4. EXPERIENCES OF MOBILITY IMPAIRMENT

If I knew you and you knew me, if both of us could clearly see, and with an inner sight divine the meaning of your heart and mine, I'm sure that we would differ less and clasp our hands in friendliness; our thoughts would pleasantly agree if I knew you and you knew me. Nixon Waterman

4.1 INTRODUCTION

Chapter three described the difficulty of defining disability and it was decided that disability is multidimensional in nature and must be seen in the problem of environmental barriers, bodily restrictions and social context of ordinary daily living, such as material and socio-cultural oppression.

Relevant for this chapter is the point made about the developmental disease course and time phases in relation to the family developmental life cycle. The reason for the relevance is that ideas are taken from these notions to shape an unfolding course, time-related phases of mobility impairment in relation to the individual's, family's and significant others' unfolding life-styles. The narrative unfolds as storytellers or research participants recount their life "stories" to a listener and interpretive measures are applied, through teller and listener together, to gain a holistic understanding (Booth 1996:247-248; Czarniawska 1998:3).

This chapter explores the question: What are the implications of acquired mobility impairment for personal and collective identity? In this chapter the empirical study is discussed in relation to a moderate postmodern orientation associated with feminist researchers' point of view (4.2). Explanations and examples are given of the strategies of narrative generation or data generation and analysis follows in reporting of the analysed text of the transcribed "stories" from interviews with the

research participants. This is followed by an introduction of the research participants (4.3). The main themes of the research are analysed and discussed in section 4.4. The chapter ends with a short conclusion (4.5).

4.2 THE METHODS OF THE EMPIRICAL STUDY

In chapter one it was pointed out that the design of the empirical research is that of qualitative research. Brid Featherstone (2000:132) makes a point when she writes that the relationship between theory and method has often not been explicit in literature about qualitative research. Incorporated in the perceptions are assumptions that postmodern-orientated research is at an epistemological level and concrete research practices are not part of its concern. Featherstone (2000) strongly suggests that it is necessary to clarify theories that the researcher holds to and how they affect what is done.

In addition, Trinder (2000:50-51) expresses that for moderate postmodern feminists, in terms of research practices, the focus is on the research participants' experiences of life. This can create problems of whether experience of life can be captured with credibility and how research can be interpreted if all claims of truth are through claims of knowledge expressed through language.

Some researchers argue that there are creative and imaginative ways of scientific study to understand human interaction, such as narrative perspective. Murray (2003:111) recalls that until recently narrative methods were considered with suspicion, but have since gained increasing importance in the social sciences. Narrative is now understood as a way of constructing reality. A narrative, therefore, involves an organised interpretation of events relating the characters in the narrative to agency.

However, the analysis of narrative remains tentative and an ongoing challenge. Although different research traditions, such as positivist/post-positivist, critical theory, interpretive and postmodern, all have different criteria for judging the validity of research, postmodern perspectives do not have agreed criteria for how this is done (Trinder 2000:54). These criticisms of postmodern feminism created a dilemma in linking theory to methods for researching.

Polkinghorne (1988:159-160) suggests the importance of emplotment as a way of combining postmodern feminist theories, narrative methods and empirical data and feasible analytical research. The action of emplotment is the action which produces meaning from a number of events in experiences of human existence to create a whole meaningful story. Science as a human activity can occur within the contextual lives of humans and narratives recounted by people (Lee 1993:18). Polkinghorne (1988:64) points out: "In this context, the story selected to be told can function to present a particular image of the teller, and the kind of interview the hearer undertakes, can affect the kind of story told." The above thoughts will be expanded as the research methods are explained in this chapter.

This research is about people who are disadvantaged in mobility and the "stories" they tell. My understanding is that people must be treated as full human beings and equally included in social life irrespective of race, gender or nationality. Thus, this study's focus is on people who are mobility impaired and their personal understanding and meanings about their reciprocal interaction with the communities in which they live.

The challenges that confront physically disadvantaged groups, in the broad sense, may sound like abstract sociological problems that are too far removed from Practical Theology and too large for this study to deal with. As a result I consider people who are physically disadvantaged in mobility

in a more concrete practical way by approaching one group who are mobility impaired, which makes the problem more manageable. The group considered comprises people who are quadriplegic. The reason for choosing participants from a group of quadriplegics is that they are usually severely mobility disadvantaged and will provide meaningful insight into problems with identity over a broad scope of experiences. I anticipate that their stories about their experiences with quadriplegia will disclose problems with environmental, material and economic and socio-cultural oppression. It will also disclose problems they experience with their own body restrictions. Quadriplegia can furthermore be associated with people who are mobility disabled because they are elderly, chronically ill or experience severe post trauma, because the severity of mobility disadvantages will be similar in nature.

4.2.1 The research design

A qualitative research design was chosen because the interest is in what is meaningful to people with severe physical disadvantages in mobility within the context of their ordinary daily lives. This research is, therefore, exploratory, flexible, data-driven or text-driven and also context conscious (Mason 2002:24). I will employ the use of narrative methods. By narrative methods I mean methods that aim at illustrating the subjective experiences of people who are quadriplegic and how they interpret their experiences and the meanings these give to their lives (Booth1996:237).

4.2.2 Selection of research participants

For the sake of convenience, the research was narrowed to a group of people who are quadriplegics. The emphasis was firstly on people who are acquired quadriplegics rather than people disabled from birth, and secondly on one or two persons severely disadvantaged in mobility. The reason for this focus was that in chapter three I argued that acquired quadriplegia

means that the individual has already formed a pre-morbid, that is life before quadriplegia identity. It means, therefore, that post-morbidly or life after trauma they will face changes that occur not only to their physical abilities, but also to their already established identity.

Moreover, the reason for the inclusion of people who are severely disadvantaged in mobility was that people who experience a high level of cervical trauma are people who usually require the aid of a battery-powered wheelchair to move about. This could possibly increase complex everyday experiences.

In relation to the above explanation it means that when I made the selection of research participants, I had three criteria in mind: the first criterion was the level of spinal cord trauma, secondly, the length of time of being quadriplegic, thirdly, acquired quadriplegia. A list of names of people who live with being quadriplegic was gathered from a number of sources. The intention was to obtain a list with the names of people who had long-term quadriplegia and some who had short-term quadriplegia. I also asked the people I had contacted to assist with making contact with people who are quadriplegic, for both genders to be included.

A co-ordinator of a Christian association ministering to people who live with quadriplegia provided the names and contact telephone numbers of persons. Nursing personnel working with spinal injury patients referred some possible participants and gave contact details. An occupational therapist put me into contact with a self-help centre for people who are restricted in mobility.

After obtaining the list of names I made contact with the people mainly by telephone, while two were contacted in person. The aim was to ascertain that those on the list would be willing to become participants in a research project if chosen. Those who were agreeable where placed on another list,

resulting in sixteen names and from this list four names were chosen. Firstly the names of people living in areas outside Pretoria were crossed off the list. This was done because I had to limit the study to the Pretoria region because of problems due to the difficulty of travelling distances for both participants and myself. This left a list of nine names. Secondly, beginning at the top of the list of names, the first two names of participants who had a history of high-level quadriplegia for long periods were selected and one person with lower-level quadriplegia which was recent, was chosen. One other person was chosen for standby.

The reason why only four participants were chosen, is that the empirical study was meant to be exploratory and illustrative of the key concepts of this study (Mason 2002:126-127). Three participants were to be interviewed and one person was kept on standby in case something unforeseen happened. Because the list consisted mainly of males, with four females, it happened that two males and one female were originally chosen, with one female on standby.

It was anticipated that the narratives of these participants explored over a number of interviews would generate sufficient text to explore and to illustrate the different points made through this study. However, if enough text should not be generated, then there were still five remaining possible participants who could be approached.

Each participant was, therefore, contacted by phone and a date for the first interview was arranged. Once a participant's interviews were completed, the stories from the interviews were transcribed, coded and analysed and finalised before the next participant was interviewed (Charmaz 1990:1164-1165; Dey 1993:103-104). The analysing and coding of text is explained in a later section on analysing the text. Although the participant's interviews were completed one at a time, contact was made with each participant by personal contact and subsequent phone calls to help build a trust

relationship between myself and the participants. Finding participants, selecting the sample, making contact and the interviews spanned more than two years.

However, there was a change in the plan of selection owing to unforeseen circumstances. The second participant chosen collapsed the day before his second interview and later died. Some data about him from his first interview were included in this research. The volunteer on standby was chosen, which meant that there were now three participants who had all been high-level quadriplegics for a long period. There were now two females and one male instead of the original two males and one female.

The first participant's interview revealed an element that directed my interest to people who have a higher level of quadriplegia. It seemed that the higher the level of quadriplegia, the more limited the mobility and the more intense the isolation. It was an unexpected turn that was regarded as important to follow. It is in agreement with Charmaz's (1990:1166) theory that in qualitative research unexpected situations often occur that influence decisions about the flow of the empirical study.

Furthermore, because of the complexity of high cervical level quadriplegia, I decided also to include a person who is an occupational therapist involved with self-help centres, to be interviewed as a participant who could give professional clarity where needed. She is an occupational therapist who works with people who are disabled. Her field of specialised experience is spinal injuries and she is a "classifier" of people who are quadriplegic for the Disabled Sports Association. She is a South African wheelchair rugby classification co-ordinator. I used the code name OT to represent this occupational therapist because it is the shortened term used in her working environment.

The occupational therapist gave support to the view that the higher the

cord damage the more decreased and complicated the degree of mobility (see table illustrated in appendix C). When asked what level of cervical injury excluded the quadriplegic from sport she explained that:

> **OT:** In South Africa the highest level is C5 because as a C5 quadriplegia they have got their shoulder muscles and they have their biceps...They have got enough arm function to be able to push a wheelchair about themselves, although it is slow and cumbersome it is enough to be able to participate.

I also chose to interview a daughter of one of the participants because she was the main care-giver and it became clear that her isolation resulted in a sense of loss of identity. The end result was a number of counselling sessions with mother and daughter together. The reason for including the daughter was that I wanted to explore if it meant a more complex life-style in the drama of a family living with the person who is quadriplegic.

The study was limited to Pretoria in exploring the ordinary daily experiences of people who are mobility disadvantaged. However, different findings may be experienced by people who are quadriplegic in other regions, such as Venda, which is rural in orientation or Johannesburg, which is urban and more cosmopolitan and different in environmental and support facilities.

An idea of the vast difference between rural and urban regions may be illustrated through what the occupational therapist narrated in her interview. When asked what the State provided regarding wheelchairs for people who are quadriplegic, she replied:

> **OT:** The problem is that their (*State*) budget is too small. If they had the money, I'm sure they would, but the thing is that there is such a huge need for wheelchairs. In some of the more rural hospitals they still have people being discharged, (*...pause*) (*without wheelchairs*) because they actually don't have money for wheelchairs to discharge people. (*Brackets researcher's*).

The occupational therapist added that it is not a common occurrence and the situation is changing. She was, of course, speaking on "hear-say" from contact with rural occupational therapists at various discussion meetings.

4.2.3 Participant observer

Because I am a wheelchair user, my presence to the participants was one in which we shared similar "stories", which sometimes aided in asking searching questions (Polkinghorne 1988:164). It made identifying with them and their identification with me easier. We were part of each other's story.

Furthermore, conventional academic research that relies on generalisations may result in the loss of detail derived from experience, but in contrast the mode of storytelling provided entry into the personal experience of the person telling the story. In addition, the articulation of narrative allowed for remembrance of the story by the teller and creative imagination through the hearer (Booth 1996:237). Booth (1996:238), however, reminds us that too often the purpose of narrative methods have been gaining data for research and too little was made of the storyteller's interpretation of his/her own story.

Consequently, the stance taken in this study was one of interaction between the researcher, the participants and the text transcribed from interviews that enabled discovery of how each participant owned and interpreted

his/her story, how they understood their mobility impairment and what it meant to them.

4.2.4 Interviews and narrative generation

Each of the participants received a code name to abide by the ethics of confidentiality discussed with the participants. I used names because it expressed the personalisation of the participants instead of a number, symbol or letters of the alphabet. One participant verbalised consent to use the transcribed text from the interview. The verbal consent was tape-recorded and transcribed. The other participants managed to sign the consent form made available to them (Bogdan & Biklen 1992:96). See appendix A for an example of the consent form.

Each participant was interviewed in her/his own place of residence. Mason (2002:133) points out that time, space and place often have significance in research. The reason, therefore, for interviewing the participants in their place of residence was that they experienced difficulty with travelling outside the home. Likewise it gave me the opportunity to get to know the participants in their home environment and to meet any others significant to them.

An example of the way narrative generation and questions were managed is as follows: I made two broad general requests, e.g., "Tell me a little about your life before your accident? Say two years before" and "Tell me about yourself after the accident". The importance of what kind of life the person had before becoming quadriplegic and then after quadriplegia had relevance for establishing if there was any sense of continuity from pre-morbid to post-morbid stage.

I then listened to what the participants narrated as their experience and only asked questions to stimulate further narration and thus, to generate

conversation (Booth 1996:242; Riessman 1993:10). See figure 4.1 for an example of the interview questions guide.

Figure 4.1 Example of a question during an interview

> In relation to conversation that developed on the need to fit into society I ask:
> *I: What does it mean to you?*
> **Reg:** I think personally, I think that's very important because I would like to fit in and not always being rejected...

The challenge during the interviews was to convince the participants that their stories of their everyday lives were important to the research and to encourage them to share their stories with confidence. Thus, time was given to reflecting on what they said and supplementary questions were introduced to provide clarification on what they were saying and what I was hearing. Questions were asked from time to time, such as: What did you think about that? How did that make you feel? Can you explain that a bit more?

The tape-recordings of the interviews were transcribed and analysed. A few open-ended questions were specifically established in relation to the uniqueness of the participant's first tape-recorded interview and used in the second interview. Each participant's interview took a similar path, but with some difference in accordance with the unique circumstances of each (Murray 2003:118-119; Riessman 1993: 12-14). See figure 4.2 for an example of one of the participants' question formed after the first interview for the following interviews.

Figure 4.2 Sample of questions flowing from first interview

> The first interview with Reg revealed that he was a high cervical level quadriplegic, which affected his mobility even more. The question was then asked.
>
> *I: Tell me a little about the manual chair and how you managed with that because you are a high cervical level quadriplegic?*
>
> **Reg:** That's right. To be honest I didn't actually manage it...

The first participant's first and second interviews were more exploratory in nature. The first interview of the person code-named Kel was not tape-recorded. Time was spent explaining the research purpose, process and expectation to her. She was given the option to tell her story from her point of view. If she did not want a matter to be exposed, she could either refuse to answer any question or not to allow the information to be used in the research. She was also told she could withdraw from the research process at any time. She was furthermore assured that I would return to discuss my interpretation of her narratives with her. It was part of the ethical strategy of the study to be honest and open with the participants (Mason 1996:105).

During the process of the interview, demographic, pre-morbid and post-morbid activity information was recorded (see appendix B). The second interview was tape-recorded and the participant was asked to tell me about her life at least two years before the accident occurred. This was followed by a question on how her accident happened. Questions then flowed from the interaction that took place. The interview was recorded for 60 minutes.

In the third interview, which was recorded for 50 minutes, semi-structured open-ended questions were asked that were drawn up from the narratives analysed from the second interview. It was decided to interview Kel's daughter because she had made some remarks about being the care-giver and handy-man around the place. Kit, her code-name, consented to be

interviewed and an interview was recorded for 45 minutes. All interviews were transcribed.

Further counselling sessions of 45 minutes each, with both participants together, were included after the last interview. After her first interview, Kit expressed that she was unsure of her future as her mother's care-giver. She broke down crying and said she needed help. Because I could not leave her in this emotional state, provoked by telling her story, I suggested we start counselling sessions with her and Kel together. They later both agreed to this. These sessions, of which there were four, were considered as narrative or data generation.

When the next two participants were interviewed, I used the first interview to tell them about the research purpose and expectations. They were both residents of a self-help centre, so were together when the path the research would take was explained. The interview was not tape-recorded because they were together and the purpose was only to explain the research expectations to them and to set up dates for further interviews.

Later, however, since the one participant, code-named Jeff, once he was alone with me, started to tell of his experiences with quadriplegia that were troublesome to him, some field notes were made of what he said. This participant, however, collapsed the day before his second interview and died a week later.

After Jeff died, the fourth participant on standby was located and an interview was arranged. At the first interview, after explaining the research protocol and obtaining consent, the interview was tape-recorded immediately. Tess, her code-name, was interviewed and the interviews were tape-recorded, one for 60 and the other for 45 minutes.

The other participant code-named Reg was not sure if he was ready to tell the story of his post-morbid state experiences. I reassured him that he had time to think about it and that he would be scheduled as the last participant to be interviewed. He was given another two and a half months to think about it. Contact was kept with him by phone and when he felt more confident it was arranged for him to be interviewed at a later date at the end of the participants' list.

I changed the structure from the first participant's first interview. I decided to leave the demographic and pre-morbid history for the next interview because Reg verbalised feeling insecure. Reg was the last respondent and was interviewed two more times, which were tape-recorded for 45 minutes each.

After interviewing Reg I decided to interview the occupational therapist who was voluntarily assisting the self-help centre in which he lived because it appeared that her influence was important to his situation. It was decided that her input was relevant to understanding the differences and complexity between people who are high-level quadriplegics and those with a lower level of quadriplegia. An interview took place in my flat and lasted for 30 minutes.

As the interviews with the participants progressed, I found that my skills and confidence at interviewing increased, which allowed for easier flow and collection of stories (Charmaz 1990:1168; Dey 1993:102-103).

4.2.5 Analysis of narratives

Mason (2002:129) points out that the researcher can develop classifications based on examples such as the division of social existence into themes or experiences. A framework of narrative events was developed in association with events of coping with chronic diseases discussed by

Rolland (1989, 1993, 1994). An example of how this was accomplished is illustrated below (see figure 4.3).

Figure 4.3 Significant events associated with the unfolding narrative of mobility impairment

1) Readjustments had to be made to family and significant others' organisational structures;

2) readjustments had to be made that influenced relationships;

3) readjustments had to be made to manage losses experienced.

I wanted to understand the sort of stressors that each participant, family and significant others experienced in relation to their social interactions. The next thing I wanted to understand was the consequences that each participant experienced because of the stressors. In other words, what narrative plots emerged from their narratives in association with the significant events. Plots are that which expresses what the significant events meant to the narrators in relation to a particular theme or events (Polkinghorne 1988:160).

In addition, it was anticipated that some features of the biomedical and social models discussed in chapter three could be traced in the narratives of the research participants' narratives. This could be done through the same framework of plots or events of living with mobility impairment.

Next, in relation to the ICF's (WHO 2001) classification of disability, it appeared that the activity of plotting could enable the possibility of tracing some measurement of performance and extent of activities and participation in society, not only according to the individual, but also the family. This was kept in mind for the task of writing a report on the research participants' narratives and will be expanded on later.

Accordingly, the first move in framing a reference to enable the writing of

a report on the narrative responses and reaction of each participant, was to build on the themes from Rolland's (1989, 1993, 1994) psychosocial model of chronic diseases. I also included my own theme relevant to the theological perspective of this study. Understanding of God was included as a theme and an example is given in figure 4.4.

Hence, the theoretically significant narrative plots pertaining to the unfolding biological narratives of mobility impairment were expanded by inserting the different stressors related to the three main significant events associated with mobility impairment. An added significant narrative plot of understanding God was included in the framework because of the importance of the theological perspective of this study. These were given codes and an example of two of the narrative plots and the coding are given below.

Figure 4.4 Framework of narrative plots in relation to mobility impairment

Code 1: Re-adjustment of organisational structures of family and significant other. Code 1.1 Adaptation to changes   i) Role expectation changes; ii) role status readjustment; iii) isolation; vi) emotional stress, such as disassociation, anxiety, avoidance, denial.
Code 4: Understanding God   i) Blame/punishment conflict, ii) religious participation or isolation, iii) belonging/non-belonging conflict, accessibility; iv) forgiveness/unforgiveness conflict.

The above rough plotting of meaningful events of experiences of life formed the basis for the first level of narrative analysis. A back-and-forth procedure took place to refine the process of analysing transcribed text (Dey 1993:99-100). The refining of significant narrative plots continued and was followed by a continued effort to clarify a frame of reference to analyse text and provide for coding of transcribed narratives allocation and

for further analysis purposes (Dey 1993:103-107,126, 133-135; Charmaz 1990:1168-1170).

According to Rolland (1989, 1993, 1994), the frequency of hospital treatment regimes, home-based versus hospital care, and the frequency of movement between the time phases and the developmental course of the illness can result in forming narratives about the response of the individual and family. The second move, therefore, was that the researcher organised the unfolding biological narratives in relation to the psychosocial time-related phases of mobility impairment under the four main significant events. An example in relation to one of the narrative plots is shown below.

Figure 4.5 An example of one narrative plot

Significant plot 2	**Unfolding narrative and time episodes**
Relationships readjustment	**Onset**: Gradual or sudden
Conflict situation	**Crisis**: Frequency, degree of adaptation

The third phase was to link the tasks and the unfolding biological course and the psychosocial time-related phases to develop a means to assess the response or reactions to these tasks in relation to each participant's experience with mobility impairment. An example of the development of one of the plots was as follows:

Figure 4.6   An example of the development of two of the narrative plots

A) Event	**B) UBN and TP**	**C) Tasks**
Relationships	Onset: Sudden	Learn to pull together
Conflict situation	Crisis: Frequent bedsores	in mutual dependence
	and urinary tract	and care-taking.
	infections.	

Note: Because of space I abbreviated the unfolding biological narrative (UBN) and time-related phases (TP).

Fourthly, during narrative analysis I arranged "text bits" according to the above plots as shown above. Next, I looked for responses and reactions to tasks during the time-related phases in each participant's narrative of living with mobility impairments. Each participant's story told of events that related the responses of individual and significant others to events of change. Thus, bits of text were coded according to the plots or events, events of disability and tasks for each participant and interpreting their reactions. An example is given below to show how this was done with one plot and how it was expanded for coding.

Figure 4.7 An example of arranging and coding text

A) Plot Code 2 Readjust to relationships	B) UBN and TP	C) Task	D) Response or reaction
2.1 Conflict situation i) Belonging/ non-belonging	Onset: Sudden Crisis: Hospital-isation	Pull together in mutual dep-endence in care-taking	(Response may be) All members of the family worked together and felt a sense of belonging as a unit

The computer was used as the instrument, after coding text bits, to organise the text through splitting and splicing, cutting and pasting and making comparisons and connections (Charmaz 1990:1163-1165; Dey 1993:131-135).

The end result was that I was able to reach some understanding of each participant's narrative as a whole picture of biological circumstances and psychosocial circumstances in his/her living with mobility impairment. It also allowed for locating similarities and contrasting differences in their

response to the tasks associated with mobility disability and their reactions to the consequences of changes that occurred. It resulted in insight and entry into each participant's world to report on a more holistic awareness of mobility disability. The reporting on the interpretations, both the participants' and mine, provided the possibility of a strategy of how Christian faith communities can plan pastoral work to assist people disabled in mobility in living a meaningful life.

4.2.6 Research participants' narrative report

When writing the report I decided, firstly, to give a summary of Jeff's, Tess's and Reg's stories and secondly, to follow this with a full report of Kel's narrative account. The reason was to give illustrations from her narrative account of relapsing and regressive narratives that emerged. A full report was given of one participant because extensive analysis of each participant would take up too much space in this thesis. Despite heavy editing of narrative text, it allowed only for presenting a full report of one participant.

Furthermore, mixed direct speech and a reported speech method was used with the intention to avoid distracting from the direct spoken narratives. Booth (1996:248-250) suggests that the use of a mixture of direct and reported speech in analysis of narrative achieves the best description and explanation of the story. The benefit was that it made the load of text collected more manageable.

Field notes and memos were included in analysis to help identify tones, patterns and rhythms to aid in giving clarity for reported speech (Booth 1996:251). Sometimes there were two or three changes of direction in one sentence while participants told their stories. The articulation of the storytellers often became disjointed and often ran together. It was sometimes difficult to know where a sentence started and ended.

The aim was to analyse any unfolding fringe narratives in relation to the discussion in chapter three of the biomedical and social models and to identify mould-breaking narratives. The combination of the two methods would give an idea of the unheard stories of management and coping with quadriplegia throughout the unfolding course of mobility disability. Simultaneously the unfolding narrative of the time-related phases gives insight into the effects on the psychosocial dimensions of life.

The next target was to report on the narratives of each participant relating to his/her personal and social context. This was done in a way that gave as much exposure to the similarities and differences between the participants in their stories of the consequence of living with mobility impairment. The benefit was that it allowed hidden fringe narratives to become more visible and to forge links between ordinary, exceptional or alternative stories (Booth 1996:239; Combs & Freedman 1994:75; Murray 2003:127).

Each participant's demographic details of the pre-morbid and post-morbid status were illustrated. The demographic details will be given in the next section of this chapter.

Reporting commenced from analysis of the narrative text of each participant; the text bits were coded according to the framework of narrative plots derived from Rolland's (1989, 1993, 1994) typology and psychosocial perspective of chronic disease. To increase accuracy of reporting, the transcribed text was thoroughly read as a whole and key emerging metaphorical expressions and emerging narrative plots relating to each participant's story were highlighted. This was done because breaking up the text into small bits of narrative can result in loss of continuity of the narrative, although it provided precise text allocation to the unfolding narrative of living with mobility impairment (Riessman 1990:1195).

However, dealing with the transcribed narratives in bulk gave greater understanding of the emotional and relational structures between the family members internally and their external social and religious environments (Murray 2003:120). In this way narrative plots and subplots were uncovered and connections made between these in the broader context of the narrative. It enabled description and interpretation of the stories of the participants.

An interpretive phase, therefore, followed the descriptive analysis of the narratives as the broader theoretical literature about disability was connected to certain narrative accounts. This enabled certain narrative accounts by the participants to illustrate what the theories discussed in this study tried to clarify (Murray 2003:121). An example is the description of crises of the post-trauma period and how the narratives recounted by the participants illustrated their coping skills and management of support systems.

Furthermore, emerging narrative plots were highlighted and it was indicated how these linked to their storytelling. Attention was given to metaphors used during storytelling, to what these were related and how each participant verbalised his/her story to the listener, such as where emphasis was placed, tone of voice and wording of the sentences which were analysed. Thus, a concern of this research was to analyse and report how each participant organised the narrative account and how the temporal narrative plots were arranged into new stories.

The organisation of narratives was considered along the lines of Murray's (2003:122) referral to Robinson's temporal narrative scheme to organise narratives of multiple sclerosis (MS): 1) those that expressed that life ended with the onset of MS were considered regressive narratives; 2) those that expressed the life changes due to MS as a changed life-style, but life as ongoing were stable narratives; and 3) those that saw the disease as

providing new opportunities were progressive narratives.

A similar scheme is used for this research and guided description of interpretations of the stories of the participants.

1) Progressive narratives indicate that the struggles with the changing life-style created opportunities to overcome the problems and find new ways of coping.

2) Relapsing narratives indicate that living with mobility impairment is an up-and-down experience.

3) Regressive narratives indicate that the struggles with changing life-style are considered as hopeless, continually painful, without resolution or fixed in ways of dealing with changes. Instability is created when these are disturbed.

4.3. SUMMARY OF THE PARTICIPANTS

4.3.1 Demographic details

Figure 4.8 Illustration of demographic profiles of participants.

Note: Abbreviations: pres = present; Bef4 = pre-morbid state; Aft = post-morbid state; (m) = married.

NAME	JEFF	TESS	REG	KEL
Sex	male	female	male	female
Age: Bef4 Pres	26 27	19 40	18 34	23 46

Marital Status: Bef4	single	single	single	divorced
Pres	single	single	single	divorced
Academic record: Bef4	degree con-servation	matric	matric Master of psychology	matric
Pres	same	matric	psychology	matric
NAME	JEFF	TESS	REG	KEL
Family: Bef4	Father died, mother, brother	Parents, brother	Parents, brother, sisters x 2 Father died 1996.	Parents, brother, sisters x 2, daughter 3 yrs
Pres	mother, brother	Parents, brother (m)	Mother, brother, sister X 2 (m)	Parents, brother (m), sister (died) sister (M), daughter 26
Accommoda-tion: Bef4	mother's home	home	correctional service quarters	home
Pres	self-help centre	home	self-help centre	home/room then flat
Occupation Bef4	sales	clerk	prison warden	secretary
Pres	unemployed	small sales skin care products	unemployed	unemployed

Church affiliation: Bef4 Pres	Catholic same	NGK same	NGK same	none charismatic none (9 yrs)
Activities: Bef4 Pres	study, dating rehabilitating (died)	horse riding, motor cycling bible study, painting by mouth, reading, video, tv	rugby, wrestling, swimming, dancing study, cell group, painting by mouth, voluntary counselling	ballet and dating videos, tv, breeding dogs and parrots

4.3.2 Participant code name: Jeff

Jeff was a 27-year-old quietly spoken male who had been quadriplegic at cervical level 5/6 for just under one year. He came across as a young man with deep thoughts, not quite sure where he was at that stage of his rehabilitation. He had been involved in a motor car accident in the Cape and was admitted to a hospital in the Cape. He was in a manual wheelchair and had some function of his biceps and triceps muscle. He could flex and extend his arms and had some wrist function. He had a degree in conservation, but had worked as a sales representative before his accident. After the accident he was unable to find employment. He was very anxious to find employment because of financial stress. There was a possibility of some employment through the help of an occupational therapist who was voluntarily assisting him. He did not have a means of transport to get back and forth to employment, which complicated his opportunities.

His mother stayed in a flat in Johannesburg, his father had died and he had a bother who was married and lived in Johannesburg. Jeff lived in a self-help centre for the disabled in Pretoria because that particular one was affordable to him at a flat rate of R700 for board and lodging, which included staff as personal helpers for the residents.

He was brought up as a Catholic, but was not a regular churchgoer. Arrangements had been made between him and the occupational therapist that he would begin attending a Methodist church cell group. Unfortunately Jeff collapsed while being assisted to shower the day of the first cell group meeting he would have attended. It was also the day before his second interview would have taken place. He died the next week in the intensive care unit without regaining consciousness.

4.3.3 Participant code name: Tess

Tess is a 40-year-old female who says she is quadriplegic from cervical level 5/6, but her physical limitations portray a higher level of quadriplegia. She is a vivacious happy person who speeds about the house, inside and outside, in a power-driven wheelchair. She was working in an administrative post for a funeral fund. She lived a very full active life of horse-riding, motor-bike riding, sports and social recreation before her accident. She lives with her parents and has a younger brother who is married. She was involved in a motor-car accident as a passenger at the age of 19 years, and was hospitalised for six months, after which she went to her parents' home, where she still lives. She has limited movement in her upper arms and wrists with no grip in her hands.

She spent the first 12 years mainly in bed because she could not manoeuvre the manual wheelchair herself or sit in an upright position. She later obtained a power-driven wheelchair when they became available and her whole life changed. The earlier version of power-wheelchairs had fixed

backrests, which was difficult for her to use because in the upright position she had difficulty breathing owing to the level of spinal cord damage. The power-wheelchair she obtained has a power reclining backrest facility which means that she can be in a semi-sitting/lying position.

She now spends minimal time in bed although she needs to have all her hygienic needs, ablutions and anything needing physical effort attended to by a personal helper. In the beginning her mother and father assisted her with her needs, but the last 10 years she has had a personal helper who helps her during the week and her parents take over the weekend period. Her mother suffers from arthritis and uses a crutch to assist her to get about.

The family is exceptionally supportive of her and each other and have done everything possible to give her as much independence as possible. The house inside is very spacious and the area outside the house is fully accessible to her. The family recreational room adjoins her bed/living room and is specifically used as the place for regular daily entertainment and communication between family members and friends or visitors. Her bedroom is in two parts. One part behind a half wall houses her bed and a heater. She tends to feel the cold because of impairment to her body temperature regulation due to the level of cord injury. The area on the other side of the wall is spacious with a working level shelf-surface. The shelves fixed to the wall have numerous ornaments of horses and there are pictures of horses on the wall. Obvious affection is expressed between parents and daughter and personal helper and Tess.

Tess is a consultant for a skin product which she sells from home with the assistance of a skin product agent. She makes a small income. She has a good selection of loyal friends. She does not manage physically to attend church often owing to home programme management, body temperature difficulties and urinary complications that are due to the quadriplegia. She,

however, over the years has had various groups of friends and contacts attending Bible study held in her parent's house.

Finances do not seem to be a problem, although Tess does get a State disability pension. The family all assist with financing to make necessary environmental changes, hire personnel for assistance and buy mechanical aid needed over the years to include Tess in family and social life. She has a combi with a ramp that she can drive into with the power wheelchair and a family member or a friend who is available at the time drives the combi.

Tess's story presented as a progressive narrative throughout the different unfolding biological narrative courses and the unfolding time-related phases. She and her family approached the different psychosocial time-related phases of living with the biological dimension of quadriplegia as opportunities for finding new ways to cope with each narrative plot that emerged. The family worked together to find solutions to problems with the result that each family member had maximum autonomy in his/her situation. More will be discussed later in this chapter about how Tess and her family managed the personal and social contexts of living with mobility impairment.

4.3.4 Participant code name: Reg

Reg is a 33-year-old male who has been quadriplegic at cervical level 3/4/5/ for 15 years. He comes across as a level-headed and positive young man with lots of ambition. He was employed by Correctional Services in Durban when he was involved in a motor car accident as a passenger at the age of 18 years. He was transferred to a hospital in Pretoria, which was his home town. He was hospitalised for five months. In the beginning he was paralysed from the neck down and he had no shoulder or biceps muscle function.

Once discharged from hospital he was cared for by his parents in his parents' home for seven years. After his father died in 1996 he was cared for by his mother for another six years. He was medically boarded from Correctional Services, but did not receive any pension or medical aid except for a power-driven wheelchair which his ex-employer sponsored. He later obtained a State disability pension and a disability helper's grant. He eventually completed Clinical Psychology studies up to Masters degree level, but was unable to gain an internship so is unable to register.

He decided to move into a self-help centre for disabled men a year ago. At present he moves about in a power-driven wheelchair and has regained function in his shoulder muscles and slight biceps muscle function. It means that he is able to eat, sign his name and smoke a cigarette with various adjustment aids that must be strapped to his hands by a helper. He can manipulate the gear to put his wheelchair in motion. For any functions such as moving out of his wheelchair or hygienic procedures he is dependent on a human helper. He receives a State disability pension of R630 and a helper's grant of R115, but pays R700 for board and lodging in the disabled self-help centre.

At present he is still unemployed, although he is involved in voluntary counselling as a participant at a Methodist Church Crisis Centre. He regularly attends the church he grew up in and participates as much as he is able to. His family, mother, brother, sisters and uncle remain very supportive and assist him to get to church each Sunday, after which he has lunch with the family at his mother's home. He enjoys the support of his family and has loyal support from a circle of friends.

Reg presented a progressive narrative to the listener because although he had many personal disappointments, he always tried to see a way to look positively toward the future. His family was a tremendous support to him and his parents and all his siblings were immediately involved in care-

giving. He had a circle of friends who got involved in helping where possible in caring and supporting him.

He openly admitted his struggles with adjusting to the changes to his lifestyle, indicating many relapsing and regressive periods in his life with quadriplegia. However, it was always followed up with narratives of a way to adapt. Despite the presence of fringe narratives of oppressive social structures, such as affirmative action and fear of tokenism, the future for him had every potential to offer and he was going to work at achieving goals he had set for himself. More will be discussed later in this chapter about how Reg and his family managed the personal and social contexts of living with mobility impairment.

4.3.5. Participants code names: Kit - daughter, Kel - mother

Because Kel's daughter became involved in the storytelling of her mother, I gave a summary of her situation and included narratives from her interviews with those of Kel to present a holistic account of their situation. Kel's daughter was interviewed as well and I will briefly introduce some particulars about her role as care-giver.

Kit is at present 26 years old and once she started telling her story about being the main care-giver to her mother she came across as frustrated, angry and feeling trapped in circumstances beyond her control. She works from home as a designer dressmaker and her dressmaking equipment is placed in her mother's room. Kit assists her mother in breeding and selling dogs and parrots. She assists at the birth of puppies and their feeding whenever a litter is born until they are sold. The first of the parrot's eggs had hatched and she hand-fed the three chicks two-hourly, as well as being a 'helper' to her mother. She seldom gets out, except for chores and seems to lack a social and recreational life. She feels that the rest of the family are unsupportive and she expressed a fair amount of aggression towards

them.

It was interesting to note that when Kit and Kel were later counselled together, Kit backed down on expressing her feelings and a lot of the time Kel answered questions addressed to her daughter. It seemed that Kit did not want to contradict anything Kel said in any way. It appeared that a lot of the time the conflict with Kel's siblings was used as a "cop-out" when the conversation turned inward to the mother and daughter's relationship.

Kel's story provided a structure of narrative referred to in chapter one, that of beginning, middle and ending. The beginning included the period in hospital until she was discharged to go home.

The middle told the major part of her story after the accident in relation to herself, family and significant others. The texts of her narration were analysed in relation to the unfolding narrative of the biological dimension of mobility impairment and the time phases of the psychosocial dimensions of life.

The end dealt with the organisation of past abstracted plots related to anticipation for the future. The focus was on looking at the disruption of the transition from the pre-trauma to the post-trauma period and how the storyteller redefined her experiences and future expectations (Human 2003:44; Murray 2003:123-124; Polkinghorne 1988:164-166; Ricoeur 1992:121-122).

The style used to analyse narrative text and write a report of the analysis was an attempt to make the participant's story heard. How the story was expressed, how emotions and feelings were interpreted and what perceptions through responses of the collective public affected the individual and family were considered.

4.3.5.1 Kel's Story

Kel's story included her daughter Kit. Kel and Kit's story held relapsing narratives during the stable course phase and chronic readjustment phase which unfolded into ongoing regressive narrative plots emerging. The beginning or background, middle or development and ending of her story are provided below to illustrate the relapsing and regressive narratives. The beginning or background deals with the history before quadriplegia through to the socio-cultural aspects associated with hospitalisation and the health-care institution and its impact on Kel's life.

a) Background to Kel's story

Kel is a 46-year-old female who had been quadriplegic with permanent cord damage at cervical level 3/4/5/6 for 23 years when she was first interviewed. She participated in ballet until the age of 19 years and worked as a secretary for a lawyer. She was divorced with a three-year-old daughter and at the time of the accident lived with her parents in their house. She was involved in a motor car accident as a passenger at the age of 23 years.

i) Course and time-related phases

- **Onset: Sudden**
- **Time-related phase: Crisis during hospitalisation**

Kel regained consciousness three days later in hospital and was told rather abruptly by a doctor, who she thought was a painter, that she would never walk again. It took her some time to realise that she was paralysed from the neck down. Kel was not well informed about what she should expect with regard to living with being quadriplegic.

She and the family seemed to be excluded from the health-care institution's agenda of managing her quadriplegia. The health-care institution's controlling care-management, pointed out in chapter three, was clearly illustrated through Kel's story during the crisis episode at the onset phase of her disability.

The humiliating effects of abusive power and controlling methods were evident in an incident where Kel, after being sent home for a weekend, sat in front of a heater. Because she had lost sensation in parts of her body, and did not realise that there was a danger of getting burnt, she burnt her legs. An episode was added to her life narrative with her disability when she returned to the hospital. She gave an account of the incident with tones of indignation and anger.

> **Kel:** The Monday morning when and the doctor came round with all the 450 medical students. He said to me "What happened to you?" I said "I burnt". He said "OK next time you will know now not to sit in front of a heater". That was my answer.

I noticed that Kel exaggerated the number of medical students who were present. However, it was a tendency she resorted to throughout articulating her story about quadriplegia, when remembering emotional events in her life. Her regular use of exaggeration as a metaphor provided an insight to her claims about the reality of the situations she experienced. In the above incident it seemed that Kel was expressing the humiliation she experienced in relation to the abusive power the doctor portrayed in front of the students. The students' presence added to her humiliation. She described her emotions as:

> *I: But how did you feel?*
>
> **Kel:** How did I feel. I didn't know, I didn't know. When he told me that // I can't even remember what I felt like. (*pause*). Actually, I felt like a fool //I mean because why did I burn, because I didn't know about it, now I do. *(Memo: // indicates breaks in sentence).*

Unfortunately the same distant behaviour and attitude were re-enforced by a member of the nursing staff. It influenced her to disregard the important role the health-care institution could play in her life when she was denied making a choice about her own body and in desperation resorted to refusing treatment suggested by medical professionals. The medical staff tried to persuade her to have her bladder removed, which was the procedure pursued at that stage of medical history. However, having failed to persuade Kel they seemed to have resorted to coercion.

> *I: Tell me what sort of assistance or involvement was there by the health-care...?*
>
> **Kel:** Nothing. That's all I can say (*laughs*)...They wanted to remove my bladder when I was in the hospital and do an illeostomy - and I wouldn't let them...they said to me "...We are going to see you come crawling back to ask us to come and remove your bladder". I have never ever been back. There was no other help or anything.

When conversation about the episodes of bladder infection or health-care came up later in her story the phrase "never been back" and "no other help" came up repeatedly. These remarks, which seemed a way of dealing with conflict, however, can be read as a metaphor for the narrative of devalued status experienced in dealing with medical professionals.

One of the powers of narrative is that it provides an inner view of the person and enabled me, as a narrative researcher, to ground abstract claims in the illustrations of concrete lived experiences of the participants. The point of the fringe narrative approach is to give a voice to previously unheard suppressed narratives of life (Booth 1996:239). This research

was, as already mentioned, interested in fringe narratives and their effect on people: the link between the onset phase and crisis time-related phases of quadriplegia, in Kel's case revealed the presence of unvoiced oppression. It had consequences for Kel, her family and significant others in her life.

Consequently, the underlying controlling care-management narrative of the health-care institution overshadowed Kel's personhood. She said it made her feel foolish and later in her story she often laughingly told me "that people think because you are paralysed you have something wrong with your brain", which metaphorically illustrated being depersonalised because of bodily impairment. The consequences were that the strength of the biomedical model, of providing specialised care management, facilitating coping skills and managing the transition to the stable phase and chronic re-adjustment time-related phases of mobility impairment, did not play a part in Kel's story.

Thus, it seemed that the important provision of specialised health-care management failed dismally because the result was that Kel did not want to return to any hospital care and found ways to avoid the health-care institution. This was to the detriment of herself and the family because as her story unfolded it was apparent that it stunted the continuity between the pre-trauma and post-trauma narrative of life. Transition should have occurred between the narrative of onset of mobility impairment and the stable time narratives of the psychosocial interactions of family and significant others to facilitate a healthy continuity of personhood.

What is important at this stage is that narratives of oppressive power, control and manipulation emerged from Kel's story and had a profound effect on the narrative of the re-adjustment period of her and her family's lives with mobility impairment.

b) Development of Kel's story

The middle or development of Kel's story is an attempt to reflect in what way circumstances climaxed and what impact it had on her life, the family and significant others. What were the crises in her story and how did these influence actions, decisions and choices made by each family member and significant others? As a narrative researcher, I tried to reflect any climax that occurred. By climax I mean events in life that resulted in unique outcomes (Human 2003:46). However, the climax in this report refers to outcomes that turn the story to positive or negative narratives.

i) Course and time-related phases

- **Course: Stable**
- **Time-related phase: Crisis episodes of re-adjustment to home**

Kel was eventually discharged to go to her parents' home permanently. What she learned from the hospital staff in their care for her, she taught her mother. Her mother became her main care-giver who catheterised, bed-bathed and assisted her in every way. Her father helped with physically lifting her when it was required. Both her parents assisted her and worked together to manage taking care of her.

> **Kel:** Um, but my family stood with me and so we learned together how to do this, how to turn and how to do whatever, but they were very helpful. Um, I must say my mum and dad very much. They took turns to feed me because I could not do much, anything in the beginning (*mumbles*) you know I could not do anything and then eventually I started lifting my arms a bit.

> *(To the question of "who taught her mother to catheterise her?" she replied:)*
> **Kel:** I had to tell them what to do, I had to teach my mum to catheterise me.
> She was never shown how to do that. (Memo:*Tone - frustration*).

Kel's story reflected that the family and she herself managed to cope well with situations of the crisis episodes that occurred when she arrived home and they adapted to the immediate changes in mobility and independence that occurred after becoming quadriplegic.

It was noted, however, that her father and mother took the role of care-givers while her siblings did not engage in active care-giving. Also, no outside help was resorted to during this period. This seemed to set the trend for the next climax situation during the period of chronic re-adjustment. Decisions were made that largely confined the care-givers to the home and resulted in isolation and conflict in the family unit.

ii) Course and time-related phases

- **Stable course: Constant/at times relapsing.**
- **Time-related Phase: Chronic adaptation. Relationships and organisational readjustments**

For Kel, her family and significant others, it seemed that the transition between the crisis time-related phases of mobility impairment and the chronic adaptation time-related phases was not fully dealt with. Accepting outside help occurred only once, and Kel described the experience as "terrible, terrible" even though the helper was a nursing sister.

Her friends remained loyal and continued their friendship, but the relationships continued as pre-trauma. Her friends continued to visit her, being company and sometimes taking her out. The outings diminished over the years and were replaced by regular visits, but Kel expressed that her

friends were unable to help in any of the care-giving activities.

The end result was that Kel always relied on one main care-giver at a time; first her mother and then her daughter. The climax came when she made the decision that she would remain in bed. Kel kept expressing the necessity of this decision as something that was determined because of circumstances and to keep peace in the home. Incidents, such as the lengthy period she had to sit in the wheelchair because her father went to work, were mentioned a few times.

> **Kel:** C3,4,5,6 and 7 (*I: OK*) and then all the other damage with it. So um my dad used to work then so if I sat in the wheelchair I had to be washed and dressed, whatever at quarter to seven in the morning before he left and I would have to sit in the wheelchair until he came home after five at night, of course. My mother is not a very strong person and she could not get me into bed.

Kel described events implying that in trying to resume some form of normal family routine, she had to be left alone for long periods, because her sisters were doing ballet dancing.

> **Kel:** ... between the two of them five days a week. And then my mother would say we are leaving sort of half past one, you know and be back at six o'clock and if you are sitting in the chair. You can't sit alone outside because there is nobody to help you. Then I start saying OK then leave me in the bed today then I can put my tape-recorder on, and then the phone and everything, then I don't need anyone // because my dad used to work and my daughter was only two and a half years old.

In the same way the problem of getting into the bathroom for ablution reasons was solved based on the avoidance of being a "hassle" to people.

(To the question as to how she bathed, she replied):

Kel: Bathing, I bed-bath because, er, to get me to the bath is a problem, between Kit and my Mom it is difficult for them also. And in the beginning my dad said he would carry me to the bath, but I don't want my dad to see me with no clothes on....it's a hassle for other people so I have a bed-bath twice a day and, um, agh I've learnt that is maar the way I keep myself clean.

The terms "it is a hassle", "I don't want to be a hassle" "because it was a hassle" surfaced continually throughout Kel's conversation about living with quadriplegia. These metaphors used resulted in decisions and choices, such as remaining in bed, not going outside the home, not visiting her friends in their homes and remaining at home even during special family occasions. The combination of the parents keeping care-giving between themselves, and later Kel's daughter replacing the parents, created an ongoing deep emotional conflict situation between them. It also made maximum autonomy for the above family members more and more difficult. Thus, the term "hassle" seemed to take on other meanings. There was an underlying emphasis on quadriplegia being an oppressive force in her life that determined the making of certain choices.

Consequently, the narrative plot emerged of Kel's role in the family changing from striving for independence to that of dependence. There seemed to be little effort in the chronic adaptation period to achieve greater independence from either her or the care-giver's point of view. It resulted in isolation of Kel and whoever was her main care-giver at the time. Blame, guilt, unforgiveness and unresolved conflict between the family members were evident throughout the interviews and during Kel's and Kit's counselling therapy.

Hence the change of role expectation when Kel's mother was the main care-giver began to take strain, as her mother expressed that she had lost contact with friends. Kel spoke about her mother's friends as being unable

to cope with her being quadriplegic and so they stayed away. Narrated events unfolded to reveal that there was tension between Kel and her mother because her mother blamed her for the isolation.

> **Kel:** Now that she is older and the children are out of the house // now she has no friends, um, but she did blame me and maybe I felt bad in the beginning but it doesn't bother me anymore. (*Talks very fast with quick breaths in between so that sentences and facts run into one another or are not completed*).

Although Kel said it did not bother her anymore these narrative plots surfaced throughout her story and her tone of voice either climbed, or she spoke quickly with stops and starts, not always finishing her sentences. Similar underlying sensitivities seemed to exist because Kel insinuated that she had feelings of guilt because her father had back problems. At one stage in her story she said:

> **Kel:** He asked me: "Can you remember if I picked you up?" And so I said "no that wasn't because of me", but for years he had something like that.....(*Field note: she spoke with a low controlled voice and emphasised her reply to her father's question*).

The role expectation and role status change also later had a profound impact on the daughter who had been the main care-giver for the past nine years. It seemed that the story Kel recounted remained attached to her past role status of mother and Kit as the child. It seemed to be her way of trying to maintain continuity between her pre-trauma status and post-trauma status. Despite her disability she remained the mother and her daughter the submissive child. Her understanding seemed to be based on the fact that because Kit was her only child she had a responsibility to take care of her.

When counselling Kit and Kel together the description of Kit being the only

child and not being a male child constantly cropped up in their conversation. The impression was given through conversation with each other that if Kit had been a male it would have excused her from care-giving or if she had a younger sister the sister could take over from her. Metaphors used, such as "only child" "only daughter" and "not male" explained away any possibility of accepting alternative narratives to resolve the situation.

Kit, however, began to express objections to the early change of role status where for the past nine years she as daughter had to act as mother tending her mother. Trying to maintain continuity between the present and future seemed an unsurmountable task to her. She had begun to see her role for the future as the possibility of "being, and becoming", being an adult or becoming in new relationships, such as courting, marriage and children. She continuously expressed anger because her mother's siblings did not help in any care-giving.

iii) Course and time-related phases

- **Course: Unfolding incapacitation**
- **Time-related phase: Unfolding losses**

Added to the stressors of unresolved conflict within the home and relationship disruption, the two major narrative plots of loss that had a formidable impact on Kel and her family were financial stress and loss of independence.

iv) *Financial loss and stress*

Kel has been unable to be employed since the accident. She lives on a State disability pension, at present R630, and a helper's grant of R115. She made some extra income breeding Chihuahuas. When there were puppies

she sold them. In 2002 she also began breeding African Grey parrots with the help of her daughter. The income from breeding the dogs dried up because of aging and the parrots brought in an erratic income. Kit did dressmaking from home, which brought in a minimal income. Kel's parents being pensioners added to the financial stress.

v) Independence/dependence/physical impairment barriers

Kel uses a manual wheelchair when going out, but is unable to manoeuvre it herself. Most of her time is spent in bed because she finds sitting for long periods too distressing and it takes too much effort for those helping her to prepare her for getting out of bed. She goes out very seldom and then mainly confines it to sitting in the car because she has problems with her body temperature regulation owing to the high level spinal injury and gets very hot or cold easily. She has difficulty with breathing when coming into the upright position, which is also due to the high level of her injury and middle body muscle weakness. She has minimal use of her right arm and hand to hook the phone receiver with her hand and get it to her ear. She is unable to feed herself or to comb her own hair, although she can use a battery-powered toothbrush to clean her teeth. She uses her computer, which fits over her bed, with an adjustable aid in her right hand.

The occupational therapist provided insight into the problem with sitting upright. Because of the high cervical level of spinal cord damage, sitting in the upright position caused a sudden drop in blood-pressure and caused fainting. The weakened abdominal and thoracic muscles made it difficult to breathe when sitting. However, she pointed out that with rehabilitation this could be overcome. The individual could learn to re-adjust to sit in a wheelchair with a chin control.

c) Ending of Kel's story up to beginning 2004

During the counselling session with Kit and Kel, because a trust relationship had already been built up between myself and them, I asked how the conflict between the family affected them. The intention of the question was what Combs and Freedman (1994:74) refer to as listening and asking for openings. It led to Kit revealing that she as caregiver felt taken for granted and nobody thought that she needed help. She answered to a question about her aunt and uncle:

> **Kit:** ...ugh, my mother to them is like a part of the furniture (*tense laugh*). They are used to her in the bed and someone is helping her // so never mind she'll carry on // I don't need help.

I asked Kit to tell me about the conflict situation to obtain a detailed description of the situation and to locate emotions and patterns in their story. A conflict between Kit and her aunt and uncle had developed and it usually ended in mother and daughter arguing. Questions were asked that invited her to develop alternative stories.

It seems that Kit saw her solution to being bound to the home as her mother's siblings taking over at times to allow her to have some life of her own. I sensed that there was a great deal of feelings of guilt because she wanted a life of her own and this involved a life separate from her mother. Kit was obviously looking for identity. When looking to the future, she questioned "Who am I?" At the same time Kel's siblings seemed to have moved on with their lives as though nothing had happened to Kel to change her pre-trauma situation.

Pursuing Kit's questioning on who she was, I referred to the "picture" developed of family conflict, that was used during the counselling therapy. I invited them to consider whether there were now two "pictures", the second picture being that to avoid dealing with the conflict between mother and daughter, the conflict between Kit and Kel's siblings was used as a smoke screen. They both nodded their heads. A question was then put to

them about the future to provide a link between the present and the future.

I: What does it mean to you regarding the future that fear has so much effect on your life now?

Kit: A big stop sign.

I: Tell me about that stop sign. What does it mean to you?

Kit: *(Field note: remains silent and Kel just looks at her).*

When Kit was asked about her future, in an interview separate from her mother, she replied to my question:

I: And tell me how do you see your future?

Kit: ...(*Field note: Long pause and then starts to cry and mumbles).* See my future.(*Long pause - wipes away tears and tries to smile*)

I: Do you think about it? How do you see it?.

Kit: Dark (*...pause*) I can't // I don't know // which way // I don't know where to start (*starts crying again...pause*). (**I:** *Um, er why?*).

Kit: Um// if I do move out // who's going to look after a mother // um my grandparents are old. They can't look after her // I do have a life but sometimes I feel like I'm // (*unclear because of crying*) the situation // that// I'm confused. I don't know what to do. Which way to go. (*Memo: // indicate stops and starts while talking and ...pauses*).

It seemed possible that unconsciously maintaining focus on the conflict issues in the family was used to avoid making changes and discarding alternative narratives to help resolve some of the problems. An example of this was illustrated when, during one of the counselling sessions, Kel was asked if she would think of an alternative to remaining in bed that could possibly give her more independence.

> *I: Do you want me to ask the occupational therapist to come and talk to you and assess how she can help you and the possibilities of acquiring a State-provided battery-powered wheelchair?*
> **Kel:** No.
> *(I asked if she would like things to stay the same and not change.)*
> **Kel:** Yes.

A climax seemed to occur at that moment as I noted that Kit responded to what her mother said with lips pressed together and a facial expression of helplessness, but also an awakening to the fact that she could make her own choice.

It was clear that Kel's story followed a regressive narrative pathway after the stable course of quadriplegia came into play. Her story reflected a painful continuation of oppressive bodily, social and cultural obstructions to the process of living with quadriplegia. The way Kel tried to resolve problems that arose was to choose fixed ways of dealing with change. The result, however, increased conflict in the immediate family. Her mother, father and Kel's daughter were drawn into the same fixed ways, but with evidence of resentment and feeling trapped. Kit eventually broke out of this pattern by deciding to leave home, which created a crisis situation in the home once again.

The next section focusses on the personal and social contexts of all the participants' narratives and their similarities and differences.

4.4 MAIN THEMES FROM THE PARTICIPANTS' STORIES

Narratives of the participants' personal and social contexts could be grasped through the way their narratives were linked within their everyday living with mobility impairment (Murray 2003:127-128). Trinder (2000:52)

points out: "Narratives or stories are a primary way in which social actors make sense of past experiences,…" Hence, the interview is not understood as a self-explanatory window to the world, rather the interviewees' narratives are a topic in their own right. The main narrative plots that emerged from the research participants' narratives were personal coping with physical impairment and understanding God, economic oppression and socio-cultural consideration with reference to environmental barriers.

The next section, therefore, discusses the personal context in relation to bodily impairment restrictions. The research participants' understanding of God and involvement with their faith communities are expanded on with illustrations from the analysed text. The social interaction between mobility impairment, the individual, family and significant others is discussed in relation to environmental and socio-cultural oppressive structures, because the participants' experiences of embodiment were influenced by environmental barriers and socio-cultural factors. Also each point above will be discussed in relation to personal and collective identity where it is relevant.

4.4.1 Narratives of personal restrictions

4.4.1.1 Personal bodily restrictions

In chapter two French (1993a:17) criticised the emphasis on a one-sided perspective. The stories of the participants supported French's point that a both/and position must be taken, in that certain bodily impairment complications decreased mobility for periods for people who are high cervical level quadriplegics.

Axtell (1999), when doing a research project on gays living with chronic disease, explored their identity as individuals living with chronic disease. In a similar way I explored the research participant identity as individuals

living with quadriplegia. The participants spoke about their disability identity as one in relation to multiple identities. In one sense they experienced their identity as constancy over time. In another sense their bodily impairments were seen in tension with other restrictions, such as economic, political policies, environmental and behavioural attitudes of others who are not disabled.

Sometimes their experiences with disability were described as fluid because it depended on so many things, such as the availability of mechanical aids and other human beings as part of their embodiment. Sometimes their disabilities were seen as something that because of their changed body-image prevented or threatened their social interaction and, thus, their identities.

Kel, for example, experienced impairment of body temperature regulation that caused overheating on hot days or getting very cold on overcast days. She had to take certain precautions against heat and cold. It often resulted in her staying at home or having to go home early because it was extremely uncomfortable for her. It was due to the permanent spinal cord damage at a high cervical level. To the question of how she felt about not being able to participate as she would have liked to, Kel replied tearfully:

> **Kel:** Maybe because I can't I feel bad. But if I see how uncomfortable I feel, OK the weather affects me. So if it's raining or it's hot then I have to stay away, you know, because of that...

Tess too had difficulty with her body temperature regulation in that she usually felt very cold on even warm days and yet sometimes distressingly hot. She had a heater on most of the time in her bedroom. Tess also explained that, combined with other problems, it meant there were long periods of isolation, an example being when her helper was off duty over weekends and both her parents helped her to wash, dress and be put into

her wheelchair. It took about three hours and by the time she was ready it was late in the morning. On Sunday morning, for instance, it made it difficult to get to church on time despite starting to get ready at 06:00. The evening service she could only attend in summertime if the weather permitted and not at all in winter because of her bodily temperature regulation impairment. This meant that there were long periods that she did not get to church.

In comparison Reg, who had below cervical 4/5 cord damage, experienced some discomfort with the temperature regulatory system of his body. His limbs, he says, become ice cold and it is difficult to get warm in winter because of poor circulation. In summer, as long as there are fans blowing, he is reasonably comfortable. Out of the three participants, Reg had the least number of periods of being restricted to home for prolonged periods owing to spinal cord related damage.

The participants' stories showed that "self-bodily" barriers and environmental barriers were connected in that the participants were reliant on people as helpers, battery-powered wheelchairs and combi-like vehicles with ramps. The participants started with a disadvantage of bodily difficulties, which were enhanced by environmental barriers that added to their frustrations.

Thus, Reg's story below reminds the reader of the limitations that a manual wheelchair creates for high-level cervical quadriplegia and indicates the difficulty of maintaining social interaction because of mobility limitations. It also reveals what impact limited employment opportunities and economic aspects had alongside bodily restrictions.

> **Reg:** …the manual chair they got me, it was just that it was very awkward // I mean I did not have the muscle strength or the endurance or capacity to really be able to use it…I only went a block and then I'd sit and look at the birds, very frustrating in a sense and I just went on and carried on from there.

Kel also described her difficulty with getting out into the environment with the complexity of finding suitable physical human helpers to assist in getting to shops, restaurants and social venues.

> **Kel:** I feel if I want to go somewhere it's a hassle for someone else so I would rather stay at home and get frustrated because I don't really have help. Those I have to ask are also limited and, er, I just feel because I can't help, it makes it very difficult if there's only one person to help. So I rather just stay at home. It's very frustrating.

To add to the difficulty of mobility because of the high level cervical cord damage, accessibility to financial necessities was important for necessary mechanical equipment for mobility.

4.4.1.2 The personal restrictions of finances

Narratives of the personal dimension also illustrated that mobility was restricted in relation to mechanical assistance because it depended on the availability of finances. However, it must also be noted that mechanical aids are very expensive.

This was verified in an interview with the occupational therapist who explained that the cheapest manual wheelchairs cost from R2 000 to R9 000 and above. The more expensive the wheelchair, the more manageable for the user to manoeuvre. Power-wheelchairs begin at the cheapest price of about R19 000 and above. State policies have been made in South Africa on regulations applying to acquiring State-provided power-wheelchairs.

The State Health and Welfare Department provides the cheapest battery-powered wheelchair. During the interview with the occupational therapist, she said:

> **OT:** Wheelchair provided by the State. There are very strict regulations as to who can get a power-wheelchair through the State. Basically, um, it depends on somebody's income...The State in Gauteng will provide a basic power-wheelchair and will fit a chin control if necessary. They do not provide reclining chairs...A person with a C4 injury would probably need a chin control for their chair. As far as I am aware this can be ordered through the State, so a person with high level quadriplegia will be able to get a State-supplied power-wheelchair.

This discussion clarified that social policy narratives were clearly involved in the availability of mechanical aid and influenced the type of assistance provided. The socio-political perspective will be discussed later in this chapter.

When speaking about the prospect of obtaining a battery-powered wheelchair Reg linked the cost of the wheelchair with employment. He stated that:

> **Reg:** So it is costly, and I didn't go back to work which I would have loved to have done.

Reg's story recounted the sense that not only was social interaction curtailed because of bodily barriers and lack of mechanical aid, but also that unemployment and economic lack were tied into decreasing social interaction. In other words, these factors all influenced social identity.

Tess brought an interesting factor to the attention, namely that the home environment must be barrier-free before the wheelchair person can even think of venturing further afield. In the first 12 years of her being

quadriplegic she was confined mainly to her home because the home environment was not suitable for movement. The home had to be changed inside first and later outside to allow for getting out into public environments. These changes were costly and took a number of years to complete, with the added expense of a battery-powered wheelchair, a combi and ramp. Tess described these years in answer to my question: How did you cope when your horizons were so very controlled?

> **Tess:** Especially before, because we did not even have paving in front of the kitchen, so I couldn't go outside my room.

4.4.2 Understanding of God

4.4.2.1 A relationship with God

The experiences of the participants disclosed an interesting part of their stories because each one had grown up in a Christian family, but each had turned away from the church and God when they became young adults. However, each spoke of their experiences of turning back to God after their accidents.

Tess recounted that a friend of her mother offered to visit her and be a listener if she needed her. The day came when Tess asked her to come and see her with the result that she helped her to find God. Consequently, Tess reflected a strong relationship and reliance on God that was encouraged by her mother and a friend of her mother. Tess and her mother appeared to maintain their sense of belonging in the church by bringing groups of friends and those they ministered to into the house by having Bible studies or other meetings. She recounted how she came to the Lord as follows:

> **Tess:** The lady came over and she started doing Bible studies with me, and stuff, and led me to the Lord.

Kel spoke with deep emotions of having turned away from God, but people from a church visited her in hospital and led her back to the Lord. These people stuck with her for five years and helped her through Bible study meetings.

Reg said that although he vaguely served God before his accident, afterward he gave all of himself to God and could not do without God in his life. An interesting part of Reg's story about reaching out to God was his preconceived ideas about what the responsibility of the church was after his accident and the influence this had on his understanding of God. He said at different times:

> **Reg:** Well right in the beginning I was very angry, um, but I kept it to myself. Um, our reverend did come to visit me from time to time...They tried to counsel me, I, I wouldn't say really counsel, but they just had a short discussion. (At another time he said).
>
> **Reg:** To be honest at the time it didn't really mean a lot to me...part of the responsibility of being a minister of a congregation is to go out to see to anybody that is in hospital. At that stage I relied on my friends and family for my own personal relationship with God.

It seemed strange that Reg did not see the role of his church leaders as anything else than visiting when one is sick. It was something he repeated a number of times in spite of recounting numerous hours of struggle with God about things like anger, disappointment, confusion, hurtful incidents and seeing his family struggling to cope. His preconceived ideas seemed to have set the tone for his relationship with his church.

4.4.2.2 The relationship with their faith communities and traditions

Zijderveld (1986:89-90) points out that exposure to relationships with significant others is the way identities are assigned and, therefore, how the individual appropriates the identities. Unfortunately, the person is often not considered a multifaceted "self" with a number of identities and roles in their society, rather they may be referred to in relation to a "disabled identity". It can result in the person who is physically disabled being perceived as someone who is consumed by disability and completely dependent on others, instead of the image of a multi-faceted person with intact abilities in other areas. The result is that such a person is considered to be non-functional for participation in the church and may often be moved to the margins or forgotten because of frequent periods of being absent (Eiesland 1994a:20-22; Webb-Mitchell 1996:32-33).

An example is given of one of the research participants who recounted the difficulty of attending church on a regular basis. When her church, which she had been attending as often as possible, decided to move to a place more distant from her home, the difficulty of attending increased. It resulted in the members of that particular faith community disappearing from Kel's life. She emotionally expressed that she no longer belonged to any church.

> **Kel:** ... because I, I don't go physically there I don't belong to a church and see the people and, um now the church is quite far away where it used to be, and used to see me on a Sunday, and used to visit and chat and come and visit. Then as the church moved, you know further away. And people, circumstances change... *(Mumbles)* and then you don't really see them....
>
> **I:** *Are you saying then that the church lost contact with you?*
>
> **Kel:** I think so.

Kel was not the only one who experienced the loss of fellowship with her faith community she once belonged to, because her daughter referred to her own disappointment that Kel's congregational members did not keep

contact. When asked how she felt about it she replied:

> **Kit:** (*Long time in thought*) I think it's wrong...I feel it's wrong because she was part of them, part of the church, or we were. Then the church moved to a bigger church (*...pause*) and then no contact, it just stopped. I can't understand why. (*Fieldnote: Facial expression shows distress and hand gestures indicate bewilderment*).

Whether exclusion comes about because the faith community ignores these people's needs, unintentionally or intentionally, it does not alter the fact that the act of excluding leads to a double action of the person feeling unwanted, and the faith community failing to manifest the love and compassion of the Triune God it professes to serve. I remind the reader that in chapter one Volf (1996:146) was referred to as expressing the fact that the metaphor "embrace" indicates how the members of faith communities should relate to one another in the same way God showed love to all humanity through giving of himself.

Kel disclosed the painfulness of being removed from the collective ritual celebrations of her faith community. She experienced feelings of devastation in not belonging to any faith community for the past nine years. However, her story discloses the separation she felt between her personal faith and her collective faith through being unable to identify with her faith community. Kel said when asked how she felt about not belonging to a church:

> **Kel:** (*........pause*) I know I belong to Jesus, but the church, it is just like so much other things that I've learnt to stay without...I still know that I will go to heaven although I don't belong to a church (**Fieldnote:** *At this time I had to switch off the tape recorder as Kel was crying too much to talk*).

It means that during interaction the interwoven stories of the faith

community reflect the religious identity of that community in the way that the members take to themselves the stories, that is, the action and non-action, of the faith community in relation to their own story (Sterkens 2001:78-79). Ricoeur (1992:151-156) refers to the responsibility of "oneself-to-another" and the fact that at the level of reciprocal interaction socio-cultural and religious traditions are internalised or ownership is taken. Identity of "self' means the active acceptance of the different "other" and not mere passive tolerance. Kel and Kit, for instance, took the actions of their faith community to mean that they no longer belonged and they felt rejected by all members of the congregation.

It must therefore be noted that both Kel and Kit read the actions of that faith community's omission to continue embracing them as a member of the congregation as not being wanted and that they no longer belonged to that faith community. In fact it had such an impact on Kel that she no longer attempted to make contact again with another faith community.

Another example of how the response of faith communities is absorbed by people and the influence it can have on religious identity is described in Tess's story. The problem occurred when her church leaders refused to serve the Eucharist in her home despite her being unable to get to church for long periods. Tess described the incident and its snowball effect as:

> **Tess:** Um, well, um the former guys wouldn't come, they, er, they um. They said they didn't want to come and provide communion in my home because they will upset the president. They would then have to go to everybody's home who cannot get to church...
>
> *(Tess later told of the effect it had on her father who felt the church leaders had rejected her by refusing to make a vital Christian ritual available to her).*
>
> **Tess:** ...a bit of a bad spirit about the church because they wouldn't come and serve me communion. He knew how bad it was for me to go to church and they didn't realise it and he couldn't understand that they wouldn't come to me after all that he's done for the church.

This part of Tess' story shows that the failure to respond positively led to her father interpreting the decision not to serve communion in the home as denying his daughter a vital part in the religious identity of their faith community. It supports what Brown (1997:111) writes, that "Narrative is that mode of discourse through which human action is interpreted as meaningful agency." The past narratives of the Eucharist express a meaningful sense of belonging for Christians in their faith communities, but refusing to serve the Eucharist resulted in removing this meaningfulness for the family in their present circumstances.

Thus, narrative can give coherence or disclose upheavals to life for people as illustrated in the story of Tess and her father. It also illustrated that collective religious identity could be denied. Tess and her father's personal story was influenced by the collective response of her congregation, that in a sense, failed to identify with the story of the suffering of Christ. It seemed that traditions of the faith community received priority attention and therefore failed to give Tess a sense of belonging and being valued as a person. Thus, the religious identities of Tess and her parents were not strengthened because of failure of their faith community to bond with them in identifying with their suffering.

It is apparent that Tess and her father's story illustrated the tension

between personal narrative and collective narrative in relation to the gospel message of love and compassion. Not only did she experience denial of belonging, but her father experienced her suffering also, to the extent that he chose not to go to church for eighteen years. What Brown (1997:110) notes about fixed preconceived particularities or traditions of a group is that it can hinder collective identity because it does not allow for the inclusion of one's narratives of one's own lived experience in situations of possible need for change. It made the sense of belonging and identifying with the faith community very fragile indeed for the family.

It seemed that in Tess's case, the decision of the church leaders at that time was based on the power structures built into their religious traditions from which they refused to budge for eighteen years. Nineteen years later the new minister of that faith community brought change to the situation by serving the Eucharist to her in her home when she was unable to get to church for long periods. It was this action that broke the rigidity of traditions that had in a sense, held Tess's father struggling with unforgiveness for eighteen years.

There were, however, two things I noted that have relevance for what is discussed above. During the telling of her story Tess had disclosed that the very minister now in charge had been in the church for more than the twenty years that she had been quadriplegic, but he was powerless to do anything about it because he was not in charge. The former minister in charge was not a man who wanted to cause problems with the traditional stance of that church. Tess described it:

> **Tess:** The old minister was a very, er, humble meek man. He was how can I say, he was brilliant with sick people and with old people dying...but he was the kind of minister that would shy away from making waves in the church...

However, it can also be noted that the present person in charge of church

leadership had not resisted any decision made during the eighteen years. Thus, the leaders possibly failed to question the rigid traditional rule critically in relation to the contextual situation of the person and the family and so did not reflect the true meaning of nourishing a sense of belonging for Tess and her family.

Another important point made by the research participants was the need for fellowship. It was very evident in the stories recounted as each research participant expressed very strongly the need for fellowship. They expressed that the thing they missed most during periods when they were unable to get to church, was fellowship. It was noted that Tess and Kel felt very strongly that fellowship meant being with a collective gathering of believers for worship. Kel explained that she needed fellowship with a group of people and although Christian friends visited it was not the same as group fellowship. At the end of the conversation I asked:

> *I: So am I hearing you rightly? Are you saying that when the church was around you had fellowship that helped you to cope better with life problems?*
> **Kel:** Ja, ja (*Fieldnote: Crying too much to say anything more*).

Tess, her mother and grandmother formed their own Bible study group in their home as a solution to finding fellowship with a group. She described the meetings.

> **Tess:** Ja, for about, whoa, it was a lot of years, and then we started forming a little Bible study group in the afternoon. My mother, my grandmother and the lady next-door...

These are some of the problems that people who are restricted physically experience in life with their religious communities. Confusion exists, especially for those who acquire disability later in life, where on the one hand, change of body-image does not mean a break in continuity of "self" over time, and on the other hand, public non-recognition of the capacity for

continuity of life has been conceived based on perceptions of an abnormal body-image.

In the cases of Kel and Tess it must be noted that their faith communities' interaction with them after the spinal cord trauma, they were sometimes treated as persons not fully capable of functioning in many dimensions of life. They were sometimes instead marginalised because discontinuity of the "self" was assumed through perceptions of them being completely dysfunctional. Rejection, non-acceptance and non-belonging were part of their lot in their daily religious living.

Unfortunately it does mean that if faith communities respond in the same way that their societies responded to their disability, a sense of belonging cannot be facilitated. Embracing of the world's standards of acceptance of a person can, therefore, be practiced by some faith communities. Webb-Mitchell (1996:xv) points out that:

> The church is frustratingly silent about what it may mean to be truly "disabled" or "handicapped" in the presence of God, which may be something radically different from what it means in the secular world.

To maintain religious identity is understandably difficult in a secular world. It is, however, even more difficult for people who are mobility disadvantaged when faith communities, with whom they want to identify, make it more difficult by being silent about oppressive structures. The point that Webb-Mitchell (1996) makes is very evident in Tess and her father's experience in their interaction with their faith community.

4.4.3 Social interaction of people who are mobility disadvantaged

The importance of reciprocal social interaction in the forming of personal

identity was referred to in chapter one. There are a number of restrictions in mobility imposed on the person who is mobility disadvantaged that make social interaction minimal. I will refer to some of these restrictions disclosed by the research participants' stories.

4.4.3.1 Environmental barriers

The question emerged as to why wider social interaction was limited in the participants' storytelling. The participants all spoke about difficulties in accessing places because of environmental barriers. Tess and Reg laughed off the problems and felt that in some way it was their daily reality.

Reg gave an explanation that describes what all of the participants spoke about. Reg described the inaccessibility of places, indicating that the matter is more complex than just getting into a building or not. According to what Reg said it appears that barriers to architectural structures and necessary facilities are not just a frustration, but also create fears and insecurities, which people who are disabled must overcome.

He explained that it is frightening if a restaurant has a flight of stairs to its seating facilities and the person in the wheelchair has to go through the harrowing experience of being carried on a wheelchair up and down the stairs. The precarious position of balancing between people shaking with the effort of carrying one in the wheelchair and looking down a flight of stairs can be terrifying and a deterrence from eating out. Reg stated that:

> **Reg:** A lot of places are not really accessible. A lot of people do not like, um. OK, um, then again, but going out obviously in a wheelchair you do get stared at. Now if you had to go, venture up a whole flight of stairs // two persons on each side carrying the chair...You do actually get a kind of a fear of going out. And it gets more and more difficult.

Then, Reg's reference to the difficulty of getting from home to another place and back expresses all the participants' difficulties. At times Reg was unable to get himself to places he wanted to be because he needed someone to drive the combi for him. Tess too experienced a period over Christmas when her combi needed repairing and it took a long time because of financial restrictions. It meant that she was unable to go out beyond her home and close environment.

Reg's short description of managing the environment in a wheelchair expressed the difficulty of getting into necessary banking, shopping and entertainment facilities.

> *I: Do you have problems getting into these places or not? Do you find it easy?*
>
> **Reg:** There are quite a lot of places that are still awkward and difficult getting into, that do have a step or two or three and unfortunately that's not accessible at all.
>
> *I: Oh, so you can't get in at all?*
>
> **Reg:** You can't get in and also some shops the racks // the aisles are very narrow so the chair doesn't normally fit through.

Although the participants had worked out ways of dealing with these barriers, it does not take away the fact that they were denied the right to facilities and left outside. This denial and being left outside reflect being excluded from rightful social interaction. There were factors of living with mobility impairment that reflected on identity in the participants' daily lived experiences similar to that referred to in Atwell's (1999) article. Similarly, Tess and Reg understood the exclusion as their daily reality, but expressed that it was also a learning experience to achieve moving on to turn negative points in life to positive ones.

There were positive ways that, for example Reg, found to have some social interaction with people around them. Reg experienced that the upright State-provided power-wheelchair was acceptable. He is able to operate

his battery-powered wheelchair, once he is placed in it, and is able to go anywhere that is accessible to wheelchairs. He said that the power-driven wheelchair has made a big difference to being more independent.

His mobility enables him to make more social contact within reach of his wheelchair around the house in which he dwells and the road within a kilometre or two of his dwelling. It means that he does go to the shops down the road. He goes to the Methodist church down the road to participate in the crisis centre and attends a cell group meeting in the house next door to where he dwells.

He has a micro-bus into which he rides via a ramp and someone drives for him. All these means have given him greater independence and the accessibility to be more interactive socially. It appears to have kept him motivated, ambitious and hopeful for the future. Reg explains that for him to be bodily mobile means incorporating appliances such as his electric wheelchair and combi, as well as strong human helpers in situations where the person needs to be physically lifted.

In contrast, Kel's personal and social context was influenced differently. Kel had chosen not to obtain a wheelchair that is power-driven from Sate funds because the power-wheelchair that is provided cannot lower the backrest. This decision resulted in ongoing regressive narratives. She said that since she was unable to sit upright without blacking out, she felt it was futile to invest in such a wheelchair for transportation. She managed with a heavy manual wheelchair with a backrest that could be lowered and someone pushing her.

Unfortunately, the choice resulted in greater isolation, loneliness and a feeling of being left out. It often resulted in loss of participation, mobility and personal well-being. Because of a sense of loss and not being part of the social interaction, she often felt frustrated, hurt and progressively

depressed.

The above stories related the importance of mobility for greater social interaction. However, it also revealed that human help was essential and without human power a great deal of social interaction was curtailed. Reg explained the difficulty that could restrict mobility even with the availability of the necessary equipment to maximise mobility.

> **Reg:** Having to depend on an electric wheelchair makes it so much more difficult because you need a bakkie or a combi or something like that. Otherwise you have to be transferred if the chair does not fold up so it is very awkward if it is just you and your friend or you and the driver. It needs to be a strong person to be able to pick you up to get you into the chair again.

It was, however, clear that mobility, because of the power-driven wheelchairs, was greater around the home and nearby facilities, whereas outings further afield required the availability of a vehicle like a combi with a ramp and a driver. Without this assistance it meant being confined to an accessible home environment and nearby areas.

Surprisingly the environmental barriers were not emphasised by the participants, mainly because their prime concerns were related to their immediate home environment, financial and transportation problems. More emphasis was placed on the problem of transferring into a motor vehicle and the help needed to accomplish it.

On the whole, the research participants either avoided places they knew were difficult to access or waited until someone could help them in whatever way possible. However, socio-cultural factors were considered by the participants as more of a concern.

4.4.3.2 Government policy's influence on the economic situation

A link with mobility and mechanical aid in connection with economic and government policy-making, such as a pension disability grant and employment/unemployment, was evident. What emerged from the stories of unemployment was the link between the extent of bodily impairment and the finances to acquire equipment to enable as much mobility as possible.

In view of the fact that high-level quadriplegics relied heavily on their wheelchairs for mobility it was once again the link with the social economic situation that was a strong deciding factor as to the extent of their mobility. In a sense the wheelchair became an extension of their bodies. The extent of their mobility had an impact on their social activities and experiences of feeling that they were wanted and accepted.
The point was that a lack of finances, lack of enforced governmental policies and employment reinforced the notion of a fixed "disability identity".

In the same way policy-making and legislation by the State had great implications for the participants. Government legislates how much disability pension and helper's grant may be paid to people who are disabled. This has an impact on the individual and the family in different ways. Legislation has also been passed by the South African government about employment of people who are disabled (South African Employment Equity Act, 1996). However, the stories of the participants reflected difficulty in finding employment.

Thus, the participants' accounts of their socio-economic situation was that of suddenly being unemployed with no compensation from their employers at the time. Despite the similarity of all losing their employment, however, they responded differently to the situation with different results to extending their mobility. Being employed before the accident and suddenly unemployed almost immediately after the accident, had a profound impact

on the immediate and present life with different anticipation, for each, of the future.

For Reg it meant an immediate role expectation change as the eldest male child who earned his own salary to that of returning to rely on his parents for financial support. For three years Reg was totally reliant on his parents for financial help because he was not told that he could claim a disability pension immediately. He was no longer on medical aid and he experienced financial distress for three years because administrative and medical staff failed to inform him of the procedure to apply for a pension. To the question about his financial situation he replied:

> **Reg:** It's very personal yes, but, um, it's very difficult at this stage. I only get a State subsidy which is, er (*..pause*) I think 640, um, (*...pause*) I also get the helper's grant (*I: What's that?*) That's, er, you can apply for that if you're a quad, um, you need help from other people, er, care-workers and that sort of thing. So that's about R115.

In an attempt to solve the problem of unemployment, Reg decided to study for a degree in psychology, believing that this would be a means to employment. Instead it became a source of frustration because he was unable to obtain an internship after obtaining a Master's degree in psychology. Strangely, it seems that affirmative action was one of the obstructions to obtaining an internship. It meant that he was unable to register as a psychologist. Reg continued to look for employment determinedly, but was disappointed time after time as he was rejected each time, yet his story presented a progressive narrative in that he remained optimistic about finding employment one day.

Tess on the other hand, although she was immediately unemployed after her accident, immediately received a State disability pension and helper's grant. Her story in the beginning contained regressive narratives because

of numerous relapsing narrative time-related phases. However these soon turned into progressive narratives as her family members found solutions to problems that occurred. Accordingly, she enjoyed medical aid support. When asked about the State hospital experience she replied:

> **Tess:** Um, well, um, I am a hospital patient, er, well I was when I was in hospital, um, now sort of get help through my Dad's medical aid.

Tess's access to a medical aid scheme benefited her in that she expressed an increased sense of health. She had first used State hospital medical facilities, but her health deteriorated as a result of the difficulty of access, medication and hospital bureaucracy. It also meant frequent urinary or respiratory infections and periods of unwellness, so she accessed a medical aid system. This meant that she had private and immediate specialised attention when needed. She felt it made a difference to her state of health.

On the other hand Kel, who had been a lawyer's secretary at the time of her accident, was also suddenly unemployed after her accident. Kel swung between relapsing narratives of experiencing financial stress, anxiety and insecurity to regressive narratives of fear about the future. Her parents were both on pension and aging. Her daughter earned a minimal income through dressmaking. A power-wheelchair with an automatic reclining backrest was out of reach because of their financial situation. The best situation she could look at was to obtain a State-provided automatic wheelchair and be held upright by a chin control attached to the wheelchair, but she still needed someone to pick her up and put her into the wheelchair. Her manual wheelchair allowed the backrest to be flattened so that she could be slid from the bed onto the wheelchair and then for the backrest to be raised to a comfortable position for her. One person could manage this task, namely her care-giver.

I noted that the narratives of the participants made it clear that there were

many factors that either increased mobility, and thus, activity and participation, or limited it. Thus, the middle ground, referred to by some proponents of the socio-cultural model, that proposes that the personal and social context cannot be divorced from each other, is important. Bodily restrictions and the social and political factors influence the extent of social interaction and isolation.

4.4.4 Socio-cultural oppression

4.4.4.1 Behaviour and attitude of family and significant others

The attitude and behaviours expressed through the earlier report on Kel and Kit's stories were considered in the reporting of their stories. There was evidence of conflict between family members which resulted in the focus of all care-giving on one or two people at a time in her life with quadriplegia. There was little evidence of family support and working together by all the members.

Reg was sufficiently secure in previous pre-quadriplegia close family relationships and interaction to be able to accept the help he needed from them post-quadriplegia.

> **Reg:** I was in the great and fortunate position that my father, mother dipped in and they helped as well. So it is costly. I didn't go back to work which I would loved to have done. *(Field note: Reg's father was a carpenter. He later died and his mother went on voluntary pension).*

However, financial lack was a "thorn in the flesh" for Reg and a large part of his recounting his story. When speaking about his lack of opportunities to earn a salary, Reg revealed evidence of being insecure about the identity of his role as a male wage earner. However, the family supportive role in his life gave him hope even in his despair.

In the beginning of her disability Tess experienced difficulty with respiration when in the upright sitting position and preferred to remain in a semi-reclining position to be more comfortable. The first 12 years Tess spent mostly in bed with intermittent use of a manual wheelchair, because no suitable power-wheelchairs were available. Later, however, Tess was fortunate that her family assisted her to acquire a battery-operated wheelchair with a reclining backrest, a combi and a personal assistant, which greatly enhanced her mobility. Her family were supportive in assisting her with finances wherever they could and this included the extended family consisting of friends and a Christian association for quadriplegics. Her wheelchair reclined automatically and so allowed her to change her own position according to her need. She explained about the power-wheelchair:

> **Tess:** It has shocks and I can just get into the car and (*...pause*) we can drive to Cape Town and back and it won't bother me, because I've got (*...pause*) now that (*..pause*) I have no more bladder problems. I have no more pressure sores. I have no more nausea, no more uncomfortable not...

In the narratives recounted by the participant, which relate to a South African situation of living with mobility impairment, the financial circumstances of the family had profound negative influences on the participants' lives. It clearly denoted a regressive narrative scenario. However, it was clear that the more supportive the family were in financial assistance and the more the larger group of significant others got involved the more progressive narratives emerged. Hence, what the family considered the family unit in their drama of mobility restrictions made a difference to addressing financial problems.

If the immediate family living with the participant, for example, considered the extended family as those living outside the home, such as relatives and friends, as part of the drama of mobility impairment the likelihood of

emerging progressive narratives of dealing with stress situations was greater. If the family living with the participant did not consider the extended family as part of their drama it meant a very "shrunken world" for family and participant.

What, however, was the relevance for the participants? It meant that the ability and willingness of the extended family to assist made a difference to actions such as mobility, social interaction and, thus, forming of identity, not only for the participant, but also for the immediate family. This was evident in Tess' and Reg's relationship, not only with their immediate family, but also with the extended family. Both told of events when cousins, uncles or aunts pitched in to help. It was not that their families were wealthy, rather various members gave towards helping to overcome difficult circumstances when required.

It was noted that when a power-wheelchair was used combined with the larger extended family, that is a family unit consisting of family and significant others, social interaction revolved around these members. Wider social interaction was more difficult. Even with maximum family support and mobility, Tess's and Reg's social interaction was still dependent on the members of their extended family group.

Their sense of being wanted, being accepted and their sense of belonging were confined within the group of family members, relatives, personal helpers and loyal friends. Even interaction with their churches depended largely on the members of their family and extended family.

4.4.4.2 Behaviour and attitude of the public

All the participants were long-term quadriplegics and over many years had developed their own life philosophies about the public reactions to them and about themselves. Reg had been a quadriplegic for 16 years and had over the

years developed a philosophy about how he regarded himself as a person who is quadriplegic. When asked what sort of response he received from the public, Reg replied:

> **Reg:** There are a lot of able-bodied people going to the shop and getting back and saying "I had the rudest person bump into me", and why should I ascribe it always to being disabled. Maybe it's just a rude person, nothing to do with me being a quad or being disabled or being in a chair and so I like to see it in that light.

Kel had some unpleasant experiences that made her wary about public places. She experienced a couple who made fun of her trying to eat with a spoon strapped to her hand. It made her angry and it hurt her. She said she preferred to eat in the car where nobody could see her when she spilt coffee or dropped food.

How others in society behaved towards them and the attitude that was shown were important to them. Preconceived cultural values, beliefs and perceptions about disability did affect each participant and family member in similar ways. Kel recounted the difference in attitude between two churches she attended that reflected what it meant to her.

> *I: Is this the church that your parents go to? Tell me a bit about that?*
>
> **Kel:** Ok, I grew up at church. I was confirmed etc, after the accident, maybe one or two people came to visit me, um, and then when I started going to church on a Sunday, you know, with my parents...I sat next to the door and the people would look the other way. And when I stood in the queue for me to leave the church they would look off the other way so they didn't have to greet me. They were embarrassed.

Although the church was an easily accessible environment, it was inaccessible because of the attitude and behaviour of the congregation members. For them the disabled were untouchable and as Kel expressed it,

an embarrassment. The other church Kel referred to was anything but environmentally friendly. She had to be picked up in her wheelchair to get into the church. There was only space in the aisles, but for Kel it made no difference because she experienced being accepted, wanted and had a strong sense of belonging, which far outweighed the inconvenience of the environmental barriers. She eagerly expressed:

> **Kel:** ...and it just made me feel I wanted to go there. I was no different than any other person (...*pause*). (*I: So it made me feel..*). **Kel:** Wanted and welcomed and loved (*Field note: Smiles and then laughs and I join in the laughter*)

Tess's congregation's expectation seemed to be that she would be healed and they applied pressure for this to happen and when it did not they withdrew. Her tone of voice indicated sadness and her facial expression some tenseness that there was lack of acceptance of the fact that she was not going to get back to full independence. The fact that they backed away seemed to have caused her some disappointment. She explained the experience with a laugh:

> **Tess:** Ja, ja, um, I think when I first got out of hospital they thought they would get to pitch in as a congregation and get me back on my feet, kind of stuff and then, um, and then and I think when it finally dawned on them that there was no way that anything that they could do would make it better (*laughs*) um, they sort of said OK then we back off.

It seemed that the narratives of the church focused on the Christian belief about healing. However, when the expectation of healing did not happen, they withdrew. I noted that the congregation's expectations of getting her on her feet again eventually created an atmosphere with which her father was unable to cope.

Furthermore, the controlling attitude of the health-care institution was reflected in the participants' stories, such as Kel's story told about the

control and attitude of the health-care institution that made her experience humiliation in a way that disregard her as a person with a right to her own choices. Tess too had found a way to belong to a medical aid because she said the State hospital personnel's attitude was not always encouraging. In a sense they experienced being tied up in a fixed "disabled identity".

The notion of a fixed identity of "the disabled" was resisted by the participants in different ways. Going back to the research participants' stories about living with quadriplegia, these could be seen to reflect the multiple identity dimension of life. Through their stories the owning of socio-cultural identities, economic-political identities and religious identity could be traced. The owning of identities was incorporated into their life-stories over time through their social interactions.

What is relevant here is what was referred to in chapter one that, because of the physical challenges of an altered body-image, people who are mobility impaired are shifted into a shared identity of "the disabled" because the fixed identity of these people is based on the perfect body-image. This means that the reality of the person who is disabled is that he/she experiences body-image changes, but the person is perceived and labelled by others as "disabled" and is identified as dysfunctional.

In a sense a loss of continuity of "self" over time is implied. However, at the same time having a disabled body does not mean discontinuity because he/she is identifiable in genetic characteristics of human existence. As well, constancy remains in the sense of being capable of "keeping promises" in faithfulness to "self" and "another" (Ricoeur 1992:115-116). Yet the perception of the disabled person, because of changed body-shape, has resulted in not acknowledging the ability to be faithful to "self" and "another". The person is judged as incapable, dysfunctional and he/she is depersonalised. What is at stake here is that the person is identified as a member of society based on a generalised type of disability and not identified

in terms of one's own living relational experiences. Identifying the person based on generalisation results in biases in judgment (Brown 1997:110).

An example of this is described when the research participants, Kel and Tess, referred to being perceived as brainless because of being quadriplegic. It is a noteworthy point that categories are valid dimensions of life, but are not the only level of identifying people. The distinction is that people not only know themselves relative to others, but also in relation to others. That is, one is identifiable in relationships with others in terms of one's daily living experiences. Reg's response, for example, to a question about fitting in with disabled people shows evidence of resistance to being boxed within a fixed shared identity of "the disabled".

> **Reg:**...Um, I don't normally go to just attend gatherings for the disabled people...when a disabled person does cross my path and we've got an interest in conversation and if there is something attracting or an interest, whatever, then a possibility of a friendship is there.

The above response by Reg illustrates that he resisted the idea that friendship was based on making friends because of the commonality of disability. Social interaction for him went beyond fitting into a social identity relegated by mis-formed public ideologies about disability.

Narrative has the power therefore to disclose other levels of identifying a person, such as recognising a multifaceted socially interacting human being that extends to identifying someone beyond that, based on generalisation that leads to bias. It also allows for interpreting "self" as actor and sufferer. I can through my actions cause someone to suffer or alleviate the suffering (Ricoeur 1992:155-156).

Narrative can therefore make one aware of suffering in relation to one's own narrative accounts and one's traditional narrative accounts. Consequently,

we discover suffering in relation to agent and tradition. In this way we can recognise and accept differences of the other. Recognition and acceptance of differences can strengthen, while non-recognition can damage personal identity and collective identity. In short, it can offer belonging or non-belonging in a community (Brown 1997:112-115).

It is therefore through social interaction and relationships that social, cultural and religious identities can be either strengthened or neglected. In turn multiple identities reflect on personal identity and collective identity (Ricoeur 1995:305-307; Sterkens 2001:78). The research participants, through recounting their interaction with their social and religious communities, frequently disclosed lack of social interaction as non-acceptance and non-belonging. In contrast, increased social interaction increased their sense of belonging, being accepted and feelings of well-being. Limited space allows for only minimal illustration from the vast narrative texts of the participants.

An example of the above can be given through reiteration of the incident of Reg offering to work as a voluntary counsellor at the crisis centre of one of the churches that made contact with the residents of the self-help centre.

> **Reg:** The Methodist church started a crisis centre. I immediately went up there, spoke to the people and volunteered my services, which I do think is a good thing so that I can keep in feeling with being able to listen...The purpose is serving God...being there, so the bottom line to me is again being involved, being needed, being able to perform a task that I know I can fulfil.

Reg's story also reflected an expanded experience because his interaction at the level of volunteer counsellor in relation to his training in psychology eventually connected to his religious identity as fellow worshipper of God when he joined a cell group. In this sense God was the link to the shaping of collective and personal identity.

> **Reg:** ...and again the cell group is a lovely bunch of people, so again the bottom line is God. So we go, we read Scripture, we cry, we sing, we laugh and I just see it as fantastic. The getting involved personally, I think, again being needed as well. Being part of the community.

The narrative content of these incidents in Reg's life illustrate a number of things about the notion of multiple identities, personal identity and collective identity. Social, cultural and religious beliefs, values and meaning are integrated and connected in the above recounting of social interactions. Reg's religious values and his understanding of God are linked to his social beliefs and values as he offers his counselling skill in voluntary service. These interactions eventually resulted in him joining a cell group, held in a house neighbouring the self-help centre he stays in, where he could enjoy social and religious interaction.

Thus, the interaction that took place through entanglement of narratives facilitated collective identity through a sense of belonging for the research participants. It also illustrates the importance of the notion of continuity of "self" over time linked to the collective identity of communities. The link between social identity and religious identity facilitated collective identity and strengthened personal identity. Reg's capacity, for instance, to identify with social dimensions of life through voluntary service to others and identifying with the religious dimension of life in response to his understanding of God strengthened his personal and collective identity. In a sense the "story" of the Methodist crisis centre linked to the "story" of quadriplegia provided the means to strengthen personal identity.

Consequently, narrative identity as mediation between dimensions of life in communities or "self" and sameness and "other-than-self" can disclose not only human agency in "body sense", but human agency with complex personality. The person can be understood in the sense of body sameness, acquired habits and traits, as well as a responsible being capable of being true

to "self" and to "another", and being true to moral issues in relation to others (Ricoeur 1992:115-118). Ricoeur's (1995:309-311) notion of narrative identity therefore has relevance for this study in that it is through narrative discourse we discover the "who" of action, the "why" of action and the "what" of action.

However, Dreyer (2000:31) points out that Ricoeur maintains that the acquired identity of a group, by its values, beliefs, meaning systems and norms, must be constantly revised and renewed to avoid tradition becoming rigid and stagnant. It is the tension between stability and change found in the narrative expressions of the group connected to the past and present, which forms the group's identity and connects past and present to the future. Recounting of the "stories" of a group's past and present collective memories paves the way for critical reflection, re-interpretation and revision for renewal.

It also allows imaginative changes for the future and movement of values, norms and meanings, which are rigid, or "power tools" for the privileged group (Dreyer 2000:32). An example of the power of rigid traditional values was recounted in Tess's story about her church's response to a request that the Eucharist be served in her home. The request was denied because the church leaders were not prepared to go against the traditional standpoint of the church. Non-action or ignoring ideologies that are oppressive or distorted utopian systems are destructive as it keeps the person under the power of the "other's" action. The point to be made here is that reflection on traditional stances can be either constructive if applied with criticism and the intention of revised action or destructive if the critical dimension is neglected.

Thus, silence or ignoring power-controlling strategies creates suffering for the "other". Hence, non-action or ignoring oppressive socio-cultural structures, ideologies or distorted utopian systems is equal to aiding and abetting the oppression of certain people.

At present it is sufficient to understand the above to mean that innovation requires critical examination and analysis of traditional stances in view of past promises being kept or not kept to avoid sedimentation that remains static to the advantage of the privileged majority. In society or the church, unrevised traditions create structures of unequal power and exclude, marginalise and disempower people, such as people who are disadvantaged in mobility. This trend of thought will be taken up in the last chapter in relation to pastoral work with people who are mobility disadvantaged.

Space limited further illustration from the participants' responses. The above analysis of the personal and social context of the participant's stories, therefore, intriguingly illustrated that the entanglement of narrative history resulted in the emergence of an unfolding narrative about mobility impairment. An example is the narrative history of the health-care management entangled with the bodily impairment restrictions and stories of unemployment that resulted in emerging narrative plots in each participant's story.

Through linking the emerging plots, similar socio-cultural aspects, but different personal consequences for each participant were illustrated. How the narrative plots emerged and how the emerging plots connected, reflected the differences experienced in similar situations. An example of this was illustrated in Reg's story when the health-care institution slipped in notifying him about his rights to a disability pension, resulting in a financial crisis. However, the further entanglement of family working together and extending their boundaries to include relatives and friends resulted in increased mobility and management of his bodily impairment.

However, it is not the end of the unfolding narrative plots identified in the participants' stories, because what happened in the past set the tone for the present and reflected positively or negatively on the future. An example of this is clearly illustrated in Kel's unfolding story. The emerging narrative

plots of bodily impairment restrictions and financial stress connected to the entangling narratives of unresolved conflicting family relationships and failure to accommodate outside help resources. It was this complex entanglement of narrative history, combined with the emerging narrative plots of controlling health-care management, that made the present circumstances of this family complicated and future prospects frightening.

It clearly illustrates how complex and expanded the concept of mobility impairment is. In relation to what was discussed about the ICF in chapter three as to the link between bodily impairment, environmental components and domains of activities and participation from both an individual and societal perspective, it enables wider consideration of mobility impairments. It is, as pointed out in the AIHW (2001), a multi-purpose classification in that it deals with the aspect that many factors are associated with the notion of disability.

Thus, the middle ground, referred to by some proponents of the socio-cultural model, that proposes that the personal and social context cannot be divorced from each other, is important. The link between bodily restriction and the social context influences the extent of social interaction and isolation.

4.5 CONCLUSION

At the beginning of the chapter the question was asked: What are the implications of acquired mobility impairment for personal and collective identity? (4.1). In relation to the points made that disability is multidimensional, what was highlighted through the participants' stories was the link between bodily impairment restrictions and social restrictions to mobility. It was clear that there were bodily restrictions due to the high cervical level damage that confined the person to the home for periods (4.3). This is relevant for a pastoral work praxis to people who are disadvantaged in mobility because the person who is a high cervical level quadriplegia will spend more time at home and be absent from the faith community's fellowship

for long periods.

It was also clear that tension must be held between similarities and differences. The participants' stories told of many similarities, but also of many differences according to their personal circumstances, as well as different actions in the personal and social context of living with quadriplegia. Linked to the socio-cultural complexity of living with mobility impairment was a sense that the participants were very aware of their body difference, but considered it a fact of life (4.3). They, however, were just as insistent that their personhood was as anyone else's. They showed resistance to being perceived as disabled persons without any personality and rightful identity of their own. Thus, it was noted that the participants objected strongly to being subjected to derogatory attitudes and actions that labelled them as items to be pitied, stupid, or a non-person. Also, despite laughing off environmental barriers, these did affect them enough to avoid such barriers or swayed them not to go where they could not get in and resulted in them being more restricted in mobility (4.4.3). This is important for pastoral work praxis because if a faith community is not accessible then it excludes these people. These difficulties makes the problem of getting to church more than it is worth the struggle.

How the contexts of biomedical, social, cultural and even economic dimensions of life connected with one another in the drama of mobility impairment, was traced. The socio-economic link with the mobility disadvantages for the participants was clearly illustrated. What was highlighted was the complexity of the financial situation in all interviews. It was explored further because most of the literature sources consulted in this study did not highlight this aspect of living with disadvantages in mobility. The financial situation clearly made any progressive narrative difficult because oppressive economic politics enhanced the difficulty of survival as a person who is quadriplegic.

In addition, what was criticised about the power and control of the biomedical model, was clearly evident in all the participants' stories. The negative role of the health-care institution imposing dominant authoritative knowledge and command about mobility impairment, sometimes resulted in regressive narratives. Lastly, the connection between biological and psychosocial living with mobility impairment was clearly evident. It highlighted the connection between the unfolding biological and psychosocial dimensions and how coping with the crises, relapses and losses resulted in different progressive, relapsing and regressive narratives. The interaction between biological and psychosocial aspects has significance for a pastoral work praxis because it removes disability from the medical dominance and the difficulties of living with mobility impairment for the individual and significant others are highlighted. This will be discussed in chapter five.

However, it was clear that the more supportive the family were in financial assistance and the larger the group of significant others who got involved, the more progressive narratives emerged. Where there was extended family support, the sense of belonging was greater and there was less conflict within the family. Lack of extended family support caused greater loss of contact with society and a greater sense of non-belonging and isolation for the individual and family. It was the manner in which their stories were entangled with biomedical, social, cultural and religious politics that influenced how each participant narrated his/her identity and how the family coped with the shift between pre-trauma and post-trauma family identity (4.4.4).

The research is valuable in that it discloses the extensive limitations of the high cervical level quadriplegic who has to live with the problems of getting to places and the added personal bodily difficulties that make it very difficult to leave the home environment. It also gives clarity to the psychosocial aspects that the individual, family members and their significant others have to deal with. These are all important aspects for Christian faith communities

to critically reflect on in relation to pastoral work with people who are mobility disadvantaged. More than visitation, prayer and encouragement is required. The next chapter will discuss a pastoral work praxis for people who are mobility impaired.