certain participants were seen up to six hours. Over the years 1999 to 2002, participant observation of two persons with disabilities living in the community were carried out. The purpose of this aspect of the research was to compare community participants' experience with that of institutionalized persons. Working with members of the G. F. Strong Sexual Health team, Vancouver Hospital and Health Sciences Centre for Sexuality, Gender Identity and Reproductive Health, and partaking in a sexual health policy development working group, approximately thirty hours of fieldwork were carried out. In addition, twenty-five hours of seminars, conferences, and workshops on issues related to the thesis topic were undertaken. Finally, document analysis helped identify current trends in the management of sexual activity and care in psychiatric, geriatric and penal facilities.

## Themes and conclusions

Data, ethical and legal analysis led to the following themes and conclusions:

- Some residents of long-term care institutions want to try to improve the quality of their lives by having opportunities to have sexual lives.
- Six negative influences on residents' sexual lives were identified: the negative attitudes of staff; the psychological and physiological limitations of residents; the lack of opportunity to find potential sexual partners; the lack of privacy; and the sense of powerlessness to change the culture, values, and attitudes to institutions against residents' sexual lives. This knowledge led to the conclusion that, unless sexual care is available, residents cannot have sexual lives.
- Nine negative influences on staff's provision of sexual care were also identified in the research process: the duties to set professional boundaries; the legal duties to provide care; personal and religious values of staff; the wish to avoid sexual harassment in the workplace; inadequate training and education of the staff; the lack of staff time and resources; lack of privacy for residents and staff; the lack of institutional guidelines to direct what assistance is appropriate; and a sense of powerlessness to change the nature of long-term care living as it is practiced today. This knowledge led to the conclusions that, if we want staff to provide sexual care, institutions must accept that it is their moral responsibility to provide it and ensure that staff are adequately supported.
- Ethical rights for residents to have sexual lives and to receive assistance to carry out sexual activity they cannot do for themselves because of their disabilities were established. Countervailing arguments of harm to self (and participating others),

harm to others and offense to others failed to cancel these prima facie rights.

Establishing these rights implies that institutions have a corresponding moral duty to provide sexual care.

- An analysis of seven common legal concerns (i.e., residents' legal rights to engage in sexual activity, the legal responsibilities of institutions with respect to residents' sexual activity, rights of substitute decision-makers, prostitution and bawdy-house legislation, professional duties of care, negligence, and staff's rights to work in a sexual harassment free environment) showed that, in most circumstances, the current law does not prevent sexual activity or sexual care. The law does require that persons in care be protected from foreseeable harm.
- Given that ethics directs us to provide sexual care and current law does not usually prevent it from being delivered, the conclusion was made that a pragmatic framework for the delivery of sexual care should be developed. This involves three changes to long-term care management strategies. First, autonomy and protectionism bioethical paradigms designed for acute care settings should be modified so that they resonate with the realities of long-term care living. Second, education curricula should promote a sex-positive ethos throughout an institution. Third, guidelines that inform caregivers what sexual care is appropriate for them to provide to capable and incapable residents must be created.

### **Research limitations**

Throughout this research, I have tried to remain reflective and avoid naive claims that a single theme provided all the answers to my questions. As a novice researcher, I came to understand over time what I imagine most experienced researchers know, that



this work describes only a fraction of reality. Although this does not mean that the research is not useful, it reminds me that reality is far more complex than can be described in linear writing, and that there are limits to the knowledge that can emanate from study data emerging from the perspective of a given researcher at a certain moment in time.

Other limitations inherent to this research are as follows:

First, qualitative and quantitative research necessarily focus on issues that are tangible and can be described. However, some aspects of the moral and social nature of sexual activity and care cannot be easily articulated. These intangible perspectives may not be represented in this work. Also, resident care aides, family members, substitute decision-makers, incapable residents and community health care providers were either under-represented or not represented in this study. Finally, the people who did participate were highly motivated, which may suggest that the views of those who chose not to participate may be different.

Second, although I tried to include subjects with different disabilities, ages and ethno-cultural and religious backgrounds, my selection criteria did not require that I include any of these diversities. The study population came from only one institution with a particular mandate. This observation raises clinical questions about the delivery of sexual care in other institutions with different populations and mandates. At the research level, questions remain regarding how these differences would intersect with ethical thinking.

Third, my analysis is limited by the fact that I have captured only certain people's experiences at one point in time. Future residents and staff may have different

experiences with, and views about, sexual activity and sexual care. Clinical practice and ethical analysis is based on current understandings, which should change in response to new knowledge and people's experience. This should remind us that there is no definitive moral vision of every aspect of how sexual activity and sexual care should be managed. Rather, we ought to apply ethical thinking to new knowledge so that the lives of institutionalized persons continually improve.

Fourth, as I only addressed legal concerns that emerged from my data, there may be other legal issues that impact sexual activity and sexual care. In addition, tomorrow's laws may change in response to social and political circumstances and thus may influence the management of sexual activity and care in ways that cannot yet be defined. It is therefore likely that legal experts will need to monitor and comment on the ongoing impact of the law.

Fifth, my study did not include incapable residents and the institution in which the study was conducted did not typically serve these people. This is not reflective of the reality of most long-term care facilities, which serve mainly demented or cognitively impaired residents. This suggests that issues that impact sexual activity and sexual care in institutions that serve residents who are incapable may not have been captured in the present study.

### **Directions for future research**

Although I believe that this study has contributed to the development of a moral vision of how long-term care institutions should manage sexual activity and sexual care, outstanding questions remain.

First, there is a need to better understand which staff should be responsible for the

various aspects of sexual care and what training they require. Researchers will need to work with clinicians, managers and administrators to determine how best this ought to be done.

Second, the experiences of front line health care providers (i.e., care aides and nurses) need further exploration so that they can be better supported to provide sexual care.

Third, it would be beneficial to gather further information from community health care providers, regarding their experiences of providing sexual care, to determine if and why it may be more available in these settings.

Fourth, the ethical rationale and pragmatic framework for the delivery of sexual care needs testing in facilities that serve incapable clients. It would also be valuable for future research to explore the concerns of substitute decision-makers and family members.

Fifth, comparative studies of sexual activity and care in psychiatric, geriatric and penal facilities should be conducted to test how the recommendations made in this thesis translate to these settings. It is foreseeable that institutions with different mandates will have specific issues that should be incorporated into the moral vision of how sexual activity and care should be managed.

Sixth, as this research focused on Canadian institutions, in continuing to develop the pragmatic framework for sexual care, researchers are advised to investigate sexual care programs that may exist in other countries.

### **Concluding reflections**

This dissertation has aimed to add new knowledge about the complex moral and social nature of sexual activity and care. The purpose of the research was to contribute to our moral vision of how institutions should manage sexual activity and care. The ethical case in favour of residents' rights to have sexual lives and receive assistance with sexual activity they cannot do for themselves because of their physical disabilities was delineated. Clinical relevance was established by the development of a pragmatic framework for the delivery of sexual care. It is my hope that researchers and clinicians will continue this work and enhance the framework. In doing so our moral vision of long-term living should improve and we will continue to give some of our most marginalized citizens the dignity and respect they deserve.

## BIBLIOGRAPHY

- Abramson, P., Parker, T. & Weisberg, S. (1988). Sexual expression of mentally retarded people: Education and legal implications. *American Journal on Mental Retardation*. 93(3), 328-334.
- Agich, G.J. (1993). *Autonomy and Long-Term Care*. New York: Oxford University Press.
- d'Agincourt-Canning, L., & Smye, V. (July, 2001). *Dealing with Morally Contentious Issues*. Vancouver: Children's and Women's Hospital. Unpublished manuscript.
- Alexander, C.J., Sipski, M.L. & Findley, T.W. (1993). Sexual activities, desire, and satisfaction in males pre- and post-spinal cord injury. *Archives of Sexual Behavior*. 22(3), 217-228.
- Althof, S.E. & Levine, S.B. (1993). Clinical approach to the sexuality of patients with spinal cord injury. *Spinal Cord Injury*. 20(3), 527-534.
- Altman, I. (1975). *The Environment and Social Behavior: Privacy, Personal Space, Territory, Crowding*. Monterey, CA.: Brooks/Cole Publishing Company.
- Ames, T.R.H. (1991). Guidelines for providing sexuality-related services to severely and profoundly retarded individuals: The challenge for the nineteen-nineties. *Sexuality and Disability*. 9(2), 113-122.
- Anderson, P. & Kitchin, R. (2000). Disability, space and sexuality: access to family planning services. *Social Science & Medicine*. 51(8), 1163-1173.
- d'Ardenne, P. (1986). Sex therapy education in a medical college. *Sex and Marital Therapy*. 1(2), 215-220.
- Aylott, J. Sense and sexuality. (1998). *Nursing Times*. 94 (23), 34-36.
- Bauer, M. (1999). Their only privacy is between their sheets. Privacy and the sexuality of elderly nursing home residents. *Journal of Gerontological Nursing*. August, 37-41.
- Barnes, I. (2001) Sexuality and cognitive impairment in long-term care. *Canadian Nursing Home*. 12(3), 5-14.
- Barrett, M. (1982). *Sexuality and Multiple Sclerosis*. (booklet). Toronto: Multiple Sclerosis Society of Canada.
- Barrett, M. (1991). *Sexuality and Multiple Sclerosis*. (Information booklet). (3<sup>rd</sup> ed.). Toronto: Multiple Sclerosis Society of Canada.

- Basson, R. (1998). Sexual health of women with disabilities. *Canadian Medical Association Journal*. 159(4), 359-362.
- Batey, M.W. Conceptualization: Knowledge and logic guiding empirical research. *Nursing Research*. 26, 324-329.
- B.C. Coalition of the Disabled. "No sex, please. We're disabled." *Transition*. (Special Issue) July/August, 1990. .
- Beauchamp, T.L., & Childress, J.F. (2001). *Principles of Biomedical Ethics*. (5th ed.). New York: Oxford University Press.
- Becker, F. (1984). Sexuality and the spinal cord injured woman. In M. Tallmer, G. Buillard, M. Roberts, P. DeSanctus, A. Kutcher & P. Patterson (Eds.) *Sexuality and Life-Threatening Illness* (pp. 174-185). Springfield, Ill.: Charles C. Thomas Publisher.
- Berard, E.J.J. (1989). The sexuality of spinal cord injured women: Physiology and pathophysiology. A review. *International Medical Society of Paraplegia*. 27, 99-112.
- Bermann, K. (2003). Love and space in the nursing home. *Theoretical Medicine*. 24, 511-523.
- Berger, J.T. (2000). Sexuality and intimacy in the nursing home: A romantic couple of mixed cognitive capacities. *The Journal of Clinical Ethics*. 11(4), 309-313.
- Bernard, D. (1999). Child sexual abuse and the black disabled child. *Disability and Society*. 14 (3), 325-340.
- Bhui, K. & Puffett, A. (1994). Sexual problems in the psychiatric and mentally handicapped populations. *British Journal of Hospital Medicine*. 51, 459-464.
- Bourgeois, M. (1975). Sexualite et institution psychiatrique. *Evolution Psychiatrique*. 41, 551-573.
- Brady, S. & Carmen, E. (1990). AIDS risk in the chronically mentally ill: clinical strategies for prevention. *New Directions in Mental Health Services*. 48, 83-95.
- Breen, S. & Rines, B. (1996). Sexual health care in British Columbia: A model of service delivery. *SCI Nursing*. 13(1), 2-5.
- Bregman, S. & Hadley, R. (1976). Sexual Adjustment and feminine attractiveness among spinal cord injured women. *Archives of Physical Medicine and Rehabilitation*. 75(9), 448-450.
- Bretschneider, J.G. & McCoy, N.C. (1988). Sexual interest and behavior in healthy 80- to 102 - year-olds. *Archives of Sexual Behavior*. 17, 109-129.

- Briggs, J.L. (1970). *Never In Anger. Portrait of an Eskimo Family*. Cambridge: Harvard University Press.
- Brock, D. (1983). Paternalism and Promoting the Good. In Rolf E. Sartorius (Ed.) *Paternalism* (pp. 237-260). Minneapolis: University of Minnesota Press.
- Brown, D.G. (1972). Mill on Liberty and Morality. *Philosophical Review*. 81(2), 133-158.
- Brown, G., Carney, P., Cortis, J., Metz, L., Petrie, A. (1994). *Human Sexuality Handbook*. Springfield, MA.:The Association for Community Living, Inc.
- Brown, H. (1994). "An ordinary sexual life?": A review of the normalisation principle as it applies to the sexual options of people with learning disabilities. *Sexuality and Disability*. 9, 123-144.
- Brown, J. & Mirenda, P. (1997). *Express Yourself! Acknowledging and Respecting the Sexual Rights and Freedoms of People with Development Disabilities: A Learning Guide*. Victoria, B.C.: Ministry for Children and Families.
- Browne, A. (2003). Helping residents live at risk. *Cambridge Quarterly of HealthCare Ethics*. 12(1), 83-90.
- Browne, A., Blake, M., Donnelly, M., & Herbert, D. (2002). On liberty for the old. *Canadian Journal on Aging*. 21(2), 283-293.
- Buchanan, A. (1978). Medical Paternalism. *Philosophy and Public Affairs*. 7(4), 270-390.
- Cahill, J.F. (2001). Implications of the new privacy standards for healthcare institutions. *Healthcare Financial Management*. 55(6), 12-14.
- Chase, J. (1988). Sexual drive of patients in psychiatric hospitals (letter). *British Medical Journal*. 297, 1129.
- Chubon, R.A. (1981). Development and evaluation of a sexuality and disability course for the helping professions. *Sexuality & Disability*. 4 (11), 3-14.
- Churchman, A. & Sebba, R. (1989). In S. Ahrentzen, D. Levine & W. Michelson *Space, Time and Activity in the Home: A Gender Analysis*. *Journal of Environmental Psychology*, 89-101.
- Civic, D. Walsh, G. & McBride, D. (1990). Staff perspectives on sexual behaviour of patients in a state psychiatric hospital. *Hospital & Community Psychiatry*. 63, 765-768.
- Collopy, B., Boyle, P. & Jennings, B. (1991). New Directions in nursing home ethics.

*Hastings Center Report*. 21(2), 1-15.

Collopy, B., Dubler, N. Zuckerman, C. (1990). The ethics of home care: Autonomy and accommodation. *A Hastings Center Report Special Supplement*. 20(2), 1-16.

*Compendium of Pharmaceuticals and Specialties* (2004). Ottawa: Canadian Pharmacists Association.

Cooper, E. & Guillebaud, J. (1999). *Sexuality & Disability: A Guide to Everyday Practice*. Abingdon: Radcliffe Medical Press.

Cornelius, D. Chipouras, S. Daniels, S.M. (1982). *Who Cares? A Handbook On Sex Education and Counseling for Disabled People*. Sex and Disability Project. George Washington University. Baltimore: University Park Press.

Cort, E. (1998). Nurses' attitudes to sexuality in caring for cancer patients. *Nursing Times*. 94, 54-57.

Cosgray, R., Hanna, V., Fawley, R., & Money, M. (1991). Death from autoerotic asphyxiation in a long term psychiatric setting. *Perspectives in Psychiatric Care*. 27, 21-24.

Cournous, F., Empfield, M., Horwath, E., & Kramer, M. (1989). The management of HIV infection in state psychiatric hospitals. *Hospital & Community Psychiatry*. 40, 153-157.

Courtois, F., Charvier, K., Leriche, A. & Raymond, D. (1993). Sexual function in spinal cord injury men. 1. Assessing sexual capability. *Paraplegia*. 31, 771-784.

Courtois, F., Charvier, K., Leriche, A., Raymond, D. & Eyssette, M. (1995). Clinical approach to erectile dysfunction in spinal cord injured men. A review of clinical and experimental data. *Paraplegia*. 31, 628-635.

Cresswell, J. (1998). *Qualitative inquiry and research design. Choosing among five research traditions*. Thousand Oaks, CA: Sage Publications.

Daniels, S., Cornelius, D., Makas, E. & Chipouras, S. (1981). Sexuality and disability: The need for services. *Annual Review of Rehabilitation*. 2, 83-112.

Dauw, D. (1988). Evaluating the effectiveness of the SECS' Surrogate-Assisted Sex Therapy Model. *The Journal of Sex Research*. 24, 269-275.

Davidhizar, R., Boonstra, C., Lutz, C. & Poston, P. (1991). Teaching safer sex in a long-term psychiatric setting. *Perspectives in Psychiatric Care*. 27, 25-29.



de Mey, C. (1998). Opportunities for the treatment of erectile dysfunction by modulation of the NO Axis – Alternatives to Sildenafil Citrate. *Current Medical Research and Opinion*. 14(4), 187-202.

Depres, C. (1991). The meaning of home: Literature review and directions for future research and theoretical development. *The Journal of Architectural and Planning Research*. 8(2), 96-114.

Devlin, P. (1965). *The Enforcement of Morals*. London: Oxford University Press.

Dewey, J. (1970) (originally published 1920) *Reconstruction in Philosophy*. New York: Henry Holt.

Dianko, A.C., Brown, M.B., Herzog, A.R. (1990). Sexual function in the elderly. *Archives of Internal Medicine*. 150, 197-200.

Dolan, M. (1985). An eternal flame. *Nursing*. 15(1), 20.

Doyle, D., Bisson, D., Janes, N., Lynch, H. & Martin, C. (1999). Human sexuality in long-term care. *The Canadian Nurse*. Jan., 26-29.

Dressel, P. & Avant, W. (1983). Range of alternatives. In R. Weg (Ed.) *Sexuality in later years: Roles and behavior* (pp. 185-207). New York: Academic Press.

Ducharme, S.H. & Gill, K.M. (1997). *Sexuality after spinal cord injury: Answers to your questions*. Baltimore: Paul H. Brookes Publishing Co.

Dupras, A. & Poissant, M. (1987). The fear of sexuality in residents of a long-term care hospital. *Sexuality and Disability*. 8(4), 203-215.

Dworkin, G. (1971). Paternalism. In Richard A. Wasserstrom, (Ed.) *Morality and the Law* (pp. 107-126). Belmont, CA: Wadsworth.

Earle, S. (1999). Facilitated sex and the concept of sexual need: disabled students and their personal assistants. *Disability & Society*. 14(3), 309-323.

Earle, S. (2001). Disability, facilitated sex and the role of the nurse. *Journal of Advanced Nursing*. 36(3), 433-440.

Ekland, M. & McBride, K. (1997). Sexual health care: The role of the nurse. *The Canadian Nurse*. 93(7), 34-37.

Ekland, M., Griffin, S., Copeland, J., Elliott, S., & Nigro, M. (1998). Exploring male fertility options after spinal cord injury: The role of the nurse clinician. *SCI Nursing* 15(4), 95-98.

- Elliott, S. (1998). *A Guide to the Technique of Erection Enhancement*. Vancouver: G.F. Strong Rehab. Centre.
- Elliott, S. (1999). Assessment and treatment of erection dysfunction in men with chronic illness. Vancouver: G.F. Strong Rehab. Centre.
- Elliott, S. (2002a). Ejaculation and orgasm: Sexuality in men with SCI. *Topics in Spinal Cord Injury Rehabilitation*. 8(1), 1-15.
- Elliott, S. (2002b). Sexual dysfunction and infertility in men with spinal cord disorders. In Lin Vernon (Ed.) *Spinal Cord Medicine: Principles and Practice* (pp. 349-365). New York: Demos Medical Publishing.
- Elliott, S. & Krassioukov, A. (in press). Malignant autonomic dysreflexia following ejaculation in spinal cord injured men. *Spinal Cord*.
- Els, C. (2001). Assuming a disability perspective. *Canadian Bioethics Society Newsletter*. 6(1), 11-12.
- Evans, G. (1999). Sexuality in old age: Why it must not be ignored by nurses. *Nursing Times*. 95(20), 46-48.
- Fielden, K.I. (1997). Sex in resident care facilities. *The Lamp*. 54(9), 24-25.
- Feinberg, J. (1973). *Social Philosophy*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Feinberg, J. (1984). *Harm to Others. The moral limits of the criminal law*. New York: Oxford University Press.
- Feinberg, J. (1985). *Offense to Others. The moral limits of the criminal law*. New York: Oxford University Press.
- Feinberg, J. (1986). *Harm to Self. The moral limits of the criminal law*. New York: Oxford University Press.
- Fiesta, J. (1997). *Legal Implications in Long-Term Care*. Albany: Delmar Publishers.
- Forman, R., Gilmour-White, S. & Forman, N. (1996). *Drug-induced infertility and sexual dysfunction*. Cambridge: Cambridge University Press.
- Fowler, C. (Ed.) (1999). *Neurology of Bladder, Bowel, and Sexual Dysfunction*. New York: Butterworth-Heinemann.
- Fulton, J. (1996). Nursing: biopsychosocial care? In N. Cooper, C. Stevenson & G. Hale (Eds.) *Integrating Perspectives on Health* (pp. 36-46). Buckingham: Open University Press.

Gamel, C., Hengeveld, M., Davis, B. Van Der Tweel, I. (1995). Factors that influence the provision of sexual health care by Dutch cancer nurses. *International Journal of Nursing Studies*. 32 (3), 301-314.

Gamel, C., Davis, B. & Hengeveld, M. (1993). Nurses provision of teaching and counseling on sexuality: review of the literature. *Journal of Advanced Nursing*. 13, 1219 - 1227.

G.F. Strong. (1999). Assessment and management of changes to sexuality in people with chronic illness or physical disability. Women's sexuality in sickness and in health. Vancouver: G.F. Strong.

G.F. Strong. (1991). Talking about sexual issues and spinal cord injury. (Videotape). Vancouver: B.C. Rehabilitation Society & Production Magic Limited.

Geiger, R.C. (1979). Neurophysiology of sexual response in spinal cord injury. *Sexuality & Disability*. 2, 257-266.

Giami, A. (1987). Coping with the sexuality of the disabled: A comparison of the physically disabled and the mentally retarded. *International Journal of Rehabilitation Research*. 10 (1), 41-48.

Gibson, M., Bol, N., Woodbury, M., Beaton, C. & Janke, C. (1999). Comparison of caregivers', residents', and community-dwelling spouses' opinions about expressing sexuality in an institutional setting. *Journal of Gerontological Nursing*. 25(4), 30-39.

Gillan, P. (1980). Psychological methods in sex therapy for the disabled. *Sexuality and Disability*. 3(3), 199-203.

Glen, S. & Jownally, S. (1995). Privacy: A key nursing concept. *British Journal of Nursing*. 4(2), 69-72.

Godfrey, J. (1999). Empowerment through sexuality. In G. Wilkinson & M. Miers (Eds.) *Power and Nursing Practice*. (pp. 172-186). London: Macmillan.

Goldstein, A. & Krasner, L. (1987). *Modern Applied Psychology*. New York: Pergamon Press.

Gordon, R. M. (2000). The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making. *International Journal of Law and Psychiatry*. 23(1), 61-77.

Griffith, E.R. & Trieschmann, R.B. (1977). Sexual function restoration in the physically disabled: Use of a private hospital room. *Archives of Physical Medicine and Rehabilitation*. 58(8), 368-369.

- Gripton, J. & Valentich, M. (1983). Assessing sexual concerns of clients with health problems. *Journal of Social Work & Human Sexuality*. 2 (1), 53-66.
- Harison, J., Glass, C., Owens, R. & Soni, B. (1995). Factors associated with sexual functioning in women following spinal cord injury. *Paraplegia*. 33 (12), 687-692.
- Hennessey, A., Robertson, N., Swingler, R., Compston, D. (1999). Urinary, faecal and sexual dysfunction in patients with multiple sclerosis. *Journal of Neurology*. 246(11), 1027-1032.
- Hingsburger, D. (1993). Staff attitudes, homosexuality and developmental disability: A minority within a minority. *The Canadian Journal of Human Sexuality*. 2 (1), 19-22.
- Hodge, A.L. (1995). Addressing issues of sexuality with spinal cord injured persons. *Orthopaedic Nursing*. 14(3), 21-24.
- Hogg, P. (1992). *Constitutional Law of Canada* (3<sup>rd</sup> Ed.) Scarborough, ON: Carswell Thompson Canada Ltd.
- Holbrook, T. Policing sexuality in a modern state hospital. (1989). *Hospital & Community Psychiatry*. 40: 75-79.
- Ince, J.G. (2003). *The Politics of Lust*. Vancouver: Pivotal Press.
- Institute of Medicine (U.S.). Committee on quality of health care in America. (2001). *Crossing the Quality Chasm. A new health system for the 21st century*. Washington, D.C. National Academy Press.
- Jacobs, P. & Bobek, S. (1991). Sexual needs of the schizophrenic client. *Perspectives in Psychiatric Care*. 27, 15-20.
- Johnson, O.S. (2004). *The Sexual Spectrum. Exploring Human Diversity*. Vancouver: Raincoast Books.
- Joseph, R. (1991). A case analysis in human sexuality: Counselling to a man with severe cerebral palsy. *Sexuality and Disability*. 9(2), 149-159.
- Kaas, M.J. (1978). Sexual expression in the elderly in nursing homes. *Gerontologist*. 18 (4), 372-378.
- Kaeser, F. (1992). Can people with severe mental retardation consent to mutual sex? *Sexuality and Disability*. 10 (1), 33-43.
- Kamel, H.K. (2001). Sexuality in aging: Focus on institutionalized elderly. *Annals of Long-Term Care*. 9 (5), 64 -72.

- Keitner, G. & Grof, P. (1981). Sexual and emotional intimacy between psychiatric inpatients: formulating a policy. *Hospital & Community Psychiatry*. 32, 188-193.
- Kempton, W. & Kah, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability*. 9 (2), 93-111.
- Kettl, P., Zarefoss, S., Jacoby, K., Garman, C, Hulse, C., Rowley, F., Corey, R., Sredy, M., Bixler, E. & Tyson, K. (1991). Female sexuality after spinal cord injury. *Sexuality and Disability*. 9 (4), 287-295.
- Kirkendall, L. (1976). A new bill of sexual rights and responsibilities. *The Humanist*, Jan/Feb.
- Koch, T. (2001). Disability and difference: balancing social and physical constructions. *Journal of Medical Ethics*. 27, 270-376.
- Koch, T., Kralik, D. & Eastwood, S. (2002). Constructions of sexuality for women living with multiple sclerosis. *Journal of Advanced Nursing*. 39(2), 137-145.
- Kolcaba, R. (1997). The primary holism in nursing. *Journal of Advanced Nursing*. 25, 290-296.
- Kreuter, M., Sullivan, M. & Siosteen, A. (1996). Sexual adjustment and quality of relationships in spinal paraplegia: A controlled study. *Archives of Physical Medicine and Rehabilitation*. 77(6), 541-548.
- Krogh, K., Nielsen, J., Djurhuus, J., Mosdal, C., Sabroe, S. & Laurberg, S. (1997). Colorectal function in patients with spinal cord lesions. *Diseases of the Colon and Rectum*. 40(10), 1233-1239.
- Kroll, K. & Klein, E. (1992). *Enabling Romance: A Guide to Love, Sex & Relationships For the Disabled*. New York: Harmony Books.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage Publishers.
- Latimer, A.M. (1981). Accountability for the sexual awareness of the spinal cord injured patient. *Rehabilitation Nursing*. 6(4), 8-11.
- Lee, H. (1960). *To Kill A Mockingbird*. New York: Warner Books Inc.
- Leo, G., Rao, S., Bernardin, L. (1991). Sleep disturbances in multiple sclerosis. *Neurology*. 41(1), 727-729.
- Lewis, K. (1993). Sexual right policies emphasize freedom, privacy and respect for all.

*Provider*. Dec., 35-36.

Lewis, S. & Bor, R. (1994). Nurses' knowledge of and attitudes towards sexuality and the relationship of these with nursing practice. *The Journal of Advanced Nursing*. 20(2), 251-259.

Lincoln, Y.S & Guba, E. G. (1985). *Processing naturalistically obtained data*. Newbury Park, CA: Sage Publications.

Linden, A.M. (1982). *Canadian Tort Law*. (3rd ed.). Toronto: Butterworths.

Lowman, J. (1990). Prostitution in Canada. *Journal of Comparative Law*. 23(3), 13-48.

Lundberg, P.O. (1978). Sexual dysfunction in patients with multiple sclerosis. *Sexuality and Disability*. 1, 218-226.

Mace, D., Banneman, R. & Burton, J. (1974). *The Teaching of Human Sexuality in Schools for Health Professionals*. Geneva: World Health Organisation.

Marchant, R. & Page, M. (1993). *Bridging the gap. Child protection work with children with multiple disabilities*. London: NSPCC.

Margolin, K.N. (1988). Risks of a privacy policy by residential institutions for handicapped adolescents. *Journal of Rehabilitation*. 54(2), 50-54.

Marshall, N. (1974). Dimensions of privacy. *Multivariate Behavioural Research*. 9(3), 225-271.

Marshall, C. & Rossman, G. (1999). *Designing qualitative research*. (3<sup>rd</sup> ed.) Thousand Oaks: Sage Publications.

Mattson, D., Petrie, M. & Srivastava, D. (1995). *Multiple sclerosis. Sexual dysfunction and Its Response to Medications*. 52(9), 862-868.

Maurice, W.L. (1999). *Sexual Medicine in Primary Care*. St. Louis: Mosby, Inc.

Maxfield, G. (1996). *The Novel Approach to Sexuality and Disability*. Nevada: Northern Nevada Amputee Support Group.

May, C. (1992). Nursing work, nursing knowledge and the subjectification of the patient. *Sociology of Health and Illness*. 14, 307-315.

Mayers, K. & McBride, D. (1988). Sexuality training for caretakers of geriatric residents in long term care facilities. *Sexuality & Disability*. 16(3), 227-236.

McAlonan, S. (1996). Improving sexual rehabilitation services: The patient's

perspective. *American Journal of Occupational Therapy*. 50(10), 826-834.

McCann, E. (2000). The expression of sexuality in people with psychosis: breaking the taboos. *Journal of Advanced Nursing*. 32(1), 132-138.

McCracken, A. (1980). Sexual practices by elders: The forgotten aspect of functional health. *Journal of Gerontological Nursing*. 14(10), 21-25.

McSherry, B. & Somerville, M. (1996). *Sexual activity among institutionalized persons in need of special care*. (Working paper). Montreal: McGill Centre for Medicine, Ethics and Law.

McSherry, B. & Somerville, M. (1998). Sexual activity among institutionalized persons in need of special care. *Windsor Yearbook of Access to Justice*. 16, 90-131.

Merriam, S.B. (1998). *Qualitative research and case study application in education*. San Francisco, CA: Josey-Bass Publishers.

Merrill J.M. & Thornby J.I. (1990). Why doctors have difficulties with sexual histories. *Southern Medical Journal*. 83 (6), 613-617.

Metz, L. (1998). *Multiple sclerosis: symptomatic therapies*. 18(3), 389-395.

Meyer, I., Cournos, F., Empfield, M., Agosin, B. & Floyd, P. (1992). HIV prevention among psychiatric inpatients: a pilot risk reduction study. *Psychiatric Quarterly*. 63, 187-197.

Mill, J.S. (1965) (originally published 1859). On Liberty. In M. Lerner (Ed.) *Essential Works of John Stuart Mill* (pp. 251-360). New York: Bantam Books.

Mill, J.S. (2004) (originally published 1848). *Principles of Political Economy*. Amherst NY: Prometheus Books.

Mishler, E.G. (1991). Representing discourse: the rhetoric of transcription. *Journal of Narrative and Life History*. 1, 225-280.

Molloy, W., Reich, M., Jacobson, J., Rock, S., Renaud, S., Milburn, G., & Sheehan, C. (1999). *Intimacy and Sexuality in Long Term Care Facilities*. Windsor, ON: Windsor Essex Geriatric Assessment/Consultation Program.

Morris, J. (1993). *Independent lives?: Community care and disabled people*. Basingstoke: Macmillan.

Morse, J. & Field, P. (1985). *Qualitative Methods in Nursing Research*. Thousand Oaks, CA: Sage Publications.

- Morse, J.M. & Field, P.A. (1995). *Qualitative Research Methods For Health Professionals*. (2nd Ed.). Thousand Oaks, CA: Sage Publications.
- Mulligan, T. & Modigh, A. (1991). Sexuality in dependent living situations. *Clinics in Geriatric Medicine*. 7(1), 153-160.
- Mulligan, T. & Palguta, R. (1991). Sexual interest, activity and satisfaction among male nursing home residents. *Archives of Sexual Behaviour*. 20(2), 199-204.
- Noddings, N. (1984). *Caring, a feminine approach to ethics & moral education*. Berkeley: University of California Press.
- Noonan, R.J. (1984). "Sex surrogates: A clarification of their functions." SexQuest/The Sex Institute, NYC Internet. Available: <http://www.sexquest.com/surrogat.htm>
- Nye, R.A. (Ed.). (1999). *Sexuality*. Oxford: Oxford University Press.
- Oakley, A. (2000). *Experiments in Knowing: Gender and Method in the Social Sciences*. Oxford: Polity Press.
- O'Brien, M. (1990). "On seeing a sex surrogate." The Sun. May, 174. Internet. Available: <http://www.pacificnews.org/pacificnews/pacificnews/pacificnews/marko/sex-surrogate.html>
- Payne, T. (1976). Sexuality of nurses: correlations of knowledge, attitudes and behaviour. *Nursing Research*. 25 (4), 286-292.
- Pederson, L. (1993). Sexuality after 70: Fact and fiction. Symposium conducted by gerontological nurses group of B.C. Vancouver, Canada.
- Perlin, M. (1993). Hospitalized patients and the right to sexual interaction: Beyond the last frontier? *New York University Review of Law and Social Change*. 20, 517-547.
- Phtiaka, H. (1994). What's in it for us? *Qualitative Studies in Education*. 7(2), 155-164.
- Picard, E. I. & Robertson, G.B. (1996). *Legal Liability of Doctors & Hospitals in Canada*. (3rd ed.). Scarborough, ON: Carswell.
- Pollard, M. & Barker, B. (1985). Straight talk on sex for the older patient. *RN*. 48(2), 17-18.
- Preinsperg, K. (2002) *What rights to sexual expression can people with disabilities living in institutions justifiably claim? Toward a Reasoned Moral Perspective*. Unpublished manuscript.



Rawls, J. (1971). *A theory of justice*. Cambridge, MA: Belknap Press of Harvard University Press.

Registered Nurses Association of British Columbia (RNABC). (2002a). *Policy Statement. Nurse-Client Relationships: Establishing Professional Relationships and Maintaining Appropriate Boundaries*. Vancouver: RNABC.

Registered Nurses Association of British Columbia (RNABC). (2002b). *Nurse to Nurse. Information for Nurses. Nurse-Client Relationships*. Vancouver: RNABC.

Reinisch, J. & Beasley, R. (1990). *The Kinsey Institute New Report on Sex*. New York: St. Martens Press.

Remnant, P. (1970). The Relevance of Mill. *Queen's Quarterly*. 77(4), 513-529.

Richardson, J. & Lazur, A. (1995). Sexuality in the nursing home patient. *American Family Physician*. 51(1), 121-124.

Rines, B. & Breen, S. (1991a). *Talking About Sexual Issues and SCI: A Guide for Professional Caregivers*. Vancouver: B.C. Rehabilitation Society.

Rines, B. & Breen, S. (1991b). *Talking about sexual issues and spinal cord injury*. (Videotape). Vancouver: B.C. Rehabilitation Society & Production Magic Limited.

Riverview Hospital. Port Coquitlam, B.C. (1993a). *Policy on Patient Sexuality*.

Riverview Hospital. Port Coquitlam, B.C. (1993b). *Patient Sexuality Manual. A Guide to the Riverview Hospital Policy on Patient Sexuality*.

Riverview Hospital. Port Coquitlam, B.C. (1994). *Charter of Patient Rights*.

Riverview Hospital. Port Coquitlam, B.C. (1996). *Policy and Procedure Manual. "Patient Sexuality: Responsibility and Support"*. No. PAT-120.

Riverview Hospital. Port Coquitlam, B.C. (1999). *Riverview's Patient Sexuality Policy*. (Dan Eldridge).

Robertson, G.B. (1994). *Mental disability and the law in Canada*. (2<sup>nd</sup> ed.). Scarborough, ON: Carswell.

Roccamo, G. & Haydon, J. (1999). *Medicine in the Litigation Process*. Scarborough, ON.: Carswell.

Roe, B. (1999). Incontinence & sexuality: findings from a qualitative perspective. *Journal of Advanced Nursing*. 30 (3), 573-579.

Rozovsky, L.E. (1994). *The Canadian Patient's Book of Rights. A Consumer's Guide to Canadian Health Law*. Toronto: Doubleday Canada Limited.

Rozovsky, L.E. (1979). *Canadian Hospital Law*. (2<sup>nd</sup> ed.). Ottawa: Canadian Hospital Association.

Rozovsky, L.E. & Rozovsky, F.A. (1982). *Legal Sex*. Toronto: Butterworths Canada Ltd.

Ryan, A. (1965). John Stuart Mill's art of living. *The Listener*. October 21, 620-622.

Sacks, O. (1982). *Awakening*. London: Pan Books

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*. 18, 179-183.

Sant Angelo, D. (2000). Learning disability community nursing: Addressing emotional and sexual health needs. In R. Astor & K. Jeffereys (Eds.) *Positive Initiatives for People with Learning Disabilities: Promoting Healthy Lifestyles* (pp.52-68). Basingstoke: Macmillan.

Saretsky, K. (1987). The right to be human: How one facility cares. *Provider*. 13(20), 22-23.

Schrover, L.R. & Jensen, S.B. (1988). *Sexuality and Chronic Illness. A Comprehensive Approach*. New York: The Guilford Press.

Schuler, M. (1982). Sexual counselling for the spinal cord injured: A review of five programs. *Journal of Sex & Marital Therapy*. 8(3), 241-252.

Seeman, M., Lang, M. & Rector, B. (1990). Chronic schizophrenia: a risk factor for HIV? *Canadian Journal of Psychiatry*. 35, 765-768.

Seymour, W. (1998). *Remaking the Body: Rehabilitation and Change*. London: Routledge.

Shabsigh, R. (1997). The effects of testosterone on the cavernous tissue and erectile function. *World Journal of Urology*. 15(1), 21-26.

Shakespeare, T., Gillespie-Sells, K. & Davies, D. (1996). *The Sexual Politics of Disability. Untold Desires*. London: Cassell Wellington House.

Shakespeare, W. (1597). *King Richard the Third*. Internet Shakespeare Editions. February, 2000. Internet. Available:  
[http://web.uvic.ca/shakespeare/Annex/DraftTxt/R3/R3\\_Q/index.html](http://web.uvic.ca/shakespeare/Annex/DraftTxt/R3/R3_Q/index.html)

Shalom Village. (1997). *Intimacy and sexuality practice guidelines*. Hamilton, ON: Shalom Village.

Sharpe, G. (1987). *The Law and Medicine in Canada*. (2nd ed.). Toronto: Butterworths Canada Ltd.

Sharpe, G. & Sawyer, G. (1978). *Doctors and the Law*. Scarborough: Butterworths Canada Ltd.

Sipski, M.L. & Alexander, C.J. (1997a). *Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide*. Gaithersburg, MD.: Aspen Publishers Inc.

Sipski, M.L. & Alexander, C.J. (1997b). Physiologic parameters associated with sexual arousal in women with incomplete spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*. 78(3), 305-313.

Sipski, M.L. & Alexander, C.J. (1993a). Sexual activities, response and satisfaction in women pre- and post-spinal cord injury. *Archives of Physical Medicine and Rehabilitation*. 74(10), 1025-1029.

Sipski, M.L. & Alexander, C.J. (1993b). *Sexuality Reborn*. (video recording). Kessler Institute for Rehabilitation. West Orange, NJ: Kessler Medical Rehabilitation Research and Education Corporation.

Sipski, M, L., Alexander, C.J. & Rosen, R.C. (1995). Physiological parameters associated with psychogenic sexual arousal in women with complete spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*. 76(9), 811-818.

Slater, L. (1999). Viagra: Does It Work with Spinal Cord Injury? *New Mobility*. 10(65), 45-47.

Smith, E.M. & Bodner, D.R. (1993). Sexual dysfunction after spinal cord injury. *Urologic Clinics of North America*. 20(3), 535-542.

Society for Human Sexuality. "An Interview with Vena Blanchard." International Professional Surrogates Association. February 1, 1999. Internet. Available: <http://www.sexuality.org/vena99.html>

Sonksen, J & Biering-Sorenson, F. (1992). Fertility in men with spinal cord or cauda equina lesions. *Seminars in Neurology*. 12, 98-105.

Spector, I. & Fremeth, S. (1996). Sexual behaviors and attitudes of geriatric residents in long-term care facilities. *Journal of Sex and Marital Therapy*. 22(4), 235-246.

Starr, B. & Weiner, M. (1981). *The Starr-Weiner report on sex and sexuality in the*

*mature years*. New York: McGraw-Hill Inc.

Stein, R. (1992). Sexual dysfunctions in the spinal cord injured. *Paraplegia*. 30, 54-57.

Steinke, E.E. (1997). Sexuality in aging: Implications for nursing facility staff. *The Journal of Continuing Education In Nursing*. 26(2), 59-63.

Stenager, E., Stenager, E.N. & Jensen, K. (1994). Sexual problems in multiple sclerosis. *International Journal of Adolescent Medical Health*. 7, 95-105.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research. Grounded theory procedures and techniques*. Newbury Park, CA.: Sage Publishers.

Sturdy, S. (1997) Prostitution in Canada. Internet. Available:  
<http://www.mala.bc.ca/www/crimweb/Student/Sturdy.htm>

Szasz, G. (1989). Sexuality in persons with severe physical disability. *Canadian Family Physician*. 33, 345-351.

Szasz, G. (1983). Sexual incidents in an extended care unit for aged men. *Journal of American Geriatrics Society*. 7(31), 407-411.

Tallmer, M. (1984). Sexual attitudes and activities in old age. In M. Tallmer, D.Bullard, M. Roberts, P. DeSanctus, A. Kutchner, P. Patterson (Eds.) *Sexuality and Life-Threatening Illness* (pp. 148-159). Springfield, Ill.:Charles C. Thomas Publishers.

Tepper, M. (1992). Sexual education in spinal cord injury rehabilitation. Current trends and recommendations. *Sexuality and Disability*. 10(1), 15-31.

Tepper, M. (1997). *Providing comprehensive sexual health care in spinal cord injury rehabilitation*. Huntington, CT: Mitchell Tepper.

Tepper, M. (1999). Letting go of restrictive notions of manhood: male sexuality, disability and chronic illness. *Sexuality and Disability*. 17(1), 37-52.

Toronto Rehabilitation Institute. (1994). The Queen Elizabeth Hospital. *Guidelines for Patients' Privacy Space Usage*. Toronto, ON: Toronto Rehabilitation Institute.

Turnstull, P. & Henry, M. (1996). Approaches to Resident Sexuality. *Journal of Gerontological Nursing*. 22(6), 37-42.

Vas, C.J. (1969). Sexual impotence and some autonomic disturbances in men with multiple sclerosis. *Acta Neurologica Scandinavica*. 45, 166-182.

Veatch, R. (1986). *The Foundations of Justice*. New York: Oxford University Press.

- Waldron, J. (Ed.) (1984). *Theories of Rights*. New York: Oxford University Press.
- Wallace, M. (1992). Management of sexual relationships among elderly residents of long-term care facilities. *Geriatric Nursing*. Nov/Dec., 308-311.
- Wasow, M. & Loeb, M. (1979). Sexuality in nursing homes. *Journal of the American Geriatrics Society*. 27 (2), 73-79.
- Waxler-Morrison, N.R. (1995). The use of qualitative methods to strengthen psychosocial research in cancer. *Journal of Psychosocial Oncology*. 13, 177-191.
- Webb, C. (1985). *Sexuality, Nursing and Health*. Chichester: J. Wiley & Sons.
- Webb, C. (1988). A study of nurses' knowledge and attitudes about sexuality in healthcare. *International Journal of Nursing Studies*. 25(3), 235-244.
- Weeks, J. (1986). *Sexuality*. London: Routledge.
- Welch, S.J. & Clements, G.W. (1996). Development of a policy on sexuality for hospitalized chronic psychiatric patients. *Canadian Journal of Psychiatry*. 41, 273-279.
- Welch, S.J., Clements, G.W. & Moreau, M.E. (1999). Developing and implementing a policy for consensual sex between inpatients. In Peter Buckley (Ed.) *Sexuality and Mental Illness* (pp. 75-109). Amsterdam: Harwood Academic Press.
- Welch, S., Magher, J., Soos, J. & Bhopal, J. (1991). Sexual behaviour of hospitalized chronic psychiatric patients. *Hospital and Community Psychiatry*. 42, 855-856.
- Westcott, H. (1994). Abuse of children and adults who are disabled. In S. French (Ed.) *On equal terms: working with disabled people* (pp. 190-206). London: Butterworth Heinemann.
- Westgren, N., Hulting, C., Levi, R., Seiger, A. & Westgren, M. (1997). Sexuality in women with traumatic spinal cord injury. *Acta Obstetrica Et Gynecologica Scandanavica*. 76(10), 977-983.
- Whipple, B. & Komisaruk, R. (1997). Sexuality and women with complete spinal cord injury. *Spinal Cord*. 25(3), 136-138.
- White, A. (2000). How should nurses respond to patient's sexual needs? *Nursing Times*. 96(5), 35.
- White, C.B. (1982). Sexual interest, attitudes, knowledge, and sexual history in relation to sexual behavior in the institutionalized aged. *Archives of Sexual Behavior*. 11 (1), 11-21.

- White, C. & Catania, J. (1982). Psychoeducational intervention for sexuality with the aged, family members of the aged and people who work with the aged. *International Journal of Aging and Human Development*. 15, 121-138.
- Whittaker, E. (1999). *Towards the ethical practice of social science*. World Social Science Report 1999. A. Kazancigil & D. Makinson. Paris, UNESCO/Elsevier.
- Williams A., Cooke H. & May C. (1998). *Sociology, Nursing and Health*. Oxford: Butterworth Heinemann.
- Williams, S. (1999). Let's talk about sex. In search of the skills to talk about sexual issues. *Nursing Times*. 95(26), 58-62.
- Willnuth, M.E. (1987). Sexuality after spinal cord injury. *Clinical Psychology Review*. 7(4), 389-412.
- Winkler, W.K. & Thorup, P.J. (1992). The duty of accommodating and its implications for the employer. Vol. 1 *Canadian Labour L.J.* 283.
- Wolfenden, J. (Sir). (1957). U.K. *Report of the Committee on Homosexual Offenses and Prostitution*. Cmd. 247. London: H.M.S.O.
- Woods, N. & Catanzaro, M. (1988). *Nursing research: theory and practice*. St. Louis: Mosby.
- Yalden, M.F. (1992). The duty to accommodate - A view from the Canadian Human Rights Commission. Vol. 1 *Canadian Labour L.J.* 283.
- Yarkony, G.M. (1990). Enhancement of sexual function and fertility in spinal cord-injured males. *American Journal of Physical Medicine and Rehabilitation*. 69(2), 81-87.
- Yin, R.K. (1994). *Case Study Research. Design and Methods*. (2nd. ed.). Thousand Oaks, CA: Sage Publications.
- Zorzon, M., Zivadinov, R., Bosco, A., Monti Bragadin, L., Moretti, R., Bonfigli, L., Morassi, P., Iona, L. & Cazzato, G. (1999). Sexual dysfunction in multiple sclerosis: a case-control study. 1. Frequency and comparison of groups. *Multiple Sclerosis*. 5(6), 418-427.

## APPENDIXES

### APPENDIX A - QUESTIONNAIRES

#### THE ETHICS OF SEXUAL ACTIVITY IN LONG TERM CARE FACILITIES

##### RESIDENTS QUESTIONNAIRE

Thank you for agreeing to participate in my research study. The purpose of this study is to gain a greater understanding of the experiences of those living and working in long-term health care facilities with respect to sexual needs, desires and activities. The findings from this study will help develop ethical policies regarding sexual activities. Please feel free not to answer any questions you do not feel comfortable with and you can withdraw at any time during the interview without effect on the services you receive.

General statistical data:

1. Name of resident
2. Gender of resident
3. Date of birth of resident
4. Date of admission to facility
5. Dates lived in an independent living setting
6. Dates and names of other group settings resident has lived in
7. Medical diagnosis
8. Competent legally
9. Place of interview
10. Date of interview
11. Follow up or referral to sexual health required
12. Consent form filled out with copy to resident
13. Name of the BC Rehab's Sexual Health Team member, if present
14. Permission to interview a family member
15. Name of family member

Part 1: Views of oneself as a sexual person:

1. What does being sexually active mean to you? (e.g. fantasy, physical experience etc.)
2. What priority do sexual activities have in your life? (i.e. compared to other things important to you)
3. Has this priority changed over time?  
How has your disability impacted your sexual life or sense of yourself as a sexual person?
4. What does the institution provide to meet your sexual needs?
5. What barriers exist in the institution to prevent meeting those needs?

6. What sorts of reactions do you get from health-care workers regarding your sexual needs? Examples?
7. Has religion or any other factor played a role in your view of sexual activities?
8. Do you believe you have the right to express yourself sexually in any way you like or do you believe the institution and yourself should share the decision?

Part 2: Sexual Experience:

1. Have you had sexual experiences in the institution?  
What sexual experiences do you want that you have not been able to have?

Part 3: Confidentiality:

1. Have you ever suffered any fears or consequences from someone knowing about your sexual desires and activities?
2. What does the institution do to protect confidentiality? (e.g. Is there charting of sexual activity)?

Part 4: Privacy Requirements:

1. Do you have privacy available to you for your sexual activities? (e.g. access to a private room etc.)
2. Given that many of your daily activities are charted and not private (e.g. your sleep, eating, bowel movements) does lack of privacy affect your needs for privacy in your sexual activities?

Part 5: Requirements for sexual partners or sexual stimulation:

1. How does your personal situation or the institutional setting affect your ability to obtain sexual partners, sexual devices, videos etc.? (e.g. finances)
2. How does the institution promote your obtaining sexual partners or sexual devices?

Part 6: Assistance:

1. What assistance do you require to carry out your sexual activities?  
(e.g. assistance getting into bed, railings, undressing, positioning sexual devices)
2. From whom would you prefer to ask assistance? (i.e. nurse, same or opposite sex person, sexual surrogate, friend)
3. What is your comfort level for asking for assistance?
4. What assistance is available?
5. What assistance is there that you would like/need that is not available?

Part 7: Education

1. Are you aware of any education that is available for residents, family or staff



- around issues of sexuality?
2. Can you suggest any that would be useful?
  3. Do you believe you have received enough education regarding how you can function sexually given your disability?

#### Part 8: Relatives

1. What role do you think your relatives should have regarding your sexual activities?

#### Part 9: Function of Institution

1. Do you see this institution primarily as a home, a hospital, a rehabilitation centre or anything else?
2. Why do you choose to live here?

#### Part 10: Other

1. Do you have anything more you would like to say about these topics?

#### Added Questions:

#### Part 11: Financial Position

1. What is your financial position and what approx. dollars do you have for spending money per month?

#### Part 12: Relatives to be Interviewed

1. Do you have any relatives that you would be willing to have interviewed regarding their views of your sexuality?

#### Part 13: Sex vs. intimacy

1. How do you view sex and intimacy? Are there differences between the two for you?

#### STAFF QUESTIONNAIRE

Thank you for agreeing to participate in my research study. The purpose of this study is to gain a greater understanding of the experiences of those living and working in long-term health care facilities with respect to sexual needs, desires and activities. The findings from this study will help develop ethical policies regarding sexual activities. Please feel free not to answer any questions you do not feel comfortable with and you can withdraw at any time during the interview without effect on your employment.

#### General Statistical Data:

1. Name of health-care provider
2. Gender of health-care provider
3. Date of birth
4. Religious Affiliation
5. Position in institution
6. Brief Job description including particular reference to sexual activities of residents
7. Date of employment with institution
8. Professional qualifications/education
9. Place of interview
10. Date of interview
11. Consent form filled out with copy to health care worker

#### Part 1: Views of Staff

1. Do you believe disabled people have sexual needs and desires?
2. Are there any specific sexual activities that you think residents should not be allowed to engage in? (e.g. watching pornographic videos, masturbation, sex with prostitutes, sex with other residents, sex requiring the assistance of staff, etc.)
3. How do the following influence your promoting or restricting of sexual activities of the residents?  
Your personal values?  
Personal values of resident?  
Institutional policies?  
Union policies?  
Professional codes of ethics?
4. What concerns do you have for residents who engage in sexual activities? (i.e. risk to self and risk to others)
5. If you believe residents should not behave sexually what do you recommend they do about their sexual needs and desires?
6. If the resident experiences difficulties when engaging in sexual activities do you think this is because of their illness/disability or to the institution's policies?
7. Do you think that sexual activity should and does play a role in long-term rehabilitation?

#### Part 2: Cognitively Impaired

1. When dealing with residents' sexual activities how if at all, do you think those who are cognitively impaired should be treated differently?
2. How would you define cognitive impairment in relation to ability to make their sexual activity decisions?

#### Part 3: Professional Autonomy

1. At what level should decisions around sexual activities be made? (i.e. residents,

- individual staff members, institutional policy or shared between...?)
2. Do you feel you have the right not to comply with policy or healthcare decisions that you disagree with?

#### Part 4: Legal Liability

1. Do you have concerns about possible legal liability, if residents are allowed to carry out their sexual desires in any way they wish?
2. If the resident needs assistance do you feel that would affect your legal liability?
3. Do you think people have a legal right to engage in sexual activity?

#### Part 5: Fear of Reprisals

1. Do you think anyone would take action against you if you assisted or knew of sexual activities taking place?
2. Who do you think might possibly take action against you?

#### Part 6: Function of Institution

1. Do you see this institution primarily as a home, a hospital, a rehabilitation centre or anything else?
2. In your view what is the primary responsibility regarding sexual activity for each of the front line health providers, professional health providers and administrators?

#### Part 7: Assistance

1. What sorts of assistance do you think the institution should offer to resident for their sexual activities?
2. What assistance are you willing to give residents for their sexual activities?
3. What are your views regarding giving assistance to residents for their sexual activities?

#### Part 8: Education:

1. Are you aware of any education that is available for residents, family and/or staff around issues of sexuality?
2. Can you suggest any that would be useful?
3. Do you require more knowledge of how residents function sexually given their disabilities?
4. When risks are involved in sexual activities do you think the decision should be shared by all concerned and what role do you think the resident should play in making those decisions?

#### Part 9: Prevalence of Sexual Activities:

1. How prevalent do you think sexual activity is in the resident population?

#### Part 10: Role of the Family

1. What role do you think relatives should have regarding sexual activities of the resident?

#### Part 11: Other

1. Do you have anything more you would like to say about these topics?

#### Added Questions:

#### Part 12: Sexual Advances

1. Have residents ever made sexual advances or sexual propositions towards you?
2. Why do you think they have done so?

#### Part 13: Action when concerns ignored

1. What actions do you take if any if you feel your concerns are not taken seriously by administration or other staff?

### ADMINISTRATIVE QUESTIONNAIRE

Thank you for agreeing to participate in my research study. The purpose of this study is to gain a greater understanding of the experiences of those living and working in long-term health care facilities with respect to sexual needs, desires and activities. The findings from this study will help develop ethical policies regarding sexual activities. Please feel free not to answer any questions you do not feel comfortable with and you can withdraw at any time during the interview without effect on your employment.

#### Part 1: Views of Administrators

1. Do you believe disabled people have sexual needs and desires?
2. Are there any specific sexual activities that you think residents should not be allowed to engage in?
3. How do the following influence your promotion or restriction of sexual activities of the residents?  
Your personal values?  
Personal values of resident?

Institutional policies?

Union policies?

Professional codes of ethics?

5. Do you believe residents think they have the right to carry out their sexual activities as they wish?
6. If you believe residents should not behave sexually, what do you recommend they do about their sexual needs and desires?
7. How diverse do you believe the staff attitudes to sexual activity are?
8. If the resident experiences difficulties when engaging in sexual activities do you think this is because of their illness/disability or to the institution's policies?
9. Do you think that sexual activity should and does play a role in long-term rehabilitation?

## Part 2: Cognitively Impaired

1. Regarding residents' sexual activities do you think cognitively impaired residents should be treated differently?
2. Are there sexual activity policies for the cognitively impaired?
3. How would you define cognitive impairment in relation to ability to make their sexual activity decisions?

## Part 3: Professional Autonomy

1. At what level should decisions around sexual activities be made? (i.e. residents, individual staff members, institutional policy or shared with....?)
2. Do you believe staff must follow the policies developed by administrators with respect to sexual activities of residents.

## Part 4: Risks

1. What do you see are the risks to the institution if you allow sexual activities?
2. What do you see are the risks to the resident themselves if you allow sexual activities?
3. What do you see are the risks to others if you allow residents to determine their own level of sexual activities?
4. Do you think it is up to you to administration to establish what level of risks should be undertaken regarding sexual activities, or is it staff's, the resident or a shared decision with others?

## Part 5: Legal Liability

1. Do you have concerns about possible legal liability if residents are allowed to carry out their sexual desires in any way they wish?
2. If the resident needs assistance do you feel that would affect your legal liability?
3. Do you think people have a legal right to engage in sexual activity?

#### Part 6: Function of Institution

1. Do you see this institution primarily as a home, a hospital, a rehabilitation centre or anything else?
2. In your view what is the primary responsibility regarding resident sexual activity of each of the front line health providers, professional health providers and administrators?

#### Part 7: Assistance:

1. What sorts of assistance do you think the institution should provide for the residents' sexual activities?
2. Who should be responsible for providing the assistance?
4. What are your views regarding giving assistance to residents for their sexual activities?
5. Are there any sexual activities you would not want staff to assist residents with?
6. What assistance regarding residents' sexual activities do you feel staff are obligated to help with?
7. Do you believe staff can be hired on the basis of their willingness to assist in "authorized" sexual activities of residents?

#### Part 8: Education:

1. Are any education programs available for residents, family and/or staff around issues of sexuality?
2. Can you suggest any that would be useful?
3. When risks are involved in sexual activities do you think the decision should be shared by all concerned and what role do you think the resident should play in making those decisions?

#### Part 9: Prevalence of Sexual Activities:

1. How prevalent do you think sexual activity is in the resident population?

#### Part 10: Role of the Family

1. What role do you think relatives should have regarding sexual activities of the resident?

## APPENDIX C - LEGAL CASES CITED

*Bouvier v. Metro Express*, (1992) C.H.R.D. No. 8

*British Columbia (Public Service Employee Relations Commission) v. British Columbia Government and Service Employees' Union (B.C.G.S.E.U.)* [1999] S.C.R. 3

*Crits. v. Sylvester*, (1956) 1 D.L.R. (2d) 502 (Ont. C.A.); [affirmed] [1956] S.C.R. 991

*Crocker v. Sundance Northwest Resorts Ltd.*, [1988] 1 S.C.R. 1186

*Dyck v. Manitoba Snowmobile Association Inc.*, [1985] S.C.R. 589

*Eldridge v. British Columbia (Attorney General)*, [1977] 3 S.C.R. 624

*E. (Mrs.) v. Eve*, [1986] 2 S.C.R. 388

*Ferguson v. Hamilton Civic Hospitals*, (1983) 144 D.L.R. (3d) 214 (Ont. H.C.)

*Frerotte v. Irwin*, (1986) S.J. No. 644 (Q. B.)

*Funk Estate v. Clapp*, (1988) 54 D.L.R. (4<sup>th</sup>) 512 (B.C.C.A.)

*Home Office v. Dorset Yacht*, [1970] 2 All E.R. 294 (HL)

*Howley v. R.*, (1973) 36 D.L.R. (3d) 261 (Fed T.D.)

*Jordan House Ltd. v. Menow*, [1974] S.C.R. 239.

*Koerber v. Kitchener-Waterloo Hospital*, (1987) 62 O.R. (2d) 613 (H.C.)

*Lawson v. Wellesley Hospital*, (1975) 61 D.L.R. (3d) 445 [affirmed], (1977) 76 D.L.R. (3d) 688 (S.C.C.)

*McKeachie v. Alvarez*, (1970) 17 D.L.R. (3d) 87 (B.C.S.C.)

*Ontario (Human Rights Commission) v. Etobicoke (Borough)*, (1982) 1 S.C.R. 202

*Park v. Park*, [1953] 2 All E.R. 1411 (C.A.)

*R.B. v. Children's Aid Society of Metropolitan Toronto*, [1995] 1 S.C.R. 315

*R. v. Beare*, [1988] 2 S.C.R. 387

*R. v. Brooks*, (1902) 5 C.C.C. 372 (B.C.C.A.)

*R. v. Davidson*, (1917) 1128 C.C.C. 44 (Supreme Court of Alta. (Appellate Div.))

*R. v. Morgentaler*, [1988] 1 S.C.R. 30

*R. v. Patterson*, [1968] S.C.R. 157

*R. v. Tremblay*, [1993] 2 S.C.R. 932

*Re: K.*, (1985) 63, B.C.L.R. 145 (C.A.)

*Reference Re: Criminal Code, ss193, 195. 1(1) (c)*, (1987) M.J. No. 453 (Man. C.A.)

*Stamos v. Davies*, (1985), 52 O.R. (2d) 10 (H.C.) (Ont. High Court of Justice)

*Stewart v. Extendicare Ltd.*, (1986) S.J. No. 419 (Q.B.)

*Swanson v. Wilson*, (1955) 3 D.L.R. 171 (B.C.S.C.); [affirmed] [1956] S.C.R. 804

*Wilton v. Genik*, (1995) O.J. No. 1901 (QL) (Ont. Court of Justice (Gen. Div.))



## APPENDIX D - STATUTES AND REGULATIONS CITED

*Adult Guardianship Act*, R.S.B.C. 1996 c. 6

*Canadian Charter of Rights and Freedoms*, Part 1 of the Constitution Act, 1982, [being Schedule B to the *Canada Act*, 1982 (U.K.), 1982, c. 11]

*Criminal Code* R.S.C. 1985, c. C-46

Correction Services Canada. 2002. Standard Operating Practice. Private Family Visits. (700-12): 2002-06-03.

*Health Care (Consent) and Care Facility (Admission) Act*, R.S.B.C. 1996 c. 181

*Hospital Act*, R.S.B.C. 1996 c. 200

*Human Rights Code*, R.S.B.C. 1996 c. 201

*Marriage Act* R.S.B.C. 1996 c. 282

*Marriage Act* R.S.O. 1990 c. M.3

*Mental Health Act* R.S.B.C. 1996 c. 281

*Nurses (Registered) Act*, R.S.B.C. 1996 c. 335

*Patients Property Act*, R.S.B.C. 1996 c. 349

*Power of Attorney Act*, R.S.B.C. 1996 c.370

*Representation Agreement Act*, R.S.B.C. 1996 c. 405