

Transfer-related experiences of people with spinal cord injury living in low socio-economic, independent living communities in Johannesburg as seen in the context of relationships of personal assistance - A phenomenological study.

By

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LIST OF ACRONYMS

AD	Assistive devices
ADL	Activities of daily living
CRPD	Convention on the Rights of Persons with Disabilities
DSD	Department of Social Development
EoC	Ethics of Care
ILC	Independent Living Community
MVA	Motor vehicle accidents
PoPI	The Protection of Personal Information Act
PWSCl	People with spinal cord injury
ROM	Range of motion
SCI	Spinal cord injury
SES	Socioeconomic status
SPH	Safe patient handling
WHO	World Health Organization

ABSTRACT

This dissertation begins from the research question “How do the nature and availability of transfers influence the lived experiences of people with spinal cord injury (PWSCI) in low socio-economic independent living communities (ILC) in the context of personal assistance relationships?” Transfers here, refers to the need for people with severe mobility impairments to be lifted or otherwise assisted in moving between locations such as bed and wheelchair, wheelchair and toilet, wheelchair and vehicle, and so forth. “Personal assistance means that users of such service exercise the maximum control over how services are organised, and custom-design their services according to their individual needs, capabilities, life circumstances and aspirations” (Ratzka, 1992, p.1). PWSCI, as is the interest of this study, have unique insights into their disability and their context. In terms of international human rights conventions, PWSCI are entitled to have control over their lives and therefore must participate in the form of consultancy on issues that concern them directly. Many PWSCI are dependent on assistance from others for transfers during activities of daily living (ADL). ADL refers to everyday activities such as rising, dressing, washing, toileting, eating, and so on. In the lives of PWSCI, access to the means of performing ADL equates, in reality, to access to the means of survival. In low socio-economic communities, it is likely that personal assistance is performed by unpaid family members or friends, or low remunerated untrained personal assistance providers, rather than paid, professionally trained employees. Unpaid / low remunerated and untrained personal support has implications for i) the ready availability of transfers, ii) the safety of transfers, and iii) reciprocal dynamics of care and accommodation within the relationship.

PWSCI represent a large portion of the South African population. Besides those already stated, a body of research shows that PWSCI may face particular limitations and obstacles in fulfilling of ordinary or normal life. These obstacles

may include negative attitudes, structures of normalcy and ableism, and environmental barriers to access for PWSCI. These obstacles may influence how PWSCI construct their identity within relationships of personal assistance. Also, the voices and own experiences from the perceptions of PWSCI are not always heard and not given political recognition.

This research aimed to explore the transfer-related experiences of PWSCI, in the context of personal assistance relationships, during activities of daily living. A qualitative study was conducted, and focused on the experiences and perceptions of nine PWSCI living in low socio-economic independent living communities (ILC) in Johannesburg. A semi-structured interview was used for data collection, and a Qualitative Thematic Analysis was applied to analyse the data. Ethics of Care (EoC) was a useful theoretical approach adopted in exploring the lived experiences of PWSCI in the interest of their taking back agency within relationships of personal assistance, being free of any assumptions and perceptions about impairment and their ability. Furthermore, the aim of an EoC approach is to foster inclusion, respect and dignity, and systems of influence and power, influencing the experiences and personal perceptions of PWSCI living in low socio-economic independent living communities (ILC).

The results of this study revealed that PWSCI find living with a spinal cord injury not being a barrier to living a fulfilling life but instead, emphasised barriers created through stigma and negative attitudes from relationships within personal assistance and communities as a whole. These serious barriers to self-expression and fulfilment come in the form of stigma of disability, ableism, negative perceptions, and the pervasiveness of the medical model. How PWSCI feel about their belonging in their society and taking back their agency in relationships of personal assistance, was found to be representative of how they respond to negative social constructions of disability within care relationships, and their communities as experienced during daily transfer-related activities.

The study revealed the importance of the need for accredited training for personal assistance providers to prevent secondary injury for PWSCI and care providers alike, and to create conducive working environments for care providers. Conducive working environments may include body mechanic training, appropriate assistive devices for safe lifting and moving of PWSCI. Furthermore, conducive working environments may contribute to positive attitudes and perceptions toward PWSCI. Access to allocated state resources will facilitate PWSCI to procure accredited, trained, paid care. The vocation of personal assistance providers should be organised, available and accredited.

CHAPTER 1: INTRODUCTION

1.1 Background of the study

In the World Report on Disability, various barriers that exist within healthcare, rehabilitation, support and services, physical environments, education, and meaningful employment, are described. These barriers can prohibit people with disabilities¹ to participate in society. While much has been done to improve the lives of people with disabilities, the World Health Organization (WHO) acknowledges that there is still a lot that remains to be done. Evidence in the World Report on Disability submits that many of these barriers are avoidable and that the difficulties related to disability, if dealt with, can be overcome by involving people with disabilities regarding their needs (WHO, 2011). People with disabilities often have unique understanding regarding their impairment and their circumstances, as they are masters of their own experiences, and therefore must be consulted on issues that concern them and their lives (WHO, 2011; UN, 2006).

PWSCI with high lesions are reliant on personal assistance for providing support within ADL (Pires, Garcia & Florex-Revuelta, 2015). One important aspect of that assistance is the issue of transfers (Hignett, Crumpton, Ruszala, Alexander, Fray & Fletcher, 2003). Transfers take place in various situations of ADL and involve a person with spinal cord injury² (PWSCI) being transferred between two locations (Skoglund-Ohman & Vayrynen, 2013). Unsafe transfers lead to potential injuries (Hignett et al., 2003). Examples of transfer situations risking injury include transferring between bed and wheelchair, wheelchair and

¹ The terminology 'people with disabilities' in the context of this study will be used instead of 'persons with disabilities' as described in the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006)

² The terminology 'people with spinal cord injury' and 'people with disabilities' are both used here as many references are made to people with disabilities in general. However, the study participants of this study were people with spinal cord injury and will thus be referred to as such.

shower chair, or wheelchair and toilet (Hignett et al., 2003; Skoglund-Ohman & Vayrynen, 2013). In addition to simple tasks related to personal care and hygiene, ADL include feeding, bathing, dressing, grooming, and moving without danger (Pires et al., 2015). ADL therefore refer to everyday tasks that individuals generally learn in early childhood (Hignett et al., 2003). In the lives of PWSCI, access to the means of performing ADL equates, in reality, to access to the means of life (Kittay, 2011). Relationships of assistance in disability may be both barriers and facilitators (Shields & Synnot, 2016) to the well-being of people with disabilities, and are reciprocal in nature (Kittay, 2011). Reciprocity is defined as the practice or behaviour in exchanging things or help between people for mutual benefit, such as privileges or advantages granted by one group or person to another (Merriam-Webster.com).

When a spinal cord injury (SCI) occurs, damage (short-term or permanent) to the spinal canal nerve-endings, or any part of the spinal cord may be caused (Nas, Yazmalar, Sah, Aydin & Önes, 2015). Damage to the spinal cord causes changes in muscle, and thus strength, sensation, and other body functions below the location of the injury (Nas et al., 2015). In low socio-economic communities, which are more common in the Global South (Hunt & Watermeyer, 2017), it is likely that care assistance is performed by unpaid family members or friends, rather than paid, professionally trained employees. This has implications for i) the ready availability of transfers, ii) the safety of transfers, and iii) reciprocal dynamics of personal care assistance and accommodation within the relationship. Across all societies, and cultures, unpaid care is synonymous with women's work, and take greater responsibility than men (Esplen, 2009).

According to the Human Rights Commission Research Brief on Gender and Equality in South Africa (2013-2017), measured in terms of income and wealth, South Africa remains the most unequal country in the world (SAHRC, 2017). In South Africa and globally, women have been subjected to multiple

discrimination due to the intersection of different characteristics such as gender, age, religion, ethnicity and disability and thus accorded lesser importance than men in terms of social and power relations (Goldblatt, 2014; SAHRC, 2017). In response to gendered inequality, the value of 'non-sexism' is provided for in the Constitution of South Africa (1996). However, according to the South African Human Rights Commission (SAHRC, 2017), basic gender divisions of labour, both paid and unpaid, continue to be important in many communities of interdependent individuals. Women are being defined in relation to motherhood. Thus, the responsibility for providing food and education, and caring for others, contributes to women's unfavourable position in labour markets and the formal economy (DSD, 2015; SAHRC, 2017). Women that perform unpaid care bear a large unequal, undervalued, and unappreciated burden. In South Africa, poverty also contributes to the vulnerability of women, particularly for those living in rural areas, often resulting in women falling victim to violence, abuse, ill health and vulnerability to HIV/AIDS (Goldblatt, 2014). Often gender based violence is not only focussed against women and girls but also directed against people as a result of their sexual preference and orientation, gender expression and identity (Eyben & Fontana, 2011).

In the context of changing dynamics of human relationships, more specifically, relationships of unpaid or paid untrained personal assistance providers, the argument in my thesis will be that an EoC model is a useful theoretical basis with which to approach the research question to give insights about the transfer-related experiences in the lives of PWSCI.

This study therefore seeks to report on transfer-related experiences through the descriptions provided by the study participants. The study seeks to understand how people living with spinal cord injury (PWSCI) perceive their transfer-related experiences of activities of daily living (ADL). Phenomenology, a qualitative research method, will be used to describe how we as human beings, and in context of this study, PWSCI, experience a certain phenomenon. This will be

presented through detailed accounts (stories) obtained through semi-structured in-depth interviews. A descriptive approach facilitates hearing about everyday lived experiences of people going about their lives. Minimal research exists regarding subjective accounts of lived experiences of PWSCI in the context of transfers in low socio-economic independent living communities, as is the interest of this study. The goal is thus to discover the universals underlying the inter-subjectively experienced phenomenon (Munch et al., 2014).

1.2 Context of the research

The next passages give background to instruments and standards of protection for all rights that are undeniable of people with disabilities. A discussion follows on the impact of high costs and expenses associated with disability, impairment and care, as contributing factors of exclusion of PWSCI and their participation in society. Inequities that South Africans living with impairments face in terms of independent living and the fluidity in relationships of unequals, as seen in experiences of PWSCI, forms part of the discussion. A brief introduction is made to study participants and independent living.

The South African Constitution promotes the right to equal opportunity for people with living with impairments (DSD, 2015). South African instruments by which to ensure the implementation of policy on the rights of people with disabilities include the Employment Equity Act (1998) and United Nations Convention on the Rights of Persons with Disabilities (CRPD). The South African Employment Equity Act (1998), defines people with disabilities as people who have a long-term or recurring physical, including sensory, or mental impairment which substantially limits their prospect of entry into or advancement in employment. The CRPD has been acknowledged as being a developmental tool that affirms the inherent dignity of every person regardless of disability or difference thus obliging societal support for individual freedom and equality to

all vulnerable groups of people who need it (UN, 2008). The CRPD is a human rights treaty and was ratified by South Africa in 2007 (DSD, 2015). The guiding principles of the CRPD (UN, 2006) offers sufficient standards of protection for all rights of people with disabilities. These rights are alienable and include the civil, cultural, economic, political and social rights (UN, 2006). Protection of these human rights are on the basis of inclusion, equality, and non-discrimination. Article 3 of the CRPD refers to respect, non-discrimination, equality of opportunity, equality between women and men, effective participation in society, accessibility, and respect for children with disabilities to preserve their identities and acceptance. (UN, 2006).

Costs and expenses associated with disability and impairment are in many instances exorbitant, resulting in many people living with impairments particularly in low-income communities to remain impoverished and often without the bare essentials to facilitate a decent life (DSD, 2015). To determine the financial and economic costs associated with living with an impairment, the South African National Department of Social Development (DSD) conducted a study in 2015. The objective of this study was to promote the rights of people with disabilities and speed up the implementation of the CRPD. The study recognised the lack of reasonable accommodation unfair burden on people with disabilities and on their families who often have to bear the associated costs which negatively affects their development economically by reducing their productivity potential (DSD, 2015). The study found that people with disabilities on average, held a lower educational status, thus less likely to be employed, resulting in less income for their households, especially people with disabilities with higher support needs as a result of their impairment. Impairment type, level of support needs and economic status have a direct bearing on spending. Major driving factors with bearing on spending included transport costs, personal assistance, communication devices and maintenance of assistive devices (AD). The study found that households with people with high needs for caregiving and support emerged as the most economically vulnerable resulting in

marginalisation from community participation (DSD, 2015). Exclusion has complications for access to education for children with disabilities.

In South Africa, the Disability Grant available for people living with impairments amounts to R1,700 per month. However, to be eligible for the grant, people with disabilities must be between 18 and 59 years and must be found medically unfit for work. The WHO (2011) states that globally people living with impairments are criticised, diminished and excluded from full societal participation (WHO, 2011). In South Africa, people living with impairments face multiple forms of inequity in respect of access to health care services, employment and education (DSD, 2015). The findings of the 2015 study conducted (DSD, 2015), states that although social grants reduce income gaps of households with and without members with disability, there is a need to improve accessibility, reasonable accommodation and support services. Key points highlighted by this DSD study that would promote the reduction of economic vulnerability, include, improvement of access to inclusive education for children with disabilities; intervention for care providers to enable them to provide for their families; to facilitate an increase in independence and thus reduce economic vulnerability, and access to affordable AD and support. The report also stated that access to affordable, accessible transport would promote improvement for access to education, employment, and healthcare services for people with disabilities. Without sustainable employment opportunities, improved health services for people with disabilities, and reviewed disability grant and tax rebates, improvement of the lives of the most economically vulnerable in lower and middle-income groups, will not be possible (DSD, 2015).

According to the 2011 survey conducted by Statistics SA, the national disability prevalence rate is 7.5%. The survey reveals that, comparing females and males, disability is more prevalent amongst females (8.3%) than males (6.5%) (StatsSA, 2011). Furthermore, this 2011 survey indicates that aging contributes

to more people with disabilities. StatsSA (2011) study states that 53.2% (more than half) of people reported to having a disability in age bracket 85+.

The participants in this study consist of nine PWSCI living in low socio-economic independent living communities in Johannesburg. In the present study, study participants consisted of seven males and two females living in low socio-economic independent living community homes (ILC). The objective of these ILC homes is to facilitate PWSCIs self-sufficiency, dignity through independence with care and community participation. ILC homes aim to foster people living with SCI to show the solutions they want and need to be in control of their lives, as they are the best experts of their own needs (Alonso, 2003). ILC homes aim for PWSCI to be in charge of their own lives through speaking and thinking for themselves, to support each other, and learn from one another (Ratzka, 2003). Independent living encourages people living with impairments to organise themselves to work for political change that may lead to legal protection of their human and civil rights (Barnes, 2003). Independent living is a movement of people living with impairments working for self-rule, self-respect and equal opportunities. Independent living means that people living with impairments demand the same choices and control in their every-day lives that abled-bodied people take for granted (Ratzka, 2003; Barnes, 2003).

Participants sustained injury through motor vehicle accidents (MVA), swimming accidents and/or acts of violence that left them with damage to the spinal cord to varying degrees. After rehabilitation, some participants returned to their familial homes where they received personal assistance from unpaid family members. Due to varying degrees of poverty, two study participants were unable to return home and had to seek alternative accommodation where they would receive personal care assistance. Further discussions regarding participants demographics follow in chapter 4. The next passages discuss the significance of the study and frame the impact of a lack of adequately trained,

paid care for PWSCI as seen during their daily transfer-related activities, in unpaid and low remunerated care work.

1.3 Significance of the study

Much is known about medical and rehabilitation aspects of the care of spinal cord injury (SCI), but very little is known about the experiential aspects of PWSCI within the context of transfers in ADL. Compared to the global North, in the global South there is not enough data on care-receiving and caregivers do mostly not have formal training in personal assistance care for PWSCI.

Care-related activities may be seen by society as 'women's work', and are part of relationships that may be undervalued or unpaid (Brear, Shabangu & Kelleher, 2016). According to the DSD (2015), in South Africa, prevailing gender norms indicates that girls and women mostly undertake the majority of unpaid care work. These caring activities generally include food preparation, cleaning, collecting fuel and water and looking after older family members and children, educating children and caring for the sick (DSD, 2015). As a result of large amounts of women and girls' time spent on unpaid care, their participation in the job, social and economic spheres, are restricted (Eyben & Fontana, 2011). Often the adverse causation of the lack of leisure time coupled with the drudgery associated with care, lead to negative influences on the wellbeing of women and girls' resulting in undesirable health outcomes. Additionally, women in the paid labour market, may also not be able to satisfactorily substitute their care responsibilities to family members who require care, which in turn implicate the type of care and human development outcomes of their families (DSD, 2015). In the context of unpaid care work, hard work increases as the demand and need for unpaid work increases, as experienced during an economic downturn. Further broad increases in unpaid care work are due to a rapidly ageing population, migration, and the impact of HIV/AIDS (DSD, 2015). This increase

is especially evident at a time when girls' education and women's paid work increases (DSD, 2015). Research shows that unpaid care work is still largely invisible in South African public policy even though a large body of evidence exists about the extent of unpaid care work done by women and girls and their contribution to human development and the economy (Eyben & Fontana, 2011). It may, therefore, appear that unpaid care work and girls and women's economic empowerment or devaluation have a direct relationship with a cause and consequence of the other (DSD, 2015). According to research in the global north, as an occupation, care work is devalued, and care work exposes individuals to high risks of violence (Kelly, 2017).

According to the WHO (2011), disability is both a cause and consequence of poverty. Economic hardship may be directly linked to disability when a person becomes impaired. Impairment may have a direct impact on poverty through potential job loss or exorbitant additional expenses incurred due to impairment (WHO, 2018), as seen in this study. After becoming impaired, the lives of study participants changed drastically. Additional costs lead to reduced earnings, and many other challenges that lead to economic hardship (Palmer, 2011) for participants in this study.

The United Nations Office of the High Commissioner for Human Rights defines human rights as "... rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination". Human dignity is an individual sense of self-respect and self-worth, physical and psychological integrity and empowerment (WHO, 2011). Human dignity is inherent to every human being, inalienable and independent of the state (UN, 2006).

Examples of maintaining dignity in the lives of individuals who require assistance with ADL may include allowing people to choose their own clothing, and to participate in decisions directly related to their care (Kung, 2018). Dignity

is also demonstrated through proper communication when addressing another person adequately. A further example of showing respect for another person's dignity may include, providing food that is cooked with precision, taste and presentation, that will not negatively affect the person for whom the meal has been prepared, (Kung, 2018). Dignity is to respect personal possessions and personal spaces, and to deal with hygiene activities in a gentle and sensitive manner (WHO, 2011).

A study of experiential accounts will deepen our understanding of how the impact of poverty on the nature and availability of transfers, in context of personal assistance, affect the transfer-related experiences of PWSCI living in low socio-economic independent living communities during the performance of ADL. This understanding may enhance the visibility and economic contribution of PWSCI, inform policy, better service provision, and enhance care for PWSCI.

1.4 Research problem

To my knowledge, no previous data has been gathered which explores the transfer-related experiences of PWSCI in the context of personal attendance relationships, in low socio-economic independent living communities in South Africa. Instead, studies have concentrated on clinical issues, such as rehabilitative interventions to improve the quality of life (Noel et al., 2011; Power-Cope et al., 2008); community reintegration, and the influences by clinical and system processes across the continuum of care (Santos et al., 2013). Research has also focussed on professional development within clinical care (Walker, 2009) and acute care management within rehabilitation (Walker, 2008).

In addition, research studies have concentrated on the implications of functional activities with a focus on the range of motion (ROM) within activities of daily

living (ADL) (Young, 1993); including, upper extremity pain after spinal cord injury (Dalyan et al., 1999); and transfer independence amongst PWSCI (Nyland et al., 2000). Other studies have concentrated on examining the depictions of the sexuality of people with physical disabilities (Hunt, 2018) and the sexuality and culture of women with disabilities in Africa (Peta & Ned, 2019).

To improve the lives of PWSCI, they need recognition as economic contributors to society (DSD, 2015). And thus, PWSCI need to share their experiences and needs for being treated with dignity and respect in the context of personal attendance relationships. Personal accounts in the context of care relationships may promote visibility in both their care situations and society as a whole. To improve the lives of PWSCI visibility through recognition, will aid their call for an emphasis on policies and practices by government and healthcare authorities to focus on the needs and issues of isolation (WHO, 2011; DSD, 2015). In this way, PWSCI may become more visible in society to live inclusively and equally in their homes and communities. The experiences of invisibility and disablement can be profound (Watermeyer, 2016; WHO, 2011; DSD, 2015).

1.5 Research question

The research question guiding this study is:

How do the nature and availability of transfers influence the lived experiences of PWSCI in low socio-economic independent living communities in the context of personal assistance relationships?

1.6 Research aim

The research aim is to explore the transfer-related experiences of PWSCI, in the context of personal assistance relationships, living in low socio-economic independent living community (ILC) homes in Johannesburg, during activities of daily living (ADL).

1.7 Research objectives

In order to fulfil this research aim, the following objectives will be undertaken

- 1.7.1 Performing a literature review on data available regarding the transfer-related experiences of PWSCI and the fluid personal assistance relationships within their daily experiences;
- 1.7.2 Ensuring all ethical considerations, obtaining preapproval from UCT's Faculty of Health Sciences Human Research Ethics Committee and the Non-Profit Organisation and Members based in Johannesburg
- 1.7.3 Gathering data through semi-structured personal interviewing of PWSCI;
- 1.7.4 Transcribing of individual in-depth, semi-structured interviews;
- 1.7.5 Analysing the data by means of interpretive phenomenological analysis (IPA) in context of this study, and in so doing, maintaining privacy and confidentiality as per the Personal Informational Act (PoPI); and abiding by UCT's ethical and trustworthy considerations and approvals;

1.7.6 Dissemination of the data will be discussed with the Non-Profit Organisation and its members / study participants in this study.

1.8 Outline of thesis chapters

This thesis consists of five chapters. Chapter 1 comprises the introduction and background to the study and SCI, and the context of personal assistance as experienced by PWSCI during transfers in ADL in low socio-economic independent living communities. Chapter 1 also gives a brief background to the context of this study concerning the study participants experiences regaining and maintaining respect and dignity.

In Chapter 2 the literature is discussed regarding models and frameworks for understanding disability and impairment, and models of care that support personal assistance from an EoC perspective. The literature review looks at theories of justice where dignity and independence are linked to justice and considered to be preconditioned to the well-being of PWSCI, while also criticising the idealisation of independence. This chapter highlights the issue of control over the kind of personal assistance provided. The literature also examines the emotional trauma of PWSCI owing to exclusion from unmet personal assistance needs and being neglected by health and social care service providers, as well as the detrimental effects on PWSCI of the lack of formal support and reasonable accommodation, all of which impact the needs and visibility of PWSCI in their families and communities.

Chapter 3 describes the chosen research design to answer the research question. This chapter explains the selected approach, which is phenomenological, to investigate human experiences in the context of unpaid and paid personal assistance relationships, and give insights from participants' perspectives, thus challenging standard assumptions about disability and

impairment. This chapter describes the location of the data and the demographics of the study participants. Furthermore, this chapter outlines the inclusion and exclusion criteria, sampling method and sampling size, and recruitment of study participants. The methodology is defined and outlines selection of study participants, data collection and analysis and monitoring thereof.

Chapter 4 describes the findings of the study. To reflect the participants' experiences rigorously, the range of topics coded and related in this study became broader than suggested and described in the semi-structured interview schedule. Themes that emerged from the data included social isolation and abandonment by the system, funding and equitable care, independence, and self-management at the care provider level, help versus disempowerment, holistic and appropriate care, poor communication and coordination of care at the health system level, tensions within personal assistance relationships, private versus public tensions and rigid rules and policies.

Chapter 5 concludes this thesis. This final chapter summarises the findings herein and references the importance of future research about the topic that relates to PWSCI voicing their needs and experiences during ADL in the context of personal assistance relationships. I believe that the opportunity to share their experiences and requirements for maintaining dignity and respect and having the choice of being in control of their assistance, may clarify what it takes to create a society that is accessible through reasonable accommodation within transfer-related experiences of PWSCI as seen in relationships of personal care.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Before we begin, it is necessary to make the following note on terminology, as these ideas will be used throughout this chapter and beyond³. The distinction between disability and impairment made by the architects of the social model of disability takes the following form: impairment is seen as the functional limitations affecting the body, whereas disability is seen as the loss or limitation of opportunities which result from injustices and discrimination resulting from societal processes affecting individuals with impairments (McKenzie & MacLeod, 2012).

This review starts by providing a sketch of key concerns of disability in the international realm and Southern context, followed by an overview of models and frameworks for understanding disability and impairment, and models of care that support dependence from an EoC perspective and critique thereof. Arguing for equity in personal assistance relationships, an EoC approach may show how relationships within personal assistance and dependency bring about autonomy for people with disabilities. Autonomy is defined as “the right or condition of self-government, the freedom from external control or influence;

³ The social model has its origins in the 70s and was developed by people with disabilities, and used as a political platform to secure the rights of people with disabilities to ensure full citizenship within modern societies (Winance, 2016). The 1976 manifesto document of the Union of the Physically Impaired against Segregation (UPIAS) in Britain, was the most noticeable contribution in the development of the social model of disability (Shakespeare, 2002), and places emphasis on the notion of the social dimension and importance of disability as a socially constructed phenomenon in the definition of disability.

independence; the act of power of making one's own choices or decision” (Merriam-Webster.com).

An EoC approach and research which addresses the lack of descriptive accounts in Global South contexts (Hunt & Watermeyer, 2017) regarding the changing dynamics of power and agency in care relationships may assist to empower people with disabilities in understanding their options and care needs better. This understanding may inform policy and better service provision for people with disabilities in the area of relationships within personal assistance. In this review, the capacity for independence for people with disabilities will be highlighted and critiqued. A description of the relationships between disability and poverty will be given, explaining their interactive effects on PWSCI. In the context of ever-shifting dynamics in human relationships and emotional trauma related to SCI, everyday interpersonal pressures on personal assistance relationships as experienced during transfers in ADL are highlighted.

2.2 Introducing Disability and Impairment

Across the world, people with disabilities' lives have historically been characterised by prejudice and power inequalities, resulting in social exclusion of those people who do not belong due to visible differences (Watermeyer, 2009). Disability is an evolving concept and is experienced as a result of the interaction of a variety of factors, such as the individual's health condition, and personal and environmental factors, but mostly as a result of experiences of interaction with society where exclusion is experienced (WHO, 2011). According to the WHO (2011), 15% of the world population are affected by disability, while less than 0.1% have SCI.

Due to the complex nature of SCI, an enormous amount of physical, financial and psychological tension may be placed on the personal assistance provider

or family (Lee, Cripps & Fitzharris, 2014). Eva Kittay (2011), American philosopher and scholar of disability studies, cautions that the need for autonomy and dependency in care relationships for people with disabilities should be seen as positive care. Kittay explains:

According to the most important theories of justice, personal dignity is closely related to independence, and the care that people with disabilities receive is seen as a way for them to achieve the greatest possible autonomy. However, human beings are naturally subject to periods of dependency, and people without disabilities are only 'temporarily abled'. Instead of seeing assistance as a limitation, we consider it to be a resource at the basis of a vision of society that is able to account for inevitable dependency relationships between 'unequals' ensuring a fulfilling life both for the carer, and the cared for (Kittay, 2011, p.1).

Discrimination and denial of individuals' socio-economic contribution via exclusion is an infringement of a person's basic human rights (Morris, 2005). Therefore, for reasons of equity and overcoming inequalities, there is motivation for researchers to engage people with disabilities to collect experiential accounts from their perspective, and, in so doing, allow for wants and needs of this community to be voiced (Wee & Paterson, 2009). Theories of justice and dignity for PWSCI form the centrepiece of the care discussion.

The next sections give a brief introduction to key pieces of international and South African law relevant to disability and inclusion.

2.2.1 Disability and global human rights

To advance the rights of people with disabilities globally, disability rights movements across the world have been lobbying for the adoption and

implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). The CRPD has been described as a global human rights' treaty which introduces new, original ideas (Degener, 2016). Article 1 of the CRPD (UN, 2006) states that the purpose of the CRPD is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity". The CRPD (UN, 2006) seeks to bring about a paradigm shift in policies for people that assumes a new understanding of people with disabilities as rights holders and human rights subjects (Degener, 2016).

2.2.2 Disability, the law and human rights in South Africa

The CRPD (UN, 2008) facilitated the implementation of programmes and policies regarding the rights of people with disabilities in South Africa. Nevertheless, significant gaps in knowledge regarding the experiences of people with disabilities, their families, and their environment still exist. As a result, opportunities for success in ameliorating the lives of people with disabilities are limited (Department of Social Development [DSD], 2016).

The South African Constitution (1996) recognises and promotes equal fundamental rights of all people and confirms the autonomous rights of dignity, equality, and self-determination (Watermeyer & Swartz, 2006). The South African White Paper on the Rights of Persons with Disabilities (DSD, 2016) foregrounds the concerns of what it takes to create a society that is accessible and makes equal opportunities available for all. The key concepts seek to achieve disability-coherence and implementation throughout all government policy integration processes. These key concepts include the protection of the most vulnerable groups of people living in South Africa, especially women, girls, and people with disabilities. The South African White Paper (DSD, 2016) calls

for ensuring the integration of all vulnerable people into society and promote equal access to health and education for all ages, genders, races, ethnicities, religions, and cultures. The South African White Paper (DSD, 2016) calls for Government and all authority bodies to strive for the acceleration of the implementation of the CRPD through all spheres of life by acknowledging people with disabilities, showing respect and promotion of their dignity.

2.3 Models and frameworks for understanding disability

Over the last two decades, there have been challenges to dominant negative attitudes towards people with disabilities, and debates regarding the value of various theoretical approaches to disability (Enwereji, 2015). According to the CRPD, disability includes physical or mental conditions that may limit a person's movements, senses, or activities (UN, 2006). Disability refers to characteristics that may be severe, and consequently restrict or prevent regular ADL (UN, 2008). The CRPD (2006) defines disability as "... long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder [the person's] full and effective participation in society on an equal basis with others" (UN, 2006).

In the western world, the history of disability has been identified by the progressive development of various models of disability, with the medical or individual model (Oliver, 1990) and the social model being the two dominant models (Enwereji, 2015). Disability research has notably evolved over the past few decades and shifted from an individual to a social approach of disability, thereby placing people with disabilities within a social context (Winance, 2016). Models of disability lead to different perceptions of people with disabilities and society, and concepts of disability and the condition of being 'normal' (Retief & Letsosa, 2018; Winance, 2016). In order to bring about change for people with disabilities, and to transform their societal contribution and the notion of

autonomy and dependency on care, it is important to take a brief look at the history of the medical and social models, the two dominant models of disability, and their achievements and shortcomings in improving the circumstances of people with disabilities.

Models of disability stem from accompanying ideologies that provided the academic rationalisation for discriminatory practices and systematic exclusion of people with disabilities from mainstream economic and social life. (Finkelstein, 1980; Oliver, 1990; Barnes, 1990, 1991, 1997; Gleeson, 1999). In the following passages, the history and shortcomings of the medical model and the social model of disability are discussed, as well as the EoC approach that considers autonomy and dependency as ways of improving the lives of people with disabilities.

2.3.1 The Medical Model of Disability

Before the emergence of disability studies, twentieth-century academic and institutional researchers focused on a medical approach to people with disabilities based on a biomedical view (Watermeyer, 2010). Disability was thus seen as a problem of dysfunctional bodies (Watermeyer, 2010; Shakespeare, 2014). This view led to much discrimination, resulting in the social and economic marginalisation of people with disabilities (Watermeyer, 2010).

The term 'medical model' was coined by R. D. Laing, a psychiatrist in his work 'The Politics of the Family and Other Essays' published in 1971, for the 'set of procedures in which all doctors are trained' (Laing, 1971). The medical model of disability replaced the moral and/or religious model due to significant advancement in medical science (Retief & Letsosa, 2018). Mike Oliver (1990), a British academic, author, and disability rights activist, Emeritus Professor of Disability Studies at the University of Greenwich, states the following:

The idea of the individual and the social model was taken quite simply and explicitly from the distinction originally made between impairment and disability by the Union of the Physically Impaired Against Segregation (1976). I wanted to put this distinction into a framework that could be understood by professionals with a limited though expanding knowledge of disability issues. The individual model for me encompassed a whole range of issues and was underpinned by what I call the personal tragedy theory of disability. But it also included psychological and medical aspects of disability; the latter being what I prefer to call the medicalisation of rather than the medical model of disability. In short, for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component (p2).

The name 'medical model' is controversial, and some writers prefer to use the term 'individual model' instead, and refer to 'medicalisation' to describe how biomedicine can take a reductionist view of disability (Watermeyer, 2009). The individual model of disability or personal tragedy model focuses on the division of people who are disabled and non-disabled (Retief & Letsosa, 2018). This focus differentiates between levels of intellectual, behavioural, and social functioning to determine whether individuals should receive medical intervention to improve the effects of their disability in their lives in order to attain the highest form of normality (Retief & Letsosa, 2018). Any deviation from the perspective of what one ought to be, able-minded or able-bodied, is to be considered abnormal and thus necessitates treatment and rehabilitation (Shyman, 2013). The individual model intensifies limitations through hierarchical and inequitable relationships by assigning tremendous power to medical professionals over individuals or patients, through the decision-making processes of who does the curing and who receives the treatment (Shyman, 2013; Hughes & Paterson, 1997). The individual model is thus rooted in biomedicine which views impairment as a problem of dysfunctional bodies and

neglects the reality of environmental and other discrimination (Watermeyer, 2010). For this reason, it is also known by some as the medical model which focuses exclusively on the individual's disability and therefore limitations associated with impairment, completely disregarding inaccessible environments that may negatively affect an individual's functional abilities (Oliver, 1990). Critique of the medical model is thus centred on the excluded social factors which influence the way in which impairment is experienced from the viewpoint of the disabled person (Watermeyer, 2010).

In response to these problems, the so-called 'social model of disability' emerged in the United Kingdom in the 1970s. According to Oliver (1990), the origin and evolution of the social model of disability are as a result of disabled people themselves rejecting all the principles of the medical model. The origin and fundamentals of the social model of disability, its shortcomings, and arguments for the adoption of EoC as a theoretical approach to improve the lives of people with disabilities are the next topics of discussion.

2.3.2 The Social Model of Disability

The social model was developed by people with disabilities in the 1970s in response to the individual or medical model and the effects that exclusion and lack of choice had on their lives (Watermeyer, 2010). The individual or medical model did not articulate experiences of people with disabilities, nor did it help to develop more ways of inclusive living (Oliver, 1990). The social model was used as a political platform to secure the rights of people with disabilities to ensure full citizenship within modern societies (Winance, 2016).

The 1976 'Fundamental Principles of Disability', the manifesto document of the Union of the Physically Impaired against Segregation (UPIAS) in Britain, was the most noticeable contribution in the development of the social model of

disability (Shakespeare, 2002). The UPIAS document (1976) places emphasis on the notion of the social dimension and importance of disability as a socially constructed phenomenon in the definition of disability which is as follows:

[D]isability is a situation, caused by social conditions, which requires for its elimination (a) that no one aspect such as incomes, mobility, or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (p. 3).

The phrase 'social model of disability' was coined by Mike Oliver in 1981 (Shakespeare, 2002, p. 28). Oliver draws attention to the social aspects of disability, more notably to the environmental limitations imposed on people with disabilities (Oliver, 2015). "The social model of disability has been used extensively in disability research over the years to explain social barriers affecting the rights of people living with impairments, and their ability to participate in society" (Oliver, 2015). Furthermore, the social model underscores the cultural and economic barriers encountered by people with disabilities (Watermeyer, 2010). In the context of the social model, disablement is considered to be society's responsibility resulting from social exclusion (Oliver, 2015; Watermeyer, 2010).

Jenny Morris, British academic and Professor of Social Work and Social Policy, (Watermeyer, 2010), holds that:

The social model of disability gives us the tools not only to challenge the discrimination and prejudice we face, but also to articulate the personal experience of impairment. Recognition of difference is therefore a key part of the assertion of our common humanity and of an EoC, which promotes our human rights. The cornerstone of this foundation is the

recognition that the language we use is central to the way we interpret our experiences (p1).

Morris (2001) explains the distinct language adopted by The British Council of Disabled People to distinguish between 'disability' and 'impairment':

Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. (Therefore, disability, like racism or sexism, is discrimination and social oppression). Impairment is a characteristic, feature, or attribute within an individual which is long term and may or may not be the result of disease or injury and may 1. affect that individual's appearance in a way which is unacceptable to society, and/or 2. affect the functioning of that individual's mind or body, either because of, or regardless of society, and/or 3. cause pain, fatigue, affect communication and/or reduce consciousness (p3).

Morris (2001) holds that people with disabilities are people with impairments disabled by society. One of the significant contributions of the social model was to show the structural dimension of inequality related to disability, and how this links to how society organises itself (Winance, 2016). The social model locates the person's impairment within society due to society's failure to provide suitable accommodation and appropriate services for people with disabilities (Watermeyer, 2010). The social model, therefore, seeks to remove these disabling societal barriers that restrict life choices for people with disabilities (Winance, 2016) by promoting social inclusion (Watermeyer, 2010). Although it is the inherent right for legal protection which would improve the social positioning (Watermeyer et al., 2016) of people with disabilities, there is much debate among researchers living with impairments and people with disabilities about whether the social model's primary aim to address disability through adopting social change and a human rights perspective has been achieved (Winance, 2016). The social model of disability claims that people with

disabilities are not disabled by their impairments but by the socially-constructed disabling barriers (Oliver, 2013). Equality within the social model helped to develop and strengthen the notion to recognise and remove persistent societal barriers (Watermeyer, 2010). Societal barriers include negative attitudes and images of people with disabilities, inaccessible transport, and the inaccessible built environment, which perpetuate the exclusion of people with disabilities from participation in the mainstream of social activities (Watermeyer, 2010). Inclusion underscores the need for all individuals to enjoy equal communal participation as a precursor to the active voicing of community needs (UN, 2006).

The social model of disability has made a limited impact on the labour market, although many immobilising barriers in the international labour market have been identified (Oliver, 2013). Some disability scholars and critiques of the social model question the applicability and worth of the social model (Watermeyer, 2009; Kroger, 2009; Shakespeare, 2002; Thomas, 2002). They argue that there is no place for impairment in the social model and claim that this model of disability fails to take account of difference and presents people with impairments as a universal group (Watermeyer, 2009; Kroger, 2009; Shakespeare, 2002; Thomas, 2002).

Even though individuals experience marginalisation in different ways, being part of a group labelled as different from broader society causes individuals to be at greater risk of being excluded (Oliver, 2013; Oliver & Barnes, 2012). Thomas (2002) argues that the medical model of disability assumes that disability is therefore a 'tragic anomaly' that affects a minority group of people (Oliver, 1986). This general assumption characterises much of the medical, social and educational behaviour towards people with disabilities (Oliver, 1990; Watermeyer, 2016). This common notion of disability also shapes the structures of environments in which people with disabilities find themselves during their everyday lived experiences (Oliver, 1990; Watermeyer, 2016). For example, the

inaccessibility of transport systems and buildings, and the way in which institutions are organised (Marks, 1999), further perpetuate individuals' social exclusion (Watermeyer, 2013; Shakespeare, 2014).

Critique of the social model is centred on the fact that this model ignores the reality of the body, and the importance of personal lived experiences and agency of people with disabilities (Watermeyer, 2014). It is based on these premises that this study argues for an EoC approach that considers the human relationships and moral conflict which are fundamental in the lives of people with disabilities requiring care to achieve autonomy and independence (Winance, 2016).

2.3.3 Ethics of Care (EoC)

EoC is rooted in feminist theory, and was coined in the 1980s by psychologist Carol Gilligan (Sander-Staudt, 2006). Care ethics is focused on the interconnectedness of people and believes that context can sometimes overrule justice (Barnes & Henwood, 2015). The EoC approach places moral significance on relationships, focusing on the roles of caregiver and care-receiver (Barnes & Henwood, 2015). Care is often seen as a practice, value, or disposition (virtue) and frequently portrayed as an overlapping set of concepts (Sander-Staudt, 2006). Care involves meeting the needs of ourselves and builds on the motivation to care for others who need care (Barnes & Henwood, 2015). Care ethics is regarded as a political theory and social movement that extends beyond the private and intimate spheres of life (Sander-Staudt, 2006). As a political theory, care ethics investigates questions of social justice, based on concepts of human rights and equality (Sander-Staudt, 2006). Social justice includes legislation and the distribution of social benefits and burdens, governance and claims of entitlement (Sander-Staudt, 2006). Human rights in the context of this study is concerned with agency and choice, with the ability of

people to make their own choices and participate unhindered in activities (McKenzie & MacLeod, 2012). According to Gallagher et al. (2008), key dignity promoting factors include caregiver attitude and behaviour, environment, the performance of specific care activities, and the culture of care.

EoC extends beyond individualism and independence, foregrounds relationships and interdependence, and assumes that we have a responsibility to one another (Shakespeare, 2002). Kittay (2011) suggests a different model of ethical interaction that positions the dependent individual at the centre and emphasises the reciprocity of interactions between equals. Kittay (2011) argues that a theory of justice (such as that of Tronto, 1993) needs to be supplemented with the EoC approach. The ability to give and receive care is a basis for self-respect for individuals when framed in the EoC approach (Winance, 2016). Care can represent elements of labour, attitude, or virtue. During a condition of need, labour represents maintenance of others and ourselves. Labour necessitates caregivers to have knowledge and skill that the care-receiver needs and will accept. Care, as an attitude, is seen to be positive and an investment in another person's well-being. The aim of an EoC approach is to foster inclusion, whereby all individuals within a network are included as respected members (Kittay, 2011).

The argument for EoC, an approach for equity in care relationships, will show how care relationships and dependency bring about autonomy (self-rule) for people with disabilities. An EoC approach looks at the notion of autonomy and dependency of people with disabilities in a positive manner, in that all human beings need to receive care from others to live at some point in their lives, and thus find themselves vulnerable or dependent on others (Kittay, 2011; Winance, 2016). Dependence is thus seen as generating care and not as a state of weakness or power (Winance, 2016). This is in contrast to the medical model notion of disablement due to an impairment or difference which embodies dependency as vulnerability, charity-seeking and pity for people with disabilities,

and the social model notion of disability causation by way of societal organisation (Watermeyer et al., 2016).

In this study, I argue for an EoC approach that considers the predicaments experienced in human relationships that PWSCI face during transfers in ADL by personal assistance care. According to leading theories of justice, being in control of one's care is seen as a way for people with disabilities to obtain the highest possible independence (Winance, 2016). EoC extends beyond individualism and autonomy, foregrounds relationships and interdependence, and assumes that we have a responsibility to one another (Kittay, 2011).

Joan Tronto, professor of political science at the University of Minnesota, defines an EoC approach as follows:

An EoC is an approach to personal, social, moral and political life that starts from the reality that all human beings need and receive care and give care to others. The care relationships among humans are part of what mark us as human beings (Tronto, 2009).

2.3.4 Critique of models that prize independence

In most leading theories of justice, dignity is linked to the capacity for independence (Kittay, 2011). A person's independence is typically a precondition to their well-being (Kittay, 2011). However, when people with disabilities find themselves reliant on others for self-care, financial security, and safety, this lack of independence can seem to threaten dignity (Kittay, 2011). Instead, disabled people pursue their right to live independent lives and to be afforded equal justice and care that is given to non-disabled people (Kittay, 2011). Kittay (2011) does, however, clarify that not everybody can or ever will live independent lives.

According to Kittay (2011), care providers co-exist with the people they care for and thus exert direct control over their lives. Caregivers control the kind of care provided as they hold direct power over intimate details of the care-receiver's life that may only be shared with those closest to them. Care, for both the caregiver and care-receiver is stigmatised by dependence, as the impairment requires a carer for the disabled individual to live life. This is particularly evident in a world where independence is the norm of human functioning (Kittay, 2011).

However, Kittay (2011) raises concern about an approach that praises independence as the path to a dignified life and views dependence as negative to the person. The idealisation of independence is considered problematic, not only for the disabled individual, but for all people. The importance of choice excludes disabled people with an intellectual disability, for whom making choices is difficult (Kittay, 2011).

2.4 Human Rights Approach

Human dignity forms the foundation of human rights (Kung, 2018). Dignity carries aspects of notions such as integrity, self-worth, personal honour and status (Hauskeller, 2018). Contravening the human rights of a person occurs when denying the fundamental rights to respect and dignity of people with disabilities (UN, 2006). The WHO (2011) defines human rights as protecting the dignity and thus individual rights of a person, from any other discrimination that prohibits their rights, and mental damage, that sickens or hurts (WHO, 2011). Human dignity is inborn in every human being and similarly, therefore, is the individual sense of self-respect, self-worth, physical and psychological integrity and empowerment (WHO, 2011; UN, 2006).

Disability is viewed as an issue of social justice. Exploring a human rights approach in the context of the CRPD (UN, 2006) illustrates how inequality is maintained through societal barriers and negative attitudes. According to the South African White Paper on the Rights of Persons with Disabilities (DSD,

2016), a human rights approach provides the required context for action on human advancement through social justice, development, and quality of life for every person. The human rights approach explains how social barriers impact the lives of people with disabilities (Gavin-Dreschnack et al., 2005). Social barriers are contributing factors to secondary health conditions in physical activities, and activities of daily living (Gavin-Dreschnack et al., 2005). Factors contributing to the lack of community integration, and societal participation include, amongst others, negative attitudes of a non-disabled society, inaccessible buildings, ramps, and curbs causing secondary medical complications (Gavin-Dreschnack et al., 2005).

Attitudinal barriers perpetuate discrimination against people living with impairments as they are characterised as being without the capacity to participate as active citizens (Morris, 2005). Consequently, they are denied the universal right to citizenship (Morris, 2005; Wilson, 2006). If people with disabilities are not seen as valid contributors to society, and therefore denied social rights, and cultural recognition, Morris (2005) questions how they would be encouraged, and supported to gain experience, and make a contribution in the market sector or employment. Discrimination, and denial of individuals' socio-economic contribution via exclusion are an infringement of basic human rights (Morris, 2005). Moreover, for reasons of equity, and overcoming inequalities, there is motivation for researchers to engage people with disabilities to explain their lived experiences, and context (Wee & Paterson, 2009). It is crucial to understand what people with disabilities experience in terms of what affects their lives by seeking their accounts, giving them a 'voice' concerning the underlying views, and values of their experiences (Wee & Paterson, 2009).

According to the CRPD (UN, 2006), the Universal Declaration of Human Rights, and the International Covenants of Human Rights recognise the inherent dignity, and worth of all human beings. The CRPD (UN, 2006) states that these

charters recognise the rights of all human beings to be indistinguishable, and unchallengeable, and globally form the foundation for freedom, justice, and peace. It is furthermore recognised (UN, 2006) that all human rights are universal, indivisible, interdependent, and interrelated. A human rights approach therefore seeks to reinforce the capacities of duty bearers – governments – to respect, protect, and guarantee these rights (UN, 2006). A human rights approach aims to holistically address development complexities by considering the connections between individuals, and systems of influence, and power (UN, 2006).

This study investigated PWSCI in low socio-economic independent living communities, and thus it is important to discuss how poverty influences the lives of people living with impairments.

2.5 Disability and poverty

Poverty may be explained, and viewed in numerous ways (Palmer, 2011). A complex and interconnected relationship exists between disability and poverty (Trani & Loeb, 2010), and, consequently, each is a cause and consequence of each other (Palmer, 2011). However, regardless of their interrelated association, this relationship has not been well understood (Palmer, 2011). Poverty is mainly addressed through its measurement with an importance placed on the monetary metrics of consumption, whereas participatory poverty assessments normally focus on material well-being (Palmer, 2011; Trani & Loeb, 2010). Poverty is multidimensional as there is no single character that describes poverty, but numerous intertwining factors involving socio-economic status, geographical area and so forth (Palmer, 2011). Exploring the relationship amongst disability and poverty has significant consequences for policy design and social protection programmes. Poverty may be presented within approaches of basic needs, capabilities and economic resources

(Palmer, 2011; Trani & Loeb, 2010). These different approaches to poverty may have different consequences in the context of people living with impairments. Poverty is recognised as being one of the most important social factors that negatively impact the lives of people living with impairments (Watermeyer, 2010), as impairments and illness contribute to reduced earning power and thus associated higher daily living costs which diminish resources to buy equipment and/or personal assistance (Trani & Loeb, 2012). People with disabilities are therefore often compelled to become reliant on family or friends for assistance to go about their daily lives (WHO, 2011). Poverty causes disability through malnutrition, poor health services, and dangerous working and living conditions (Trani & Loeb, 2012). Poverty may therefore be a contributing factor in sustaining disability during the interaction of an individual (in the context of personal characteristics such as age, gender, ethnicity and impairment) and the environment (physical, social, cultural, political and economic) (Trani & Loeb, 2012). According to the WHO (2011) World Report on Disability, poverty has a direct correlation to barriers to assistance and support for people living with impairments. “The lack of effective financing for support – or its distribution within a country – is a major obstacle to sustainable services” (p.144). Due to poverty, often support services are paid by families and donations, including international assistance (WHO, 2011).

An introduction of the physical and psychological aspects of SCI will be presented in the following passages as background to this study’s participants’ daily lived experiences within transfer-related activities.

2.6 Spinal cord injury (SCI)

2.6.1 Physical aspects of SCI

SCI is a tremendous assault to the human mind, soul and spirit (Westie, 1987). A person who had been independent of care becomes dependent on others to meet their most basic needs (Tulsky, et al., 2015). SCI occurs when the spinal cord is severed or severely damaged as a result of compulsion, incision or contusion (Nas et al., 2015), and leads to paralysis from the site of the lesion in the vertebrae downwards (Kirshblum, et al., 2011). Approximately 40 million people worldwide are affected by SCI annually (Nas et al., 2015). The majority of people incurring SCI are typically young men between 20 and 35 years of age, with 1% of this population being children (Kirshblum et al., 2011).

Possible causes of SCI include trauma, inflammation, tumours, or illness such as polio, spina bifida and Friedrich's Ataxia (Rahimi-Movaghar et al., 2013). However, the most common cause of SCI is trauma, often sustained during motor vehicle and motorcycle accidents (Tulsky et al., 2015). Worldwide, the most common causes of SCI are traffic incidents, gun-shot injuries, knife injuries, falls, and sports injuries such as diving (Nas et al., 2015; Kennedy, Cox, & Mariani, 2013). Unusually, in South Africa, violent crime is cited as the cause of SCI in more than half of the cases (Rahimi-Movaghar et al., 2013), with gunshot wounds ranking the highest, followed by stab wounds. Categories of paralysis as a result of SCI include paraplegia and quadriplegia (also referred to as 'tetraplegia') (Kirshblum et al., 2011). The term paraplegia refers to thoracic and lumbar or sacral impairment, and excludes cervical function (Nas et al., 2015). Depending on the level of injury, paraplegia results in impairment of the trunk, legs and pelvic organs, with no consequence to arm functioning. Quadriplegia results in impairment of function which affects the level below the neck and chest area, including the four extremities (Nas et al., 2015). Rahimi-Movaghar et al. (2013) report that paraplegia is more prevalent (58%) than quadriplegia (40%) among people living with SCI in developing countries. SCI

has a huge impact on independence and results in many other complications, both physical and psychological, which are linked to a person with a SCI's life expectancy and quality of life (Nas et al., 2015; Power-Cope et al., 2008).

SCI results immediately in life-changing consequences, and this may thus signify a long-term psychological adaptation process (Tulsky et al., 2015). For a PWSCI, immense psychological energy, and motivation is required to learn psychosocial coping skills, self-care, and independence (Nas, Yazmalar, Sah, Aydin & Önes, 2015). Emotional adjustment is thus vital to aid the recovery process resulting from SCI (Nas et al., 2015).

Shoulder pain is commonly reported by people with thoracic SCI, and said to be a contributor to falls during transfers (Alm et al., 2008; Salisbury et al., 2003). Shoulder pain limits participation in ADL, and mobility (Salisbury et al., 2003). However, the most serious consequence of shoulder pain is the contribution to falls during transfer-related activities (Alm et al., 2008; Kennedy et al., 2013).

2.6.2 Psychological trauma and recovery related to SCI

Many negatively perceived health-related changes due to physical complications occurring after SCI may contribute to psychosocial distress, and delay to societal integration (Nas et al., 2015). Health complications may contribute to extended hospitalisation, and thus exacerbate further experiences of limitations within ADL.

Emotional responses such as grief and loss may be part of an individual's reaction to sustaining a SCI, which may be expressed in the form of "anger, guilt, anxiety, sadness and despair" (Tulsky et al., 2015, p.262). For some, these feelings lead to depression, involving feeling sad, hopeless, helpless and

worthless, while, for others, feelings of anxiety, such as panic, fearfulness and hyperarousal, are more prominent (Tulsky et al., 2015, p.262).

2.6.3 Emotional trauma owing to exclusion from participation in society

Social exclusion of the world's disabled population is linked to poverty, mass unemployment, discrimination, indignity and social prejudices (Watermeyer, 2014). Social participation comprises a person's ability to contribute to and participate in activities in a satisfying manner, in the domains of family, friends, work and leisure (Heinemann et al., 2015). Perceived independence and autonomy are also an important part of social participation, in the sense of our need to feel control and mastery in our lives (Tulsky et al., 2011). However, stigma and its psychological effects can impact people with SCI's quality of life (Power-Cope et al., 2008) through negative stereotyping, language and attitudinal barriers that lead to discrimination. Stigma relates to personally and publicly enacted opinions of self, negative attitudes, bias and judgment that result from visible manifestations of SCI (Russell et al., 2016). An emphasis on the emotional aspects of living with SCI are highlighted in this study. Research shows that negative attitudes towards disability may have particular implications for the quality of assistance and support (Shakespeare, 1996; WHO, 2011).

Next, the methodology employed in this study is described to explained how the research question was answered

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Research design

3.1.1 Introduction

For good research practice, a thorough study of methodologies is required. An important aspect to consider during the research design selection process is that authors often contradict one another, thus necessitating researchers to substantiate their selection of research design (Groenewald, 2004). In order to investigate human experience (Lin, 2013), a suitable explorative research design was required, which may restrict or prevent, my biases (Groenewald, 2004). The phenomenological approach was selected. Phenomenology is a retrospective attempt to discover the depth and richness of the study participants' fundamental experiences (Chuang, Yang, & Kuo, 2015).

The University of Cape Town's (UCT) online libraries hold a vast collection of titles on phenomenology, which were drawn on. The study design also included elements of an interpretivist approach to enrich the qualitative methods used to collect, and analyse data (Denzin & Lincoln, 2011). The concepts of phenomenology, and the qualitative research paradigm are discussed in this chapter.

The following passages explain how the study unfolded, including the selection of the topic, the research problem in the area of interest, and the research paradigm (Creswell, 1994; Groenewald, 2004).

3.1.2 Qualitative paradigm

The origins of the word 'paradigm' can be traced back to its Greek origin, 'paradeigma', and Latin origin, 'paradigma', denoting pattern, model for example (Groenewald, 2004). A paradigm is defined as the "patterning of the thinking person; it is a principal example among examples, an exemplar or model to follow to which design actions are taken" (Groenewald, 2004, p. 6). A research paradigm is defined by Denzin and Lincoln (2011) as "a basic set of beliefs that guide action" (p.157).

To reveal the essence (Lin, 2013) of everyday lived experiences of PWSCI, the qualitative paradigm was selected as it was the most appropriate approach to answer the research question. Of note here is that the characteristics of the qualitative paradigm, as opposed to those of the quantitative paradigm, allow for the exploration of a person's lived experience for deeper understanding (Denzin & Lincoln, 2011). Qualitative research was employed to advance the understanding of primary reasons, opinions, and motivations that provided insights into a problem (Groenewald, 2004). The qualitative research study aided the researcher to investigate and report the social phenomena that were explored (Denzin & Lincoln, 2011).

Phenomenology was thus employed to describe how the nature and availability of transfers influenced the experiences of PWSCI in the context of care (Denzin & Lincoln, 2011). Phenomenology as the research paradigm is explained next.

3.1.3 Phenomenology

"Phenomenology is the study of structures of consciousness as experienced from the first-person point of view. The central structure of an experience is its intentionality, its being directed toward something, as it is an experience of or

about some object” (Stanford Encyclopaedia of Philosophy). In phenomenology the interview serves the very specific purpose of exploring and gathering experiential descriptive stories that may serve as a resource for developing a richer and deeper understanding of a human experience. (Groenewald, 2004).

The origins of the phenomenological approach dates back to German philosophers, Kant and Hegel (Vandenberg, 1997). Edmund Husserl (1859-1938), German professor of philosophy, however, is regarded as the “fountainhead of phenomenology in the twentieth century” (Groenewald, 2004, p.3). Husserl’s most notable argument about phenomena was that people can be certain about how things present themselves to their consciousness (Groenewald, 2004). People’s realities are treated as pure and the only data from where absolute data, and thus phenomena begins (Denzin & Lincoln, 2011). This was the birth of Husserl’s philosophical research theory, phenomenology, which illustrates the science of pure phenomena, thus a theory of knowledge rather than a theory of metaphysics (Groenewald, 2004). The aim of the phenomenological method is therefore to be free from any assumptions or persuasions (Denzin & Lincoln, 2011). Phenomenology, which is derived from the Greek word ‘phenomenon’ meaning ‘appearance’, was therefore employed.

From the outset, the intention of this research was to gather data from the perspectives of study participants (Denzin & Lincoln, 2011) regarding the phenomena of influence of power and agency, and autonomy and dependence on human relationships by means of investigating how the nature and availability of transfers in the context of care relationships influenced the experiences of PWSCI.

In summary, phenomenology as a research paradigm, located in a qualitative research design, was employed in this study to describe the aim of the research as accurately as possible, the phenomenon of accounts of descriptive

experiences of PWSCI during transfers in ADL. In the next section, I discuss the research sample in a qualitative research design, describing how the study participants were located.

3.1.4 Location of the data

The study participants lived in low socio-economic independent living communities in Johannesburg. While no formal assessment of poverty levels was performed, participants in the study were broadly of low socio-economic status (SES) (Coppin et al., 2006). People with higher SES tend to enjoy better health than people with lower SES (Arrow, Bowles & Durlauf, 2000). SES is a complex measure, which, when formally assessed, includes economic status, measured by income, social status, measured by education, and work status, measured by occupation (Coppin et al., 2006).

For the purpose of this study, participants were viewed as living in low SES communities on the basis of i) dwelling in poorer neighbourhoods, and ii) not being able to afford 'professionally' trained paid care (Coppin et al., 2006). There is an important distinction here between 'paid care' and 'professionally trained and paid care'. In this study, participants trained domestic workers to assist with their daily care activities within their transfer-related activities. Professionally trained, paid care is generally more accessible by affluent communities due to the exorbitantly high costs (WHO, 2018) as discussed in section 4.3.2. The inclusion and exclusion criteria of the study are stated below.

In this study of PWSCI and their experiences of fluid care relationships, and predicaments thereof, as experienced during their daily living, the participants had to:

- a) be 21 years old or older;

- b) have been living with a SCI post-injury for a minimum of 3 years to ensure adequate experiences with numerous caregivers assisting with transfers during ADL;
- c) have had unpaid/paid caregivers such as a family member or friend assisting with ADL;
- d) be living in low SES communities in Johannesburg where professional paid care is inaccessible;
- e) have a basic understanding of the English language. (An interpreter would be available for translation if study participants do not have a basic understanding of the English language);
- f) have the cognitive ability to reason, understand and remember.

Exclusion criteria was based on the recognition of the following:

- a) Although I recognise that the study of people living with an intellectual disability is important as a research topic, it will not form part of the discussion in this study. I selected participants to be known not to have a cognitive disability.

The following sections outline the demographics of the participants, the time since their injury, their experiences after SCI and of rehabilitation at home in the context of care providers, and unpaid and/or paid care as defined in this study and in the context of study participants' current (time of interview) living circumstances.

3.1.5 Study participants - Demographics

Table 1 below depicts the number and demographics of the study participants, categorised by age, race and sex, and the time since their injury, and gives context of initial ‘unpaid’ care assistance after rehabilitation and subsequent ‘paid’ care assistance.

TABLE 1 – Demographics, time since injury, unpaid and paid care

Partici- pants	Demographics			Time since injury	Unpaid and paid care	
	Age- years	Race	Sex	Number of years since injury	Home care (unpaid care)	ILC (paid care)
SP1	23	White	Male	6	Yes – mother and brother	Yes
SP2	26	Black	Male	11	Yes – aunt	Yes
SP3	26	Black	Male	6	No – trained caregiver	Yes
SP4	48	White	Male	20	No	Yes
SP5	39	White	Female	15	Yes – father	Yes
SP6	44	Black	Male	8	Yes – wife	Yes
SP7	46	Black	Male	5	Yes – fiancé	Yes
SP8	41	Black	Male	11	Yes – wife and father	Yes
SP9	27	Black	Female	3	Yes – father	Yes

Note: Race was noted, due to post-apartheid in South Africa (SA), racial categories used by the former regime are still relevant as these reflect histories of inequality which persist in our demographic dispensation.

In order to maintain confidentiality and anonymity of the study participants, pseudonyms have been used. In table 1 above, the pseudonyms of the participants have been generated by using the alphabet letters 'SP' for 'study participant', and range from SP1 to SP9, representing the number and order in which study participants were interviewed.

The 'unpaid caregivers' referred to in table 1 above denote family members of the study participants, who have taken on roles of personal care assistants (Tharp, 2013). Personal assistance services are governed by the individual needs of the person living with SCI (Tharp, 2013), and may range from food shopping to meal preparation, toileting and bathing, and so on. Personal care assistants provide PWSCI with assistance within their ADL (Pires et al., 2015). Living with SCI and the need for personal care assistance may be challenging to both care provider and care-receiver (Tharp, 2013). Personal care assistants are also referred to as caregivers (Roth, Fredman & Haley, 2015) and may include spouses, parents, children, friends or paid caregivers (Tharp, 2013). Care assistance provided by family members typically includes unpaid care on an ongoing basis (Roth et al., 2015).

The 'paid caregivers' referred to in Table 1 above, were selected on a basis of either untrained caregivers that were previously employed as domestic assistants or referred to the ILC home by various types of organisation. These 'paid caregivers' fulfil both the roles of paid domestic worker and personal assistance provider. These domestic assistants have received in-house training by PWSCI themselves, to become caregivers providing care for the residents of that specific ILC home. As these caregivers were not professionally trained, they were remunerated by means of very low wages paid monthly by residents of these ILC homes. The fact that the caregivers were remunerated deviate

slightly from my initial intention to study unpaid care assistance. This study is still relevant as the essential concern of the study is the experience of PWSCI in environments where access to transfers is limited and potentially complex in terms of the navigation of relationships. Furthermore, I was interested not only in the study participants current experience in the environment they are living in, but their previous experience of care assistance in other environments Thus, the circumstances of these participants fulfil this description.

All study participants were, during the time of the interview, living in Johannesburg, in ILC homes with seven other residents with SCI, with care provided by previously unskilled domestic care assistants. SP1 is a 23-year-old man who has lived with SCI for six years. After rehabilitation, SP1 was cared for by his mother, younger brother and grandmother in certain circumstances, at his family home in Johannesburg.

SP2 is a 26-year-old man who sustained a SCI eleven years previously. SP2 was 15 years old at the time of his injury and came from a very resource-poor family in Kwa-Zulu Natal, with only an elderly grandmother as direct family. Due to poverty, SP2 was unable to return to his grandmother's home after his rehabilitation and was relocated to an alternative ILC-type home where a distant aunt was employed as a domestic assistance provider. She also contributed to her nephew's personal care as unpaid assistance. SP3 is a 26-year-old man who received home care assistance provided by a paid, trained caregiver within his familial home. SP3 has been living with SCI for six years. SP4 is a 48-year-old man, who, due to difficult familial circumstances, was unable to return to his family home after rehabilitation but moved into a formal ILC home in Johannesburg twenty years prior. SP5 is a 39-year-old woman, with fifteen years since injury, who had moved into her family home and, due to family dynamics at that time, received personal care assistance from her father. SP6 is a 44-year-old man, who has lived with SCI for eight years. Initial personal care provision at his family home was provided by his wife. SP7 depicts a 46-

year-old man who initially received personal care provision from his fiancé and other family members at their family home. He has been living with SCI for five years. SP8, as depicted in Table 1, is a 41-year-old man, who has been living with SCI for eleven years and initially received personal care provision from his wife and elderly father. SP9 is a 27-year-old woman, with three years since her SCI. This woman initially received personal care assistance from her father due to complex family circumstances.

3.1.6. Data gathering – sampling method

The study was introduced to a non-profit organisation in Johannesburg, with a member database consisting of PWSCI. The introduction was made through telephonic and then followed up with written contact (see Appendix 1). This non-profit organisation was requested to assist in identifying participants from their member database who had previously indicated that they were willing and available for third party research participation. Through convenience sampling, participants were selected from candidates recommended by the non-profit organisation according to the inclusion and exclusion criteria to avoid sampling bias, and participants' interest of participation. Once identified, the participants were contacted telephonically and by text message to explain the purpose of the study (see Appendix 2) and ascertain their interest and participation. More males than females were willing to participate in this research.

To answer the research question, convenience sampling (Etikan, Musa, Alkassim, 2016) was used. Convenience sampling is also known as a non-probability or non-random sampling method (Etikan et al., 2016). Initially, my intention was to use purposive sampling, however due to easy access to the study participants living in the same ILC home, convenience sampling was selected (Given & Given, 2008).

3.1.7 Semi-structured interviewing

To answer the research question, individual interviews with semi-structured questions were used to gain insights and knowledge into how the nature and availability of transfers influenced the experiences of PWSCI in the context of care relationships. Semi-structured interviews do not have a rigorous set of questions, but instead are open, allowing new ideas to emerge based on what the interviewee reports (Groenewald, 2004).

According to Barriball and While (1994), every research project consists of several phases, from the selection of topic to dissemination of the research findings. To mitigate error risk while increasing result credibility, researchers must take cognisance of the fact that each step within research may potentially influence the research output. It is argued (Barriball & White, 1994) that researching credibility, reliability and validity, are often exacerbated by employing semi-structured interviewing. However, there are advantages to employing semi-structured personal interviewing as a method for data collection (Barriball & White, 1994). The advantages of employing semi-structured individual interviews are:

- (1) that it overcomes potentially poor response rates resulting from questionnaire surveys;
- (2) that it is well suited to investigating people's "attitudes, values, beliefs and motives" (p. 329);
- (3) that, when discussing potential sensitive issues such as changing dynamics of power and agency in human care relationships, semi-structured interviewing provides validity evaluation opportunity through observance of non-verbal indicators;

- (4) that it facilitates comparability of similar question answering by numerous participants of the same study;
- (5) that it insures the study participant's opinion without external assistance from family or friends.

In this study, the flexibility of semi-structured interviewing ensured the collection of valid and reliable data from study participants for whom English was their second or third language (Groenewald, 2004; Barriball & While, 1994). Barriball and While (1994) further cite benefits of using semi-structured interviewing as a method to gather data, in that it provides the researcher/interviewer with a choice of wording while probing to retrieve information about interviewees' daily lived experiences of changing dynamics, as is the focus of this study. Probing ensures the reliability of data by allowing the clarification of relevant and interesting issues raised by study participants while investigating sensitive issues of human relationships. It also ensures valuable and complete information, assists the interviewer in further exploration to clarify potential inconsistencies within study participants' feedback on their daily lived experiences, and assists study participants in recalling from memory information for questions asked during interviews about their lived experiences (Barriball & While, 1994).

Individuals and context of projects may also contribute to or impact the validity and reliability of the data gathered (Barriball & While, 1994). Reliability and validity here refer to the truth value, consistency, neutrality and applicability, which depend on whether the researcher has presented the perspectives of study participants of their experiences clearly and honestly (Noble & Smith, 2015). Examples of the behaviour of 'good' research respondents are appearances of comfortable, untrained, open and truthful interactions with detailed, reflective answers, yet hiding sensitive unspoken areas. Barriball and While (1994) hold that further contributions to credible, reliable and valid

information during data collection may be as a result of study participants' altruism and less related to the topic of investigation.

Data were collected by means of individual in-depth, semi-structured interviews (Angel, Kirkevold & Pedersen, 2009) that lasted for 45 to 60 minutes. The researcher used words and language that were easily understandable to the study participants (Chuang, Yang, & Kuo, 2015). Interviews were conducted in English as this was not a barrier to any participant. The study participants were informed that there were no 'right' and 'wrong' answers (Chuang, Yang, & Kuo, 2015) related to their transfer-related lived experiences in care relationships. The data were captured through audio recordings, field notes, and the researcher's reflection notes. Field notes refer to notes of conversations recorded by researchers conducting qualitative field research (Schwandt, 2015). Field notes are made during or after researchers' observation of a specific phenomenon being studied. Field notes are read as evidence that gives meaning and aids in the understanding of the phenomenon (Schwandt, 2015).

The data were transcribed by a professional transcriber. Confidentiality was agreed to with the transcriber prior to the commencement of the study. The interviews took place at the homes of participants in a private room, to ensure their comfort and safety.

Questions were designed to trigger accounts of meaningful features of experiences in the course of their history of care relationships since injury (Groenewald, 2004). Groenewald (2004) cautions researchers to allow the data to emerge, as "doing phenomenology means capturing descriptions of phenomena and their settings" (p.11). For this purpose, semi-structured questions were put to the participants (see Appendix 5). While discussing topics to which the study participant had a strong personal connection, trust and a good level of understanding and compassion were vital to achieve depth of information (Denzin et al., 2011).

3.1.8 Methods of data analysis

Interpretative phenomenological analysis (IPA) is an approach to data analysis that aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon (Groenewald, 2004). Data were analysed thematically after codes were extracted from the transcripts. Coffey and Atkinson (1996) regard analysis as the “systematic procedures to identify essential features and relationships” (p.9). It is a way of translating the information by means of interpretation. The explication implies “...investigation of the constituents of a phenomenon while keeping the context of the whole” (Groenewald, 2004 p. 9).

Data explication entailed several thorough readings of the interview transcripts from which categories of meaning were developed and for which criteria were established (Groenewald, 2004). Through descriptive accounts of study participants, the researcher sought to understand the essence of lived transfer-related experiences of PWSCI in low socio-economic independent living environments in the context of human relationships (Groenewald, 2004). Audio recordings of interviews were transcribed verbatim (Groenewald, 2004). Completed transcriptions were returned to each study participant in feedback sessions for their perusal to ensure that no mistakes or bias existed (Chuang, Yang, & Kuo, 2015). This method of participant validation contributed to the credibility and confirmability of the study.

As researcher, I attempted to consciously remove myself from any bias during the interpretation of data and focus on the research objective, thus avoiding distortions while simultaneously being aware of my thoughts and feelings. I used a simplified version of Hycner’s (Groenewald, 2004, p. 17) explication process, which involved the following:

- a) bracketing and phenomenological reduction;

- b) defining units of meaning;
- c) grouping units of meaning to form themes;
- d) summarising each interview, validating it by means of member checking through feedback sessions and where necessary modifying it;
- e) extracting general and unique themes from all the interviews and making a composite summary.

No software was used to assist with data analysis.

3.1.9 Privacy and Confidentiality

The Protection of Personal Information (PoPI) Act prescribes how and by whom personal information may be collected, processed, stored and shared. I abided by and respected these prescriptions by means of prior conclusion of confidentiality agreements between myself and the transcriber (see Appendix 6). Confidentiality of participants was ensured by keeping study information in a secure location in my home. Assurance was given that all notes, recordings, and transcriptions will be destroyed after completion of the study process. The results of the study will be presented to the university, at professional meetings and to staff of concerned NGOs, but the identity of participants will never be revealed.

Interviews were conducted in the privacy of each participant's home to ensure that the participant felt comfortable and could speak freely without interruptions or intimidation from family or caregivers. A quiet room allowed for clear recording of the interview. No distressing emotional concerns or contradictions regarding care relationships were reported. Referral to counselling structures of

the non-profit organisation for emotional support was therefore unnecessary, although arrangements to facilitate such referral had been made in advance.

3.1.10 Ethical Considerations

To ensure that the research was ethical, the proposed study received approval from UCT's Faculty of Health Sciences Human Research Ethics Committee, and the non-profit organisation's head office based in Durban, prior to commencement (WMA, 2013). The Helsinki Declaration cautions that when human subjects are used in research studies, researchers must promote, and safeguard the participants' rights, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information, and act in their best interest (WMA, 2013). Furthermore, special ethical consideration is required for research with vulnerable groups (Shivayogi, 2013) to provide the necessary support, and protect, and respect their freedoms, and capability to protect themselves from inherent risks. Scientific rigour of the study addressing credibility, transferability, and dependability will be discussed in the next section.

Risks related to the participants' sharing of their experience of care relationships could be that this sharing was emotionally evocative for them, and could bring certain difficult aspects of the relationship to the fore. As noted, if participants expressed any unsettling or painful emotional concerns regarding care relationships, they would be referred to counselling structures of the non-profit organisation for emotional support.

Human relationships are complex, and, in the context of care, even more so. I believed that the discussion with an unbiased observer, trying to be as objective as possible about care relationships, may foster helpful new ideas. Knowledge is useful in the design of support services of PWSCI. The dissemination of information in accessible formats, information of how care relationships surrounding SCI are shared in low socio-economic independent living

communities, will aid in deepening the understanding of care needs to participants, and society as a whole. Better understanding of self and facilitating voice to people who had not participated in this study will enable the phenomena of influence, of power and agency, and autonomy and dependence on human relationships to be heard. This will be done by means of investigating how the nature and availability of transfers in the context of care relationships influenced the experiences of PWSCI.

On identification of willing participants by the non-profit organisation, I obtained consent from each participant telephonically, prior to commencement of the study. A verbal informed consent agreement (WMA, 2013) was made with individuals willing to participate in the study prior to the start of the study. This informed consent agreement introduced the researcher and explained the following to study participants:

- a) that they were participating in research;
- b) the purpose of the research;
- c) the reason the individual was invited to participate in the research;
- d) the procedures of the research;
- e) highlighted risks, and benefits of the research;
- f) the voluntary nature of the research;
- g) their right to stop participation in the study at any time;
- h) that their participation, and information would be treated with utmost confidentiality .

For the informed consent letters, see appendices 2 to 4.

To ensure and maintain privacy, and confidentiality of data, all files are stored on my computer, and are password protected. None of these files are accessible to anyone else. All print-versions of data files are stored at my home in lockable cabinets. Due to confidentiality requirements, the transcriber has assured me that all data files are password protected with no access to other users.

3.1.11 Clarification of special protection for vulnerable participants

Children and people with intellectual disabilities did not form part of the domain of this study. None of the participants reported experiences of emotional trauma stemming from issues in the lives of PWSCI or that resulted due to volatile care relationships.

3.1.12 Scientific rigour of the study

In addressing credibility, researchers strive to reveal that the findings regarding the phenomenon under scrutiny are believable, and trustworthy (Shenton, 2004). To allow for judgments about transferability, I attempted to make adequate detail of the context of the study available for readers to decide the degree to which the results of the study can be generalised or transferred to other contexts (Shenton, 2004). To meet the dependability criterion in qualitative research, I strived to enable any future investigator to replicate the study concerned (Shenton, 2004). Within phenomenological studies, the researcher cannot detach herself from her assumptions as she holds clear views. Through applying 'bracketing', the researcher endeavours to "bracket her own preconceptions, and enter into the individual's lifeworld, and use the self as an experiencing interpreter" (Groenewald, 2004, p.24; Tufford & Newman,

2010). To secure content validity of the descriptive accounts from study participants, development of general theories from phenomenological findings were applied with complete transparency (Conroy, 2003).

3.1.13 Compensation for research-related costs

Costs incurred were self-funded. Participants did not incur any costs such as travelling as the interviews were conducted at the home of each participant. There was no remuneration for participation in this study.

3.1.14 Dissemination

Dissemination of accessible formats of results of the study will aid in deepening the understanding of care needs to participants, organisations, and other people living with SCI, and society as a whole. The selected non-profit organisation in Johannesburg, and its members will be consulted on how the findings of this study should be disseminated. This may include distribution to the non-profit organisation member database by means of inclusion in a monthly newsletter, training manuals, and professional meetings. The participants' identities will not be divulged.

3.1.15 Conflicts of interest

The researcher's primary employment is focused on supplying equipment solutions for people with disabilities, and safe patient handling (SPH) training for nurses, and therapists. However, this information was not shared with

participants as I was not interested in providing equipment solutions or training in this study, as my research interest was in human relationships. Ethical requirements caution that when human subjects are used in research studies, researchers must promote, and safeguard the participants' rights, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information, and act in their best interest (WMA, 2013). Furthermore, special ethical consideration is required for research with vulnerable groups (Shivayogi, 2013) to provide the necessary support, and protect and respect their freedoms and capability to protect themselves from inherent risks.

CHAPTER 4: FINDINGS AND DISCUSSION

4.1 Introduction

The purpose of the study was to investigate the lived experiences of PWSCI in low socio-economic independent living communities, with specific attention to the context of relationships between individuals living with SCI, and untrained friends, family or community members who provide unpaid care assistance.

In the Global South context very little is known about the intersection of untrained personal assistance relationships with how transfers occur, against a backdrop of uncertain availability of care, and economic resources. In order to rigorously reflect the accounts provided by participants, the range of topics coded, and covered in this study became broader than what was reflected in the research plan as described in the semi-structured interview schedule. Participants clearly wanted to discuss topics beyond those covered in the interview schedule. Thus, to do justice to the interview data, the themes presented below reflect a set of issues which are broader than those planned for in the interview schedule.

4.2 Revisiting the objective of the study

The key objective set out in the study proposal was to collect the transfer-related experiences of PWSCI in ADL, and investigate what factors frame such attributes in the context of personal assistance. This was to be done in communities where economic resources were limited, using semi-structured interviews (Barriball & While, 1994). It was important to get the PWSCI's

perspectives (Carpenter, 1994), as they have unique insights into their impairment, and daily lives.

4.3 Themes

Themes, and sub-themes that emerged during the analysis of the data from semi-structured interviews inform this section. Thematic analysis is a form of analysis used in qualitative research (Greg, 2012). The purpose of thematic analysis is to identify both implicit (unspoken), and explicit (obvious) ideas (Guest & MacQueen, 2012), and patterns of meaning across a dataset (Saldana, 2009) that provide an answer to the research question of how do the nature, and availability of transfers influence the lived experiences of PWSCI in low socio-economic independent living communities in context of personal assistance relationships. Quotes from the participants' responses are used to illustrate the common themes that emerged relating to their experiences.

4.3.1 Appropriate support during care

According to Perry et al. (2014), transfers between two areas require a minimum of two people, and transfers between bed, and a stretcher require a minimum of three to four people, considering the person's weight. Thus, the heavier the user, the more attendants needed to transfer the user in a safe and dignified manner. Participants expressed mixed opinions regarding their experiences of safe and dignified transfers to avoid secondary injury, with only have one person assisting with transfers, and, hence the importance of appropriately trained caregivers. According to Powell-Cope, Hughes, Sedlak and Nelson (2008), patient handling is the application of evidence-based approaches to reducing the risks related to manual patient handling. The inclusion of patient handling

training, and mechanical devices can facilitate people with severe physical disabilities' safety and comfort during their ADL. Patient handling is two-pronged: it concerns the care-receiver and the care provider. Emphasis is placed on the user and caregiver as a unit, as the user depends on the caregiver for his or her safe transfers. The focus is to reduce friction, to protect the user against further injury such as skin sheering, to avoid pressure ulcers, and, to avoid falling when dropped by caregivers. Inadequate training, and fatigue could contribute to secondary injury (Powell-Cope et al. 2008). Minimal training is required to prevent injury. It is evident that none of the care assistants in this study have had such training.

One participant explained the need for training of care assistants in community settings, he explains:

...to train caregivers to help people in the communities because there is a lot of people who die cos their parents have to go to work in the morning and they don't have money to take care of the people and then they just leave them in bed and so...the whole day...so we send in a caregiver there. He will help you in the morning out of bed an then stay with [you] during the day and at night [your] parents will put [you] back in bed (SP4). (SP4 is a 48-year-old man who has been living with SCI for twenty years since injury).

SP4 stresses the importance of proper care for people living with SCI in low socio-economic communities. Safe and dignified transfers impact the quality of living for PWSCI (Powell-Cope et al., 2008). The avoidance of secondary injury through falls and being dropped are thus contributors to the dependence on care for PWSCI (Powell-Cope et al., 2008). This research agrees with the CRPD (2006) Article 4 which states that the State should undertake to "...promote the training of professionals and staff working with people with disabilities in the rights recognised in the present convention so as to better provide the assistance and services guaranteed by those rights." (p.2).

Another participant expressed his anxiety about lateral transfers and falling, fearing further injury. This participant explains:

It was very difficult at first because you're weak in your arms and your shoulders and to lift yourself and move yourself, it's, because you're scared, you see the floor, you're balancing it's not hundred percent and you're just afraid, you're mostly afraid of falling than of trying to actually transfer yourself. We train them [female caregivers] ourselves because finding the more qualified people is a little bit expensive so I don't think we would be able to live here... not through an agency but ja,...through the street. But here you are like word of mouth, they use[d] to work for others...(SP1). (SP1 is a 23-year old man who severed his spinal cord in a diving accident six years prior).

In the context of care, assistive technology coupled with body mechanic training for all attendants has multiple benefits for both care receiver and care provider. Research shows that back injuries during manual lifting, moving and transferring of patients during ADL, cost Health Departments huge amounts per annum (Nelson et al., 2003). Consequently, injuries frequently result in job dissatisfaction, high staff turn-over, early retirement and unemployment - which puts a further financial strain on economies. By ensuring a conducive working environment, the avoidance of musculoskeletal injury to care providers incurred during manual transfers of PWSCI, with appropriate mechanical equipment and training for attendants, may aid the transfer process of PWSCI. In doing so, secondary injury (further damage) and associated costs may be avoided to both PWSCI and care provider (Nelson, Wickes & English., 1994). Improved working conditions may aid a better relationship between the personal assistance provider and care receiver (PWSCI). According to WHO (2018), assistive technology may enable PWSCI to continue to live at their familial homes and potentially delay or to some degree prevent the need for long term care. The

lack of appropriate training of care assistants, as well as the lack of access to essential assistive devices, thus has multiple negative consequences.

4.3.2 Financial impact due to disability and impairment

SCI has a significant impact on the financial resources of PWSCI and may perpetuate their exclusion from society, and decrease their quality of life (Power-Cope et al.,2008) and their ability to be in charge of their care. The World Health Organisation (WHO, 2018) acknowledges that there is an increasing demand for evidence of the cost-effectiveness of AD. Due to the high cost of AD and in context of this study, in many instances, access to patient handling equipment is denied for the majority of people with disabilities living in low socio-economic environments with little to no means to financial resources. Ready access to AD often is available only to disabled people living in privileged circumstances (WHO, 2018). Financial resources aid easier access to both ADs and adequately trained personal care attendants, facilitating PWSCIs safe and dignified transfer, moving and handling between two locations (Powell-Cope et al. 2008). AD prevent the risk of falls and dropping users of such equipment, thus preventing secondary injury to some extent.

In addition to adequately trained caregivers and devices, participants shared their experiences regarding the exorbitant costs of living with an impairment and focused on topics that impact their daily living, such as appropriate wheelchairs and the maintenance thereof, and accessible transport. They felt that a lack of mobility access in the form of accessible transportation was a way of creating barriers to participation in society (Watermeyer, 2009; Shakespeare, 2002; Kroger, 2009). One participant explains:

I still need a new battery but it's quite expensive...I got different quotations. It started off and went up to R14 000. I got a quote from

another wheelchair shop, they were around R6000, R7000 or something. Everything we use is expensive...(SP3). (SP3 is a 26-year-old man who has been living with SCI for six years prior and who received home care assistance provided by a paid, trained caregiver within his familial home).

Participants echoed the high cost of accessible transport, and the time it took, impacted on by the ordinary daily tasks of travelling to and accessing their place of work to earn a living. Participants discussed the exorbitant expense and double fares charged for both the person and the wheelchair, as societal discrimination and barriers that impact their independence and societal participation. The financial implications of SCI have large negative effects on the maintenance of equipment and excessively high public transport costs are societal barriers. These barriers highlight difference and exacerbate the societal exclusion of PWSCI, thus creating further necessity for and dependence on care support (DSD, 2015; WHO, 2018).

Participants expressed their anger at the State for not honouring the CRPD. One participant explains:

...the norms which we still having a challenge...we keep on quoting the UN convention rights for disabled people. We said we should live by that because the country have signed off saying, people disability should be respected. Transportation wise it's a hell of a[n] issue. You know when you are disabled if you go in a public transport now, they charge you and charge you[r] wheelchair also. The transportation system of South Africa they don't have an automatic lifts which will come, you go in and then it pulls you up, it put[s] you in the car. No. They must lift you up, shuffle you, throw you in there. Some complain your wheelchair will dirty them, you see, those kind of thing[s]. That's why we [are] not considered (SP6). (SP6 is a 44-year-old man who has

lived with SCI for eight years and was initially cared for by his wife at their family home post injury).

The CRPD states that society should not be discriminating against people with disabilities due to their disability and that their human rights must be protected (CRPD, 2006, Article 4). The World Health Organization (WHO, 2011) states that enhancing the independence of people with disabilities may be aided by providing AD or rehabilitation. However, people with disabilities living in low socio-economic environments typically lack access to devices and proper health treatment. The WHO (2011) states that access to rehabilitation can decrease the consequences of disease or injury, improve health, quality of life, and reduce the use of health services.

Although many study participants were concerned about safe and dignified transfers, the need for proper trained personal assistance providers and accessible transport, others indicated more pressing concerns relating to their human rights in politics of control and agency, as well as the emotional and psychological impact of SCI.

4.3.3 Human Rights and politics of control and agency

In drawing a parallel with studies conducted in nursing practices, research shows, to promote trust in relationships of assistance and enhance care-receiver satisfaction, respecting patient dignity is identified as a significant principle in nursing practice (Raee, Abedi & Shahriari, 2017). Respecting patient dignity may establish desirable care relationships and feelings of security. In contrast, emotional responses (such as anger, sadness, and hatred), and violation of patient dignity may cause deep, long-lasting feelings of worthlessness, and lead to distancing and social isolation (Raee, et al., 2017).

The following experiences underscores violation of dignity and thus violation of individuals' human rights. All participants expressed their frustration about caregivers disregarding their right for proper care pertaining to correct seating, dressing, comfort, and self-presentation. A participant explains:

...sometimes people they lift you up, they throw you in bed without putting you at the right position, like taking you from maybe dressing after bathing, dressing you, putting you into a chair. Only if your trousers are skew, they are all over, the more you tell them, I'm not comfortable...they are employed to take care of us...not to get angry about asking for perfection... (SP6).

Study participants felt that their right to being treated with respect and dignity became a secondary priority to that of the caregivers'. Various articles of the CRPD (UN, 2006) highlight the inherent respect and dignity for all people with disabilities (Art.1, Art.3(d), Art.8(b)). Article 1 emphasises the imperative to respect and afford dignity to all people with disabilities. Article 3(d) (UN, 2006) confirms respect for fundamental rights related to dignity, difference and acceptance of people with disabilities as part of human diversity and humanity. Article 8(b) of the Convention speaks about fostering an attitude of respect for the rights of people with disabilities (UN, 2006).

Participants verbalised their frustration and anger regarding the perceived power attendants held over them. Further experiences reflecting perpetuation of stigma and thus discriminating against people with disabilities (Green et al., 2005) are related through delayed attendance by personal attendants when care is required. One participant shares his feelings of disrespect, devalue and worthlessness while being forced to wait for assistance from his family. He explains:

Eh, that's one of the challenges I had, not only with my caregivers, even my wife or my children are, you know... When you are independent you

don't think someone, or one wants something, you want it at that time, when I say I want water, I want to drink water, you want that water...now, not after three hours or thirty minutes. Anything I want, and I have to wait, it was affecting me, you know. But I ended up getting used to it... because you know, when you had these challenges...there are days where I get depressed and I get angry with and everyone, especially...things they don't go my way. This is that what frustrate you (SP8). (SP8 is a man who is 41 years old with eleven years since his injury and post injury, SP8 was cared for by his wife and elderly father).

Green et al., (2005) state that stigma is brought upon individuals through acts of omission of care needs. Status loss and discrimination within the context of a power differential is one of the components of the notion of stigma (Green et al., 2005). People with disabilities may often experience a state of slow acting from others, which leads to low self-image, isolation and depression (Green et al., 2005). Priestly (1999) states that both current and historical uses of care are oppressive in the form of control and equates 'care for' by people with disabilities who are unable to care for themselves, with the individual or personal tragedy model which conveys a dependency experience. In contrast with Priestley's (1999) view here, I agree with Kittay (2011) in that "...not all care is seen as oppressive or viewed as a limitation but care with dignity may be viewed as a resource in a relationship of inevitable dependency between 'unequals', ensuring a fulfilling life for both the caregiver and care receiver" (p.1). The female gendered nature of care in both paid and unpaid circumstances has been highlighted in research (Kroger, 2009). Often care is defined in relation to dependency in many circumstances.

Some participants gave further examples of perception of losing control and thus agency in relationships of personal assistance when boundaries of respect between employer-employee were potentially overstepped. One participant explains:

...there's a boundary where a female worker must know that she's here to work, that she's not my lover... The problem with caregivers, caregivers always they want you to beg, to beg for the job which they came and ask you of saying, can you offer me a job sir? And then you offer them a job. After a while they get used to you, now they treat you like you've got no brain. You have to beg, ah can I, I need food, they know we have to eat (SP6).

This participant is expressing his concern for providing employment, and thus subsistence to an unemployed person; and perhaps due to the stigma surrounding people with disabilities and their ability, or the stigma surrounding gendered care roles that are viewed in society as women's work and thus less important, a female personal assistance provider may turn on her employer through acts of power in an attempt to level the playing field. Perhaps this is evident of the stigma surrounding women's work in the care realm as explored in Brear et al., (2016). This example of power and agency is in line with Kittay's (2011) view of relationships of interdependence between the care-receiver and care-provider. This example clearly shows the interdependence between care-giving and care-receiving whereas the care-receiver is dependent on the personal assistance provider for taking care of daily needs in order to live; and the care-provider needs employment for own subsistence to life (Tronto, 2009; Kittay, 2011). Dependence here is thus not a state of weakness or power (Winance, 2016) as described below.

In the second phase of the EoC discussion, researchers such as Joan Tronto (1993) and Selma Sevenhuijsen (1998) moved the care ethics discussion from issues of moral psychology to issues of political philosophy and social policy (Kroger, 2009). In other words, Tronto and Sevenhuijsen have drafted a way of analysing public systems from an EoC perspective. These views contrast with dominant theories of independence and autonomy in that, care, vulnerability, and mutual dependence are central to and shared by all human beings and

pertain not just to selected groups of people such as older people or people with disabilities (Kroger, 2009). In contrast to binary concepts of the “...active givers and passive takers of care...” (p.4), this perspective of care recognises that care is interdependent for all human beings and that all people may have the need to be ‘cared for’ and to be caring at a stage in our lives (Williams, 2001; Kroger, 2009). The notion of ‘care for’ is further explained in the next paragraph.

Jenny Morris (1997), British disability researcher, states that the meaning of care has shifted in the latter part of the twentieth century (Kroger, 2009). Care has taken the form of ‘caring for’ someone, thus taking responsibility for – instead of ‘caring about’. Morris states that ‘caring for’ is assumed that someone is unable to exercise choice and control (control and agency). Morris (1997) therefore argues that someone cannot have both care and empowerment, as this ideology has led to the perception that people with disabilities are powerless. This argument may be misconstrued that it is as simple as this for Morris, which means that people with disabilities or people who are in a position of needing care can never be powerful. This, I argue, is not true. British care researcher, Hilary Graham (1983; Kroger, 2009) defines caring as ‘labour of love’ (p.4), meaning that caring is both physically and mentally demanding and contains an emotional bond between two people, the care-attendant and care-receiver. British care researchers, Qureshi and Walker (1989, Kroger, 2009) concur with Graham (1983) and state that caring emotions of feeling, thought and acting are expressed between two individuals in a care relationship (Hochschild, 1995), thus, caring requires both hand and heart (Leira, 1993, Sevenhuijsen, 1998 as cited in Kroger, 2009). American philosopher, Eva Feder Kittay (2011) concurs and states that care is ‘a labour, an attitude and a virtue’. Kittay states that care may be seen as being interdependent and explains the dependence between inevitable ‘unequals’ and that care should be seen as mutually beneficial by means of subsistence, and provides the example of her relationship with her impaired daughter. Kittay (2011) gives life to her daughter

by loving her and caring for her, maintaining her dignity as she ages and being able to see her daughter grow and live life.

More experiences of power and agency, perhaps subconsciously on the part of the care-provider, were expressed by participants. Participants want care providers to acknowledge and respect their independence within a relationship of dependence. Some participants expressed their irritation about lack of knowledge and thus the perception of SCI that is held by care providers; and thus PWSCI's ability relating to the associated level of dependence and independence post-injury. One study participant explains:

Ah, it was such a relief because with the family members, they want to do everything for you. I understand it's out of love and everything but sometimes it can get a little annoying...You want to do something, at least try and do something for yourself (SP1).

In contrast to earlier experiences of violation of human rights, SP1 above, expresses the need for familial care attendants' understanding for respecting another's dignity in one's ability and thus 'independence' with a relationship of 'dependence.' SP1 felt disempowered and wished for an environment where he may attempt to do things for himself as proof of his independence within this relationship of dependence on others for personal assistance. Green et al., (2005) states that when a disability is visible, the disability can affect the reactions of others.

As explained elsewhere, personal assistance providers can be a diverse group of people and may include immigrants, stay at home parents, students and recently retired individuals seeking extra income (Kelly, 2011). Canadian care ethics researcher, Christine Kelly (2011) explains that regardless of prior relationship, the intimate nature of personal assistance tasks and home location often result in complex relationships where care providers and receivers care about one another (Kittay, 2011). Researchers argue that this work is care work,

caregiving, bodywork (Kelly, 2011), helping (Shakespeare, 2002; Kelly 2011), support work, attendant care, personal assistance or personal support. Care is thus also seen as something which can function as a sophisticated form of oppression (Priestly, 1999) and thus the potential for abuse under the guise of 'caring for' (Kelly, 2011, p.563). Raee et al., (2017) states that violation of a person's dignity may lead to deep, long lasting feelings of worthlessness which may lead to distancing and social isolation. Green et al., (2015) concurs with Raee et al., (2017) and state that disconnection from society (withdrawal from social activities) or "separation occurs when the reactions of others produce a pronounced sense of being devalued, disrespect, or viewed as less than human" (p.205).

Agency and control are further negotiated in the lives of PWSCI and their experiences as they explain the importance for clear dialogue and choice over care and decisions. Some participants expressed the importance for clear dialogue and to be included in decisions concerning them (SP2). One participant explains:

If you be new in this place of disabled, you...wouldn't understand...I've been here some time so I understand...they're helping me and then... someone may be looking for help, I understand that pain. So that's why most of the time we must have communication...if I'm waiting, I ring the bell and you come and you switch it off and you leave without communication, that's why I'm going to be angry...if there's no communication, there will be conflict...there's nothing I can do, but it really hurts (SP2). (SP2 is a 26-year-old man who has been living with SCI for eleven years. Due to severe poverty, SP2 was relocated to an alternative ILC-type home where a distant aunt was employed as a domestic assistant and contributed to her nephew's personal care as unpaid assistance).

Kelly (2011), states that under independent models of support, people with disabilities who require assistance with ADL not only choose but also instruct their attendants how and when to assist them. In the context of this study, personal assistance providers are thus employees and remunerated by the study participants living in ILC homes. Attendants, therefore in theory, may perform tasks according to employment terms and conditions and job descriptions as set out by their employers, people with disabilities for whom they work. The varied duties may include assistance with cleaning and laundry, meal preparation and eating, bathing, dressing, administering medication and running errands (Kelly, 2011). However performing tasks according to job descriptions is clearly not always true in practice, since care is so often at odds with what the disabled person needs, as stated repeatedly in my data. I therefore acknowledge that this reality is a diversion from my initial plan to investigate only situations where care was unpaid. After rehabilitation and due to their low socio-economic status, some participants could not return to their familial homes. However the consequences of SCI is in the short term extremely painful (Kelly, 2011). Due to stigma related to disability in terms of dependence, study participants moved to ILC homes to regain their identity as husband, father, son/daughter and friend instead of being seen as a dependent individual who requires care from a personal assistance provider (Shakespeare, 2002). A lack of professionally trained paid care created a situation of breaking / separating bonds in families and caused study participants to move to ILC homes where they trained their domestic assistants to take care of their daily care needs against a very low wage. Despite of this move, participants still felt the brunt of stigma and thus invisibility.

Participants expressed mixed emotions of both sadness and rage as they felt invisible during care, as their presence was often not acknowledged and evident in how attendants treated them. One participant explains:

I ask people, first thing when I appear, what's the first thing you see, me or the wheelchair? Most people they don't see the personality of the person, they sommer...classify us as a piece of equipment...which I am not...I'm feeling human being...I can still reason. We feel offended because people take decisions on our behalf without consulting with us (SP6).

The wish to be acknowledged and seen as contributors to society (Watermeyer, 2009; Green et al., 2005) was evident among study participants. According to Green et al., (2005), while structures and values go unchallenged, unbalanced power relationships that may disadvantage PWSCI, will persist. Some participants felt that visibility and understanding of disability can facilitate the removal of stigma surrounding disability and the ability of an individual within a relationship of dependence and thus unbalanced power relations. Stigma can be defined as "an adverse reaction to the perception of a negatively evaluated difference" (Green et al., 2005 p.197).

A participant shared his experiences within love relationships, the perception about able women engaging in relationships with men with disabilities for financial gain and consequences due to the perceived stigma surrounding disability. He explains:

Relationships...That one is really, it's not an easy, you know when you're in this condition. I've been in a relationship several times, you know. All of them they, we break up, we break up, we break up. But the moment we meet you have to understand me and I have to understand you. So, nowadays a relationship now it's all about money. To others black people it's about money... Demanding... So, a relationship it doesn't work for me....I do get compliment(s) from women, you're handsome and so forth. I want a person who are...we going to grow together. Become

friends...don't be shy when you walk with me here in public. I want to inspire other people who live with disability out there. That if I can make it in my relationship, my person, clearly you can make it too... But, of course it's about money and so forth. So, it's not really working for me. Also, when we do what lovers do, it doesn't work for us because of our condition. I also blame our condition on that, but they just run away...Like no, there's nothing satisfying here, you don't satisfy me here and there. So, they just leave...So, it is what it is.

Stigma may not be an attribute of the individual with the physical impairment and thus bears the difference, but Green (2005) states that the difference rather lives in the interactions between the person with the physical impairment and the other person who appraises the 'difference' in a negative way. Participants thus felt that invisibility contributed to feelings of devaluation and marginalisation, living in a society where the values that dominate are power and wealth, competition, beauty, self-control and autonomy (Watermeyer, 2009; Barnes, 1996; Green et al., 2005). According to Green et al. (2005), many people are scared of wheelchairs as it may be seen as a sign of a physical impairment and thus a human vulnerability, and thus, many people do not like to think about having a physical impairment. The individual or medical model of disability has created an ideal of normalcy, and excludes bodies considered to be different or disabled which need fixing (Hughes & Paterson, 1997; Thomson, 2002). As such, a fear of imperfectability may arise, creating a social norm in society, leaving people with disabilities invisible and unaccounted for by mainstream society (Thomson, 2002; White, 2005; Campbell, 2008; Shakespeare, 2009).

Factors influencing emotional and psychological impact as a result of SCI include fear of rejection by partners and peers, poor coping skills, struggle with

self-identity and emotional challenges of living with a chronic disabling condition (North, 1999). These factors inform the next discussion.

4.3.4 Psychological impact of SCI

SCI usually necessitates considerable changes not only in the life of an individual but also their family members (North, 1999). In addition to adjustment to difficult psychological factors, SCI places enormous strain on familial roles and relationships (North, 1999). Glass (North, 1999) states that “The experience of spinal cord injury is one of the most devastating injuries which might affect an individual. The resultant disability, after which normal cognitive function and intellectual ability usually remain, produces not only an inability to move and feel limbs but also the inability to control the function of internal organs and even, in severe cases, the ability to breathe independently.” (p.1)

Participants shared the feeling of an almost instantaneous sense of loss and grief after injury, regardless of positive experiences during the rehabilitative period. One participant explains:

At the beginning I was very depressed, and I was very emotional. I don't want to live like this (SP5). (SP5 is a 39-year-old woman, with fifteen years since injury, who had moved into her family home and, due to family dynamics at that time, received personal care assistance from her father).

Another participant concurs and states:

At, at first it was hard to, to understand it, because of the, the condition that I'm going to live for the rest of my life now. So, whatever the nurse was saying to me or do to me, I was not satisfied (SP2).

Another participant states:

I got my mind set. At the beginning I was very depressed and I was very emotional. I didn't know when they dropped me here I thought ag, I don't want to stay in a place like this. I don't want to live like this. This is not the life. I mean I used to play rugby, I have been a mechanic and all that and now all of a sudden I can't do that. Even in the hospital I was very negative, I even told the doctor I didn't want to live my life like this. This is not the type of life I'm wanting.

Participants mourned their loss of dignity as the newly found dependency on care post-SCI was not the life they wanted. Following the sudden onset of SCI, research has shown that many people with SCI will develop severe negative emotions in response to the injury which could threaten both psychological and social integration (North, 1999; Rae et al., 2017; Green et al., 2005). There are some critical underlying questions relating to appropriate care and protection of human rights here. With a more accommodating social environment, will some of this distress be alleviated? The central challenge remaining here is the societal suffering due to exclusion, stigma and negative attitudes towards people with disabilities.

Trying to understand and grasp the magnitude of this new state of dependence on others for care to pursue life was compared to a prisoner who was unable to take care of his hygiene due to being captured and shackled. One participant explains:

You are lying on the bed; they have to take the blankets off you...Your privacy now is in the hands of someone, has to bath, he has to wash you, you have to eat, they have to turn you, they have to dress you up... How would you feel if your privacy is in the hands of somebody? Because now if you are disabled...a quadriplegic...in essence what it means you cannot do anything. You are forced to take a [tooth] brush

to brush your teeth, your hands are tied up, you are forced to take a bath when your hands are tied up. Would you be able to do it? No, right...you have to call someone...(SP7).

It is clear that these study participants are suffering due to their perceived independence transformed into perceived dependence on care. Some critical questions posed here about social interventions and the ameliorating of this suffering may relate to some potential shortcomings within these ILC home environments, or it may be their experience of a stigmatised society as a whole. Like poverty and disability, respect and dignity are interdependent (Kittay, 2011). Respect and dignity differ in that dignity is the inherent value and worth as a human being that everybody is born with and thus contrary to the meaning of respect that needs to be earned through one's actions (Kung, 2018). Thus, treating another person with dignity means being sensitive to the other person's needs and doing the best one can for her, involving him/her in decision-making processes, respecting his/her individuality, allowing the other person to do things for him/herself and allowing his/her personal space and privacy (Kung, 2018; Kittay, 2011, Kelly, 2011). Having dignity means that the person is worthy of respect, undermining another person thus means that one is acting without dignity. Making sure that all people are treated with respect and dignity is a basic human right (WHO, 2011; UN, 2006).

Another participant explains about the waiting period for a device to assist with his breathing, due to his low socio-economic status, he explains:

I had to wait in hospital until the device arrived. I was the third person in South Africa receiving this pacemaker. Ja, so I had to wait in ICU on a ventilator the whole time. It took about two months for it to get here and they had to do the operation and then after the operation I had another month that I had to get used to the pacemaker because it implants into me and then there was a machine on the outside of me that was monitoring it and that. But

ja, and then... At that stage my medical aid was finished so the moment they took out the 'traggie' they said to me I cannot stay longer in the hospital so I didn't really had time for rehabilitation. So they just showed me the basic transfers to get into the wheelchair, or my family because as you can see I can't move at all (SP4). SP4 is a 48-year-old man, who, due to difficult familial circumstances, was unable to return to his family home after rehabilitation but moved into a formal ILC in Johannesburg twenty years prior.

According to research, factors influencing adjustment include grieving the loss of life prior to the injury, the feeling of being institutionalised and restrictions on both social and physical ability (North, 1999). Participants expressed their frustration about their increased dependency on others for ADL in care. Some participants described the issue of self and attendant fatigue and the impact thereof on appropriate care. Personal assistance fatigue was explained as being due to a state of physical, emotional and mental exhaustion, and as bringing about a change in attitude for many attendants, changing from caring to a negative view and a lack of concern (Kung, 2018). One participant commented as follows:

You call someone, that someone when he pops in he or she is in her own mode. You don't know how that person feels...someone is going to put you in whatever way, it depends on the mood that, that person is in...one thing that you need to know, people do get tired, and being disabled, one thing that is very annoying, we are very, very annoyed of been every time asking for something (SP7).

SP7 is communicating a basic experience of dependence which may be far removed or possibly non comprehensible for most non-disabled people to imagine. He continues and says:

You need to drink water, you need to call someone, the TV now is off, you need someone, you want to watch TV, you need to call someone...Bed sores, so what do you do then? Do you call, do you not call, if you call you are saving yourself, if you not call you are injuring yourself (SP7).

According to Watermeyer (2009), the way in which non-disabled people consider loss in the lives of people with disabilities is a politically complex issue. Watermeyer (2009) states that non-disabled people may be less aware of their internal emotions about projected human vulnerability when seeing or dealing with people with disabilities. The effect that these emotional processes have on shared societal action through segregation and control is due to perceived differences. Watermeyer (2009) states that:

...the issue here is the manner in which access to that part of human experience in which one's losses dwell is distorted and perverted in the lives of disabled persons through the deeply prejudiced construction and controls exercised upon this group by an ignorant society (p.93).

Green et al. (2005) concur in that people with disabilities may be perceived "to possess traits that others do not want to acquire" (p.202). People may, therefore, be overcome by feelings of sadness and pity when they encounter people with disabilities. Others, consequently seek to avoid these feelings and thus, avoid people with physical impairments, and inadvertently avoid people with differences they fear (Green et al., 2005). Barnes (1996 as cited in Green et al., 2005) states that the stigma associated with disability is intrinsically entwined with the values associated with industrial capitalism within western society. Barnes (1996) furthermore states that "at its core lies the myth of bodily and intellectual perfection or the 'able-bodied' ideal" (p.57).

On the question of acceptance of life post-SCI, almost all participants reported that they did not accept this way of life and dependence on care, but merely opted to adopt it and continue to live. One participant explains:

To tell the truth...you don't accept you just act out. Because there are days where I get depressed and I get angry with and everyone, especially things they don't go my way. I've learnt that for me to adapt to move on...(SP6).

It was rough for me... I struggle to accept that I'm in a wheelchair and accept that I... I could walk, not walk and I started to try take in and try to walk. Then I got some drops that could stimulate down the left-hand side for me to walk better... believe you me. I don't want to lie to you, am I sitting right here, I haven't accepted (SP5).

Watermeyer (2009) states that the question of 'acceptance' is a problematic and contested subject. On the subject of acceptance of dependence on care, and thus managing life, Wickenden and Elphick (cited in Watermeyer, 2016) noted that practical discussions, in the form of socially inclusive solutions instead of remedial approaches to the impairment itself, are essential to people with disabilities.

4.3.5 Post-injury shift in relationship dynamics

In this study SCI had a tremendous impact on spousal relationships and on self-identity. One participant explains:

She becomes my caregiver...And I become...I'm no longer now her husband and I'm a husband at the very centre of my nature, you know.

It was affecting not only her, even me, it was taking toll on even me...(SP8).

According to Dickson et al. (2010), after the injury of a party, spousal care roles may lead to the shift from a relationship between two adults into more of a parent-child relationship. Study participants reported that post SCI, their dependency on care was often too much to bear and was taking a toll on both spouses. In some instances, the daily dependency on spouses for feeding, dressing, bowel and bladder management, and so forth, resulted in the employment of paid care. One participant explains:

I will get frustrated because I used to be independent, you know when you are, I used to do things on my own at my own time, you know, when I want to sit, when I want to do... So I was spending the rest of the day with my caregiver and then I decide...to come here [ILC] (SP8).

According to Dickson et al., (2010), other members of the family often take on extra roles when a family member becomes injured or ill. For example, with a temporary illness, another family member might do the chores until the member with a temporary illness recovers and resumes the tasks. Unlike a temporary injury or illness, changes in family roles occur after SCI, and are typically not temporary. Role changes are challenging when they involve a spouse or partner. This can create a change in the relationship with one person feeling resentful of the attention, support and help the other person receives (Dickson et al., 2010). Thus, when one spouse gets injured, the other spouse becomes responsible for the physical and emotional support of the couple. Another participant explains:

...actually, things were not sharp...look sister I don't need your favour, I can still do more without you. If you don't believe just watch this space (SP6).

As a result of identity transformation, many participants relocated to ILC homes to live independently from their family in order to regain their identity as husband and father or wife and mother, and not as someone in need of familial care. The change in identity post-SCI may contribute to breakdown in spousal relationships, often resulting in parties with impairments feeling betrayed by non-disabled parties due to their dependency on care (Dickson et al., 2010). Green et al., (2005) states that enacted stigma on people with disabilities is “directly enacted within the context of unbalanced power relationships – specifically when the person with the stigmatised trait has less power than those who stigmatise him or her” (p.209). Link and Phelan (2001), points out that “where both parties hold equal power...the individual with the stereotyped trait may be able to resist overt attempts at discrimination without loss of status” (p.209).

4.4 Conclusion

The following passages include the key findings of this study. The study revealed the importance of the need for accredited training and assistive devices for personal assistance, and the potential impact of conducive working environments that may contribute to positive attitudes and perceptions toward PWSCI. It is evident that access to allocated state resources will facilitate PWSCI to procure accredited, trained, paid care. The vocation of personal assistance providers if organised, available and accredited, will positively impact the lives and experiences of PWSCI in low economic independent living communities.

In the context of appropriate support during care, the need for safe, and dignified transfers during ADL is evident for PWSCI in avoiding further or secondary impairment (Power-Cope et al.,2008; Tulsy et al., 2015). In maintaining relationships of equity between care-receiver, and personal assistance

provider, PWSCI wish for their dignity to be respected (Gavin-Dreschnack et al., 2005; Hignett et al., 2003). Being treated with dignity is essential for PWSCI to the means of living a meaningful life (Lebech, 2010; Yuval-Davis, 2010). Evidence suggests that being in control and having a choice over one's care, is seen as a way for PWSCI to obtain the highest possible independence in relationships of dependence (Winance, 2016).

Ultimately, the quality of life for PWSCI, is influenced by each of the contributing factors identified in this study, as experienced during transfer-related activities.

- The lack of secure and dignified transfers impacts the quality of life for PWSCI in that secondary injury due to falls, as a result of being dropped during transfer-related activities, contributes to care dependence. In addition, falls may deepen dependency through exacerbating impairment (Power-Cope et al., 2008; Tulsy et al., 2015). In this context, secondary injury (Power-Cope et al., 2008; Tulsy et al., 2015), as a result of the lack of reliable transfers lead to an experience of limited access to the means of life.
- The economic impact (lack of resources) due to disability and impairment, also directly affects the quality of life of PWSCI (WHO, 2018). With limited or no financial resources, PWSCI may not afford to employ personal assistance providers. The lack of appropriate personal assistance may lead to a spiral effect. For example, the lack of transfers can become implicated in, the lack of societal participation, lack of access to appropriate health care, lack of access to education, lack of employment. The lack of appropriate assistance results in the lack of quality of life for PWSCI (WHO, 2018). The lack of personal attendants affects the quality of life of PWSCI, given that the reliance on care now becomes the responsibility of unpaid family members and friends. In many instances, unpaid care may affect the overall health of PWSCI

since, waiting or delayed care may exacerbate the lack of transfers and thus quality of life. Consequently, the absence or delayed attendance (Green et al., 2005) of transfers, becomes a direct contributor to deteriorating health and possible further medical-related injury. Quality of life is thus directly influenced by further medical-related injury (Power-Cope et al., 2008; Tulskey et al., 2015; WHO, 2018).

Post-injury shift in relationship dynamics and post-injury identity transformation are contributing factors that may influence the quality of life for PWSCI, as seen through control and agency in personal assistance relationships. To maintain one's dignity and identity as father/mother, husband/wife, son/daughter within a family domain, participants of this study opted to move to ILC homes with paid personal support. Paid personal assistance has multiple advantages and associated disadvantages. One of the advantages here refers to the choice of and employment of staff (personal assistance providers) against remuneration (Shakespeare, 2002). Employed staff are expected to provide a service (personal assistance), as they take instruction from the employer (PWSCI). Maintaining of employer-employee boundaries, and showing mutual respect at all times, may work in theory but not necessarily in practice as seen in this study. As seen in the daily lived experiences of PWSCI, the overstepping of boundaries is, in reality, challenging. Overstepping of boundaries may be due to the stigma surrounding disability, assumptions about living with SCI and the ability of PWSCI. Caring roles are considered women's work, less important, thus devalued and not respected (Brear et al., 2016). Due to the stigma surrounding women's work in the care realm, overstepping boundaries are displayed by female personal assistance providers, through acts of power by turning on their employers in attempting to level the playing field (Brear et al., 2016).

- The lack of recognition by non-disabled people, thus, lack of respect for PWSCI as rights holders, may perpetuate conflict between care receivers and personal assistance providers, the latter on whom PWSCI depend on for care, and thus all transfer-related activities, and ultimately, life (Watermeyer, 2016; Lebech, 2010). According to Lebech (2010), the human desire for dignity goes beyond human differences and places the social or shared human identity (rights holders), as central to their existence. In essence, this means that all human beings are rights holders and therefore, need respect and dignity (WHO, 2011). Lebech (2010) states that mutual recognition of the desire to be seen, heard, listened to, and treated fairly, to be recognised, understood, and to feel safe in the world, is that bond of humanity, rights holders, that holds human relationships together. When different identities are accepted, and we feel included, we experience a sense of freedom and independence, and a life filled with hope, possibility and belonging (Yuval-Davis, 2010; Shakespeare, 2009). Successful relationships within the domain of care, may be achievable through mutual recognition and respect of employee-employer domains.

In conclusion, this chapter seeks to demonstrate the magnitude to which the nature, reliability and availability of transfers, in the context of relationships of personal assistance, affect the quality of life of PWSCI. The data shows that participants exist in an extremely precarious state of not having access to reliable transfers, and other forms of care (professionally trained personal assistance) to support their ADL. The data furthermore shows how inadequate training, or a lack of any form of training, in combination with poor remuneration, can leave PWSCI vulnerable to neglect and abuse, and the negative psychological implications of indignity and stigma. Suffering is the central challenge here due to the lack of reliable care during transfers. Intensifying suffering is visible through lenses of exclusion (both within their immediate environments and communities), and negative attitudes and prejudices toward

PWSCI. The critical underlying questions in this study, as seen in the experiences of participants, relate to the protection of human rights, and taking back agency in the context of inevitable unequal relationships ensuring quality of life.

4.5 Reflexive self-awareness

In this final section, I reflect briefly on my positionality as a researcher, in relation to the participants in this study. According to Nunkoosing (2005), the power of the interviewer lies within her expertise and being a knowledge seeker. Nunkoosing (2005) states that, in contrast, the power of the interviewee rests in being more or less a knower. Ibrahim and Edgley (2015) describe reflexivity as a practice of self-awareness, achieved by looking into the self in an attempt to understand the dynamics between the researcher and the researched. Reflexivity is considered to form an integral part of rigour in qualitative research as it involves researchers attempting to make sense of their influence over the research process, either with intent or unintentionally (Jootan et al., 2009).

Research (Yuval-Davis, 2006; McCall, 2005) indicate the need for more explicit attention relating to power, identity, and intersectional positionality of researchers, based on social divisions such as gender, race and class, sexual orientation, ability, educational, and other forms of identity, required amongst researchers. The researcher's identity may affect research use and building knowledge, and thus may, in the end, impact the goals set out in the research itself. For researchers to engage with study participants, the what, how and who must address all aspects of the research question, and design, in terms of looking at the identities, and how they interrelate, and affect one another in certain contexts (Yuval-Davis, 2006).

Perhaps my social identity and status as a white, educated female and business owner, are contributing elements of power and privilege between study participants and researcher and thus influenced their stories in this study. (Nagata, 2005). However, I found the interviewing process to be rewarding as I got to know the study participants on a deeper level. I had to continually be aware of my feelings, and not to assume that the study participants needed help in any way. Initially, I was nervous that they would not open up to me, and thus tried to make them understand that I was not judging them, but as a disability researcher, I wanted to hear their stories about their lived experience in the context of a relationship with their assistance providers. I was rather emotional in some instances and could feel their immense frustration listening to how negative attitudes and thus stigma within society as a whole and relationships with their assistance providers, prohibited them from living a happy and meaningful life.

CHAPTER 5: CONCLUDING THOUGHTS AND RECOMMENDATIONS

5.1 Introduction

In this study, I argued for an EoC approach that considers the predicaments experienced in human relationships, faced by PWSCI during every day transfer-related activities, provided by personal assistance providers. An EoC approach redefines independence as having control and choice over the assistance required rather than attempting to do all for oneself (Kittay, 2011; Shakespeare, 2002). Being in control of one's care is seen as a way for PWSCI to obtain the highest possible independence (Winance, 2016). An EoC approach foregrounds relationships and interdependence, and assumes that we have a responsibility to one another (Kittay, 2011). Interdependence in the context of this study, is seen through the lenses of employer-employee relationships of mutual dependence to live (Kelly, 2011; Shakespeare, 2002; Shakespeare, 2014).

Study participants selection was from low socio-economic ILC homes in Johannesburg. Through phenomenology, the approach chosen for this study, a retrospective attempt was made to discover the depth and richness of the study participants' experiences, and perceptions about particular obstacles or limitations in fulfilling of ordinary or normal life (Chuang, Yang, & Kuo, 2015). These obstacles included perceptions of disability, stigma through negative attitudes, barriers to an environment which is accessible for people living with impairments, and structures of normalcy and ableism (Watermeyer, 2009). These obstacles influenced how PWSCI constructed their identity within relationships of personal assistance. The study revealed that the voices and experiences of people living with impairments were not always heard and not given political recognition (Watermeyer, 2009). The study thus drew on shared

experiences, and requirements for maintaining dignity, and respect, and having the choice, and control over personal assistance, which places PWSCI in the centre stage of their families, and communities, and provides the opportunity to reclaim their agency (Watermeyer, 2009; Shakespeare, 2002).

The nine participants living with SCI, were living in ILC homes in low socio-economic circumstances. The study participants were a mix of woman and men who sustained SCI, varying from three to twenty years since the injury. Study participants consisted of seven males, and two females, between the ages of 23 and 48 years. The unequal gender participation is a deviation from my initial intention of equal number male and female participants. It was accidental that more men than women living in the same ILC homes were willing to participate in this research study. The objective of these ILC homes is to facilitate PWSCI self-sufficiency, dignity through independence with care, and community participation. A summary of my findings follow next.

5.2 Summary of findings

This thesis investigated how PWSCI perceive their transfer-related experiences, and what attributes framed such experiences. Accounts of transfer-related experiences in the context of fluid human relationships between PWSCI and personal assistance providers answered the research question, of how do the nature and availability of transfers influence the lived experiences of PWSCI living in low socio-economic independent living communities in the context of personal assistance relationships. Accounts of experiences give the public, and communities insight to PWSCI wants and needs in terms of agency and control over relationships of personal assistance during transfer-related activities, in being acknowledged and treated with respect, and dignity.

In this study, I argued for an EoC approach that considers the predicaments experienced in human relationships that PWSCI face during transfers in ADL administered by personal assistance providers. Research shows that an EoC approach redefines independence as having control and choice over the assistance required rather than attempting to do all for oneself (Kittay, 2011; Shakespeare, 2002). Being in control of one's care is seen as a way for people with disabilities to obtain the highest possible independence (Winance, 2016). An EoC approach, extends beyond individualism and autonomy, foregrounds relationships and interdependence, and assumes that we have a responsibility to one another (Kittay, 2011). Interdependence here, is seen through the lenses of employer-employee relationships of mutual dependence to live (Kelly, 2011; Shakespeare, 2006; Shakespeare, 2014).

Respect and dignity is a human right and a responsibility of personal assistance providers in relationships of equity and respect (Raee, Abedi & Shahriari, 2017). Safe and dignified transfers impact the quality of life of people living with SCI during ADL (Power-Cope et al.,2008). Research shows that the avoidance of secondary injury contributes to the dependence on care for PWSCI (Green, 2005). Stigma and negative attitudes towards PWSCI also contribute to their negative identities.

The WHO (2018) states that improved working conditions may aid a better relationship between the personal assistance provider and care receiver. Assistive technology may enable PWSCI to continue to live at their familial homes and potentially delay or to some degree prevent the need for long term care (WHO, 2018). Regarding the promotion of training of professionals and staff working with people with disabilities, the Convention on the Rights of Persons with Disabilities (CRPD), Article 4 states that training in the rights recognised, may provide better assistance and services guaranteed by those rights (2006).

According to the WHO (2018) and DSD (2015), the financial implications of SCI have significant adverse effects on the mind and body of people living with impairments. Prohibitive mobility expenses in aid of services and maintenance of equipment and excessively high public transport costs are societal barriers. The DSD (2015) and WHO (2018) state that these barriers highlight difference and exacerbate PWSCI's societal exclusion, and therefore creating a further necessity for and dependence on care support.

The WHO (2018) estimates that more than one billion people worldwide may benefit from one or more AD. This number is likely to rise above 2 billion by 2050 with many older people requiring more devices as they age (WHO, 2018). According to WHO (2018) people that need AD include people with disabilities, people with noncommunicable diseases, people with mental disabilities, older people, and people with a gradual decline in functionality. Furthermore, WHO (2018) recognises that the impact of AD goes far beyond well-being and other health benefits to both individuals and their families but also has socioeconomic benefits. The WHO (2018) states that reducing direct health and welfare costs may aid a more productive labour force and thus stimulating growth in economies. One such example is lowering the risk of falls in older people and people with disabilities. By managing declines in intrinsic capacity and mobility, as an example, the risk of falls may be lowered (WHO, 2018).

According to Kelly (2011) care, in the context of disability, is haunted by "institutionalisation, medicalisation and paternalistic charities" (p.564) which systematically marginalise people with disabilities. Examples of oppressive ideologies that exist today under the guise of 'caring for', regardless of progress made by disability movements worldwide, also include physical and emotional abuse amongst others. Kelly (2011) states that the daily awkward negotiation between people with disabilities and their assistance providers take place during some of the most intimate moments of support that may reflect these negative legacies and conceptualisations of care. In care ethics as a conceptual

approach, 'interdependence' instead of 'dependence' has been emphasised in the 'ethics of care' discussion (Kroger, 2009). Some feminist care researchers (Gilligan, 1982; Noddings, 1984 and others), initially emphasised that women's (responsibility) and men's (justice) actions are grounded on different moral frameworks. The notion of responsibility is rooted in an EoC approach which contrasts with the notion of impersonalised rights which is grounded in an ethics of justice framework (Kroger, 2009).

On the onset of SCI, the loss of dignity and dependency on care dramatically influenced the lives of the study participants. Some critical underlying questions relate to the appropriate care and protection of human rights. Will some of this distress be alleviated with a more accommodating social environment? Suffering due to societal exclusion, stigma, and negative attitudes towards people with disabilities is the central challenge here.

Before conducting the semi-structured interviews, my priority was to hear the stories of PWSCI, from their perspectives (Carpenter, 1994), through the investigation of their daily transfer-related experiences during ADL in the context of ever-changing personal attendance relationships and control and agency. In addition to the independent living predictors (marital status, transportation barriers, education, financial difficulties and the severity of a person's disability) as per DeJong et al. (1984), my expectations of the feedback from PWSCI included:

- the need for better training of care attendants during transfer-related activities, and
- fear of falling and potentially being dropped during transfer-related activities, and
- physical and emotional abuse by personal assistance providers.

Some findings were in some instances contrary to prior research. A variety of issues were raised during the sampling of this study. My initial intention was to focus on transfer-related experiences of PWSCI in context of unpaid care relationships within low socio-economic ILC homes. However, poverty has implication for access to professionally trained and paid care, and experiences arising differs from the lack of care. Due to low remuneration within poor resourced ILC homes, female caregivers, may not always be in the best caring frame of mind and therefore may resort to abuse of their employers (care receivers). Examples of abuse include overstepping sexual boundaries, withholding food and transfers. These attitudes of personal assistance providers align with the medical model view, assigning power to medical professionals over individuals or patients, through the decision-making processes of who does the curing and who receives the treatment (Shyman, 2013; Hughes & Paterson, 1997).

Focussing on the experiences of care providers was not my initial intention, however, the study revealed that the availability of transfers could not solely be focused on and the subject got bigger than expected. My intention was low SES and unpaid care but found PWSCI's experiences within transfers in context of relationships of personal assistance to be more complicated (Kelly, 2011). Initially after rehabilitation, study participants received personal care (unpaid care) from their respective families. However the consequences of SCI is in the short term extremely painful (Kelly, 2011). A lack of professionally trained paid care created a situation of breaking / separating bonds in families and caused study participants to move to ILC and unprofessionally paid care.

The picture that emerged was that PWSCI might be present in the community but remain invisible, and thus do not enjoy full societal participation. Daily occurrences of stigma through discrimination and exclusion were reported as frustrating realities. In addition to limited resources, considerable emphasis was

placed on the inaccessible public transport system in South Africa, which further exacerbates the visible exclusion of PWSCI from community participation and thus living full and meaningful lives. Limited resources have contributed to the difficulty in accessing aids required in facilitating the mobility of PWSCI to access services and support in their communities. It was evident that the emerging picture was one of lack of respect for the freedom to shape one's life according to one's values and norms (Ram-Tikin, 2018) and thus the potential imbalance between capabilities and actual functioning of PWSCI. Basic human functional capabilities are essential factors for the well-being of all people, including PWSCI however it appears that being treated with respect and dignity were the significant factors that emerged from this study.

Participant feedback revealed that many people might believe that disability does not touch their lives. Non-disabled people may give very little thought to the experiences of living with an impairment or caring for someone living with a SCI, and thus to the potential contribution of PWSCI to society. Perhaps, without first-hand experience through a close family member or friend, non-disabled people hold on to the belief that, at best, things are better than they could have been.

The motivation for researchers to engage people with disabilities to explain their lived experiences and context (Wee & Paterson, 2009) is for reasons of equity and equality. By seeking their accounts, it is crucial to understand the experience of PWSCI, by hearing their 'voices' concerning the underlying views and values of their experiences (Wee & Paterson, 2009).

People with disabilities have, over time, found themselves to be hidden away in institutions (Kelly, 2011; Watermeyer, 2016). Today, in contrast, it appears that people with disabilities still find themselves segregated from societal participation due to various societal barriers because of visual differences (Gavin-Dreschnack et al., 2005; Watermeyer, 2016), for example, having a mobility impairment. Moreover, PWSCI expressed their anger and frustration

about still being shut out, as they are excluded from their communities and societal participation at large due to stigma and negative attitudes about visual differences, inaccessible environments and potentially due to ignorance about impairments and prejudices (Gavin-Dreschnack et al., 2005; Watermeyer, 2016). Also, due to the constructions of normalcy, people living with impairments are still excluded due to the lack of considering human variation or unmet needs in inaccessible built environments. Disability is thus not only associated with physical differences but also due to a lack of civil, social and economic rights as associated with the social model of disability (Barnes, Mercer & Shakespeare, 1999; Oliver, 2013).

The issue about the potential overstepping of the boundaries of employee-employer relationships raised by participants may be due to the lack of knowledge, understanding and assumptions about living with SCI and the variances in impairment. Factors that may promote and bring change, inclusion and thus improvement to the lives of PWSCI, in the context of the relationship of personal assistance, include:

- treating PWSCI with respect and dignity and thus honouring them as rights-holders.
- recognising, and respecting differing individual identities;
- hearing and listening to the experiences of PWSCI, about their needs and wants within more inclusive services;
- acknowledging the value of PWSCI through their involvement in decisions that concern them directly; and
- changing general perceptions and negative attitudes toward PWSCI.

There has been little change in care and service provision for PWSCI and their caregivers over many years, regardless of increasing numbers of PWSCI worldwide (Kelly, 2011; Green et al., 2005). The needs of people with impairments have thus, to a great extent, gone unrecognised over this period (Kelly, 2011; Green et al., 2005). It is therefore evident that the lack of development and growth within support services to PWSCI, impacts both the lives of people living with SCI and their family at large.

More concerning is the fact that there have been very few studies that have investigated the vast range of care and support services required in the context of low socio-economic independent living communities to address the needs of PWSCI. It appears that much of the familial and PWSCI-centred research focus on social isolation, family dysfunction, and, unmet support service needs for the whole family (DSD, 2015). In achieving a basis for true gender equality, the 2015 DSD report focussing on people with disabilities, recommends that authorities and communities recognise the role of women and girls providing unpaid care and thus redistribute unpaid care work from family to communities and the state, and very importantly, from women to men (DSD, 2015).

Social care and health service providers, often neglect PWSCI and their families, which exacerbates further risk of adverse impacts. The lack of, or failure of the provision of the necessary formal support, leads to various damaging effects on PWSCI and their family members, both immediate and extended families (DSD, 2015). These effects include impacts on social isolation and mental health, employment and thus, financial stability of families (DSD, 2015). Reviews of inadequate service delivery drew attention to failing policies and practices, resulting in unmet needs and isolation of family members, across a range of ages and development stages in their life - more notably, the detrimental effects thereof on PWSCI (Kelly, 2011; DSD, 2015). These reviews have placed extreme demands on all family members, regardless of age. Requirements to provide free support was often at the

expense of family members' well-being (both physical and emotional). A gap thus remains in the literature for how the influences of lack of care impact the abilities of PWSCI to become more visible in society (Kelly, 2015; DSD, 2015). A further gap remains for how PWSCI live equally and in an inclusive manner in their community (Kelly, 2015; DSD, 2015). It appears that broader society does not have an appreciation of the magnitude to which the social environment contributes to the disabling experiences of PWSCI (Kelly, 2015; Watermeyer, 2016). Furthermore, it appears that there is little or no recognition of the fact that both PWSCI and their family members across all ages experience disablement. As the needs of PWSCI and their families are mostly unmet, experiences of disablement and invisibility can be profound (Watermeyer, 2010; WHO, 2011; DSD, 2015).

Through further research, some of the common themes revealed by PWSCI to describe their experiences within personal assistance relationships during transfers in ADL may reveal how to bring change in their lives and contexts (Muhammad et al., 2015). Future research by scholars should consider using people with disabilities to guide the research process (McKenzie & McConkey, 2015). To enable amelioration of the lives of PWSCI, through government structures and involving PWSCI in decisions that concern them, a shift in attitude towards people with disabilities should be encouraged. This shift in attitude may regard people living with impairments not as disabled, but rather as people with unique abilities (Muhammad et al., 2015).

5.3 Limitations of research

Every research has its limitations. There are a few limitations to this work worth noting. Insufficient data focussing on care-receiving exist in the global South. My initial focus was transfers but as seen from the rest of the thesis, experiences of care providers in relation to transfers provided by caregivers,

and the availability of transfers could not solely be focused on and the subject got bigger than expected. This research reflects findings of PWSCI in three ILCs in Johannesburg, as the city selected for this study enquiry. Multiple case studies would be warranted for future research in the examination of transfer-related experiences of PWSCI as seen through the lenses of personal assistance relationships, in comparison with other public environments such as ILC homes, nursing homes, special need schools, and in comparisons with private facilities and homes. Studies and feedback from PWSCI and their families living in low socio-economic environments and the voices from their very low remunerated care assistants may further highlight class and race disparities and the influence of poverty on personal assistance relationships. Comparisons of case studies would be beneficial especially in the context of poverty and more affluent environments with paid care personal assistance. These studies may highlight differences in what access to paid, trained and educated personal assistants and AD can make to the lives of PWSCI.

My initial intention was selecting participants from low SES and unpaid care households. It became increasingly evident, as seen in my research, the understanding of caregiving and the predicament thereof and what the effect of caregivers' experiences have on the care for care-receivers. Perhaps the inclusion of PWSCI and their care attendants will increase the understanding and options of their own needs and wants better, thus contributing to better visibility through recognition in both cases. Another potential limitation of the study may be the anonymity of each study participant within the same ILC home, as they may learn intimate details about one-another through peer reviews.

5.4 Implications for future research

Through the daily transfer-related experiences of study participants, the study revealed that stigma and negative attitudes of ableism within their communities and society as a whole were contributing factors to prohibiting PWSCI from living a happy and meaningful life. Lack of respect and dignity within transfer-related activities, as seen through the lens of relationships of personal assistance, had a negative effect on PWSCIs quality of life (Noel et al., 2011; Power-Cope et al., 2008). To improve the lives and circumstances of PWSCI, in the context of relationships of personal assistance, further research in the area of this study is required. New research, with the involvement of people living with impairments, will provide opportunities for the voicing of their needs and wants towards creation of better care services. To be heard and acknowledged, and incorporated within all structures and decisions regarding their lives, people living with impairments will be able to take back their agency and control over their care and experiences. Community participation will aid to break down barriers to self-expression and fulfilment for PWSCI. Societal inclusion will support breaking down barriers created through ableism, stigma of disability, thus negative perceptions, and the pervasiveness of the medical model (Watermeyer, 2009).

5.5 Recommendations

This chapter has summarised the importance of how the study participants feel about the lack of agency in relationships of personal assistance as experienced during daily transfer-related activities, and the lack of belonging in their communities. These factors were found to be representative of how people living with impairments respond to negative social constructions in disability (Watermeyer, 2009) as experienced in personal assistance relationships. The following recommendations may foster better understanding of the intricacies

within relationships of dependency in care, psychological, emotional and physical barriers experienced in environments and communities that do not consider reasonable accommodation for PWSCI.

- By including PWSCI in research processes and decisions that concern them directly will further voicing their needs and wants in the realm of personal assistance within daily transfer-related activities;
- maintaining dignity and respect and having the choice of being in control of their assistance.
- Clarification to this end, may foreground what it takes to create a society that is just and offers reasonable accommodation through access in their homes and communities, and importantly, experiences and perceptions, illuminating wants and needs in unequal relationships of equity.
- The vocation of personal assistance providers should be organised, available and accredited by the State. The need for accredited training of personal assistance providers may prevent secondary injury of both care receiver and care provider. Access to allocated state resources may facilitate PWSCI to attain accredited, trained paid personal assistants and appropriate assistive devices, thus create conducive working environments which may foster positive attitudes and perceptions toward PWSCI.

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APPENDICES

APPENDIX 1 - LETTER TO NON-PROFIT ORGANISATION

November 2017

Non-Profit Organisation

CEO, Mr X

Transfer-related experiences of people with spinal cord injury in low socio-economic independent living communities in the context of relationships of assistance – A phenomenological study

Dear X

As you know, I am a masters' student in the Department of Health and Rehabilitation Sciences at the University of Cape Town (UCT). I am conducting a research study as part of the requirements of my Master's Degree in Disability Studies. I would like to request your/your organisation's assistance in selecting Members from your Database that have previously indicated that they are available to participate in third party research, to participate in my study.

My study will investigate how an Ethics of Care (EoC) approach can bring relief to the predicaments of human relationships and moral conflict that people with spinal cord injuries (PWSCI) are faced with during transfers in activities of daily living (ADL) as experienced in the context of relationships of assistance. This EoC approach is in response to the simplistic application of discourses of human rights and independence. I am aware of the importance to acknowledge the experiences of caregivers. However, they will not form part of the study participants and will therefore not be interviewed for this study.

According to the most leading theories of justice, personal dignity and the care received by disabled people are seen as a way of obtaining the greatest possible independence.

Aim:

In Global South contexts, very little is known about how transfers occur within availability of care and resources. The aim of the study is thus to examine how the nature and availability of transfers during ADL influence the experiences of PWSCI in the context of care relationships living in independent living communities in Johannesburg.

Objective:

To collect experiential data from PWSCI from previously disadvantaged groups, from their viewpoints as experienced during transfer-related incidents in ADL, to better understand how poverty influences care relationships. Personal accounts through semi-structured interviews of PWSCI are likely to be rich with emotion, lived values and experience.

Significance:

The significance of this study is the lack of descriptive accounts about transfer-related experiences within care relationships of PWSCI from historically disadvantaged groups, living in independent living communities in Global South context . A study of experiential accounts of PWSCI may assist society as a whole to understand care needs better. This understanding may inform policy and better service provision for PWSCI around care.

Demographics of Participants:

In order for this study to be as representational as possible, an equal number of adult men and women from historically disadvantaged groups living with quadriplegia will be selected to reflect diversity in race and gender. The study sample will consist of PWSCI who live in independent living communities in Johannesburg. In the context of this study, poverty will thus be defined as a state in which a person with quadriplegia lacks the financial means and essential social support to enjoy a minimum standard of living and well-being that is acceptable in society.

Inclusion criteria:

Participants must be from historically disadvantaged groups; be over 21 years of age and have had quadriplegia post injury for a minimum of 3 years to ensure adequate experiences with numerous caregivers assisting with transfers during ADL; have / have had paid or unpaid caregiver/s assisting with transfers during ADL; live in independent living communities in Johannesburg and have a basic understanding of the English language or speak isiXhosa or isiZulu as home language. Cognitive acuity is an important inclusion criterion, as the participants must possess the ability to think clearly, reason and remember.

Exclusion criteria:

People not from historically disadvantaged groups and people with alternative impairments, such as cognitive disabilities. I acknowledge that the subject of cognitive disabilities is hugely important and therefore should be addressed as a separate research topic. Although it is acknowledged that the needs and experiences of caregivers are important, this topic will not form part of the domain of this study.

Recruitment of participants:

Telephonic and email introduction of the study will be made to selected Non-Profit Organisation Members that have previously indicated that third parties may approach them for participation in research. In an attempt to avoid sampling bias participants will be selected through purposive sampling, according to the inclusion criteria as stated above. Participants will be contacted telephonically, and or by letter or email to explain the purpose, risks and benefits – as described below - of this voluntary study; that they may withdraw from the study at any time and do not need to answer any question that makes them feel uncomfortable. The participants will be ensured of utmost privacy and thus all notes, recordings and transcriptions will be destroyed after individual feedback sessions. Translation and transcription will be done by a suitably experienced translator and professional transcriber. To avoid coercion issues related to home, interruptions and privacy, it will be made very clear that the researcher is there to investigate the participant's experiences and thus not there to judge the home; and that the interview will be conducted in privacy where the participant is comfortable and can speak freely. A quiet room will allow for clear recording of the interview. The interview will last between 45 and 60 minutes.

Risks:

Related to participants in terms of care assistance involved may be emotionally evocative and through discussion may bring certain aspects of the relationship to light. Any emotional concerns or contradictions within the lives of people with SCI surrounding care assistance will be referred to counselling structures of Non-Profit Organisation for emotional support.

Benefits:

Human relationships are complex, and in the context of care, even more so. The discussion with an unbiased observer, trying to be as objective as possible about such a complex topic as care relationships, may foster new ideas. Knowledge is useful in the design of support services of people with SCI.

Consent and assent:

On identification of willing participants by the Non-Profit Organisation, I will obtain consent from each participant both telephonically and in writing, prior to commencement of the study.

Clarification of special protection for vulnerable participants:

Only adult participants with cognitive acuity will be considered for this study. Children and people with cognitive disabilities will not form part of the domain of this study. If any of the participants experience any emotional trauma stemming from contradictions of the lives of PWSCI or as a result of volatile care relationships, I will assist with referrals to the counselling structures of the Non-Profit Organisation.

Address of ethical issues and extra protection:

The Protection of Personal Information (PoPI) Act prescribes how and by whom personal information may be collected, processed, stored and shared. I will abide by and respect these prescriptions by means of prior conclusion of confidentiality agreements between myself and both interpreter and transcriber. Participation will be kept confidential. Study information will be kept in a secure location in my home. All notes, recordings and transcriptions will be destroyed after individual feedback sessions. The results of the study will be presented to the university and at professional meetings, but the identity of participants will never be revealed.

Compensation for research-related costs:

My research costs incurred will be self-funded. Participants will not incur any costs due to travel if the interviews are conducted at each respective home.

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case you or your colleagues or participants have any questions regarding their rights and welfare as research subjects on the study.

I will be happy to answer any questions about the study and concerns you or any member of your organisation or member database may have. You may contact me on my cell, number 082 5700 613, and/or email address jssron002@myuct.ac.za.

Thank you for considering assisting me in selecting from the Non-Profit Organisation members to participate in my study. Participants choosing to participate voluntarily, will be requested to sign the attached two forms and return to me by email if available, or notify me when I can collect them.

a) Consent form to participate in the study

b) Consent form for me to record the participant interview.

I will call you within the next week. I look forward to your feedback.

Kind regards

Ronel Jessen

Phone 082 5700 613

Email jssron002@myuct.ac.za

Encl.

APPENDIX 2 – INFORMED CONSENT LETTER TO PARTICIPANTS

November 2017

A Voluntary Research Study - Transfer-related experiences of people with spinal cord injury, in low socio-economic independent living communities in the context of relationships of assistance – A phenomenological study

Dear Participant

My name is Ronel Jessen. I am a masters' student in the Department of Health and Rehabilitation Sciences at the University of Cape Town (UCT). I am conducting a research study as part of the requirements of my Masters' Degree in Disability Studies, and I would like to invite you to participate in my study.

What is the background to the study?

Many SCI rely on care assistance for transfers during everyday activities such as getting up, dressing, washing, toileting, eating, and so on. In communities where a paid caregiver is unaffordable, care assistance is often performed by family members or friends. This affects the ready availability of transfers, the safety of transfers, and give-and-take dynamics of care within the relationship.

What is the purpose of the study?

The purpose of the study is to investigate the transfer-related experiences from their own perspectives of people living with spinal cord injury in the context of care relationships in communities where caregiving is unpaid.

Who can participate in the study?

Participants must be over 21 years, been living with quadriplegia for between 3 years or more, have a family member or friend assisting with transfer-related activities, living in a Johannesburg, have a basic understanding of the English language or speak isiXhosa or isiZulu as home language, and can remember, and talk about personal experiences.

What are the risks to taking part in this study?

There is a risk that our discussion may raise difficult emotions, and memories of experiences with caregivers, friends or family members. If difficult feelings that upset you emotionally are raised through our discussion, and you feel you require further professional support, I will refer you to the counselling structures of the Non-Profit Organisation.

What are the benefits to taking part in this study?

Although you will not benefit directly from this study, the information gathered will assist in advising policy writers, and service delivery for people living with quadriplegia in communities with less resources.

What is the procedure of the research?

If you decide to participate, you will be asked to meet with me for an interview. You will be asked questions about your experiences in daily wheelchair-related transfers, and your relationship with the caregiver/family member/friend who assists you in these transfers.

Where will the meeting take place, and how long will the interview be?

The meeting will take place either in a private room at your home or an alternative venue, and time that is suitable for both of us. The interview should last between 45 and 60 minutes.

What language, and methods will be used to record the meeting?

Should you wish to participate in this study in your home language, an experienced translator will help you, and me to ensure a correct translation of your experiences. I will make hand written notes, and would like to make an audio recording of our discussion for me to accurately reflect on your experiences as shared during the interview.

Will a follow up session be required and how will confidentiality be ensured?

Once the information has been inspected, I will send you the notes to ensure that you are happy that your experiences have been recorded correctly. A follow up feedback session will then be scheduled at your home. After the feedback session, all notes of our interview will be destroyed.

If you feel uncomfortable answering some of the questions, you can opt not to answer those questions that you do not wish to. Your participation will be kept private and confidential. Study information will be kept in a safe place in my home. The results of the study will be given to the university and discussed at professional meetings, but your identity will never be exposed. Taking part in this study is entirely your decision and you do not have to participate in this study if you do not want to. You may also decide to leave and quit the study at any time.

I will be happy to answer any questions about the study and concerns you may have. You may contact me on my cell, number 082 5700 613, and/or email address jssron002@myuct.ac.za.

Thank you for considering participation in my study. If you choose to participate, please sign the attached two forms and return to me by email if available, or let me know when I can collect them.

a) Consent form to participate in the study

b) Consent form for me to record our conversation.

I will call you within the next week. I look forward to meeting with you.

Kind regards

Ronel Jessen

Phone 082 5700 613

Email jssron002@myuct.ac.za

Encl.

APPENDIX 3 (MUST BE READ IN CONJUNCTION WITH APPENDIX 2 – INFORMED
CONSENT LETTER TO PARTICIPANTS)

INFORMED CONSENT FORM FOR STUDY PARTICIPANTS

I, _____, hereby agree to participate in this voluntary study regarding transfer-related experiences of people with spinal cord injury, in low socio-economic independent living communities in the context of relationships of assistance, as set out in the information letter attached.

I have read and understood the information letter and understand what will be required of me.

I understand that participation is voluntary and should I wish to withdraw I may do so at any time with no negative consequences (no costs or penalties).

I understand that all information collected during the study is confidential and no mention will be made of my nor my family's personal details.

I understand that should I have any questions related to the study, the interview, or the confidentiality of information provided, I can direct these at any time to the Researcher (Ronel Jessen) on 082 5700 613 or by email jssron002@myuct.ac.za.

Furthermore, the UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

Signed _____

Witness _____

Date _____

APPENDIX 4 – CONSENT FORM FOR AUDIO-RECORDING

I, _____, hereby give consent for my interview with Ronel Jessen concerning transfer-related experiences of people with spinal cord injury, in low socio-economic independent living communities in the context of relationships of assistance, to be recorded.

I understand that once the information needed from the recordings has been gathered, and approved by myself, the recordings will be destroyed.

In addition, I understand that all information on the recording is confidential and that at no point will any reference be made to me nor my family's personal details.

Signed _____

Witness _____

Date _____

APPENDIX 5 - SEMI-STRUCTURED QUESTIONS

Semi-structured questions put to the study participants will be:

“Describe your everyday lived experiences since injury, in terms of transfers.”

“Tell me about some of the issues with present and past caregivers during these transfers.”

“How do you perceive your caregiver’s needs?”

Possible probing questions will include the following keywords:

- Reliability and unreliability of caregiver/s
- Relationship housekeeping with existing and new caregiver/s
- Treatment by caregiver/s
- Emotions due to absence of caregiver/s
- Reliance on caregiver/s
- Transitions of caregivers

Interview questions will be complemented by prompts to elicit depth such as:

‘What happened next?’

‘Tell me more.’

'So how did you feel about that?'

APPENDIX 6 - CONFIDENTIALITY AGREEMENT BETWEEN RESEARCHER AND TRANSCRIBER

November 2017

Transfer-related experiences of people with spinal cord injury, in low socio-economic independent living communities in the context of relationships of assistance – A phenomenological study

I, _____, the Transcriber, have been hired to _____.

I agree to –

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., transcripts) with anyone other than the Researcher.
2. Keep all research information in any form or format (e.g., transcripts) secure while it is in my possession.
3. Return all research information in any form or format (e.g., transcripts) to the Researcher when I have completed the research tasks.
4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding the research project that is not returnable to the Researcher (e.g., information stored on computer hard drive).

Name	Signature	Date
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Ronel Jessen, Researcher	Signature	Date
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APPENDIX 7 – STUDY APPROVAL LETTER

APPENDIX 8 - TRANSCRIPTION 1-9 (SP1-SP9)