Caregivers of Adults with Physical Disabilities: Perceived Stress Levels and Impact on Caregiver-Care Recipient Relationship

A research report in partial fulfilment of: *MA in Social and Psychological Research*,

School of Human and Community Development; University of Witwatersrand

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Declaration

I declare that this research project is my own, unaided work. All information taken from other sources have been rightfully acknowledged. It has not been submitted before for any other degree or examination at this or any other university.

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Abstract

Caregiving is reported in numerous studies to have adverse effects on caregivers, including caregiver stress; mental and emotional strain; feelings of burden; and even the risk of mortality. Specifically for caregivers of adults with physical disabilities (AWPD), it is appreciated that caregiving is a life-changing experience as major modifications have to be made. These numerous changes have been reported to expedite the manifestation of stress that is differently perceived by the caregivers. Caregivers of AWPD are therefore anticipated to be at high risk of stress as this type of caregiving has been reported to be burdensome. In South Africa, researchers seem to have overlooked caregivers of adults with physical disabilities as a group that potentially have specific and unique perceptions in the role of caregiving. Most importantly the literature seemed limited in presenting how caregivers of AWPD qualify stress levels. Another paucity observed in the existing literature is that there are no accounts by caregivers on how the qualified stress levels impact on the relationship between the caregiver and care recipient. The aim of the current research was to explore perceived stress levels of caregivers of AWPDs. A second aim was to establish how caregivers of AWPD perceive stress levels to impact on the caregiver-care recipient relationship. The results highlighted that caregivers perceived stress levels to be fluctuating with time and affecting their health. According to the perspectives of the caregivers of AWPD, stress has either positive or negative impacts on the caregiver-care recipient communication, cooperation and closeness, differing amongst caregivers.

Keywords: caregiver, care recipient, stress level, Adults with physical disabilities

Acknowledgements

This research was encouraged by the support and supervision offered by Mrs Clare Harvey for which I am most grateful. Gratitude also goes to the course coordinator Professor Kevin Whitehead for the support and guidance. My appreciation goes to my family for the encouragement through the entire project. My humble gratefulness goes to the Association for the Physically Disabled (APD) including: Miemie, Luckmore, Nokuthula, Vusi, Mama, and the participants of the study. Utmost appreciation to the Almighty God for the divine guidance and intervention in this research activity. Thank you to all, if it wasn’t because of your input this project would not be a success.

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Chapter 1

INTRODUCTION AND RATIONALE

Caregiving is reported to have adverse effects on caregivers, including caregiver stress; mental and emotional strain; feelings of burden; and even the risk of mortality (Fredman, Cauley, Hochberg, Ensrud & Doros, 2010; Lund, Ross, Petersen & Groenvold, 2014; Pinquart & Sörensen, 2003; Schulz & Beach, 1999; Schulz & Sherwood, 2008). Schulz and Beach (1999) found that high stress level indicators, such as mental and emotional strain associated with caregiving, exposes caregivers to the risk of death. Fredman et al. (2010) also supported this argument in a study which found that caregivers reported to be more stressed than non-caregivers, and highly stressed caregivers seemed to be at a higher risk of mortality than low-stressed caregivers. In studies (Anetzberger, 2000; Burgener & Twigg, 2002; Ejem, Drentea & Clay, 2015; Gupta & Chaudhuri, 2008; Ingersoll-Dayton & Raschick, 2004) of caregiver-care recipient relationships it is further illustrated that caregiver stress has been associated with a number of issues such as care recipient depression; care recipient abuse; and care recipient problem behaviours. However, these previous studies of caregiver-care recipient relationships investigated caregiver stress and its associated outcomes, overlooking possible contributors to these outcomes, including communication; cooperation and efforts to maintain a good relationship. Additionally, studies on levels of stress (Fredman et al., 2010; Schulz & Beach, 1999) have not covered the detailed perspectives, expressions and descriptions assigned to these stress levels in caregivers. Hence, the current study's focus on perceptions of caregivers of adults with physical disabilities and the perceived stress level impact on the caregiver-care recipient relationship.

According to Barer and Johnson (1990), *caregivers* are often defined and described according to their care recipients and the roles that they perform in caregiving. *Caregiving* is defined as “looking after, giving special help or some regular service that is not provided in the course of paid employment” (Hirst, 2005, p.3). *Caregivers of adults with physical disabilities* are defined as primary care providers who are above the age of 18 years, and have been/are providing the majority of care, without reimbursement for a period of at least three months, to an individual (also above 18 years old) with physical disabilities (Lawang, Horey & Blackford, 2015). Janssen, Baumgartner, Ross, Rosenberg and Roubenoff (2004) defined *physical disability* as a bodily impairment that leads to one having difficulty in performing activities of daily living. Physical disabilities may include: hemiplegia, paraplegia, quadriplegia, amputations, weakness of limbs, painful limbs, amongst others (Lawang et al., 2015). Yee and Schulz (2000) reported that the majority (72%) of caregivers of adults with physical disabilities (AWPD) tend to be females as caregiving is a socially constructed female role. It has also been found that most caregivers of AWPD tend to be family members - a blood relative; spouse or a member of the extended family (Lund et al., 2014). The current study adopted the above mentioned definitions and refers to caregivers as family and unpaid care providers.

The roles of caregivers of AWPD involve physical assistance (such as transfers and mobility); assistance in activities of daily living (such as bathing, feeding, toileting and dressing); emotional support (guides AWPD to accept themselves, deal with trauma, and feel that they are not alone); financial support (provision of basic needs and special needs); and support during therapeutic rehabilitation sessions (physiotherapy, occupational therapy, orthopaedic fitting and counselling) (Lund et al., 2014). Additionally, caregivers may have to undertake other tasks such as cooking; cleaning the home; child care; and employment duties (Lund et al., 2014). The concept of ‘community based rehabilitation’ holds that caregivers and AWPD should learn some disability management techniques from their therapists and exercise these at home for the sake of therapy continuity (Curran, Dorstyn, Polychronis, &

Denson, 2015). This seems an additional task to the already long list of roles of caregivers of AWPD.

Studies (Lund et al., 2014; Pinquart & Sörensen, 2003; Schulz & Sherwood, 2008) have reported that substantial caregiving seems to adversely affect various aspects of caregivers' health. Pinquart and Sörensen (2003) conducted a study in the United States of America comparing psychological and physical health of caregivers and non-caregivers. In their study, they assessed psychological and physical aspects as follows: perceived stress; depression; general subjective well-being; physical health; and self-efficacy. The caregivers reported higher levels of stress and depression, and lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers. These results indicate that caregiving exposes caregivers to psychological and physical suffering. This may be due to prolonged and hopeless caring; restrictions to personal/social life; and multi-tasking (Pinquart & Sörensen, 2003).

Schulz and Sherwood (2008) studied physical and mental health effects of family caregiving. These authors found that extensive caregiving tends to lead to self-neglect; poor diet; increase in stress hormones; reduced immune system functioning; changes in body weight; cardiovascular problems; and even mortality among caregivers. Schulz and Sherwood (2008) therefore argue that caregiving is a major public health issue which policy makers need to seriously take note of. In their study of consequences of caregiving among caregivers of cancer patients, Lund et al. (2014) found that caregivers frequently reported negative consequences such as depression; fatigue; anxiety; stress; and sleep problems.

South Africa is a country that encompasses different race groups with a history of race based discrimination, various economic classes and environmental settings. Caregivers in the country are faced with additional adverse challenges such as poverty; inequalities;

unemployment; social isolation; domestic violence; and intersecting epidemics of HIV/AIDS; alcohol and drug abuse; diseases; and poor access to basic services and education (Tomlinson, 2013). Hence, in addition to personal consequences of caregiving mentioned earlier, South African caregivers are bound to be vulnerable due to contextual factors. These contextual factors, may limit a caregiver’s capacity to be effective and influence the way caregivers describe their levels of stress.

From the above studies it is argued that caregivers’ psychological and physical well-being is at risk, hence the need for continuous and detailed research to possibly inform future intervention strategies for caregivers. Specifically for caregivers of AWPD, it is appreciated that caregiving is a life-changing experience as major modifications have to be made. These modifications include adaptations of physical surroundings; procurement of new assistive devices (which are costly); alterations in routine work; retraining the AWPD on activities of daily living; accommodating therapeutic schedules; and balancing one’s needs with the needs of the care recipients (in most cases caregivers have been found to neglect themselves) (Vroman & Morency, 2011). These numerous changes have been reported to expedite the manifestation of stress that is differently perceived by the caregivers (Stamataki et al., 2014). A study by Muller-Kluits (2017) revealed that although some caregivers of people with physical disabilities reported a link between positive experiences and support services used, others reported to be subjected to negative experiences which are related to encountered barriers and support needs. Caregivers of AWPD are therefore anticipated to be at high risk of stress as this type of caregiving has been reported to be burdensome and associated with perceived loss, “prolonged distress, physical demands, biological vulnerabilities and compromised physiological functioning” (Schulz & Beach, 1999, p.937). It is also considered that caregivers of AWPD may be vulnerable to stress as they provide care to people who are cognitively abled; can assess situations; consciously experience their own stress; and display similar responses to themselves.

The aim in the current study was also to address the dearth in the existing literature by conducting an exploration of the perspectives, expressions and descriptions constructed by caregivers about their stress levels. This study also intended to explore how caregivers perceived their stress to impact on communication, cooperation, and efforts to maintain a good relationship between themselves and the care recipients. To my knowledge there is limited information and studies carried out that have explored caregivers' perceptions on caring for an AWPD in South Africa. Rather such coverage has been given to caregivers of people with intellectual disabilities (Rapanaro, Bartu & Lee, 2008; Murphy, Christian, Caplin, & Young, 2007).

This current study was conducted to contribute to the existing literature on caregiving, specifically on caregivers of AWPD through the discussion of meanings and themes described by such caregivers with regard to their levels of stress in the current South African context. This exploration may pave the way for intervention methodologies which are in line with subjective appraisals and expressions of caregiving by caregivers. It is anticipated that initiatives informed by this study will contribute to the reduction of perceived stress related problems among caregivers and the improvement of caregiver-care recipients' relationships.

1.1 Research Aim(s)

The aim of the current research is to explore perceived stress levels of caregivers of AWPD. A second aim is to establish how caregivers of AWPD perceive stress levels to impact on the caregiver-care recipient relationship.

1.2 Research questions

1. What are caregivers of AWPD perceptions' on their stress levels?

2. How do caregivers of AWPD perceive that their stress levels impact on the caregiver-care recipient relationship?

1.3 Outline of this thesis

Chapter two will critically discuss the existing literature on caregivers' perceptions on caring for an AWPD; the fulfilments and/or difficulties of caring for an AWPD as described by caregivers; caregivers' perceived stress levels; caregiver-care recipient relationship; perceived stress levels impact on the caregiver-care recipient relationship; and perceptions on caregivers' required support. Further, an expansion on the study's rationale will be given within this review. A description of the study's methodology will be given in chapter three. Chapter four will deliberate on the results and discussion, before the study is concluded in chapter five.

Chapter 2

LITERATURE REVIEW

2.1 Introduction

It was imperative to first review literature on perception on caring for people with physical disabilities in order to acquire an insight into caregivers' perspectives on caring which might be influencing their perceived stress levels. The perceptions on caring were explored by identifying benefits and difficulties of caring. Most importantly, a review of the literature on caregivers' perceived stress levels and impact on caregiver-care recipient relationship informed the principal purpose of the current study. Finally, literature was reviewed on required support by caregivers in order to identify gaps in the intervention systems addressing caregivers' issues.

2.2 Caregivers' perceptions on caring for an adult with physical disability

In exploration of stress perception among caregivers of AWPD, it was imperative to first acquire an insight into caregivers' perceptions of caring for people with physical disabilities. Beach, Schulz, Yee and Jackson (2000) reported that caregivers of patients with dementia have higher levels of stress due to caregiving being seen as a burdensome role. To my knowledge there is limited information and studies carried out to explore caregivers' perceptions on caring for an AWPD in South Africa. One study, (Mthembu, Brown, Cupido, Razack & Wassung, 2016, p.87) which looked into perceptions on caregiving, targeted caregivers of patients with chronic diseases, including intellectual disabilities, in the Western Cape. That study revealed that "providing care to an older adult with chronic disease was a difficult occupation and that they were struggling to balance their caregiving role with work and social life." Other themes presented by caregivers of individuals with dementia included: God given role, stronger self and uniqueness (Mthembu et al., 2016). At the time of the current study, there was no study found that solely focused on caregivers of AWPD in South Africa.

2.3 The benefits and/or difficulties of caring as described by caregivers

Rohr and Lang (2016) have illustrated that caregiving is not only associated with difficulties but there are also benefits allied to this role. Different caregivers have expressed their perspectives on the difficulties and/or benefits of the caregiving role in various studies (e.g. Pinquart & Sörensen, 2004; Rohr & Lang, 2016; Roth, Dilworth-Anderson, Huang, Gross & Gitlin, 2015). Benefits of caregiving as expressed by caregivers of cancer patients include: finding a life meaning; learning to appreciate life; and companionship (Rohr & Lang, 2016). Roth et al. (2015) found benefits of caregiving to include personal growth among caregivers of dementia patients. Pinquart and Sörensen (2004), in their review of 60 studies of caregivers found that in addition to the above mentioned benefits, caregivers reported better subjective health and higher life satisfaction as benefits of caregiving. Pinquart and Sörensen (2004) also found that caregivers reported difficulties such as time constraints; feelings of burden; behaviour problems of the care recipient; and dealing with progressive deterioration of the care recipient.

Roth et al. (2015, p.814) notified that "benefits and difficulties might be perceived or experienced quite differently by caregivers from different backgrounds or distinct demographic subgroups." Hence, a detailed exploration into the perceptions of disability orientated caregivers, in different contexts, is warranted. Thus, one of the reasons for the current study.

In various studies (Green, 2007; Rapanaro et al, 2008; Murphy et al 2007; Sandler & Mistretta, 1998; Stainton & Besser, 1998; Scorgie & Sobsey, 2000; Hastings & Taunt, 2002) caregivers of people with disabilities have reported benefits in their role of caring. However, these studies investigated either caregivers of children with disabilities, or caregivers of adults with intellectual disabilities. Rapanaro et al. (2008), in the exploration of benefits in caring for young adults with intellectual disabilities, reported that perceived benefits include enriched personal growth of the caregiver; enhanced social support; and improved access to resources. When Green (2007) explored benefits of caring for children with disabilities he found that caregivers reported to have developed the courage to face other life challenges. Caregivers were also reported to have gained knowledge on disability and expanded their social bonds.

Not only did the above studies explore benefits of caring, but also challenges (Rapanaro et al., 2008), which are referred to as ‘burdens of caring’ in Green (2007), and as *difficulties* in the current review. Rapanaro et al. (2008) found challenges of caring for adults with intellectual disabilities to include: problematic behaviours of an adult with intellectual disability; poor service provision by service providers; care recipient’s vulnerability to abuse; and care recipient’s maximum dependence in activities of daily living. Murphy et al. (2007) found burdens of caring for children with general disabilities to include: time constraints; lack of control by caregiver over daily activities; and the need to continually advocate for the child with the disability. The studies above were all conducted outside South Africa and did not focus on caregivers of AWPD. It was therefore significant to explore what benefits and difficulties caregivers of AWPD in South Africa experienced.

2.4 Caregivers’ perceived stress levels

Perceived stress is defined as the extent to which individuals appraise their situation to be stressful (Garey, Farris, Schmidt & Zvolensky, 2016). Garey et al. (2016) explained that perceived stress comprises of feelings and thoughts involving uncontrollability, unpredictability and overload in one’s life. Nolan, Grant and Ellis (1990, as cited in Hunt, 2003) extended the definition to caregivers, and stated that *caregiver perceived stress* refers to an imbalance between the perceived nature of the demand, and perceived capabilities of a person (caregiver). The current research study adapted Garey et al.'s (2016) definition; hence the construct *caregivers' perceived stress* is used to refer to the degree to which caregivers appraise their caregiving role as stressful.

Studies on perceived stress (Pinquart & Sörensen, 2003; Reinhard, Given, Petlick, & Bemis,2008; Schulz & Sherwood, 2008) have reported that caregivers' perceived stress can be associated to concepts such as: behavioural problems of the AWPD (e.g. mood swings or emotional tantrums); the assumption that the AWPD is also stressed; extended and vast amount of care given to AWPD; unpredictability of both the caregiver's and care-recipient's future; overload of duties (caregiving, other household duties, and employment, in some cases); inability to cope with societal expectations; and/or limited social participation. Pinquart and Sörensen (2003) also added that caregivers reported that it is challenging to maintain their sense of competence and confidence when caregiving tasks are difficult to manage, and when they have little control over the disability of the care receiver. The aforementioned circumstances tend to lead to caregivers perceiving their situation as more or less stressful. However, the degree to which caregiving is perceived to be stressful may vary due to a number of aspects.

These aspects may include caregiver's gender and age; perception of caregiving as a burden, the degree to which the care-recipient is dependent for his/her activities of daily living and caregiver's perception of potential caregiving benefits. These aspects may contribute to caregiver perceived stress rated as low, medium or high (Sellers, Caldwell, Schmeelk-Cone & Zimmerman, 2003). In terms of gender, higher levels of perceived caregiving stress have been reported among female caregivers compared to male caregivers (Kim, Baker & Spillers, 2007). In terms of age, higher levels of perceived caregiver stress have been reported among younger caregivers than older caregivers (Carter, Lyons, Stewart, Archbold & Scobee, 2010). It has been found that caregivers who perceive caregiving as a burden tend to report higher levels of stress than those who do not (Lawrence, Tennstedt & Assmann, 1998). Lawang et al. (2015) found that caregivers who reported that the care recipient is mostly dependent on them for his/her *activities of daily living* (ADLs) tend to report higher levels of stress than those who reported ADL independence of care recipients. Haley et al. (2009) found that caregivers who perceived caregiving as beneficial reported low to medium levels of stress compared to caregivers who perceived it as non-beneficial.

A number of studies (Haley et al., 2009; Kim et al., 2007; Lawang et al., 2015; Lawrence et al., 1998) have explored and compared perceived stress levels among caregivers and non-caregivers. However, these explorations are limited to classifying the perceived stress according to the levels of high, medium and low. The studies did not explore the descriptions of the levels from the caregivers' perspectives, specifically what a high, medium or a low stress level entails for caregivers of AWPD. The previous studies were further limited in presenting the categories used in describing the different levels, or the themes attached to the descriptions. Not only were the previous studies limited in presenting the perceptions of caregivers on stress levels, but also the perception on how the stress affects the caregiver-care recipient relationship. Thus, the need for the current study to explore perceptions of caregivers of AWPD and the impact on the caregiver-care recipient relationship.

2.5 Caregiver-care recipient relationship

A *care recipient* is defined by Lawrence et al. (1998) as someone who receives resources, assistance and support for a particular problem, disease or special need. Studies (Gitlin et al., 2003; Lawrence et al., 1998; Spitznagel, Tremont, Davis & Foster, 2006) have interpreted the concept of caregiver-care recipient relationship from two different perspectives. Firstly, the caregiver-care recipient relationship has been studied and interpreted in terms of a caregiver's kinship to the care-recipient, particularly if they are a spouse (Gitlin et al., 2003; Spitznagel et al., 2006). The second perspective has interpreted this concept to explore the quality of the relationship in terms of closeness and the caregiver's desire to continue caring for the care-recipient (Lawrence et al, 1998). The current study explored this construct in line with Lawrence and colleagues' (1998) perspective. It explored the caregiver-care recipient relationship in terms of closeness; understanding of each other's roles; communication; co-operation; similarity of views about life; and efforts from both parties to maintain a good relationship as perceived by the caregiver.

2.6 Impact of perceived stress levels on the caregiver-care recipient relationship

These concepts of caregiver perceived stress levels and caregiver-care recipient relationship have rarely been explored together. A few quantitative researches that have studied these concepts have investigated each of them in relation to other issues. For example, Burgener and Twigg (2002) investigated caregiver-care recipient relationship and problem solving among caregivers of dementia patients. They reported that caregiver-care recipient relationship is a predictor of problem solving. Ejem, Drentea and Clay (2015) presented that high caregiver stress levels are associated with increased depression symptoms in care recipients. Caregivers' high stress levels have also been associated with high incidences of care recipient abuse (Anetzberger, 2000; Gupta & Chaudhuri, 2008). Additionally, Ingersoll-Dayton and Raschick (2004) found that high stress levels can be associated with prevailing problematic behaviours of care recipients. These studies generally presented that caregiver stress levels can be attributed to a number of outcomes in care recipients, of which it was observed that high stress levels tend to be associated with more negative outcomes. Though the previous studies displayed these associations, a gap was recognised in the research where there was no literature providing descriptions of the perceptions of caregivers of AWPD on caregiver-care recipient relationship as a result of the stress levels. Thus the current study was deemed important in attempting to address this dearth in the existing literature.

2.7 Perceptions of caregivers' required support

A number of studies (McKenzie, 2016; McKenzie & McConkey, 2016; Mthembu et al., 2016) in South Africa have explored perceived support needed by different caregivers. Mthembu et al. (2016) presented that caregivers of adults with chronic illnesses required professional support of occupational therapists in order to strike a balance between caregiving, work, activities of daily living, and leisure. McKenzie (2016) found that caregivers of children with intellectual disabilities reported to be in need of financial support and 'another mother', referring to an alternative caregiver who will love and care for their children the way they do. McKenzie and McConkey (2016, p.540) discussed how caregivers of adults with intellectual disabilities required support in the form of "community based education, training and leisure options that will further the competence of persons with intellectual disabilities to become more self-reliant at home and provide opportunities for them to engage in activities outside of the home." The above South African studies provide information on support required by caregivers of adults with chronic illnesses, and intellectual disabilities, however more information is needed on support required by caregivers of AWPD.

2.8 Summation of the review of the literature

This literature review illustrates that in South Africa researchers seem to have overlooked caregivers of adults with physical disabilities as a group that potentially have specific and unique perceptions in the role of caregiving. Most importantly, the literature seemed limited in presenting how caregivers of AWPD qualify stress levels. Another paucity observed in the existing literature is that there are no accounts by caregivers on how the qualified stress levels impact on the relationship between the caregiver and care recipient.

Additionally, and to potentially inform future interventions in support of caregivers, existing studies relevantly considered caregivers' required support; however as previously stated, the required support for caregivers of AWPD could not be found. This oversight of caregivers of AWPD may be because they are assumed as not critical hence less prioritized than caregivers of people with intellectual disability or of people with chronic illnesses. They might be assumed as not critical because their care recipients have perceived greater abilities compared to other care recipients. The current study was therefore vital to bring insight into the criticality of caregivers of AWPD.

Chapter 3

METHOD

3.1 Introduction

The methods used in carrying out this study are outlined in this chapter with reference to the research design, sampling and methods of data collection. The procedure section illustrates a step-by-step unfolding of how the study proceeded. The analysis section outlines the nature in which data was processed to produce comprehensible information. Ethical considerations and reflexivity are also discussed to conclude the chapter.

3.2 Research design

This study employed a qualitative research design as it was “a research process that used inductive data analysis to learn about the meaning that participants hold about a problem or issue by identifying patterns or themes” (Lewis, 2015, p.1). Specifically, a phenomenological research design was implemented so to understand and interpret meaning and perceptions of stress levels and the impact on caregiver-care recipient relationships as produced by caregivers of AWPD. The main focus of this design is to bring insight on the experiences of participants and the meaning that participants attach to the constructs studied (Wagstaff & Williams, 2014). In this study, data was collected from interviews with caregivers of AWPD. This data was analysed using thematic analysis in order to identify patterns or themes pertaining to perceived stress of caregivers and how this is perceived to impact on caregiver-care recipient relationships.

3.3 Participants and sampling

The participants of the study were six caregivers of adults with physical disabilities. There were five females and one male. The caregivers' ages ranged from 21 to 76 years. The care recipients comprised of: three with impairment of the left side of the body; one with impairment of the right side; one with weak hands and legs (trembles when handling objects), and one who could not walk. The following table further presents the demographics of the participants; the names used here, as throughout the thesis, are pseudonyms.

Table 1: Participants demographics

Participant Pseudonym	Age	Gender of Participant	Race	Relation to CR	Disability of CR	Time since disability onset	Length of time caring for the CR
Dan	76	M	White	Father	Left Hemiplegia	3 years	12 months
Gloria	50	F	Black	Aunt	Weakness of limbs	7 years	5 years
Mary	53	F	Coloured	Aunt	Left Hemiplegia	15 years	6 years
Agnes	47	F	Black	Mother	Right Hemiplegia	17 months	17 months
Gladys	21	F	Coloured	Daughter	Unable to walk	7 years	7 months
Brenda	52	F	Black	Mother	Left Hemiplegia	10 years	10 years

CR: Care Recipient CP: Cerebral Palsy

A purposive, non-random sampling technique was used to recruit participants. In this technique, participants are selected for the purpose of obtaining insights, perceptions and maximizing understanding of the constructs discussed (Onwuegbuzie & Collins, 2007). The selection of participants with this technique is useful because participants are selected for certain knowledge or a particular skill (Onwuegbuzie & Collins, 2007) which in this study is the skill and knowledge of caregiving for an AWPD. Participants were recruited through an association to which they belong, Association of the Physically Disabled (APD). This association purports to provide holistic and fundamental services to people with physical disabilities and their families. APD is situated in Pallinghurst road, Westcliff, Johannesburg, South Africa. At the time of the study the participants resided in various residential areas in Johannesburg.

Specifically, the APD invited the researcher to a meeting of caregivers of people with different disabilities. The researcher informed those at the meeting about her study and invited those interested to participate. The participants were given a week to decide on whether to participate or not. Upon deciding to participate, caregivers were advised to privately inform the researcher after the second scheduled caregivers meeting.

The inclusion criteria included that the participants were required to be aged above 18 years. Further, they needed to have been a caregiver for the AWPD for at least three months, as it was expected that in that period a relationship would have been formed and perspectives developed which they could hopefully share with the researcher. The caregiver was also to identify themselves as a family member who had been providing the majority of care without reimbursement. The AWPD cared for needed to have a physical disability only. Finally, the participants were required to be able to communicate verbally and use English or Tswana as their languages of communication in the interview in order to reduce language barrier challenges. The researcher is an expatriate who is not competent with other South

African languages. A total of ten caregivers volunteered to participate in the study. However, four did not meet the participation criteria (Two potential participants were taking care of 17 years old people with physical disabilities, whom the study did not consider as adults; one potential participant was a caregiver for someone with multiple disabilities; and another potential participant was non-English/Tswana speaking).

3.4 Data collection

An one-on-one, semi-structured interview was used to collect data for this research project. This technique is a method of data collection where the conversation between two individuals (researcher and participant) is guided by a set of open-ended questions which follow a certain order and are intended to cover a certain topic(s) (Harrell & Bradley, 2009).

The interview questions were devised by the researcher and formed an interview schedule (see Appendix 1). Devising of the questions was guided by the reviewed literature in relation to the research questions. Specifically, questions evaluating the caregivers' perceived stress levels were derived from the literature by Garey et al. (2016). Questions evaluating perceived impact on caregiver-care recipient relationship were derived from the literature by Lawrence et al. (1998), concepts explored within this construct include perceived impact on closeness, cooperation, communication and on efforts to maintain a good relationship. The researcher asked individual participants a series of open-ended questions on perceived stress levels and the impact on caregiver-care recipient relationships. Examples of questions asked include:

> Please describe what it is like to take care of an adult with a physical disability. Elaborate on your feelings and day-to-day experiences.
>
> How do you understand the impact of your stress levels on both yours and your care-recipient's efforts to maintain a good relationship? Please elaborate.

How do you think your stress levels affect the relationship between you and your care recipient?

Please find the full interview schedule in Appendix 1. The interviews were audio-recorded and transcribed verbatim. Interviews that were conducted in Tswana were translated by the researcher during transcription.

3.5 Procedure

Initially a research proposal was written for this study with the guidance of the researcher’s supervisor. The proposal was submitted to a method’s and an ethic’s reader before a departmental presentation was made. Once the proposal had been approved and ethics clearance had been received from the University of the Witwatersrand Psychology Department’s internal ethics committee, the researcher wrote a letter to the Director of APD informing her about her study. The Director granted the researcher permission to conduct the study (please see Appendix 2) and referred her to social workers within the same association who agreed to support participants with post-interview counselling where necessary.

The social workers also assisted the research process by inviting caregivers of people with different disabilities to a meeting where the researcher informed them about the study. The potential participants were informed that it would be of their choice and decision to inform their care recipients about their involvement in the study. The potential sensitivity of the topic concerned was also discussed. The participants were given one week to decide on whether to participate or not. Upon deciding to participate, caregivers were advised to privately inform the researcher after the second scheduled caregivers meeting. Interviews were conducted at times and places convenient for the participants. Each participant was interviewed alone in a private room. At the interview a letter (Please see Appendix 4) explaining the study and its purpose was presented to each participant together with a consent form (Please see Appendix 5) for signing as evidence of informed consent from the participant. The participants were also requested to consent for recording of the interviews. The average time the interviews lasted was 50 minutes.

The interviews were then transcribed verbatim and analysed.

3.6 Data analysis

Thematic analysis according to Braun and Clarke (2006) was selected as the relevant method of data analysis because it is argued to be a method of analysis that focuses on meaning across a data set. Further, it provides a researcher with an opportunity to observe and understand the collective or shared meanings and experiences. Identification of issues as themes was based on frequency of the issues across the data set and the relevance in answering the research questions. Braun and Clarke's (2006) six steps of thematic analysis were followed. The first step was *familiarisation with the data* by the researcher. This familiarisation involved revising the transcripts and re-listening to audio recordings in comparison to each transcript at least twice. The second step was *generation of initial codes*. This was carried out across the data set. This initial coding was conducted to elucidate the general description of data content. Generating initial codes involved assigning systematic codes to fascinating features of the data which might later contribute to particular themes. These features were then organized according to relevance to a specific code. Manual coding was exercised with the use of highlighters where a certain colour represented a specific code. The third step involved *searching for themes*, where the generated codes were sorted into potential themes. In this step overlapping codes, similar codes and broader issues in which codes clustered were identified. This involved gathering and combining all extracts and/or codes which are relevant to each potential theme. The combination elucidated that the codes defined a meaningful pattern in the data. The themes were presented in the form of a thematic map. In the fourth step, *themes were reviewed.* A critical revision of the extracts within each data set was exercised to identify those extracts which could be combined, those that needed to be separated, those that supported the theme, and those that did not contribute much to the theme. A further revision of the themes was carried out to examine which theme works in relation to the entire data set. The revision of themes involved making enquiries such as how each issue is a theme, how it is relevant to the research question, if it says something about the data set, if there is enough data supporting the theme, and if the data is coherent enough? A revised thematic map of analysis was produced at this step. The fifth step, involved *defining and naming themes* where the researcher provided details and clarifications on each theme. A closer look into the extracts that make up a particular theme was used to define the aspects of that theme. A clear explanation of each theme was outlined at this step. The final step was the *production of the report*. This step is where reporting on each theme was exercised. It involved interpretation of the themes and a display of the story told by the data. This is where the argument of the validity of the data in connection with the research questions is presented. Illustrations from the themes arguing for the story behind the data is provided and supporting evidence outlined in the form of quotations from participants are given. It was also in this step where interpretations and connections of data to the research questions were made. Five themes emerged from this data analysis: "*It's not that bad*"; "Health affected"; "Avoidance"; "Emotions provoked" and "Tension." These will be explored in the results and discussion chapter to follow.

3.7 Ethical considerations

This study was granted ethical approval by the Human Research Ethics Committee at the University of the Witwatersrand. A certificate of approval was issued to the researcher (please see Appendix 3). Permission was also sought and granted from APD to carry out this study amongst their members. A participant information sheet (please see Appendix 4) was read out to participants and/or given to participants to read for themselves, detailing the study and its aims before commencement of interviews. It was made explicit to the participants that participation was voluntary and participants were allowed to withdraw from the study at any point without any negative consequences. Consent forms (please see Appendix 5) were also presented to the participants before the interview, and signing of the form signified consent to participate and permitting to be audio-recorded. Final anonymity in the form of this research report was guaranteed to the participants. Confidentiality was also ensured as participants' data is referred to using pseudonyms and no identifying detail is shared. The data collected was accessible to the researcher and supervisor only. The study posed no foreseen major risks or harm to the participants; however, an arrangement was made for potential debriefing of participants and further free counselling post the interview considering the potential sensitivity of the topic.

3.8 Reflexivity

Reflexivity is defined as "self-awareness and agency within that self-awareness" (Rennie, 2004, p. 183). This means that a researcher acknowledges that he or she relates to the research process and is not detached from it. The researcher appreciates that his or her experiences, perspectives, motivation to carry out the study, and previously held assumptions, have the potential to influence or be influenced by the research process (Morrow, 2005).

Reflexivity is acknowledged as an important practice in qualitative research because it gives the researcher an opportunity to examine how he or she might have been influenced by personal/professional values, beliefs, culture or preferred research perspective (Northway, 2000). Reflexivity also promotes researcher honesty, transparency, and a reflection of the complexities of the research process, hence giving the reader a chance to make a fair judgement on the quality of the report and the limitations of the research (Northway, 2000).

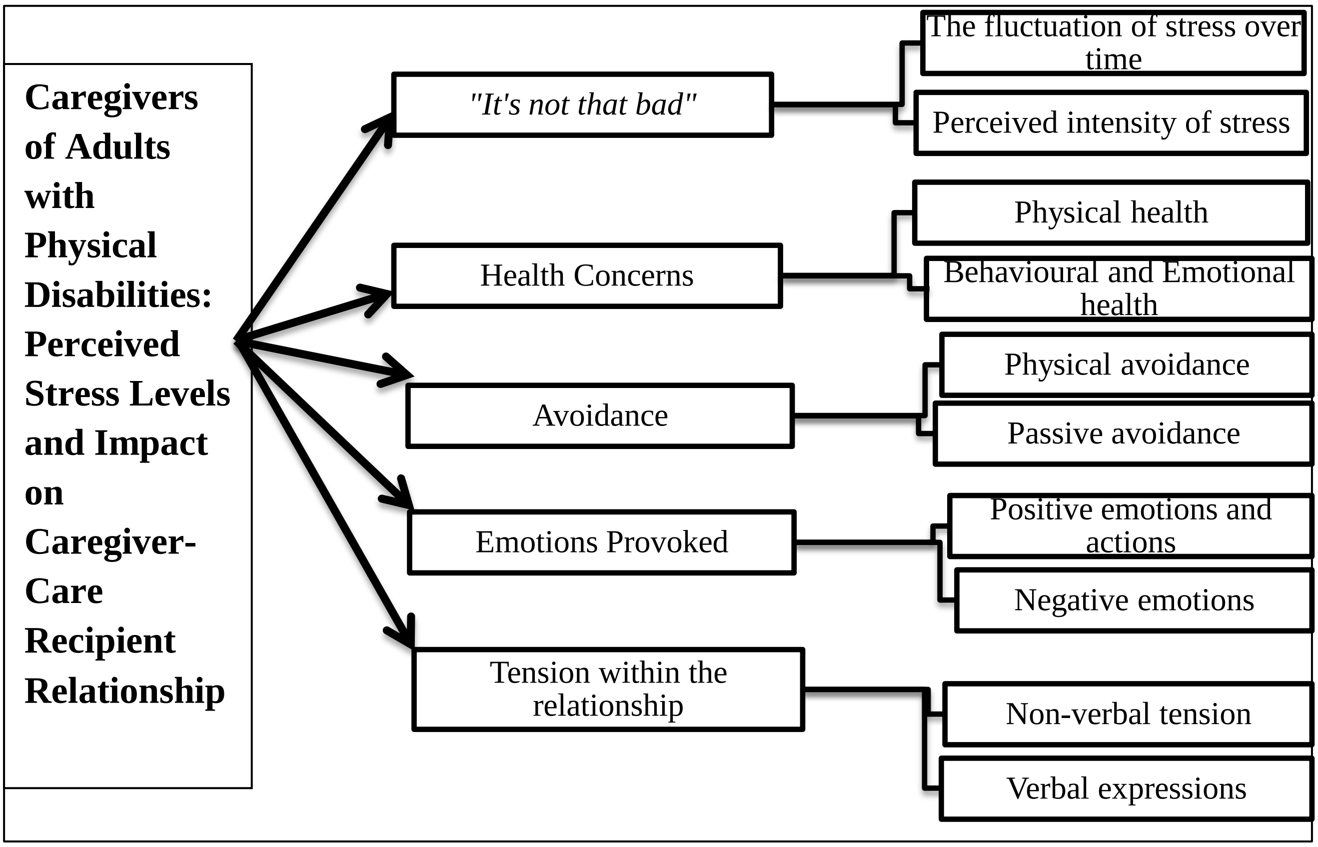
As the researcher in this study I am also an employee of a disability rehabilitation centre in Botswana. I work as a lay counsellor and I have had exposure to a number of caregiver-care recipients' conflicts as part of my role in this centre. Initially I had assumptions that caregivers of people with disabilities experience extreme stress judging from the number of caregiver-care recipient conflicts I was exposed to. As a researcher I had been groomed within the quantitative research approach and had no exposure to qualitative research until this project. I was conscious of the fact that my experience in working in a disability rehabilitation setting with caregivers of people with disabilities may bring a particular perception and this may influence my judgement on the data. With all the above noted, self-reflexivity notes were made post interviews in which I detailed my experiences and reactions. Further, discussions conducted in supervisory meetings helped me to reflect on my responses to the research process, language used in reporting and phrasing of the study findings. The notes and the supervision assisted me to be more conscious of my role and thoughts with regards to the way I interpret the data on caregiver-care recipient relationships. These reflexivity strategies also made me aware that some of my previously held assumptions might be erroneous, for example, the stress experienced by caregivers of AWPD might not be as extreme as I had always assumed. It is hoped that these measures went some way in reducing the potential implications my knowledge and experience might have had on the data.

Chapter 4

RESULTS AND DISCUSSION

This chapter outlines the results of the current study and discusses these accordingly, in conjunction with the existing literature. Five themes emerged from data analysis: *"It's not that bad;"* Health concerns; Avoidance; Provokes feelings; and Tension. The table below illustrates the themes and sub-themes.

Table 2: Themes and sub-themes



4.1 Theme 1: *"It's not that bad"*

"It's not that bad" is one of the themes that emerged when caregivers of AWPDs were asked for their perceptions on their stress levels with regards to caregiving. Specifically, Gloria expressed *"It's not that bad"* and some of the other participants made sentiments which had a similar meaning. *"It's not that bad"* suggested that the stress levels of caregivers

of AWPDs are not as severe as it might be assumed by external people. Importantly, this sentiment was not experienced by all the caregivers in the current study, as will be discussed in theme two. *"It's not that bad"* was a description assigned to a medium stress level by Gloria and Dan. This theme is further defined by two sub-themes, time and perceived intensity of the stress.

4.1.1 The fluctuating nature of stress over time

With regards to the fluctuating nature of stress over time, Gladys, Dan and Gloria expressed that caregiving does not mean that they live under constant stress. They conveyed that stress is occasional as it may be triggered by certain events or occurrences.

Gladys, Dan and Gloria described stress level fluctuation overtime through the sentiments made during interviews. Gladys said, *"Ok sometimes she* [person she cares for] *does give me stress-sometimes I am not stressed."* This excerpt suggested that the stress levels can neither be comprehended as strictly high nor low. *"Uhh look I don't live under constant stress; well I am not stressed all the time. At the moment I have got no stress, sometimes everything goes alright; another day it's frustrating."* is what Dan said. This suggested that there are moments of low stress levels and there are moments of high stress levels experienced by caregivers in the current study. In this quotation Dan expressed moments of low stress levels as "*good*" or "*ok"* times, and high stress levels he defined as *"frustrating."* Gloria also expressed the sub-theme of time by saying, *"most of the time my stress is low, I am happy because it* [her stress] *goes away quickly. You won't see me angry the whole day because I am stressed or something."* This quotation implied that stress levels are defined by how they bring upon negative emotions and how long this state lasts for; the shorter the time the lower the stress levels.

Furthermore, Agnes explained that her stress levels have decreased with time in caregiving. She said, *"I had stress that time when my child was young, she is 18 now, I am no* *longer stressing too much."* These words implied that stress levels may change over time even though the caregiver is still in the same role.

These findings do not wholeheartedly support the literature by Pinquart and Sörensen (2003) who stated that caregivers have been found to have high levels of stress. Rather the current findings reveal that the levels of stress among some of the caregivers of AWPDs fluctuate with time.

4.1.2 Perceived intensity of stress

In relation to perceived intensity of stress, certain caregivers of AWPDs expressed that their stress levels do not necessarily impair their functioning. Dan explained that he can still maintain certain functionality in his life because he has adapted to, and accepted, the situation and condition of his care recipient. He said, *"I don't wake up in the morning overly stressed. I get up in the morning when I want to get up. If I … the other day I wake up in the morning and decide to go make myself a cup of coffee, then I'll get the paper and I will read the pa … I'll look at the paper, is it yesterday's paper and then my wife will come through and then half past seven, quarter to eight we start waking her* [Care recipient] *up."* These words indicated that as a caregiver he is able to get the opportunity to access media and know what is happening around the world, alongside taking care of an AWPD. Gloria said in a similar vein, *"It's not that bad, I personally do not allow myself to be stressed too much because I don't want to do any mistake. If I let myself to become stressed I might to do something bad but I do not want it to come to that"* which suggested her ability in self-control and implementation of coping mechanisms to manage her stress levels.

In contrast to the findings by Reinhard et al. (2008) which indicated that caregivers tend to find maintaining their sense of competence and confidence when they have little control over the disability of the care receiver challenging; the current results reveal that with acceptance of their role and conditions of their care recipients caregivers of AWPDs tend to maintain their sense of competence and confidence, hence describing their stress levels as *"not bad."* This diverse finding may be due to the type of disability (physical) being considered in this study or due to historical adversities that South Africans have been through.

In this regard, Mary and Gladys also indicated that they are coping with the caregiving role and have control over their lives. Mary indicated this, *"We survive, there is always food on the table, she is always clean and I am always clean ... I do not feel that bad ... thanks God I do not have children of my own, I can give all my attention to her, though it is not easy I am doing my best ... I mean, it's my life, I control it"* and Gladys relayed her coping ability in saying *"I have accepted, I am surviving, it's not like I am failing to cope."*

This theme indicated that some caregivers of AWPDs who tend to rate their stress levels as medium; perceive the stress levels to be not as extreme as other people including researchers may do. These caregivers define their stress levels using time and perceived intensity (coping).

4.2 Theme 2: Health Concerns

It became apparent in the data that the health of caregivers of AWPDs is affected due to their caregiving responsibilities. This theme seems to contradict the above theme, suggesting that *some* of the caregivers are avoiding and defending against how stressful they experience caregiving of an AWPD. This may possibly be that they were thinking they would be judged by the researcher had they acknowledged that they are stressed. It is also possible that the perceptions on stress levels genuinely differ; depending on situation acceptance and coping level of the caregivers. Mary and Brenda pointed out that they perceive their stress levels to be high as they are experiencing challenges in physical and/or behavioural and emotional health.

4.2.1 Physical health

Brenda reported experiencing high levels of stress that is expressed in physical symptoms and conditions. She related her hypertension to the high stress levels she experiences caring for an AWPD by saying, *"at times when I am stressed my blood pressure goes high, I have been diagnosed with hypertension and that exposes me to be at high risk of stroke as well. I did not have any blood pressure problems before she* [care recipient] *acquired stroke"*. This sub-theme supports the argument by Schulz and Sherwood (2008) that caregiving tends to lead to health problems such as reduced immune system functioning; changes in body weight; and cardiovascular problems thus policy makers need to note caregiving as a one of the major sources of public health issues.

4.2.2 Behavioural and emotional health

With regards to behavioural and emotional health, Mary explained how she sometimes behaves due to her disturbed emotions. She perceives this as not healthy for her. She said: *"I smoke a lot, I was drinking and I gave up. Now it's tea, smoke, tea, smoke, coffee, and smoke. I do become very agitated you know, the least sound that I can hear I will go and I will shout, and it's not healthy, not even healthy for myself"*. These words suggest that Mary experiences high levels of stress in caring for an AWPD and she copes with this stress by turning to unhealthy behaviours.

This sub-theme supports the findings by Lund et al. (2014) who reported that extensive caregiving tends to have negative mental health effects on caregivers and is associated with negative consequences such as depression; fatigue; anxiety; stress; and sleep problems. It is within the same argument that Schulz and Sherwood (2008) contend that caregiving is a major public health issue which policy makers need to seriously take note of. The current study therefore emphasises the need for a caregiver's policy that is inclusive of caregivers of AWPD, and that takes into account their specific needs, including frequent medical examinations, relief caregivers or caregivers' excursions and establishment of support groups.

4.3 Theme 3: Avoidance

Avoidance was one of the themes that were identified when caregivers of AWPD expressed how they perceive their stress levels to impact on the caregiver-care recipient relationship. All six caregivers of AWPD interviewed explained that during the occasional times when they are stressed and their emotions are affected, the caregiver-care recipient relationship is negatively affected. The participants pointed out that the relationship is affected in the sense that there is a tendency of avoiding one another, either by the care recipient or by the caregiver. This avoidance is expressed either physically or passively.

4.3.1 Physical avoidance

With regards to physical avoidance, Dan, Mary and Gladys shared that sometimes when they are feeling stressed they stay away from their care recipients. This avoidance involves being in a separate room from the AWPD or just outside the house. Caregivers explained that they physically avoid their care recipients during these stressful times as a way of protecting the care recipients from seeing them in a stressed state, or to give themselves an opportunity to calm down. Dan described his avoidance, *"I go outside, or go read a book, or something like that"*. Similarly, Mary said, *"Umm, what I normally do is go into a prayer and try to calm down and come back to her later. Sometimes when I am stressed I either have my neighbour or her sister to look after her, and then I will be away five, ten minutes, then after that I will calm down, drink tea, take a cigarette then come take her"*. Gladys related that she goes to her room and cries on her own. This sub-theme illustrates a negative effect on the caregiver-care recipient relationship where a strain, or a gap in the physical interaction of the two parties takes place during stressful times for caregivers. Although this argument does not seem to have been explored in the previous studies, the current study outlines that high stress levels tend to negatively affect the caregiver-care recipient relationship on the aspect of physical interaction. That is, the higher the stress level, the more the caregiver will avoid his or her care recipient.

4.3.2 Passive avoidance

With regards to passive avoidance, Gloria, Agnes and Brenda shared that sometimes when they are stressed they remain quiet. Though they might be physically present, they will be silent and/or try by all means to hide their stress from the AWPD. Gloria said, *"when I am stress I try not to show her because when I show her she becomes hurt. So I avoid talking to her"*. These words indicate that Gloria's passive avoidance is based on the intention to protect the AWPD. However, her statement is also indicative that communication is negatively affected, or becomes limited in the caregiver-care recipient relationship when the caregiver is stressed. More illustrations of limited communication in the caregiver-care recipient relationship are outlined in the statement made by Agnes, *"I just sit and I just keep quiet"*. Brenda also made a similar comment, *"When I am stressed I don't say much, I just keep quiet"*.

These silences are an indication of limitations in communication between caregiver and care recipient, which is argued by Burgener and Twigg (2002) as a challenge in problem solving between the caregiver and care recipient. Burgener and Twigg's (2002) argument is related to the findings of the current study because less communication equated to more challenges that may occur in problem solving. This sub-theme implies that high levels of stress among caregivers of AWPD tends to lead to care recipient avoidance and consequently affects the caregiver-care recipient relationship in the sense that there is limited communication and difficulties in problem solving between the two of them.

4.4 Theme 4: Emotions provoked

Caregivers of AWPDs also reported that when they are stressed either positive or negative emotions are provoked within them, or the care recipient, which affects the closeness of their relationship in either a positive or negative way.

4.4.1 Positive emotions and actions

Dan, Gloria, Agnes and Brenda reported the display of empathy shown by their AWPDs, towards them, as their caregivers, during the times of stress. It was reported that although the caregivers try to hide their stress from the care recipients, most of the time AWPDs are able to recognize that their caregivers are feeling stressed and consequently they tend to empathize with them. This empathy is expressed in the form of AWPDs asking questions, obliging to instructions, or trying to be more humble. Dan said in this regard,

> *"I think she can pick it in my words if I am getting stressed a bit, like if I shout and say 'COME ON EAT YOUR FOOD NOW STOP PLAYING WITH IT' she will pick that my tone is different and she will eat. But when I check her later I will realize that she did not hold a grudge even though I spoke to her like that. Instead she would want to know if I am fine".*

The positive actions here reflected include the AWPD following instructions and/or doing what is expected at that time e.g. eating the food she has been given. The question by the care recipient in asking if the caregiver is fine is indicative of concern and care, and can encourage closeness between the caregiver and care recipient. A positive behavior outcome of high stress levels experienced by a caregiver of AWPD was also demonstrated in the statement given by Gloria, *"if she comes and realizes I am a bit tearful she will ask me 'mama, what is it?' Sometimes I would just take her to my room and start praying, or I would take her for shopping, and when we go shopping she will be telling me things which make me laugh and I will be laughing a lot".* This statement indicated the closeness between a caregiver and a care recipient that is brought about by the high stress levels of a caregiver. Further, it suggests that the relationship is reciprocal at times. More examples were revealed in illustrations by Agnes and Brenda. Agnes said, *"when I am stressed it seems as if she sees it in me because when I look at her she will laugh but I will realize that she is not laughing because I am looking at her, she is laughing because she can see that I am stressed and want to make me feel better".* And Brenda said, *"when she realizes that I am stressed she tries by all means to humble herself".* Displayed in this sub-theme is the fact that care recipients are not only the beneficiaries in the relationship. In stressful times experienced by givers of AWPD, care recipients appear to be caring, loving and appreciative of their caregivers.

This sub-theme of positive emotions and actions reveals an aspect of stress experienced by caregivers that has not been explored much in the existing literature. This finding is in contrast with the previous studies (Anetzberger, 2000; Burgener & Twigg, 2002; Ejem, Drentea & Clay, 2015; Gupta & Chaudhuri, 2008; Ingersoll-Dayton & Raschick, 2004) that generally presented that high stress levels in caregivers tend to be associated with negative outcomes in the relationship between caregivers and care recipients. For example, Ingersoll-Dayton and Raschick (2004) reported care recipient problem behaviours as an outcome associated with high stress levels of caregivers.

4.4.2 Negative emotions

Mary and Gladys reported that in some instances care recipients will recognize that the caregiver is stressed and they will also show emotions of sadness, stress and anxiety. Mary said, *"when I am upset she looks at me with signs of unhappiness on her face because I do use vulgar language and she sometimes cries. Sometimes she also seems scared to come close to me when I am stressed".* Further, Gladys recalled, *"when I am stressed I would shout at her, then we fight, then we spend some days angry at each other".*

These two excerpts suggest that high stress levels of caregivers can negatively affect the closeness of the caregiver and the care recipient when it provokes negative feelings in both parties. Previous studies related to this finding, including Ejem et al. (2015) presented that high caregiver stress levels are associated with increased depression symptoms in care recipients. Additionally, Ingersoll-Dayton and Raschick (2004) found that high stress levels in caregivers can be associated with prevailing problematic behaviours of care recipients, including alcohol and drug abuse, and ill-mannerisms. The two above studies presented only the negative outcomes of high stress levels experienced by caregivers. However, different from these previous studies, the current study found a positive outcome of high stress levels in the caregiver-care recipient relationship, namely enhanced closeness.

4.5 Theme 5: Tension within the caregiver-care recipient relationship

Mary and Gladys reported that when they are feeling stressed and their care recipients realize that they are stressed; sometimes tension arises within the caregiver-care recipient relationship. This tension is reported to be conveyed non-verbally or verbally.

4.5.1 Non-verbal tension

Mary expressed, "*she* [care recipient] *knows that I was fighting because she can hear and see, then she won't be cooperating much during exercises or other activities, she will be tense but not saying it*". This statement indicated that co-operation between the caregiver and care recipient is negatively affected when caregivers' stress levels are high. Gladys also indicated the impact of a caregiver's high stress levels on the co-operation between the caregiver and care recipient: *"it's only that she still needs me to give her water and food but she will still act angry after I shouted at her due to my stress, she will be dragging herself to do some things like bathing"*. This sub-theme indicates that high stress levels of caregivers affect more than the care recipient's cooperation in the sense that the care recipient's interest and motivation to do exercises or other daily activities are lowered. This implication also leaves the researcher wondering if high stress levels of caregivers also impact on the stress levels of care recipients; however, this could be explored in a different study.

4.5.2 Verbal expressions

Gladys also indicated that sometimes the care recipient will verbally express her unwillingness to co-operate. Gladys remarked in this regard, "*there are times when I try to talk to her and she will just say 'Uh hey you shouted at me the other day why must I speak to you or why must I work with you, leave me alone'".*

The above excerpt suggests that high stress levels among caregivers of AWPDs can negatively impact on co-operation between the caregiver and care recipient. Only one previous study implied impact on co-operation, namely Ingersoll-Dayton and Raschick (2004) who found that high stress levels amongst spouse caregivers can be associated with prevailing problematic behaviours in care recipients. The current study supports Ingersoll-Dayton and Raschick (2004) and adds to the literature by arguing that high stress levels among caregivers of AWPDs impact negatively on co-operation in the caregiver-care recipient relationship; hence, problematic behaviours of care recipients.

Generally, the findings of this study outline that caregivers of AWPDs perceive their stress differently, ranging from medium to high. Medium stress levels were argued on an account of time and perceived intensity; where participants explained that it is not all the time that they are stressed and even when they are stressed, they can still maintain some level of functionality. High stress levels were described in association with health concerns and other behavioural presentations, such as hypertension since taking the role of caregiving, smoking and occasional avoidance of the care recipient by the caregiver. According to the perceptions of caregivers of AWPDs in the current study, the medium to high stress levels can impact both negatively and positively on the caregiver-care recipient relationship, specifically on aspects of co-operation, closeness and communication. However, from the researcher's viewpoint, the negative impact of caregivers' stress levels on the caregiver-care recipient relationship seems to be more than the positive impact. The next chapter further concludes this research report by summarizing the study, offering critical observations, outlining the limitations of the study, and presenting the implications of the study for psychology practice and research.

Chapter 5

CONCLUSION

The current study firstly aimed at exploring perceived stress levels of caregivers of AWPD. Generally the findings of the study highlighted that the stress levels of caregivers of AWPD are perceived to range from medium to high. The medium stress level was described as stress fluctuating over time, and caregivers able to maintain some kind of competence and functioning. This means that there are times when caregivers of AWPD are stressed and there are times when they are not stressed. Additionally, it was highlighted that the stress does not even amount to the whole day. For others, the stress levels are decreasing with years in the role of caregiving. The high stress level was described as evidenced by associated health conditions developed by caregivers of AWPD; acts of outbursts; anger and frequent/overuse of cigarette or coffee.

The findings of the current study also revealed caregivers of AWPD perceive their stress levels to affect the caregiver-care recipient relationship in areas of communication, cooperation and closeness. This argument was observed as a dearth in the existing literature. However, it is evident, according to caregivers of AWPD's perspective, that communication is either affected negatively or positively during the stress peak times amongst caregivers. Either there is silence or reduced communication between the caregiver and the care recipient, or frequent questioning hence increased communication. The two-way effect was also highlighted in cooperation and closeness. In some scenarios when care recipients realize that caregivers are stressed they become more cooperative by following instructions and showing humility. Whereas on the other hand, some care recipients would become tense and not willing to cooperate. In relation to closeness in the relationship, the findings of the study have revealed that the caregiver's stress can be an attracting or a repelling factor. Stress as a repelling factor was evidenced by avoidance of each other during stressful times of caregivers of AWPD. The attraction was described in instances of praying together and going shopping together. It should be noted however, that in this two-way effect caregivers who described a positive effect have reported that they, together with their care recipients have had exposure to some disability supportive workshops. This observation is seen to be in support of the findings by Muller-Kluits (2017) stating that there is a link between positive experiences and support services used. The current study has therefore, answered the two research questions, namely:

1. What are caregivers of AWPD perceptions' on their stress levels?
2. How do caregivers of AWPD perceive that their stress levels impact on the caregiver-care recipient relationship?

5.1 Limitations of the study

This study was conducted with caregivers of AWPD around Johannesburg; it is cautioned that the results may not be applicable to other urban areas and rural areas. It is also cautioned that, as this is a qualitative study, the results of this study are relevant to the participants of this study and may not be applicable to other caregivers of AWPD.

5.2 Implications for psychology practice and research

As previously mentioned, caregivers of AWPD describing positive effects of stress on the caregiver-care recipient relationship have reported exposure to psychological support. The results of the current study therefore implies that psychological empowerment of caregivers of AWPD is paramount in equipping caregivers with the capability to turn stressful occasions to have positive impacts in their caregiver-care recipient relationship. The findings of this study may be used in contribution to community psychology education on the role of community psychologists, social workers and other workers in the lives of AWPDs and their caregivers. Future studies are recommended to conduct a similar study beyond the Johannesburg area.

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Appendices

Appendix 1: Interview Schedule

Demographics

Gender?

Race?

Age?

Relationship to current AWPD in your care?

Disability of the person in your care?

Disability congenital or acquired?

Can the disability be rehabilitated or not?

How long have you been caring for an AWPD?

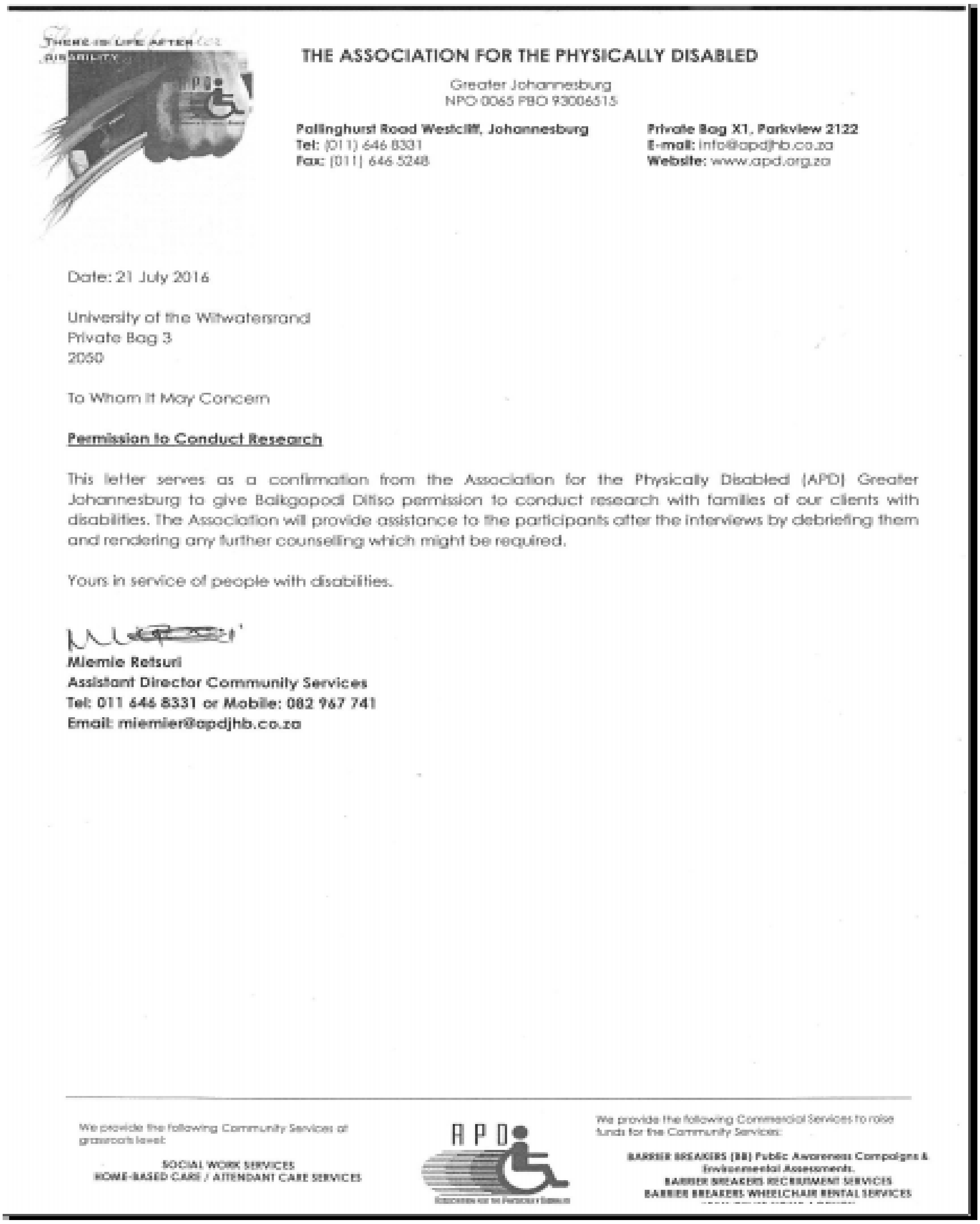
Which economic class do you classify yourself with? Why?

Questions

1. Describe what it is like to take care of an adult with a physical disability? Please elaborate on your feelings and day-to-day experiences.
2. What do you enjoy about caring for an AWPD?
3. What do you find difficult in caring for an AWPD?
4. What do you do when you are stressed because of caring for an AWPD?
5. Where do you see yourself in the next five years? What are your thoughts and feelings about this future?
6. Where do you see your care recipient in the next five years?
7. How much control do you think you have over your life as a caregiver of an AWPD? Please elaborate.
8. How do you think your stress levels affect the relationship between you and your care recipient? Including on the closeness between you two, as well as your communication?

9. How do your stress levels affect cooperation between you and your care recipient?
10. How do you understand the impact of your stress levels on both yours and your care recipient’s efforts to maintain a good relationship? Please elaborate.
11. How do you think you should be assisted to manage or cope with caregiving stress? Please elaborate.
12. How, if at all, does society’s and others’ perceptions impact on your role as an AWPD carer? Please elaborate.

Appendix 2: Permission letter from APD



THE ASSOCIATION FOR THE PHYSICALLY DISABLED

Greater Johannesburg
NPO 0065 PBO 93006515

Pallinghurst Road Westcliff, Johannesburg
Tel: (011) 646 8331
Fax: (011) 646 5248

Private Bag X1, Parkview 2122
E-mail: info@apdjhb.co.za
Website: www.apd.org.za

Date: 21 July 2016

University of the Witwatersrand
Private Bag 3
2050

To Whom It May Concern

Permission to Conduct Research

This letter serves as a confirmation from the Association for the Physically Disabled (APD) Greater Johannesburg to give Baikgapodi Ditiso permission to conduct research with families of our clients with disabilities. The Association will provide assistance to the participants after the interviews by debriefing them and rendering any further counselling which might be required.

Yours in service of people with disabilities.

Miemie Retsuri
Assistant Director Community Services
Tel: 011 646 8331 or Mobile: 082 967 741
Email: miemier@apdjhb.co.za

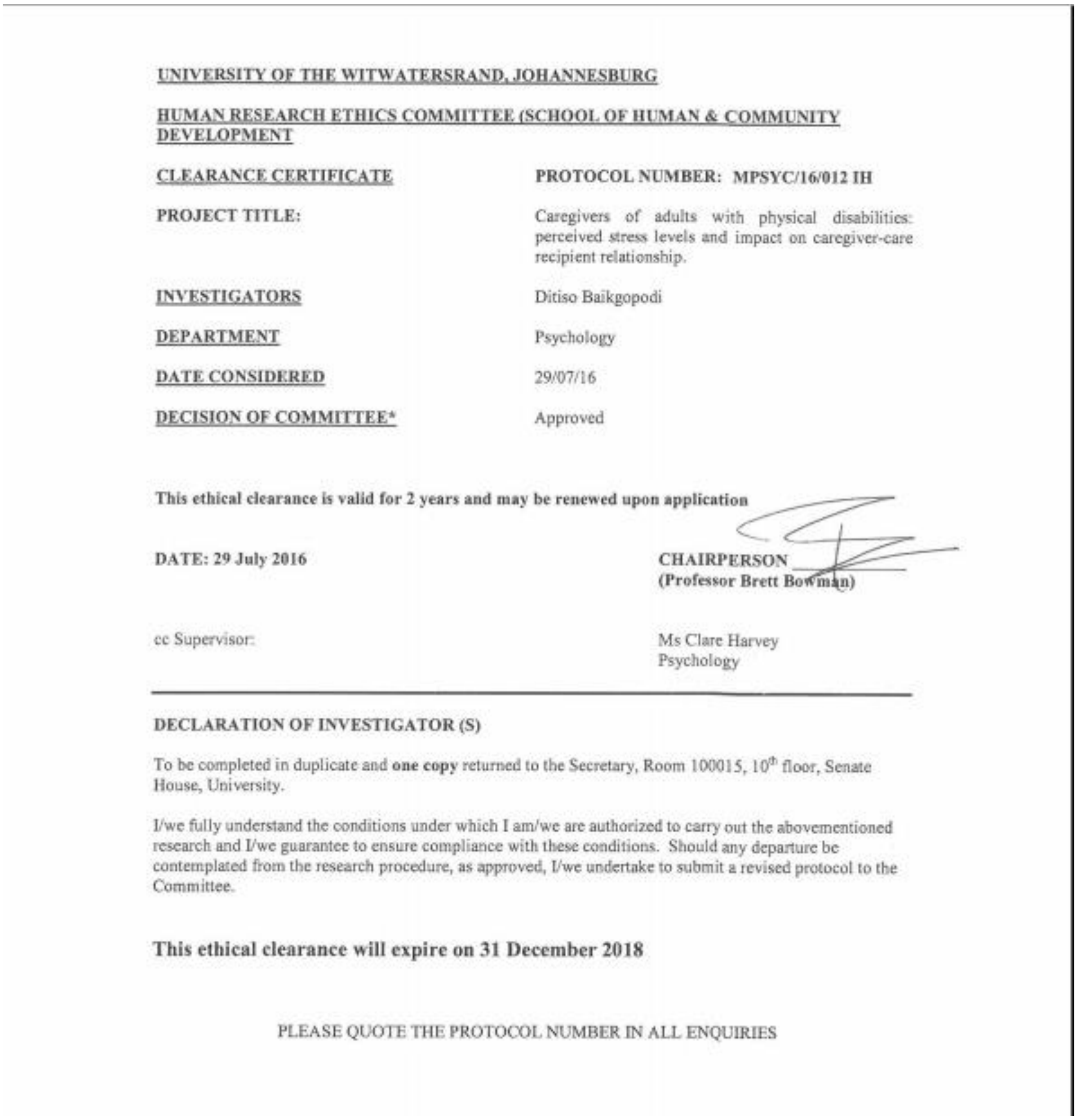
We provide the following Community Services at grassroots level:

SOCIAL WORK SERVICES
HOME-BASED CARE / ATTENDANT CARE SERVICES

We provide the following Commercial Services to raise funds for the Community Services:

BARRIER BREAKERS (BB) Public Awareness Campaigns & Environmental Assessments.
BARRIER BREAKERS RECRUITMENT SERVICES
BARRIER BREAKERS WHEELCHAIR RENTAL SERVICES

Appendix 3: Ethics clearance certificate



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MPSYC/16/012 IH**
PROJECT TITLE:	Caregivers of adults with physical disabilities: perceived stress levels and impact on caregiver-care recipient relationship.
INVESTIGATORS	Ditiso Baikgopodi
DEPARTMENT	Psychology
DATE CONSIDERED	29/07/16
DECISION OF COMMITTEE*	Approved

This ethical clearance is valid for 2 years and may be renewed upon application

DATE: 29 July 2016

CHAIRPERSON
(Professor Brett Bowman)

cc Supervisor:

Ms Clare Harvey
Psychology

DECLARATION OF INVESTIGATOR (S)

To be completed in duplicate and **one copy** returned to the Secretary, Room 100015, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure, as approved, I/we undertake to submit a revised protocol to the Committee.

This ethical clearance will expire on 31 December 2018

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 4: Participants Information sheet

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 011 717 4559

Dear Sir/Madam,

Good Day! My name is Baikgopodi Ditiso and I am currently doing my Masters degree in Psychology at the University of the Witwatersrand. I am conducting a qualitative research project in the form of individual interviews which will explore **Caregivers of Adults with Physical Disabilities: Perceived Stress Levels and Impact on Caregiver-Care Recipient Relationship.**

I would like to formally invite you to take part in my research study. This will involve you taking part in an interview conversation around the topic mentioned above. The interview should last about an hour to an hour and a half and is completely voluntary. Taking part in the interview will not advantage or disadvantage you or others in any way. For analysis reasons, the interview will be tape-recorded, however only my supervisor and I will have access to these tapes. Once the information of the interview has been transcribed verbatim, the tapes and transcripts will be protected on a password protected laptop. Although I will have access to your name, you will remain anonymous throughout the study and anonymity and confidentiality will be maintained by not disclosing any of your personal information in my results or the final research report. During the study, I will assign a pseudonym to all the participants. Importantly, you have the right to withdraw from this study at any time and therefore also have the right to not answer any questions that you do not wish to. Withdrawing from the study will have no benefit or risk for you if you choose to do so.

Once the study has been completed, you may request a summary of the study and the findings if you so wish and this can be emailed or sent to you by either myself or my supervisor. You can find our contact details at the end of this letter and the results will be available six months after the data collection. If by the end of the interview you feel the discussion has elicited sensitive and emotional effects in you, a free counselling service will be availed to you upon request at the Association for the Physically Disabled (Telephone: 011 646 8331/2/3/4).

Before the interview can begin, I will ask you to read through and sign the two consent forms and detach them from this letter. These forms will just confirm that you understand what is required of you and the confidentiality for the study. If you have any questions or concerns, please feel free to contact myself or my supervisor.

Kind Regards,

Baikgopodi Ditiso	Clare Harvey (Supervisor)
____________________	__________________________
073 123 2139	011 717 4509
931228@students.wits.ac.za	clare.harvey@wits.ac.za

Appendix 5: Consent Forms

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 011 717 4559

Title of study: **Caregivers of Adults with Physical Disabilities: Perceived Stress Levels and Impact on Caregiver-Care Recipient Relationship**

I, ____ consent to taking part in the interview conducted by Baikgopodi Ditiso, for her study.

As a participant in her study, I understand that:

- My participation is voluntary.
- I am able to withdraw from the study at any time.
- I do not have to answer any question(s) I do not wish to.
- All my personal details and information will remain private and confidential, although I may be quoted in the final report.
- If however, I am quoted, it will be under a pseudonym given to me.
- None of my personal information will be stated in the final research report (I will remain anonymous).
- The results of the study will be used in the research report that is required for the completion of the MA in Social & Psychological Research degree.

Signed: ______________________________

Date: _______________________________

Psychology

School of Human & Community
Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 011 717 4559

Title of study: **Caregivers of Adults with Physical Disabilities: Perceived Stress Levels and Impact on Caregiver-Care Recipient Relationships**

I, ____consent to the audio-recording of the interview with Baikgopodi Ditiso for her study. I understand that:

- The tapes and transcripts from the individual interview conversation will remain confidential to only Baikgopodi Ditiso and her supervisor and therefore will not be available to anyone else.
- The tapes and transcripts will remain in a safe place (such as a password protected laptop) at the University of the Witwatersrand.
- No personal information about any of the participants will be used in the transcripts for the final research report.
- Although I may be quoted in the research report, I will be referred to by the pseudonym given to me and thus my identity will be protected.

Signed: ________________________________

Date: ________________________________