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Understanding the Lived Experiences of Women with Spinal Cord Injury who Undergo Urinary Diversion Surgery

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

Following spinal cord injury (SCI), bladder management is of primary importance. As an activity of daily living (ADL), it affects community integration and quality of life (QOL). Women with SCI have neurogenic bladders that require self-catheterization, but they are unable to catheterize the native urethra, thus making bladder management physically and emotionally challenging. The purpose of this study was to understand the experiences of women with SCI who undergo urinary diversion surgery for bladder management. Qualitative data were collected using semistructured interviews from 10 women with SCI after urinary diversion surgery for bladder management. Qualitative Nvivo analysis of interview data was based on cognitive adaptation theory, which emphasizes adaptation to life-threatening events. Analysis showed improved quality of life among these 10 women, with improvements in independence, convenience, aesthetics, confidence, and sexuality. The women's lived experiences also showed enhanced privacy, dignity, normalcy, and safety. The lack of awareness in health care workers to offer this procedure was universally highlighted by participants. The social change implications include the need to advocate for women with SCI with bladder management needs who are unaware of this surgery option. Understanding the bladder management needs of women with SCI may help this population make choices for a better quality of life.

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Dedication

I dedicate this dissertation to my husband Dr. Manjit Dhillon, MD. The constant support, encouragement, guidance, and patience that I received from him provided me with the motivation, strength and opportunity to complete this endeavor. I appreciate him for providing finances, trusting me, and allowing me the time that it took to pursue my degree.

I miss my father Dr. Jaswant S Dhaliwal, PhD and my father in law Dr. Atma S Dhillon, PhD, to share my happiness of this achievement like them. They supported me from heaven and served as a guiding light.

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Chapter 1: Introduction to the Study

Background

In the United States, there are over 250,000 people living with a spinal cord injury (SCI)—about 20% of whom are women (NSCISC, 2013)—and approximately 12,000 individuals sustain this injury annually, raising concern about how they are managed (Pelletier-Cameron, 2012). With loss of motor and sensory function, and sometimes paralysis, a spinal cord injury causes a sudden and drastic change in a person's life (Pelletier-Cameron, 2012). There are two types of paralysis: (a) *paraplegia*, where the individual has use of upper limbs but lacks use of lower limbs and (2) *tetraplegia* or *quadriplegia,* where the individual has lost use of all four limbs. The most important health concerns for these individuals are the sexual, bowel, and bladder functions (Pelletier-Cameron, 2012).

Prior studies of urinary diversion surgery for the management of neurogenic bladder looked at different surgical approaches rather than the affected individual (Karsenty et al., 2008). What were lacking in current literature were the influence of this surgery on quality of life and the overall adjustment of women with SCI to bladder management. This study seeks to close the gap in the literature by examining the quality of life of women with SCI and urinary diversion by focusing on their lived experiences. Quality of life is affected: The individual either has to (a) accept the limitation of being unable to leave home for more than couple of hours because they need intermittent catheterization or (b) use an indwelling catheter that can lead to serious medical complications when used for a prolonged time. While the physical and emotional trauma of spinal cord injury is a common reason to lose hope in life (Lohne, 2009), hope of survival gets stronger over the years as victims better adapt to their new life situation (Lohne, 2009).

Historically, renal failure was the major cause of mortality in individuals with SCI, but in the recent past, several advances have been made in neurogenic bladder management (Akhavan et al., 2007). Currently, pneumonia, septicemia, and suicide are the most common cause of death, but the fact that renal failure is no longer the most common cause suggests that advances in bladder management have helped improve the quality of life for people with SCI .Compared to the general population, people with SCI have a higher risk of suicide; in fact, suicide is a frequent cause of death (Ahoniemi, Pohjolainen, & Kautiainen, 2011; Soden et al. 2000). In a study by Thietje et al. (2011), a high number study subjects had committed suicide within 10 years of the injury. This indicates that such injuries affect victims' psychological state and thus quality of life.

Akhavan et al. (2007) suggested that for improved quality of life for people with SCI, helping them regain voiding capabilities, urinary diversion procedures have been useful, including continent urinary diversion through an abdominal stoma, cutaneous urinary diversion, and orthotopic bladder replacement. However, these procedures are associated with several disadvantages, including voiding difficulties, formation of urinary calculi, consistent urine infections, and malignancy.

A neurogenic bladder can be atonic or hyper-reflexive, depending on the level of spinal cord injury (Pazooki et al., 2006). The main aim of proper bladder management is to maintain renal function and prevent lower and upper urinary tract infections, bladder calculi, renal calculi (Benevento & Sipski, 2002; Stein, Schroder, & Thuroff, 2012), and metabolic and electrolyte disturbances (Somani, MacLennan, & N'Dow, 2010). Factors that are considered when deciding on a bladder management regimen include the individual's ability to self-catheterize and to dress and change position, the level of SCI, and the type of voiding dysfunction (Benevento & Sipski, 2002).

Benevento and Sipski (2002) also stated that for individuals with functioning hands and the ability to self-catheterize, the standard bladder management protocol for a neurogenic bladder is referred to as "clean intermittent catheterization" (CIC). The CIC regimen can be performed only by individuals with trunk stability and a good hand grip. Those with tetraplegia are dependent on an assistant to help them catheterize. Other factors, such as urinary leakage between catheterizations, makes the CIC regimen less than ideal for some individuals with SCI.

Other common bladder management options for preserving renal function are indwelling, external sphincterotomy, urethral or suprapubic catheters, and urinary diversion (Akhavan et al., 2007). Akhavan et al. also suggested that even though these methods work, shortcomings limit their effectiveness. For example, indwelling catheters can lead to urethral injuries, urinary tract infections, malignancy, and calculi. External sphincterotomy has a 30% failure rate and a risk of upper urinary tract disease (Cite needed.). Other complications with this option include stenosis, nonfunctioning stoma, hemorrhage, and erectile dysfunction in men (Abdul-Rahman, Ismail, Hamid, & Shah, 2010). The diversion procedure may take many forms, such as conduit diversion, incontinent ileovesicostomy, and continent cutaneous urinary diversion (Gudziak et al., 1999). Urinary diversion procedures have been suggested for some individuals with SCI for whom the CIC regimen is not suitable for better quality of life (Pazooki et al., 2006).

Quality of Life (QoL) is an ever-changing, multidimensional construct. In clinical settings, QoL is assessed through the health-related quality of life (HRQoL) framework whose domains encompass symptoms, physical function, psychological and social well-being, mental functioning, satisfaction with care, role activities, and global judgment of health. QoL is significantly influenced by patients' physical health problems, such as bodily pain, and problems with emotional and social functioning. Moreover, the impact of these problems on QoL is amplified by the presence of a stoma, by body image issues, and by the practical problems that disrupt patients' everyday lives (Somani et al., 2010). Gillenwater (2001) argued that 95% of patients who undergo urinary diversion enjoy excellent QoL, regardless of the type of operation performed; that 51% of the patients are satisfied with their body image, and that 70% experience no limitations on their activities. Yet 15% describe challenges with recreational activities, 24% experience problems with athletic activities, and sexual dissatisfaction is a major concern area. According to Gillenwater, QoL issues cannot be over-emphasized, because understanding such issues helps physicians to better advise patients and to adopt modalities that are best suited to address patients' concerns.

In summary, to improve QoL following SCI, it is important that researchers, health care providers, and mental health professionals who work with these individuals understand the factors that shape their neurogenic bladder experience. A qualitative approach is ideal for developing this in-depth understanding.

Problem Statement

Bladder function and continence are issues of central importance to people with spinal cord injury, their families, and community support groups (Elliott & Boone, 2000). People with SCI may lose urinary bladder function and require clean intermittent self-catheterization (CISC) as the standard bladder emptying regimen (Pazooki et al., 2006; Karsenty et al., 2008; Ramm & Kane, 2011). The choice of long-term indwelling catheters may lead to serious complications, such as urinary infections, bladder stones, deterioration of urethral upper urinary tract, and even pressure ulcers leading to frequent and long periods of hospitalizations (Cameron, 2011). Women who have lost bladder control, but who retain upper body control, may be trained for CISC (Ramm & Kane, 2011). Women with tetraplegia who use a wheelchair with limited upper body control are unable to self-catheterize through the native urethra because they can't reach it (Karsenty et al., 2008). They are dependent on a caretaker to transfer them to a flat surface and perform intermittent catheterization. These women may be eligible for a urinary diversion surgery, which connects the bladder through a stoma to the abdomen (Karsenty et al., 2008). They can then self-catheterize through the abdominal stoma while sitting in a chair, thus enhancing their QoL significantly (Pazooki et al., 2006).

The somatic innervation of the lower urinary tract, peripheral parasympathetic, and sympathetic system collectively control bladder storage and emptying (de Groat, 1995). The somatic innervation that is modulated by central nervous system loses control after SCI. Jamison (2011) attempted to conduct a literature review on the best practices regarding effectiveness of bladder management with intermittent catheterization—but there is not much empirical evidence available to suggest any specific practice guidelines. There is a lack of clarity regarding the specific aspects of neurogenic bladder dysfunction that are most troubling to persons with SCI. A review of the literature indicates that there are many independent aspects of neurogenic bladder dysfunction that could impact and determine the experience of bladder management of individuals following SCI. This includes fear of incontinence, loss of dignity, frequency of intermittent catheterization, caregiver burden, reliance on others, and secondary medical complications e.g., urinary tract infection, bladder infection, and scarring of the urethra.

Unfortunately, women with SCI who have quadriplegia are not offered the urinary diversion surgery assuming that they cannot self-catheterize due to their limited hand function. According to Karsenty et al. (2008), urologists have operated on some individuals with quadriplegia after getting an assessment of ability and motivation to self-catheterize by the occupational therapists. The individuals reported satisfaction, improved QoL, and independence after the urinary diversion surgery, but no specific QoL assessment tools were used for (QoL) evaluation (Karsenty et al., 2008). The surgery provides upper urinary tract protection and continence (Karsenty et al., 2008). Women who have no hand function can also benefit from this surgery as a caregiver can catheterize for them conveniently, anywhere, without having to transfer and undress them. Women who are paraplegic can benefit from this surgery too because it helps them to have fewer accidents, maintain hygiene, and avoid urethral scarring from repeated self-catheterization while maintaining their dignity, independence, and self-esteem. There is sparse information in the literature to support the benefits of this surgery including its impact on adjustment and QoL.

Previous studies have focused on QoL after the renal diversion post-operation period. Merenda et al. (2007) examined the QoL among children with SCI, while Philip et al. (2009) compared the impact of orthotopic neobladder versus ileal conduit urinary diversion after Cystectomy on QoL. Ku et al. (2006), through a review of the literature, explored the influence of management of neurogenic bladder on QoL in SCI. A-study by Gacci et al. (2013) focused on QoL among women undergoing urinary diversion due to bladder cancer. Another study by Hwang, Yi, Park, and Kwon (2012) focused on the lived experiences of women with SCI, in general. Hwang et al. provided the reason for not using only the women who had the urinary diversion, as there is limited material of studies focusing on women after urinary diversion. The women with SCI were seen to perceive their body image differently—some women held a positive body image while others held a negative body image with an effect on areas such as their sexuality and sexual outcomes. Women reported stigma, discrimination, and alienation as a result of their condition.

There is a paucity of studies focusing exclusively on QoL of women with SCI after urinary diversion surgery. Existing studies focus on bladder cancer patients, neurogenic bladder patients, and interstitial cystitis patients (Gillenwater, 2001). Despite the paucity of research, researchers agree that urinary diversion results in substantial limitations in health-related QoL among women (Gacci et al., 2013).This study is an effort to add to current knowledge by understanding the lived experiences of women with SCI who have undergone urinary diversion surgery.

Purpose Statement

The purpose of this study was to explore lived experiences of women with SCI with the neurogenic bladder management who have undergone the urinary diversion procedure and its influence on their QoL.

Research Question

This study was guided by the following question: What are the lived experiences of women with SCI who undergo urinary diversion surgery?

Theory

The study used cognitive adaptation theory (Taylor, 1983), which hypothesized that when any individual experiences a tragedy, they make efforts to adapt cognitively or regain the psychological ability to function. This theory suggests that the adjustment process after a threatening event involves three stages. The stages include (a) an understanding of meaning in the experience, (b) an effort to overcome and regain control in one’s life, and (c) an attempt to use self-enhancing appraisals to reinstate one’s self-esteem. Initially, the affected person seeks an understanding of the threatening event by finding out why it occurred and how it impacts on their life. Then the individual makes effort to overcome the event in order to gain control over their life and body. Lastly, the individual undergoes self-enhancement to gain a sense of self-worth and restore the self-esteem that had been lost due to the threatening experience. This theory has been applied in several fields to explain the adaptive nature of human beings to situations that are threatening and traumatic for example in the event of a tragic loss or the occurrence of a terminal illness (Taylor, 1983). Mona et al. (2000) used cognitive adaptation theory to explore sexuality after spinal cord injury. They studied the cognitive involvement in adaptation to sexual adjustment and self-esteem. The theory provided a framework to this research inquiry on how the urinary diversion surgery influences the QoL of women with SCI. The cognitive adaptation theory explains why in spite of the negative physical, psychological, and social impact resulting from the occurrence of SCI there is evidence that many individuals with SCI make adaptations to the extent that they experience growth in self, their way of living, and their view of other people. Research shows that persons with SCI report a lower QoL than the general population mainly due to impaired body functions such as the neurogenic bladder (Manns & Chad, 2001). QoL is a major issue for individuals with SCI. Several studies suggested factors that must be considered when determining the QoL—both social and health-related—that persons with SCI led before and after urinary diversion procedures (Manns & Chad, 2001).

Among the factors considered are physical well-being, the relationships formed and maintained, occupation and doing meaningful work, emotional well-being, and independence. Many studies show that individuals with SCI who underwent urinary diversion procedures reported greater satisfaction and higher QoL in that the individuals were now able to self-catheterize and the leakage problems were reduced (Pazooki et al., 2006). Pazooki et al also suggested that the individuals who had been recommended for urinary diversion due to the inability to use the CIC regimen to manage the neurogenic bladder expressed satisfaction with the outcomes of the urinary diversion procedures and reported less frequency of urinary tract infections and reduced use of medication.

Moreover, urinary diversion procedures are associated with various complications that can negatively impact a patient’s QoL (Hellenthal et al., 2009). The major aim of proposing urinary diversion procedures other than for an individual who cannot use CIC regimen, has been to avoid the irreversible complications associated with long-term indwelling catheters. However, the urinary diversion procedures also report complications such as perforations, leakages, wound infection, stomal dysfunction, and vesicovaginal fistula. Some of these complications are severe and require reoperations to correct or reverse the complication (Hellenthal et al., 2009).

Methodology

In terms of the research, there is much to commend to choose the qualitative approach. The qualitative studies may use a specific research design such as a case study, grounded theory, phenomenology, narrative, or ethnography (Caelli, Ray, & Mill, 2003). The focus of the current study is to understand the QoL issues for women who had urinary diversion surgery. This qualitative study has a holistic perspective that emphasizes subjective realities, social context, and social change. Phenomenological study is appropriate for answering the research question. To study the experiences of women who have had urinary diversion procedures and understand the ways in which their QoL has been affected, in-depth, semistructured interviews were conducted. NVivo 10 software was utilized for data management. Qualitative themes were identified using Colaizzi’s technique (1978).

Definitions

A *spinal cord injury* (SCI) is an acute traumatic injury to the spinal cord that leads to varying degrees of motor and/or sensory deficits and paralysis. Although an injury of the cauda equine (lower part of spinal cord) is included, the definition excludes isolated injuries to other nerve roots (National Spinal Cord Injury Statistical Center, 2013).

Complete injury is a loss of sensation and movement below the level of injury resulting in paralysis (Waters, Adkins, & Yakura, 1991).

Incomplete injury occurs when there is some voluntary movement or sensation below the level of injury that may improve with time (Raineteau & Schwab, 2001).

Incontinence is an inability to control bladder or bowel (Hunskaar, Lose, Sykes, & Voss, 2004).

Indwelling catheter is a flexible tube that is connected to a bag for continuous drainage of urine from the urinary bladder (Jamison, Maguire, & McCann, 2011).

The *clean intermittent catheterization (CIC)* occurs when the urinary bladder is emptied on a regular schedule using a catheter. It is the standard bladder management protocol that is utilized and recommended for individuals with neurogenic bladder, who can perform self- catheterization instead of a long-term indwelling catheter (Karsenty et al., 2008).

Neurogenic bladder is a complication resulting from the spinal cord injury where the individual loses bladder control develops either atonic or a hyper-reflexive bladder depending on the level of injury (Pazooki et al., 2006).

Paraplegia is a loss of function or paralysis of legs due to an injury to the spinal cord below the neck area such as in the thoracic, lumbar, or sacral spine (Huston et al., 2011).

Autonomic dysreflexia is a complication as a result of injury in the spinal cord above the 6th thoracic vertebra involving sweating, high blood pressure, headache, and chills, when the bowel is impacted or bladder is overfilled (Krassioukov, Furlan, & Fehlings, 2003).

Quadriplegia is loss of function or paralysis of all four extremities due to a disease or an injury to a spinal cord injury (Monageng, 2007).

Residual urine is the urine remaining in the bladder after micturition (Yumru, Çakmak, Öndeş, & Ergez, 2012).

Suprapubic cystostomy is an opening created in the urinary bladder to drain urine with a suprapubic catheter (Feifer & Corcos, 2008).

Urinary Tract Infection (UTI) is an infection of the urinary tract that includes the kidney, ureters, urethra, and urinary bladder (Roberts, 2011).

Transfer is a process of shifting the paralyzed person from one place to another.

The *bladder diversion surgery* is the surgical procedure carried out to connect the bladder to abdominal stoma to ease self-catheterization in individuals with SCI (Akhavan et al., 2007).

Quality of life is an expansive concept, which covers a population's perception of their position in life in the framework of their value system, culture within which they exist relative to personal objectives, principles, apprehensions, and expectations. QoL is influenced by an individual’s physical and psychological health, independence levels, interpersonal relationships, personal beliefs, and relations with prominent environmental features (World Health Organization, 1997).

Health-related quality of life is a multidimensional concept that encompasses physical, mental, emotional, and social functions. The concept focuses not only on the direct health measures, including life expectancy and reasons for death, but also pays attention to the influence of health status on the populations’ QoL (Somani et al., 2010).

Assumptions

This study was conducted under the assumption that achieving bladder self-management is a desire of the individuals with SCI and if bladder self-management is achieved then the QoL lived by the individual with the injury is affected. The individuals with SCI may accept the limitations that their injury brings such as difficulty in self-catheterization and complications resulting from long-term indwelling catheters, thus make a choice for the urinary diversion surgeries, which is aimed at improvement of life. The individuals who go for the urinary diversion surgeries might have the desire to restore their independence and maintain their dignity thus raising the QoL after the injury. It was also assumed that individuals do not lose hope in life and hope to get better with time once the traumatic injury occurs (Lohne, 2009). This assumption was necessary to this research because it helped in understanding the inquiry to the women with SCI’s life situation. Given the conditions surrounding the bladder care experience for women with SCI, the assumption that these women desire to improve the QoL, restore independence and dignity is understandable. Urinary diversion surgery offers a chance to improve the women’s neurogenic bladder management.

Scope and Delimitations

This research addressed the experiences of women with SCI, including neurogenic bladder management through the urinary diversion procedures and their influence on QoL. The unique experiences of women have not been explored as widely as research on men. Researchers have emphasized the need to focus exclusively on women with SCI (Gillenwater, 2001). Women with SCI who have undergone urinary diversion procedures experience substantial reduction in health-related QoL (Gacci et al., 2013). Urinary diversion procedures as the regimen for neurogenic bladder management was chosen for this study because supporting research indicated its potential to affect the QoL of the individuals with SCI.

The study did not take into consideration the age differences in the participants, the level of injury (other than its effects on a neurogenic bladder), the cause of injury, and the time since the injury occurred. This research did not study the impact of these additional complications on QoL: medications, neurogenic bowel problems, pressure sores, sexual dysfunction, pain, and others (Liu et al., 2009).

This research has potential transferability in the clinical field where the urinary diversion surgery is useful such as people with cancer and people living with physical disabilities.

Limitations

This research was subject to several limitations related to the methodology. The study participants is women with SCI who have undergone urinary diversion surgery. A study sample was identified through criterion sampling technique. Snowball sampling was used as a recruitment method. The technique enabled the study participants' to be recommended for the study purposes by knowledgeable individuals such as professionals working with spinal cord injury population or other women with SCI. It is based on the fact that the process of snowball sampling starts with asking well-situated people to recommend other participants (Patton, 1990). The limitation of this snowball sampling is that it did not include women who are not actively involved with professionals who helped to recruit. However, the results from this study provided a basis for future in-depth research in this field.

Another limitation facing this type of research was the risk of both personal and professional bias. Bias in research can occur at any stage (Pannucci & Wilkins, 2010).It can be avoided by proper study designs and, in case of interviewer bias, by standardizing the interview process (Pannucci & Wilkins, 2010). To keep a detailed audit trail on how the research was conducted, I used a reflective, research journal, which, in turn, helped to eliminate any researcher bias by enhancing my ability to maintain a reflective stance (Tufford & Newman, 2012). Bracketing, with its foundations in phenomenology, was used (a) to shield the researcher against the collective effects of exploring emotionally challenging material and (b) to enable the researcher to achieve insightful thought process during the research process..

Significance

According to Jamison (2011), there is little empirical evidence available to suggest any guidelines bladder management with catheterization. There is a lack of clarity on the specific aspects of neurogenic bladder dysfunction that are most troubling to persons with SCI. Many aspects of neurogenic bladder dysfunction could impact QoL, including fear of incontinence, loss of dignity, frequency of urination, caregiver burden, reliance on others, and secondary medical complications (e.g., urinary tract infection), bladder infection, and scarring of the urethra. Therefore, this research sought to examine and understand the lived experiences of women who have undergone urinary diversion in the light of these fears and thus inform the development of better bladder management programs. In addition there is need to take a different approach to the study of the urinary diversion surgery that focuses on the affected individuals rather than on the surgery (Karsenty et al., 2008).

Bladder management is an issue of primary importance to persons following SCI. Following injury, neurogenic bladder dysfunction can be a significant barrier to reintegration into the community and negatively impact QoL (Elliott & Boone, 2000). The concerns about bladder incontinence can prevent persons from re-entering the workplace, resuming their studies, and engaging in recreational activities (Schmerzler, Goldstein, & Parkin, 2001). Women with SCI, in particular, are often not included as participants in scientific investigations since there are fewer women than men who incur traumatic SCI. Even when they are included in the research, their numbers may be too few to merit separate analysis and comparisons with men. The same can be said for research focusing on women with physical disabilities (Schmerzler et al., 2001). Women with SCI may or may not be a part of the study sample, and if they are, their numbers may be insufficient to make specific comparisons with other disability groups. Despite their lack of representation in rehabilitation studies, the needs of women are great especially in terms of bladder management after SCI.

Hammell (2010) suggested that people with SCI recognize bladder management as one of the priorities for future research. There is no study in the literature to suggest empirical evidence about the impact of the urinary diversion surgery on QoL evaluation in SCI women. Many women with SCI are not recommended for this surgery, and they struggle to manage their bladder over their lifetime. They experience urinary incontinence, are restricted to home, and remain dependent on others for transfers and catheterization every couple of hours. This study addressed this gap in the research and offered options for this population to be considered for a urinary diversion surgery. This study sought to close the gap in knowledge on psychological impact of urinary diversion surgery on women by capturing and describing the experiences of women with SCI who have undergone urinary diversion surgery and the influence of such procedures on their QoL. The findings give health care providers the opportunity to understand individuals' experiences, and through in-depth understanding to develop better bladder management programs.

Summary

Spinal cord injury causes drastic changes in an individual's life. In the United States, 20% of these individuals are women. The loss of urinary control and its subsequent complications are one of their major health concerns. The bladder management for women with SCI is more of a problem due to a difficult approach for catheterization. Thus, urinary diversion surgery is performed to make an access to the catheter easy by creating an abdominal stoma that connects to the urinary bladder. Some of the new advances and management of urinary control using urinary diversion surgery have improved individual's outcomes. Through in-depth interviews, this study explored the lived experience of 10 women who chose to undergo urinary diversion surgery and how it impacted their QoL overall.

Most of the research studies to date on this topic have been from the surgical perspective. The influence of urinary diversion surgeries on the day-to-day life of women with spinal cord injury has not been studied. This study used a qualitative approach, which was an ideal for coming to an in-depth understanding of women with SCI, to learn about their lived experiences. Urinary diversion surgery helps individuals with spinal cord injury have independence with bladder function during activities of daily living, and this improves their independence, self-esteem, and dignity.

In Chapter 2, I explore the research studies on women with SCI regarding their QoL, neurogenic bladder problems, and the management. In Chapter 3, I discuss the generic qualitative methodology that I used to collect and analyze the data for the current study. In Chapter 4, I discuss the results and in Chapter 5 I interpret the findings and note implications and recommendation or future research.

Chapter 2: Literature Review

Introduction

The purpose of this study was to explore the lived experiences of women with SCI who needed neurogenic bladder management; as a result, these women underwent urinary diversion surgery. This study sought to understand the influence of the surgery on QoL. The purpose of the chapter was to review the literature on SCI and urinary diversion surgery to gather knowledge about the previously conducted research studies on this topic.

Research Strategy

To locate the relevant literature, the following databases were used: EBSCOhost-Academic Search Complete, MEDLINE with Full Text, ProQuest Health & Medical Complete, and PubMed. The following keywords used in the searches: *SCI, neurogenic bladder, management, QoL, women, qualitative, augmentation cystoplasty, urinary incontinence, continent cutaneous urinary diversion, continent stoma*, and *incontinent ileovesicotomy.* I began by reviewing the abstracts and then moved to reviewing full papers where promising. Approximately 100 studies were reviewed, all of which were peer-reviewed. All qualitative studies on the use of catheters to manage neurogenic bladder using augmentation cystoplasty and urinary diversion in individuals with SCI were included. All studies on the impact on QoL after SCI, and QoL after urinary diversion procedures, were also considered. Most of the articles reviewed focused on the procedure rather than the patients' experiences. No study was found that treated women's experiences with bladder management after urinary diversion holistically and with reference to QoL.

The majority of the studies I found included male patients more often than female patients, given that spinal cord injuries are more frequent in more men. Thus, for inclusion in the review, all the articles on qualitative studies had to include at least two female participants. The studies included in the review had to focus on the urinary functions of patients after spinal cord injuries. Any study on bladder management in cancer or multiple sclerosis were excluded except for Taylor's article on cognitive adaptation theory (1983), which served as the theoretical foundation for the study.

The chapter is broken down into many subsections: a restatement of the problem, bladder management after SCI, major themes revealed in literature, strength and weaknesses of the previous studies, further studies, application of theory, conclusion and the chapter ends with summary.

Restatement of the Problem

Clean intermittent self-catheterization (CISC) is the standard bladder emptying regimen for those who have lost urinary bladder function (Castro-Diaz, n.d.). But there are complications associated with a long-term, in-dwelling catheter, including urinary infections, bladder stones, and the deterioration of urethral upper urinary tract. Individuals with tetraplegia or quadriplegia and confined to a wheelchair cannot self-catheterize due to reduced hand function (Castro-Diaz, n.d.). The CISC is especially difficult for women with SCI due to the position of the female urethral meatus, which requires undressing and moving into the supine position, thus limiting the patients' ability to self-catheterize (Akhavan et al., 2007). These women with SCI require assistance during catheterization, which means that their privacy and independence are compromised and their QoL and social functioning are dependent on others (Akhavan et al.).

These patients are therefore eligible for urinary diversion surgery to enable them to self-catheterize. The surgical construction of a stoma on the abdominal wall is one option for continent urinary diversion; several studies have reported successful outcomes (Akhavan et al., 2007). However, urinary diversion procedures can lead to complications that may reduce QoL of women with SCI. There is scant literature on the impacts of urinary diversion procedures on the QoL of women with SCI. The study sought to contribute to the literature by exploring the lived experiences of women with SCI who had undergone urinary diversion and thus determine its impact on QoL.

Bladder Management after Spinal Cord Injury

For a long time, renal failure was the primary cause of mortality in individuals with SCI but in the recent past several advances have been made in the neurogenic bladder management (Akhavan et al., 2007). Neurogenic bladder is one complication resulting from an atonic or a hyper-reflexive bladder that is dependent on the level of injury (Pazooki et al., 2006). The primary aim of carrying out bladder management is to maintain renal function and prevent lower and upper urinary tract infections such as bladder calculi and renal calculi (Benevento & Sipski, 2002; Stein, Schroder, & Thuroff, 2012). Factors that are considered when deciding bladder management regimen include the patient's ability to self-catheterize, the ability to dress and change position, the level of SCI, and the type of voiding dysfunction (Benevento & Sipski, 2002).

CIC is applied as the standard bladder management protocol for the two types of neurogenic bladder management where patients have hand function and can self-catheterize. The CIC regimen is self-performed only by patients with trunk stability and an active grip. The patients with tetraplegia are dependent on assistants to help them catheterize. Other factors such as urinary leakages between catheterizations make CIC regimen ideal for only some of the individuals with SCI.

Other standard options for preserving the renal functions in the event of SCI are indwelling catheters that are urethral or suprapubic catheters, urinary diversion, and external sphincterotomy (Akhavan et al., 2007). Though these methods work, there are shortcomings that limit their effectiveness. For example, indwelling catheters lead to urethral injuries, urinary tract infections, malignancy, and calculi. External sphincterotomy has a 30% failure rate, and the patient faces a risk of upper tract disease. The other complications associated with sphincterotomy include stenosis, technical failure, hemorrhage, and erectile dysfunction (Abdul-Rahman, Ismail, Hamid & Shah, 2010). Urinary diversion procedures have been suggested for some individuals with SCI whom the CIC regimen is not appropriate (Pazooki et al., 2006). The diversion may take many forms e.g. conduit diversion, incontinent ileovesicostomy, and continent cutaneous urinary diversion (Gudziak, Tiquert, Puri, Gheiler, & Triest, 1999).

Cognitive Adaptation Theory

The study uses the cognitive adaptation theory (Taylor, 1983) that was proposed in response to threatening events. There is evidence to support the claims that a traumatic experience such as a spinal cord injury disrupts social relationships, has negative psychological impact i.e. anxiety, depression, and distress, and disrupts the affected person’s well-being (Chun & Lee, 2010). The occurrence of SCI may impair the functioning of the bladder, bowel, respiratory, bone, and vascular physiology (Pelletier-Cameron, 2012). Depending on the level of injury in the spinal cord, body functions such as bladder control are affected thus requiring bladder management regimen such as CIC and urinary diversion. As the individuals with SCI grow old, they experience even greater challenges such as reduced strength and endurance, decline in functionality, and an increase in levels of dependency (Verhaagen & McDonald, 2012).

In spite of the negative physical, psychological, and social impact resulting from the SCI, many individuals with SCI make adaptations to the extent that they experience growth also referred to as post-traumatic growth, which comes from the human ability to change the perspectives towards others, their way of living, and self (Chun & Lee, 2010). It explains why people can move on after facing other traumatic experiences such as life-threatening illnesses like HIV/AIDS, cancer, and heart diseases.

Cognitive adaptation theory was developed to explain the effort by individuals to cognitively adapt to traumatic experiences and life-threatening situations. Taylor (1983) advanced this theory to explain how women handled a threatening life experience using cancer patients. The theory argues that when an individual is faced with a personal tragedy or a traumatic experience, he responds by putting cognitively adaptive efforts that aim at overcoming the threat and restoring the previous psychological functioning. The cognitive factors in an individual are essential in determining and understanding the adaptation process of patients to traumatic experiences like a spinal cord injury. The importance of the cognitive factor is further emphasized by its influence on the emotional and behavioral factors (Verhaagen & McDonald, 2012).

This theory involves three stages that are (a) understanding the meaning of the traumatic/life-threatening experience, (b) putting an effort to overcome the experience and regain control over the life of the affected person, and (c) the attempt by the affected persons to use self-enhancing appraisals to build back their self-esteem (Taylor, 1983). The theory relies on the assumption that the individual will go through the three stages and in the stated order. The human nature to overcome threatening situation leads to achievement of a high QoL characterized by satisfaction and happiness. Sometimes the patient achieves a higher QoL than what they had experienced before the threatening experience.

The rationale for choosing the cognitive adaptation theory. Spinal cord injury is a traumatic experience that can be life threatening. The changes that come with it are significant and life changing. Adapting to life after SCI is a dynamic and challenging process that presents both physical and psychological challenges to the individual with SCI (Verhaagen & McDonald, 2012). The adapting and coping strategies are categorized as behavioral, cognitive, or emotional, and they play a role in determining whether the individual with SCI will have positive or negative outcomes. Individuals with SCI report lower rates of well-being and QoL than people without disabilities. However, in the recent past, individuals with SCI were reporting better QoL with about 75% referring to their lives as either good or very good (Middleton, Tran, & Craig, 2007).

Stage 1. The first stage of the cognitive adaptation theory, which refers to understanding the meaning of the traumatic/life threatening experience, may take a positive or negative approach depending on how the affected person perceives the traumatic experience. The positive perception of the experience gives the affected person the ability to make an adjustment to the new life and face the challenges that come with the adjustment positively. Many people make maladjustments or poor adjustments to a traumatic experience as a result of cognitive distortions that result from maladaptive ways of viewing and understanding a traumatic experience (Verhaagen & McDonald, 2012).

Extremely negative perceptions escalate to negative emotions and outcomes. For example, persons with SCI may develop poor views of themselves and others. They develop a sense of vulnerability with expectation of rejection and failure as a consistent occurrence (Verhaagen & McDonald, 2012). The patients with a negative perception of the traumatic experience are said to make the experience into a catastrophe leading to high emotional distress, pain, and failure to achieve functionality (Raichle, Hanley, & Jensen, 2007). According to Taylor (1983) it is in this first theme that the patient tries to understand why the threatening experiences occurred and its impact so far. Many patients will look for causes to explain why the threat occurred to them, and they will search for meaning of the experience to their lives at that particular point.

Stage 2. To further understand the patient's adaptation to the traumatic experience, the second theme of the cognitive adaptation theory comes into play. The patient attempts to overcome the experience and regain control over his or her life. This theme corresponds to the idea of locus of control advanced by Rotter to explain the psychological adaptation in the individuals with SCI (Rotter, 1966). Locus of control refers to the beliefs held by an individual on their ability to direct life's outcomes. An individual has internal locus of control if he believes they can change the outcomes after the experience while an individual with locus of control that is external believes that they cannot control the direction their life takes after the experience (Verhaagen & McDonald, 2012). There is evidence supporting the influence of these cognitions (Raichle, Hanley & Jensen, 2007).

The occurrence of a threatening event, such as SCI, may undermine a patient's sense of control over her body and life (Taylor, 1983). The affected patient aims at mastering the threatening event to control its effects and the possibility of recurrence. Some patients felt that they had direct control over their cancer while others felt that they had no control as it lay with their doctor who would help them gain control. It is an example of the internal and external locus of control.

Stage 3. The experience of a traumatic event has an impact on how the individual regards themselves. Due to an SCI, a patient may end up paraplegic or quadriplegic. Normal body functions like bladder and bowel control are impaired, and the management of these functions using methods like catheterization is unfamiliar thus may cause embarrassment to the patient. It translates to reduced self-esteem and self-worth. The third theme comes in at this point in the patient's adjustment to the threatening experience by enhancing the self-worth and restoring the self-esteem lost (Taylor, 1983). One way that self-enhancement can be achieved is by social comparisons. The patient may look at other individuals who were faced with a similar situation and how these individuals overcame or the patients can compare their situations and find out that there are other patients worse off than they are. This comparison enables the patients to feel good about them thus raising their self-esteem.

Major Themes Revealed in Literature

Research explains the well-being and QoL of the individuals with SCI as using the following factors. First, the individual with SCI has a high level of perceived safety and health, which means that the health needs are met as they occur (Verhaagen & McDonald, 2012). The second factor is the formation and maintenance of strong social relationships with friends and family (Verhaagen & McDonald, 2012). Third, the individual with SCI has the opportunity and ability to do meaningful work. The individuals with SCI with the ability to participate in leisure activities have high QoL. Lastly, the individuals with SCI who can fulfill their spiritual and religious obligations record high QoL. In their investigation Manns and Chad (2001) identified nine themes that determined the QoL for people with SCI. These themes are physical well-being, employment, emotional well-being, spontaneity, stigma, physical function and independence, accessibility, finances, and social relationships. Of these nine themes physical well-being, independence, and physical function were found to have the greatest impact (

A study carried out by Seung-June et al. (2005) on 132 patients using CIC to manage neurogenic bladder to determine the health-related QoL concluded that the QoL was significantly lower than that of the normal population. A cross-sectional study by Seung-June, Shin, Paik, Yoo, & Ku (2006) on individuals with SCI using CIC for management of neurogenic behavior supported the conclusions derived from their earlier study. The study used 102 patients with SCI and 110 individuals as a control group. The results showed that 69.6% of the individuals with SCI were severely depressed, 23.5% had higher than moderate but lower than severe depression, 3.9% had mild depression, and 3% were normal. Women with SCI had higher depression rates and lower confidence levels in comparison to men with SCI in the study. The study also established that patients who were incapable of performing catheterization on their own had a higher risk of depression as compared to those who could perform self-catheterization. The researchers concluded that individuals with SCI using the CIC regimen had higher levels of depression than the general population. The reports that individuals with SCI using the CIC regimen to manage neurogenic bladder reported a lower QoL gives support to the use of urinary diversion procedures to enhance the QoL in individuals with SCI.

Research has often indicated that persons with SCI and bladder management problems often have lives that are of lower quality (Gacci et al., 2013: Liu, Attar, Gall, Shah, & Craggs, 2010; Kennedy & Rogers, 2000). Pazooki et al. (2006) carried out a retrospective study on 10 individuals with SCI with the aim of determining the impact of continent cutaneous urinary diversion on the QoL before and after the urinary diversion. The participants consisted of 5 males and 5 women and each underwent the urinary diversion with 6 of the patients getting a Kock reservoir that had two intussuscepted nipples, one patient with cutaneous double T-pouch, and three patients with a combination of both. The common cause of the SCI in the patients was trauma, and all the patients were confined to wheelchairs. A questionnaire was used to gather data from the patients that they completed during their regular annual visit to the outpatient ward. This method was appropriate for the study because the researchers were able to get the patients' view on reservoir function and the QoL before and after the diversion.

Another study by Akum (2005) examined the experiences of individuals with SCI who used an indwelling catheter to manage neurogenic bladder. The study utilized a purposive sample of six subjects between the age of 34 and 78 years, from Mbingo Baptist Hospital, who had an indwelling urinary catheter for a period of between 3 to 2 and a half years. Data collection was done through face-to-face interviews. The patients accepted the management method only because of the health condition they faced. Akum noted that adjusting to the indwelling catheter is a challenge because of pain associated with its use, the loss of dignity, financial constraints, and the hindrances it causes in the life of the patient. The participants admitted that they accepted to undergo the procedure because they experienced difficulty during self-catheterization and also had incontinence. After the urinary diversion, the patients reported a higher level of satisfaction and an improvement of the situation as compared to the preoperative period. The reservoirs were reported to work well and very well in some patients. The urinary diversion procedure was seen to influence the patients' ability to perform leisure activities and daily activities, and increase the working capacity.

Akhavan et al. (2007) studied five individuals with SCI who had undergone urinary diversion to determine the effectiveness of the questionnaire in identifying candidates for a continent urinary diversion. Four of the patients were female and one was male, and the median age of the participants was 19 years at the time of injury and 23 years at the time of the continent diversion. Of the five participants: two could self-catheterize taking 20–40 minutes, the other three could not self-catheterize before the procedure. After surgery, the four participants could self-catheterize in five minutes. Only one patient was unable to self-catheterize even after the creation of the catheterization stoma. All the patients reported reduced incidence of incontinence episodes and urinary tract infections (Akhavan et al., 2007). The women with SCI did not have to undress or change into the supine position in order to carry out self-catheterization. It was an indicator of improved QoL of the patient (Akhavan et al., 2007). The study, however, was limited due to the relatively small sample size and the conclusions made could not be conclusive.

A study conducted by Merenda et al. (2007) investigated the outcomes of urinary diversion using the Mitrofanoff procedure in individuals between the ages of 6 and 27 years. In this group, 13 of the 16 participants were female, and the remaining 3 were male. The Mitrofanoff procedure is a continent diversion technique that utilizes the appendix to create a continent urinary channel where the colonic end is used as a catheterizable stoma (Merenda et al., 2007). The data for this study were gathered from structured phone interviews and retrospective patients’ chart reviews. These methods played a significant role in helping the researcher to gain quantitative and qualitative data to answer their research questions. The findings indicated that bladder management for 84% of tetraplegia patients and 25% of paraplegia improved with patients identifying increased independence and freedom as indicators of a better QoL (Merenda et al., 2007). Karsenty et al. (2008) conducted a follow-up study on patients with urinary incontinence related to neurogenic bladder who underwent Mitrofanoff or Politano-Leadbetter anti-reflux and Young–Monti principle technique. The study adopted a descriptive technique and prospective follow-up study design and was conducted in University Hospital in Paris, France. A study sample of 13 patients was selected from a population of individuals with SCI suffering from urinary incontinence resulting from neurogenic detrusor overactivity and/or poor bladder emptying for over 1-year period and the incapability to self-catheterize through native urethra. The surgical procedures that had been carried out on the patients included open bladder neck or low maximum urethral pressure (MUP < 30 cm H_2O), and bladder neck aponeurotic sling affixed to Cooper's ligaments in female patients and supratrogonal cystectomy in male patients. The study findings indicated that during the preoperative period the patient could not self-catheterize through the native urethra. The postoperative phase had the patients reporting improved continence and self-catheterization. The researchers concluded that continent urinary diversion enhances independence and self-esteem, protects the upper urinary tract, and ultimately improves the QoL of the patient. The researchers proposed a multidisciplinary approach and collaboration between neuro-rehabilitation practitioners and urologists in order to meet patients' expectations and physician goals.

A study by Hellenthal et al. (2009) explored the complications and long-term outcomes of incontinent ileovesicostomy. The researchers reviewed the outcomes of 12 patients who underwent the procedure over a period of five and a half years. The study findings indicated that twelve patients expressed their satisfaction with the outcomes of the procedure given that they had exhausted all the other noninvasive therapies of bladder management without much improvement. After the urinary diversion procedure, they reported improved management of their neurogenic bladder. Management of urinary bladder, coupled with the reduced use of antibiotics and number of hospital admissions, can be considered as an improvement in the QoL of the patients. As a result of incontinent ileovesicotomy, the patients reduced their usage of antibiotics and the number of hospitalizations due to chronic urinary tract infections decreased. The researchers concluded that though incontinent ileovesicostomy is helpful to patients with lower urinary dysfunction who cannot perform clean intermittent catheterization, the procedure should be reserved for patients with completed less-invasive therapy and where the procedure is the only means of improving the patient’s QoL. Gauthier and Winters (2003) conducted a follow-up study with quadriplegia patients with neurogenic bladders to find out the outcomes of incontinent ileovesicotomy on those who underwent the diversion procedure to manage chronic catheter drainage problems and leakage. The study utilized seven patients of a mean age of 33.7 years composed of five males and two women. The study established no intraoperative complications. However, two patients experienced postoperative complications including fascial stenosis that required stoma revision, wound infection, and postoperative ileus. The patients expressed satisfaction with the outcomes of the procedure because better urinary drainage was achieved, leak-point pressure was lowered, and the upper urinary tract was preserved.

Research studies have indicated that long-term indwelling catheters including suprapubic and urethral catheters lead to serious complications. One such study by Chartier-Kastler et al. (2002) assessed the outcomes of cutaneous non-continent diversion for neurogenic bladder management. The study was conducted in Pitie-Salpetriere Hospital, Department of Urology and adopted a prospective monocentric follow-up design. The researchers reviewed the charts of 33 consecutive patients comprising of 19 women and 14 males operated on between 1997 and 1999. Among the patients 21 had SCI, four experienced multiple sclerosis, and three had different forms of myelitis, while five suffered central neurological diseases. The researchers noted that though the procedure resolved all the problems related to catheters and incontinence, 36% of the participants reported one or more pre-operative complications including uretero-ilea anastomosis leak, sepsis, ileus, and pyocystitis in patients who had not undergone cystectomy. Wilde and Carrigan (2003) emphasized that long-term urinary catheters amplify the risk of urinary tract infection (UTI), while catheter blockage disrupts patients’ daily activities. In a descriptive study aimed at establishing the urine flow factors that contribute to UTI among 24 patients with indwelling urinary catheters, Wilde and Carrigan identified problems including catheter blockage among 13 participants and urinary infections as problems associated with catheterization.

The problems resulting from catheterization have led to increased support for urinary diversion procedures. However, studies have indicated that urinary diversion procedures also have a number of complications that arise in the preoperative stage, during the operation, and after the operation. One such study by Merenda et al. (2007) on urinary diversion showed that the patients reported increased satisfaction and independence after undergoing the procedure. However, some of the patients studied reported a range of complications. The study adopted a descriptive, retrospective design, using 16 individuals with SCI between 6 to 27 years of age who had undergone a Mitrofanoff procedure. The study findings indicated that 25% of the subjects experienced stenosis, 75% experienced urethral incontinence, 19% experienced renal/bladder calculi, while 44% experienced a stomal leakage. Findings by Shpall and Ginsburg (2004) supported the argument that urinary diversion results in various complications. In their study, the researchers adopted retrospective interviews with 39 patients with lower urinary tract (LUT) dysfunction. The researchers established an overall complications rate of 31% including vesicourethral fistula among 15% of the patients with 4 of them requiring eventual transabdominal or transvaginal surgical correction. The researchers concluded that urinary diversion through the Mitrofanoff procedure greatly improved patient satisfaction and level of independence in bladder management and recommended frequent application of the procedure in children with SCI.

Another study by Pazooki et al. (2006) examined the functional results and impacts on QoL of continent cutaneous urinary diversion among individuals with SCI. The study was conducted using 10 participants. The researchers adopted a questionnaire to determine the patients’ opinions on reservoir function, QoL, and different activities. The study established that one patient died in the third year after the procedure after developing pulmonary embolism. Reoperations were also performed on two patients with one patient getting three reoperations due to perforations. Another complication was with the retained sensitivity of the natural urinary bladder that caused problems to the patient. It meant that some patients required catheterization and an occasional rinse to solve the natural urinary bladder problems. Though seven of the patients with SCI reported that they never had leakages, one patient had occasional leak, while another participant had continuous leaks but she stated that the situation was much better that the preoperative period. Pazooki et al. suggested an alternative to decrease perforation risk is to perform incontinent diversion or ileocystoplasty. The researchers recommended frequent use of cutaneous urostomy that improves patients' QoL.

Gudziak et al. (1999) affirmed a variation of these complications in a study aimed at reviewing the complications experienced by patients who had undergone incontinent ileovesicostomy. The study utilized preoperative data and surgical findings of 13 patients who had undergone the procedure between 1994 and 1998. Eight of the patients had SCI, four had multiple sclerosis, while one had tuberculous meningitis. The study established that one patient of the thirteen who underwent incontinent ileovesicotomy needed reoperation, another patient reported ureteral stone after two years, and another patient recorded recurrent urinary tract infections. The patients also reported leakages with an average leak point pressure of 8.2 cm H_2O at the stoma.

In a comprehensive review of literature on complications associated with urinary diversion, Hautmann, Hautmann, and Hautmann (2011) argued that in the long run complications are expected to occur in at least 60% of the patients with 40% among this requiring surgical intervention. The authors noted that the complications can occur even 20 years after the urinary diversion surgery, which makes it necessary to have a long-term follow-up. The authors cited various complications including functional complications such as renal function, metabolic consequences, ureteroenteric stenosis, voiding dysfunction, and oncologic complications. The authors noted that urinary diversion in segments of the bowel preserves the renal function. However, the risk of renal deterioration remains though it is asymptomatic, and it is necessary to monitor the patients closely and perform corrective measures at early stages.

A study by Walsh, Troxel, and Stone (2004) on the assessment of continent catheterizable stoma in individuals with SCI showed that the women developed a positive body image after the urinary diversion. The study included six female patients with tetraplegia (lesion at C7 or above) aged12–22 years. The researchers evaluated the time taken to complete catheterization in the presurgery and postsurgery period and a quality-of-life survey at a mean of 44 months to evaluate the participants' QoL. The study established that patients had increased independence for mobility and the time spent in catheterization is reduced because the stoma is at a position that is easily accessible to the patient. All patients reported increased satisfaction with the new procedure and possibility of recommending it to a friend.

Wilde (2003) explored the lived experiences of long-term users of urinary catheters through a hermeneutic phenomenology. The study established that the patients had to acknowledge that the catheter was a part of their being, coupled with feelings of alienation and vulnerability due to stigma. Hammell (2007) affirmed these problems through a meta-synthesis of qualitative research that sought to compare and synthesize the factors that influenced QoL after SCI. The study utilized seven published articles identified from Medline, CINAHL, and Sociological Abstracts databases. The main concepts identified during the study included body problems, occupation, self-worth, self-continuity, environmental context, responsibility for and control of one's life, and deterioration of relationships. Importantly, Hammell noted that patients who had urinary management problems reported feeling embarrassed if the catheters made noises in the presence of other people. They also indicated that sometimes they faced stigma and alienation due to their condition. One individual with SCI felt stigmatized, and as often she feels reminded that she is different. Hammell proposed further qualitative research in order to probe how SCI affects QoL among patients in order to establish rehabilitation services to address QoL among individuals with SCI.

Hwang, Yi, Park, and Kwon (2012) conducted a study on Korean women with SCI to gain understanding of their experiences. The phenomenological study adopted in-depth interviews and open-ended questions to explore the perspectives of 9 women with SCI. The researchers established five themes including frozen mind with rigid body, shame resulting from physical function restrictions and lack of independence, visible disabilities, obsession with the past, and struggles to revert to previous normal life functions. The women reported that they were alienated from the society to some extent. The women were especially ashamed of the disability due to the restrictions it imposed on the physical function leading to dependency. The women also have to struggle towards the life they had before their injury. These difficulties are then important in shaping the new meanings they attach to their new lives after SCI. The researchers recommended development of effectual nursing interventions for improving QoL among women with SCI.

After undergoing urinary diversion, many female patients have been known to undergo a change in perception of their body image. Bjerre, Johansen, and Steven (1997) carried out a study using a questionnaire to determine the impact of urinary diversion on the sexuality of female patients. Of the 33 female participants in the study, 30% felt that they were less sexually attractive as a result of the procedure in addition to the traumatic SCI that presents physical problems. The participants expressed the desire for sex counseling. A study by Person and Hellstrom (2002) established that ileovesicostomy surgery influences participants' daily life in various unexpected ways, with some participants highlighting severe difficulty in coming to terms with the surgery. The study, aimed to explore the experiences of Swedish men and women after 6 to 12 weeks of the post-operation period, utilized interviews in order to explore the participants' feelings, attitudes, and life experiences in the post-operation period. The study established important themes including alienation from the body, changes in body image, uncertainty, influences on sexual life, social life, sports and leisure activities, and physical problems. The participants reported that their level of sexual attractiveness had reduced. The women interviewees who had undergone surgery for the formation of a stoma reported that they felt different or abnormal. However, the partners of these patients did not share this view proving that the view was entirely based on the patient's perception of their body image. The researchers emphasized the need for deeper understanding of patients' experiences in order to enable health care staff to prepare and support patients to adapt to their new situation during the post-operative period.

Brown and Randle (2005) in a comprehensive review of the literature argued that having a continent stoma invoked feelings of embarrassment, hate disgust, devastation, repulsion, and non-acceptance. The researchers emphasized that stoma formation negatively affects a person's QoL on aspects such as body image, and creating the sexuality and sexual concerns. However, there are those patients who view urinary diversion procedures to aid them in leading a normal life. These patients do not possess negative feelings towards their body image but they showed acceptance, adaptation, and tolerance. The researchers emphasized the need for further research on the influence of stoma surgery on QoL. The researchers also called for adoption of large prospective studies designs to enhance understanding of the effects of stoma on individuals and employment of qualitative and quantitative designs in order to acquire an enriched understanding of individual's experiences and comparison of the experiences.

Hammell (2007) established that coping strategies are also an essential aspect of the lived experiences of people with SCI. Many find that an occupation or employment makes their adjustment to the new condition more tolerable. The occupation gives the patient something to anticipate, makes them feel useful, and gives them an avenue to participate in meaningful activities. Walsh et al. (2004) in their study emphasized that the occurrence of SCI brings in its wake shattered dreams, loss, and depression. Female patients may feel that their dreams of raising a family have been completely altered.

However, with time the persons with SCI are able to let go of the pain, hopelessness, and worthlessness to create a new life for themselves by developing a sense of self-worth.

The Strengths and Weaknesses of Previous Studies

The studies on the impact of SCI on patients, the bladder management for individuals with SCI, urinary diversion procedures for individuals with SCI, and the lived experiences of patients who have undergone the urinary diversion procedures have been reviewed in this literature review. The studies had several strengths as well as weaknesses.

The major strengths of the studies reviewed here are the appropriate choice of the methods applied. The studies seeking to evaluate the outcomes of the urinary diversion procedures used the information given on the history of the patient and that obtained from follow-ups to gain factual data as well as interviews and questionnaire to gather relevant data from patients. Examples of such studies are Bjerre et al. (1997), Seung-June et al. (2005), Liu, Attar, Gall, Shah, and Craggs (2010), Kennedy and Rogers (2000), and Pazooki et al. (2006). For the studies that sought to understand the perspective of the patients and their experience the researchers utilized a qualitative approach and employed such methods as interviews and questionnaires for data collection. Such studies include Persson and Hellstrom (2002), Ku (2006), Hwang et al. (2012), and Shpall and Ginsburg (2004).

However, some of the studies such as Gudziak et al. (1999) utilized preoperative data and surgical findings while Brown and Randle (2005) and Hautmann et al. (2011) adopted comprehensive reviews of literature, as opposed to gaining first-hand information from patients with SCI. This creates the possibility of bias resulting from the researchers' perception due to the nature of the interpretive data analysis.

Further Studies

Research has established that urinary diversion procedures have different outcomes and complications that significantly influence the patient's QoL in the post-operative period (Brown & Randle, 2005; Hammell, 2007; Hwang et al., 2012; Persson & Hellstrom, 2002; Walsh et al., 2004). However, most of the studies utilized both men and women as the study subjects with some such as Hwang et al. (2012) exclusively focusing on women subjects. Some of the studies reviewed in the literature adopted techniques through which they indicate the impacts of urinary diversion on the QoL among patients with SCI, but do not bring out the lived experiences of such subjects. This includes studies adopting comprehensive review of literature on the research design such as Brown and Randle (2005), Hautmann et al. (2011), and studies adopting preoperative data and surgical findings such as Gudziak et al (1999). Moreover, researchers including Hammell (2007) and Brown and Randle (2005) have called for further research on the impact of SCI on QoL. Brown and Randle (2005) specifically emphasized the need for qualitative studies for acquiring richer understanding of the experiences of patients who have undergone stomal surgeries. Persson and Hellstrom (2002) also accentuated the need for deeper understanding of patients' experiences in order to enable health care staff to prepare and support patients to adapt to their new situation during the post-operative period, while Hwang et al. (2012) called for development of effectual nursing interventions for improving QoL among women with SCI. Gillenwater (2001) accentuated the paucity of studies exclusively focusing on QoL issues experienced by women with SCI in the post-operative period of urinary diversion surgery. This creates the need to explore the experiences after urinary diversion procedure from the women's perspective to equip the clinicians with the knowledge to improve the care given to this specific group of patients.

Application of the Theory

The cognitive adaptation theory has been widely applied in studies on patients' adjustment to life-threatening diseases like cancer (Taylor, 1983), chronic illnesses like mental health diseases (Ratelle, Vallerand, Chantal, & Provencher, 2004), among others. Taylor (1983) concluded that the coping ability of patients with cancer depended largely on their ability to modify and sustain illusions that block the threats and possible setbacks in the future. The Ratelle et al. (2004) study shows that cognitive adaptation benefits mental health through motivational processes.

The theory has also been applied in other research on understanding the patients' experience with SCI where the patients attempt to regain control and life back. Mona et al. (2000) applied the cognitive adaptation theory in their study on sexuality after SCI. The study made the conclusion that the cognitive adaptation constructs would influence the sexual self-esteem leading to the adjustment in the sexual behavior of individuals with SCI. Babamohamadi, Negarandeh, and Dehghan-Nayeri (2011) used cognitive adaptation to study the coping strategies applied by persons with SCI. This study showed the three strategies used by patients to cope with SCI that are relying on religious beliefs for understanding why the condition occurred, striving towards independence, and how that the condition would get better. The conclusions made were that the nurses, healthcare professionals, and families of the affected patients needed to understand the coping strategies used by individuals with SCI so as to offer the best care (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011). This theory was utilized in the study to explain the influence of urinary diversion procedures on the self-esteem of women with SCI and dependent on CIC. Application of the theory will be described further in the methodology chapter.

Conclusions

The reviewed studies have indicated that urinary diversion procedures result in various complications that could negatively impact the patients' QoL in the post-operative period. The literature review affirms the paucity of studies exclusively focusing on the experiences of women with SCI, as most of the reviewed studies utilized both male and female subjects. Hammell (2010) explained that there are fewer women with SCI than men, and fewer women are recommended for urinary diversion procedures by urologists. Moreover, researchers such as Hammell (2007) and Brown and Randle (2005) have called for further research on the impact of SCI on QoL. Brown and Randle (2005) especially call for adoption of qualitative design in order to acquire richer understanding of the experiences of patients who have undergone stomal surgeries. This study takes up the call by exclusively focusing on the lived experiences of women with SCI who have undergone urinary diversion procedures.

Summary

The population in United States affected by spinal cord injury is reported to be over 250,000 with approximately 12,000 people added to that number annually. The number of women affected by SCI is about 20%, making them a substantial group to be studied to reveal the unique aspects in this group. The occurrence of SCI is a catastrophic or devastating experience that impairs many body functions including bladder management. Impaired bladder functions lead to renal failure that may be fatal if proper management measures are not taken. Therefore, bladder management in individuals with SCI takes great priority with the major aim being the preservation of the urinary tract, preventing urinary tract infection, and maintaining renal function.

Several bladder management regimens have been used over the years. They include the use of CIC regimen, indwelling catheters, external sphincterotomy, and urinary diversion procedures. These methods of bladder management have different effectiveness, and all have limitations in terms of the complications resulting from their use. The CIC regimen is limited by the fact that many individuals with SCI with paraplegia or quadriplegia cannot use them due to reduced hand function and trunk stability. In addition complications such as urinary tract infections make them unfavorable (Chartier-Kastler et al., 2002).

Urinary diversion procedures have been recommended for some individuals with SCI for whom the CIC regimen is not appropriate. The urinary diversion procedures may take many forms i.e. conduit diversion, incontinent ileovesicostomy, and continent cutaneous urinary diversion.

This study used the cognitive adaptation theory to explain how women with SCI adapt to bladder management with urinary diversion procedures. This theory was put forward by Taylor in 1983 in an attempt to explain how human beings perceive and deal with threatening and traumatic experiences. The theory explains why, in spite of the negative physical, psychological, and social impact resulting from the occurrence of SCI, there is evidence that many individuals with SCI make adaptations to the extent that they experience growth in self, their way of living, and their view of other people.

The theory utilizes three stages to explain the human adaptation to threatening experiences. First, the person affected seeks an understanding of the threatening event by finding out why it occurred and how it impacts on their life. Secondly, the patient makes effort to overcome the event in order to gain control over their life and body. Lastly, the patient undergoes self-enhancement to gain a sense of self-worth and restore the self-esteem that had been lost due to the threatening experience. This theory has been applied in several fields to explain the adaptive nature of human beings to situations that are threatening and traumatic for example in the event of a tragic loss or the occurrence of a terminal illness.

The literature reviewed showed QoL of individuals with SCI as the major theme. Research shows that persons with SCI report a lower QoL than the general population mainly due to impaired body functions such as the neurogenic bladder. Several studies suggested factors that must be considered when determining the QoL both social and health-related that persons with SCI led before and after urinary diversion procedures.

Among the factors considered are physical well-being, the relationships formed and maintained, occupation and doing meaningful work, emotional well-being, and independence. Many studies show that individuals with SCI who underwent urinary diversion procedures reported greater satisfaction and higher QoL and that the patients were able to self-catheterize, and the leakage problems were eliminated. Patients who had been recommended for urinary diversion due to the inability to use the CIC regimen to manage the neurogenic bladder expressed satisfaction with the outcomes of the urinary diversion procedures and reported reduced urinary tract infections and reduced use of medication.

A primary theme revealed in the literature review is the reported complications arising from the urinary diversion procedures. The major aim of proposing urinary diversion procedures other than for patient who cannot use CIC regimen was to avoid the irreversible complications associated with long-term indwelling catheters. However, the urinary diversion procedures also report complications such as perforations, leakages, wound infection, stomal dysfunction, and vesicovaginal fistula. Some of these complications are severe and require reoperations as an intervention to correct.

The other theme discussed in the review was the lived experiences of persons with SCI who had undergone urinary diversion. However, due to limited material of studies focusing on women’s experiences after urinary diversion, lived experiences of women after SCI were also included. The women with SCI were seen to perceive their body image differently. Some patients held a positive body image while others held a negative body image with an effect on areas such as their sexuality and sexual outcomes.

Women reported stigma, discrimination, and alienation as a result of their condition. A number of patients also admitted to being frustrated by the limitations that are present as a result of the SCI.

The review of the literature confirmed the gap existing in research. There were limited studies that exclusively focused on women and their experiences after urinary diversion procedures in order to explore the influence of such procedures on their QoL. Moreover, researchers have recommended further research on QoL among individuals with SCI and research utilizing a qualitative design in order to acquire an in-depth understanding of the lived experiences of individuals with SCI in terms of their QoL. Further, researchers have emphasized the need for research on an influence of urinary diversion procedures on homogenous groups of individuals with SCI as opposed to where previous studies have utilized both male and female subjects. In Chapter 3, I discuss the qualitative methodology that I used to collect and analyze the data for the current study.

Chapter 3: Research Method

This study explored the experiences of women with SCI who had undergone urinary diversion surgery; the goal was to understand life after surgery with respect to QoL. This chapter describes the research design and rationale, role of the researcher, and data collection, which included recruitment, instrument development, informed consent, the interview process, and data analysis. This chapter ends with a discussion of trustworthiness and ethical considerations.

Research Design and Rationale

This study used a qualitative design because it permits a more comprehensive description of participants' lived experiences; it is an especially valuable approach in understanding personal experiences. The focus is on respect and thorough listening for the participants' life experiences (Ponterotto, 2010). The qualitative tradition asks questions about individuals' perspectives of the world and seeks insight into peoples' experiences. (Frost, 2011). Creswell (2009) identified the origin of this tradition in the disciplines of sociology, psychology, and philosophy, and explained that it sought, primarily, to understand and the essence of personal experiences and events.

The objective of this study was to understand the lived experiences of women with SCI who underwent urinary diversion procedures and their subsequent QoL. The design fit the study because it enabled the researcher to gain a deeper understanding of the lived experiences of women with SCI who had undergone urinary diversion surgery, in particular their QoL.

The study adopted a generic qualitative research approach, which sought to discover and understand personal perspectives (Caelli, Ray, & Mill, 2003). This qualitative approach did not follow a set of guiding philosophies or procedures, such as those found in the other established qualitative strategies, such as grounded theory, case study, phenomenology, narrative, ethnography, or action research. Rather, the generic approach exhibited some of the characteristics of each of them.

In the following paragraphs the qualitative methods for recruiting and selecting participants, instrument development, data collection and analysis, and the methods used to establish the trustworthiness of the study findings are presented.

Rationale for Research Tradition

The qualitative research approach chosen for this study was appropriate as the study explores human experiences. This approach allowed the researcher to gain insight into the research topic, explored the uniqueness of each participant’s experience and the perspectives which the participants held, and helped the researcher to explore the other aspects of the social phenomenon such as the experiences of women with SCI (Frost, 2011). A phenomenological approach aims to establish the meanings derived by individuals from their lived experiences. Elements of this approach have been used in the current study, as the experiences addressed in this study are lived experiences. According to Moustakas (1992), the qualitative approach in research aims at discovery, which entails seeking understanding of human experiences using scientific research. A generic qualitative research tradition covered all the aspects that need to be covered in this study. It helped to answer the research question fully because first the individual experiences, perspectives, views, and beliefs were explored and then themes were revealed by looking through the data (Frost, 2011).

Other research strategies were considered for this study. Ethnography focuses on describing the cultural and social systems of a group of interest to researchers in order to view research phenomena in the context of their occurrence (Al-Busaidi, 2008). An ethnographic approach was not therefore appropriate for the study as it seeks to understand the lived experiences of the women with SCI. Grounded theory methods, are not congruent with phenomenological approach. Case study or narrative study was not chosen as this study had very specific interview questions.

Role of the Researcher

The role of a researcher in this study was both as an observer and a participant. As an observer, the researcher took an outside view as an objective listener in order to determine such issues as the nonverbal cues given off by the participants. As a participant, the researcher used interviewing as the instrument of data collection. Hence, the researcher participated in the activities of the study rather than being a passive observer. The researcher was required to ask questions, listen, and then ask more probing questions to obtain detailed information from the participants (Postholm & Madsen, 2006).

Power relationships can exist between researchers and participants. According to Scantlebury (2005), researchers often fail to recognize the usage of their power as they build and maintain boundaries that separate the researcher from the participant, and then they set a procedure or process for the participants to follow. However, the researcher must ensure that participants are given a voice in the study. To ensure this, I had to make the participant feel comfortable, valued, and appreciated.

According to Pannucci and Wilkins (2010), bias in research can occur at any stage of research. Biases can occur in the choice of topic, design and data collection methods, data analysis, and interpretation. In the process of data collection through interviews, bias is likely to happen in how the interviewer collects the data, records, and interprets the data. Bias can be avoided by proper study designs and in case of interviewer bias, standardizing the interview process can eliminate the bias (Pannucci & Wilkins, 2010). This research presented no conflict of interest with the researcher. The researcher had no relationship with the participants. In addition, there were no issues arising related to the work environment as the study is not conducted from the researcher's place of work. So there is no clinical relationship. The participants in this study did not have any previous contact with the researcher. The researcher also used bracketing in order to ensure a balance between subjectivity and objectivity. Bracketing involved elimination of preconception and phenomenological reduction in which researchers blocked out presuppositions in order to acquire findings in their pure form (Moustakas, 1994). This was achieved by identifying the key phrases that directly relate to the study phenomenon prior to the design of the study where the researcher identified preconceptions, assumptions, beliefs, and biases and then as that study was being conducted consistently checked to make sure that none of these appeared in the study.

Denzin (1989) suggested that bracketing involved identifying main ideas in the study during the data collection, interpreting the meanings of the collected data as informed by the participants, acquiring the meanings derived by the participants' from their lived experiences in terms of how urinary diversion surgery has changed their life, and identifying recurring themes/meanings. Moustakas (1994) argued that bracketing can be achieved through immersion in the participants' world of experience, incubation or ensuring awareness of the experiences, illumination in order to provide deeper understanding of the experiences, and reflecting on the experiences and creative synthesis where the experiences are brought together to indicate patterns and relationships.

Sample and Sampling Technique

The participants in this study were women with SCI who have undergone urinary diversion procedures. Criterion-based sampling was used. The participants included in this research met the following criteria: participants must be women who suffered variable level of spinal cord injury with a standard surgical indication of neurogenic bladder; participants must have received a urinary diversion procedure; and participants must be fluent in English. The participants were expected to talk about their experiences, feelings, thoughts, concerns, worries, and problems hence the last criterion was important.

Recruitment

The IRB approved the research proposal on October 7, 2014 (approval number: 08-15-14-0149544). An approved Recruitment letter (Appendix A) was emailed to a Resource Coordinator Spinal cord injury unit in Ontario, Canada. The recruitment letter was also emailed to a few other SCI support organizations and uploaded on the website of a mobility magazine in the United States. Five of the participants meeting the criteria were enrolled in the study and interviewed within 10 days of the first email circulation through the resource coordinator in Canada while the remaining five were enrolled after sending recruitment letters through other sources in the United States. All participants participated in the scheduled interview and completed all requirements for the research study.

The study used a purposive sample of 10 participants who met the inclusion criteria for participation in the study. Snowball sampling was used to recruit participants. Snowball sampling involves identification of study participants through referrals from individuals who share or know other individuals with the characteristics of research interest. The researcher started the snowball sampling procedure by finding a few respondents and initiating the referral chain. It was very difficult to find this specific population to approach for participation in the study. Criterion sampling was used to identify the participants needed for the study, women with SCI who had chosen urinary diversion surgery for bladder management. Snowball sampling was used to recruit potential participants who met the criteria. The researcher had sought help from spinal cord injury resource coordinator Ontario. She had access to a list serve of population with spinal cord injury. She sent out a recruitment letter (Appendix A) to invite eligible participants. The procedure for identification, contacting, and recruiting the participants included the following steps: (a first, I contacted the resource coordinator and emailed her the flyer to send out to the list serve email; (b) eligible interested participants contacted me via email; (c) I communicated with the participants via email and phone to answer any questions they had regarding the study; (d) and I emailed the informed consent to them. The participants were also encouraged to recommend potential participants who met the required criteria. I could only enroll five participants through this emailed flyer from the resource coordinator. I was able to enroll the rest of the participants with the help of an online magazine for women in wheelchairs called mobilitywomen.org.

Sergeant (2012) states that the qualitative research does not require a predetermined sample size, thus the number of participants in the study depends largely on the number that will deliver all the necessary elements that will be enough to answer the research questions. A sample size is considered sufficient when the addition of a number of participants does not lead to the identification of new themes or concepts. The choice of a sample of 6–12 participants was based on empirical findings of a study by Guest, Bunce, and Johnson (2006), which established that data and thematic saturation are achieved after the first 12 interviews.

Guiding Question and Instrumentation

This following question guided the data collection: What are the lived experiences of women with Spinal Cord Injury who undergo urinary diversion procedures?

The method of data collection in this study consisted of in-depth semistructured interviews. In-depth interviews were used to help the researcher get a broad and comprehensive understanding of experiences and perspectives of participants. The interview questions are attached as an Appendix. An expert panel of qualitative methodologists was used to assist with ensuring that the interview questions are framed to answer the research questions. The participants who expressed an interest and willingness to participate via email were asked to provide any convenient date, time, and a preferred phone number to contact for an interview.

Informed Consent

All participants were sent informed consent to read and understand via email. They were requested to sign the consent form electronically if they agreed to participate. The participant’s name typed with their e-mail address on the signature line was accepted as their electronic signature. The informed consent form was explained verbally at the beginning of the interview, and a verbal consent was recorded. The participants were encouraged to ask questions about the study. All study participants indicated understanding and willingness to participate in the research study by sending the signed informed consent form back except one of the participants who was technologically limited. The particular participant was made an exception for not getting a signed consent form back, and only a verbal consent was recorded.

Interviews

To arrange the interview, I sent an e-mail to all participants to schedule a convenient and uninterrupted time for a phone interview. They were asked to provide their preferred phone number to contact. The interviews were scheduled via email. The participants were encouraged to choose a time when they could be by themselves for about an hour to maintain the confidentiality. Each participant provided a phone number that was used to conduct phone interview. The researcher made a phone call for each interview at an agreed upon time between the researcher and the participant from private home office to ensure privacy and confidentiality.

Phone interviews with all participants were conducted during months of October and November. The interview process took about six weeks for all participants. The time taken for interviews ranged from 30–40 minutes. The phone interviews were recorded after obtaining their permission. The recordings were stored as mp3 files in the password protected files with initials of the participant and date of interview to protect the identity of the participant. Interviews were conducted using approved interview questionnaire as a standard format. Standardization of the interview process was used to eliminate bias and hence increased the reliability and validity of the data obtained through this process. Through the use of open-ended questions, the researcher probed to get the detailed experiences of the participants before and after undergoing urinary diversion techniques. Questions and probes explored participants’ experiences, thoughts, feelings, concerns, and worries about neurogenic bladder problems before the urinary diversion surgeries.

Some probes were used to get more information. Paraphrasing was used to ensure the accuracy to some responses. At the end of the interview, each participant was asked if she would be willing to go over the transcript for approval to satisfy member checking. All participants agreed to check the transcript. The interviews were transcribed, and the word document files were emailed to participants. All participants sent the transcripts back with minimal corrections. A brief summary of the study findings was emailed to all the participants after the interviews were completed for verification. I received an approval on the summary of study findings from all participants except one who had mentioned that she does not use computers on a routine basis. The interview protocol can be found in Appendix A. A sample of the interview transcriptions can be found in

Appendix D. The collected data including electronically signed informed consents, communication emails, digital audio-recording mp3 files of interviews, and transcriptions of interviews have been encrypted and saved on my password protected personal computer. My computer is backed up with a Carbonite server to protect from computer crash.

Data Analysis

The researcher audio-recorded, transcribed verbatim, and reviewed each interview for accuracy. NVivo 10 software was utilized for data management. Qualitative themes were identified using Colaizzi's technique (1978). Colaizzi's technique begins with a several readings of the interview transcripts to gain a sense of their content. The second step involves extraction of phrases significant to the phenomenon being studied. Meanings are formulated in the third step in the process. The fourth step includes identifying "clusters of themes." During the fifth step in the process, the researcher formulates the emerging codes into an exhaustive description of the phenomenon being studied. Then, the exhaustive description is reduced to a fundamental structure of the experience as portrayed by the participants and in the final step, the researcher returns to participants to validate the themes (Colaizzi, 1978). Despite the linear presentation of this process, steps occurred and re-occurred as appropriate as they continued to be immersed in the data and consider the experience of these participants and the potential meanings they conveyed.

The following approach was used in the analysis of the data collected in this study: First, the digital audio files recorded in the interview were transcribed by the researcher and the resulting transcripts were used for detailed analysis. The transcripts were analyzed one by one, reading them to identify descriptions, conceptual comments, linguistic elements, and themes. To protect the identity of the participants, each participant was identified by a code number. Once the analysis of each transcript was done using NVivo 10 software, after participants had approved the transcripts, I read the transcripts thoroughly and the significant sentences were coded into free node categories. I continued to code the transcripts after reading them repeatedly from the free nodes and created tree nodes and some child nodes. I used NVivo 10 software to organize the content themes into major themes and subthemes for tree nodes and child nodes respectively. After coding I read the transcripts again and reviewed to look for the recurrent themes.

I used a 15-point checklist of measures for good quality of thematic analysis through all processes including transcription, coding, analysis, and written report. The checklist highlighted the activities necessary for ensuring that the entire process of thematic analysis provided quality findings. During the transcription stage, researchers are required to ensure that transcription occurs at a suitable and detailed level and that the transcripts are checked against the original tapes for accuracy. During coding, researchers should pay equal attention to every data item, ensure a thorough, inclusive, and comprehensive approach rather than an anecdotal approach, collate extracts for each theme, check established themes against each other and the original data, and ensure coherence, consistency, and distinctiveness. The analysis stage calls for interpretation of the findings as opposed to paraphrasing or describing the findings, ensuring that the analytic claims are supported by data extracts, ensuring that the data provides a compelling, ordered story about the data and study topic, providing equilibrium between the data extracts and the interpretive narrative. Under the written report, researchers are required to outline the assumptions adopted for the analysis, provide a fit between what is done and what the researcher claims to have done, and ensure alignment between the language and concepts of the report and the epistemological position held during the analysis. In overall, the checklist requires allocation of sufficient time to all phases of thematic analysis (Braun & Clarke, 2006). The researcher followed these guidelines during the thematic analysis process. The researcher, through bracketing, ensured that the prior knowledge and understanding gained from the other transcripts will not influence the analysis of the other transcripts (Pringle, Drummond, McLafferty, & Hendry, 2011). The collected data were categorized into emergent key themes reflecting the QoL issues brought out by the participants in order to answer the research question. The Cognitive Adaptation Theory was applied to the analysis to indicate how persons with SCI move through the adaptation process in order to deal with QoL issues that were brought out by the participants' experiences.

Issues of Trustworthiness

To ensure credibility of the findings made in this research, I ensured that all themes identified in the data analysis process could be traced back from the write-up to the audio files recorded during the interview. I checked the audio file with the written transcript for accuracy and additionally got approval by the participants. Another strategy that was utilized to check conformability in the research was the use of a reflective diary

(Frost, 2011). I ensured that a reflective diary was kept from the moment contact was made with the participants to the final write-up. I also kept a research journal that helped in maintaining a detailed audit trail on how the research was conducted and how data collection was carried out. To ensure the data trustworthiness during data collection, the researcher used member checking, and clarified researcher bias. I asked the participants to confirm the responses by paraphrasing the interpretation of responses. The researcher utilized member checking to ensure the accuracy, credibility, and validity of the data collected through interviews. It involved summarizing the analysis of collected data and presenting the key themes in one to two pages and sharing this with each participant. I had asked permission from the participants to email the transcripts during interview if they were willing to go over the transcripts to check the accuracy for transcript review. For member checking, I sent the brief summary of findings to each participant for approval. All of them agreed and were sent the transcripts and summaries, eight of the participants responded by sending transcripts back to me with positive feedback regarding the accuracy. It provided the participants with a chance to determine whether they were reflecting their views, perceptions, and experiences. Credibility of the study was confirmed where the participants' affirm the accuracy and completeness of the collected data.

Clarifying researcher bias was achieved by answering their question about the reason for my interest to choose this topic for research. I shared with them about a female friend's experience with spinal cord injury and urinary diversion surgery. I consistently tried to ignore the knowledge about my friend's experience to maintain objectivity of the research. I used structured interview questions and used probes to record the experiences of participants before and after the urinary diversion surgery. They were asked open-ended questions to share anything else they wanted to share regarding bladder care experience before and after the urinary diversion surgery.

Ethical Procedures

The researcher ensured that the entire research process adhered to the guidelines regarding the treatment of human subjects. The researcher informed all participants that their participation was voluntary, and the participants' written consent was obtained. The researcher held high levels of integrity in the entire research process by maintaining a transparent research process. The researcher also assured the participants that their confidentiality and privacy would be maintained. The participants were able to withdraw without any repercussions at any given time during the course of study. All participants completed the study. A $25 Starbucks gift card was mailed to each participant of the study as token of appreciation for their time. They were told they would receive the gift card regardless of whether they completed the interview. The study participants' were provided with a one–two page summary of the study findings.

The data collected in this study were protected; the audio files as well as any other digital data were stored in a secure desktop computer with password protection, while all hardcopy materials were stored under lock and key where only the researcher has access. In ethical issues such as the informed consent and data dissemination there is a need to maintain privacy and confidentiality, which requires that the data do not reveal the identity of the participant (Keen & Todres, 2007). The transcripts for each participant did not include their identification. The only person with access to the data collected in this research was the researcher. The researcher will keep the data for a period of five years after the study has been completed after which it will be destroyed.

Summary

This research studied the lived experiences of women with SCI who have undergone urinary diversion procedures. A generic qualitative approach was utilized as the most appropriate qualitative research tradition for this research. The study utilized primary data obtained through interviews to meet the research objectives. The criteria used in the selection of participants included adult women with SCI neurogenic bladder urinary diversion procedures as the bladder management regimen who were fluent in English. The sample for the study was ten women; each participated in an in-depth interview~~s~~. The researcher took conscious measures to ensure that the research is trustworthy and that all ethical issues arising were handled in an appropriate way. The IRB requirements were met so that approval to conduct the study was granted. The interviews were recorded in digital audio files, transcribed, and analyzed. Limitations such as biases were identified, acknowledged, and efforts applied keep them at bay through bracketing. Themes, concepts, and descriptions were identified through the process of data analysis that will be presented in the next chapter. In Chapter 4 I also discuss the results from the participant interviews.

Chapter 4: Results

Introduction

This study used interviews to explore the experiences of 10 women with SCI who had undergone urinary diversion surgery; the goal was understand the influence of the surgery on QoL. Chapter 4 presents the demographics of the participants, the data collection and analysis process, data storage, the themes that emerged from the thorough data, and an explanation of the quality of the collected data.

Description of the Participants

*P*1 was a 56-year-old married woman who experienced a spinal cord injury when she was 45 years old. She described her injury level as T3–T4 complete, and her condition as complete paraplegia. She was in the hospital for 2 months and in rehabilitation for 6 months. Before her injury, she had earned an undergraduate college degree and was working full-time in sales. She could not work after the injury, but she was able to return to work part-time after the surgery. She chose to undergo urinary diversion surgery about 3 years after injury. She worked part-time and was involved in volunteer work. She is a mother of three grown children. She lives with her husband, two of the three children, and a nanny.

P2 was a 53-year-old married woman who experienced a spinal cord injury when she was 50 years old. She described her injury level as T3 complete, and her condition is classified as having a complete paraplegia. She was in the hospital for three weeks and in rehabilitation for four months. She is a high school graduate, and before her injury, she worked as a store manager. She did not go back to work after her injury or after surgery.

She chose to undergo urinary diversion surgery about one and a half years after injury. She lives with her husband, two children, and her mother.

P3 was a 52-year-old married woman who experienced a spinal cord injury when she was 44 years old. She described her injury level as T11–T12 incomplete and her condition as involving incomplete paraplegia. She was in the hospital for two weeks in rehabilitation for three months. Her education level was Grade 10 and she worked 30 years in customer service, then she worked as a receptionist/assistant, which was her dream job but she could not work after the accident due to accessibility. She chose to undergo urinary diversion surgery about one and a half years after injury. She is a mother of two grown children. She lives with her husband and adult son.

P4 was a 53-year-old woman who experienced a spinal cord injury more than 20 years ago when she was in her early thirties. Her injury occurred at the C5–C6 level, causing complete quadriplegia. She spent three months in the hospital, followed by seven months in the rehabilitation. She was a high school graduate with some college courses, and before her injury she worked in marketing and administration. She had to change her position in the same company after her injury as it required too much hand work. She chose to undergo urinary diversion surgery about 12 years after injury. She lives with her boyfriend. She never had any children.

P5 was a 42-year-old woman who experienced a spinal cord injury about 18 years ago, when she was 24 years old. She described her injury level as C6–C7 complete, resulting in a complete quadriplegia. She was in an acute care hospital for six weeks, then in the intensive care unit for three weeks, and then she spent nearly a year in rehabilitation. She had just finished undergraduate degree before her injury, and she completed master’s degree about six years ago. Before her injury, she had just started a full-time job and was working for three months in computer operations. After her injury and surgery, she had been involved in research. She chose to undergo urinary diversion surgery about a year and a half after injury and only three months after discharge from rehabilitation. She lives with her husband and her six year old daughter. She got married after her injury and had her daughter after her injury.

P6 was a 41-year-old never married woman who experienced spinal cord injury about 25 years ago when she was 16 years old. She described her injury level as C6–C7 complete, leading her to live with complete quadriplegia. She was in the hospital for two weeks and in the rehabilitation for two and a half months. She was in high school when she was injured, she went to college and completed Masters in counseling psychology. She does not work in counseling psychology but uses some of those skills. She works with an organization that has 350 missionaries in about 40 different countries. She chose to undergo urinary diversion surgery about 17 years after injury. She lived with her parents until about eight years ago but has been living independently for last eight years. She has no children.

P7 was a 46-year-old woman, who experienced a spinal cord stroke about 10 years ago when she was 38 years old. There was no preexisting condition and a back surgery was performed to confirm that it was not happening due a bulging disc in the spine. But the paralysis was due to ischemic stroke. She described her injury level as T8–T10 complete that resulted in a complete paraplegia. She was in an acute care hospital for two weeks that included intensive care unit for one week then 6 weeks in the rehabilitation. She had finished her law degree before her injury, and she was working as a lawyer. After her injury, she had been still working as a lawyer but mostly part-time. She chose to undergo urinary diversion surgery about eight years after the injury and only about a year ago in 2013. She lives independently and was never married.

P8 was a 35-year-old never-married woman who experienced a spinal cord injury about 15 years ago when she was 20 years old. She suffered cervical spinal cord injury while sledding in the snow. She described her injury level as C6–C7 complete, her condition is classified as a complete quadriplegia. She was in the hospital for three weeks and in the rehabilitation for about three months. She was in college when she got injured, and she went back to college to finish an undergraduate degree and later completed Masters while living independently away from home. She lived with a boyfriend for four years but broke up few years ago. She worked as an administrator in education. She chose to undergo urinary diversion surgery about one and a half years after injury. She has been living independently for last 15 years. She had no children.

P9 was a 42-year-old divorced woman who experienced spinal cord injury when she was 27 years old. She described her injury level as C7–T1 complete, resulting in complete paraplegia with some fine motor skills deficit for grip and dexterity. She was in the acute care hospital for six months and in the rehabilitation about nine months. She finished college and was married when she got injured. She was divorced in ~~since~~ 2007. She worked in the cosmetics industry. She chose to undergo urinary diversion surgery about two years after injury. The surgery was recommended to her when she was in the rehabilitation. She lives with common law partner. She had no children.

P10 was a 37-year-old never married woman who experienced a spinal cord injury when she was 18 years old. She described her injury level as C6 with some areas of C7 and C8 function, causing quadriplegia. She was in the hospital for 2 weeks, and in the inpatient rehabilitation for 2 months, and then spent 3 months in the outpatient rehabilitation. She was a senior in high school when she got injured; she went to college and completed a Ph.D. She worked as a full-time faculty member in a university. She chose to undergo urinary diversion surgery about 8 years after injury during her first year in the doctoral program. She was living with her boyfriend and was in a long-term relationship. She had no children.

Table 1 summarizes the demographic information of all the participants. The average age of participants was 45.7 years and the average years between injury and surgery was 5.4 years. Six of the participants had quadriplegia, and four of them had paraplegia.

Table 1

Demographics of Participants

P #	*Age*	*Age when injured*	*Year of injury*	*Years between injury and surgery*	*SCI level*	*Bladder care before surgery*	*Work after injury*	*Work after surgery*	*Education*	*Status*	*Children*
1	56	45	2004	3	Para	IC	No	PT	BS	M	3
2	53	50	2011	1.5	Para	IC	No	No	HS	M	2
3	52	44	2007	1.5	Para	IC	No	No	10th Gr	M	2
4	53	32	1993	10	Quad	Foley	PT	PT	HS	P	-
5	42	24	1996	1.5	Quad	Foley	No	FT	Masters	M	1
6	41	16	1989	17	Quad	Foley	FT	FT	Masters	S	-
7	46	38	2006	8	Para	IC	PT	FT	Law	S	–
8	35	20	2000	1.5	Quad	Foley	FT	FT	Masters	S	-
9	42	27	1999	2	Quad	IC	No	FT	Assoc	D/P	-
10	37	18	1996	8	Quad	Foley	FT	FT	PhD	P	-

Note. Para- Paraplegia, Quad-Quadriplegia IC- Intermittent Catheterization

FT- Full Time, PT-Part Time, M- Married, S –Single, D- Divorced, P-Partner

Data Collection and Analysis

The transcription of digitally audio-recorded interview data marked the first step in data analysis. The transcribed files were emailed back to the participants for transcript review. I used Nvivo 10 software to code and analyze the data. After participants had approved the transcripts, I read the transcripts thoroughly and the significant sentences were coded into free node categories. I continued to code the transcripts after reading them repeatedly from the free nodes and created tree nodes and some child nodes. I used NVivo 10 software to organize the content themes into major themes and subthemes for tree nodes and child nodes respectively. After coding I read the transcripts again and reviewed to look for the recurrent themes. Subsequent to this process two themes emerged from the significant statements identified in the interview data. Two themes emerged from these interviews are related to QoL and social support. Tables 2 and 3 illustrate the total of 17 key statements extracted from the transcripts and the corresponding formulated meanings made by the researcher. The formulated meanings were first organized into themes and then subthemes within each theme. Two prominent themes emerged: QoL and social support. The faint horizontal lines represent each cluster of formulated meanings that became subthemes. Together, the clustered subthemes in each table represent the theme. Tables 2 and 3 illustrate the two themes and their subthemes. There were 11 subtheme for the theme QoL and two subtheme for the theme of social support.

Theme 1: QoL

Table 2

Lived experiences of the participants, Theme 1 QoL

Subtheme	Key Statements	Formulated Meanings
a. Independence	1. Could not move out of the house more than 3–4 hours and feel dependent on attendant	1. Inability to leave home caused loss of independence.
b. Health	2. Foley increases the risk of bladder cancers so I was looking for an alternate bladder management techniques.	2. It felt healthy to not have to worry about risk of bladder cancer.
	3. Any time I got off of prophylactic antibiotics I got a UTI, a very severe UTI.	3. Surgery helped to alleviate recurrent urinary infections
	4. Had to empty my bladder and very scared of autonomic dysreflexia.	4. Feeling of safety after surgery by not having the risk of life threatening autonomic dysreflexia.
	5. Staying away from all perineal area so it was much cleaner.	5. Felt hygienic to catheterize from the stoma after surgery
c. Convenience	6. No need to transfer or accessible bathroom.	6. It was convenience of lifestyle and accessibility.
d. Major Barrier	7. After SCI, I accepted paralysis but bladder management was a major barrier to being functional.	7. Despite adaptation, urinary issues continue to be a major barrier prior to surgery
e. Aesthetics	8. I had urine smell, urine bag and	8. Very limited in clothing options and

	tubes, could not wear certain clothes, bathing suits, skirts, etc.	odor issues affected aesthetics
f. Confidence	9. I did not have fear of incontinence after surgery or feeling of dependency	9. Having urinary control made them feel safe and confident.
	10. Nobody needs to know my business.	10. Privacy was enhanced after surgery.
g. Privacy	11. Don't have to expose myself to attendants multiple times in a day	11. Surgery restored the feeling of dignity.
h. Dignity	12. With the surgery I got my dignity back.	12. Important for self-respect.
i. Sexuality	13. Having tubes coming out is not sexy at all	13. Impaired sexual appeal prior to surgery
j. Normalcy	14. I can use bathroom like others with no help or tubes hanging out	14. Feeling normal like other people.
k. Safety	15. No worries falling during transfer to a toilet or about incontinence	15. Enhanced feeling safety since fewer chances of falls or urine leakage.

Overview. The participants compared their life with bladder management after injury with their life after surgery. Many of the responses presented evidence related to the theme of QoL. All ten participants mentioned how the urinary diversion surgery affected their QoL. When asked about their reason for the decision to get the surgery done and the way it changed their routine, the responses were indicating how their life was oriented around bladder management. Five participants were managing bladder with indwelling Foley catheter, and five of them managed it with intermittent catheterization. All of the participants with CIC management and four out five participants who used Foley catheter felt that their QoL improved tremendously after the urinary diversion surgery. This theme of QoL is illustrated in the following comments shared by participants:

P1: I wanted to live my life. You know, just couldn't continue living like that. It was depressing before the surgery. It has been amazing because I think I can go anywhere I'm up and about all the time I could be gone from morning to the night. I was able to start working again. And because I wanted to go to work earlier but I could not, as it prevented me from doing that. I travel a lot more now than I did before. It has just changed my whole life. It changed everything. It’s great, much more than anyone can think.

P5: I can honestly say my surgery was a huge success, “Huge” life changer, I was certainly not be as happy and comfortable with myself as I am after the surgery.

P7: I’m relieved, I’m happier, I feel like I have more hope that I can do more things with my life. It’s just the happiness about it. Like going to movies, movies are now three hours long.

Participant 10: It has been one of the best decisions I have ever made. It had a huge impact on my QoL. It made bladder management less of a burden and less of something that I had to work hard to manage, plan, and think about. So it is a very positive, hands down high benefit to me

Subtheme 1a: QoL—Independence. Independence achieved after surgery was a subtheme that emerged to affect the QoL for the women with spinal cord injury after they chose to undergo the urinary diversion surgery for bladder management. All of the participants experienced freedom and flexibility that made them a lot more independent after the surgery. The following comments from participants demonstrated this subtheme of independence:

P1: I feel pretty independent. It has given me different type of independence that I didn’t have before.

P2: For me, I’ve been independent all my life. It was a horrible feeling to be dependent on other people. I’m completely independent for bladder management.

P5: Independence was huge. That was #1 thing. I am not restricted to that 3–4 hour limit to be in and out of the house. I have someone that just comes in the morning now to help me with getting ready in the morning bathing and toileting then I am completely independent for the rest of the day compared to needing someone every 3-4 hours.

Subtheme 1b: QoL—Health. Another subtheme that emerged is the effect and need of surgery on the participant’s health. Most participants shared how the urinary diversion surgery was the healthier choice for them. The participants shared that prolonged use of Foley catheter causes frequent UTI and may cause bladder cancer. The inability to empty the bladder can cause life-threatening emergency of autonomic dysreflexia. The comments from participants exemplified this subtheme of improved health. Some of the examples of their comments were as follows:

P4: Autonomic dysreflexia is the body's way, when you are paralyzed at my level of injury to tell you something is wrong, and it could be life-threatening. I had to be rushed to the hospital for that; basically it did not allow me to live my life the way I wanted to. I also had bladder infections.

P5: Staying away from all perineal area, so it was much cleaner and lot less urinary tract infections. I feel that it is cleaner, and more hygienic.

P8: I can alleviate one of the major discomforts that are urine infections. I feel like I have my body much more healthy because of having that surgery.

P10: I rarely have UTIs now, and I was able to stop the prophylactic antibiotics. I was actually able also to stop my Ditropan, which is for bladder spasms because I learned that indwelling catheter balloon sits on a very sensitive area of the bladder.

Subtheme 1c: QoL—Convenience. The participants discussed convenience as another subtheme as a result of urinary diversion surgery. All participants talked about the convenience when asked about the change in routine life after they had the urinary diversion surgery. They found intermittent catheterization through abdominal stoma very convenient to empty their bladder. This subtheme of convenience is illustrated in the following comments shared by participants:

P1: Oh it is so easy, very comfortable like even if I'm outside somewhere. I could be in my car or somewhere there is no accessible washroom I can just go in my Van and as long as I have couple of plastic bottles, my catheters with me, I always have them in a bag on my chair. I can pretty much do it anywhere.

P3: It is a matter of convenience. When I go out, all I need is what I call my pee bag, that contains my supplies, my gloves, catheters, my boat(dish), and I'm good to go anywhere.

P5: I think it is very convenient sometimes I feel that even more convenient than the paraplegic's who have to do intermittent catheterizations because they have to be still restricted but making sure that they have an accessibility to bathroom.

P7: Now I can go to a basketball game which I used to like to go to University basketball. I can go with anybody. I don't have to arrange to go with someone who can help.

Subtheme 1d: QoL—Major Barrier. When participants were asked about the major barrier they perceived in life after the spinal cord injury, most of them stated that bladder management was the major barrier to lead a functional life as a woman in a wheelchair. The participants commented specifically on this subtheme of major barrier, following were some of the comments shared by participants:

P5*:* I found it very challenging to be able to get out in the community and just do anything at any sort of productive level because I was always limited by this 3–4 hour of the time limit.

P7: If you can get the bladder and bowel management under control it would be much easier to live a life with spinal cord injury.

P9: Other than bladder, nothing really. It was very awkward, was very unfortunate that my life was cut short for a bit there because I had to be the one to worry about bladder and so forth. So bladder was always the issue.

Subtheme 1e: QoL—Aesthetics. Some of the participants mentioned the change in appearance and expanded the options in the choice of clothing after urinary diversion surgery. The participants shared the following comments demonstrating this subtheme of aesthetics:

P4: The fact that you have a tube coming down your leg I just didn't like that as I like to wear skirts, shorts, and tights. So it didn't go with my fashion sense either. I can wear a bathing suit not having to worry about a visible tube.

P5: Aesthetically I didn't like the idea of wearing a leg bag and especially because I can't be active as I would like to wear a capri or a skirt or shorts or bathing suit to go swimming. So the leg bag was not attractive at all. I wear a bathing suit, and I don't have to worry about the leg bag showing. That was really big for me.

P6: My clothes can fit a little bit better they don’t have to be as big to hide the bag. I can wear clothes little bit tighter fitting. I really went into it hoping to get rid of the tubing and the bag. When the bag was really full, it would show a little bulge on my belly.

Subtheme 1f: QoL—Confidence. All of the participants expressed that they gained confidence after the urinary diversion surgery and could go places without worrying about incontinence. The participants conversed about confidence in a variety of ways in the following comments shared by participants:

P1: It has given me confidence, and I don’t look so needy in front of people.

P4: I am not worried about going anywhere or doing anything as long as I have my bag beside me that carries all my catheters in that.

P5: Aesthetically, it has given me the confidence to wear what I want.

P8: Overall it has given me an incredible amount of confidence and sort of ability to do more with my life. The level of confidence that I gained, I want to tell the world about it.

Subtheme 1g: QoL—Privacy. Six out of ten participants mentioned about feeling comfortable with surgery as it gave them privacy. Even though it was not the reason to decide for the surgery, but they enjoyed privacy after the surgery. This subtheme of privacy was repeatedly noted in the following comments shared by participants:

P1: It’s not something I discuss with people what I have done as it is none of their business. It is my privacy.

P3: Nobody else has to know my business.

P8: Almost feels like comical in the sense that it is easier for me to catheterize myself quickly and without really anybody noticing in my car or someplace than any able-bodied woman I know.

Subtheme 1h: QoL—Dignity. Exposing the private parts and feeling dependent on others for going to the bathroom bothered these women with SCI. Seven of them expressed how they felt comfortable to get their dignity back after the surgery. The participants shared this subtheme of dignity in the following comments:

P3: It has given me a little bit back my dignity because I am not walking around with wet pants. I don’t have to undress either I just have to pull my pants a little lower and left my shirt up.

P5: Basically, because I don't have to undress. I am not showing genitalia or anything in the process. I feel I got my dignity back.

P9: Obviously, it’s not fun to have to open your legs to someone for every time you had to pee. So you can say, it gave me my dignity and privacy back.

Subtheme 1i: QoL-Sexuality. Some of the participants got injured while they were in their teens or twenties while some were in their fifties. The ones who managed their bladder with an indwelling catheter mentioned how their sexuality improved after the surgery. The following comments shared by participants are the example of this subtheme of sexuality:

P4: Definitely and especially he'll have to worry about the tubing being pulled or caught. And it's just not very sexy having it in there. It gets in the way. So definitely it has changed.

P6: I know for sexuality, I am single and if I were to be married, I would feel much more comfortable with having this surgery to manage my bladder than Foley. I'm not at that point yet but if and when it happens I think that would be a huge thing.

P8: Being sexually active a little bit easier with the surgery and less cumbersome with the tubes and bags and bladder infections. I think it just would have made everything so difficult awkward uncomfortable. Whereas I think I might have been too encumbered or desensitized to the process. Yeah, it was something that was enjoyable again.

Subtheme 1j: QoL—Normalcy. Six out of ten participants stated that they felt safe and close to normal with the change in routine with bladder management after urinary diversion surgery. The participants who used indwelling catheter for bladder management felt that they were normal or close to normal to look at because of no tubes or bags hanging out after the urinary diversion surgery. The participants who were using intermittent catheterization to empty the bladder felt that they could use the restroom like normal people. This subtheme of normalcy is illustrated in the following comments shared by participants:

P4: I feel like my body looks more normal, I don't have a tube sticking out of me. Because just because you are paralyzed does not mean that you look like you are a hospital patient.

P5: I feel now what I am having is normal, and this is what it should be. I would say before I did the surgery it was really awful.

Subtheme 1k: QoL— Safety. The participants who used CIC as their bladder management felt safe after the surgery to move about freely without fear of having an accident and those who used Foley catheter did not fell scared that it will fall out. The women with paraplegia who intermittently catheterized to void felt safe for not having to transfer over the toilet out of the wheelchair. The participants commented on this subtheme of safety in the following examples:

P3:_It was hard because I never knew when I was going to get wet. I don't leak any more out the bottom.

P4:_I am not worried about going anywhere or doing anything as long as I have my bag beside me that carries all my catheters in that.

P9: I gained peace of mind, not having to worry. Also that I do not have upper body strength, to transfer myself from a chair to toilet, I do not have muscles, so it is also, safety.

Theme 2: Social Support

Table 3

Lived experiences of the participants, Theme 2, Social Support

Subthemes	Key Statements	Formulated Meanings
a. Awareness	1. Nobody discussed about Urinary diversion as an option of bladder management after my injury.	1.There is lack of awareness of urinary diversion surgery for women with SCI.
b. Suggestion	2. I didn't find out about it (urinary surgery) until much later when I was in rehabilitation because none of the professionals told me about it. My urologist did not tell me about it.	2.Suggestion about educating health care providers the merits of urinary diversion surgery in women with SCI.

Almost all participants stated concern that they did not know the choice to get urinary diversion surgery done to manage their bladder till they came to know from other women who had this surgery done.

Subtheme 2a: Awareness. All the participants except one did not learn about the option of having urinary diversion surgery from health care providers. They found out about this choice from other women who had this surgery done. The participants talked about this subtheme of awareness in the following comments:

P1: I didn't find out about it until much later when I was in rehabilitation because none of the professionals told me about it. My urologist did not tell me about it. I found out from other women with spinal cord injury because I would ask them questions about how do you get around, how do you manage. In turn actually I do peer support now

P6: Why didn't I know about it? Since I have had the surgery done, I think there have been at least 6 women who have had this procedure done. This was simply because I told them about it.

P9: It was recommended to me when I was in rehabilitation. The doctor had mentioned it to me and told me how it works and all that. I found that I did not get a lot of information online.

Subtheme 2b: Suggestion. Eight out of ten participants suggested that this option of bladder management with urinary diversion surgery should be discussed with the women with spinal cord injury by the health care providers. The women with spinal cord injury can decide if they want it or not by weighing their risks and benefits. One of them also suggested that it is a good option to consider for men too. The physician had discussed about the option of urinary diversion with only one out of ten participants while she was in rehabilitation center after SCI. The comments from participants demonstrated their opinion about this theme of suggestion in the following comments:

P1*:* I didn’t find out about it until much later when I was in rehabilitation because none of the professionals told me about it. My urologist did not tell me about it. I found out from other women with spinal cord injury because I would ask them questions about how do you get around, how do you manage.

P8: I have been Peer Mentor for maybe 13 years. I’ve been a very strong advocate for the procedure. Just knowing how much better your life can be afterward, better in the sense of freedom, mobility, and unrestrained; and I think it has made me scream off the roof.

Conclusion

The data analysis yielded results that suggested high satisfaction and life changing experiences of the participants after urinary diversion surgery. They narrated their experiences with bladder management before and after the surgery. All the participants highly appreciated the improved QoL after the urinary diversion surgery. Five of the participants who were using CIC as a bladder management felt significant independence, and convenience, while the other five who used Foley catheter emphasized the positive outcomes of surgery for health reasons and aesthetics. The interviews presented evidence that urinary diversion surgery could help the women with SCI to feel confident, and maintain privacy and dignity. The women who used Foley to manage their bladder talked about improved sexuality after the surgery.

The participants emphasized the perception of feeling normal to use the bathroom and ability to move about independently without actually having to plan for help and look for accessibility. Those who had paraplegia and used CIC communicated a feeling of physical safety for not having to transfer onto the toilet and others stated the safe feeling by not having to worry about incontinence. All the participants stressed the importance of awareness about the option of this urinary diversion to all newly injured population with SCI. Eight of the participants were actively involved in peer mentoring and advocacy for the surgery. Nine of them suggested that this option should be discussed with women with SCI while they are in rehabilitation.

Summary

This chapter elaborated on demographics, detailed data collection, and data analysis in response to the research question: What are the lived experiences of the women with spinal cord injury who choose to undergo urinary diversion surgery? QoL emerged as an influential theme indicating the importance of getting the urinary diversion surgery for women with SCI. They shared that bladder management was the major barrier in life after they suffered SCI to live a functional life. After surgery, they felt the independence and convenience, which along with health and aesthetics were the contributing factors to their QoL. They regained personal identity issues such as confidence, privacy, dignity, and sexuality after the urinary diversion procedure. They also perceived that they felt safe and closer to normal body with the change in bladder management after surgery. The analysis suggested that 9 out 10 participants did not get any recommendation or information from healthcare providers. They appreciated the social support from peers. They were unaware of this procedure until they learned from other women with SCI.

Chapter 5 includes an interpretation of the results, limitations of the research, implications for social change, and comments on the scope of future studies.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

SCIs are life-changing, traumatic injuries; they often result in paralysis for life. There is a lot of research on men with SCI—SCI is more common among men—but very few studies on women with SCI (NSCISC, 2013). And although bladder function is critical[?], there is limited discussion about bladder management in women after SCI. Bladder management issues in women are entirely different from those in men because sitting in a wheelchair makes it difficult to gain proper anatomical access for catheterization . To help women with bladder management after SCI, one of the options is urinary diversion surgery, although it is not offered widely by healthcare providers. There are no studies in the literature that reflect awareness about this procedure among women with SCI. Therefore, understanding the lived experiences of women with SCI will help healthcare providers better recognize the importance of urinary diversion surgery in improving both physical and psychological well-being. Sharing these experiences with providers who care for women with SCI will improve access to this procedure. This study of lived experiences of women with SCI could help other recently injured women; it could also help healthcare providers consider urinary diversion as an option for bladder management.

In the current study, 10 women between the ages of 35 and 56 with SCI and urinary diversion surgery discussed their lived experiences with bladder management before the surgery and how their lives changed after the surgery. A generic qualitative design was used to answer the research question using. Data were collected using semistructured phone interviews. The researcher transcribed each interview and used the Colaizzi phenomenology method to analyze the data. Nvivo 10 software was used for data management. QoL and peer social support were the two themes that emerged out of the transcript analysis. Nine of the ten participants had been unaware of the urinary diversion surgery as an option;, they learned about the surgery through their network of other women who had undergone it. All of them expressed satisfaction with their decision to undergo urinary diversion surgery. Most aspects of their lives improved after the surgery. The collected data suggested that all participants shared a substantial increase in QoL, irrespective of their level of injury. Depending on the means of bladder management prior to surgery, the reasons to appreciate surgery were different.

Interpretation of Findings

Cognitive adaptation theory and earlier research on SCI can be used to explain the findings. Cognitive adaptation theory (Taylor, 1983) hypothesized that individuals who experience a tragedy make efforts to adapt cognitively or regain the psychological ability to function. Mona et al. (2000) used cognitive adaptation theory to explore sexuality after spinal cord injury.

The theory states that an individual faced with a personal tragedy or a traumatic experience the person adjusts to the event or tragedy or trauma to overcome the threat and restoring the previous psychological functioning. The experiences of the participants of this study reflect their adaptation from the traumatic experiences of their spinal cord injury. Cognitive Adaptation Theory includes three stages a person moves through: (a) understanding the meaning of the traumatic/life-threatening experience, (b) putting an effort to overcome the experience and regain control over the life of the affected person, and (c) attempting to use self-enhancing appraisals to build back their self-esteem (Taylor, 1983). The theory relies on the assumption that the individual will go through the three stages and in the stated order. The human nature to overcome threatening situation leads to achievement of a high QoL characterized by satisfaction and happiness.

QoL

The primary essence of the participants’ responses suggested that most participants indicated improvement in their QoL because they gained independence after they got the urinary diversion surgery done for bladder management. This finding confirmed research from Pazooki et al. (2006) that the individuals able to self-catheterize through the abdominal stoma while sitting in a chair resulted in enhancement of their QoL significantly. Earlier research suggested that independence is the highest priority for quality life of women with spinal cord injury (Akhavan et al., 2007; Hammell, 2010; Walsh, Troxel, & Stone, 2004). For instance, P3 stated, “I can honestly say my surgery was an enormous success, ‘Huge’life changer, I was certainly not be as happy and comfortable with myself as I am after the surgery.” P5 stated, “It completely changed my life, I do feel a lot more independent.”

Many participants articulated that they had experienced a lot more convenience after the surgery. This finding further supported the research by Yavuzer et al. (2000) who showed least compliance with intermittent catheterization protocol in women with tetraplegia and paraplegia was seen due to inconvenience to self-catheterize and being dependent on caretakers. Using the abdominal stoma to catheterize after urinary diversion surgery makes it convenient to self-catheterize. P4 commented that it’s just so convenient, and it has changed my life immensely.

Most participants stated that they came to accept their disability after the injury, but bladder management was the major barrier that limited them from lead a fulfilling active functional life. P2 shared, “I had almost accepted the situation, but I always had to worry about bladder till I got the surgery done.” This finding resonates with research findings by Hammell (2010) suggesting that bladder management takes the highest research priority for individuals with neurogenic bladder after SCI. The participants who used indwelling catheter noted that they could wear different types of clothes without worrying about the tubing or urine bag. P8 stated, “I just didn't like that as I like to wear skirts, shorts, and tights. So it didn't go with my fashion sense either. The bags are smelly; they don't get cleaned properly. Now I can wear a bathing suit not having to worry about a visible tube.” This finding supported the research by Gillenwater (2001) that suggested aesthetics was a common theme with women after SCI with an indwelling catheter for improved QoL.

Almost all participants talked about the improved health with minimum urinary tract infections and no hospitalizations due to autonomic dysreflexia. One of the participants stated, “I have not had bladder infections in the last 15 years after surgery, which is remarkable. I can alleviate one of the major discomforts that is a urine infection. I feel like I have my body much more healthy because of having that surgery.” Hellenthal et al. (2009) had also suggested that the urinary diversion surgery reduced the usage of antibiotics and number of hospitalizations due to chronic urinary tract infections decreased. This finding supported the research by Akhavan et al. (2007) that suggested reduced incidence of UTI after the surgery.

Almost all of the participants indicated that they felt confident to move about and present themselves in public. One participant stated, “It has given me confidence, and I don’t look so needy in front of people.” This finding suggests that the surgery helped the women gain confidence that is an important aspect for women with SCI. The research by Seung-June, Shin, Paik, Yoo, and Ku (2006) concluded that women with SCI have lower confidence compared to normal population. The participants who were managing bladder with CIC shared that the self-catheterization through stoma after urinary diversion surgery helped them maintain dignity and privacy by not having to undress with the assistance of a caretaker. One participant explicitly commented, “Obviously, it’s not fun to have to open your legs to someone for every time you had to pee. So you can say, it gave me my dignity and privacy back.” These findings supported the research by Akum (2005) that showed that adjusting to the indwelling catheter is a challenge because of pain associated with its use, the loss of dignity. The participants who used indwelling catheters for bladder management stated that CIC through stoma eliminated the tubing and bag that helped their sexuality. One of the participants shared, “I just could not imagine that I could be able to have sex and enjoy it. Being sexually active is a little bit easier with the surgery and less cumbersome without the tubes and bags and bladder infections.” These findings supported the research on women with SCI by Hwang, Yi, Park, and Kwon (2012), which suggested that participants perceived definite improvement in their sexuality after urinary diversion surgery.

The urinary diversion surgery in these women resulted in physical convenience which improved their QoL and independence. The surgery helped these women regain control over their life and helped build self-esteem. Thus, the surgery was crucial in assisting the participants to get to second and third phase of cognitive adaptation of the traumatic life event. One of the participants stated, “It completely changed my life, I do feel a lot more independent.” Another participant stated, “It has given me confidence, and I don’t look so needy in front of people.”_All these comments highlight the fact that surgery helped the progress of all these different participants along the cognitive adaptive theory.

The relevance of cognitive adaptation theory was highlighted in participant #6 interview. The participant had spent 17 years with SCI prior to having the urinary diversion procedure. She had already adapted to her injury. She was functioning relatively independently and going to school when she decided to undergo this surgery. The surgery acted like a catalyst and allowed her to progress in the Stages 2 and 3 of adaptation as highlighted by her comments,

> My clothes can fit a little bit better; they don’t have to be as big to hide the bag. I used to wear a size bigger to fit the catheter tubing and the bag. So I think, getting a little bit girlier with the clothes. I can wear clothes little bit tighter fitting. So a vanity thing. I really tell people that it is a vanity surgery. And to more to feel like closer to normal.

The surgery allowed her to get to the last stage of cognitive adaptation, building self-esteem. This is reflected in her comments,

> I know, I am single and if I were to be married. I would feel much more comfortable with having this surgery to manage my bladder than Foley. I’m not at that point yet but if and when it happens I think that would be a huge thing for sexuality.

This example clearly demonstrates that for this participant, the surgery acted as an accelerator to further her adaptation and bring her closer the last stage of cognitive adaptation psychologically. This theme is repeated to ~~a~~ varying degrees in all the comments made by participants in this study.

Many participants reflected that using stoma for CIC for bladder management after urinary diversion surgery made them feel that they were going to use restrooms like normal able-bodied people. The comments from one participant indicated, “I hate to say that it makes me feel so more normal, but I think that is the easiest way to put it.” Another participant stated, “I feel like my body looks more normal, I don't have a tube sticking out of me. Just because you are paralyzed does not mean that you look like you are a hospital patient.” The findings of previous research by Hwang, Yi, Park, and Kwon (2012) suggested that sense of normalcy and safety was enhanced for many of them. Brown and Randle (2005) suggested that some individuals view urinary diversion procedures to aid them in leading a normal life.

Normalcy of life is more relevant to stage II of cognitive adaptation theory as the person tries to gain control over their life. Statements like, “I feel like my body looks more normal, I don't have a tube sticking out of me. Because just because you are paralyzed does not mean that you look like you are a hospital patient”, highlight this fact clearly. The surgery enhances and stimulates advancement of the cognitive adaptive process by providing physical normalcy, which translates into psychological regain of control of life.

Social Support

The participants were not aware of the choice to get urinary diversion surgery as a way to bladder management until they came to know from other women who had it done. Almost all of them stressed the importance of awareness and concern that they had to live and bear discomfort until they chose to get the surgery done. One participant commented,

> I have been a peer mentor for maybe 13 years. I've been a very strong advocate for the procedure. Just knowing how much better your life can be afterward, better in the sense of freedom, mobility, and being unrestrained. I think it has made me scream off the roof.

Another participant stated,

> I didn't find out about it until much later when I was in rehabilitation because none of the professionals told me about it. My urologist did not tell me about it. I found out from other women with spinal cord injury because I would ask them questions about how do you get around, how do you manage. In turn, I do peer support now.

Most of the participants have been involved in peer support now and create awareness about urinary diversion surgery as an option for bladder management for the other women with SCI.

The fact that the majority of the participants are involved in peer support indicates that the surgery helped move these women into the last stage of cognitive adaptation. Their self-esteem and awareness is at a level where they can share their experiences and outcomes with others in the society and feel comfortable and strong about it. This indicates restoration of feeling of normalcy and well-being since they are able to project to other peers and offer support to them.

The one universal suggestion that almost all participants mentioned was about dissemination of education regarding the possibility of urinary diversion surgery procedure. According to a comment from P3, “Doctors should tell people when they are in rehabilitation. I remember meeting a woman from Australia, who had this procedure done while she was in rehabilitation. Only 6 months post injury.” The participants suggested that the healthcare providers including rehabilitation physicians and therapists should be talking to women about this surgery as an option before they get discharged to go home. One participant also suggested that not only women with quadriplegia and paraplegia can benefit from this surgery but also men with paralysis can reduce the risk of bladder cancer. She stated,

> Even men, I have talked to them about having suprapubic tube kind of surgeries. I had a dear friend that I met when I was in rehabilitation down in Miami few years ago, and he died of bladder cancer. It was a wake-up call for me that any time I met someone and counseled newly injured person that this is something they need to consider.

The findings from study by Persson and Hellstrom (2002) also accentuated the need for deeper understanding of patients' experiences in order to enable health care staff to prepare and support them to adapt to their new situation during the post-operative period. These findings also supported a study on Korean women with SCI recommended development of effectual nursing interventions for improving QoL among women with SCI (Hwang, Yi, Park, & Kwon, 2012).

Limitations of the Study

The interviews were conducted via phone and the collected demographic data did not seek the geographical information of the participants. Geographical variations in care can affect lived experiences. Telephone interviews did not capture information about observation of body language and that some participants may not be comfortable expressing themselves on the phone. This research is based on obtaining qualitative data via phone interview and is dependent on interviewer's skills. Since I am a novice researcher, my lack of experience adds a limitation to the qualitative data gathered for the study. I did not have experience in using phone interviews for data collection. I used an interview questionnaire but felt limited in observation of expression and body language. I sent the transcripts to participants and confirmed with them that I had transcribed verbatim and captured their thoughts. The emerging themes were shared back with the participants for accuracy of interpretation, thereby completing a member check.

The data were obtained by phone interviews and was thick qualitative data. Peer review was not carried out secondary to lack of peer resources and this may reflect weakness/bias in the interviews. Since the data were collected with one interview, triangulation with different time points could not be carried out to validate the lived experiences. Only one theory of cognitive adaptation was used to explain lived experiences hence triangulation of different theories was not used.

This study focused mainly on bladder management issues and experiences, and there can be other concerns influencing the perception of QoL of these women that were not considered in this study. The qualitative perceptions in the thick data obtained with interviews could have influence from other factors in participants' lives. These factors were not explored or sought in this data collection.

Recommendations

The results of this study may be used as the groundwork for future research to include more participants and expand on the outcomes of the urinary diversion surgery experiences using quantitative or mixed methods. I intend to publish this research in healthcare journals so that the healthcare providers including rehabilitation doctors, urologists, neurosurgeons, physical therapists, and psychologists review the results of this study and suggest urinary diversion surgery as an option for women with SCI. In future studies, the sample may include participants from different geographical areas and provide different perspective.

The quantitative approach using standardized QoL surveys with larger sample size may provide supporting and stronger empirical evidence to suggest the impact of urinary diversion surgery on the life of women with SCI. Recommendations for future studies are to compare economic evaluation and experiences of women with SCI who undergo urinary diversion surgery with experiences of women with SCI using other forms of bladder management.

Implications for Social Change

The implications of this study for positive social change comprise better understanding of the experiences after urinary diversion surgery to improve mental and physical health of the women with SCI and their caretakers. The ability to gain independence, confidence, feel close to normalcy, and higher life satisfaction after getting the urinary diversion surgery done helps to lead a more enriched life for women with SCI. The decrease in urinary tract infections contributes to lower cost of medical treatments (Hellenthal et al., 2009). Autonomic dysreflexia leads to life-threatening situations and hospitalizations for women with SCI who use indwelling catheter to manage their bladder. After urinary diversion surgery, women do not have to go through such situations (Krassioukov, Furlan, & Fehlings, 2003). Research indicates that indwelling catheter increases chances of bladder cancer in individuals with SCI (Groah et al., 2002; Kalisvaart, Katsumi, Ronningen, & Hovey, 2010; Welk et al., 2013).

Urinary diversion surgery can help to eliminate the use of indwelling catheters, thus improving lives of individuals with SCI. The ability to self-catheterize decreases the need for the long attendant hours hence reducing the financial burden. Publications and presentations of lived experiences of women with SCI who chose urinary diversion surgery will help healthcare providers understand the impact of this surgery on women with SCI and to offer the surgery as a choice to manage the bladder after SCI. This surgery has been considered as cosmetic procedure by insurance companies and not covered unless certain codes are used indicating medical need for the surgery. The study may help in policy recommendation for funding of this procedure and encourage peer support programs, so people can learn from others in similar situations.

I plan to make conference presentations at American Spinal Injury Association (ASIA), International Spinal Cord Society (ISCOS), American Congress of Rehabilitation Medicine (ACRM), and Society for Disability Studies, and/or National SCI conference. I also would try to publish in journals: *Topics in Spinal Cord Injury Rehabilitation*, *Archives of Physical Medicine and Rehabilitation,* and/or *Spinal Cord, Disability and Rehabilitation.*

Conclusion

Traumatic SCI has a significant impact on a person with varying levels of paralysis. A generic qualitative research design was used to understand the lived experiences of women with SCI who choose to undergo urinary diversion surgery to manage their bladder. The primary question that guided this research was to understand the change in life of women with SCI after the urinary diversion procedure. The theoretical foundation guiding this study was Cognitive Adaptation Theory. The cognitive adaptation perspective lends itself to view efforts to adapt cognitively or regain the psychological ability to function after an individual experiences a tragedy. There were significant challenges to face for a person with SCI for the whole life. The most significant challenge for women with SCI being the bladder management in addition to other life adjustments; urinary diversion surgery is a good option to manage the bladder. It helps women with spinal cord injuries become independent, functional, confident, and live a healthier life with fewer UTIs and free of fear of autonomic dysreflexia. Results from the study were consistent with findings from previous literature that revealed bladder management is the highest priority for QoL of an individual after SCI. Urinary diversion procedure improved QoL, perceptions of normalcy, safety, confidence, privacy, dignity, and sexuality. The participants had cognitively adapted to accept their life after SCI and had been trying to live a functional life by choosing urinary diversion surgery for bladder management for better QoL. This was consistent with the cognitive adaptation theory. Findings of this study confirmed the results of the earlier studies on this topic.

This study fills an important gap in the literature for experiences of women with SCI after urinary diversion surgery. This study clearly shows that urinary diversion surgery is significant accelerator in progressing adaptation towards normalcy and independence in women with SCI leading to improved QoL. Even participants who have adapted to SCI for a long time showed further cognitive adaptive gains after the urinary diversion surgery. The results of this study can help health care providers such as urologists and rehabilitation clinicians to understand the need of this surgery for women with SCI, hence discuss and recommend this surgery. The study may help in policy recommendation for funding of this procedure and encourage peer support programs so people can learn from others in similar situations.

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Appendix A: Interview Questionnaire

Understanding the Lived Experiences of Women with a Spinal Cord Injury Who Undergo Urinary Diversion Procedures

START TAPE RECORDER HERE

INTRODUCTION:

The purpose of this interview is to learn more about your experiences living with a spinal cord injury specifically focused on bladder management. With your permission, I would like to use a tape recorder. Be assured that what you say will be held in the strictest of confidence. Keep in mind, there are no right or wrong answers. I am interested only in how you experience your life. If you feel you can't answer a question, or would prefer not to, we can move on to the next question. We can take a break whenever you need one.

After Spinal Cord Injury

1. Let us start talking about your injury. When did your spinal cord injury happen?
2. How would you describe your injury? In terms of level of injury.
3. About how long were you initially hospitalized for treatment and care related to your spinal cord injury?
4. What was bladder management like for you then? How did you empty your bladder? Did you need assistance and if so what kind of assistance?
5. After your injury, how were you able to manage an independent lifestyle with respect to your daily life?
6. During that time what barriers limited you from moving about freely or prevented you from achieving what you wanted out of life?

After Urinary Diversion Surgery

1. How long after your injury did you have urinary diversion surgery? What made you decide to undergo the surgery?
2. How was your experience with the urinary diversion surgery?

Impact of surgery on life

3. How has urinary diversion surgery changed your daily routine?
4. Overall how has this surgery made you feel about yourself as an individual?
5. Is there anything else you would like to share about your bladder care experience that we have not talked about?

Following demographic questions will be asked in case they have not already been answered during the interview:

1. How old are you? _____How old were you at the time of injury?_____
2. How many years of education have you completed? What schooling, if any, did you complete after your surgery?_____
3. Did you work before your injury and if so what type of work did you do? ____Did you work after your injury______ after surgery _____what type of work do you do?____
4. What is your current marital/partner status?__ What was your marital/partner status before the injury?__
5. Who currently lives with you in your house (relative, personal care attendant)?
6. Do you have children and if so how many children do you have? ________________
7. Were any of your children born after you got injured? ____
8. How do you currently pay for your healthcare?

Appendix B: Recruitment letter

If you are a female with Spinal Cord Injury and have undergone a urinary diversion surgery procedure, you are invited to participate in a study

My name is Sukhpinder Dhillon. I am a doctoral student at Walden University. I am working on my dissertation as part of the degree PhD in Clinical Psychology. My topic is Understanding Lived Experiences of Women with Spinal Cord Injury Who Undergo Urinary Diversion Procedures.

The purpose of this research study is that your narrated experiences will identify bladder management concerns before and after the urinary diversion that influence the day to day life of women with spinal cord injury. This will facilitate better understanding of the experiences of women with spinal cord injury and possibly inform development of better bladder management programs.

You may be eligible for this study if you are a woman, who had a Spinal Cord Injury that lead you to urinary bladder management concerns and you chose to undergo urinary diversion surgery and are able to speak and understand English. I would like to interview you by phone per your convenience. I would be asking you about your experiences with bladder management before and after the surgery.

It is important to know that this letter is not to tell you to join this study, but instead to inform you that it is happening and to see if you are interested in participating. It is your decision. Your participation is voluntary. You will receive $25.00 Starbucks gift card as a token of my appreciation for your participation in the study. If you are interested in learning more, please contact me via email and I can send more information and consent to you to sign. You can also call/text me at 804-837-8383

You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you. Feel free to pass this letter on to other women with spinal cord injury you may know who have also had the urinary diversion procedure and may be interested in participating.

Thank you for your time and consideration. I look forward to hearing from you.

Sincerely,
Sukhpinder Dhillon