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## The lived experience of self-intermittent catheterisation in people with spinal cord injury

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**The lived experience of self-intermittent catheterisation  
in people with spinal cord injury.**

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**Master of Nursing by Research**

**Edith Cowan University  
School of Nursing, Midwifery & Postgraduate Medicine,  
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**May 2008**

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## Abstract

Self-intermittent catheterisation (SIMC) is one of the most common and safest methods of bladder emptying in people with spinal cord injury (SCI). There is a large amount of literature relating to the biomedical aspects of SIMC, such as infection rates and renal complications. There is however, very little information about how people actually experience SIMC and its effect on their daily lives. Through a series of semi-structured interviews this study describes the lived experience of eight men with spinal cord injuries who perform self-intermittent catheterisation to empty their bladder. The study uses Husserlian phenomenology and Colaizzi's method to analyse data gathered through the interviews. Clusters of similar themes were extracted from the transcribed interviews and reduced into six theme categories. The data showed that SIMC has an effect on almost all aspects of a person's life including work and social lives, their personal relationships and body esteem, even what they drink and how they sleep. The themes are discussed and relevant literature provides a legitimate basis for the issues that arose for participants. New knowledge is detailed and there are recommendations for changes in practice and suggestions for further research.



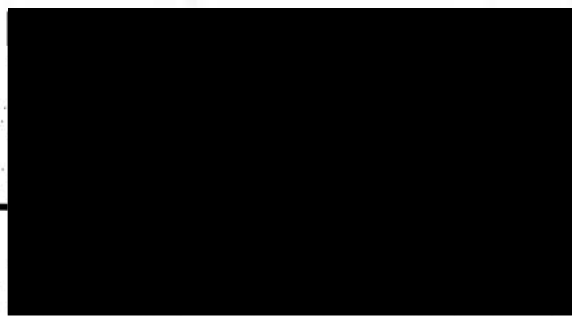
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5<sup>th</sup> November 2008

## Acknowledgements

This research and thesis would not have been possible without the generous support and guidance of the following people:

Mr John Drury was principal supervisor for the first half of the project and provided me with valuable support and feedback, especially during the proposal, ethics, recruitment and interviewing phases of the research. John was always positive, available and genuinely dedicated to Husserl's phenomenological method.

Associate Professor Christopher Churchouse generously took over as principal supervisor when Mr Drury was on leave. He was immediately liberal with his time and feedback and allowed me to see things from a different perspective. His support provided for a polished thesis which reflected the original objectives.

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*Sometimes we are compelled to draw off the urine by hand when it is not passed naturally.*

(Celsus, AD30)

## CHAPTER 1

### *INTRODUCTION*

#### Statement of Purpose

The purpose of this study is to describe the lived experience of people with spinal cord injury who practice self-intermittent catheterisation (SIMC) as their primary bladder emptying technique. The researcher has extracted rich descriptions of the participants' experiences from transcribed interviews to describe how they feel about SIMC. The information will contribute to the current body of knowledge relating to SIMC and provide a basis for future education programs.

#### Definition of Terms

Some of the terminology used in this study may be unfamiliar to the reader who does not have a background in clinical urology. The following list provides a working definition of specialist terms used throughout the study.

- Spinal cord injury (SCI): Irreversible damage to the spinal cord at any level resulting in loss of function including motor and sensory disturbances and bladder, bowel, and sexual dysfunction.
- Self-intermittent catheterisation (SIMC): The process of a person passing a catheter into their bladder to empty urine. The catheter is removed immediately after the bladder is drained.
- Indwelling catheter (IDC): A urethral catheter inserted into the bladder that is attached to a drainage bag and remains permanently in place.
- Suprapubic catheter (SPC): A permanent catheter inserted directly into the bladder through an incision in the abdominal wall.
- Continence: In the context of this study continence is defined as the ability to remain dry from urine leakage between each SIMC.



- Incontinence: In the context of this study incontinence is the unintentional, uncontrolled leakage of urine from the bladder between SIMC. Sometimes referred to by participants as “accidents” or “wetting”.
- Urinary Tract Infection (UTI): Bacterial infection within the urinary tract between the kidneys and external urethral meatus. Often associated with unclean catheterisation or extended periods between SIMC.
- Voiding: The act of passing urine.

## Background

Self-intermittent catheterisation (SIMC) is the optimum method of bladder emptying for men and women with spinal cord injury (Jamil, 2001; Wyndaele, Madersbacher, & Kovindha, 2001). It involves the patient passing a catheter into the bladder to completely empty urine and then removing that catheter. SIMC mimics the bladder's spontaneous action of filling and emptying, reduces residual urine volumes, and in most cases dramatically lowers the risk of infection (Moore, 1995). SIMC also enhances the effectiveness of antimicrobial therapies in those being treated for urinary tract infections and improves self esteem (Moore, Day, & Albers, 2002).

Guttmann and Frankel proposed intermittent catheterisation in the acute phase of spinal cord injury as early as the 1960's but it was not considered a long term option. In fact, Guttmann wrote that intermittent catheterisation should be carried out exclusively "... by a medical officer familiar with the non-touch technique and not left to the nursing staff, let alone to orderlies or technicians" (1973, p.347). It was not until the early 1970's that Lapedes introduced the idea that clean intermittent catheterisation performed by the patient could provide a clinically safe method of bladder management (Hunt, Whitaker, & Doyle, 1984). Since then there have been a number of studies relating to this procedure but most have looked at issues such as frequency of catheterisation, sterile versus clean techniques, and levels of bacteriuria (Guttmann, 1973; Moore, 1995; Berkov & Das, 1998). Considering how common SIMC is, there is surprisingly little information about its effect on people's lives or how they feel about performing this procedure.

### Significance of Study

Much has been written about the biomedical aspects of SIMC (Barton, 2000; Wyndaele, 2002; Penders, Huylenbroeck, Everaert, Van Laere, & Verschraegen, 2003; Levendoglu, Ugurlu, Ozerbil, Tuncer, & Ural, 2004) but to date, researchers have neglected to determine how patients feel about having to perform this intimate procedure and the lived experience of its daily impact on their lives. The researcher has identified this deficit initially in his own clinical practice and later whilst reviewing current literature. It is the researcher's experience in clinical practice that the urology medical team generally determines the method of bladder emptying for patients based on their level of physical function and urodynamic testing. The patient is advised of this method and is expected to comply, with little or no input in the decision making process. There appears to be minimal consideration for current or projected lifestyle circumstances or the psychological impact it may have. Spinal cord injured individuals are as diverse in educational and socio-cultural background as other hospital patients and it is important to consider any issues relating to the quality of their lives. This study will document the lived experiences of SIMC and provide this information to health care workers and others who are performing the procedure, both to new patients and those with longer term spinal cord injury.

### Objectives of Study

This study will begin to correct the information deficit regarding the lived experiences of people who perform self- intermittent catheterisation. The objectives of the study include:

- 1) To describe the lived experiences of people who perform self- intermittent catheterisation.
- 2) To describe the broader issues of SIMC including what, in the participants' views, constitutes effective teaching, and whether SCI participants are satisfied with this method of bladder control.
- 3) To analyse and define the meaning of the described experiences.
- 4) To contribute to the body of knowledge relating to the experiences of SIMC.

## Thesis Overview

Chapter one contains an introduction to the study including its statement of purpose and some background information. The significance of the study is discussed within the context of the researcher's own practice and the greater body of available literature. Four broad objectives have been outlined in this chapter that should govern the direction and outcomes of the study.

Chapter two contains a review of the available literature relevant to the experience of SIMC and examines the relevance and rigour of these studies to identify potential knowledge deficits. This literature review was undertaken before any data was collected.

Chapter three outlines the research method used in the study. There is an exploration and justification of the qualitative paradigm and, specifically, Husserlian phenomenology. This chapter also discusses the sampling process, participant demographics and the ethical considerations pertinent to the study. Finally chapter three describes data collection and analysis, and describes Colaizzi's method of data analysis.

Chapter four contains the findings. Data analysis is presented as six theme categories which are identified from theme clusters. As well as textual discussion there is supporting evidence of the data analysis in the form of participant quotes extracted from the interviews.

Chapter five is also structured around the theme categories and compares and contrasts the findings with current available literature to establish validity and areas that will benefit from further investigation.

Chapter six discusses limitations to the study, new knowledge identified and recommendations for further research followed by the conclusion.



## CHAPTER 2

### *RELEVANT LITERATURE*

#### Literature review

Hart (1998, p.1) has written that “a review of the literature is important because without it you will not acquire an understanding of your topic, of what has already been done on it, how it has been researched, and what the key issues are”. From preliminary readings it was apparent that there are difficulties in obtaining adequate information about the human experience of SIMC. There is no shortage of studies looking at SIMC from a clinical science perspective but a review of the literature shows an obvious deficit in studies relating to the patient's experience of having to perform SIMC. Utilising the databases CINAHL, Medline, and PubMed a search was conducted using one or a combination of the following keywords:

**intermittent, catheterisation / catheterization, self-intermittent, clean-intermittent, experience.**

From the results of the search, articles were obtained that included those looking at the patient's experience of having to perform SIMC on a regular basis.

Bradley (2000) looked at patients' experiences of self-catheterisation as a treatment for recurrent urethral strictures. Although not focussing on spinal cord injured people, the study was included for its potential to elicit responses about performing SIMC as a procedure. Bradley claimed her work was unique as no other study, quantitative or qualitative, had been conducted that focussed on SIMC for stricture treatment. Using a grounded theory method Bradley looked at eight patients randomly selected from a urology clinic that used SIMC for stricture management. Informal interviews were conducted with the participants beginning with the lead question, “tell me about your experience using ISC (intermittent self catheterisation) for your stricture treatment” (2000, p.535). Bradley coded the initial data and revised it before establishing categories such as, ‘being supported’, ‘getting through’, ‘becoming philosophical’, and ‘what is working’ (2000, p.536). The participants described their initial reluctance to perform SIMC and their journeys to the procedure becoming part of their life. The study recommended better training programs for SIMC patients, ongoing referrals, and nurse-led SIMC clinics.

McConville (2002) conducted a study that looked at the experience, knowledge, and level of satisfaction of patients using SIMC. She claimed that she decided on a quantitative approach using a questionnaire as the method of data collection. She also stated that the inclusion of some open-ended questions provided greater feedback and "added a qualitative aspect to the study" (2002, p.55). Sixty-nine questionnaires were sent out with a response rate of 67%. Most of the data was quantitative and included a percentage of respondents who knew why they had to do SIMC, length of time, frequency, education, and infection rates. The 'qualitative data' provided single word and single line responses about the patients' initial feelings of SIMC and about the impact it has on their daily lives. Patients raised issues such as socialisation and SIMC, embarrassment, sex, and decreased confidence. 74% of respondents said that ongoing support was essential for people performing SIMC (2002). McConville recommended a further qualitative study to explore the lived experience of patients performing SIMC (2002). As a research project this study was quite crude and, although the author discussed research methods, it was really just an explanation of the questionnaire results. The 'quantitative data' was not validated and the 'qualitative aspect' was merely reporting of the answers to open-ended questions.

Woodward and Rew (2003) examined the available literature pertaining to patients' quality of life and SIMC. They found that there were "very few articles addressing the day-to-day problems that having to perform clean intermittent self-catheterisation (CISC) presents to patients" (2003, p.1066). These authors were able to obtain anecdotal evidence and expert opinion on this topic but could not identify any more studies than those already included in this paper.

Watts, Lloyd, Brown, Clarke and Wilson (2002) implemented a SIMC program into the Hunter Area Health Service in New South Wales and in their preamble discussed the need to improve quality of life for their patient population (2002). Although recognised as important, there was no formal evaluation of patient satisfaction. The only post-implementation comment was a seemingly anecdotal remark in the discussion that the technique had "been well received by patients who report a positive impact on their quality of life" (2002, p.123).

Reviewing the literature confirmed the suspicion that there is little information looking at the whole person and their experience of performing SIMC. It is hoped that this study will contribute to the scant information on this topic and allow for a greater insight into the personal experience of SIMC as a regular bladder emptying method. The study may also provide a basis for further research into quality of life of the broader population who practice SIMC.

## CHAPTER 3

### *METHODOLOGY*

#### Research question

The research question, 'what is the lived experience of self-intermittent catheterisation in people with spinal cord injury' formed the basis for unstructured interviews aimed at describing how participants feel about this procedure.

#### Research Design

An important consideration when selecting a research design is whether the method chosen facilitates answering the research question. (Holloway & Wheeler, 1996; Speziale & Carpenter, 2003). Creswell (1994) says that following selection of a topic, a study requires a research paradigm, namely quantitative or qualitative. The quantitative paradigm incorporates studies that take an "objective, systematic" approach to describe variables and test theories (Burns & Grove, 2001, p.26). Research with a focus on cause, diagnosis, prevention, and treatment of health issues are ideal for adopting a quantitative design (Roberts & Dicenso, 1999).

#### Qualitative Paradigm

This study utilised a qualitative paradigm to describe and try to give meaning to life experiences (Burns & Grove, 2001). Qualitative research is used to answer questions such as 'what is this?' or 'what is happening here?' (Ploeg, 1999, p.36). The question asked in this study does not involve determining a hypothesis or generating statistics, but rather is seeking information about the human experience of self-catheterisation. Therefore, the study was one of qualitative inquiry.

#### Phenomenology

The study used a phenomenological approach to attempt to describe the experience of SIMC in people with spinal cord injuries. Speziale and Carpenter (2003, p.51) state that phenomenology is well suited to nursing research as professional practice is "enmeshed in people's life experiences". Merleau-Ponty (Oiler-Boyd, 2001, p.96) claims "that the whole effort of phenomenology is to

describe experience as it is". Phenomenology has undergone a complex evolution from the study of phenomena, through philosophical inquiry of perception and essence, to a recognised, rigorous research method (Speziale & Carpenter, 2003).

There are two main styles of phenomenological method, descriptive and interpretive (Van Manen, 1990). Descriptive phenomenology has its significant origins in the work of the German philosopher Edmund Husserl (1859-1938). Husserl's phenomenology is based on experience in the lived world and attempting to describe these experiences and the phenomena that manifest through this process (Sadala & Adorno, 2002). Husserl, initially a mathematician, was opposed to the positivist paradigm that was prominent in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries and developed his phenomenology to study the essence of experiences (Kockelmans, 1994). He believed that experience created knowledge and access to this knowledge was through consciousness (Priest, 2002).

Interpretive, or hermeneutic, phenomenology is conducted in essentially the same manner as descriptive phenomenology but the investigator goes beyond merely providing a description of the phenomena and attempts to interpret the data. This method was a focus for philosophers such as Gadamer, Hirsch, Ricoeur and, notably, Husserl's one time assistant, Martin Heidegger (Van Manen, 1990). Heidegger's phenomenology also focused on lived experiences but the method required the researcher interpret this experience by analysing and aligning it with their own lived experience (Walters, 1995).

In revisiting the proposed question, "what is the experience of performing self-intermittent catheterisation for people with spinal cord injury", the researcher wishes to gain a rich description of the person's experience. The researcher does not want to classify the person or define the experience but will attempt to formulate an unbiased description from the subject's perspective. For these reasons the study specifically used Husserlian phenomenology to collect and present the data.

Husserlian phenomenology as a method for nursing research has come under some criticism in recent years for its increasing move away from Husserl's ideals as nurses try to force the method into an evolving discipline (Paley, 1997; Caelli,

2000; Yegdich, 2000). To try and maintain rigour and authenticity this study attempted to remain true to Husserl's ideals of intentionality, phenomenological reduction, and lifeworld (Van Manen, 1990).

### Sample

Participants for the study were recruited initially through purposeful sampling of SCI patients attending Royal Perth Hospital's urology outpatient clinic. The researcher attended clinics to speak directly to patients or was given names of potential participants by the outpatient nursing staff. Outpatient Nurses were also kind enough to hand out participant information letters to suitable patients they saw in clinics that the researcher was unable to attend.

Purposeful sampling is almost exclusively used in qualitative research and involves the selection of participants according to a predetermined criteria, in this case a willingness and ability to articulate the experience SCI and SIMC (Tuckett, 2004). This approach provided the first participants and snowball sampling of these people provided other suitable contacts. Snowball sampling is, again, specific to the qualitative paradigm and involves participants contacting others whom they know to be in the same situation (Streeton, Cooke, & Campbell, 2004).

All eight participants were male although there was no intentional discrimination in the sampling process. The fact that they were all male may be attributed to two main factors. Firstly, the incidence of spinal cord injury is, and has always been, significantly higher in males. In 2004-05 the ratio of SCI for males and females was 82 percent and 18 percent respectively (Cripps, 2006). Secondly, the sampling process involved snowball sampling to recruit some of the participants. It could be surmised that males with spinal cord injury would know other males with similar injuries and would refer the researcher to them.

The criteria for participants was any person, male or female, who had suffered a traumatic SCI and presently use SIMC as their primary bladder management technique. Traumatic SCI was preferred as this provided experience from the perspective of someone who has, at some stage in their life, had normal bladder function. The proposed initial sample was eight to ten people and the final number of participants was eight. The only similar study to compare sample groups with was that of Bradley (2000) who contacted twelve patients and had



eight respond. After the first eight interviews it was determined that saturation had been reached as there were no new concepts emerging in the final two interviews (Tuckett, 2004).

### Demographics

The eight participants ranged in age from 25 – 68 years with a mean age of 43.5. Time since injury ranged from 1 – 25 years with mean of 8.6 years. Four participants were paraplegic and four were tetraplegic. Injuries were sustained by motorbike or motor vehicle accident in three cases; falls in three cases; one diving accident and one resulting from complications of treatment for Non-Hodgkins Lymphoma.

### Ethical considerations

This study was conducted under the direction of principal supervisor, Mr John Drury and, in the absence of Mr Drury, Associate Professor Christopher Churchouse, Edith Cowan University School of Nursing. As the study involved potentially sensitive interviews with people with spinal cord injury the approval of the Edith Cowan University Human Research Ethics Committee (HREC) and Royal Perth Hospital Ethics Committee was sought and gained before the recruitment of participants.

Participants were informed about the study through the participant information letter (see Appendix A) and direct discussion with the researcher. At this stage participants were encouraged to ask questions about the study and its design, advised that the study was voluntary, that at any stage they could decline to answer questions, request that the tape be stopped, or withdraw without consequence. Participants who wished to proceed signed a consent form (see Appendix B) documenting their understanding of the study and acknowledging their rights as a participant. After this they were invited to attend an informal interview at a location suitable to the participant. These locations included the participant's home or workplace, or the researcher's work place. Prior to the interview participants were advised about the confidentiality of the interviews through the consent form and preliminary discussions. They were also given details of how the data will be handled and the steps taken to ensure that their identities and disclosed information remain private.

### Bracketing

As the person conducting interviews, the researcher undertook bracketing of any preconceived ideas and beliefs about SIMC. Crotty (1996, p.19) claims that "... researchers bring a great deal of intellectual 'baggage' to the tasks they undertake" and these preconceptions have the potential to influence and contaminate the data. Bracketing, or reduction of bias, was first introduced by Husserl and requires the researcher to overcome preferences, inclinations, or expectations that may prevent them from achieving full understanding of the phenomenon (Van Manen, 1990). Speziale (2003, p.23) states that "bracketing is essential if the researcher is to share the informants' views of the studied phenomena". In this study the researcher recorded all his own thoughts, opinions, and prior knowledge of SIMC before the interviews commenced in order to understand and prevent these ideas from permeating and tainting the current investigations (see Appendix C). The process of bracketing allowed for a more thorough appreciation of the participants experiences but was not limited to the interviews only. The researcher practised this process throughout the entire study and particularly during the data description and analysis where such bias could influence the way some data is interpreted.

## *DATA COLLECTION*

### Interviews

Data was collected through the audio taping of interviews using a digital audio recorder. Eight interviews were conducted over a period of eight months and were between twenty eight and forty eight minutes in length. The average interview length was thirty nine minutes.

The interview process was relatively unstructured with one or two leading, open-ended questions and a few prompt questions if necessary (see Appendix D for question list). Informal interview as a data collection method is effective because it allows the researcher to ask questions and focus or expand conversations under the guise of "seemingly natural conversation with the interviewee" (Melia, 1997, p.34). Anecdotally it is found that because SIMC is such a major part of daily living for people with spinal cord injury, most are more than happy to discuss how it affects them. For this reason there did not need to be too much input from the interviewer other than starting and guiding the conversation.



Following each interview the researcher made handwritten field notes about the participant and the interview in the same book used for initial bracketing (see Appendix E). This provided a different perspective to refer back to when looking at the transcriptions at a later date. Interviews were transcribed as soon after the event as possible to ensure accurate reflection of the conversations. The researcher initially considered using the services of a professional typist to transcribe the interviews but decided to type them up himself. This decision occurred because it was found that the process provided a more sensitive and intimate relationship with the data and allowed for increased accuracy in the analysis. After transcription a numeric code was attached to identify the participant. All other identifying information including names and personal or work addresses were removed from the transcript to ensure participant anonymity.

## *DATA ANALYSIS*

### Colaizzi's Method

Thorne (2000, p.68) claims that "data analysis is the most complex and mysterious of all of the phases of a qualitative project". Many phenomenologists have tried to formalise data analysis by developing steps for examining the data. These include Van Kaam, Giorgi, Parse, and Husserl himself had a logical method for analysing data (Burns & Grove, 2001). The most common method of data analysis used with Husserlian phenomenology, and the method to be used in this study, is that of Colaizzi (1978). Colaizzi developed seven steps for analysing data from recorded interviews (Webb, 1999) and these were:

- 1) Read all participants descriptions of the phenomenon to acquire a feeling for them.
- 2) Return to the transcripts to extract significant statements.
- 3) Spell out the meanings of each significant statement (formulate meanings).

After step 3 the transcripts were reviewed by the principal supervisor who is competent in the phenomenological method and Colaizzi's analysis, to formulate his own meanings for comparison with those of the researcher.

- 4) Arrange the formulated meanings into clusters of themes.
- 5) Theme categories (this will allow for reduction of theme clusters).
- 6) Integrate the resulting ideas into an exhaustive description of the phenomenon.

7) Return to participants to validate findings.  
(Colaizzi, 1978, p.59).

### Significant Statements

Significant statements were extracted from the interviews using the criteria that a significant statement was anything that related to the participants experience of SIMC. An example of this process is the following statement from interview 04:

*"Um, it's kind of, it's also, there's like an element of embarrassment in it too, like having to do a cath cause, cause it takes so long. You usually say 'oh I'm going to do a pee' or you know, 'I've got to do a catheter' or something like that, it's like, even though no one else really cares, it just like 'oh yeah, whatever' it's still kind of, um, you know, a bit embarrassing".*

The extracted significant statement was:

SS49. Um, it's kind of, it's also, there's like an element of embarrassment in it too, like having to do a cath cause, cause it takes so long. You usually say 'oh I'm going to do a pee' or you know, 'I've got to do a catheter' or something like that, it's like, even though no one else really cares, it just like 'oh yeah, whatever' it's still kind of, um, you know, a bit embarrassing.

The significance being the experience of embarrassment suffered through the perceived need to advise people about impending catheterisation.

Each significant statement was allocated a sequential number, the above example being 04SS49 (Interview 04, Significant Statement 49). A total of 374 significant statements were identified from the eight interviews.

### Formulated Meanings

Step three of Colaizzi's method involves spelling out the meaning of each significant statement. Colaizzi (1978) described this as a process of "creative insight" that requires the researcher to "leap from what his subjects say to what they mean". In the previous example where a participant felt embarrassment at telling people about the need to catheterise, the formulated meaning was:

FM49. Participant feels embarrassed about having to do SIMC due to the time it takes, he feels that he needs to tell people even if they are not really interested.

Each formulated meaning was allocated a number corresponding with its related significant statement, the cited example being 04FM49 (Interview 04, Formulated Meaning 49).

### Theme Clusters

Step four was to arrange the formulated meanings into theme clusters to begin the data reduction process. For example, any formulated meanings relating to the various types of bladder management in the short or long term were grouped under cluster 1, Stuck for choice. This cluster included statements such as:

02SS01. no, no. I was told that that was the better option to go and I went down that path.

02FM01. participant was never really given any other options to SIMC.

and

05SS55. I'm happier with the catheters I'm using than the other way, I don't want a bag on my leg all the time.

05FM55. Participant is happy doing SIMC compared to the alternatives, "I don't want a bag on my leg all the time".

Formulated meanings relating to the effect SIMC has on a participant's social life were grouped under cluster 20, Social life and SIMC This cluster included statements such as:

03SS25. only better

03FM25. Compared with previous bladder management techniques the participant finds that going out socially using SIMC is "only better".

and

04SS67. oh yeah, it definitely makes you less confident.

04FM67. Having to perform SIMC 'definitely makes you feel less confident' when out socially.

A total of twenty six theme clusters were identified to incorporate the 375 formulated meanings. Extensive review of the theme clusters is found in Chapter Four.

### Theme Categories

To further reduce the data the twenty six theme clusters were reviewed for similar meanings and organised into six theme categories. The theme categories were named to reflect the clusters they represent. For example, Theme Category 1 (TC1) was titled 'The Journey to SIMC' and reflected the trials and processes that individuals had to endure before becoming proficient in SIMC. It included the theme clusters:

- 1 Stuck for choice
- 2 The learning experience: 'how do I do this?'
- 3 Is there anybody out there?
- 4 "it just sucks"

Further discussion of the theme categories can be found in Chapter Five. See Figure 1 for summary of data analysis process.

### Validating the Findings

Following the arrangement of data into theme clusters and the reduction of these into theme categories, the data was extracted and re-allocated to its original interview for validation by the participant. For example, all themes evolving from interview 01 were put into one document and this was sent to the participant for critique and feedback. This validation process allows participants to review the formulated meanings and the structure in which their comments were used to ensure that they reflect actual meanings.

Six of the eight participants were contacted and agreed to look at their own findings to ensure truthfulness in the data analysis. Four participants (01, 04, 05, and 06) were e-mailed the document and responded electronically and by phone to discuss the findings. After reviewing the data all four believed that it accurately reflected the interview and their feelings about SIMC. Validating comments included:

*It all reads good to me. You make me sound like a Aussie ock'er, but I guess the tape doesn't (sic) lie.*

Participant 01 (28/08/2007).

*Brendan i have read the attachment and it was fine sorry i did not reply sooner, i was just talking ... yesterday about not having done it.*

*Feel free to contact me at any time regarding this matter.*

Participant 04 (21/09/2007).

*Hi Brendan*

*I have added some comments and highlighted them so i hope this will help you more with what was discussed.\**

Participant 05 (12/09/2007).

*Hi Brendon,*

*Your interpretation of what I said there is fine (didn't realise I ummed and ahed so much!). I hope that information helps in your work.*

Participant 06 (05/10/2007)

\*Participant 05 made some minor clarification to some of the comments in the findings but there were no new issues that come out of his review. Below is an example of the type of comments made with the italics section being the new comment:

05SS35. yeah, you can't, I mean I'd love to be able to go and stand at the toilet,  
05FM35. When talking about the lack of control with SIMC participant believes life would be easier if he could stand at the toilet.

*When talking about the lack of control with SIMC participant believes life would be easier if he could stand at the toilet or even get off my chair and sit in the toilet.*

One (Participant 07) was contacted by phone and did not wish to meet again but consented to discuss the findings during the phone conversation. After hearing examples of data themes from his interview he agreed with the findings and was confident that they were an accurate reflection of his experiences.

Participant 08 wanted to meet in person and read the findings of his interview at this meeting. He agreed with the findings but wanted to remove a comment about the way in which he cleaned his catheters because he claimed that he no longer re-used and cleaned catheters. It was explained that this was the method he used when he did clean catheters and, although he now used single-use catheters, this information may benefit other people. After some hesitation he agreed that it could remain in the findings.



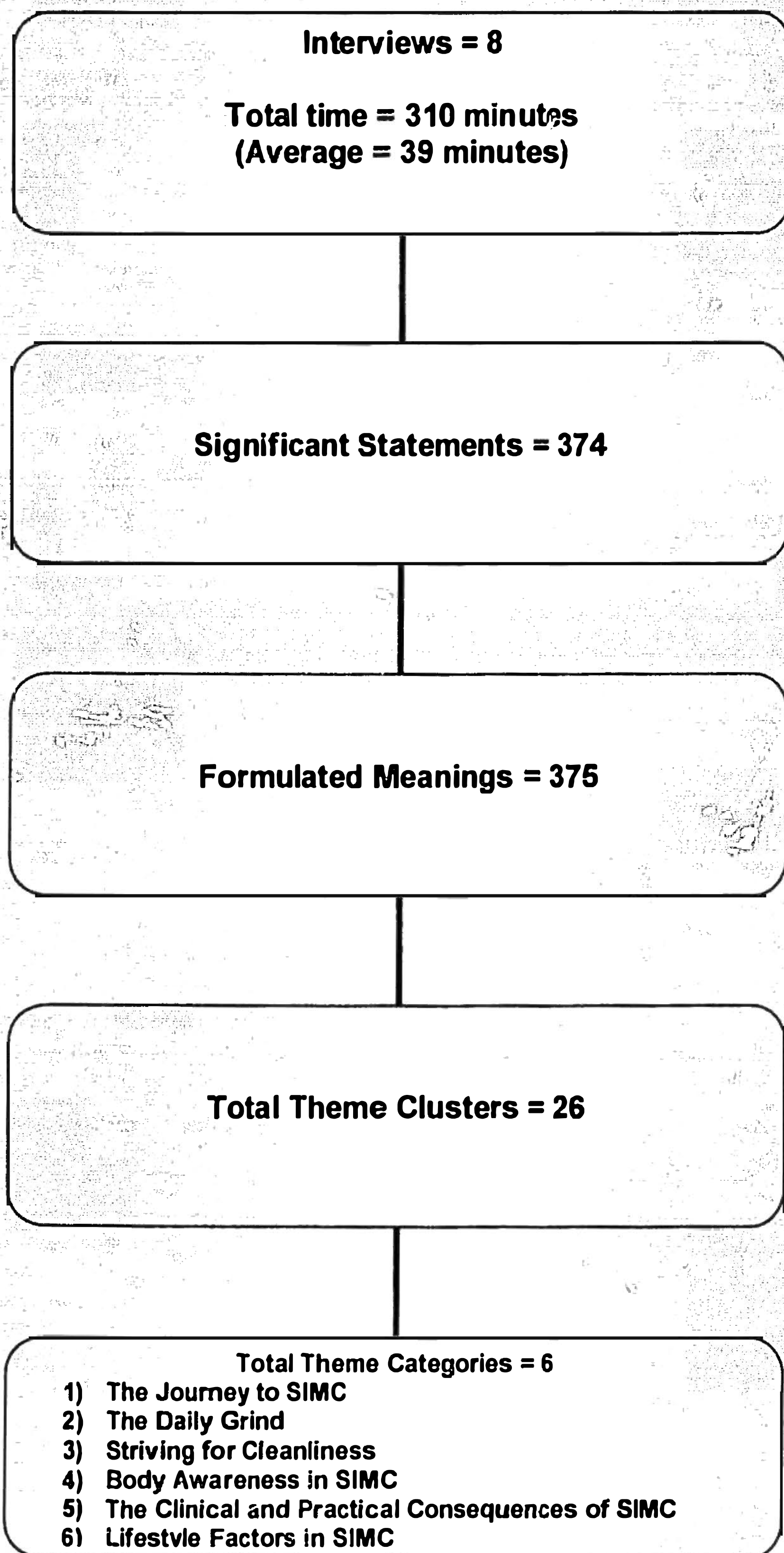


Figure 1: Data Analysis Summary

## CHAPTER 4

### *FINDINGS*

The lived experience of self-intermittent catheterisation (SIMC) in people with spinal cord injury varies between individuals. Some experience SIMC as incidental to daily living with a catastrophic spinal cord injury, while others are focussed on the process of SIMC in almost every aspect of their lives. In this chapter the findings of interviews looking at the lived experience of SIMC in people with spinal cord injury will be reviewed and explored. Findings are detailed within the theme categories that are a reduced from the original theme clusters identified from the significant statements and formulated meanings.

Three hundred and seventy five (375) formulated meanings were allocated to twenty six (26) theme clusters. From the twenty six theme clusters the data was further refined to six (6) theme categories that included theme clusters with similar subject matter.

#### **Theme Category 1: The Journey to SIMC**

Theme category one is called The Journey to SIMC and incorporates the trials that participants went through to get to the point they were at when interviewed. Participants described the paths they took to SIMC and these stories were reminiscent of a journey that transpires from their initial introduction to catheterising, through to acceptance of the method in their lives. The category includes clusters relating to the choices participants were presented with, the teaching process, and the levels of support provided. It also looks at the negative reactions participants related in the cluster "It just sucks".

#### Stuck for choice

The first theme cluster 'stuck for choice', contains statements that relate to the various bladder management options that participants have been offered or exposed to during their spinal cord injured lives. The title reflects the fact that most of those interviewed were never offered a choice in their own bladder management.

Some participants were not given the option of SIMC in the early days of their post injury bladder care and consequently tried different methods over many years before coming to SIMC as their preferred method:

*... you were only told it's either leg bag or nothing.* Participant 03

Others had only been offered SIMC because they had adequate hand function or their injury occurred in recent years where the practice of SIMC was taught as routine:

*... I was told that that was the better option to go and I went down that path.* Participant 02

When asked about trying other methods one participant had trialled a permanent indwelling catheter during his initial rehabilitation but it was not what he considered a long term method:

*... just for a short time while I was in rehab there, and yeah I didn't take to it at all.* Participant 06

During discussions on bladder options and choice participants were asked if they considered SIMC to be a long term option. Most considered it a long term or life long method although some wondered if there were other choices in the future:

*oh, yeah, ... as far as I'm concerned it's the only way I'll do it.*

Participant 02

*well, you do it for the rest of your life don't you?* Participant 05

*well I'll have to won't I?* Participant 07

Participants explored alternative options to SIMC, either practically or theoretically, during the interview with most having a reasonable understanding of available options:

*... well I've not seen another option that I think 'oh that's better than doing a catheter', everything else sounds pretty horrendous to me.*

Participant 04

Surgical alternatives were generally considered to be unattractive and unpleasant options to SIMC:



*I mean, holes drilled in you, stuff glued to the end of your knob, things dug out, oooh, not gunna be happening, I'll just keep putting the tube down there. Participant 04*

*... just the idea of constantly going, you know, constantly dribbling and having to wear a leg bag all the time is not too appealing for me, so I really wanted to pick the lesser of evils I suppose. And yeah, I guess IMC's were the best. Participant 06*

One participant was philosophical about trying alternatives:

*Well if they can come up with a better option, I'm willing to try it.*

Participant 08

All eight of the participants interviewed were happy with their current bladder management and the way they had arrived at that point. This feeling was summed up by one participant:

*So I, I'm really at peace with the way my life is going as far as that goes.*

Participant 02

#### The learning experience: how do I do this?

An important phase in the journey to SIMC is the way that patients are taught and learn SIMC and the level of medical and social support they receive during this process. Many patients are initially taught by a nurse who often has time constraints and may not be available to provide follow up tuition or advice. Most do not receive any advice or input from other people who perform SIMC and this was mentioned as something which may provide another level of support through the process.

Like any procedure, SIMC needs to be taught effectively for the person to get maximum benefit from the method. Several participants commented on their own learning experiences and reflected on the benefits and inadequacies of this. Many were taught initially in hospital by nursing staff and then perfected the process through trial and error:

*(the nurse) taught me a little bit about it and then, basically, through the knowledge of other people, got to where I am now. Participant 03*

*And she (the nurse) showed me a few times how to use it and that, and I was quite happy at it. Participant 08*

*Just do whatever you feel is the right way to do it because, you know... the staff and everything, they'll only tell you what every, what the most common thing is, not what's right for you. Participant 06*

*... making a hell of a mess so that was early in the piece, that was one of the things that the hospital was sort of telling me to do initially, was, do that. Because I think the longer I've been out of hospital, the more control I've got of my bladder. Participant 05*

*I mean they didn't say I had to do it but they, they showed me how to do it by myself and I said 'yeah that's fine, I'll do it'. Participant 07*

One participant claimed that he should have taken more notice when staff were teaching him SIMC because he felt this caused him problems afterwards:

*One thing I would say to them is, take on board what the staff at the hospital tell you. Because it is, it will be good for you in the future, definitely. Participant 07*

*... now when I go back to you know, what they were telling me in hospital, if I took that more seriously, which I didn't, it would be better you know? Participant 07*

A number of inadequacies in the teaching process were highlighted:

*Learning about catheter care was never taught, we learnt by "trial and error". Participant 03*

*It was frustrating, like the nurses would come in and drop a couple of bottles there for you for the night and you know, a few of this and that, and catheters and then you did yourself, tried to do it yourself. Participant 05*

*... the nurses didn't have the time to put in, and to stop infections was pretty near on impossible. Participant 05*

*Since then I have had two small operations because, due to the inadequacies of the teaching process, for instance, so what you were taught, you were taught to use a small catheter, as in small diameter. You weren't told what types to use, you just had to work it out yourself so, hence, the first three or four years I was using a 12 or 14, 12 gauge catheter. Participant 03*

*They were explaining things to do and saying you should be able to feel, but I didn't have feeling in my hands. Participant 05*

There were a few suggestions on how to make the teaching process better for new patients going through the same ordeals as the participants had been:

*I suppose in some ways really, the wrong people are teaching people how to use catheters in the hospital. I think maybe people, there should be more interaction with people that have left the hospital to talk to the people that are coming out of the hospital, maybe as a group.*

Participant 05

*Hopefully the knowledge which is gathered now is passed onto the customer, ah onto the patients, because in my day it wasn't.*

Participant 03

*And the ability to, I suppose also, we were never taught things like the cleaning of catheters, how to do it, what's the best, all those things, and hopefully they are now. Participant 03*

### Is there anybody out there?

This is a question many participants asked during their introduction to SIMC. In most cases they were taught how to catheterise and, once competent, left to their own devices. In some cases partners were left to provide the initial support and encouragement. A quarter of those surveyed acknowledged that support:

*... then (participants wife) hounded me to do it right and helped out a bit.*

Participant 01

*I had to talk about it with my partner because she obviously, does them.*

Participant 06

Multi-level support is vital to prolonged, efficient SIMC and supportive health professionals can provide this. One participant found that the urology doctors involved in his care did not meet his needs:

*Hospital urology staff were only “averagely” supportive of participant wanting to learn SIMC. Participant 03*

*(Doctors were not supportive of SIMC because) “... function wise and maybe it was that time where it was not necessarily the thing to be done”. Participant 03*

### “It just sucks”

Without adequate education and support patients can be overwhelmed by the negatives related to SIMC and be tempted to take shortcuts or try alternative options. Generally participants were accepting of the fact that they had to perform SIMC although most claimed that there were some aspects that they found to be negative. This begrudging acceptance of the method was summed up by one participant who acknowledged that he was “used to” SIMC but, compared to normal voiding, the process “just sucks”:

*... just the whole thing kind of sucks, it's weird, it depends on which way you look at it. If you look at it, you know, at one way yeah doing caths is alright, it's just normal, I'm used to it, that's cool. But then when you look at it to every day life, how it was before I started needing to use catheters, it just sucks because it's now turned into a clinical, on the dot, got to think about it, it's got to be planned, you got to pay for it, you've got to clean up after yourself, that part of it just sucks. Participant 04*

When asked if there were any aspects of SIMC that were good, responses included:

*No. I mean it's a necessity of life, you've got to go to the toilet and that's it. Participant 05*

*It is a pain in the arse, you know ... bladder management in any form. Participant 06*

## **Theme Category 2: The Daily Grind**

People who perform SIMC develop a usual daily sequence of activities that relate to this process. Theme category two, The Daily Grind, contains clusters

that involve the intricate but necessary steps that are needed to get through every day performing SIMC. The daily grind is a phrase often used to describe the tedium of a working day with its associated regulations, time frames and deadlines. Participants spoke of SIMC as almost a job which required specified periods of time between catheters, the development of a routine, and monitoring of the amount one drinks.

### Regulation

Participants seemed to take a ritualistic approach to the frequency with which they perform SIMC, generally three to six hourly, but sometimes much more often if there is infection or complications. They became regulated to performing catheters at certain times of the day and deviation from this regime caused some distress. This regime can vary considerably between individuals:

*I normally do it three hourly. Participant 01*

*I'm supposed to do them every four hours, that can vary from day to day. Participant 08*

*And I found that really the four hour bit, you know, is basically, it's the key. Participant 03*

*I find that five times a day is really good for me so every five hours I tend to catheterise, unless I need to go earlier. Participant 02*

*At the beginning, I mean when I was in hospital, every six hours was you know, the proper thing to do. Participant 07*

Others work out catheter frequency per day:

*Just one when I wake up, one when I go to bed, one about lunch time, one about six o'clock. Participant 06*

*Four, sometimes three if I forget, but then if I have done three in one day, I've done days where I've done one catheter in the morning and been real busy all day and not done another cath until six o'clock at night, and gone 'ooh'. Participant 04*

Environmental factors and illness also affect catheter frequency:

*I might do six a day, but I might do four of them at night. You know, but in the winter time I might do nine. Participant 05*

*... usually four caths, if I've got a UTI I can do, I remember one UTI I did like twelve catheters in one day, just drinking water flat out just trying to flush it. Participant 04*

*... because I've got a problem at the moment, it's leaking so, yeah, so I do it very often, sometimes I could do it every half an hour.*

Participant 07

### All in good time

Each person that performs SIMC knows how long the process takes, for many it is about five minutes, but in unfamiliar environments this time can be much longer. The amount of time SIMC takes to perform was discussed in almost all interviews and participants were quite cognisant of the exact time required:

*it's probably five or ten minutes, ten minutes maximum you've done a catheter and you're out of there. Participant 01*

*But it's a good five minutes, it's long enough to be an inconvenience, but I'm lucky, well I'm kind of lucky I reckon, the way my bladder goes.*

Participant 04

*It's, you know, literally takes me, takes us two minutes and it's done.*

Participant 06

Waking at night can increase the amount of time it takes to catheterise:

*... you're fully awake by the time you get to the toilet and then, of course, you've got to insert the catheter and that takes a good bit of time so it could be a, easy a five minute turn around from the moment you wake up, get out, go to the toilet and come back. Participant 02*

### Habit forming

All those who catheterise develop a routine surrounding the actual practice of performing SIMC. This involves the preparation, environment, cleaning, and completion of a catheter. Many people link the development of an efficient routine with their individual effectiveness in continuing SIMC. Developing a

routine is important to effectively manage the bladder using SIMC. Most participants developed this routine to suit their lifestyle and bladder behaviours after they had left hospital and settled into daily life. In all the participants interviewed these routines evolved through trial and error:

*... and it's fiddly, it's a pain in the arse. It's God damn frustrating going through that stage of working out what works for you and what doesn't but it's a matter of sticking with that and then eventually it comes together and then it just becomes part of routine life after that.*

Participant 01

*As soon as I left hospital I started experimenting I suppose and I decided I'd do it as often as I needed to but wouldn't go over six times a day if I could help it.* Participant 02

*We just fell into a routine and we've been doing it ever since. It's really, we've managed to get it down to you know, it takes like two minutes and, you know I don't have to, we can just do it in the chair and it's pretty quick and easy.* Participant 06

Following the development of an efficient routine the process of SIMC becomes almost a normal way of life:

*... it just becomes habit I think more than anything.* Participant 01

*I've been doing it for so long now it's just another daily occurrence, you know. I don't sort of think 'oh God, it's fifteen minutes and I've got to go and have a catheter', it's my bladder's full, I'll just go and relieve myself.* Participant 02

*... I don't have a problem with it now at all. It's just, doing a catheter is just doing a catheter now, it's just normal way of life.* Participant 04

*I haven't had that (accidental leakage) happen for a long time, it's just a matter of once you get used to your routine and everything,* Participant 06



### What goes in must come out

Frequency of catheterisation is linked to the amount of fluids a person drinks and people are vigilant in their awareness of how much is consumed. This can become an issue when out in a social setting where friends are drinking alcohol and the restriction of leaving to perform frequent catheters is not conducive to an enjoyable time. A fairly basic principle for the adequately hydrated person is that what goes in should come out:

*One of the reasons I don't consume a lot of fluid is, as soon as I consume it I have to get rid of the bloody stuff again you know, so, it sort of puts me off. Participant 08*

For this reason most participants were acutely aware of the amount of fluid they consumed during a day and the consequences of drinking too much or too little:

*... phew, one and a half litres at the most. Participant 05*

*A certain routine day would have so much drinking anyway, so like I have a cup of tea in the morning, a glass of water in, during the morning, have lunch, I'd have, you know, couple of glasses, a glass of water, in the afternoon have another cup of tea and then dinner I'd have something to drink so, yeah, so not really. I mean I definitely don't drink the volumes. Participant 03*

Many of those surveyed were encouraged by health professionals to drink a reasonable amount of fluid, often on the pretence of flushing bacterium through the bladder. Some found this quite difficult and often did not feel like drinking a lot:

*I don't drink a lot, that's one of the big bugs that people go on, I don't drink as much as I should. Participant 05*

*I didn't want my life ruled by the amount of fluid intake you know? And that's how they tried to train me... you know, they wanted me to go every six hours. Participant 02*

*People say 'you've got to drink, you've got to drink', and that's one of the things they hammered down the hospital, but I don't want to drink if I'm not thirsty. Participant 05*



*The reason is that the water (urine) stinks, and some of them say that the reason it does that is because you don't drink more water and more fluid. I don't know whether it is that or not but I'm not a drinker, I don't consume a lot of fluid.* Participant 08

### **Theme Category 3: Striving for Cleanliness**

Due to the invasiveness of SIMC cleanliness is an important factor in maintaining a healthy bladder. Theme category three relates to the issues surrounding hygiene and catheterisation technique and reflects the active measures that participants took to ensure clean equipment and reduced infection risk. A good technique reduces the risk of infection through clean hands and environment and no or minimal touching of the clean catheter before use.

#### Developing a good technique

To remain free of infection and associated complications one must have clean catheters and equipment, and a clean, efficient technique. Maintaining this cleanliness is through good hand washing and assembling clean equipment during the routine of SIMC. All those interviewed claim they had quickly developed a technique for catheterising that suited their lifestyle and minimised the risk of urinary tract infection:

*I found i was getting a lot of UTI's to start with but it was just working out technique.* Participant 01

Hygiene was another factor in good technique and included clean equipment and hand washing:

*... as I came home after, they did say that you know, you got to wash your hands before you do it and all that because you might get infections.* Participant 07

*... also, to try and be hygienic, and sort of wash my hands with one of these ah, bottles of (alcohol gel) or whatever they call it.* Participant 08

#### Catheter cleaning

Good personal hygiene and clean technique form the basis for efficient SIMC but to significantly decrease infection risks any catheters or equipment must be clean before use. Five out of the eight participants reused single use catheters

or used a reusable catheter to cut down on costs associated with SIMC.

Methods for cleaning the catheter between uses varied from washing with soap and water to soaking in sodium hypochlorite. A few participants talked about their cleaning routines:

*... with the Kliney's I wash, I have a group of five that I wash out once ... at the end of the week with soapy water and clean them.* Participant 03

*yeah we clean them. We put them in a thing and we put detergent and hot water, then drain that out and we put more hot water in again and then we put them in the fridge.* Participant 05

Some participants soaked catheters in the chemical Milton (sodium hypochlorite 1%) to kill any bacteria.

*... we just soak them in Milton's solution, oh we wait til there's a pile, well you know, half a dozen or something and then soak them in some solution yeah. Um, and they'll last for a few goes.* Participant 06

*... the idea was sort of get a long spaghetti bottle, put a bit of Milton, which is a bleach type, into that bottle and sort of, have a way of hanging these in the Milton would kill any germs.*

Participant 08

Two participants mentioned the negative aspects of cleaning and storing reused catheters:

*yeah, it does become a pain in the bum because you've got to clean your gear out.* Participant 01

*... when I was using the throw away caths I was just getting infections after infections 'cause it is, that's a pain in the arse because it goes from being a five minute operation to being a fifteen minute operation because you've got to get the reusable catheter, use it, clean up.* Participant 04

### The worst thing: incontinence

Cleanliness, or lack of, was often associated with contamination and infection.

Urinary tract infections and complications may cause urine incontinence

between catheters and this can be embarrassing and is considered to be one of

the worst aspects of SIMC. Some people wear a pad or nappy to protect against unexpected leakage, either in certain circumstances or all the time.

Almost without exception participants agreed that the worst part of SIMC was actual or potential incontinence between catheters. Most medications that participants took were to help prevent leakage between catheters and all those interviewed had a high sense of awareness regarding this issue.

Five of the eight participants used pads to catch any urine leakage. Some wore pads all the time, others only when out, and some just used them for peace of mind:

*... sometimes wear a nappy so, you know, when I know I'm going for a long ride, and you know, I'd have the tingles and know I'd have to go to the toilet but like, if you're on a three hour ride and you're in the middle of nowhere, well, it's not an easy thing so, Participant 03*

*I've got to put a nappy on, oh definitely. Otherwise I'll have an accident, and get wet. Participant 07*

*I use the paper nappy and that holds a hell of a lot of fluid and I've seen me taking that off and it's actually saturated, you know? Participant 08*

A pad was often referred to as a safeguard to protect against accidental leakage and prevent embarrassment of wet pants, particularly in public:

*I don't wear pads during the day at home because I'm convenient. But if I go out I wear it more or less for humility rather than getting embarrassed of wetting. Participant 05*

*... you know, have a pad in there and soak it up that way. I mean, no one knows, no one knows you've got it there, it's only a vanity thing I suppose in some people. Participant 01*

*... every now and then, not very often. I do, I wear a pad normally and that's more a safeguard I suppose, than anything. Participant 01*

It was not uncommon for participants to wear pads overnight but one used another method for managing leakage in bed by placing a urine bottle between his legs to catch any leakage:

*sometimes at night when I'm asleep, I sleep with a bottle, just in case ... probably most days, most mornings I wake up and it's empty you know, but now and then there's a bit in there and, yeah. It's just to save on the washing I suppose.* Participant 06

When asked what the worst aspect of SIMC was, accidental leakage between catheters was the most common answer:

*Having accidents.* Participant 03

*You know that's frustrating, that's the worst, yeah I suppose UTI's, leaking, the whole thing is just a pain in the arse really when it comes down to it.* Participant 04

*... I mean I don't, you know, it doesn't worry me but as I said to you, if you ever had an accident like that you know, it's not good you know?*  
Participant 07

Participants spoke of how traumatic and episode of incontinence can be:

*And that's just the worst thing, like peeing the bed, I've got leather seats in the car, peeing on leather seats and stuff like that, and like you go out, or something with the boys, and you're going 'oh yeah, I'm peeing'.*  
Participant 04

*yeah, a couple of times early on, I drunk a lot before going to bed and woke up in the middle of the night, you know, busting to go.*  
Participant 06

*I have had times where I've leaked nearly two litres in the night and I've got a second bottle which I use.* Participant 05

*It's not nice having an accident you know, so everyone looks at you and I got to go.* Participant 07

#### **Theme Category 4: Body Awareness in SIMC**

Spinal cord injury has an obvious and lasting effect on body image and esteem. Participants who perform SIMC felt that it impacted on their personal perception of themselves and their intimate relationships with others. Theme category four,

Body Awareness in SIMC, contains clusters that relate to the way individuals understand and interpret the impact of bladder management on their bodies. These clusters consider how participants felt initially and the journey to acceptance, how some strive to maintain privacy in SIMC, and how the process is perceived to alter body image. It also contains comments that relate to sexuality and intimacy and the issue of embarrassment at performing SIMC.

### Introduction to acceptance

This cluster explored the way that participants felt when they were initially introduced to the concept of SIMC. At first participants had feelings of distress at the thought of a lifetime of self-catheterisation but this initial trauma gave way to different feelings about the body and SIMC. Most had concerns about such an invasive and long-term procedure:

*oh, originally it was pretty daunting, yeah.* Participant 01

*at the very start it was a bit of a drama because early in the stage I couldn't feel my bladder being full.* Participant 02

The thought of physically having to perform SIMC was also initially traumatic for some participants:

*oh, it's a mindset change because obviously, putting a plastic tube down your, you know, down your penis is not really, necessarily a good thing to, you know, and that really is a mindset change.*

Participant 03

Another participant described his initial feeling in a single word:

*Horrendous.* Participant 04

He went on to define the practice as:

*I relate it to punching your best mate in the nose, well you can't feel it but you just wouldn't do it.* Participant 04

One participant compared his feelings of SIMC with being told that he would never be able to walk again and considered it in this context:

*You're never going to walk anymore, I mean, how would you feel about that, you know, my heart just sunk, ... telling you to use a catheter was nothing, to something I've that, you know?* Participant 08

## Privacy

Participants try to maintain a degree of privacy when performing SIMC by using suitable toilets or shielding themselves from discovery by those they are with. The practice of SIMC is a personally intimate process and most participants try to keep the details of this private where possible. Telling others about the need to do SIMC is difficult and people may have pre-conceived ideas about how the person with SCI manages their bladder:

*... going to the toilet, I'm assuming that they wouldn't know, and if they did know well, they obviously would realise that, you know, there's a particular reason why I catheterise.* Participant 03

*And everyone knows you've got to go for a pee, and everyone knows you've got to go and do a catheter ...* Participant 04

Some are more open with sharing the details of catheterisation:

*yeah, well it's kind of, I pick the people that I like to tell you know, like every one of my mates knows that I stick a tube down my knob four times a day cause I think it's funny like, to show them the catheter, make them cringe.* Participant 04

Trying to maintain privacy when in public is a challenge:

*You don't want to embarrass yourself as well as other people and I suppose it's really against the law to do that anyway in public.*

Participant 02

*I mean you can if you're just with your boys it's cool because you can pee in a beer bottle and no one cares, and just tip it in the garden. But I mean, when you're out with people that you don't know or that, you know, are a bit more civilised or whatever, you just don't want the headache of stuff going bad when you're around people you don't know.*

Participant 04

## Body image

Alternatives to SIMC involve urodomes or permanent catheters with attached leg bag and this is considered to contribute to a negative body image. For some people one of the attractions to SIMC is the fact that they do not need to have any fixed drainage device. It allows people to look and feel relatively normal

between catheters and this is important for those who are conscious of their image.

Participants who talked about body image had generally experienced the urodome alternatives and compared this experience:

*You're not dragging a night bag that's hanging off your dick.*

Participant 01

*... never was happy with the leg bag, having something strapped to your leg, and with the glue and the um, condoms, it was just ah...*

Participant 03

Others had considered alternatives but did not find them very appealing:

*oh mate, I reckon using a cath, compared to whatever I've seen on other things, is just, there's no way I would want anything hanging off me twenty four, seven.* Participant 04

*... she (participant's partner) agreed with me that it was, you know she doesn't want to see me with a leg bag or anything either.* Participant 06

*... and obviously with the permanent catheter you've got to wear a leg bag when you go out, it doesn't look great.*

Participant 07

*... if you had a catheter in, but you see, and a leg bag. But then again, you have gum, different stuff stuck around you which is ah, what would you call it, awkward, and messy you know so, it's something you wouldn't like you know, well I wouldn't like it anyway.* Participant 08

SIMC allowed participants to feel 'normal':

*... because like, my body is just exactly the way it should be right now and just every six hours I've got to put a tube in it.* Participant 04

### Sex and Intimacy

Sexual relations are also enhanced in those who perform SIMC because fixed drainage devices are considered to be dirty and a turn off. As with body image, many people choose SIMC because it enhances intimacy by eliminating visible



drainage devices and urine bags. Spinal cord injury significantly affects sexual function and having to wear a urodome and leg bag compounds intimacy issues:

*You haven't got anything glued on to your dick so the accessibility is right there, sexually plus catheter wise you've got the freedom of moving around.* Participant 01

*... if there's one reason, one reason I suppose, to have an intimate relationship with your wife without having a leg bag on is probably pretty high.* Participant 03

SIMC can have an effect on relationships but most participants had understanding, supportive partners:

*... just a couple of other girls I've been with since I had my crash, they really didn't care about that and then my girlfriend now is well cool with it.* Participant 04

*... but previous, in my youth it was obviously an issue, you know. The freedom of not wearing one, anything.* Participant 03

*I've had chicks like go 'oh that's cool, like can I watch', you're like, 'yeah that's weird'.* Participant 04

### Embarrassment

It is understandable that an intimate procedure such as SIMC would be embarrassing for some people. At some stages all the participants were embarrassed by their need to self-catheterise, particularly if they are in the toilet for an extended period of time. Those surveyed were open about their experiences but there were some factors of SIMC that caused embarrassment to participants.

Some felt uncomfortable about the amount of time it took to perform SIMC when in the company of other people:

*... there's like an element of embarrassment in it too, like having to do a cath, because it takes so long. You usually say 'oh I'm going to do a pee' or you know, 'I've got to do a catheter' or something like that, it's like, even though no one else really cares, it just like 'oh yeah, whatever' it's still kind of, you know, a bit embarrassing.* Participant 04

*It's a, you know, you could be in there for half an hour you know?*

*But it can be an embarrassment that way, you know? Participant 08*

Often family and friends are unaware of the process participants need to go through to empty their bladder and disclosure of these details can lead to further embarrassment:

*It's bad enough them not being used to spinal injury and not knowing exactly how to handle it and then for you to tell them 'oh yeah I've got to go and do a catheter, to have a pee I've got to put a tube down my knob to drain my bladder manually'. You just don't want people knowing that because you don't want them thinking 'oh, whoa that's weird' or you know, something like that. So it always makes you feel a bit funny, as it would. Participant 04*

*But I'd have to rig it (catheter equipment) up and it'd be sitting in the toilet and if you get visitors, you've got all your stuff sitting there and I like to be a little bit private. Participant 05*

*And the family don't, even the children don't think anything of it now you know, it was a bit of an embarrassment for me at the start, and probably them but now it's not, you know? Participant 08*

### **Theme Category 5: The Clinical and Practical Consequences of SIMC**

SIMC reduces the risk of medical complications associated with many other bladder management options (Berkov & Das, 1998; Wyndaele, Madersbacher, & Kovindha, 2001) but participants still reported a clinical perspective to the process. Theme category five incorporates those clusters which contain comments about the medical and practical complications of SIMC such as urinary tract infections and the medications used to enhance the procedure. It also covers the financial implications that participants encounter in obtaining supplies.

#### **Urinary tract infections**

Poor technique can be linked to increased incidence of urinary tract infections (UTI's) and consequently, an increased need for antibiotics. UTI's cause people to feel unwell as well as changing the behaviour of the bladder, generally

causing more incontinence and the need to perform more frequent catheters. All participants claimed they had suffered from UTI at some stage although they believed that the rate of infection is less with SIMC:

*(the) best part, well, infection free, or limited, a lot less of infection.*

Participant 01

Some people reuse single-use catheters to save money and wastage but several of the participants linked this practice to increased rates of UTI:

*Somebody outside who was using a catheter told me he used the catheter twice and I wasn't happy about this but tried it and, I got a couple of infections. And I said that's it, one catheter at a time and one catheter per operation, that was it.* Participant 08

*I went through a stage where I got a lot of UTI's because I was using the reusable catheter, which sucks. But I wasn't using it properly, I was rinsing it under the tap and just chucking it back in the case. Mind you, the water coming out of the tap I used was bore water so I had infection after infection, so I got rid of them and went onto throw aways.*

Participant 04

UTI's can make the person feel quite unwell and manifest in a variety of symptoms:

*... you do feel pretty crappy and yeah, I have to go a lot more often and with the, you know, much smaller amounts each time.* Participant 06

*... I had an inflamed testes, it was like the size of a grapefruit and that was just a really bad bladder infection, the worst I've done.*

Participant 03

*if I've got a UTI and I'm firing off, that's it, leave me alone for a week, until I'm all fixed because that sucks. It's just waiting for a time bomb to go off.* Participant 04

### Medications that assist in SIMC

Most medications used in SIMC are aimed at relaxing the bladder muscle so that it can hold larger volumes. Many of these medications have fairly

unpleasant side effects and there is always a need to find a more efficient method to achieve greater bladder capacity.

Generally any medications used adjunct to SIMC are aimed at increasing bladder capacity by relaxing the detrusor (bladder) muscle, thus allowing the bladder to hold more and preventing 'accidents'. The two most common types of medication used in the participants surveyed were oral anticholinergics (oxybutinin) and Botox® (injection of botulinum toxin directly into detrusor muscle).

The anticholinergic medications that help relax detrusor muscle also have unpleasant side effects:

*... since I started catheterising, which is not great because it gives you such, you know, it gives you a dry mouth and, you know, it doesn't really work that well. Participant 03*

*... it (Botox®) also helps your bowel movements too because oxybutinin blocks up your bowels a bit too, causes problems.*

Participant 05

Botox® injections into the detrusor muscle have been successful in relaxing the bladder without the side effects associated with anticholinergics (Klaphajone, Kitisomprayoonkul, & Sriplakit, 2005). Although Botox® is relatively new and trials looking at its effectiveness are continuing all the participants were keen to re-use it or to trial its effectiveness if it was more widely available:

*... that's one of the advantages of Botox®, you don't leak. You don't leak, it just, it just builds up and then you do it and then you have a good catheter. Participant 05*

### Financial implications

Another clinical issue in SIMC is the cost of buying catheters and equipment. Some of the participants received compensation for their injuries and, consequently, have to pay for everything related to their disability. For the non-compensable person catheters and equipment are provided through government funded continence schemes and allowances. The compensable person has to pay for these supplies and therefore cost becomes a factor in bladder management:

*But I mean you pay a dollar ten a catheter, so every time I go to pee, minus the lignocaine, just the catheter on it's own is a dollar gone straight in the bin ... it's fifteen hundred bucks a year... that pisses you off, knowing that to go to the toilet. So that fifteen hundred bucks a year is fifteen thousand every ten years, or twelve whatever, that's a lot of money, it's expensive being a cripple, having to pee out of a tube.*

Participant 04

*... you use one and then throw it away ... it costs you heaps then.*

Participant 07

*I was buying my catheters, ninety cents each, and I was buying them from the East, and these people in the East used to supply catheters from sixteen years of age to, I think about fifty-nine. Once you come to fifty-nine, they didn't want to know you.*

Participant 08

*But you see, this is where the government and people like yourself should be putting out that type of information (catheter costs) to people like us, you know?*

Participant 08

### **Theme Category 6: Lifestyle Factors in SIMC**

The pervasive and demanding process of bladder management in spinal cord injury means that any method must have the flexibility to allow for a reasonable level of social activity. Participants spoke at length about the good and bad aspects of SIMC in their daily lives. Theme category six, Lifestyle Factors in SIMC, encompasses these comments in theme clusters that look at areas such as freedom and control. Other clusters relate to physically accessing toilets and public facilities, the problems encountered in long distance travel and the various methods used to manage continence overnight. Theme category six also looks at the wide-ranging comments on the effect SIMC has on social and, to a lesser extent, work lives.

#### Freedom to be normal

SIMC provides freedom to move around physically without the concern of attached drainage bags and devices. This allowed people to feel 'normal' between catheters. One participant who had used these drainage bags for many years and now catheterises felt it gave him an aesthetic freedom:

*You know, going out, wearing shorts more, always in summer.*

Participant 03

The same participant also related this freedom to playing with his small children:

*...when you're playing, you know, on the ground or on the bed, there's, you know yeah, it's just freedom I think.* Participant 03

Another participant claimed that, despite being confined to a wheelchair, SIMC gave him the freedom to feel relatively normal between catheters:

*I guess doing catheters when you're, once it's done, for six hours you can feel like a, you know, fairly normal person. You don't have to, I mean, you're not leaking or carrying a leg bag with you.* Participant 06

### Physical access

Physical access in the community is a significant issue for people who perform SIMC because many public toilets are difficult to get into with a wheelchair. A simple shopping trip or dinner date can turn into a nightmare of navigating back entrances, cluttered ramps and hidden lifts. Access in private homes is also an obstacle to maintaining relationships with family and friends, although many who perform SIMC feel comfortable enough to do this in alternate areas such as garages, laundries, or backyards. Access was a problem for all those interviewed and, despite better legislation and understanding of the rights of people with disabilities, continues to impact on their daily lives.

Toilets in restaurants are notoriously hard to access and most people in a wheelchair have to phone ahead to check if they can access these before making a booking:

*... you just have to think ahead or ring to make sure there's someone there.* Participant 01

*yeah, you just plan ahead, a lot of it is just planning.* Participant 02

*Like before I went down ... on the weekend I was thinking, I was like, double checking like you know, can I get in the toilet at this place, can I get in the bathroom. So that's always in your head, thinking oh I've got to pee somewhere.* Participant 04



*... going out to dinner, the first thing you say 'are you wheelchair accessible'? Participant 04*

Even finding a disabled toilet is no guarantee that participants will be able to get close enough to the toilet to perform SIMC:

*... the main effect I probably find on them is finding a disabled toilet that you can get close to if you're out, just out in the city or something like that. Participant 01*

*... obviously there's not many that, you know, a lot of toilets that are inaccessible, I have a very small chair so I can get into, close to a toilet so it's a bit easier. Participant 03*

*And then some places you do rock up and you have spoken to a waitress or whatever and she goes yeah, yeah it's fine and then you rock up and it's not wheelchair accessible. And that pisses you off.  
Participant 04*

*... we used to go at least once, twice a month to a restaurant, but a lot of places aren't built for this (wheelchair), even yet you know?  
Participant 08*

Many of those interviewed were innovative when it came to finding an alternative place to catheterise if there were no accessible toilets:

*But most fuel stops, if they haven't got a toilet then you go around the back of it and drain out around the back of there. Participant 01*

*well yeah, general rule of thumb is you'll always find somewhere to go, you might not be able to access 'the toilet' but as long as you can access something. Participant 02*

*... you carry a drainage bag in a bag so then if you can't get to a toilet at anytime you just go to a corner and then just catheterise into that and then it's just like a leg bag. Participant 03*

Visiting the homes of friends and family also posed access problems because most people do not have large, wheelchair accessible toilets:



*That's probably the most uncomfortable thing, but my close group of friends, they all know that so they're prepared for that when I go visiting.*  
Participant 02

*... it gets more of an issue sort of when you're out and about because you know, ninety percent of the time you're at a friends house you can't access their toilet so you've got to duck into their bathroom or whatever.*  
Participant 02

*But that's another thing with, that's one of the inconveniences of catheters if you go and visit someone, if you take the stuff, have they got the facilities in their place that you can go into at different peoples places.* Participant 05

### Perils of travelling

Like other activities involving SIMC, travelling in a wheelchair is an incredibly difficult process and requires meticulous planning. Many people are nervous or defer travel, particularly if there is a need to fly as part of the process. Others use short term measures such as indwelling catheters or urodome appliances and leg bags to avoid the need for SIMC whilst flying. For shorter trips a common practice is to dehydrate oneself before take off and restrict any fluid intake during the flight to eliminate the need to catheterise. All participants were acutely aware of the potential for embarrassment if there is incontinence during a flight and actively planned to prevent such problems.

For the spinal cord injured person who performs SIMC to empty their bladder this process is even more difficult because aircraft, and particularly aircraft toilets, are notoriously confined:

*When I first travelled overseas that (SIMC) was one of my first worries, I'd never travelled before.* Participant 02

The planning process for travel begins well before any bookings are made and a few of those surveyed were preparing for trips, both booked and hypothetical. Most of these plans involved placing an indwelling catheter in for the duration of the journey:

*But I've already though like, when I go to New Zealand, even when I go to Sydney on the plane, just in case there's delays or stuff like that, I'm putting an IDC in before I go. Participant 04*

*Flying over to Melbourne with, with catheters, you know, I have to put a bag on and all that. Participant 05*

*... so I'd have to, I guess, leave a catheter in or, and have a leg bag for that but I mean it's a one off trip, I can handle that. Participant 06*

Some could not bring themselves to use an indwelling catheter, even for a short time:

*I haven't got past the mindset change to do indwelling catheters and stuff like that, where to blow the balloons up, I'll prefer to go just normally catheterising because I haven't gone past that mindset change.*

Participant 03

The more experienced travellers had worked out fairly sound regimes for flying:

*You limit your fluids before you get on and then...so if you limit your fluids before you go, do a catheter at the airport directly before you get on the plane and then don't drink too much on the way over.*

Participant 01

*So I mean planes, yeah, I just, I catheterise, I just you know, on the long flights obviously you don't drink as much, slightly dehydrate yourself and then I get an aisle chair to the toilets and then catheterise in the toilets, I haven't found it an issue. Participant 03*

*well yeah, yeah. It can get a bit painful, or embarrassing in the sense that if you can't go to the toilet, you'll just void. Participant 02*

### Make it through the night

Crucial to a healthy lifestyle is the need for adequate rest and an unpredictable bladder can be detrimental to a good nights sleep. Most participants had to wake at least once overnight to perform SIMC but many incorporate this into a routine and try to get a block of five or six hours of good sleep. The most common method for waking is to set an alarm clock when the next catheter is

due. Feeling tired during the day is not uncommon if the person wakes of a night to perform SIMC but most have the process so streamlined that it does not take very long and they get used to it quite quickly.

Leakage in the bed is considered to be particularly bad and, although most have experienced this at some stage, people go to some lengths to avoid it.

Preventative measures used to combat accidental leakage overnight include wearing urodome drainage connected to a urine bag, wearing a nappy or pad, sleeping on plastic sheets, and sleeping with a urine bottle between the legs. Performing SIMC requires a sound routine and some degree of forward planning. The need to catheterise during the night varies between individuals with some being able to have long periods of sleep and not worry about their bladder:

*I can do a catheter at ten at night and wake up at nine the next day and do a catheter then, I don't have to wake up in the middle of the night to do one. Participant 04*

*I used to do the catheter at twelve o'clock and then do one at six o'clock in the morning, which was pretty good. Participant 07*

Others may wake several times each night to perform SIMC:

*...so if I go to bed at, you know, nine-thirty then I'm up around between three and five. Participant 03*

*Sometimes I do a lot at night and sometimes I don't do much at all. Participant 05*

*... but at night time you know, I might go six or seven times rapidly, right up to about one-thirty and then I sleep. Participant 05*

People with some types of incomplete spinal cord injury or those with an element of bladder sensation are able to feel when the bladder is full and, if they are lucky, wake to catheterise. If a person does not have this sensation they must rely on other methods to wake for SIMC:

*So if I go to bed and try and rely on waking up when my bladder's full it won't work and most times I'll wake up and there, I'll be lying in a pool of urine so I set an alarm clock every night. Participant 02*

*If I go to the toilet when I go to bed at ten o'clock, well then at three o'clock in the morning I'll have the alarm to wake me up, and I'll go out.*  
Participant 02

*No, no I just wake up, just wake up and it (the bladder) says 'oh, I'd better go'.* Participant 05

*I find the best way is to have a little alarm clock and, say I done a catheter at eight o'clock and got down for the night to sleep, before I'd get down I'd just set it at twelve. Sometimes I'd hear it, most times, or most times I'd hear it...* Participant 08

Waking for a catheter is one thing, getting back to sleep afterwards can be an entirely different problem:

*And then of course you've got to go back to sleep again so, if I'm lucky I'm that tired that when I jump back into bed I just zonk out, and if not well then you take about half hour to go to sleep.* Participant 02

*No not really, because I mean, once you do it, you know, you go straight back to sleep.* Participant 07

A couple of the participants used appliances such as urodome drainage to help overnight, either as a prophylaxis for incontinence or to eliminate the need to get up and perform SIMC:

*...at the moment, overnight I wear a leg bag, and a ah, what do you call it, those um, a urodom or whatever.* Participant 07

Others have tried this method with less success:

*I tried it initially to try to sleep at night so that I'd see if I could sleep all night, but I found that if I rolled in the wrong position I'd pulled it off, and then that created a problem. You know, you'd knocked them off so, and then you started leaking on the bed and leaking on the floor and, making a hell of a mess.* Participant 05

When considering whether waking for SIMC during the night is disruptive to sleep patterns some believed that it was detrimental:

*oh, it wasn't that flash of a morning. Participant 02*

*It's not good for regular sleep patterns for sure but, I've been doing it for that long now that I don't know any different so your body gets used to it.*  
Participant 02

*I thought it was infections and it wasn't, it was just my bladder was full. And it would say I had, and that, that knocked my sleep pattern around.*  
Participant 05

#### Control: "it's just another way of going to the toilet"

The freedom of SIMC increases independence and some believe that SIMC gives them more control over their bladder management. Participants interviewed claimed that they enjoyed the control that SIMC gives them compared to other bladder management methods. This can be reflected as positive control:

*It's changed my life. Didn't think something would like that but yes, it absolutely has. Participant 03*

*I can say look, doing catheters is no real huge issue, it's just another way of going to the toilet, it's not quite as easy as what we used to do before but, I mean, it's a way that we can manage it, and do it quite well.*  
Participant 02

Control can also be perceived as a negative factor in SIMC:

*Lack of control, where, like when I say lack of control you have to do it when it says you've got to go, you can't sort of cross your legs and put it off. Participant 05*

*I mean, it's an inconvenience but it's, that's the only downside I suppose to catheterisation is having to rely on some other people every now and then to empty your waste. Participant 02*

#### Social life and SIMC

A social life could be defined as going out in public, to pubs, clubs, restaurants, concerts and the like. A lot of the participants, particularly the younger men, talked about the effect that SIMC had on their social lives. The desire to go out

socially, to drink alcohol, and to mix with others is considered a ritual for many young people but SIMC makes it difficult to drink to excess. Generally these outings require planning and the person may not get maximum enjoyment as the need to perform SIMC is always in the back of their minds.

Drinking to excess can be difficult as finding an accessible toilet and getting away from the group for the time needed to catheterise detracts from the experience. The constant concern of having to perform SIMC can also cause people to feel less confident about themselves when out socially.

*The down side to catheterisation I suppose is when you do want to socialise a bit is the amount of times that you would have to go, you know, if you have four or five cans of beer instead of just going probably once in that four hour span, you'd probably have to go two or three times.*

Participant 02

*Like if you're going to the pub you've just got to always have it in the back of your head, even when you're drunk you know, to 'oh I've had a few drinks now, I've got to go do a cath'.*

Participant 04

*It's frustrating when you go to the pub. It's mainly the pub, cause you know, you're there to drink...*

Participant 04

*... and I guess I can't, you know, sit around and drink a hell of a lot of beer or anything with mates.*

Participant 06

The need to perform SIMC regularly can have a negative effect on a person's social life through inconvenience when out or as a deterrent from going out at all:

*Yeah it is a bit of an inconvenience, it's a turn off, you don't really want to be going to the toilet all the time, you know, every fifteen, twenty minutes your bladder's full so you duck off to the toilet, it seems to be ... crippling as far as going out and socialising the way you used to when you were younger.*

Participant 02

*And that's not a drama, but it's a pain in the arse when you're sat there and you're going, you know the pubs going off or whatever and you go 'oh, I've got to go for a pee', you know what I mean.*

Participant 04



*But I mean things like the Big Day Out and stuff like that, like an all day festival, there's no way that you're gunna go and do a catheter somewhere there, it's just not going to happen. Participant 04*

*You know, 'oh this is shit, I'm just not going to bother, fuck it, I'll stay home today', but like, I dunno, like seven times out of ten you just go and sort it out anyway. Participant 04*

*I'd find somewhere to do it, yeah. But it, but I haven't, I don't go and visit other peoples places. Participant 05*

SIMC was not always the major factor that prevented people from going out socially. Some were conscious of being in a wheelchair and felt that this took away their confidence in public:

*But I don't even go to the shops because of the wheelchair situation, I just 'oh well' and I stay at home, let my wife go and do what she wants to do. Participant 05*

*I think, just how I feel about, you know, being in a chair and that is probably what stops me going to places a lot. Participant 06*

*Oh yeah, it definitely makes you less confident ... it's like an element of paranoia, you know like 'oh I'm just not gunna do that because it's just a bit easier not to fuck it up'. Participant 04*

Some of those surveyed could see the positives of SIMC and social life or had come to terms with the method:

*Compared with previous bladder management techniques the participant finds that going out socially using SIMC is "only better". Participant 03*

*But yeah, I'm just used to it now, catheters are just a normal everyday part of life, it just sucks that you've got to plan around it sometimes when you're going out, and that it makes you feel a bit uncomfortable.*

Participant 04

*I don't think that doing catheters would stop me going other places.*

Participant 06

When asked whether family and friends understood what participants had to go through to empty their bladder, most believed they did not know:

*No, not a lot, no.* Participant 05

*Ummmm, not really.* Participant 08

Having a reasonable social life, as with many other aspects of being in a wheelchair and performing SIMC, requires a level of forward planning:

*Because that's one of the big problems with your, you do a catheter before you go to the movies cause that's, if you want to have a quality of life and you go there, but when you go to the movies, um, the only place you can sit together is too far close to the screen.* Participant 05

*I just do it before I go and don't stay that long, or I don't stay five hours.*

Participant 05

*I can't remember any particular time, I'm sure I've probably been caught out, you know, if I've got an infection because I've had a lot of infections. But normally if we're going to the shops we'll either, you know, do a catheter before I leave.* Participant 06

*If I'm going to family, there's no problem. Because I can get into the bathroom there or I take a bag, which I've had made, and I put a catheter in there and a bottle, catheter, some gel, and I use that if I'm wheeled into a bathroom or anything like that.* Participant 08

### Work – life imbalance

Work provides people with spinal cord injury with income and a feeling of value in the community. Performing SIMC in the workplace can be challenging because many work sites are not setup for wheelchair access or the employee has difficulty getting away for the amount of time required. Often the toilets were not accessible or suitable for SIMC and needing to catheterise at work can be problematic:

*It wasn't set up for toiletry and I was using pads.* Participant 05

*They've got a disabled toilet in there, we've just got to go down the lift, it's on a different level than work. Participant 01*

*I haven't done any paid work but I was, I did go and work at my mates engine shop, not work per se, but just go up the engine shop and just muck about all day with cars and stuff like that. But even that, when I was there and I was having to use their toilets and, you know, I would say if you were at work it would be very easy to forget to do a cath cause you're, you know, you're doing stuff, you're minds ticking. Participant 04*

Another was planning to go back to work but this was delayed due to recurrent urinary tract infections:

*... but I said at the moment I can't, I'll learn, I'd love to get back there but at the moment I can't because of, you know, the problems.*

Participant 07

### Summary

Chapter four has highlighted the findings of interviews conducted to determine the lived experience of self-intermittent catheterisation in people with spinal cord injury. Comments from participants were presented within the theme clusters and greater theme categories that incorporate similarly themed clusters. This format provides a framework on which to base a review of relevant literature to determine if the experiences of these eight participants are congruent with previous research.

## CHAPTER 5

### *DISCUSSION*

The findings of this study detail the varied and complex issues that people with spinal cord injury face when they perform self-intermittent catheterisation to empty their bladder. Chapter Four reported these findings and provided a valuable insight into the experiences of these people and the challenges they face on a daily basis. Chapter five will focus on discussion of the issues arising from the interviews seeking to explore the lived experience of SIMC in people with spinal cord injury. It will include findings from existing research that relates to the concepts and phenomenon described. These concepts are presented under the same six theme categories that emerged throughout the findings chapter.

#### **The Journey to SIMC (Theme Category One)**

SIMC is considered the method of choice for bladder management in SCI for those who meet the criteria of low bladder pressures, unobstructed urethra, adequate hand function, and compliance (Wyndaele, Madersbacher, & Kovindha, 2001; Moy & Amsters, 2004). Data from participants in this study showed that SIMC evolved with them to become an efficient bladder emptying method. In some cases this evolution had taken many years of different methods while others had always done SIMC but the process had evolved to fit their lifestyle and continence needs.

The participants in this study had varying exposure to other bladder management options but most found that the choices were minimal and that these alternatives were not conducive with their lifestyles. Generally, they were only offered one type of bladder management in the post acute stage of their injury and they felt that this was a decision that could not be questioned. Participants felt that they were denied access to information about bladder care and this led to them being uninformed about the options. Reviews of the literature confirm that there is not a large amount of choice when it comes to bladder management in spinal cord injury. Jamil (2001) identified three main bladder management options in the post-acute phase of SCI; reflex voiding, indwelling catheter and clean intermittent catheterisation (SIMC).

Reflex voiding is a fairly inefficient method and the frequent, prolonged suprapubic tapping and expressing associated with this method can be detrimental to a persons work or leisure activities (Jamil, 2001). Two participants had tried reflex voiding and urodome drainage for many years but were unhappy with the method claiming it was messy and disruptive to their daily lives. Often this method requires surgical incision of the external sphincter or insertion of a stent to allow for uninterrupted urine flow from the bladder. The general consensus among participants was that surgery to the urinary tract should be avoided where possible and that wearing drainage devices was an unsightly alternative.

Indwelling or suprapubic catheters are common in females and high tetraplegics but complications are high. These are generally associated with the rapid bacterial colonisation of an insitu catheter and the systematic effect that such an infection can have including sepsis, pyelonephritis and renal calculi (Jamil, 2001). Two participants tried indwelling catheters for longer periods during hospital stays but both were unhappy with this method and claimed that having a permanent catheter was distressing. Sheriff et al (1998) reviewed the records of 185 patients with suprapubic catheters (SPC) to assess clinical outcomes and satisfaction with the method. Sixty-three of these patients had SPC inserted as a result of failed SIMC, with the most common reason for failure being poor hand function. The second and third most common reasons for failed SIMC were persistent incontinence and recurrent urinary tract infections respectively. Eighty-two percent of respondents believed that the insertion of a SPC improved their lives and ninety-five percent were very pleased with the catheter (Sheriff et al., 1998). The high rate of satisfaction with SPC found by Sheriff et al was not reflected in this study because participants believed that a permanent catheter was not a reasonable option for them and they could not see themselves using this method in the future.

Although the options are minimal there is choice and those who wanted to explore these alternatives mostly had to do so on their own without support from hospital staff. This need for independent research by participants caused some to feel that they were being kept in the dark about what else was available to them. When considering alternatives all eight participants claimed that they were happy with their current method of SIMC and would not change to any other technique.

In discussions on bladder management options participants talked about their personal time frames for SIMC with most assuming that they would need to perform this for a long period, several claimed for the rest of their lives. They all expressed a desire to continue SIMC long term and were hesitant to consider changing. Although the intention of treating urologists and the patients is generally to perform SIMC long term, the literature demonstrates that this is often not the case. Yavuzer et al (2000) retrospectively looked at fifty patients in Ankara, Turkey to determine ongoing compliance with bladder management. The study found that of the thirty-eight (38) patients who were discharged on SIMC, twenty (20) had reverted to indwelling catheters by an average of twenty-four months after discharge (2000, p.763). They concluded that consideration should be given to choosing a bladder management method that suited the patient's lifestyle. This was supported by King and Green (2002, p.61) who claim that, as well as being clinically efficient, a bladder program should also consider the "level of function, preference, and social environment upon discharge". Participants in this study believed that SIMC suited their lifestyles and in most cases provided for a satisfactory social life.

Another retrospective study of 233 participants in Denmark examined the method of bladder emptying at least ten years after traumatic spinal cord injury (Hansen, Biering-Sorensen, & Kristensen, 2004) and found the opposite to Yavuzer et al (2000). They found that the use of SIMC increased from 11 percent at initial discharge to 36 percent at follow up. Reflex voiding by suprapubic tapping decreased from 57 percent to 31 percent at follow up. Of those reviewed, 46 percent had changed their bladder emptying method at some stage after initial discharge. The time post injury that participants in this study were reviewed ranged from ten to forty-five years with the mean years from time of injury being twenty-four years. This may account for the increase in SIMC as increased knowledge and education about the benefits of SIMC have evolved in the last twenty years.

The experiences of participants, and the above studies, show that bladder management can be transient with people trying different methods at different stages of their lives. This is not always the case and an interesting report presented in 2004 documented the experience of a Japanese paraplegic lady who had successfully performed SIMC for more than twenty-seven years without complication or formal urological review (Mizuno et al., 2004). Participants



believed that SIMC could be more successful long term if there was ongoing support from health professionals and people with personal experience in performing SIMC.

The success of SIMC may be shaped by early experiences of the procedure and of interest in the findings were the circumstances and processes by which participants learnt to catheterise. Most were taught the procedure in hospital during the rehabilitation phase of their injury. Two participants had their injuries approximately twenty years ago and their journey to SIMC was more complex than others. They essentially taught themselves how to catheterise and look after the equipment. All participants received initial education and support through the learning process by nurses. In her study on patients' experiences of self-catheterisation Bradley claimed that her sample group highlighted the importance of the clinical expertise of the person teaching the technique. Her participants summed up the process as "give us the facts and support and let us get on with it" (2000, p.536).

Most of the literature pertaining to teaching SIMC is generally prescriptive and based on the writers clinical experiences of teaching catheterisation (Doherty, 1999; Barton, 2000; Robinson, 2007). Doherty (1999, p.78) states that the concept of SIMC is difficult to grasp but most people can become proficient with "understanding and sensitivity on behalf of the educator". Two of the participants in this study felt that the nursing staff teaching them SIMC did not have the necessary skills or time to adequately impart this knowledge. This caused participants to lose confidence in the teaching process because if the professionals do not know how to do it, how can they succeed. They believed that teaching of SIMC may be enhanced through the involvement of people who have had direct experience with SIMC, namely ex patients. This level of support from others who have been through the process may provide a level of empathy that nursing staff do not seem to have. This concept was supported by several of the participants who claimed that they learnt a lot of valuable information from fellow patients and through trial and error.

Most of the participants surveyed claimed that they received adequate information about SIMC before commencing the method but the level of support diminished after that. They believed that nurses were too busy to provide adequate support after initial education and most were left to fend for

themselves. This resulted in feelings of decreased confidence and frustration which were generally directed at the nursing staff. These findings are reflected in the study by McConville (2002) who claimed that seventy-eight percent of respondents in her study believed that they received adequate information before starting SIMC. After learning the technique forty-six percent stated that they did not receive ongoing support in relation to SIMC. Barton (2000) claims that SIMC requires the nurse to provide support to the patient throughout the teaching period and with ongoing follow up. Although this concept is valuable, that level of follow-up support was unavailable to most participants in this study. In almost all cases they were given the basic advice and left to work it out for themselves which produced feelings of frustration and anger. They felt alone and believed that they would have coped better with their introduction to the procedure if they could have accessed longer term support.

Participants believed that support from their families and relevant health professional was imperative to continued success with SIMC. Support from families and spouses allowed them to continue SIMC and maintain routines that prevent complications. Support and encouragement from health professionals provided reassurance that they were using the appropriate method. Without this support participants expressed decreased confidence in the process of SIMC and their health professional generally. Tzonichaki and Kleftaras (2002) surveyed thirty-eight people with spinal cord injury to determine their level of overall life satisfaction by assessing areas such as self-esteem and loneliness. They claimed that social support was an important factor related to loneliness and life satisfaction and compared subjects who were married with those who lived alone or with parents or room mates. They found that those who were married generally had higher self-esteem, lower incidence of loneliness and considerably greater life satisfaction. In this study five of the study participants were married or in long term relationships and three were single. Those in relationships acknowledged the support of their partners but there was no evidence to indicate significant differences between the two groups in their satisfaction with SIMC.

### Summary

Participants discussed their journey to SIMC and the challenges they faced along the way. They explored and contrasted the options available to them, particularly in the initial stages of their bladder management. These options

were minimal and not efficient when compared to SIMC. Participants assumed that they would need to perform SIMC for the rest of their lives although some were keen to try different methods if something new was discovered.

### **The Daily Grind (Theme Category Two)**

Participants in this study were found to develop a sequence of activities surrounding the process of catheterisation. This usually manifests in routines and regimes related to how often they perform SIMC, how long the process takes, and when and how much fluid should be consumed to allow for the most efficient management.

The concept of routine was a recurring theme in interviews, with participants talking about the importance of a routine that allowed SIMC to become a seamless part of their day. The concept of routine usually began in rehabilitation following their injury but most developed an appropriate routine after they were discharged home. During this transitional period participants talked about getting to know their bladder and experimenting with different timeframes to establish a routine that suited their lifestyle. One participant remembered this learning period as enormously frustrating because it was so difficult to balance out the need to catheterise with social, work, and family time. Participants developed routines for how they performed a catheter, how they cleaned the equipment, and how frequently they did this. Once a routine was established participants felt it was important to stick to it so that it became a normal part of life. They talked about their bladder care in terms of it being a habit and a way of life that became a normal occurrence rather than a trial that deviated from daily living. Current literature relating to the development of routines in bladder management could not be sourced but the significance that participants placed on this would indicate that future research may be beneficial in educating new patients about managing SIMC.

Relative to the establishment of an effective routine is the frequency in which participants performed SIMC. This varied significantly between individuals surveyed and ranged from every three hours to every six hours on an average day. The criteria that participants used to work out how often they performed SIMC depended on whether they had sensation but most had an accurate knowledge of how much was in their bladder and how long they could go between catheters. Polliack et al (2005) claim that the SIMC should be

performed at optimal bladder volume, that is, the maximum volume that does not cause distress or over-filling. They also say that without knowing how much is in the bladder, patients must perform SIMC at fixed hours to prevent complications. This is the method that most people with spinal cord injury without bladder sensation practice. When discussing the frequency with which they performed SIMC participants invariably raised the issue of compliance with medical or nursing directions. Even though they had managed their bladder with this method for long periods of time they still talked about frequency as six hourly being the "proper thing to do" or being "supposed to do it every four hours". Despite this belief that there was a proper frequency for SIMC, all eight participants had developed safe, regular routines and were able to articulate the aim of SIMC as needing to consistently empty the bladder rather than becoming obsessed with timeframes.

In their study of bladder emptying in spinal cord injury Hansen, Biering-Sorensen and Kristensen (2004) did not look specifically at SIMC frequency but did ask about catheter usage. The amount of catheters used per day should equate to frequency of SIMC per day and they had 81 responses to this question. Of these responses thirty-two percent used between one and four catheters daily (SIMC six hourly or less), thirty percent used five (five hourly), and thirty-eight percent used six to ten catheters per day (three to four hourly). These frequencies correlate with this researcher's study which found that participants performed SIMC three, four, five, or six hourly.

Frequency of SIMC is naturally linked to fluid intake and this was a topic that most participants raised during the interviews with the majority claiming to drink fairly low amounts. A general rule when starting SIMC is to maintain a fluid balance diary of input and output to establish how often the procedure is required (Doherty, 1999; Barton, 2000; Robinson, 2007). This will allow the person to develop an SIMC routine that suits their lifestyle and ensures safe bladder care. Participants talked about their introduction to SIMC and how they recorded fluid intake and monitored output. In most cases this practice quickly gave way to the individual's intuition and their daily routines. As participants became more aware of their paralysed bodies and their bladder management needs they were able to ensure that SIMC was performed in timeframes that suited their lifestyle whilst maintaining bladder safety.

Some of those surveyed actively dehydrated themselves if they were travelling or going out where it may be difficult to catheterise. The risks of inadequate fluid intake and subsequent dehydration are well documented and include electrolyte imbalances, infection, and increased incidence of renal calculi (Metheny, 2000; Hodgkinson, Evans, & Wood, 2003). Heard and Buhrer (2005) consider inadequate fluid intake equates to less than 1200 millilitres of urinary output per day. They claim that people are less likely to catheterise regularly with these small volumes and therefore, are more likely to have stagnant urine and increased infection risk. Several participants in this study claimed to drink volumes of one to one and a half litres of fluid daily and confessed to going for long periods during the day and night without drinking.

Shirreffs, Merson, Fraser, and Archer (2004) claim that there were few studies that actually looked at the subjective effects of fluid restriction in humans and so they conducted a study that included physical feelings in low fluid intake. They looked at fifteen subjects who were randomised to a fluid restricted or normal fluid intake group. Blood tests showed that the fluid restricted group had decreased plasma volume and increased serum osmolality and serum sodium during the trial. The fluid restricted group subjectively reported feelings of greater thirst, dry mouth, more headaches, and difficulty in concentrating as the trial progressed. Shirreffs et al (2004) conducted their study over a thirty-seven hour period, however many of the participants restrict their fluids over months and years with the long term effect of this never being studied.

Participants were unanimous in claiming that they did not want their lives ruled by fluid intake but all were acutely aware of how much they drank and the consequences on their lives if they deviated from their normal fluid routine. One stated that as soon as he had a couple of beers he found himself performing SIMC at least every hour while another said he would like to drink more alcohol socially but did not because of the need to catheterise. The researcher was unable to find any available literature that looked at the use of alcohol and SIMC in people with spinal cord injury. The effect of alcohol consumption on participant's social lives is further discussed in Theme Category Six but clearly they are conscious of the effect fluid volume has on their bladder management and the impact on their social life.



Participants talked about the length of time that each catheter took to perform and the impact that this time had on their day. On average each catheter took approximately five minutes although this time was increased when in a different environment or if there were complications such as infections or strictures. All participants had managed to streamline the process as much as possible and found that the quickest and easiest place to catheterise was their own home where they had everything set up and felt most comfortable. SIMC became more of an inconvenience when participants were in unfamiliar surroundings such as work or social settings. This was due to poor access to facilities, difficulty in reaching equipment, and longer to empty urine and clean equipment in different environments. Participants mentioned an element of embarrassment if they had to excuse themselves for what may seem an inordinate amount of time to other people with whom they socialise. Pentland, Harvey, Smith and Walker (1999) compared time use data between 312 men with spinal cord injury and 3617 able-bodied men in Canada. They found that the SCI group spent on average 3.7 hours per day on personal care compared with 2.3 hours per day for the able bodied men. Personal care was defined as time spent washing, dressing, toileting and personal medical care but there was no time breakdown of the activities within this group. The overall results are not unexpected given the complexity of the needs of the SCI group in activities of daily living and toilet regimes. Time taken to perform SIMC is potentially an issue for those who work or travel frequently and further research into this area may benefit people who want to plan outings or provide potential employers with downtime estimates.

### Summary

Participants developed a routine relating to practices surrounding SIMC which allowed them to take control of their bladder management on a daily basis. This routine incorporates how and where they perform SIMC and what steps they take in maintaining equipment. The frequency with which participants emptied their bladder varied between individuals but most were aware of the importance of reducing residual urine volumes to prevent infections. Participants were aware of the amount fluid they had consumed and considered this when catheters were due. All participants knew how long it took them to perform SIMC although this time varied depending on where they were and what type of access to facilities was available.



### **Striving for Cleanliness (Theme Category Three)**

Cleanliness and hygiene are important factors in successful, long-term bladder emptying using SIMC. Participants were found to have sound knowledge of the importance of maintaining clean environment and equipment for performing SIMC. They also talked about the consequences of not having a clean technique or equipment, namely urinary tract infection. They discussed the unclean and unpleasant consequence of urinary leakage and incontinence between catheters and the effect this has on their lives.

Most of the participants believed that the method was cleaner and more hygienic than alternatives that require the use of leg bags for urinary storage. Participants were aware of the need to ensure the process was as clean as possible and did this by washing hands before the procedure and limiting the amount of times they touched the catheter before use. They discussed the value of having a good technique to prevent urinary tract infections by limiting contamination of equipment. It was considered that there were different degrees of technique and these ranged from having an obsessively clean technique requiring good hand hygiene and sterile equipment, through to the haphazard approach of using any catheter at any time in any place. Participants also considered the cleanliness of the environment in which they performed SIMC. The cleanest, safest setting was generally the participants home where they had all their equipment set up and had absolute control over their environment.

At the other end of the scale were dirty environments and these included areas where there was no access to toilets or public facilities which were not clean or conducive to performing such an intimate procedure. One participant claimed that he never used public toilets because just to go inside them required him to push his wheelchair through other people's urine and germs. This was a concept that the researcher had never considered but raised a valid point, being that a manual wheelchair requires the user to push the wheels for propulsion and contamination from wheels to hands and whatever else is touched seems logical. It may be an interesting future research project to swab the wheels and hands of a wheelchair user to determine if this is a genuine source of potential infections.

The process of cleaning catheters and equipment was also a recurring theme in interviews with participants having various methods and opinions on how to

maintain clean equipment. For those who reused catheters proper cleaning is considered an important step in reducing unnecessary bacteria in the bladder (Heard & Buhrer, 2005). Several of the participants washed and reused single-use catheters to save on costs and decrease overall waste. Participants acknowledged the importance of cleaning catheters but generally considered it was tedious and the worst part of the catheter procedure. It was found that the time taken to perform SIMC increased significantly if the catheter had to be cleaned afterwards. For this reason many of the participants stockpiled their used catheters for a few days before cleaning them all at once. There are a number of different methods for cleaning catheters for reuse and these include soaking in various chemicals, washing with tap water and detergents, and boiling to sterilise (Barton, 2000; Moy & Amsters, 2004; Getliffe, Fader, Allen, Pinar, & Moore, 2007). Data from participants showed that most had used one or more of the above methods at some stage to clean their catheters and equipment. Opinion on whether to reuse or not varied with a two of the participants vowing to only use single-use catheters once because they believed the risk of infection was too great.

Kovindha, Na Chiang Mai, and Madersbacher (2004) conducted a comprehensive, cross-sectional study of 28 men with spinal cord injury who reused silicone catheters to perform SIMC. In this study the average frequency of SIMC was four times per day and the average time each catheter was used was thirty-five months. They found that the incidence of UTI was higher than comparative studies using disposable catheters but other complications such as urethral trauma and irritation were similar. The study concluded that the benefits of reusing catheters outweighed the slightly higher risk of infection and recommended that this risk may be lessened by not reusing the catheters for such a long period.

The data supported the belief among this study's participants that reusing catheters may increase infection risk but overall there is minimal difference. In the previously mentioned case report of a Japanese lady who performed SIMC for over twenty-seven years it was discovered that she reused the same twenty catheters she was given when originally discharged from hospital. She cleaned the catheters by washing in un-sterilised water and detergent and occasionally sterilised them by boiling in water (Mizuno et al., 2004).

Probably the most distressing issue that participants raised in interviews in this study was that of incontinence between catheters. Incontinence, or accidents as most participants referred to it as, was described as the worst part of SIMC and in most cases was due to low bladder capacity or urinary tract infection. These accidents were frustrating and embarrassing for the participants because they felt out of control with their bladder management. Most described a traumatic event where they had been incontinent in public or with other people. One described wetting all over the leather seats in his new car when someone else was with him. Another described the looks that he gets from others if he has an accident and how he has to get out of that environment as quickly as possible. All participants were able to express the triggers for incontinence and, as well as infection, two claimed that pressure from bending while working or getting in or out of a car caused leakage.

Incontinence overnight while participants were asleep was another common complaint and most had methods of managing night time leakage. Two used a urine bottle to place between their legs to catch any leakage while another had a protective sheet that he used under his normal bedding. One wore a pad twenty-four hours a day and another used a urodome drainage to remain dry overnight. The remaining three participants felt confident enough in their bladder regimes to wake and perform SIMC and remain continent overnight. Night time bladder management and sleep are further discussed in Theme Category Six.

Other methods for managing incontinence were generally referred to as safety measures to protect the participant from embarrassment in case of potential accidents. These included wearing pads when out socially or at times of high risk such as in a car or working. Participants described the use of pads at these times as acts of "vanity" or "humility" and used them to protect from embarrassment and maintain a sense of pride in their appearance and quality of life. Although incontinence was a traumatic event and there was always a degree of concern that it could happen at anytime, participants claimed that they were satisfied with their bladder management.

Brillhart (2004) studied life satisfaction in people with spinal cord injury undergoing urinary management. She found that, of the 230 respondents, forty-five had one accident per year, eighty-seven had one per month, nineteen had one per day, and fourteen had more than one accident each day (2004, p.125).

Regardless of how frequently this occurs, any incidence of urinary incontinence causes personal frustration and can be socially embarrassing (Fitzgerald, Palmer, Berry, & Hart, 2000; Powel, 2000). Paterson (2000) examined the stigma associated with urinary incontinence in men following prostate surgery. She conducted in-depth interviews on three men and then conducted thematic analysis of the data to get a rich description of their issues. These men wore pads and appliances to prevent exposure of incontinence in public and were selective of where they went. "Embarrassment" was commonly used to describe how they felt about their incontinence and fear of being caught out (2000, p.170). Her findings reflected the data from participants, many of whom wore pads and often went to some effort to prevent or hide episodes of incontinence.

### Summary

Participants recognised the value of performing a clean catheter, which is having clean equipment and environment, and having a good technique. Those who reused catheters had a number of different methods for cleaning their equipment but all seemed to be effective and limited infection. The most frustrating and embarrassing aspect of SIMC is bladder infection and incontinence between catheters.

### **Body Awareness in SIMC (Theme Category Four)**

People with spinal cord injury still have emotional needs, they want to look good, to feel good about themselves and to indulge and explore sexual desires. Some participants were quite private about their personal feelings relating to SIMC while others were open and honest about the process. Most were happy to disclose some of their thoughts and feelings related to their experience of body image and its impact on their lives.

Participants discussed the way they felt when they were first introduced to the concept of SIMC to manage their bladder. Their feelings ranged from horror and fear to begrudging acceptance of the procedure and their general disability. Most found the initial concept of SIMC to be daunting, shocking and "a bit of a drama". There was an emotional hurdle surrounding the idea of having to physically introduce a catheter into the bladder through the penis and three participants talked about coming to terms with this before proceeding to SIMC. One participant was "nearly fainting" the first couple of times he did his own catheters but all agreed that it was easier after they developed some

experience. These findings are supported by Doherty (1999, p.78) who writes that "... some patients are horrified at the thought of introducing a plastic tube into their bodies". Subjects in McConville's study of intermittent catheterisation experiences expressed similar initial feelings to surveyed participants including being "worried, shocked, annoyed, frightened and depressed" (2002, p.56). Barton (2000) claims that psychological adjustment to SIMC is not easy and may require ongoing support. None of the participants in this study received any psychological support through the process of learning SIMC or in any period afterwards, which may seem unfortunate given the initial stresses raised.

Participants varied in their disclosure of the intricacies of SIMC to family and friends because they wanted to maintain some degree of dignity or they were embarrassed about the need to actively empty their bladder. Most assumed that people outside their immediate family and close friends did not know what they had to do to empty their bladder and were generally hesitant to share this information. One participant took great pleasure in showing his close male friends what he had to do when performing SIMC, to "make them cringe", but was equally reserved when around people he did not know so well. Participants were openly selective about the people they disclosed the need to perform SIMC to. This may relate to their ability to hide this aspect of their disability, something that cannot be done when it comes to their paralysis and wheelchair. Joachim and Acorn (2000) reviewed qualitative literature relating to chronic illness and conditions and determined that there were visible and invisible conditions and there was a stigma attached to disclosing invisible conditions. If a person who performs SIMC decides to disclose the process to others they may be open to negative responses and subsequent embarrassment of the practice (Joachim & Acorn, 2000). Price (2001) claims that embarrassment is heightened when specific intimate areas of the body are involved, in this case the genitals and urinary continence. Participants talked about embarrassment in specific circumstances, for example, the amount of time they may be in the toilet. Three of those surveyed raised the concept of being embarrassed if they had to go to the toilet for a long period, sometimes up to half an hour just to do a catheter.

All of the participants believed that spinal cord injury had a profound effect on their physical appearance as they presented in a wheelchair and with varying degrees of movement and ability. Neurogenic bladder, bowel and sexual dysfunction are not outwardly apparent to most people but can have a dramatic



impact on the person in a wheelchair. Most of the participants worked hard to portray a positive body image and SIMC has been described as more socially acceptable than alternate, visibly obvious types of bladder management (Moy & Amsters, 2004). Participants discussed body image and SIMC mostly in the context of comparing it with these alternate bladder management methods, namely urodome drainage and leg bags. In this context SIMC allows for improved body image because they did not have anything "hanging off" their penis or a bag strapped to their leg. Participants who had tried this method found it frustrating, inconvenient, embarrassing, and generally creating a negative body image. Positive issues relating to SIMC included the ability to go to bed and sleep without anything attached to their body (for those who did not use safeguard devices mentioned in Theme Category Three) and the fact that their bodies looked "the way they should be". This was an interesting idea that was articulated by two participants who believed that, although they were paralysed, SIMC allowed them to look at their bodies as normal. Normal incorporated them being in a wheelchair but otherwise having a body that was essentially natural, not having tubes and other devices hanging off them.

The literature relating to body image and spinal cord injury looks broadly at issues around paralysis and being in a wheelchair rather than specific aspects such as bladder management. Taleporos and McCabe (2001) surveyed thirty-five people with physical disabilities on how their disability impacted on self body image. Most of those surveyed believed that their disability made them feel less physically attractive, less comfortable with their disability, and envious of people with 'normal' bodies (2001). In another study by the same authors they explored the relationship between type of physical disability and body esteem (Taleporos & McCabe, 2005). In this study they surveyed 748 people with physical disabilities (23 percent had spinal cord injuries) using questionnaires to assess their severity of disability and body and self esteem. They found that those with more severe disabilities had lower body esteem than those with minimal or no disability. These findings concur with data from participants, all of whom could be considered to have moderate to severe disability, who described feeling less confident when needing to perform SIMC in public. Although public exposure to SIMC decreased confidence, all participants felt that SIMC improved their overall self esteem and body image compared to other types of bladder management.



Increased confidence and self esteem allows people to socialise better and establish relationships with friends and significant partners. An important aspect in many relationships is the ability to have some level of sexual intimacy with a partner. Sexual function in men, as all participants of this study were, is significantly affected after spinal cord injury (Benevento & Sipski, 2002). Participants talked about the positives of SIMC, particularly the freedom it gave them when moving around in bed or engaging in sexual activities. Another participant mentioned accessibility as important in intimate relationships because there was no need to remove anything beforehand, it was "right there". Sexual partners were not discouraged by the need to perform SIMC with most being supportive of the method. One participant even claimed that he had a partner who enjoyed watching him perform SIMC. This was important because most participants were young to middle-aged men who were in relationships and expressed an ongoing interest in sex while those who were single expressed a desire to meet someone. These feelings were supported by a study of sexual functions in one hundred Indian patients following spinal cord injury (Sharma, Singh, Dogra, & Gupta, 2006). This study involved statistical analysis of questionnaire responses to 42 specific questions and found that ninety-three percent of males and sixty-five percent of females still had an active interest in sex following their injury.

### Summary

Participants experienced feelings of horror and shock when initially introduced to the idea of having to perform SIMC and none of them were provided with psychological support during the process. It took some time to come to terms with the procedure and become comfortable with it as a bladder management method. Those surveyed were selective about disclosure to others of their need to perform SIMC because they felt it may cause them embarrassment and increase their sense of disability. Participants felt that using SIMC as an alternative to methods such as urodome drainage enhanced their sex lives and sense of positive body image.

### **The Clinical and Practical Consequences of SIMC (Theme Category Five)**

One of the biggest bladder complications facing people with spinal cord injury who perform SIMC is risk of urinary tract infection (UTI). All those surveyed in this study claimed that they had suffered from UTI and subsequent leakage and believed that it was probably the worst aspect of SIMC. UTI's are usually caused

by the introduction and colonisation of bacteria in the lower urinary tract. Clinical diagnosis of UTI is generally defined as the presence of greater than 100,000 colony forming units (cfu) per one millilitre of urine (Heard & Buhrer, 2005). This level of colonisation would cause significant symptoms of dysuria in the able bodied, normal voiding population. In people with spinal cord injury these symptoms would rarely be appreciated due to lack of sensation. Heard and Buhrer (2005) claim that virtually all people with neurogenic bladder will demonstrate measurable levels of bacteruria.

In a comprehensive review of the literature relating to SIMC complications, Wyndzele (2002) found that the most frequent complication was infection of the urinary tract. In a retrospective study of 733 patients over a five year period, 56 were re-hospitalised for secondary complications (Paker et al., 2006). Of those readmitted, UTI was the fourth most common diagnosis making up 16.1 percent of the total. A review of service statistics by the Spinal Outreach Team from Queensland Spinal Cord Injury Service found that twenty-five percent of their referrals were for bladder management problems, mostly UTI (Moy & Amsters, 2004). These statistics reflect the lived experiences from participants in this study who claimed that urological issues were the most common reason for seeing their General Practitioner or being hospitalised. Participants claimed that they experienced a lot of UTI's when they first started performing SIMC but, once they established a routine and good technique, the number of infections dropped. With this drop in infection rates came a decrease in the use of antibiotics which two participants mentioned as being positive because regular antibiotic use caused gastrointestinal upsets and disruptions to bowel regimes. Participants were well aware of the symptoms and feelings they encountered when they suffered from a UTI and these ranged from leakage between catheters, fever and general malaise through to epididymo-orchitis and significant sepsis. Some of the descriptions associated with UTI included "feeling crappy", being "pissed off", and wanting to "hibernate" until the infection resolved.

It is widely accepted that the key factors in reducing risk of UTI are prevention of over distension of detrusor muscle, avoiding high post catheter residual volumes, and performing regular catheters (Moy & Amsters, 2004; Heard & Buhrer, 2005; Getliffe, Fader, Allen, Pinar, & Moore, 2007). To enable these factors to be adhered to it is often necessary to prescribe medications that allow

the neurogenic bladder to comply with storage and continence issues. The most commonly used medication for relaxing the bladder muscle among participants in this study was the anticholinergic, Oxybutynin. This medication acts to decrease spasm in detrusor smooth muscle and inhibits the muscarinic action of acetylcholine. Some of those surveyed were on relatively high doses of oxybutynin in order to maintain some degree of bladder control. Participants talked about the unpalatable side effects of oxybutynin, particularly dry mouth and constipation secondary to decreased gastric motility (MIMS, 2007). Oxybutynin is generally the first line medication for neurogenic bladder overactivity but if patients do not respond to it or suffer significant side effects, other options must be considered.

There are few alternatives to oxybutynin and most of these cause the same adverse reactions. A relatively new alternative that several participants mentioned as having actual or perceived benefits is Botox® (botulinum toxin A). Botox® is a derivative of the highly toxic bacterium *Clostridium botulinum* and causes localised paralysis or weakness of detrusor muscle when injected in small amounts (De Laet & Wyndaele, 2005; Klaphajone, Kitisomprayoonkul, & Sriplakit, 2005). This weakened bladder muscle allows for enhanced bladder volumes and thereby reduces overactivity and urinary incontinence. Although there have been good results using Botox® in this population, the procedure remains largely experimental and expensive. A Cochrane review of randomised and quasi-randomised trials looking at the efficacy of botulinum toxin in the treatment of neurogenic, overactive bladder found that there is an increasing body of literature relating to its use. This review concluded that there have been a small number of rigorous clinical trials conducted and its use shows promise, however, there is insufficient data to safely recommend it over other, proven treatments (Duthie, Wilson, Herbison, & Wilson, 2007).

Those participants who had tried Botox® injections claim it was effective but it did wear off, generally within six months of administration. A 2005 study of ten people who had Botox® injections for detrusor overactivity found that the positive effects were maintained for at least sixteen weeks but returned toward baseline by week thirty-six (Klaphajone, Kitisomprayoonkul, & Sriplakit, 2005). Studies looking at the long term effects of Botox® are minimal and the consequences of repeated dosing over a prolonged period are not known (Denys et al., 2006). Most of the participants were confident that Botox® would

be beneficial and eliminate the unpleasant side effects of oral anticholinergics. They were keen for the drug to be more widely available and affordable to patients with spinal cord injury in the absence of any other proven medications to relax the bladder muscle.

Bladder management methods are generally chosen by considering the level and degree of injury and, as discussed previously, to a lesser extent social and employment needs. Another issue that does have some bearing on management decisions is the financial cost of the method. Those participants who had received compensation for their injuries were required to pay for related disposables, including catheters and other continence equipment. Paying for a disposable catheter each time the procedure is performed can be expensive and most participants tried to clean and reuse them where appropriate. Heard and Buhner (2005) state that cost should not be the only consideration to intermittent catheterisation but conceded that cost differences vary significantly between treatment options. They calculated that the approximate monthly cost of reusing catheters was around US\$17.00 while using a new catheter each time would put the cost in excess of US\$200.00 per month. Robinson (2007, p.51) quotes the United Kingdom National Health System cost for single use catheters between £1.25 and £2.44 each. This would equate to a minimum £194.00 per month just for catheters in the UK. Participant 04 in this study claimed to spend a minimum AU\$170.00 per month on disposable catheters without taking into account costs of lubricant and other items. Cost was considered to be one of the major factors for those participants who reused catheters. One participant believed that information related to cost was not well presented because he had been paying for catheters for two years before a nurse informed him that he could access them through the hospital for free. Catheter cost is not the only aspect of participants' continence budget because most also used this money to purchase lubricant, anaesthetic gel, pads, and hand wipes.

### Summary

Infections of the urinary tract were considered the most common and distressing complication of SIMC. All participants had experienced UTI's and were aware of the causes, signs and symptoms of infection. Medications used to assist in SIMC are aimed at relaxing the bladder muscle and oral medications, although quite effective, can have unpalatable side effects. Some participants had used Botox® injections to get the same effect on the bladder and claimed this was

beneficial while others expressed a desire to try this procedure in the future. The cost of SIMC was an issue for some participants and most cleaned and reused catheters to reduce the cost associated in purchasing equipment.

### **Lifestyle Factors in SIMC (Theme Category Six)**

Although SIMC is recommended because of its proven clinical efficiency, the decision to initiate or to persist with the method can be affected by several lifestyle factors. Successful SIMC is based on a routine that encompasses all areas of a person's life. Participants highlighted a number of areas where the method impacted in a positive or negative way on their daily lives.

A common theme in several interviews was the issue of access to wheelchair suitable toilets. Participants were generally well setup in their own homes but claimed there was a lack of accessible disabled toilets in the community. Even in instances where there were disabled toilets, some participants had difficulty getting their wheelchairs close enough to the toilet bowl to perform SIMC. In some cases the toilets were too small while one participant had a particularly large electric wheel chair which he claimed could not be turned in most toilets. To overcome this problem he had to use parenting rooms in shopping centres because they had more room to manoeuvre his chair around. This lack of accessible toilets caused feelings of frustration and anger and placed unnecessary stress on what would normally be an enjoyable social outing. Equity in access to services for all community members has been a point of contention for disability support groups for many years. Despite local and federal legislation requiring wheelchair accessible buildings and facilities, most participants were able to recount stories of regular access problems. Another area of access stress that participants raised was when visiting the houses of family and friends. Most houses are not set up to cope with wheelchairs in the bathrooms and participants had a number of strategies for overcoming this problem. One claimed that he just did not go to other peoples houses because it was too difficult but acknowledged that his family condemned him for not mixing with people. Another participant stated that if one wanted to go out badly enough there was always a way to get around problems and you could generally find somewhere quiet and private to perform a catheter. This creativity was common with participants claiming to catheterise out the back of service stations, in a friends laundry, and in a car when there were no designated toilets around.



A study in the American city of Boston looked at how three people with disabilities, one visually impaired, one mobility impaired person not in a wheelchair, one paraplegic in a manual wheelchair, and one non-impaired control, could access thirty public buildings (Thapar et al., 2004). The subjects were given tasks that reflected the nature of a normal visit to identified premises, for example, using public telephones, drinking fountains, and restrooms. The wheelchair user had the lowest task performance with a score of 81 percent compared to the others (97 percent for visually impaired, 98 percent for mobility impaired, and 100 percent for the non-impaired control) (2004, p.285). The results of this study support the data from participants who recounted similar problems with access when out in the city.

The problem of access was an inconvenience and caused feelings of frustration in some of the participants. The need to contact restaurants and accommodation providers to see if they had accessible toilets before booking was stressful as they were often unable to provide accurate information. An Australian study by Furlong and Connor (2007) surveyed 119 wheelchair users to determine levels of disability related stress in daily encounters. They applied a tested Physical Disability Stress Scale (PDSS) to respondents that contained twenty-two situations that would normally be considered stressful to people with physical disabilities. Lack of access relating to travel, social activities and community accounted for the greatest levels of stress in respondents. The results concur with information from participants of this study that claimed access to these areas, and to toilets within these areas, caused high levels of stress and frustration in the community.

In another Boston study (Meyers, Anderson, Miller, Shipp, & Hoenig, 2002) researchers looked at twenty-five wheelchair users and their experiences in reaching specific destinations and what barriers they encountered in this process. Respondents reported extensively on their progress and the most common successful destinations included banks, shops, restaurants, and professional offices. Destinations that were the most difficult to access included religious buildings, the homes and workplaces of friends and relatives, and automatic teller machines. The most common barriers to access were lack of, or unsuitable, ramps and high curbs. The findings of Meyers et al concur with participants in this study who claimed that the main access problem related to SIMC was the inability to get into toilets when away from home. The most



difficult places to access included toilets in restaurants, holiday accommodation and friend's houses. Due to these access problems two of those interviewed claimed that they no longer went out to dinner as frequently or go on holidays the way they did before they were injured.

Four out of the eight participants in this study worked, either in paid full time or part time employment or in a voluntary capacity. Of the remaining four, one was retired and the other three expressed an interest in employment in the future if they could find something that suited their needs. Jongbloed, Backman, Forwell, and Carpenter (2007, p.145) state that "employment plays a significant role in defining people's lives" and provides income and community identity. Those who worked discussed some of the difficulties they encountered with performing SIMC in the workplace, particularly finding an accessible toilet and having adequate privacy. One participant claimed that he had to wear pads to work and sit in a wet pad for several hours because his workplace at the time did not have accessible toilets or a suitably private area for him to perform SIMC. Another who was doing unpaid work said that he got so busy and distracted by his work that he actually forgot to perform SIMC for long periods during the day. Of the participants who did not work but were interested in gaining employment, their main concern was bladder complications, particularly UTI and incontinence. Brillhart (2004) surveyed 230 people to determine quality of life and life satisfaction among spinal cord injured people undergoing urinary management. She found that scores for Quality of Life Index (QLI) and Satisfaction With Life Scale (SWLS) were significantly higher for those whose bladder management allowed them to work or attend school. Almost half of the subjects performed SIMC or a combination of SIMC with external drainage to manage their bladder. It could be concluded that people who work and perform SIMC are happy with their quality of life. The four study participants who worked claimed to be satisfied with their work lives and none of them expressed a desire to stop working or change their jobs. Two worked for themselves while the other two said their employers were supportive of them taking time off during the day for bladder management.

Several of the participants travelled interstate and overseas for disabled sports or for holidays, while at least one was planning to travel overseas in the near future. For the person in a wheelchair air travel poses a number of logistical problems just to get on and off the plane without considering the need to get out

of the seat to access a toilet during the flight. Participants talked about the difficulties in accessing aircraft toilets and alternatives for managing their bladder on a flight. In a column on the perils of flying with a wheelchair, Levinson (2004, p.82) described airline travel as "...both an adventure and challenge". He recommended that any wheelchair user undertaking air travel should not take diuretics the day before the flight, restrict fluid intake on the day and avoid known diuretics such as caffeine. Although this article was purely an editorial based on personal experiences and without academic basis, Levinson's description accurately reflected the experiences of those surveyed. Participants who were regular flyers advocated monitoring diet and medications and reducing fluid intake, in some cases to the point of clinical dehydration, before any flight. One participant discussed how embarrassing an episode of incontinence could be on a plane and how helpless he felt, although he added that the risk could be minimised through good forward planning. Participants were divided on the issue of inserting a temporary indwelling catheter and leg bag for air travel. Two claimed that they could not get their head around the idea of doing this procedure while another was planning to insert an indwelling catheter on an upcoming overseas flight. The two who did not like indwelling catheters described how they were able to access the toilets of certain larger aircraft using an onboard wheelchair and claimed that they tried to get this type of plane when travelling on long flights. Tasiemski, Kennedy, and Gardner (2006) examined the continuity of recreation engagement in people with spinal cord injuries. In their survey of 985 people from the United Kingdom they found that twenty-four percent of those surveyed stopped travelling after a spinal cord injury. One of the participants in this study refused to travel because of perceived access and bladder problems on the flight and when he reached his destination. People with paraplegia were also more likely to continue travelling than those with tetraplegia. Of the three most frequent travellers among participants, one was paraplegic and two were tetraplegic. With increased independence and access for people with disabilities there is a place for further research and guidance that focuses on flying and access to onboard facilities to perform SIMC.

All participants in this study reported that SIMC had some effect on their social lives. This effect seemed to be greater in the younger participants who tended to go out to pubs and clubs more often. Two of them believed that a downside to SIMC is that they could not drink the volume of beer that they used to because it

meant that they had to catheterise more frequently, sometimes one to two times per hour. Planning to go out with friends involved making enquiries about accessible toilets and this was frustrating because it removed the spontaneity from going out for a few drinks. Even when out most of the participants claimed that the need to catheterise was always in the back of their minds and they had to be vigilant about catheter times. One participant described SIMC as “crippling” as far as going out socially was concerned while another felt that it made him feel less confident when out with friends. Two of those surveyed stated that they did not go to other people's houses because of access for SIMC but most claimed to visit family and friends as one of their most common social activities. It was believed that family and friends are more accepting of the need to catheterise than a social group in public. Carpenter, Forwell, Jongbloed, and Backman (2007) studied community participation in 357 people with spinal cord injury to determine social and physical activities, relationships and access issues. They found that the three most common social activities were visiting and going out with family or friends (71%), attending social gatherings and events (37%) and engaging in physical activities (36%). The most common social activities for participants in this study were visiting friends and families, going out to pubs and restaurants, shopping, and going to the movies.

Although most participants claimed that SIMC did not impact significantly on their choice of social activities, one stated that it was too difficult to go to events such as large outdoor concerts and another no longer went to his local shopping centre. The previously mentioned study by Tasiemski et al (2006) found that nearly twenty-one percent of their 985 subjects discontinued socialising with community contacts and almost twenty percent stopped going to concerts and cinemas after their injury. The same study found that the most common post-injury recreational activities were watching television and listening to music, so called passive forms of recreation. Many of the participants in this study who continued to socialise developed ways of managing their bladder when out. Usually this involved performing SIMC before leaving home and limiting the amount of time they were away from an accessible toilet. Most agreed that forward planning was the key to socialising with SIMC, and participants almost always rang restaurants and clubs to enquire about accessibility before attending a function.

Crucial to a positive level of function in the community is the need to get an appropriate amount of rest. The nature of spinal cord injury leads to increased risks of broken sleep due to the need to manage bladder and bowel problems and to reposition to avoid skin breakdown. Six out of the eight participants claimed to wake at least once overnight to perform SIMC while the remaining two slept for periods of eight to eleven hours. Biering-Sorensen & Biering-Sorensen (2001) conducted a comprehensive study of sleep disturbances by applying a modified Nordic Sleep Questionnaire (NSQ) to 408 spinal cord injured persons and comparing it with 339 normal people. The NSQ was modified for the SCI group to include questions about bladder emptying method, mobility, and frequency of spasms. Voiding dysfunction was problematic with almost eighteen percent of respondents claiming that urinary symptoms were their primary problem with sleep. They also found that the number of hours respondents slept was very similar, the mean for the SCI group just over seven hours and just under seven hours for the normal group. The previously mentioned study on time use following spinal cord injury (Pentland, Harvey, Smith, & Walker, 1999) showed that men with SCI slept on average 8.5 hours compared with 8 hours for the able bodied group. Most of the participants in this study did not provide exact hours of sleep but many of those who woke during the night felt that it did not impact significantly on their waking hours. There were a number of strategies used to lessen the effect of SIMC on sleep patterns including reducing fluid intake in the evening, staying up later to avoid waking as often, and setting an alarm clock to avoid sleeping through catheter times.

Another area where SIMC can improve lifestyle is by providing the person with control over their bladder emptying and the physical freedom to have a relatively normal bladder function. Participants generally felt that SIMC gave them more independence and control over when and where they emptied their bladder. This control, along with freedom, was discussed in the context of comparing SIMC with other methods, namely urodome drainage or permanent catheters. There was no available literature that related to the phenomenon of control in SIMC however, future investigation of this as a concept for maintenance of SIMC as a long term method would be valuable.

### Summary

Access to suitable toilet facilities was an ongoing issue for participants and extensive forward planning was required if they wanted to visit restaurants or

other people's houses. This often resulted in feelings of frustration and anger. Those who worked felt satisfied with their positions but most had encountered problems with suitable toilets in the workplace. Travel was a challenge for participants, particularly on long plane flights. Those who travelled frequently had established regimes for minimising the disruption of bladder management. SIMC had an effect on the social lives of participants and this generally was related to an inability to drink lots of fluid and the need to leave a gathering for periods of time to perform a catheter. Most participants needed to wake up overnight to perform SIMC but this did not have any long term effects on their daily lives and they claimed to get adequate amounts of sleep. SIMC afforded participants a level of freedom and control that other bladder management methods could not provide.

### Conclusion

A review of the literature relating to the findings showed that data from the interviews reflected existing research in some areas such as frequency of SIMC, cleaning of catheters and incidence of UTI's. In other areas there were issues raised by participants that were unsupported by current, available literature. Some of these experiences contribute to the current body of knowledge in this area whilst others raise previously unreported issues. Chapter six will describe the new knowledge that arose from this study and will detail recommendations for further research or changes to practice.



## CHAPTER 6

This chapter will consider the limitations of the study and the effect that they may have on disseminating the results. It will also document the new knowledge that was obtained from interviews and make recommendations for further research and changes in practice.

### Limitations

The limitations of this study were minimal with the most significant being the perception of a small sample size. The sample size was sufficient to address the question and there was evidence of data saturation among the group. Concerns about the sample size include that the number may have excluded some of the target population, in this case there were no females surveyed. It is a recommendation that a similar study be conducted to elicit the experiences of females. It is also possible that the Snowball sampling method may have generated a cohort of socially and culturally similar participants although, anecdotally, this did not appear to be the case in the surveyed group.

Another limitation to this study was the depth of emotional experience that was described. Participants expressed emotions such as frustration, stress, embarrassment and decreased confidence as responses to various aspects of the SIMC process. To remain true to the ideal of describing the essence of an experience one could assume that a deeper description of how these emotions affect the experience would be sought. Participants were able to accurately describe the above emotions and when they were experienced but none of them were able or willing to expand on how these emotions made them feel or their effect on the experience of SIMC. It will be recommended that further research be conducted on how these emotions affect the lived experience of SIMC.

The descriptive nature of the study also means that the results cannot be generalised to the greater community. This is not necessarily a limitation as the purpose of a phenomenological study is to describe the essence of an individual's experience. It is therefore not meant to be data that is generalised but rather information that forms a basis for the evolution of further study. For this reason it is recommended that a similar, qualitative study be conducted with a larger sample to allow for generalisation.



It should also be noted that SIMC rates, teaching methods, and follow-up can vary between states and countries and so the results may have less relevance in regions outside of Western Australia.

Apart from these there were no other limitations identified by the researcher or associated ethics and supervision staff.

### New Knowledge

This study highlighted many issues that people with spinal cord injury face if they perform SIMC to empty their bladder. Chapter five discussed these issues and related them to appropriate, available literature. Chapter five also identified a number of concepts that have not been previously explored in the literature and may be considered beneficial or have relevance to other people in similar situations. There were nine distinct areas of new knowledge identified and this knowledge may be disseminated and expanded on to enhance current ideas and to provide future spinal cord injured patients with a more comprehensive education and follow up. The new knowledge identified includes:

1. SIMC enables the development of routines surrounding the procedure:

Participants in this study developed routines surrounding the way that they prepared, performed, and cleaned up after a catheter. These routines shape the way that they plan and conduct their days activities and are aimed at ensuring the method of SIMC maximises their independence and provides the best outcome for their bladder health. Routines provide important structure by reminding people when a catheter is due and reducing short cuts in preparation and cleaning.

2. SIMC provides a person with control over bladder management:

SIMC provides the spinal cord injured person with a sense of control over their bladder care because they have the opportunity to choose when they perform a catheter. This control increases independence and allows them to empty their bladder at a suitable time and place which is something no other method can provide.

3. SIMC enhances normal body appreciation:

SIMC allows a person to view their own body as a natural entity and to maintain their bladder in a manner as close as possible to the way they believe it should be. It was established in this study that SIMC contributes to feeling normal because of the control over bladder emptying and the absence of a fixed catheter. This concept of altered normality improves body self esteem and increases confidence. It was particularly important in the context of developing and maintaining intimate and sexual relations with a partner.

4. Incontinence between SIMC causes frustration:

Participants in this study claimed that the worst part of performing SIMC is the problem of incontinence between catheters which is an ongoing dilemma for many people. Episodes of incontinence cause distress, frustration and decreased personal confidence. Often incontinence is due to bladder complications or infection and people go to great lengths to prevent or hide it from others. This problem is significant and often not openly discussed due to its socially embarrassing and unpleasant nature.

5. Problems with physical access to toilets and facilities:

Participants who perform SIMC have regular problems with physical access to toilets in public places such as restaurants, shopping centres, and other buildings. Often they are able to access buildings but cannot get into the toilet facilities within due to size or location. These access problems result in feelings of frustration and stress and can lead to people not going out in the manner they would do if access was not an issue.

6. SIMC causes embarrassment through increased time taken in the toilet:

Participants in this study were acutely aware of how long it takes them to perform SIMC to empty their bladder. Often this is prolonged due to unfamiliar environments and this can be embarrassing if they are with other people or in a social setting. It was established in this study that those who perform SIMC are more sensitive to the embarrassment of extended toilet time than the people they socialise or work with but it is still an area that causes concern.

7. SIMC has an effect on the way people socialise:

SIMC has an effect on a person's social life for a number of reasons including the inability to drink large volumes of alcohol due to increasing catheter frequency, the need to leave a party for extended periods to perform SIMC and the problem of access to many social settings. These problems combine to remove some of the spontaneity of a social outing and can discourage some people from attending social gatherings. It was determined that the need to perform SIMC was the biggest factor influencing decisions on how, where, and how frequently people socialise.

8. SIMC enforces limitations on air travel:

Participants who performed SIMC have difficulty travelling on planes due to self imposed restrictions and the logistics of accessing aircraft toilets. Some consider that the only condition they would travel in was if they inserted an indwelling catheter or urodome drainage for the duration of the flight. These problems can deter people from travelling or create stress for those who do travel due to the level of forward planning required.

9. The current method of education in SIMC leaves people feeling unsupported:

Participants claimed that when they were learning SIMC they felt unsupported, both initially, and in longer term follow up periods. Many feel that peer support from others who have been in the same situation would be beneficial and allow them to cope better with the process. None of the participants who perform SIMC received any psychological counselling to assist in overcoming the emotional hurdles involved in learning and living with this bladder management method.

Recommendations

The confirmation of existing knowledge and the generation of new knowledge provided a number of recommendations for further research or to improve current practices. There were thirteen recommendations to improve practice that developed from interviews conducted to determine the lived experience of self-intermittent catheterisation in people with spinal cord injury and these include:

1. Improved education for Nurses caring for people who perform SIMC:

Participants highlighted the knowledge deficits and inability of some of the nurses who cared for them during the process of learning SIMC. It is recommended that an education program be implemented in areas where SIMC is initiated or managed to improve this problem. Such a program could be delivered through lectures and interactive sessions that encourage nurses to learn and recognise the needs of clients who perform SIMC.

2. Replication of the study in a larger population:

Due to the qualitative nature of the study and relative sample size, the results of this study cannot be generalised to the greater population. It is recommended that the study be repeated with a larger sample to provide results that have relevance to all those who perform SIMC. This type of study would likely require a mixed method of qualitative and quantitative data to obtain results that could be generalised.

3. Replication of the study in a female population:

All participants were male as discussed in the sample and limitations sections of this paper. It is recommended that a similar study be conducted to survey the experiences of females who perform SIMC. This would ensure that the information gathered is not gender specific and may be disseminated to all people who perform SIMC. Such a study would ideally utilise a phenomenological method to achieve a similar level of documented experiences.

4. Further research into the development of routines:

This study identified the importance that participants placed on developing routines surrounding SIMC. There was no available literature looking at these routines but participants were able to articulate how they evolved and why it was valuable to work within their established routine. It is recommended that there be further research and documentation relating to how these routines develop and whether their efficiency can be quantified and translated to help others. This research may benefit people who are just beginning SIMC by providing a better understanding and sharing of the phenomenon of routines. This study would benefit from a quantitative methodology that surveyed a larger sample of people with spinal cord injury to determine what routines they implement to perform SIMC.

5. Further research into long term fluid restriction:

This study raised the concept of people with spinal cord injury who perform SIMC intentionally restricting their fluid intake to control the frequency of catheterisation. The available literature only considers acute dehydration and it is recommended that there be rigorous investigation into the physiological effect of long term fluid restriction on the person with spinal cord injury. Such research should consider bio-chemical analysis of electrolytes and the assessment of the effect fluid restriction has on the entire renal tract. It may be worth also considering the effect long term fluid restriction has on the specific complications of those with SCI, namely disruption to skin integrity and impaired wound healing. If this research considered a large enough sample, and was methodologically sound, it would provide clinicians and those with spinal injury with scientific evidence to promote as safe or warn of the risks of long term fluid restriction.

6. Further research into the emotional impact of SIMC:

Participants in this study described the emotional impact of SIMC with terms such as frustration, stress, embarrassment and decreased confidence but were unable to expand on the effect these emotions had on the lived experience of SIMC. It is recommended that further research be conducted into the expanded, enhanced emotional experience of SIMC on the lives of people with spinal cord injury. This research should utilise a qualitative method to allow for the documentation of a greater depth of emotion and contribute to the scant literature relating to the lived experience of bladder management in spinal injuries.

7. Establishment of guidelines for managing incontinence:

Incontinence between catheters was probably the most distressing complication of SIMC that participants identified in this study. It is recommended that effective guidelines be developed to provide people with direction in the specialised management of temporary incontinence related to short term complications such as urinary tract infections. The development of such guidelines would allow patients to have more confidence and control over incontinence between catheters and may allow them to recognise early warning signs to better manage this complication. These guidelines would need to be based on evidence that evolved from a

quantitative study that surveyed a larger sample of people who perform SIMC.

8. Establish support networks for people who perform SIMC:

This study identified the importance of support from family, health professionals, and other spinal cord injured people as an important factor in successful long-term SIMC. It is recommended that formal support networks be established to provide initial and ongoing support for people with spinal cord injury who perform SIMC. This support should include psychological counselling throughout the process of learning and becoming proficient with SIMC and a peer support program to give new patients the opportunity to meet and discuss SIMC with people who have gone through the same process and had similar experiences. The implementation of these recommendations should provide those who are new to SIMC with the necessary support to develop and enhance their skills. This type of support program should be based on reviews of current, relevant literature and may benefit from visiting and exploring similar programs that are in place, both nationally and internationally.

9. Establishment of a resource centre for information related to SIMC:

This study found that the participants' introduction to SIMC as a bladder management method was often indirect and they generally were not given sound information about what was expected of them or any alternative options that may be available. It is recommended that a resource centre be established to provide people who perform SIMC with information about SIMC and any alternatives that may be available to them. This information should be current and based on the best available evidence. The establishment of such a centre would allow for informed assessment of the benefits and risks associated with various options and increase the knowledge base of this group of patients.

10. Review of funding for continence products:

Several participants in this study referred to the financial cost of performing SIMC, particularly if they only use each catheter once as recommended by the manufacturer. It is recommended that a review be undertaken to look at funding and supply arrangements in Australian states and territories. The aim of such a review would be to identify deficits and benefits in subsidies



and to ensure that funding covers the cost of unlimited catheters for people who are not financially compensable. The implementation of this funding would allow patients who experience recurrent infection or other complications to use single-use catheters without the financial burden associated with it.

**11. Review of personal experiences of physical access to public facilities:**

This study highlighted the significant and ongoing issue of access to disabled toilets and facilities being a problem for people who need to perform SIMC when in public. It is recommended that a review be conducted of how people with spinal cord injury experience access problems when needing to perform SIMC. This type of forum would allow users to inform governments and policy makers about their access needs, particularly in areas such as door width, toilet height and size and manoeuvrability of electric wheelchairs. Such a review would benefit from a quantitative survey of wheelchair users who perform SIMC in all Australian states and territories.

**12. Further research into the impact of SIMC on employment:**

The biggest issue with employment for participants in this study was the lack of accessible toilets or suitable facilities to maintain good bladder health in the workplace. It is recommended that further research be conducted into the impact of SIMC on employment for people with spinal cord injuries. This research could quantitative provide data to improve employment options for people with spinal cord injury and to inform employers about the specialised needs of employees who perform SIMC.

**13. Research into the effect of SIMC and airline travel:**

Many of the participants in this study identified problems and concerns with air travel. Most of these issues related to in-flight access to toilets and the concern of potential incontinence during the flight. Due to a lack of available literature in this area it is recommended that research be conducted into the effect of air travel on people who have spinal cord injury and perform SIMC. Such research would allow people with spinal cord injury to share their travel stories and needs and for airlines to develop relevant travel guidelines. This may provide better experiences for those who already fly and could give those who are reluctant more confidence to try air travel.

This type of research would benefit from a qualitative methodology that documented the experiences of both wheelchair travellers and airline staff.

### Conclusion

This study has documented the lived experiences of eight men with spinal cord injury who perform SIMC to empty their bladder. These experiences were the result of data from in-depth interviews and analysis using Husserlian phenomenology and Colaizzi's method of data analysis. Pre-study literature reviews showed that this approach had not been used previously in the sample group. Therefore some of the findings equated to new knowledge and added to the current body of literature surrounding this procedure. Participants discussed a wide variety of issues relating to their bladder management and this information was allocated to theme clusters and discussed under six broad theme categories. Nine areas of new knowledge were identified and fourteen recommendations were made to improve practice or conduct further research. The findings of this study should be used to improve the teaching and learning process for new patients beginning SIMC and to support those who currently perform this procedure to continue.

## *APPENDIX A: PARTICIPANT INFORMATION LETTER.*

Dear Sir / Madam,

I am a nurse researcher from Edith Cowan University, Perth, WA who is conducting research into the experience of people with spinal cord injury who perform self-catheterisation to manage their bladder. As part of this research I am seeking volunteers who fit the above criteria to participate in interviews that will focus on self-catheterisation. The interviews will be a maximum of 1 hour in duration, be one on one and strictly private and confidential.

The interviews will be conducted at a location convenient for participants and will be audio-tape recorded. This research is being undertaken as part of the requirements of a Master of Nursing at ECU but no identifying personal details will be published or disclosed. I will be the only person who can link your name to interview data and all other information will be held in a locked, secure location.

Participation is voluntary and no financial incentive is offered. You are under no obligation to complete interviews and are not required to have an ongoing involvement with the study. Support is available for participants who may be upset by information raised in the interview process.

It is hoped that the data will provide for better education and follow up of people who perform self-catheterisation, as well as providing more efficient bladder care options for newly injured patients.

If you would like to participate in this exciting new research project please contact myself or principal supervisor, Mr John Drury as below, many thanks in advance for your participation.

Brendan Bakes



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If you have any concerns or complaints about the research project and wish to talk to an independent person you may contact:

Research Ethics Officer

Human Research Ethics Office

Edith Cowan University

100 Joondalup Drive,

Joondalup, WA 6027

Phone: (08) 6304 2170

Email: [research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au)

*APPENDIX B: CONSENT TO PARTICIPATE IN INTERVIEWS.*

I \_\_\_\_\_ give my consent to participate in interviews related to the study, **'The lived experience of self-intermittent catheterisation in people with spinal cord injuries'**. I acknowledge that the interviews will be taped, transcribed, and that the material will be used as part of the above research. I understand that the tapes will be wiped on completion of data analysis. I understand that only relevant information will be used and that my name or other identifying information will not be disclosed to any person outside of the author of this study and his supervisor. My name or other identifying information will be held securely in a separate location to the data generated from interviews.

I also understand that I have the right at any stage to withdraw my consent to participate, or refuse to answer any questions. I understand that there will be no financial penalty or gain to myself or others, or alteration to my ongoing medical management.

I have been provided with a copy of the information letter relating to this study and have been given the opportunity to discuss all aspects of this study before, during, and after the interview.

Participant \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

## *APPENDIX C: BRACKETING.*

Extract from personal notes: 3<sup>rd</sup> October 2006

Tomorrow is my first interview and I feel it is important to document and "bracket" my own feelings and beliefs about SIMC.

Firstly I understand that SIMC is scientifically the best way to manage the neurogenic bladder. However, I have formed an opinion that sometimes we push it on our patients too much. Maybe we could give them an easier way to manage their bladder while they get their head around the significance of a spinal cord injury.

I need to ensure that this attitude does not creep into my interview style, I need participants' experiences of SIMC without encouraging them to think about other methods of bladder management.

I should also be aware of the potential to direct the interview, either in a positive or negative way. I am trying to do this by having balancing questions eg: what is the best thing about SIMC? What is the worst thing about SIMC? If at all possible I will try to have minimal input into the interviews, encouraging participants to detail their experience.

Some of the participants will be known to me and this may influence their responses or desire to fully describe their experiences. I will ensure that they fully understand the confidentiality and ethics of the study and that they are aware of its detachment from my role as a spinal injury nurse.



## **APPENDIX D: QUESTION LIST.**

**Lead -**

- 1) "Tell me as fully as possible about your experience of performing self-intermittent catheterisation."
- 2) "What are the best aspects of self-intermittent catheterisation?"
- 3) "What are the worst aspects of self-intermittent catheterisation?"

**Prompt –**

- 4) "What were your first impressions of having to perform self-intermittent catheterisation?"
- 5) "What effect does self-intermittent catheterisation have on your work and social life?"
- 6) "Do you see self-intermittent catheterisation as a long or short term management option?"
- 7) "How do you see self-intermittent catheterisation as a bladder management option?"

## ***APPENDIX E: EXAMPLE OF POST INTERVIEW FIELD NOTES.***

Extract from personal notes: 4<sup>th</sup> October 2006

Interview went quite well I think. Participant welcomed me into his home. Music was playing in another room and his children were also playing in the house, neither of these seemed to be a distraction for myself or participant. He was relaxed and open about his experiences with several different types of bladder management techniques and how he manages SIMC

He talked about the initial problems he had in developing a routine for SIMC's. He was comfortable and open about the effect catheters have on his relationships, both intimately with his wife and with children and others.

Talked about the effects of leakage between catheters and how this affects him personally.

Participant is happy for follow-up of initial interview.

Total interview time: 48 minutes.

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