

QUALITY OF LIFE AMONG PEOPLE WITH ACQUIRED BRAIN INJURY  
LIVING IN THE COMMUNITY

A thesis submitted to the College of  
Graduate Studies and Research  
in Partial Fulfillment of the Requirements  
for the Degree of Master of Science  
in the Department of Community Health and  
Epidemiology  
University of Saskatchewan  
Saskatoon

By  
**Lisa Brownstone**  
Spring 1997

©Copyright Lisa Brownstone, 1997. All rights reserved.

902001120167

## PERMISSION TO USE

In presenting this thesis in partial fulfillment for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work, or in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis.

Requests for permission to copy or to make other use of material in this thesis in whole or in part should be addressed to:

Head of the Department of Community Health and Epidemiology  
University of Saskatchewan  
Saskatoon, Saskatchewan  
S7N 0W0

## ABSTRACT

Utilizing qualitative research methods, this study explored and then described perceptions of quality of life among six adults with Acquired Brain Injury (ABI), living in or near Regina, Saskatchewan. Theoretical frameworks regarding quality of life, disablement and sense of coherence were employed. Participants were 2-8 years post-injury. Each participated in three in-depth interviews, which followed an open-ended question format.

Data were transcribed and then analyzed, resulting in complex and thick descriptions of participants' perceptions of quality of life. Losses due to the injury affected all aspects of their lives. They had fewer friends, and difficulty integrating into the community. There were fewer educational and work options, and less financial security. They relied on family to meet many of their needs.

Participants also had a greater recovery than expected. All saw continued improvement. They recognized that life could be both better and worse. The perception of how good their lives were depended on a) what they were comparing it to, b) their attitude towards their lives, and c) what was currently happening to them.

An exploration of personal attitudes and internal resources for living led to an examination of why people perceived their quality of life positively or negatively. This linkage between Antonovsky's Sense of Coherence and Quality of Life was a significant finding, and warrants further study.

For the participants, quality of life was a highly individualized concept. Quality of life went beyond the traditional dimensions, to include those aspects that allow a person to feel good, account for life experiences and circumstances, and allow for hopefulness.

## ACKNOWLEDGEMENTS

A graduate degree is the product of the support of many people. Dr. Linda McMullen was the external examiner. I appreciated her commitment and willingness to share her expertise. I valued the ongoing dedication of my advisory committee members Dr. Anne Leis and Dr. Nazeem Muhajarine, and supervisor Joan Feather. Joan Feather was a constant source of support, encouraging me to delve deeper into the data, the analysis, interpretation, and findings, as well as the writing of this document. A heartfelt thanks to all of you.

I would like to acknowledge the Wascana Rehabilitation Centre Division, Regina Health District for allowing access to the study participants, and the College of Graduate Studies and Research, University of Saskatchewan for financial support.

## DEDICATION

This thesis is dedicated to the participants of this study and others with Acquired Brain Injury. As participants, you let me into your homes and lives, sharing with a willingness that was humbling. I hope that this document and the work I am pursuing on your behalf will in some small way return your gifts.

I also dedicate this to my family; Merle, Teva and Midori. Dear ones, thank you for your patience, love and support.

TABLE OF CONTENTS

PERMISSION TO USE . . . . . i

ABSTRACT . . . . . ii

ACKNOWLEDGEMENTS . . . . . iii

DEDICATION . . . . . iv

TABLE OF CONTENTS . . . . . v

CHAPTER 1: INTRODUCTION . . . . . 1

    1.1 The Problem . . . . . 1

    1.2 Need for the Study . . . . . 3

    1.3 Purpose of the Study . . . . . 4

    1.4 Significance of the Study . . . . . 4

    1.5 Theoretical Frameworks . . . . . 5

        1.5.1 Disablement . . . . . 6

        1.5.2 Empowerment . . . . . 8

        1.5.3 Quality of Life . . . . . 9

    1.6 Definitions . . . . . 10

CHAPTER 2: LITERATURE REVIEW . . . . . 12

    2.1 Introduction . . . . . 12

    2.2 Quality of Life . . . . . 12

        2.2.1 Philosophers and Quality of Life . . . . . 13

        2.2.2 Medical Quality of Life . . . . . 14

        2.2.3 Economic Quality of Life . . . . . 16

        2.2.4 Social Policy and Quality of life . . . . . 17

        2.2.5 Health Promotion and Quality of Life . . . . . 18

        2.2.6 Quality of Life and Qualitative Research . . . . . 21

    2.3 Sense of Coherence . . . . . 21

        2.3.1 History of the Sense of Coherence . . . . . 22

        2.3.2 Defining Sense of Coherence . . . . . 22

        2.3.3 Sense of Coherence and Quality of Life . . . . . 24

    2.4 Acquired Brain Injury . . . . . 25

        2.4.1 Use of the Term: ABI . . . . . 25

        2.4.2 The Size of the Public Health Problem . . . . . 25

            2.4.2.1 Incidence and Prevalence . . . . . 25

            2.4.2.2 Pre-Injury Status . . . . . 26

            2.4.2.3 Disablement among ABI survivors . . . . . 27

        2.4.3 ABI and Quality of Life Research . . . . . 29

        2.4.4 ABI and Sense of Coherence Research . . . . . 31

CHAPTER 3: METHODOLOGY . . . . .	33
3.1 Introduction . . . . .	33
3.2 Summary of Method . . . . .	33
3.3 Site selection . . . . .	35
3.4 Sampling . . . . .	35
3.4.1 Selection Criteria . . . . .	35
3.4.2 Selection Process . . . . .	37
3.5 Instruments . . . . .	38
3.6 Interviews . . . . .	38
3.7 Social Contacts Chart . . . . .	38
3.8 Memory Album . . . . .	39
3.9 Procedures . . . . .	40
3.9.1 Discussion of the Procedure . . . . .	40
3.10 The Pilot . . . . .	41
3.11 Data Collection Methods . . . . .	43
3.12 Time Line . . . . .	43
3.13 Analysis . . . . .	44
3.14 Limitations . . . . .	46
3.15 Trustworthiness . . . . .	48
3.15.1 Credibility . . . . .	48
3.15.2 Generalizability . . . . .	49
3.15.3 Dependability . . . . .	49
3.15.4 Confirmability . . . . .	50
3.16 Ethical considerations . . . . .	50
CHAPTER 4: RESULTS . . . . .	53
4.1 The Participants . . . . .	54
4.2 Discussing Their Lives . . . . .	55
4.3 Perceptions of Life Before the Injury . . . . .	56
4.4 Perceptions of The Injury . . . . .	57
4.5 Perceptions of Changes in Participants' Lives . . . . .	57
4.5.1 Physical Changes and Well-Being . . . . .	59
4.5.2 Psychological Well-Being . . . . .	61
4.5.3 Intellectual and Perceptual Well-Being . . . . .	64
4.6 Perceptions Regarding the People in Their Lives . . . . .	65
4.6.1 Family Life . . . . .	66
4.6.2 Marriage . . . . .	67
4.6.3 Significant Other . . . . .	68
4.6.4 Friends . . . . .	68
4.6.5 Social Interactions . . . . .	69

4.7	Perceptions of Changes in Choices, Opportunities and Activities . . . . .	72
4.7.1	Finances . . . . .	73
4.7.2	Getting into the Community . . . . .	75
4.7.3	Leisure Pursuits . . . . .	76
4.7.4	School . . . . .	77
4.7.5	Paid Work . . . . .	77
4.7.6	Summary of Changes . . . . .	79
4.8	Perceptions of Living with the Changes . . . . .	80
4.8.1	Role of Survival . . . . .	80
4.8.2	Attitude to Limitations and Losses . . . . .	82
4.8.3	Role of Time . . . . .	84
4.8.4	Family and the Environment . . . . .	85
4.8.5	Managing their Lives . . . . .	86
4.8.6	Perceptions of Meaning to Participants' Lives . . . . .	90
CHAPTER 5: DISCUSSION . . . . .		95
5.1	The Role of Disablement . . . . .	96
5.2	Quality of Life . . . . .	97
5.2.1.	The Being, Belonging and Becoming Framework . . . . .	97
5.2.2	Belonging . . . . .	97
5.2.3	Becoming . . . . .	99
5.2.4	Being . . . . .	100
5.2.5	Defining and Measuring Quality of Life . . . . .	100
5.3	The Sense of Coherence Framework . . . . .	102
5.3.1	Comprehensibility . . . . .	103
5.3.2	Manageability . . . . .	104
5.3.3	Meaningfulness . . . . .	104
5.4	The Sense of Coherence and The Quality of Life . . . . .	105
CHAPTER 6: CONCLUSIONS . . . . .		106
6.1	Findings and Implications of the Study . . . . .	107
6.1.1	People with ABI as Primary Sources . . . . .	107
6.1.2	Use of the "Being, Belonging and Becoming" Dimensions . . . . .	109
6.1.3	Exploring Attitudes to Life, and Internal Resources for Living . . . . .	109
6.1.4	The Three Dimensions of the Sense of Coherence . . . . .	111
6.1.5	Quality of Life as a Concept . . . . .	111
6.1.6	Limitations to the Research . . . . .	112
6.2	Implications for Promoting Health after an ABI . . . . .	113
REFERENCES . . . . .		115

BIBLIOGRAPHY . . . . .	131
APPENDIX A LETTER OF INVITATION TO PARTICIPATE . . .	138
APPENDIX B INFORMATION FOR PARTICIPANTS FORM . . . .	141
APPENDIX C PARTICIPANT CONSENT FORM . . . . .	144
APPENDIX D ICD-9 CM AND N CODES . . . . .	146
APPENDIX E THE INTERVIEW GUIDE . . . . .	147
APPENDIX F SOCIAL CONTACTS CHART . . . . .	150

## CHAPTER 1

### INTRODUCTION

#### 1.1 The Problem

As our ability to survive life threatening illnesses and injuries increases, there is more disablement (for this and other terms requiring definition in this document see 1.6 Definitions found on pages 10 and 11) and/or chronic disease in the community. More people live with disablement, and they live longer lives.<sup>1</sup>

Studying the amount of disablement in the community is difficult and controversial. There are many definitions of disablement, and discussions on who is considered disabled.<sup>2 3</sup> Disablement is a multidimensional concept<sup>4</sup> and no measurement tool can grasp its totality. Different methods of collecting information about people with disabilities have been attempted.<sup>5 6</sup> Studies have spanned qualitative and quantitative methods and have attempted to explore incidence, prevalence, quality of life, employment, employability, nutrition and physical activity levels (associated with disablement), to name a few. In Canada, data regarding the incidence and prevalence of disablement are extrapolated from health surveys, insurance company, social assistance, and human rights data. In 1988 the Health and Activity Limitation Survey (HALS) reported that 12 percent of the population considered themselves as disabled. Women had a higher rate of disablement than men. Sixty-one percent of people with disabilities were of employment age and not working. These high unemployment rates have implications regarding an individual's socio-economic status, lifestyle and social isolation.<sup>7</sup>

While they may physically survive the original injury, people with Acquired Brain Injury (ABI) have long-term difficulties with cognitive and social functioning. These difficulties are misunderstood, and rarely accommodated. When people with ABI re-enter the community they often become members of the "walking wounded." People with ABI physically appear to be disability free, but often have hidden disabilities.<sup>8</sup> They have difficulty living independent and fulfilling lives. Not only do they have to adjust to their internal changes, but family and community also treat them differently. Rarely is the extent of disablement recognized outside the family unit. Few survivors have access to support services and sometimes services are nonexistent.<sup>9</sup> Lack of social interaction and/or services leave them isolated, with few choices in their lives.<sup>10 11</sup>

ABI occurs when the brain is damaged by a traumatic or non-traumatic source. Included are those who have had a Traumatic Brain Injury (TBI), for example a blow to the head, and those who have had an infection, illness, or other internal injury affecting brain function. Examples of internal injuries include poisonings, cerebral vascular accidents (CVA), brain tumours and anoxia. This study recognizes that regardless the cause, people with ABI have similar difficulties finding adequate services once they re-enter the community.

People with ABI make up a growing proportion of those living with disablement.<sup>12</sup> With the prevalence of disablement estimated at 59 per 100,000 for TBI alone,<sup>13</sup> brain injury and its sequelae have important community health implications. With advances in medical technologies, the ability to survive the original injury has improved dramatically. This trend is expected to continue.<sup>14</sup> Survivors who are younger than 30 at the time of their injury live with disablement for most of their lives.

Quality of life has become a prominent concept in health care. While commonly used, it is not well defined. Indeed some claim that the definition of quality of life is specific to the situation.<sup>15</sup> There is agreement that the concept is important even if its definition remains controversial.<sup>16 17 18</sup> However it is defined, more of the population lives with chronic conditions and the quality of life has become as important as the length of life. Having physically survived the injury, the actual quality of life issues of people with ABI gain significance.

## 1.2 Need for the Study

This study comes at an opportune time. Saskatchewan Health and Saskatchewan Government Insurance are presently piloting three-year provincial projects to enhance rehabilitation services to people with ABI and their families. With new program money becoming available, this study can influence the types of services provided.

A review of the literature suggests that there have been some studies that centre on aspects of the quality of life of people with TBI. There are virtually no data exploring personal perceptions of quality of life. There is one Canadian study that investigates the prevalence and incidence of disablement among people with TBI based on data from the HALS.<sup>19</sup> In Saskatchewan, there have been several needs assessments (of people with TBI and ABI), the latest in 1992 and 1996.<sup>20 21</sup> A study of people with TBI and their employment experiences in the Regina area was completed. Dr. D. Alfano (University of Regina) has completed several studies from a neuropsychological standpoint.<sup>22 23</sup> These have not focused on quality of life, and only included the TBI population. Far from overstudied, there is a real need for more information about people with ABI, especially about their lives in the community.<sup>24 25</sup>

### 1.3 Purpose of the study

The major purpose of this research was:

To describe how adults with ABI, who had returned to live in the community, perceived their quality of life.

Sub-purpose:

To describe how they saw their quality of life affected by the ABI.

Participants were 18-35 year old adults with ABI who had returned to the community and were living in or near the Regina Health District. In depth information about adults with ABI was gathered and they had the opportunity to express their perceptions. The study described the issues relating to the quality of life of adults with ABI, as perceived by those adults.

### 1.4 Significance of Study

Quality of life is not a well-defined concept. The definition (as it particularly relates to people with ABI and to people with disabilities in general) was clarified by exploring perceptions of quality of life from the perspective of people with ABI. The specific quality of life issues facing people with ABI were explored, adding to the knowledge regarding ABI and its sequelae. An unexpected result was the importance that people's sense of coherence plays in their perceptions of quality of life. This adds to our knowledge of quality of life, by linking the two concepts.

In the future, the most immediate effect of this study will be on service providers and the community. Results of

this qualitative research will increase the knowledge base of the long-term sequelae of ABI. Rehabilitation services in Regina have requested summaries of the completed study. The stories participants told will be powerful aids in helping service providers empathize with the realities of ABI, which in turn should affect their ability to work in a client-centred fashion. Better education of communities can occur, using the shared perceptions. With greater understanding of ABI and how it affects people, there is the potential to decrease their social disadvantage, or handicapping conditions.

The study may also have an impact on policy. As a member of the group advising Saskatchewan Health and Saskatchewan Government Insurance on service needs of people with ABI, I am in the position to use this study to assist in policy development. Analysis of perceptions of quality of life of people with ABI can lead to a greater understanding of their needs. This could assist policy makers in developing improved goals and objectives for program delivery, based on consumer identified needs. Where participants point to difficulties in their lives, providers may be able to develop services aimed at minimizing those challenges.

Finally the study can contribute to hypothesis formulation, and the development of research. This could include additional exploration of the relationship between quality of life and the sense of coherence.

### 1.5 Theoretical Frameworks

Theoretical frameworks exploring disablement, empowerment and quality of life were all important to this study. Disablement and empowerment frameworks affected the overall approach to the study. Quality of Life frameworks

influenced the data collection and analysis. All three will be discussed in the following section.

### 1.5.1 Disablement

As my study included people with disabilities, I needed to clarify my overall approach by exploring theoretical frameworks around disablement.

There are three separate and competing models of disablement. The different perspectives of each model determine how we understand and react to health problems and the types of planned interventions. Each model developed out of a major dimension of disablement: impairment, disability and handicap. These are correspondingly the bio-medical, economic and socio-political models.<sup>26 27</sup>

In the bio-medical model, diagnostic entities have a real, objective and measurable existence. Paraplegia has its own unique category, with a list of signs, symptoms and functional losses. This is independent of any activity limitations or social roles of the individual. It is the physical reality that is crucial. The model is neutral. Impairment is either present or not, without any implied judgement.<sup>28</sup>

Members of the medical profession are the experts and gatekeepers in this model. People with disabilities need curing/ameliorating. With the physician as the expert, people with disabilities take on a passive role, becoming "medicalized".<sup>29 30 31 32</sup>

The principal objective of the economic model is to reduce costs of disablement by improving employability. The model has become the driving force behind social policy regarding disablement. Canadian Pension Plan (CPP), Workers Compensation (WCB) and the Social Assistance Plan (SAP), are examples of programs based on this model.

This model focuses on disability, those activity limitations resulting from impairment. Evaluation of the individual focuses on needs, capabilities, and whether the person can work.<sup>33</sup> With high rates of unemployment, it is an easy step to view disablement as an economic problem.

In periods of funding restraint, economic efficiency affects programming. Moral rights, human rights, and needs, are overshadowed by whether it is economically efficient to fund one group or another. The question becomes what is the most efficient way to reduce the economic drain on society due to disablement. People with disabilities are legitimate users of the system, but economic realities dictate whether they can retrain, live and work in an accessible environment, or be isolated within their homes.<sup>34 35 36</sup>

Economic analysts and the medical profession share power in the economic model. In recent years there has been some move to involve people with disabilities, but they remain weak partners.<sup>37 38</sup>

Over the past twenty years there has been a growth in the number of disablement organizations. Spurred on by the civil rights and women's liberation movements, they are demanding that societal attitudes, legislation and policies must change.<sup>39 40 41 42 43 44 45 46</sup> This has given rise to the socio-political model of disablement.

This model arose out of the social sciences, though rehabilitation was another of its roots. The early concepts developed from the labelling, stigma and normalization theories hypothesized by Erving Goffman (1963), Wolf Wolfensberger (1972) and Beatrice Wright (1983).<sup>47 48 49</sup>

Viewing handicap from a deviance approach, this model sees disability as leading to stigmatization. People with disabilities are members of a group that society views as deviant (non-normal). The label of disability creates certain interactions, and self-perceptions of inferiority,

neediness, and dependence.<sup>50 51 52</sup> With labelling the person's social role changes, creating handicap.

Accepting the presence of deviance and stigma, the politicalization of the model was the next logical step. People with disabilities became active in consumer and self-help groups. As the groups developed they redefined themselves as an oppressed group within society. Equality rose as an important issue. Disparate disability groups began to see common goals. They formed united fronts to organize a political agenda and a more cohesive approach to changing social policy.<sup>53 54 55 56</sup>

This model allows, or more importantly, makes people with disabilities the owners of the model and the direction it takes. People with disabilities can act on a community and societal level, rather than only on an individual basis. Exploring quality of life using this model leads to improving social policy, goals and objectives.<sup>57 58 59 60 61</sup>

All three models have strengths and weaknesses. A fourth model encompassing the strengths of all three would be ideal. It would need to embrace equality as a guiding principle.<sup>62</sup> While I identified with the socio-political model, none of the models completely fit my own perspective on disablement. Therefore, I complemented it with a theoretical framework that embraced empowerment. Empowerment is part of two of the three models. It is included in the economic model,<sup>63</sup> and is strongly emphasized by the socio-political model.<sup>64 65 66</sup>

### 1.5.2 Empowerment

Empowerment is another controversial concept. While there are many definitions available, the following one was used in this study:

*a social action process that promotes participation of people, organizations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice.*<sup>67</sup>

This definition implies that empowerment can occur on many levels from the individual, or personal, to that of nations.<sup>68</sup> When exploring empowerment at the individual level, it is assumed that 1) individuals understand their own needs better than anyone else; 2) all individuals have strengths that can be further developed; 3) individuals have to continuously struggle for empowerment throughout their lives; and 4) knowledge and understanding help individuals cope.<sup>69</sup>

A way to enable a person is by giving credence to their words.<sup>70</sup> Thus people with disabilities are best able to define and measure the quality of their lives.<sup>71</sup> The research method used adopted empowerment assumptions, by respecting that people with disabilities themselves are the experts in their own lived experiences. By enabling ABI survivors to give words to their experience, we gained a greater understanding of their quality of life and how they live their lives.

### 1.5.3 Quality of Life

Having chosen an empowerment framework, I realized that the quality of life approach needed to embrace that same perspective. This meant that the perceptions regarding quality of life were those of the participants, rather than mine, their family's, their medical doctor's, or society's perspectives. The literature review following this chapter explores the differing definitions of and approaches to quality of life. It shows why I chose the approach followed

in this research, the one which fit most closely to the theoretical frameworks embraced.

### 1.6 Definitions

Acquired Brain Injury (ABI): ABI is a generic term referring to damage to the brain. This damage occurs as a result of traumatic, chronic or pathological injury and is not related to a congenital disorder or a degenerative disease such as Alzheimer's disease or multiple sclerosis. The injury is caused by bruising, tearing, or bleeding into the brain tissue, or from anoxia (e.g. from near-drowning, choking or strangulation) where there is interference with the oxygen supply to the brain.

Community: In this project the community is the area in or near the Regina Health District.

Disability: Activity limitation resulting from impairment.<sup>72</sup> Examples include inability to walk because of paraplegia, or difficulty sitting because of a painful back.

Disablement: This is a collective term encompassing the impairment and/or disability and/or handicap that is a consequence of disease.<sup>73</sup> Included are the intrinsic (to the person) and the extrinsic (societal) dimensions involved in disablement. For example, it includes the lack of leg movement ( e.g. intrinsic dimension), the inability to walk independently, and accommodation issues (e.g. extrinsic dimension) that are part of being a paraplegic.

Empowerment: A process whereby people, organizations and communities participate in developing increased control of

their individual lives and communities, resulting in an improved quality of life for all.<sup>74</sup>

**Handicap:** The social disadvantage caused by the impairment and/or disability. Handicap validates the reality of social attitudes and behaviours causing difficulties beyond the control of the individual.<sup>75</sup> Examples include inability to go to a movie because the cinema is not wheelchair accessible or unwillingness of an employer to adapt the work station for both sitting and standing work, so that the person with low back pain can return to work.

**Impairment:** The loss or functional limitation resulting from disease or injury.<sup>76</sup> Examples include inability to move leg muscles because of paraplegia, or perform full back movements because of low back pain.

**Perceive:** To become aware, or understand, and in the context of this project, how ABI survivors understand and are aware of the quality of their lives.

**Quality of Life:** There is no one accepted definition of quality of life. In this thesis it is defined as what makes life go well for an individual.<sup>77 78</sup> The definition is discussed at length in Chapter 5.

**Traumatic Brain Injury (TBI):** This is an injury that occurs through an external impact on the skull. The brain itself is injured, with the extent of injury defined from mild to severe.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Introduction

In this chapter I will first explore the literature pertaining to quality of life, its definition(s), and how it is measured by different professional and interest groups. Next, sense of coherence will be explored, including how a sense of coherence develops, and the potential links between quality of life and the sense of coherence. Finally the size of the public health problem around ABI will be explored, what is known about people with ABI living in the community, and the literature linking quality of life, sense of coherence and ABI.

#### 2.2 Quality of Life

Quality of life is a concept understood to be important, but whose definition remains elusive.<sup>79 80 81 82 83 84 85</sup> Many researchers explore dimensions of quality of life, usually without defining it.<sup>86 87 88 89 90 91 92</sup> Often the perspective and dimensions employed depend on the background of the researcher. Those utilizing the research may assume erroneous definitions, make incorrect assumptions, and use the research findings inaccurately.<sup>93 94</sup> This part of the literature review will explore the definition and use of quality of life from the perspective of philosophers, the medical professions, economists, social policy analysts and health promotion practitioners. This will assist the reader in understanding the direction chosen.

### 2.2.1 Philosophers and Quality of Life

*...but with regard to what happiness is, they differ, and the many do not give the same account as the wise. For the former think it is some plain and obvious thing, like pleasure, wealth, or honour; they differ however, from one another - and often even the same man identifies with different things, with health when he is ill, with wealth when he is poor.....<sup>95</sup>*

As the above quote from Aristotle's *The Nichomachean Ethics* shows, philosophers have grappled with the concept of quality of life for centuries.<sup>96 97</sup> Though they have not reached a consensus regarding a definition, it is fair to say that many philosophers believe that:

*we need, above all, to know how people are enabled by the society in question to imagine, to wonder, to feel emotions such as love and gratitude, that presuppose that life is more than a set of commercial relations, and that the human being....is an 'unfathomable mystery', not to be completely 'set forth in tabular form'.<sup>98</sup>*

Amartya Sen sees our lives as various 'doings' and 'beings'. 'Functionings' follow a continuum from fulfillment of basic physiological needs to those higher order needs of self respect, dignity and participation in one's community.<sup>99</sup>

Sen believes that quality of life should be measured in terms of personal capabilities. Capability is the potential to achieve 'functionings'. Capabilities allow people to go beyond what is, to what could be. What the person can presently accomplish, and of what they would be capable, given certain circumstances, can be evaluated. These capabilities must be examined in terms of social and personal goals. Additionally, individual freedoms must always be set within society's overall goals.<sup>100 101 102</sup>

Well-being and personal goals are distinct dimensions of quality of life in the models proposed by some philosophers.<sup>103 104 105</sup> A person may decide that it is within his/her best interests to forgo surgery that may improve his/her physical well-being, but negatively affect his/her personal goals. Autonomy therefore becomes a crucial part of quality of life.<sup>106 107</sup>

There is disagreement among philosophers regarding how much weight to give the dimensions of quality of life and how to measure them. Some believe that desire fulfillment<sup>108</sup> is the way to measure quality of life. (For example if a person desires something and that desire is fulfilled, their overall quality of life improves.) Others<sup>109</sup> believe that there should be a narrower conception that would allow for sufficiently well-informed desire. (A new heart may be desired, but in the context of the risks, potential outcomes and costs, may not continue to be desirable to the individual.)

Although philosophers have discussed the concept of quality of life over many centuries, the closest they have come to an all encompassing definition is 'that which makes life go better'.<sup>110</sup> There is a more general acceptance that the dimensions of quality of life include a person's capabilities (his/her potentials, not just his/her present functional levels); their functionings; his/her autonomy, self determination or right to make choices for his/her self; his/her well-being; and the quality of his/her conscious experiences. Some areas can be measured objectively, others are purely a result of the individual's personal experience.<sup>111 112</sup>

### 2.2.2 Medical Quality of Life

The medical community views quality of life as objectively testable. The actual definition of quality of

life has frequently been ignored.<sup>113 114 115 116</sup> Instead there is an emphasis on disease categories, functional limitations, disability and medical interventions as opposed to potentials and ability.<sup>117</sup> Definitions (where given) concentrate on those areas directly affecting illness and health care.<sup>118 119 120</sup> Measurement tools are either specific to the particular disability, or more generalizable to the population as a whole. Quality of life is measured by a combination of whether the intervention was successful (as defined by the medical profession) and what the medical costs were to society.<sup>121</sup> There is a great deal of overlap between medical quality of life measures and economic quality of life measures. See section 2.2.3 for further information.

Spilker *et al* have taken a more client-centred perspective of quality of life. Their general definition is:

*Quality of life represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient. Four broad domains contribute to the overall effect: physical and occupational function; psychologic state; social interaction and somatic sensation.*<sup>122</sup>

Spilker notes that quality of life can be seen from a number of different levels. At the base are the components of each domain of quality of life. Next come the broad domains themselves, and finally there is overall well-being.<sup>123</sup> Those domains are:

1. *physical status and functional abilities*
2. *psychological status and well being*
3. *social interactions*
4. *economic status and factors*<sup>124</sup>

Quality of life is seen as multidimensional, client-perceived and changing over time. Measures assess gaps related to quality of life, for example those between

expectations and achievements, and those between potentials and achievements.<sup>125</sup> Control of definitions and measures remains within the medical establishment. The definition itself comes from an illness or disability perspective. The measures developed from this type of definition become focused on function and disability, rather than on handicapping issues, abilities, autonomy or capacities.<sup>126 127 128 129</sup>

### 2.2.3 Economic Quality of Life

Economic quality of life measures include those dimensions that allow the economist to explore the costs of intervention in comparison to individual gains. It is a cost-benefit analysis, and in this sense uni-dimensional. For example, the cost of a coronary bypass is balanced by whether the person returned to work or if he/she remains on long-term disability. Quality of life is not defined, though in practise it is the financial aspect of quality of life that is assessed. The medical establishment itself has become critical of this method as they recognize the limitations of this type of outcome measure. These measures do not take into account situations where a person may not return to work, but may feel that his/her quality of life was greatly improved by the intervention. In times of economic distress, this method of evaluating the quality of life can be used as an easy method to cut programs and health care interventions.<sup>130 131 132 133 134</sup> The economic approach to measuring quality of life can be quite devastating to health care, but in combination with multidimensional measures, could provide a balance to costs of the system.<sup>135</sup>

#### 2.2.4 Social Policy and Quality of life

Exploration of quality of life dimensions by social policy analysts developed out of a reaction to economic measures of quality of life. Quality of life was viewed as more than an economic issue by those involved in social policy. It was recognized that in measuring well-being from a purely economic standpoint, a whole aspect of well-being, the impact of quality of life on the social good, was ignored. Quality of life measures used in social policy research include those which assess the impact of public services (i.e., unemployment insurance) on people's lives (i.e., number of people living in poverty).<sup>136 137</sup>

Quality of life is frequently measured in social policy areas by using five levels of human needs. These levels are based on the theories of Abraham Maslow. The levels are hierarchical. Often depicted as a pyramid, with level one at the base and level five at the apex, each level's needs must be achieved before proceeding with the next. Physiological needs must be met before security and safety can, and so on, until the person reaches self-actualization. The levels are (in ascending order):

1. Physiological need - access to food, shelter, clothing.
2. Security and safety for self and family.
3. Belongingness and love within one's community.
4. Independence and freedom
5. Aesthetic beauty and knowledge as ends in themselves (self-actualization).<sup>138</sup>

Quality of life is assessed by exploring each level. Quality of life is not defined and it is viewed as an indicator of social well-being, with measurable dimensions.<sup>139</sup> Additionally, research in the field of social

policy has shown that objective measures using common indicators do not necessarily correlate with measures of individual life satisfaction.

*One objective condition (such as poor accessibility to public open space) can quite easily elicit very different subjective responses from different individuals....similar subjective responses can result from widely differing objective situations. For example people may experience as complete satisfaction with life in a mobile home as with life in a large country home.<sup>140</sup>*

As with the medical approach, those involved in social policy do not use a clear definition of quality of life. The definition depends on the particular situation. Researchers recognize that objective indicators are not precise, and that subjective measures are necessary to catch life satisfaction. Social policy research is presently attempting to develop measures based on a population or community's prioritization of the dimensions of quality of life.<sup>141</sup>

#### 2.2.5 Health Promotion and Quality of Life

Recently, health promotion practitioners have begun to focus on quality of life. Quality of life is considered an important indicator of health;<sup>142</sup> is a desired goal of programs; sheds light on a population's overall health, resulting in more appropriate policy applications;<sup>143 144</sup> and gives a human face to the determinants of health.<sup>145</sup>

*Essentially, a quality of life focus expands the field of vision of health promoters beyond that of physical, mental, and social health to a concern with the individual within the entire proximal and distal (or mezzo and macro) environments.<sup>146</sup>*

Raphael, et al, have used the following definition of quality of life:

*The degree to which the person enjoys the important possibilities of his/her life.*<sup>147 148</sup>

This definition covers some of the dimensions suggested in the philosophical approach. 'What makes life better' becomes measurable with the inclusion of the word 'degree'. 'Degree' also suggests a continuum, and that quality of life is a relative concept. 'Important possibilities' suggest capabilities, with the assumption that one can go beyond what is presently possible, to what could be, given certain changes. Enjoyment is analogous to 'better'. Just as there is some agreement between the economic and medical approach to quality of life, there is overlap between the approaches of philosophers and some health promotion practitioners.

Assumptions of the Raphael, et al, model are that:

1. the concept of quality of life must apply to all people, not just specific groups within society
2. conceptualizing and measuring of quality of life requires a multi-dimensional, holistic approach
3. personal control over one's life becomes integral to the concept
4. the perspective of the person with the disability is recognized and emphasized in data gathering and the study of quality of life
5. the normalization theory is supported.<sup>149</sup>

Inclusion of the last assumption is controversial. Normalization arose out of recognition that people with developmental disabilities were not well treated within the medical system and especially in institutions (schools, nursing homes, work sites). Its concepts were well meaning:

*.... based upon a humanistic, egalitarian value base, emphasizing freedom of choice and the right to self determination.*<sup>150</sup>

However, it was developed by professionals who were in power positions, and essentially they remain in control. There is little actual participation from people with disabilities in definition, implementation, or evaluation of normalization.<sup>151 152 153 154 155 156</sup> Further to that, some claim that people with disabilities are often not included in goal setting, decision making, implementation and evaluation of their own normalization process.<sup>157 158</sup> This may be the antithesis of the third and fourth assumptions of Raphael, et al. Moreover, it is in opposition to one of health promotion's stated goals, the empowerment or enabling of individuals, communities and society.<sup>159</sup> None-the-less, while some of their assumptions may be controversial, overall the health promotion model proposed by Raphael, et al, follows empowerment concepts.

The Centre for Health Promotion and ParticipACTION's *Quality of Life Project* (University of Toronto) saw quality of life as having 3 dimensions (Being, Belonging, and Becoming).<sup>160</sup> These are discussed below.

"Being" explores the present internal environment of the person. Included in this dimension is the person's physical, psychological and spiritual well-being.

"Belonging" explores how people fit into their environment, physically and socially, both within their home and community. "Becoming" explores what the person does,

practically (work, school, homemaking), for leisure (fun and enjoyment), and for self actualization purposes.<sup>161</sup>

These dimensions offer a flexibility that encompasses the ever-changing nature of personal health and quality of life. They have the potential to contain multiple perspectives, and can be used with the general population, not just with people with disabilities. They suggest a continuum, from the present to a future state of being.

#### 2.2.6 Quality of Life and Qualitative Research

Clearly, there are many ways that people are defining and measuring quality of life. Far from narrowing into a particular type of measurement tool, paradigms are actually softening their edges and expanding the scope to include tools previously viewed as unacceptable. The traditional quantitative methodology is no longer the only method used to measure quality of life in medical and social policy research.<sup>162 163</sup> The use of qualitative methods in researching quality of life is not new. Indeed there is a growing body of knowledge, suggesting that it may be the preferable method.<sup>164 165 166 167 168</sup> Additionally, it is recognized that the type of measure used is indicative of the perspective of the person developing and using the measure.<sup>169 170</sup> Use of qualitative methods is in keeping with an empowerment model of research, and is accepted in the literature.

### 2.3 Sense of Coherence

As the analysis phase of the study progressed, I realized that I needed to further the exploration of participants' perceptions of their quality of life. Those perceptions led to more questions. What enabled

participants to perceive their lives in the way they had? Why did they give certain answers? It became clear that:

1. the degree to which their lives were meaningful,
2. their understanding of how society works, and
3. their ability to manage their own lives, provided at least some of the answers.

Those three points corresponded to the domains of the sense of coherence described by Antonovsky. This realization brought me to a review of the literature regarding the sense of coherence, and its relationship to the quality of life. The literature regarding the sense of coherence and ABI is explored in section 2.4.4.

### 2.3.1 History of the Sense of Coherence

Antonovsky began developing the concept of the sense of coherence while working with holocaust survivors.<sup>171 172</sup> Some of the survivors were able to cope with their experiences, put them aside and develop a new, healthy life. Others did not do as well. Those who did cope, had what he called a strong sense of coherence. They found their lives comprehensible, manageable and meaningful.<sup>173</sup>

Antonovsky also developed a scale to measure sense of coherence, though he clearly stated that other measures were as important, including qualitative ones.<sup>174</sup> Since it was first posited, the sense of coherence concept has been used in research and treatment around the world. The scale itself has been used in at least 20 countries.<sup>175</sup>

### 2.3.2 Defining Sense of Coherence

*The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the*

*course of living are structured, predictable, and explicable; (2) the resources are available to meet the demand imposed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.*<sup>176</sup>

Sense of coherence develops throughout the lifespan, but is basically stabilized by the time we enter our early adult years. While we all strive to make our lives comprehensible, manageable and meaningful, our ability to do so depends on our genetic makeup, personality and childhood environmental conditions.<sup>177</sup> Barring major changes in our life experiences, there are few changes in the sense of coherence in adulthood. If anything, Antonovsky saw the sense of coherence deteriorating in later years.<sup>178 179</sup>

The experience of an ABI would qualify as a major change in a person's life. Awakening to a world of different abilities, where previously learned rules are no longer applicable, people with ABI struggle to make their lives comprehensible, manageable, and meaningful.

Meaningfulness, comprehensibility and manageability are the three core components of the sense of coherence. People having a strong sense of coherence will be high on these components. Comprehensibility is the extent that one is able to make sense out of one's surroundings, both internally and externally. Confronted with a stimulus, one is able to make sense of it. People whose lives are comprehensible can find order, structure, consistency and clarity. They still encounter negative experiences, for example job loss, death, divorce, but they are able to make sense of those experiences.<sup>180</sup> Comprehensibility is a cognitive process.

Manageability is the

*....extent to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one.*<sup>181</sup>

This component is instrumental. Resources for daily living are perceived to be controllable and one's resources can be used to ameliorate situations.<sup>182 183</sup>

Meaningfulness refers to the *extent to which one feels that life makes sense emotionally*.<sup>184</sup> Meaningfulness is the motivational component of the sense of coherence. The person with a strong sense of meaningfulness will be able to take up the challenges of life and find meaning in them.<sup>185 186</sup>

The boundaries between the three components are blurred, and they are often dependent upon each other. It is possible for one or more of the components to be very strong, and the other(s) weak, in any combination.<sup>187</sup> The strength of our individual sense of coherence is what enables coping.

### 2.3.3 Sense of Coherence and Quality of Life

In reviewing the literature I was unable to find any studies that directly explored the links between quality of life and sense of coherence. Writers do discuss sense of coherence and health, well-being, and other dimensions,<sup>188 189 190</sup> but quality of life as a concept is not directly linked to the sense of coherence.

During the data analysis stage, I wondered why people were able to go through a catastrophic injury and see themselves as healthy, just as Antonovsky had asked how people going through the concentration camp experience could see themselves as healthy.<sup>191</sup> I felt there was a link between perceptions of quality of life and a person's sense of coherence. The results of this study will begin to clarify those linkages.

## 2.4 Acquired Brain Injury

In this section of the literature review I will explain the use of the term ABI; explore the size of the problem, and the cost impact on society; and identify the 'typical' young adult with ABI. I will follow this by a review of the pertinent literature regarding quality of life once people with ABI return to live in the community.

### 2.4.1 Use of the Term: ABI

The term ABI has become more common over the past few years. Survivor and family support groups have recognized that many limitations resulting from TBI also occur with those having other types of brain injuries. A young person surviving a cerebral vascular accident (CVA) can have service challenges, similar to a person with a TBI. Support groups have decided to include people with ABI in their vision, support, education and advocacy work. Recent provincial strategic planning reports have also recognized that people with ABI must be included in planning. They recommend inclusion because people with ABI have similar service needs, and etiology should not be a barrier to necessary services.<sup>192 193 194</sup>

### 2.4.2 The Size of the Public Health Problem

#### 2.4.2.1 Incidence and Prevalence

One of the limitations in using the term ABI is that most studies exploring the size of the problem have focused on the subgroups that make up ABI: TBI, CVA, Tumours, etc. There are few published studies using only ABI. TBI makes up the largest subgroup within ABI, and occurs most frequently in the age group explored in this study. Where

information about ABI was not forthcoming, I have used studies of TBI.

The literature reports that there are real difficulties in accurately measuring incidence and prevalence rates for ABI and TBI.<sup>195 196 197</sup> The following rates have been noted in the literature.

TBI incidence rates vary from 100 to 700 per 100,000.<sup>198</sup> Prevalence rates vary from 200 to 800 per 100,000.<sup>199</sup> In British Columbia, incidence rates for ABI have been calculated at 150 per 100,000 (including children).<sup>200</sup> Higenbottam estimated the national prevalence for ABI as 74.3 per 100,000. He also estimated that 16 percent of institutional beds are used by people with ABI.<sup>201</sup> In Ontario incidence rates for ABI have been estimated at 119 per 100,000, of which 15 to 24 per 100,000 are moderate to severe injuries. Prevalence rates are not available.<sup>202</sup> While incidence rates in Saskatchewan are estimated at 220 per 100,000,<sup>203</sup> these are probably high, given the rates in other provinces.

Costs of providing acute care and rehabilitation services to this population are astronomical. In Canada, it is estimated that costs are \$4 billion annually. The lifetime costs for a young person with ABI living in an institution can easily be over \$3 million.<sup>204</sup> The Queen Elizabeth Hospital in Toronto (which specializes in ABI) found that its annual cost of direct patient care (for people with TBI) was \$10.5 million.<sup>205</sup>

#### 2.4.2.2 Pre-Injury Status

Demographic studies exploring TBI have found that at the time of the injury, people with TBI are typically young, male, never married, living in a private residence, with less than high school matriculation. Most are not working at the time of their injury.<sup>206 207 208 209 210 211</sup> Many have a

previous history of a learning disability, or difficulty learning.<sup>212</sup> In one study, 51 percent of the subjects were intoxicated at the time of their injury, with this percentage growing to 71 percent for those age 26 to 35.<sup>213</sup>

Typically the way the injury occurs (with TBI) changes according to age. In Canada the majority of injuries are the result of motor vehicle, or motor vehicle/pedestrian injuries. These occur most frequently in the 10 to 30 age range. Falls are the next largest category, occurring most often with those under 10 and over 50 years of age. Assaults are the next category, with young children and 16 to 35 year-olds most frequently affected. Sports-related injuries are the smallest category, tending to occur among those under 30.<sup>214 215 216</sup>

#### 2.4.2.3 Disablement among ABI survivors

Many of those sustaining a moderate to severe ABI will require long-term and/or permanent assistance.<sup>217 218 219 220 221 222</sup> There is disagreement regarding how many will require ongoing assistance. Anywhere from 1 to 5 percent will be completely dependent on others for their daily needs,<sup>223</sup> while 20 percent may require some ongoing assistance.<sup>224</sup> Using the Health Activity Limitation Study (HALS), Dawson found that the prevalence rate of disablement for TBI was 49 per 100,000. She felt that this was a conservative prevalence rate, with a more realistic figure closer to 59 per 100,000.<sup>225</sup>

Degree of disablement can affect quality of life. Disablement can affect income level, ability to access the community, care for oneself and others and have choices and opportunities in one's life. Results of Dawson's study on the prevalence of disablement (which used HALS survey self reports from people with TBI), suggested the following:

1) 34.4 percent of respondents with TBI had incomes below the poverty line. This was in contrast to all other disablement populations, of whom 13.6 percent fell into this category.

2) 69 percent of the respondents with TBI had not completed high school, as opposed to 51.3 percent of other disablement populations.

3) 66 percent of the respondents with TBI had difficulty with their activities of daily living (dressing, self care, etc), and/or their instrumental activities of daily living (meal planning, personal finances).

4) 51 to 81 percent reported difficulty with working and 80 percent of these felt that they would be unable to, or have difficulty in changing jobs.

- 23.3 percent were employed. Of these 25 percent were working in sheltered workshops.

- 66 percent indicated that they were completely unable to work, because of the TBI.

5) 10 percent of the respondents could be considered socially integrated. Few were involved in social activities other than with family and friends, occasionally talking on the phone, and shopping. The social isolation was far higher than for other people with disabilities.<sup>226</sup>

Her conclusion was that:

*The handicap, or disadvantage, with which the TBI population lives is deplorable. The majority was unable to participate in the activities considered by society not only to be 'normal' but essential to living. The quality of life of those individuals who are socially isolated, unable to work, and dependent on others for assistance with*

*everyday activities such as meal preparation is undoubtedly meagre.*<sup>227</sup>

While most other studies do not explore disablement *per se*, they do explore the neurobehavioural sequelae to the ABI. Many discuss impaired memory functions, disturbances in balance, disturbances in basic attentional functions, impaired integrative functions, and speed of information processing, impaired language and communications skills, thinking disorders, inadequate awareness, reactive affective responses and damaged self-esteem and ego-identity.<sup>228 229</sup> While these sequelae are important, they do not necessarily address how people's lives progress after leaving institutions. Higebottam reported that up to 80 percent of inmates incarcerated in a lower mainland British Columbia correctional centre are estimated to have sustained a significant ABI previous to their first incarceration.<sup>230</sup>

Other studies note that depression, anxiety, and loneliness are higher among people with ABI than other disability groups.<sup>231 232 233 234</sup>

Most studies exploring outcomes of treatment paint a bleak picture of those with moderate to severe ABI. It is many years (if ever) before survivors can return to a "normal" life style.<sup>235 236 237</sup>

#### 2.4.3 ABI and Quality of Life Research

While there are many studies that explore components of quality of life,<sup>1</sup> and people with ABI, few explore all the domains. In the recent literature, community re-integration of people with TBI and ABI has been used as a measure of quality of life (for an example see Willer).<sup>238</sup> Community

---

<sup>1</sup>For domains see section 2.2.5 Health Promotion and Quality of Life

re-integration is related to quality of life, and can be used as a proxy, but is not identical to quality of life.<sup>239</sup> Even fewer studies have explored ABI and quality of life from a naturalistic research perspective. Some of the studies of quality of life and people with TBI using a qualitative methodology are highlighted below.

Karpman, et al,<sup>240</sup> explored the quality of life of ten (10) subjects, 2-5 years post-injury. One broad domain of quality of life ("Being") was explored. Family members and survivors were interviewed. All participants agreed social isolation was a concern; six reported extreme loneliness.

Kozloff<sup>241</sup> explored social support and outcome, using 37 survivors and 39 significant others. This qualitative study primarily explored the domain of "Belonging". Participants noted an increase in social isolation and loneliness. They became increasingly distanced from friends and spent more time with parents. The importance of developing strong social supports, and including it in the rehabilitation program was stressed. Data collection methods included participant observation, interview guides and unstructured interviews.<sup>242</sup>

Krefting explored social networks, re-defining self, and loss of self-identity.<sup>243</sup> Participants included 21 survivors with moderate head injuries and their families. The primary domain explored was "Belonging" though the other domains were also touched upon. The purpose of the research was to develop a better understanding of disability, from the perspective of people with disabilities and their families, and not overall quality of life. Data collection methods included participant observation, semi-structured interviews and documentary review.<sup>244</sup>

Crisp explored the different experiences and meanings about living with TBI.<sup>245</sup> There were ten (10) participants with TBI, who were involved in a series of 7 - 10 interviews over 12 months. All domains ("Being, Belonging

and Becoming") were explored. Rather than focusing on their perceptions of quality of life, the study reflected on the respondents' experience of TBI and its effect on their lives.<sup>246</sup>

In summary, research into ABI and quality of life have explored some but not all of the dimensions on quality of life. This includes qualitative and quantitative studies. Results of many of the studies pointed to the social isolation faced by people with ABI.

#### 2.4.4 ABI and Sense of Coherence Research

A review of the literature regarding the sense of coherence and ABI showed few studies of the sense of coherence have included people with ABI. There can be little doubt that personal sense of coherence undergoes a major change as a result of experiencing an ABI. The person with a moderate to severe ABI wakes up to a changed environment, externally and internally. Even those with a mild ABI can have significant changes. Many people with ABI (and their families) spend years trying to rebuild lives that are comprehensible, manageable and meaningful.

Charmaz explored identity issues among chronically ill men.<sup>247</sup> These included men who had had a CVA, myocardial infarct or multiple sclerosis. One of the processes she explored was *preserving self to maintain a sense of coherence while experiencing loss and change.*<sup>248</sup> She does not define sense of coherence, so it is not clear whether she holds the same meaning as does Antonovsky. She notes that:

*...preserving self means maintaining a way of being in the world and a way of relating to and knowing self, others and social worlds. Through preserving self, men maintain continuity throughout the past, present and future.*<sup>249</sup>

This quote bears a resemblance to the "Being, Belonging and Becoming" posited by the Centre for Health Promotion and ParticipACTION.<sup>250</sup> in their exploration of quality of life. It also echoes the sense of coherence as described by Antonovsky. It bridges all three aspects covered in this literature review, people with chronically disabling conditions, (in this case ABI) quality of life and sense of coherence. As data collection and analysis proceeded in this study, it became apparent that exploration of sense of coherence enriched the description and understanding of the perceptions of quality of life of adults with ABI.

## CHAPTER 3

### METHODOLOGY

#### 3.1 Introduction

A theoretical framework of empowerment, used in research, means that the acquiring, analyzing and reporting of data must not contradict empowerment concepts.<sup>251</sup>

*It should give voice to the people of concern, allow for paradoxical, qualitative understanding and seek descriptive authenticity.*<sup>252</sup>

The naturalistic paradigm best fulfils this tenet, and was used for this project.

Use of a naturalistic paradigm allows research to occur in the participant's natural setting.<sup>253</sup> The researcher can understand issues from an exploratory, holistic standpoint. Respecting people's subjectivity is important.<sup>254</sup>

Naturalistic research methods allow people to tell their own stories. The process is a reciprocal one, allowing both the participant and the researcher to learn and grow through the interaction.

#### 3.2 Summary of Method

The study proceeded as follows:

1. An application for ethical approval to conduct the research was made to, and accepted by, the University Advisory Committee on Ethics in Human Experimentation (University of Saskatchewan).
2. Applications were made to The Research Science and Ethics Review Committee (RSERC), the Adult Program Manager,

and the Manager, Health Information Management System (HIMS) at Wascana Rehabilitation Centre (WRC) as well as the Associate Vice President of Patient Care Services (Regina Health District - RHD) for permission to conduct the research in the RHD, and for HIMS to contact potential participants.

3. Following approval by those individuals and RSERC, HIMS was given the selection criteria. They developed a list of potential participants. Because there were only five on that list, the criteria were changed (as outlined in section 3.4.1). Enough potential participants were then located, allowing the research to proceed.

4. HIMS sent out letters of invitation to participate and a form letter to send back (see Appendix A). A second letter was sent one month later.

5. Those interested in participating sent the form letter back to me. I contacted them, and arranged an initial meeting with each potential participant. At that meeting I reviewed the research project and their role (See Appendix B). The participant then signed a consent form (see Appendix C) agreeing to take part in the study.

6. There were a series of at least three, approximately one-hour-long semi-structured interviews with each participant. The three interviews occurred sequentially over a three-week period. This allowed me to analyze each interview before proceeding to the next.

7. During each three-week period, two participants were interviewed, and those interviews analyzed. After that another group of two were interviewed.

8. Following analysis, and preliminary interpretation of the interviews, the participants were re-contacted to discuss those parts pertaining to their involvement, and the results of the study. This took place after all the interviews were completed.

The next section explores the methodology in greater detail.

### 3.3 Site selection

The geographic location chosen was in the area of the Regina Health District (RHD). The location decreased the amount of travel necessary. Participants were present or former clients of the Wascana Rehabilitation Centre Division (WRC), and lived in or near the RHD. Wascana Rehabilitation Centre is the major rehabilitation centre in southern Saskatchewan. Most people with moderate to severe ABI are seen at Wascana Rehabilitation Centre. Interviewing took place in their homes, unless they chose otherwise.

### 3.4 Sampling

#### 3.4.1 Selection Criteria

Initially, I proposed to include participants who:

1. had one of the ICD-9 CM or N codes listed in Appendix D as a primary diagnosis

2. had been back in the community between 2 - 5 years

The first year back in the community is spent adjusting to many changes. Two years is the time period in which spontaneous recovery is currently said to occur. I wanted to interview people after that time period.

3. were age 16 - 25 at the time of the injury

This age group lives with any disablement for the majority of their lives. They were proposed as the focus of this research.

4. were residents of the RHD

WRC can see clients from anywhere in southern Saskatchewan. The study was limited to those living within close driving distance of my residence in Regina.

5. had a moderate to severe brain injury according to medical diagnosis

6. had the ability to communicate verbally

Participants needed to communicate verbally. They could not participate in the interviews, if they were not capable of two-way communication.

7. had access to a social worker at WRC.

There was concern that during the interview process issues requiring professional assistance might arise. Having access to a social worker might have been important. In fact, this was not needed by any of the participants.

The above were the selection criteria developed during the proposal phase. Using these criteria, HIMS was able to find five potential participants. Some of the selection criteria were then changed to allow for a greater pool of potential participants. The selection criteria changed were:

2. had been back in the community between 2 - 8 years

3. age 15 - 33 at the time of the injury

This still encompassed the age group in which I was most interested. Nobody was interviewed who was younger than 18 years of age.

4. residents of or near the RHD

The geographic area was slightly widened, to include potential participants from outlying areas.

#### 3.4.2 Selection Process

Health Information Management Services at WRC developed a list of all ABI survivors who met the new selection criteria. They sent letters of invitation to participate to the 20 people on that list. Seven of those letters were undeliverable, six were sent a reminder letter. Eight people responded positively to the letter of invitation to participate. Unfortunately two lived too far away to interview. That left a pool of six potential participants. They sent the form (see Appendix A) back in the self-addressed envelope, indicating:

- their interest in participating in the research
- name, address and telephone number
- age at time of injury
- time since leaving in-patient care
- whether or not they had a social worker at WRC.

Those responding positively to the letter, and fulfilling the selection criteria, were contacted by phone, in the order their response arrived. Individual initial meetings were held to discuss the research in greater detail. This initial meeting allowed the potential participant a chance to "look me over," and began the process of establishing trust. I reviewed the consent form with the prospective participant. The participant signed

the consent form if he/she so chose. All the participants agreed to proceed with the research.

### 3.5 Instruments

This research followed a human instrument<sup>255</sup> approach. The interviews were semi-structured, with some guiding questions, followed up by probes. The probes helped to elicit further information.<sup>256</sup> While there were several areas that I wanted to explore, the participant led the way by how he/she answered the questions.

### 3.6 Interviews

An outline of the interviews is found in Appendix E. The interviews started with "grand tour" questions.<sup>257 258</sup> This allowed us to establish trust and share more general experiences before moving into specific life satisfaction areas. At times, I was more directive as the interviews progressed. This helped narrow the discussion to quality of life issues. Participants usually led the process by sharing their perceptions. More in-depth quality of life questions were left for the end.<sup>259 260</sup> The following domains were addressed: daily activities and routines; family life; social life; work and school; leisure; choices and possibilities; things that make life enjoyable; personal belief systems.

### 3.7 Social Contacts Chart

A social contacts chart (see Appendix F) was developed. With it, participants explored their important personal relationships: those people with whom they were the closest. Use of the chart broke up the question and answer format, by providing a visual stimulus, and a type of

snapshot of support networks. The outer circles represent family, friends, co-workers, the community and professionals. The heart shape, represents a significant other. If the participant had a significant other, they could place the heart on the chart, where he/she felt the person belonged. People named towards the inner section of the participant's circle were his/her closest contacts. Those outside were people who were important, but not as close as those at the inner edge. This was an important tool in the interview process: it allowed the participant and myself to have a visual picture of support systems, allowed him/her to discuss what those people meant to him/her, and how the networks had changed over time, and often opened new areas of discussion. This included loneliness, role of religion, people who used the participant, lack of a significant other, and divorce.

### 3.8 Memory Album

Sometimes it is difficult to remember typical daily, weekly and yearly activities. People with ABI often have memory deficits, that could affect their ability to answer questions around the dimensions of quality of life. To facilitate memory, I developed a memory album. The first part of the album had pictures of daily activities: dressing, self care, household tasks, eating, attending school, working, talking on the phone, visiting with family and friends, exercising. The next part contained pictures of activities that are not generally as frequent: banking, shopping, eating out, involvement in recreational activities, vacations and major celebrations. The participant was shown that part of the album depicting activities that he/she was having difficulty remembering. While it was expected that the album would facilitate memory, stimulate discussion, and allow for in-depth

exploration that might otherwise not occur, none of the participants chose to use the album. While I did not explore the reasons for this, I believe that people may have seen it as childish, or a negative statement regarding their thinking abilities.

### 3.9 Procedures

There were three interviews, taking from 45 to 90 minutes per session. The length of time depended on the participant's attention span and stamina. Interviews usually took place in the participant's home, though one took place in a parental home. Two participants were interviewed three times (each participant interviewed separately), over a period of three weeks. I transcribed and began data analysis after each session. The next group of two were interviewed after completion of the previous cycle. Data analysis was on-going throughout the interviewing stage. After each series of interviews the data were synthesized into an overview of the major themes, including appropriate quotes.

#### 3.9.1 Discussion of the Procedure

All the participants wanted to be interviewed in their own homes. Interviewing in their own homes usually worked out very well. People were relaxed, and open to discussion in their own surroundings. It gave me a visual picture of the participants' homes, and sometimes I met the participants' family and friends. Some difficulties did arise out of this procedure. During one interview a spouse came into the room, and sat through part of the interview, even though it was made clear that the interviews were private. It was arranged for later interviews to occur when the spouse was away from the home. In another case, a

parent sat in the next room. Anytime the interview focused on parents, the participant dropped the topic. The parent insisted on staying in the next room, noting that there were no secrets in that home. In another case, the participant barely whispered while interviewed in the parental home, but was far more outgoing in his/her own home. I tried to negotiate privacy, or in the case of the third example, changed the location to the participant's own home, but this was not always successful, as in the second example. Quite clearly the participants wanted to be interviewed in the locations they had chosen, but it sometimes meant that there were some areas not fully explored.

The process of interviewing two participants per cycle, with transcribing and analysis occurring between interviews, worked well. The information from each interview helped structure the next one, leading to a more in-depth exploration.

### 3.10 The Pilot

Once the ethics committees at WRC and the University of Saskatchewan agreed to allow the study to proceed, the project was piloted with two people with ABI. The pilot allowed me to hone my interviewing skills, try out the interview guide, the social contacts chart, and the memory album. I could develop potential categories and themes for the analysis of the interviews. It also helped assess how many interviews could be handled in a week, along with transcribing and analysis.

The pilot took place from October, 1995 to December, 1995. Each person was interviewed once a week for three weeks. Only when an interview was transcribed and analyzed did the next interview take place. In between the end of the first pretest and the start of the second, there was a

meeting with the research supervisor to discuss the results and brainstorm ways of dealing with problems that had arisen.

Participants for the pilot were chosen because:

1. They were at different stages in their lives when injured, and could represent a variety of people who might be involved in the study.

2. They had good communication skills, and insight. They would be able to provide valuable feedback about the interview process.

The pilot participants were able to give very detailed accounts of their present lives, with some detail regarding the time before and since their injuries. The categories that arose out of the pilot interviews fell into the domains of quality of life discussed in the literature.

One difficulty encountered during pilot interviews was the sometimes thin line between researcher and therapist. This was especially true where I had previously worked as a therapist with the participants. I found myself falling into my well learned role of interviewer/therapist rather than the less known interviewer/researcher. Parallel to this was a concern regarding how deeply to probe, given the already deep insights that people were sharing. At what point was the line between therapeutic probing and research probing broken? I found that I had to double check some questions and probes to make sure that this was necessary for the research. The interview guide was helpful in keeping me on track.

Closure following the last interview was another area of difficulty. I felt that they had shared and given me so much during those interviews, that I wanted to give back to them by sharing the insights that they had given. I found a number of ways around this. First of all, I realized that I would meet with them later to share how they influenced the study, and the results of the work. Secondly, they chose to

participate, and wanted to share their stories. Therapeutically they gained, just by talking through their present and past situation, the injury and its aftermath. As both of them clearly said, healing has to come from within.

The pilot was very successful. I honed my interviewing skills, the interview guide, and social contacts chart. Out of the interviews came potential categories, and major themes. These appeared to fit the domains and dimensions noted in the quality of life literature. It appeared that the interviews would be able lead to a description of how ABI survivors perceive the quality of their lives.

### 3.11 Data Collection Methods

With permission, there was audio taping of each interview. The tapes were then transcribed. During each interview I wrote observations, and enlarged upon these after each session. I kept a reflective journal. In it, I contemplated the session, interviewing style, areas I could improve upon, and what could be re-addressed and focused on in the next session. Some of my early interpretations, "gut feelings", and participants' emotional reactions were included.

### 3.12 Time Line

Interviews began in December 1995, and continued through to March 1996. Data analysis began almost simultaneously with the data collection. Thesis writing began in March 1996 and continued to March 1997.

### 3.13 Analysis

*Analysis finally makes clear to researchers what would have been most important to study, if only they had known beforehand.*<sup>261</sup>

Data analysis involved inductive processes to describe and interpret the findings. Inductive analysis meant that the patterns, themes and categories emerged out of the data, instead of being hypothesized as patterns and categories prior to analysis.<sup>262 263 264</sup> The reflective journal (described above) was of assistance in this process.

Patton describes inductive analysis as involving two processes. The researcher uses categories named by the participants themselves, but can also become aware of other categories, which participants did not name, but that need to be described.<sup>265</sup> He calls the first process *indigenous concepts*<sup>266</sup> and the second *sensitizing concepts*.<sup>267</sup> Both were used in data analysis for this study.

Data analysis began with case analysis of each participant's interviews (which had been transcribed *verbatim*), followed by cross-case analysis of all the cases.<sup>268</sup> Case analysis allowed me to explore the individual experience, while the cross-case analysis showed commonality and differences between participants. For both processes I identified, coded, categorized and sub-categorized patterns. While gathering data, I had ideas about the data analysis. These were noted in the reflective journal.

Rothe's strategy for initial analysis was followed. I began by reading the data from beginning to end. Then I selected the major themes, named and wrote them down. I highlighted ideas and comments, etc, that fell under the themes. Those ideas that did not fit with the themes were explored. New information was compared with that already categorized. I focused on the total picture, as well as the

categories. The categories were synthesized, overlapping data searched out, and the data re-read.<sup>269</sup> I completed a thick description following this initial analysis.

Thick description allows the reader to live the experience and assess whether the study has consistency.

Thick description:

*gives the context of an experience, states the intentions and meanings that organized the experience and reveals the experience as a process.*<sup>270</sup>

I undertook a phenomenological analysis as part of the thick description. The first step of phenomenological analysis - *Epoche*<sup>271</sup> - entailed becoming aware of my own biases, so that I could analyze the data with an open mind. In this way I saw the experience for itself. The second step has been called *phenomenological reduction*.<sup>272</sup> In his discussion of phenomenological reduction, Denzin noted that one should:

- 1) *Locate within the personal experience, or self-story, key phrases and statements that speak directly to the phenomenon in question.*
- 2) *Interpret the meanings of these phrases, as an informed reader.*
- 3) *Obtain the subject's interpretations of these phrases, if possible.*
- 4) *Inspect these meanings for what they reveal about the essential recurring features of the phenomenon being studied.*
- 5) *Offer a tentative statement, or definition, of the phenomenon in terms of the essential recurring features identified in step 4.*<sup>273</sup>

The final step involved a *structural synthesis*.<sup>274</sup> The most essential aspects of the analysis were unearthed, revealing the essence of the phenomenon. At this point I had thoroughly explored all major themes and any discordances, described and interpreted them.

### 3.14 Limitations

Short-term memory difficulties, limited insight, repeated telling of their histories and previous contact with me, were all potential limitations to the research. These are explored next.

i. ABI survivors often have short-term memory difficulties. This might affect their ability to answer questions regarding daily activities. Any long-term memory deficits may affect the ability to remember what life was like before the injury. Indeed, participants had difficulty recalling details of their pre-injury daily activities. All could talk more generally about their pre-injury lives. They could remember their friendship networks, their home, school or work situations, the kinds of activities they were involved in and their hopes and dreams for the future. All remembered what their lives felt like, and compared those feelings to present perceptions. While their histories might have been sketchy in terms of details, they were able to compare: a) their perceptions and feelings about how their lives were going before their injuries, with b) their present lives.

ii. A second difficulty is that ABI survivors often have limited insight. This is usually manifested by a lack of understanding of how they have changed since their injury. Lack of insight is not only found among ABI survivors.

In this study, part of the art of interviewing relied on framing questions properly, or setting up an environment that helped participants develop their own answers. I became adept at recognizing when the participant needed cueing, and gave him/her time to develop in-depth answers. Discovering the core often took a layer of questions, accompanied by gentle probing and re-framing of questions, seeking the deeper perceptions. Where there was no way

around the limited insight, it was recognized and respected for the depth of which the participant was capable.

iii. Some had been asked similiar questions since their injury. I needed to probe deeply to make sure answers were not pat.

iv. In my capacity as an Occupational Therapist, I had worked with both of the pilot participants and two of the research participants. This previous relationship was a problem with one of the pilot participants. I had difficulty letting go of my therapist role, and she had difficulty seeing me as a researcher. A framework was developed to address the issue as follows. If the participant asked questions of a therapeutic nature, I asked him/er to wait until the end of the interview and at that point addressed these issues. Participants asked me about further therapy, assistive devices, accessing educational services for people with disabilities, and help in their personal injury litigation. These were addressed after interviews were completed. In this way I was able to separate the "therapist" from the "researcher," and no further difficulties were encountered.

v. Among those whom I had known previously, I had heard their story in other contexts, and was concerned that this would colour my interpretations. In other words, I might not be hearing them anew. However, a long time had passed since our initial contact, and I was seeing them in a totally different environment. This was not a problem.

### 3.15 Trustworthiness

There are four aspects to trustworthiness used in qualitative research. Those aspects are credibility, generalizability, dependability and confirmability.<sup>275 276 277</sup>

#### 3.15.1 Credibility

Credibility looks at truth value of the study. It is developed through prolonged engagement with each participant, persistent observation, supervisor debriefing and negative case analysis.<sup>278 279 280</sup>

A minimum of four hours was spent with each participant. The time spent is in keeping with the Centre for Health Promotion and ParticipACTION's recommendations regarding researching quality of life.<sup>281</sup>

Negative case analysis actively encourages the researcher to explore for what does not fit, and then analyze its meaning.<sup>282 283</sup> It arises when there are differences in personal opinions, or unexpected aspects.<sup>284</sup> Further interviewing is sometimes necessary to bring understanding to, or avoid misinterpretation of, the negative case analysis.

Supervisor debriefing helped control for any personal biases and inaccurate judgements creeping in to data analysis. It also allowed for reflection. Participant checks, undertaken during the analysis section of the project, confirmed whether the researcher heard what she thought she heard. These involved the participants and myself (one-on-one).

### 3.15.2 Generalizability

There are two types of generalizability cited in the literature: statistical generalizability and analytical generalizability.<sup>285</sup> Statistical generalizability is not a concern to the qualitative researcher.<sup>286</sup> In analytical generalizability the results of the analysis are compared to a theory. This allows the researcher to generalize her/his findings to broader theory. The research can then lead to policy development.<sup>287</sup> Analytical generalizability can be used in qualitative research. In this research I compared the results with and contributed to quality of life and sense of coherence theories. I sufficiently described the method, so that others may attempt to replicate the study in their own settings and assess the extent to which findings of the study generalize to their situation.<sup>288 289 290</sup>

### 3.15.3 Dependability

Dependability shows whether the themes and findings are consistent with the real experience. An audit of the research process (the audit record),<sup>291</sup> regular consultation with the supervisor, and thick description of the research process authenticated its dependability.<sup>292 293</sup>

Guba describes the inquiry audit as divided into two parts. He likens it to accountancy where examining the books makes sure that: 1. the process of entering figures and categories is reasonable, and 2. the product of the process is correct. Within qualitative research the examining of the process of the inquiry is a way of assessing dependability, while assessing the product (or the data) is part of confirmability.<sup>294</sup>

The process was partially assessed through an audit record that listed all meetings, dates of written

communication, and interviews with participants, research committee, research supervisor and others involved in the project. A short description of each event was included.

I also kept a reflective journal. It allowed reflection on the day's events, the learning experiences, interviewing style, decisions around methodology, etc.<sup>295</sup>

#### 3.15.4 Confirmability

The audit trail allowed the researcher and supervisor to confirm that what was completed was well done. The audit trail included how and when raw data were collected, field notes, how data reductions were completed, a process audit and information acquired through piloting the study, use of question facilitators<sup>296</sup>, and participant checks.

People with expertise in both developing open-ended questions, and working with people with ABI, assisted me in designing the key questions and structure of the interviews.

Following qualitative methods, new participants were included in the study until little new information of a substantive nature was elicited, or saturation occurred. There were two people involved in the pilot, and six in the research.

#### 3.16 Ethical considerations

As with any research activity, there are ethical considerations to contemplate. The researcher subscribes to the belief that:

*ethical considerations are inseparable from your everyday interactions with your others, and with your data.*<sup>297</sup>

The choice of research paradigm was partially based upon ethical extensions of the theoretical framework of empowerment.<sup>298</sup>

As an Occupational Therapist, I am a member of the Saskatchewan Society of Occupational Therapy, and the Canadian Association of Occupational Therapists, and adhere to their code of ethics. I am also a Canadian Certified Rehabilitation Counsellor, a member of the Canadian Association of Rehabilitation Professionals and the Canadian Association for Vocational Evaluation and Work Adjustment. All of these organizations' code of ethics demand that I conduct myself appropriately with clients. This same code meant that the project's participants' needs had primacy.

This study delved deeply into the lives and values of the participants. All attempts were made to guarantee that participants were respected and valued. An unforeseen ethical dilemma arose when I began writing short biographies of the participants. I changed the name, and some of the identifying characteristics, but realized that without totally changing the biographies (and thereby making them unusable), people were still identifiable. In a small health professional community like the Wascana Rehabilitation Centre, almost all people with ABI are seen by the same staff. As a former member of that staff, I know that we remember the type of accident (i.e., train-truck, single car roll-over, pedestrian-car, motorcycle-truck), gender, age, working situation, the family situation, and can thereby identify people from such case characteristics. The dilemma became whether to include the biographies, which added to the strength of the overall study by putting the quotes and analysis into a context, or whether to err on the side of conservatism, and make sure that identities were protected. In the end I felt that confidentiality was paramount, and did not include those biographies.

Because some of the discussion might have brought up emotionally trying issues, all participants had access to a social worker for follow-up counselling. As a clinician who is doing research, I was also concerned that I might have difficulty not becoming a counsellor/clinician. Availability of the social worker helped alleviate this concern, by providing an alternative.

All participants were given an outline of the proposed study, and I discussed the research with them prior to signing a consent form. They were informed of the voluntary nature of the study, and issues of confidentiality and anonymity. Additionally they reviewed those parts of the report concerning their involvement. The study was reviewed and accepted by the ethics committees of the University of Saskatchewan in Saskatoon, and the Wascana Rehabilitation Centre in Regina.

Tapes and transcripts of interviews were kept in a locked closet, in my home. The tapes were taken to the Department of Community Health and Epidemiology, University of Saskatchewan, and locked into a cabinet soon after completion of the transcription process. The tapes will be erased and the transcripts destroyed no more than three (3) years after the thesis is accepted.

## CHAPTER 4

### RESULTS

This chapter discusses the results of the interviews, and provides an interpretation of the data. I begin with a brief introduction to the participants. This is followed by a description of how they discussed their lives. I then explore the results of those interviews. Those results begin with a picture of the participants' pre-injury lives, and how the injury affected them. Finally I look at the changes in their lives, and how the participants have learned to live with those changes.

Structurally I have used the Being, Belonging and Becoming dimensions posited by Raphael *et al*, to provide the framework for discussing changes in participants' lives (section 4.5 - Being, 4.6 - Belonging & 4.7 - Becoming). Section 4.8 uses the Comprehensibility, Manageability and Meaningfulness framework developed by Antonovsky. While the Raphael *et al* model was helpful in exploring changes in their lives, it was not as useful in exploring how people adapt to and experience life.

While it appears that these frameworks have been externally imposed, instead of arising out of the data, it was the data that kept leading back to these frameworks. The participants did discuss who they were, what they were part of, what was possible, and what was probable in their lives. They discussed what allowed them to look positively to the future, feel okay about their present lives, how their lives had become more understandable, manageable and meaningful. Further discussion will take place in the following chapter.

All names, locations and circumstances have been changed to ensure confidentiality.

#### 4.1 The Participants

Three women and three men participated in the study. At the time of injury 4 were under 20 years old, the others were 25 and 33. Two were attending high school, 3 were high school graduates and 1 was attending a post-graduate institution. Two were married, with 2 children each: the rest were dating. In terms of work status, 2 were working full-time, one had a summer job and one was working casually.

One person's injury was pathological, the others' were traumatic in origin (car-car, car-truck, single-car rollover, etc). In some cases other people were injured or died in the accident.

All the participants were in a coma of greater than 24 hours duration (Glasgow Coma Scale, or other rating system not available for all participants). They all had extended periods of post-traumatic amnesia. All participated in inpatient rehabilitation, from 6 weeks to 6 months duration.

At the time of the interviews, half the participants were 3 - 5 years post-injury, the other half 5 - 10 years. Two people were working full-time, one worked a few hours a month. Two participants lived with their family-of-origin, one lived with a spouse and children. One lived part of the week with his/her family-of-origin. Two lived alone.

All of the participants identified impairments in cognitive, perceptual, behavioural and physical realms. The type and severity was different for each participant. For example: three of the participants had difficulty with mobility, one used a wheelchair. All had some degree of impairment in balance and coordination.

## 4.2 Discussing Their Lives

The participants' life concerns, dreams and aspirations were similar to those you would expect when discussing anyone's life: health, independence and financial well-being, friends and family, dating, marriage and children, careers, leisure and living situations. Participants spoke in a straight-forward fashion about their lives. At times they used humour during discussions of hardship in their lives, sometimes they spoke with sadness, other times with frustration. For the majority of the discussions, the tone was direct, and often optimistic.

Participants were well able to discuss their lives; they realized their losses; their gains; and the people who were important in their lives. People identified difficulties in physical, cognitive and behavioural areas. They experienced isolation from their peers, and rarely felt part of a community. They frequently had financial hardship, with few options in their lives. Most were unable to work, those who were working were not satisfied with their situation. A return to school was not an option for most of the participants. Access to leisure activities was quite limited. Most noted a loss of ability to participate in sports as a severe limitation. All the participants noted how important their family had become as a result of the injury. All saw slow, but on-going improvements in their situation. With time they were able to take more control over their lives, and manage with what they had. All struggled with and found meaning in their lives. Indeed the majority felt that given everything, things were going as well as could be expected.

*They're not going too bad. I mean everybody would like things to be easier for them. When I take everything into consideration, it's actually going good.*

### 4.3 Perceptions of Life Before the Injury

The participants described pre-injury lives that consisted of friends and family, work or school, sports and other leisure activities. Most had lifestyles that kept them busy from when they woke up, to when they went to bed.

*Before the stroke I got up at 7. One foot on the floor, and the other foot on the skateboard... The kids woke up at 7, quarter after 7, I had to breast feed one, feed the other one. Arthur was working all night, so he would get, He'd come home at 4 in the morning. So he was still out cold. I had to get up and get ready for work. So then I would, when Alice was a baby, before I had Andy, just Alice, I would get up, she would get up at a quarter after 7, I would get up at 7, head for the bathroom, get cleaned up so that by a quarter after seven, I was ready for work. Quarter after 7 I would have to get her up, I'd pack the diaper bag, fed her, did everything she needed. Took whatever she needed downstairs, 'cause my parents would take care of her for up to 3 hours. It would take us into lunch time. I'd come home. (I'd go to work, work the morning, at that time I was loading goods, so if I went to work in the morning, it meant I was hauling. I carried goods up and down a flight of stairs. In 3 hours I loaded a trailer.) Came home, breast feed!... Tried to grab lunch, threw a load of laundry in, did one load of laundry in my lunch break, nursed the kid, fed the kid, woke him up... Yelled out whatever had to be done, or what was going on for the afternoon, took off out the door, and most times... Ate on the way to work in the car. Went back to work, 'til 5 o'clock, 6 o'clock, whatever. By then, I'd come home, he'd be gone for work already, and Mom and Dad, usually about 15 minute overlaps, and Mom and Dad would have Alice. I'd go downstairs, grab her, take her, bring her upstairs... I made her babyfood, I froze her babyfood, I nursed her, I used cloth diapers, I washed them, I sewed all her clothes, that's how my days compared. I'd get up at 7 in the morning and I didn't get to bed before 11 o'clock at night. It was nothing to sew for 5 hours after work...*

The majority saw themselves as living normal lives, a few were extreme risk takers, seeing themselves as living on the edge.

*It was my drug of choice, it was my drug of want, my drug of need. Everything basically I did was based around cocaine... That's why I had to come home...*

#### 4.4 Perceptions of The Injury

The injuries were devastating to all the participants. They saw their lives as turned inside out, as a result of the injury. For most the effects were long term, if not permanent. Where the participant was "at fault," he/she had to learn to cope with his/her own personal responsibility.

*No. I know what happened to me. I'm at ease with it. I know it was purely what I did. And I've just... I've just accepted what I did was something wrong. I know I was wrong... 'Cause I'm a different driver when I'm, you're drunk... But I really feel sorry for my children... Because they don't have a father that can do things with them...*

#### 4.5 Perceptions of Changes in Participants' Lives

When asked about a typical day, half of the participants described days that had little purposeful activity, where loneliness was frequently experienced.

*I come down here, and watch TV... And that's about it.*

*Lately, they haven't - I've not been waking up to have much of a day. (Laughs)... 'Cause I've been like up all night. And then I won't wake up until the afternoon... Then I usually lay around and watch TV, and... And... When I get the energy I go over to a friend's place and play cards or*

crib, something that will keep me busy, cause I don't have a, like a job, or anything else. That's not working out. So my days - there's not too much involved in them right now.

Some handled this by learning to live in the present, and hope for changes, others changed their day/night cycle to be up and with people, and some became angry and frustrated.

*I'm very momentary... when I'm in the moment I'm in, it's important to me, but planning on the future isn't important to me, because it isn't here yet.*

*But I can't really go out there too much, in the winter... Which is depressing, being stuck in this stupid house...*

The rest of the participants were either working or going to school full-time. School and work left them with little energy to do other things. They had to learn to apportion their energy for those things/people that were important outside of work.

*Yeah, I'll come in the door, and I'll see if there's been any catastrophes I have to deal with immediately and I'll go straight to bed. I've a VCR and TV in there, and the soaps are taped and I'll sit down - lay on the bed and flick on my soaps and I'll watch those, and the kids will come in and jump on the bed, and I'll yell at them to get off, 5 or 6 thousand times. Before I go "Arthur get rid of these kids!" and he'll yell at them to stop jumping on the bed...*

*And then I come home, and most times just wiped after work. Just totally wiped... So I'll want to go to bed, but then I'll remember that I taped my soaps, so it's, it's on, (laughs) so I watch it...*

#### 4.5.1 Physical Changes and Well-Being

All the participants initially had significant physical impairments. During the acute rehabilitation phase these improved. All still perceived themselves as having physical impairments, most of them hidden. Of the six participants, one used a wheelchair, and two had some limitations in ambulation and performing two-handed activities. Among the hidden difficulties were easy fatigability, poor balance and coordination, slight muscle weakness and decreased bladder control. Physical disabilities affected many areas of their lives.

*... Actually, I'm, I knit, but crocheting is so painfully slow. Like I, I don't like to do it. But I can do it. Okay, before the stroke I could knit, I could crochet a 4 ounce ball of wool in half an hour, easy. That was giving me lots of time, okay. My last time was 2 and a half hours. Okay, so it's very tedious now, everything's very tedious to do.*

*Well it just used to be my friends right after my accident, like I couldn't do certain things like, well I'm so uncoordinated now, it's not even funny. I hate running. Cause it's too awkward. And the...I - I played slow pitch after my accident, I was - I wasn't as good as I used to be...*

*Um... Well I can't do heavy lifting, because of my back and the knee. Um... I don't even know if I could have a laid back office job, because I can't sit for that long. Like I mean, even if I had a special Obus Forme chair or whatever. I couldn't sit for a long time. Because I know it would start to bother my back... I couldn't be, I couldn't do like a a trucker's job or whatever, because I couldn't, that's a lot of sitting. Um... Excuse me, I don't know. I don't know what kind of job I actually be able to do.*

*Because I can't. Because I don't feel stable enough. To dance... Like I do once in a while. But my legs hurt really bad after I've danced.*

Fatigue was identified as a major physical limitation. Because of fatigue less was accomplished. Participants attempted to minimize it through practising energy conservation, and by developing a routine. While there were improvements in energy level, none had returned to their pre-injury energy levels.

*And that's one of the things, I can't seem to get any energy... I don't know why... I don't know if that has to do with my head injury, that I'm always tired, but I don't know.*

*Well I'm usually tired when I get home. If it's a real bad day, I'll just go and lay down for a while.*

*How am I dealing with it? Um... I don't know. I feel I'm really lazy. And I don't do - I lay around and I, I sleep a lot of the time... But that's about it.*

Participants felt those physical changes affected the length of time it took to complete activities, what they could accomplish and the quality of the activity. For example, one participant needed more than 2 hours to get ready for work in the morning because of physical disabilities. Another fatigued quickly, affecting ability to perform homemaking activities. None were able to participate in competitive or contact sports.

Changed physical abilities had implications as to how participants viewed themselves, for instance, affecting their self esteem, and self-image. Those changes impacted on leisure and occupational pursuits, and affected interpersonal communication (see social interactions section). Most participants had found ways of compensating for the changed physical function, but the memory of previous abilities was a continued source of frustration.

*I find it frustrating. My left hand doesn't work. I, I used to be ambidextrous, my left hand could do just about anything my right hand could. I*

could write with my left hand, and if I was working on the machine, it was nothing for me to make folds with my left hand. Like I would never press in a hem or press in a fold. I could do it just by sight... I need to think twice about it now. I can't even... reach over and pick up my pin cushion without looking at the reach.

It kind of bugs me that I can't play any more...it just gets me, like sitting on the bench... Where I'm like the trainers, I want to go out, 'cause I know what has to be done. Like I wish I could go out and do it, but, I can't so...

#### 4.5.2 Psychological Well-Being

Psychological issues were frequently discussed in conjunction with topics such as loss of friends, family, work, school, leisure pursuits.

Many indicated they had difficulty controlling emotions, whether that be by getting angry easily, or very sad.

*Well I feel like I got a volcano going off in me and I'm about to explode. And I do explode.*

*Yeah, like I can just fly off the handle, just like that...I always had a short temper, but it's shorter, now. Like I, I usually don't think before I do something. Like my - that's what my Mom always says. So. That's what my ex-girlfriend always said...*

*Well, I get... When things start to bother me... As in being screwed around by SGI or whatever, I show a lot more emotions. Like I'll... I'll start crying in front of my parents or whatever.*

There was a general loss of self-esteem and pride in accomplishments. This was especially true where the person realized that he/she was previously able to perform an activity easily and competently, and found it now difficult to accomplish.

Like I guess my doctor, tried to, ...tried to get me more self confidence. Like, he goes "walk with your head up, don't look down all the time" and I do both now, like there's people I don't, I don't know, I don't - okay I think of myself as somebody pretty good sometimes, but then others I don't. So... it's kind of weird.

Sometimes I can't think of certain words that I should be able to think of. Like for example we were playing this game and the answer was "casino". And I was, my partner was giving me hints and stuff to say the word, and I was like can't think of it, and in the background my uncle says " casino." ... So I can't really think of some simple words that I should be able to think of, and I don't understand a lot of things that I should like, for example yesterday, I went to a... horse meeting and I was like... They were all talking and discussing stuff and I was just sitting there... Like I didn't understand... Not at all...That's about it, just... Just being stupider...

Many experienced frustration at how difficult things had become, or became more easily frustrated than before their injury.

...usually what I've done has to be redone the next day... I've been trying to make one ba -one pan of chocolate chip cookies, for 2 days now... I still haven't got it.

...cause I hate waiting... For her to get her butt out to the car... And I hate having to go to her, "can you take me here" I wish I could just jump in my own vehicle and go and say "see you!" ... But I can't... So not only are you bodily disabled, you're disabled in that way kind of too... I can't really go out there too much, in the winter... which is depressing, being stuck in this stupid house. All the time, and nothing to (unintelligible) go outside and enjoy yourself, 'cause in this weather you can't enjoy yourself.

Isolation and/or loneliness was another common experience.

*I'd be too lonely. 'Cause I even get lonely here, when no-one's around. Except I usually get her to leave one of her dogs. Otherwise I just can't handle it...*

Some experienced suicidal ideation, feeling that they did not feel worthy of life, that things were just too difficult.

*Okay. Yeah I just - I don't mind talking about the time I wanted to, the time I was thinking about suicide, because I don't want people to feel sorry for me, so... My social worker said it's a big part of head injured peoples' lives too. So, I guess I didn't feel so different. I, the reason why I, well I'll just give you a basic overview of, that I didn't feel worthy of... I didn't feel as good as I...I guess it was worthy of things any more - like I couldn't do what I used to be able to do, so I was getting depressed. And... Then I - I never tried anything, but I had thought about it. I had just never tried it, 'cause I was scared to, but... I was just - I couldn't... I just - one night I broke down...*

Some had to come to terms with their own actions vis-à-vis the accident before they could live with a sense of ease.

*Well my first year at home, I don't know, I don't know if this is answering your question or not... That I blamed myself of what I had done to me and my friend. And I felt like I wrecked his life... And... I didn't think that I was - it was really worth it anymore. Like I couldn't do things I could do before, so... Why even care anymore?...*

#### 4.5.3 Intellectual and Perceptual Well-Being

Most participants identified changes in cognitive and perceptual function. The changes meant that tasks that were once easy became difficult and time consuming. Memory was the problem most frequently discussed, often in the context of trying to learn new things, and function at work. Participants discussed types of situations where their memory problems posed a danger to themselves and others, for instance forgetting the stove was on. Participants identified difficulties with memory, concentration, information processing and retrieval.

*Like I've noticed... That I can't hold that great of a conversation with someone, 'cause I can't think of what to say, right at that moment. And I think of things that I should have said later.*

*And my writing's not legible sometimes. Especially when I'm in a hurry. So... But, just I can't, to be able to, what I want to write down and process in my brain to my hand, usually I'll start writing it down, and then I'll forget half way through it. So that's why I need a notetaker... That's what it would be during an exam too... I, now, I've requested to write separate from anybody else now. In a different room altogether... 'Cause every time somebody got up I'd have to look around. I guess if nobody else is there, I can't look around...*

*I had, if I put cookies in the oven, I will forget they're there, in 8 minutes. I have to set, I have to set the timer. Anything I do, cook, I have to set the timer on the oven. If I want to stir something in 20 minutes, I have to put the timer on, or I'll forget I've even got it cooking.*

*Short-term memory is a basically, really, really bad. Long-term memory is pretty good... 'Cause 'cause it's like I said, I'll forget something one week, and then the next week I'll look at the calendar, oh damn. I was supposed to do that wasn't I. And then...*

Participants also noted perceptual changes. These included difficulty with map reading, following recipes and patterns, problems with left-right discrimination and neglect of their left space.

*No, I have to read the instructions the day before, in order to be able to - like I have to sit down and read. I never read that. I mean I could cut something out... And just do it. With no problem. I mean I designed clothes before, I made little, I made my wedding gown, I made wedding gowns, I made, I did all that stuff. No big deal. Like this was a minor detail for me. So you just cut this and cut that. And you sit down and you cut out a pattern and you sit down and you sew it. And then, sometimes the instruction sheet got (unintelligible to do with losing it) I mean I have patterns that only have French instructions. I, I actually never used the English and never realized it... Now I have to sit down and open the pattern. I have to read the instructions, piece it out in my head, break it down to, I can cope with about 3 steps at a time...*

#### 4.6 Perceptions Regarding the People in Their Lives

Personal networks dramatically changed following their ABI. For all but one participant, that network became more limited, at least for the first year or so. Family became the main source of support. Participants talked about the loss of friendship networks, and the difficulty of ever establishing new ones. Many felt that they were not part of a community, and indeed that the community did not understand ABI. All discussed the importance of family. Even with a more limited network of supports, participants perceived that those remaining were a more solid support, because they had stayed with them throughout recovery.

#### 4.6.1 Family Life

Relationships with family were perceived as changed as a result of the injury. For the majority of participants, family were not as important previously as they became after the injury. Roles within the family frequently changed. Those who were injured as young adults, poised on independence, reverted back to roles previously vacated. Their families once more became the primary resource for physical, emotional, interpersonal, financial, and transportation support. The emotional dependence often grew as contact with friends became more limited. While most were becoming less dependent the further they were from the injury, all depended on a small number of family members in a remarkable way.

*Yeah. My family has become real important to me. Ever, like - my Mom stayed with me... Well my parents both stayed up here while I was in my coma. Dad got work off for the 2 weeks I was in my coma. And he went back home. And my Mom was up at the hospital every day until I got moved... So... my... my parents are my best friends too. So... they mean lots, more to me now than, they meant lots to me before, but they mean more to me now. I, I don't know what I'd do without my family.*

*... Well, I've, I've, I feel I've grown a lot closer... To my family. And, and that's another thing, growing up, my family means a, a lot more to me. Like I mean the family as a whole. It means so much to me.*

*Family. Basically that's the support group. My family. So I think if I hadn't had that, I think it would have been longer. But because I had the support, of everyone in my family...*

#### 4.6.2 Marriage

Two were married at the time of injury. One of those marriages broke down shortly after the ABI. At the time of the interviews, the participant had quite limited access to his children. Every moment together was important. The family of origin had become the main support for that participant.

*When did your marriage break up? Right when this happened. Like when it happened, my wife couldn't handle it... Because I was supposed to die...*

The second of the two marriages has been put under special stress by the ABI. The participant noted significant role changes, fatigue and less emotional control as affecting marital life. The spouse was viewed as taking on increased responsibility in the family, especially in childcare and homemaking areas. Both had learned to deal with the changes in a way that kept the marriage positive.

*Well I've been very fortunate with my husband... I mean he was there all the time - he was there, right before, obviously before the stroke. And I had the stroke and he was there for me, too. He - it was up to him whether or not I could come home from hospital or not. Like he went to bat and made sure that he did everything, so that he could let me get home. And he knew. I was home all weekend, and he knew. He, he, he was prepared, he was going to have to take care of me... But there was no question, but that, that if I could make it to come home, that he would take me home. So... And he would help dress me, and he... No he, I've got lots of them... Lots of people I can...*

*Usually he goes with me now, he never used to, but now he goes with me to buy groceries. He does all the lifting and everything for me. And, preferably he'll drive me too.*

#### 4.6.3 Significant Other

Those without a spouse found that the world of dating had changed dramatically. It was difficult to start the process anew after their injury. Some of the participants found that they just couldn't attract people anymore, while others found that they attracted people who exploited them. Establishing positive long-term relationships became difficult for all the single participants, though marriage remained a goal for most.

*All my exes came to the hospital to see me and stuff, and took me out and stuff but, now that I'm home, they don't even phone me or anything... Which I don't understand at all...*

*Okay this is the way I, I see it. Like when I was in high school I was one of the wanted guys. And now, ever since the - actually ever since after my accident, it's totally changed. They don't see me as the same person any more. I don't know if I have some deformity or something, or what it is. I guess I am a different person now... Like before, I was, people would want to talk to me, like "hey I talked to Dan. Like ooh. There's something there." But now, nobody will talk to me, or, or they feel intimidated to come over to talk to me...*

*But they were after one thing. And one thing only. You know? That wasn't very nice. But this one guy I really liked. But... He was just in it for the... sex*

#### 4.6.4 Friends

All but one participant found that friends disappeared in the first year after the injury. Loneliness was a typical sentiment expressed. This remained a source of sorrow and frustration for years after the injury. Many discussed going through a period of introspection, trying to reassess self, what friendship was, who were

acquaintances, who were friends, what peer pressure meant. Some were able to turn the negative into a positive.

The negative statements included:

*I've lived here for now almost three years, and I don't know that many people, I don't have that many friends, so I wish I could... How would you say it... Not - well relate more with other people I guess and make more friends.*

*I don't even really have a friend, to call up (unintelligible) and say hey - let's go and do dot dot dot... Like sure I may be disabled, but I can still talk on the phone... But they don't even phone me...*

On a more positive note:

*No, I didn't care what people thought. That was good. Because before my accident, I get the impression that I was. I gave into a lot of peer pressure. But after my accident I didn't care what anybody thought. I thought - well I did at first. Like when I was first... I don't know... When I was first in the accident. Out of the hospital... I guess, I really cared what people thought then. But, then I thought - why am I doing this? I'm different than anyone else. (unintelligible) Then I never did. So I'm not going to do anything -like just for them. But I do care what people think now. But I didn't then, like it was a while in my life. Probably about 2 or 3 years I didn't care what other people thought.*

#### 4.6.5 Social Interactions

Most participants noted a decrease in the number and quality of social contacts and interactions since their injury. Ability to interact in the community and with others in general was seen as dependent on: 1. ability to communicate; 2. accessibility of the community; and 3. how the community and individuals reacted to them. As expected, those working and going to school had more social interactions than those who were more house bound. When I

explored their closest social contacts before and after the injury, the change was quite marked.

There were fewer friends, co-workers and significant others in the participants' lives. They felt closer to family members and professionals. After their injuries, professionals usually meant their general practitioner, though social workers also played a prominent role.

Professionals functioned as the participants' counsellor, and sometimes were seen as friends. Previous to their injury a significant professional was usually a teacher. Family included parents and siblings. Most indicated that they did not feel part of any community, since their injury.

Often participants saw themselves as treated differently because they had a disability. They felt that society's lack of knowledge about ABI affected their ability to lead normal lives. Participants met up with the handicapping conditions of disablement when interacting with employers, people on the street, teachers and friends.

*But... I guess SGI is still treating me like I'm... still in a coma kind of... Basically they're treating me like I'm still dead, or like I'm dead.*

*I've had a lot of people come to look at me... they've heard that I've had a stroke, so they come just to look at me. To see how I'm doing you know. Like they could tell to look at me that something's weird. They're expecting me to drool, and go do the things that they think I should do. I've had so many people say to me, "but you don't drool." ...*

*I was looking all the time. And I was, I belonged to the cooperative program. And that was, that was I guess there were better students, that were, that I guess were more involved than me, like with better marks and stuff... I don't know, I think some of them, this is just what I think, because... Some of the girls, I should have been, but I didn't because of my disability... And like*

when I was, like not at school, but when I was applying for other jobs, They'd say "oh, do you have a disability?" "Yeah." "What kind of stuff do you" like wheelchairs. "So what kind of stuff do you want us to do?" And I went "nothing, I don't need anything." And then they would get suspicious. Like you know! Cause I have a head injury they would kind of get... Scared...

Participants coped with this in different ways: by ignoring people's attitudes, being understanding of others' ignorance, attempting to educate the person, or trying to hide the disability. One participant with a hidden disability wished that others realized that the participant had disabilities.

*Well, I, before, when I was first out of the hospital, people would introduce me, as: this was the guy who was hit by the semi. I didn't like that, but my parents told me that well it was well publicized so... Everybody knows about it so... Then now I wish people knew about it, like, they, he survived that and well we'd better be careful now, or not expect too much because... He does have a head injury. And he doesn't look disabled or anything, but in here I am.*

Some participants noted that people may treat the person with ABI differently, but in a more caring, protective way. This was especially true of family. Sometimes family was seen as taking on more than necessary, in their need to protect the participant.

*Well, I find people are more protective of me. But, it's right away, "Are you okay?" not "Did you have a rough night and you're tired and your kids were up?" no - Its "Are you okay?" "Are you going to pass out?" and that sort of thing. Things like that.*

#### 4.7 Perceptions of Changes in Choices, Opportunities and Activities

The area of choices, opportunities and activities is complex. While participants discussed a change in the choices in their lives, the types of opportunities they had, and the activities in which they could participate, these changes were not always negative. For example: those who viewed their lifestyle as negative before their injury could now choose a more positive one. Those with the most severe restrictions took pride in the choices they did have control over. While most discussed difficulty making decisions, relying on others was not necessarily seen as negative.

*I usually ask one of my sisters to help me, because I can't make decisions at all.*

*What kinds of directions could you take your life in at this point do you think? ...Depends on what I want to do. I'm quite happy going in the direction I'm in. It's meeting my own needs of it. I'm not an ambitious person. The world sort of just comes by, and I catch the train when ever I feel like it, and take it where it goes.*

Participants noted that activities that were once easy had often become difficult and time consuming. Lifestyle had to be restructured, to decrease stress and fatigue, or because of changed abilities. Physical limitations often meant that self-care activities took longer. The few that needed assistance in basic self care noted that this affected their self image.

*We set time for anything, we have our calendar, like the kids, - the kids want to do something, they'll come and tell me and then we'll plan for it. We plan everything out. Everything's planned ahead of time. We will set our Christmas tree up on Friday, we will go, Daddy will take them Christmas shopping on Sunday. And, while Mommy's*

at work, and we will go and see Santa on the end of November... And we do this and we do this and we schedule everything ahead of time.

*I'm disabled towards jobs, and I'm disabled in, in ... {deleted to protect confidentiality}...in other ways I'm not disabled because I know I could have been a lot worse. Then I, then it came out in the end. And, that's... a positive look. I mean I could have been a lot worse then I am, now. But I still am not where I would like to be. I mean I wish I was like through the accident.*

Those further along in recovery had learned to accept the changes and sometimes used their disability to help them get ahead, or to get extra assistance.

*... Not much really. Really it doesn't bug me, sometimes I like to use it to my advantage. And like not take advantage of it for money and everything. But like if I have to use it towards my advance, like schooling and everything, like I'll use it, like I can't help it... It's not an excuse, it's - how would you say it? It's more or less reality. Like it did happen, so... I think by me being able to use it, in that way, I've learned to accept it.*

A few participants had difficulty completing homemaking tasks. This depended on physical status, stamina and initiative. Whether or not this affected self image depended on the participant's approach to homemaking.

*What are the things that you need help with?  
Like... With my balance and with my makeup and putting my contacts in, and cooking, and... the list goes on and on and on.*

#### 4.7.1 Finances

Financial restrictions were viewed negatively by all participants. Most lived on quite restricted incomes, or were dependent on their families. Most had waited for a financial settlement from their injuries for years. There

was a real frustration with how they were treated by insurance companies.

How about things around your legal stuff, the settlement stuff. Do you get input from the rest of the family as well, on that kind of thing? ... I'm basically not included. And don't know what's going on... I wish that I would be included already. Like I know I'm head injured, and I was in a coma back then, and that's why she was handling it there for that long, but now I'm not in a coma no more and I can handle it myself I think. And I said that if I don't understand... anything then I'll just say, 'Could you explain that?'

Well like they, had a Board of Discovery. And then they said - okay the Board of Discovery is fine, or what ever. And then we went to a - well it was supposed to be a pre-trial, and then - so they - about 2 days before the pre-trial they cancelled the pre-trial and said they wanted to have another Board of Discovery. ... Um... To ask me more questions or whatever. So we said fine. And then, we had to wait about 2 months for that next Board of Discovery. So I was living up here, and I was supposed to have that other Board of Discovery and I went home, the night before the Board of Discovery. I took the next day off work, that's back when I was working, um... I sat at home... The Board of Discovery was at one in the afternoon. They called at 11, the morning of the Board of Discovery, and said that they didn't want to have the Board of Discovery any more. So... I mean.

Some had gone through periods where they could not control their own spending. Some had gone into debt by misuse of credit cards, others by gambling. While they viewed those debts as negative, they also saw others' attempts to control their financial matters as even worse.

I charged every credit card I had up to full hilt. I just went absolutely panicked. I just - I should have had my credit cards taken away from me! But I, nobody - nobody was going to take them away from me! I'm a responsible adult. They weren't going to take my cards away from me,

*nobody was going to say I couldn't cope with it! They weren't going to degrade me like that, they were going to take and support me. And boy did they end up supporting me! I charged everything - I panicked.*

It can be difficult for people with ABI to make long-term goals, but easier to break things down into smaller, more reachable components. Financial matters may further limit goal-setting ability.

*Are you a person who will set personal goals for yourself? Not really, just start walking. that's, that's the goal yep. Yep. That's a definite goal. that's something I will do... No doubt about it... I just set a goal and I just keep attempting to achieve that goal... No matter how outrageous it is... Because every journey starts with the first step.*

*Do you do any goal setting for yourself? Very short term... I break everything down. It's almost boring me, but I break everything down. And get it all done, but in its turn. But it works for you? Well yeah, it works for me, and we get it done and the kids, the kids seem a little more patient, because they know its coming.*

#### 4.7.2 Getting into the Community

Four participants had driver's licenses, though one frequently did not drive because fatigue levels affected the ability to drive safely. Those without a driver's license depended on others for transportation. People felt strongly about driving, and the type of freedom it gave them.

*I didn't have the wheels. I didn't have the freedom to go where I wanted to go, when I wanted to go, what I wanted to do, whenever. Like... If I wanted to do something right now, I can. And if I don't have my wheels I can't and it just kills me. I hate that! If I had to be confined to something, I could never do it... I like my*

freedom, and I like... the ability to go where I want, when I, when I want... So if I had to rely on the bus or anything it wouldn't be good, 'cause well I guess the bus goes around every once in a while, but it's not, like if I want to go now, I want to go now, not a week, or not a week but not a couple of hours from now. I want to go now. A couple of hours from now I may not want to do it.

You pretty well have to wait until others can take you? Uh huh. They're, when they get off of work. Or something, or it's when they get off of work, if they have time for me... which they usually don't because they usually are cleaning and stuff. So how does that feel? Poopy. 'Cause... I'm kind of stuck... All day...

#### 4.7.3 Leisure Pursuits

Typically those participants who were injured as teenagers discussed changes to their leisure pursuits as being negative. For most, sports were either no longer possible, or possible on only a limited basis. Those sports still available were often perceived as less enjoyable. Where friends were no longer available, leisure time was spent with family, playing cards and video games, and watching television.

Well usually the guys I guess the guys in the hockey team are my friends. My brother - I'm pretty close to my younger brother now. So... And the guy I was in my accident with, he's part of the team now so, I'm usually with him, or we go to the bar, for when they go for a couple - I guess I used to go for a couple but now I usually - I'm home early, go to sleep.

Then Saturday I'll usually spend like a bunch of time like with my Dad and I, I, do a lot with my Dad and his friends, cause his friends come over on Saturday, and I get along with them. And so we like play crib, and go and play pool and you know... Then Saturday night I usually watch the hockey game...

#### 4.7.4 School

Returning to school was difficult for all who made the attempt. Participants noted that they had to work far harder to get similar results. All found learning more difficult, especially new learning. Half of those interviewed could not even contemplate returning to school, because of recognized difficulties.

*My memory was worse than it is now. Which is hard to believe, but it is. It was really bad, and I couldn't remember a lot of things. Except for tests and stuff... I used to hate writing tests, 'cause I couldn't remember stuff... And I couldn't really underst- comprehend some stuff. So it was really hard that way... But then again it depended on the teachers, sometimes. But...*

*My school marks. Way back then, were, well I had a 70 average without having to do any work at all. And since the accident I had a really low 50s average. And that's with doing - where I worked my butt off doing like, and I had 50s. Well I can't say I worked my butt off. I did a lot more work than I did before the accident...*

*Do you need to do, a lot of kind of repeating to get stuff into your head? Just studying wise, or... Yep. 'cause I, I - my memory, my short-term memory is - it's not shot, but it's, it's terrible. I guess other people's - nor - normal people's is, but mine is pretty bad. And I tend to have to repeat it, or learn it, something like use it practically to be able to learn it. I guess everybody has to do that, but I, I can't like people can memorize their whole course. I can't do - I have to learn it. So...*

#### 4.7.5 Paid Work

Only 2 participants were working full time. One had had her job previous to the injury. Her return to work was successful, however she identified the costs involved: little energy left to give her family, or to pursue leisure

activities. This was balanced by a sense of pride in having returned to her job and performed adequately. The other began working permanently 8 years after her injury, having first completed high school and post-secondary school. She also found that she had little energy left after a work day.

*I just had no choice but to turn it around. I had, had to go back to work. He didn't have a job. I had a job. They informed me at the disability office that if I didn't go back to the bank, they would find me a job that I could do, and I would have to take it, or lose the disability... And I had 17 years seniority on that job and there was no bloody way I was going to a minimum paying job! ... I had a job where we were able to live on my salary, although maybe not in a high class way, but were able to live. I don't think this is quite the slum. I mean it's not too bad a place. It could use a good cleaning, but it's not too bad. But... I was not going to a minimum wage job that I didn't even want because they told me I had to. So I didn't have any choice but to come back to work.*

All participants pointed to a lack of career choices for themselves. Not only were their changed abilities a limiting factor, but so were the reactions of employers.

*... Because of my disability I can't do certain things that I might want to do, sometimes... Like different areas of... Like I think secretarial work is... actually when I went to school... It was the only kind of work that I could do...*

*And I don't know if that has just been drummed into my head, that I have to work twice as hard to get just as far as anyone else... Or if it's, I think it's kind of a reality, because... People look down on you when you say you have a disability. And you have to show them, like I stay at work lots of times because I think, I don't think they would do this, but I think - well some days I think they would - I think they look down on you because you're disabled. I don't think they, they think that you have the qualifications. So I work really hard. I work*

*damn hard. And I still don't get the recognition I need. But... That's beside the point. But still... A disabled person - it's always that - it's been said that a disabled person has to work twice as hard to get as far as an average person... And I think that is really true...*

All but one participant wanted to work. Participants saw paid work as proof of their recovery. Many had difficulty imagining the kinds of careers in which they might be successful.

*Yep - you know, actually I, honestly wish I could work again... Like I haven't worked in, it'll be... 4 years this summer since I worked last, and I don't know if I could work a full 8 hour day. So I wouldn't - I'd like to see if I could work again.*

#### 4.7.6 Summary of Changes

The above discussion shows that the participants had undergone real changes as a result of their injuries. Most of these changes had made life more difficult. Whether one follows the framework proposed by Spilker et al, or Raphael et al, quality of life had been affected in a negative way. People's lives had become more fragile. They had less access to a community, less access to work, friends, marital partners, less financial stability, lowered physical, cognitive and behavioural health, fewer choices and opportunities.

Participants also identified real gains. Their families had become closer, they had realized the importance of family to their lives. Constant (though slow) improvement in their abilities continued. They felt that they had become stronger as people, for beginning all over again. They felt that their life priorities had become more appropriate since their injuries.

*It's an awful way to have to learn things, but it's, it teaches me about the ability of humans to get over it. To live through it. That gives me great hope for a future... I don't mean to speak over you or nothing, but that's just my attitude it gives me great hope for a future... There's nothing out of the question until you die... And you can't have it no more. Nothing out of the question until you die. You can do anything as long as you're alive...*

There was a real sense of optimism as people talked about their lives. This seemed to arise out of their belief systems, and the strong family supports. They had found meaning in their lives. This allowed them to go beyond the devastation the injury caused. The next section will explore how participants discussed learning to cope with their changed lives, how they have adapted, and gained in their lives.

#### 4.8 Perceptions of Living with those Changes

##### 4.8.1 Role of Survival

Most participants noted that family were told that they probably would not survive the injury. Once they survived, family were told that the person with ABI would likely be a "vegetable". At almost every step along the way the family was prepared for a worst case scenario. But the participants in this study went beyond the expected outcome. During the initial post-comatose period, participants and their families identified almost daily recovery of function. This was a real source of optimism. All had beaten the odds, all had worked hard at recovery, and come further then expected. Not only that, all could look back and say compared to the original prognosis, or 6 months, or one year, or two years... after the injury, their lives were going well.

'Cause of my accident. When I got out of the hospital, I was thankful that I was, like I was told how lucky I was, and I was thankful for it, and... That, that point on I wanted to... Like, I don't like sleeping in that much, because... I've, I was in a coma for two weeks, there's two weeks of my life I'll never get back. I don't, I don't want to sleep my life away. So... I guess, I want to experience life now I guess. I won't, I don't go out and do all that gung ho things or anything still, but... I want to exp, want to experience what I want to...

Like they said I wouldn't walk again, I'm walking. Like I don't know, I just kind of have this attitude about me. Like, "you say I can't do it - you want to see me!" it happens at work to - like "Frances, you won't be able to get that done will you?" Like watch me. 'Cause when people say I can't do something, I'm all the more determined to do it.

While recovery had slowed for the participants, all still saw gradual improvement. A new way of doing things, a new way of being had developed. The participants had found themselves following a different path, with different abilities, but hoped that the path would lead them to circumstances not too different from where they were going before their injuries.

I'm just going in a little bit of a - I'm going down the same path, I'm just taking a little different road... Like before, to save money, to get our bud - to make it through the month I sewed all my kids' clothes. I made their undershirts, I did everything. I sewed all their clothes, I made all their gifts, I, okay I did all that. Now, I will, I still make all, most of our Christmas gifts that we give, but I don't maybe sew as many clothes up for the kids, as much as I go to second hand clothing sales, or take advantage of garage sales, or okay I, I just don't quite hit the same, I'm going down the same road. It's a little different.

#### 4.8.2 Attitude to Limitations and Losses

Many participants discussed the importance of accepting those limitations. People continued to work on changing the limitations, but felt more peaceful about their present lives. Some did not accept the limitations to life choices. Indeed some things were recognized as harder to accept than others. The current inability to ride horseback was not accepted by one of the participants. For others, it was the loss of friends that was unacceptable.

*It's like planning a budget, you know you've got to compensate somewhere for something else.*

*Yeah, I've learned to accept it more and more, that I have a head injury and I can't do what I used to be able to do. But still a tiny, a little small fraction of me that can't accept it yet still. It's been like 4 years. Has it been 4 years? Oh God it has too! (laughter) Yeah it'll be 4 years this June... It - I'll learn to accept it, fully I guess, just, I guess what's hard for me is not to accept it, is other people don't realize it. Like they expect me to do what I was able to do before. I mean I can't. I try to, and if I fail, I hate always saying, well it's because of my head injury. I think its an excu - I think they think it's an excuse and sometimes they say that, but...*

Participants recognized that there were many sources of frustration and limitations to their lives. It was often hard to see what had been accomplished in a day, because completing activities took so long, and often had to be re-done. But participants took pride in the gradual positive changes that occurred, for instance living on their own five years after the injury.

*What's it been, then, if it hasn't been easy?  
HELL. It's been hell. ... Uuhu basically. In what way? I've just tried so hard to get so (unintelligible) to normal, and I've worked so*

hard and it doesn't seem to be, I know it is kind of, but it doesn't seem to be paying off like it should... Like, I should be riding my horse a lot better than I am, I feel... And I feel that I should be walking a lot better than I am, and I feel like with all my therapy and everything that I should be talking a lot better than I am and I feel that if only I had worked harder, maybe it would have happened. But I'll never know... I'm trying to work harder at therapy and stuff now, but... who knows, it may be too late.

I've been living on my own like for it'll be 3 years in September, and I love living by myself, I couldn't live under my parents again... 'Cause I like having my independence, and being dependent on myself, so. In that way I think I've grown up, because I've become dependent on myself, I'm not dependent on my parents any more.

There was also a recognition of losses: friends, work, abilities. Most preferred life before their ABI, but without any of the negative lifestyles in which they may have been involved. They felt that they had learned and grown through their injuries. Knowing there were good things before, helped participants rebuild their lives. Memory of the past was a double-edged sword, bringing with it both positive and negative aspects, memories of past abilities, but also a reminder that life can go well.

And in a way I'm kind of - not thankful I had my accident, but it's been a positive more than a neg - guess I can't say that!!!! (Laughter) ... it was probably, not as much good as bad has happened, but, some good has come out of this, like with me taking school the way I do, that was probably kind of good too. And why I'm going into the field of work I'm going in to, is 'cause of my accident too, so... I guess some good did come out of it...

So I've been concentrating more on, I read recipes, I used to read patterns. I used to read patterns in all my free time, now I read recipes. I read things on how to cut back on this, or how to save this or how to - to redo this, or how to make this work for this, and how to use this and

recycle this, and you know, making skipping ropes out of plastic bag, you know things like that. That's the kind of thing I'll, I'll read now, where before it was how to, I would sit down and learn how to make a craft. But I, I've changed my way of thinking that I did it, okay now I'm going to go in a different direction...

I haven't accepted them. I expect to be able to change them. Some day. I don't know when, or anything, but I expect to be able to... okay ... so maybe I'll re-phrase it, how do you, how have you learned to live with the way things are right now? ... Do I have a choice?... Not really. I just have learned, because I really don't have a choice. So have you gone through different feelings about that? ... No just depressed really, lots... Is that how you're feeling today? Talking about it - yeah... (laughs)

#### 4.8.3 Role of Time

Time was important to many of the participants. Over time the feelings about successfully completing activities they were capable of previous to their injury, were no longer as fresh. Inability to accomplish the same thing was not as frustrating. Skills not previously emphasized were developed, so that the person had a new sense of self-worth. For some participants the blunting of either the memories of abilities, or how those accomplishments felt, was key to developing a positive perception of quality of life.

Oh yeah... I'd say that the worse thing is that, I mean as phony as this sounds, if I think back and like if somebody said this to me, I probably would have thrown something at them, was: "give it time, things will get better" but it's like I said, once you start forgetting how it was, it gets better. Like it's like a bad affair. You know. Like once you forget what the asshole was like, you can get on with your life type of thing. Like once you start forgetting what it was like before, you can start - I mean I know I could do things better, and when I'm in the

middle of something, and I'm pushed for time, and I'm goofing, and I'm throwing yeast all over the house, because I go into a jerking spasm, and I and I get upset, and I'm ready to cry. I know... I know I did it better before, it's not that I don't know that I did it better, but I'm starting to forget just how much better I could do it. And it's getting easier. But it's just a matter of forgetting.

#### 4.8.4 Family and the Environment

Participants often discussed being surrounded by love and caring, and living in safe physical surroundings. This gave them a sense of security and well-being. Thus their environment had a real impact on their overall feelings about their lives. The participant who lived part of the week in an apartment talked of his discomfort there and how it affected his emotional well-being. Coming home to his parents every weekend was a holiday. Another talked of having lived in a long-term care facility, and how it made him sick. He indicated that without love around him, he had difficulty surviving. Once back in the community his sense of well-being improved dramatically. Another discussed the warmth and love of family along with the frustration of the physical isolation of the home.

*Well it is, every, every Friday I look forward to coming home for the weekend. Because our, our family is so close. Like my, my, my brother and sister-in-law, they live, like a ways away here, like still in Weyburn, but like another part of Weyburn. And they usu- they come every, every Sunday for supper, Sunday supper is a big, big deal here... I come home with my sister, and Mom and Dad. And Mom and Dad enjoy it too, 'cause they get all the kids home. Like, around the same time...*

*That I feel I can count on? Oh yeah. Yeah... Um, I've always had a very close family. My family is, is very super close to me. I can ask them for anything, they would do anything for me.*

Oh yeah... If you didn't have a little love, you'd die. You'd dry up and die. Is that what was happening to you at {name of place deleted}? Yep. I seen old people who didn't have nobody there, I just felt like dying. I knew I had to get out of there... And I did something about it! I got out of there!... because if, because when you're around a lot of people, it don't really care about anything... you get like that mentality, you don't hardly care about anything. And you just dry up...

I wish I could just jump in my own vehicle and go and say "see you!" ... But I can't... So not only are you bodily disabled, you're disabled in that way kind of too, and it's all the harder out here because we're on a farm. Sure I have my horse and every thing, but I can't really go out there too much, in the winter... which is depressing, being stuck in this stupid house. All the time, and nothing to (unintelligible) go outside and enjoy yourself, 'cause in this weather you can't enjoy yourself.

#### 4.8.5 Managing their Lives

Participants had differing amounts of control over their lives. The ability to compensate and manage their own lives was viewed as important. How this was actualized was dependent on the individual participant and his/her abilities. All took pride in having learned to manage within their capabilities. Even those with the least amount of control (most dependent on others) were able to identify areas where they were in control, and the degree to which they themselves managed their lives. Some were frustrated by areas where they had difficulty managing. Others had accepted what they couldn't change.

Are you able to push that yourself? ... Or do you need somebody else to push for you? ... Can you navigate the wheels on it? Yep... But I tell them not. (Laughter) Is this laziness coming through! Yep!!! It's true! So could you be doing more than you are? Yep!

I can sew... with less stress? Less stress now, because I'm not, I know I could do this better before, but I'm trying really hard not to do the things I did before, I'm still sewing, I'm still doing knitting, crocheting things like that, but I'm trying to knit things that I wasn't knitting so much before. I'm trying to focus more on things that I wasn't doing a lot of before, because then I can't compare it as much...

... I think I'm basically on the same path, that I, that I kind of wanna be. So I think I'll stay here... Are you free to chose that path? ... no. 'Cause if I wanted, because of my disability I can't do certain things that I might want to do, sometimes... Like different areas of... Let - I think secretarial work is actually when I went to school... It was the only kind of work that I could do...

Coping was a way of life for all participants. It was the way they got around or minimized the limitations posed by the ABI. Coping mechanisms became automatic over time. For some this included the use of aids to assist them in accommodating to their changed status. People who had deficits to immediate and short-term memory learned to use appointment diaries or other reminder systems.

Uh hu. I compensate because I know. Like at work I, I, work on a computer, but I stand up. I'll get up and demonstrate for you! I will demonstrate. I have to stand like this, okay. So if I stand like this, I forget, I lean, and I fall over. I have to stand with my legs apart and I have to. And if I know I'm going to be typing on the computer for a few minutes, I have to pull the chair up and sit down on the chair to do it. or I'll fall over... I prop myself up against things and I'll...

Like I always make notes to myself, 'cause I'll forget to do things. Like I have a daily schedule I have to write out, like in my room 5 things I have to do each day, or whatever. So I feel stupid at it, but... I have to do it.

Humour played an important part in coping for most participants. It helped deflect sorrow and grief, and allowed the person and their family to get on with their lives in a more positive framework. Humour also kept participants intellectually active. One participant felt her sense of humour was the one positive thing about her personality. Another chose to act the clown with friends, doing things that others saw as outrageous.

*Me?!!!! Who me make fun of it?!!!! Yes I try to - other people get upset if, if you get so upset that you... other people get upset, if you're upset and there's basic things and it always lightens every one else up. But I tell people, cause it would be real easy to - okay I have 2 choices, I can either laugh about it, or cry about it. And I'm tired of crying. So, I might as well start (laughing) now.*

*It plays a big part. That's kind of the only thing that I have going for me anymore. Like I can always make people laugh. Like I've asked my sisters I said "so what do I have going for me now anyways?" and they always say "well you always have a way of making me laugh."*

*Oh yeah. Yeah I mean that's - like and the, the kind of, when I be funny, it's not like... I don't, I don't cut down other people or whatever, you know, and I, I it's not that the, well sometimes the people are laughing at me, I'll admit that. And sometimes with me, or what ever. But a lot of the time it is, they're laughing at me, but not because I'm an idiot. You know, because I'm doing something stupid, like.*

*Well, 'cause some things you should take seriously, or you shouldn't or something. About this mad thing, if I took everything humorous, I would never get mad... and that would be so relieving, but... Some days, it's not that possible. But, I don't know. I guess laughter is the best medicine, because... It's been good. Because you get to laugh, like make fun about, like if they make fun of you or something. You get to do it right back at them.*

Those around the person also learned to accommodate. For example children learned to respect the parent's fatigue level and always planned family activities ahead of time. Co-workers would leave reminders, helping the participant remember tasks.

*I would write it on it and stick it up. And then one day all of a sudden I come in and there's like notes there! and I'm going "oh!" and they went "that's your place isn't it?" They had, they had decided, they, I mean people at work, they just go okay fine, she doesn't make any bones she can't remember, we're not going to make any bones... I cannot remember, and they step back and say okay, she can't remember, that's all there is to it, she's going to live with it. We're going to live with it...*

*The kids are getting older enough, older now that they're realizing that when I say enough today, they know this is enough today. That if they push it any further, we're going to blow.*

A support network was seen as important in managing their lives. Participants did not feel they needed many people. Most felt that those remaining in their lives had proven that they were there for the long term. Knowing there was someone they could turn to and trust was crucial. All participants felt they had at least one person fulfilling that role.

*No. My family's important to me... I don't have that many friends, I haven't worked in so long... Well I'm not really that close to my, the therapists that I worked with at... and ... for the professional people, it's good to have people that you can go and talk to, and I wished I knew more people in the community. Because then, it's like, it's coming now - it's not what you know, it's who you know. But...*

*Huh! But I think if my support group wasn't as strong as they were... I don't think I would have come out of it as fast as I did... 'Cause although that's a long time, that's pretty*

*remarkable considering... how badly I was... hurt... Cause like the coma for 2 or 3 months, well like you can't even imagine that.*

Participants felt that even with severe limitations, they had choices. These went from choosing to let others push the wheelchair, instead of operating it independently, to choosing when to shop, visit relatives, etc. They made at least some of the decisions in their lives. Most recognized a need to consult others for major decisions.

*I feel it is. I know it's supposed to be my decision. That's why, that's why my Dad didn't take it to court until I was old enough to sign the papers myself. Like he didn't wanna, he didn't wanna go and settle and then have him sign and regret it later in life. So he said he was going to leave it up to me, as it is... And I make my own decisions or whatever. But, a lot of it will still be on what my parents say. And what the lawyer says...*

#### 4.8.6 Perceptions of Meaning to Participants' Lives

Finding meaning to their lives was important to all the participants. That meaning was unique to each participant. To some it was a religious meaning, to others it was not based on a spiritual plane. At some point, participants had to believe in themselves. They noted that without that belief, they would not take control and make choices in their life. They recognized that they needed other people to believe in them, too.

*If I can get through today, I won't worry about not getting through tomorrow until tomorrow comes... My children aren't going to be sick unless I'm capable of taking care of them. If I meant to have my kids, if I, if it's meant to be that this is what's supposed to happen to me, I'll only get what I can deal with... I didn't survive the stroke unless I was intended to survive... And once I survived it, well there was*

no question I would get off my fat ass and I wouldn't sit around.

... I figured I was in it, I got myself into it, I had to do something about getting myself out of it... I was asked, I took a step... I'm still walking. And where my journey ends, I don't know. But I'm still stepping... Depending on how much I believe in myself and how much people around me believe in me. 'Cause that's what, that's what recovery comes from, believing in yourself, and how much people around you believe in you... You can't walk unless you get some help...

I don't know. I figured, well this is what I figure. I figured I'm different than everyone. I can do this or that or whatever. You know. I can do whatever I want to do. That's one thing: I can do whatever I want to do. After the accident... I proved that to myself because I got out of the accident.

You look at things in a totally different way... like totally. It is so different. Like you basically have to rearrange your life, like from day one. In a totally different way than you ever did before. So it kind of strengthens you. And it kind of... makes you look at things in a totally... new way.

Often participants saw family as giving actual meaning to their lives. Where the pre-injury family relationships were tense, or relatively non-existent, the present relationships were positive. The love and caring provided by family was crucial to participants' overall feelings about their lives. This was stated by all the participants. There was no question that their families' support and caring affected their positive approach to their lives, and meant much to them.

I, I just, like I talk to my sister. Every time we come back from, well not every time, but most of the time we're coming back from Regina, or going home to Weyburn. And I ask her questions about when I was in the hospital, And, how my, my family reacted when I was in there. My, my, my aunts, and well they were all in the hospital

with me. And she and then I have her tell me - well I guess I did a lot of funny things when I was in the hospital. And she tells me funny stories about when I was in the hospital. And that's what I really look forward to. I'm not, I'm not religious, or anything, I don't have no, no religion or whatever, so I don't you know, really look at, I mean in a way I believe that we evolved from apes or whatever. So, and I don't know. That's what I really looked at. How my family was so close to me, and how I mean, that it has brought me a lot closer to my family. Having this happen, like having, I mean we probably were that close before, but it took me that to realize. I mean that's how I say I had to grow up in a way. Because, I mean it brought me to realize how much family means to me, compared to before.

The experience of living through an ABI was catastrophic for all participants. It was an experience not to be wished on anyone. However participants also felt that there were ways they had changed for the better as a result of the injury. They had gained a greater appreciation of life, what they had and lost, what could be strived for, and what was negative in their previous lifestyle. In this way the injury was seen as offering a second chance at life.

*I feel I was given a second chance. So, I want to make something out of it.*

Some belief systems helped participants accept their injury and its repercussions. With acceptance they lived at ease with themselves, and experienced some happiness. Many believed that there was a reason that they survived, and having survived, their job was to work at getting as well as they possibly could. There was also a belief that they were given as much as they could deal with, that everything else would be taken care of.

*I can accept it. That's the way it is... And there's nothing that can be done about it. So go on...*

But I know what I believe and where I stand. I know that. I don't have to deal with anything. I don't have to deal with anything I can't deal with... That it's done for me, and I really believe that when I had the stroke, I only had to do, the best I could. Anything else would be taken care of... I mean like I'm, I'm a Lutheran which is - our basis is you have to work for what you get. You don't get nothing handed to you. But you also don't have to sit there and worry about tomorrow - am I going to do this, am I going to do that - if you just sit back, it's going to be taken, have faith it'll be taken care of for you. I only have to deal with what I have to deal with.

For a few, participating in a religious community gave them a sense of security and belongingness, not just within their community, but worldwide. This gave meaning to their lives, with an ability to accept the present, confident in a better future, with all taken care of.

*It (the church) has given me the security of knowing it's there. And like they give me end results. Everything will be okay. And the comfort from knowing that is good... so everything works out, Yep everything will work out Yep... as long as my faith stays high. Everything will work out. My faith is a high. Yep, I keep it high, because that's the right thing to do.*

The meaning of enjoyment in their lives changed. For many it became those more basic aspects: hearing birds singing, having a good conversation with friends, or a quiet evening spent with family. All spoke of and recognized the good times in their lives, and the importance that those times had for them.

Do you have actual enjoyment times with your kids, are you able to enjoy being with them? Oh yeah, I can, we can have our quiet times together or our conversations doing things. I'm easier to get along with when I'm not doing something physical. But, but we do, we do our - we are both looking after the kids, so we keep up with them (unintelligible)... I don't get to play

with them, like physically play with them, or anything. I mean I, I'm too scared I'd hurt them. They'd rely on me to have the strength to hold on, when they say flip them over backwards or something. And I wouldn't be able to make it for... We have our, we do our thing together, we have our conversations, we...

Do I enjoy doing? I enjoy being around my friends... and, playing cards, playing video games with my - my one friend up here, we play a lot of video games. Cards with him and his girlfriend... I enjoy spending time with my father and his friends and... It's a lot of fun. and... I don't know. I just, just getting out of this apartment I enjoy, because I get so bored in here a lot of the time. So...

... I like spending time with family. And doing stuff... Like it doesn't really, like you don't have to do something major, it's just... To get out. Like spend, like socializing and...

... I like to, I like to hear a baby cry. Because that gives me a reason for being here. I like laughter... I like conversation... Even if I can't do much of it. I like it, because it keeps the mind going.

The previous discussion indicates the complexity of quality of life, and the delicate balance between the positives in one's life and the negatives. It is also highly individual; what is perceived as positive for one, can be negative for another. Overall, participants were able to look at their lives and say:

*Considering everything? It's going excellent...*

This chapter has explored the results of the interviews, and described the participants' perceptions of the quality of their lives. In the next chapter I will discuss those results.

## CHAPTER 5

### DISCUSSION

Looking back, I realize that I had preconceived notions regarding the quality of participants' lives. Having worked for many years with people with ABI, I knew that their lives were tough. I interpreted this to mean that there was little quality to their lives. I anticipated that they would all say that their lives were going badly. The very first interview began to turn that notion inside out. For that participant, as for all others, life was hard. She had great difficulty remembering things, had an overwhelming fatigue to battle with, and difficulty controlling her emotions. She had difficulty interacting with her family, and had to plan every day in detail to complete tasks. But she had also found areas of happiness, accepted her changed life, and felt she was a better person for what she had gone through. She was the first to say: considering everything, things were going fine. The complexity underlying personal perceptions of quality of life became apparent.

One after another, using different words, but having the same undercurrent of meaning, the other participants echoed her sentiments. Clearly, their injuries made their lives more difficult. They struggled with physical, cognitive and behavioural changes, loneliness, reduced possibilities and choices in their lives. And that was on top of the typical life events, for example loss of work due to tough economic times, illness and/or death of a loved one, children leaving home, separation and divorce. There were also good times, and there was a recognition that things could be both better and worse. Every participant's life had

positives; it was the degree of positives that made the difference. The previous chapter provided an in-depth description of how the participants perceived their quality of life. This chapter will discuss those perceptions in the context of the frameworks used, the role of disablement, and quality of life in general.

### 5.1 The Role of Disablement

A theme that the participants wove through the interviews was that of disablement. Each category of disablement (impairment, disability and handicap) was touched upon by the participants. Disablement is a collective term encompassing impairment, disability and handicap as defined by the WHO. Impairment is the loss or functional limitation resulting from injury or disease. Disability is any activity limitation resulting from impairment. Handicap is the social disadvantage caused by the impairment and/or disability. When discussing "Being," impairment and disability were frequently involved. For example hemiparesis affected the ability to run, and play sports. Handicap mostly affected perceptions of "Becoming" and "Belonging", with disability having some effect as well (especially on "Becoming"). For example, inability to play sports affected leisure activity and the amount of contact with peers.

While participants felt they could change themselves, there was more difficulty with societal barriers. Each participant had to first understand the barriers. Once understood, they could (1) accept the barrier and get on with their lives, (2) try to change the barrier, or (3) pull back from society. Inability to understand the barriers led to frustration and a perception of a decreased quality of life in some, anger in others.

## 5.2 Quality of Life

### 5.2.1 The Being, Belonging and Becoming Framework

The Being, Belonging and Becoming framework provided a useful tool in categorizing the data and exploring changes in participants' lives. The injuries, in a long-term and often enduring fashion, affected all three dimensions ("Being," "Belonging" and "Becoming"). The impact of these changes decreased over time, but those negative changes that remained were real obstacles to a clearly good quality of life.

While each dimension ("Being," "Belonging" and "Becoming") is separate, and has its own categories, the interdependence of the dimensions became apparent during the interviews. For example, if a participant did not attend school or work, and could not drive because of coordination difficulties, he/she had less chance of interacting with others in the community. Restrictions in the Being and Becoming dimensions limited participants' sense of Belonging.

This next section discusses difficulties affecting quality of life identified by the participants, using the Being, Belonging and Becoming dimensions. The most challenging areas occurred within Belonging, followed by Becoming and Being.

### 5.2.2 Belonging

Belonging speaks to the degree and quality of our interaction with others. Belonging provides the link between who we are, and the important possibilities and choices in our lives. The words that summarize what the participants discussed about Belonging would be *isolation, acceptance, interdependence and societal understanding.*

*Isolation* speaks to the degree that participants felt separate from their peers and the community in general. Many spoke of the experience of an ABI, and facing dying at so young an age, as making them different from their friends. Because their peers could not understand the experience, or the resulting changes, participants became isolated. They had less in common; participants no longer travelled along the same path as their former friends.

Participants felt that those remaining in their lives were people who unconditionally accepted them. They often wished for the same *acceptance* from others. Frequently discussed together were the two opposites of isolation and acceptance. For example, discussion of the loss of friends and a more closely knit family often occurred together.

For the most part, participants discussed *societal understanding* in negative terms. Interacting with community was problematic. Participants often discussed being treated differently because of their ABI. Sometimes they felt it was due to a lack of knowledge, other times due to stereotyping, and occasionally outright discrimination. Some confronted this when trying to find work, others when interacting with the community. This included incidents while out shopping, at school and while involved with leisure activities. Lack of understanding by society clearly affected the degree of belongingness that participants experienced. Participants felt marginalized and wanted inclusion based on acceptance. They needed the community to recognize that they were different, and despite those differences, accept them as members of that community.

The degree to which participants were *interdependent* with others was another aspect of belongingness. Participants saw their own ability to give back to others as important. Just as their families gave them their love and acceptance, it was important for participants to see

concrete examples of what they gave others. This included such things as: making others laugh, providing companionship, and doing tasks independently.

### 5.2.3 Becoming

Becoming depends on aspects intrinsic to the individual, and on external factors such as choices and opportunities open to them. Participants discussed how their own abilities and external factors affected their choices and possibilities. Two words, *independence* and *time*, summarize the effect of this dimension on the participants' lives. *Independence* speaks to the ability to make decisions and take control over one's life. Participants had concerns regarding their financial independence (short- and long-term), their ability to learn, to work and be involved in satisfying leisure activities. Driving was often an important indicator of independence for the participants. The loss of this option was very negative for those affected.

*Time* addresses both the healing effects of time (more improvement and increased work potential as more time had elapsed since the injury) and the amount of time some participants had on their hands. Only two of the participants felt that they had enough or too much activity in their lives. The majority found that time dragged by.

The long-term effects of time were spoken of with more optimism. Participants felt that they would continue to improve, because they had improved since their injury. This optimism positively affected their perception of quality of life.

#### 5.2.4 Being

Being provides the base out of which Belonging and Becoming can grow. Where the dimensions of Being are affected, one's chances of Belonging and Becoming are compromised. Participants' cognitive, behavioural, perceptual, and physical beings were all affected by their injuries. Yet most had seen their greatest success in the Being dimension. All awoke dependent on others. All had gone on to improve remarkably. Participants viewed impairment as something that could improve. Its effect on the other dimensions was what was critical to quality of life. For example, reduced coordination was not an important factor, until it affected the ability to play sports, drive, or ride a horse.

#### 5.2.5 Defining and Measuring Quality of Life

For purposes of the research proposal, I used a definition of quality of life that was flexible and open-ended, and accepted in quality of life research. That definition was: What makes life go well for an individual. As the research progressed, I realized that the participants themselves perceived quality of life with more precision.

For the participants, quality of life was a highly individualized concept, made up of those aspects that:

1. allow people to feel relatively good about their lives;
2. account for life experiences and circumstances;
3. allow them to look forward to the future.

The participants recognized that life was hard for them, and that there were positive features to their lives. They

had survived a life-threatening incident, and gone on to develop meaningful lives, with changed abilities. While life may have been better before their injuries, their present lives were far better than during those first years post-injury. The knowledge of the love and caring of family, and how far they had come since the injury gave them hope and expectations of a better future. Hopefulness has an important role in perceptions of quality of life.

What allows people to feel relatively good is highly personal. What allows one person to feel good about his/her situation may make another person unhappy. Throughout the interviews, participants acknowledged individual differences and approaches to life. Each of them had his/her own perception of the quality of his/her life.

Personal perception of quality of life is a relative measure. If participants compared their lives to pre-injury only, most would say that there was no comparison, that life was far better before the injury than since. But most compared it to that period just post-injury, when their very lives were at stake, and early rehabilitation when they had to relearn walking, talking, dressing, writing, remembering, and so on. In comparison to that period, their lives were going better. Participants perceived quality of life as fluctuating. Within the interview period there were events that affected participants' outlooks, so that one interview might be quite positive, the next negative. This speaks to the fragility of quality of life for the participants. The balance of experiences can change when new events occur. For people who have greater restrictions in their lives, it takes little to push the balance to the negative.

### 5.3 The Sense of Coherence Framework

As participants' relatively positive attitude to their lives became apparent, I wondered how people could go through such a difficult, life-changing situation, and be optimistic. Antonovsky's Sense of Coherence became critical to exploring why participants perceived things positively.

The sense of coherence affects how people perceive their lives. Whether we are confident in ourselves, our loved ones, our community, whether we perceive ourselves as managing, and whether we find reasons for existing, constitutes our personal sense of coherence. The sense of coherence is a dynamic and highly individualized concept.

Sense of coherence also affects how people react to life events. Two people with differences in their sense of coherence will react dissimilarly to comparable situations. One will walk away from a terrible situation and go on to develop a healthy life, while the other may never get over that experience, forever spiralling into it. That reaction affects the perception of their quality of life.

As the participants talked about their lives and the continuing process of recovery, they discussed learning to cope, to find meaning, and to understand their lives. Their success in these endeavors affected how they perceived their lives, in terms of the balance of negatives and positives. While I had automatically thought that the degree of recovery affected their perceptions, this was not always true. The participant who used a wheelchair, needed total assistance in dressing, and only left the house with the help of others, had developed an extremely strong belief system. This belief system made his life understandable (if he believes strongly enough everything will turn out all right), and manageable (there is only right now to manage, and God will look after everything else).

The participants have had varied degrees of success in developing a strong sense of coherence. All have found meaning to their lives. Most have difficulty making their lives comprehensible. Some have learned to manage their lives (or manage within their restrictions). As with the "Being," "Belonging" and "Becoming" dimensions, there is a strong connection between these three concepts (comprehensibility, manageability and meaningfulness). However, it was possible to see differences in the development of each concept with the participants.

### 5.3.1 Comprehensibility

Participants struggled to get to the point where life was not a complete mystery. They needed a reasonable understanding of their present lives. That included understanding the rules of their community (for example: what is acceptable behaviour), and where their lives could go. For some, acceptance of their lot in life was important. For others it meant recognizing that this was their present life, but that they could struggle and work towards a better life for themselves.

For the participants, developing this dimension was perhaps the most difficult of the three. Making sense of life becomes harder when previously tested rules no longer hold. A participant discussed how hard she was working to get better, yet she was not improving. Her previous learning was that hard work paid off by success. Another wondered why even though he looked the same, others were no longer attracted to him.

Comprehensibility depends on society itself being understandable, and individuals making sense of their personal milieu. The same rules do not necessarily apply to people with disabilities as to those without. Certainly in discussing ways that others reacted to them, (for example

employers' reaction to disability) participants did perceive that they faced different rules compared to their pre-injury status. Not only did participants need to relearn how to relate to others, but they had to learn a new set of rules about how others might react to them.

### 5.3.2 Manageability

Participants took great pride in managing their own lives. It was a source of friction for those who had difficulty managing. While personal management was initiated during in-patient rehabilitation, it only became real once participants were in their home environment.

No matter the restrictions, even some degree of personal control over their lives made a difference. The participant who used a wheelchair let others push him, because he preferred that others complete that task. For him, it was not important to propel his chair. Participants' reactions to the amount of external management of their lives seemed dependent on their comprehension of their needs, and on whether independence was personally meaningful.

### 5.3.3 Meaningfulness

This was the most strongly developed of the three dimensions for all participants. It was perhaps the most important to perception of quality in their lives. Development of overall meaning came from a combination of previous experiences and belief systems, and reaction to the injury itself. A belief system allowed participants to have hope in the future and in their ability to improve.

Across the board, participants recognized that they could not have reached their present recovery level without others believing in them. The enduring support of their family, their family's belief in them, their own survival,

and the degree of on-going recovery kept people hopeful and positive. This occurred even in the presence of difficulty managing and understanding what was happening in their lives.

#### 5.4 The Sense of Coherence and The Quality of Life

Quality of life and the sense of coherence build upon and influence each other. No one would say that a person interred in a concentration camp has a good quality of life. A person with a strong sense of coherence will cope with those surroundings better than a person with a less developed sense of coherence. This in turn will affect their perception of quality of life.

Quality of life is measurable and so is the sense of coherence. Sense of coherence, like quality of life, is changeable. As the participants' rehabilitation process evolved (and that process continues), their own ability to manage, comprehend and find meaning changed. They went through the process of developing a sense of coherence just as a developing child, adolescent and young adult would.

Sense of coherence goes beyond how a person perceives their quality of life to answer why they react to their quality of life in a certain way. "Being," "Belonging" and "Becoming" explores quality of life by asking who is the person, where does he/she belong and into what can he/she grow. Sense of coherence explores why the person gives a particular answer to the questions. When exploring people's quality of life, it is important to go beyond his/her answer, to find out why he/she gave that particular answer. If you do not ask why, then there is no context within which to put the answer. For the participants the context was having found meaning to their lives, surviving the injury, and the love and support of their families.

## CHAPTER 6

### CONCLUSIONS

Following a qualitative research method, this study explored and then described how adult ABI survivors who had returned to live in the community perceived their quality of life.

In preparation for the research, I undertook an in-depth literature review. That review explored ABI, quality of life, and those research methodologies used in measuring quality of life. Following the literature review, I proceeded with the pre-test and interviews.

Six participants, living in or near the Regina Health District, took part in the research. Each participated in three in-depth interviews. Those interviews, while following an interview guide, used open-ended questions. This allowed the participants to share their personal perceptions of quality of life. The participant led, and I followed, asking probing questions, or questions of clarification, until I felt there was little of substance left to explore. Approximately 6 hours was spent with each participant.

Throughout the interviewing stage, data were transcribed and data analysis initiated. Following completion of all the interviews, there was a more in-depth analysis. This analysis led to a further review of the literature, exploring the sense of coherence. That review helped me reach a deeper understanding of the data. The results were highly complex pictures of the participants' lives, and their perceptions of quality of life.

The study gave participants the opportunity to explore the positives and negatives, victories and losses in their

lives. At every step along the road to recovery, they perceived themselves as having done better than expected. On the negative side, there were losses in physical, cognitive and behavioural well-being, fewer friends, difficulty with community integration, fewer educational and work options, decreased financial security and more limited choices in their lives. However, with the passage of time, all saw an improvement in their lives. This allowed them to say that considering everything, things were going okay. A rider often accompanied that perception. For example:

*if I could walk, I would be really happy . . .*

*not as much good as bad has happened . . .*

*I was going to say not great, but I did get to go on that trip to . . .*

Clearly life was difficult: the participants had struggles beyond that of most of us. The consideration of everything meant that things could be worse, and things could be better. For the participants, quality of life and its measurement, was very complex. A clear yes/no, good/bad response was not possible. The description given by the participants was as complex as the quality of life concept itself. This final chapter will delve into the findings of the study, the implications to our knowledge of life after an ABI and the concept of quality of life.

## 6.1 Findings and Implications of the Study

### 6.1.1 People with ABI as Primary Sources

In the literature, use of the person with ABI as the only informant is controversial. Typically, studies use other informants and the person with ABI. I used an

empowerment frame of reference, and wanted to focus on personal perceptions. Participants with ABI were selected who could provide the necessary insights and actively participate in the interviews. Because they were the only informants, I could go beyond their personal perceptions and explore attitudes toward life that affected those perceptions. This would not have been possible if I had used family or professionals as the informants. Use of the person with ABI as the primary source can work well in exploring perceptions of quality of life. It is necessary to develop appropriate selection criteria so that participants can provide the depth of insight needed.

Use of personal perceptions also brought with it potential problems. There was the danger of participants' perceptions being overly positive. A positive outlook did not necessarily mean the participant had a high quality of life. Like many people, participants took their situations and tried to make them as positive as possible. Exploring personal perceptions of quality of life must include the context and inner resources of the person. When participants described their present quality of life positively, they compared it to that immediate post-injury period. They also portrayed the struggle they went through to find meaning, manage and comprehend their changed situations. Success in that struggle affected the participants' perceptions of their quality of life.

Where the line between an obviously good quality of life, and a poor one, is thin, the fragility of that person's or group's quality of life needs underlining. For all participants their perceptions were fluid, depending on day-by-day events.

### 6.1.2 Use of the "Being, Belonging and Becoming" Dimensions

During the literature review and proposal writing stage, the "Being, Belonging and Becoming" dimensions helped me explore quality of life. During the data analysis stage, it provided a useful tool in categorizing the data. The participants themselves raised the topics of who they were, where they belonged and the opportunities in their lives. This confirmed the usefulness of these dimensions.

The participants viewed the "Being" dimension (Who am I?) as critical to quality of life; it provided the building blocks to success in "Belonging" (Where do I belong?) and "Becoming" (What options do I have?). When the data analysis was completed, there were a number of words that summed up the "Belonging" and "Becoming" dimensions. These were *isolation, acceptance, interdependence, societal understanding, time* and *independence*. Further exploration and research might find that these are key dimensions for perceptions of quality of life.

The "Being," "Belonging," and "Becoming" dimensions did have their limitations. They were essentially categories, and not useful in answering why participants responded as they had to quality of life questions. The dimensions were too narrow for full exploration of either personal attitudes to life, or internal resources for living. These are more thoroughly explored in the next section.

### 6.1.3 Exploring Attitudes to Life and Internal Resources for Living

Antonovsky's Sense of Coherence concept became critical in exploring participants' attitudes to their lives. Personal perceptions are governed by our understanding of the world around us, our ability to find meaning and direction in our lives, and our ability to manage daily

living. Our heredity and life experiences shape our attitudes to life, and our internal resources for living.

People with ABI come out of a coma and begin to re-establish their personal sense of coherence. In describing their lives and the changes that had occurred, participants discussed them in ways that corresponded closely to Antonovsky's three dimensions. They described their victories in those areas, and the inner strength and optimism that accompanied success. Those successes led to a stronger sense of coherence. With that stronger sense of coherence, came a more hopeful attitude to life and a more positive perception of their quality of life.

The above has implications for measuring personal perceptions of quality of life. If one's attitude toward life, or inner resources, colour one's perception of quality of life, then measurement of personal perceptions of quality of life should also consider those areas. Perceptions of quality of life may be dependent on our overall attitude to living, and our inner resources. While findings from this study cannot be generalized to the population, further exploration of the connection between personal perceptions of quality of life and personal attitudes towards life is warranted. It is my belief that there is a connection, and that attitude provides at least some of the answer about how people will perceive their quality of life.

Antonovsky saw the sense of coherence as fully developed by the time people reached young adulthood. He suggested that there was little change after that, and if anything, the sense of coherence was lessened with age. One of the questions arising out of this study is whether the sense of coherence can change after a catastrophic injury such as an ABI. This merits further study.

#### 6.1.4 The Three Dimensions of the Sense of Coherence

Antonovsky felt that the dimensions of the sense of coherence (comprehensibility, manageability and meaningfulness) could not be separated. In this research there were differences in the development of each dimension for participants. Perhaps this was because the participants were in the process of redeveloping their sense of coherence. Alternatively, there may be some members of the population for whom the dimensions may be more distinct than Antonovsky proposed. This could have treatment implications. Those working with the person with ABI could develop programs aimed at nurturing the dimensions during the post-injury period.

#### 6.1.5 Quality of Life as a Concept

Participants' perceptions showed the fluidity and fragility of quality of life. Quality of life (to the participants) was a relative concept, changing dramatically at the time of their initial injury, and since then constantly changing to larger and smaller degrees. Successes in their lives allowed participants to look forward to a better future. They examined the negative and the positive and took an overall measure. They realized that what they presently had, could change again, for better or worse. Their life experiences had taught them that what they had was fragile.

Participants saw their quality of life as difficult, but balanced that view within the context of their life experiences. All the participants wanted a better quality of life. They realized that they had limited access to services and that societal attitudes affected their daily life. Participants realized they were marginalized by the ABI. They had the capacity to overcome despair and

adversity, and find positives and hope in their daily existence. Measurement of quality of life went beyond "what makes life go well for an individual" to:

- Who have I been?
- Who am I now?
- What am I part of?
- Who is my community?
- What can I do?
- Where do I belong?

The answers to those questions and a belief that a) life gets better, and b) everything in life is relative, gave participants a positive approach to their personal perceptions of quality of life. Hopefulness was especially important to perceptions of quality of life. Current definitions of quality of life and its dimensions do not adequately capture all of these aspects. Redefining quality of life is beyond the objectives of this thesis, but a holistic definition needs to take the above into account. The definition should encompass a) what allows people to feel relatively good about their lives, b) accounts for their life experiences and circumstances and c) allows them to look forward to the future with a sense of control over their lives.

#### 6.1.6 Limitations to the Research

The following are noted as limitations to the research:

1. The research involved the person with ABI and did not include the primary caregivers and/or their families. Catastrophic injuries affect the whole of a family unit, not just the injured person. ABI has consequences beyond the person themselves, encompassing all who live with ABI (family and person with ABI). The burden of care carried by the family may make their quality of life quite low, even

when the person with ABI's quality of life is perceived as high. This may give the family a different perspective on quality of life, both of the person with ABI and the family unit. This is important to the understanding of ABI and its long-term consequences.

2. There were limitations to the degree of thick description I could provide in this document. ABI involves a relatively small number of people. Most professionals working in the area of ABI in the Regina region have worked with the participants. Because it would have been easy to guess who those participants are, I was unable to include biographies, without encroaching on confidentiality. Those biographies would have strengthened the study by providing the background and context for understanding participants' perspectives.

## 6.2 Implications for Promoting Health after an ABI

Participants lived through circumstances of which most of us cannot conceive. They had done so with anger, with frustration, with sadness, with love and with laughter. Participants struggled to rebuild lives completely changed within a moment of time.

They expressed the need for more support services for people with ABI. Services needed to be timely. For some, services included teaching family members about ABI; all indicated a need to teach society to be more accepting of others.

Other service needs included more residential living options, and easier access to appropriate education and rehabilitation. Access to transportation was particularly important. Those without a driver's license spoke negatively of their dependence on others.

The majority spoke to the need for personal support networks. Many suggested that rebuilding support networks

should begin during early rehabilitation. That rebuilding needs to include developing more positive interpersonal relationships, and appropriate ways of interacting with others.

Participants spoke of the need for greater control over their lives and decision-making, even if it meant making mistakes. This included greater control of their finances.

The participants also discussed the need for community education regarding disablement issues. Participants continually pointed to the negative ways they were treated. Education about ABI would facilitate communities to change attitudes, and be more inclusive of people with disabilities. This would improve the quality of life for people with ABI.

For the participants, developing their inner resources, as well as increasing their levels of independence and well-being led them to a more positive approach to living. The findings of this study suggest that the sense of coherence plays a large part in personal perceptions of quality of life and how one copes on a daily basis. The isolation, acceptance, interdependence, societal understanding, time and independence that summed up the "Becoming" and "Belonging" dimensions are also part of making one's life manageable, comprehensible and meaningful. Programs that recognize and support the struggle of the person with Acquired Brain Injury in redeveloping his/her sense of coherence, and foster interdependence, independence, societal understanding and acceptance, while minimizing the isolation faced by people with Acquired Brain Injury, will promote overall health.

## REFERENCES

1. Robine J, Michel J-P, Branch L. Measurement and utilization of healthy life expectancy: conceptual issues. *Bulletin of the World Health Organization*. 1992;70(6):791-800.
2. Bickenbach JE. *Physical disability and social policy*. Toronto: University of Toronto Press Inc., 1993.
3. Last J. *Public health and human ecology*. East Norwalk, Connecticut: Appleton & Lange, 1987.
4. World Health Organization. *International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease*. Geneva: World Health Organization, 1980.
5. Minister of National Health and Welfare. *Disabled persons in Canada*. Minister of National Health and Welfare, 1981.
6. Rice DP, LaPlante MP. Chronic illness, disability, and increasing longevity. In: Sullivan S, Lewin ME, editors. *The economics and ethics of long-term care and disability*. Washington, D.C.: American Enterprise Institute for Public Policy Research, 1988.
7. Statistics Canada. *The health and activity limitation survey: selected data for Canada, provinces and territories*. Statistics Canada, 1988.
8. Willer B, Rosenthal M, Kreutzer JS, Gordon WA, Rempel R. Assessment of community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation*. 1993;8(2):75-87.
9. SP Research Associates. *Planning for the needs of people with acquired brain injury in Saskatchewan*. 1992.
10. Brown H, Smith H. Assertion, not assimilation: a feminist perspective on the normalisation principle. In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.

11. Edgerton RB. Quality of life from a longitudinal research perspective. In: Schalock RL, editor. *Quality of life: perspectives and issues*. Washington, D.C.: American Association on Mental Retardation, 1990.
12. SP Research Associates. *Planning for the needs*.
13. Dawson D. *The nature and prevalence of disability and handicap among Canadian traumatically brain injured adults living in the community: an analysis of the Canadian Health and Activity Limitation survey (1986-1987)*. University of Toronto, 1993.
14. *ibid.*
15. Edlund M, Tancredi L. Quality of life: an ideological critique. *Perspectives in Biology and Medicine*. 1985;28(4):591-607.
16. Brock D. Quality of life measures in health care and medical ethics. In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
17. Edlund. Quality of life.
18. Schalock RL. *Quality of life: perspectives and issues*. Washington, D.C.: American Association on Mental Retardation, 1990.
19. Dawson. *The nature and prevalence of disability*.
20. Acquired Brain Injury Working Group: *Acquired brain injury: a strategy for services*. Saskatchewan: Saskatchewan Government Insurance and Saskatchewan Health, 1995.
21. SP Research Associates. *Planning for the needs*.
22. Alfano DP, Neilson PM, Fink MP. Long-term psychosocial adjustment following head or spinal cord injury. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*. 1993;6(2):117-125.
23. Alfano DP, Paniak CE, Finlayson MAJ. The MMPI and closed head injury: a neurocorrective approach. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*. 1993;6(2):111-116.
24. Dawson. *The nature and prevalence of disability*.
25. SP Research Associates. *Planning for the needs*.

26. Bickenbach. *Physical disability*.
27. Oliver M. *The politics of disablement: a sociological approach*. New York: St. Martin's Press, 1990.
28. World Health Organization. *International classification*.
29. Bickenbach. *Physical disability*.
30. Hahn H. The politics of physical differences: disability and discrimination. *Journal of Social Issues*. 1988;44(1):39-47.
31. Hahn H. Alternate views of empowerment: social services and civil rights. *Journal of Rehabilitation*. 1991;57(4):17-19.
32. Kallen E. *Label me human: minority rights of stigmatized Canadians*. Toronto: University of Toronto Press, 1989.
33. Bickenbach. *Physical disability*.
34. *ibid*.
35. Kallen. *Label me human*.
36. Oliver. *The politics of disablement*.
37. Bickenbach. *Physical disability*.
38. Hahn. Alternate views.
39. Bickenbach. *Physical disability*.
40. Brown. Assertion, not assimilation.
41. Hahn. The politics of physical differences.
42. Hahn. Alternate views.
43. Kallen. *Label me human*.
44. Oliver. *The politics of disablement*.
45. Wendell S. Toward a feminist theory of disability. *Hypatia*. 1989;4(2):104-124.
46. Whitehead S. The social origins of normalisation. In: Brown H, Smith H, editors. *Normalisation: a reader for*

- the nineties*. London: Routledge, 1992.
47. Bickenbach. *Physical disability*.
  48. Kallen. *Label me human*.
  49. Oliver. *The politics of disablement*.
  50. Bickenbach. *Physical disability*.
  51. Emerson E. What is normalisation? In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
  52. Whitehead. *The social origins*.
  53. Bickenbach. *Physical Disability*.
  54. Hahn. *Alternate views*.
  55. Oliver. *The politics of disablement*.
  56. Wendell. *Toward a feminist theory*.
  57. Patton MQ. *Qualitative evaluation and research methods*. (2nd Edition). Newbury Park: Sage Publications, 1990.
  58. Hahn. *Alternate views*.
  59. Kallen. *Label me human*.
  60. Oliver. *The politics of disablement*.
  61. Wendell. *Toward a feminist theory*.
  62. Bickenbach. *Physical disability*.
  63. Hahn. *Alternate views*.
  64. Bickenbach. *Physical disability*.
  65. Kallen. *Label me human*.
  66. Oliver. *The politics of disablement*.
  67. Wallerstein N. Powerlessness, empowerment, and health: implications for health promotion programs. *American Journal of Health Promotion*. 1992;6(3):197-205, p. 198.

68. Labonte R. Health promotion and empowerment: reflexions on professional practise. *Health Education Quarterly*. 1994;21(2):253-236.
69. Lord J, Hutchison P. The process of empowerment: implications for theory and practice. *Canadian Journal of Community Mental Health*. 1993;12(1):5-22.
70. Rappaport J. Research methods and the empowerment social agenda. In: Tolan P, Keys CB, Chertok F, Jason L, editors. *Researching community psychology*. Washington, DC: American Psychological Association, 1990.
71. Lord. The process of empowerment.
72. World Health Organization. *International classification*.
73. Patrick DL, Peach H. *Disablement in the Community*. Toronto: Oxford University Press, 1989.
74. Wallerstein. Powerlessness.
75. World Health Organization. *International classification*.
76. *ibid*.
77. Brock. Quality of life.
78. Sen A. Capability and well-being. In: Nussbaum M, Sen A, editors. *The quality of life*. Oxford: Clarendon Press, 1993.
79. Brock. Quality of life.
80. Edlund. Quality of life.
81. Kinney W, Coyle C. Predicting life satisfaction among adults with physical disabilities. *Archives of Physical Medicine and Rehabilitation*. 1992;73(September):863-869.
82. Raphael D, Brown I, Renwick R, Rootman I. *Quality of life and assessment: What are the implications for health promotion?* Centre for Health Promotion and ParticipACTION, 1994.
83. Robine. Measurement and utilization.

84. Scanlon T. Value, desire and the quality of life. In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
85. Sen. Capability and well-being.
86. Brock. Quality of life.
87. Carley M. Social indicators research. In: Finsterbusch K, Llewellyn L, Wolf C, editors. *Social impact assessment methods*. Beverly Hills: Sage Publications, 1983.
88. Carr AJ, Thompson PW. Towards a measure of patient-related handicap in rheumatoid arthritis. *British Journal of Rheumatology*. 1994;33:378-382.
89. Kinney. Predicting life satisfaction.
90. Raphael. *Quality of life*.
91. Rootman I. *Quality of life project - phase I*. Centre for Health Promotion and ParticipACTION, 1992.
92. Ziebland S, Fitzpartick R, Jenkinson C. Tacit models of disability underlying health status instruments. *Social Science Medicine*. 1993;37(1):69-75.
93. Spilker B. Introduction. In: Spilker B, editor. *Quality of life assessments in clinical trials*. New York: Raven Press, 1990.
94. Szymanski EM, Trueba HT. Castification of people with disabilities: potential disempowering aspects of classification in disability services. *Journal of Rehabilitation*. 1994;6(3):12-20.
95. Ross WD. *Ethica nichomachea, magna moralia, ethica eudemia*. (2nd edition) London: Oxford University Press, 1925, p. 1095a.
96. Brock. Quality of life.
97. Nussbaum M, Sen A. Introduction. In: Nussbaum M, Sen A, editors. *The quality of life*. Oxford: Clarendon Press, 1993.
98. Nussbaum. Introduction. p. 1.
99. Sen. Capability and well-being.

100. Korsgaard C. Amartya Sen: capability and well-being (commentary). In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
101. Nussbaum. Introduction.
102. Sen. Capability and well-being.
103. Brock. Quality of life.
104. Scanlon. Value, desire and the quality of life.
105. Sen. Capability and well-being.
106. Brock. Quality of life.
107. Scanlon. Value, desire and the quality of life.
108. Brock. Quality of life.
109. Griffin J. Dan Brock: Quality of life measures in health care and medical ethics (commentary). In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
110. Brock. Quality of life.
111. *ibid.*
112. Sen. Capability and well-being.
113. Brock. Quality of life.
114. Edlund. Quality of life.
115. Kinney. Predicting life satisfaction.
116. Raphael. *Quality of life*.
117. Szymanski. Castification of people.
118. Edlund. Quality of life.
119. Fitzpatrick R, Fletcher A, Gore S, Jones D, Spigglehalter D, Cox D. Quality of life measures in health care. I. Applications and issues in assessment. *British Medical Journal*. 1992;305:1074-1077.
120. Raphael. *Quality of life*.
121. Fitzpatrick. Quality of life.

122. Schipper H, Clinch J, Powell V. Definitions and conceptual issues. In: Spilker B, editor. *Quality of life assessments in clinical trials*. New York: Raven Press, Ltd, 1990, p. 16.
123. Spilker. Introduction.
124. *ibid.* p. 5.
125. Schipper. Definitions.
126. Carr. Towards a measure.
127. Edlund. Quality of life.
128. Kinney. Predicting life satisfaction.
129. Raphael. *Quality of life*.
130. Bickenbach. *Physical disability*.
131. Carley. Social indicators.
132. Edlund. Quality of life.
133. Fitzpatrick. Quality of life.
134. Raphael. *Quality of life*.
135. Bickenbach. *Physical disability*.
136. Carley. Social indicators.
137. Raphael. *Quality of life*.
138. Carley. Social indicators.
139. *ibid.*
140. *ibid.* p. 156.
141. Carley. Social indicators.
142. Rootman I. *Health Promotion: past, present and future*. Toronto: Centre for Health Promotion and ParticipACTION, 1993.
143. Carley. Social indicators.
144. Finsterbusch K. Evaluation methods. In: Finsterbusch K, Llewellyn L, Wolf C, editors. *Social impact assessment methods*. Beverly Hills: Sage Publications,

- 1983.
145. Raphael. *Quality of life*.
  146. *ibid.* p. 5.
  147. Raphael. *Quality of life*. p. 34.
  148. Rootman. *Quality of life project*.
  149. Raphael. *Quality of life*.
  150. Emerson. What is normalisation? p. 3.
  151. Brown H. Assertion, not assimilation.
  152. Dalley G. Social welfare ideologies and normalisation: links and conflicts. In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
  153. Emerson. What is normalisation?
  154. Lindley P, Wainright T. Normalisation training: conversion or commitment? In: Brown H, Smith H, editors. *Normalisation: A reader for the nineties*. London: Routledge, 1992.
  155. Szivos S. The limits to integration? In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
  156. Whitehead. The social origins.
  157. Szivos. The limits to integration?
  158. Whitehead. The social origins.
  159. World Health Organization. *Ottawa Charter for Health Promotion*. Canadian Public Health Association, 1986.
  160. Rootman. *Quality of life project*.
  161. *ibid.*
  162. Carr. Towards a measure.
  163. Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *Journal of Clinical Epidemiology*. 1992;45(7):743-760.

164. Edlund. Quality of life.
165. Kinney. Predicting life satisfaction.
166. Lord. The process of empowerment.
167. Raphael. *Quality of life*.
168. Schalock. *Quality of life*.
169. Edlund. Quality of life.
170. Ziebland. Tacit models.
171. Antonovsky A. *Unravelling the mystery of health: How people manage stress and stay well*. San Francisco: Jossey-Bass Publishers, 1988.
172. Antonovsky A. Complexity, conflict, chaos, coherence, coercion and civility. *Social Science and Medicine*. 1993;37(8):969-981.
173. *ibid*.
174. Antonovsky. *Unravelling the mystery*.
175. Antonovsky A. The structure and properties of the sense of coherence scale. *Social Science and Medicine*. 1993;36(6):725-733.
176. Antonovsky. *Unravelling the mystery*. p. 19.
177. Antonovsky. *Unravelling the mystery*.
178. *ibid*.
179. Antonovsky. The structure and properties.
180. Antonovsky. *Unravelling the mystery*.
181. *ibid*. p. 17.
182. Antonovsky. *Unravelling the mystery*.
183. Antonovsky. The structure and properties.
184. Antonovsky. *Unravelling the mystery*. p. 18.
185. Antonovsky. *Unravelling the mystery*.
186. Antonovsky. The structure and properties.

187. Antonovsky. *Unravelling the mystery*.
188. *ibid*
189. Antonovsky. Complexity, conflict, chaos.
190. Antonovsky. The structure and properties.
191. Antonovsky. *Unravelling the mystery*.
192. Carolyn SC. *A continuum of opportunity for people in Ontario with Acquired Brain Injury: final report*. The continuum of Opportunity Task Force, 1994.
193. Higenbottam JA. *Restoring hope: British Columbia's strategic plan for brain injury*. Government of British Columbia, 1994.
194. SP Research Associates. *Planning for the needs*.
195. Dawson. *The nature and prevalence of disability*.
196. SP Research Associates. *Planning for the needs*.
197. The Pennsylvania Interagency Head Injury Committee. *Traumatic Brain Injury: Ideal rehabilitation system report*. The Pennsylvania Interagency Head Injury Committee, 1988.
198. Dawson. *The nature and prevalence of disability*.
199. *ibid*.
200. Higenbottam. *Restoring hope*.
201. *ibid*.
202. Carolyn. *A continuum of opportunity*.
203. SP Research Associates. *Planning for the needs*.
204. Higenbottam. *Restoring hope*.
205. Wong PP, Dornan J, Schentag CT, Ip R, Keating AM. Statistical profile of traumatic brain injury: a Canadian rehabilitation population. *Brain Injury*. 1993;7(4):283-294.
206. Carolyn. *A continuum of opportunity*.
207. Dawson. *The nature and prevalence of disability*.

208. Gordon WA, Mann N, Willer B. Demographic and social characteristics of the traumatic brain injury model system database. *Journal of Head Trauma Rehabilitation*. 1993;8(2):26-33.
209. Higenbottam. *Restoring hope*.
210. Sosin DM, Sacks JJ, Smith SM. Head Injury - associated deaths in the United States from 1979 to 1986. *Journal of the American Medical Association*. 1989;262(16):2251-2252.
211. The Pennsylvania Interagency Head Injury Committee. *Traumatic Brain Injury*.
212. Dawson. *The nature and prevalence of disability*.
213. Gordon. Demographic and social characteristics.
214. Dawson. *The nature and prevalence of disability*.
215. Higenbottam. *Restoring hope*.
216. Sosin. Head injury.
217. Carolyn. *A continuum of opportunity*.
218. Dawson. *The nature and prevalence of disability*.
219. Egan M. The price of poor prevention. *OT Week*. July 9, 1992;14-15.
220. Higenbottam. *Restoring hope*.
221. Sosin. Head injury.
222. The Pennsylvania Interagency Head Injury Committee. *Traumatic Brain Injury*.
223. Carolyn. *A continuum of opportunity*.
224. Higenbottam. *Restoring hope*.
225. Dawson. *The nature and prevalence of disability*.
226. *ibid.*
227. *ibid.* p. 149.
228. Alfano. Long-term psychosocial adjustment.

229. Kreutzer JS, Gordon WA, Rosenthal M, Marwitz J. Neuropsychological characteristics of patients with brain injury: preliminary findings from a multicentre investigation. *Journal of Head Trauma Rehabilitation*. 1993;8(2):47-59.
230. Higebottam. *Restoring hope*.
231. Alfano. Long-term psychosocial adjustment.
232. Condeluci A, Ferris LL, Bogdan A. Outcome and value: the survivor perspective. *Journal of Head Trauma Rehabilitation*. 1992;7(4):37-45.
233. Morton MV, Wehman P. Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury*. 1995;9(1):81-92.
234. Willer B, Ottenbacher KJ, Coad ML. The community integration questionnaire: a comparative evaluation. *American Journal of Physical Medicine & Rehabilitation*. 1994;73(2):103-111.
235. DeJong G, Batavia AI, Williams JM. Who is responsible for the lifelong well-being of a person with a head injury? *Journal of Head Trauma Rehabilitation*. 1990;5:9-22.
236. Morton. Psychosocial and emotional sequelae.
237. Racino JA, Williams JM. Living in the community: an examination of the philosophical and practical aspects. *Journal of Head Trauma Rehabilitation*. 1994;9(2):35-48.
238. Willer. The community integration questionnaire.
239. Schipper. Definitions.
240. Karpman T, Wolfe S, Vargo JW. The psychological adjustment of adult clients and their parents following closed head injury. *Journal of Applied Rehabilitation Counselling*. 1986;17(1):28-33.
241. Kozloff R. Networks of social support and the outcome of severe head injury. *Journal of Head Trauma Rehabilitation*. 1987;2(3):14-23.
242. *ibid*.

243. Krefting L. Reintegration into the community after head injury: The results of an ethnographic study. *Occupational Therapy Journal of Research*. 1989;9(2):67-83.
244. *ibid.*
245. Crisp R. Personal responses to traumatic brain injury: a qualitative study. *Disability, Handicap and Society*. 1993;8(4):393-404.
246. *ibid.*
247. Charmaz K. Identity dilemmas of chronically ill men. *The Sociological Quarterly*. 1994;35(2):269-288.
248. *ibid.* p. 270.
249. Charmaz. Identity dilemmas. p. 278.
250. Raphael. *Quality of life*.
251. Rappaport. Research methods.
252. *ibid.* p. 54.
253. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Newbury Park, California: Sage Publications, Inc, 1985.
254. Lord J, Schnarr A, Hutchison P. The voice of the people: qualitative research and the needs of consumers. *Canadian Journal of Community Mental Health*. 1987;6(2):25-36.
255. Lincoln. *Naturalistic inquiry*.
256. Glesne C, Peshkin A. *Becoming qualitative researchers*. White Plains, NY: Longman, 1992.
257. *ibid.*
258. Lincoln. *Naturalistic inquiry*.
259. Glesne. *Becoming qualitative researchers*.
260. Lincoln. *Naturalistic inquiry*.
261. Patton. *Qualitative evaluation*. p. 371.
262. Glesne. *Becoming qualitative researchers*.
263. Lincoln. *Naturalistic inquiry*.

264. Patton. *Qualitative evaluation*.
265. *ibid.*
266. *ibid.* p. 390.
267. Patton. *Qualitative evaluation*. p. 391.
268. Patton. *Qualitative evaluation*.
269. Rothe JP. *Qualitative research: a practical guide*. Heidelberg, Ontario: RCI Publications, 1994.
270. Denzin NK. The art and politics of interpretation. In: Denzin NK, Lincoln YS editors. *Handbook of qualitative research*. Thousand Oaks, California: Sage Publications, Inc., 1994, p. 505.
271. Patton. *Qualitative evaluation*. p. 407.
272. Patton. *Qualitative evaluation*. p. 408.
273. Denzin NK. *Interpretive interactionism*. Newbury Park: Sage Publications, 1989, p. 55 - 56.
274. Patton. *Qualitative evaluation*. p. 409.
275. Lincoln. *Naturalistic inquiry*.
276. Rappaport. *Research methods*.
277. Rothe. *Qualitative research*.
278. Glesne. *Becoming qualitative researchers*.
279. Lincoln. *Naturalistic inquiry*.
280. Rappaport. *Research methods*.
281. Raphael. *Quality of life*.
282. Lincoln. *Naturalistic inquiry*.
283. Rappaport. *Research methods*.
284. Raphael. *Quality of life*.
285. Yin RK. *Case study research: design and methods*. (2nd edition). Thousand Oaks: Sage Publications, Inc, 1994.
286. Lincoln. *Naturalistic inquiry*.

287. Yin. *Case study research*.
288. Lincoln. *Naturalistic Inquiry*.
289. Rappaport. *Research methods*.
290. Yin. *Case study research*.
291. Lincoln. *Naturalistic inquiry*.
292. *ibid*.
293. Rappaport. *Research methods*.
294. Lincoln. *Naturalistic inquiry*.
295. *ibid*.
296. Glesne. *Becoming qualitative researchers*.
297. *ibid*. p. 109.
298. Rappaport. *Research methods*.

## BIBLIOGRAPHY

1. Alfano DP, Neilson PM, Fink MP. Long-term psychosocial adjustment following head or spinal cord injury. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*. 1993;6(2):117-125.
2. Alfano DP, Paniak CE, Finlayson MAJ. The MMPI and closed head injury: A Neurocorrective approach. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*. 1993;6(2):111-116.
3. Antonovsky A. *Unravelling the mystery of health: How people manage stress and stay well*. San Francisco: Jossey-Bass Publishers, 1988.
4. Antonovsky A. Complexity, conflict, chaos, coherence, coercion and civility. *Social Science and Medicine*. 1993;37(8):969-981.
5. Antonovsky A. The structure and properties of the sense of coherence scale. *Social Science and Medicine*. 1993;36(6):725-733.
6. Bickenbach JE. *Physical disability and social policy*. Toronto: University of Toronto Press Inc., 1993.
7. Brock D. Quality of life measures in health care and medical ethics. In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
8. Brown H, Smith H. Assertion, not assimilation: a feminist perspective on the normalisation principle. In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
9. Carley M. Social indicators research. In: Finsterbusch K, Llewellyn L, Wolf C, editors. *Social impact assessment methods*. Beverly Hills: Sage Publications, 1983.
10. Carolyn SC. *A continuum of opportunity for people in Ontario with Acquired Brain Injury: final report*. The continuum of Opportunity Task Force, 1994.

11. Carr AJ, Thompson PW. Towards a measure of patient-related handicap in rheumatoid arthritis. *British Journal of Rheumatology*. 1994;33:378-382.
12. Charmaz K. Identity dilemmas of chronically ill men. *The Sociological Quarterly*. 1994;35(2):269-288.
13. Condeluci A, Ferris LL, Bogdan A. Outcome and value: the survivor perspective. *Journal of Head Trauma Rehabilitation*. 1992;7(4):37-45.
14. Crisp R. Personal responses to traumatic brain injury: a qualitative study. *Disability, Handicap and Society*. 1993;8(4):393-404.
15. Dalley G. Social welfare ideologies and normalisation: links and conflicts. In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
16. Dawson D. *The nature and prevalence of disability and handicap among Canadian traumatically brain injured adults living in the community: an analysis of the Canadian Health and Activity Limitation survey (1986-1987)*. University of Toronto, 1993.
17. DeJong G, Batavia AI, Williams JM. Who is responsible for the lifelong well-being of a person with a head injury? *Journal of Head Trauma Rehabilitation*. 1990;5:9-22.
18. Denzin NK. *Interpretive interactionism*. Newbury Park: Sage Publications, 1989.
19. Denzin NK. The art and politics of interpretation. In: Denzin NK, Lincoln YS editors. *Handbook of qualitative research*. Thousand Oaks, California: Sage Publications, Inc., 1994.
20. Edgerton RB. Quality of life from a longitudinal research perspective. In: Schalock RL, editor. *Quality of life: perspectives and issues*. Washington, D.C.: American Association on Mental Retardation, 1990.
21. Edlund M, Tancredi L. Quality of life: an ideological critique. *Perspectives in Biology and Medicine*. 1985;28(4):591-607.
22. Egan M. The price of poor prevention. *OT Week*. July 9, 1992;14-15.

23. Emerson E. What is normalisation? In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
24. Finsterbusch K. Evaluation methods. In: Finsterbusch K, Llewellyn L, Wolf C, editors. *Social Impact Assessment Methods*. Beverly Hills: Sage Publications, 1983.
25. Fitzpatrick R, Fletcher A, Gore S, Jones D, Spieglehalter D, Cox D. Quality of life measures in health care. I. Applications and issues in assessment. *British Medical Journal*. 1992;305:1074-1077.
26. Glesne C, Peshkin A. *Becoming qualitative researchers*. White Plains, NY: Longman, 1992.
27. Gordon WA, Mann N, Willer B. Demographic and social characteristics of the traumatic brain injury model system database. *Journal of Head Trauma Rehabilitation*. 1993;8(2):26-33.
28. Griffin J. Dan Brock: Quality of life measures in health care and medical ethics (commentary). In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
29. Hahn H. The politics of physical differences: disability and discrimination. *Journal of Social Issues*. 1988;44(1):39-47.
30. Hahn H. Alternate views of empowerment: social services and civil rights. *Journal of Rehabilitation*. 1991;57(4):17-19.
31. Higenbottam JA. *Restoring Hope: British Columbia's strategic plan for Brain Injury*. Government of British Columbia, 1994.
32. Kallen E. *Label me human: minority rights of stigmatized Canadians*. Toronto: University of Toronto Press, 1989.
33. Karpman T, Wolfe S, Vargo JW. The psychological adjustment of adult clients and their parents following closed head injury. *Journal of Applied Rehabilitation Counselling*. 1986;17(1):28-33.
34. Kinney W, Coyle C. Predicting life satisfaction among adults with physical disabilities. *Archives of Physical Medicine and Rehabilitation*. 1992;73(September):863-869.

35. Korsgaard C. Amartya Sen: capability and well-being (commentary). In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
36. Kozloff R. Networks of social support and the outcome of severe head injury. *Journal of Head Trauma Rehabilitation*. 1987;2(3):14-23.
37. Krefting L. Reintegration into the community after head injury: The results of an ethnographic study. *Occupational Therapy Journal of Research*. 1989;9(2):67-83.
38. Kreutzer JS, Gordon WA, Rosenthal M, Marwitz J. Neuropsychological characteristics of patients with brain injury: preliminary findings from a multicentre investigation. *Journal of Head Trauma Rehabilitation*. 1993;8(2):47-59.
39. Labonte R. Health promotion and empowerment: reflexions on professional practise. *Health Education Quarterly*. 1994;21(2):253-236.
40. Last J. *Public health and human ecology*. East Norwalk, Connecticut: Appleton & Lange, 1987.
41. Lincoln YS, Guba EG. *Naturalistic inquiry*. Newbury Park, California: Sage Publications, Inc, 1985.
42. Lindley P, Wainright T. Normalisation training: conversion or commitment? In: Brown H, Smith H, editors. *Normalisation: A reader for the nineties*. London: Routledge, 1992.
43. Lord J, Hutchison P. The process of empowerment: implications for theory and practice. *Canadian Journal of Community Mental Health*. 1993;12(1):5-22.
44. Lord J, Schnarr A, Hutchison P. The voice of the people: qualitative research and the needs of consumers. *Canadian Journal of Community Mental Health*. 1987;6(2):25-36.
45. Minister of National Health and Welfare. *Disabled persons in Canada*. Minister of National Health and Welfare, 1981.
46. Morton MV, Wehman P. Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury*. 1995;9(1):81-92.

47. Nussbaum M, Sen A. Introduction. In: Nussbaum M, Sen A, editors. *The quality of life*. Oxford: Clarendon Press, 1993.
48. Oliver M. *The politics of disablement: a sociological approach*. New York: St. Martin's Press, 1990.
49. Patrick DL, Peach H. *Disablement in the Community*. Toronto: Oxford University Press, 1989.
50. Patton MQ. *Qualitative Evaluation and Research Methods*. (2nd Edition). Newbury Park: Sage Publications, 1990.
51. Racino JA, Williams JM. Living in the community: an examination of the philosophical and practical aspects. *Journal of Head Trauma Rehabilitation*. 1994;9(2):35-48.
52. Raphael D, Brown I, Renwick R, Rootman I. *Quality of life and assessment: What are the implications for health promotion?* Centre for Health Promotion and ParticipACTION, 1994.
53. Rappaport J. Research methods and the empowerment social agenda. In: Tolan P, Keys CB, Chertok F, Jason L, editors. *Researching community psychology*. Washington, DC: American Psychological Association, 1990.
54. Rice DP, LaPlante MP. Chronic illness, disability, and increasing longevity. In: Sullivan S, Lewin ME, editors. *The economics and ethics of long-term care and disability*. Washington, D.C.: American Enterprise Institute for Public Policy Research, 1988.
55. Robine J, Michel J-P, Branch L. Measurement and utilization of healthy life expectancy: conceptual issues. *Bulletin of the World Health Organization*. 1992;70(6):791-800.
56. Rootman I. *Quality of life project - phase I*. Centre for Health Promotion and ParticipACTION, 1992.
57. Rootman I. *Health promotion: past, present and future*. Toronto: Centre for Health Promotion and ParticipACTION, 1993.
58. Ross WD. *Ethica nichomachea, magna moralia, ethica eudemia*. (2nd edition) London: Oxford University Press, 1925.

59. Rothe JP. *Qualitative research: a practical guide*. Heidelberg, Ontario: RCI Publications, 1994.
60. Scanlon T. Value, desire and the quality of life. In: Nussbaum M, Sen A, editors. *Quality of life*. Oxford: Clarendon Press, 1993.
61. Schalock RL. *Quality of life: perspectives and issues*. Washington, D.C.: American Association on Mental Retardation, 1990.
62. Schipper H, Clinch J, Powell V. Definitions and conceptual issues. In: Spilker B, editor. *Quality of life assessments in clinical trials*. New York: Raven Press, Ltd, 1990.
63. Sen A. Capability and well-being. In: Nussbaum M, Sen A, editors. *The quality of life*. Oxford: Clarendon Press, 1993.
64. Sosin DM, Sacks JJ, Smith SM. Head Injury - associated deaths in the United States from 1979 to 1986. *Journal of the American Medical Association*. 1989;262(16):2251-2252.
65. SP Research Associates. *Planning for the needs of people with acquired brain injury in Saskatchewan*. 1992.
66. Spilker B. Introduction. In: Spilker B, editor. *Quality of life assessments in clinical trials*. New York: Raven Press, 1990.
67. Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *Journal of Clinical Epidemiology*. 1992;45(7):743-760.
68. Statistics Canada. *The health and activity limitation survey: selected data for Canada, provinces and territories*. Statistics Canada, 1988.
69. Szivos S. The limits to integration? In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
70. Szymanski EM, Trueba HT. Castification of people with disabilities: potential disempowering aspects of classification in disability services. *Journal of Rehabilitation*. 1994;6(3):12-20.

71. The Acquired Brain Injury Working Group: *Acquired Brain Injury: A Strategy for Services*. Saskatchewan: Saskatchewan Government Insurance and Saskatchewan Health, 1995.
72. The Pennsylvania Interagency Head Injury Committee. *Traumatic Brain Injury: Ideal rehabilitation system report*. The Pennsylvania Interagency Head Injury Committee, 1988.
73. Wallerstein N. Powerlessness, empowerment, and health: implications for health promotion programs. *American Journal of Health Promotion*. 1992;6(3):197-205.
74. Wendell S. Toward a feminist theory of disability. *Hypatia*. 1989;4(2):104-124.
75. Whitehead S. The social origins of normalisation. In: Brown H, Smith H, editors. *Normalisation: a reader for the nineties*. London: Routledge, 1992.
76. World Health Organization. *International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease*. Geneva: World Health Organization, 1980.
77. World Health Organization. *Ottawa Charter for Health Promotion*. Canadian Public Health Association, 1986.
78. Willer B, Ottenbacher KJ, Coad ML. The community integration questionnaire: a comparative evaluation. *American Journal of Physical Medicine & Rehabilitation*. 1994;73(2):103-111.
79. Willer B, Rosenthal M, Kreutzer JS, Gordon WA, Rempel R. Assessment of community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation*. 1993;8(2):75-87.
80. Wong PP, Dornan J, Schentag CT, Ip R, Keating AM. Statistical profile of traumatic brain injury: a Canadian rehabilitation population. *Brain Injury*. 1993;7(4):283-294.
81. Yin RK. *Case study research: design and methods*. (2nd edition). Thousand Oaks: Sage Publications, Inc., 1994.
82. Ziebland S, Fitzpartick R, Jenkinson C. Tacit models of disability underlying health status instruments. *Social Science Medicine*. 1993;37(1):69-75.

APPENDIX A

Using Regina Health District Letterhead

Letter of Invitation to Participate

Dear

This letter is to invite you to take part in a research project. Wascana Rehabilitation Centre has approved of the research, and agreed to send you this letter. You have been selected to receive this letter as it was found that you had received services from the Centre, making you eligible to take part in the research project. Taking part in the project is voluntary. No information about you will be given to the researcher, unless you send her your name, address and phone number, and sign a consent form.

The research is about the experiences of people who have had an injury or illness involving the brain (Acquired Brain Injury). The purpose of the study is to learn how people with Acquired Brain Injury are doing after they have left the Wascana Rehabilitation Centre.

Your taking part in this study will help others understand the experiences and concerns of people with Acquired Brain Injury. The study may point to the strengths and weaknesses of services offered to people with Acquired Brain Injury. This would help improve services.

I am a graduate student at the University of Saskatchewan. I have worked for many years with people with disabilities, as an Occupational Therapist. Right now, I am working towards a Master's degree in Community Health and Epidemiology. This research is part of my thesis. The research is conducted under my supervisor, Joan Feather, Research Scientist at the University of Saskatchewan.

If you are interested in joining, I will meet with you to explain more about the study. With your consent, I will interview you about three more times, for an hour each time. The interviews could take place in your home, or you may choose to be interviewed somewhere else. The interviews will explore your present life, and how your life went before your injury.

Taking part in the study is voluntary. Taking part, or not taking part in the study will not affect any treatment you are having, now or in the future. If you choose to take part, you are free to withdraw from the study at any time. Your name will not be used in the study and your history will be changed so that others cannot guess who you are. Every attempt will be made to maintain that confidentiality.

There are no anticipated side effects. Sometimes talking about life experiences brings up difficult subjects and memories. Your social worker at Wascana Rehabilitation Centre will be available for meetings with you, if you want to talk with her about those subjects and memories. Also, you are free to change the subject during the interviews.

You will also be asked to sign a release allowing me to tape the interviews and have access to your records at Wascana Rehabilitation Centre. This will allow me to read your history and learn about the treatments in which you took part.

If you are willing to take part in, and/or want to know more about the study, fill in the following form and mail it in the self addressed and stamped envelope. Please call me if you have any questions at: **522-8241** and leave a message, or contact my research supervisor, Joan Feather, at 1-306-966-7932.

Yours Sincerely,

Lisa Brownstone  
Researcher

Research Supervisor: Joan Feather, Research Scientist,  
Department of Community Health and Epidemiology, College of  
Medicine, University of Saskatchewan, Saskatoon.

PLEASE MAIL BACK THIS FORM IN THE ATTACHED ENVELOPE

I would like to learn more about the study, and  
am interested in participating Yes

No

Name:

Address:

Phone Number:

How old were you at the time of your injury?

How long has it been since you left the hospital?  
year(s)

Do you have a social worker at WRC? Yes   
No

APPENDIX B

Using University of Saskatchewan Letterhead

**INFORMATION FOR PARTICIPANTS FORM**

for involvement in a study of people with Acquired Brain Injury living in the community

**INTRODUCTION**

This research project is about the experiences of people who have had an injury or illness involving the brain (Acquired Brain Injury). The purpose of the study is to learn how people with Acquired Brain Injury are doing after they have left the Wascana Rehabilitation Centre.

**ORGANIZATION OF THE STUDY**

- If you decide to take part in the study you will be involved in about three interviews.
- Each interview will take about an hour.
- Interviews could take place in your home.
- You may choose to be interviewed somewhere else.
- We will explore your present life, and how things were before your injury.
- Later I will meet with you to discuss your part in the study, and tell you the results of the study.

**POTENTIAL BENEFITS OF THE STUDY**

- The study will help others understand the experiences and concerns of people with Acquired Brain Injury.
- It may point to the strengths and weaknesses of services offered to people with Acquired Brain Injury.
- It may help improve the services that people with Acquired Brain Injury receive.

## **RISKS OF THE STUDY**

- There are no anticipated side effects.
- Sometimes talking about life experiences brings up difficult subjects and memories.
- You are free to change the subject.
- Your social worker at Wascana Rehabilitation Centre will be able to meet with you, if you want to talk with her about difficult subjects and memories.

## **RESEARCH PERSONNEL**

- This study is being conducted through the Department of Community Health and Epidemiology, College of Medicine, University of Saskatchewan, Saskatoon.

Researcher (Lisa Brownstone):

- I am a graduate student at the University of Saskatchewan, working towards a Master's degree in Community Health and Epidemiology.
- This research project is part of my thesis.
- I am also an Occupational Therapist, and have worked for many years with people with disabilities.

Research Supervisor (Joan Feather):

- Joan Feather is a Research Scientist in the Department of Community Health and Epidemiology, College of Medicine, University of Saskatchewan, Saskatoon and Director of the Prairie Region Health Promotion Research Centre.

## **CONFIDENTIALITY**

- Your name will not be used in the study.
- Your personal history will be changed so that others cannot guess who you are.
- Every attempt will be made to maintain that confidentiality.

## CONSENT

- You will be asked to sign a consent form allowing me to tape the interviews and have access to your records at Wascana Rehabilitation Centre.
- Access to your records will allow me to read your history and read about the treatments in which you took part.

## VOLUNTARY PARTICIPATION

- Taking part in the study is voluntary.
- Taking part, not taking part and/or withdrawal from the study will not affect any treatment you are having, now or in the future.
- If you choose to take part you are free to withdraw from the study at any time.

Please call **Lisa Brownstone** if you have any questions at: **522-8241** and leave a message, or contact the research supervisor, Joan Feather, Department of Community Health and Epidemiology, University of Saskatchewan, Saskatoon, 1-306-966-7932.

**PARTICIPANT CONSENT FORM**

for involvement in a study of people with Acquired Brain Injury living in the community

I, \_\_\_\_\_,  
volunteer to take part in a study of the experiences of people with Acquired Brain Injury living in the community.

**I understand that:**

- My taking part in the study is voluntary.
- I may withdraw from the study at any time.
- If I do withdraw, everything relating to my participation will be destroyed.
- Taking part, not taking part or withdrawal will not have any affect on treatment I am having now, or in the future.

**The researcher, Lisa Brownstone, has explained her intended study and the approach she is taking:**

- My part in the study includes a series of taped interviews.
- Those parts of the report relating to my participation, and the results of the study will be shared with me.
- Lisa Brownstone will give me any new information that might affect my continuing in the study.
- The study will be part of a Master's degree thesis.

**I understand that people will not be able to identify me:**

- My name will not be used.
- The only people who will have access to the tapes and typed copies of my interviews are Lisa Brownstone, and her research supervisor, Joan Feather.
- The tapes will be erased and typed copies destroyed within 3 years after acceptance of the thesis.

**If there is a service or information that may benefit me, or my treatment program, Lisa Brownstone will discuss this with me. With my permission, she will contact the person or agency that could help me.**

The above contents have been explained to me, and I understand them:

- I agree to allow the interviews to be taped.
- I agree to allow the researcher, Lisa Brownstone to have access to my health record at Wascana Rehabilitation Centre.
- I have received a copy of the consent for my own records.

I can contact the researcher, or her research supervisor, through the phone numbers listed below, during in the study.

Date: \_\_\_\_\_ Signed: \_\_\_\_\_  
(Participant)

Date: \_\_\_\_\_ Signed: \_\_\_\_\_  
(Researcher)

Date: \_\_\_\_\_ Signed: \_\_\_\_\_  
(Witness)

Researcher: Lisa Brownstone, BSc. O.T., O.T. Reg.(Sask),  
CCRC Tel.: (306) 522-8241

Research Supervisor: Joan Feather, Research Scientist,  
Department of Community Health and Epidemiology, College  
of Medicine, University of Saskatchewan, Saskatoon.  
Tel.: (306) 966-7932

The following codes can be used to identify cases of Acquired Brain Injury:

- 310.0 - frontal lobe syndrome
- 430 - subarachnoid hemorrhage
- 431 - intracerebral hemorrhage
- 432.0 - non traumatic extradural hemorrhage
- 432.1 - subdural hemorrhage
- 432.9 - unspecified intracranial hemorrhage
- 433 - basilar artery
- 433.1 - carotid artery
- 434.0 - cerebral thrombosis
- 434.1 - cerebral embolism
- 436. - acute, but ill defined, cerebrovascular disease
- 437.2 - hypertensive encephalopathy
- 437.3 - cerebral aneurysm, non-ruptured
- 437.4 - cerebral arteritis
- 437.8 - other
  
- 852.00 - 852.59 - subarachnoid, subdural, and extradural hemorrhage, following injury
- 853.00 - 853.19 - other and unspecified intracranial haemorrhage following injury
- 854.00 - 854.19 - intracranial injury of other and unspecified nature

## Part I: Overview of the sessions:

1. I would like to get a general picture of what you do in the course of a day, not necessarily the special things, just the routine type of things.

Depending on the detail provided by the participant further in depth questions will be asked.

2. Now I would like to get a general picture of what you do in the course of a week, again lets talk about the routine things.

3. Now that I have a picture of your day and week, could you tell me about a year in your life. Why don't we start with holidays and vacations?

4. Tell me about the special things that happen in a day or week or month? Some people describe special things as anything that doesn't usually happen to them ... like a friend calling who you haven't heard from in a while or a visit to another city, or a trip to the dentist.

5. I show them a drawing of overlapping circles - one in the middle is them, outer ones are friends circle, family circle, professionals circle, community circle - they mark where most intimate people in the lives are within those circles. This will help (I hope) initiate discussions (if not already initiated by the participant) about their social domains.

6. Overall- how is life going for you?

7. Tell me about the kinds of things you were doing in the months before your accident. (similiar questions to 1-6)

## Part II: A more in-depth guide to the interviews:

1. "I would like to get a general picture of what you do in the course of a day, not necessarily the special things, just the routine type of things."

Depending on the detail provided by the participant further in depth questions will be asked

"I would like to explore your day in greater detail. Perhaps this photo album will help you to think about a typical day. Let us start with the morning:

What time do you usually get up?  
Do you get dressed right away, or do other things first?  
How long does it take you to do your self care and get dressed?  
What do you usually eat for breakfast? lunch? Supper? snacks?  
Do you make it yourself?  
Do you clean up after yourself?  
How would you describe your living arrangements?"

3. "Now I would like to get a general picture of what you do in the course of a week, again lets talk about the routine things."

Probes could include:

Do you do the laundry?  
Do you meet with friends in a usual week?  
Does the family have a special meal once a week?  
Do you do banking, or grocery shopping weekly?  
Where are groceries purchased from?  
Do you go out to movies regularly?  
How easy is it for you to get out into the community?  
Do you feel safe in this neighbourhood?  
Are you involved in community activities - sports - learning - organizations, etc?  
Do you regularly go out with your family

4. "Now that I have a picture of your day and week, could you tell me about a year in your life. Why don't we start with holidays and vacations?"

Probes would include who they spend holidays and vacations with, whether they fill in income tax themselves, if they see their doctor yearly, etc, how often they get their hair cut

The interviews would then start to focus on those things that the person enjoys doing, the people they spend time with:

Tell me about the special things that happen in a day or week or month. Some people describe special things as anything that doesn't usually happen to them ... like a friend calling who you haven't heard from in a while or a visit to another city, or a trip to the dentist.

What kinds of things do you enjoy doing?  
What is the favourite part of your day?

Tell me about your friends network.  
How often do you see them?  
How often do you talk on the phone with them?  
Are there people in your life that you can count on?  
Do you do things for other people in your life?  
Who are the most significant people in your life?  
Will show them a drawing of overlapping circles - one in the middle is them, outer ones are friends circle, family circle, professionals circle, community circle - they mark where most intimate people are.  
Tell me about your relationship with them.

The third session would focus on the choices and possibilities in the persons life.

Examples of questions include:

Have you gone back to school or work since your injury?  
Are there things you would like to do but are presently unable?  
What stops you from doing those things?  
What are the possibilities in your life?  
What choices do you have in your life?  
What decisions are you free to make?  
How are decisions handled in your family?  
What kinds of things are you able to make decisions about without consulting others?  
Do you set goals for yourself?  
What kinds of things do you do to improve your physical, thinking and memory skills?  
Overall- How is life going for you?  
How does your present life compare to your life before your accident? (similiar questions to those posed above)