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# **Counselling Patients with a Spinal Cord Injury**

By

**Susan Sliedrecht**

MA (Soc Sc) Soc Wk Admin

Submitted for the Degree of Master of Counselling in the School of  
Education at the University of Waikato

February 2007

## Abstract

The aim of this study was to improve current counselling services at the Auckland Spinal Unit. This purpose was achieved by co-researching the topic with people who have extensive experience of living in the community with a spinal cord injury to reveal what they believe was helpful, or believe would have been helpful, in terms of the counselling, when they were newly injured.

Listening to the stories of the research participants, through supervision of my own practice, doing a literature review and writing a journal became sources that provided rich knowledges to reflect on my current counselling practice.

A qualitative study was conducted using aspects of action research, feminist research and post-structuralist methods.

In November 2005, an information pack was mailed to the sixteen patients who had been discharged from the Auckland Spinal Unit between June 2002 and June 2004, who were under the age of sixty -five and lived in the Auckland area, inviting them to participate in this research. Seven people agreed and were available to participate.

I interviewed these seven participants, using unstructured interviews. All the interviews were audio-taped and then transcribed *verbatim*. These *verbatim* transcripts were then sent back to the participants for any additions/deletions/alterations they chose to make.

To initiate the reflecting process, I then went through all the interviews and identified common themes. I understand that if the research participants had been involved in this process, other themes might have emerged for them.

The themes identified were loss and grief as a result of a spinal cord injury, sexuality, family (*whanau*) involvement and how counselling services should be positioned in a setting such as the Auckland Spinal Unit. These themes formed the

foci of the chapters, with an additional chapter on weaving cultural threads into counselling.

The main findings of the study centre on the very important role of counselling at the Auckland Spinal Unit. In particular, the study highlighted the importance of counselling as a place for conversations that make room for multiple positionings and multiple versions of events, a space that respects a patient's hopes, beliefs and dreams for his/her life (which often does not include wheelchairs, catheters and caregivers) but that also supports the patient to make meaning of living life with a spinal cord injury.

The study also identified the importance of sexuality counselling. Not including sexuality as a topic in the rehabilitation services provided perpetuates dominant discourses that a person with a spinal cord injury does not want sexual intimacy or cannot be sexually intimate and cannot have children.

Family (*whanau*) involvement in and family's becoming part of the rehabilitation team was very important to most participants. This study looks at how this involvement can be achieved and explores some of the structures currently in place at the Auckland Spinal Unit to facilitate this involvement. Participants in this study expressed a desire for counselling to be highly accessible to both themselves and their families (*whanau*). They would prefer the counsellors to get to know the patients in their own environment first (in their rooms), so that the patients are positioned to have agency to make choices about how they would like to use the available counselling services.

The study concludes with my personal journey of working as a counsellor at the Auckland Spinal Unit and how this research has shaped and fine-tuned my practice.

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I declare that the work presented in this thesis is to the best of my knowledge original except as acknowledged in the text and that the material has not been submitted either in whole or in part, for a degree at this or any other university.

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# Table of Contents

<b>Abstract</b> .....	<b>ii</b>
<b>Statement of Sources</b> .....	<b>iv</b>
<b>Acknowledgements</b> .....	<b>v</b>
<b>Table of Contents</b> .....	<b>vii</b>
<b>1. An Introduction to the Study</b> .....	<b>1</b>
1.1 Spinal Rehabilitation Services in New Zealand.....	1
1.2 Auckland Spinal Rehabilitation Unit .....	2
1.2.1 In- patient services .....	2
1.2.2 Outpatient Services .....	3
1.2.3 Others Services and Facilities on Site.....	3
1.2.4 Summary .....	4
1.3 Funding Streams .....	5
1.4 Why Was This Study Conducted? .....	5
1.5 Personal Positioning.....	8
1.6 Research Curiosity .....	11
1.7 Purpose of the Study .....	14
1.8 Strands that Informed my Research .....	15
1.8.1 Action Research .....	15
1.8.2 Poststructuralism Strands.....	17
1.8.3 Feminist Strands.....	18
1.9 Research Design.....	19
1.10 The Structure of the Research Report .....	21
<b>2. Disability Discourses</b> .....	<b>24</b>
2.1 Introduction .....	24
2.2 Individual Model.....	24
2.3 Social Model .....	26
2.3.1 Limitations of the social model.....	28
2.4 What is Social Constructionism? .....	29
2.4.1 Discourses / Language and the Production of Power .....	31
2.5 Social Construction of Disability .....	35
2.5.1 Disability and New Relationships.....	37
2.6 Conclusion .....	38

<b>3.</b>	<b>Spinal Cord Injury: Grief, Loss and Hope .....</b>	<b>39</b>
3.1	Introduction .....	39
3.2	Discourses about Losses and Spinal Cord Injury.....	40
	3.2.1 Psychological Theories of Loss and Grief .....	42
	3.2.2 Christian ideas of illness and suffering that inform storylines....	50
	3.2.3 Ethno-Cultural Discourses of Illness, Suffering and Injury.....	52
	3.2.4 Summary .....	55
3.3	Participants' Voices .....	55
	3.3.1 Lequecher.....	56
	3.3.2 Paul.....	58
	3.3.3 Avril .....	62
	3.3.4 David.....	65
	3.3.5 Brett.....	66
	3.3.6 Matthew .....	69
	3.3.7 Larry.....	71
3.4	Reflecting on my Practice .....	72
	3.4.1 Acceptance / holding hope / multiple versions of events.....	72
	3.4.2 Acceptance .....	74
	3.4.3 Illness Narratives.....	75
	3.4.4 Loss and Control .....	77
3.5	Conclusion .....	78
<b>4.</b>	<b>Sexuality and Spinal Cord Injury.....</b>	<b>79</b>
4.1	Introduction .....	79
4.2	What Did The Participants Say? .....	79
	4.2.1 Sexuality counselling is not for everyone .....	80
	4.2.2 Sexuality counselling should be included in spinal cord rehabilitation .....	80
	4.2.3 Timing of counselling .....	82
	4.2.4 Fertility.....	83
	4.2.5 Female Participants .....	84
	4.2.6 Summary .....	86
4.3	Strands taken from the Literature Review .....	86
4.4	Physiology and Sexuality.....	88
	4.4.1 Complete and incomplete spinal cord injuries.....	89

4.4.2	Asia Scores.....	89
4.4.3	Level of injury and its impact on sexual functioning.....	91
4.4.4	Injury Level T12 and above (T12 – C2) .....	92
4.4.5	Injury level T11 and below .....	93
4.5	Implications for Counselling.....	93
4.5.1	Physiological knowledge and sexuality counselling.....	93
4.5.2	Fertility .....	95
4.5.3	Psychological and Social Considerations .....	95
4.6	Personal Journey .....	98
4.7	Sexuality Project .....	100
4.7.1	Sexuality project at the Auckland Spinal Unit.....	102
4.7.2	Sexuality Counselling - Evaluation of Services Offered .....	103
<b>5.</b>	<b>Care and Counselling.....</b>	<b>105</b>
5.1	Introduction .....	105
5.2	History of Counselling Services at the Auckland Spinal Unit.....	105
5.3	The Ideas of the Participants .....	106
5.3.1	Counselling Invitation.....	106
5.3.2	Focus of Counselling .....	110
5.3.3	Timing of counselling .....	115
5.4	Counselling Practices at the Auckland Spinal Unit .....	118
5.4.1	Meeting all inpatients.....	118
5.4.2	Scheduling the initial counselling appointment.....	119
5.4.3	The first counselling appointment.....	121
5.4.4	Different knowledges and counselling.....	124
5.4.5	Counselling practice of attending goal setting meetings .....	126
5.5	The Fabric That Holds It All Together – Care.....	127
5.6	Conclusion .....	130
<b>6.</b>	<b>Families (<i>Whanau</i>) a Part of the Rehabilitation Team.....</b>	<b>131</b>
6.1	Introduction .....	131
6.2	What did the Participants Say? .....	131
6.3	Family Involvement - Personal Strands .....	136
6.4	New Possibilities of Positioning – Bio Psycho- Social Model .....	141
6.4.1	Attending to agency and communion in families .....	142
6.5	Implications for the Auckland Spinal Unit .....	144

6.5.1	Attending to agency and communion .....	144
6.5.2	How do we attend to agency at the Auckland Spinal Unit .....	145
6.6	Working with Young Children .....	148
6.7	Future Considerations .....	148
6.8	Conclusion .....	149
<b>7.</b>	<b>Weaving Cultural Strands into my Counselling Practice .....</b>	<b>151</b>
7.1	Introduction .....	151
7.2	Racism and Power/ Knowledge Relations .....	153
7.2.1	Enacting privilege and racism.....	153
7.2.2	A moment of colour evasiveness .....	157
7.2.3	Race cognizance.....	159
7.2.4	How will ideas about race cognizance inform my counselling practice? .....	160
7.3	Privilege and Dominance at the Auckland Spinal Unit .....	161
7.4	Implications for me as a Counsellor at the Auckland Spinal Unit....	162
7.5	Maori Patients and their <i>Whanau</i> .....	164
7.5.1	Whanau involvement and visiting.....	164
7.5.2	Whakama .....	168
7.6	Conclusion .....	170
<b>8.</b>	<b>Personal Development .....</b>	<b>172</b>
8.1	Introduction .....	172
8.2	Historical Roots.....	172
8.3	Medical Model and how it Positions a Counsellor .....	174
8.4	Modernist Ideas of Counselling Relationships – Position Calls .....	174
8.5	Searching for Answers to the above Dilemmas .....	176
8.5.1	Focusing on knowledge and skills at the expense of focusing on self.....	176
8.5.2	Focussing on the alternative story.....	179
8.5.3	Witnessing self.....	181
<b>9.</b>	<b>Additional Strands and Conclusion.....</b>	<b>184</b>
9.1	Other Themes .....	184
9.1.1	Discharge .....	184
9.1.2	Practical help.....	184
9.1.3	Talking about the actual injury .....	184

9.1.4	Counselling preferences .....	185
9.1.5	Confidentiality .....	185
9.1.6	Accident Compensation Corporation.....	185
9.1.7	Other.....	185
9.2	Conclusion .....	186
<b>10.</b>	<b>References .....</b>	<b>188</b>
<b>11.</b>	<b>Appendix I .....</b>	<b>194</b>

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# Table of Contents

<b>Abstract</b> .....	<b>ii</b>
<b>Statement of Sources</b> .....	<b>iv</b>
<b>Acknowledgements</b> .....	<b>v</b>
<b>Table of Contents</b> .....	<b>vii</b>
<b>1. An Introduction to the Study</b> .....	<b>1</b>
1.1 Spinal Rehabilitation Services in New Zealand.....	1
1.2 Auckland Spinal Rehabilitation Unit .....	2
1.2.1 In- patient services .....	2
1.2.2 Outpatient Services .....	3
1.2.3 Others Services and Facilities on Site.....	3
1.2.4 Summary .....	4
1.3 Funding Streams .....	5
1.4 Why Was This Study Conducted? .....	5
1.5 Personal Positioning.....	8
1.6 Research Curiosity .....	11
1.7 Purpose of the Study .....	14
1.8 Strands that Informed my Research .....	15
1.8.1 Action Research .....	15
1.8.2 Poststructuralism Strands.....	17
1.8.3 Feminist Strands.....	18
1.9 Research Design.....	19
1.10 The Structure of the Research Report .....	21
<b>2. Disability Discourses</b> .....	<b>24</b>
2.1 Introduction .....	24
2.2 Individual Model.....	24
2.3 Social Model .....	26
2.3.1 Limitations of the social model.....	28
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2.4.1 Discourses / Language and the Production of Power .....	31
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2.6 Conclusion .....	38

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3.1	Introduction .....	39
3.2	Discourses about Losses and Spinal Cord Injury.....	40
	3.2.1 Psychological Theories of Loss and Grief .....	42
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3.3	Participants' Voices .....	55
	3.3.1 Lequecher.....	56
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	3.3.5 Brett.....	66
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	3.3.7 Larry.....	71
3.4	Reflecting on my Practice .....	72
	3.4.1 Acceptance / holding hope / multiple versions of events.....	72
	3.4.2 Acceptance .....	74
	3.4.3 Illness Narratives.....	75
	3.4.4 Loss and Control .....	77
3.5	Conclusion .....	78
<b>4.</b>	<b>Sexuality and Spinal Cord Injury.....</b>	<b>79</b>
4.1	Introduction .....	79
4.2	What Did The Participants Say? .....	79
	4.2.1 Sexuality counselling is not for everyone .....	80
	4.2.2 Sexuality counselling should be included in spinal cord rehabilitation .....	80
	4.2.3 Timing of counselling .....	82
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	4.2.6 Summary .....	86
4.3	Strands taken from the Literature Review .....	86
4.4	Physiology and Sexuality.....	88
	4.4.1 Complete and incomplete spinal cord injuries.....	89

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4.4.4	Injury Level T12 and above (T12 – C2) .....	92
4.4.5	Injury level T11 and below .....	93
4.5	Implications for Counselling.....	93
4.5.1	Physiological knowledge and sexuality counselling.....	93
4.5.2	Fertility .....	95
4.5.3	Psychological and Social Considerations .....	95
4.6	Personal Journey .....	98
4.7	Sexuality Project .....	100
4.7.1	Sexuality project at the Auckland Spinal Unit.....	102
4.7.2	Sexuality Counselling - Evaluation of Services Offered .....	103
<b>5.</b>	<b>Care and Counselling.....</b>	<b>105</b>
5.1	Introduction .....	105
5.2	History of Counselling Services at the Auckland Spinal Unit.....	105
5.3	The Ideas of the Participants .....	106
5.3.1	Counselling Invitation.....	106
5.3.2	Focus of Counselling .....	110
5.3.3	Timing of counselling .....	115
5.4	Counselling Practices at the Auckland Spinal Unit .....	118
5.4.1	Meeting all inpatients.....	118
5.4.2	Scheduling the initial counselling appointment.....	119
5.4.3	The first counselling appointment.....	121
5.4.4	Different knowledges and counselling.....	124
5.4.5	Counselling practice of attending goal setting meetings .....	126
5.5	The Fabric That Holds It All Together – Care.....	127
5.6	Conclusion .....	130
<b>6.</b>	<b>Families (<i>Whanau</i>) a Part of the Rehabilitation Team.....</b>	<b>131</b>
6.1	Introduction .....	131
6.2	What did the Participants Say? .....	131
6.3	Family Involvement - Personal Strands .....	136
6.4	New Possibilities of Positioning – Bio Psycho- Social Model .....	141
6.4.1	Attending to agency and communion in families .....	142
6.5	Implications for the Auckland Spinal Unit .....	144

6.5.1	Attending to agency and communion .....	144
6.5.2	How do we attend to agency at the Auckland Spinal Unit .....	145
6.6	Working with Young Children .....	148
6.7	Future Considerations .....	148
6.8	Conclusion .....	149
<b>7.</b>	<b>Weaving Cultural Strands into my Counselling Practice .....</b>	<b>151</b>
7.1	Introduction .....	151
7.2	Racism and Power/ Knowledge Relations .....	153
7.2.1	Enacting privilege and racism.....	153
7.2.2	A moment of colour evasiveness .....	157
7.2.3	Race cognizance.....	159
7.2.4	How will ideas about race cognizance inform my counselling practice? .....	160
7.3	Privilege and Dominance at the Auckland Spinal Unit .....	161
7.4	Implications for me as a Counsellor at the Auckland Spinal Unit....	162
7.5	Maori Patients and their <i>Whanau</i> .....	164
7.5.1	Whanau involvement and visiting.....	164
7.5.2	Whakama .....	168
7.6	Conclusion .....	170
<b>8.</b>	<b>Personal Development .....</b>	<b>172</b>
8.1	Introduction .....	172
8.2	Historical Roots.....	172
8.3	Medical Model and how it Positions a Counsellor .....	174
8.4	Modernist Ideas of Counselling Relationships – Position Calls .....	174
8.5	Searching for Answers to the above Dilemmas .....	176
8.5.1	Focusing on knowledge and skills at the expense of focusing on self.....	176
8.5.2	Focussing on the alternative story.....	179
8.5.3	Witnessing self.....	181
<b>9.</b>	<b>Additional Strands and Conclusion.....</b>	<b>184</b>
9.1	Other Themes .....	184
9.1.1	Discharge .....	184
9.1.2	Practical help.....	184
9.1.3	Talking about the actual injury .....	184

9.1.4	Counselling preferences .....	185
9.1.5	Confidentiality .....	185
9.1.6	Accident Compensation Corporation.....	185
9.1.7	Other.....	185
9.2	Conclusion .....	186
<b>10.</b>	<b>References .....</b>	<b>188</b>
<b>11.</b>	<b>Appendix I .....</b>	<b>194</b>

# **1. An Introduction to the Study**

## **1.1 Spinal Rehabilitation Services in New Zealand**

New Zealand has two specialised Spinal Cord Injury Rehabilitation facilities. The one facility is in Auckland and it is called the Auckland Spinal Rehabilitation Unit and the other specialised spinal unit is in Christchurch and it is called Burwood. These facilities are funded by their respective District Health Boards and Accident Compensation Corporation (ACC).

The services offered at both specialised units are in principle the same. Both facilities offer services to in-patients and outpatients. Both facilities have as part of the medical multi-disciplinary team doctors, nurses, physiotherapists, occupation therapists, dietician, social workers and counsellor / psychologist.

One of the differences in the two services is the geographic area within New Zealand that they are responsible for. The Auckland Spinal Rehabilitation Unit provides services to the areas north of Palmerston North excluding New Plymouth and Taranaki. Burwood's service area is South of Palmerston North, including Palmerston North and Taranaki.

Another difference in service delivery between the two facilities is that Burwood is equipped to admit patients who still need very intensive medical care and require a ventilator to assist them with their breathing. The Auckland Spinal Rehabilitation Unit does not admit patients with this specialised level of medical need. Patients who still require intensive medical care would tend to remain at the tertiary hospital, usually Middlemore, Waikato or Auckland Hospital until medically they are assessed to be stable and or do not need a ventilator for breathing.

The implication of the above is that the Auckland Spinal Rehabilitation Unit only admits patients once they are medically stable and ready for rehabilitation. This would normally be about five to eight weeks post injury, depending on the waiting list at the Auckland Spinal Rehabilitation Unit.

This research study was located at the Auckland Spinal Rehabilitation Unit.

## **1.2 Auckland Spinal Rehabilitation Unit**

The Auckland Spinal Rehabilitation Unit (henceforth called the Auckland Spinal Unit) is part of the Counties Manukau District Health Board. It is located off site from Middlemore Hospital and situated in the suburb of Otaro in South Auckland. There is a staff complement of approximately 65 people. Which are comprised as follows:

Medical Director

Medical Registrar

Service Manager

Five Administrative staff

Fifteen Allied Health staff (five physiotherapists, one physiotherapist therapist assistant, four occupational therapists, one occupational therapy assistant, two social workers and one counsellor)

Forty two Nursing staff

Outpatient Co-ordinator

### ***1.2.1 In-patient services***

The Auckland Spinal Unit has twenty inpatient beds.

Any person admitted to the Auckland Spinal Unit must have a spinal injury. The two main reasons for admission are for rehabilitation if a person is newly injured and the second main reason for admission is for the management of pressure areas. Pressure areas (colloquially referred to as pressure sores) are caused due to lack of blood circulation to a particular area of the body which is caused by sustained pressure to that particular area. The priority for admission is people with new spinal injuries, needing rehabilitation.

Patients with new injuries spend on average about three to five months at the Auckland Spinal Unit.

The focus of rehabilitation is to assist people to become as independent as possible. For some patients this may include learning how to walk again, learning how to use a

wheelchair, learn how to manage their bowels and bladder independently, learn how to get dressed independently, learn about pressure management. For other patients independence may mean learning how to direct other people to care for you in a way that positions you, as the recipient of care, as agentic and in control of how your personal cares are attended to.

Patients who have been admitted to the Auckland Spinal Unit for the management of pressure areas could spend up to seven to eight months at the Auckland Spinal Unit. The reason why they would be admitted to the spinal unit, instead of being medically managed in the community is because the pressure area is not healing. The length of stay at the Auckland Spinal Unit will depend on the depth of the pressure area and how it is being managed. It is preferred for a pressure area to be medically managed in the community but this is not always possible. The reason for this is that no additional pressure should be placed on the pressure area which means that he/she would frequently not be able to sit in his/her wheelchair. There are some patients that have spent two to three years on bedrest, in the community, trying to get rid of a pressure area. These patients are usually eventually admitted to the Auckland Spinal Unit for intensive nursing care.

### ***1.2.2 Outpatient Services***

Any person who has a spinal injury and has received medical attention at the Auckland Spinal Unit is a 'patient for life'. In other words a person is not discharged from our services. A person's needs change over time, and so his/her equipment and personal support levels need to accommodate these changes. The Auckland Spinal Unit has outpatient clinics at the Auckland Spinal Unit as well as outreach clinics in Whangarei, Taupo, Rotorua and Tauranga. These outreach teams consist of a nurse, doctor, occupational therapist, social worker and physiotherapist.

### ***1.2.3 Others Services and Facilities on Site***

Situated on the site of the Auckland Spinal Unit is a gym, a recreation room and a computer room / television lounge that patients have access to. There are also four motel units available on site at a minimal cost for families and patients to stay in for week-end leave and or visiting patients.

In addition to the above there are three non governmental organisations situated on the premises of the Auckland Spinal Unit. These organisations are specifically for the benefit of people with spinal cord injuries and they provide services to both inpatients and outpatients. These organisations are The Association for Spinal Concerns (TASC) Parafed and Kaleidoscope.

TASC is a non-profit organisation which has a vast network of volunteers who with their various experiences are able to offer moral support, advice and information to the new patients in the Spinal Unit. They offer a “buddy support” to patients and their families. (<http://www.tasc.org.nz/about.htm> retrieved 22/06/06).

Parafed provides sporting and recreational opportunities such as tennis, archery, adventure sports, skiing, fishing, archery to people with physical disabilities.. Parafed uses the gym facilities at the Auckland Spinal Unit for the Wheelblacks for rugby, wheelchair basket ball and archery. The Wheelblacks and wheelchair basket ball teams represent New Zealand in international competitions, so we have a few international stars working out in our gym facilities.

Kaleidoscope is an early intervention vocational rehabilitation programme dedicated to getting people who happen to have disabilities into jobs they love. (<http://www.kaleidoscope.org.nz/rehab.asp> retrieved 22/06/06). A person can self refer or he/she can be referred by any member of the multi-disciplinary team.

#### ***1.2.4 Summary***

As can be seen from the above there are many people at the Auckland Spinal Unit on any one day. There are people wheeling and walking themselves around and some of these people may be staff, some may be visitors, some may be people partaking in the sports activities, some could be “support buddy’s” to other people and others could be very newly injured.

The environment of the Auckland Spinal Unit attempts to offer a perspective that centralises ability and what can be done rather than on disability which tends to focus on deficit and loss.

### **1.3 Funding Streams**

There are two very inequitable funding streams in New Zealand for people with spinal injuries, ACC and Ministry of Health.

If the injury is as a result of an accident the person would qualify for ACC funding. This funding includes equipment, home based care, temporary accommodation on discharge if the house has not been modified, house modifications, vocational assistance and 80% of the person's income prior to the injury.

The Ministry of Health funding stream is for people whose spinal injury has a medical reason such as cancer of the spine, tumours, infections, blood clots. The funding from Ministry of Health would include equipment but in certain instances more limited than funding from ACC. For example with ACC funding a person could qualify for a wheelchair and a stroller. With Ministry of Health funding it would be one or the other. There is funding for home based care from the Ministry of Health but the maximum amount of hours is much less than ACC. ACC will provide twenty four hour care, Ministry of Health will provide a maximum of four hours care per day. There is a limit in the funding for house modifications from the Ministry of Health, the maximum is \$7,500-00 whereas ACC funds in excess of \$100,000-00 for house modification. There is no specialised funding for vocational assistance and loss of income from the Ministry of Health.

In summary, ACC patients are better positioned in terms of finances and access to care and equipment in comparison to Ministry of Health patients. There is an inequality in what patients can and cannot access in terms of funding. Usual patient concerns are: Will I be able to support my family? What type of care will I be able to access? Will I be a burden on my family? Where will I live? The way these concerns are addressed may differ depending on whether services are funded by ACC or Ministry of Health.

### **1.4 Why Was This Study Conducted?**

The Auckland Spinal Unit has employed a part-time counsellor for approximately the past eight years. I am the third counsellor at the Auckland Spinal Unit and I started my

employment there in February 2004.

There had been a gap of about six months between the previous counsellor leaving and my starting. As a result of this time gap I did not receive a handover of patients or any orientation into how counselling services were previously offered. It was my responsibility to decide how I wanted to position counselling and how counselling services should be offered. The supervision I received was from an external supervisor, this person did not have specific experience in working with people with spinal cord injuries.

Whilst I appreciated the freedom I was given to implement the counselling services in the way that I thought was most appropriate I also felt quite isolated and missed not having a close interdisciplinary team to give me feedback and support.

Whilst I had extensive experience in the field of trauma (sexual abuse and working with burns patients), at a previous workplace, I had little or no experience in counselling patients in the non-acute stage of spinal injury. My experience was more in hospitals as a social worker counselling acutely ill patients and their families (whanau). My previous experience was as a social worker who also did counselling, rather than a counsellor.

My expectation was that counselling patients at the Auckland Spinal Rehabilitation Unit would not be too different to my experience of counselling patients in the hospital. I expected that, given the extent of the life changes most patients would need to be making, emotional turmoil, confusion, hopelessness and lack of purpose in life would be very present and obvious.

To the contrary, what I more often saw was people (seemingly) very adequately making these adjustments to their lives and managing to find resources and reasons for bringing about these changes. I frequently heard people talking about the gains they had made with their physical rehabilitation, how supportive their families were and how grateful they were that the situation was not worse. I did not very often witness hopelessness and disinterest in their futures.

This presentation of how patients and the family (whanau) adequately managed took me

by surprise It seemed as though most patients sorted things out for themselves. They knew they had to make adjustments but they felt confident they would be able to do this. They were noticing improvements day by day through their physiotherapy and occupational therapy programmes and emotionally were appearing to manage well. There were some patients who requested to see the counsellor on a regular basis but it seemed to be the minority.

This presentation of appearing to manage well made me wonder what was the role of the counsellor at the Auckland Spinal Unit? As a social worker seeing a patient I had the option, if people were seemingly managing well emotionally, to discuss the practical aspects of their stay in hospital and practical concerns about discharge. This pathway of conversation, focus on the practical aspects was no longer open to me as I was now working as a counsellor and not a social worker who also did counselling.

However, in contrast to the above situation, (patients seemingly managing well), I was also counselling some patients who were at the Auckland Spinal Unit because of pressure areas. These patients had had their injury for a number of years and had returned because they needed bed rest and specialized nursing care for their pressure areas.

What I noticed with many of these patients was in stark contrast to what I had come to learn from the patients who had recently been injured. Some patients who had lived with their injury for a number of years were having relationship problems. Two patients that I counselled had so much anger and difficulty with accepting their bodies that they turned to drugs and alcohol as a way of dealing with problems. One patient refused to meet up with old friends to the point of avoiding them and never contacting them, hence not only did he have to deal with his injury but also his whole social support network had been cut off. One patient stopped all educational pursuits because of fear about “what will people think of me when they see me in a wheelchair.”

This seemingly stark contrast between people with a new injury and people who had lived in the community with an injury for some time, certainly caused me to question the efficacy of counselling. I wondered whether this was part of the development of living with a spinal cord injury or whether the absence of addressing some issues early enough

in counselling had contributed to this development. I reflected on how as a counsellor I could best support patients with new spinal injuries. What was missing from the initial counselling that could have been useful for patients once they were discharged from the Auckland Spinal Unit and living in the community. A question that developed was: – what role does counselling have in enabling patients and their families to live a satisfying, fulfilling life, despite the injury?

The reason why this study was conducted was because through my counselling conversations with patients who had lived in the community for a number of years I heard about struggles living with a spinal cord injury. In contrast to this many of the patients who I was counselling, who were newly injured seemed to have few concerns about their future and how they would manage.

In summary the reason for this study was to find out what would be the best way to offer counselling services to people who were newly injured so that when living in the community with a spinal injury they would not let disability get in the way of them living a satisfying and fulfilling life.

### **1.5 Personal Positioning**

As previously mentioned I have been working at the Auckland Spinal Unit as a counsellor since March 2004. Prior to that, I worked as a social worker in the field of adolescent sexual abuse. This position in sexual abuse included counselling. Prior to that I worked in the Burns and Plastics wards at Middlemore Hospital, as a social worker and once again counselling was an integral part of that role.

This position of counsellor, at the Auckland Spinal Unit, was the first time that I was employed specifically as a counsellor as opposed to a social worker who also does counselling. Two social workers are also employed at the Auckland Spinal Unit. One of the initial challenges for me was working out what the distinction was between the practices of a social worker and those of a counsellor.

This distinction between social worker and counsellor was quite unfamiliar to me. I trained as a social worker in South Africa. In South Africa social workers and

psychologists (as well as many other helping professions) offer counselling. Counselling, in my experience was not seen as a distinct profession. I saw it rather as an action. Very broadly speaking social workers counselled people with 'normal responses' to grief, loss and trauma and psychologists provided therapy for people with the more unusual responses that would tend to meet the criteria detailed in the Diagnostic and Statistical Manual for Mental Disorders (DSM IV).

One of the ongoing complexities for me, in working as a counsellor in New Zealand was defining the role of the counsellor as opposed to a social worker. Advocating for patients, speaking to family (*whanau*) members, discussing issues of concern with patients and counselling, these are all things I had previously done as a social worker.

My experience in my first year and a half as a counsellor was at times very isolating and inadequacy never felt very far away. I was trying to come to grips with the complexities of counselling people with spinal cord injuries and the complexity and variation within disability discourses. Coupled with that was the difficulty of trying to define my role as counsellor in a way that did not overlap too much with the social worker. In many ways it was like trying to find a niche for my counselling practice and defining my position within the professional team.

Lather (1986) states that some feminist researchers discover that their research has sustained their lives. According to this approach researchers hope that their research will clarify their vision and improve their decisions. At the time of deciding to do this research study I felt that this research would sustain me professionally and guide me in my decisions. My hope was that this research would clarify my vision at the Auckland Spinal Unit and give me a better focus on how best to counsel people with a spinal cord injury.

In my research proposal which was written in about December 2005 (10 months after I started working at the Auckland Spinal Unit) I wrote the following:

I have walked what I have felt to be a lonely unsupported road this past year. I am never really sure if what I am doing is best practice and question myself as to whether there are better counselling practices. In a sense I need to validate my

practice, reflect on and scrutinize it. My practice must be grounded in sound theory and ethical practice. My hope is that this research will develop and grow my practice.

Heshusius and Ballard (1996, pp.4-5) talk of essential truth being an interior one. That Western science demands that we believe in the possibility of separating fact from value, mind from body, mind from emotion, and self from other. Western thought marginalises other ways of knowing such as intuition, imagination, feelings and spiritual knowing. With the emphasis on rationality Western thought has begun to liquidate other ways of knowing such as knowing through connecting, knowing through participation and knowledge that the body holds.

My intention when I embarked on this research journey was to come to a place where I could know in my body, in my imagination and in my connection with a patient that I am doing the right thing. Intuitively I wanted to know that I was linking with a patient in a way that helped him/her, fine tuning my listening to pick up on the pathways of conversations that would be useful for him/her and following that path, in step with the client's pace. I call this practice 'dancing' with a patient, the patient taking the lead role and I sensitively follow.

I am very relieved and excited to share that my hopes that I initially had for this research have more than been realised. This research has sustained me, it has supported my intention to ensure that my practice is well grounded in ethical practice and sound theory. It has clarified my vision and given me a far better understanding of counselling patients with spinal cord injury.

In summary my initial experience of working at the Auckland Spinal Unit was quite isolating. Unsureness about best practice in counselling people with a spinal cord injury and personal questions around my effectiveness as a counsellor fuelled my desire to ensure that what I was offering in my counselling conversations with patients was going to support patients in making the changes and adjustments they wanted to make. My intention was that disability would not get in the way of their hopes, dreams and aspirations for the future.

## 1.6 Research Curiosity

Fuelled with a desire and a personal commitment to evaluate my practice I started looking at the literature about spinal cord injury and counselling. In my initial searches I tended to find many articles on the effects of a spinal cord injury on a person such as people with spinal cord injuries are at higher risk of experiencing depression than the general population and people with spinal injuries report a poorer quality of life. However, this information about depression and quality of life did not shine any light on what would be helpful to people with a spinal cord injury to prevent this from happening, if that was their preference, and or to support them in making changes they wanted.

The work of Frank (1995) around narratives and how we use them for listening, filtering in some things but filtering out others resonated strongly with me and it was something I found to be immediately applicable and useful to my counselling practice. (In a later section of this research report I will give more detail about the work of Frank. However in this section I am briefly touching on it as a way to explain my research curiosity.)

Frank (1995) suggests that narratives are used as listening devices to filter in, or filter out available information. We make sense of what is happening to us by the use of various narratives. These narratives are based on the various discourses that are informing and producing us as well as we forming and producing these discourses.

Frank (1995) states that there are three dominant narratives operating when the body becomes ill. "In any illness all three narrative types are told alternatively and repeatedly. Both institutions and individual listeners steer ill people toward certain narratives and other narratives are simply not heard" (Frank, 1995, p.77).

The first narrative is the restitution narrative. This narrative supports the belief that ill people get better, they do not remain ill. This narrative structures ideas of illness and health according to the following: Yesterday I was sick, but today I am feeling better. This narrative reflects the desire and the expectation that one will get better. This narrative 'filters in' improvement and healing and 'filters out' contrary information when improvement is not available. Frank talks about the idea that we share a cultural

reluctance to say that our lives have gone badly. This may result in physicians even interrupting patients when their stories become uncomfortable. They want to filter out that which is not easy to hear, the non-restitutive narrative (Frank, 1991, p.64).

The restitution narrative accepts that the body, just as a machine breaks down from time to time, but like an engine it can be fixed and it will be as good as new. The aim in this narrative is to get back to the status quo. In spinal cord injuries this narrative is seen in people's pursuit to walk again – “my body cannot fail me, it can be fixed, it needs a bit of work but it will be fixed.” If a person does not regain their ability to walk or their condition remains chronic, the restitution narrative is limiting in that it cannot help to make sense of what is happening.

The second narrative is the chaos narrative. This is when, in a sense, illness has no words, it has no coherent story. This is the story that happens before the more coherent narratives emerge. The chaos story presupposes lack of control, it has no sequence and there is an absence of narrative order. The question present is whether life will ever get better.

Frank (1991), relating his experience of his own illness, shares that the questions he wanted to ask about his life were not allowed, they were not speakable, they were not even thinkable....“the gap between what I feel and what I feel allowed to say widens and deepens and swallows my voice” (Frank, 1991, p13).

He further states that “one of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy ” (Frank, 1991, p.25). Narrative preferences tend to centralise coherent logical versions of events. Ill people may be positioned non agentically because of their hesitant speech and, at times their incoherent and muddled messages.

Frank (1995, p. 110) also states that “the need to honour chaos stories is both moral and clinical. Until the chaos narrative can be honoured, the world in all its possibilities is being denied. To deny a chaos story is to deny the person telling this story, and people

who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care.... Often they cannot even accept help when it is offered”.

The third narrative that Frank (1995) describes is the quest narrative. This narrative enables the person to have a voice in his or her own story. The ill person is the central player, not the remedy or the physician. Quest stories talk of alternative ways of being ill, illness is a journey and it leads to new insights and new opportunities without denying the chaos narrative.

A research curiosity of this study is how do I, as a counsellor, honour these stories, especially the chaos stories? How can I ensure that in my practice I am not avoiding or ignoring the voices of the injured? Am I making space and providing a safe environment for patients to share with me their chaos and other narratives such as their restitution and quest narratives?

Another research question is: Am I making space for all stories to be told, at the time that they need to be told? Are there times when some issues are more appropriate to discuss than other times? If there are, how will I know? Do patients need, in the initial stages of rehabilitation, to feel as though they are fine and will manage but at some later stage need to re-visit these ideas?

Another research curiosity is the area of loss and grief and what counselling practices are suitable for people with a spinal cord injury. For most people with a spinal cord injury there are initially significant losses. Judith Zaruches (1993, cited in Frank, 1995, p. 54) talks of her experience of illness and the related losses and likens it to being shipwrecked and losing her map and her destination. What counselling practices could position a person, if he/she wanted to, to re-discover / re-design his/her destination map if the previous map has been wrecked by injury and losses?

Another aspect that I wonder about is what type of relationship would a person, with a spinal injury like to have with his/her “previous body”. White (1997) talks about his experiences of grief work in therapy and how he noticed that discourses about disconnecting yourself from “lost” relationships or as he calls it the “saying goodbye

metaphor” may position a person grieving with a “sense of emptiness, worthlessness and feelings of depression” (White, 1997, p.29). He found that many people who have consulted with him over problems relating to unresolved grief have uncovered that discourses about remembering, re-connecting and the “saying hullo again metaphor” have positioned them with new possibilities for an ongoing relationship with the person they have “lost”.

I am very curious about what kind of relationship a person with a spinal cord injury would like to have with his/her previous body - the body that would usually respond, at will, to the commands of the brain. Are there elements or aspects of the “saying hullo metaphor” that could be useful? Are these ideas about loss and grief for illness and death useful when counselling people with a spinal cord injury? What are the similarities and what are the differences in counselling people with losses that relate to injury as opposed to losses that relate to illness and or death? Advancing this idea further – What kinds of counselling conversations about losses would be useful for a person who has recently had a spinal cord injury?

Issues such as sexuality and long term personal plans are two areas that do not seem to be routinely addressed as part of the “rehabilitation process”. Is it best for the patient to address these issues once they become more visible or should it be incorporated in the rehabilitation process? Is it very visible to the patient but the professionals do not want to see it? What will be a counselling practice that will best serve the person dealing with these issues?

At its most basic level my curiosity is: Am I asking the right questions, at the right time and in the right way?

An additional research curiosity was to become aware of my own narrative preferences so that patients can talk about what they want and not that “I am steering ill people toward certain narratives and other narratives are simply not heard” (Frank, 1995, p.77).

## **1.7 Purpose of the Study**

The purpose of this study was to reflect on the current counselling services that I offer at

the Auckland Spinal Unit and where needed make improvements / fine tune my current practice. The voices of the research participants, ideas from the literature and my personal experience will be the filters used for this reflexivity. The final destination being to improve counselling services at the Auckland Spinal Unit, not only for myself but my hope is that this will be a useful research report for other counsellors working in similar settings. The approach used for this study is social constructionism. Chapter two gives a detailed outline of social constructionism discussing, discourses, position calls and agency specifically in relation to disability.

## **1.8 Strands that Informed my Research**

According to Libby Plumridge (2005) any one research methodology will have its limitations and leave some research issues beyond its reach. No research method is inherently better or worse, only more or less appropriate to the research problem posed. Given the abovementioned, I took threads from the methodologies of action research, poststructuralism and feminist theory. A major consideration in choosing the most appropriate methodologies for this research was to ensure that the research methodologies produced useful knowledge and that it did not further oppress or objectify disabled people (Oliver, 1999, p.183).

### ***1.8.1 Action Research***

The aim of action research is that it should be of direct benefit to the participants or the community they represent. In this research study the community represents people with a spinal cord injury. Lather (1988) suggests that our intent in research should more consciously be to use the research to help participants understand and change their life situation. Moore et al (1998) calls on prospective researchers of disability to maximize the extent to which their activities promote the rights of disabled people within the research process.

The action research process involves feedback loops, each loop containing, planning, action, observing and reflecting. This is known as an action research spiral with the intention of incorporating new knowledges and ideas from these feedback loops as one progresses along with the research. This research report details many examples of how ideas from the participants have shaped and refined my counselling practice producing real benefits to the spinal injury community. Some of these areas are grief and loss in

relation to a spinal cord injury, involving family members, positioning of counselling and ideas about sexuality counselling. This research has also benefited the other professionals working at the Auckland Spinal Unit as through this research I have become more aware of power/knowledge relations and through a series of workshops have shared these ideas with the professional staff.

Although not documented in this report, participants themselves benefited from participation as there were at times, in the interviews, concerns that emerged about adjusting to life with a spinal cord injury and I followed these up with participants after the research. For example further discussions with some participants about sexuality and spinal cord injury, one participant reported that he found the interview itself to be very therapeutic and another participant wanted to reconsider the option of ongoing counselling.

#### *1.8.1.1 Knowledge and positioning in action research*

According to Hesse (1980, p.247) the attempt to produce value neutral social science is increasingly being abandoned as at best unrealisable, and at worst self-deceptive. It is being replaced by social sciences based on explicit ideologies. In action research the initiating researcher openly acknowledges their explicit interest. There is no pretence that objectivity is possible and or desirable. In this research all participants knew that I was the counsellor at the Auckland Spinal Unit and they knew that I was doing this research to review and reflect on my current practice. Some of the participants were people whom I had counselled and they took up the opportunity to reflect and comment on their experiences of counselling with me.

The purpose of action research is for learning and reflection and the co-creation of knowledge. There is no intent that throughout the research process the initiating researcher remains the same, in fact it is the very opposite. Lather (1986) mentions that an empowering approach to research is where the researcher and the researched become the changer and the changed. The research process has the potential to enable people to change by encouraging self reflection and a better understanding of their particular situation. Action research is a social process of co-generative inquiry which feeds into collaborative learning (Kemmis & Mc Taggart, 2005, p. 254). Chapter eight of this research report details my personal research journey and how through reflection and

deconstruction the co-production of knowledge has positioned me with clearer vision and a significantly more thorough understanding of illness and trauma narratives, multiple positionings, my own narrative preferences and positioning of counselling at the Auckland Spinal Unit.

Co-generative inquiry is based on professional researchers and knowledgeable local stakeholders who work together to define the problems to be addressed. The relationship between the professional researcher and the local stakeholders is one of bringing the diverse bases of their knowledge and their distinctive social locations to bear on the problem collaboratively. This collaboration must be based on an interaction between local knowledge and professional knowledge. Conventional social research privileges professional knowledge over local knowledge, action research questions this. Given the complexity of the problems addressed, only local stakeholders, with their years of experience in a particular situation, have sufficient information and knowledge about the situation to design effective social change processes. Both forms of knowledge, local and professional, are essential for co-generative inquiry (Greenwood & Levin, 2005, p.55). The purpose of the research interviews was to consult with people who had lived with a spinal injury for a number of years (local stakeholders) about their ideas of counselling and spinal cord injury. In addition professional knowledge from books and my own experience, both personal and professional is weaved into this research.

In summary the strands from action research that seemed to be useful to this study was the positioning of the initiating researcher in that I could openly acknowledge my interest, and that good research co-produces knowledge which is of benefit to the research participants / community they represent and the researcher – the researcher becomes the changed and the changer.

### ***1.8.2 Poststructuralism Strands***

An aspect of poststructuralist research is an interest in how knowledge and language come to represent aspects of reality which then become accepted practices and assumptions. In the health care arena there are “correct” (Cheek, 2000, p.41) and accepted ways of acting and thinking. This research report looks at some of the particular ways of representing health care and how these are given legitimacy and how such legitimacy is conferred. In particular this research looks at how aspects of

rehabilitation discourses, grief and loss discourses and medical discourses may position patients with a spinal cord injury non agentically. This report also identifies how modernist ideas of counselling may position a counsellor, working in a setting such as the spinal unit, as remote, unavailable and inaccessible.

This research report looks at the language of disability and how language is not objective and neutral but that the language we have available to us produces and constructs our realities. How to make language available in a way that supports meaning making and enables the accessing of subjugated discourses about disability and spinal cord injury is an important part of this research report. This process of meaning making troubles (Davies, 2006) centralised discourses about spinal cord injury and thus holds them up for review and consideration.

“Poststructuralism values plurality, fragmentation and multi-vocality” (Cheek, 2000, p.40). This research report draws heavily from these ideas of multiplicity of versions of events and stands against a unitary version of an event. In this way space is made for power knowledge relations in that it is not only the medical version of events that is centred but other knowledges that patients hold about their cultures, themselves and their hopes and dreams for the future.

Consideration was also given to differences in the way that a counsellor can view a person – the counsellor gaze or the counsellor look. The counselling gaze is very evaluative and assessment orientated and can objectify patients by focussing on categorising clients so that appropriate treatment plans, based on the categorisation of the person can be selected. In comparison to the counselling gaze, the counselling look was seen to be an approach where counselling attended to knowing people’s needs and the situations in which they occur and a willingness to centralise caring solidarity as a part of counselling practice by being willing to see things through a care perspective (Sevenhuijsen, 1998, p. 137).

### ***1.8.3 Feminist Strands***

An aspect of feminist research methodology that informed my research was that the personal is the professional and in particular how my personal stories can inform and enrich my counselling practice rather than detract from it. This research weaves some of these personal strands of my life into this report.

Through reflecting on these personal strands, my own cultural lenses and narrative preferences have been made more visible both to myself and to the reader. This aspect of visibilising the personal and using these personal experiences as a resource in my counselling practice has, prior to this research been a very subjugated discourse. I have in the past practiced more out of dominant discourses that value a clear divide between my personal life and professional life. Davies (2006) ideas about “trouble the boundaries” resonates very closely with me in relation to the personal and the profession. I have appreciated the opportunity to trouble my ideas about the personal and the professional and review my positioning. My preferred positioning is aligned with feminist ideas of transparency of self and using oneself as a resource within the counselling relationship.

### **1.9 Research Design**

All patients under the age of 65 who had been discharged from the Auckland Spinal Unit from June 2002 to June 2004 and who lived in the greater Auckland area were sent an information pack about the research. This information pack contained a letter of introduction from myself, information sheet re the research and the informed consent form. (See appendix I for Information Pack)

This pack was posted to sixteen people, thirteen males and three females. This gender balance represents the gender mix at the Auckland Spinal Unit. The identified ethnicities (as shown on the patient’s hospital notes) were three Maori, eight New Zealand Europeans/Pakeha, one Indian one Tuvalu, two Tongans and one Samaon.

Two weeks after receiving the information pack potential participants were contacted telephonically by Sharon Hutchins a student social worker at the Auckland Spinal Unit and asked if they would like to participate in the research. The hope was to be able to interview a minimum of four people and a maximum of seven people. Eight people agreed to be interviewed but unfortunately one person (Maori male) was not able to participate due to personal commitments at that time of the year. He offered to be interviewed in the New Year (2006) but I had already completed the interviews.

Detailed below is a table indicating the demographics of the participants.

<b>Gender</b>	<b>Children</b>	<b>Ethnicity</b>	<b>Reason for admission in 2002 - 2004</b>
Male	yes	NZ European /Pakeha	New injury
Male	yes	NZ European /Pakeha	New injury
Male	adult children	NZ European/Pakeha	New injury
Male	no	NZ European/Pakeha	New injury
Male	no	NZ European/Pakeha	Re-admission
Female	yes	Samoan	New injury
Female	adult children	Maori	Re-admission

During the period November 2005 to December 2005 all seven participants were interviewed. The interviews were taped and verbatim transcripts were made of these interviews.

The interviews were unstructured. Raymond (cited in Reinharz, 1992, p.19) states that unstructured research interviews maximizes discovery and allows researchers to make full use of differences among people. It also offers researchers access to people's ideas, thoughts and memories in their own words rather than the words of the researcher. Sociologists Pauline Bart and O'Brien (cited in Reinharz, 1992, p.21) explain that careful listening allows the interviewer to introduce new questions as the interview proceeds. Questions can be added when unanticipated responses emerge.

This method of interviewing had the flexibility to accommodate new ideas and themes but also incorporate some of the prior knowledge that has already been gained from patients regarding what is important. Thus new patterns of what is important and what should be covered emerged from the interviews.

I started off each interview by explaining that the purpose of the research was to gain an understanding of what participants thought was useful to discuss in counselling as well as what would have been useful in the counselling when they were newly injured. Participants knew that this would be the focus of the interviews because of the information pack they received. (Appendix I) The interviews lasted for about an hour, no

interview was longer than 1.5 hours. All participants but one had a preference for me coming to their house to interview them. One participant came to my home office.

Once all the transcripts were typed up I worked through them identifying the various themes that emerged. These themes were grief, loss and hope, sexuality, family involvement and how to position counselling services/ make it available to patients. It must be acknowledged that these were the themes that I as the initiating researcher selected. I realise that the research participants may have selected out very different themes. These themes formed the basis of the research. This research is a combination of what the research participants have said, ideas from the literature and my reflections on the actions already taken to improve my counselling practice.

### **1.10 The Structure of the Research Report**

The purpose of this report was to document participants ideas about what they believe would have been helpful or was helpful in terms of counselling when they were newly injured. These knowledges and ideas of the participants are the foreground of the report. The backdrop of the report is knowledges from my experience of counselling patients with a spinal cord injury, my own personal experience and knowledges from books and journals. The intention of this report is that these knowledges from different sources be blended in together and be a useful resource for people who have an interest in counselling people with a spinal cord injury.

The chapter outlines are as follows:

Chapter One is an introduction to the study. This chapter gives a brief background to Spinal Rehabilitation in New Zealand and the specialised medical facilities available for rehabilitation. It highlights why this research was conducted and the purpose of the research. Included in this chapter are the research questions which centre on narrative preferences and how room can be made for the listening of competing narratives and open space for marginalised discourses. The research approach is included in this first chapter.

The theme of Chapter Two is disability theory over the past thirty years. This chapter

looks at the individual, medical and social models of disability and their implications for a person with a spinal cord injury. Chapter Two also looks at a poststructuralist perspective on disability.

All of the participants in this research shared stories of grief, loss and hope in relation to their spinal cord injury. Society is steeped in discourses about loss of bodily functions and the accompanying grief and how one should respond to it. These discourses come predominantly from cultural and medical ideas about grief and loss as well as spiritual beliefs. Chapter Three details discourses of grief, loss and hope and how these various discourses position a person along a continuum of subjugated to agentic positioning.

There is a common saying amongst people who have a spinal cord injury that the first question an injured person is confronted with, is “will I be able to walk again?” The second dilemma / question that the person is confronted with is “will I still be able to have sex?” In Chapter Four I reflect on the injured person’s sexuality and the questions and concerns that may arise as a result of a spinal cord injury. Participants in this research study identified sexuality counselling as an important part of their rehabilitation. Chapter Four also discusses a sexuality project that was initiated at the Auckland Spinal Unit whilst I was engaged in this research project.

The focus of Chapter Five is the positioning of counselling at the Auckland Spinal Unit and invitations to counselling. How can invitations to counselling be extended to patients and their families (whanau) in a way that patients and their families (whanau) can make selections to attend / not attend based on preferences rather than dominant discursive practices that position patients as weak or ‘not managing’ if they select to consult with a counsellor. This chapter addresses some of the discursive practices that stigmatise people who use counselling services. Participants in this study had specific ideas and recommendations about how counselling could be offered. These ideas focussed on making counselling accessible to all inpatients in ways that positioned the patients in an agentic position with regards to the use of counselling services.

The model of practice that is used at the Auckland Spinal Unit endorses that the patient, the family (whanau), the rehabilitation specialists are all part of the same team. For families (whanau) to be able to be part of this team they need to be included and consulted – this view was strongly supported by the participants. Attending to agency

and communion of families was seen to be integral in supporting the family (whanau) to make the adjustments and changes they wanted/needed to make and in this way enabling them to give support to the injured person. Chapter Six looks at how a counsellor can support families (whanau) to be positioned agentially in their caring and involvement at the Auckland Spinal Unit.

If my intentions as a counsellor are to create a collaborative relational stance with clients, attention needs to be given to power / knowledge relations. Chapter Seven puts the spotlight on how power /knowledge relations can be attended to by reflecting on three moments or discourses about ethno cultural differences/similarities. Deconstructing these discourses opens up possibilities for a counsellor at the Auckland Spinal Unit to pay close attention to the position calls he/she offers patients and especially those patients from marginalised ethno-cultural groups which would include Maori patients and their *whanau*.

Chapter Eight reflects back on my personal journey, my victories, my struggles, my hurdles and my joys.

In Chapter Nine I pull together the threads from all the above chapters and I make some recommendations as to counselling practices that could be cautiously used /introduced in the counselling of spinal cord injury counselling. The intention of this is to provide some guidelines that a counsellor can hold with tentativeness, when working alongside people whose lives have been changed by the impact of a spinal cord injury. Included in this chapter will be some suggestions about possible areas for further research.

## **2. Disability Discourses**

### **2.1 Introduction**

In this section I will briefly introduce disability theory as it has developed over the past thirty years. This chapter will show how disability has been viewed through different lenses and depending on the lens used to view disability different aspects or elements about disability become foreground and or background.

The models as well as the discourses that will be discussed are the individual model, the medical model, the social model and social constructionism. These discourses about disability offer different subject positions to the person with a disability which in turn then offer very different identity claims.

The focus of disability theory over the past thirty years has shifted from centralising the individual person with a disability (individual and medical model) to societies' responses and attitudes towards disability (social model) to the social construction of disability.

I will discuss all three of these with particular emphasis on how these discourses position a person with a disability. The perspective from which this research report has been written is from a social constructionist's perspective.

### **2.2 Individual Model**

The individual model of disability suggests that disability is an intrinsic deficit or personal flaw. It positions the individual who has the disability with ideas that there is something wrong with her/him and therefore the person with the disability is responsible to adapt and adjust to her/his disability. Disability, viewed through the lens of the individual model sees disability as something very undesirable and should if possible or as much as possible be hidden away. Stories that people tell of not wanting to be seen in public or people attempting to keep their disability hidden away stem from the ideas held in the individual model.

Closely associated with the individual model of disability is the medical model. Both of these models place the responsibility on the individual to change. The medical model focuses on the failure of the body to achieve normative standards of appearance, functioning or behaviour (Frank, 1995). The goal of treatment within the medical model is to fix what is flawed. The taken for granted assumption within the medical model is that 'the flaw' is situated within the individual - hence the close alignment between the individual model and the medical model. The intention in "fixing what is flawed" is to, as much as possible, get back to "normal" (Frank 1995).

The perspective that disability is a personal problem tends to promote ideas that disabled people are seen as damaged or inadequate and are subsequently viewed almost exclusively in terms of their problem or their deficits (Frank, 1995). According to the medical model the disorder or problem needs to be fixed and the specialists from the medical team can intervene to fix the problem (Oliver, 1996).

An assumption of the medical model and individual model is that the medical experts hold the knowledge as to what is best. Valued knowledge is viewed as stemming from books, technological equipment, empirical research and other medical professionals. Local knowledge of a patient, socio political and cultural knowledges are viewed as too subjective, highly unreliable and of not much value within these models of describing and understanding disability (Oliver 1996).

The medical model and the individual model position the individual as the one who has to adjust and bring about the necessary changes and be compliant with the treatment programme. This stance positions people as passive recipients of care who receive what others have to offer rather than active agents in their own lives. The medical and individual model do not challenge society as being responsible for their attitudes towards and responses to people with disability. Within this model the individual with the disability have to take responsibility to fit in and adjust to society. This model also positions professionals with the responsibility of "knowing how to fix it" and the need to have all the answers and solutions which if followed would sort "the problem out".

Oliver (as cited in Corker & Shakespeare, 2002, p.33) suggests that the individual model and medical model of disability were very limiting. The models were problematic as

people's personal experience with disability showed them that their disability was "not the problem" but rather society's attitude towards disability was the stumbling block. For example needing a wheelchair for mobility is not the problem but rather societies attitude towards a person who needs a wheelchair for mobility is the problem. The social model developed out of this above-mentioned challenge.

### **2.3 Social Model**

The social model of disability challenges society as needing to make changes and adjustments around its attitude and ideas about disability. From this perspective, people are not viewed as disabled but rather society's responses to disability are disabling.

The social model locates the key interventions for disability to be within the realm of social policy and institutional practice. It implies that people with disabilities should be actively involved with decision-making about their own lives rather than being merely passive recipients of services.

The two basic characteristics of the social model are its rights-based approach, which requires that people with disabilities receive the help that they need as an entitlement, and its orientation to community-based support, so that people with disabilities are recognised as participants in the community (Ministry of Health, 2002).

The implications of these aspects of the social model are that it is a person's right to have access to amenities, to have access to sufficient care and the right to active participation in the community. People with disabilities should not have to lobby and beg for these services, these services should be provided.

The social model further suggested that there are two aspects to disability to be taken into account namely impairment and disability.

Impairment is viewed as the functional limitations caused by physical, mental or sensory deficits (Barnes, 2003). For example if a person with a spinal cord injury is unable to move their arms this inability to move their arms and hands would be regarded as impairment. If a person cannot walk as a result of a spinal injury the not being able to walk would be a walking impairment. A person who is hard of hearing is for example

hearing impaired. Solutions for functional impairment are usually addressed by technology such as the use of a wheelchair for the person confronted with a walking impairment or the use of a hearing aid for the person with a hearing impairment.

Disability is the second aspect to be considered within the social model. Disability is defined in the social model as the loss of opportunity and limitations. This loss is imposed on top of the person's functional impairment. The loss of opportunity or limitation is the disadvantage or restriction of activity caused by contemporary social organisation that takes little or no account of people's physical impairments.

An example of how a person with a spinal injury experienced disabling practices was when she went to the hospital for a gynaecological examination. The hospital did not have a hoist (the equipment used to transfer a person from their wheelchair to the bed) in that particular outpatient clinic. The woman was therefore asked to open her legs whilst sitting in her wheelchair, so the gynaecologist could attempt to examine her. These kinds of practices are disabling. The disability is the social context in which the impairment is experienced and the way it is treated rather than the actual functional impairment. It is not the functional impairment that is disabling, it is the way people are treated (loss of opportunity or limitation to have a dignified examination) that is disabling.

Hockenberry (1995 p. 107) shares his experience of being dependent on a wheelchair for mobility and trying to enrol in university study. He mentions that whilst universities today may be a lot more accessible to students with a disability, there are still many lecture theatres that are not wheelchair accessible. In his experience lecturers were not very open to accommodating people using wheelchairs. Hockenberry was informed that the lectures he selected could be moved to wheelchair accessible rooms. The professors however all tried to avoid moving their classes. The administration then asked that he complete a formal request to the university for the required changes. One professor queried whether John Hockenberry was absolutely sure that he wanted to put the department of Humanities to all that trouble. John found this request an unexpected spin on the meaning of the word humanities. The above example of Hockenberry's struggle to enrol in university papers is what the social model would define as disability. It is viewed as the disadvantage or restriction of activity placed on top of one's physical / functional impairments.

The social model advocated that the problem was societies' oppressive attitudes towards disability, not the functional impairment itself that could be regarded as being disabling. Society discriminated against people with impairments. Within the social model this discrimination of society was the disability, the disability was the barriers to participate in all aspects of society. The disability was not the inability to be able to do certain functional things. According to this stance if there was no discrimination against the person with the disability, there would be no such concept as disability. From this perspective disability was imposed by society on people with impairments.

Michael Oliver (1996) thus proposes that disablement has nothing to do with the body of a person with impairment. In terms of the social model, impairment neither equals, nor causes, disability; rather, disability is a form of social disadvantage, which is imposed in addition to the person's specific impairment. This distinction between impairment and disability served as a useful focus for the organisations for people with impairment/disability to advocate and lobby for the rights of people with impairment/disability to participate more extensively in society. The model also altered the position of the disabled / impaired person as it took the focus off the individual's responsibility to change and focused on the actions and responsibilities of society. Society was then held accountable to accommodate all its members and value differences and diversity. It shifted the struggle from the individual to a challenge of a disabling society.

### ***2.3.1 Limitations of the social model***

The distinction in the social model between impairment and disability has been useful as it has brought into focus the rights of disabled people. However, it also turns out to be limiting as it holds these ideas of disability and impairment as separate discrete entities. Tremain (2002, p.33) in critiquing the social model mentions that the dichotomy between impairment and disability denies the experience of the person's body, the personal experience of functional impairment. She asks about the personal effects that the impairment has on each individual.

In this regard to the personal effects of impairment, Slack (1999) relates how after a spinal cord injury she needed to find a new 'voice'. The voice she knew was one of movement. Prior to her injury she had been a top athlete. One of her preferred ways of expressing herself was through movement. As a result of her injury the 'language' that

she knew and felt at ease with, the one of movement, was no longer accessible to her. When she felt stores of anger which grew into volcanic proportions within her, she had no knowledge that she was aware of, at that point in time, what to do with the anger. She relates how frightened she was of the anger. She states “I had lost my dominant language (physical movement) and had not yet learnt the new one” (Slack, 1999, p.29). This experience shared by Slack is about the personal affects of functional impairment on her. For her it was not about society’s responses to her disability. She was struggling with her own personal response to her body and the impairment that she found limiting and frightening. The social model does not seem to encompass these personal aspects of functional impairment.

Another limitation of the social model is that it does not pay attention to those functional impairments that are invisible. If the social model is focussing mainly on disability as society’s oppressive responses to functional impairment, does that mean that if there is no oppression/limitation of the person with impairment, then a person is seen as not disabled?

Not all spinal injuries are visible to the outside observer. However, persons with such injuries may have a high degree of pain, tire more easily than other people and are not as agile and strong as before their injury. The symptoms may be invisible to an outside world. The question that arises when using the social model lenses is the following: Are people with invisible impairments only impaired (functionally limited) or are they disabled as well?

Social construction theory offers an alternative lens of making meaning of disability. This theory goes some way in shining light on some of these aforementioned difficulties.

## **2.4 What is Social Constructionism?**

Freedman and Combs (1996, p.16) state that the main premise of social constructionism is that beliefs, values, institutions, customs, labels, laws and anything else that makes up our social realities are socially constructed by members of a culture. These social constructed realities are not static realities but are fluid and change over time; it is an ongoing dynamic process. Reality is re-produced by people acting on their interpretations of this reality and their knowledge of it. In other words societies construct

the 'lenses' through which their members interpret the world. These interpretations then come to be regarded as 'facts' and 'truth' but they are only socially constructed ideas and concepts that change over time. These lenses which we use to interpret the world are the knowledges that we hold about the world and about how things are in the world. These knowledges are continuously being constructed and co-constructed by society.

Social constructionism therefore questions the possibility of finding essential, objective facts. This approach questions the validity of theories that apparently predict underlying essential truths. Social constructionism suggests we are multiplied positioned and are constantly producing and being produced by the discourses that are available to us.

The implications of this ongoing production of ourselves, in a multiplicity of positions, for a medical setting such as the Auckland Spinal Unit is that social constructionism would question the usefulness of a heavy reliance on standardised methods of care. These standardised methods and practices are based on the assumption that there is such a thing as an essential fixed reality which can be measured, altered and described in some predictable way. These ideas about predictability of how for example a person will respond to a spinal cord injury invites professionals into practices of care that tend to be standardised based on diagnosis rather than the individual needs of the patient. Flowing out of these discourses about predictability patients are given standard treatment depending on their type, category or label for example "C5 complete male in room 921 needs a super pubic catheter" rather than an individual approach that pays attention to individual difference. Practices informed by discourses about predictability position a patient to be 'within normal ranges of progress' or alternatively 'not responding as expected'. This standardised approach to care risks objectifying patients (through the medical gaze) and there is a risk that patients are treated as objects rather than unique people with multiple realities.

Social constructionism stands against 'one size fits all' practices of care.

Social constructionism would argue that realities are socially constructed and not based on objective facts. Social constructionists are thus far more interested in how people are making sense of their experiences and how these experiences are influencing the 'lenses' through which they live their lives. Social constructionists are interested in how

patients are making sense of the information they have available to them and how this is positioning them on their journey of living with a spinal cord injury. This approach requires careful attention to detail and the unique experiences of each person. The filters or lenses that people use to make sense of what is happening to them will be discussed in more detail in the next section.

#### **2.4.1 *Discourses / Language and the Production of Power***

Another key concept in social constructionism is that reality is socially constructed through language. Social constructionism deems that language constitutes our world and our beliefs:

... the only worlds that people can know are the worlds we share in language and language is an interactive process not a passive receiving of pre-existing truths.... Every time we speak, we bring forth a reality. Each time we share words we give legitimacy to the distinctions that those words bring forth (Freedman & Combs, 1996, p.28).

For example the language used in the following excerpts about wheelchairs offers different position calls and brings forward different realities - being wheelchair bound, in a wheelchair, using a wheelchair for mobility, and using a wheelchair to get around.

Taking the idea of language even further, just by talking about disability legitimises disability as a concept to be talked about. From this perspective it means that if there was no language for disability, disability would not be seen as a concept.

The language that we use is organised as narratives or stories of events. These stories of events cluster together and are called discourses. Language is structured into a number of discourses.

A discourse refers to a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular picture that is painted of an event... The point is that numerous discourses surround any object and each strives to represent or 'construct' it in a different way. Each discourse brings different aspects into focus, raises different issues for

consideration and has different implications for what we should do (Burr, 2000, p.48).

There are many discourses constantly at work constructing and producing a person's multiple identities. Within these multitudes of discourses different positions are available which we can accept, change or resist (Davies, 1991). Positioning within a discourse is "the process by which discourses place people in relation to each other – usually in power relations of some kind" (Monk, Winslade, Crocket, & Epston, 1997, p. 304). These positions provide possibilities and or limitations for what we may or may not do. These different positions offer different speaking rights and depending on the position we take up we have available a limited set of concepts, images, metaphors and ways of speaking that we take on as our own. "Our sense of who we are and what is therefore possible for us to do, what is right and appropriate for us to do, and what is wrong and inappropriate for us to do all derive from our occupation of subject positions within a discourse" (Burr, 2000, p.146). These discourses however are not static, we are continuously constructing and co-constructing the discourses through which our version of events / meaning making is produced. This in turn shifts and changes our positioning within those discourses which then in turn changes the power/knowledge relations.

For a patient at the Auckland Spinal Unit there are multiple position calls which offer different speaking rights depending on the position taken up. Within disability there are also a multitude of position calls which offer different speaking rights and inform a person with a disability about what is right and appropriate and what is inappropriate. Fortunately a person is not stuck in a particular position call. These position calls can be resisted, subverted, changed or accepted – hence we are constantly produced and producing ourselves within discourse. In the same way as there are multiple positions that a person can accept, change or resist within a discourse there are also numerous discourses available to a person.

Davies (1991) states that we are constituted through multiple discourses at any one point in time. These multiplicities of positioning within discourses are not always congruent with each other, but may even contradict each other. A move we make as correct within one discourse may be equally inadvisable / dangerous within another. For example a patient at the Auckland Spinal Unit may be positioned as afraid to speak out against

practices of care that they are not in agreement with as they are positioned within the medical discourse as non agentic and the 'experts' know what is best for you. However in opposition to this, flowing out of discourses of patient's rights these discourses position patients to speak out and inform health practitioners if they are not in agreement. These two discourses (patient's rights discourse and medical discourse) may be contradictory to one another and a move made in one discourse may be risky in another one.

Within discourses and the positions taken up / resisted there is the concept of agency. Agency is "the extent to which individuals can act for themselves and speak on their own behalf (Monk et al., 1997, p.301). Davies mentions that agency "is never freedom from discursive constitution of self but the capacity to recognise that constitution and to resist, subvert and change the discourses themselves through which one is being constituted" (Davies, 1991, p.51). A person is never free from discourses. However, a person has the possibility to take up certain positions and attempt to resist others. The extent to which she/he is able to do this is referred to as agency. If a person is able to select and or resist the position calls that are being offered she/he would then be agentially positioned within that discourse.

For example some patients that I work alongside actively resist the idea that because they are unable to wipe their own bottoms, control their bladders or their bowels that this gives them any less speaking rights when it comes to decisions about their lives. Whereas other patients experience this loss of this ability to control their bodily functions as a loss of agency to such an extent that they also become hesitant to use their speaking rights. According to Winslade (1994) for counselling to be truly transformative every counselling interview should be seen as a socio political context in which dominant discourses are at work. The counsellor should work with the client to name the oppressive force(s) at work in the client's life and then support developing awareness through resistance. The intention of counselling is to give patients the opportunity to reflect and deconstruct various discourses and their position calls that are on offer and they can then select and develop preferred subject positions.

In summary therefore the way we understand the world and make meaning of the events in our lives (such as a spinal cord injury) is socially constructed. According to social

constructionism there is no such thing as an essential truth. Reality is not singular or objective, it is rather something that we are producing and co-producing in relation to each other. Our ways of understanding the world are always historically and culturally relative. The way spinal cord injury is known is historically and culturally relative and this knowledge is produced and co-produced through language. Language is the context through which these worlds are known. Language is an interactive process bringing forward certain constructs and rendering invisible others. These constructs or version of events represent discourses which in a sense are our filters or lenses which we use to understand the world and our life experiences. Within these discourses some knowledges are dominant and therefore taken for granted assumptions that they represent an accurate version of events, in a sense these dominant knowledges hold the stamp of truth. Whereas other knowledges within these discourse are subjugated and less known and do not have the same 'authenticity' as those more dominant knowledges. The more dominant a discourse is the more power/knowledge that representation of that version of events holds. Within discourses a person can take up, resist, subvert or change the position calls on offer. The extent to which a person is able to do this (resist, take up, subvert, change) is the degree of agency that they have within that particular discourse.

In this next section of the report I turn to social constructionism and disability resulting from a spinal cord injury. There are many dominant discourses about disability. According to Roberts, Francis and Eastham (1999, p 56 -57) these dominant discourse about disability attempt to position people with disabilities into:

Keeping us housebound, try to keep us invisible, try to break our will, try, try to tell us we aren't good enough, try to tell us we are unemployable, that we can't do it, we are not desirable to others, we haven't got a life, we don't have the same desires as other people, focus on what is wrong with us and on and on it goes.

The purpose of counselling is to liberate / make known subjugated or marginalised knowledges that stand against these dominant discourses.

## 2.5 Social Construction of Disability

If our values, beliefs customs and categorisations of people are socially constructed and they are being constructed and co-constructed it follows that disability will be viewed in many different ways depending on the lenses selected / available. The selection / availability of these discourses or lenses are culturally and socially constructed and they are dynamic and change over time. There is no one unitary definition of disability. From my experience of working at the Auckland Spinal Unit I have noticed numerous discourses (taken for granted assumptions) about disability. I have also noted how for many patients and their families (*whanau*) these discourses about disability and spinal cord injury change and alter over time.

From a social constructionist perspective our repertoire of actions are guided by the discourses available to us. The focus for counselling people with a disability thus becomes discourses about disability and their productive power which patients and their family (*whanau*) may select to take up and /or resist and/or change.

From my experience of working alongside people with a spinal cord injury I have observed and been informed about some centralised dominant discourses about spinal cord injury. In particular there seems to be dominant discourses that relate to an inability to walk and inability to control (in the “normal” way) bladder and bowel and a dependency on other people to assist with personal cares. The subject positions offered by these dominant discourses tend to invite people with a disability into identity claims that may position them as less agentially positioned than a person who does not have a disability. I have however noted at the Auckland Spinal Unit that there are many subjugated discourses about disability that stand against these dominant discourses and offer an agentic positioning to people with disability.

When a person is newly injured the readily available dominant discourses that may inform a person about how to go on may position them non agentially. For example some of the ideas, beliefs and values that I have noted that have been produced by discourses of monetary success, independence and individuality as well as parenting discourses are as follow:

~ If I am in a wheelchair, people will think I am retarded.

- ~ If my body is not perfect how will any person be attracted to me?
- ~ If I am in a wheelchair, I will be an object of pity, and I do not want anyone's pity.
- ~ It is not possible to have a normal sexual relationship if you have a spinal cord injury.
- ~ I am less of a person if I cannot be completely independent.
- ~ I have let my family down because I cannot continue to be a breadwinner.
- ~ How can I really be a mother if I cannot care properly for my children?

The position calls that these discourses mentioned above invite a person into are almost without exception not the person's preferred positions. To give opportunity for people to review their current positioning, alternative narratives need to be reconstructed by accessing counter narratives (subjugated narratives) about disability. This gives opportunity to bring different aspects into focus, raises different issues for consideration and offers different implications for what a person could do (Burr, 2000, p.146).

In addition we are constituted through a multiplicity of different and at times incongruent and or competing discourses. The potentially life changing impact of a spinal cord injury challenges a person to take up and or resist position calls about disability and the many many other discourses that accompany it such as body image, independence, health and wellness, sexuality, how we measure worth to name but a few. This quote highlights the complexity of disability.

The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas. Considering the range of impairments under the disability umbrella: considering the different ways in which they impact on individuals and groups over their lifetime; considering the intersection of disability with other axes of inequality; and considering the challenge which impairment issues to notions of embodiment, we believe it could be argued that disability is the ultimate post-modern concept (Corker & Shakespeare, 2002, p.15).

In western society there seem to be very prevalent centralised discourses that relate to body image, sexuality, financial independence, ability to walk, being able to physically

control ones bowel and bladder, being able to physically control ones body, parental responsibilities and a spinal cord injury has the potential to call into question all these taken for granted assumptions. It is for this reason that I agree with Corker and Shakespeare when they say that disability is too complex to be rendered within one unitary model and I have found that it continues to challenge my taken for granted assumptions about what is “normal” and what is “natural” – hence my experience resonates with Corker and Shakespeare’s suggestion that it is the ultimate post modern experience.

### ***2.5.1 Disability and New Relationships***

When disability as a result of a spinal cord injury comes into a person’s life the person with the disability is positioned as needing to develop a whole set of new relationships with the equipment and carers which she/he need as a result of the spinal injury. The equipment could include catheters, standing frames, wheelchairs, banana boards, strollers, commodes. For some people there is so much additional equipment that a spare room is required to store it all. The relationship that a person has with this equipment can be quite central in how she/he adjusts to disability as a result of a spinal cord injury.

For example some people who have a spinal cord injury and need wheelchairs for mobility have informed me in counselling that they view their wheelchairs as being “quite cool”, they are very specific about the colours, the size, the weight and how manoeuvrable they have to be. These people take up the positioning of being “cool” and view their wheelchairs as giving them the opportunity to be different in a crowd of people. There are other people who are positioned in a friendship relationship with their wheelchairs. I have known patients at the Auckland Spinal Unit become very upset and angry if their wheelchairs were not in their rooms. They have told me that it feels as though a part of them “has been removed”. I have also seen people who need a wheelchair for mobility who are positioned in a hate relationship with their chairs. This hate relationship invites them into being ashamed and trying as much as possible to hide the chairs away (which normally means themselves as well) from the public eye.

Relationships and the position calls they offer are central to social constructionism. In working alongside people with a disability as a result of a spinal cord injury relationships with equipment and carers may need to be deconstructed and reviewed.

## **2.6 Conclusion**

It is my observation that there are some very problematic centralised discourses (taken for granted ways of being) that are available to patients and their families about disability. At any given moment a variety of discourses can be in circulation and some of these discourses may compete or contradict each other. Each discourse brings different aspects into focus, raises different issues for consideration and has different implications for what we should do (Burr, 2000, p.45).

The purpose of counselling is to assist the client in identifying the discourses influencing them, and to give them opportunity to consider the influence these discourses may have on their lives. This recognition of discursive positioning allows for degrees of choice for people to then claim, resist or relate differently with those identified discourses (Burr, 2000).

The intention of counselling is to open space for the consideration of these discourses and if needed bring forward alternative or subjugated (not currently visible) discourses that may not be as readily available to a person. The problematic nature of these centralised and pervasive (in Western society) discourses, relating to disability, is challenged in counselling by making visible the marginalised discourses.

Disability affects people in very individual ways and so whilst there may be common themes each person needs to be respected as uniquely positioned. There is no such thing as a “one size fits all solution.” This research clearly demonstrated the vast differences in the way that people responded to their injury.

### 3. Spinal Cord Injury: Grief, Loss and Hope

#### 3.1 Introduction

Nobody is exempt from loss – loss of innocence, functionality, health, loved ones, hopes and dreams, money, status ... The list continues almost *ad infinitum*. Sluzki (cited in Neimeyer, 2000, p.4) comments that losses “are the shadow of all possessions – material and immaterial.” If we have possessions, either material or immaterial, we are vulnerable to loss. When we experience loss, we often respond with grief.

Much has been said and written about loss and grief. Religious writings, cultural traditions, medical and psychology textbooks, and even family therapy all present discourses about loss and the accompanying grief; and they suggest various ways of responding to loss and the grief and other feelings associated with loss. The discourses available to us shape the meaning we attach to the losses we experience, and suggest how we can and or should respond to these losses.

The many losses experienced by those who have had a spinal cord injury also lead to grief. Because patients with a spinal cord injury, the staff at the Auckland Spinal Unit and the family (*whanau*) members of the injured person are all exposed to a variety of discourses about loss and grief, they are positioned in relation to their loss and grief in various ways by the discourses available to them about loss and grief. These discourses inform a person with a spinal injury and that person’s family how they live with a spinal injury. Such discourses offer different positions of power and agency, and confer different speaking rights. Various positions taken up and/or resisted around loss and grief are reflected in the interviews with the participants in this research.

In the first part of this chapter, I discuss some of the discursive practices commonly associated with losses relating to a spinal cord injury to show how these practices position people with a spinal cord injury, their families (*whanau*), friends and acquaintances, as well as the professionals working alongside them. This positioning reflects the degree of agency the injured person has and the options available to that person to go on with life.

In the second part of this chapter, the voices of the participants reveal how such discourses positioned them in their journey with the losses and the grief that resulted from their spinal cord injury. Lastly, I reflect on my own practice, weaving together ideas from the participants, the theory, as well as my experience of working alongside people who have experienced very significant losses in their lives.

### **3.2 Discourses about Losses and Spinal Cord Injury**

A person and/or his/her family (*whanau*) may experience numerous losses as a result of a spinal cord injury. These losses could include a loss of physical functioning, significant relationships, status and *mana*, any belief in the predictability of life, money, recreational pursuits, body image, personal significance, a physically pain-free life, dignity, mothering and fathering opportunities, intimacy, career opportunities, employment, and many other losses.

Loss is a central theme for most people with a spinal cord injury, especially just after they have sustained the injury. As Frank (1995) suggests, life will be different. This difference includes both losses and gains, but at the time of illness or injury, the gains are unknowable, while the losses are very self-evident. Because loss is such a central theme in working with people who have had a spinal cord injury, identifying the discourses commonly associated with the losses listed above is important – these discourses affect people’s responses to these losses.

The dominant discourses around the losses and grief associated with a spinal cord injury that seem to inform the storylines of the staff, the patients and their families at the Auckland Spinal Unit tend to centre mainly on psychological theories of loss and grieving, religious teachings about loss and grief, and cultural traditions about loss and grief. These three areas are not mutually exclusive and they all influence one another to various degrees.

Discourses have implications for what we can do and what we should do (Burr, 2000, p.54). Discourses inform us “how we should go on,” how we should act or respond. A multitude of discourses are constantly at work – they range on a continuum from centralised (dominant) to decentralised (marginalised). In Chapter Two of this research

report I showed that the more centralised or dominant a discourse is, the more it is a taken-for-granted “truth” that is accepted as the “true” version of an object or idea. As has already been explained, this taken-for-granted truth is not the truth; it is a particular version or construct of the object or idea.

A number of centralised discourses about the losses and grief associated with spinal cord injury are taken-for-granted “truths” informing the staff, the patients and their families (*whanau*). The more commonly accepted or ‘obvious to all’ a discourse is, the more difficult it is to “trouble” (Davies, 2006) it and to deconstruct it. In other words, the ideas, values and beliefs that a particular discourse represents are so prevalent that little or no space is opened up for the ideas, values and beliefs that feed into that discourse to be reviewed and reflected on or deconstructed. The more similarities there are between the dominant discourses that influence a group of people, the more difficult it is to see other constructs or versions of an object or idea. If everyone within a group sees something in the same way, it becomes extremely difficult to see alternatives and other ways of viewing something, or other constructs or versions.

At the Auckland Spinal Unit, the ethnicities of the staff and the patients are similar. They are predominantly Pakeha, New Zealand Europeans, Maori and Pacific Islanders. Because of the resonance between the ethnicities of staff and patients, the storylines of loss and grief are often informed and influenced by the same dominant discourses. This can sometimes be problematic, especially if the dominant discourse about loss places the patient in a position where he/she has no agency. The discourse may be so powerful (because everyone clings to that storyline) that to “trouble” or “unsettle” it can be difficult.

In this research, I focused specifically on the discourses of loss and grief held by Maori, Pacific Islanders and New Zealand Europeans. However, at the Auckland Spinal Unit, a small minority of the patients are Asian. I had a sense that, culturally, the dominant discourses about loss and grief held by Asian patients are quite different from the dominant discourses of the other patients. The role of retribution and “making right” with the aggrieved person seems to be more in the forefront in the discourses used by Asian patients than with other patients I have worked alongside of. I voice this observation about retribution and “making right” extremely tentatively, as I do not have

much knowledge of discourses of loss and grief in the Asian community. I am intensely aware that there are likely to be vast differences within the Asian community itself. While it falls beyond the scope of this report to explore the discourses that affect the Asian patients, the brief comments about these patients here emphasise that different cultures are influenced by different discourses.

### ***3.2.1 Psychological Theories of Loss and Grief***

In this section I discuss three psychological theories regarding loss and grief. The first theory is that of Elisabeth Kübler-Ross. The second is that of Robert Neimeyer, who writes from a constructivist perspective to grief therapy. The third is that of Arthur Frank, who writes from a post-structuralist perspective. Some ideas about hope and grief from the writings of Kaethe Weingarten are also discussed. Her approach to loss and grief also tends to be post-structuralist.

The three writers whose theories are discussed in detail below write about loss in relation to illness, but Elisabeth Kübler-Ross and Robert Neimeyer write primarily about loss as a result of death (impending or actual). It must be noted that, while these discourses relate to loss and grief related to death and illness, there is little or no literature on loss and grief related specifically to a permanent injury such as a spinal cord injury.

The literature specifically about loss and grief relating to an injury that is not an illness and an injury that has permanent implications such as a spinal cord injury is very limited, indeed, virtually non-existent. There are several studies about spinal cord injury and depression, but there is scant information on spinal cord injury, and loss and grief in relation to this. This paucity of information about loss and grief in relation to a spinal cord injury may be influenced by discourses that suggest that grieving and depression are closely aligned with each other. In other words, the words “depression” and “grieving” are used almost interchangeably and are therefore taken to mean almost the same thing. However, as Neimeyer points out, “recent research evidence fails to support cherished models that assume that grieving is necessarily associated with depression” (Neimeyer, 1999, p.65).

### 3.2.1.1 Elisabeth Kübler-Ross

The writings of Elisabeth Kübler-Ross on loss and grief have had a significant impact on both the medical profession and the general public. Her book, *Death and Dying*, which was first published in 1975, has been described as a world-famous best-seller, as an important book that can help families understand what is going on as the death of a loved one draws near, and as a “must read” for anyone seriously interested in issues surrounding death and dying (<http://www.growthhouse.org/books/kubler1.htm> - date 2/06/06).

Based on Kübler-Ross’s interviews with hundreds of people who were dying, she theorised that people go through five stages when they die. These stages are sequential. In other words no stage can be skipped and all stages must be experienced sequentially. If someone does not resolve the challenges associated with one of these stages successfully, he/she could ‘get stuck’ in this stage and not move to the next. The last stage of grief is acceptance. Kübler-Ross’s work implies that acceptance is the desired result before one dies and or “comes to terms with a loss”.

The first stage that Kübler-Ross identified was denial and isolation. In this stage, a person denies that he/she is going to die or that he/she has experienced a significant loss. The person continues as if nothing has changed and/or as if the change will not be permanent and/or as if perhaps there has been some mistake in the diagnosis, and as if more tests are needed for confirmation.

The person then begins to realise the reality of the loss; and the second stage of grief starts, namely anger. The person realises that he/she cannot change the outcome of events. This anger may also be a form of blaming, blaming others or oneself for things done or not done, for example, anger at the medical team for not intervening more quickly.

The third stage involves bargaining. In this stage, the person tries to understand why this has happened to him/her and then tries to bargain his/her way out of the situation, for example, by reasoning that if the person starts treating his/her family better, or starts praying more, or eats healthy foods, or attends all therapy appointments, then the person will not have to experience this loss.

According to Kübler-Ross, from bargaining, a person moves to depression. Once the person can see that he/she cannot bargain his/her way out, or strike any bargains to remove the situation from him/her, the reality of the loss becomes very apparent to the person; and this results in depression.

Giving grieving people an opportunity to talk about their sadnesses and the losses they are experiencing helps them to move to the acceptance stage of grief. Acceptance is the preferred end point for any person dealing with loss and grief, according to Kübler-Ross.

Kübler-Ross's theory is deterministic, in the sense that there is a cause and a direct effect. So, for example, when she describes the stage of depression, she states that when a terminally ill person can no longer deny his/her illness, when the person is forced to undergo more surgery or hospitalisation, he/she cannot laugh the situation off anymore. His/her numbness or stoicism, his/her anger and rage is soon replaced with a great sense of loss. This loss causes the first type of depression, which is a preparatory grief. The second type of depression is a result of impending loss. When the depression is a tool to prepare for the impending loss, in order to facilitate the state of acceptance, it is contra-indicated to tell the person not to be sad. If he/she is allowed to express his/her sorrow, he/she will find a final acceptance much easier and he/she will be grateful to those who can sit with him/her through this stage of depression (Kübler-Ross, 1970, pp. 75 -77). This very direct relationship between cause and effect creates an impression that there is a right way to grieve, one which will result in acceptance; and there are also wrong ways to grieve. The theory suggests that there is only one experience and one reality which is consistent and deterministic.

Because this theory is so deterministic, it has the potential to place people in a position where they have no agency when it seems as if they are not following all the required steps and stages in the grief process. The underlying assumption of this theory is that, if a person grieves in the "normal" way, which is also the "right" way, the person will progress through these stages and come to accept the inevitable. If a person does not do it in the "right" way, he/she will not progress through all the stages and may get stuck in one of the stages, never "coming to terms with" or "accepting" the loss. So, for example, one person whom I was counselling said to me: "I do not think I grieved properly

because I never went through the anger stage.” The discourse placed this person in a position where he had no agency, leaving him with a sense that there was some deficit in the way he managed his grief process and that this should have been done in the prescribed or expected way.

Kübler-Ross’s work has had an enormous influence on society and on discourses on how people in a Western tradition respond to loss and grief. Her pioneering work in the 1970s was a forerunner in deconstructing the then dominant discourse in Western society that the best way to deal with death was to not talk about it. Her work has encouraged people to talk about death and dying and has itself become a dominant discourse on ways of dealing with different kinds of loss.

### *3.2.1.2 Robert Neimeyer – A Constructivist Approach*

Neimeyer’s writings about loss and grief suggest that there are a number of common reactions, feelings and processes of healing for those who are bereaved. There is a “typical” grief response, but this response is not universal. Although many people would have a “typical” grief response, there are also important variations among mourners as a result of who they are, and how they usually cope with adversity. Neimeyer regards popular grief theories as mere simplifying assumptions about stages of emotional adjustment to loss and universal tasks to be mastered by a bereaved individual. Instead, he argues that the intimate details of people’s stories of loss suggest a complex process of adaptation to a changed reality, a process that is at the same time immensely personal, intricately relational and inevitably cultural (Neimeyer, 1999, p.66).

The “typical” grief cycle that Neimeyer refers to consists of three sequential stages. These are avoidance, assimilation and accommodation. However, Neimeyer cautions that it is misleading to speak of “stages” of grieving, as if all mourners follow the same path in their journey from painful separation to personal restoration – there are many individual differences. He refers to them as phases, but he mentions that the grief cycle may be more accurately described as a process where one takes two steps forward and one step back (Neimeyer, 2000, pp.5-9). Additional details about these three phases are set out below.

***Avoidance*** – Especially with losses that violate their expectations, people may find the

reality of the loss impossible to comprehend and so avoid the reality of the loss. People may respond with shock, numbness, panic or confusion. In other words, there may be physical, cognitive, emotional and behavioural responses to the loss. As the reality of the loss sinks in, the loss may invite angry responses. Alternatively, people may find that one moment they are denying the reality of the loss, but a short while later they are overcome with grief and anguish as a result of the loss.

***Assimilation*** – To some extent, avoidance and anger protect people from the full impact of the loss. Neimeyer suggests that, once the avoidance and the anger subside, people begin to assimilate the loss into their lives. People start to see the significance of the loss for their lives. This is often accompanied by loneliness and sorrow and possibly deepening despair.

***Accommodation*** – This part of the cycle of grief comes as people accept the reality of the loss and start to think about the future, accommodate the losses and begin rebuilding their worlds. This rebuilding of people's worlds may be a balancing act between remembering the past and re-investing in the future, for example, remembering the loss of a spouse while investing in new romantic relationships.

Neimeyer (2000) suggests that the grieving process is full of choices, with many possible paths to venture down or options to avoid. The path he suggests is detailed below.

The initial step is to acknowledge the reality of the loss. This could include yielding to the idea that the changes which have resulted because of the loss are permanent. As part of this acknowledgement, Neimeyer suggests that a person allows him/herself to feel the pain of the loss. He also talks of the notion of periodic grief where the grieving person gives him/herself specific times to experience and feel the loss. Because loss often challenges taken-for-granted assumptions about the world and about ourselves, as part of the grieving process, these assumptions may need to be revised and reviewed. So, for example, I have heard patients at the Auckland Spinal Unit saying that they never thought they would have a sporting or a motor bike accident. They had always assumed that those things only happened to people who were careless. After an accident, assumptions may need to be reviewed to accommodate the new information.

A key aspect of Neimeyer's work is his idea of reconstructing a person's relationship with what has been lost. Neimeyer suggests that the aim of grieving is not to forget or "get over" losses; it is rather to reconstruct relationships with them in a way that accommodates the loss(es). As a result of loss, Neimeyer says, lives are changed forever, and therefore people need to reinvent themselves. The idea is to build an identity appropriate to new role(s), whilst establishing continuity with old ones.

In conclusion, the central process in grieving, according to Neimeyer, is to relearn the world, a world that has been changed forever by the loss. The aim is to accommodate losses rather than try to "get over them".

### *3.2.1.3 Arthur Frank – a post-modernist approach*

Frank suggests that humans are perpetually recreated in stories. Frank argues that illness and trauma disrupt people's destinations and the plot structures of their lives. This plot structure of life needs to be re-established, people need to put order into a confusing series of events and tie them together in a way that makes them, if not acceptable, at least comprehensible. Telling and retelling their stories in the context of listeners who care and who contribute in their unique way assists people in making meaning of their unique life experiences (Frank, 1995, p. 55).

According to Frank, when a person becomes ill, there is a call for stories in at least two areas. The one area is in repairing the damage that illness has done to the ill person's sense of where he/she is in life and where he/she is going, the person's destination map as Frank calls it. Stories help people to re-draw the maps that guide them in life and help them to find new destinations. The second area where stories are called for is to give an account of what is happening to friends, family, medical staff, employers and colleagues. Whether ill people want to tell stories or not, illness calls for stories (Frank, 1995).

Frank believes that when people are ill, it is imperative that they tell their stories. Doing so reaffirms relationships with others, as well as people's relationship with themselves. Illness is an interruption. Frank mentions that

... the ill person as a medical patient is one who having been interrupted by disease [or a spinal cord injury] is now considered infinitely interruptible in

speech, schedule, sleep, solvency and anything else. Living an interrupted life requires a new kind of narrative. It cannot be a conventional story with a tidy neat ending. The stories are often confusing or inconsistent, like the interrupted life. The stories are uncomfortable and their uncomfortable quality is all the more reason they have to be told. Otherwise the interrupted voice remains silenced...The narrative attempts to restore an order that the interruption fragmented, but it must also speak the idea that interruptions will continue. Part of this is that tidy ends are no longer appropriate to the story (Frank, 1995, pp.58 - 59).

Frank proposes that there are three types of illness narratives. Frank is not trying to create generalised unifying categories to fit ill people's stories into. Instead, his intention is to encourage close attention to the stories ill people tell. Frank supports the idea that one of our most difficult duties as human beings is to listen to the voices of those who suffer. These three narrative types serve as an aid to listening to the ill. These three narrative types are restitution narratives, chaos narratives and quest narratives.

**Restitution Narratives** - The basic plot of a restitution narrative is "yesterday I was healthy, today I am sick but I will be better soon." The dominant discourse in this narrative about illness is that people get better.

I was recently reminded strongly of the dominance of this restitution discourse when I went looking for a card for someone who was ill and who was not going to recover physically. There were no cards that I could see in the shop which would have been suitable. There were plenty of "get well soon" cards, but no cards that were willing to acknowledge an illness that did not have a "happy" ending. Weingarten (2001) describes these illness narratives without a "happy" ending, without the possibility of stabilized or improved health, as narratives where there is a downward or a backward slide. I could see no cards in the shop for an ill person whose narrative was regressive.

The restitution narrative projects a future that will not be disrupted by illness. Thus illness is portrayed as a temporary glitch in an undisrupted future; the illness is not memorable. Ill people who tell restitution stories live out illness as a matter of doing their jobs as patients, preparing for the future after illness. The restitution narrative

displays heroism in the face of bodily breakdown, which is in turn often linked to the heroism of the healer. In medical talk, a person with a restitution narrative would be described as compliant (he/she accepts the authority of the medical team), as motivated, as being in an appropriate mood (positive) and as being a future-focused person – the ideal patient.

The active player in a restitution story is the remedy, which is frequently the medical team and the advances of medicine today.

*Chaos Narratives* - A chaos narrative is the opposite of a restitution narrative, as it imagines a life that will never get better. A chaos story does not have narrative order; these stories are told in the same way that the storyteller experiences life – as a lot of random events with no logical sequence or outcome. A chaos story reveals vulnerability, futility and impotence. In one sense, a chaos story is not a narrative, as it is not a sequence of events. The person living the chaos story has no distance from his/her life, the body is imprisoned in the frustrated needs of the moment. In a chaos narrative, troubles seem like a bottomless pit, with no way of escape.

A chaos story is hard to listen to, as it threatens people's very sense of continuity and invulnerability. The challenge of encountering the chaos narrative is how not to steer the storyteller away from his/her feelings. The chaos story needs to be honoured and listened to:

...to deny a chaos story is to deny the person telling this story, and people who are denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care (Frank, 1995, p.109).

Frank suggests that the impulse of most would-be helpers is first to try to drag the teller out of this story, in other words to try to move the teller away and out of the chaos story. Frank adds that getting out of chaos is desired, but people can only be helped out of the chaos story when those who care are first willing to become witnesses to the story.

There is no active player in the chaos story; life is random, there is no control.

*Quest Narratives* - Quest stories accept illness and there is a belief that something is to be gained through the experience by the listener to and the teller of this illness narrative. Quest stories tell of a journey of searching for alternative ways of being ill, a journey of transformation where the teller has been given something by the experience, often something that must be passed on to others. Illness (in this case a spinal cord injury) is an interruption a person would not have chosen, but in a quest narrative, it is the cost of making changes that the person appreciates and the person would not want to live without these gains. The losses continue to be mourned, but the emphasis has shifted to the gains being made:

The quest narrative recognises ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore moral agency that other stories sacrifice. Ill people need to be regarded by themselves, their caregivers and by our culture as heroes of their own stories (Frank, 1995, p. 134).

The active player in a quest story is the patient. Unlike in a restitution story, where the remedy (or doctor) is the active player, in a quest story, the patient is positioned as the agent making choices about how he/she wants to use the experience of loss.

Some of the psychological theories that inform the discourses surrounding the loss and the grief associated with a spinal cord injury have been mentioned above. As previously mentioned, at the Auckland Spinal Unit, discourses about loss and grief associated with a spinal cord injury predominantly come from such psychological theories, but also from Christian teachings and cultural beliefs. A number of discourses that emerge from and through Christian teachings are discussed in more detail below.

### ***3.2.2 Christian ideas of illness and suffering that inform storylines***

Christian beliefs stem predominantly from interpretations of teachings from the Bible. There are many verses in the Bible that talk about suffering and hardship and how a person should respond to such difficulties.

Perhaps one of the best known verses in the Bible is Psalm 23. This psalm talks about suffering and how God is always present in this suffering. Despite hardships, God's

abundant protection, goodness and guidance are always available:

Even though I walk through the valley of the shadow of death,  
I will fear no evil, for you are with me,  
Your rod and your staff they comfort me, (*symbolic of guidance and protection*)  
You prepare a table before me in the presence of my enemies,  
You anoint my head with oil (*customary treatment of an honoured guest at a banquet*)  
My cup overflows  
Surely goodness and love will follow me all the days of my life  
and I will live in the house of the Lord forever.

If a person believes what is said in the psalm, even in loss, which may be experienced as the “valley of the shadow of death,” God is present, protecting and guiding, and therefore there is no need to fear. Not only is God comforting the person, God is preparing a banquet (figuratively speaking) for him/her, a banquet in which the person experiencing the suffering is the honoured guest. This idea of being the honoured guest raises the notion that suffering is not something to be avoided, as, with God’s love and protection, suffering can result in blessings.

This idea that losses and difficulties bring some benefit is closely aligned with another central idea in Christian Biblical teachings, which is that nothing in life is random; everything happens for a purpose. An individual may not understand exactly what the purpose is, but God will work all circumstances for good, no matter what the actual event is. The Bible states:

We know that in all things God works for good of those who love him, who are called according to his purpose... For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord (Romans 8:28 & 29 NIV).

Christian beliefs such as these can position a person with hope, because God loves him/her, God will never leave the person and God will work out the illness or the suffering the person is experiencing to the person’s benefit.

There are, however, also other Christian discourses that see God as a wrathful God, a God that is quick to punish any wrongdoing. According to this discourse, if a person sins, God will punish him/her and that punishment may be an illness or an injury. An injury or a sickness may therefore be interpreted as a punishment from God. Discourses focused on a wrathful God can position a person as having no agency, and leaves him/her feeling like a victim of God's power and wrath. Such discourses can also invite guilt, as a person could believe he/she has done something wrong.

To summarize, then, Christian discourses about injury, illness and suffering may position a person as either more available to receive God's blessing through the experience of suffering or as being guilty of and punished for some offence.

### ***3.2.3 Ethno-Cultural Discourses of Illness, Suffering and Injury***

There are a number of central ideas about loss and grief that may inform the storylines of Maori, Western Europeans and Pacific Islanders as patients and their families (*whanau*).

#### *3.2.3.1 Centralised ideas that may inform a Maori world view*

Durie (1977, p.483) claims that "for the Maori of old" an illness was believed to reflect an infringement by a person against some law of *tapu*. He adds that

...it would be rare to find a patient in hospital who spoke openly about some infringement against a law of *tapu* but frequently there is an unspoken and an unconscious fear of some infringement against the community as a whole....There is for the family the possibility that they might also have been involved in some cultural offence and a certain amount of guilt is likely – especially if they are not actively involved in the treatment plan (Durie, 1977, p. 483 - 484).

In dealing with loss and grief from a Maori perspective, Durie seems to suggest that patients and their *whanau* may have some concern that there has been an infringement against the law of *tapu* and that the patient is being punished for it. This discourse could result in the patient's being positioned as being deserving of punishment and could imply that the patient must possibly suffer the consequences until the infringement has been addressed by the *whanau*. In Chapter Seven of this research report, I discuss the concept of *whakama*, which may perhaps be a manifestation of the infringement of the law of *tapu*.

In my experience of working alongside Maori patients, I have found that there seems to be a strong preference for the discursive practice of talking about their experience and sharing it with the *whanau*. My understanding of this is that suffering is regarded as a communal experience; in a sense, if one person suffers, all suffer. Talking about loss and the accompanying grief within the *whanau* seems to be an important practice for many Maori.

### 3.2.3.2 *Central ideas that may inform a Western (European) world view*

In stark contrast to the discursive preferences of some Maori patients to talk about and share their experience of their losses and the accompanying grief, Western (European) discursive practices appear to promote the notion of not talking about things that are sad or emotionally painful. One dominant discourse stemming from a Western (European) world view about loss and grief focuses mainly on not dwelling on difficulty but rather just getting on with life, or “moving forward”. A very popular song that was sung by the Allied armed forces after World War II encapsulates this discourse very aptly. It goes as follows:

Pack up your troubles in your old kit bag and smile, boys, smile.

What’s the use of worrying, it never was worthwhile.

So pack up your troubles in your old kit bag and smile, boys, smile.

Some English sayings that reflect this reluctance to express feelings and not dwell on difficulties are

- ~ It’s no use crying over spilt milk.
- ~ Look on the bright side of things.
- ~ Every cloud has a silver lining.
- ~ Pull yourself together.
- ~ British stiff upper lip.
- ~ Just buck up.
- ~ All you have to do is focus on the positives.
- ~ Boys don’t cry.
- ~ Don’t be a baby – stop crying.

Frank (1991, p.64) mentions that “many if not most North Americans share a cultural reluctance to say that their lives have gone badly in some significant respect and to mourn the loss of what was desired but will never happen.” Based on my own experience of working with New Zealand Europeans, and of being of Western European descent, I believe that this statement is valid for many Western Europeans in general.

The dominant discourses among Western Europeans about loss and grief have the potential to silence mourning and expressions of grief, as they could be interpreted as a sign of weakness. All the patients that are seen at the Auckland Spinal Unit experience significant losses, either permanent or temporary ones. Many centralised Western European discourses about loss and grief may position patient and/or their families in such a way that they view the grief they experience related to their losses as something that should not be shared, that should be kept private, and that they believe they have to be strong for each other. A sense that they may be seen as weak would then tend to exacerbate a potential feeling of powerlessness (“not only can I not wipe my own bottom, but I am crying like a baby as well”).

#### *3.2.3.3 Centralised ideas that may inform Pacific Islanders’ world view(s)*

My experience of working alongside people from the Pacific Islands suggests that Christian discourses are very central in their lives. There is a strong belief that God will take care of them and that their responsibility as far as loss and grief is concerned is to trust God and leave it to Him.

There are also strong discursive practices around being respectful, especially to people in authority. This respect means that a person does not question the opinion of a person in authority and that authority figure’s opinion is the one that should be followed, even if the patient or a family member disagrees with it. At the Auckland Spinal Unit, the medical team are viewed as people in authority; they are the experts; they know best; and even if a patient or family member disagrees, this disagreement should not be voiced in public – that is disrespectful.

These discursive practices seem at times to place Pacific Islanders in a position where they have no voice to express dissatisfaction or articulate how services could be improved. Morgan and Coombes (2001) point out that silence should be understood as a

speech act, open to multiple meanings. Silence can be a not saying as well as an unsaying. My understanding of silence in a medical setting such as the Auckland Spinal unit with patients and their families from the Pacific Island Culture is that silence is often a speech act rather than a “nothing further to say.” The implication of this for me as a counsellor is that I should beware of interpreting silence as indicating that the person has nothing further to say, and I can take care to ensure that space is opened up for patients and their families to step into to express their concerns without this “stepping into” being seen as disrespectful.

### **3.2.4 Summary**

Different discourses position us in multiple ways, and these discourses guide us in how to act and think. At any one time, there are always a number of discourses surrounding an event, each offering an alternative view and each bringing with it different possibilities for action (Burr, 2000, p.64). The above overview of perspectives on loss and grief has shown that there are a multitude of discourses surrounding loss and the grieving associated with a spinal cord injury; and it has shown that some of these discourses are in conflict with each other. So, for example, some psychological discourses emphasise the importance of talking about difficulties and sharing with others the sadness and pain that we are experiencing. This may be in conflict with Christian discourses that emphasise trusting God and believing that God has a person’s best interests at heart. This multiple positioning can leave a person with guilt or uncertainty about how to respond to the losses experienced due to a spinal cord injury.

In the next part of the chapter, the research participants voice their experiences of these multiple options and the choices they have made for their lives.

### **3.3 Participants’ Voices**

All the research participants shared their ideas about the losses they experienced after their spinal injury. In this section I briefly introduce each participant. I then reflect on the discourses of loss and grief that seemed to inform these participants and how these discourses positioned them. In the last part of this chapter I focus on the role of counselling in respect of loss and grief associated with a spinal cord injury.

### 3.3.1 *Lequecher*

When I interviewed her, Lequecher had had her spinal injury for at least ten years. Her injury was in the cervical area, so that she had very limited hand functioning and needed carers for most of her activities for daily living, including caring for her children. In the research interview, she shared with me her ongoing struggles with the effects of her spinal injury on her life and that she would prefer to be free from the influence of depression. Lequecher reflected on the many losses that she has experienced:

When I look back to how I was and I was standing and just being a mum, yeah, I just get in such a depression...I grieve everyday, there is not one day that has gone past that I have not cried. Just starting to talk about it yeah. Not one day has passed that I don't cry. The loss of my motherhood to my children has had a very traumatic impact on me. I was very jealous of the ladies who worked for me, I really hated them but I hated but I liked them. I hated it because my children used to run to them for cuddles and hugs, it is very hard you know a young mum with young children....I have lost a lot of things and part of the loss is on that side. [In the interview Lequecher referred to a part of her that she has never shared with anyone; she referred to this as "that side".] I tried thinking I will be okay, I counselled myself but it doesn't work, it doesn't work...I have never got over it, I still have not, that is a hard thing. But I need to talk about it to at least make sense of it, not make sense, actually accept being paralyzed and loving myself and loving me for what I look like. Because in my situation now this is how it is. I can't change it.

Lequecher seems to be positioned by discourses about accepting her injury and getting over it. It seems that the discourses that inform Lequecher about how to go on tell her that she must accept her injury and get over it. At the same time, I get a sense (see excerpt below) that for Lequecher the losses relating to her spinal injury are so enormous that she just cannot accept her injury or get over it. This conflict leaves her in a position where she has no agency. What she "should" do is accept her injury (according to the discourses that seem available to her), but because of how she experiences her losses, the possibility of acceptance seems remote and getting over it seems like an unreachable goal.

Lequecher attempts, it seems, to make sense of this discrepancy by saying that it arises “because we never got the proper counselling.” In the interview, Lequecher expressed the expectation that if only she and her family “had got proper counselling”, for a sufficient length of time, she would not be facing her current difficulties. This expectation surrounding counselling again positions Lequecher as lacking agency, as she believes that the counselling will enable the acceptance, rather than that she can come to a point where she does not grieve every day. It seems that Lequecher sees grief as a linear process in which there are steps that one has to go through (similar to the ideas of Elisabeth Kübler-Ross), and the end result is acceptance.

However, Lequecher also questions the notion of acceptance:

Yes, why I say I will never accept my injury is because I was too much of a sporty person, I never had time to sit around and do nothing, that was not me, I was always on the go, doing something, wiping my walls, wiping my ceilings, changing around the house, mowing the lawns on the outside, being more active, doing everything, going to play sports, taking my children with me, I still did my sports even although I did not have much money, martial arts and those are the kinds of things I did when I was still walking, those were the types of things I put my children through when I was still walking.

There seems to be a struggle within Lequecher: there are discourses that inform her that the way to go on is acceptance, but there are other discourses that inform her that she was too active and sporty to accept her injury now.

I wondered in the interview whether Lequecher had some ideas about how counselling might have helped her with this dilemma. I wondered whether acceptance was something that Lequecher herself was interested in, or whether it came from other people’s ideas of how she should manage her spinal cord injury. When I asked her about this, she replied:

It is not something that I never want to accept, I want to accept it, but there are things on that side that I keep away that needs to be brought up and brought out. Hopefully I can see myself and love myself. You know how they say love

yourself first before you can love others. I can love others but I still don't like myself. I see me as a big blob and a yark and I look at my skin like here and it is going on my thighs and it never used to be like that before. When I look at that and I think back to when I wasn't like that and I know and I ask why why why and that is the thing on my left.

What Lequecher shared with me seems to indicate that she is reaching for this destination of acceptance and believes that when she gets there, all will be well. She wants to accept the situation, but, on the other hand, she feels she can never accept it. This leaves her without agency; she believes she “should” accept the situation, but there is part of her that resists acceptance of a “big blob and a yark.” In Section 3.4.2 of the “Reflecting on Practice” section of this chapter, I discuss the notion of acceptance and how it could be deconstructed in more detail.

Lequecher's story was similar to what Frank (1995) calls a chaos story. Frank argues that when a person is able to start talking about his/her experiences, the story is no longer a true chaos story. Chaos stories cannot literally be told, they can only be lived. Lequecher refers to “the thing on her left,” things she has never shared with anyone: “Those ones about my children about not being able to hold them myself. I have lost a lot of things and part of the loss is on that side [the left side]. I tried thinking I will be okay, I counselled myself but it doesn't work, it doesn't work, counselling myself.” I sense that these things that she referred to on her “left side” are lived, but they have not been storied yet. In Section 3.4.4 of the “Reflecting on Practice” section of this chapter, I discuss counselling and chaos stories / loss and control in more detail.

### **3.3.2 Paul**

Paul sustained his injury as a result of a motor vehicle accident. At the time of the accident, he was in his thirties. He was single and it seems as though during his rehabilitation he had very little support from family or friends. His injury was in the lumbar area, which means that initially he needed a wheelchair for mobility, but over time Paul learnt to walk with walking aids, which he now uses mainly to help him balance. Paul's hand functioning was unaffected by the accident.

In the research interview Paul said that, when he was in hospital for his rehabilitation,

his focus was just on how to get out of hospital. He mentioned that while he was in hospital, he never really worried about his injury:

No, I never really worried about my injury, to tell you the truth. I was just more interested in getting into a wheelchair so I could go outside and have a cigarette. That's what got me out of the bed ... I used to freak the nurses out. They would come around to make my bed and I was already gone. I would probably be sitting outside in my pyjamas, because I had no clothes. I didn't have any friends or relatives living handy, so, because of that, I did not get any clothes. I had to wear the hospital pyjamas the whole time. I was out there in my pyjamas at six o'clock in the morning freezing cold, but, shit, I could not feel it anyway. I've still got no feeling in my feet ... Oh yeah, hospitals suck. There were too many sick people in there. It was too morbid. It was even more morbid than the cemetery that I used to work at. I used to work at the cemetery as a gardener. Even that place had more life in it than the hospital. And it was a crematorium where we burnt people.

Paul's determination to get out of the hospital as quickly as possible is a central theme. In the interview he also often said that there was just no-one to talk to while he was in hospital. He indicated that having someone to talk to would have been useful:

Just someone coming around talking to you. Because they have people like, not sure what you would call them, but it is like friends of the court and you have the chaplain or like the people that come around with a trolley of biscuits and then you have reps from ACC coming around and then you have a social worker, but you do not get to see counsellors. You see everyone else.

Paul's parents lived in the south of New Zealand and they were not able to visit very frequently. Paul mentioned that he did not have any friends or other family that visited him, so he had no-one that he could really talk to about how things were for him and how he was feeling.

My understanding of what Paul said seems to resonate with Frank's (1995) comment that it is imperative for the person with illness (spinal cord injury) to tell the illness

story. Telling stories of illness is an attempt to voice an experience that medicine cannot describe. A serious illness or trauma is a loss of the destination or map that previously guided a person's life. Ill people, Frank says, have to learn to live differently through hearing themselves tell their stories and absorbing others' reactions. Through this telling, a new map or destination takes shape (Frank, 1995, p.1).

Paul noticed that a few months after he was discharged from hospital, he cried a lot:

It was not such an issue in the hospital, but a month or two after I left that is when you really sort of needed it [counselling]. I think I just sort of cracked up. I did a hell of a lot of crying, but it made me more determined to walk again.... I try not to think about it [his injury and the losses and the pain that he experiences] and then something happens and it all comes out... There are some nights that I sit down and have a bit of a cry, nothing too much, well, just sometimes, I will sit down for no reason and just cry and get it all out.

For Paul, there are times when "something happens" and it all comes out. I have heard other patients who have lived with their spinal injury for a number of years say similar things – every now and again they just "let it all out". Paul seems to experience this as being useful. I wonder whether, if Paul had other options for telling his story and having it witnessed, this would still be his preferred way of grieving. Paul's grieving seems to depend on circumstances – when something happens. He mentioned in the interview that he "tries to push it away." Paul seems to be positioned by dominant discourses of loss and grief that suggest that he should not talk or think about his losses. Pushing them away, not allowing himself really to think about his losses are ideas that Paul seems to have about managing his grief related to his injury.

I asked Paul whether that is the way he wants it to be, that is, just pushed away. He replied:

Ah, not really. It just seems as though I have had this problem forever; it just does not seem to worry me too much basically. It has its moments every now and again, but generally I get on with it, because no-one is going to help me, you have got to do it yourself.

Neimeyer (2000) comments on periodic grief work, where a person who has experienced a loss gives him/herself permission to immerse him/herself in the grief, feel the pain and the sadness of the loss, but at other times will distract him/herself from pain and sadness and do other things. According to Neimeyer, from this perspective, grieving only becomes complicated if the person engages in one orientation (feeling or doing) to the exclusion of the other.

Neimeyer (1999) also mentions an accommodation of the loss into people's lives, a new relationship with the loss rather than an attempt to exclude it completely. What I understand Paul to say is that he is trying not to think of the losses relating to the spinal injury, and then something happens and it all comes out. Paul's main strategy for managing every day is "just keep myself busy and keep my mind on other things, I try not to think about it." I wonder whether notions of accommodating loss may give Paul more agency and control over his responses to grief. Although Paul says it does not worry him that much any more, I am curious what difference it would have made if, in the first six months of his rehabilitation, ideas of accommodating his losses had been talked about. Would these ideas of accommodating loss be more useful to Paul than ideas of keeping busy and trying to push his grief away, as prescribed by one dominant discourse from one particular world view?

As suggested above, Frank (1995) argues that telling one's story is a way of finding a new destination map. Paul had specific ideas about this destination map. I asked him what advice he would give a counsellor about some of the topics or things that he would have found useful to talk about in counselling. He answered: "What are you going to do for the rest of your life?' is a pretty good start." It seems as though Paul was looking for a revised destination map, as the previous map was unable to give Paul the guidance he now required.

I wonder how a clearer destination map (what he was going to do for the rest of his life) would have positioned Paul. Would invitations to try to push the losses away still have been so central if Paul's destination map was more clearly known to him?

Paul's experience brings into question the timing of counselling. I believe that one could not have predicted that Paul would "just crack up" about two months after leaving

hospital. As far as I know, there is no predictor of the timing of such an event. However, Paul mentioned many times that there had been no-one to talk to. I sensed that at the time that Paul “cracked up”, according to him, he had no relationship with anyone at the hospital whom he could have turned to for counselling. In Chapter Five the positioning of counselling is discussed, which includes the availability of counselling after discharge.

### **3.3.3 *Avril***

Avril was a young mother with three children and a very supportive husband. Avril’s injury was in the thoracic area of her spine, so that she had full hand functioning but depended on carers for her personal cares such as showering, bowel and bladder cares.. Avril’s injury was the result of a medical misadventure.

Avril had a similar experience to Paul’s, in terms of the timing of her grief responses, but for different reasons. Whilst she was at the Auckland Spinal Unit, Avril initially focused on her family. She first had to ensure that her family was “in order” before she could attend to herself:

I myself probably did not grieve as much because there was no time. You know, it did not really hit me like that, [how would the injury affect me personally] it was like, oh, my gosh, what if, and my first thought went out to my family. More than anything else, I didn't really think of myself, I thought, oh, my gosh, I would have to get my family in order, that was more or less my thinking...I had to move on at the time, just had to pick up and go with it.... it was not until later on that it hit me, coming home to family and to kids, just trying to get things back into family life.

Avril felt, however, that it would have been good to talk more about the emotional side of her injury. She felt this would have helped her “to cope mentally,” as she knew she “just had to get on with her life. Being a mother and being a paraplegic, I had to think about getting back into motherhood again.” She felt that the main focus of counselling should be on the grieving, because after a person has had an opportunity to talk about losses relating to a spinal cord injury “things like fall into place.” This “falling into place” seemed to be important to Avril, as it supported for her “realizing that you just

have to move on.”

Avril believed that counselling would have been useful for her children:

They are going through an ordeal. One of their parents is left paralysed and to them it is a big grieving. Their minds are confused and in my situation they would have had to deal with myself and that they have a younger sister with Spina Bifida...they would have needed support trying to understand the whole aspect of life as to why these things happen to them...so when I got home they were still going through a whole lot of confusion and we had to sit down as a family and discuss things openly.

Avril seems to be describing a chaos narrative. Her understanding of how not to be positioned in this narrative was that the children needed support in trying to understand the whole aspect of life and why these things happen. “Understanding why these things happen” is a notion that resonates Niemeyer’s (2000) suggestion that for many people reviewing assumptions is part of the grieving process. Avril’s children did not have the lenses to make sense of what had happened within their family – their mother now has a spinal cord injury and their baby sister has spina bifida. As Neimeyer suggests, as a result of injury and loss, people’s assumptions about life are challenged. Part of grieving may be to review assumptions, so that sense or meaning can be made of the losses. Avril also supported talking as a way of making sense of what is happening. This resonates with Frank’s ideas about telling the story of loss in her own preferred way and time.

In thinking about Avril’s children and the ongoing adjustments that they have made and will continue to make as a result of their mother’s injury, I realised that Orchardson’s (1997) story of her bereavement could resonate with the experiences of Avril’s children. Orchardson (1997) talks of her bereavement experience as a result of her son’s disability, mentioning “losing her ‘old’ son (as in the way he previously functioned) and feeling sad as he struggled to regain the abilities that he had lost.” In some ways, Avril’s children have lost aspects of the mother they once knew. Orchardson (1997) searched the literature and found it very limiting in helping her to understand the process of adjustment to the loss of living with someone who is not the person he/she was before. For her, a sense of episodic grief and stress evolved. Episodic grief in the context of

disability differs from that in bereavement, in that the process does not naturally come to an end with an acceptance of the reality of the loss of the person who has died. This grief is living with daily reminders of loss accompanied by extra difficulties in coping with the effects of the disability. She found that her preferred destination was acknowledging the existence of the loss and finding ways to manage the impact of the loss, both for her child and the family.

Reflecting on Orchardson's story, I wondered whether, if Avril's children were positioned in ways that make space for them to acknowledge the existence of the loss and that gave them agency to find ways to manage the impact of the loss, I wondered whether this would be as helpful to them as it was for Orchardson.

In the interview, Avril also told me that three years after the injury, she has now had time to sit back and reflect and plan ahead. This process of sitting back and reflecting is something she has done on her own and in discussions with God. Her preference would have been to have some counselling support through this process. Avril mentioned that this process of reflecting and planning ahead has taken her a lot of time. It has given her opportunity to think about herself, how to keep herself well and "to keep on top of herself." Avril's suggestion to herself was that she needed to "keep a free spirited mind, to keep yourself going, be positive, just keeping positive about a lot of things in life because really you need to keep well."

This "keeping positive" is something that I frequently hear patients identifying as their main way to keep themselves going. This raises the following questions for me: What role does "keeping positive" play in supporting or hindering the person in making sense of the losses related to a spinal cord injury? How does keeping positive position a person with a spinal cord injury if he/she wishes to tell and retell their story in a way that assists him/her in making meaning of a unique life experience (Frank, 1995, p. 55)?

At the end of the interview, Avril shared how she enjoys keeping contact with the people at the Auckland Spinal Unit. She has also maintained contact with some former patients. Avril is a committee member for The Association for Spinal Concerns (TASC), a voluntary organisation for people with a spinal cord injury. She mentioned that "it is good just to get out and be a voice for the disabled." Avril sees this activity as important,

because “the only people I really get good information from are the disabled themselves.” Frank (1995) would define this as a quest narrative – a belief that something is to be gained from the experience – in this case, an opportunity to help others and to be a voice for the disabled.

### **3.3.4 David**

David’s spinal injury was a result of medical / physical reasons as opposed to an accident. His injury was progressive, so that prior to being admitted to the Auckland Spinal Unit he already had difficulty walking and he used crutches for mobility.

David lived on his own. When he was discharged, he returned to his own house with the expectation that he would be able to manage independently. He needed a wheelchair for mobility, but had full use of his hands and very good trunk control, which is very useful for balancing in one’s wheelchair. I asked David about the adjustment from being able to walk with crutches to needing a wheelchair. He replied:

Oh yeah, big adjustment, big adjustment, a lot of learning about how to do things...if you were not very confident you would find it really hard to do... like when I fell out of my wheelchair trying to get my washing out, that really buggers your confidence up. You think, gawd, can I really keep going like this, am I going to have to go to a rest home? How the hell am I going to cope with all this?

In David’s description of his adjustment to the losses he experienced, his focus seemed to be very much on “learning how to do things.” Frank (1995) suggests that control and chaos are at opposite ends of the continuum. Throughout the interview, David talked about his attempts to gain control of his environment. In reflecting on these attempts, I wondered whether gaining control of one’s environment is an alternative story to the problem-saturated story of disability. Another question that emerged for me was whether this alternative story (gaining control) is what Roberts, Francis and Eastham (1999, p.62) would call resisting disability by “staying in touch with what is right with you.”

Roberts et al. also mention that their preference was to stay in touch with what is right

with them because “you really do have to keep pushing so that disability doesn’t numb you to life. It hasn’t got good intentions” (Roberts et al. 1999, p.59). Is David’s focus on learning how to do things supporting staying in touch with what is right with him and standing up against disabilities’ bad intentions to numb him to life? David’s focus was predominantly on what he could do rather than on what he could not do.

I have noticed at the Auckland Spinal Unit that during the inpatient phase of rehabilitation many people prefer to focus on their gains – the alternative story, in many ways, to disability. An ongoing source of curiosity for me is how a person is positioned in relation to loss and grief as a result of a spinal cord injury when these physical gains stop and/or the rate of progress is not very obvious. Brett, the next research participant to be introduced, may cast some light on this matter.

### **3.3.5 Brett**

Brett was in his late thirties when he had a sporting accident that resulted in his spinal cord injury. At the time of his accident, Brett was married and had two children. Brett’s injury was in the cervical area of his spine, but the damage to his spine was partial or incomplete. This means that Brett has a weakness in all four of his limbs and in other parts of his body, but he is able to walk and his injury often goes unnoticed by other people.

Boyle et al. (2003) describes a similar type of injury to Brett’s. Boyle describes these invisible injuries as living between different worlds – the world of the able-bodied and the world of people with spinal injuries. The notion of living between two worlds resonates with Brett’s story of his spinal injury.

Brett’s spinal injury is invisible to an outside observer most of the time. He prefers to let only people that he is close to know about his injury. He declines invitations to go to work sports nights or to play indoor netball or soccer, and in this way manages to keep his injury invisible to others. Whilst Brett is really grateful for the amount of functionality he has regained, he said in the research interview that there is a very strong part of him that is upset at not having 100% functionality back. Brett sustains hope on a daily basis that this physical functioning will return. Hope, sadness and gratitude all seem to be a part of Brett’s relationship with disability:

There is a part of me that hopes every day that something is going to click or snap in a good way and that I will have 100% back. But I have realistically been told on a number of occasions that pretty much after two years is what you have got is what you have got. So that is what I am saying, it is now coming up for three years. So there are times when I have a whole lot of things that I am grateful for, that I can chase the kids around albeit that in a couple of years they will be able to outrun me. Even although I am tired I am grateful that I am still walking and that I live in a two story house and that is fantastic etc. etc.

But there is a very strong part of me that is upset; not having 100% I am not able to run and sprint and I do not have that much feeling in my hands... I had one friend say to me you are doing quite well and I said to him, 'Look how I walk down these stairs' [Brett needs to support himself on the balustrades when he walks down stairs] and he said to me, 'But hey, at least you are walking.' He was basically saying, 'Just get over it; look what you've got.'

In the interview, Brett and I talked about the invisibility of his injury, his gratitude about the recovery that he had made, but the sadness at what had been lost. I asked him whether he had any suggestions to counsellors about what would be useful for a person such as himself. Brett shared that he would have found it useful if, about a year ago (in other words, two years after his injury), he had been given the option of a counselling appointment, or alternatively one had been made for him. Brett did not think that he would have made the appointment himself, because in "Kiwi society generally we just shove it all in a jar and one day have a party explosion." From this I understood Brett to be saying that the dominant discourse which he notices himself at times subscribing to is not to talk about concerns but rather to bottle them up until they explode. Brett said, however, that if someone had made the counselling appointment for him, as part of the spinal unit process, he would have been quite accepting of that. I understood Brett to mean that he would not specifically have initiated making a counselling appointment, but that if a follow-up counselling appointment was part of the rehabilitation follow-up process, he would have found this quite acceptable.

Brett felt that at that counselling appointment it would have been good to discuss things

in a similar way to the way things that were discussed in the research interview. Brett said that he really wishes that he could do the things he used to be able to do. He thought that if he had had an opportunity to talk to someone about these losses, he might have been able to rationalise them and accept them more quickly, and then maybe there would be fewer occasions when these thoughts (about the losses) came to him. Brett himself realises that they will never go away and he guesses that a person wishes for what used to be. However, Brett feels that “just talking to someone about it would have been motivating.”

Weingarten (2000) suggests that matters of life and death are sometimes too hard to do alone and that illness can be isolating, as people may withdraw from distressful conversations and downplay the sufferer’s pain. Discursive practices of “downplaying the pain” seem to come from some centralised Western European discourses about pain and difficulties, which, it is argued, should not be talked about or discussed. This ‘private information’ should be kept to ourselves. Despite the reluctance of people to engage in distressful conversations, Weingarten says that talking and having this pain witnessed is crucial to recovery. Brett seems to feel much like Weingarten, when he says that just talking about it would have been helpful. This statement of Brett’s is similar to Paul’s comment: “I just wanted someone to talk to.” Weingarten’s suggestions about talking and having pain witnessed resonate with Frank’s (1995) notions about the importance of telling and retelling a story in the context of listeners who care and who contribute in their unique way. This kind of listener assists a person to make meaning of his/her unique life experiences (Frank, 1995, p. 55).

Brett’s illness narrative seems to be one of hope, gratefulness and being upset, all alongside one another, and fairly present in his everyday experience. Weingarten (2001) argues that there are many illness narrative schemas. She describes, *inter alia*, one narrative she calls a Roller Coaster with Acceptance Narrative. This narrative recognises the non-linearity of many illness experiences. The experiences are jumbled up together; they are not sequential and they are more present at some times than at others. This Roller Coaster with Acceptance Narrative seems to be similar to what Frank (1995) calls a chaos narrative. This non-linear experience of disability seems to be close to what Brett is experiencing.

The Roller Coaster with Acceptance Narrative and episodic grief (Orchidson 1997) seem

to describe Brett's experience quite closely. Brett's story seems to fit with Neimeyer's (1999) ideas of accommodating the loss, relearning the world, a world that has changed forever by the loss. The aim of grieving is to accommodate the losses rather than try to "get over them."

Another key aspect that Brett talks about is "holding hope." Every day, he hopes that something is going to click or snap in a good way and he will have 100% functionality back. This idea of holding out hope and also who can hold hope is discussed in more detail in Section 3.4.1 of the "Reflection of my Practice" section of this chapter.

### **3.3.6 Matthew**

Matthew was injured in a contact sporting accident. He was married and had two children of school going age. Matthew's story resonates with the restitution narrative as outlined by Frank (1995). Matthew's preference when confronted by his spinal cord injury was not to focus or think about any of the losses as a result of his injury, but to only think about being well again. He saw the losses as a temporary event:

I was only on that continuum to be completely well again...naturally you go through the roller coaster of emotions...and one of the most important things when that is happening is that you know that there is a likelihood of a reasonable set of outcomes for you.

The dominant discourse in this restitution narrative is that a person will get better again. The spinal injury was a minor interruption in Matthew's life, but Matthew was on the continuum to getting well. Frank (1995, p.94) mentions that the risk of the restitution story is that if a person does not get better, there is no other story to fall back on. When restitution does not occur, other stories have to be prepared or the "narrative wreckage" will be real.

I asked Matthew whether his hope of being completely well was based on what the doctors had told him, or whether it was his own knowledges that he was listening to. He said that, from the time he was injured, there was a part of him that considered being injured and a part that only thought of his getting back to full health because he is an optimistic person. The medical prognosis, according to Matthew, was that he would

probably not be able to walk properly again. However, I get a sense from Matthew that no matter what the doctor's prognosis was, Matthew would still have held onto his own knowledges that he was going to be completely well again. In Matthew's situation, the knowledge that he held about himself was accurate: he has made a 100% recovery.

Matthew expressed his ideas about loss and grief as follows:

You do not want to have your situation mirrored for you. I think you know well enough your situation. And also some people may not want too much help with that [the situation] because it acknowledges that there is an issue or a problem that they have that is more serious than what they would like. It is maintaining the delusion but I think it can be important. I think that people can only come down on their own steam; they realize they can't do these things anymore.

Dominant and modernist discourses about loss and grief would term what Matthew is describing as denial. When a therapist informed by these discourses does not mirror the client's situation back to the client and therefore maintains the delusion that the situation is not serious, he/she may be labelled as colluding with the patient's denial.

Centralised rehabilitation discourses emphasise the importance of patients' facing the reality of their loss. According to these centralised rehabilitation discourses, "coming to terms" with the losses as a result of a spinal injury and knowing and accepting the functional limitations that have resulted because of the injury is seen as an important first step in "dealing with the disability." In my counselling practice, I question the usefulness of these ideas of facing the reality of the loss as an important first step for all patients. My preference is to understand what would be useful to the patient and work from there. Matthew seems to have similar ideas about the usefulness of "making sure that patients and their families face the reality of their situation": he thought that people will "come down on their own steam." A question I reflect on in the next section is how a counsellor can support a person or a family "coming down on their own steam," in other words, dealing with loss in their preferred way, rather than prescriptions from dominant discourses about how a person "should" deal with loss and grief.

Matthew's way of managing was gaining control over what he calls the small things. He started to make an impression on his surroundings and gain control of his situation to the

extent that he could and that he needed to. One example that he gave of this controlling his environment was having his mobile telephone so he could talk to people and arrange for things to be brought to him. This gaining control of the environment is similar to what David did – David learnt how to do things such as working out how to get his washing out of the washing machine and how to hang washing from a wheelchair (how do you keep the washing on your lap and at the same time stretch up and at the same time grab the pegs and, with limited balance and an uneven floor surface, how do you make sure that you do not topple over?) In many ways, Paul also focused on gaining control of his environment – getting in his wheelchair so he could go outside and have a cigarette. One way of storying the chaos in their lives was to gain control of their environment, as these examples indicate.

### **3.3.7 Larry**

Larry was on his “overseas experience” (OE) when he was injured in a sporting accident. His parents lived in New Zealand and he returned to New Zealand for rehabilitation once he was medically stable enough to travel.

In the interview, Larry reflected that he had never really focused on grieving. He thought that for himself, “he just dealt with it.” He did, however, think that “putting a label on it (grief) was a nice-to-have,” as it helped him to realise what grief was. Larry found that the counselling that he had once he left the Auckland Spinal Unit was really useful for him. He could not really identify what in particular was useful about it, but the counsellor definitely made Larry think more about how he was feeling. Larry could not, at the time of the interview, be more specific about these feelings; he just thought it was useful to be given the opportunity to think more about how he was feeling. Larry also noted that he talked a lot more to the psychologist than to any other person. Larry thought that this process of talking to the psychologist and talking about his feelings was something that he would not have been able to “do on his own.” He did not, at the time, see this as a grieving process. On reflection, however, he sees that it probably was; and having a psychologist there whom he could share his feelings with and talk to was very useful.

Neimeyer (2000) has recognized that, as part of the grieving process, for some people it is useful to open themselves to their pain and their loss, not to try and push pain and loss

away, but to allow themselves to experience the emotional impact of this pain and loss. Larry seems to be saying that talking about his feelings gave him an opportunity to do this. In addition, he realised that it he needed outside help, in this case, the help of the psychologist, to do this. It was not something that he was able to do on his own.

### **3.4 Reflecting on my Practice**

The voices of the participants suggest that there is not one single way in which patients express and experience their grief. The sections above have raised some important themes for reflection about loss and grief and the role of counselling in this regard. In this section I discuss some of these themes in more detail.

#### ***3.4.1 Acceptance / holding hope / multiple versions of events***

It is not uncommon at the Auckland Spinal Unit for patients to hold very different beliefs about their medical prognosis from those held by the doctors and the rest of the medical team. So, for example, the medical team may assess the person's injuries to be such that he/she will not be able to walk again and/or use his/her hands again, while patient may believe that he/she will walk and use his/her hands again. The way I as a counsellor make sense of the patients' holding out hope for a different outcome from that suggested by the medical prognosis is that hanging on to hope is a part of grieving the losses associated with a spinal cord injury. In counselling conversations, I have endeavoured to support the person in holding on to hope and at the same time to support the person to understand from a medical perspective what the different possibilities of the prognosis are.

A question that frequently guides my practice is this: how in the counselling conversations that I have with patients and their families (*whanau*) can space be made for discussions about a person's hopes and beliefs, but also for the medical team's understanding of what that person, from a functional perspective, may or may not be able to do?

From a social constructionist point of view, I prefer not to label "hope to walk again" as denial. My preference is to create space for the patient to story the chaos story of loss, grief and hope. Patients have informed me that, for some patients, when the primary

focus and emphasis in rehabilitation is on making sure that the person understands the medical prognosis, this approach is often seen to be cruel, negative and unhelpful. In an approach where the focus is only on the medical prognosis, space is only being made for medical knowledge and there is no space for the patient's knowledge about him/herself. I do not subscribe in my counselling practice to the notion that the therapist has to be cruel to be kind.

At the Auckland Spinal Unit, there have been many occasions when patients were reluctant to engage in their rehabilitation, such as learning about how to use a wheelchair, about how to use their intermittent catheters, about skin and pressure areas, because they do not see the relevance of the information, as they believe that they will make a full recovery. In these kinds of situation, as a counsellor, I acknowledge that the patient has expert knowledge about him/herself and what works for him/her and what does not. I frequently ask the patient how we as the medical team can respect and uphold his/her beliefs about hope for walking again, but at the same time have conversations about what we would see as important for rehabilitation in case this restitution narrative does not happen. This approach positions the patient as an authority on his/her own life and on how we can work more effectively with the patient. In all the discussions with patients where I did not diminish their version of events, they were very willing to engage in conversations about how they would like to use the rehabilitation services available to them at the Auckland Spinal Unit.

Holding contradictory ideas together deconstructs the notion that there is only one version of events. For most patients, there are many versions of events. Some of the versions that I have heard from patients is a "hope version" – hope that the medical prognosis is wrong and/or hope that medical science will come up with a cure. There is a "faith version" – "I will be healed". There is a "bodily experience version" – what a person notices about his/her own body and how it responds. There is a "medical version" – what the doctors say. There is a "personal belief version" about positive thinking – "as long as I try my hardest, my body will respond." All these different versions may operate together; they may compete at times; there may be a comfortable relationship between them at times; they may jostle for position, depending on what space is opened up for the patient.

In counselling conversations with people with spinal injuries, all these versions need at

various times to be held and respected, and they do not need to be seen as mutually exclusive. As a counsellor, I need to find ways to work alongside patients respecting the multiplicity of their versions of events and not only regard the dominant medical discourse as the only version of the “truth”. This is not to say that the medical discourse should not be discussed with a patient: the Auckland Spinal Unit is a Western medical health facility; however, other versions of events also need to be respected. In this way, I am not crushing hope in counselling and insisting on a unitary totalising version of events where there is no space for other ideas and beliefs. If as a spinal unit we insist on a single version of events, we potentially increase the experience of loss by expecting a person to loosen his/her relationship with his/her ideas, hopes and dreams and strengthen his/her relationship with our version of events.

### ***3.4.2 Acceptance***

The above ideas of holding multiple versions of events deconstruct notions about “denial” and “accepting the reality of the loss.” Accepting an injury is such a dominant discourse in rehabilitation that it needs to be deconstructed further. In Lequecher’s case, this discourse trapped her in a position from which she felt she could not escape. She wanted to accept her injury, but how could she when she saw herself as a “blog” and a “yark”? How can she accept something that prevents her from cuddling and caring for her children?

Boyle et al. (2003) describe how health systems can use the concept of acceptance to disqualify and categorise people. They argue that although acceptance may sound harmless, it is actually a very powerful word. Any person who does not act in a socially sanctioned way can be defined as not accepting a disability. This “diagnosis” of an unwillingness or inability to accept a disability can silence a person and very niftily shifts all responsibility for change onto the disabled person, enabling the professional to abdicate any need for further involvement until “acceptance” has been reached.

In Boyle et al., (2003, p.15) one of the writers says that, accepting her disability is not something she is interested in doing. She agrees that she needs to adapt to her disability – “But welcome it? Accept it? That’s not for me.”

Described below are some questions that can deconstruct acceptance in counselling conversations:

- ~ What does acceptance mean to you?
- ~ Whose ideas are these about acceptance – yours, someone else’s or both?
- ~ Is acceptance something you are interested in?
- ~ Are there aspects of acceptance that you think could be useful?
- ~ Are there aspects that you think would not be useful?
- ~ Some people talk about adapting to their disability. Does this have anything to do with acceptance?

In this section I have discussed ideas about holding on to hope and making space for patients and their family (*whanau*) to be hold multiple positions in relation to their beliefs about spinal cord injury. At times, respecting the knowledges about their bodies that people bring to counselling conversations on the one hand, and talking about the medical knowledges that the Auckland Spinal Unit has about a spinal cord injury both need to be considered. Pushing a patient towards “dealing with the reality of the situation” and ensuring that the person “accepts” the injury denies patients agency: they are expected to do something that some medical and psychological discourses regard as a good idea, when their own bodies and knowledges at that particular time are telling them something very different.

In counselling patients with a spinal cord injury, counsellors often need to maintain a fine balance between supporting hope and sharing the Western medical knowledge available to the Spinal Unit. This is one of the reasons why I have found it very helpful to have a very good understanding of the physiology of a spinal cord injury and the likely prognosis in terms of physical functionality, so that I can have these kinds of conversation with patients.

### **3.4.3 *Illness Narratives***

For Frank (1995), after an illness or a trauma, making meaning of life’s experiences is the central work in the journey to find a new destination map and to establish a new plot structure. As we relearn the worlds of our experience, we reweave the fabric of our lives and come to a new wholeness. Relearning the worlds of our experience is a blend of meaning-finding and meaning-making (Attig, 1996). This relearning is a re-shaping and

a re-storying of a person's identity when he/she cannot go back to the old one (Boyle et al., 2003).

Frank (1995) emphasises the need for listeners who care and contribute in a unique way to assist people in making meaning of their unique experiences. In what unique way can I, as a counsellor at the Auckland Spinal Unit, listen and contribute?

Weingarten (2001) has shared how, when she was first diagnosed with cancer, she quickly learned that people wanted to hear a restitution narrative. I have noticed at the Auckland Spinal Unit that this would be true of many staff members, and sometimes of myself too. I have also noticed that many patients prefer a restitution narrative. The restitution narrative at the Spinal Unit would go something like this: "I have had a significant accident, I am over the worst, in the hospital they thought I may not live, I am now at the spinal unit and you guys are specialists in this area and every day I notice that I am becoming more and more independent. I am really fine."

Weingarten (2001) tells of another illness narrative she wanted to tell, not about restitution, but a chaos narrative. She says this narrative consumed her. She would hide this illness narrative like a jewel, unwrapping it under special conditions of agreement about secrecy and safety to only a few who met her stringent criteria of trustworthiness. Weingarten explains that she chose her listeners as carefully as she would rocks in a quickly moving stream she had to cross.

Weingarten writes that in her counselling practice she now works very hard to help people tell the story that fits their experience. In her experience, it is the chaos narrative that people have learnt to censor. She adds: "I am trying to master the art form of helping to call forth the chaos narrative" (Weingarten, 2001, p.7). It gives me hope in my counselling practice that Weingarten claims that she is still trying to master calling forth the chaos narrative. Her comments suggest that this is not easy; it is a real art and it needs mastery. I am still a persistent and determined traveller on this road to some "mastery of calling forth the chaos narrative."

Trauma and disability narratives co-exist. They are multilayered and multi-storied. When I listen to the trauma and disability narratives of the patients at the Spinal Unit,

my intention is to make space to hear the multi-stories of disability and trauma. Boyle et al. (2003) mention how non-disabled people have a tendency to attend only to the story of sorrow, misery and hopelessness. In my counselling conversations, I would like to open up space for the multiple stories of disability, the stories of hope, of success, of positive thinking, of fear and of loss. It is important that I am available to be that listener who cares and contributes in a unique way to assist patients in making meaning of their unique life experiences (Frank, 1995, p.55). In the chapter in this research report entitled “How Counselling should be Offered” more detail is given about maintaining contact with a person throughout his/her stay at the Auckland Spinal Unit.

#### ***3.4.4 Loss and Control***

It seems to me that most of the literature about loss and grief relate to death and/or illness. A review of the literature reveals a gap in the information about loss and grief in relation to trauma. Addressing trauma itself becomes invisible, as it tends to be lumped in with loss and grief in relation to bereavement and/or illness. People with a spinal injury are regarded as well. They are not sick or ill, but their bodies do not function in the ways that they previously did. In many instances, they no longer have control over what they could control before.

Frank (1995) argues that chaos and control are at the opposite ends of a continuum. If there is chaos, there is little or no control; and conversely, if there is control, there is little or no chaos. Frank and Weingarten have both identified the importance of being able tell a chaos illness story. I believe that this is an important aspect in a counselling practice, but in a setting such as the Spinal Unit, in my experience, it is also very important that the physical practical aspects of control are attended to. The notion that a person can only have control if he/she does something him/herself needs to be deconstructed.

How can staff on a medical team at the Auckland Spinal Unit offer agency to people who depend on others for to meet all their personal needs – to feed them, wash them, deal with their bowel and bladder function, turn them in bed or get them out of bed. How does attending to agency position a person along the chaos control continuum?

When a person starts to feel that he/she can still control his/her environment, even if it is

through the hands of another person, this repositions the patient in relation to the dominant discourses that imply that independence is only achieved if one does something oneself, shifting him/her to an alternative marginalised notion of independence through other people. We as staff have to consciously attend to the power positions that we offer our patients if our intention is to ensure that patients are offered agency when we work alongside them. We can do this by being very conscious of how we as health practitioners use our power/knowledge relations and by ensuring that in all our interactions with patients we offer patients agency. Positioning a patient with agency stands against a chaos narrative.

### **3.5 Conclusion**

In this chapter I have looked at some of the discourses that influence people's ideas about loss, grief and grieving. I have noted that some of the dominant discourses about grief, especially the claim that the grief process is linear and sequential with acceptance as the end point, may position patients in a discourse where they are made to feel that they "have not done it properly" and/or that they are forced to accept something that is totally unacceptable to them.

The participant's voices have revealed the wide variation in how people work with their grief. These voices indicated that there is no single universal way or process when it comes to loss and grief.

The multi-layered and multi-storied narratives of loss and grief associated with a spinal cord injury need to be heard. It is an art to work alongside a patient in such a way that the person wants to share his/her chaos story, if that story reflects the person's experience. It is the storying of such chaos stories and other stories that helps people to relearn the world, a world that has been changed forever by the loss.

Specifically when working with patients with a spinal cord injury, the physical aspects of attending to agency and control need to be addressed, so that discourses surrounding independence can be deconstructed to make room for alternative ways of viewing independence.

## **4. Sexuality and Spinal Cord Injury**

### **4.1 Introduction**

A number of participants, in this research study, identified the importance of sexuality counselling when they were newly injured. Participants' feedback about sexuality and sexuality counselling will form the first part of this chapter. Participants did not give specific indications as to how this sexuality counselling should be presented and or made available. In the second section of this chapter I turn to the literature on sexuality counselling which will include suggestions as to how sexuality counselling could be offered. This overview will be followed by a fairly detailed explanation of the potential physiological affects of a spinal cord injury on a person's physical sexual functioning. The reason these physiological affects are included are because depending on a person's level of injury different aspects of a person's sexual functioning may or may not be affected. Once the physiological affects have been highlighted the focus of the chapter turns to the potential impact of cultural and social factors and how these factors can influence, limit and or enhance a person's expression of their sexuality. Included in this section will also be my personal reflections of how I selected to review some of my own discursive practices about sexuality. This reviewing positioned me more agentically in deconstructing some of the discourses about sexuality that were available to patients at the Auckland Spinal Unit. The concluding section of this chapter will discuss a sexuality project that I was integrally involved in at the Auckland Spinal Unit. The intention of discussing this project is to demonstrate how counsellors can, through projects at an organisational level, make more visible subjugated discourses about spinal cord injury and sexuality.

### **4.2 What Did The Participants Say?**

Of the seven participants who were interviewed for this research five of the participants were males and two of the participants were females. Both females identified the importance of sexuality counselling. Of the five males two of them now have normal bowel and bladder functioning and neither of them identified the need for sexuality counselling. Matthew specifically said that sexuality counselling was not important for

him. This will be discussed in more detail in the next section of this report. Brett did not mention sexuality in the research interview and I did not ask him. Both of these men (Matthew and Brett) were in the thirty to forty age ranges at the time of the injury and both were married and had families. It is very likely that their injuries had not significantly impacted on the physical aspects of their sexuality. One other male participant, called David also did not identify the need for sexuality counselling. David is in his late 50's and he lives on his own. During the research interview, David focused very much on the practical aspects of care and counselling. Unlike some of the other participants who I specifically asked about sexuality counselling, I did not directly ask David about sexuality counselling and he did not bring the subject up.

In summary three men did not highlight the need for sexuality counselling, two male participants were not asked and they did not comment on it, one male specifically said he did not think it was important for himself personally. Both women in the research study identified the need for sexuality counselling.

#### ***4.2.1 Sexuality counselling is not for everyone***

As mentioned above, Matthew specifically said that he was not interested in sexuality counselling. Matthew's reason for not wanting sexuality counselling or not feeling that it was important for him was because as he states "I was only on the continuum to be completely well again". From Matthew's perspective he was going to make a 100% recovery so something like sexuality counselling was irrelevant to him because he only wanted to talk about issues that confirmed his viewpoint that he was going to recover completely. From a medical perspective there was an initial level of uncertainty as to whether Matthew would re-gain his normal sexual functions. This statement of Matthew's (only wanting to focus on and talk about issues that confirmed that he was going to recover fully) is very important for counsellors to heed to. Sexuality counselling is not for everyone and sensitivity is needed in finding out what is of interest to the client, what they would like to address and when they would they like to address it.

#### ***4.2.2 Sexuality counselling should be included in spinal cord rehabilitation***

Four of the seven participants identified that sexuality counselling was important to them and that it should be part of the rehabilitation services offered to patients in the rehabilitation phase of their spinal cord injury.

Paul, one of the research participants, aged forty four and living on his own, with no children shared his immense sadness about his belief that he was not able to have children. I asked Paul about his ideas on sexuality counselling and spinal cord injury. Paul's response was as follows: "That (*sexuality counselling*) is very very important." Paul said:

Everything from here down was affected. [Paul was indicating just below his belly button] My bowels, my bladder, everything, it does not work the way it is supposed to. That is why I have to wear these silly bags, all piped up and everything. But sexually, no help, absolutely nothing, didn't even talk about it, nothing. And to a man that is very very important. I do not know, I suppose it is to most men, you know. But the only way I can get help through ACC, I have to get myself into a relationship and then we have to have a problem, because of the sexual side and then once we start arguing and getting into real friction and we are going to split up and we have argued and fought then they will help but until then they will not help, which is stupid. If I am single, I get nothing.

Paul continued to share about how he "brought it up heaps of time when I have been for examinations at the urology department" with no positive results. At the superclinic, where he went a couple of times he tried again "I always brought it up there but no, no-one could be bothered, .... I just give up on them, I just carry on."

Paul's frustration seems similar to some of the twelve participants that Mc Alonan (1996) interviewed. Mc Alonan (1996) interviewed people with a spinal cord injury to investigate their level of satisfaction with the sexual rehabilitation services they received. "Participants reported feelings ranging from frustration and disappointment to embarrassment and intimidation when encountering health care professionals who seemed to be either unwilling or unable to address sexuality. Often participants perceived an evasive or avoidant quality during discussions with their physicians."(McAlonan, 1996, p.830).

The extent of the sexuality counselling that Paul did get was:

All I ever got for that part [sexuality counselling] was a little page about that size

[indicating with his hands an A5 size] on the exercises you can do to keep your bladder working but hey, you are paralysed from there down, the muscles don't work, how are you supposed to do the exercises? The things they give you are just stupid, it drives you insane, drives you nuts, it makes you more determined to think well just stuff them. And then again it might not be like that for everybody because it may be because of the way it was at the time, I might have just missed out on everything, just bad luck.

#### ***4.2.3 Timing of counselling***

Miller (1988) in her study of ninety participants who experienced a traumatic spinal cord injury found that there was a need to increase efforts to provide sexual information and counselling services for those who are in the acute care (approximately 6 weeks post injury) and the rehabilitation phase of their treatment (approximately 6 months post injury). From the information that Paul shared it would seem that he would be in agreement to this suggestion.

In Miller's (1988) study a need for sexuality counselling in the acute and rehabilitation phases of injury was identified rather than in the post acute phase (approximately a year post injury). Len, another research participant had similar ideas about the timing of sexuality counselling - sexuality counselling was important during rehabilitation, post rehabilitation was a bit late.

Larry was in his twenties when he had his spinal cord injury. Larry's injury is in the thoracic area of his spine and this means that he has full use of his arms and hands but is dependent on a wheelchair for mobility and his bowel and bladder would not function normally. His sexual functioning would also be effected by his injury. I asked Larry whether sexuality was addressed or discussed with him when he was in rehabilitation. Larry mentioned that the urologist did mention it to him but he did not recall anyone else talking about it. He felt that sexuality was a difficult subject to talk about but it definitely needed to be talked about. He said " I think when you are in the spinal unit it seems as though it is all totally lost [he was referring to his ability to have sex in the future])...so it might help I think, if I had a girlfriend or wife at the time it might have made a big difference. It would definitely need to be talked about" Larry mentioned that the not talking about it positioned him to think "oh my god all is lost!"

I asked Larry about his views on the timing of the sexuality counselling. His response to this was “I think I know my capabilities now; [this was approximately two years post injury] it probably would have been a good time to talk about it when I was at the spinal unit, at least know there are options”

Smith and Bodner (1993) suggest that practitioners should introduce the topic of sexuality during the initial rehabilitation period (one - six months post injury). The process of adjustment to life also involves adjustment to the new sexual self and thus the early introduction of sexual education and counselling may encourage the individual to experiment with his or her partner during week-end home visits. The participants in Mc Alonan’s (1996) study had a slightly different view on the timing. She found that participants felt they were not ready to deal with the sexuality aspect of their rehabilitation immediately after their injury but wanted to know that the information would be available when they were ready. Some of the participants in Mc Alonan’s study felt that they needed to gain confidence in their other abilities first and that a discussion on sexuality was a reminder of yet another dysfunction. However “participants stressed the need to know what their options were regarding sexual rehabilitation so that they could make timely and intelligent choices that best suited their needs” (McAlonan, 1996, p.831).

Sensitivity to individual’s needs seems to be the main criteria in terms of timing. However, a counsellor cannot interpret a patient’s not asking about this topic as lack of interest or lack of need. As Len made meaning making of the fact that nobody talked about it as “oh my god all is lost!”

Herson, Hart, Gordon, Rintala (1999) suggest that health practitioners look for opportunities to offer information about sexuality and initiate the discussion. The health practitioner should not assume that the lack of asking either by the patient or his or her partner indicates lack of interest in sexuality information. The patient may just be too fearful or too embarrassed to ask.

#### ***4.2.4 Fertility***

Of the seven research participants five of them had children varying in ages from two years to approximately thirty years. Although I did not specifically ask, it seemed to me

that of these five participants none of them wanted to have more children and so fertility was not something that was personally important to them. Two research participants did not have children – Paul and Larry. In the research interview Larry did not discuss whether he wanted to have children or not but Paul shared the following about fertility:

...it affects you a hell of a lot, I do not want to realise it but it does. Yes well you see in like in our family, dad has been doing our family history and so far he has gone back eight hundred years. And the way I look at it, it has come to a screaming halt because some bastard sat in the middle of the road and caused my accident. [Paul swerved to avoid hitting someone, lost control of the vehicle, the car rolled and Paul sustained his spinal cord injury.] That is the end of our family tree, just because of some dickhead. Those are the little things [Paul's voice fades away and I noticed that he was fighting back tears]

Fertility will be further discussed in section 4.5.2 of this research report.

#### ***4.2.5 Female Participants***

The two women in this research study, Avril and Lequecher, both had children. Avril was living with her husband, she was in her thirties and the Lequecher had separated from her partner after her spinal injury.

Lequecher's experience of sexuality counselling at the spinal unit was very positive. I mentioned to Lequecher that we had been looking more closely at sexuality counselling at the spinal unit and she said "they did get couples and partners together and they went through the sex talk. Like we could have an accident [she means a bowel or bladder accident] during sex, to clean before and to clean after and to make sure that he is clean and everything like that. And that I could get pregnant again."

I asked Lequecher if she realised that she could get pregnant again and she said that initially she thought that "once I am paralysed everything else is paralysed." Lequecher did not want to have any more children and especially not in the initial stages after her injury. She mentioned in the interview that she was sexually active during her week-end leaves so she appreciated the information about fertility.

The literature emphasises the need for a holistic approach to sexuality and intimacy. This

holistic approach would include fertility, contraception and sexual intimacy. Lequecher also talked about the safety aspects of sexuality, not just from a physical health perspective such as sexually transmitted infections but from an emotional safety perspective.

Lequecher had been called on in the past as a peer sexuality counsellor. I was interested in her perspective on the group counselling which she was involved in at the Auckland Spinal Unit as well as the individual based counselling. Lequecher expressed the following ideas:

...the best is one on one [counselling], because then there is total confidentiality, partners or married couples, they would not like it in a group. Well I would not, I would say it would have to go one on one, because you get the total focus on that one person or a couple, because they won't be so open in a group.

Cushman (1988) asked inpatients in a rehabilitation hospital (patients with spinal cord injuries and those who were requiring rehabilitation for other reasons) what their preference was in terms of delivery and presentation for sexuality counselling. She found that most participants (irrespective of their reason for rehabilitation) preferred a private talk with staff, which the staff member initiated, or being provided with a printed booklet.

Avril mentioned that the Auckland Spinal Unit lacked a lot of information when it came to sexuality counselling. Avril's first priority for counselling was her family. Once she knew her family was supported and taken care of she wanted "more information just being a spinal cord injury person." Two main areas that she identified were "getting back into motherhood again" and "getting back into a relationship." Avril felt that couple counselling for both herself and her husband would have been useful because "it is a whole new world", referring to sexuality and intimacy with her husband after her spinal cord injury. Avril was given a booklet about sexuality but for her this was not adequate information.

The above experience of Avril was similarly found by McAlonan (1996) who interviewed twelve participants who had a spinal cord injury and their level of

satisfaction with the services received. Eleven of the twelve participants in Mc Alonan's study reported having received some form of sexual rehabilitation services. Generally the participants found it helpful but only three of the twelve participants in this study judged the quantity of information as satisfactory.

Avril further commented that as an outpatient she has now received more information on spinal injury and sexuality. She mentioned that "the doctor brought it up [sexuality] and I was quite comfortable. I thought oh cool, I was quite pleased that it was mentioned, and I did ask for more information on it". I also offered to send to Avril the two DVD's that we have on sexuality. The one is *Sexuality Reborn* which is a DVD on some of the experiences of four couples, one or both of whom have a spinal cord injury, and their experience of sexuality and their injury. The other DVD is by Marcia Spica and is specifically for woman. This DVD discusses the experiences of three women with different levels of injury and some of their experiences of sexuality and intimacy.

#### **4.2.6 Summary**

In summary to this section on the views of the participants there was strong support from the participants for sexuality counselling which included discussions about fertility and contraception. The optimum timing of counselling seemed to be during the rehabilitation phase (one – six months post injury) however for some participants, if they did not receive this counselling during this time period, they appreciated it being discussed after this time. There seemed to be strong support for couple counselling. Despite the strong support for sexuality counselling, counselling needs to be sensitive to the individual patient's needs and not everyone wants sexuality counselling. It is the responsibility of the practitioner to initiate the discussion and not to interpret the not asking by the patient as lack of interest. Letting patients know what is available and what are the options as far as sexuality counselling is concerned is important but being sensitive to which of these options the patient is interested in (and when) is really key to effective counselling.

#### **4.3 Strands taken from the Literature Review**

A review of the literature on the impact of a spinal cord injury on sexuality tends to focus on three broad topics. These topics are sexuality counselling, research relating to the physical sexual abilities of a person after a spinal cord injury and levels of sexual satisfaction after a spinal cord injury.

Detailed below is a review of the literature on sexuality counselling and training. This will be followed by the literature on the physiological aspects of a spinal cord injury and the functional implications of this on sexuality.

#### ***4.3.1 Sexuality Counselling and Training of Health Practitioners***

In reviewing the literature on sexuality and spinal cord injury there was strong support that sexuality counselling should be included as a standard part of rehabilitation. Doctor Sandra Cole, professor in the Department of Physical Medicine and Rehabilitation at the University of Michigan medical centre and Director of the Sexuality Evaluation Clinic (as cited in I. Smith, 1995, p.83), states that sex should be viewed as just another activity of daily living (ADL). Cole says that sexual health, sexual activity, sexual desires, body image and self esteem are all activities of daily living. Sexuality should be treated in the same way as any other aspect of health care. It should not be sectioned off and regarded as being out of bounds for discussions.

Booth, Kendall, Fronek, Miller and Geraghty (2003, p.249) say that a “spinal cord injury may result not only in physical losses and permanent disability but also cause disruption to the psychosocial, vocational and sexual functioning of the person. Philosophies of rehabilitation have expanded to encompass all life domains and therefore a holistic rehabilitation program should include opportunities to address sexuality issues.” In other words rehabilitation should not only be focussed on the physical aspects of recovery, what the social model would call functional impairment, it should also include emotional adjustment, vocational guidance and sexuality. Spica (1989, p.56) agrees with this holistic view of rehabilitation highlighting that a spinal cord injury “invariably affects sexual functioning challenging the usual ways one thinks about sexuality. Rehabilitation and development of standards of care for sexual counselling is essential.”

Sexuality is a complex phenomenon, which pervades our biological being, our sense of self and the way we relate to others (Mendius, 1989, p.68). Sexuality has been described as having a physical, emotional, psychological, social and spiritual dimension (Lysberg & Severinsson, 2003). Sexuality counselling therefore needs to include biological, psychological, social and cultural factors. Wah Yun and Tunku Zubir (2000) in their study on sexuality using eight focus groups consisting of twenty eight adults with spinal cord injuries reported that participants wanted information on sexuality, reproduction, contraception and fertility treatment. The literature highlights the need for sexuality

counselling to be included as part of rehabilitation and that this counselling should not only focus on functional impairment (erections and vaginal lubrication) but also on the social, psychological, spiritual and cultural aspects of sexuality.

Summerville and McKenna (1998) point out that despite the strong evidence to support the importance of sexuality counselling in rehabilitation there seems to be low levels of addressing this issue of sexuality during or even after a person's rehabilitation. They further highlight that men were almost twice as likely as woman to receive sexuality counselling. They conclude that there is consumer support for the inclusion of such an intervention in the overall rehabilitation process but existing programmes do not adequately meet patients' needs. Ray and West (1984) found that people with a spinal cord injury who received comprehensive and accurate information report being better adjusted sexually.

In summary there is a high level of agreement in the research literature that sexuality counselling should be included in rehabilitation. Feedback however from studies indicates that consumers feel that their needs in this area are not being adequately addressed. To adequately address these needs for sexuality counselling it is important to include the physiological, psychological social and cultural factors. This next section covers these aspects.

#### **4.4 Physiology and Sexuality**

The impact of a spinal cord injury will most likely effect a person's sexual functioning. This section will detail the physiological changes that may occur as a result of a spinal cord injury. These physiological changes will be dependent on the level of injury. By level of injury I mean at what level the injury took place on the spinal cord. The specific site of the injury effects different parts of the nervous system, which in turn will effect different parts of the body. The physiological changes will also be dependent on the severity of the injury. Severity of injury, in medical terminology, is described in two ways, complete or incomplete spinal injury and or using what is called Asia Scores. These two descriptions will be explained below.

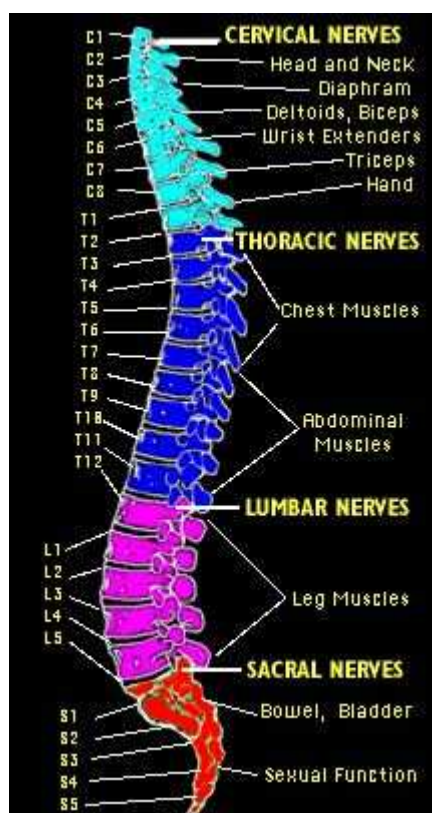
#### ***4.4.1 Complete and incomplete spinal cord injuries***

If the spinal cord injury is complete, it means that the spinal cord, at the point of injury is completely severed. In other words there is no transmission of signals from the brain past the point of the injury. An incomplete spinal injury means that the spinal cord is only partially severed. This injury could be minimal and although there would be some loss of function, the body would adapt and compensate for this loss so there would be minimal visible or noticeable effects of the injury. The injury could also be very severe but not resulting in the spinal cord being completely severed. In this situation the person would have more extensive loss of functionality but there may be areas of their body, below the level of injury that are not affected. The question really is how incomplete is the injury? Depending on the answer to this question (which often cannot be fully answered in the first few months of rehabilitation) this will determine what bodily functions are retained and what is lost. This is why, when a person's injury is incomplete, from a medical perspective, it is difficult to know exactly how it will effect the person. In terms of sexuality counselling if the person's injury is incomplete there are often no definites as to how exactly it will effect a person's physical sexual functioning.

The level and degree (complete to incomplete) of a person's injury may affect their person's ability to be sexually aroused. Sexual arousal happens in two ways - a psychogenic arousal and reflex arousal. The implications of these different forms of sexual arousal will be discussed later in this chapter (Section 4.4.3).

#### ***4.4.2 Asia Scores***

The Asia Score for a spinal cord injury is a far more detailed description of the severity of the injury. The scores go from A to E. These scores also detail where the injury is located ranging from (Cervical) C1 – C7, (Thoracic) T1 – T12 and (Lumbar) L1 – L5 and (Sacral) S1 – S5. Where these areas are located is shown in the diagram below.



**Schematic Representation of the Spinal Cord and the Nerve Endings**

[http://whyfiles.org/023spinal\\_cord/images/spinemap.jpg](http://whyfiles.org/023spinal_cord/images/spinemap.jpg) retrieved 20/11/06

An 'Asia A' score would be the equivalent of a complete spinal cord injury, as described above. In other words the spinal cord is completely severed and no motor or sensory function is preserved below the level of injury. An 'Asia B' score indicates that the injury is incomplete but the expectation is that there will be significant loss of bodily function. Sensory function may be preserved but motor function will be compromised. The amount of loss is also dependent on the level of injury in other words at what level was the spinal cord damaged. An 'Asia C' score indicates that there will be loss of functioning but it will probably not be that extensive. In the long term (one – six months) the expectation is that the person would be able to walk but perhaps with a walking frame or stick and that there may be some loss of hand and arm functioning but not to the extent that it would prevent the person from using their hands for normal day to day activities. There may be short term loss of functioning of the bowel and the bladder but it would be more usual that these functions returned, but there are no guarantees. The expectation is that there would not be long term loss of one's physical

sexual functioning, but once again there can be no guarantees. An 'Asia D' score indicates that the expectation is that the person will regain full functioning. An 'Asia E' score would indicate that there is normal motor and sensory functioning.

The scoring 'A – E' indicates the severity of the injury. The C1 –C7, T1 – T12 and L1 – L5 indicates the level of injury. The highest level of injury that a person can have is a C1, which is the 1<sup>st</sup> vertebrae in the cervical area of the spine, which is the very top of your spine. A person would not survive if the injury was severe and at this level to the spine. The lowest injury level of injury is S5 which is in the sacral area.

In terms of Asia Score a person's injury would be described for example as C5 Asia A or T10 Asia D. As a counsellor I have found it very important to have a good understanding of the Asia Scores and their possible implications when counselling both patients and their partners. From a medical perspective these scores determine a person's prognosis. It is important for a counsellor to understand the medical prognosis to effectively work alongside the patient and his/her partner.

Nerve endings in the lumbar and sacral area (in other words the bottom of the spine) are primarily responsible for sexual functioning. It is therefore not unusual for a person to be mobilizing independently, full arm and hand functioning but their sexual physiological functioning has been effected.

#### ***4.4.3 Level of injury and its impact on sexual functioning***

(The information detailed below is from the spinal workshops on sexuality held at the Auckland Spinal Unit in 2005 – the guest speaker was Debbie Hagan, Clinical Nurse Consultant, Royal North Shore Hospital)

The impact of a spinal cord injury on a person's physical sexual functioning will be dependent on the level of injury and the severity of the injury. These implications will be discussed below.

However before discussing these it is important to have an understanding of the different forms of sexual arousal which for a female results in an engorged clitoris and vaginal lubrication and for men an erection. The two types of sexual arousal are psychogenic

arousal and the other type of arousal is reflex arousal.

Psychogenic sexual arousal originates with stimulation of the nerve cells in the brain as a result of erotic thoughts, fantasies or visual, auditory and olfactory stimulation. This form of arousal originates in the brain and travels down the spinal cord to the sacral and lumbar areas of the spine.

Reflex sexual arousal comes from direct genital stimulation or direct stimulation of other erogenous zones. The nerve endings responsible for the response to genital stimulation are centred in the L1, L2 area of the spinal cord. Reflex sexual arousal is generally of a 'better quality' than psychogenic arousal. It is regarded to be more sustainable and in a male, the erection is more likely to be sufficient for penetration in comparison to a psychogenic erection. It is however not unusual for either a psychogenic erection or a reflex erection not to be sufficient for intercourse. So although many patients with a spinal cord injury retain some reflexogenic or psychogenic erectile function, these erections are frequently unsuitable for sexual intercourse (Smith and Bodner, 1993).

#### ***4.4.4 Injury Level T12 and above (T12 – C2)***

As a general guideline if a persons' injury is from the level of T12 or above and their lesion is regarded as being complete physiologically they should be able to have a reflex erection (male) and for the women vaginal lubrication and clitoral engorgement. If the injury is incomplete sexual arousal will be dependent on the extent of the injury to the nerve endings. The more severe, the more likely there will be increased loss of functioning.

For a male the reflex erection is often not sustained for a sufficient period of time for penetration, hence the use of erectile enhancing medication and or sexual aids may be required. If the injury is at the level of T12 and above, and the lesion is complete, ejaculation and 'conventional orgasm' are unlikely.

Estores and Sipski (2004, p.117) assessed sixty two women with a spinal cord injury. Forty of the women had injuries that were regarded as being complete and twenty two as incomplete. Their findings supported the hypothesis that women with upper motor neuron injuries (T12 and above) preserved reflex genital vasocongestion (clitoral engorgement). In this same study they found that 55% of the woman with a spinal cord

injury achieved orgasm. They found there was no difference in the ability of the woman with different degrees of severity of the trauma to the spinal cord to achieve orgasm. The results did however indicate that it is easier and quicker for able bodied women to have orgasms than it is for women with a spinal cord injury. The results also indicated that the ability to achieve orgasms was significantly lower in women whose spinal cord injury was located in the sacral spinal area, in other words in the lower part of the spine from L1 to L5. The conclusion that they drew from their data was that an intact sacral reflex arc is important in maintaining the capacity for orgasm.

Irrespective of gender, if the spinal injury is at the level of T12 and above, and the injury is complete, it is unlikely that the person would be able to experience genital sexual arousal from psychogenic stimuli. The reason for this is that the stimulus cannot be transmitted through the spinal cord to the genital area.

#### ***4.4.5 Injury level T11 and below***

As a general guideline if a person's injury is from level T12 and below and their injury is regarded as being complete there will most likely be an absence of reflex erections. There is the possibility of being sexually aroused from psychogenic stimulation as well as being able to ejaculate and or have a 'conventional orgasm'. Once again if the injury is incomplete it will depend on which nerve endings have been affected.

As the quality of a psychogenic erection may not be sufficient for penile penetration, once again erectile enhancing medication or sexual aids may be needed.

### **4.5 Implications for Counselling**

The next section of this report will weave the ideas from the participants plus ideas from the literature into the practical application of how a health practitioner can offer sexuality counselling.

#### ***4.5.1 Physiological knowledge and sexuality counselling***

From a social constructionist perspective no event has intrinsic meaning. The meanings attributed to an event will be influenced by the positioning of a person within the prevailing discourses available to him or her. Ensuring that a person is knowledgeable about how his/her body works after a spinal cord injury, could affect the way he/she

interprets or makes meaning of altered sexual responses such as the ability to have an erection or vaginal engorgement. Ensuring that a person with a spinal cord injury has an understanding of why his/her body may respond differently after the spinal injury may prevent misunderstandings from occurring and inaccurate conclusions being reached. A person with a spinal cord injury may very easily misinterpret physical sexual responses as he/she may be using the lenses / discourses that he/she used prior to the injury for meaning making. Ensuring that patients and their partners have accurate information about how their 'new' body may function, positions them (patient and partner) to reflect and deconstruct various discourses about sexuality and the position calls that are on offer and they (patient and partner) can then select and develop preferred subject positions.

For example if prior to a person's spinal injury erotic stimuli played a large part in his/her sexual satisfaction but after the injury these erotic stimuli have no effect on sexually arousing him/her, this lack of affect could be very confusing to the person with a spinal injury and or his/her partner/s. He/she may wonder why previous erotic thoughts, fantasies and visual, olfactory and auditory stimulation do not have the same effect as prior to the injury. He/she may interpret this inability to become sexually aroused in the genital area as 'not finding someone sexually attractive' when in fact it is just that the body cannot transmit the signal through to the genital area. This lack of sexual arousal could also be confusing for the partner/s and once again the reasons could be misinterpreted – some of the misinterpretations could be of lack of interest, lack of desire to be intimate, an inability to have sex or lack of sexual attraction.

As a result of the physiological changes in the body, the length of time needed to become sexually aroused and to have an orgasm may take longer than previously required. This 'needing more time' to be sexually satisfied may be interpreted as lack of ability and or interest rather than just the fact that it just takes longer to be sexually satisfied.

A good understanding and knowledge of the body (or partner's body) may stand against these misunderstandings and open possibilities for alternative ways and ideas of becoming sexually aroused and sexually satisfied.

As a counsellor at the spinal unit I have found it to be important to personally have a good understanding of the physiological aspects of spinal cord injury and how this may

affect a person's sexual functioning. I have noted that people are often more comfortable initially to talk about the physiological / biological side of intimacy before talking about other concerns and worries relating to sexuality.

#### **4.5.2 Fertility**

A woman's ability to conceive is not affected by a spinal cord injury. A woman may experience amenorrhea for the first few months after her injury as a result of the trauma but this is not normally long lasting. For a man however, the sperm quality is frequently affected by a spinal cord injury. However, sperm retrieval techniques are so advanced these days that through artificial means sperms can be retrieved and used for in vitro fertilization. This would normally involve going to a fertility clinic. In New Zealand there is certain funding from ACC for couples who would like to pursue the option of in vitro reproduction.

From a counselling perspective I have found it to be important to have this information and to be able to refer people to fertility experts so they can discuss their particular situation in more detail. Especially with younger men and woman, parents are often very concerned about their child's ability to reproduce offspring. The Auckland Spinal Unit has a urologist who has clinics on site and he is available to discuss fertility issues with both in-patients and outpatients.

#### **4.5.3 Psychological and Social Considerations**

In Chapter two of this report the discursive production of discourses was discussed. It was noted that discourses are taken for granted assumptions and ideas about how things are and how things should be. These discourses constitute and shape the meanings people make of their experiences. Truth is viewed as subjective rather than a scientific fact.

Arkwright (2005, p.35) sharing his experience of working as a counsellor at the Auckland Spinal Unit mentions that the meanings people held about ability and disability prior to their spinal cord injury significantly impacted their reactions to their impairment and these meanings were inevitably embodied within discourses specific to disability, culture, gender, age and often career as well.

Whilst Arkwright did not specifically mention discourses about sexuality the point he was making was that the discourses that are available to a person prior to their spinal injury will influence the way they make sense and the meaning they attribute to their spinal injury. Likewise discourses about sexuality will impact on a person's reaction and the meaning they attribute to their sexual functioning. As Arkwright (2005) has stated these will be embodied within discourses specific to culture, gender and age. The discourses that a person held about sexuality prior to his /her spinal cord injury will most likely be the lens through which he /she initially make sense of sexuality.

In spinal cord injury sexuality counselling, making more known the lenses and discourses through which a person has in the past made sense of his/her own sexuality, can be important both for the person themselves as well as tentatively guiding the counselling conversation. For example if a person shares with me that his/her approach to sexuality prior to his/her spinal cord injury was very innovative with very few boundaries about what was acceptable and what was not I would be tentatively holding ideas that he/she is positioned in a way that there would not be too many limitations placed on him/her to discover alternative ways of meeting his/her sexual desires and needs. This would affect both the person with the spinal cord injury and his/her sexual partner/s. If a person shared with me that he/she had very definite and fixed ideas about what was acceptable and what was not acceptable in terms of sexual expression I would tentatively be wondering if this person may be interested in deconstructing some of those ideas to open space and new possibilities about sexuality. For many people with a significant spinal cord injury 'conventional' sex may not be a possibility in the future.

Kaufman, Silverberg and Odette (2003, p.3) state that "wrong ideas about sex and disability affect us all....when we align ourselves with these ideas we limit our possibilities as sexual beings. " These ideas and myths about sex produce discursive practices that influence a person's ability to adapt and adjust to changes in their own sexuality. Kaufman et al (2003, p.3) identifies a number of common myths:

- ~ People living with disabilities and chronic illness are not sexual.
- ~ People living with disabilities and chronic illness are not desirable.
- ~ Sex must be spontaneous.
- ~ People living with disabilities and chronic illness can't have "real" sex. "Real" sex progresses from light activities like kissing to the "real" thing

which is penis in vagina intercourse, to simultaneous orgasm in ten minutes or less.

- ~ People living with disabilities and chronic illness are pathetic choices for partners
- ~ People living with disabilities and chronic illness have more important things to worry about.
- ~ People living with disabilities and chronic illness are not sexually adventurous *and if they are they have a sexual perversion. (Italics mine)*
- ~ People living with disabilities and chronic illness who have sex are perverts.
- ~ People living in institutions shouldn't have sex.
- ~ Sex is private.
- ~ People living with disabilities and chronic illness don't get sexually assaulted.
- ~ People living with disabilities and chronic illness don't need sexual education.
- ~ People living with disabilities and chronic illness are unnatural.

The discourses mentioned above may position a person with a disability in a non agentic position in terms of his/her freedom to express and experience his/her sexuality. A person with a spinal cord injury may have a preference for being able to express him/herself sexually but the discourses that tell him/her how to go on may inform him/her that other people will not be interested in him/her sexually and or it is 'abnormal' to have interests in sexuality if you have a disability. Sexuality counselling would include deconstructing and de-centering some of these above-mentioned discourses which could be problematic for a person with a spinal cord injury. As Kaufman et al. (2003) mentioned, if a person holds these ideas it may limit his/her possibilities as a sexual being.

A video called Female Sexuality, narrated by Dr Marcia Spica and used at the Auckland Spinal Unit for teaching and educational purposes, highlights that some women experience an improvement in their sexual relations after their spinal cord injury. This highlights the point that a person's possibilities as a sexual being need not be limited as a result of a spinal cord injury. In this video the one woman who was aged about forty five discusses her experiences of sexuality after her spinal cord injury. She talks about how

for her to have an orgasm takes much longer than what it did prior to her injury. She, however, also shares how as a result of her spinal injury, her and her partner have had to pay much more attention to stimulating other parts of her body and being in a sense much more innovative and creative around sexuality than what they previously felt was required. In many ways they have now a more satisfying sexual relationship than what they previously had. This would be an example where as a couple they reviewed their 'taken for granted assumptions' and practices about how long sex should take and what is included and excluded in intimacy. Through this reviewing process they took up new ideas and possibilities about sexuality.

Jackson (cited in Smith, 1995, p.164) mentions that people with spinal cord injuries have made a number of surprising discoveries about sex. Although genital sensation is lost many men and woman with spinal cord injuries develop erogenous sensations in other parts of their body and they report that they are able to have orgasms in other parts of the their body. Some people that I have spoken to with a spinal cord injury report similar experiences of discovering erogenous zones in other parts of their bodies. Jackson (cited in Smith 1995, p.164) concludes that for some people sexuality can actually get better after a spinal cord injury.

Having satisfactory enjoyable sexual experiences is possibly more dependent on the discourses through which we make sense and make meaning of our experiences rather than the actual physical abilities of our bodies.

#### **4.6 Personal Journey**

I started working as a counsellor at the Auckland Spinal Unit in January 2004. When I was interviewed for the position and asked a question about what do I see included in the counselling role, I informed the panel that I thought that sexuality counselling could be an important aspect of the counselling role but my knowledge was not sufficient, at this stage to fulfil that requirement. My previous role had been working with adolescents who had been sexually abused. I was very comfortable to talk about sexuality but I did not have the required knowledge needed to competently offer sexuality counselling to people with a spinal cord injury.

At that stage (when I was initially interviewed) I thought it was only a lack of

knowledge that prevented me from effectively counselling in this area. However I have since realised that it was lack of knowledge and also some discourses about sexuality and disability that I held that positioned me with an inability to see other possibilities and options. This inability to see other options stood in the way of my being able to deconstruct some of the discourses that patients and their partners held that prevented them from being able to adequately satisfy their sexual needs and desires. I believed in the right of all people to sexual expression and satisfaction. However, I noticed that there were certain myths about sexuality that I needed to deconstruct for myself, if I was going to be able to support patients and their partners in their own deconstruction process.

Kroll and Klein (1995, p.16) note that:

One of the most common misconceptions about people with disabilities is that they can't have sex, don't want sex or are not interested in sex. People seem to think that a disability neuters you sexually. This attitude can be found even among professionals who work with disabled people. Unfortunately the way people are perceived often becomes the way they perceive themselves.

In my first few months, working at the Auckland Spinal Unit, it became quite apparent that sexuality was not something that was really talked about; there was talk about bowels, bladders, catheters with the patients at goal setting meetings and in the multidisciplinary meetings but not sexuality. I occasionally saw in the notes 'Viagra prescribed' – not successful or perhaps successful. This tended to be the only documented evidence of our input with regards to sexuality. The invisibility of sexuality communicated that this is not something that we as health practitioners really talk about at the Auckland Spinal Unit.

At the end of this chapter I will detail the project that I took a lead role to address this invisibility. However, in terms of my personal journey I have made a concerted effort to increase my knowledge base in this area and examined some of my discursive practices about sexuality and intimacy that were barriers for me.

For example I remember one wife discussing sexuality with me and she mentioned that by the time her husband is out of the wheelchair, the catheter is sorted out where is the spontaneity and fun in having sex – so what is the point? At that stage, when she shared

this with me, I was similarly positioned to her in the discourse of sexuality needs to be spontaneous, that I just tended to agree with her. If one has to put so much planning into having sex, where is the spontaneity? I have now, as a result of deconstructing some of my own discourses about sexuality come to question my taken for granted assumption that unless sex is spontaneous it cannot be fun and enjoyable.

Now when faced with similar comments I respond very differently. I am very comfortable to deconstruct the idea of sex needing to be spontaneous. I am comfortable to talk about the idea that intimacy should only occur in certain places. Is there possibility for one to be intimate in one's wheelchair? This ability to respond differently with increased comfort in this area is a result of my gaining knowledge about sexuality and spinal cord injury plus questioning some of my own discourses about sexuality. I have also noticed that the more discussions I have with patients the more my confidence level and skill increases.

#### **4.7 Sexuality Project**

In December 2004 a project team was formed at the Auckland Spinal Unit to develop ways of consistently addressing sexuality with all patients and their partners.

The model that the project was based on was the P –LI-SS-IT model. This model was developed by psychologist Annon (1976). This model provides different levels of therapeutic intervention appropriate to the level of skill, knowledge and comfort of the individual health professional. These levels are:

- P - represents permission
- Li – represents limited knowledge
- SS – specific suggestions
- IT – represents intensive therapy

The idea of the model is that within a rehabilitation facility such as the Auckland Spinal Unit every clinician should at least be at the (P) Permission Level. This 'permission level' involves an acknowledgement of the patient's sexuality concerns and a permissive environment where these concerns can be voiced. This requires a level of comfort in discussing sexuality with a patient or their partner if they bring the topic of sexuality up.

It also includes an ability to competently discuss with the patient and or their partner who within the medical team would be able to talk about sexuality and or to make a referral to that health practitioner. There is no expectation at this 'permission level' that a health practitioner initiates a conversation about sexuality.

The next level according to this model is (Li) Limited Knowledge which involves the ability to clarify misconceptions about sexuality and address some frequently heard concerns about sexuality. For example questions that patients or their family (*whanau*) frequently ask me is: Will I still be able to have children? Am I allowed to have sex on week-end leave or will it damage my back further? Will I be able to have sex again?

At this 'limited knowledge' level of the model a health practitioner would have the knowledge and skills to run group education sessions about sexuality.

At the third level of the model (SS) Specific Suggestions the expectation is that a health practitioner would be competent to offer individual counselling to facilitate a problem solving approach to a patient's particular problem. This counselling could include couple counselling. The model encourages an interdisciplinary approach to sexuality counselling so any member of the multidisciplinary health team would be suitable for this 'specific suggestions' level. The ideal is to have a diversity of professions, ethnicities and gender at this 'specific suggestion' level so that a person with a spinal injury and or their partner can choose who they feel the most comfortable with to discuss sexuality.

The final level (IT) Intensive Therapy is undertaken by a professional sexuality counsellor when intervention via the other three levels has not been effective. This would tend to be longer term counselling and would most likely require a referral to a specialised service (Summerville & McKenna, 1998).

The philosophy behind the P –LI-SS-IT model is that it is multidisciplinary – sexuality counselling is not the domain or territory of any specific discipline. All health professional should have a level of comfort in speaking to people about sexuality, the very minimum being able to direct a person to someone within the multi disciplinary team with the appropriate knowledge and skills. This model also recognises that

sexuality is often a difficult topic for people to address and thus relationship and rapport with the health practitioner is probably more important than the particular discipline of that clinician. Ideally a patient would be able to choose from a number of staff within the multi disciplinary team who they would feel comfortable to discuss sexuality with. The choice should ideally include a choice of gender, age and ethnicity.

#### ***4.7.1 Sexuality project at the Auckland Spinal Unit***

The sexuality project team for the Auckland Spinal Unit organised for Debbie Hagen, a Clinical Nurse Consultant from Royal North Shore hospital in Australia to run a series of day long workshops so that every clinician (social workers, doctors, registered nurses, enrolled nurses, healthcare assistants, physiotherapists, occupational therapists social workers and counsellor) at the Auckland Spinal Unit attended an introductory one day training in sexuality and spinal cord injury.

The introductory training that we received from Debbie Hagen addressed level one and two of the P –LI-SS-IT model. As a result of this training there was a very noticeable shift in staff being willing to introduce the topic of sexuality to patients. A more advanced training program was also organised which approximately ten people from the Auckland Spinal Unit attended. This training was focused more on the level two (knowledge) and level three (specific suggestions) of the P –LI-SS-IT model. As a result of this training there were about five clinicians that were comfortable to offer sexuality counselling to patients.

A number of staff now had the knowledge to offer sexuality counselling to patients. The next challenge was to ensure that it was introduced as a regular part of a person's rehabilitation in a similar way to the way topics such as skin care, managing your bladder and bowel are introduced. The next step was to include sexuality as one of the generic goals that all patients have at the Auckland Spinal Unit.

These six generic goals are documented in the patient's notes as follows:

- 1) Bowel Management: I will remain clean and dry and free from accidents.
- 2) Bladder Management: I will remain clean and dry and free from accidents.
- 3) Skin Care: I want to be able to recognise any skin problems and prevent skin breakdown.

- 4) Personal Hygiene / Activities for Daily Living (ADL): I want to be able to meet / direct my personal hygiene needs.
- 5) Discharge: I want to be discharged to a safe environment.

Now added is:

- 6) I will have the opportunity to discuss my sexual health and how my spinal cord injury has impacted on this.

This additional sexuality generic goal positions sexuality in the same way as discharge, bowel and bladder management. In other words, in the same way that we have a generic goal for discharge, managing one's bowel and one's bladder, sexuality is included in this.

The implications of the inclusion of this goal into a patient's rehabilitation plan is that sexuality is very visible to the patient and in making it a specific goal, the rehabilitation team is expected to discuss this goal with the patient and to find out from the patient what in particular would be useful to them (if anything) in the achievement of that goal. As the counsellor I am usually the person who discusses the sexuality goal with the patient.

In addition to the inclusion of sexuality as a rehabilitation goal, sexuality education has now been included in the weekly one hour spinal education programme. This means that on average, once every two months there is a group education session on sexuality that is provided. It is not compulsory to attend the sexuality training but the opportunity is there.

Through the initiation of this sexuality project the Auckland Spinal Unit has ensured that sexuality and the discussion of concerns and issues relating to sexuality are very visible. This project opened up a position for me and other team members to address sexuality issues and concerns on an organisation basis and not limit it only to one on one counselling.

#### ***4.7.2 Sexuality Counselling - Evaluation of Current Services Offered***

Mc Alonan (1996) researched the efficacy of spinal cord injury sexual rehabilitation services. She interviewed 12 people with a spinal cord injury. This research was done in

America. She notes that participants in her study preferred a direct open style of communicating with an apparent comfort with the subject matter. A willingness to listen and answer any questions was consistently mentioned by participants as desirable traits. Neistadt and Baker (1978) highlight that it is the practitioner's responsibility to initiate the discussion and not interpret a lack of inquiry by the patient as a lack of concern.

Through staff training, the implementation of a generic goal relating to a patient's sexuality plus the patient sexuality education sessions as well as individual discussions with patients and the use of videos the staff at the Auckland Spinal Unit have become very proactive in initiating and addressing sexuality with patients. Almost without exception all in-patients (and their partners) have the opportunity to receive education and or discuss individually any questions or concerns they may have in relation to their sexual functioning.

In conclusion the topic of sexuality is far more visible at the Auckland Spinal Unit than what it was prior to 2005. Exploration of the relevance of sexuality counselling is now a specific goal for every patient, we do have regular education modules on this topic and staff are far more comfortable at the P (permission) and LI (limited information) level. Within the Auckland Spinal Unit there is the expertise to address more specialised concerns when required. Patients are also given a manual called "Back on Track" which is an informative manual covering key topic areas of a spinal cord injury. One of the chapters in this manual is on sexuality. In addition I have networked with the Auckland Sexual Health Services who have two specialized sexuality counsellors working there. If required we are able to make referrals to their service.

Cushman (1988, p.68), in her study on spinal cord injury patients level of satisfaction with staff efforts to address sexual concerns, identified that written educational material, consistently provided to all patients, as well as staff initiated discussions, create the most effective routes to creating a higher level of consumer satisfaction. At the Auckland Spinal Unit this is currently what we are doing – all patients receive written information in their Back on Track manuals, almost all in-patients are now approached either by me and/or the medical consultant or another member of the multidisciplinary team and a discussion about sexuality is initiated. There may be the very few exceptions where a person is not approached and this would normally be because the person is medically unwell. In addition to this patients can attend education sessions on sexuality.

## **5. Care and Counselling**

### **5.1 Introduction**

This chapter gives a very brief overview of the history of counselling services at the Auckland Spinal Unit and the referral process to this service. The participants in this research study had some very definite ideas about the way in which the counselling service should be offered to them and their families and this will be discussed in the next section. In line with the intentions of action research as detailed in chapter one I will discuss my current counselling practice and how this has been shaped and modified as a result of the input from the participants. The concluding section of this chapter will look at care as an integral part of counselling. I will also briefly discuss the different position calls that the counsellor gaze as opposed to the counsellor look can offer patients.

### **5.2 History of Counselling Services at the Auckland Spinal Unit**

Since 1996 there has been a dedicated counselling service for the Auckland Spinal Unit. In this time period there have been three counsellors including myself. When I started at the Auckland Spinal Unit as a counsellor, there had been a gap of about six months between counsellors. My knowledge about how the counselling service was previously offered has predominately been gained from the information that staff have passed onto me.

I therefore cannot be sure how previous counsellors positioned the counselling services within the Auckland Spinal Unit but the impression that I got from the staff at the Auckland Spinal Unit was that counselling was mainly by referral, either self or from staff. Once the counsellor received a referral an appointment would be made to see the patient. It did not seem to be the practice that the counsellor initiated the first contact and saw all inpatients on admission. This way of referring would be in line with the way referrals within Counties Manukau District Health Board are made to Psychiatric Liaison Services.

Staff also informed me of a programme called Family Net which was a support group for family (*whanau*) members. This group was facilitated by the counsellor and many

staff reported how successful it was.

It did not seem to be the counsellor's practice to attend patient goal setting meetings. Counselling seemed to be more one on one, by appointment and for families a group work approach.

### **5.3 The Ideas of the Participants**

A very consistent theme that came through in this research was participants' ideas about how counselling should be offered at the Auckland Spinal Unit. Ideas from the participants included how the counsellor should make him or herself known to the patients, the practice of setting up appointments, when counselling should start and finish and the role of the counsellor. Other chapters in this research report have already detailed the content of counselling such as sexuality, grief and loss and family involvement. This chapter attends to the agentic positioning that participants in the research wanted to have in relation to counselling, and how counselling services are currently positioned at the Auckland Spinal Unit. Listening to these voices and incorporating this with the paradigm I stepped into through my studies and this research, I formulate what it is that I can offer in all my relationships with the patients whom I introduce the service to.

#### ***5.3.1 Counselling Invitation***

In terms of the counsellor making him/herself known to every newly injured person being admitted to hospital, every participant in this research project, without exception, indicated that the counsellor should take the initiative to meet and introduce themselves to the patient and not wait for the patient to request to see a counsellor. There was a strong preference for the counsellor to develop a relationship with all patients by just 'popping in' to see a patient in her/his room, rather than only relying on a practice of formalised appointments in the counsellor's office. Larry, one of the research participants discussed in his interview how this practice of formalised appointments with the counsellor did not meet his needs.

Larry was 24 years old when he injured himself overseas in a sporting accident. His initial rehabilitation was overseas but he was moved to the Auckland Spinal Unit (approximately one month after his injury) for further rehabilitation. Larry suspected that staff members at the Auckland Spinal Unit were concerned about how he was managing

emotionally with his injury and he assumes that they referred him to the counsellor. Larry discussed, in the research interview, his experience of how counselling was offered to him. He did not experience being agentially positioned in the way the counselling appointment was offered to him. The expectation that he sees the counsellor in his/her office without actually having met the counsellor first was not his preferred way of making contact with the counsellor. During the research interview I asked Larry what his advice would be about how counselling could be offered. He commented on his experiences and then gave a recommendation. He observed that the counsellor:

...never saw me when I was in the room [his room]... never really made herself known, she was either in her office or not around... the first time I talked to her it was in her office, but it would have been easier if she had introduced herself from the start and then every now and again you know, maybe once a week just pop in and just to say that you are making sure that you don't need anything, as opposed to waiting for us to approach her.

My understanding of the above comment of Larry's was that he would have preferred to have seen the counsellor around the wards (not only in the office). His preference was that the counsellor makes him/herself known to a patient in the person's 'own' space. He preferred this introduction to happen prior to consulting the counsellor in his / her office.

This idea of a counsellor 'making him / herself known' in the patients 'own' space has the potential to significantly address power imbalances between patients and the counsellor. It has the potential to reposition the patient in an agentic position where the patient makes decisions about what she/he would or would not like. This agentic positioning of making choices is exceptionally important in a setting such as a spinal unit. In a matter of seconds a person shifts from being totally independent to in many instances, initially very dependent for the most intimate of cares - bowel cares, bladder care, being turned two hourly for pressure relief, using hoists for mobilising as just a few examples. Attending to agency in this situation is essential. Larry was requesting for a counsellor to get to know him as a person so that he can decide whether what the counsellor can offer would be of use. This way a client would be given the opportunity of negotiating power positions with the counsellor and at the same time this can deconstruct the idea that it is the professional expertise of a counsellor that is important

in defining the relationship and counselling process.

Larry was interested in getting to know the counsellor first. This opens space for Larry to experience himself as the senior partner in the counselling relationship. He is not just the recipient of counselling, something that is done to him, rather he is a significant agent in the production of the counselling process (Winslade, Crocket, & Monk, 1997, p.53).

Continuing with this theme of how counselling should be offered or made available, Paul's experience of rehabilitation, as previously mentioned in Chapter Three was that there was no-one to talk to. Throughout the research interview he mentioned this a number of times, "just no-one to talk to". Paul thought that a counsellor should be available to talk to him. He mentioned:

You see like me I did not have anyone to talk to, apart from the other patients you know, that was about it because nobody came to visit me when I was in hospital, just my mom and my dad and they had to come all the way from Taupo. All my other friends – no [they did not visit me] I had nobody around me. I just got treated like shit so I had no-one to talk to.

Paul's preferences as to how counselling should have been offered is reflected below in this transcript from the research. There are a number of similarities between Paul's ideas and Larry's ideas in that the counsellor should initiate the contact and see patients on the wards.

Paul: Ye just basically to know that there was someone there to talk to or better still they should have a counsellor that walks around, around these wards, just talking to people

Susan: You mean like just popping in

Paul: Yes like they did with everyone else, like ACC or the priest or the social worker, or the person selling little sweets and the paper, people to talk to. But you know there are a lot of things that you cannot talk to them about.

Susan: So are you saying not waiting to ask for a counsellor the counsellor should just pop in and see you.

Paul Ye Ye, I cannot see why not, just pop in and out just like a friend does, it would be a lot more relaxed and a lot more sociable

Susan: And that would have worked for you?

Paul: Ye well it would have worked for most people I would think, it is a helluva lot more friendly, you get on better with people that way. Like if you go to an office and you sit on one side of the table and the other person on the other side – no, not interested in that bullshit, you just sit there and you [counsellor] sit there, and you don't know what it is all about. Later on something pops into your head. Just come round, hi how are you, better that way. You get on better that way it is more relaxed. But it would have been good to have someone to talk to at the time. It just seems such a long time ago, it was only five years, almost a lifetime away, trying to push it away.

Paul also thought that a more relaxed, social, friendly informal visit would have opened a stronger invitation for him to consult with the counsellor. Despite Paul's very clear and strong desire to have someone to talk to, he would not, it seems have been willing to have these talks in an office – as he said “no, not interested in that” meaning not interested in sitting in a counsellors office in a formal environment. Winslade et al (1997, p.57) mentions how before we even see a person, position calls are already offered. “Counsellors need to understand how attitudes and beliefs about counselling influence an initial meeting even before any words are uttered”. For Paul, having to talk to someone in an office was not an option that he wanted to consider. To see a counsellor in his or her office would have silenced Paul before any words were uttered.

Paul, in his comments above, is deconstructing the idea that all meaningful counselling conversations must take place behind closed doors in a counsellor's office, in a formal environment.

Paul was a gardener, he used to attend to the gardens at the cemeteries and in the parks prior to his accident. He was not used to spending too much time inside. Being outside with his plants was what he enjoyed. Even on the day of the research interview, although the interview happened inside his house, Paul took me to look at his beautiful garden and his birds. He showed me his garden tools that he himself had adapted so that he could use them. He shared with me how he at first could only do one small strip of the garden

because of poor balance. He had to lean on the fence with one hand and he could use the other hand for gardening. He initially only developed the strip of his garden right next to the fence. As his mobility improved he was able to lean on his crutch and so he could access more places in his garden.

The interview with Paul touched my heart and sadness was very present as I thought of this man who loved the outdoors, loved his garden, was so innovative in the way that he had used scrap materials to adapt his garden tools and used scrap materials for his bird cages. He had an experience in the hospital that he interpreted as being “treated like shit”. His last comment “just trying to push it away” seems to indicate that struggling is still there and he is still “trying to push it away”. I cannot help but wonder if Paul was given opportunity for counselling conversations that were more in line with his preferences (relaxed casual chats), would he still be “trying to push it away?” Perhaps walks in the park with Paul may have been more therapeutic and useful for him in his “trying to push it away” than any amount of scheduled appointments.

### ***5.3.2 Focus of Counselling***

In the previous section participants in this research highlighted their preference for getting to know the counsellor in an informal way at the time of their admission. Research participants preferred the counsellor to take the initiative in making this contact. This next part draws attention to participants’ suggestions regarding the role of the counsellor.

#### ***5.3.2.1 Meaning making role of a counsellor***

Brett, was injured in a contact sport. He initially was unable to use his arms and hands at all and was not able to walk. His initial prognosis was that it would be unlikely that he would be able to walk again and if he was able to, this would take a number of years. Brett was married, he had a young family (children under five years old) and he was the breadwinner in the family. Despite the initial predictions of Brett’s progress he recovered very quickly, he gained a significant amount of functioning in his hands, although there is still a weakness in his hands, and he is able to walk without the use of a mobility aid, but he tires quickly.

Brett thought that, in his situation he would have appreciated someone to help him and his family make sense of all the information and knowledge that they were being

presented with. He used the metaphor of an umbrella service, which Brett thought was a very suitable role for the counsellor – someone who helps you make sense of all the information that you are given. Brett said that patients at times feel a bit aimless and lost and not sure what they should be doing next. He mentioned that there are so many people involved in a person's care like Accident Compensation Corporation (ACC), the doctors, the nurses, physiotherapists, occupational therapists and it is at times confusing who is responsible for what service. He suggested that one of the functions of a counsellor could be to assist patients with the integration of all this information and providing direction or guidance in how to make meaning of all the information given and the services of the different professionals involved. His expectation was not that the counsellor would know everything but that he or she could be a type of umbrella, a person one can go to if you are not quite sure who to turn to.

Matthew, also a married man with a young family, had a similar idea to Brett's in terms of the role of the counsellor being someone who could provide "some form of tying together of all the elements". All the elements that he was referring to were similar to Brett's – ACC, doctors, physiotherapist and occupational therapist. Matthew felt that if this "tying together was done a person's experience would be "more of a tunnel rather than a set of circumstances, and it happens across a certain time frame."

The two metaphors used above for the role of the counsellor in the Auckland Spinal Unit spinal unit were "an umbrella" and a "tunnel" and these indicate to me that patients appreciate the availability of specialist services (such as physiotherapy, urology services, counselling) but the fitting together of these specialist services so a person can make sense of the big picture and not just the specialised segments is what needs attention. The participants wanted to see a pattern and a sequence of how all the specialities fit together ("umbrella or a tunnel") and not a disjointed un-coordinated approach to their rehabilitation.

A risk of specialisation of care is that professionals see only the part of the body that they are specialised in. The body becomes fragmented and instead of seeing it as a whole the danger can be that we as professionals only see the parts. I did not get the sense from either Brett or Matthew that they did not want the specialised input. What they however wanted was a weaving together of all these different specialised knowledges in a way that they could make meaning themselves of the information given. I often hear patients

at the Auckland Spinal Unit talking about needing to learn about their new bodies. I am wondering if Brett and Matthew are referring also to the process of reclaiming (Frank, 1995) their bodies, bodies that are actually quite unfamiliar to them.

Brett seems to take this idea of meaning making a bit further. As previously mentioned, Brett's progress was much faster than initially predicted. However, if he had not made the "leapfrogging" progress that he made, he felt that it would have been good to have someone "come in and be able to lay it out for me, as opposed to a doctor, to have someone come in and talk to you, what type of support do you want, do you need, what kinds of questions do you have that may not be purely of a medical nature, someone with a bit of experience who can actually answer that for you." Brett felt that about a year after his injury it would have been useful to have had someone that he could "rationalise" with. Brett talked about this rationalising in the context of not making any further physical progress and thus coming to the realisation that he would have permanent loss of certain functions. I understood him to be saying that he would have liked to be able to talk with someone about this in a way that would help him to integrate this knowledge of loss and ability.

Brett specifically felt that to have someone come in and talk to him, as opposed to a doctor, would be helpful. This is a very interesting point as it deconstructs the idea that only doctors are qualified and able to speak with patients about medical diagnosis and prognosis. Brett was asking that "he could talk to someone as opposed to talking to a doctor". Later in the research interview Brett expands on his ideas of talking to someone:

If I had the opportunity to talk to someone about it, I may be able to rationalise it and to accept it quicker perhaps just to bring it fresh into the mind, then maybe there would be less of those occasions [wishing I could do the things I used to do], it will never go away, but just talking to someone about it would have been motivating.

Both Brett and Matthew saw one of the roles of counselling as assisting patients to make meaning of what is happening to them. This meaning making stands against "aimless and lost" (Brett) and "a set of circumstances" (Matthew). Matthew and Brett recommend

the counsellor to step into being positioned as the one to co-construct meaning of their experiences and the information being received.

### *5.3.2.2 Advocate role of a counsellor*

David, a participant in this research study had a spinal injury as a result of medical reasons as opposed to many of the other participants whose spinal injury was because of an accident. Prior to David coming to the spinal unit his mobility had already decreased and he was using crutches to walk around. I was working at the Auckland Spinal Unit, as the counsellor during David's inpatient stay. David's experience of his inpatient period, at the spinal unit was that he was frequently positioned in a non agentic position and that I could have supported him more in having a voice about his concerns. One example that he shared in the research interview was his experience of physiotherapy. David's experience of physiotherapy was that other patients received much more attention than he did. He shared with me how he had the potential to walk but the physiotherapist was so focussed on other patients (he referred to a young man in particular) and that he (David) was never really given the opportunity to practice. David therefore had ideas about the role of the counsellor being more of an advocate and or a mediator. The transcript below details David's experience of physiotherapy and also his ideas about how counselling could have assisted him, had it been viewed more from the position of an advocate and mediator.

David: At first I was really motivated to walk but to motivate people you have to have more people and more attention to encourage you... And one day I said to her [physiotherapist] do you think I would ever be able to walk and she said no I don't think so. So I just thought what am I doing here [at the spinal unit] why am I wasting my time. Then one day before I left [discharged from the spinal unit] about maybe two weeks before I left I said could I please have a go on that walking thing [walking frame] because I had seen another lady do it ...And I could do it, [able to walk in the walking frame] I made myself . She [physiotherapist] could not believe it, I do not think. And then she started timing me and all that sort of rubbish. Well it probably wasn't rubbish in her book but I thought it was. Then she let me go on the parallel bars and at first I could hardly do it, she had to help me but after two or three days I was getting better and better at it. And I was thinking I should have been doing this two months ago not just the last week. So, I was really disappointed. I should have really talked to

you about it but I didn't. So maybe you could talk to people about things like that ...Maybe if you [Susan] had come along and said look what is happening with your physio, are you happy with what she is doing, if I had talked to you privately I would probably have told you these things that I'm not really happy. This is what is happening I don't like to complain but I don't think that things are going that good.

Susan But what I'm hearing you say is that you needed those very specific questions to be asked to you, how was physio going, do you have any concerns. How did your home leave go, what were the things that worked well, what did you have difficulty with? So just a lot more specific enquiry into things.

David Yes that's right...Yes that is one thing that I think you could really have helped people with, act as a sort of go-between or mediator or whatever.

David seems to be seeing the role of the counsellor as a socio political role. According to Monk and Gehart (2003) narrative therapist's focus remains on countering oppressive practices encountered directly in society or indirectly through the dominant discourse we adopt. David saw the role of the counsellor as countering, in his opinion, an oppressive practice where a younger person was given preferential treatment to him. He saw the role of counsellor as not just one on one counselling but someone who will go beyond that and address inequality and unfairness.

As I reflect on David's comments from the above transcript I am wondering what were the discursive practices that positioned David in a way that silenced him so he could not speak out for walking again. David in his research interview often talked about "not wanting to complain". I wonder if this discursive practice of respecting professionals with knowledge and not wanting to complain, silenced him? David was in his late 50's. Did discourses about age and who is important, silence him? David did refer to a young man (he was aged about 22) who in David's perception got all the attention from the physiotherapist. Did the discursive practice of young people are more important than older people, or ideas that he (David) has had in his life, position him in a way that silenced him?

The question I ask myself is how did I not hear something that was so important? How did I not hear something that was causing a patient “so much disappointment?” In reflecting on my counselling practice I think that my assumptions and story preferences got in the way of my hearing what was so important to David. David had been on bed rest for approximately three months. I just took it for granted that once he was up and about in his wheelchair everything was fine. I know that I had also had a discussion with David about the possibility that he may in the future be dependent on a wheelchair for mobility. His response was that he would be okay with using a wheelchair as long as he could go home and not have to go to a rest home or a private hospital. Maybe I had a strong preference for hearing the “I’m fine story” or as (Frank, 1995) calls it, the restitution story – the idea of “I was sick but now I am better” - and did not make space in our counselling conversation for the story of disappointment and hope: disappointment about physiotherapy and hope to be able to walk again.

### ***5.3.3 Timing of counselling***

All of the participants in this research study would have spent a period of time (which could vary from about two weeks to two months) in what would be called an acute medical facility such as Middlemore Hospital, Waikato Hospital, Whangarei Hospital before coming to the Auckland Spinal Unit for rehabilitation.

In the interviews participants did not make a very clear division between when they were at the acute hospital and when they came to the Auckland Spinal Unit. I also did not see this division as being something that I wanted to focus in on in the research interviews. It was interesting however to me that the participants talked about the total experience not the ‘Middlemore Experience’ and then the ‘Spinal Unit Experience’ for example. The ideas presented below would be referring to the acute phase of a person’s injury, the rehabilitation phase whilst at the spinal unit and also once discharged.

All participants in this research indicated that counselling should be available throughout their hospital stay and many identified the need for it after discharge as well. Two participants (David and Matthew) did not specifically identify the need for counselling after discharge.

Every participant identified ways in which counselling would have been of benefit to

them personally and most identified how it could have benefited their families as well. This finding, emphasizing the benefits of counselling, really surprised me. Prior to doing this research I thought that many of the participants would say that counselling is a good idea for others but not something that they would really have found useful for themselves. This finding about counselling being useful has positioned me in being a lot more confident in offering counselling to patients as the participants have identified the service as important.

Lequecher, who has had her spinal injury for more than ten years, voiced her idea about the timing of counselling as follows:

As for me, people who have been newly broken, as I would put it, they need to be counselled as soon as. To stop anything further on in life happening and once they get counselling they should get it for as long as they need it and that will make a big difference to that person.

Lequecher did not receive counselling when she was newly injured, she did not indicate in the research interview whether she had declined counselling or whether it was not offered. Subsequently however Lequecher has, over the years, had counselling from a number of different counsellors, including myself. Although Lequecher did not have counselling for herself, when she was newly injured, she was very pleased that her children received counselling from the church that she belonged to. Lequecher said “I felt that my children needed counselling as well. Because they were slapped with a mum that they once knew was walking and then all of a sudden not walking. That was very hard on them, on your children, they grow up very fast.”

Lequecher’s local knowledge of counselling services, needing it “as soon as and you should have it for as long as you need it,” brings to the foreground funding issues for counselling. Accident Compensation Corporation (ACC) limit counselling outpatients to eight counselling sessions, unless the counsellor writes a report as to why the counselling should be extended. The not said in this requirement is that the person with the spinal injury should be able to address all relevant issues that a spinal cord injury produces within the limited sessions. If this is not possible the counsellor should provide a good report to request extended sessions. Unfortunately there is no provision of

funding for counselling for children and or family members from ACC. These funding criteria of ACC support a very individualistic approach to health and well-being after such a major life-changing event such as a spinal cord injury.

Avril, another research participant, when asked for any comments that she would like to make about counselling indicated that for her personally counselling would have been a big advantage.

The whole ordeal of being paralysed and having to face my future now as being a paraplegic. And I think to have counselling to support me through this, not just for myself but also for my family ... to cope mentally with it [effects of her spinal cord injury] because I knew I just had to get on with my life being a mother.

Avril's experience was that she did not have time to grieve at the spinal unit, she was too concerned about her family and how they were managing. I asked Avril whether she would have appreciated counselling support from the Auckland Spinal Unit when she was discharged. Her response was: "Oh for sure. I think it would have been a plus. To have it there, on side because you need it. You just need that interaction with someone in that field, you just cannot do it on your own."

The expression that Avril uses "to have it there, on side" seems to so graphically explain how available she preferred the counselling to be, it should be right on side. It conjures up images that counselling is really close and accessible, an image of a sports team where if you are "on side" you are in the right place and there is agreement of direction. I wondered how it would have been if everyone who was discharged from the Auckland Spinal Unit felt that counselling was "on side" and easily accessible.

To conclude this section on the participants responses to counselling and how counselling could be offered I thought that Mark's account of how he thought counselling was offered and his suggestions for the future was very descriptive and most appropriate for a medical setting.

...make informal communication and contact about anything else and then across the time you have your chances to talk about some of the bigger issues.

And certainly that was not in evidence; I do not recall seeing people doing that when I was there. I suspect that counselling was applied in the same way that a band-aid would be. As a reactive service not a proactive service. Counselling should be more like a systemic drug that it is there a little bit all the time as positively as it can be all the time, not just focusing on the wound to try and seal it over but looking at it from different angles.

If one had to understand what Mark was saying in terms of narrative therapy he seems to suggest that one should not be focusing on the problem saturated story and try to fix it up or seal it over but looking at different angles for those unique outcomes and marginalized stories.

## **5.4 Counselling Practices at the Auckland Spinal Unit**

### ***5.4.1 Meeting all inpatients***

I started working as a counsellor at the Auckland Spinal Unit in 2004. Prior to this I had been worked with adolescents whose lives had been affected by sexual abuse. These adolescents informed me that they had a strong preference to meet a counsellor ‘outside of the counselling room’ before they actually consulted with the counsellor. This way of working – meeting a counsellor before making a decision about consulting with the counsellor- seemed to be relevant to the Auckland Spinal Unit as well.

My usual practice therefore is to try to meet all new patients and preferably their families (*whanau*) within the first few days of their admission to the Auckland Spinal Unit. My intention in doing this is that patients meet me, Susan, as a person first. My hope is that this will shift or trouble (Davies, 2006) any totalising labels that patients may hold of counsellors. One patient described to me her initial fears of counselling: “When you go into counselling you think you are going to be psychoanalysed from the head down. It is scary. You say one thing and it means another. So you try and tell the counsellor what you think they want to hear so you can get out as fast as possible.” Troubling these types of totalizing labels is my intention in meeting all patients.

Hearing from the participants of this research their preferences for initially a more informal introduction to the counsellor has reminded me again of its importance. It has also brought more visibility to those ‘casual chats’ that I have with patients, for example

to inquire about how the week-end leave went, and for me not to discount these informal connections as insignificant. It has also brought more visibility to just how much some people really feel uncomfortable or even intimidated in a more formal environment, like an office.

#### ***5.4.2 Scheduling the initial counselling appointment***

The counselling practice of scheduling an initial counselling appointment with all newly injured patients and not waiting for a person to specifically ask to see the counsellor was one of the practices that I stepped into when I started working at the Auckland Spinal Unit. My intention in doing this was to position counselling in a similar way to how the other rehabilitation services such as physiotherapy and occupational therapy were positioned, as a part of the rehabilitation process. This practice of seeing everyone, also contributed to demystify counselling as both the staff and patients saw me speaking to everyone. This practice deconstructed the idea that counselling is reserved only for people with problems. I have noted with this practice that it has become much easier for the interdisciplinary team to ask me to see someone, as patients and their family (*whanau*) already know who I am. This first appointment would usually be in their room. (In this section 5.4.3 I will discuss in more detail this first appointment).

The responses of the participants, from this research in how counselling should be offered has positioned me comfortably with this practice of taking the initiative to see everyone and not waiting for a patient to ask to see the counsellor.

In the past (2005) I have however questioned this practice of mine of scheduling counselling appointments with all patients at the Auckland Spinal Unit. During a university peer supervision consultation where I presented my counselling practice, colleagues questioned me around the position calls that I was offering to patients if I scheduled an appointment with a patient and went to see them. The particular concerns of this practice of scheduling the appointment seemed to centre on patient's agency and the question arose whether this practice was limiting a patient's choice to have counselling as well as what agentic position was being offered to a patient if she/he preferred not to see me.

The peer supervision consultation mentioned above invited me to carefully reflect on my

practice. A counselling practice of making an initial appointment to see all patients which I had always seen as being an opportunity for patients to meet me and for me to meet them and to discuss counselling services was, seen by others as me imposing my counselling service on the patients. A taken for granted practice that I thought was a good idea, and it seemed to work well, was given a very different meaning. This experience unsettled my taken for granted assumption and I needed to reflect on this very carefully.

Schon (1999, p.61) mentions how reflecting on our practice can serve as a corrective to overlearning. By this he means that some things we have done so often we have overlearnt them and we just take it for granted that these must be the correct way of addressing issues. Through reflection, a practitioner can surface and criticise the tacit understandings that have grown up around the repetitive experiences of a specialised practice, and can make new sense of the situations of uncertainty or uniqueness which she/he may allow her/himself to experience. The peer supervision consultation certainly invited me into uncertainty about my practice and it gave me the opportunity to unsettle some of my practices and re-consider what I would like to do about them. This reflecting on my practice of meeting new patients and introducing the service gave me an opportunity to reconsider the position calls that I was offering to patients.

Reflecting on the process of my counselling practice about introducing myself and the counselling services to everyone, positioned me more firmly in the belief that for the patients I was seeing at the Auckland Spinal Unit, this practice was very appropriate and inviting.

This practice seemed appropriate for a number of reasons. One of the reasons is that patients initially are not very mobile and so from a practical perspective it is difficult for them to approach me. Another reason and more importantly is that many people do not really know what counselling is and what it can offer. There are some centralised discursive practices about asking for help – it may indicate that one must be weak because you need someone else. Another discursive practice that Brett identified was: “I think Kiwi society generally we just shove it all in a jar and one day have a party explosion”. There are also discursive practices about if one needs a counsellor one must be “mental” and who would want to admit to something like that?

To deconstruct these discursive practices of `asking for help means you are weak` or `if you see a counsellor you must be mental` it seemed appropriate to demystify counselling. Taking the first step, scheduling an appointment and discussing with a patient what counselling is, positioned the patient in an agentic position to decide what relationship they would like to have with me in relation to counselling.

#### ***5.4.3 The first counselling appointment***

The reflection on my practice mentioned above, supported my decision that the position calls that are offered to patients are dependent on the content of the counselling conversation rather than whether an appointment was scheduled or not. Even although the counselling appointment is scheduled by me, when I first approach a patient, I always ask them whether it is okay that we spend a bit of time together. I also explain my role as counsellor to the patient saying something to the effect of “Most of the rehabilitation team are focussing more on your physical rehabilitation but the role of the counsellor is more on the emotional side, do you think this could be useful?” From this type of opening I am not making any assumptions about whether counselling would or would not be useful or required, we are to a certain extent negotiating together (the patient and myself) whether counselling could contribute to clarity, richer meaning and new understandings. My intention with this approach is that the patient should experience counselling as something that is negotiated between the two of us, not something that is forced upon them or done to them. I do not want to position myself as the expert and that every patient needs ‘professional counselling’. My preference is that it is a negotiated relationship in which the patient is agentially positioned because they understand what counselling is and they can make an informed choice of whether counselling would be useful for them.

Hearing from the participants of this research their unanimous support for this counselling practice of seeing all inpatients, was exceptionally exciting and has been very effective in standing against niggling doubts about my forcing my services onto patients and my questions to myself about my counselling abilities and the usefulness of counselling.

The feedback from the participants has supported my confidence in introducing the counselling services to all newly admitted patients within the first two weeks of their

being admitted to the Auckland Spinal Unit. As intended by action research this feedback has moved and refined my current practice closer to what participants identified as useful both for themselves and their families.

#### *5.4.3.1 Additional strands to support the idea that the counsellor should initiate the first appointment*

Haley et al (1998) sheds a different light on why psychologists working in a primary healthcare setting should “not wait for your patients to come and see you” (Haley et al., 1998, p.237). The reason they give for this is that physicians commonly fail to detect common psychological problems such as depression and anxiety. For this reason they suggest that psychologists need to adapt their practice style to the unique characteristics of the primary healthcare environment. The reasons given by Haley et al for this counselling practice seem to be relevant to the unique setting of the Auckland Spinal Unit as well.

Given the time allocated to most medical appointments (approximately 15 minutes) it is not surprising that many common psychological problems go undetected and or unexpressed and patients are therefore not referred onto a psychologist or counsellor for help in these areas.

This comment about failing to detect common psychological problems reminded me of Frank (1991) when relating his experience of his own illness. Frank shares that the questions he wanted to ask about his life were not allowed, they were not speakable they were not even thinkable. ... “the gap between what I feel and what I feel allowed to say widens and deepens and swallows my voice” (Frank, 1991, p13).

The experience of Frank (1991) is similar to the experience that a patient shared with me about seeing the doctors on ward rounds. This patient had many questions about her body and was trying to understand how this new body of hers was working. She identified that this lack of knowledge about her body was significantly standing in the way of hope for the future. ‘Lack of understanding about her new body’ teamed up with debilitating fear and anxiety and positioned her into very centralised identity claims of being a cripple and of no use to anyone. When talking with her about the possibility of getting more information from the doctors about her body her response was “You go and

see the doctors and they ask you how are you? But you know that all they want to hear is I am fine” The gap between what she felt (I really want to know more about my body) and what she felt allowed to say (the doctors expect me to say that I am fine) widened and deepened and almost swallowed her voice and silenced her. The reason why it did not manage to permanently silence her voice was that through our counselling conversation we decided that I would write (because of her injury she was not able to write) down all the questions that she had and at the ward round she would take this paper in to her medical appointment and ask her questions. This patient did this and was very satisfied with the answers that she got from the doctors and the information she received and the process of consultation made more space for the story of hope for the future to be known.

This patient’s experience of the doctors confirms Haley et al (1998) suggestion to psychologists not to wait for referrals from a physician as physicians commonly fail to detect common psychological problems. If a patient senses that all the doctors really wants to hear is “I am fine” what space is being opened up for the “not fine story”, or as Frank (1991) would call it, the chaos story.

The practical reality is that the doctors at the Auckland Spinal Unit have on average seventeen patients to see in a two to three hour period. It is not realistic to expect them to be able to detect all problems and make referrals for counselling.

I believe that if I only counselled patients who had been referred to me by the medical doctors and or other health practitioners at the Auckland Spinal Unit the criteria for the referral would tend to be when the multi disciplinary team was having difficulties with a patient. I would like to be offering patients the opportunity of counselling well before there are difficulties. This intention of wanting to initiate counselling services when patients first arrive at the Auckland Spinal Unit acknowledges that disability is multi-storied. I am interested as a counsellor in the stories of hope and resistance of how patients have not let disability become the landlord of their lives and they the tenant as well as the turbulent process of trying to reclaim preferred identity claims (Boyle et al., 2003). This invited me to double listening to acknowledge stories of loss and grief as discussed in chapter three and to hear stories of hope and triumph (Denborough, 2005).

Haley et al (1998) also states that the most successful mergers between psychology and primary care services have been when the two services are located in the same clinic. From my experience I would agree with this. My office at the Auckland Spinal Unit is approximately fifteen meters away from the wards. I have my tea and lunch breaks with the nurses and the doctors. We share the same tearoom. I frequently interact with them. If there is a problem I am very accessible, they just need to pop into my office, we are in frequent contact with each other. Likewise because of my office is so close to the wards I am frequently walking about and casually meeting with the patients. I intentionally make my presence known and make the effort to chat with patients and their families (*whanau*).

#### ***5.4.4 Different knowledges and counselling***

As previously mentioned some participants in this research study saw the role of the counsellor as supporting them in meaning making. They used the metaphor of an umbrella or a tunnel as a way of organising and making sense of all the information and new knowledges that they were experiencing. Boyle describes it as “re-shaping and re-storying your identity and to develop a new story for your life when you can’t go back to the old one” (Boyle et al., 2003, p. 8).

These new knowledges are integrally linked with the new way that a person’s body is working. I frequently hear patients talking about “learning about their new bodies”. Frank (1995, p.34) says that modernist medicine does much to discourage body association. Modernist medicine is reliant on tests, diagnostic images, and laboratory results as being more reliable than how a person feels or how the person makes meaning of the experience. Participants in this research preferred the counsellor to co-construct meaning of their experiences and the information they receive. To be able to do this I do need to have a good understanding of the medical implications of a person’s injury.

Brett, one of the participants in the research, thought it was important to have a counsellor who had specific knowledge about spinal cord injury rather than generic knowledge. His reason for this was that he saw the role of the counsellor as being able to discuss with a patient the type of injury they have and an explanation of what they can expect. Brett felt that if he had this type of counselling support he would have been able to rationalise things a bit better. In Brett’s situation he was making a very rapid recovery. However, he said:

If I was not going to make the progress I was making, to have someone come in and be able to lay it out for me, as opposed to a doctor, this is your scenario, this is what you are going to be able to do, to have someone come in to talk to you, what type of support do you want, do you need, what kinds of questions do you have that may not be purely of a medical nature, someone with a bit of experience who can actually answer that for you.

As the counsellor at the Auckland Spinal Unit I have made a concerted effort to have a good understanding of the physiological implications of a person's injury as these must form part of the background and context from which I work.

Weingarten (2000) deconstructs the idea that hope is a feeling that is the property or quality of one person, something that is inside us. She talks of hope being something communal and that we can do hope with and for each other. Hope is something that I am quite familiar with in my counselling conversations. Most of my clients hold hope for walking again. However the type of conversation I will have about hope will differ depending on the medical implications of their injury.

For example when talking with a patient who, hopes to walk again, but from a medical perspective it is unlikely, some of the questions I may ask would be:

- ~ What happens to your 'hope for walking' in physiotherapy and occupational therapy?
- ~ What influence does your 'hope for walking' have on your thoughts about the future?
- ~ Is it possible for 'hope for walking' to sit alongside the information professionals are giving you about your body?
- ~ Do you want this hope to sit alongside or does it stand in opposition to the information you are receiving?
- ~ How would you like your hope for walking to be known to the professionals? How would you like them to hold onto this hope with you?
- ~ What relationship do you have in mind for hope for walking and the information you receive?
- ~ Is hope for walking standing in the way of you learning about your body?

The focus of narrative therapy on co-authorship makes space for different knowledges to be weaved together for meaning making. A counsellor is well positioned to weave together medical knowledge about a spinal cord injury as well as holding and respecting hope for other outcomes, such as walking again. Participants in this research indicated that meaning making was an important aspect in their rehabilitation. This meaning making takes place in one on one counselling conversations and another opportunity for this meaning making for both the patient and their family is at fortnightly goal setting meetings.

#### ***5.4.5 Counselling practice of attending goal setting meetings***

At the Auckland Spinal Unit all patients have a fortnightly goal setting meeting. These meetings are scheduled for one hour and the team of people responsible for that particular patient are expected to attend. The key worker (the person assigned to the patient prior to admission to co-ordinate services for the patient) organises and facilitates the meeting. The purpose of the meeting is to give the patient, and their family (*whanau*) the opportunity to raise any concerns that they may have as well as setting goals for the patient for the next two weeks. Typically a goal may be – trialling another wheelchair, practicing floor to chair transfers, week end leave.

When I started working at the Auckland Spinal Unit it did not seem to be the usual practice for the counsellor to attend these goal setting meetings. In line with my intention to position counselling as an integral part of the rehabilitation services not something that stands to one side, reserved only for ‘people with problems’, I started attending these goal setting meetings.

This attending gave me opportunity to hear the multi stories of disability (Boyle et al., 2003). This included hearing the stories of hope, satisfaction and triumph when a person achieves their goals as well as the stories of disappointments and difficulties.

Attending these meetings has also given me the opportunity to ensure that space is opened up for families and patients to talk about the aspects, concerns, questions that are important to them. I have detailed this more thoroughly in the chapter six on Families (*Whanau*) a Part of the rehabilitation team.

At one stage I stopped regularly attending the goal setting meetings. The rehabilitation team noticed this and asked that I try to attend more frequently. They appreciated my involvement as it supported and helped them in having some of the difficult conversations that we at times do have with patients and their families (*whanau*) in these meetings. This offered me a position as a valuable team member who provided at times the language to build a bridge between team and patient.

### **5.5 The Fabric That Holds It All Together – Care**

“If there is one thing I feel I have learned from an adult life lived inside an unreliable body, it is that care not cure will keep us floating in the ocean” (Weingarten, 2001, p11). It is the relational bonds that develop between myself and the patients and their families (*whanau*) that enables me to incorporate caring into the way that I counsel. As I have said in the heading of this section, care is the fabric that I hope holds my counselling practice together. I have an absolute commitment to working hard at creating caring relationships with patients and their families (*whanau*). These caring relationships provide the context or the vessel for counselling conversations about intimate details of patients’ lives in an atmosphere of respect, acknowledgement of my privilege and trust. I am committed as a counsellor to fine tune my skills to be able to listen and to hear what patients are saying and listening and hearing in a way that patients feel cared for, valued and heard and respected.

Engster (2005) mentions that having a relational history with a person needing care enables the carer to more easily anticipate and understand the person’s needs. Friedman (1993) says that knowing something about someone’s particular circumstances makes it easier to help or care for her effectively than if one knows nothing in particular about her. Greater familiarity lessens the risk of non agentic positioning.

Because of my counselling practice of introducing myself to all the patients, and scheduling an initial appointment to meet with them plus attending most of the goal setting meetings, I get to know patients and their families (*whanau*) fairly well. Through this ongoing relationship that I have with patients and their families (*whanau*) I am frequently familiar with their particular joys, needs and concerns. I am therefore often very well positioned to care as my intention is to develop that relational history (Engster,

2005) with them and understand their particular circumstances (Friedman, 1993).

In my counselling practise I often see patients at their most vulnerable points. Patients and their families (*whanau*) share with me some of their most intimate and personal details of their lives. Based on what patients have told me and my own personal experiences, this kind of intimate, personal sharing is best encouraged in a caring environment. A caring environment opens up multiple possibilities for patients to make themselves known and to be known. Caring supports an environment where patients can story their experiences even when words are not that readily available and the story may be hesitant, jumbled and chaotic but it is the beginnings of meaning making and making sense of what has happened.

I have no words to describe the intimate relationship that I at times experience with some of the patients that I see as they share with me about their fears, sorrows, hopes and dreams for their lives. For me there is almost nothing more intimate than a person having tears rolling down their cheeks and I as the counsellor carefully, very carefully (with their permission) wipe them away because they do not have the hand capacity to wipe away their own tears. There is an intangible bond of caring when one joins with a patient and literally move in step with where they want to take a counselling conversation. I am often positioned as having detailed knowledge's about a person and or their families (*whanau*) and this positioning according to Friedman (1993) makes it easier to help or care effectively.

This kind of caring was something that Brett identified in his interview as important to him. He talked about how in any job, where you are working with the same problems every day it is easy to become callous and to forget that for this person this is their first experience. Brett was saying that it is easy to respond to the problem in an automated mechanistic way and not respond to the person with the problem. This comment of Brett's invited me to reflect on Cheek's writings about nursing care and how discourses constitute and reproduce the social act of nursing. Cheek (2000) talks about the nursing gaze which designates the patient as an object on which technalized and medicalised knowledge is applied. Standing against the nursing gaze is the nursing look which is a more empathic look and pays attention to the whole person. According to Sevenhuijsen (1998, p.137) this type of look is developed by our willingness to see things from a care

perspective, our willingness to know people's needs and the situations in which they occur. This type of look forms a caring solidarity which is important because everyone in different ways and to different degrees needs care at some point in their lives

Cheek (2000) mentions that this type of caring solidarity look is often marginalised in health care settings and the gaze which produces evaluative, corrective and restoration to 'normality' knowledge is centralised.

My intention in counselling is to have the counselling look which produces knowledges about the unique experiences of each person and 'freshly' hears each person's story as it is a totally new experience for that particular person and the family (*whanau*) as well.

Many patients, especially when newly admitted to the Auckland Spinal Unit do feel very, very vulnerable. At night, lying in their beds, unable to move, totally dependent on someone responding to their bell – and what if the bell slips away, will anyone hear them if they shout. One patient shared with me in tears how he was sitting in his chair and he was told that someone would come and help him and he sat for over an hour just waiting, he could not ring his bell because he could not move sufficiently to reach it. He informed me that in that hour of desperation so many unwanted thoughts about the value of life and his future came to mind and he could not move, he was stuck. Some patients feel very vulnerable when their personal cares are not done in the way they want them to be done and despite trying to direct their cares they feel they are not being listened to. Some patients have shared with me that they are afraid to complain because if they do they fear being victimised. One patient through her tears asked me why the staff had not got her up in her wheelchair for the day. She thought she was being punished for something but she had no idea what it was – this is vulnerability. Patients have also shared with me how upsetting it is when their bodies are treated roughly, even although they may not be able to feel their body they still want it to be treated respectfully. In the initial stages of rehabilitation patients can be very powerlessly positioned. This powerlessness invites vulnerability. It is my heart that holds me to this work of counselling at the Auckland Spinal Unit. This type of practice is supported by the counselling look, a look that is interested and curious about how is this person making sense of this particular situation rather than what category or label can we fit this behaviour into.

To conclude this section, as a counsellor I know I cannot always cure but I can always try to care – this in itself is healing.

## **5.6 Conclusion**

Research participants identified the need for the counselling service at the Auckland Spinal Unit to be positioned in a way that it is very accessible to all patients and their families (*whanau*).

The practice of scheduling a first appointment to see all patients' positions counselling in a similar way to other rehabilitation services – you see the doctor, you see the physiotherapist and you see the counsellor. Based on the findings of this research I will continue with this practice of scheduling a first appointment and taking the initiative to get to know all the patients and their families (*whanau*). All participants identified the importance, for themselves, of counselling support.

This chapter highlighted the importance of the counsellor knowing all the patients and their families and the families and the patients knowing the counsellor. This relational history frequently positions the counsellor as someone who is able to care, especially when patients are feeling vulnerable and not listened to.

## **6. Families (*Whanau*) a Part of the Rehabilitation Team**

### **6.1 Introduction**

Participants in this research identified that it was important that their families (*whanau*) could access counselling support services if required. The participants identified the importance of families (*whanau*) being included in information giving about the patient and his/her injury. Support and assistance in these two areas would have or did make a significant difference to some of the participants.

In this chapter the initial focus will be on the participant's ideas about counselling support for their families. This counselling support includes information sharing to families in a way that family members can integrate and understand the implications of the spinal cord injury. This refers to not only providing the bare facts but information sharing in a way that a family (*whanau*) can make meaning for themselves of what is happening. This meaning making facilitates the joining of a family (*whanau*) in times of illness and trauma. I will share a personal story about information giving and families joining / not joining together.

In the last section of this chapter I weave ideas from the participants, my own personal experience and the literature and I make some suggestions about what counselling could bring when working alongside families (*whanau*) who have a family (*whanau*) member who has recently had a spinal cord injury. Included in this section will be some of the organisational structures that are in place at the Auckland Spinal Unit to facilitate family involvement.

### **6.2 What did the Participants Say?**

Of the seven participants in this study five of the participants identified their appreciation of their families (*whanau*) support towards them during their rehabilitation. Three of the research participants mentioned the importance of access to counselling for their family (*whanau*) members as well. For some research participants like Avril, counselling for her family was a top priority.

Avril mentions in the research interview that when she realised that she had a spinal injury her very first thought was about her family:

My first thought went out to my family, more than anything else, I thought my gosh I would have to get my family in order, my focus was on my family rather than myself....It would have been good for my family to have had counselling. [Avril was the research participant whose child had Spina Bifida and so she thought that with all the events that had taken place in their family life over the past few months that her family, especially her children would be confused and would benefit from counselling.]

This description of Avril about her concerns for her family highlights the disruption and challenges a family has to face as a result of a spinal cord injury. In my experience, working with patients at the Auckland Spinal Unit, many patients' (who are also parents) initial focus is on their families (*whanau*) and their families (*whanau*) adjustment to the disruption in their lives rather than on themselves. Avril's concern was for her children getting the support they needed to "understand the whole aspect of life as to why these things happen". Avril's hope was that her children would be able to make sense of why these things happen / why does illness and injury happen to some people?

When I asked Avril about her ideas about counselling for her husband and/or for patients' partners, her response was as follows:

For Gavin I think counselling would be a bonus in that area because he has had to take on a lot, he has had to leave his job so there is the emotional side to it, the financial side to it and then the family side to it. So he has had to take on a lot and then also having to take on Mary with her special needs, it is big. So someone for him to talk to and let out what he's going through would be very ideal. Because at the time the social worker at Child Development was a really big help. She was able to come up to the spinal unit and see me and speak with Gavin and keep our family together ... she just stepped in and supported our family.

In the research interview it was clear that Avril really appreciated the social worker from

Child Development “just stepping in and supporting the family”. Avril’s family were so immersed in managing the day to day practicalities of family life that had changed so radically in such a short space of time, they were not in a position to think about what they needed for themselves and what counselling support was available. The social worker therefore just stepped in and supported. In crisis intervention theory this is the exact role of a social worker – step in and support. As a counsellor I am at times similarly positioned – I just step in and assist and support with what is of concern to the patient. However, throughout this process of stepping in and supporting still paying very careful attention to patient agency and ensuring that through this stepping in, the patient and their family (*whanau*) continues to be agentically positioned.

For example it is not unusual, in a counselling appointment for patients to inform me of practical concerns that they have such as not being able to access money from the bank, not having any clothes to wear, concerns about attending a special family function – at times I see it as part of my role to just step in and support rather than referring the patient to perhaps the social worker or another member of the multidisciplinary team. Dominant discourses about the role of counselling may position the counsellor as viewing this caring and responding to immediate needs as not ‘strictly’ part of the counselling role. For me, stepping in is about caring and relating to a situation, as a person who cares and is concerned. It is the human element that needs to be demonstrated in counselling relationships rather than modernist discursive practices that relate to professionalism.

Matthew, in the research interview, said that he thought that in many ways dealing with the effect of his injury was more difficult for his family than what it was for him. He felt that they were in some ways “outside of the situation ... with all the emotions” and all the focus of care on him. I asked Matthew about counselling for his family and whether that would have been something that he would have valued. Matthew felt that lack of knowledge both for himself and his family created stress. He said that his family “were unsure about what was going to happen and they were very worried”. This lack of knowledge created stress for everyone involved.

Matthew defined counselling as “helping you with your peace of mind”. In his opinion, ensuring that families are given the information they need, would decrease stress, increase peace of mind and this, in Matthew’s opinion is the aim of counselling.

From Matthew's perspective whether it was the counsellor who gave this information or anyone else was not important in the acute phase of a spinal injury. The important aspect was that the information needed to be given. This raises the idea of what information structures are in place that supports peace of mind and information sharing. In the last section of this chapter (6.5) I will detail structures that are in place at the Auckland Spinal Unit for information sharing.

Lequecher, a research participant who was a solo parent, had a young family at the time of her injury. She was really pleased that counselling was offered to her children because "they were slapped with a mom that they once knew was walking and then all of a sudden not walking. That was very hard on them, on your children, they grow up very fast". Later on in the interview Lequecher shared about how, now that her children are older (all of them were over eighteen at the time of the interview), they have told her how they hated her not being able to walk. They have told her how they did not like to have other people in the house, they just wanted their "mum". Lequecher's level of injury is in the cervical area of her spine which means that she was unable to lift her children, unable to make their food, unable to bath or dress them when they were young.

Lequecher mentioned that counselling for her family (*whanau*) would have been useful to help her children have a better understanding of what she was experiencing – "they would understand why mom was in those moods, when I snapped at them quite often."

She identified the need for family (*whanau*) involvement as really important in supporting and helping her with the difficulties she had and in many ways still has with her injury. Lequecher identifies herself as Maori. Situating her comments within a cultural perspective her family (*whanau*) is thus viewed as the significant people to support and help her, and in this way she could have been stronger to support and help them.

Brett, another research participant, found the support his family (wife and two young children) were able to give to him, was really important and adequate for his needs. His family were positioned as able to give Brett the emotional support he needed, from his family, in order for him to make meaning of his injury.

David's daughter was very supportive and caring towards David, whilst he was at the Auckland Spinal Unit. David's family were very involved in ensuring that the practical aspects of returning home were attended to. For example his family speedily organised for his bathroom to be modified whilst David was on week-end leave. They initiated this because according to them Ministry of Health funding "was too slow". David's daughter seemed well positioned to offer her father the support he required from her. She did not need any counselling input.

Larry made no reference to his family and I did not specifically ask him about their involvement or whether he would have appreciated counselling being offered to them.

In his interview, Paul mentioned that his family were unable to be very involved in his rehabilitation. Family visits were very irregular because his parents had to travel a long way to get to the hospital. In the interview Paul mentioned that his experience of rehabilitation was that there was no-one to talk to and he was treated really badly. (His description was "like shit") A number of questions come up for me when reflecting on Paul's comments:

- ~ Would Paul have liked his family to be more involved?
- ~ How would Paul have liked his family to be positioned in relation to him feeling like he was treated really badly?
- ~ Was space opened up for family involvement – such as a telephone call from the hospital to the family to find out how they were managing / whether they felt they were properly informed?
- ~ In what way would family involvement have positioned the hospital to better understand Paul?
- ~ How could this information have assisted the hospital to tailor their services to meet his needs so he was not left feeling as though he was treated really badly?

Families (*whanau*) often have a very good understanding of what is the best way to work alongside their family (*whanau*) member. Families (*whanau*) have a detailed understanding of local knowledge about the patient that is at times invaluable to the rest of the rehabilitation team. For example there are times that I have consulted with family (*whanau*) members and the local knowledge about the patient they have shared, such as information about the patient's behaviour before the injury, what values are important to

that person, what are the things they enjoyed doing. This shared local knowledge positions health practitioners to more adequately tailor their contribution to meet the specific needs of the patient.

In summary two of the participants, Lequecher and Avril, both woman with children, felt that counselling should have been offered to their children. Avril thought that counselling would be important for her husband because of all the changes that he was having to make. Matthew felt that it was maybe more difficult for his family than it was for him and to decrease this difficulty, it would have been useful if the staff shared information with his family to equip them to face the dilemmas and challenges of living with a spinal cord injury. Don and Brett's family were positioned as able to give them the emotional support they required from their family. Larry, a young man who sustained his injury overseas, but then came to the Auckland Spinal Unit made no comment about family involvement in the research interview and I did not specifically ask him.

Participants in this research study identified the importance of their families (*whanau*) being involved in caring and supporting them emotionally during their rehabilitation phase of their spinal injury. Some participants also identified the importance of their family (*whanau*) having counselling to help them (the family *whanau* member) to deal with the challenges and difficulties they were facing because a family member had a spinal injury. In this next section I turn to my personal story about family involvement in caring and supporting family members who are ill and how the discourses available to me which at times I accepted and other times resisted positioned me in varying degrees of subjectivity and agency and the resulting consequences of these positions.

### **6.3 Family Involvement - Personal Strands**

One of the purposes of this research study was to review some of my own narrative preferences and through this become more aware of what I may be filtering in and/or filtering out in counselling conversations. This next section attempts to visibilise some of these narrative preferences as my own life stories shape and influence the values, beliefs and ideas that I bring to counselling. These values, beliefs and ideas if not visibilised and made apparent can position me in privileging certain ideas, beliefs and values and subjugating others. For this reason it is important that I deconstruct these

values beliefs and ideas so I am more available to really listen to my clients' storylines in a way that my own experience can be used as a resource for deconstruction. This requires, as Bird (2000) mentions, a transparency about our own life stories.

The therapeutic relationship understanding requires a willingness to be transparent to our selves, and to others such as supervisors, consultants and colleagues. Transparency occurs when we make available thoughts, feelings, values, judgements and intuitions for self and other reflection....Positioning our selves as discoverers requires a self and other reflective practice that emphasises a practical deconstructive process. We are listening to those themes that are central to meaning making. If the frame of reference [that we uses as a counsellor] is unacknowledged then its invisibility prevents critique (Bird, 2000, p. 109 - 111).

I will share two personal examples of family illness and death and how I have been very differently positioned in terms of speaking rights and what actions seemed possible and what seemed impossible and the consequences of the positions and possibilities. The personal examples that I share are the illness and death of my mother and the illness and death of my father.

From my personal experience and from my experience at working at the Auckland Spinal Unit it seems that the dominant discourses about caring and emotional involvement position some families as very able to care both emotionally and practically for their family (*whanau*) member. Dominant discursive practices take for granted that most families (*whanau*) know how to do this caring 'naturally'. I have noted however that there are some families (my own included) that may at certain times be positioned as less able to offer their family (*whanau*) member the care and emotional support required. Families (*whanau*) then can call on outside assistance from a counsellor to help them be agentially positioned to make selections about the type of care and emotional support they want to offer their family (*whanau*) member.

The first example that I share, my mother's illness and death shows how I was positioned non agentially. I was not positioned in a way that I could make selections as to the type of care and emotional support I (or my family) were able to offer.

At the age of fifty one my mother was diagnosed with cancer. At this time I was in my final year at university studying social work, aged twenty one and I was no longer living at home but I was living in reasonably close proximity (ten kilometres) to my parent's home. Very shortly after receiving this diagnosis of cancer my mother was admitted into hospital to have the cancerous growth removed. Evidently during the operation the doctors made the assessment that the cancer was too far progressed and they were not going to remove the cancerous growth.

The only medical information that we received as a family was “we opened her up and it was too far gone to do anything, so we closed her up again.” This was the only medical information that we were offered as a family. There was no family meeting, no further discussions from the doctors with regard to her prognosis, no negotiations or discussions with any of the medical team about treatment options / or lack thereof - that was the extent of the information. This lack of information positioned us non agentically. The unspoken in this for us was that the doctors were the experts, we as a family did not need any knowledge because as a family we were not being called on to make any medical decisions; this was medical territory not family territory.

This way of communicating information positioned me as a daughter with no speaking rights, and with no bridge to walk across to talk about matters of life and death with my mother.

Mc Daniel, Campbell, Hepworth, Lorenz (2005) describe this approach - only sharing a minimal amount of medical facts with a patient and their family (*whanau*) as reflecting the bio medical model of patient care. The biomedical model accounts for illness by its biochemical factors without considering the social or psychological dimensions of peoples' lives. This practice separates the mind from the body. The medical team caring for my mother were focussed on the biological factors – cancer is inoperable, too far advanced, nothing we can do. The social or psychological implications of my mother's diagnosis of cancer – what are my mother's thoughts, fears, beliefs, hopes about dying /not dying? Is the family joining together? Is the family being given the opportunity to say their good-byes? These practices of care were not seen to be an important focus for the medical team. Modernist medical practices position health practitioners as valuing

facts and information. The production of knowledge flowing out of these discourses is that families should be given the facts. Social constructionism would argue that realities are socially constructed and so it is not the 'objective facts' that should be the focus but rather how patients and their families (*whanau*) are making sense of the information that they have available to them and how this is positioning them.

The implications that the approach of focussing only on the bio-medical facts had on our family, was that it isolated us from each other. There was no joining and support, we were all positioned to deal with the information given in an isolated way or 'fighting our own battle'. The way the medical information was offered provided no position for us to connect and talk about this outside of the isolation and trying to make meaning in our own individual way.

For my mother the effects of how we as a family were positioned by discourses of how to deal with difficulties were even more severe. Not only were we isolated from each other (father and siblings) but we were emotionally isolated from my mother as well. Dominant discourses within our family about how to manage bad / sad news positioned us as thinking that 'staying strong for each other' (which meant you do not talk about it) was the 'right and correct' way to act. Depression became a central part of my mother's life – something my mother had little or no experience of in her past.

My mother's general practitioner assessed that she needed nursing home care for the treatment of this depression. As a family we were not positioned as needing to be involved in this decision. The doctor said this was what was to happen. Dominant discursive practices about the power/knowledge relations of doctors was that their version of events was 'true' and therefore not questioned. My mother was therefore admitted into a nursing home for long term care where 'medical experts' continued to treat her depression with technology - medication and electroconvulsive therapy. No active treatment for the cancer, as it was apparently too advanced. There was no counselling about death or dying either for my mother or for us as a family. Approximately a year after my mother's initial diagnosis of cancer she died in a nursing home, on her own, with no family members by her bedside. In this time period that my mother was in the nursing home my father and I visited her regularly but I was not positioned as able to talk to my mother as I call it about 'matters of the heart'.

Weingarten (2001) mentions the concept of cultural resonance – the more familiar people are with the situation described, the more easily they will be able to participate in the person’s narrative in a way that supports and endorses it and contributes towards meaning making. In my experience cultural resonance was absent.

To this day I have no sequential narrative about my mother’s death. There are images and isolated events that I remember and none of these memories are ones that I cherish much. However I am pleased that I do have some memories as there are so many gaps and so much that I do not remember, I am pleased that I have snippets of memories, even although they are not very pleasant ones.

Weingarten (2001, p.10) mentions how making sense of illness narratives will create, metaphorically, a variety of rafts and docks and buoys and life preservers for us to cling to, together, in the illness-waters that we will all face at some time in our lives. Weingarten (2001) says that it is in the process of making sense from illness narratives that rafts, docks and life buoys are created or found.

My experience of my mother’s death was that there were no rafts, docks or buoys to cling to. My family, at the time of my mother’s illness, was more like drift wood floating in a big ocean of uncertainty, untravelled waters with no-one pointing us in any kind of direction. This ‘driftwood’ family was not a family that did not love and care for each other, it was not a family that had no interest in being supportive, it was a family that needed some outside help in finding those rafts and docks and buoys to help us to cling together in the illness waters, providing a space for us to make meaning of our experience.

I was twenty one when my mother died, and the sadness in my heart, that is still there twenty seven years later, is that it could all have been so very different.

If the focus of the medical team had been on care not cure (Weingarten, 2001), what new possibilities of positioning may that have offered my family? What agentic positions could have been offered to my mother and our family had the medical team taken a different stance? These new possibilities will be further discussed in the next section of

this chapter.

In stark contrast to my mother's illness and death was my father's illness and death. My father had suffered from a number of strokes which resulted in him needing full time care. His preference was not to go to a nursing home and as a family we were supportive of this decision. In line with this intention to care for my father at home, family members were assigned times that they were responsible for taking care of him. We had our rosters and as a well developed team we cared for my father for eight months before he died, at home with his family all around him.

Whilst there are so many things that I wish could have been different when my mother died, I cannot think of anything that I would have changed when my father died. As a family, during my father's illness we were agentically positioned, we were well informed about his illness, we had easy access to the medical team if we wanted it and we made decisions about how we would like to care for him.

These two personal examples demonstrate how the positioning of families at times of trauma and illness will radically affect the amount of care and support they are able to give the person who is ill as well as how they manage their own grieving process and the meaning making alongside other family members.

#### **6.4 New Possibilities of Positioning – Bio Psycho- Social Model**

The experiences shared above highlights, for some families the gaps of a practice of medical care that only focuses on medical information. Mc Daniel et al (2005) suggests that whilst the biological aspects are important, cultural and social factors need to be woven into the fabric of care available to patient and family. Their suggestion is that the bio psycho social model which is a systems model of care, initially developed by Engel provides a framework for a more holistic approach to healthcare. This approach includes considerations of ways people communicate, patients understanding of their illness, family involvement, medical diagnosis, cultural considerations and the inter-connections of all these factors. All these aspects need to be considered if one is to effectively work alongside patients and their families through these illness waters (Weingarten 2001).

#### **6.4.1 Attending to agency and communion in families**

As mentioned above Mc Daniel et al (2005) promotes the bio-psychosocial approach in medical family therapy and they state that the two general goals or intentions for this type of therapy are agency and communion.

Agency is a sense that one can make personal choices in dealing with illness and the healthcare system. For patients with an illness, agency means not remaining passive. It means coming to grips with what they must accept while discovering what action they can take. Agency is a sense of activism about one's own life in the face of all that is uncertain (Mc Daniel et al., 2005, p.6).

Communion refers to emotional bonds that often are frayed by illness, disability and contact with the health care system. One of the medical family therapist's most important tasks is to help family members join together to cope with an illness and to do so within the context of allowing the patient the maximum feasible autonomy and agency (Mc Daniel, Hepworth, & Doherty, 1992, p.10).

To refer back to my personal experience of my mother's illness, Mc Daniel (1992) seems to be saying that for a 'driftwood family' such as ours was, at the time of my mother's illness, one of the medical family therapist's most important tasks would have been to help family (*whanau*) members to join together. It should not just be assumed that a family will join together and know how to go forward. In hindsight, the person who would normally have 'joined us together to cope' as a family, was my mother. She however was not available to do that. We needed outside assistance to walk alongside us.

Possibly if someone from outside our family, such as a counsellor had called us together, as suggested by McDaniel to help us review the discourses or lenses we were using to make sense of the medical information given, this could have positioned us very differently. Nobody extended the invitation to assist our family to join together and we did not know how to join together. At the time we thought we were doing fine.

Burr (2000) talks about how discourses produce a particular version of events and thus produce knowledge as to how we should respond / not respond. Some of the discursive practices that informed our families actions were that you get on with life and deal with

whatever it offers you. Another discursive practice was that you do not really talk about sad personal feelings or thoughts - that was being emotional and gushy. There were also societal dominant discourses that positioned families in believing that not talking about death and dying was the kind thing to do and the appropriate response to death.

These discursive practices about how one deals with difficulties did not serve us as a family very well when my mother was so ill. It was however, the only way known to us. If one defines agency in the way Mc Daniel et al (2005) does as being able to make personal choices about dealing with illness and the healthcare system, we as a family had no agency. We had very little communion because we had no story of trauma, hardship and loss.

As a family, at the time of my mother's illness, our discursive practices were informed by the same discourses that informed the medical team – their suggestions about care just seemed to resonate with the dominant ideas (at that time) and taken for granted assumptions about illness and death and what was best for a patient. Being positioned in this way has left me for years, with blame-talk asking myself the question, “Susan, surely you should have known better, you were in your last year of social work, how come you did not know about the importance of talking about death and dying?” Deconstructing the discourses that informed my actions and positioned me, has provided making different meaning of this, the regret however is still there.

Storying my own powerlessness, in this situation, helps me to appreciate more the need for me as a counsellor to actively attend to agency and communion in families. Not just to assume that families (*whanau*) are always supportive – even although they may be visiting regularly, they may not know how to do the support. At the time of my mother's illness I needed someone to approach me; I ‘could not do it on my own.’ In contrast, when my father was ill, we as a family knew how to join together, we were not in a place where we needed any outside assistance. We were positioned and positioned ourselves differently. My hope is that for the families I work alongside, I may be able to put the spotlight on discursive practices that may stand in the way of joining and communion and offer the family (*whanau*) the opportunity to review and consider this way of working together.

To conclude this section on the personal strands that inform my practice I would like to

finish with Mc Daniel, Hepworth, Doherty (1997) who share how our personal journeys with illness and loss help create connection between our journeys and the struggles of the patients and their families. Our journey helps us to maintain a personal connection with a patient's experience. However this connection can be established and agentic positions offered in a way that does not impose our own struggles onto an already burdened family. Each person's experience of illness/trauma is unique and it deserves a unique response.

The art of medical family therapy is in maintaining a personal connection with a patient's experience without imposing the therapist's own struggles onto a family that is grappling with their own concerns and burdens.

## **6.5 Implications for the Auckland Spinal Unit**

### ***6.5.1 Attending to agency and communion***

According to Monk et al (1997, p.301) agency is "the extent to which individuals can act for themselves and speak on their own behalf". Roberts et al. (1999) states that there are some very dominant discourses about disability that marginalises and silences people. There are also some very dominant medical discourses that preference medical knowledge and can position patients and their families without a voice. Therefore attending to the agentic positioning of families (*whanau*) and the patient is an exceptionally important focus for counselling in the initial stages of rehabilitation. If families (*whanau*) are positioned agentially in the initial stages of rehabilitation my assumption is that this will support them in maintaining this position through their life journey of living with spinal cord injury and disability.

Attending to communion is also important as it helps the family to join together. Illness / trauma journeys are eased when they are shared with others. Matters of life and death are too hard and too onerous to do alone (Weingarten, 2001). At the Auckland Spinal Unit helping families (*whanau*) to join together in their struggles is important. I hope that as a counsellor I am able to support 'driftwood families' find those rafts and docks and buoys and life preservers so they can cling to - together - in the trauma - waters of a spinal cord injury.

### **6.5.2 How do we attend to agency at the Auckland Spinal Unit**

The following questions came to mind as I reflected on the practices of the Auckland Spinal Unit:

- ~ Do members of the Auckland Spinal Unit medical team open space for families (*whanau*) to co-develop and negotiate preferred ways of being in relation to the patient and also the medical team?
- ~ Is space made for the co-construction of knowledge or is there only space for medical knowledges?
- ~ Does this co-construction of knowledges include ethno-cultural knowledges and other local knowledges?
- ~ Do we as a medical team consistently attend to the position calls that we make available for families (*whanau*) to step into / resist?
- ~ As a counsellor at the Auckland Spinal Unit, how do I facilitate the joining of families together to find those rafts and docks and buoys and life preservers?
- ~ Do I in my counselling practice consistently facilitate communion within families and offer agency (are patients and families positioned as being able to act for themselves and speak for themselves)?

There are a number of structures at the Auckland Spinal Unit that have been put in place to facilitate family communion and offer agency. These organisation structures within the Auckland Spinal Unit have the potential to promote agency and communion. These structures are as follows:

#### **6.5.2.1.1 Fortnightly goal setting meetings**

All in-patients at the Auckland Spinal Unit have a fortnightly goal setting meeting. The purpose of these meetings is to ensure that the team working alongside the patient and the patient's family (*whanau*) have a common and shared understanding of the treatment plan for the patient for at least the next two weeks. Patients can invite whoever they want to, to these meetings, this would include family (*whanau*) friends and support people. An attempt is made to make the time of the meetings suitable for family (*whanau*) members to attend. The medical team assigned to that patient also attends the meeting. This would include the primary nurse, occupational therapist, counsellor, social worker and physiotherapist. The doctors attend the first goal setting meeting but thereafter only if there is a specific need.

The goal setting meetings are a forum for discussing concerns and issues, both for the family and the rehabilitation team. The extent to which it opens opportunity for agentic positioning for the patient and their family (*whanau*) is to a large extent dependent on the skill of the facilitator of the meeting. However as a counsellor I see my role in these meetings to ensure that family and patients' perspectives are heard.

For example in one of my counselling conversations with the wife of a patient, she had told me how worried she was about some medical information that the doctors had given her. We agreed that a good place to further discuss this concern would be at the next goal setting meeting. She requested that I raise the issue at the meeting. In the goal setting meeting I opened space for her to discuss this concern by saying "Jane, you had mentioned there were some medical concerns, would you like to use this forum to discuss these further?" She took the opportunity to share her concerns, but I could see that her request was brushed off by the medical team. They had not realised how important this was for her and her family. I then said in the meeting, I know this point is very important for the family, I am not sure that we have adequately addressed it. As a result of my comment a much more detailed discussion developed and I could visibly see, at the end of the discussion, just how relieved the family and the patient were. Had I not persisted in opening a space to ensure her question was attended to, the family would have been left with their concern and worry and the invisible message would have been: 'it is not important enough a topic for the medical team to discuss further, it may be important to you as a family but basically this is our agenda not yours'. This is not the positioning I want to be offering families at the Auckland Spinal Unit.

#### *6.5.2.2 Understanding medical information at goal setting meetings*

Another important role in terms of agency is ensuring that families (*whanau*) and patients understand the medical discussions relating to them and the jargon and abbreviations that are at times used in goal setting meetings.

Some of the families (*whanau*) that we work alongside have very very little knowledge of the anatomy of the body. English for many of the patients and their families is their second language. The risk is, as a team, we take for granted that everyone has a basic knowledge of biology. Many of the patients and their families (*whanau*) do not have prior knowledge about what the spinal cord looks like and what its function is. Many patients and families (*whanau*) would not know about the different systems in the body

such as respiratory and digestive systems – important biological knowledge for a person with a spinal injury. Most families would have no idea about IMC's (intermittent catheters), SPC's (super-pubic catheter) tilt tables, propping, transfers, flickers, sliding boards, pressure areas to name but a few terms that are often used and often assumed that people would know what is meant. The way the medical team communicates the information has the potential to give families speaking rights and or to silence a family (*whanau*). If our communication is clear and easily understood families (*whanau*) will be more likely to seek clarification, ask questions and express their concerns. On the other hand if jargon is used and medical terms that the patients and their families (*whanau*) do not understand is used, we should read this silence, not as having nothing to say, but rather as marginalisation through social power relations in which the absence of speech is constituted as a position of incompetence as the speaker does not have the words to ask the questions they want to ask ( Morgan & Coombes, 2001).

My role as a counsellor in these goal setting meetings is to open space and allow the voices of families (*whanau*) to be heard and to ensure that families (*whanau*) are really being properly informed in a way that they can make sense and make meaning of the information given.

In summary, the aim of the goal setting meetings is to open space for families to discuss their concerns, a place for the sharing of medical information and a place for agreeing on future directions. Whilst the structure is in place to promote this, it is dependent on the facilitation of the meeting and the way in which information is shared. My role as a counsellor is to ensure that the intended outcomes of family meetings are achieved because it is so central in promoting agency and communion.

I have volunteered that in 2007 I will take this on as a project – offering training to all staff about how to facilitate goal setting meetings and ensuring that facilitators understand the purpose of the goal setting meetings.

#### *6.5.2.3 Participation in patient's rehabilitation programme*

Every Tuesday the doctors do a patient ward round. All patients have a scheduled doctor's appointment in their time table on a Tuesday. Families (*whanau*) are very welcome to attend this appointment provided they have the patient's consent. Families (*whanau*) are specifically informed that should they have any medical concerns this is

one of the forums they can use to discuss these concerns. The appointment normally takes place in a private consultation room (as opposed to behind the curtains in a hospital ward) and time is given to the patient and their family to discuss any medical concerns they have. Many families take up this opportunity to meet with the doctors. Family members are also welcome to attend physiotherapy and occupational therapy sessions with the patient. Counselling is available to both the patients and their families. In order to make myself more available, I am willing to see families after hours. Despite this availability after hours, families tend to see me during working hours.

## **6.6 Working with Young Children**

Participants in the research who had dependent children identified the need for counselling involvement with these children. There is no funding from Accident Compensation Corporation (ACC) or the Ministry of Health for the counselling of dependents. Ongoing support and counselling is possibly required way past the rehabilitation phase at the Auckland Spinal Unit. One participant, Lequecher felt that counselling should be available for children whilst their parent is at the spinal unit as well as once the parent has been discharged from the spinal unit. This is more of a structural and funding issue and is beyond the scope of this research report.

## **6.7 Future Considerations**

In terms of counselling, as a result of this research I have been reflecting on the invitations to counselling that I give to families and wonder if it is strong enough. I have also been reviewing the way I work alongside patients with complex (from a medical perspective) personal issues such as non compliance, drug addiction, depression, mental health difficulties and issues around visitation. I am wondering if I too am not using all the resources that are available to me / too heavily reliant on biological and medical knowledge and the patient's knowledge about him/herself and not consulting sufficiently with family (*whanau*) members in the production of knowledges about how best to work alongside a patient. In this next section I will briefly reflect on the complexities in terms of the Privacy Act of 1994 consulting with families (*whanau*). Despite these difficulties working with families needs further consideration and cannot be flagrantly dismissed by hiding behind the excuse of The Privacy Act.

In terms of patient confidentiality, as a counsellor I am not free to contact a family and discuss concerns without the patient's permission. The very high risks involved in not caring for oneself adequately after a spinal cord injury makes the ethics of what families should and should not know potentially very complex. Where does patient confidentiality end and "serious risk of harm" (Privacy Act 1994) begin. According to the Privacy Act 1994 if there is imminent danger or risk of serious bodily harm patient confidentiality can be waived.

Self care is literally vitally important for a person with a spinal cord injury. If for example you do not pressure relieve you can get pressure areas and these pressure areas can be a very serious health risk. Pressure relieving needs to be done three or four times an hour. It is very unlikely that someone who is under the influence of illegal drugs and or alcohol will remember to pressure relieve. If you neglect your bladder and bowel cares you can start having very high temperatures and if your level of injury is above a certain level (T12) you risk having autonomic dysreflexia which is a life threatening health risk. How do I as a counsellor balance risk and confidentiality or is there another way?

This area of family involvement in complex situations needs, from my perspective as a counsellor needs more attention and consideration. It is out of the scope of this research report.

## **6.8 Conclusion**

In this chapter I have shown how the lenses or discourses that informs medical practices and in particular the way medical information is shared can position families with varying degrees of agency. Participants in this research study indicated a definite preference for family (*whanau*) members to be positioned agentically which supported emotional connection and caring. Discourses that produced knowledges about paying attention to the interplay and interdependencies of biological, social and psychological factors of a spinal cord injury made more space for the co-construction of knowledge. This co-construction of knowledge was viewed to be important as a patients experience of their spinal injury occurs in a familial and relational context (Mc Daniel et al., 2005).

The Auckland Spinal Unit does have certain organisational structures in place such as

goal setting meetings and attendance at appointments that facilitates family (*whanau*) involvement. In terms of counselling, agency and communion were identified as important backdrops to guide my practice. If these two considerations are guiding my practice when I initially meet with family members, I should be more alert to ensuring that the invitation I am giving to families is strong enough for them to be able to approach me as a counsellor and discuss their concerns. This strong enough invitation includes being flexible with my working hours to accommodate families that only visit over the week-end and or at night. Developing a relationship both with the patient and their family (*whanau*) is an important role of a counsellor working in a medical environment such as the Auckland Spinal Unit.

Working on an intensive basis with dependant children whose parents have a spinal injury was seen to be beyond the scope of this research report. This however is not to say that it is not an important area.

## **7. Weaving Cultural Strands into my Counselling Practice**

### **7.1 Introduction**

This chapter highlights the integral role of culture in counselling. The content of this chapter is based on my own experience at the Auckland Spinal Unit, a review of the literature and other cultural knowledges that I hold. In the research interviews participants did not specifically name culture as an area of significance. However, I believe that taken for granted discourse around race, ethnicity, class, sexual orientation, and so on, strongly shape people's experiences, often without their awareness. In addition dominant cultural discourses are usually shaped by dominant cultural groups, like Pakeha in New Zealand and the medical team at the Auckland Spinal Unit. These discourses have real effects on people from less dominant cultural groups, like Maori and Pacific Islanders. The effect is that the experiences of non-dominant groups are often pathologized, minimized, or disqualified, hence the importance of including this chapter in the research document.

Waldegrave (1990) states that cultures carry within them history, beliefs, ways of doing things, and processes of communication. Cultural stories are what help people make sense of intimate events in their lives. Events and experiences do not hold intrinsic meaning, they hold meaning through the cultural lenses that a person uses for meaning making. Cultural stories, however, are not static or unidimensional. We are never only Maori or only female or only disabled. We are multi-positioned and this multiplicity of positionings is ever changing, negotiable, and contestable. Each meaning produces and limits possibilities for being. In considering the weaving of ethno-cultural strands into counselling practices, Durie (1984) cautions health practitioners that if they only seek traditional interpretations of culture, they are denying the impact of time. Cultures change over time.

Because culture has potentially such a pervasive impact on how a person views the world, Laird's (2000, p.108) suggestion for mental health practitioners is that the concept of 'culture' should be the central metaphor for practice, not a peripheral one. Cultural narratives are experience near and provide storylines of interpreting everyday

life and everyday experience, more than the abstract and objectifying metaphors invented to label consumers of mental health services. Waldegrave (1998, p. 422) extends this idea of culture being a central metaphor for counselling practices further when he states that “therapies and psychological practices that do not address cultural meaning webs in informed ways are racist.” If therapists do not take account of cultural narratives as well as power/knowledge this may position therapists as not attending to culture in an informed way. Waldegrave would see this as a perpetuation of colonization and this perpetuation of colonization is an act of racism.

As a therapist committed to centering culture in my work, I believe it is important for me to develop and practice self-reflection and accountability skills. This self reflection will support me in being as “unfettered as possible with my own cultural luggage... so I can create the conversational spaces wherein the voices of the ‘other’ can emerge” (Laird, 2000, p.109).

My intention in my counselling practice is to work alongside families (*whanau*) in weaving new threads of meaning which stand against discourses of disability taking over a person’s whole life and eroding their confidence (Boyle et al., 2003). These new threads of meaning, need to be strong enough to hold against some of the dominant discourses about disability. It is critical that the meanings that are storied about disability sit comfortably with a person’s cultural narratives (Waldegrave, 1990). If I am to work alongside families in this journey of threading new meanings I need to know and deconstruct my own cultural assumptions by making myself available to learning from my clients about their local cultural knowledge. Furthermore, I need to hold any cultural knowledge tentatively as I believe each person has an idiosyncratic understanding of what is culturally important for them.

An important consideration in attending to culture has to do with power/knowledge relations. Drewery and Winslade (1997, p.35) suggest that if we acknowledge that there are many valid ways of seeing the world, we need to be vigilant about which accounts dominate and which are less often heard. In other words, how as a therapist do I address dominance and privilege in my work? How do I hold, in my counseling conversations and my interactions with the rehabilitation team, multiple versions of events and not privilege the account that belongs to the dominant discourse? This privileged account

would tend to be ideas from Western European professional medical discourses that have not been shaped by people from Maori or Pacific Island cultures to any significant degree.

In this next section I will consider these three areas of accountability and self reflection by using Frankenberg's (1993) ideas on race and cultural relationships.

## **7.2 Racism and Power/ Knowledge Relations**

Frankenberg (1993) names three moments in the contemporary history of racial and cultural relationships. These are essentialist racism, colour evasiveness and race cognizance. In this section I will look at each of these moments and the challenges and invitations these open up and/or close for counselling.

### ***7.2.1 Enacting privilege and racism***

The first moment is called essentialist racism (Frankenberg, 1993) with the emphasis on race or cultural differences being understood in hierarchical terms. This moment first became apparent with the emphasis of dividing qualities according to essential biological categories. In other words some people are viewed or view self as superior to others based on biological factors such as skin colour, gender and eye colour for example.

It seems unlikely that counsellors in New Zealand would intentionally position themselves superior to their clients based on biological factors such as skin colour and gender. However, cultural biases are often internalized in ways that are invisible to the persons reproducing them in practice. Thus, there are still possibilities for a counselling practice to produce essentialist racism or what Raheim et al (2006) calls "enacting privilege" in an unintended or invisible way. This can happen when counsellors are positioned in expert professional discourses that suggest their knowledges are superior to clients in general, which diminishes a position of concern for how they may be reproducing cultural injustice in their therapeutic relationships.

For example a counsellor holding ideas about the importance of patients 'going through the five stages of grief and loss' which are denial, anger, bargaining, depression and acceptance may position themselves as holding a version of events that is regarded as preferable or even 'normal' and this positioning may silence or subjugate other cultural

knowledge of events about grief that a client may hold.

If a counsellor privileges, in their counselling conversations their own 'expert and superior knowledge' and marginalises the client's local knowledge about their (the client's) own culture and themselves this practice may be informed by threads of invisible or unintended racism. This patronizing way of holding one's own cultural and professional knowledge as central may result in expectations that if the client just follows the counsellor's advice all will be well. In other words the counsellor based on their 'superior education' 'more modern culture' and their 'more relevant experiences' and hence their 'centralized wisdom' positions the client as non agentic and subject to evaluation.

In a setting such as the Auckland Spinal Unit the potential for health practitioners to enact privilege by positioning self or be positioned by threads from the discourse of racism to centralize their knowledge and by subjugating cultural knowledge of the patient, is always present. Most patients come to the Auckland Spinal Unit feeling very helpless and powerless and physically most of them initially are reliant on the staff for their needs to be met. In many instances, in the initial stages of rehabilitation, it is difficult even for family members to help with the physical aspects of care because they do not have the necessary knowledge in how to care for the physical needs of a person with a spinal cord injury. Health practitioners at the Auckland Spinal Unit hold a sophisticated body of knowledge about spinal injuries and rehabilitation. If health practitioners are not very conscious of how their power/knowledges can objectify patients they can unwittingly find themselves enacting privilege which may be informed by discourse of racism or privileges ascribed to class, gender, education and physical ability.

In a rehabilitation setting such as the Spinal Unit there are often strong invitations to health practitioners to step into an expert position. These invitations come at times from the patients (you are the expert, you know what is best, what would you advise), time pressures can offer strong invitations to enact privilege (I have not got the time to discuss, I know best, I have the experience, please just do it the way I am asking you to do it). To resist invitations to this expert position and to take a stand against enacting privilege and re-producing racism, I am committed to step into a reflexive practice to

consider my practice on an ongoing basis.

Laird (2000, p.113) calls the health practitioners to responsibility not only to surface cultural stories of oppression and marginalisation in peoples' lives in our offices, but to go beyond to help clients tell their stories in new and larger contexts and to bear witness to those suppressed stories in the schools, courts, legislatures, and mass media. Health practitioners need to add their own voices when those larger cultural discourses do not fairly represent the experiences of clients and do not allow clients' stories to be told. Whilst I cannot claim, as a counsellor, to be helping clients to tell their stories of oppression about disability to the media and legislatures, I have learned from clients that it is important to them that I continue to be very instrumental in supporting and helping patients at the Auckland Spinal Rehabilitation Unit voice their concerns when actions of the staff are interpreted by the patient or their families (*whanau*) as misuses of power by the 'dominant group' (even if unintentional). Through this privileged invitation to hold the experts accountable I have an opportunity to create a space where patients' version of events may be visible and be heard, which is something I value as a professional.

It is not uncommon, for example, for patients at the Auckland Spinal Unit, who should be on bed rest because of pressure areas select not to adhere to the bed rest protocol as set out by the medical team. In other words the patient does not stay in bed the whole time and/or lies on the pressure area. Medical discourses interpret or label this behaviour as non-compliance. However, we have had Maori patients select to attend a *Tangi*, a special family event or church services despite the recommendation from the medical team that this is not in his/her best interest. When in counselling conversations the voices of the patient are heard his/her version of events seem to be informed by discourses of a holistic approach to wellbeing which promotes practices of paying attention to *oranga tinana* (physical health) *oranga wairua* (spiritual health) and *orange hinengaro* (emotional health). Therefore taking care of spiritual health such as attending a *tangi* or going to church is integrally linked with holistic health. Surfacing these cultural stories of health, making them more visible, supporting patients to resist colonizing ideas of well-being and standing against labelling of patients as non compliant is a health practitioner's responsibility (Laird, 2000).

In an ongoing attempt to deconstruct unintentional practices of power and dominance I

have recently been running lunchtime workshops for staff at the Auckland Spinal Unit. The purpose of these workshops is to hold up for review how much power we as staff potentially hold and how often staff ideas can be inadvertently problematic for patients. I invite staff to consider power/knowledge relations in our interactions and attend to ways of positioning patients to maximize agency possibilities when speaking and caring for a patient. Whilst these workshops did not specifically address ethno cultural power/knowledge relation the intention was that learning about privilege and increasing awareness of power/knowledge would move practitioners toward a more curious and interested stance that respects all forms of difference, including cultural ones.

However, Raheim et al (2006) cautions narrative therapists that in talking about privilege, sometimes it can be tempting to tell stories that put us in a good light – the times we have responded to other people’s bad behaviour; the friends that we have from marginalised groups; the sacrifices we make to look at these issues. And yet, retelling these sorts of stories can make it more difficult to look at the mistakes we may still be making, the things we overlook, the ways we reproduce those dominant cultural ideas that have produced histories of injustice. Often talking about our mistakes, what we are not so good at, can open space for more constructive conversations.

Whilst I can give examples of ways that I have addressed racism or surfaced stories of oppression and marginalisation that stem from dominant discourses about disability, culture and the medical model of patient care, I can also think of some examples of where I have unintentionally enacted privilege which was informed by racist discourses. In reflecting on my practice and considering these ideas of enacting privilege I realise that I have at times positioned myself to ‘reach an agreement’ with a patient or their *whanau* that centralised dominant rehabilitation discursive practices and was dismissive of or acted out of ideas of token acknowledgement of cultural practices. In particular I am thinking about some of the conversations that I have had especially with Maori *whanau* about visiting and caring for a patient. Cultural practices of Maori visiting and caring for a patient will be further discussed when I reflect in a later section (7.5.1) on the implications of these ideas on my practice.

Raheim et al (2006) suggest that therapists develop knowledges and skills related to noticing when they are enacting privilege. Some reflexive questions offered by Raheim

to surface these practices of enacting privilege are as follows: When am I most likely to enact privilege? In what sort of circumstances will I most likely enact privilege? How can I tell when I am enacting privilege?

In response to the first question about when might this happen, for myself as a counsellor, when I move away from curiosity, consultation and a tentative holding of knowledge; that for me is the red flag (warning light) that I may be stepping into enacting privilege. In response to Raheim's second question about the circumstances it will most likely occur, this would be when there are competing and contradictory opposing discourses (Davies, 1991) usually between the patient and the rehabilitation team, or myself and the patient because I may inadvertently support ideas from the dominant group, to which I belong. This is most likely to happen when the rehabilitation team have certain ideas about how things should be done and the patient and their family (*whanau*) hold other ideas and I am asked as the counsellor to negotiate or mediate around this issue. In answer to the third question about how can I tell that I am enacting privilege this takes ongoing reflection and an acute awareness of power/knowledge relations. Hopefully this process of questioning offered by Raheim above will be useful to follow in the future when I detect, within my practice, that I am enacting privilege.

### ***7.2.2 A moment of colour evasiveness in racial relation development***

The second moment in racial relation development defined by Frankenberg (1993) is based more on the similarities of the human race or what is common to us all rather than a focus on the differences. From this viewpoint a person may carry the assumption that all people, irrespective of colour are all the same, there are no real differences between people of different ethno-cultural groups. This viewpoint is sometimes also known as colour blindness or colour evasiveness. However, this assumption marginalizes the real and asymmetrical effects of power relation between culturally dominant and marginalized groups. For example, colour evasiveness may fail to take into account the history of colonization and the effects that it has had on communities of people and on the cultural narratives. As previously mentioned Waldegrave would say that "therapies and psychological practices that do not address cultural meaning webs in informed ways are racist" (Waldegrave, 1998, p.412). If as a therapist I assume sameness, in all likelihood I am using my own "cultural lenses" for meaning making. This in turn centralizes my cultural knowledges and requires alternative cultural knowledges to adapt

accordingly.

For example if I am facilitating a goal setting meeting or a family meeting for a Maori *whanau* and I act out of my own cultural lenses and discourses about efficiency and individual responsibility I would ensure that the meeting followed an agenda and that discussion items stayed close to this agenda. I would launch straight in to the first item on the agenda with a possible brief introduction from each person which I would initiate, probably just going around in a circle – no particular order. I would primarily address the patient and expect him/her to answer for him/herself. If someone else from the meeting had a point of view that related to the patient I would openly ask the patient if they were in agreement with this and expect them to verbalise their opinion. If the patient was silent I would most likely accept that as agreement. I would ensure that the meeting started and ended on time.

From the dominant cultural discourses I have internalised, this would be regarded as a well facilitated meeting. However, from a Maori cultural perspective, my actions would likely be considered disrespectful, rude and very insensitive. Moreover, my action would likely place a Maori patient and *whanau* in a very difficult place to protest my understanding as they would not necessarily know whether their protest would make things better or worse. In fact, they would have a good reason given the history of cultural relations to be suspicious of the effects of protesting.

This above example demonstrating the practice of colour evasiveness does not address dominance and privilege and may desensitize a counsellor to marginalised stories that have not been voiced. It also does not position practitioners well as they inadvertently reproduce injustice in ongoing ways. Facilitating a meeting based on my cultural discourses would privilege my version of events and my way of doing things. This way of facilitating a meeting /hui would usually not make space for a Maori *whanau* to surface their stories and these stories would thus, in the meeting, remain unheard and marginalised. My own cultural lenses would have me believe that the family did not have much to contribute and they were in agreement with everything. Opie (cited in Hartman, 2000, p.21) suggests “we must not appropriate those whom we would try to know and understand by ‘colonizing’ their experiences, by interpreting them from the perspective of the privileged expert. We must enter into a collaborative search for

meaning with our clients and listen to their voices, their narratives and their construction of reality.” We cannot step into this practice if we think that we are all the same.

In reflecting on my practice and considering further these ideas on colour evasiveness, I have become mindful of colour evasiveness when working alongside Maori *whanau* and the significance of relationships within the *whanau*. One area in particular that I need to consciously step back from assuming a sameness is the relationship between a grandmother and her mokopuna. The significance and the meaning of this relationship and the obligations that it may carry seem quite different to my own cultural narratives about grandparents and grandchildren. Laird (2000, p.101) mentions that “our own cultural narratives help us to organize our thinking and anchor our lives, but they can also blind us to the unfamiliar and unrecognizable and they can foster injustice.” If I use my own cultural narratives to make sense of or to understand the significance of the relationship between a grandmother and her mokopuna there are aspects of that relationship, from my own ethno-cultural lenses that would be unrecognizable and unfamiliar. In particular, as previously mentioned the particular significance of that relationship and the rights, obligations and responsibilities that the relationship may carry is something that is unfamiliar to me. If I do not stand back and take up a position of curiosity, I may assume similarity in experiences and I may disregard or render invisible some of the very important nuances of that relationship.

As a counsellor if I practice from discourses of colour evasiveness this may position me in a way that I do not recognize power knowledge relations and I may continue to marginalise subjugated discourses which in turn continues to marginalise certain ethno-cultural groups.

### **7.2.3 Race cognizance**

The third discourse or moment called race cognizance (Frankenburg 1993) acknowledges cultural difference but these differences signal self-sufficiency of culture, values, beliefs, traditions and aesthetic standards. These differences are something to be valued, celebrated and respected. This celebration of difference is in stark contrast to essentialist racism where the differences accentuated a hierarchy and a power/knowledge difference, with the dominant ethno-cultural group positioning their version of events as being taken for granted truth. In race cognizance marginalised ethno cultural groups are

agentially positioned and define for themselves what within their culture is to be valued respected and celebrated. This recognition of what is important is not static, culture is contextual – “it is always more or less changing and it is always emerging... we are all multiple cultural selves” (Laird, 2000, p.103). No categorization of culture is stable or fixed, we are multiply positioned and at different times one categorization may be more salient in one context than in another.

For example when I am at home with my children the categorisation of ‘mother’ is usually more salient for me than some of the other fluid categorisations that I belong to. However when I am at work the categorisation of counsellor is more salient for me than mother.

#### ***7.2.4 How will ideas about race cognizance inform my counselling practice?***

I stand with Laird’s (2000, p.101) perspective that if health practitioners are to unpack cultural stories they need to know enough about a person’s culture to ask good questions, and to notice culture in its many guises and complexities as well as the preferences of cultural storylines and practices that people bring to counselling. This ‘knowing enough’ helps to surface for review client’s cultural meanings but it also makes it possible for clients to hear their own cultural stories in a newly reflective way.

To be able to surface for review and possible deconstruction client’s cultural meanings, Laird continues that it is vital that we continue to work on understanding our own local knowledge and our own cultural narratives and to make them as accessible as possible to ourselves and transparent to others.

In an attempt to uncloud our processes and understand our own local knowledge Bird (2000, p.35) offers some ideas for an ongoing reflective practice by asking the following questions:

- ~ What assumptions underpinned my decision to highlight, using an enquiry process, some themes over others?
- ~ When I reflect on this taken for granted truth statement, what are the cultural practices that this statement serves?
- ~ Who is advantaged by these cultural practices?
- ~ How did this enquiry direction invisibilise or visibilise power/knowledge relations?

By having an understanding and deconstructing his/her own culture it is more likely that a health practitioner will be able to “stand back” (Bird, 2000, p.93) from their own cultural knowledges so as to make space for clients’ voices to be heard. Narrative counsellors often look for marginalized stories that can stand in opposition to the problem saturated story. These marginalized stories are often hidden and not that easily accessible. Counsellors must prevent, as much as is possible, “delving into the meanings of the client’s life with our own cultural noises and assumptions” (Drewery & Winslade, 1997, p. 43).

In summary race cognizance discourses invite me as a counsellor to deconstruct and surface my own cultural stories which positions me to be able to stand back from my own culture and make accessible to clients their own cultural storylines. This making accessible and deconstructing the client’s own cultural storylines gives the client the opportunity to reflect and review these storylines. In this way a client is agentially positioned to review what version of events, at this particular point in time they would like to select, resist, and change.

### **7.3 Privilege and Dominance at the Auckland Spinal Unit**

Burr (2000, p.63) mentions that some constructions of knowledge will have a greater tendency to be seen as common-sense or truthful. She mentions that in contemporary western societies it is commonplace for the ‘versions’ of natural events provided by science and medicine to be given greater credence than those offered by religion, magic or superstition, folk psychology or cultural storylines.

Foucault (White, 1990, p.25) uses the term “global unitary knowledges” that through a struggle over time, have come to subjugate a whole set of knowledges and disqualify them as a lower level of scientificity and cognition. These other subjugated knowledges could be erudite knowledges - written out of the record by the revision of history or local or indigenous knowledge - they are lowly ranked, considered insufficient and exiled from the legitimate domain of the formal knowledges and the accepted sciences (White, 1990, p.25).

At the Auckland Spinal Unit, rehabilitation perspectives are the global unitary

knowledges that subjugate a whole set of alternative knowledges and disqualify them as less relevant. Rehabilitation knowledge and 'evidence based practice' are the foundation stones on which service delivery is organized. Beliefs / knowledges / values produced by rehabilitation discourses centre academic study and specialist knowledge which is disciplined based (physiotherapist, doctor, nurse) as privileged information. These rehabilitation discourses are the taken for granted truth on international models of practice which from this rehabilitation perspective is 'evidence based best practice' – the ultimate stamp of approval! This global unitary body of knowledge does not make much space for other cultural knowledges and it can quickly disqualify other knowledges leaving the holder of those knowledges in a less power/knowledge relations.

Given this enormous body of western medical knowledge that has been elevated to a level of almost absolute truth, as health practitioners at the Auckland Spinal Unit we all need to be constantly asking ourselves what position calls we are offering patients in our interactions with them? As staff at the Auckland Spinal Unit if we act out of discourses about the legitimacy of rehabilitation knowledge in the power/knowledge relations we have with patients, we may only make space for the production of knowledge that is in agreement with the dominant centralised rehabilitation discourse, which only privileges white, patriarchal, professional, and medical ways of understanding.

#### **7.4 Implications for me as a Counsellor at the Auckland Spinal Unit**

The Dulwich Centre in Adelaide has been running a project on dominance and privilege. They invited participants in the project to write about what they have found helpful in considering their own privilege. One respondent's reflections resonated very closely with me and in many ways I have been similarly positioned and need to actively guard against being subtly repositioned in this way:

It has come as something of a shock to me to realise that the expert knowledges which I have been trained in may not only be unhelpful in trying to interact with people of other cultures, they may also be disrespectful and even damaging. I have been trained to believe that 'knowledge' is what appears in books and in journals and in university curricula. The more I try to deconstruct professional privilege, the more I come to see that there are other forms of knowledge too: insider

knowledges, knowledge about culture or gender or sexual identity (Raheim et al., 2006).

When I first started working at the Auckland Spinal Unit my focus for improving my practice was very much on trying to learn more from books and learning how to ask the right kind of questions. I was strongly positioned as a professional who should be well qualified, well prepared, properly organised to make and have plans and directions. What I believed I needed, to improve my counselling practice, and what I pursued was 'acquiring' even more expert knowledge. On reflection I view this now as looking for answers but searching in the wrong places. I was positioning myself more firmly in the medical model of care which values expert knowledge and objectivity and marginalises intuitive and local knowledges, as well as collaboration and negotiation. Discourses about professional responsibility (which I have since deconstructed and reviewed) positioned me into thinking that I had to be able to offer a solution, from my repertoire of expertise and I needed to find the right remedy that would "fix the problem."

Over a period of time through reflexively considering my practice through the process of supervision, peer review and university assignments I am now more closely aligned with the following:

The stance of coauthoring does not imply that we give up our authority as professionals. We do not withdraw completely from the authoring role in counselling relationships. But we do endeavour to use our authority in ways that put our weight behind the client's preferences for agency in his own life (Winslade, Crocket, & Monk, 1997, p.63).

My focus is now in putting my weight behind the client's preference for agency. It is giving space for the client to decide on the direction that the interview should take and more checking in with the client as to whether this direction or practice was useful. In this way I trust new threads of meaning have a better chance of sitting more comfortably with their culture (Waldegrave, 1990, p.15) rather than my feeling compelled to decide on the direction and offer solutions.

## 7.5 Maori Patients and their *Whanau*

In working alongside Maori patients and their *whanau* there are some particular cultural aspects that I have noted at the Auckland Spinal Unit that perhaps warrant further discussion and consideration. The two areas that I will discuss further and they are interlinked are *whakama* and *whanau* care and what positions these storylines offer a patient, *whanau* and professionals.

### 7.5.1 *Whanau involvement and visiting*

The discursive practices relating to visiting at the Auckland Spinal Unit are to a large extent drawn from rehabilitation discourses. These rehabilitation discourses hold ideas about the importance of people being independent and to learn independence you need to do it on your own. Viewed from this perspective, too much help from *whanau* gets in the way of a patient learning how to be independent.

As a general guideline the Auckland Spinal Unit allows *whanau* to be very involved with a patient in the first few weeks of rehabilitation. Visiting hours are not too strictly adhered to and in certain situations (especially when the patient is under eighteen years old) the patient could have a *whanau* member sleeping in the same room as them. But very soon into the rehabilitation process *whanau* are encouraged (and at times it is insisted) that they do not come onto the wards except during visiting hours. This means that a person's personal cares are done by the nursing staff rather than a *whanau* member. From a rehabilitation discourse perspective or lens, patients need to learn how to direct their own cares and be independent. A question that arises for me is how the rehabilitation discourse positions Maori and what agentic position is offered to them? Is there a possibility that for Maori patients, positioned in their cultural views, we are marginalising cultural knowledges of protection and care and position the patient more vulnerable and shaming the family even further by acting on knowledges produced from the rehabilitation discourse? Durie (1994, p.484) states that "for a family there is a need and a desire to be involved and their presence in large numbers reflects that desire. By helping to care for the patient they are assisting the *tohunga*, fulfilling the expectation of their community and alleviating their own sense of guilt."

The above highlights the dilemma that we are "constituted through multiple discourses

at any one point in time, and while we may regard a move we make as correct within one game or discourse, it may be equally dangerous within another” Davies (1991, p.49). As the counsellor at the Auckland Spinal Unit I am often called on to have discussions with *whanau* about visiting and in particular not adhering to visiting hours. The above comment about a move we make might be regarded as correct within one discourse may be equally dangerous within another resonates very strongly with me in terms of these discussions regarding visitation. In talking to families about ideas of independence and the importance of patients learning to do it on their own (the rehabilitation discourse) is a potentially disempowering or disrespectful practice when *whanau* believe that they need to protect the patient and be closely involved in the care. These kinds of discussions are exceptionally delicate and one runs the risk of being seen, by families as culturally very insensitive.

Mc Kinnon and Miller (cited in Waldegrave, 1990, p.31) suggest the following questions in helping people to reflect on the patriarchal meaning webs in families. Although these questions were aimed at deconstructing gender equity within a family, they seemed to me to be very relevant questions for the Auckland Spinal Rehabilitation team to be asking about our ideas about family involvement.

I have adapted the questions to make them more pertinent to the Auckland Spinal Rehabilitation Unit. They are as follows:

- ~ Who has been most influential in determining current beliefs about visiting hours and how patients learn to become independent?
- ~ Who is best served by the current beliefs about patient independence and social definitions of problems and relationships?
- ~ What has been the socio-historical evolution of these beliefs about visiting and patients learning to become as independent as they can in managing their cares?

Mc Kinnon and Miller further comment that these questions force us as professionals to examine the social construction of our own theories and ideologies. These questions enable us to re-examine the location of the so called problem. In this particular situation the ‘problem’ is that at times Maori *whanau* are positioned as wanting to attend to a patient’s cares on the wards. The rehabilitation staff holds ideas that if the patient’s cares are carried out by nursing staff the patient will be better positioned to learn how to direct their own cares and learn independence. Is the ‘problem’, as Mc Kinnon and Miller ask

mainly located within the cultural ways of *whanau* or is the 'problem' mainly located within ideas about independence and rehabilitation?

In the past I think there have been difficulties with coming to an agreed solution about these complexities of *whanau* care and learning independence because the solution has been set up as a binary - *whanau* care and the patient does not learn how to be independent versus nursing care and the patient learns how to direct their cares. In the next section of this chapter I will discuss how if 'this problem' is not viewed as a binary (either /or) it may be easier to come to agreements that suit all parties.

In terms of ongoing conscientisation of our systems and processes such as *whanau* involvement, visiting hours, *whanau* members sleeping on the wards, family (*whanau*) meetings Tamasese, Waldegrave, Tuhaka and Campbell (1998, p.51) state that the primary responsibility for the day to day check and balance of power knowledge relations lies with the group that is associated with dominance. The group that is positioned with holding the dominant discourses is responsible to continue to work on their conscious around issues of power and all the biases associated with it. Calling a stop to certain discriminating practices or policies is not left to the marginalized caucus. This is crucial. It is the group whose production of knowledge is held as the stamp of truth who is responsible for the deconstruction of their dominance. The Auckland Spinal Rehabilitation Unit staff are without doubt being positioned with professional knowledge and privilege. It thus becomes our (the staff) responsibility to address on issues around power/knowledge relations and deconstruct these.

To go back to those three questions posed by Mc Kinnon and Miller to deconstruct power/knowledge relations - Who has been most influential in determining current beliefs about visiting and *whanau* involvement? The Auckland Spinal Rehabilitation Unit has been the most influential in determining current beliefs.

The answer to question number two is far more ambiguous. Who is best served by the current beliefs about *whanau* involvement and visiting hours? In many ways it would be much easier for the nurses at the Auckland Spinal Unit if *whanau* were with the patients when they were on the wards and receiving their personal cares. The *whanau* could assist with their cares. However, a difficulty is whether this is really in the best interest

of the patient's rehabilitation and even what is defined as rehabilitation. The concern is that the *whanau* in caring will not know when and how to 'stand back' and let a patient try to accomplish tasks for themselves and will step in to care and assist too quickly. It may be difficult for a *whanau* member to see a person you love struggle, get frustrated, ask for help and assistance but help and assistance is not given immediately. Discourses about rehabilitation support views that too much practical assistance can stand in the way of a patient gaining independence. Independence, according to rehabilitation discourses means a person is able to do as much for themselves as possible and the things they are not able to do for themselves they are able to direct a carer to do it for them in such a way that it is almost the same as if the person was doing it for themselves. If a patient has everything done for them it is a view within the rehabilitation discourse that the person is unlikely to develop the skill and the physical ability to do it for themselves. Although independence is very much a western concept, there are very few patients who do not want to gain maximum independence. I have noticed, at times, that in some Pacific Island cultures independence for an older adult, especially a male, does not seem to be at the front of the family's concerns. However, in general, the ability to be independent seems to be an important achievement for all the patients at the Auckland Spinal Unit irrespective of gender and ethno-culture.

#### *7.5.1.1 Future intentions when noticing these opposing discourses (Davies, 1991)*

On reflecting on these seeming opposing discourses about *whanau* being involved in a patient's care and a patient learning their own cares I think the difficulty in the past has perhaps been that it has been viewed as a binary, that the discursive practices informed by these two discourses are in opposition to each other. Perhaps if more attention is paid to how these ideas can work together solutions can be found that centralise local Maori knowledge about *whanau* care and also make space for rehabilitation knowledge about learning independence.

In future when these situations arise, I will take a lot more time in talking with the *whanau* about their intentions for involvement. I will take more time to talk about the Auckland Spinal Units perspectives and talk about the *whanau*'s perspectives. I will also endeavour to involve Counties Manukau District Health Board Maori Cultural Support in these discussions. (This service is only available one afternoon per week so the logistics in getting them involved is not always possible) All parties (*whanau*, patient and Auckland Spinal Unit health practitioners) all want the same end result – as much

independence as possible for the patient. If we all have the same goal in mind we must surely be able to come to an agreement as to how we as a team can best achieve this. This agreement may in some instances require professionals to deconstruct their taken for granted truths and offer space for cultural knowledges to stand alongside the former.

In this next section I will briefly discuss the Maori word *Whakama* and the possible implications it has in terms of working in a culturally sensitive and appropriate way alongside Maori clients.

### 7.5.2 *Whakama*

Nikora et al (2004, p.9) describe *whakama* as an attitude which can result from an infringement of *tapu* and it is a “sheltering and a secrecy by Maori, their *whanau* and the broader community” Sachdev (1990) states that there is no equivalent English word for *whakama* but words such as shy, embarrassed, shame or feeling at a disadvantage would be the English equivalents. None of these terms embody the concept in its entirety. When *whakama* occurs it is considered a weakening of the person. *Whakama* can be momentary or it can last a number of years “unless it is properly dealt with” (Sachdev, 1990, p. 436).

Some of the manifestations of *whakama* according to Sachdev (1990) are lack of expression of affective responses which could include silence, appearing dumbfounded, seeming to lose sharpness of intellect and unresponsive. *Whakama* may also manifest itself by a withdrawal from friends and relatives and removing oneself from social contact. According to Sachdev (1990) sleep and appetite are usually not disturbed. These behaviours mentioned above are usually not considered abnormal by some members of the Maori community but may be so regarded by an outsider who is not positioned well to make meaning of these within the cultural storylines. Medical discourses may give a diagnosis of depression to a person experiencing *whakama*.

In counselling Maori clients at the Auckland Spinal Unit I have on a number of occasions witnessed *whakama*. The Maori concept of *whakama* seems for certain clients with a spinal cord injury to be so central that all or most other experiences seemed to be interpreted through this lens of *whakama*. I have noted that this ‘lens of *whakama*’ seems to position a person with decreased *mana* and inferiority, and it seems to get in

the way of making contact with networks of friends and *whanau*. I have noted how this *whakama* has invited Maori clients to be hesitant to contact friends or return back to their home town on discharge. Reflecting with them on their understanding of this, Maori clients have told me that this is because of *whakama*.

Hirini (1997) mentions that the aim in service provision such as the Auckland Spinal Unit is to develop practices that are competent and effective in working alongside Maori rather than merely informed or sensitive. My understanding of this comment is that practitioners need to be able to go beyond sensitivity and empathy and work alongside Maori patients to deconstruct cultural storylines which give the patient the capacity to recognize the constitution of the discourse and to take up, resist, subvert and change the discourses (Davies, 1991, p.51). In this co-construction of knowledge Waldegrave (1990, p.12) says that the task of the therapist is to weave new threads of meaning and possibilities that give new colour and new textures. If a patient, through counselling, wants to review the effect of *whakama* on his/her life, the task of the therapist is to offer up for consideration alternative ways of making sense of disability that stand against identity claims offered by *whakama*. These alternative ways or new colours and textures as Waldegrave (1990) calls them must sit comfortably within the culture of that person for them to be sustainable.

In terms of this concept of *whakama* I feel as though I have been informed and positioned more sensitively but not very competent and effective in weaving the new colour and the new texture of this knowledge into my practice. The discourse of *whakama* for certain Maori clients, seems to be so central in producing and constructing identity claims that as someone from a different cultural background, it almost seems insensitive and rude to talk about it. I sense that I do not have an adequate understanding of *whakama* to deconstruct *whakama* with patients.

For the deconstruction of the stories that people live by White (1992) suggests that a starting point is having externalizing conversations which encourage a person to provide an account of the effects of those stories on their lives. Externalising *whakama* and having a conversation with a patient about the effects of *whakama* (or what the patient names it) on their lives which could include the effects on *whanau* relationships, future hopes and possibilities, could be a useful starting point. Patients can then start

considering their relationship with *whakama* (or what the patient names it) and whether or not they would like to review this relationship.

Discourses about ethical and safe practice for myself as a counsellor inform me that it is good counselling practice to recognize and know one's limitations. There are situations that it is more culturally appropriate for a Maori Health Practitioner to be invited in. This inclusion of Maori Health Practitioners is in line with the recommendations of the National Advisory Committee on Health and Disability (1996). This committee suggests that appropriate utilization of non conventional mental health services such as *tohunga* and or Maori Health Workers or Maori elders adept and experienced in Maori mental health and spiritual issues should be called in to assist with culturally complex situations. At the Auckland Spinal Unit we have a budget for such specialized services and I am able to make referrals to specialists in this area if required. I have on a number of occasions offered this to patients at the Auckland Spinal Unit.

## **7.6 Conclusion**

In conclusion the purpose of this chapter was to reflectively consider power /knowledge relations at the Auckland Spinal Unit with particular emphasis on power /knowledge relations between health practitioners and Maori patients and their *whanau*. Frankenberg's three moments or discourses about race were used as a backdrop to consider racism. In the first two moments, essentialist racism and colour evasiveness it was shown how cultural biases are often internalized in ways that are invisible to the persons reproducing them in practice. This reproduction of cultural biases tends to subjugate cultural /local knowledge about health and rehabilitation and privileges western medical knowledges – whether intentionally or unintentionally.

The deconstruction of power and dominance or as Raheim calls it “enacting privilege” is the responsibility of the dominant group. Raheim's three reflexive questions (when am I enacting privilege, in what circumstances am I enacting privilege and how can I tell that I am enacting privilege?) were identified as useful in this ongoing journey of deconstructing practices of power and privilege.

The chapter concluded with discussing some specific cultural issues relating to Maori patients – in *whanau* involvement in caring for a patient and the role of *whakama* in a

patient's life.

In conclusion surfacing cultural stories of health, making them more visible, supporting patients to resist colonizing ideas of well-being and standing against labelling of patients through the lenses of dominant medical and rehabilitation discourses was the intention of this chapter. According to Laird (2000) this is a health practitioner's responsibility.

## **8. Personal Development**

### **8.1 Introduction**

This chapter stories aspects of my personal development in counselling patients with a spinal cord injury. My journey started in February 2004, and at that time I was primarily using modernist discourses about counselling to make sense of my counselling practice. Over the past three years I have reviewed and selected other discourses through which to make sense of my counselling practice and this chapter reflects this journey.

### **8.2 Historical Roots**

Social construction theory proposes that we are constrained in our thoughts, feelings beliefs and actions by the discourses that are available to us and our positioning within them. “Not only do our subject positions constrain and shape what we do, they are taken on as part of our psychology, so that they provide us also with our sense of self, the ideas and metaphors with which we think, and the self narratives we use to talk and think about ourselves” (Burr, 1995, p.152).

When I started at the Auckland Spinal Unit in 2004 I came with some very centralised and persuasive discursive practices about professionalism. These discursive practices principally originated from my undergraduate training in the counselling components of my social work studies.

One centralised discourse related to the personal and the professional and my belief in the importance and the possibility of having a clear divide between the two areas. The quote below is from Perlman, one of the main textbooks that initially shaped my ideas/practices of the professional relationship:

Any subjective involvement on the part of the caseworker with his client or the client’s problem may be part of a real counter-transference, or it may represent only a single instance of loss of professional objectivity.

The need for achieving objectivity is readily apparent. If he remains in his own

feelings, the caseworker is in no position to perceive with any clarity or judgement the feelings and needs of his client... nor will he be ready to lend himself freely to enabling his client to progress (Perlman, 1974, p.82).

The second centralised discursive practice that emerged from my undergraduate training was the responsibilities of a professional in terms of holding knowledge, planning and preparation. The quote below is from the same textbook mentioned above:

The social caseworker is involved in the relationship with his client ...because he knows how to be of help and is charged and authorized by his agency to be of help. A person in need of help seeks someone who has the authority of knowledge and skill to help him; he goes to someone who knows more or is better able than himself, and it is the client's very assumption that the caseworker carries this authority which infuses the relationship with safety and security and strengthens his response to guidance (Perlman, 1974, p.69).

Over these past two years these two discursive practices have been seriously troubled, unsettled and deconstructed. This deconstruction process has been through reflecting on my counselling practice, addressing my practice and professional relationship in supervision, embarking on this research journey and the writing of this research report.

The discursive practices mentioned above (division between the personal and the professional and that the professional holds expert knowledge needed to fix problems) have their origins in a modernist paradigm of counselling. These modernist ideas would be similar to the medical model of health care provision where 'objective' knowledges from books, journals and independent studies are privileged over local knowledge of the patient and family. I am very differently positioned in my ideas about knowledge and professional responsibility to what I was two years ago. My preferred positioning, which will be detailed further below, holds more to ideas that I should not attempt to neatly incise my personal life and removed it from my professional life and that there are many ways that we have of knowing (Heshusius & Ballard, 1996) and knowleges from books or study should not be privileged above other ways of knowing.

### **8.3 Medical Model and how it Positions a Counsellor**

In chapter two of this research report, I mention that the medical model has positioned professionals with the responsibility of 'knowing how to fix it' and the need to have all the answers which if followed would sort 'the problem out'. This discourse has the potential to position the professional with an enormous amount of responsibility for the well-being of other people. If as a professional you do not have the answers in how to fix it, identity claims of inadequacy and incompetence can be very available. If the professional does not 'succeed' in bringing about changes, the patient may be positioned as non compliant with the treatment.

The self narratives that this medical discourse of expertise frequently invited me into was that I evaluated myself as having inadequate knowledge and expertise and started to question at times my efficacy as a counsellor. In the initial stages of my working at the Auckland Spinal Unit I felt responsible for fixing problems but very frequently felt impotent and powerless to do so. In terms of the responsibility that I felt, I notice that in January 2005 I wrote in my research journal:

Looked at my program for the day, I have got two goal settings meetings, no individual counselling appointments, what a relief the responsibility is not on me. I then continued to question myself in my journal "What is this responsibility that I believe I hold?"

This responsibility at times felt like a physical burden, a weight that I carried around, believing that I was responsible to know how to fix emotional problems but knowing that a lot of the time I did not know how to fix it.

### **8.4 Modernist Ideas of Counselling Relationships – Position Calls**

Modernist ideas of a counselling relationship value the idea of therapists being 'self aware' so that their personal lives are very separate from their professional lives. The idea is that a therapist responds to a client from their professional selves and not their personal selves. The assumption in this approach is that it is the use of our professional selves that will be of help to a client because this is objective, value free and shaped by objective / expert knowledge. According to this paradigm the use of our personal selves

could cloud our judgement and interfere with the professional relationship. This is built on the assumption that it is in fact possible to keep your personal and professional lives totally separate.

These ideas about a separation between the personal and the professional in a relationship value separation and question a person's counselling ability if it cannot be managed to keep the two separate. Within this paradigm professionals are educated to believe that objectivity is possible and necessary to be effective in one's job. Being educated within this model I have been taught to maintain control over emotions lest I inadvertently display 'inappropriate feelings'.

Within modernist paradigms of counselling, to split the personal from the professional is seen as a hallmark of professional competency. This separation creates certain dilemmas of practice with regard to empathy. Weingarten (2003, p.106) calls this separation the dilemma of empathy. As a counsellor at the Auckland Spinal Unit I am witnessing violence and violation almost everyday of my life. On a daily basis I am confronted with some of life's hardest realities. Weingarten (2003) mentions that violence and violation demand empathy. The dilemma of empathy is however that we are submerged in a wider culture that believes that the expression of emotion is healthy, yet the professional norms that many subscribe to posit that emotionality on the job undermines performance. On the one hand health professionals agree that it is healthy and important to express emotions yet on the other hand if as a health professional we show 'too much' emotionality (with the exception of humour) on the job there are questions raised as to whether we are managing.

Where did these ideas, about separating the personal and the professional, position me, at the Auckland Spinal Unit when at times I felt such deep sorrow and sadness witnessing patients and the trauma that they were experiencing? What did it say about me as a professional when I spoke to a young man and reflecting on the interview I thought about his age and the fact that he could have been my son experiencing the impact of the spinal cord injury? How did that place me when I wanted to cry because a young woman was so ashamed of her disability that she did not want to return to her family to live with them? These experiences were clearly crossing that boundary of empathy that I, at that time, thought it was important to keep. What type of identity

claims did these empathy/ sympathy actions invite me into?

Working out of the modernist counselling discourse that there should be a divide between the personal and the professional the experience of events (White 1995) was that I was emotionally affected by the patients that I was counselling. As previously mentioned sadness, fear, sorrow, unfairness of life, vulnerability were at times present in my 'professional life' which frequently intruded on my 'personal life'. The identity claims invited me into evaluating myself as over involved and not able to control and manage my emotions.

The identity claims that a modernist approach to counselling invited me into was that I was lacking objectivity and this was compromising my professional competence.

## **8.5 Searching for Answers to the above Dilemmas**

### ***8.5.1 Focusing on knowledge and skills at the expense of focusing on self***

At the beginning of 2005 my main focus in improving my counselling practice was the active pursuit of gaining additional knowledge and information about people with spinal cord injuries and improving my technical skills, such as questioning techniques in narrative therapy.

On reflection however whilst knowledge and skills is an important ingredient in the counselling process the ability to effectively use that knowledge with clients starts with self.

In my journal I wrote a question that I asked to Elmarie, my university supervisor:

Why do I find it so hard to weave my way around an interview? I can do it with sexual abuse but why is this (working at the spinal unit) so difficult? Elmarie replied "Because it is about disability."

I did not really understand what Elmarie was meaning by this statement. It was such a definitive statement. About six months later I asked her what exactly she meant by this statement. By this time I had mulled it over in my head. I was beginning to suspect that what she meant was that disability has the potential to affect every area of one's life.

There are multiple discourses that surround disability such as body image, independence, sexuality, what is valued in society, body functioning, body disfigurement, permanency of life, value of life and how these offer very different positioning in terms of agency. Elmarie and I discussed together how disability and in particular a spinal cord injury affects every aspect of one's being.

I started to realise more and more that additional knowledge and skills whilst important was not the only missing ingredient. One aspect that was missing was permission from myself to acknowledge that the personal is the professional. To acknowledge that disability is affecting the patients and family (*whanau*) that I am working alongside but that it is also affecting me. I needed to allow myself to witness self (Weingarten, 2003) and not allow myself to treat those feelings as alien and unwelcome in my life. My starting point was an acceptance that it was okay to feel that way – feeling that way was not a reflection of my inadequacy as a counsellor.

When my heart felt crushed because a father had lost his son, when I was too scared to ride my bicycle because of the injuries that I saw at the spinal unit, when I was so outraged and angry about how a patient was treated with seemingly such disrespect, when sadness just gripped me when a young woman, talking about her partner who had been injured looked at me and told me her heart is broken in a thousand pieces and she does not know if she will ever be able to put them back together – allowing myself to feel what I needed to feel, witnessing myself and just acknowledging the affects that the people I work alongside have on me, that was not about being unprofessional, this was about being professional.

Starting this process of witnessing myself, I wrote in my research journal:

Do I make space for my own compassion to be witnessed?

Is there anyone who witnesses my compassion?

Does my compassion need to be witnessed?

I also note in my journal that I said to Elmarie: I would not know how to witness my compassion. How and where would I start?

Giving myself permission to acknowledge how the work affects me, witnessing my own compassion through supervision and writing in my research journal was a journey I needed to embark on. I need to witness myself to make place for care and compassion

for others to break through. The reason why I use the expression “break through” is because the care and compassion for the people I work alongside was always there. Not witnessing self however at times got in the way of my being able to demonstrate this care and compassion and opening space for chaos narratives. As Weingarten states:

We cannot afford for people to believe that they must blunt their feelings to stay ‘sane’. We need those who serve us to be in touch with their emotions as they perform their duties, for it’s this comfort that allows them to express care and concern for others as they do their jobs. We want to preserve not crush this ability (Weingarten, 2003, p.115).

Through attending to this witnessing self it supports my finding a balance between what Bird (2000) calls connection and detachment. Connection is that ability to really listen and move in step with my client. Detachment is not being over involved in a way that makes it difficult to decide what will be useful and what is not useful in the counselling relationship. Connection assists me to listen for intonation, emotions, body sensations, visions, dreams and for what is partially said. Detachment assists me to stand back from the experience and decide whether the knowledge I hold belongs to the therapeutic relationship and or to my life experiences. Detachment helps me to decide how and if to use this knowledge as a partial knowing, a possibility (Bird, 2000, p.93).

This journey of witnessing myself is not something that I find easy. I still need to almost force myself to talk about those aspects in the work that are affecting me. I am still very cautious about it and very selective as to who I discuss it with. This is not to say that I have not found great benefit from sharing more freely about how the work affects me. This reticence to talk and a careful selection of my audience constantly reminds me of how difficult it probably is for many of the patients to talk about how their injury is affecting them. What I am constantly reaching for in my counselling conversations is how can I link in with the patient /family/*whanau* in a way that offers an invitation that makes the person want to talk about their hopes, dreams and concerns and that through this talking the stories that are co-produced are more helpful and more healing and not “regurgitated chapters from an old chronicle of despair (Wylie Sykes, 1994, p.46).

### 8.5.2 *Focussing on the alternative story*

When I initially started learning about narrative therapy I quickly warmed to the idea of the concept of the alternative story. Morgan (2000) describes this formulation of an alternative story as noticing and exploring the significance of unique outcomes – an event or action that does not fit in with the dominant story, and how this contributes to the creation of an alternative, non-problematic story or narrative. Reflecting on my practice I have come to see that in my attempt to work alongside patients who had a spinal cord injury I was focussing on the alternative story and not allowing the story of grief and sorrow to be known.

In the initial stages of working at the Auckland Spinal Unit I interpreted this idea of the alternative story to be the story of agency, the story of overcoming difficulties, and the story of making progress every day. In hindsight now probably this was closer to what Frank (1995) would call the restitution story. My understanding was that the progress was what should be focussed on. My concern was that if patients or their family (*whanau*) were talking about the story of loss and pain, the talking would do more harm than good. The example that follows demonstrates this inappropriate focussing on the alternative story.

In the first month of my working at the Auckland Spinal Unit a couple came in to see me and they were sharing with me just how much difficulties and sorrow they were experiencing as a result of the wife's spinal injury. I asked them whether there were times that there was just a glimmer or a ray of light that was different to difficulties and sorrow. They mentioned that there are times that it does not all look totally gloomy but most times it does. I remember moving the counselling conversation to what may be described as the unique outcomes – an event, thought, action, belief, idea, dream or hope that does not fit in with the dominant story (Morgan, 2000, p.60). My concern was that if they kept talking about the story of difficulties and sorrow it was just making it worse not better – thickening the problem saturated story.

I noticed that they basically disengaged from the counselling conversation and did not return. On reflection I was too quick to focus on the alternative story – I was the senior partner (Winslade et al., 1997) in this counselling conversation deciding on the direction.

My concern was that if patients and their families (*whanau*) were talking about the story

of loss and pain I was doing more harm than good and supporting the thickening of the problem saturated story.

This move away from talking about pain and difficulties was a new shift in my counselling practice. Two reasons that I can think of have possibly accounted for this shift. The one area is concern around not re-traumatising a person. Especially in the field of sexual abuse (where I had previously worked) the concern about not re-traumatising a person as they talk about the abuse was a very important consideration in counselling. Added onto those concerns mentioned above when I was exposed to ideas about the alternative story I did not want to cause harm and so I just stopped paying attention to and or making space for the story of pain.

In my research journal, at the start of the journey into reflecting on counselling with spinal cord injured people I wrote the following:

I realise that somewhere along the way I have stopped asking about the painful questions. In other words asking about the emotional pain that a person is experiencing.

This not 'making space for the story of grief and pain to be known' was quite a shift from previous counselling practices of mine. Previous ideas that I held about counselling encouraged the idea of people talking about the most difficult things in counselling conversations because the idea was that if you can talk about these difficult things, then the less difficult things are easier to talk about and that talking about them was therapeutically useful.

In previous parts of this research report I have described how within my family of origin there were some definite narrative preferences not to talk about your emotions and not to talk about things that were difficult. The idea that no good will come from it, was a dominant idea in my family of origin. These concerns about not re-traumatising someone and ideas about the alternative story in many ways made sense to me. It was as I have said very much in line with the discursive practices that I grew up with. So in my previous counselling practices I did at times wonder what use it would do to talk about the pain and the grief that a person was experiencing. In addition I also personally found

it hard and difficult to talk about the painful things, I found it much easier to talk about the things that were going well.

Although my initial counselling training highlighted the importance of talking about painful and difficult things my concern about re-traumatising a person, ideas about the alternative story and my own personal narrative preferences to talk about what is going well blurred for me the importance of what Weingarten would call “mastering the art form of helping to call forth the chaos narrative” (Weingarten, 2001, p.7).

Despite this idea of not talking about the painful things, on one level made sense, on another level what I was noticing that in some instances my counselling conversations seemed to be quite shallow and superficial. I got the sense at times that what people were discussing with me they could have been discussing this with a friend or anyone else. I was questioning the generative nature of my counselling conversations.

These shallow and superficial counselling conversations made me question the effectiveness of my counselling and highlighted concerns as to whether counselling was really making a difference. Once again there seemed to be something missing and on reflection it seems that the starting point had to start with me.

### ***8.5.3 Witnessing self as preparation for being a compassionate listener***

Through reading Arthur Frank’s work on illness narratives and his personal experience of illness made me think again about my counselling conversations and what was I making space for? In particular this quote has really challenged me:

The questions I wanted to ask about my life were not allowed, they were not speakable, they were not even thinkable...the gap between what I feel and what I feel allowed to say widens and deepens and swallows my voice (Frank, 1991, p.13).

This quote really invited me to think about what are my narrative preferences? What am I listening for? Do people leave my office thinking that there were questions and things they wanted to say but I gave them a sense that these things were unspeakable.

At the same time that I was asking questions to myself about illness narratives and what

am I making space for, my experience from my university supervision was very much centred on witnessing myself. This witnessing myself was deconstructing the idea of separating a personal self and a professional self. It helped me to see how some of my personal life experiences were in fact a wealth of knowledge that I could be using with clients. This ‘permission’ to use my own personal life experiences was like having a whole new wing of a library opened up for me, all this information readily available for me to sift through and use, use at any time day or night with no ‘due back by’ dates.

This witnessing self focussed on how the work at the Spinal Unit was impacting on me, how it was affecting me. I never got the sense that Elmarie (university supervisor) was uncomfortable hearing these stories. I never felt as though I had to curtail what I wanted to say because she was finding what I was saying too difficult to hear. Elmarie was giving me space to talk about these things, allowing them to be known and not shifting or guiding me to pay attention to alternative stories of success with clients – of which there were quite a few.

This experience of **making known** to someone else what my struggles at work were was a very new experience for me. I noticed that there was a very big difference between my knowing it in my head and thinking about it (something which I was very aware of) to actually telling someone else about it. Most importantly in the telling, the listener being willing just to listen and understand and not try to steer me in a different direction. It was this kind of listening that I wanted to do more of with the patients at the spinal unit.

Hearing the stories of the participants in this research study has further supported these listening intentions. As Paul, the one participant said “I just wanted someone to talk to.” A process sometimes sounds so easy when it is put into words. My experience of this process was that it was not easy to do at all. Once again from my journal:

Spoke to John (pseudonym), he said he’d been feeling quite sad for a few days, just thinking about the past, but he was fine now. Asked him whether he “welcomed the sadness” whether he wanted to talk about his memories. He was very clear – no and the reason was that he would be too scared to.

When John said that he was too scared to talk about sadness and the memories of the past I could so relate with this: That day in church when I felt so sad I had

the same thought, if I just let go and felt what I wanted to feel would I be able to “get out of it”. This is unknown territory for me and it is scary.

How can I work with my clients “I am holding it together but if I think about this too much maybe it will all fall to pieces and how will I know how to put them (the pieces) back together again?”

I notice another time in my journal I write: I am not going back to see Elmarie, I am not going to sit in her office again and cry.

I do not think that I am alone in my experiences of how difficult some people find this kind of talking. I hear patients or family (*whanau*) members saying to me: I decided I was not going to cry again in your office today Susan, I am fine the whole week and then I come in here and all I do is cry.

The process is not always easy, it is at times scary, it is for many people unknown territory. It does however invite a difference.

The two writers that I have found to be exceptionally useful have been Kaethe Weingarten and Arthur Frank. Both seem to acknowledge the importance of grief and sadness being made known, known not just to the individual themselves but to compassionate witnesses that are really willing to listen. As a counsellor I want to be able to listen in this way, with ongoing compassion, care and understanding. For this listening to be present the starting point was witnessing self (Weingarten, 2003).

## **9. Additional Strands and Conclusion**

### **9.1 Other Themes**

In this research report the main themes that emerged from the participants were how counselling should be offered, family involvement, sexuality and grief and loss. Other themes that emerged were:

#### ***9.1.1 Discharge***

Research participants identified the difficulty in being discharged from the spinal unit. Larry mentioned “It is really quite difficult leaving the spinal unit, it is really quite scary and a daunting prospect.” David said “I was scared to leave in the end because I got so used to the routine”

Telephone contact or a home visit after discharge, were favourably viewed by the participants.

#### ***9.1.2 Practical help***

Two of the research participants talked about the need for more opportunities for learning practical tasks. Larry mentioned that “it would have been nice to be shown what you still can do.” His suggestion was that being taken shopping, cooking lessons, how to get clothes out of the cupboard and house cleaning were some of the practical things that he would have valued being shown / taught. David wanted to be taught how to push a supermarket trolley in his wheelchair, how to take washing out of a front load washing machine and how to hang up washing in a wheelchair.

Avril (mother with three dependent children) was not able to cook food for her family for approximately two years. This was because her house was not modified. Perhaps there may have been ways that she could have cooked if she had been shown how.

#### ***9.1.3 Talking about the actual injury***

Two participants said that they found it very useful to talk extensively about how they sustained their actual injury. My usual counselling practice is not to specifically ask people about their injury – it is already documented in the patient notes. This is however

an area for future consideration in my counselling practice.

#### ***9.1.4 Counselling preferences***

One research participant had a strong preference to be counselled by a counsellor with a physical disability. She felt that she could relate better to someone who she perceived had a similar experience to her.

A male research participant wondered if it made a difference being counselled by a male as opposed to a female. He was initially counselled by a female and then a male. He thought gender might make a bit of a difference but thought it was probably more the approach and style of the counsellor that was the deciding factor.

#### ***9.1.5 Confidentiality***

One research participant felt that due to lack of privacy in the wards, he was not really able to discuss the things that he wanted to in counselling. This participant was on bed-rest and so counselling happened at his bedside. His definite preference would have been for his bed to be moved to another room for privacy.

Another participant was very concerned about confidentiality and ACC. Her concern was that if she discussed things with a counsellor from the spinal unit, because both are government organizations, ACC would have access to that information. She identified this as a barrier to engage in ongoing counselling.

#### ***9.1.6 Accident Compensation Corporation***

Three research participants detailed problems and difficulties with dealing with ACC. As one person said “living with ACC is not all blissful”. All three participants found that they it was difficult to get what they were seemingly entitled to.

#### ***9.1.7 Other***

One participant mentioned ongoing problems with pain, two research participants mentioned vocational guidance would have been very useful and one participant said that more assistance with weight management would have been welcomed.

## 9.2 Conclusion

The purpose of this research was to improve counselling services at the Auckland Spinal Unit. The two main themes that have emerged are the content of counselling and the context in which this counselling should be offered.

Research participants indicated a preference for counselling to be positioned as something very accessible to all patients and their families. This accessibility could be achieved through introducing counselling services to patients when they are newly admitted, attending goal setting meetings, and having ad hoc, less formal catch-ups with patients on a regular basis. These activities mentioned above do not preclude the more traditional one on one counselling appointment in the counsellor's office.

This research report has placed importance on paying very close attention to power/knowledge relations. In particular power/knowledge relations and the position calls offered to patients from marginalised ethno-cultural groups including Maori and Pacific Island patients and their family /*whanau*.

In terms of the content of counselling loss, grief and hope was a central theme that came through this research report. Listening for, and making space for the multiple storylines of illness and trauma to be made known, and to be made sense of, was important for generative counselling conversations. In addition, counselling from a social constructionist perspective, which posits that we are multiplied positioned and there are many different versions of events, counselling conversations need to hold and respect a person's hopes, beliefs and dreams for their lives (which frequently does not include wheelchairs, catheters, caregivers) and be able to talk about another reality of living life with a spinal injury that may be dependent on some of these things. This holding of multiple realities in counselling conversations makes space for local and medical knowledges.

The invisibility of sexuality counselling invited some participants to align themselves with dominant discourses about spinal cord injury and sexuality. Sexuality counselling needs to be visibilised and the sexuality project at the Auckland Spinal Unit was an example of this. An area for future research is whether this project is adequately meeting

the needs of the consumer.

Ensuring that families (*whanau*) are included so they can be part of the rehabilitation team was very important to the participants. This research highlighted the importance of actively paying attention to agency and communion within a family (*whanau*) and not just assuming that this will automatically happen.

Finally witnessing self and deconstructing my own narrative preferences was an important component in helping me to see which storylines I may be privileging and which storylines I may be filtering out.

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## **11. Appendix I**

**Information pack posted to all potential research participants**

Dear ....

The Auckland Spinal Rehabilitation Unit is looking at ways to improve and evaluate their counselling services and your input in this process would be really appreciated.

My name is Susan Sliedrecht and I have been working at the Spinal Unit, as a counsellor, since March 2004. I have seen the important role that counselling can offer patients and their families, but I am really interested to research where improvements could be made.

I am currently studying towards my Masters in Counselling at the University of Waikato, and this research forms part of that study.

The aim of this study is to co-research what you believe was helpful, what would have been helpful for you and your whanau/family, in terms of counselling /emotional support, when you were newly injured.

The interviews will be taped and should be no longer than 1½ -2 hours. The interview can be at the Spinal Unit, your home or a mutually agreed venue. Taxi cabs can be provided, if transport is a problem. Support people are welcome at the interview.

To give you more information about this research a detailed information sheet is enclosed.

What is the next step? Please read the attached information carefully and consider whether you would like to participate in this research. Sharon Hutchins from the Spinal Unit will contact you in the next few weeks to find out if you are interested.

Should you have any questions or concerns regarding the project, either now or in future, please feel free to contact me: Tel: 09 2709004 or my supervisor Dr Elmarie Kotzé at the University of Waikato Tel: (07) 856 2889 ext 7961

Kind Regards

Susan Sliedrecht  
Counsellor : Auckland Spinal Rehabilitation Unit

## **Research Information Sheet**

Name of researcher: Susan Sliedrecht

Contact number: 09 270 9004

Date: 12<sup>th</sup> of September 2005

### **You are invited to participate in a study named:**

Counselling Patients with a spinal Cord Injury

### **Aim of the Research**

The purpose of this research is to reflect on the existing counselling services offered at the Auckland Spinal Rehabilitation Unit with the intention of improving current services offered. In particular I am keen to develop my own practice in response to listening to the stories of people who have experience living in the community with a spinal cord injury.

A further aim is to share this research with other professionals working in the area of rehabilitation.

In reflecting on my own practice I would like to gain a better understanding of what topics or aspects patients could benefit from discussing, in counselling, and the timing of this. A focus for this study will be the first year post injury.

Some of the areas that I suspect are not being adequately addressed, or the timing is perhaps not right are body image, sexuality and grief and loss issues. However, the aim of the research is to get the relevant feedback from the participants, the people who have the experience in this area.

## **Personal Details of Researcher Susan Sliedrecht**

I have been working at the Auckland Spinal Rehabilitation Unit for the past year as a part time counsellor. Prior to that I counselled adolescents who had been sexually abused. My initial training was in South Africa in social work and I hold a Master's degree in social work. I have lived in New Zealand for the past 7 years.

I am currently studying at the University of Waikato completing my Master's degree in counselling. This research is done as part of this degree. From a professional and personal perspective I believe this research will assist me in enhancing the counselling service provided at the unit.

I am currently registered with Aotearoa New Zealand Association of Social Workers and adhere to their code of ethics. In addition, The University of Waikato requires all counselling students to adhere to the New Zealand Association of Counsellors code of ethics.

## **Methodology**

My intention is to interview four to seven people who have experienced living in the community with a spinal cord injury. Participants would be welcome to have family / whanau or a friend with them during the interview.

These interviews will be audio taped and a verbatim transcript written up of the interview. This transcript will then be given or posted back to you, the participant to make any additional comments. These changes will either be done telephonically or for participants who are patients at the spinal unit, face to face. Commenting on the transcripts provides further opportunity to add information, make additions or deletions.

The interviews will be approximately 1.5 hours long and definitely not longer than 2 hours. Interviews will be at the Auckland Spinal Unit or in a mutually agreeable venue. Taxi chits can be organised if transport is a problem.

All patients, under the age of 65, who have been discharged from the Auckland Spinal

Unit from June 2002 to June 2004 and who live in the greater Auckland area have been sent the information pack.

## **Confidentiality**

The written transcripts will use pseudonyms. You may choose what pseudonyms you would like for your written transcript. The identifying details in the written transcript would be age, ethnicity, level of injury and reason for injury. The only other person who may listen to the audiotape is my university supervisor Dr Elmarie Kotze'. Her contact details at the University of Waikato are: email [elmariek@waikato.ac.nz](mailto:elmariek@waikato.ac.nz) and phone 07 856 2889 ext 7961.

## **Participation**

Participation in this research project is voluntary. Should you decide not to participate this will not disadvantage you in receiving any of the services currently offered at the Auckland Spinal Rehabilitation Unit.

In order to ensure that participants are clear about what they are agreeing to participate in, a consent form will need to be signed or alternatively if signing is difficult verbal agreement would be recorded on the tape. This would confirm that participants understand that:

- They can withdraw their permission to be recorded at any stage of the interview.
- Any portion of the interview may be erased at the request of a participant.
- Prior to any of the information being used, participants will receive a written verbatim transcript for their approval.
- Participants will have up to 7 days to withdraw their approval once they have looked through their written transcript. No reason needs to be given for the withdrawal of approval.
- The research will be written up as a research report and may also be used for publication purposes.

## **Storage of Information**

The tapes and transcripts will be stored in the medical records room at the Spinal Rehabilitation Unit or in a lock up safe in my home office. At the completion of the study the written transcripts and audio recordings can be returned to the participant and/or shredded/destroyed. All other data will be kept for 10 years.

## **Results**

A summary of the finding will be sent to all participants. A copy of my thesis will be kept in the library at the Auckland Spinal Unit.

## **Complaints procedure**

- If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a health and Disability Advocate, telephone 0800555050 Northland to Franklin
- Alternatively should you, at any time in the research, feel that your trust has been abused or your rights have not been respected you could contact my University supervisor Dr Elmarie Kotze' (07) 856 2889 ext 7961.

## **Other**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. The ACC website is: [www.acc.co.nz/claimscare/making-a-claim/medical](http://www.acc.co.nz/claimscare/making-a-claim/medical) misadventure

## **Statement of Approval**

This study has received ethical approval from:

- Northern X Ethics Committee
- Waikato University

## Consent Form

**Name of study:** Counselling patients with Spinal Cord Injuries

I have read the information sheet dated 30<sup>th</sup> of June 2005 concerning this project and understand the aim of the project. I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study. I have had the opportunity and sufficient time to discuss this study. I am satisfied with the answers that have been given.

I understand that I will be asked to comment on what was helpful or would have been helpful, in terms of counselling, when I was in rehabilitation for my spinal cord injury. I have an understanding of what this conversation will require of me and I know what time this will require. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I understand that the purpose of the research is to share my experiences of what was helpful or what I believe would have been helpful, in terms of counselling, when I was newly injured. The purpose of this would be to improve current counselling services to patients with spinal cord injury. I further understand that Susan Sliedrecht is doing this research as her thesis for her Masters qualification in counselling. I therefore understand that the final research report will be shared with other people. I understand that the findings may be written up for publication in professional journals or used for education of professionals working in this area.

I agree to my interview being audio-taped but I understand that my privacy will be protected and confidence respected by the following precautions being observed.

- I can withdraw my permission to be recorded at any stage – before during or after the interview, and need not give any explanation.
- Any portion of the interview may be erased at my request.
- I will receive a written transcript of the interview that Susan Sliedrecht wants to use for research purposes. I can add, delete or alter any part of that written transcript. Once I have seen the written transcript I can also choose to withdraw my permission to be involved and the tape will be erased and the written transcript shredded.

- I understand that after I have read and accepted or changed the written transcript I will have within 7 days to withdraw my consent. After 7 days Susan has my permission to use the transcript in her thesis and to use the research for publication purposes.
- I understand that taking part in this study is voluntary. If I decide not to participate in this research or to withdraw my participation, I understand that this will not disadvantage me in receiving any of the services currently offered at the Auckland Spinal Unit, including counselling.
- I understand that should the interview bring up issues for me that I would like to discuss further with a counsellor, Gayle Saxton, the social worker at the Spinal Unit or Susan Sliedrecht would be available to see me. I also understand that if I would like my doctor to be made aware of any aspects of the interview, Susan would be willing to pass this information on, with my permission.
- I understand that the written transcripts or parts thereof will form a part of the research report and possibly publication.
- I understand that the tape will be kept in a safe place and it will be erased when the work for which it was recorded is completed, or returned to me, if that is my preference.

The tape recording of the interview will not be played to anyone other than Susan's research supervisor Dr Elmarie Kotze'. The written transcript will use pseudonyms that I will select and therefore not contain any names or identifying material. It may state my age, gender, level of injury, reason for injury and ethnicity. If I want any of the above identifying details to be removed I can request this.

In addition to the above I would like the following additional precautions:

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I .....(full name) hereby fully consent to take part in this study.

Date.....Signature.....

OR Verbal consent given on the audio recording: yes no

Full name of the researcher Susan Beverley Sliedrecht

Contact telephone number: 09 270-9004

Project explained by.....

Project role.....

Signature.....

Date.....