Leisure needs of caregivers caring for persons with disabilities in the North West Province

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Anke Burger

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DECLARATION

The co-authors of the two articles which form part of this dissertation, Dr. J Theron Weilbach (supervisor) and Mr. Francois G Watson (co-supervisor), hereby give permission to the candidate, Ms. Anke Burger to include the two articles as part of a Masters dissertation. The contribution (advisory and supportive) of these two co-authors was kept within reasonable limits, thereby enabling the candidate to submit this dissertation for examination purposes. The dissertation, therefore, serves as partial fulfilment of the requirements for the degree Master of Arts in Recreational Science at the North-West University.

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Supervisor

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SUMMARY

Demands when caring for a person with disability are far more than in cases of a child of normal development (Brandon, 2007:668; Brehaut *et al*., 2014). As a result, these caregiving demands have negative consequences for the psychological and physical health of a caregiver (Bakker *et al*., 2000:885; Brehaut *et al*., 2014:183; Goodhead & McDonald, 2007:6; Greenlee & Scharlach, 2001:20; Whal & Newmark, 2009:293), such as chronic stress, depression, sedentary behaviour, poor nutrition, exhaustion and burnout (Vitaliano *et al*., 2003:957-959). Also, these demands and heavy workload that caregivers face have substantial impacts on a caregiver's life, including their leisure lifestyle (Dupuis, 2000; Hung *et al*., 2002). Therefore, this study aimed to explore the leisure needs and the impact that caregiving has on the leisure of the formal caregivers of disabled people in the North West province.

Limited research exists regarding the influences of formal caregiving for persons with disability on caregivers' leisure and the needs they develop for it, especially in a South African context and under resourced areas. Therefore, this study aimed firstly to explore and describe the influence of caregiving for individuals with a disability on the leisure of caregivers in the North West province. Secondly, the study aimed to explore and describe the leisure needs of formal caregivers of individuals with disabilities in the North West province. This study made use of a qualitative approach based on an exploratory case study design as explained by Yin (2003:6). Data was collected through semi-structured one-on-one interviews as recommended by Greeff (2011:351), and it included 12 formal caregivers. The central theoretical statement of this study was that the primary caregivers of persons with disabilities experience high levels of unmet leisure needs and that such caregiving has a negative impact on the leisure of caregivers of disabled people in the North West province.

From the first article, categories included a) caregiver perceptions of leisure, b) leisure time influences (constraining factors), and c) caregiving as leisure. The researcher found that caregiving has a negative influence on the leisure of caregivers and that caregiving acts as a constraint to leisure. In contrast, it was also found that some caregivers experience leisure in certain caregiving roles. From the second article, categories that emerged included a) caregiver perceptions of leisure, and b) leisure needs. It was found that caregivers experience high levels of unmet needs of which needs for time and money was the highest. This information will be useful to centre managers or care-institutions caring for people with disability, as well as leisure service providers to know how to design programmes to address the leisure needs of caregivers in an under resourced context.

Keywords: Leisure, leisure needs, care giving, disability, constraints, leisure perceptions

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DEFINITION OF TERMS

The following [1]terms used in the study can be clarified as follows:

Caregiving: According to Williams and Crooks (2008:244), caregiving can be formal, in which case there is paid care provided by practitioners such as social workers or home care workers who have formal training or a degree like nursing, or it can be informal where family, a parent or a relative provides unpaid care to a chronically ill or disabled loved one (Bedini, 2002:25; Buchanan, 2009:1244; Carter, 1994:3-4; Gladwell & Bedini, 2004:686; Schultz & Martire, 2004:240).

Leisure: Leisure can be defined as the percentage of a person's time that is not devoted directly to work or to other forms of obligations, self-care or maintenance (Edginton *et al*., 2004:6; Mclean *et al*., 2008:39). It involves freedom and choice to pursue individual interests like reflection, pleasure, self-enrichment, or relaxation, and also involves some form of participation in activities, but such activities may also be experienced as a spiritual experience or a holistic state of being (Edginton *et al*., 2004:6; Mclean *et al*., 2008:39).

Leisure needs: Dekker *et al*. (2014:66), describe a need as an "inherently dynamic factor developing over time and triggering activity participation". For example, an individual will possibly be driven to make the decision to visit the gym, relax on the sofa, or take a walk when the need for physical exercise is present or absent (Dekker *et al*., 2014:66). A need can also be defined as a state of deprivation coming from the instinctive biological characteristics that human beings have (Fourie, 2006:30). Rossman (1995:137) explains that the need for leisure is therefore inherent to the human nature, and that it does not have to be created by programmers through any form of techniques.

Leisure constraints: Constraints can be defined as those elements that limit someone from participating in leisure activities (Bulent *et al*., 2010:362), to enjoy their current leisure activities, or to use leisure services, such as programs and parks (Scott, 2005:280).

Disability: The World Health Organization (2014) describes a disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions". When there is a problem in the functioning or structure of a person's body, it can be seen as impairment (WHO, 2014). When an individual experiences difficulty in executing an action or task, it can be seen as an activity limitation, while a restriction in participation is when an individual experiences problems when involved in situations of life (WHO, 2014).

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[1] References for "Definition Of Terms" and "Summary": Chapters1 and 2

CHAPTER 1: INTRODUCTION

1.1 Problem statement

In 2011, 7.5% of the total population of South Africa was reported to be disabled (Stats SA, 2014:152). As a consequence, many individuals find themselves becoming the primary caregiver for a disabled family member (Aoun *et al*., 2005:551; Bedini, 2002:25). Unfortunately, in some cultures, more often rural areas in South Africa, it is common for parents to reject their mentally disabled child because of embarrassment, being overburdened, or feelings of disappointment (Govender, 2002:64-67). For those relatives with a more positive attitude towards their disabled child or sibling, competing employment or familial responsibilities, poor health, a lack of resources, and geographical distance may limit their ability to provide care for a family member with disability (Allen & Ciambrone, 2003:207). Furthermore, the resources needed for informal caregiving (family or relatives) might be untrustworthy or not existent on a constant basis, and individuals turn to the formal sector for the assistance they need (Allen & Ciambrone, 2003:207). Bakker *et al*. (2000:885) mention that formal caregivers providing paid care (Williams & Crooks, 2008:244)) experience many demands when working with patients with disability.

Accordingly, when caring for a child with a disability, demands are far more than in cases of a child of normal development (Brandon, 2007:668; Brehaut *et al*., 2014:183). Hence, Brehaut *et al*. (2014:183), Vitaliano *et al*. (2003:957, 959) and Bakker *et al*. (2000:885, 888) argue that caregiving creates demands that have negative consequences for the psychological and physical health of a caregiver, such as chronic stress, depression, sedentary behaviour, poor nutrition, exhaustion and burnout. These outcomes are a result of time pressure, difficult patients, emotional involvement or depersonalisation of individuals, fewer social activities, limited visits with friends and family, restrictions in daily routines and movement, and difficulties with going out (Bakker *et al*., 2000:885; Brattain, 1997:231; Coetzee, 2007:34; Dunn & Strain, 2001:32, 34; Pekkarinen *et al*., 2004:640-641; Wiles, 2003:1310, 1311). Therefore, various researchers conclude that caregiving leads to a reduction in leisure participation due to the demands and responsibilities caregivers face (Bedini, 2002:26; Bedini & Guinan, 1996b:274; Coetzee, 2007:41; King *et al*., 2000:361).

Before one can understand why caregiving has such a significant influence on leisure, it is important to understand the concept of leisure. Leisure can be defined as the percentage of a person's time that is not devoted directly to work or to other forms of obligations, self-care or maintenance (Edginton *et al*., 2004:6; Mclean *et al*., 2008:39). It involves freedom and choice to pursue individual interests like reflection, pleasure, self-enrichment, or relaxation, and also involves some form of participation in activities, but such activities may also be experienced as a spiritual experience or a holistic state of being (Edginton *et al*., 2004:6; Mclean *et al*., 2008:39). Leisure plays a significant role in helping people meet their personal needs. For that reason, ceasing or reducing leisure participation as a result of care giving, might lead to negative consequences like increased stress and decreased life satisfaction (Bedini, 2002:25,26; Dunn & Strain, 2001:44,50). Bedini (2002:26), Bedini and Guinan (1996b:278, 281) as well as Dunn and Strain (2001:43, 44) elaborate by explaining that the reasons why caregivers cease or reduce their leisure might be due to internal barriers like experiencing physical and emotional fatigue, feeling too tired, and feeling guilty about taking a break, or external barriers like a lack of time, lack of outside help, and financial strain. Although, reductions in leisure time are inescapable in many situations of caregiving, leisure participation may serve as a vital support for caregivers (Dupuis & Smale, 2000:308).

Various studies argue that leisure protects people from the stress created by life circumstances as it benefits health (Brattain, 1997:240; Coleman & Iso-Ahola, 1993:114; Iwasaki & Mannel, 2000:165, 167; Rodriguez & Gamble, 2010:50, 51; Stebbins, 2007:43). Furthermore, research found that leisure participation may provide people with companionship, which creates the perception that they will have social support during a serious life crisis; and that certain types of leisure may foster self-determination (Coleman & Iso-Ahola, 1993:114; Rodriguez & Gamble, 2010:60). Leisure might also help reduce or overcome loneliness and social isolation and contribute to one's spiritual life (Caldwell & Smith, 1988:46,47; McLean & Hurd, 2015:94), for example, walking on the beach might result in creative thought and inner energy.

Apart from understanding the benefits of leisure and the factors that prevent caregivers from participating in leisure activities, knowledge about caregiving is also essential in the effort to examine this problem. According to Williams and Crooks (2008:244), caregiving can be formal, in which case there is paid care provided by practitioners such as social workers or home care workers who have formal training or a degree like nursing, or it can be informal where family, a parent or a relative provides unpaid care to a chronically ill or disabled loved one (Bedini, 2002:25; Buchanan *et al.*, 2009:1244; Carter, 1994:3-4; Gladwell & Bedini, 2004:686; Schultz & Martire, 2004:240). This study will focus only on formal caregivers, but specifically the primary caregiver who offers the most assistance and support to the individual with a disability (Banes *et al*., 2007:400).

In this context, the role of a caregiver could be better understood when one understands the concept of disability. The World Health Organization (2014) describes a disability as “an umbrella term, covering impairments, activity limitations, and participation restrictions”. When there is a problem in the functioning or structure of a person’s body, it can be seen as impairment (WHO, 2014). When an individual experiences difficulty in executing an action or task, it can be seen as an activity limitation, while a restriction in participation is when an individual experiences problem when involved in situations of life (WHO, 2014). Moreover, according to the WHO (2014) “disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives. Therefore, taking care of a person with a disability involves spending a considerable amount of time and energy on caregiving activities (Schultz & Martire, 2004:240). The caregiver becomes responsible for uncomfortable and unpleasant tasks that could be physically exhausting and stressful to the caregiver, such as cooking, grocery shopping, transportation, changing dressings, personal care and bathing, shaving, toileting, inserting feeding tubes and giving shots, emotional support, counselling, and watching over the disabled person (Bedini, 2002:26; Carter & Golant, 1994:3,4; Elmore, 2014:17; Lo´pez *et al*., 2005:82; Schultz & Martire, 2004:240; United Nations, 2012:200). Given this context it is understandable that not only the person with a disability might develop a need to participate in leisure, but also the caregiver of that person.

Findings by Marchal *et al*. (2013:4246) in a study on the health-related quality of life in parents of six- to eight-year-old children with Down syndrome, revealed that parents need a break from their responsibilities and experience the need for more time for themselves. Accordingly, Gladwell and Bedini (2004:687) found that caregivers experience the need to participate in leisure for social interaction, challenge, relaxation, escape from daily stress, education and learning, stimulation, and visiting friends and relatives. However, most caregivers’ interest in leisure is the same, but their ability to fulfil them differs (Bedini & Guinan, 1996a:230). Activities such as reading, exercise classes, music, travel, card games, movies, tennis, golf, eating out, swimming and socialising are interests that are mentioned in their study (Bedini & Guinan, 1996a:230). Several studies, including the latter, focus on leisure and caregiving by considering diverse approaches, such as formal and informal caregiving; and different aspects related to such a situation, such as caregiving burden, changes in leisure participation, impact of caregiving on leisure travel, family caregiving and leisure; as well as caring for patients with different conditions like dementia, Down Syndrome, Cerebral Palsy, or elderly people (Bedini, 2002; Brehaut *et al*., 2014; Del-Pino-Casado *et al*., 2011; Dunn & Strain, 2001; Gladwell & Bedini, 2004; Green, 2007; Kim & Letho, 2013; Koerner *et al*., 2009; Marchal *et al*., 2013; Schultz & Martire, 2004; Paraponaris *et al*., 2012). However, not much attention has been given to the leisure needs of primary caregivers of disabled people. Furthermore, most of the literature is from an international perspective, with limited research available on the South African context. Therefore, this study explored the leisure needs and the impact that caregiving has on the leisure of the primary caregivers of disabled people in the North West province. Since this study is based on a case study approach the focus was only on a single centre.

This study's aim was to provide useful information to leisure service providers and various health care organisations about the leisure needs of primary caregivers and the consequences if caregivers have unmet leisure needs. It will also help leisure service providers to know how to adjust the programmes they offer to address the leisure needs of the caregivers. The study furthermore examined the impact of care giving on the leisure of primary caregivers. The information that emanated from the research will enable service providers to provide the necessary leisure services and opportunities to caregivers and parents. It will also encourage service providers to identify the caregivers in the community to enable them to increase leisure awareness and education among caregivers. Little attention has been given to the leisure experiences of caregivers in South Africa and how they perceive leisure when they find themselves in that context. Understanding their perception of leisure needs and the impact that caregiving has on these needs is important to gain a deeper understanding of how to practically contribute to the situation, and how to address these needs. The study also aims to encourage further research on this subject.

1.2 Central theoretical statement

The available literature shows that caregiving is stressful to caregivers and that it has various physical and psychological effects. However, the loss of leisure as a result of caregiving responsibilities is often overlooked (Bedini, 2002:28; Bedini & Gladwell, 2014:130; Brehaut *et al*., 2014:183; Chien & Lee, 20:2013; Dupuis, 2000:259; Geere *et al*., 2011:390; Kuster & Merkle, 2004:258). According to Bedini (2002:28) it is evident that leisure participation, as well as access to leisure is associated with better health and that caregivers find leisure important in their lives. Bedini (2002:28) also concludes that although caregivers frequently reduce their leisure, they "generally want it in their lives, miss it when it is gone, and need it for their health". Therefore, the central theoretical statement of this study was that:

Primary caregivers of people with disabilities experience high levels of unmet leisure needs and that such caregiving has a negative impact on the leisure of caregivers of disabled people in the North West province.

1.3 Objectives

The objectives of this study were:

- To explore and describe the influence of caregiving for disabled persons on the leisure experience of caregivers in a centre in the North West province.
- To explore and describe the leisure needs of formal caregivers of disabled persons in a centre in the North West province.

1.4 Structure of dissertation

The structure of the dissertation is as follows:

Chapter 1: Introduction

Chapter 2: Leisure, care giving and disability: A review of literature

Chapter 3: (Article 1): The influence of caregiving for individuals with a disability on the leisure of caregivers in the North West province: A case study. This study will be published according to the guidelines of the journal.

Chapter 4: (Article 2): The leisure needs of formal caregivers of individuals with disabilities in the North West province: A case study. This study will be published according to the guidelines of the journal.

Chapter 5: Summary, conclusions, limitations and recommendations.

References

Allen, S.M. & Ciambrone, D. 2003. Community care for people with disability: blurring boundaries between formal and informal caregivers. *Qualitative health research*, 13(2):207-226.

Aoun, S.M., Kristjanson, L.J., Currow, D.C. & Hudson, P.L. 2005. Caregiving for the terminally ill: at what cost? *Palliative medicine*, 19(7):551-555.

Bakker, A.B., Killmer, C.H., Siegrist, J. & Schaufeli, W.B. 2000. Effort-reward imbalance and burnout among nurses. *Journal of advanced nursing*, 31(4):884-891

Bedini, L. A. 2002. Family caregivers and leisure: an oxymoron? *Parks and recreation*, 37(1):25-31.

Bedini, L.A. & Gladwell, N.J. 2014. Caregiving as life transition: implications for leisure service providers. *Journal of park and recreation administration*, 32(1):128-141.

Bedini, L. A. & Guinan, D. M. 1996a. "If I could just be selfish...": caregivers' perceptions of their entitlement to leisure*.* *Leisure sciences*, 18(3):227-239.

Bedini, L.A. & Guinan, D.M. 1996b. The leisure of caregivers of older adults: implications for CTRS‟s in non-traditional settings. *Therapeutic recreation journal*, 30(4):274-288.

Blanes, L., Carmagnani, M.I.S. & Ferreira, L.M. 2007. Health related quality of life of primary caregivers of persons with paraplegia. *Spinal cord*, 45(6):399-403.

Brandon, P. 2007. Time away from "smelling the roses": where do mothers raising children with disabilities find the time to work? *Social science & medicine*, 65(4):667-679.

Brattain, R.N. 1997. Centrality of the caregiving role and integration of leisure in everyday life: a naturalistic study of older wife caregivers. *Therapeutic recreation journal*, 30(4):230-243.

Brehaut, J.C., Kohen, D.E., Raina, P., Walter, S.D., Russell, D.J., Swinton, M., O'Donnell, M. & Rosenbaum, P. 2004. The health of primary caregivers of children with Cerebral Palsy: how does it compare with that of other Canadian caregivers? *Journal of American academy of paediatrics*, 114(2):182-191.

Buchanan, R., Ranin, D., Chakravorty, B.J. & Tyry, T. 2009. Informal caregiving to more disabled people with multiple sclerosis. *Disability and rehabilitation*, 31(15):1244-1256.

Caldwell, L.L. & Smith, E.A. 1988. Leisure: An overlooked component of health promotion. *Canadian journal of public health*, 79(2):44-48.

Carter, R. & Golant, S. 1994. Helping yourself help others: a book for caregivers. New York, NY: Three Rivers Press.

Chien, W. & Lee, I.Y.M. 2013. An exploratory study of parents' perceived educational needs for parenting a child with learning disabilities. *Asian nursing research*, 7(1):16-25.

Coetzee, M.J. 2007. The psychological health implications of social support for the Alzheimer caregiver. Pretoria: University of Pretoria. (Dissertation - MBA).

Coleman, D. & Iso-Ahola, S.E. 1993. Leisure and health: the role of social support and self-determination. *Journal of leisure research*, 25(2):111-128.

Del-Pino-Casado, R., Frias-Osuna, A. & Palomino-Moral, P.A. 2011. Subjective burden and cultural motives for caregiving in informal caregivers of older people. *Journal of nursing scholarship*, 43(3):282-291.

Dunn, N.J. & Strain, L.A. 2001. Caregivers at risk: changes in leisure participation. *Journal of leisure research*, 33(1):32-55.

Dupuis, S.L. & Smale, B.J.A. 2000. Bittersweet journeys: meanings of leisure in the institution-based caregiving context. *Journal of leisure research*, 32(3):303-340.

Dupuis, S.L. 2000. Institution-Based caregiving as a container for leisure. *Leisure sciences*, 22(4):259-280.

Edginton, C.R., Hudson, S.D., Dieser, R.B. & Edginton, S.R. 2004. Leisure programming: a service-centred and benefits approach. 4th ed. New York, NY: McGraw-Hill.

Elmore, D.L. 2014. The impact of caregiving on physical and mental health: implications for research, practice, education, and policy (*In* Tally, R.T., Fricchione, G.L. & Druss, B.G., *ed*. 2014. The challenges of mental health caregiving. New York, NY: Springer. p. 15-31)

Geere, J.L., Gona, J., Omondi, F.O., Kifalu, M.K., Newton, C.R. & Hartley, S. 2011. Caring for children with physical disability in Kenya: potential links between caregiving and carers" physical health. *Child: Care, health and development*, 39(3):381–39.

Gladwell, N.J. & Bendini, L.A. 2004. In search of lost leisure: the impact of caregiving on leisure travel. *Tourism management*, 25(6):685–693.

Govender, N. 2002. Attitudes of parents towards their mentally retarded children: a rural area examination. Ulundi: UniZulu (Dissertation - MA).

Green, S.E. 2007. “We are tired, not sad”: benefits and burdens of mothering a child with a disability. *Social science & medicine*, 64(1):150-163.

Iwasaki, Y. & Mannel, R.C. 2000. Hierarchical dimensions of leisure stress coping. *Leisure scienc*e: *An interdisciplinary journal*, 22(3):163-181.

Kim, S. & Letho, X.Y. 2013. Travel by families with children possessing disabilities: motives and activities. *Tourism management*, 37:13-24.

King, A.C., Castro, C., Wilcox, S., Eyler, A.A., Sallis, J.F. & Brownson, R.C. 2000. Personal and environmental factors associated with physical inactivity among different racial-ethnic groups of U.S. middle-aged and older-aged woman. *Health psychology*, 19(4):354-364.

Koerner, S.S, Kenyon, D.B. & Shirai, Y. 2009. Caregiving for elder relatives: which caregivers experience personal benefits/gains. *Archives of gerontology and geriatrics*, 48(2):238-245.

Kuster, P.A. & Merkle, C.J. 2004. Caregiving stress, immune function, and health: implications for research with parents of medically fragile children. *Issues in comprehensive paediatric nursing*, 27(4):257–276.

Lo´pez, J., Lo´pez-Arrieta, J. & Crespo, M. 2005. Factors associated with the positive impact of caring for elderly and dependent relatives. *Archives of gerontology and geriatrics*, 41(1):81-94.

Marchal, J.P., Maurice-Stam, H., Hatzmann, J., Van Trotsenburg, A.S.P. & Grootenhuis, M.A. 2013. Health related quality of life in parents of six-to-eight-year-old children with Down Syndrome. *Research in developmental disabilities*, 34(11):4239-4247.

McLean, D.D., Hurd, A.R., & Rogers, N.B. 2008. Recreation and leisure in modern society. 8th ed. Sudbury, MA: Jones & Bartlet.

McLean, D.D. & Hurd, A.R. 2015. Recreation and leisure in modern society. 10th ed. Sudbury, MA: Jones & Bartlet.

Paraponaris, A., Davin, B. & Verger, P. 2012. Formal and informal care for disabled elderly living in the community: an appraisal of French care composition and costs. *European journal of health economics*, 13(3):327-336.

Pekkarinen, L., Sinervo, T., Pera¨la", M. & Elovainio, M. 2004. Work stressors and the quality of life in long-term care units. *The gerontologist*, 44(5):633-643.

Rodriguez, A. & Gamble, D. 2010. Leisure and quality of life (*In* Human Kinetics. 2010. Dimensions of leisure for life. Champaing, IL: Human Kinetics. p. 1-367).

Schultz, R. & Martire, L.M. 2004. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *American association for geriatric psychiatry*, 12(3):240-249.

Stats SA (Statistics South Africa). 2014. Census 2011: profile of persons with disabilities in South Africa. (03-01-59). Pretoria: SSA

Stebbins, A.R. 2007. Serious leisure: a perspective of our time. New Brunswick, NJ: Transaction.

United Nations. 2012. Social Panorama of Latin America. New York, NY: United Nations.

Vitaliano, P.P., Scanlan, J.M. & Zhang, J. 2003. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological bulletin*, 129(6):946-972.

WHO (World Health Organisation). 2014. Health topics: disabilities. http://www.who.int/topics/disabilities/en/ Date of access: 5 May 2014.

Wiles, J. 2003. Daily geographies of caregivers: mobility, routine, scale. *Social science & medicine*, 57(7):1307-1325.

Williams, A. & Crooks, V.A. 2008. Introduction: space, place and the geographies of women's caregiving work. *Gender, place and culture*, 15(3):243-247.

CHAPTER 2: LEISURE, CARE GIVING AND DISABILITY: A CRITICAL REVIEW

2.1 Introduction

In rural areas in South Africa, it is often common for parents to reject their mentally disabled child because of embarrassment, being overburdened, or feelings of disappointment (Govender, 2002:64-67). For those relatives with a more positive attitude towards their disabled child or sibling, competing for employment or familial responsibilities, poor health, a lack of resources, and geographical distance may limit their ability to provide care for a family member with a disability (Allen & Ciambrone, 2003:207). Furthermore, the resources needed for informal caregiving, for example by family or relatives, might be untrustworthy or not existent on a constant basis, and individuals turn to the formal sector for the assistance they need (Allen & Ciambrone, 2003:207). Bakker *et al.* (2000:885) mention that formal caregivers experience many demands when working with patients with disability. Moreover, when caring for a person with a disability, demands are far more than in cases of a child of normal development (Brandon, 2007:668; Brehaut *et al.,* 2014:183).

For this reason, it might be that caregiving could influence the leisure of the primarily involved caregivers negatively due to all their caregiving demands. In fact, available literature shows that caregiving is stressful to caregivers and that it has various physical and psychological effects on caregivers (Bakker *et al*., 2000;885, 888; Brehaut *et al*., 2014:183; Vitaliano *et al*., 2003:947, 949). Accordingly, the loss of leisure as a result of caregiving responsibilities is often overlooked (Bedini, 2002:28; Bedini & Gladwell, 2014:130; Brehaut *et al.,* 2014:183; Chien, 2013:20; Dupuis, 2000:259; Geere *et al*., 2011:390; Kuster & Merkle, 2004:258), even though it is evident that leisure participation, as well as access to leisure, is associated with better health and that caregivers find leisure important in their lives (Bedini, 2002:28).

In this chapter the terms leisure, caregiving and disability will be thoroughly discussed from a theoretical perspective to understand the effect that it has on one another. Firstly, the term leisure will be thoroughly described in the context of this study. Secondly, caregiving will be discussed and also how caregiving for people with disability and leisure affect one another.

2.2 Leisure concepts

2.2.1 Introduction

As mentioned above, a caregiver's life, as well as their leisure lifestyle, can be impacted significantly by their responsibilities (Dupuis, 2000:259). According to Organization for Economic Cooperation and Development (2009:20) the quality and the amount of time spent on leisure is essential for the well-being of people because it brings direct satisfaction. Edginton (2012:2) also explains that leisure is playing a more vital role to assist in identifying an individual's sense of self-worth and own identity. Furthermore, people have a concept of the meaning of leisure and also whether they have enough leisure or not (Henderson, 2012b:531). Nevertheless, Torkildson (2005:3) also mention that the meaning of leisure and what it is to people are now more important than ever. However, a lack of participation in leisure is now one of the major health problems globally, and it affects a lot of older people from developed and developing countries over the world (Mthembu *et al.,* 2015:215). Its value, interpretations, and meaning worldwide also differ a lot (Coles *et al.,* 2012:684). Therefore, it is critical to get a better concept or understanding of leisure, as to understand why caregivers' responsibilities have such a great impact on their leisure which will be discussed later in this chapter.

2.2.2 Conceptualizing leisure

Leisure is a powerful force in contemporary society, and its power lies in the benefits it provides for cultures, communities, groups and individuals (Edginton, 2012:2; Edginton *et al.,* 2004:2). According to Edginton *et al*. (2005:2), the contribution of leisure to the quality of our lives is essential and something that individuals seek continuously. They also mention that people use their leisure pursuits and interests as a way to define who they are and to enhance, nourish and enrich their lives (Edginton, 2012:2; Edginton *et al*., 2005:2). Furthermore, leisure serves to help increase development, growth, and overall individual well-being, it also provides opportunities for release, restoration, renewal, relaxation and reflection (Edginton, *et al*., 2004:2). Henderson (2012b:532) and Caldwell (2011:170) go further by explaining that learning, experiencing enjoyment, and expressing oneself are also outcomes of leisure. Nevertheless, most normal and educated people see a good life as having a healthy body and mind (Rojek, 2010:1-2). In order to achieve that outcome they use leisure as a reward for their work, as the main element in their work-life balance, to reduce crime, to increase mutual understanding, and also to serve as an asset for the community (Rojek, 2010:1-2).

Hayward (2000:2), Torkildsen (2005:10-11), as well as McLean and Hurd (2015:3) state that leisure is not a new development and that our leisure behaviour and culture is partly rooted in the past. Accordingly, even though perceptions of leisure around the world differ (Mclean & Hurd, 2015:1), Henderson (2012b:532) and Roberts (2006:3) also state that leisure has been part of all periods of time, societies, and places, and that it has not necessarily been learned but has been embodied in culture. Furthermore, the philosopher Aristotle described leisure as an engagement with the highest capacities of the soul and not as rest or recreation (Henderson, 2012b:532; Holba, 2014:182). He believed that, only after the pleasures of recreation have reached their purpose and have been enjoyed, the role of leisure started entering the scene fully (Owens, 1981:716). Thus, recreation only counts as a leisure activity if it provides an individual with pleasure and enjoyment, as well as free will to participate or not. If an individual does not enjoy a recreation activity, it is not regarded as leisure. According to Owens (1981:716), Aristotle also explained that leisure provides a panorama more independent and more positive than entertainment or relaxation or recreation. Although there are many components to leisure, it can be described as a state, of which the most important and basic characteristic is the freedom to do what one desires (Ateca-Amestoy *et al.,* 2008:65; Caldwell, 2011:170; Owens, 1981:718).

We live in a time where the value of leisure is increasing (Edginton & Chen, 2008:1), yet it's a term not easily defined (Cordes, 2013:1; Edginton & Chen, 2008:6). To some people, it may be related to work life, and to others, it may be perceived as a separate and distinctive cultural concept (Edginton & Chen, 2008:6). Moreover, leisure can be seen as an expressive activity that is mainly orientated to the experience which can be found at any place or time (Freysinger & Kelly, 2004:3; Kelly & Godbey, 1992:6). Therefore, it's not limited to one place, organisation, or part of our lives (Godbey, 2008:1), but part of the essential components of work, family, community, school, religion and the marketplace (Kelly & Godbey, 1992:6). It is interlaced within the structure of social action and interaction (Kelly & Godbey, 1992:6). It might also be creativity to some and idleness to others (Kelly & Godbey, 1992:11). Furthermore, Coles *et al*. (2012:684), Ministry of social development in New Zealand (2010:92; 2016:189) suggest that it can also be characterised by the search for discovery, satisfaction and contributing to people's quality of life. However, to better understand the meaning of the term leisure, one may ask why do people participate in leisure? Kraus *et al.* (2001:2) explain that people will take part in leisure and recreation pursuits voluntarily for many reasons. For instance, people may be motivated to participate mainly for the fun or pleasure they gain when watching the arts of a skilful performer or competing in a sports activity (Kraus *et al.,* 2001:2). Others may desire to increase their fitness and health, to experience new surroundings, to express themselves creatively, to enjoy the companionship of others, or just to enjoy a change of pace and to unwind (Kraus *et al.,* 2001:2).

However, several researchers indicate that most people pursue leisure activities for pure enjoyment and fun (Freysinger & Kelly, 2004:3; Kelly and Godbey, 1992:11; Parr & Lashua, 2004:4). In view of that, Stebbins (2004b:8) elaborates that the term “fun” normally means to find amusement or pleasure in a specific activity, whereas the word “enjoyable” refers to an activity that brings delight or pleasure. Furthermore, he connects the term “satisfying experience” as similar meaning to the words “fun” and “enjoyable”; however, in another sense it refers to a particular want or need that separates it from the words fun and enjoyable (Stebbins, 2004b:8). In other words, the word “satisfying experience” in the second sense can be described as a “fulfilling experience” that can be a set of sequential experiences that leads an individual to develop to the fullest of his/her character and gifts, and as a result developing to the fullest of that individual’s potential (Stebbins, 2004b:8). Thus, the fourth term “fulfilling experience” is more related to serious leisure (satisfying achievement and accomplishment, personal development and exploiting gifts) whereas the first three terms are more common with casual leisure (experiencing pleasure through an activity) (Stebbins, 2004a:112; Stebbins, 2004b:9). However, any of these four experiences may be experienced during casual and serious leisure (Stebbins, 2004b:9). For example, in an interview with skilled and experienced kayakers, Stebbins (2004b:10) explains that they said it’s fun to paddle, thus meaning that it’s gratifying because they have acquired practical qualifications in time which makes it relatively easy to carry out the activity. He also concludes that these meanings will undergo change over time and that the researcher’s definitions must continue to be sensitive to this transformation (Stebbins, 2004b:10). In brief, Dattilo and Schleien (1994:53) state that for someone to partake in leisure fully is to reveal capabilities, express talents, reach one's potential and experience a variety of positive emotions. However, for the purpose of this study, it is important to define the term leisure in order to have a better understanding of its role in the lives of caregivers and how it can be affected by caregiving.

2.2.3 Definition of leisure

The term leisure is a broad concept that can be defined in a variety of ways. According to Edginton *et al.* (2004:6) leisure can be defined from seven main orientations such as a holistic experience, anti-utilitarian, a symbol of social class, as an action, free time, an activity, and state of mind. However, literature concludes that the three most important characteristics for which leisure is known for are free time, activity, and a state of mind (Edginton *et al.,* 2005:26; Godbey, 2008:3-5; Henderson, 2010:6; OECD, 2009:20; Parr & Lashua, 2005:17). When defining leisure as free time, leisure is considered as the time when you’re free to pursue the things that you are interested in (Edginton *et al.,* 2005:26). It can be seen as a block of time free from obligations, discretionary time, time when we do what we choose (Caldwell, 2011:170;

Edginton *et al.,* 2004:6; Edginton *et al.,* 2005:26; Godbey, 2008:3; Henderson, 2010:6; Henderson, 2012b:532; Kelly, 1990:16-17; Kelly & Godbey, 1992:17; OECD, 2009:20). For that reason, free time may have different outcomes for different people, for instance, retirement differs fundamentally in meaning from a holiday (Godbey, 2008:4). Nevertheless, there are difficulties when defining leisure as free time, since one can be physically free, politically free, economically free, socially free, morally free, and ecologically free (Godbey, 2008:6). Also, the definition does not describe to which extent one is free from their obligation (OECD, 2009:20).

According to Godbey (2008:6), the above-mentioned dominions of freedom are constantly changing for many people regarding the level of their existence. Sometimes they are seen as essential preludes to leisure (Godbey, 2008:6; Iso-Ahola, 1999:36). However, leisure may occur from unfree circumstances like education, work, and other social spheres as well (Godbey, 2008:6; Iso-Ahola, 1999:36; Leitner & Leitner, 2012:12). For instance, a young boy may be forced to take trumpet classes by his parents (Godbey, 2008:7). Still, he may experience leisure when playing the trumpet in the end, or a parent may feel obligated to take his/her child to the play area but still find leisure there (Godbey, 2008:7). Nevertheless, caregiving daughters in the study of Dupuis experienced leisure while performing their caregiving duties (Dupuis, 2000:260). Henderson (2012b:533) also expand by explaining that many activities are done at work blended with leisure. However, Godbey (2008:7) explains that our preludes to leisure in many of these domains are not free and that the probability to experience leisure when the preludes to leisure are relatively free may be higher. Thus, leisure may occur when we are free from preludes to leisure and also when we are not free from the preludes to leisure (Godbey, 2008:7). Therefore, leisure cannot be defined by free time only.

Leisure can also be defined as an activity which refers to the activities we engage in during our free time like running, volunteering, arts, traveling, reading, and other recreation activities (Edginton *et al.,* 2004:6; Edginton *et al.,* 2005:26; Leitner & Leitner, 2012:11). Nevertheless, leisure is more than just an activity. According to Godbey (2008:11), it is a process involving a particular act. It's more about meaning through one's actions than it is about the activities (Godbey, 2008:11). Hence, to define leisure only as a cluster of activities, you ignore the internal world of leisure (as a state of mind) (Godbey, 2008:11). Accordingly, when an individual experiences leisure in a specific activity, it can no longer be compared or replaced by a similar variety of alternative activities, since it's more about the love for an inner experience (Godbey, 2008:7, 11). In other words, the action or activity only acts as the context for that experience (Kelly & Godbey, 1992:19). Thus, Kelly and Godbey (1992:19) describe leisure as an action that creates and has meaning. According to them, the meaning within an experience as well as self-determination distinguishes it from other types of action (Edginton *et al*., 2004:6; Kelly &

Godbey, 1992:19). Therefore, leisure can be described as an action that is self-determined with (and /it has) meaning that is primarily confined to the experience (Edginton *et al*., 2004:6; Kelly & Godbey, 1992:20).

When we refer to leisure as a state of mind or existence, it can be an attitude or behaviour that occurs in an activity, and the psychological condition of the individual located in the consciousness of the individual (caused by intrinsic motivation) (Edginton *et al.,* 2004:6; Henderson, 2010:6-7; Kelly & Godbey, 1992:18). According to Edginton *et al.* (2005:26), when individuals feel or think that they are experiencing leisure, they are in fact experiencing leisure. Godbey (2008:5) goes further by explaining that a leisure experience is when people are free or in control of events rather than being controlled by it. For that reason, leisure may occur at various places and times and a variety of circumstances (Edginton *et al.,* 2005:26; Kelly & Godbey, 1992:18). Lastly, Edginton *et al*. (2004:8), Edginton *et al.* (2005:26), and Godbey (2008:6) conclude that the most important criterion of leisure is perceived freedom, a condition where any activity is carried out freely without any constraint or force. However, to assume that leisure is produced by the state of mind alone would lead to the belief that nothing but the self is real or exists (Godbey, 2008:8). Thus, in leisure, individuals lose themselves during the activity and surrenders themselves gladly to the experience (Godbey, 2008:8). During this process, the mind becomes so focused that self-awareness becomes constricted (Godbey, 2008:8). The relevance of state of mind is therefore inevitable, and two different states of mind can be identified, namely, a state of which the attention is constricted to a joyous, captivating experience and a state of wonder and the realization that we are part of something bigger and that “self” is a made-up boundary (Godbey, 2008:9; OECD, 2009:20).

Although leisure has many definitions and interpretations, none of the previously discussed definitions provides a complete understanding of leisure. In the context of this study, however, leisure will be defined as follows:

The percentage of a person’s time that is not devoted directly to work or other forms of obligations, self-care or maintenance (Edginton *et al.,* 2004:6; Mclean *et al*., 2008:39). *It involves freedom and choice to pursue individual interests like reflection, pleasure, self-enrichment, or relaxation, and also involves some form of participation in activities, but such activities may also be experienced as a spiritual experience or a holistic state of being* (Edginton *et al.,* 2004:6; Mclean *et al.,* 2008:39).

The latter definitions might describe the term leisure and identify the main characteristics of leisure, however, over the world leisure is valued differently, and different people have different interpretations and meanings that they attach to it (Coles *et al.,* 2012:684; Edginton *et al*., 2004:6; McClean & Hurd, 2015:1). For instance, Henderson (1996:140) focusing on the leisure of women, revealed that many meanings of leisure have emerged due to life circumstances in which many women find themselves but, also because of what different individuals understand under gender differences and leisure when considering the changing nature of leisure. Furthermore, Henderson concludes that there are numerous and a variety of definitions that leisure holds for women when leisure is examined as other- or self-orientated (Henderson, 1996:150). According to Henderson (1996:151), leisure may create a situation where empowerment is being felt by women, and, in some cases, leisure may also create a situation where oppression is experienced by women. It can also be an opportunity for resistance or conformity to social roles (Henderson, 1996:151). Moreover, a study conducted by Parr and Lashua (2004:7, 8) compared the perceptions of leisure service providers and individuals outside the field and determined that participants agreed that what one person experience as leisure, may not necessarily be leisure for another person, that there may be different values and meanings for leisure, depending on the cultural background someone has, and that it can be experienced in different spheres of life, for instance, education, religion, work, family, and more, while leisure is seen as an attitude.

In the case of caregiving, the meaning of leisure changes as the role and context of caregiving changes according to Dupuis and Smale (2000:309, 334) and Dupuis (2000:260). This study revealed that informal caregivers' (adult daughters) roles changed depending on their relationship to the care receiver, their gender, and the functional health of the care receiver (Dupuis & Smale, 2000:310). Furthermore, findings revealed that the cause of change in the informal caregivers' (daughter) roles and their meaning for leisure might also include factors like an ethic of care (which entails a complete moral response based on professional caring), it is based on "decision-making" and "relation based moral reasoning", it recognizes vulnerability and dependency of people of everyday life, specifically to people whose wellbeing and lives depend on specific, continual, and daily attention, if they were comfortable with the facility and satisfied with the way that the staff provides care, how far the cognitive impairment has developed and also the amount of loss that is felt by the caregiver (daughter), the level of connectedness that the caregiver felt to the care receiver (parent), the capability of the caregiver (daughter) to deal with the situation and the process of grief, and the other healthy parents' (partner of care receiver) presence who still lives in the community (Bedini & Guinan, 1996a:234; Dupuis & Smale, 2000:334; Laugier, 2015:219; Wada, 2014:353, 361; Ward, 2011:173; Woods, 2011:272). However, the meanings of leisure in the context of caregiving have been explored by only a small number of studies (Dupuis & Smale, 2000:309). Furthermore, these findings are only based on the leisure meanings of informal caregivers, and may thus differ from what formal caregivers may experience as leisure since their roles would also differ a lot from those of an informal caregiver. Additionally, a study of Bedini and Guinan (1996a:230) stresses that a caregiver's participation in leisure determines what their perception of leisure is, how leisure fit in their caregiving role, how they deal with resolving their need for leisure, and how they prioritize their personal tasks compared to their leisure. Nevertheless, many caregivers choose to actively avoid leisure given the problems that leisure might evoke for them, like feelings of losing control, anxiety, or feelings of betrayal to the care receiver (Dupuis & Smale, 2000:307). According to Bedini and Guinan (1996a:228, 230) as well as Dupuis and Smale (2000:308) it is inevitable for caregivers to reduce leisure in many situations, but leisure participation might serve as a vital support for caregivers. It is, therefore, also important to look at both active and passive leisure activities and how it is applied in the caregiving context, since both active and passive leisure have benefits to caregivers.

2.2.3.1 Active and passive leisure

Leisure researchers have lately focused on preventative potentials that leisure offers and the health benefits it holds when participating in it (Ainsworth *et al*., 2007:24). Ainsworth *et al*. (2007:24) explain that from the perspective of public health, leisure could be seen as beneficial or problematic because of the opportunities it offers for engaging in behaviour that could be either healthy or unhealthy. This reflects a dilemma as many people describe leisure as activities that are sedentary (passive leisure) while it could also be physically active (active leisure), which is also healthier (Ainsworth *et al*., 2007:24). However, since leisure provides freedom of choice, it provides opportunities for personal development and growth, opportunities to affirmation and formation of positive identity, and opportunities for involvement in activities that pay off for the needs not met in other areas of life and work (Ainsworth *et al*., 2007:28). Nevertheless, the latterly mentioned benefits that leisure provides may come from passive or active leisure.

Anon (2011:44), Kiernozek (2015:37) and Williams (2013:7) describe passive leisure activities as activities that do not require a person using vast amounts of physical or mental energy while engaging in it. It can be done when you're alone, indoors, and it can even be done when there is just a small amount of free time available (Anon, 2011:44; Kiernozek, 2015:37; Williams, 2013:7). Accordingly, passive leisure may also include recreation activities. Passive recreation can be described as something people participate in during leisure time, something not bound to rules, non-competitive, something people do for enjoyment and fun, something that overlap with areas such as education, arts, and culture (Department of Sport and Recreation, 2012:14; Majnemer *et al*., 2015:77). For example, in a study of Kiernozek (2015:37) it's mentioned that caregivers participate in passive activities such as reading, relaxing, being still, watching television and movies, sleeping, and being on the computer, while other caregivers/parents preferred creative arts and crafts, like scrapbooking, quilting, cooking, playing the piano, crocheting, photo journaling, and beading.

Passive leisure often causes concern among experts since many of these activities are believed to have fewer benefits than active leisure activities could offer (Anon, 2011:44). Furthermore, a study of Holder *et al*. (2009:383) also showed that passive leisure is negatively related to well-being, whereas active leisure has a positive effect on wellbeing. However, many people claim that they are relaxing the most during passive leisure activities (Anon, 2011:44). Sonnentag (2001:199) explains that spending time on passive leisure does not mean that it has negative effects as when not participating in any active activity. Participation in passive leisure may add to predict well-being beyond the assumption that active leisure activities have a positive effect on individuals (Sonnentag, 2001:199). Accordingly, Sonnentag (2001:199) is not convinced that poor well-being is a result of time spent on activities with low effort (passive leisure). Nevertheless, this study reveals that low effort activities are sometimes essential for a person to recover and for that reason low effort activities has a positive effect on the well-being of an individual (Sonnentag, 2001:199). In fact, the study of Sonnetag (2001:205) states that both active and passive activities positively affect one's well-being (Sonnentag, 2001:205). This is also evident when looking at Nash's pyramid of leisure activities where he refers to several forms of leisure activities, including several passive activities, that leads to positive effects on the individual's life including: (1) creative participation (for example composing a poem), (2) emotional participation (like watching a play), (3) and entertainment, amusement, escape from monotony, and killing time (which involve things like watching TV) (Archibald, 2008:3). Nash argues that these activities, including active leisure activities, could lead to development, progress, and enrichment of a person's life (Archibald, 2008:3). Therefore, it is also important to understand the content of passive and active leisure.

Unlike passive leisure, active leisure can be described as participating in activities involving the mental and physical exertion of energy which mostly include lower impact physical activity like walking or yoga (Anon, 2011:44). However it can also include high impact physical activities like kickboxing and aerobics (Anon, 2011:44). Furthermore, the Department of Sport and Recreation (2012:14) also talks about active recreation which can be seen as physical activity and it is characterized as activities with rules (however to some extent flexible). It is also described as activities that are beneficial for the physical and mental health of a person, something that people do to compete against nature or themselves, activities pursued for fitness and the fun of it, and a stepping stone to formal sport (Department of Sport and Recreation, 2012:14). However, since recreation is just one of the things done during leisure time, it might differ from leisure to some extent. For instance, active leisure activities may not necessarily be rule-bound (like running in a park) or be used as a stepping stone to the formal sport (Department of Sport and Recreation, 2012:14). In the context of this study, it would rather be pursued for health benefits. Nevertheless, referring back to the study of Kiernozek (2015:37), caregivers/parents mentioned that they participate in active activities such as running, swimming, exercising, walking, and biking, while other caregivers/parents enjoyed being able to participate in outdoor activities like hiking, fishing, shopping, traveling, socialising, camping and gardening.

Bearing in mind that active leisure activities are mostly done outside, Kiernozek (2015:37, 44) explains that caregivers face challenges that require caregivers/parents to do additional planning and scheduling for them to fully participate in the activities they chose (especially when involving the child with disability), they need to find someone to watch over the child/ren when they leave home for some time, and there are also extra costs involved when a caregiver/parent want to participate in that specific activity. Since parents/caregivers cannot participate unless proper adaptations are made, it can be concluded that caregivers' choices between active leisure and passive leisure may be influenced by their circumstances and resources (Kiernozek, 2015:44). A study of Ainsworth *et al*. (2007:29-30) also support this statement by expanding on how friends who do not value physical activity and family responsibilities acted as barriers to being active. On the other hand, active neighbours and friends who find it easy to engage in an activity can be described as a physical active, friendly neighbourhood (Ainsworth *et al*., 2007:29). Also, neighbourhoods in this study were safe from crime, walking distance from recreation facilities and free from stray dogs, which is seen as an enabling factor for physical active leisure time (Ainsworth *et al*., 2007:30). Thus, it is clear that one's circumstances may influence their choice of leisure.

In conclusion, the literature reveals that active and passive leisure holds benefits to people, however concerns regarding passive leisure may arise (Ainsworth *et al*., 2007:24; Anon, s.a.:44; Kiernozek, 2015:37; Sonnentag, 2001:199, 205; Williams, 2013:7, 16). Passive leisure seems to be the more common form of leisure to be pursued, especially by women (Ainsworth, 2007:28; Hickerson & Beggs, 2007), due to limitations of circumstances and recourses (Kiernozek, 2015:37, 42, 44, 52). Furthermore, findings revealed that parents/caregivers experienced many challenges to participate in leisure, especially active leisure, due to limited finances, limited respite care, and physical limitations of the children with disabilities (Bedini & Guinan, 1996b:280, 282; Kiernozek, 2015:37). As a result, it may be that many caregivers do not only choose passive activities because of the personal benefits it provides, but also due to these challenges they face. Hence, to emphasize the importance of leisure for caregivers, it is necessary to explore the benefits that leisure may offer to caregivers.

2.2.4 Benefits of leisure

Internationally, leisure is something that is more and more sought after (Coles *et al.,* 2012:684). If someone is asked why they work hard, they will respond that they do so regularly to gain leisure as a way of life enrichment, especially their wellbeing and health (Coles *et al.,* 2012:684). In other words, people seek the benefits that can be derived from leisure participation (Edginton *et al.,* 2004:14). According to Coles *et al.* (2012:684), Cosgriff, (2011:58), as well as OECD (2009:20), they do so in order to often find satisfaction, happiness (Edginton *et al.,* 2004:15), and joy in their lives (Caldwell & Witt, 2011:22). Furthermore, Stumbo and Peterson (2004:6) state that there are several benefits of leisure participation relating to health and wellbeing that can be separated into three categories of human functions: (a) social, (b) physical, (c) and psychological.

2.2.4.1 Physical Benefits

When participating in leisure, physical activity plays an important role in sustaining the well-being and physical health of individuals (Stumbo & Peterson, 2004:6). Physical activity also include physical development which includes physical fitness that leads to higher levels of energy and strength, improved coordination and balance, as well as self-worth and self-image (Cosgriff, 2011:57; Crombie *et al.* 2004:287; Driver & Burns, 1999:352; New Zealand, 2010:92). Rose and Williams (2015:61) mention in their article that for one of their research participants, a nurse, physical active leisure was her way to be alone, let go of worries, and to renew. This helped her to be energetic, productive, refreshed, and efficient at work (Rose & Williams, 2015:61). Her physical active leisure lifestyle also encouraged other nurses to participate in some form of physically active leisure which helped them lose weight, increased work attendance, made them feel better in general, and their work performance also increased (Rose & Williams, 2015:62). Expanding on that, physical activity during leisure may contribute to decreased fatigue, cardiovascular benefits (like decreased risk of coronary heart disease), improved responsiveness to health, and enhanced modifications of lifestyle for better health, like reduced tobacco and alcohol use (Driver and Burns, 1999:352; Rose & Williams, 2015:62; Stumbo & Peterson, 2004:7). It may also improve self-efficacy, perceived freedom, social support and intrinsic motivation (Stumbo & Peterson, 2004:8). For example, nurses started to share stories about weekend adventure activities, do yoga over breaks, and go for walks over the lunch hour (Rose & Williams, 2015:62).

2.2.4.2 Psychological benefits

Leisure participation is often used more for the psychological benefits it provides than for its social or physical benefits (Stumbo & Peterson, 2004:9). Accordingly, Henwood *et al*. (2012:1751), agree by mentioning, in their study on nurses, that it is well known that exercise and physical activity benefits one's emotional and psychological health. In the above-mentioned study nurses' wellbeing increased when they had more than 30 minutes per day of leisure-time activity (Henwood *et al*., 2012:1751). Moreover, Rohrer *et al.* (2005:439-440) explain how people often pursue a balanced life style to encourage good mental health. Participation in leisure activities helps individuals to engage in new or creative activities (Creek, 2008:300; Stumbo & Peterson, 2004:9; Whiting & Hannam, 2015:373, 381), to relax, cope with, or release stress, and associate with other individuals (Stumbo & Peterson, 2004:9-10). This may have healing or therapeutic outcomes, and in turn contribute to mental health (Driver & Burns, 1999:352; Iwasaki & Mannell, 2000:164; Iwasaki, *et al*., 2005:90; Trenberth, 2005:1-2).

Through leisure, individuals also have several opportunities to make their own choices and take responsibility for new experiences and new identities (Driver & Burns, 1999:352; Stumbo & Peterson, 2004:10). Therefore, people can change their self-perception of their abilities through leisure because they can control their experiences (Stumbo & Peterson, 2004:10). Furthermore, leisure activities might provide opportunities for self-expression (Roberson, 2005:209; Whiting & Hannam, 2015:381), and help individuals to define their sense of self-worth and identity (Edginton, 2012:2; Son *et al*., 2007:92). This is often done by selecting specific recreation activities which serve to furnish the identity images associated with the activity (Stumbo & Peterson, 2004:10).

Leisure involvement may also protect people from stress, which helps individuals to cope better with the demands and circumstances of daily life (Brattain, 1997:240; Coleman & Iso-Ahola, 1993:114; Iwasaki & Mannell, 2000:165, 167; Rodriguez & Gamble, 2010:50-51; Stumbo & Peterson, 2004:10). This was found to be true in different studies, where leisure assisted caregivers to cope with the stresses of their caregiving role (Dupuis & Smale, 2000:309; Gahagan *et al*., 2007:54; Schryer *et al*., 2016:19). Moreover, Duipuis and Smale (2000:309, 333-334) argue in their study of informal caregivers that leisure pursuits help caregivers to cope with continued weakening of their relatives in their care, as well as to maintain their individual identities. In their study, some caregivers did not make time for leisure (Dupuis & Smale, 2000:309). However, those who did, reported that leisure recharged or energised them for their responsibilities as a caregiver (Dupuis & Smale, 2000:309). Research of Gahagan *et al*. (2007:50, 54) mention how leisure provides a personal sense of escape or relaxation, fulfilment, and enjoyment to a diversity of unpaid caregivers ranging from caregivers of different ethnicity, socioeconomic status, rural/urban status and type of caregiving.

Leisure can also be a spiritual or aesthetic experience (Driver & Burns, 1999:352; Heintzman & Mannell, 2003:207,208; Richards, 2001:70). For example; when someone is experiencing the magnificence of nature, it can foster feelings of humility, admiration, connectedness, and beauty (Cosgriff, 2011:57; Driver & Burns, 1999:352; Heintzman & Mannell, 2003:208; Priest & Gass, 2005:13; Richards, 2001:70). It might also cause individuals to relive or recall pleasurable experiences (Mackellar, 2009:94), as well as reducing tension and confusion (sensory overload) (Thayer *et al.*, 1994:921).

One of the main benefits that leisure also provide is that individuals experience a sense of achievement or mastery (Shannon, 2014:148; Caldwell & Witt, 2011:19). For example, when a person learns a new skill, makes a new friend, or takes part in sport or an exercise program it nurtures pride in them which increase self-confidence and self-esteem and they feel like they achieved something (Tiggemann, 2001:139). Also, Stumbo and Peterson (2004:10) explains that if people experience the same life stressors, the one with more significant leisure companionship will be able to adapt to and cope with life stress easier.

2.2.4.3 Social benefits

According to Stumbo and Peterson (2004:12), leisure is important for the interplay of social exchanges and the development of social skills. Leisure might also provide opportunities for social bonding where individuals can interact with one another by meeting new people and network with them, supporting and bonding with family and building stronger bonds with friends and other contacts (Caldwell & Witt, 2011:21-22; Dodd *et al.*, 2009:264; Driver & Burns, 1999:352; Freeman *et al.,* 2006:206; Patterson & Pegg, 2009:397; Poff *et al.*, 2010:367; Shaw & Dawson, 2001:223; Ministry of social development New Zealand, 2010:92; 2012:92; OECD, 2009:20). For example, a study of Dupuis (2000:267-268) revealed how daughters providing secondary care to their parents visited their parents at the care facility to bond with their parents and family members which gave them a sense of joy. Nonetheless, research shows that social ties as a form of leisure, even in a paid work context, alleviate emotional and physical stress caused by caregiving responsibilities (Gahagan *et al.*, 2007:55).

Furthermore, the research found that leisure participation may provide people with companionship, which creates the perception that they will have social support during a serious life crisis; and that certain types of leisure may foster self-determination (Coleman & Iso-Ahola, 1993:114; Rodriguez & Gamble, 2010:60). Leisure might also help reduce or overcome loneliness and social isolation, provide settings more relaxed for social interaction (Stumbo & Peterson, 2004:13), and contribute to one's spiritual life (Caldwell & Smith, 1988:46-47; McLean & Hurd, 2015:94). For example, caregivers in the study of Gahagan *et al*. (2007:59) revealed that their spirituality (a form of self-defined leisure) gave them a sense of comfort and a better understanding of themselves. Moreover, caregivers reported how stressors and negative health effects that is associated with caregiving where mediated through the support from others which provided spiritual connections with their communities (Gahagan *et al*., 2007:58-59). Caregivers also experienced positive outcomes through self-defined leisure such as a heightened sense of spirituality, personal enjoyment, and relaxation (Gahagan *et al*., 2007:59). However, Gahagan *et al*. (2007:59) argue that access to leisure may be difficult due to the responsibilities of caregiving, which on the other hand, may not have such positive effect.

Through leisure, someone can also have the chance to clarify and examine their values (Caldwell & Witt, 2011:19; Shaw & Dawson, 2001:222, 225), perspectives, and beliefs. Caldwell and Witt (2011:21) explain that this may enable someone to see new thinking patterns, different ways to interact with others and new ways to approach problems. Lastly, in the study of Dupuis and Smale (2000:308) caregivers stated that leisure offered them rewarding relationships with other people, on improved sense of accomplishment and self-confidence, assisted them with staying healthy, and helped them to restore physically. In the context of this study and with the hopes to satisfy the leisure needs of caregivers to derive the benefits from leisure, it is important to know and understand what hinders or constraints them to participate or have satisfied leisure experiences.

2.2.5 Leisure constraints

According to Bedini (2002:28) caregivers often reduce or cease their leisure, even though they find leisure important in their lives and critical for their health. Also, most caregivers have similar leisure interests, but their ability to fulfil these interests differ (Bedini & Guinan, 1996:230). Moreover, Bedini and Guinan (1996a:227) mentioned that a growing number of the population of informal caregivers lack perceived entitlement to leisure. For that reason, it is important to understand the possible reasons why caregivers fail to participate in leisure activities, but also how to avoid the constraints that are preventing them from participating.

Constraints can be defined as those elements that limit someone from participating in leisure activities (Bulent *et al*., 2010:362), to enjoy their current leisure activities, or to use leisure services, such as programs and parks (Scott, 2005:280). Moreover, it's important to know that constraints are negotiable, and not a static, impossible obstacle to the enjoyment and participation of leisure (Burns & Greafe, 2007:158; Hutchinson & Kleiber, 2005:144; Jackson, 2005:115; Scott, 2005:280). According to Jackson (1999:196) and Samdahl (2007:409) this means that when people are motivated to engage in a specific leisure activity they tend to reach their goals for leisure by using a variety of approaches to negotiating around their constraints, even though their leisure may differ from what it would have been if the constraints had not been there. The term constraints must, however, not be confused with the term barriers, since barriers are insurmountable (leading to nonparticipation) and constraints are not (Scott, 2005:280; Tu, 1993:43). Leisure constraints can be further explained by the three main types of constrains, namely intrapersonal constraints, interpersonal constraints, and structural constraints.

Intrapersonal constraints are factors internal to a person, a psychological condition, that limits someone's activity preference such as attitudes, shyness, perceived lack of skill and ability (Stanis *et al*., 2010:274), personality factors, and more momentary conditions, for instance mood (Chick & Dong, 2003:338; Jackson & Scott, 1999:307; Palen *et al*., 2010:436; Scott, 2005:281; Son *et al*., 2008:199; Stuart *et al*., 2005:301). Interpersonal constraints result due to social interaction with other people including co-workers, family, neighbours and friends (Chick & Dong, 2003:317; Hawkins *et al*., 1999:180; Scott, 2005:281), where one might be constrained by family obligation, lack of partners, friends and/or family who prefer different activities, or conflicting schedules (Jackson & Scott, 1999:308; Son *et al*., 2008:199; Stanis *et al*., 2010:274; Stuart *et al*., 2005:301). Structural constraints are external conditions (environmental circumstances) which involve factors such as the unaffordable price of activities, absence of opportunities, time limitations, lack of transport, or inconvenient facilities (Chick & Dong, 2003:317; Hutchinson & Kleiber, 2005:139; Son *et al*., 2008:199; Stanis *et al*., 2010:274). It can also be described as factors that interfere between actual activity participation and the preferences someone already has for leisure (Hawkins *et al*., 1999:180; Shaw & Henderson, 2005:24; Jackson & Scott, 1999:307; Scott, 2005:281). When considering the constraints of leisure, it may cause people to experience many needs and therefore, it is necessary to take a closer look at the Post Hoc satisfaction approach of Mannel (1999:238) focusing on need satisfaction. The "Post Hoc Satisfaction Approach" will be applied to this study to see leisure from the caregiver's perspective (Mannell, 1999:238).

2.2.6 Post Hoc satisfaction approach

Leisure satisfaction can be defined as "the degree to which one is presently content or pleased with his/her general leisure experiences and situations" (Tu, 1993:37-38). The Post Hoc Satisfaction approach focuses on determining how satisfied a person is with his/her leisure after participating in it. It exists of two constructs, namely needs satisfaction and appraisal satisfaction (Mannell, 1999:238). According to Mannell (1999:239) the *appraisal satisfaction* approach helps to assess people's quality of leisure by letting them evaluate it through various forms of scales and or rating their satisfaction with their leisure style. Furthermore, this approach evaluates the quality of leisure by how often people participate in leisure (Mannell, 1999:238). In contrast, the *need satisfaction approach* is focused more on motivations to leisure which includes psychological outcomes and benefits, preferences, and experience expectations to leisure (Mannell, 1999:242), and it will be used as a tool on the findings of this study. Need satisfaction is also concerned with what arouses, activates, or energises leisure behaviour, thus, the forces in people that drive them to get involved with particular behaviours (to act) (Guha, 2009:12; Mannell, 1999:242). Also, Mannell (1999:242) explains that people are attracted to specific leisure activities instead of others because of the interest they have in the characteristics of leisure settings and leisure activities. Thus, people will not have similar need satisfying properties due to different activities, experiences and settings (including early socialization experiences and parental support, or lack of it) and, therefore, people will experience the attractiveness of an activity and how well it satisfies their needs differently (Iso-Ahola, 1999:48; Mannell, 1999:242; Ryan *et al.,* 2009:110). Iso-Ahola (1999:46) supports Mannell's theory by explaining that the activities that motivate a person may fluctuate due to social and personal factors. However, motivational tendencies remain somewhat unchanged (Iso-Ahola, 1999:46). Furthermore, from a history of people engaging in recreation participation and therefore undergoing a socialisation process, Mannell (1999:242) came to the knowledge that when specific needs of people are aroused, these needs can be satisfied through specific engagements with recreation.

Mannell (1999:143) also refers to a motivational model to explain the process of satisfying a need. Firstly, a need emerges which leads to a disequilibrium (desire, or lack of something) within a person, which in turn they will attempt to lessen (Cordes, 2013:4; Fodness, 1994:555; Guha, 2009:19, 22, 28; Mannell, 1999:243). When a need like that is present, people believe that the disequilibrium (tension) will be reduced by a certain action (Cordes, 2013:4; Fodness, 1994:555; Guha, 2009:22, 28; Mannell, 1999:243). In other words, when there is a disequilibrium people reduce this internal state by acting or behaving in certain ways that they believe will lead to satisfaction. For example, if a caregiver needs to relax and revive she might act on this need by taking a walk in the park. When participation in this activity fulfils their specific need, this satisfying experience is interpreted as positive, and that reassures an individual that the activity or behaviour is appropriate to satisfy that specific need (Mannell, 1999:243). On the other hand, if this behaviour results in negative feedback, people will terminate or modify their behaviour or activity (Mannell, 1999:243). Reasons for terminating or modifying behaviour may also be because the person does not feel capable of carrying out the activity due to possible lack of skills or necessary knowledge to do it, because the desired outcome and the action has no connection with the person, or because the person chooses not to act (Ryan *et al*., 2009:114). For instance, several studies reveal that caregivers reduce leisure participation due to the demands and responsibilities they face (Bedini, 2002:2; Bedini & Guinan, 1996b:274; Coetzee, 2007:41; Dun & Strain, 2001:49; King *et al*., 2000:27). This might be because of inadequate attention to other responsibilities if they do participate in leisure activities (act on their need), for instance, caregiving duties, or family responsibilities, and therefore they would rather reduce or terminate their activity (Dun & Strain, 2001:49).

Lastly, the need satisfaction approach has been successfully used many times by leisure service practitioners for planning programmes, support, and services for the needs of people they work with (Mannell, 1999:145). However, this construct also has limitations (Mannell, 1999:145). For instance, a person may have a lot of desires, expectations, and needs at a given time, but they change over time and may also be in conflict with each other. Due to the changing and conflicting nature of a person's specific set of motives, it is particularly difficult to measure and observe them (Mannell, 1999:146). Also, researchers experience difficulty when people seek a variety of satisfactions in one activity, for example a person may choose to pursue exercise activities for identified regulation (like running for health benefits) as well as intrinsic reasons (like finding it inherently enjoyable) at the same time (Mannell, 1999:146; Ryan *et al*., 2009:113; Schneider & Kwan, 2013:776; Williams *et al*., 2014:154). On the other hand, people may experience similar satisfaction through different activities (Mannell, 1999:146). However, for this study, the need satisfaction approach will serve its purpose well. This approach will be further explained and incorporated in the following chapters of this study. It will be used as a structure and guideline to explore the leisure needs of the caregivers in this study and also the reasons why they participate or do not participate.

2.3 Caregiving

2.3.1 Introduction (Definition of caregiving)

According to Greenlee and Scharlach (2001:7) caregiving is a term that includes a variety of situations and experiences. It can be understood as caring for someone in an institutional setting, in the care recipient's home, or in the caregiver's home (Greenlee & Scharlach, 2001:7). It can include providing care to the physical health, or emotional well-being of an individual that is bedridden or have mental or physical limitations (Greenlee & Scharlach, 2001:7; Lucchetti *et al.,* 2014:404). In addition, Uren (2009:1) explains that caregiving is mainly the holistic care of a person that is ill. Furthermore, it can also be caring for a person with a physical disability and/ or chronic illness over the long term, or it can be providing care for someone with an acute illness or an acute episode of an illness on an irregular base (Greenlee & Scharlach, 2001:7).

The above-mentioned research of Greenlee and Scharlach is based on informal caregiving, however it might also be true for formal caregiving. Therefore, to get a clear understanding of the different forms of caregiving, formal and informal caregiving will be discussed. Accordingly, Uren (2009:2) explains that what makes formal and informal caregiving most different from each other is the relationship between client and caregiver as well as the principles regarding the relationship, especially when it comes to the professional sphere.

2.3.1.1 Formal and informal caregiving

In a study of Uren (2009:1), focusing on the emotional experiences of formal caregivers in palliative care, he explains that formal caregiving may involve an area where individuals in various professions are trained to provide diverse services that range from support to medical treatment. This may also include professionals that provide patients with health service by giving direct care on a day-to-day basis (Lucchetti *et al*., 2014:404). Furthermore, Uren (2009:11) states that caregiving is a form of work, which is regarded as obligatory, in other words, responsibilities should be performed as commitments to work. Moreover, formal caregiving is usually a career that an individual chooses to pursue and therefore the contexts, processes, and concepts of caring will be different from informal caring (Uren, 2009:11). It is something that requires formal skills and knowledge and does not rely on the basic characteristics of care (Uren, 2009:11, 59, 65). Uren (2009:14) also reveals that the formal relationship has multiple dimensions to consider, including the relationship that is nurtured between patient and caregiver, the relationship between caregivers and their workplace position, and the relationship as a whole with other caregivers and the community. Williams and Crooks (2008:244), Du Preez (2010:8) and Escandon (2013:821) go further by explaining that formal caregiving involves paid care provided by practitioners such as social workers or home care workers who have formal training or a degree such as nursing. However, it may not always be the case, for instance in the context of Lucchetti *et al*. (2014:404) study, licensed nurses supervised formal caregivers, and these formal caregivers helped residents from long-term facilities to be connected with the outside world and they were also the first to be in contact with the residents.

Informal caregiving, on the other hand, differs from formal caregiving in several ways (Riana *et al*., 2004:2). Informal caregivers provide unpaid care to a chronically ill or disabled loved one and can be a family member, parent, relative or neighbour, but mostly an immediate family member, like a child or spouse (Bedini, 2002:25; Buchanan *et al.*, 2009:1244; Carter & Golant, 1994:3-4; Du Preez, 2010:8; Escandon, 2013:821; Gladwell & Bedini, 2004:686; Peckham, 2009:34; Peckham *et al*., 2014:123; Schultz & Martire, 2004:240; Uren, 2009:58). According to Riana *et al.* (2004:2), informal caregivers do not have all the prerogatives, rights, and privileges that formal caregivers mostly have and society do not usually recognise this work (informal care) as a pursuit that is worthwhile. Furthermore, informal caregiving also differs from the formal career in that any form of progression taking place is driven by the condition of the patient and the functional needs it creates, and not by ambition (Riana *et al.*, 2004:2). Thus, the informal caregiver does not choose to become one, but circumstances have forced them to become a caregiver. Furthermore, Riana *et al.* (2004:2) explain that informal caregiving is not like a formal caregiving career that you can enter and leave at own will but rather depend on the time it takes to care for the care receiver and if the disability is curable or permanent. It might be that informal caregivers in many cases would have to take care of the care receiver until the person goes to a formal care facility or until the person passes away (Peckham *et al*., 2014:132), or until someone else takes over the primary caring role.

Nevertheless, it appears that expectancies about the role of formal caregivers differ from context to context. Findings from the study of Buscher *et al*. (2011:709-710) revealed that families expected formal services to be helpful in the following ways; getting the work done, to have someone at your side, to get a feeling of security, recognizing one’s efforts giving assertion, to be able to share the care experience with a person with knowledge, and to get recommendations and hints that are useful. These formal caregivers apply professional and personal skills to situations in in-home care and their everyday tasks are described as a process of “shaping different realities” to keep the person they provide care for at home (Buscher *et al*., 2011:710).

From the latter literature, it is evident that formal caregiving has specific characteristics that set it apart from informal caregiving, but their services and roles may vary in many ways. For instance, some formal caregivers do caregiving for residents in long-term caring facilities (a more formal role) (Lucchetti *et al.,* 2014:404), whereas other formal caregivers do home care services which may vary between personal preference of the (family) and more strict care packages (Buscher *et al.,* 2011:710; Peckham *et al.*, 2014:132). Furthermore, it is not always evident if these formal caregivers act as a primary or secondary caregiver of the care receiver since some of them, depending on the formal caregiver’s relationship with the family and/or care receiver, may spend an equal amount of time with the care receiver. Also, not all formal caregivers work in a home care context, and not all informal caregivers stay with the care receiver. Therefore, the roles might differ significantly depending on the context and agreements between the care receivers and caregivers. Since the participants from this study are mostly primary caregivers, it is important to discuss the difference between primary and secondary caregivers. This will give a better understanding of what their role entails and how it may influence their leisure time.

2.3.1.2 Primary and secondary caregiving

The primary caregiver is someone who offers the most assistance and support to the individual with a disability (Blanes *et al*., 2007:400). It is also the principal person responsible for caring for an ill person, whereas secondary caregivers are normally family members, neighbours or friends that provide support to the primary caregivers or undertake caregiving tasks with no payment (Barbosa *et al*., 2011:491). Furthermore, research revealed that primary caregivers are the ones responsible for getting professional help when necessary (Barbosa *et al*., 2011:497). According to Barbosa *et al*. (2011:497) the caring tasks of primary caregivers might be too strenuous, which makes professional care very useful. Barbosa *et al*. (2011:497) also mention that secondary caregivers are not as much involved in giving care, while the provision of assistance in activities is less and for shorter periods of time compared to primary caregivers and for that reason they might be less aware of progression on the care receiver's disease. Furthermore, it is important to bear in mind that the caregivers in the study of Barbosa *et al*. (2011) were informal caregivers and that the role of a primary and secondary caregiver might slightly differ when he/she is a formal caregiver. However, the element that mainly defines the primary caregiver (the person that offer most assistance and the principal person responsible for caring for an ill person) and secondary caregiver (person, mostly family, that undertake some caregiving tasks and assists the primary caregiver) would mostly stay the same.

Since there are so many different contexts in which caregiving can take place at so many different levels, it would be difficult to describe a definite role and definition of primary and secondary caregivers as well as for formal and informal caregivers. Therefore, even though this study is focusing on primary formal caregivers, it is necessary to have a broad outlook on the many different roles and tasks that caregivers have to perform, keeping in mind that every primary caregiving context differs.

2.3.2 The caregiver role and disability

Within the caregiving field, individual caregivers have several and different roles (Uren, 2009:14). Accordingly, From (2011:22) explains that different formal caregivers caring for older people have different roles and their views about relation to their work also differs. Furthermore, research indicates that as the need for care of care recipients and the caregivers' role expectations change, caregiving activities will also change over time (Greenlee & Scharlach, 2001:29). Caregiving activities involve spending a significant amount of money, energy and time over long time periods, while caregivers' tasks may also be uncomfortable and unpleasant as well as physically exhausting and psychologically stressful (Schulz & Martire, 2004:240; Axelsson, 2015:206, 208). This is supported by Shaddock *et al*. (1998:315) who found that residential workers providing services for people with intellectual disabilities experienced caregiving as a demanding job that is performed under difficult conditions. However, this might differ from caregiver to caregiver as well as the context they find themselves in.

Moreover, this study mainly focuses on formal caregiving. Thus, the following literature will be focusing mostly on the roles of caregivers in the formal sector, however roles of informal caregivers may also be incorporated since the tasks and roles of formal and informal caregivers may overlap. Thus, the role description of the formal caregiver may include the tasks of an informal caregiver and vice versa. To understand the nature of caregivers' roles and how it may have an influence on caregivers' leisure it is important to have a closer look on this matter.

Several studies indicate that caregivers' roles include responsibilities such as patient and family advocacy, administrative duties, and monitoring (Kaasalainen *et al*., 2013:479; Klassen *et al*., 2012:74; Morrison & Korol, 2014:3471). Patient advocacy involves protecting and supporting the well-being, safety, health and rights of vulnerable patients including to counsel, support, or educate the patients and their family, and also to give advice and consult with other health-care providers about plans for treatment or the condition of the patient (Kaasalainen *et al*., 2013:484; Klassen *et al*., 2012:74; Morrison & Korol, 2014:3471-3472;). This includes physical care such as attending to wounds, assisting patients with personal hygiene and administering their medication (managing symptoms), however their role is not limited to only these tasks, but also to the patients' sexual, bio-psycho-social, and spiritual needs (Hanass-Hancock & Casale, 2014:355; Kaasalainen *et al*., 2013:484; Klassen *et al*., 2012:74; Morrison & Korol, 2014:3472). Furthermore, it involves treating patients according to what they can or are not able to understand, however, being an advocate for a patient also increased criticism from doctors, family, colleagues and management due to different opinions on what the best might be to the client (Morrison & Korol, 2014:3472). Monitoring involves checking up on the status of the patient on a continuous basis, which enables them to recognise subtle changes in the condition of the patient (Morrison & Korol, 2014:3472). This monitoring role means that caregivers constantly have to check vital signs or monitor treatment side effects (Klassen *et al*., 2012:74), monitor doctors' orders (making sure if something is safe or not), observe how the patients are doing (i.e. psychologically), and also checking themselves to make sure they cope under circumstances (Morrison & Korol, 2014:3472). Thus, their job can be very unpredictable since a medical or non-medical emergency may occur at any time (Morrison & Korol, 2014:3469). Lastly, administrative duties include the charting of information and documentation of patients, which can require a great amount of mental energy due to the pressure of well-organised documentation, especially with more complex problems leading to added difficulty concerning documentation (Morrison & Korol, 2014:3472). According to Morrison and Korol (2014:3469) nurses' needs for emotional decompression and self-care increase because they are frequently exposed to human suffering, but these needs go unmet very frequently as their family and professional responsibilities increase.

Except for the formal and job-related roles that caregivers have to participate in, formal caregivers' role may also expect of them to provide a more informal and personal form of care. For instance, in a study of Wahl and Newmark (2009:297) formal caregivers at a facility for adults with intellectual disability were required to care for the clients when they were ill and to comfort them when they needed it, also to walk with them in the evening and take them to gym in the mornings before work, which was experienced by the caregivers as something good (walking were seen as a breakaway from the premise), since some of these caregivers stayed at the premises of the facility. It was understood that staying there gets to caregivers in a sense that they never get to switch off, their work hours and pressure are excessive, and it makes them feel like it is going to drive them to insanity (Wahl & Newmark, 2009:297). A caregiver's role is also more than just tasks, their roles include respect, being honest when performing tasks, concern, sensitivity, and having a mutual relationship with the care receiver (Axelsson, 2015:206, 209; Ford & Honnor, 2000:358; From, 2011:45). Similarly, a study on untrained formal caregivers caring for developmentally challenged children revealed that caregivers were committed to increasing the children's' physical, emotional and social well-being and as a result formed close bonds with the children (Du Preez, 2010:50-51). According to several studies on formal caregivers who performed a role as personal assistant for children with multiple disabilities, their roles involved: cooking, changing nappies and help with dressing, help with exercise, making sure the child is safe, giving medicine and perform care in any area the child needed it, and playing leisure activities for a sense of connectedness with the children (Axelsson, 2015:204, 206; Du Preez, 2010:47-48, 51). Caregivers from the study of Du Preez (2010:70) experienced their role as a caregiver as positive because of the deep level of connectedness and engagement with the children. However, they experienced communication barriers in their role as caregiver which made it very difficult to meet the children's needs (Du Preez, 2010:70). Also, a lack of recourses made it difficult for caregivers to perform their role (Du Preez, 2010:60).

On the other hand, caregivers from the study of Axelsson (2015:206, 208) experienced different difficulties since their responsibilities were more enfolding, these non-relative assistants (formal caregivers) had concerns regarding their roles and overstepping boundaries of the privacy of the families they worked for. It was also found that external assistants sometimes find it uncomfortable when families are experiencing very intimate moments (Axelsson, 2015:206, 208). Taking a closer look at their role, it involved helping with basic functions (interpret the child's signals, assist the child with communication (including being a spokesperson), help the child with physically control and body movements, support in their daily life, to support children with relationships (supporting the child to have relationship with others and to be part of his/her family), and also to support them with maturation, which include, assisting the child with engagement and to support the development of the child for instance building the child's self-esteem and getting the child to do practical things for him/herself (Axelsson, 2015:206).

In conclusion, it is clear that a caregiver's role can be very complex and also have different challenges. Depending on the client and role description, formal caregivers' roles may also have responsibilities that are similar to informal care, like in the studies of Axelsson (2015:206), Du Preez (2010:47,48,51), and Wahl and Newmark (2009:297) where caregivers formed close bonds or relationships with the care receiver due to playing a big role in the development of the care receiver. Furthermore, Riana *et al*. (2004:2) mentioned that formal caregivers normally choose to be a caregiver, whereas informal caregivers usually do not have a choice to be a caregiver. However, this might not always be that straightforward when looking at caregiving in a South African context. It might also be that caregivers' roles and the challenges that come with it might differ when compared with those of caregivers in other countries.

2.3.3 Caregiving and leisure in SA

Several studies regarding caregiving and disabilities in South Africa have been conducted (Baloyi *et al*., 2015; Bingham, 2017; Breen *et al*., 2007; Capri & Buckle, 2015; Chhagan, *et al.,* 2014; Gurayah, 2015; McKenzie & McConkey, 2016; Mudzi, 2010; Uren, 2009), however literature involving leisure of caregivers for persons with disabilities in South Africa is still limited. Also, the available literature focuses mostly on caregiving for people with HIV/AIDS and old age care (Akintola, 2008a; Akintola, 2008b; Demmer, 2006; Govender *et al*., 2012; Hanass-Hancock & Casale, 2014; Ogunmefun *et al*., 2011; Shobede, 2011; Simpson, 2006; Uren, 2009; Uren & Graham, 2012), whereas research on caregiving and disabilities remain limited. Nevertheless, available literature provide insight into caregiving, focusing on caregivers in general, and reveal needs and gaps where leisure can be incorporated for the benefit of caregivers in South Africa.

Research on caregiving from a South African context reveals that many caregivers who care for people with disabilities and HIV/AIDS experience challenges and, therefore, risk burnout and other negative experiences affecting their mental, physical and social wellbeing. (Akintola, 2008b:129; Baloyi *et al*., 2015:202; Hanass-Hancock & Casale, 2014:356, 360; Simpson, 2006:46). For example, a study of Mudzi (2010:40) reveals that caregivers find it difficult to get support making it possible for them to take breaks, which prevents them from opportunities to leave the house to attend to social events or parties. Other challenges include a lack of finance, lack of training, overwhelming responsibility to care for patients, and lack of resources, knowledge and education (Baloyi *et al*., 2015:199, 201; Bingham, 2017:178; Breen *et al.,* 2007:333, 332; Hancock & Casale, 2014:355; Mudzi, 2010:40, 109, 156, 159, 163). Nevertheless, Mudzi (2010:191, 193) and Gurayah (2015:198) explain that training and caregiver education will reduce caregiver stress and the risk of death since caregivers will be able to cope better with caregiving duties and care better for their care receiver.

In addition, challenges that cause burnout, may also include stigmatization among caregivers of patients with HIV/AIDS and disabilities (Akintola, 2008a:360; Capri & Buckle, 2015:174; Hanass-Hancock & Casale, 2014:355; McKenzie & McConkey, 2016:353; Ogunmefun *et al*., 2011:92,98). It may be that HIV/AIDS creates a stigma for the people who are disabled or infected with the illness and also for the caregivers associated with them, which might lead to them being isolated from friends or family due to the fear of getting infected if they get in contact with them, or due to distrust in people gossiping about them (Akintola, 2008a:360; Akintola, 2008b:134; Demmer, 2006:441, 443; Ogunmefun *et al*., 2011:92,98). Similarly, in the study of McKenzie and McConkey (2016:353) caregivers of persons with 'intellectual disability' experienced stigma in their community that discouraged them from participating in any leisure activities, and as a result, isolated them from society like staying away from church gatherings. Apart from stigmatization, caregivers also experience lack of safety and materials like gloves and bandages, lack of family support, financial hardship, rejection by patients (denying they are sick, ignorance to the illness), loss of a patient or loved one, work overload and work problems (competition, policy limitations, conflict among colleagues and exploitation) (Baloyi *et al*., 2015:201-202; Shobede, 2011:44-45). According to Shobede (2011:49-51), in a study of the perceptions of health and wellbeing among home-based caregivers who lived with their patients with HIV/AIDS, some caregivers used leisure activities to cope with their caregiving stress such as doing something for/by themselves, including doing domestic tasks, watching television, reading (Bible), listening to the radio, sleeping, taking a bath, spending time on their own, or talking to friends or family. Yet, caregivers in this study still experienced emotional burnout despite the coping techniques (Shobede, 2011:53). This may be due to some caregivers that are better trained than others (Shobede, 2011:53), and as a result, the caregivers with less training may experience more burnout.

Furthermore, Uren (2009:31) explains that healthcare services in disadvantaged areas in South Africa are under-resourced, limited, and very often overburdened. Despite no resources or funding, caregivers often make caregiving their livelihood as they have no other alternative since they need to provide for their family (Uren, 2009:32, 112-113). Also, employment opportunities in South Africa are limited, and there is a high demand for palliative care services which provides the opportunity for unemployed members of the community to be volunteers in the position of a full-time job, however, they only receive certain compensations and small payments that normally functions as stipends and not salaries (Uren, 2009:31; Uren & Graham, 2012:62). Consequently, some of them stay with the patient to take on the caring role due to cultural beliefs and limited finances and/or resources for formal care for the person with the disability, which brings more stress to their individual life, as well as on their work abilities (Akintola, 2008b:122, Breen *et al*., 2007;329, 332-333; Gurayah, 2015:196; Mudzi, 2010;1,2,3; Ogunmefun *et al*., 2011:98-99; Shobede, 2011:13; Simpson, 2006:46; Uren, 2009:32; Uren & Graham, 2012:68). Yet, in low-income countries, including South Africa, it is not known how many caregivers are prepared for the role of caregiving, and what the level of caregiver strain is they experience (Mudzi, 2010:3).

Additionally, literature makes it evident that, in South Africa and all over the world, it remains a challenge on how to utilise caregivers without them being overstrained (Mudzi, 2010:4). Therefore, it is so critical that more research on caregiving and leisure in South Africa should be conducted so that the caregivers' current circumstances (including burdens), as well as their leisure needs, could become known in order for different authorities to help enhance these circumstances. It also seems that many of these studies focusing on caregiving, disability and HIV/AIDS in South Africa are based on low income and low resourced areas (Akintola, 2008a; Akintola, 2008b; Baloyi *et al*., 2015; Bingham, 2017; Breen *et al*., 2007; Capri & Buckle, 2015; Chhagan, *et al.,* 2014; Demmer, 2006; Govender *et al*., 2012; Gurayah, 2015; Hanass-Hancock & Casale, 2014; McKenzie & McConkey, 2016; Mudzi, 2010; Ogunmefun *et al*., 2011; Shobede, 2011; Simpson, 2006; Uren, 2009; Uren & Graham, 2012), and less in high income areas. Therefore, more research on caregiving, disabilities and leisure should be conducted in both urban and rural areas in South Africa.

2.4 Leisure and caregiving

2.4.1 Caregiver burden and leisure needs

Rose and Williams (2015:61), as well as White (2008:97) state that these days formal caregivers face high workloads, heavy emotional stress, long hours, and staffing shortages as burdens. Furthermore, caregivers also face variable amounts of physical work depending on assistance and resources available (Geere *et al*., 2011:382; Rose & Williams, 2015:61). The heavy workload that caregivers face lead to health problems (Hung *et al*., 2002:103). Hence, caregiving creates demands that have negative consequences for the psychological and physical health of a caregiver, such as chronic stress, depression, sedentary behaviour, poor nutrition, exhaustion and burnout (Bakker *et al*., 2000;885, 888; Brehaut *et al*., 2014:183;

Vitaliano *et al*., 2003:947, 947,949). However, Nikzad-Terhune (2011:123, 124) explains that the physical health of a caregiver also depends on the severity of the condition of the care receiver. The following findings reveal a variety of different caregiving roles along with the burdens that each of these caregivers bare.

Thomas and Greenop (2008:31) explain that formal caregivers caring for, and staying with, people with disabilities (as a result of having a stroke) associated a sense of burden, loneliness, and depression, as forms of distress, with a negative adaptation to caregiving as a result of the caregiver's roles. These caregivers mentioned that they experienced physical difficulties like elevated levels of fatigue as a result of caregiving and that they get sick often (Thomas & Greenop, 2008:35). Some caregivers mentioned that they use antidepressants because they get lung infections from stress (Thomas & Greenop, 2008:35). They also experienced emotional distress like burnout; for example, one caregiver had a panic attack because he did not have enough emotional support (Thomas & Greenop, 2008:36). Moreover, financial strain was also a cause of stress, while anxiety and frustration emerged as psychological themes (Thomas & Greenop, 2008:36). In a study that focused on the burden of formal caregivers of people with dementia, agitation and aggression were also found to be associated with distress among formal caregivers (Song & Oh, 2014:351).

Additionally, informal caregivers caring for children with moderate-severe motor impairments reported spinal pain due to their caregiving activities (Geere *et al*., 2011:386, 390). These caregivers were from rural areas and they reported that carrying and transferring the children was some of the biggest causes of their pain, partly because of a lack of equipment like wheelchairs and callipers (Geere *et al*., 2011:386, 388). Furthermore, a study on informal caregivers of children with disabilities found that caregivers experienced a lot of stress because they felt that they lacked control over daily events, they had too little time to complete daily tasks, and had uncertainty about how well they meet the children's needs (Murphy *et al*., 2006:182). Some caregivers mentioned that the children's impulsive and occasional violent behaviours led to direct injuries and that their health suffered from it during later years (Murphy *et al*., 2006:183). They explained that their health was worsening because of their caregiver tasks and that it would jeopardize their ability to meet their children's long-term needs continuously. Consequently, many of them experienced anxiety, depression and guilt (Murphy *et al*., 2006:183). Furthermore, similar to the study of Geere *et al*., these caregivers also had to lift their children regularly, which in turn led to back and shoulder pain (Murphy *et al*., 2006:183). As a conclusion, it was also found that caregivers overlooked their personal chronic conditions (like chronic fatigue and sleep deprivation) and prioritised their own health very low to that of their children and family (Murphy *et al*., 2006:184).

Likewise, a woman caring for older adult family members also mentioned that helping others took priority over their own lives, though it compromised their leisure (Bedini & Guinan, 1996a:234). The same findings were also reported by formal caregivers who claim that they sacrificed their own health by dedicating their energy and time to aid the well-being and health of others (Rose & Williams, 2015:61). As a result, Bedini and Guinan (1996a:234) explain that by placing others' needs above their own, caregivers are not only restricted in their freedom to perform leisure tasks, but also their state of mind, and/or their cognitive and emotional perspectives. The study also found that caregivers appreciated and desired leisure in their lives, however barriers to accessing it were formed by their ethic of care (Bedini & Guinan, 1996a:234). Accordingly, Bedini and Guinan (1996a:235) noted that ethic of care was an underlying power that influenced the perception of caregivers' situational demands, apparent entitlement to leisure, responsibilities of caregiving, and perceived leisure benefits. Some caregivers suppressed their desire for leisure, some expressed frustration and disappointment due to their inability to access leisure satisfactorily, others included their care receivers in their pursuits of their leisure, and lastly there were caregivers who found ways to access leisure because they felt like it was important for them in fulfilling their caregiver role (Bedini & Guinan, 1996a:234).

Moreover, Geere *et al*. (2011:389) found that some caregivers denied negative impacts on their health and that caregiving made them feel good. Similarly, in a study by Dupuis and Smale (2000:335) one caregiver stated that she does not see caregiving as work, but rather as something she enjoys as leisure. She also mentioned that it was also a way of returning what her mother gave to her all her life (Dupuis & Smale, 2000:335). Therefore, Dupuis and Smale (2000:335) conclude that a caregiving career can be experienced as positive or negative, pleasurable and painful, satisfying and difficult, depending on the circumstances at a certain time. Keeping the different caregiving experiences in mind, it's important to know that the roles of formal and informal caregivers, as well as their forms of support, might differ in different social contexts and also change over time (Sing Nam, 2004:36). Hence, it might be that these different caregiver roles, experiences, and social contexts could also have an influence on the leisure of caregivers, and also lead to different leisure experiences and health outcomes. Besides, formal caregivers of a primary home care centre reported lower perceived time for leisure due to more hours dedicated to caring per day, and also care for patients who are more functionally impaired (Losada *et al*., 2010:349). Consequently, it was explained that caregivers with less leisure time had less perceived social support, higher burden and lower mental health (Losada *et al*., 2010:349). For this reason, addressing the caregivers' needs are important in preventing a reduction in caregivers' health (Hung *et al.*, 2002:103)

For caregivers to keep healthy, Rose and Williams (2015:61) explain that it is important for caregivers to have a good balance between their work and personal lives by incorporating leisure activities and realising the health benefits leisure provides. However, the physical demands of a caregiver's work reduce the desire to engage in leisure (Rose & Williams, 2015:61). Research also indicates that nurses who are physically active at work, but do not participate in physically active leisure away from work, tend to be more depressed, anxious, and in general not well (Henwood *et al*., 2012:1751; Rose & Williams, 2015:61). Therefore, leisure remains important for the overall health and wellbeing of caregivers (Rose & Williams, 2015:61). Leverson *et al*. (2012:1596-1597) conclude that leisure activities have proved to be beneficial for the wellbeing of an individual when their leisure needs are satisfied.

Furthermore, Aslan *et al*. (2006:2) conclude that if the social, psychological, physical, and emotional needs of caregivers are well met and defined they may feel more comfortable to carry out their roles effectively and constantly. Accordingly, Lee *et al*. (2015b:142) also mention that responding to caregivers' needs are important because it may ensure and improve their working standards and in turn improve their quality of care. Hence, it should be a priority to meet and define the needs of caregivers (Aslan *et al*., 2006:2). Dekker *et al.* (2014:66), describes a need as an "inherently dynamic factor developing over time and triggering activity participation". For example, an individual will possibly be driven to decide to visit the gym, relax on the sofa, or take a walk when the need for physical exercise is present or absent (Dekker *et al.*, 2014:66). A need can also be defined as a state of deprivation coming from the instinctive biological characteristics that human beings have (Fourie, 2006:30). Rossman (1995:137) explains that the need for leisure is therefore inherent to the human nature and that it does not have to be created by programmers through any form of techniques. However, in the study of Rose and Williams (2015:61) tired and stressed nurses only wanted to sleep, do nothing and rest to prepare for work, which seem to grow into their centre of existence while leisure participation was almost unthinkable. But, these nurses started to avoid a lifestyle without leisure and started to spend more time away from work (Rose & Williams, 2015:61). One nurse responded that she likes to go running, and that it was her way to be alone, to let her concerns and worries go, to renew and detach from work problems, which helped her to be refreshed at work, to be productive, energetic, and effective (Rose & Williams, 2015:61). Other caregivers responded to their needs by cycling, going for walks over the lunch hour, yoga during the break, and rafting and hiking on weekends (Rose & Williams, 2015:61). Similarly, Barbosa *et al.* (2011:492, 497) found that caregivers who care for dependent elderly persons used strategies such as walking, swimming or other physical exercise to get rid of excess energy, although this was more common among secondary caregivers as to primary caregivers since secondary caregivers do not have principal responsibility for the person being cared for. Barbosa *et al.* (2011:491) state that secondary caregivers were less burdened and distressed than primary caregivers, and therefore, differences will emerge for effectiveness and use of coping strategies between the two groups. Therefore, it is also important to develop relaxation and exercise interventions for primary caregivers that will make it possible for them to engage in these activities at their own homes (Barbosa *et al*., 2011:497).

Contrary to the findings of Barbosa *et al.* (2011), hospice caregivers in South Africa as well as caregivers in a study of informal caregivers used music to help them get relief from stress (Kiernozek, 2015:39; Repar & Reid, 2014:951). Caregivers from the study of Repar and Reid, (2014:951) explained they could not help someone if they have stress and that they use music and therapy to release stress before they go to work. Caregivers would also compose songs and sing to have fun, it inspires them and makes them feel better. Other activities that seemed to encourage intuitive thinking were arts (Repar & Reid, 2014:953). According to the caregivers, artwork gave them different ways of seeing and being in situations that are complex, which allow new things that may not have been considered before to happen (Repar & Reid, 2014:953). They also mention it can help people to come up with new ways to work, find new solutions to and perspectives on old problems, and inspiration even if things may seem difficult (Repar & Reid, 2014:953). Nevertheless, Repar and Reid, (2014:953) explains that under conditions where there are limited resources in Africa, the approach of creative arts is just as effective as in different parts over the world. Lastly, in a different study done by Korpela and Kinnunen (2010:10), working people had the need for recovery from work stress. Findings revealed that exercise, relaxation, and being outdoors (an off-the-job time activity) in nature during free time was effective activities for recovery from work demands (Korpela & Kinnunen, 2010:11).

Although it is evident that formal caregivers, who participate in leisure outside of working conditions on a regular base, will benefit tremendously from it (Rose & Williams, 2015:61), Bedini and Gladwell (2014:132, 133) explain that leisure participation does not necessarily reduce stress or meet caregivers' needs. They found that leisure experiences will only be effective in stress reduction and increasing health and quality of life if they are fulfilling and meaningful for the caregivers (Bedini & Gladwell, 2014:133). Accordingly, caregivers have to be satisfied with the quality of a leisure experience as well as the time for leisure to gain the positive effects from it (Bedini & Gladwell, 2014:132). It was found that family caregivers (informal caregivers) experienced perceived stress and reported that they were only satisfied with their actual quality of life to some extent (Bedini & Gladwell, 2014:132). In order to, enhance the leisure experiences and opportunities for caregivers to gain the benefits that leisure may hold, it is important to identify the constraints that may prevent them from it.

2.4.2 Leisure constraints of caregivers

Although leisure constraints have been well researched and represent a specific field of study, limited research has been done on the leisure constraints within a caregiving context. The following discussion will focus on available literature regarding leisure constraints and how it relates to caregivers.

In a study on the leisure experiences and perceptions of informal caregivers of older adults, caregivers experienced several internal constraints (which in this case referred to intrapersonal constraints namely emotional and physical fatigue, and perceived responsibility for the care of recipients' wellbeing and care), and external constraints (which included structural constraints such as a lack of time, financial strain, and lack of help from outside) (Bedini & Guinan, 1996b:281-282, 284). This caused caregivers to experience lack of health and to be so tired that they "don't feel like doing anything" (Bedini & Guinan, 1996b:280-281). From this study it was found that caregivers were interested in leisure and had an appreciation for the benefits and value of leisure but as a result of their caregiving responsibilities their leisure were hampered by internal and external constraints (Bedini & Guinan, 1996b:284).

Dupuis and Smale (2000:330), in a study of leisure meanings in an institution-based caregiving context, found similar results to that of Bedini and Guinam (1996b). In an institution-based caregiving context, the women experienced caregiving as a constriction to leisure opportunities that might have negative implications to the leisure experience itself (Dupuis & Smale, 2000:330). Informal caregivers (who were the daughters of the care receivers) in this study experienced a perceived sense of responsibility to care (intrapersonal constraint), and access to free time (structural constraint) as some of the major constraints to their leisure (Dupuis & Smale, 2000:306, 331). However, in contrast to the study of Bedini and Guinan (1996b), the caregivers in this study were only daughters of the care receivers, not spouses, and were not living with their care receivers (Dupuis & Smale, 2000:331). Accordingly, Dupuis and Smale (2000:331) explain that the impact of the caregivers' roles on leisure might be described in more negative ways if the caregiver would have had to live with the care receiver (Dupuis & Smale, 2000:331).

Conversely, findings by Bedini and Guinan (1996a:232) revealed that some caregivers were able to negotiate constraints of time, responsibilities and energy, but their motivation to pursue leisure was not mainly for the sense of entitlement, it was rather to recharge for their caregiving duties. Other caregivers also found a way to participate in leisure; however, they included the care receivers into their leisure plans and unfortunately it compromised their enjoyment of the leisure activities (Bedini & Guinan, 1996a:231). It can be concluded that leisure is appreciated and desired by these caregivers, but their ethic of care (intrapersonal constraint) created constraints to access it (Bedini & Guinan, 1996a:231). Although this study does not only focus on woman caregivers as participants, the larger number of participants are women and therefore it may be relevant and of major importance to expand on female caregivers also to get an understanding of the nature of the constraints of caregivers. Also, findings from Shaw and Henderson (2005:24) reveal that leisure constraints of women are mostly structural interfering between an individual's need for leisure participation and their actual levels of participation. Caregivers from their study experienced structural constraints including a lack of financial resourses and financial independence, and a lack of leisure programmes and opportunities (like soccer that is more available for men), lack of time for leisure including a lack of time for self-care and time stress, due to family-related work, housework, and paid work (Shaw & Henderson, 2005:24,25). These women also experienced intrapersonal constraints, including ethic of care and a lack of entitlement to leisure, which relate to family roles and the obligation to put others' well-being first (Shaw & Henderson, 2005:25).

Furthermore, women from their study also experienced cultural constraints such as social disapproval of activities that do not seem appropriate to family and friends (Shaw & Henderson, 2005:26). This is also supported by Henderson (2012a:58) who explains that a person's cultural meanings and social interactions (for example, family, colleagues, and peers) may determine what they do. For example, in Japan older family members (grandparents) in the community expect that Japanese women should take care of their children, stay at home and do house work (Chick & Dong, 2005a:2). Thus, the leisure activities of Japanese woman are constricted by their Japanese culture and it causes them to give up their leisure activities (Chick & Dong, 2005a:2). Accordingly, Chick and Dong (2005a:3) and Chick and Dong (2005b:169) state that culture both proscribe (people should not do certain things) and prescribe (people should do certain things) interpersonal and intrapersonal behaviour, including leisure activities, differently. They go further by explaining that leisure activities are integrated into the culture, and thus coevolves with other facets of leisure (Chick & Dong, 2005b:169). Lastly, Chick and Dong (2005b:169) explain that if someone is not enabled by their culture, they are constrained by their culture.

In conclusion, Godbey *et al*. (2010:119) mention that not all individuals, in all cultural, social or historical contexts, experience a similar set of constraints or find it equally important or strong. Burns and Graefe, (2007:162) also state that leisure is not perceived in the same way by all caregivers. Therefore, it might also be that formal caregivers will not perceive constraints to leisure in the same manner, as the experience of constraints could also depend on the context and the role of the caregiver. However, it is clear that most of the women and caregivers from the above-mentioned scenarios experienced similar constraints in certain areas. This included financial constraints, time constraints, as well as an ethic of care.

From this literature, it is clear that research on formal caregivers is limited, and the constraints to formal caregivers are even more limited. Although it is beyond the scope of this study to explore the constraints to leisure of formal caregivers, or the negotiation of leisure constraints by caregivers, knowledge of these constraints will assist in understanding the caregivers' leisure, and secondly, highlight the need for research on leisure constraints among South Africans, as it is currently somewhat unfamiliar (Palen *et al*., 2010:437).

2.5 Summary

To understand the influence of caregiving on leisure, as well as the leisure needs that formal caregivers caring for persons with disability experience, it was important to undertake a complete literature review. This review provides readers with the literature that is necessary to understand the concept caregiving and leisure, and how caregiving can influence the leisure needs of caregivers.

This chapter consists of a thorough review of literature regarding topics that this study was based on. It also highlights the importance of leisure in the lives of caregivers, as well as the unique challenges that caregivers face in terms of their leisure. Throughout, the literature review provides reasons for care centres, and leisure programmers, to be more aware of the leisure needs and constraints caregivers face in under resourced areas in South Africa. Moreover, the literature review highlights areas that care centres, and leisure programmers, can focus their attention to support caregivers or provide solutions in order for caregivers to meet their leisure needs and experience fewer constraints. Lastly, the chapter illustrates that diverse contexts of caregiving exists, and that despite their diversity, caregivers experience similar challenges reminding them that they are not alone.

References

Ainsworth, B.E., Mannell, R.C., Behrens, T.K. & Caldwell, L.L. 2007. Perspectives of public health and leisure studies on determinants of physically active leisure. *Journal of physical activity & health*, 4(1):24-35.

Akintola, O. 2008a. Defying all odds: coping with the challenges of volunteer caregiving for patients with AIDS in South Africa. *Journal of advanced nursing*, 63(4):357-365.

Akintola, O. 2008b. Unpaid HIV/AIDS care in Southern Africa: forms, context, and implications. *Feminist economics*, 14(4):117-147.

Allen, S.M. & Ciambrone, D. 2003. Community care for people with disability: blurring boundaries between formal and informal caregivers. *Qualitative health research*, 13(2):207-226.

Anon. 2011. Leisure and recreation. Bishop Challoner Catholic Secondary School. Chapter 3:43-48. http://www.bishopfoxs.co.uk/wp-content/uploads/2011/06/Chapter-3-Leisure-and-Recreation-p43-48.pdf Date of access: 19 April. 2018.

Archibald, K. 2008. Leisure time and human happiness. *Perspective, mind and spirit lecture,* 8(2):1-14. https://www.byui.edu/Documents/instructional_development/Perspective/V8n2PDF/v8n2_Archibald.pdf Date of access: 28 Aug. 2017.

Aslan, O., Kav, S., Meral, C., Tekin, F., Yesil, H., Ozturk, U., Bulut, Z., Anaboifo, A., Dover, M. & Yazar, B. 2006. Needs of lay caregivers of bone marrow transplant patients in Turkey. *Cancer nursing*, 29(6):1-7.

Ateca-Amestoy, V., Serrano-del-Rosal, R. & Vera-Toscano, E. 2008. The leisure experience. *Journal of socio-economics*, 37(1):64-78.

Axelsson, A.K. 2015. The role of the external personal assistants for children with profound intellectual and multiple disabilities working in the children's home. *Journal of applied research in intellectual disabilities*, 28(3):201-211.

Bakker, A.B., Killmer, C.H. Siegrist, J., & Schaufeli, W.B. 2000. Effort-reward imbalance and burnout among nurses. *Journal of advanced nursing*, 31(4):884-891.

Baloyi, P.P., Thopola, M.K. & Kgole, J.C. 2015. Experiences of caregivers for children with cerebral palsy in Lebowakgomo hospital, Limpopo province, South Africa. *African journal for physical, health education, recreation and dance*, (2015 Supplement number 1):194-204.

Barbosa, A., Figueiredo, D., Sousa, L. & Demain, S. 2011. Coping with the caregiving role: differences between primary and secondary caregivers of dependent elderly people. *Aging & mental health,* 15(4):490-499.

Bedini, L.A. 2002. Family caregivers and leisure: an oxymoron? *Parks and recreation*, 37(1):25-31.

Bedini, L.A. & Gladwell, N.J. 2014. Caregiving as a life transition: implications for leisure service providers. *Journal of park and recreation administration,* 32(1):128-141.

Bedini, L.A. & Guinan, D.M. 1996a. If I could just be selfish: caregivers' perceptions of their entitlement to leisure. *Leisure science,* 18(3):227-239.

Bedini, L.A. & Guinan, D.M. 1996b. The leisure of caregivers of older adults: implications for CTRS's in non-traditional settings. *Therapeutic recreational journal*, 30(4):274-288.

Bingham, J.R.K. 2017. Experiences of caregivers of children with disabilities in semi-rural areas near Cape Town, South Africa. Stellenbosch: University of Stellenbosch. (Dissertation - MA).

Blanes, L., Carmagnani, M.I.S. & Ferreira, L.M. 2007. Health related quality of life of primary caregivers of persons with paraplegia. *Spinal cord,* 45(6):399-403.

Brandon, P. 2007. Time away from "smelling the roses": where do mothers raising children with disabilities find the time to work? *Social science & medicine*, 65(4):667-679.

Brattain, R.N. 1997. Centrality of the caregiving role and integration of leisure in everyday life: a naturalistic study of older wife caregivers. *Therapeutic recreation journal,* 30(4):230-243.

Breen, A., Swatrz, L., Flisher, A.J., Joska, J.A., Corrigal, J., PLaatjies, L. & Mcdonald, D.A. 2007. Experience of mental disorder in the context of basic service reforms: the impact on caregiving environments in South Africa. *International journal of environmental health research*, 17(5):327-334.

Brehaut, J.C., Kohen, D.E., Raina, P., Walter, S.D., Russell, D.J., Swinton, M., O'Donnell, M. & Rosenbaum, P. 2014. The health of primary caregivers of children with Cerebral Palsy: how does it compare with that of other Canadian caregivers? *Journal of American academy of paediatrics*, 114(2):182-191.

Buchanan, R., Ranin, D., Chakravorty, B.J. & Tyry, T. 2009. Informal caregiving to more disabled people with multiple sclerosis. *Disability and rehabilitation*, 31(15):1244-1256.

Bulent, G., Fatih, Y., Beyza, A.M. & Saut, K. 2010. Measuring constraints to leisure activities: demographic differences. *Science, movement and health*, 20(20):362-364.

Burns, R.C. & Graefe, A.R. 2007. Constraints to outdoor recreation: exploring the effects of disabilities on perceptions and participation. *Journal of leisure research*, 39(1):156-181.

Buscher, A., Astedt-Kurki, P., Paavilainen, E. & Schnepp, W. 2011. Negotiations about helpfulness – the relationship between formal and informal care in home care arrangements. *Scandinavian journal of caring sciences*, 25(4):706-715.

Caldwell, L.L. 2011. Leisure. *Encyclopaedia of adolescence,* 2:169-177.

Caldwell, L.L. & Smith, E.A. 1988. Leisure: an overlooked component of health promotion. *Canadian journal of public health*, 79(2):44-48.

Caldwell, L.L. & Witt, P.A. 2011. Leisure, recreation, and play from a developmental context. *New directions for youth development*, 130:13-27.

Capri, C. & Buckle, C. 2015. We have to be satisfied with the scraps: South African nurses' experiences of care on adult psychiatric intellectual disability inpatient wards. *Journal of applied research in intellectual disabilities*, 28(3):167-181.

Carter, R. & Golant, S. 1994. Helping yourself help others: a book for caregivers. New York: Three Rivers Press. http://www.amazon.com/Helping-Yourself-Help-Others-Caregivers/dp/0812925912 Date of access: 11 Oct. 2017.

Chhagan, M.K., Mellins, C.A., Kauchali, S., Craib, M.H., Taylor, M., Kvalsvig, J.D. & Davidson, L.L. 2014. Mental health disorders among caregivers of preschool children in the Asenze Study in KwaZulu-Natal, South Africa. *Maternal and child health journal*, 18(1):191-199.

Chick, G. & Dong, E. 2003. Possibility of refining the hierarchical model of leisure constraints through cross-cultural research. (*In* Murdy, J.J., *ed.* Proceedings of the 2003 Northeastern Recreation Research Symposium. New York, 6-8 April. p. 338-344). https://s3.amazonaws .com/academia.edu.documents/45293812/download.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1507576170&Signature=PW6n4eHsTeDHgfmD394eDFUxSw8%3D&resp

onse-content-disposition=inline%3B%20filename%3DDoes_distance_matter_Differences_in_char.pdf#page=346 Date of access: 10 Oct. 2017.

Chick, G. & Dong, E. 2005a. Culture constraints on leisure through cross-cultural research. Paper presented at the Eleventh Canadian Congress on Leisure Research, Pennsylvania, PA, 17 May. http://lin.ca/sites/default/files/attachments/CCLR11-30.pdf Date of access: 22 Feb. 2016.

Chick, G. & Dong, E. 2005b. Cultural constraints on leisure. (*In* Jackson, E.L., *ed.* Constraints to leisure. State College, PA: Venture. p. 169-183).

Chien, W. & Lee, I.Y.M. 2013. An exploratory study of parents" perceived educational needs for parenting a child with learning disabilities. *Asian nursing research*, 7(1):16-25.

Coetzee, M.J. 2007. The psychological health implications of social support for the Alzheimer caregiver. Pretoria: University of Pretoria. (Dissertation - MBA).

Coleman, D. & Iso-Ahola, S.E. 1993. Leisure and health: the role of social support and self-determination. *Journal of leisure research*, 25(2):111-128.

Coles, R., Edginton, C.R. & Jalloh, A. 2012. Africa and the World Leisure Organization. *African journal of physical, health education, recreation and dance*, 18(4:1):484-693.

Cordes, K.A. 2013. Applications in recreation and leisure for today and the future. 4th ed. Urbana, IL: Sagamore.

Cosgriff, M. 2011. Learning from leisure: developing nature connectedness in outdoor education. *Asia-Pacific journal of health, sport and physical education*, 2(1):51-65.

Creek, J. 2008. Creative leisure opportunities. *NeuroRehabilitation,* 23(4):299-304.

Crombi, L.K., Irvine, L., Williams, B., Mcginnis, A.R., Slane, P.W., Alder, E.M. & Mcmurdo, M.E.T. 2004. Why older people do not participate in leisure time physical activity: a survey of activity levels, beliefs and deterrents. *Age and ageing*, 33(3):287-292.

Dattilo, J. & Schleien, S. 1994. Understanding leisure services for individuals with mental retardation. *Mental retardation*, 32(1):53-59.

Dekker, T., Hess, S., Arentze, T. & Chorus, C. 2014. Incorporating needs-satisfaction in a discrete choice model of leisure activities. *Journal of transport geography*, 38:66-74.

Demmer, C. 2006. Caring for a loved one with aids: a South African perspective. *Journal of loss and trauma*, 11(5):439-455.

Department of Sport and Recreation ***see*** South Africa. Department of Sport and Recreation.

Dodd, D.C.H., Zabriskie, R.B., Widmer, M.A. & Eggett, D. 2009. Contributions of family leisure to family functioning among families that include children with developmental disabilities. *Journal of leisure research*, 41(2):261-286.

Driver, B.L. & Burns, D.H. 1999. Concepts and uses of the benefits approach to leisure. (*In* Jackson, E.L. & Burton, T.L. *eds.* Leisure studies: prospects for the twenty-first century. State College, PA: Venture. p. 349-369).

Du Preez, R. 2010. An ethnographic study of caregiving at a day care centre for developmentally challenged children. Pretoria: University of South Africa. (Dissertation - MA).

Dunn, N.J. & Strain, L.A. 2001. Caregivers at risk: changes in leisure participation. *Journal of leisure research*, 33(1):32-55.

Dupuis, S.L. 2000. Institution-Based caregiving as a container for leisure. Leisure sciences, 22(4):259-280.

Dupuis, S.L. & Smale, B.J.A. 2000. Bitter sweet journeys: meanings of leisure in the institution based context. *Journal of leisure research,* 32(3):303-340.

Edginton, C.R. 2012. Leisure services and infrastructure: transforming communities and economies. *African journal for physical, health education, recreation and dance*, (18):1-13.

Edginton, C.R. & Chen, P. 2008. Leisure as transformation. Champaign, Ill: Sagamore.

Edginton, C.R., Hudson, S.D., Dieser, R.B. & Edginton, S.R. 2004. Leisure programming: a service-centered and benefits approach. 4th ed. New York, NY: McGraw-Hill.

Edginton, C.R., Hudson, S.D. & Scholl, K.G. 2005. Leadership for recreation, parks, and leisure services. 3rd ed. Champaign, Ill: Sagamore.

Escandon, S. 2013. Cross-cultural caregiving and the temporal dimension. *Issues in mental health nursing*, 34(11):820-826.

Fodness, D. 1994. Measuring tourist motivation. *Annals of tourism research*, 21(3):555-581.

Ford, J. & Honnor, J. 2000. Job satisfaction of community residential staff serving individuals with severe intellectual disabilities. *Journal of intellectual & developmental disability*, 25(4):343-362.

Fourie, J. 2006. Tourism and leisure needs of high school learners in Potchefstroom. Potchefstroom: North-West University. (Dissertation - MA).

Freeman, P., Palmer, A.A. & Baker, B.L. 2006. Perspectives on leisure of LDS women who are stay-at-home mothers. *Leisure sciences*, 28(3):203-221.

Freysinger, V.J. & Kelly, J.R. 2004. 21st Century leisure: current issues. Edmonton, Alberta: Venture.

From, I. 2011. Health and quality of care from older peoples' and formal caregivers' perspective. Karlstad: University of Karlstad**.** (Dissertation- MA). https://www.diva-portal.org/smash/get/diva2:747422/FULLTEXT01.pdf Date of access: 23 Apr. 2016.

Gahagan, J., Loppie, C., Rehman, L., Maclellan, M. & Side, K. 2007. Far as I get is the clothesline: the impact of leisure on women's health and unpaid caregiving experiences in Nova Scotia, Canada. *Health care for women international*, 28(1):47-68.

Geere, J.L., Gona, J., Omondi, F.O., Kilafu, M.K., Newton, C.R. & Hartley, S. 2011. Caring for children with physical disability in Kenya: potential links between caregiving and cares' physical health. *Child: care, health and development*, 39(3):381-392.

Gladwell, N.J. & Bedini, L.A. 2004. In search of lost leisure: the impact of caregiving on leisure travel. *Tourism management*, 25(6):685-693.

Godbey, G. 2008. Leisure in your life: new perspectives. Edmonton: Venture.

Godbey, G., Crawford, D.W. & Shen, X.S. 2010. Assessing hierarchical leisure constraints theory after two decades. *Journal of leisure research*, 42(1):111-134.

Govender, N. 2002. Attitudes of parents towards their mentally retarded children: a rural area examination. Zululand: Unizulu. (Dissertation - MA).

Govender, K., Penninga, S., George, G. & Quinlana, T. 2012. Weighing up the burden of care on caregivers of orphan children: the Amajuba district child health and wellbeing Project, South Africa. *Aids care*, 24(6):71-721.

Greenlee, J. & Scharlach, A. 2001. Caregivers' characteristics and needs. (*In* Family caregivers in California: needs, interventions and model programs. Berkeley, CA: University of California. Center for the Advanced Study of Aging Services. p. 7-48). http://citeseerx.ist.psu.edu/viewdoc /download?doi=10.1.1.547.783&rep=rep1&type=pdf Date of access: 11 Oct. 2017.

Guha, S. 2009. Motivational push factors for visiting re-enactment sites. San Jose: San Jose State University. (Thesis - PhD).

Gurayah, T. 2015. Caregiving for people with dementia in a rural context in South Africa. *South African family practice*, 57(3):194-197.

Hanass-Hancock, J. & Casale, M. 2014. An exploratory model to illustrate the interrelationship between HIV, disability, and caregiving in Southern Africa. *Journal of the association of nurses in aids care*, 25(4):351-363.

Hawkins, B.A., Peng, J., Hsieh, C-M. & Eklund, S.J. 1999. Leisure constraints: a replication and extension of construct development. *Leisure sciences*, 21(3):179-192.

Hayward, P. 2000. Leisure and tourism: Heineman GNVQ intermediate. Oxford: Heineman Education.

Heintzman, P. & Mannell, R.C. 2003. Spiritual functions of leisure and spiritual well-being: coping with time pressure. *Leisure sciences: an interdisciplinary journal*, 25(2-3):207-23.

Henderson, K.A. 1996. One size doesn't fit all: the meanings of women's leisure. *Journal of leisure research*, 28(3):139-154.

Henderson, K.A. 2008. Expanding the meanings of leisure in a both/and world. *Society and leisure,* 31(1):15-30.

Henderson, K. 2010. Importance of leisure to individual society. (*In* Human kinetics. Dimensions of leisure for life: individuals and society. Champaign, IL: Human Kinetics. p. 3-26).

Henderson, K.A. 2012a. The contributions of leisure and active recreation to health and well-being. *African journal for physical, health education, recreation and dance,* 18(Suppl. 4):52-63.

Henderson, K.A. 2012b. Leisure. (*In* Encyclopedia of Human Behavior. https://ac-els-cdn-com.nwulib.nwu.ac.za/B9780123750006002214/3-s2.0-B9780123750006002214-main.pdf?_tid=8c1fba81-2734-4c2e-b672

00c3257d3abd&acdnat=1521711054_59ecf9a9d1396fa054f7f5cafc404a06 Date of access: 22 March. 2017).

Henwood, T., Tuckett, A. & Turner, C. 2012. What makes a healthier nurse, workplace or leisure physical activity? Informed by the Australian and New Zealand e-Cohort Study. *Journal of clinical nursing*, 21(11-12):1746-1754.

Hickerson, B.D. & Beggs, B.A. 2007. Leisure time boredom: issues concerning college students. *College student journal*, 41(4):1036-1044. http://eds.a.ebscohost.com.nwulib.nwu.ac.za/eds/detail/detail?vid=1&sid=fc68acd8-b020-484b-994586ee22143668%40sessionmgr4007&bdata=JnNpdGU9ZWRzLWxpdmU%3d#AN=28341354&db=s3h Date of access: 13 Feb. 2018.

Holba, A.M. 2014. In defence of leisure. *Communication quarterly,* 62(2):179-192.

Holder, M.D., Coleman, B. & Sehn, Z.J. 2009. The contribution of active and passive leisure to children’s well-being. *Journal of health psychology*, 14(3):378-386.

Hung, L.-C., Liu, C.-C. & Kuo, H.-W. 2002. Unmet nursing care needs of home-based disabled patients. *Journal of advanced nursing*, 40(1):96-104

Hutchinson, S.L. & Kleiber, D.A. 2005. Leisure constraints, and negative life events: paradox and possibilities. (*In* Jackson, E.L., *ed*. Constraints to leisure. State College, PA: Venture. p. 137-149).

Iso-Ahola, S.E. 1999. Motivational foundations of leisure (*In* Jackson, E.L. & Burton, T.L. *eds*. 1999. Leisure studies: prospects for the twenty-first century. State College, PA: Venture. p. 35-51).

Iwasaki, Y. & Mannell, R. 2000. Hierarchical dimensions of leisure stress coping. *Leisure sciences*, 22(3):163-181.

Iwasaki, Y., Mannell, R.C., Smale, B.J.A. & Butcher, J. 2005. Contributions of leisure participation in predicting stress coping and health among police and emergency response services workers. *Journal of health psychology,* 10(1):79-99.

Jackson, E.L. 1999. Comment. Leisure constraints: a replication and extension of construct development by Hawkins *et al*. *Leisure sciences*, 21(3):195-199.

Jackson, E.L. 2005. Leisure constraints research: overview of a developing theme in leisure research. (*In* Jackson, E.L., *ed*. Constraints to leisure. State College, PA: Venture. p. 3-19).

Jackson, E.L. & Scott, D. 1999. Constraints to leisure. (*In* Jackson, E.L. & Burton, T.L. *eds*. Leisure studies: prospects for the twenty-first century. State College, PA: Venture. p. 299-316).

Kaasalainen, S., Ploeg, J., McAiney, C., Martin, L.S., Donald, F., Martin-Misener, R., Brazil, K., Taniguchi, A., Wickson-Griffiths, A., Carter, N. & Sangster-Gormley, E. 2013. Role of the nurse practitioner in providing palliative care in long-term care homes. *International journal of palliative nursing*, 19(10):477-485.

Kelly, J.R. 1990. Leisure. 2nd ed. New Jersey, U.S.A: Prentice-Hall Inc.

Kelly, J. & Godbey, G. 1992. Sociology of leisure. State College, PA: Venture.

Kiernozek, K.S. 2015. Leisure participation and perceived constraints of parents and caregivers of children with disabilities. Knoxville: University of Tennessee. (Dissertation - MA).

King, A.C., Castro, C., Wilcox, S., Eyler, A.A., Sallis, J.F. & Brownson, R.C. 2000. Personal and environmental factors associated with physical inactivity among different racial-ethnic groups of U.S. middle-aged and older-aged woman. *Health psychology*, 19(4):354-364.

Klassen, A.F., Dix, D., Papsdorf, M., Klaassen, R.J., Yanofsky, R. & Sung, L. 2012. Impact of caring for a child with cancer on single parents compared with parents from two-parent families. *Pediatric blood and cancer*, 58(1):74-79.

Korpela, K. & Kinnunen, U. 2010. How is leisure time interacting with nature related to the need for recovery from work demands? Testing multiple mediators. *Leisure Sciences*, 33(1):1-14.

Kraus, R., Barber, E. & Shapiro, I. 2001. Introduction to leisure services: career perspectives. Champaign, IL: Sagamore.

Kuster, P.A. & Merkle, C.J. 2004. Caregiving stress, immune function, and health: implications for research with parents of medically fragile children. *Issues in comprehensive paediatric nursing*, 27(4):257–276.

Laugier, S. 2015. The ethics of care as a politics of the ordinary. *New literary history*, 46(2):217-240.

Lee, H.Y., Shin, J.H. & Harrington, C. 2015b. Comparing the nurse staffing in Korean and U.S. nursing homes. *Nursing outlook*, 63(2):137-143.

Leitner, M.J. & Leitner, S.F. 2012. Leisure enhancement. 4th ed. Urbana Ill: Sagamore.

Leversen, I., Danielsen, A.G., Birkeland, M.S. & Samdal, O. 2012. Basic psychological need satisfaction in leisure activities and adolescents’ life satisfaction. *Journal of youth adolescence*, 41:1588–1599.

Losada, A., Peres-Penaranda, A., Rodiquez-Sanchez, E., Gomes-Marcos, M.A., Ballesteros-Rios, C., Ramos-Carrera, I.R., Campo-de la Torre, M.A. & Garcia-Ortiz, L. 2010. Leisure and distress in caregivers of elderly patients. *Archives of gerontology and geriatrics,* 50(3):347-350.

Lucchetti, G., Lucchetti, A.L.G., Oliveira, G.R., Crispim, D., Pires, S.L., Gorzoni, M.L. & Koenig, H.G. 2014. Nursing home care: exploring the role of religiousness in the mental health, quality of life and stress of formal caregivers. *Journal of psychiatric and mental health nursing,* 21(5):403-413.

Mackellar, J. 2009. An examination of serious participants at the Australian Wintersun Festival. *Leisure studies*, 28(1):85-104.

Majnemer, A., Shikako-Thomas, K., Schmitz, N., Shevell, M. & Lach, L. 2015. Stability of leisure participation from school-age to adolescence in individuals with cerebral palsy. *Research in developmental disabilities*, 47(1):73-79.

Mannell. R.C. 1999. Leisure experience and satisfaction. (*In* Jackson EL. & Burton, T.L., *eds*. Leisure studies: prospects for the twenty-first century. State College, PA: Venture. p. 235-248).

McKenzie, J. & McConkey, R. 2016. Caring for adults with intellectual disability: the perspectives of family carers in South Africa. *Journal of applied research in intellectual disabilities*, 29(6):531-541

McLean, D. & Hurd, A. 2015. Kraus’: recreation and leisure in modern society. 10th ed. Burlington, MA: Jones & Bartlett Learning.

McLean, D.D., Hurd, A.R. & Rogers, N.B. 2008. Kraus’: recreation and leisure in modern society. 8th ed. Sudbury, MA: Jones & Bartlett.

Ministry of Social Development ***see*** New Zealand.

Morrison, K.B. & Korol, S.A. 2014. Nurses’ perceived and actual caregiving roles: identifying factors that can contribute to job satisfaction. *Journal of clinical nursing,* 23(23-24):3468-3477.

Mtenbu, T.G., Abdurahman, I., Ferus, L., Langenhoven, A., Sablay, S. & Sonday, R. 2015. Older adults’ perceptions and experiences regarding leisure participation. *African journal for physical, health education, recreation and dance*, 21(1:1):215-235.

Mudzi, W. 2010. Impact of caregiver education on stroke survivors and their caregivers. Johannesburg: University of the Witwatersrand. (Thesis - PhD).

Murphy, N.A., Christian, B., Caplin, D.A. & Young, P.C. 2006. The health of caregivers for children with disabilities: caregiver perspectives. *Child: care, health and development,* 33(2):180-187.

New Zealand. Ministry of Social Development. 2010. The social report 2010. Wellington. http://socialreport.msd.govt.nz/2010/downloads.html Date of access: 11 Oct. 2017.

New Zealand. Ministry of Social Development. 2016. The social report 2016. Wellington. http://socialreport.msd.govt.nz/documents/2016/msd-the-social-report-2016.pdf Date of access: 5 May 2015.

Nikzad-Terhune, K. 2011. Dementia caregiving outcomes: the impact of caregiving onset, role occupancy, and care-recipient decline. Lexington, KY: University of Kentucky (Thesis - PhD).

OECD. 2009. Society at a glance 2009: OECD social indicators. Paris: OECD. http://dx.doi.org/10.1787/soc_glance-2008-en. Date of access: 23 Jun. 2016.

Ogunmefun, C., Gilbert, L. & Schatz, E. 2011. Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. *Journal of cross cultural gerontology,* 26(1):85-102.

Owens, J. 1981. Aristotle on leisure. *Canadian journal of philosophy*, (11)14:713-723.

Palen, L., Patric, M.E., Gleeson, S.L., Caldwell, L.L., Smith, E.A. & Wegner, L. 2010. Leisure constraints for adolescents in Cape Town, South Africa: a qualitative study. *Leisure sciences*, 32(5):434-452.

Parr, M.G. & Lashua, B.D. 2004. What is leisure? The perceptions of recreation practitioners and others. *Leisure sciences*, 26(1):1-17.

Parr, M.G. & Lashua, B.D. 2005. Students' perceptions of leisure, leisure professionals and the professional body of knowledge. *Journal of hospitality, leisure, sport and tourism education*. 4(2):16-26.

Patterson, I. & Pegg, S. 2009. Serious leisure and people with intellectual disabilities: benefits and opportunities. *Leisure studies*, 28(4):387-402.

Peckham, A.L. 2009. Caring for caregivers: balancing formal and informal care for frail older persons. Toronto: University of Toronto. (Thesis – PhD).

Peckham, A., Williams, A.P. & Neysmith, S. 2014. Balancing formal and informal care for older persons: how case managers respond. *Canadian journal on aging*, 33(2):123-136.

Poff, R.A., Zabnskie, R.B. & Townsend, J.A. 2010. Modeling family leisure and related family constructs: a national study of U.S. parent and youth perspectives. *Journal of leisure research*, 42(3):365-391.

Priest, S. & Gass, M.A. 2005. Effective leadership in adventure programming. 2nd ed. Champaign, ILL: Human Kinetics.

Repar, P.A. & Reid, S. 2014. Creatively caring: effects of arts-based encounters on hospice caregivers in South Africa. *Journal of pain and symptom management*, 47(5):946-954.

Riana, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russel, D., Swinton, M., King, S., Wong, M., Walter, S.D. & Wood, E. 2004. Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC paediatrics*, 4(1):1-13.

Richards, R. 2001. A new aesthetic for environmental awareness: chaos theory, the beauty of nature, and our broader humanistic identity. *Journal of humanistic psychology,* 41(2):59-95.

Roberson, D.N. 2005. Leisure and learning: an investigation of older adults and self-directed learning. *Leisure/Loisir*, 29(2):203-237. https://www-tandfonline-com.nwulib.nwu.ac.za/doi/abs/10.1080/14927713.2005.9651330 Date of access: 18 Oct. 2017.

Roberts, K. 2006. Leisure in contemporary society. 2nd ed. Cambridge, MA: CABI.

Rodriguez, A. & Gamble, D. 2010. Leisure and quality of life (*In* Human Kinetics. 2010. Dimensions of leisure for life. Champaign, IL: Human Kinetics. p. 1-367).

Rohrer, J.E., Pierce, J.R. & Blackburn, C. 2005. Lifestyle and mental health. *Preventive medicine*, 40(4):438-443.

Rojek, C. 2010. The labour of leisure: the culture of free time. London: Sage.

Rose, T. & Williams, D.J. 2015. Nurse leadership: the importance of balancing work with leisure. *Nurse leader*, 13(3):60-62.

Rossman, J.R. 1995. Recreation programming: designing leisure experiences. 2nd ed. Champaign, IL.: Sagamore.

Ryan, R.M., Williams, G.C., Patrick, H. & Deci, E.L. 2009. Self-determination theory and physical activity: the dynamics of motivation in development and wellness. *Hellenic journal of psychology*, 6(2):107-124.

Samdahl, D.M. 2007. Similarities are not enough: a response to Schneider and Wilheim Stanis about coping and leisure constraint negotiation. *Leisure sciences*, 29(4):407-413.

Schneider, M. L., & Kwan, B. M. (2013). Psychological Need Satisfaction, Intrinsic Motivation and Affective Response to Exercise in Adolescents. *Psychology of sport and exercise*, 14, 776-785. https://ac-els-cdn-com.nwulib.nwu.ac.za/S1469029213000447/1-s2.0-S1469029213000447-main.pdf?_tid=54ef50ba-121e-11e8-a46c-00000aacb361&acdnat=1518678392_d47a8c6c9d09f92fd0ab8a74e3484302 Date of Access: 15 Feb. 2018.

Schryer, E., Mock, S.E., Hilbrecht, M., Lero, D. & Smale, B. 2016. Use of leisure facilities and wellbeing of adult caregivers. *Leisure sciences*, 38(1):17-33.

Schultz, R. & Martire, L.M. 2004. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *The American journal of geriatric psychiatry*, 12(3):240-249.

Scott, D. 2005. The relevance of constraints research to leisure service delivery (*In* Jackson, E.L., *ed.* Constraints to leisure. State College, PA: Venture. p. 279-293).

Shaddock, A.J., Hill, M. & Van Limbeek, C.A.H. 1998. Factors associated with burnout in workers in residential facilities for people with an intellectual disability. *Journal of intellectual & developmental disability*, 23(4):309-318. http://eds.b.ebscohost.com.nwulib.nwu.ac.za/eds/detail/detail?vid=15&sid=3897108c-e165-40b3-9ab1-6a0a0cc0f24e%40sessionmgr104&bdata=JnNpdGU9ZWRzLWxpdmU %3d#AN=107180046&db=c8h Date of access: 18 Oct. 2017.

Shannon, C.S. 2014. Exploring the leisure experiences of children who are overweight and obese: parent and child perspectives. *Leisure*, 38(2):139-163.

Shaw, S.M. & Dawson, D. 2001. Purposive leisure: examining parental discourses on family activities. *Leisure sciences*, 23(4):217-231.

Shaw, S.M., & Henderson, K. 2005. Gender analysis and leisure constraints: an uneasy alliance. (*In* Jackson, E.L., *ed.* Constraints to leisure. State College, PA: Venture. p. 23-34).

Shobede, S.L. 2011. Perceptions of health and well-being among caregivers of people living with HIV/AIDS. Johannesburg: University of Witwatersrand. (Dissertation – MA).

Simpson, S. 2006. A technical report exploring whether caregivers of people living with HIV/AIDS receive sufficient psycho-social support. Stellenbosch: University of Stellenbosch. (Dissertation - MA).

Sing Nam, H. 2004. Exploring the changing relationship between formal carers, informal carers and carees during the elder-care process. Hong Kong: Lingnan University. (Thesis- PhD)

Social report ***see*** New Zealand. Ministry of Social Development

Son, J.S., Kerstetter, D.L., Yarnal, C.M. & Baker, B.L. 2007. Promoting older women's health and well-being through social leisure environments: what we have learned from the red hat society. *Journal of women & aging*, 19(3/4):89-104.

Son, J.S., Mowen, A.J. & Kerstetter, D.L. 2008. Testing alternative leisure constraint negotiation models: an extension of Hubbard and Mannell's study. *Leisure sciences*, 30(3):198-216.

Song, J-A. & Oh, Y. 2015. The association between the burden on formal caregiver and behavioural and psychological symptoms of dementia (BPSD) in Korea elderly in nursing homes. *Archives of psychiatric nursing*, 29(5):346-354.

Sonnentag, S. 2001. Work recovery, activities, and individual well-being: a diary study. *Journal of occupational health psychology*, 6(3):196-210.

South Africa. Department of Sport and Recreation. 2012. The white paper on sport and recreation for the republic of South Africa. Pretoria.

Stanis, S.A.W, Schneider, I.E. & Pereira, M.A. 2010. Parks and health: differences in constraints and negotiation strategies for park-based leisure time physical activity by stage of change. *Journal of physical activity and health*, 7(2):273-284.

Stebbins, R.A. 2004a. Between work and leisure: a study of the common ground of two separate worlds. New Brunswick, NJ: Transaction Publishers.

Stebbins, R.A. 2004b. Fun, enjoyable, satisfying, fulfilling: describing positive leisure experience (Leisure reflections, no. 7). *Leisure Studies Association Newsletter*, 69:8-11. http://people.ucalgary.ca/~stebbins/reflections7.pdf Date of access: 21 Jan. 2016.

Stuart, S.J., Stone, C.F. & Rider, C.Y. 2005. A paradigm shift in therapeutic recreation: from cure to care. (*In* Jackson, E.L., *ed.* Constraints to leisure. State College, PA: Venture. p. 295-309).

Stumbo, N.J. & Peterson, C. 2004. Therapeutic recreation program design: principles and procedures. 4th ed. San Francisco, CA: Pearson.

Thayer, R.E., Newman, J.R. & McClain, T.M. 1994. Self-regulation of mood: strategies for changing a bad mood, raising energy, and reducing tension. *Journal of personality and social psychology*, 67(5):910-925.

Thomas, M. & Greenop, K. 2008. Caregiver experiences and perceptions of stroke. *Health SA,* 13(1):29-49.

Tiggemann, M. 2001. The impact of adolescent girls' life concerns and leisure activities on body dissatisfaction, disordered eating, and self-esteem. *Journal of genetic psychology,* 162(2):133-142.

Torkildsen, G. 2005. Leisure and recreation management. 5th ed. New York, NY: Routledge.

Trenberth, L. 2005. The role, nature and purpose of leisure and its contribution to individual development and well-being. *British journal of guidance & counselling*, 33(1):1-6.

Tu, S.F. 1993. The relationship between leisure and perceived burden of spouse caregivers of persons with Alzheimer's disease. Denton, TX: University of North Texas. (Dissertation - MSc).

Uren, S. 2009. An investigation into the emotional experience of caregiving. Johannesburg: University of the Witwatersrand. (Dissertation – MA).

Uren, S.A. & Graham, T.M. 2012. Contextual elements of palliative caregiving in a low-income community. *South African journal of psychology*, 42(1):61-70.

Vitaliano, P.P., Scanlan, J.M. & Zhang, J. 2003. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological bulletin*, 129(6):946-972.

Wada, Y. 2014. Relational care ethics from a comparative perspective: the ethics of care and confucian ethics. *Ethics and social welfare*, 8(4):350-363. http://dx.doi.org/10.1080/17496535.2014.894109

Wahl, S. & Newmark, R. 2009. The self-perceived quality of life of staff caring for adults with intellectual disabilities. *Journal of humanities,* 49(2):287-304.

Ward, N. 2011. Care ethics and carers with learning disabilities: a challenge to dependence and paternalism. *Ethics and social welfare*, 5(2):168-180.

White, S.A. 2008. Increasing longevity: the challenges of aging and caregiving. *Journal of vascular nursing*, 26(4):96-99.

Whiting, J. & Hannam, K. 2015. Creativity, self-expression and leisure. *Leisure studies,* 34(3):372-384.

Williams, A. & Crooks, V.A. 2008. Introduction: space, place and the geographies of women's caregiving work. *Gender, place and culture*, 15(3):243-247.

Williams, T. 2013. Conflict between women's physically active and passive leisure pursuits: The role of self-determination and influences on well-being. Ottawa: University of Ottawa. (Dissertation - MA).

Williams, T., Geurin, E. & Fortier, M. 2014. Conflict between women's physically active and passive leisure pursuits: the role of self-determination and influences on well-being. *Applied psychology: health and well-being*, 6 (2):151–172.

Woods, M. 2011. An ethic of care in nursing: past, present and future considerations. *Ethics and social welfare*, 5(3):266-276.

CHAPTER 3: THE INFLUENCE OF CAREGIVING FOR INDIVIDUALS WITH DISABILITIES ON THE LEISURE OF CAREGIVERS IN A CENTRE IN THE NORTH WEST PROVINCE

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This article will be submitted for consideration in the "*Journal of Leisure Research*". The article was written in accordance with the specific guidelines of the journal. The guidelines for authors are included as Annexure A.

The influence of caregiving for individuals with disabilities on the leisure of caregivers in a centre in the North West Province: A case study

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Abstract

The researcher explored and described the impact of caring for persons with disability on the leisure of formal caregivers. This study made use of a qualitative approach and semi-structured one-on-one interviews, and included 12 formal caregivers. It was based on an exploratory case study design. The central theoretical statement of this study was that the primary caregivers of persons with disabilities will experience caregiving as a negative impact on their leisure. Themes that emerged included caregiver perceptions of leisure, leisure time influences (constraining factors), and caregiving as leisure. The researcher found that caregiving has a negative influence on the leisure of caregivers and that caregiving acts as a constraint to leisure. Thus, it is critical for centre managers and leisure service providers to implement programmes and interventions in order to facilitate in satisfying the caregivers' leisure needs and reduce constraining factors where possible.

Keywords: Leisure, care giving, influence of caregiving on leisure, constraints

These days, formal caregivers face high workloads, long working hours, staffing shortages, and emotional stress as burdens (Rose & Williams, 2015; Whal & Newmark, 2009 White, 2008). Limited training and promotion, little resources, and uncertainty of their role also contribute to caregivers being over worked (Whal & Newmark, 2009). Furthermore, they also face variable amounts of physical work depending on assistance and resources available, such as heavy lifting, lack of sleep, and constant monitoring of the care receiver’s condition (Geere, Gona, Omondi, Kilafu, Newton & Hartley, 2012; Rose & Williams, 2015; Kuster & Merkle, 2004). As a result, these demands have negative consequences for the psychological and physical health of a caregiver, such as chronic stress, depression, sedentary behaviour, poor nutrition, exhaustion and burnout (Bakker et al., 2000; Brehaut et al., 2014; Hung et al., 2002; Vitaliano et al., 2003; Whal & Newmark, 2009). Due to this demanding work, caregivers’ desire to take part in active leisure diminishes even though it is essential for their well-being and overall health (Bendini, 2002; Rose & Williams, 2015).

Moreover, the demands when caring for a person with disability are far more than in cases of a child of normal development (Brandon, 2007; Brehaut et al., 2014). Also, the study of Losada et al. (2010) reveal that caregivers experience lower perceived time for leisure due to more hours dedicated to care per day, and also care for persons who are more functionally impaired. Caregivers are persons who provide care to individuals in an institutional setting, or home-based care at the care recipient’s or the caregiver’s home (Greenlee & Scharlach, 2001). In the context of this study, caregivers provide long term care to persons with a physical disability, however, caregivers may also care for someone with a chronic illness over the long term, or on an irregular base as in the case of someone with an acute episode of chronic illness (Greenlee & Scharlach, 2001). They may also provide care to the physical health, or emotional well-being of an individual that is disabled or have physical or mental limitations (Greenlee & Scharlach, 2001; Lucchetti et al., 2014). Furthermore, caregiving can be formal, in which case there is paid care provided by practitioners such as social workers or home care workers who have formal training or a degree, such as nursing (Williams & Crooks, 2008), or it can be informal where family, a parent or a relative provides unpaid care to a chronically ill or disabled loved one (Bedini, 2002; Buchanan et al., 2009; Carter & Golant, 1994; Gladwell & Bedini, 2004; Schultz & Martire, 2004). This study will focus only on formal caregivers, but specifically the primary caregiver who offers the most assistance and support to the individual with disability (Blanes et al., 2007).

In addition to the support caregivers provide, the roles of formal caregivers may include: cooking, changing nappies and help with dressing, help with exercise, making sure the child is safe, giving medicine and perform care in any area needed, and playing leisure activities for a sense of connectedness with the children (Axelsson, 2015; Du Preez, 2010). It also involve spending a significant amount of money, energy and time over long time periods, while caregivers' tasks may also be uncomfortable and unpleasant as well as physically exhausting and psychologically stressful (Schulz & Martire, 2004; Axelsson, 2015). Furthermore, caregivers in a study of Bedini and Guinan (1996b) mentioned that the caregiving responsibilities they undertake resulted in changes in their leisure and that they had difficulty accessing leisure. The feelings they experienced involved a loss of freedom, social contact, spontaneity, and independence (Bedini & Guinan, 1996b). For that reason, it is important to understand the possible reasons why caregivers fail to participate in leisure activities, but also how to avoid the influences that are preventing them to participate in leisure. Accordingly, Bedini and Guinan (1996b) reveals that caregivers are interested in leisure activities and find leisure valuable, but they feel that certain constraints and barriers limit them to pursue leisure.

Constraints are as those elements that limit someone from participating in leisure activities (Bulent et al., 2010), to enjoy their current leisure activities, or to use leisure services, such as programmes and parks (Scott, 2005). Constraints and barriers must, however, not be confused since constraints are negotiable and barriers are insurmountable (leading to nonparticipation) (Jackson, 2005; Scott, 2005; Tu, 1993). However, in the context of this study the focus will lay more on how the influence of caregiving can be a constraint to the leisure of caregivers. Leisure constraints can be further explained through the three main types of constrains, namely intrapersonal constraints, interpersonal constraints, and structural constraints. Intrapersonal constraints are factors internal to a person, a psychological condition, such as emotional and physical fatigue, and perceived responsibility to care, or ethic of care (Bedini & Guinan, 1996b; Bedini & Guinan, 1996a; Bedini & Guinan, 1996b; Dupuis & Smale, 2000; Stanis et al., 2010). Interpersonal constraints result due to social interaction with other people, including co-workers, family, neighbours and friends (Chick & Dong, 2003; Hawkins et al., 1999; Scot, 2005), where one might be constrained by family obligation, lack of partners, friends and/or family who prefer different activities, or conflicting schedules (Son et al., 2008; Jackson & Scott, 1999; Stanis et al., 2010; Stuart et al., 2005). Lastly, structural constraints are external conditions (environmental circumstances) which involve factors such as the financial strain, lack of help from outside, absence of opportunities, time limitations, lack of transport, or inconvenient facilities (Bedini & Guinan, 1996b; Chick & Dong, 2003; Dupuis & Smale, 2000; Hutchinson & Kleiber, 2005; Shaw & Henderson, 2005; Son et al., 2008; Stanis et al., 2010). It can also be described as reasons that interfere between actual activity participation and the preferences someone already has for leisure (Hawkins et al., 1999; Jackson & Scott, 1999; Shaw & Henderson, 2005; Scot, 2005).

In conclusion, Godbey et al. (2010) mention that not all individuals, in all cultural, social or historical contexts, experience a similar set of constraints or find it equally important or strong. Burns and Graefe (2007) also state that leisure is not perceived in the same way by all caregivers. Therefore, it might also be that they will not perceive the influence of constraints to leisure in the same manner, as the experience of constraints could also depend on the context and the role of the caregiver.

From this literature it is clear that research on formal caregivers' leisure is limited, and the research on the influences of formal caregiving on the leisure of caregivers is even more limited. Thus, this study aimed to explore the influence of care giving for persons with disability on the leisure experience of caregivers in the North West province. Hence, the research question asked, is "What is the influence of caring for individuals with a disability on the leisure of caregivers in the North West province? This study will aim to provide useful information to therapeutic recreation service providers, managers of disability centres, and various health care organisations about the constraining factors influencing the caregivers' leisure. The information that emanates from the research will enable centre managers and service providers to provide the necessary leisure services and opportunities to caregivers. It will also encourage service providers to identify the caregivers in the community to enable them to increase leisure awareness and education among caregivers.

Methods

Research design

This study made use of a qualitative approach based on an exploratory case study design as explained by Yin (2003). Data was collected through semi-structured one-on-one interviews as recommended by Greeff (2011), since the study aimed to explore the leisure needs of formal caregivers of persons with disabilities in the North West province. The central theoretical statement of this study is that the primary caregivers of persons with disabilities experience high levels of unmet leisure needs and that such caregiving has a negative impact on the leisure of caregivers of disabled people in the North West province.

Study population

The study population included formal caregivers employed at a full-time care centre from an under resourced area in Rustenburg, in the North West province of South Africa. The centre exists of 25 caregivers and more than half of them reside at the centre permanently. The other caregivers reside in under resources areas in Rustenburg and work at the centre on a full time basis. Participants are also the primary caregivers of the persons with disability and get paid for taking care of the individuals as their full-time job. The time that the caregivers have been working for the centre varies, with a minimum of one (1) year and a maximum of 20 years.

Furthermore, caregiving roles are rotated among caregivers, which mean that every caregiver are continually exposed to different caregiving task. For the caregivers staying at the care centre, responsibilities are similar to having responsibilities of a normal household, accept that caregivers have the responsibility to care for 30 children and the children they care for require much more care than children of normal health. The children with disabilities stay at the centre on a permanent basis and only visit their relatives or parents during school holidays, if at all. Room space at the centre is limited and some children sleep on the floor on matrasses as an alternative sleeping space. Most of the caregivers who stay at the centre share rooms with the children, since some of the children need 24-hour care, which means that they have to provide care and watch over the children throughout the night. Their main roles include, toileting, making food, feeding, bathing, medication, doctor visits, cleaning the rooms, watching over the children, washing clothes, helping and teaching the children certain life skills (i.e. toileting and dressing up), play games with them, sport coordination, and shopping.

The formal caregivers in this study included two male and ten female caregivers older than 18 years (both single and married). Although most of the caregiver’s highest level of education is grade 12, a smaller number only went to school up to grade 7. Furthermore, only a few caregivers have higher education, including first aid, early childhood development level 5, and a diploma for pre-nursing. Two of the caregivers (including the owner of the centre) has a degree in education and also take on the role of teaching and stimulating the children.

The centre takes care of 30 children with a variety of disabilities, including Down syndrome, Cerebral Palsy, Epilepsy, Autism, Paraplegia and Mental Disorders. The minimum age of children at the centre is three years, since many children are not diagnosed before they reach the age of three years (Kalb, 2005). The level of the children's disability is of such nature that it is an additional burden to the caregiver, and included, persons with physical disability[1] ranging between "moderately severe" and "extreme vegetative state", and persons with mental disability[2] at a pervasive or extensive level.

Data collection

After permission from the centre manager, and ethical clearance from the university's ethics committee were obtained, a purposive sampling technique was used to recruit the sample of caregivers. A period of five days was used to conduct the interviews at the full-time care centre in Rustenburg. Considering that, this was a qualitative study, the semi-structured interview schedule was not subjected to a validated validation process similar to those of quantitative studies. Rather, the process that was followed in this study adhered to follow the qualitative epistemiological standards encapsulated by trustworthiness. The semi-structured interview schedule was reviewed by experts to establish theoretical validity

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[1] Physical disability
Physical disability is measured by the Rappaport disability rating scale based on the following levels (CNS, 2014; COMBI, 2000; Dijkers & Greenwald, 2007): 0 (none), 1 (mild), 2-3 (partial), 4-6 (moderate), 7-11 (moderately severe), 12-16 (severe), 17-21 (extremely severe), 22-24 (vegetative state), and 25-29 (extreme vegetative state).

[2] Mental disability
Persons with mental disabilities are classified into the four levels of support namely; intermittent (support needed occasionally, not on continuous daily basis), limited (support during transition from one place to another or in time- limited situations), extensive (assistance needed at home on a daily basis), and pervasive (support that is constant and may include life sustaining measures) (Pitetti & Fernhall, 2005).

(content validity), and by quantitative terms also face validity in the fields of health care and qualitative research. The researcher also attended workshops presented by an expert who focuses specifically on qualitative research and how to do interviews in establishing and maintaining credibility (internal validity) and transferability (external validity), techniques included, persistent observation, peer debriefing, negative case analysis and referential adequacy, saturation of data and thick descriptions. A trial run was conducted with experts in the field of recreation, as well as a caregiver who care for persons with disability (transferability through purposive sampling, similar quantitative standard of external validity) to determine if the proposed interview questions were comprehensible and have elicited the necessary information, establishing credibility through peer debriefing (internal and measurement validity) and confirmability through an inquiry audit (objectivity). The information gained from the trial run with the caregiver was also used as part of the findings. All the steps of the research process that was planned, described and followed was captured accurately (empirically how they happened) in the research report to give legitimacy and relevance (inferential validity) not only to the data but also to the manner in how the data was collected (i.e., the interview schedule).

Voice recordings as well as field notes were made to keep record of information. A qualified translator was available for clarifying any issues or answering any questions regarding the research in the participant’s first language. Information was gathered until data saturation was reached (Dick, 2012). Participants had the right to withdraw from the study at any stage if they chose to. A minimum number of 12 participants participated in the study which is in line with recommendations by Dick (2012).

Interviews lasted for 60- 90 minutes, which also included the time before the interview when the researcher had to make sure that the participants knew all the procedures and the time after the interview, which are open for discussion about the interview. Semi-structured one-on-one interviews were used to gather information from participants and were divided into four themes. Questions were open-ended with the maximum amount of questions being six. The four main themes included 1) what the perceptions and experiences of caregivers' leisure are, 2) what the influence that leisure has on caregivers are, 3) what the leisure needs of caregivers are, and 4) how caregiving impact the leisure of caregivers. Probes were also used, but kept to the minimum.

Data analysis

Firstly, interviews were audio taped, then transcribed verbatim. The recordings were stored safely after it was transcribed. Interviews were then analysed to make changes if necessary and to see when saturation is taking place, as recommended by Greeff (2011). Secondly, the researcher applied microscopic examination by going through the raw data to help with identifying words that might have different meanings to the participants, or to identify different words that might have the same meaning to them (Henderson, 2006). After the microscopic examination, the data were analysed by using ATLAS.ti as a computerised tool, with the researcher using guidelines as proposed by Yin (2014). Information was then coded and analysed into categories, themes and subthemes, until certain patterns appeared. Lastly, data were presented in a discussion and integrated with the existing literature.

Anonymity was ensured by using data only for academic purposes and by not exposing anyone's identity. Reporting of findings was kept anonymous by replacing names with numbers. Recordings were stored safely after it was transcribed.

Findings and Discussions

From this study, 13 themes resulted from the caregivers' quotes and three main categories emerged, including (a) leisure perceptions of caregivers, (b) constraining factors to leisure, and c) caregiving as leisure, which is consistent with previous studies associated with leisure perceptions (e.g. Bedini & Guinan, 1996a; Bedini & Guinan, 1996b; Dupuis, 2000; Wood & Tirone, 2013), constraining factors to leisure (Bedini & Guinan, 1996; Dupuis & Smale, 2000; Schryer et al., 2016; Wood & Tirone, 2013), and caregiving as leisure (Dupuis, 2000).

Leisure perceptions of caregivers

For this study it was important to gain an understanding of the leisure perceptions of caregivers in order to have a better understanding of how their caregiving roles influence their leisure and why they develop specific needs for specific leisure pursuits. Therefore, the researcher firstly explored the perceptions of the formal caregivers who participated in the study. Eight themes regarding caregivers' perceptions of leisure emerged, including (a) time they had free from responsibilities, (b) social interaction, (c) different forms of relaxation, (d) something they do out of their free will, (e) as something that can take place or can be experienced anywhere or any time, (f) as personal time or escape, (g) as different forms of activities they like to participate in, and h) leisure as a positive experience.

Within the theme *Time free from responsibility*, eleven out of the twelve caregivers who participated in the study felt that leisure is something they do after their work is completed, away from responsibilities and that it is something they do voluntary. When asked what their perception of leisure is, Participant 10 replied: "Free time, is my free time and where I do things out of my own volition because I'm away of work". This perception of leisure is consistent with literature which describes leisure as time when you are free to pursue the things you would like to do and time away from responsibilities (Bedini & Guinan, 1996a; Caldwell, 2011; Edginton et al., 2004; Edginton et al., 2005; Godbey, 2008; Henderson, 2010; Henderson, 2012; Kelly, 1990; Kelly & Godbey, 1992; OECD, 2009). A study of Bedini and Guinan (1996b) also revealed findings supporting this theme by elaborating that caregivers' perceived leisure as freedom from worry and responsibility. However, to experience leisure, the condition of freedom alone is not sufficient, a person must also enjoy their experience in order to have leisure (Dupuis, 2000).

Most of the caregivers also perceived leisure within the theme *Social interaction*. They expanded on many different interactions. However, interaction with family was mentioned the most. All twelve caregivers who participated in the study mainly included *family* as a way of social interaction. Also, they valued family time as the most import among the social interactions they prefer to spend time on during their leisure time. Their perception of social interaction with family included having conversations, such as sharing dreams and ideas among each other, bonding with their family, and doing things for each other, and also doing spiritual activities together. This normally takes place during leave due to limited time their work provides to have free time. Participant 2 elaborated: "No normally, because you take a long time before you can actually be with your family. So therefore, during annual leave you sit with your family, bond with your family, you do everything that isn't done at home and sometimes you team together to attend to church together and the other things that you yearn to do while you … ja." One caregiver also mentioned that they cook and eat together, and do things as a family together to treat themselves. Caregivers found it very important to be able to bond with their family, especially because spending time with their family happens only after a long period of time. In the same way, Participant 12 went on to say: "Ja (Yes), sitting around table like that we will be able to chat and exchange ideas, and it is my wish that every time, because it does form bonding element or it serves as a bonding element, and then so that it should be a tradition that whatever, when no one has gone out for work or school we should always have joined meals, common time together". Similar to findings from this study, caregiving daughters in a study of Dupuis (2000) found a sense of connectedness to their parents or people in their care very rewarding. They identified affiliation and relationship to others as important descriptions of leisure (Dupuis, 2000).

Moreover, among things caregivers perceived as family leisure activities, caregivers especially expanded a lot on spending time with their own *children*. Their children are their first priority and, therefore, it may be that they would rather involve their children during their limited leisure time, rather than other family or friends. These caregivers felt that their leisure time is when they can enjoy their time with their own children. Participant 4 answered "Ja (Yes) normally, because leisure is your free time and so forth, I really enjoy it or experience it when I'm home and in company of my kids", while Participant 10 described it as follows: "Well I, when I'm home and you know, children are there, because … homely personality to your kids … for love, they come and they're free, they hold you by your nose, kiss my eh, they … , they nag you sometimes, but they, because of love, they cover you all over and sometimes kiss you all, I mean, in your face all over and you are pleased with them, you feel relieved as, you just feel relieved."

Caregivers' perception of leisure also involves forms of *Relaxation* as a theme. Most of the caregivers work very hard at the centre and find it necessary to relax. Participant 6 explained how her way of relaxing involves spending time in the presence of someone they know when she elaborated: "Ja (Yes), leisure may be just as I explained to you just to be … leisure being to relax amongst or with another person where you can enjoy this or that together". Findings from Bedini and Guinan (1996a) and Dupuis (2000) were consistent with the leisure perceptions of caregivers in this study. As caregivers in Dupuis (2000) stated: "Leisure is fun. Leisure is something you do to relax, take your mind off other problems" (p. 270). Some caregivers also concluded that they have no time for leisure during the week and that they went to sleep after they finished working for the day, because they are too tired from the day's work. In this context caregivers actually perceived resting as a necessity and not as leisure since their primary need was to get rest to be able to survive or have the strength to get up the following day to perform their daily tasks. Participant 7 explained: "To be honest, during the week there’s nothing that I do. When I knock off from here at work I just get there, bath and actually, and because I’m tired I sleep.”

Similar to the theme *Time free from responsibility,* the theme *Free will or freedom of choice*, emerged. All twelve the caregivers who participated in this study perceived leisure as something they do voluntary or out of free will. However, in this context, the main perception was not only about free time and being away from responsibilities, but also to do what they would like to do for leisure. Participants 7 and 2 especially emphasised the importance of leisure as freedom more than once. In this regard, Participant 7’s point of view is that leisure is something they are supposed to enjoy if it is done out of free will as s/he elaborated: “Because anything that you do voluntarily you definitely enjoy, and you do it with love and passion and so forth.” Therefore, because they are free to choose what they want to do, Participant 2 believes that a person has the power to determine or create their own satisfaction from the activities they choose to pursue, saying: “To me leisure would mean, entails when you are able to generate your own satisfaction and perhaps with your family as well”. These perceptions of leisure are consistent to the perceptions of caregivers in a study of Wood and Tirone (2013), as one caregiver stated: “Leisure time is doing what I've want to do without a man telling me what to do. Or having to put up with their foolishness, their drinking. It's nice to know I can go out with a friend, go shopping, or spend a day with my daughters and not have to really answer to anybody for that” (p. 595).

Another theme that emerged was *Leisure as an experience.* Some caregivers, however, a smaller number of caregivers, described leisure as something that can take place anywhere. This perception was also less familiar among previous findings of caregivers’ perceptions. When asked if they also experienced leisure as something voluntary, Participant 6 replied with a slightly different answer: “Ja (yes), I think it’s something interesting, you can’t decide where it is, it just comes automatically that you’re at ease, and it does come or it does not come.” Participant 6 also explained how only she can create her own peace of mind and soul and that no one else can do that for you. This caregiver realised that leisure is something that happens from within, and that their experience does not necessarily depend on the people or places they are surrounded with, however she still needed to be away from the work environment. This may be because of interruptions during their leisure time if they try to do it at the centre, which might limit or terminate the satisfaction of their experience. This caregiver went on to say: “Whilst at home or outside this work environment what I do is I create my own peace. My mind and soul, because there’s no other person who can do that for you.”

Many caregivers also mentioned different leisure activities when asked what they participated in and what their perception of leisure was. As a result, the theme *Leisure as an activity* emerged. To have a better understanding of what one of the caregivers’ perception of leisure was, s/he was asked to name the type of things a person could do as leisure, and Participant 11 mentioned the following activities as things she perceived as leisure: “Going out at the mall, watching movies, later going to the clubs, partying … Going at a park, having fun, meeting with friends”. When looking at activities they actually participate in, the list of activities is much shorter, as in the case of Bedini and Guinana (1996b). For example, Participant 4 mentioned: “Because I am not repeatedly off, when I get home I do the home chores, I clean, I do the washing and also cook for them”.

Furthermore, time to be alone by themselves and having *Time to escape* from their normal routine was another theme that the caregivers revealed. This is also consistent with caregivers’ leisure perceptions in the study of Dupuis (2000) where caregivers experienced leisure moments during certain caregiving roles as an escape. Even though the context in which the caregivers experienced leisure as an escape differs, the definition for leisure is similar to that of the caregivers in Dupuis’s study. Participant 10 explained that she watches television during her leisure time as a mental escape that takes her mind and thoughts away from the daily worries which made her feel refreshed, and like she was in a different world. According to her, concentrating on something on the TV helps to take the focus away from those daily things. This was her response: “But then, when you switch off and you go to a TV that’s another type of a, let me put it as an escape. Because you’ve got a mental fresh, I mean, I won’t say revival, you are concentrating on something on TV which may be educative. Or sometimes it’s informative, that’s in terms of news, but the focus is taken away from all this and that, the daily things, now you are really … also it takes away from the harshness of life, now you are here in another world and you feel refreshed as well, because you are resting away from the daily yes.” Participant 6 also explained how her leisure time involves being by herself, she explained: “Now that’s time where I confine myself alone to myself, even telling my son just please give me peace of mind.”

All twelve caregivers perceived leisure within the theme *Leisure as a positive experience* and reveal several benefits it contains. This is consistent with literature regarding leisure benefits revealing that participation in leisure activities helps individuals to relax, increase energy and happiness, cope with, or release stress and demands of daily life, and associate with other individuals (Brattain, 1997; Coleman & Iso-Ahola, 1993; Iwasaki & Mannell, 2000; Rodriguez & Gamble, 2010; Stumbo & Peterson, 2004; Wood & Tirone, 2013). Similar, but to some extent different from those findings, caregivers from this study were of the opinion that leisure time is a recuperative, uplifting, and refreshing experience and it makes them feel like they are in another world. The outcome of having these positive leisure experiences is that caregivers can come to work without all the negative emotions and with more energy. Participant 6 elaborated how her alone time helped her to see things clearer and that she feels lighter. She went on to say: “Ja (yes) during that time of … or my loneliness, actually I am going through a lot of things, and that is, it is emotional and psychological therapy, because thereafter, after doing all of that and [take deep breath in and out as demonstration] I have a better heave and a sigh, and I feel lighter again”. Along the same line, Participant 9 explained that leisure time helps to forget about work, to have better judgement over things, and that they can come to work without anxiety by stating: “… you’ll always yearn to get satisfied when you get there then you are lift up and you are able to judge whether this is good, this is bad, and then when you come back that anxiety is satisfied”.

Furthermore, Heintzman and Mannell (2003) explain that leisure can influence people’s spirituality, spiritual well-being, and overall health. Caregivers in the study of Gahagan et al. (2007) also revealed that their spirituality gave them a sense of comfort and a better understanding of themselves. Moreover, leisure recharges and energises caregivers from their responsibilities as a caregiver (Dupuis & Smale, 2000). Findings from Dupuis and Smale (2000) as well as Heintzman and Mannel (2003) are consistent with findings from this study. Seven caregivers during the interviews specifically expanded on leisure as attending church and spiritual activities. From those seven caregivers, many also explained the positive experiences that they gained by going to church and participating in spiritual activities. One of them, Participant 12, said: “Aaah, I feel so free and so good that it appears I’m in just another world. Ja (yes), I feel rejuvenated actually, feeling rejuvenated … that as if I’m going to my original self.”

Leisure time influences: Constraining factors

When the researcher explored the influences of caregiving on the leisure of the caregivers it was found that most of the influences caregiving had on their leisure was experienced negatively, which is similar to several previous studies (Bedini & Guinan, 1996b; Dupuis & Smale, 2000; Wood & Tirone, 2013; Wahl and Newmark, 2009). These negative influences can be described as constraining factors, limiting the caregiver’s ability to participate in leisure, or to have a satisfying leisure experience. Dupuis and Smale (2000) reveal similar findings, explaining that some informal caregivers in their study experienced their caregiving role “as a constraint to their leisure”. The constraining factors that emerged as themes in this study included (a) time related factors, (b) organisational factors, (c) physiological factors, (d) social factors, and (e) psychological factors.

The theme that emerged the most during the interviews was *Time related factors* as a constraint to the caregivers’ leisure. All the caregivers mentioned that they have limited time for leisure, due to their caregiving duties. Caregivers also explained how the intensity of their work made it very difficult for them to have leisure, and that they would neglect their duties if they would have to take time for leisure. When asked what makes time for leisure difficult, Participant 2 responded: “Because of the intensity of the work here, you hardly even have time for leisure, and if you had wish for certain things and you cannot say I’m going for leisure now at the expense of suffering of the work for which …, so you normally have this and this to do. And then to jump for this or that, to patch up here or there”. Similarly, Participant 1 also explained: “The very things I like and love most that I like to do, that’s just to mention them, to … do this and so forth, in terms of my free time, is that I sacrifice them because I know if I’m going to attend to do some of my likes and my free time or my pleasure, if I do that, neglect it, something else negatively happens there. So that’s why I, it’s difficult, to really do things that I like here in terms of free or leisure time because of this commitment”. It also seems that if caregivers had any free time at the centre that they have to see to their personal responsibilities first before they can think of leisure. They would also possibly prefer to do something else for leisure instead of doing laundry, if time was more available. Participant 12 went on to say: “Little free time, when I am able to get it I do my washing.” Time constraints is quite a major theme emerging from research on caregivers (e.g. Bedini & Guininan, 1996b; Dupuis & Smale, 2000; Wood & Tirone, 2013). For example, Bedindi and Guinan (1996b) state that caregiving demands affect caregivers’ accessibility for leisure. One of the caregivers in their study explained: “I would like to have time to get my house clean. I would like to have time to do my own work, I'm kind of letting that go now, because she is constantly needing to know where I am. If I walk out of the room, she calls and says, where are you? (Bedini & Guinan, 1996b, p. 282)” According to Bedini and Guinan (1996b) time demand creates time pressures associated with responsibilities and increased duties which lead to emotional and physical fatigue. Also, according to Schryer et al. (2016) more caregiving duties and less time spent on leisure may have a negative influence on the mental and physical health of caregivers. Thus, it can be concluded that time related factors in this study can be associated with the themes psychological and physiological factors, since less time for leisure leads to a negative impact on the physical and mental wellbeing of caregivers.

Furthermore, many caregivers explained that their leisure time is cut short due to staff shortage at the centre or assistance with something specific, which fall within the theme *Organisational factors*. Caregivers would be away from the centre during their leisure time when they receive calls from the centre to come and help out with certain situations. They would have no choice, but to go back to assist where help is needed. Participant 12 stated: “Seeing that when I shall have left here, time to relax and enjoy my time, I’ll be called again to come to work for this and that.” Similarly, Participant 11 lamented: “When I’m day off they’ll call me and say, [manager] will say come, let’s go to town, go with me in town, or come and help us with this, we don’t know how to switch on the TV, the DSTV is doing like this.”

It seems that caregivers from different contexts’ experiences of not having enough outside help (e.g. Bedini & Guinan, 1996b; Wahl & Newmark, 2009) are consistent with findings from this study. One of the caregivers in the study of Wahl and Newmark (2009) explained that at the previous facility she worked the care receivers were just as much as where she is working now, but the previous facility had almost double the number of caregivers or staff working there than where she works now.

One of the other major constraints reported in previous research, and also found in this study, is *financial difficulties*, which makes it difficult for caregivers to always do what they like to do during their leisure time (Bedini & Guinan, 1996b; Wood & Tirone, 2013). Financial difficulty was mainly caused by organisational factors such as lack of structure and financial management at the centre, which results in caregivers not always receiving their monthly payments on time. The caregivers explained that they cannot do much without money. Most of their relatives stay far from the centre and it is difficult to visit their family or do something during leave when finances are limited. Many caregivers get discouraged by this issue. This may also be because of no money to pay for transport (Wood & Tirone, 2013). How financial difficulties affect leisure is reflected by the response of Participant 4: “No normally it’s quite a long time to leave, I mean annual leave is a quite a substance of time, but because of limitations of fees, I mean of money, wages, because when I’m there for the month, my pay won’t follow me there. Then you are not able to do all that you wanted to do because of limitation of the money that you have, but I do go out and meet my… where it is possible, meet my relatives and visit them. But there is not much you can do outside the scope of money.”

Within the theme *Physiological factors,* caregivers elaborated on caregiving-related factors that influence them physically, which is also consistent with findings from Wahl and Newmark (2009), as well as Bedini and Guinan (1996b). In the study of Wahl and Newmark (2009) one caregiver explains that she gets physically ill from the hard work, because she is an asthmatic. According to caregivers from this study, they have a very physical demanding work to perform every day, since they need to pick the children up, sometimes carry them, and do their basic daily responsibilities at the centre. All twelve caregivers in this study responded that their work is tiring, as reflected by Participant 9: “Jaa (Yes) … sometimes you’ll feel tired and then you maybe said that you want to go see someone or just do something and then you end up feeling tired and say “nah” I don’t want to go there anymore. Too tired, ja (yes).” However, some of them went on to explain how it is negatively impacting their time for leisure or their leisure experience. Some caregivers explained that caregiving causes their bodies to get exhausted or painful, which is similar to findings by Bedini and Guinan (1996b), and as a result they rather cancel the plans they had for doing something in their free time and rest. In terms of physical pain caused by caregiving, Participant 7 noted: “Hm. Indeed it is so, because our work is really manual, you have to bend and pick them up sometimes, carry them and cook, you wash. Definitely when, at the end of the day you are exhausted, you’ve got painful. You’ve got pains here and there, and that definitely impact on your leisure time, impeding any leisure time. Because you will not be able to exercise that leisure because of this, the impact that you have, the results of that type of exercise of work.” When asked with what type of activities caregiving would mostly impact, Participant 7 responded: “Ja (yes), well firstly and foremost, it is that it will affect your happiness, because you can’t enjoy anything with pain.”

Furthermore, within the theme *Social factors*, 10 caregivers revealed that they miss their family, and friends, however, there are things that keep them from spending time with their relatives, or influence the time they may have with each other. This included caregivers being too tired to spend time with their family, or they long for spending time amongst their family or friends, but distance and available time do not make it possible. It is clear that these caregivers’ opportunities to interact with the people they love is very limited due to their caregiving role. The effect of exhaustion on social interaction is reflected in the comment of Participant 7: “[Short laugh] I hardly even sit to get around with them because by then I’m dead tired. … Ja (yes) I’m referring to my two kids and their father”, while Partricipant 6 highlights how much s/he longs for interaction with family: "You know sometimes it just occurs that you really yearn and long for people just to feel I wish I was in company of my siblings or family members*"*. These sentiments are in line with findings from Bedini and Guinan (1996a), Bedini and Guinan, 1996b), and Wahl and Newmark (2009), who found that in their studies caregivers also experienced social isolation and could not get out from their circumstances often enough. They concluded that not having enough social interaction or getting out enough leads to stress and burnout (Wahl & Newmark, 2009).

Caregivers also experienced constraints within the theme *Psychological factors* that influence their levels of leisure satisfaction. Caregivers' stress and tiredness from work influenced their quality of time they spent on leisure. They also felt like their minds were constantly at the centre because they are worried that things would be left unfinished in their absence. These constraints were of such nature that the caregivers could not really enjoy their time with their friends and family. Furthermore, negative emotions also affect their leisure when they are with family since they feel they must pretend that they are happy. Participant 11 clearly describes how caregiving influences leisure satisfaction in the following: "Ah, let me say like this. No if I leave here tired and have a lot of stress, when I go home there, that stress, that tiredness, I must leave it there. Because at home they don't see me most of the time, they see me once a month, once a year, twice a year. So, I must go there, when I open up the door I'm like, I'm angry or I'm sad, or I'm tired, I must go there with a smile, no matter what. I pretend."

The findings in terms of psychological factors are also supported by several studies including Bedini and Guinan (1996b), as well as Wahl and Newmark (2013). Wahl and Newmark (2013) found that caregivers have to suppress their feelings when they are around care receivers. However, different from this study, they also expressed moodiness, and became depressed due to their working circumstances (Wahl & Newmark, 2013). On the other hand, caregivers from the study of Bedini and Guinan (1996b) expressed that they experience a loss of dependence which make them angry and upset. They also experienced a loss of mental freedom (Bedini & Guinan, 1996b). This constraint to mental freedom was more of an emotional experience to caregivers since they felt that they constantly have to worry and think about the care recipient (Bedini & Guinan, 1996b) which is consistent to the findings from this study, as in the case of Participant 12: “Ja (yes), it does really definitely have a type of influence, for instance I was off for two days, that is yesterday and today, but you know, as I was on off yesterday, being there, I was not actually there, because I was here in mind, because then the others say “Oooh”, knowing the people that I work with, have they really checked the hospital dates or the … of the kids to be taken to hospital? So each time when I’m out here you always have these little think-think, you are not really relaxing to an extent that when you are sitting and enjoying your moments with whoever. They’ll be able to see … that you are not concentrating. And often they ask you, “but what are you thinking of now?” I’m sorry I’m thinking of my job. So that’s how it impacts physically and, no I mean mentally.”

Caregiving as leisure

Although caregivers have their main perceptions of leisure in general, and most caregivers see caregiving only as their work and responsibility, there were a few who expressed that they also experience part of their caregiving work as leisure. Seven of the twelve caregivers said that they experience some parts of their work at the centre as leisure. About three caregivers also specifically expanded on playing cricket with the children whereas other caregivers experienced other forms of responsibilities as leisure. Participant 6 explained how taking the kids to play cricket is leisure for her by stating: “During my leisure time here I normally take these kids, because they are cricketers, I take them for training just across Morocco road where there’s a cricket stadium”. She also went further to say: “The … to my kids really is recreational … say I'm a cricket trainer or something, and I accept that … of all cricket in my spare time and actual time, I'm able to teach them traditional dance songs". Participant 5 also went on to say: "… the way you use your mind to try to come up with activities that might benefit malenas (children?) in this case, like we'll be all cutting paper and paper drawing somewhere so that it can aid my teaching, I mean teaching me and the children. Uh, also preparation, I did during my leisure time. Even preparation for lessons and so forth, I do the preparations during my leisure time". These findings can be supported by Dupuis (2000) who argue that a person does not have to be separated from life and daily obligations to experience leisure. According to Dupuis (2000), a caregiver may also experience a sense of escape in some obligatory activities, depending on the context. Therefore, these leisure experiences during work may even act as a facilitator to their demanding roles, however this is a topic for another study.

Conclusion

Considering the findings from this study it is clear that caregivers perceive their meanings of leisure and the influence that caregiving has on their leisure in very different ways. They perceived leisure as time they had free from responsibilities, social interaction, different forms of relaxation, something they do out of their free will, as something that can take place or can be experienced anywhere or any time, as personal time or escape, and also as different forms of activities. These perceptions are consistent with literature revealing that leisure is time free from responsibilities, an activity which involves a certain action, and a state of mind which entails an attitude occurring in an activity, or a psychological condition (Edginton et al., 2005; Godbey, 2008; Henderson, 2010; Kelly & Godbey, 1992; OECD, 2009; Parr & Lashua, 2005).

Constraining factors caregivers experienced included time related factors, organisational factors, physiological factors, social factors, and psychological factors. These factors were not clustered under the three basic constraints that most literature refers to namely, intrapersonal constraints, interpersonal constraints, and structural constraints, since the researcher preferred that the unique voices of caregivers in this study should stand out, instead of trying to fit them into predetermined “compartments” established through research on other constrained populations. However, intrapersonal constraints involved the themes *psychological factors* such as worry over children, tired from work, and having to pretend to be happy when they are with family, and *physiological factors* such as physical pains and tiredness preventing them to enjoy leisure or to participate. Interpersonal constraints included the theme *social interaction* where caregivers where too far to interact and bond with family, but also due to their working schedule that interferes with their family time. Structural constraints included *organisational factors* such as staff shortage, financial difficulties and time related factors. Nevertheless, findings on research of Bedini and Guinana (1996), Dupuis and Smale (2000) and Rogers (2001) can be compared to caregivers’ experiences in this study, which is that caregiving acts as a constraining factor to the leisure of caregivers in this study. The central theoretical statement of this study was that the primary caregivers of persons with disabilities will experience caregiving as a negative impact on their leisure, which is supported by the study’s findings, even though some of them also experienced leisure in certain caregiving activities, such as doing sport activities with the children, which is similar to Dupuis (2000) who found that caregiving can be a container of leisure.

Limitations

When conducting the study, the sample mainly consisted of black African female participants and two black African male participants, therefore, failing to reveal the opinions on different genders or races. Also, limited literature revealing leisure time influences and leisure constraints to caregivers, such as Bedini and Guinin (1996b) and Whal and Newmark (2009), hampered the researcher’s ability to integrate and compare the findings with a wide range of research. Therefore, future research should attempt to request a more diverse sample by applying approaches that include recruitment in centres or institutions that have greater diversity. Furthermore, most of the participants are residing at the care centre, and only a few of them have their own residence to which they go to after working hours. This should be taken into consideration when conducting future research since it could influence the level and type of constraints caregivers experience to their leisure. The study was also limited by language barriers since the caregivers' first language are Setswana, in which there are no exact translations for the term leisure. With the help of a translator, the researcher had to find other ways to explain the concept of leisure in order to conduct meaningful interviews. Furthermore, communication difficulties were experienced since both the researcher and participant had to communicate through a third person in their second language. Lastly, this study was based on an exploratory case study approach focusing on a specific case which means that the study findings cannot be generalised.

Recommendations

This study provides information on the leisure perceptions and the negative influences that caregiving has on the leisure. It was focused on a specific group of formal caregivers who provided primary care to children with disabilities on a long-term basis in an under-resourced area. Yet, limited previous research is based on the leisure of formal caregivers in South Africa, especially in under-recourse areas. Uren and Graham (2012) go on to say, "it is important to acknowledge the realities of the under-resourced and overburdened healthcare system in South Africa, in particular in providing palliative medical care in poorer communities." In community-based institutions caregivers are often exposed to longer working hours, less support, limited opportunities for debriefing and also have to deal with the needs of care receivers (Freeman et al., 1998). Therefore, it may be helpful to conduct more research on the supporting factors to the leisure of formal caregivers in South Africa, in order for centre managers and leisure programmers to be able to provide the necessary leisure programmes or support interventions. These leisure programmes and support interventions could assist caregivers, as Uren and Graham (2012) emphasise that caregivers should be able to access interventions, support groups, and therapeutic assistance to help relieve the severity and the impact of their own situations.

References

Axelsson, A.K. (2015). The role of the external personal assistants for children with profound intellectual and multiple disabilities working in the children's home. *Journal of Applied Research in Intellectual Disabilities,* 28(3), 201-211.

Bakker, A.B., Killmer, C.H., Siegrist, J. & Schaufeli, W.B. (2000). Effort-reward imbalance and burnout among nurses. *Journal of Advanced Nursing,* 31(4), 884-891.

Bedini, L. A. (2002). Family caregivers and leisure: An oxymoron? *Parks and Recreation,* 37(1), 25-31.

Bedini, L. A. & Guinan, D. M. (1996a). "If I could just be selfish...": Caregivers' perceptions of their entitlement to leisure. *Leisure Sciences*, 18(3), 227-239.

Bedini, L.A. & Guinan, D.M. (1996b). The leisure of caregivers of older adults: Implications for CTRS's in non-traditional settings. *Therapeutic Recreational Journal,* 30(4), 274-288.

Blanes, L., Carmagnani, M.I.S. & Ferreira, L.M. 2007. Health related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord*, 45(6), 399-403.

Brandon, P. (2007). Time away from "smelling the roses": where do mothers raising children with disabilities find the time to work? *Social Science & Medicine,* 65(4), 667-679.

Brattain, R.N. (1997). Centrality of the caregiving role and integration of leisure in everyday life: a naturalistic study of older wife caregivers. *Therapeutic Recreation Journal*, 30(4), 230-243.

Brehaut, J.C., Kohen, D.E., Raina, P., Walter, S.D., Russell, D.J., Swinton, M., O'Donnell, M. & Rosenbaum, P. (2014). The health of primary caregivers of children with Cerebral

Palsy: how does it compare with that of other Canadian caregivers? *Journal of American Academy of Paediatrics*, 114(2), 182-191.

Buchanan, R., Ranin, D., Chakravorty, B.J. & Tyry, T. (2009). Informal caregiving to more disabled people with multiple sclerosis. *Disability and Rehabilitation*, 31(15), 1244-1256.

Bulent, G., Fatih, Y., Beyza, A.M. & Saut, K. (2010). Measuring constraints to leisure activities: demographic differences. *Science, Movement and Health*, 20(20), 362-364.

Burns, R.C. & Greafe, A.R. (2007). Constraints to outdoor recreation: exploring the effects of disabilities on perceptions and participation. *Journal of Leisure Research*, 39(1), 156-181.

Caldwell, L.L. (2011). Leisure. *Encyclopaedia of Adolescence*, 2, 169-177.

Carter, R. & Golant, S. (1994). Helping yourself help others: A book for caregivers. New York: Three Rivers Press. Retrieved from http://www.amazon.com/Helping-Yourself-Help-Others-Caregivers/dp/0812925912

Chick, G. & Dong, E. (2003). Possibility of refining the hierarchical model of leisure constraints through cross-cultural research. In Murdy, J.J., (Ed.). *Proceedings of the 2003 North-eastern Recreation Research Symposium* (pp. 338-344), New York, 6-8 April. Retrieved from https://s3.amazonaws.com/academia.edu.documents/45293812/ download.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1507576170& Signature=PW6n4eHsTeDHgfmD394eDFUxSw8%3D&response-content disposition=inline%3B%20filename%3DDoes_distance_matter_Differences_in_char.pdf#page=346

CNS (Centre for Neuro Skills). (2014). Disability rating scale. Retrieved from http://www.neuroskills.com/resources/disability-rating-scale.php

Coleman, D. & Iso-Ahola, S.E. (1993). Leisure and health: The role of social support and self-determination. *Journal of Leisure Research*, 25(2), 111-128.

COMBI (The Centre for Outcome Measurement in Brain Injury). (2000). The disability rating scale. Retrieved from http://www.tbims.org/combi/drs

Dick, B. (2012). *Convergent interviewing essentials: An introduction to the key features of a combined interviewing and data analysis technique*. Retrieved from http://www.aral.com.au/resources/coin.pdf

Dijkers, M. & Greenwald, B. (2007). Functional assessment in TBI rehabilitation. In Zasler, N.D., Katz, D.I. & Zafonte, R.D., (Eds.), *Brain injury medicine: Principles and practice* (pp. 225-246). New York, NY: Demos Medical Publishing.

Du Preez, R. (2010). *An ethnographic study of caregiving at a day care centre for developmentally challenged children* (Masters dissertation). Pretoria: University of South Africa. Retrieved from ir.unisa.ac.za/bitstream/handle/10500/4685/dissertation_depreez_r.pdf?sequence=1

Dupuis, S.L. (2000). Institution-based caregiving as a container for leisure. *Leisure Sciences*, 22(4), 259–280.

Dupuis, S.L. & Smale, B.J.A. (2000). Bitter sweet journeys: Meanings of leisure in the institution based context. *Journal of Leisure Research*, 32(3), 303-340.

Edginton, C.R., Hudson, S.D., Dieser, R.B. & Edginton, S.R. (2004). Leisure programming: A service-centered and benefits approach. (4th ed.). New York, NY: McGraw-Hill.

Edginton, C.R., Hudson, S.D. & Scholl, K.G. (2005). Leadership for recreation, parks, and leisure services. (3rd ed.). Champaign, IL: Sagamore.

Freeman, M., Ramanathan, S., Aitken, A., Dunn, P. & Aird, J. (1998). Rural palliative care volunteer education and support program. *Australian Journal of Rural Health*, 6(3), 150-155.

Gahagan, J., Loppie, C., Rehman, L., Maclellan, M. & Side, K. (2007). Far as I get is the clothesline: the impact of leisure on women's health and unpaid caregiving experiences in Nova Scotia, Canada. *Health Care for Women International*, 28(1), 47-68.

Geer, J.L., Gona, J., Omondi, F.O., Kilafu, M.K., Newton, C.R. & Hartley, S. (2012). Caring for children with physical disability in Kenya: potential links between caregiving and cares' physical health. *Child: Care, Health and Development*, 39(3), 381-392.

Gladwell, N.J. & Bedini, L.A. (2004). In search of lost leisure: The impact of caregiving on leisure travel. *Tourism Management*, 25(6), 685-693.

Godbey, G. (2008). Leisure in your life: new perspectives. Edmonton, Alberta: Venture.

Godbey, G., Crawford, D.W. & Shen, X.S. (2010). Assessing hierarchical leisure constraints theory after two decades. *Journal of Leisure Research*, 42(1), 111-134.

Greeff, M. (2011). Information collection: Interviewing. In *Van Schaik Publishers*, (Ed.). *Research at grass roots* (4th ed.) (pp. 341-374). Pretoria: Van Schaik Publishers.

Greenlee, J. & Scharlach, A. (2001). Caregivers' characteristics and needs. In *Family caregivers in California: Needs, interventions and model programs* (pp. 7-48). Berkeley, CA: University of California. Center for the Advanced Study of Aging Services. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.547.783&rep=rep1&type=pdf

Hawkins, B.A., Peng, J., Hsieh, C-M. & Eklund, S.J. (1999). Leisure constraints: A replication and extension of construct development. *Leisure Sciences*, 21(3), 179-192.

Heintzman, P. & Mannell, R.C. (2003). Spiritual functions of leisure and spiritual well-being: coping with time pressure. *Leisure Sciences: An Interdisciplinary Journal*, 25(2-3), 207-230.

Henderson, K.A. (2006). *Dimensions of choice: Qualitative approaches to parks, recreation, tourism, sport and leisure research*. (2nd ed.). State College, PA: Venture Publishing.

Henderson, K. (2010). Importance of leisure to individual society. In Human kinetics. *Dimensions of leisure for life: Individuals and society* (p. 3-26). Champaign, IL: Human Kinetics.

Henderson, K.A. (2012). The contributions of leisure and active recreation to health and well-being. *African Journal for Physical, Health Education, Recreation and Dance*, 18(Suppl. 4), 52-63.

Hung, L.-C., Liu, C.-C. & Kuo, H.-W. (2002). Unmet nursing care needs of home-based disabled patients. *Journal of Advanced Nursing*, 40(1), 96-104.

Hutchinson, S.L. & Kleiber, D.A. (2005). Leisure constraints, and negative life events: paradox and possibilities. In Jackson, E.L., (Ed.). *Constraints to leisure* (pp. 137-149). PA: Venture publishing.

Iwasaki, Y. & Mannell, R. (2000). Hierarchical dimensions of leisure stress coping. *Leisure Sciences*, 22(3), 163-181.

Jackson, E.L. (2005). Leisure constraints research: overview of a developing theme in leisure research. In Jackson, E.L., (Ed.). *Constraints to leisure* (pp. 3-19). State College, PA: Venture.

Jackson, E.L. & Scott, D. (1999). Constraints to leisure. In Jackson, E.L. & Burton, T.L. (ED.). *Leisure studies: prospects for the twenty-first century* (pp. 299-316). State College, PA: Venture.

Kalb, C. 21-25 Feb. (2005). *When does autism start?* Newsweek magazine. Retrieved from http://www.foothilltech.org/krenger/psychology/unit7_research/when_autism_start.pdf

Kelly, J. & Godbey, G. (1992). *Sociology of Leisure*. State College, PA: Venture.

Kelly, J.R. (1990). *Leisure*. (2nd ed.). New Jersey, U.S.A: Prentice-Hall Inc.

Kuster, P.A. & Merkle, C.J. (2004). Caregiving stress, immune function, and health: implications for research with parents of medically fragile children. *Issues in Comprehensive Paediatric Nursing*, 27(4), 257–276.

Losada, A., Peres-Penaranda, A., Rodiquez-Sanchez, E., Gomes-Marcos, M.A., Ballesteros-Rios, C., Ramos-Carrera, I.R., Campo-de la Torre, M.A. & Garcia-Ortiz, L. (2010). Leisure and distress in caregivers of elderly patients. *Archives of Gerontology and Geriatrics*, 50(3), 347-350.

Lucchetti, G., Lucchetti, A.L.G., Oliveira, G.R., Crispim, D., Pires, S.L., Gorzoni, M.L. & Koenig, H.G. (2014). Nursing home care: exploring the role of religiousness in the mental health, quality of life and stress of formal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 21(5), 403-413.

OECD. (2009). Society at a glance 2009: OECD social indicators. Paris: OECD. Retrieved from http://dx.doi.org/10.1787/soc_glance-2008-en.

Parr, M.G. & Lashua, B.D. (2005). Students' perceptions of leisure, leisure professionals and the professional body of knowledge. *Journal of Hospitality, Leisure, Sport and tourism Education*, 4(2), 16-26.

Pitetti, K.H. & Fernhall, B. (2005). Mental retardation. In Skinner J.S., (Ed.), *Exercise testing and exercise prescription for special cases: Theoretical basis and clinical application* (3rd ed.) (pp. 392-401). Philadelphia, PA: Lippincott William & Wilkins.

Rodriguez, A. & Gamble, D. (2010). *Leisure and quality of life*. In Human Kinetics. *Dimensions of leisure for life* (p. 1-367). Champaing, IL: Human Kinetics.

Rogers, N.B. (2001). Family obligation, caregiving, and loss of leisure. *Activities, Adaptation and Aging*, 24(2), 35-49. DOI: 10.1300/J016v24n02_03

Rose, T. & Williams, D.J. (2015). Nurse leadership: The importance of balancing work with leisure. *Nurse Leader*, 13(3), 60-62.

Schryer, E., Mock, S.E., Hilbrecht, M., Lero, D. & Smale, B. (2016). Use of leisure facilities and wellbeing of adult caregivers. *Leisure Sciences*, 38(1), 17-33.

DOI: 10.1080/01490400.2015.1038373

Schultz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249.

Scott, D. (2005). The relevance of constraints research to leisure service delivery. In Jackson, E.L., (Ed.), *Constraints to leisure* (pp. 279-293). PA: Venture publishing.

Shaw, S.M., & Henderson, K. (2005). Gender analysis and leisure constraints: an uneasy alliance. In Jackson, E.L., (Ed.), *Constraints to leisure* (pp. 23-34). PA: Venture publishing.

Son, J.S., Mowen, A.J., & Kerstetter, D.L. (2008). Testing alternative leisure constraint negotiation models: An extension of Hubbard and Mannell’s study. *Leisure Sciences*, 30(3), 198–216.

Stanis, S.A.W, Schneider, I.E., & Pereira, M.A. (2010). Parks and Health: Differences in constraints and negotiation strategies for park-based leisure time physical activity by stage of change. *Journal of Physical Activity and Health*, 7(2), 273-284.

Stuart, S.J., Stone, C.F., & Rider, C.Y. (2005). A paradigm shift in therapeutic recreation: from cure to care. In Jackson, E.L., (Ed.), *Constraints to leisure* (pp. 295-309). PA: Venture publishing.

Stumbo, N.J. & Peterson, C. (2004). *Therapeutic recreation program design: Principles and procedures*. (4th ed.). San Francisco, CA: Pearson.

Tu, S.F. (1993). *The relationship between leisure and perceived burden of spouse caregivers of persons with Alzheimer’s disease* (Masters dissertation). Denton, TX: University of North Texas. Retrieved from https://digital.library.unt.edu

Uren, S.A. & Graham, T.M. (2012). Contextual elements of palliative caregiving in a low-income community. *South African Journal of Psychology*, 42(1), 61-70.

Vitaliano, P.P., Scanlan, J.M. & Zhang, J. (2003). Is caregiving hazardous to one’s physical health? A meta-analysis. *Psychological Bulletin*, 129(6), 946-972.

Wahl, S. & Newmark, R. (2009). The self-perceived quality of life of staff caring for adults with intellectual disabilities. *Journal of Humanities*, 49(2), 289-306.

White, S.A. (2008). B Increasing longevity: The challenges of aging and caregiving. *Journal of Vascular Nursing*, 28(4), 96-99.

Williams, A. & Crooks, V.A. (2008). Introduction: Space, place and the geographies of women's caregiving work. *Gender, Place and Culture*, 15(3), 243-247.

Wood, S. & Tirone, S. (2013). The leisure of women caring for people harmfully involved with alcohol, drugs, and gambling. *Journal of Leisure Research,* 45(5), 583-60.

Yin, R.K. (2003). *Applications of case study research*. (3rd ed.). Thousand Oakes, CA: Sage.

Yin, R.K. (2014). *Case study research: design and methods*. (5th ed.). Washington, DC: Sage.

CHAPTER 4: THE LEISURE NEEDS OF FORMAL CAREGIVERS OF INDIVIDUALS WITH DISABILITIES IN A CENTRE IN THE NORTH WEST PROVINCE

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The leisure needs of formal caregivers of individuals with disabilities in a centre in the North West Province: A case study

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Abstract

The researcher explored and described the leisure needs of formal caregivers of persons with disability. This study made use of a qualitative approach and semi-structured one-on-one interviews, and included 12 formal caregivers. It was based on an exploratory case study design. The central theoretical statement of this study was that the primary caregivers of persons with disabilities will experience high levels of unmet leisure needs. Six themes and seven sub-themes emerged and where clustered into two categories, namely leisure perceptions and leisure needs. The categories that emerged included caregiver perceptions of leisure, and leisure needs. It was found that caregivers experience high levels of unmet needs of which needs for time and money was the highest.

Keywords: Leisure, leisure needs, caregiving, leisure perception

Needs of caregivers of persons with disabilities often go unrecognised by professionals and those dependent on them (Kersten et al., 2001), especially in the South African context (Greyventstein, 2010; Kreuger, 2007). Caregiving in the context of this study involves formal care, which is paid care provided by practitioners such as social workers and home care workers, including people who have formal training such as nursing (Williams & Crooks, 2008), whereas informal caregiving include family or relatives who provide unpaid care to a chronically ill or disabled loved one (Bedini, 2002; Buchanan et al., 2009; Carter & Golant, 1994; Gladwell & Bedini, 2004; Schultz & Martire, 2004). Bingham (2017) states that caregivers sacrifice their own needs to care for others, and as a result they are overworked and mostly unappreciated. The responsibilities and heavy workload that caregivers face may lead to psychologic and physical health problems (like emotional exhaustion, distress and burnout), and have substantial impacts on a caregiver's life, including their leisure lifestyle (Brehaut et al., 2004; Dupuis, 2000; Hung et al., 2002). For caregivers to keep healthy, Rose and Williams (2015) explain that it is important for caregivers to have a good balance between their work and personal lives by incorporating leisure activities and realizing the health benefits leisure provides.

Leisure activities have proved to be beneficial for the wellbeing of an individual, especially psychologically, when their leisure needs are satisfied (Leverson et al., 2012; Tinsley & Eldredge, 1995). Rose and Williams (2015) also mention that formal caregivers, who regularly participate in leisure outside of working conditions, will benefit significantly from it. However, leisure participation does not necessarily reduce stress or meet caregivers' needs (Bedini & Gladwell, 2014). Bedini and Gladwell (2014) found that leisure experiences will only be effective in stress reduction and increasing health and quality of life if they are fulfilling and meaningful for the caregivers. Thus, in order for caregivers to gain the positive effects from leisure, caregivers have to be satisfied with the quality of their leisure experiences as well as the available time for leisure (Bedini & Gladwell, 2014). Furthermore, Aslan et al. (2006) concludes that if the social, psychological, physical, and emotional needs of caregivers are well met and defined, they may feel more comfortable to carry out their roles effectively and constantly, but, if these needs go unmet or unrecognised, it will have a negative effect on caregivers' burden (Akkus, 2011). Lee et al. (2015) also mention that responding to caregivers' needs is important because it may ensure and improve their working standards and in turn improve their quality of care.

A leisure need is something inherent to the human nature, rather than something learned; it is dynamic and develops over time, it triggers activity participation, and it does not have to be created by programmers through any form of techniques (Deci et al., 2001; Dekker et al., 2014; Fourie, 2006; Rossman, 1995). White and Kenneth (1985) goes on to say that an individual is motivated to participate in leisure when there is a desire to satisfy certain needs. Furthermore, literature reveals that when psychological needs are satisfied in the domain of leisure activities, it is positively associated with increased life satisfaction (Leversen et al., 2012; Tinsley & Eldredge, 1995). These psychological needs include for instance needs for affiliation, self-expression, enhancement, nurturance, and sensibility (Tinsley & Eldredge, 1995). Several researchers also refer to psychological needs in Ryan and Deci's theory of self-determination, which include needs of autonomy, relatedness and competence, which means that the satisfaction of these needs would promote wellbeing and motivation, in all cultures (Barkoukis et al., 2010; Deci et al., 2001; Leversen et al., 2012).

However, according to Barkoukis et al. (2010) the influence of need satisfaction on activity motivation in leisure is limited. More specific, it is unclear what the leisure needs of formal caregivers in South Africa are. Since leisure plays a significant role in helping people meet their personal needs, this study aims to explore the leisure needs of formal caregivers in the North-West Province. This specific focus is important because of the large number of people in underresourced areas in South Africa, who are removed from essential services, including leisure (Singh, 2011:70). It is also critical that leisure programmers and managers of disability centres understand leisure needs in the context of formal caregiving since the demands of caring for a child or individual with a disability are far more than in cases of a child of normal development (Bakker et al., 2000:885; Brandon, 2007:668; Brehaut et al., 2014:183).

Henceforth, the research question is, “what are the leisure needs of formal caregivers of individuals with disabilities in the North West province? This study will aim to provide useful information to leisure service providers and various health care organisations about the leisure needs of formal caregivers and the consequences if caregivers have unmet leisure needs. It will also help leisure service providers and centre managers to know how to adjust the programmes they offer to address the leisure needs of the caregivers.

Methods

Research design

This study made use of a qualitative approach based on an exploratory case study design as explained by Yin (2003). Data was collected through semi-structured one-on-one interviews as recommended by Greeff (2011), since the study aimed to explore the leisure needs of formal caregivers of persons with disabilities in the North West province. The central theoretical statement of this study is that the primary caregivers of persons with disabilities experience high levels of unmet leisure needs and that caregiving has a negative impact on the leisure of caregivers of disabled people in the North West province.

Study population

The study population included formal caregivers employed at a full-time care centre from an under resourced area in Rustenburg, in the North West province of South Africa. The centre exists of 25 caregivers and more than half of the caregivers reside at the centre permanently. The other caregivers reside in under resources areas in Rustenburg and work on a full-time basis. Participants are also the primary caregivers of the persons with disability and get paid for taking care of the individuals as their full-time job. The time that the caregivers have been working for the centre varies, with a minimum of one (1) year and a maximum of 20 years.

Furthermore, caregiving roles are rotated among caregivers, which mean that caregivers frequently perform different caregiving tasks. For the caregivers residing at the care centre, responsibilities are similar to having responsibilities of a normal household, accept that caregivers have the responsibility to care for 30 children and the children they care for require much more attention and care than children of normal health. The children with disabilities stay at the centre on a permanent basis and only visit their relatives or parents during school holidays, if at all. Some children at the centre also sleep on the floor on matrasses as an alternative sleeping space since room space at the centre is limited. Most of the caregivers who stay at the centre share rooms with the children, since some of the children need 24-hour care, which means that they have to provide care and watch over the children throughout the night. . Their main roles include making food, toileting, bathing, feeding, medication, doctor visits, washing clothes, watching over the children, cleaning the rooms, helping and teaching the children certain life skills (i.e. toileting and dressing up), sport coordination, play games with them, and shopping.

The formal caregivers in this study were both single and married, and included two male and ten female caregivers older than 18 years. Although most of the caregivers' highest level of education is grade 12, a smaller number only went to school up to grade 7. Furthermore, only a few caregivers have higher education, including early childhood development level 5, first aid, and a pre-nursing diploma. Two of the caregivers (including the owner of the centre) has a education degree and take on the role of stimulating and teaching the children.

The centre takes care of 30 children with a variety of disabilities, including Autism, Down syndrome, Epilepsy, Cerebral Palsy, Paraplegia and Mental Disorders. The minimum age of children at the centre is three years, since many children can not be diagnosed before they reach the age of three years (Kalb, 2005). The level of the children's disability is of such nature that it is an additional burden to the caregiver, and included, persons with physical disability[1] ranging between "moderately severe" and "extreme vegetative state", and persons with mental disability[2] at a pervasive or extensive level.

Data collection

After ethical clearance from the university's ethics committee, and permission from the centre manager were obtained, a purposive sampling technique was used to recruit the sample of caregivers. A period of five days was used to conduct the interviews at the full-time care centre in Rustenburg. Since this study is qualitative, the schedule for the semi-structured interview was not subjected to a validated validation process like those of quantitative studies. The process that was followed in this study was rather based on the qualitative epistemological standards encapsulated by trustworthiness. Experts reviewed the semi-structured interview schedule to establish theoretical validity (content validity), and also

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[1] Physical disability
Physical disability is measured by the Rappaport disability rating scale based on the following levels (CNS, 1995; COMBI, 2000; Dijkers & Greenwald, 2007): 0 (none), 1 (mild), 2-3 (partial), 4-6 (moderate), 7-11 (moderately severe), 12-16 (severe), 17-21 (extremely severe), 22-24 (vegetative state), and 25-29 (extreme vegetative state).

[2] Mental disability
Persons with mental disabilities are classified into the four levels of support namely; intermittent (support needed occasionally, not on continuous daily basis), limited (support during transition from one place to another or in time- limited situations), extensive (assistance needed at home on a daily basis), and pervasive (support that is constant and may include life sustaining measures) (Pitetti & Fernhall, 2005).

face validity in the fields of qualitative research and health care. The researcher also attended workshops that were presented by an expert who concentrates on qualitative research and how to do interviews in establishing and maintaining transferability (external validity) and credibility (internal validity), techniques included, persistent observation, peer debriefing, referential adequacy and negative case analysis, data saturation and thick descriptions. A trial run was conducted with specialists in the field of recreation, as well as a caregiver who care for persons with disability (transferability through purposive sampling) to determine if the interview questions that were proposed were comprehensible and have elicited the needed information, establishing credibility through peer debriefing (internal and measurement validity) and confirmability through an inquiry audit (objectivity). The information that the researcher gained from the caregiver during the trial run was also used as part of the findings. All the steps of the research process that was planned, described and followed was captured accurately in the research report to give relevance (inferential validity) and legitimacy to the data, but also to the way in how the data was collected (i.e., the interview schedule).

Voice recordings as well as field notes were made to keep record of information. A qualified translator was available for clarifying possible issues or answering any questions regarding the research in the participant’s first language. Information was gathered until data saturation was reached (Dick, 2012). Participants had the right to withdraw from the study at any stage if they chose to. A minimum number of 12 participants participated in the study which is in line with recommendations by Dick (2012).

Interviews lasted for 60- 90 minutes, which also included the time before the interview when the researcher had to make sure that the participants knew all the procedures and the time after the interview, which were open for discussion about the interview. Semi-structured one-on-one interviews were used to gather information from participants and were divided into four themes. Questions were open-ended with the maximum amount of questions being six.

The four main themes included 1) what the perceptions and experiences of caregivers' leisure are, 2) what the influence that leisure has on caregivers are, 3) what the leisure needs of caregivers are, and 4) how caregiving impact the leisure of caregivers. Probes were also used, but kept to the minimum.

Data analysis

Firstly, interviews were audio taped, then transcribed verbatim. The recordings were stored safely after it was transcribed. Interviews was then analysed to make changes if necessary and to see when saturation is taking place as recommended by Greeff (2011). Secondly, the researcher applied microscopic examination by going through the raw data to help with identifying words that might have different meanings to the participants, or to identify different words that might have the same meaning to them (Henderson, 2006). After the microscopic examination, the data were analysed by using ATLAS.ti as a computerised tool, with the researcher using guidelines as proposed by Yin (2014). Information was then coded and analysed into themes and subthemes until certain patterns appeared. Lastly, data were presented in a discussion and integrated with the existing literature.

Anonymity was ensured by not exposing anyone's identity, and by using data only for academic purposes. Reporting of findings was kept anonymous by replacing the participants' names with numbers. Recordings were stored safely after it was transcribed.

Findings and Discussions

From the findings of this study, six themes and seven sub-themes emerged and where clustered into two categories, namely leisure perceptions and leisure needs. These categories are consistent with findings from previous studies that also reflected leisure perceptions (Bedini & Guinanb, 1996b; Dupuis and Smale, 2000; Dupuis, 2000; Gahagan et al., 2007), and leisure needs (Aslan et al., 2006; Atkinson, 1992; Bedini 2002; Dupuis & Pedlar, 1995;

Gahagan et al., 2007; Kim & Letho, 2013; Mactavish et al., 2007; Rogers, 1999), although most of these findings were based on informal caregiving. To understand the leisure needs of formal caregivers in this study, their perceptions of leisure will be discussed first. Moreover, Bedini and Guinan (1996) reveals that understanding the leisure perceptions of caregivers can provide information to health care providers that are valuable, especially for practitioners in the field of therapeutic recreation.

Leisure perceptions

Leisure perceptions involved the themes a) *leisure activities that caregivers participate in,* b) *limited leisure time,* and c) *leisure experiences*.

From the findings that emerged in the theme *Leisure activities that caregivers participate in*, many leisure activities were mentioned, of which passive leisure activities were mentioned slightly more often than active leisure activities. It may be due to the physical tiredness that many of them experience, and therefore they may choose to rather do something less physical in order to rest (Rose & Williams, 2015). Passive leisure activities do not require a person using vast amounts of physical or mental energy while engaging in it (Anon, s.a.; Kiernozek, 2015; Williams, 2013). Therefore, passive leisure is believed to have fewer benefits than active leisure activities could offer, which often causes unease among researchers (Anon, s.a.). Yet, many people claim that they are relaxing the most during passive leisure activities (Anon, s.a.). Hence, Sonnentag (2001) explains that low effort activities are sometimes essential for a person to recover and for that reason low effort activities have a positive effect on the well-being of an individual. Within the context of passive leisure, this study revealed that many caregivers like to watch TV during their leisure. Most of them also preferred to be in the presence of their family when participating in leisure. Participant 3 mentioned: “I know that a child must never watch TV for more than an hour, so I lay in front of the TV watching maybe the soapies, after that I just let her watch for fifteen minutes the Popeye's".

Active leisure, on the other hand, are those activities involving the mental and physical exertion of energy, like exercising, walking, gardening, yoga, or aerobics (Anon, s.a.; Kiernozek, 2015). Among the many physical activities that caregivers perceive as leisure, doing house chores was one of the most common activities. Eight caregivers felt that house chores are their way of doing leisure. Since they don't have many free days or free time, house chores are a way of spending leisure or free time. Some caregivers specifically mentioned that it was a way of getting physical exercise, including Participant 10 who said the following: "Ja, when I'm there, when you get engaged in cleaning your house that is manual... Something you use your body to do this and that. And then it also serves as an exercise, you know, exercising the body … So, when you exercise you get some fitness of some sort…"

Caregivers were also asked about the frequency of their leisure participation and a theme *Limited leisure time* emerged. Caregivers had one day off per week, one weekend off every three months, and then they had 30 days leave. Most of them participated in leisure activities during that time, especially during leave, although a few also participated in leisure activities at the centre when they had time free from responsibilities during the week. Most of the caregivers reside at the centre, however a few caregivers go to their own homes after 18:00 on week days. The caregivers reported experiencing leisure at their homes after working hours as well, but it was limited due to little time and exhaustion from work. One caregiver explained that he would do something if he had little time at the centre after hours. However, it seems that there is no definite time set out for caregivers to have time free for themselves. Participant 9 went on to say: "Ja, if I have maybe stolen time [laugh] I would play the game. I just play then. Maybe at night. Something around, because at six we are no longer working that much, we are just looking for …" A bigger group of carers would expand on leisure during off days or weekends, and during annual leave. However, they went on to say that they do not get to do it very often due to money and time. Other caregivers felt that time for certain leisure pursuits, like spending time with family, were only possible during leave, because weekends are too short and they only get it once a quarter. Participant 9 replied with the following statements: "Eeh, mostly during maybe weekend offs and on the holidays, but not all of the holidays, because money "eish". [Laugh]" Along the same lines Participant 6 said: "Uh, I'm able to see them during my long week, I mean, annual leave because really weekends are only one day which you could have done more in much..."

Interestingly, some of the caregivers explained how they make it possible to visit more often by skipping some of their off days to accumulate enough days to go away for longer, as Participant 5 stated: "So what I do is I accumulate my weekend days …, I skip them so that they can grow … so that there can be more, maybe Saturday I skip, I mean weekend which I'm given, so like maybe I can leave them. … and when I go out I'll be going for those longer weekends …."

Within the theme *Leisure experiences,* it is important to know the benefits and positive experiences that leisure provides for the caregivers, as well as the negative experiences they may have during leisure. The importance of this is reflected by Wood and Tirone (2013) who explain that a loss of leisure could result in a loss of the associated benefits, such as escape, relaxation, self-improvement, and skill building.

From what can already be observed regarding the leisure of caregivers in this study is that it is something they do not have very often. However, in the cases where they did have leisure they mention the following positive experiences they gained from it. Many caregivers revealed that the positive experiences they get from participating in leisure were that they get rejuvenated at a physical and/or mental level, and it also causes them to have more energy. They also mentioned that leisure reduces their stress levels, that they feel more refreshed when participating in leisure, and that it causes them to concentrate better when they are back at work. Furthermore, many caregivers experienced happiness when at leisure. Participant 9 described his/her experiences as: “I would say maybe physically or mentally it rejuvenate my mind. Physically I get at least a little bit of energy ja (yes). And happy too.” Additionally, Participant 10 mentioned: “No as I said, when I come back from there I’m refreshed and now less … stressed, because I have nothing outstanding at my work. So, when I come here I can concentrate with vigour.” This caregiver also elaborated: “Okay … briefly, having rested well, and interacted, the benefit of that is that I come now more refreshed when I come to work”.

These findings are consistent with Rose and Williams (2015) who, in a study about nurses, revealed that physical active leisure was a way to be alone, let go of worries, and to renew. One nurse revealed that leisure helps her to be energetic, productive, refreshed, and efficient at work (Rose & Williams, 2015). Similarly, Stumbo and Peterson (2004) go further to say that leisure activities helps individuals to relax, cope with, or release stress, and associate with other individuals.

On the other hand, caregivers also had negative experiences during their leisure time. There were different reasons for the negative experiences, but the main reasons for their negative experiences were caused by work related matters. Some of the experiences involved caregivers who felt that their leisure time, including their personal time (when they want to be alone by themselves), are interrupted by other people at the centre and that it influences the quality or level of satisfaction of their leisure experience. Tu (1993) explains that “the satisfaction of needs involves the degree to which a person is pleased with their specific situation or experience” (p. 37,38). In this context, some caregivers felt that their experience is spoiled, whereas other caregivers were left with worries about things at the centre while they are at leisure, thus hampering the degree to which they experience satisfaction. When these caregivers were asked what makes it difficult for them to enjoy their leisure or to be able to participate, they replied as follow:

P 6 “So I get one thing, sometimes when you’re engaged with something mentally somebody keeps on enclosing, you ultimately sometimes get fed up with that person and become indignant and that’s when you want to avoid … please. … because other people will spoil your loneliness or your comfort zone.”

P 10 “Yes, the work will even impact your free time or leisure time … you get a call and they reported serious illness or death case within the centre. It worries you.”

Participant 10 and 6 had similar experiences to that of a caregiver in the study of Bedini and Guinan (1996) who explained it as a loss of mental freedom, since she could not go on walks or do anything without worrying about the person she is responsible to care for.

Leisure needs

When implementing research on the leisure needs of caregivers, it was decided to use the Post Hoc Satisfaction Approach by Mannel (1999) as a guideline in providing more background and insight on leisure needs, since little research has been completed on this topic in the field of caregiving. To explain the process of satisfying a need Mannell (1999) refers to a motivational model. When a need emerges within a person, it leads to a disequilibrium (desire, or lack of something), which in turn they will attempt to lessen (Cordes, 2013; Fodness, 1994; Guha, 2009; Mannell, 1999). When someone experience a need like that, they believe that the disequilibrium (tension) will be reduced by a certain action (Cordes, 2013; Fodness, 1994; Guha, 2009; Mannell, 1999). Thus, when there is a disequilibrium people reduce this internal state by acting or behaving in certain ways that they believe will lead to satisfaction. For example, if a caregiver needs to relax and revive s/he might act on this need by taking a walk in the park. The needs mentioned in this study are not always direct leisure needs, but also needs that can be satisfied through leisure participation, or they are leisure needs that may be influenced by caregiving. The needs that emerged from this study included the themes *physical needs, psychological needs and social needs.*

The theme *Physical needs* included the sub-themes *need for time* and *money* which had an influence on their leisure time or leisure experiences. *Needs for time* was something that all twelve caregivers felt very strongly about. Although time is influenced by many other factors at the centre, for instance money and no shifts, all of them explained that free time or leisure time were something very scarce in their lives and that their caregiving circumstance was one of the major causes. This need for time is consistent with a study of Gahagan et al. (2007) where caregivers experienced time poverty and could not take time to care for themselves. Caregivers explained that if they had to take time away from work that it would leave a gap for something negative to happen at the centre and therefore they rather sacrifice their own leisure time, as Participant 1 stated: “As I already explained previously that the impact is grossly on the free time, because you hardly have it. When you leave, you leave a day at work, you leave a vacuum for something to happen. Therefore, definitely these, multi-facet roles that I have, I mean, and broad roles, it has an impact on my leisure needs.”

As one of the other physical needs, eleven caregivers experienced a *need for money* and expressed their concern about not having money to do what they would like to do during their leisure time. These caregivers feel that money would make it easier to buy things for their children or family during leisure time and that it will enable them to do things that they would not be able to do without money, for example entertainment. The fact that they cannot afford to do certain things during leisure is a painful experience for them. Many caregivers explained how they would do window shopping instead. These caregivers' need for money is to satisfy their personal needs including leisure, however their financial shortcomings are mostly due to the centre that is unable to support them financially as well as it should. Participant 8 commented: "Ja (yes), well, when I take them (her/his children) out it will be painful for me to take them out because we'll go to shop and then I might not able to meet that demand of their wishes in terms of buying (power?). So it will pain me to be able to go out for window shopping with them because I can't afford buying anything for them." Similarly, Participant 10 also explained: "The major driver towards fulfilment of these needs is the money. Because when you have it you'll be able to do a, b, c, d for satisfaction. You'll buy a cold drink for the children and you give them an, you enhance their entertainment and then they laugh. But you leave the drivers, so there are many other issues that you can satisfy when you have... To make your family happier you need money to do that."

Within the theme *psychological needs*, *needs for escape* as well as needs for *mental and physical rest* emerged. As caregivers are constantly in the presence of the disabled children and working amongst each other every day, they do not have a lot of time to break away, therefore have a great *need for escape* from their busy daily circumstances. The caregivers' need for escape was mostly driven by a need to be alone by themselves, or just to rest, away from the normal routine and all their responsibilities; even to be away from their personal responsibilities. This is their opportunity to refresh and forget about everything so that they can be emotionally available to the people and children at the centre. Here are their comments:

Participant 10 "How I wish during those long days that I really had money, and enough money, so that I could take, leave and go to the coast or just Cape Town and just go there and relax. To stay and see the sea or whatever … forget the work and the children way way way and going to rest. When I come in from the … or Cape Town I'll be FRESH! Fresh fresh fresh fresh! I like outing."

Participant 2 "Well I wish that we would be having some breaks at work, that you definitely … to satisfy as a need of lonely, of not loneliness, or being lonely or being lonesome. I don't know. Or to, you know, to pull yourself from the madding cloud, we need this type of work, I wish that we would be having some breaks in between so that one could definitely be alone by himself."

When asked how caregiving affects one caregiver's time with his friends, Participant 9's response with regard the need to be alone were: "You start feeling like you could be alone ... No … I mean the feeling that you really feel you'd have been left alone, and your friend begin to realise this, that why is he funny or something like that, and then when he come to find to say what's happening … you just, you know, chop them away". These findings are consistent with findings of Gahagan et al. (2007) where caregivers felt the need to get out of the house as a form of physical removal from their caregiving setting. This concept, however, was contradicting since the intend of leisure in their study's context was also to address the isolated nature of caregiving, since the caregivers in their study were family members staying in the same house as the care receiver. However, Gahagan et al. (2007) and Bedini and Guinan (1996) explains that caregivers' leisure still requires time for oneself and isolation without worry or attending to any duties which is consistent with caregivers' needs in the context of this study. Formal caregivers from this study worked all day a centre in the presence of the children and co-workers and have a need to escape from people they see every day and from their responsibilities.

The needs for *Physical rest* were revealed by almost all the caregivers. They mentioned getting tired or exhausted from their caregiving job, nevertheless, ten caregivers expanded that they have a need to rest their bodies and refresh to feel better. Their form of resting mostly included sleeping. Some of them said that their tiredness prevented them from doing leisure, because of their need to sleep or rest, while others did not refer to rest as sleep, but only mentioned resting their body to be fresh for work again. It can be observed that most caregivers' need for sleep overrides their need for leisure and that there is limited or no time for leisure when the little time they have free is used to sleep. This is also similar with findings in a study of Rose and Williams (2015) where nurses were tired and stressed and only wanted to sleep, do nothing and rest to prepare for work, which seem to grow into their centre of existence while leisure participation was almost unthinkable. Caregivers, therefore, cannot do what they would like to do normally for leisure since they are too tired and need to attend to their primary need for sleep and rest first. When asked about their needs and influences on their leisure, two participants responded:

Participant 7: "Ja indeed it is, you know, … taxing work, it is in that at the end of the day wherever I come to for your little leisure time, all that you wish "ooh" this body is tired I wish I could sleep and rest. So you, there's nothing you can think about, you are exhausted, it does impact on yourself because you cannot think properly, you are just tired, you have got a whole of fatigue. So, you are not able to do that which you'd be doing normally of this leisure."

Participant 10: "You know …, as I said, free time, when you get it, my own, my own free time, I want to get home, and this body gets exhausted. I want to really rest, body rest so that when I come back to the job the next day I'm fresh again"

Except for physical rest caregivers also expressed a need for *Mental rest*. Mental rest almost merge with the need for escape, however caregivers with a need for mental rest did not necessary feel the need to be alone or escape, but for their mind to refresh and rest. Nevertheless, if the caregivers' needs for mental rest can be satisfied through leisure, it can contribute to the mental health of caregivers, such as improved coping, more energy, social connection, decreased stress, and increased happiness (Wood & Tirone, 2013). Participant 10 especially spoke a lot about mental rest (at least three times). Her idea of metal rest was to do house chores and getting mentally engaged with something while cleaning the house as well as watching TV. She mentioned that it is not always possible for her to do other things in her free time like visiting friends, and therefore she works her mind through TV watching and house chores. If she gets a long enough break, however, she would visit far away friends and family and do things like spoiling themselves with entertainment and going to restaurants for mental rest. Even though Participant 10 did not directly express mental rest as a need, it is clear that she values mental rest and see it as something she would like to do more often. She stated: “Well, as I clean and go on with my cleaning chores, because I’m involved in my body and my body parts, I’m also engaged in my mind and in a way that you relief it, because you cannot always say now I got free time, we are going to visit there and sit in there all the time, to say I’m ... So, as you work and you work, and you look at TV and so forth, and you work the mind also”. Furthermore, she said: “You see, that weekend is just by mere visitation to really far away friends and so forth, it’s not only physical resting, it’s also mental rest, because you are there, and then you maybe, you know, spoil … entertainment, to say let’s go to a restaurant and there then you maybe, you’ll be entertained and through you know, a host and so, your host would definitely entertain you this way or the other and that’s also mental rest.”

Within the theme *Social needs, time with family, time with children,* and *time with friends and community* emerged. According to Rogers (2001) caregivers experience social isolation, limited visits and contact with friends and family, and missing out on opportunities to participate in additional social activities. In the context of this study, the most common social need mentioned by the caregivers was spending *time with their family*. Most caregivers need was to be able “to bond” with their family if they had the time. They explained that they long for their family and wish that they could only be in their family’s presence some times. Due to the limited time they have it is something that they get to do very little. Participant 12 elaborated with the following statement: “Ja, during that time I wish the time could be increased, it’s so little that I think you know one would definitely, if there was enough time, go and bond with his own child and family.”

As part of the social needs for family, caregivers often referred only to *time with their children* since many caregivers are single parents. Caregivers did not have enough opportunities to spend time with their children, as Participant 8 stated: “Ja, I’ve got a need, a dying need to meet my children regularly, not once in a quarter”. Furthermore, some caregivers mentioned needs to provide love for their kids, and spend time with their kids to make sure they influence their kids positively and implement discipline. Caregivers also had a need for authority over their children and reasoned that if they could spend time with their children their presence would make that difference. This was how they described their needs:

P 8 “Well I’d, I think the main thing that I realise is that meeting my child …, it’s a need for, you know, to give love to my kids. And because it’s something that … lacks, so going there is a need. I provide love for my kids”

P 5 “Ja, the … is that when you have interrelating with your kids, that way, it symbolises morale because they want to see that you are able to, or that it’s some form of organised energy within the family whilst in opposite yes, energy that is influential to a child as suppose to others, their children have no guidance, so your being there, it’s because … guidance and discipline and authority within the family”

Lastly, caregivers also revealed needs to socially interact with *friends and community* members. They were of the opinion that networking would help them to learn what each other’s needs are and that they are then empowered and informed to provide support where possible. Furthermore, caregivers also wish to interact in society, by gaining information so that they are more informed about things happening around them, and visiting people. From another perspective, socialising with friends and community members might also help to put their own needs and problems in perspective since they grow aware of other people's life situations, such as struggles they may go through. Nevertheless, this was the comments caregivers made:

P 1 "It's to go, it's to go out and meet other people, and meet people. Because you learn a lot of things from mixing … You are also able to learn from other people to see what their needs are, what your needs are and how we can help and support each other."

P 10 "Apart from resting you are able to go around, such people like us who have got illnesses of this nature and that nature, you really need to rest, and you can do that by visiting people, interacting in society, and learning and gaining information about this and that, because you have not been there, but the main thing is to inter-mingle with other people of society. And to learn from them and what the developments are around you, because you're affected by those."

Participant 10 also expressed her need for acceptance and to feel worthy in the context of going to parties or gatherings: "Eh, you see that else, or whilst you are helping, give a helping hand and, you know, time to fill up spaces here and there, as requested, you really feel your human worth when, you know, you are being appreciated and so forth and I'm a meaningful person."

When looking at all the different spectrums in which the theme *social needs* emerged, in can be concluded that caregivers experienced a need for bonding, influence and authority over their family, acceptance, to feel worthy and part of something, to receive and give love, interaction and networking with family, friends, and community such as sharing advice, being updated on things, and support amongst friends and family. These findings are consistent with literature revealing limited opportunity for interacting with friends, a need to interact outside the caregiving environment or residence (Bedini & Guinan, 1996), time with relatives and friends in the same situation as they are, talking and sharing about their problems (Gahagan, 2007; Fernandes & Angelo, 2016).

To have a better understanding of the nature of leisure needs of the caregivers, a closer look was taken on the need satisfaction approach, evolving from the Post hoc Satisfaction approach by Mannel (1999). Need satisfaction is concerned with what arouses, activates, or energises leisure behaviour, in other words, the forces in people that drive them to get involved with particular behaviours (to act) (Guha, 2009; Mannell, 1999). When considering the leisure needs of caregivers in this study, there were many different needs that emerged which can be explained by Mannell (1999), who argues that people are attracted to specific leisure activities instead of others because of the interest they have in the characteristics of leisure settings and leisure activities. Iso-Ahola (1999) goes further to say that the activities that motivate people may fluctuate due to social and personal factors. In context of this study, caregiving was the major drive for caregiver's leisure needs. However, participants in this study expressed that they are not able to attend to, or satisfy, most of these needs, at least not as often as they like.

Conclusion

Given the caregiving impact that cause substantial challenges and demands resulting in mental and physical exhaustion of caregivers (Goodhead & McDonald, 2007; Greenlee & Scharlach, 2001), there is a great need for available time to pursue activities that would bring caregivers relief from their current circumstances. The data collected revealed that caregivers experienced a high need for leisure, which included physical needs (need for time and money), psychological needs (needs for escape, and mental and physical rest) and social needs (with family, children, community and friends). These findings are consistent with literature regarding financial difficulties (Aslan et al., 2006; Bedini & Guinan,1996; Kersten et al., 2001), social life, including family interaction (Aslan et al., 2006; Bedini & Guinan,1996; Kersten et al., 2001), short breaks from work (Kersten et al., 2001), escape from worry and work circumstances (Bedini & Guinan,1996; Dupuis, 2000), holidays (longer breaks) (Kersten et al., 2001), and psychological needs (Aslan et al., 2006; Kersten et al., 2001). From all the needs in this study, needs for time and money were pointed out the most, which overflowed to the rest of their needs. If these needs are not attended to, caregiving may cause negative outcomes to the caregiver's physical and psychological health (Bakker et al., 2000; Brehaut et al., 2004). However, if their needs can be satisfied, it will surely increase their well-being and quality of life (Edginton, 2009; Gahagan et al., 2007; Greenlee & Scharlach, 2001; Henderson, 2008; Leverson et al., 2012; Tinsley & Eldredge, 1995; Wood & Tirone, 2013). It can even motivate them to engage in future leisure or recreation activities if they find it satisfying (Mannel, 1999). However, Kersten (2001) explains that it is unknown if caregivers' needs are recognised by the people dependent on them and the professionals involved in caring for them, and the individuals with disability in their care, since it has not been previously investigated. Therefore, it is critical to explore strategies and programmes for leisure programmers and service providers to be able to attend to these leisure needs of caregivers.

Limitations

This study provided information on the leisure needs of formal caregivers taking on a primary care role for children with disabilities. The aim of this study was to gain understanding of a specific case, and therefore, the intention is not to generalise the findings. Also, this study only included mostly black African female caregivers and just two black African male caregivers. Therefore, further research should aim to focus on a more diverse population of gender and race among formal caregivers and their leisure needs, especially in under resourced areas. It is also recommended that research should be done on the contextual elements of formal caregiver needs (Greenlee & Scharlach, 2001), for example, in this study some of the caregiver resided at their own place while the rest of the caregivers resided at the centre which means that there will be differences in the needs they develop for leisure. Furthermore, with the help of a translator, the researcher had to find different ways to explain the concept of leisure to the caregivers since there is no exact translation for the term leisure in the Setswana language. Furthermore, since both the researcher and participant had to communicate through a third person in their second language, communication difficulties caused the researcher and participant to sometimes misunderstand questions or statements being made.

Recommendations

This study provides useful information to centre managers or care-institutions caring for people with disability, as well as leisure service providers to know how to design programmes to address the leisure needs of caregivers in an under resourced context. Mannel (1999) explains that satisfying activity participation reassures individuals that their behaviour is appropriate to satisfy that specific need, but also that negative feedback from that behaviour may cause people to terminate or modify their behaviour or activity. Reasons for terminating or modifying these behaviours may be due to feeling incapable to carry out the activity as a result of possible lack of skills or necessary knowledge to do it, because the desired outcome and the action has no connection with the person, or because the person chooses not to act (Ryan et al., 2009). Moreover, numerous studies reveal that caregivers reduce or cease leisure participation due to the demands and responsibilities they face (Bedini, 2002; Bedini & Guinan, 1996; Coetzee, 2007; Dun & Strain, 2001; King et al., 2000). Therefore, it is also recommended that further research should be done on how to enable, empower, and educate caregivers to be able to satisfy their own leisure needs and also to be aware of opportunities to access leisure. It is also advised that more research should be conducted focusing on how centres can enhance their working circumstances and management to support the caregivers to have a more satisfying leisure lifestyle and also to have more available time for leisure.

References

Akkus, Y. (2011). Multiple sclerosis patient caregivers: the relationship between their psychological and social needs and burden levels. *Disability and Rehabilitation*, 33(4), 326-333.

Anon. s.a. *Leisure and recreation*. Bishop Challoner Catholic Secondary School. Chapter 3:43-48. Retrieved from www.bcs.hants.sch.uk/attachments/download.asp?file=1390&type=

Aslan, O., Kav, S., Meral, C., Tekin, F., Yesil, H., Ozturk, U., Bulut, Z., Anaboifo, A., Dover, M. & Yazar, B. (2006). Needs of lay caregivers of bone marrow transplant patients in Turkey. *Cancer Nursing*, 29(6), 1-7.

Atkinson, F.I. (1992). Experiences of informal carers providing nursing support for disabled dependants. *Journal of Advanced Nursing*, 17(7), 835-840.

Bakker, A.B., Killmer, C.H., Siegrist, J. & Schaufeli, W.B. (2000). Effort-reward imbalance and burnout among nurses. *Journal of Advanced Nursing*, 31(4), 884-891.

Barkoukis, V., Hagger, M.S., Lambropoulos, G. & Tsorbatzoudis, H. (2010). Extending the trans-contextual model in physical education and leisure-time contexts: Examining the role of basic psychological need satisfaction. *British Journal of Educational Psychology*, 80(4), 847-670.

Bedini, L.A. (2002). Family caregivers and leisure: An oxymoron? *Parks and Recreation*, 37(1), 25-31.

Bedini, L.A. & Gladwell, N.J. (2014). Caregiving as life transition: implications for leisure service providers. *Journal of Park and Recreation Administration*, 32(1), 128-141.

Bedini, L.A. & Guinan, D.M. (1996). The leisure of caregivers of older adults: Implications for CTRS’s in non-traditional settings. *Therapeutic Recreational Journal*, 30(4), 274-288.

Bingham, J.R-K. (2017). *Experiences of caregivers of children with disabilities in semi-rural areas near Cape Town, South Africa* (Masters dissertation). Stellenbosch: University of Stellenbosch. Retrieved from citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.424.1676&rep=rep1...

Brandon, P. (2007). Time away from “smelling the roses”: where do mothers raising children with disabilities find the time to work? *Social Science & Medicine*, 65(4), 667-679.

Brehaut, J.C., Kohen, D.E., Raina, P., Walter, S.D., Russell, D.J., Swinton, M., O’Donnell, M. & Rosenbaum, P. (2004). The health of primary caregivers of children with Cerebral Palsy: How does it compare with that of other Canadian caregivers? *Journal of American Academy of Paediatrics*, 114(2), 182-191.

Buchanan, R., Ranin, D., Chakravorty, B.J. & Tyry, T. (2009). Informal caregiving to more disabled people with multiple sclerosis. *Disability and Rehabilitation*, 31(15), 1244-1256.

Carter, R. & Golant, S. (1994). Helping yourself help others: A book for caregivers. New York: Three Rivers Press. Retrieved from http://www.amazon.com/Helping-Yourself-Help-Others-Caregivers/dp/0812925912

CNS (Centre for Neuro Skills). (2014). *Disability rating scale.* Retrieved from http://www.neuroskills.com/resources/disability-rating-scale.php

Coetzee, M.J. (2007). *The psychological health implications of social support for the Alzheimer caregiver* (Masters dissertation). Pretoria: University of Pretoria. Retrieved from https://repository.up.ac.za/bitstream/handle/2263/27526/dissertation.pdf;sequence=1

COMBI (The Centre for Outcome Measurement in Brain Injury). (2000). *The disability rating scale.* Retrieved from http://www.tbims.org/combi/drs

Cordes, K.A. (2013). *Applications in recreation and leisure for today and the future*. (4th ed.). Urbana, IL: Sagamore.

Deci, E.L., Ryan, R.M., Gagné, M., Leone, D.R., Usunov, J. & Kornazheva, B.P. (2001). Need satisfaction, motivation, and well-being in the work organizations of a former eastern bloc country: A cross-cultural study of self-determination. *Personality & Social Psychology Bulletin*, 27(8), 930-942.

Dekker, T., Hess, S., Arentze, T. & Chorus, C. (2014). Incorporating needs-satisfaction in a discrete choice model of leisure activities. *Journal of Transport Geography*, 38, 66-74. DOI: 10.1016/j.jtrangeo.2014.05.015

Dick, B. (2012). *Convergent interviewing essentials: An introduction to the key features of a combined interviewing and data analysis technique*. Retrieved from http://www.aral.com.au/resources/coin.pdf

Dijkers, M. & Greenwald, B. (2007). Functional assessment in TBI rehabilitation. In Zasler, N.D., Katz, D.I. & Zafonte, R.D., (Eds.). *Brain injury medicine: principles and practice* (pp. 225-246). New York, NY: Demos Medical Publishing.

Dunn, N.J. & Strain, L.A. (2001). Caregivers at risk: changes in leisure participation. *Journal of Leisure Research*, 33(1), 32-55.

Dupuis, S.L. & Pedlar, A. (1995). Family leisure programs in institutional care settings: Buffering the stress of caregivers. *Therapeutic Recreation Journal*, 29(3), 184-205.

Dupuis, S.L. & Smale, B.J.A. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving context. *Journal of Leisure Research*, 32(3), 303-340.

Dupuis, S.L. (2000). Institution-based caregiving as a container of leisure. *Leisure Sciences*, 22(4), 259-280.

Edginton, C.R. (2009). Leisure: Enhancing the human condition: Priorities & strategies 2009–2014. A new strategic plan for the World Leisure Organization. *World Leisure Journal*, 51(2), 130-131. DOI: 10.1080/04419057.2009.9674595

Fernandes, C.S. & Angelo, M. (2016). Family caregivers: what do they need? An integrative review. *Journal of School of Nursing*, 50(4), 672-678.

Fodness, D. (1994). Measuring tourist motivation. *Annals of Tourism Research*, 21(3), 555-581.

Fourie, J. (2006). *Tourism and leisure needs of high school learners in Potchefstroom* (Masters dissertation). Potchefstroom: North West University. Retrieved from dspace.nwu.ac.za/bitstream/handle/10394/1685/fourie_johannesj.pdf?sequence=1

Gahagan, J., Loppie, C., Rehman, L., Maclellan, M. & Side, K. (2007). "Far as I get is the clothesline": The impact of leisure on women's health and unpaid caregiving experiences in Nova Scotia, Canada. *Health Care for Women International*, 28(1), 47–68.

Gladwell, N.J. & Bedini, L.A. (2004). In search of lost leisure: The impact of caregiving on leisure travel. *Tourism Management*, 25(6), 685-693.

Goodhead, A. & McDonald, J. (2007). *Informal Caregivers Literature Review: A report prepared for the National Health Committee*. Health Services Research Centre. Victoria: University of Wellington.

Greeff, M. (2011). *Information collection: Interviewing.* In Van Schaik Publishers, (Ed), *Research at grass roots*. (4th ed.) (pp. 341-374). Pretoria: Van Schaik.

Greenlee, J. & Scharlach, A. (2001). *Caregivers' characteristics and needs.* In *Family caregivers in California: Needs, interventions and model programs* (pp. 7-48). Berkeley, CA: University of California. Center for the Advanced Study of Aging Services. http://citeseerx.ist.psu.edu/viewdoc/download? doi=10.1.1.547.783&rep=rep1&type=pdf

Greyvenstein, E. (2010). *A needs assessment of caregivers in children's homes* (Masters dissertation). South Africa: University of South Africa. Retrieved from https://core.ac.uk/download/pdf/43167140.pdf

Guha, S. (2009). Motivational push factors for visiting reenactment sites (Doctoral Thesis). San Jose: San Jose State University. Retrieved from scholarworks.sjsu.edu/cgi/viewcontent.cgi?article=4700&context=etd_theses

Henderson, K.A. (2006). *Dimensions of choice: Qualitative approaches to parks, recreation, tourism, sport and leisure research*. (2nd ed.). State College, PA: Venture Publishing.

Henderson, K.A. (2008). Expanding the meanings of leisure in a both/and world. *Society and leisure*, 31(1):15-30.

Hung, L.-C., Liu, C.-C. & Kuo, H.-W. (2002). Unmet nursing care needs of home-based disabled patients. *Journal of Advanced Nursing*, 40(1), 96-104.

Iso-Ahola, S.E. (1999). Motivational foundations of leisure. In Jackson, E.L. & Burton, T.L. (Eds.). (1999). *Leisure studies: Prospects for the twenty-first century* (pp. 35-51). State College, PA: Venture.

Kalb, C. 21-25 Feb. (2005). *When does autism start*? Newsweek magazine. Retrieved from http://www.foothilltech.org/krenger/psychology/unit7_research/when_autism_start.pdf

Kersten, P., McLellan, L., George, S., Mullee, M.A. & Smith, J.A. E. (2001). Needs of carers of severely disabled people: are they identified and met adequately? *Health and Social Care in the Community,* 9(4), 235–243.

Kiernozek, K.S. (2015). *Leisure participation and perceived constraints of parents and caregivers of children with disabilities* (Masters dissertation). Knoxville: University of Tennessee. Retrieved from trace.tennessee.edu/cgi/viewcontent.cgi?article=4747&context=utk_gradthes

Kim, S. & Letho, X.Y. (2013). Travel by families with children possessing disabilities: Motives and activities. *Tourism Management*, 37, 13-24. DOI: 10.1016/j.tourman.2012.12.011

King, A.C., Castro, C., Wilcox, S., Eyler, A.A., Sallis, J.F. & Brownson, R.C. (2000). Personal and environmental factors associated with physical inactivity among different racial-ethnic groups of U.S. middle-aged and older-aged woman. *Health Psychology*, 19(4), 354-364.

Krueger, M. (2007). Four areas of support for child and youth care workers. *Families in Society*, 88 (2), 233-240.

Lee, H.Y., Shin, J.H. & Harrington, C. (2015). Comparing the nurse staffing in Korean and U.S. nursing homes. *Nursing Outlook*, 63(2), 137-143.

Leversen, I., Danielsen, A.G., Birkeland, M.S. & Samdal, O. (2012). Basic psychological need satisfaction in leisure activities and adolescents' life satisfaction. *Journal of Youth Adolescence*, 41(12), 1588-1599. DOI: 10.1007/s10964-012-9776-5.

Mactavish, J.B., MacKay, K.J., Iwasaki, Y. & Betleridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives on life quality and the role of vacations. *Journal of Leisure Research*, 39(1), 127-155.

Mannell. R.C. (1999). *Leisure experience and satisfaction*. In Jackson EL. & Burton, T.L., (Eds.), *Leisure studies: Prospects for the twenty-first century* (p. 235-248). State College, PA: Venture.

Pitetti, K.H. & Fernhall, B. (2005). *Mental retardation*. In Skinner J.S., (Ed.). *Exercise testing and exercise prescription for special cases: Theoretical basis and clinical application*. (3rd ed.) (pp. 392-401). Philadelphia, PA: Lippincott William & Wilkins.

Rogers, N.B. (1999). Caring for those who care. *Activities, Adaptation & Aging*, 24(1), 1-12.

Rogers, N.B. (2001). Family obligation, caregiving, and loss of leisure. *Activities, Adaptation & Aging*, 24(2), 35-49.

Rose, T. & Williams, D.J. (2015). Nurse leadership: The importance of balancing work with leisure. *Nurse Leader*, 13(3), 60-62.

Rossman, J.R. (1995). *Recreation programming: Designing leisure experiences*. (2nd ed.). Champaign, IL: Sagamore.

Ryan, R.M., Williams, G.C., Patrick, H. & Deci, E.L. (2009). Self-determination theory and physical activity: The dynamics of motivation in development and wellness. *Hellenic Journal of Psychology*, 6(2), 107-124.

Schultz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249.

Singh, P.C. (2011). The changing patterns of work and leisure: Revolutions in leisure behaviours. *African Journal for Physical, Health Education, Recreation and Dance*, 17(1), 69-80.

Sonnentag, S. (2001). Work recovery, activities, and individual well-being: A diary study. *Journal of Occupational Health Psychology*, 6(3), 196-210.

Stumbo, N.J. & Peterson, C. (2004). *Therapeutic recreation program design: Principles and procedures*. (4th ed.). San Francisco, CA: Pearson.

Tinsley, H.E.A. & Eldredge, B.D. (1995). Psychological benefits of leisure participation: a taxonomy of leisure activities based on their need-gratifying properties. *Journal of Counselling Psychology*, 42(2), 123-132.

Tu, S.F. (1993). *The relationship between leisure and perceived burden of spouse caregivers of persons with Alzheimer's disease* (Masters dissertation). Denton, TX: University of North Texas. Retrieved from https://digital.library.unt.edu

White, J.W. & Kennith, G.J. (1985). Gender differences in leisure-need activity patterns. *Sex roles*, 12 (11-12), 1173-1186.

Williams, T. (2013). *Conflict between women's physically active and passive leisure pursuits: The role of self-determination and influences on well-being* (Masters dissertation). Ottawa: University of Ottawa. Retrieved from https://ruor.uottawa.ca/bitstream/10393/24335/3/Williams_Tamara_2013_thesis.pdf

Wood, S. & Tirone, S. (2013). The leisure of women caring for people harmfully involved with alcohol, drugs, and gambling. *Journal of Leisure Research*, 45(5), 583-60.

Yin, R.K. (2003). *Applications of case study research*. (3rd ed.). Thousand Oakes, CA: Sage.

Yin, R.K. (2014). Case study research: Design and methods. (5th ed.). Washington, DC: Sage.

CHAPTER 5: SUMMARY, CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

5.1 Introduction

This chapter will firstly provide a summary of all five chapters of the dissertation and what each chapter entails. Secondly, it will provide a combined conclusion of the two articles and how the findings merge with each other. Thirdly, the limitations of the study will be discussed, followed by recommendations for future studies on leisure and caregiving as well as recommendations for practitioners to take into consideration when considering the leisure needs of caregivers. This chapter constitutes a base for future studies in the field of leisure science since little research in South Africa is done on ways to care for the caregiver. Furthermore, it also encourages managers of care centres, or institutions for disabilities, and leisure experts to be more responsive to the leisure needs of caregivers.

5.2 Summary

Literature reveals that caregivers may benefit from leisure since leisure may act as a coping or buffering mechanism against stress associated caregiving demands (Schreyer, 2016:19; Schuz *et al*., 2015:241), influence overall health and spiritual wellbeing, and also help caregivers to get in touch with their true self, and forget about their daily roles (Heintzman & Mannell, 2003:208; 211; 226). Leisure can also provide an escape for caregivers, develop self-determination, provide social support, empower caregivers, and enhance their mood (Heintzman & Mannell, 2003:212, 226). Yet, many caregivers experience the negative influences of caregiving as constraining to their leisure and, therefore, developing multiple needs that often goes unsatisfied.

The focus of this study was to explore and describe the leisure needs of formal caregivers of individuals with disabilities in a centre in the North West province. For the purpose of this study needs were conceptualised as a broad term containing the influence of caregiving on leisure of caregivers, as well as leisure needs they experience. Chapter 1 provided a brief summary of the problem statement, which serves as a foundation of the research questions and theoretical statements of this study.

Chapter 2, a literature review of relevant topics, discussed the main concepts of caregiving, constraints, and needs in the scope of leisure in order to provide a theoretical perspective on these concepts. Firstly, a contextual background was provided on different concepts regarding leisure, including the benefits derived from it as well as the influences that may develop into constraints and/or needs that are generally experienced. Secondly a discussion on caregiving and the caregiving role in the context of disabilities was provided, followed by an integration of the two concepts to have a better understanding of how caregiving for people with disabilities influences caregivers and their experiences of leisure.

This dissertation was submitted in article format, as approved by the Senate of the North-West University; thus, two articles (Chapters 3 and 4) were included.

5.3 Conclusion

The first article, namely "The influence of caregiving for individuals with a disability on the leisure of caregivers in the North West province" revealed that caregivers experienced negative influences that is constraining their leisure time and experiences. From this study, three main categories emerged including (a) leisure perceptions of caregivers, (b) constraining factors to leisure, and c) caregiving as leisure, which is consistent with previous revisions associated with leisure perceptions (e.g. Bedini & Guinan, 1996a:233-236; Bedini & Guinan, 1996b:275; Dupuis, 2000:270; Wood & Tirone, 2013:589), constraining factors to leisure (Bedini & Guinan, 1996b:280; Dupuis & Smale, 2000:319,327-328; Schryer *et al*., 2016:18; Wood & Tirone, 2013:585, 586), and caregiving as leisure (Dupuis, 2000:275). From these categories 13 themes emerged. Eight themes related to caregivers' perceptions of leisure emerged, including (a) time they had free from responsibilities, (b) social interaction, (c) different forms of relaxation, (d) something they do out of their free will, (e) as something that can take place or can be experienced anywhere or any time, (f) as personal time or escape, (g) and as different forms of activities they like to participate in. The constraining factors that emerged as themes in this study included (a) time related factors, (b) organisational factors, (c) physiological factors, (d) social factors, and (e) psychological factors. Lastly, the category leisure as caregiving was very small containing no themes, however this category revealed that some caregivers experience leisure in their caregiving activities as also explained by Dupuis (2000:275) saying that a person does not have to be separated from their daily tasks to experience leisure. In conclusion, the central theoretical statement, as revealed in chapter 1, is in line with findings from this article, in that caregiving has a negative impact on the leisure of caregivers of disabled people in the North West province.

The second article titled, “The leisure needs of formal caregivers of individuals with disabilities in the North West province” revealed that caregivers experience a need for leisure due to their caregiving responsibilities. Leisure needs included two categories namely *leisure perceptions* and *leisure needs.* From these categories six themes emerged. *Leisure perceptions* involved the themes a) leisure activities that caregivers participate in, b) limited leisure time, and c) and leisure experiences. From the category *leisure needs*, the themes a) physical needs, b) psychological needs and c) social needs emerged. The theme *Physical needs* included the sub-themes, *need for time* and *money*, which had an influence on their leisure time or leisure experiences. Within the theme *psychological needs*, needs for escape as well as needs for mental and physical rest emerged. Within the theme *Social needs*, time with family, time with children, and time with friends and community emerged. From this article it was stipulated that caregivers experience a high need for leisure. They found leisure important and necessary, but were mostly unable to access it. It can be concluded from this article, that the findings are in line with the central theoretical statement as set out in chapter 1, namely that the primary caregivers of people with disabilities experience high levels of unmet leisure needs.

From the information gathered from the research, it is evident that the caregiver’s life, including their leisure lifestyles, are impacted significantly by their care responsibilities, as also mentioned by Dupuis and Smale (2000:259). Similar to previous studies, this study revealed that caregivers mostly experience their caregiving responsibilities as a negative influence on their leisure (Bedini & Guinan, 1996b:275, 280; Dupuis & Smale, 2000:319; Wood & Tirone, 2013: 585,586; Wahl and Newmark, 2009:293, 298, 299), limiting the caregiver’s ability to participate in leisure, or to have a satisfying leisure experience. In can be concluded that caregiving acts as a constraint to their leisure (Dupuis &Smale, 2000:319). The caregivers specifically laid attention on time and financial constraints which mostly resulted into the rest of the constraining factors to their leisure.

Literature reveals that the quality and the amount of time spent on leisure is important for the well-being of people since it brings direct satisfaction (OECD, 2009:20). Information obtained from the research indicated that caregivers sometimes have free time, but are not able to use it for leisure purposes. Even if they did participate in leisure, it was not completely satisfying due to their caregiving role interfering, or due to worries over the children during their leisure time.

In conclusion, the constraining factors that caregivers experienced caused caregivers to have unmet needs and/or unsatisfied leisure experiences. In addition, Mannel (1999:243) explains unmet needs in the context of the Post Hoc Satisfaction Approach, as a disequilibrium emerging in an individual, causing them to believe that the tension or disequilibrium will be reduced through a certain action (Cordes, 2013:4; Fodness, 1994:555; Guha, 2009:22, 28; Mannell, 1999:243). Mannell (1999:234) goes on to say that if participation in an activity is satisfying, a person will continue to behave in the same way for that outcome, but if it the experience is negative, the person will terminate it. Caregivers in this study mostly chose to put their leisure needs aside or terminate their leisure due to the negative outcomes if they decide to reject their duties, which are in line with findings of Dun and Strain (2001:49). Thus, considering the negative effects that caregiving has on caregivers, and the absence of leisure benefits due to little or no participation in leisure as well as unsatisfied leisure experiences, it is critical for centre managers and leisure service providers to implement programmes and interventions in order to facilitate in satisfying the caregivers leisure needs and reduce constraining factors where possible.

5.4 Limitations

The sample mainly consisted of black African female participants and two black African male participants, therefore, this study failed to reveal the opinions on different genders or races. Also, literature involving caregiving for disabilities and leisure in a South African context are limited, therefore, hampering the researcher’s ability to integrate and compare the findings with a wide range of research. Limitations were also experienced in the area of language and communication since the participants’ first language was Setswana and there are no exact translations for the term leisure in their language. Furthermore, this study was based on an exploratory case study approach focusing on a specific case population which means that the study findings cannot be generalised. Lastly, in this study some of the caregivers resided at their own place while the rest of the caregivers resided at the centre which means that there will be differences in the needs they develop for leisure. Therefore, research should be done on the contextual elements of formal caregivers’ needs and constraints.

5.5 Recommendations

5.5.1 Recommendations for future research

Findings of this study provided information on the leisure perceptions and the negative influences that caregiving have on the leisure. This information will be useful to centre managers or care-institutions caring for people with disability as well as leisure service providers to know how to design programmes to address the leisure needs of caregivers in an under resourced context. It is recommended that future research should focus on:

- How to enable, empower, and educate caregivers to empower caregivers to satisfy their own leisure needs and also to be aware of opportunities to access leisure.

- How centres can enhance their management and working circumstances to support the caregivers to have a more satisfying leisure lifestyle and also to have more available time for leisure.

- Conducting more research on facilitating factors that may help caregivers to negotiate concerning the constraints they face.

- How leisure programmers can assist formal caregivers in South Africa through interventions and leisure programs specifically designed for their personal leisure needs. As Uren and Graham (2012:69) emphasise, caregivers should be able to access interventions, support groups, and receive therapeutic assistance to help relieve the severity and the impact of their personal situations.

It is also recommended that future research should attempt to utilise a more diverse sample of caregivers in South Africa by applying approaches that include recruitment in centres or institutions that have greater diversity.

5.5.2 Recommendations for practitioners

Caregivers from this study indicated that there is a great need for leisure time and also that there are many constraining factors influenceing their leisure or preventing them from participating in leisure. It is therefore important that centre managers and leisure programmers focus their attention on the following reccomendations:

- Centre managers should focus more on what the leisure needs that caregivers experience are and also they should determine how they can help the caregivers to satisfy those needs and overcome the constraining factors preventing or limiting their time for leisure.
- There needs to be a system, such as a schedule or time shifts, that provides caregivers the security to be able to plan for, and experience, leisure on a regular basis and not just ocassionally. This will help combat burnout and caregivers may lead to increased motivation and effectiveness among caregivers.
- Leisure programmers should take a closer look at institutions for persons with disabilities in communities, determine what their needs are and try to provide opportunities, facilities and programmes that will suit their leisure needs.
- Since many caregiving contexts limit caregivers to go out of their working environment, and allow limited time and finances for leisure, it should be the leisure programmer’s priority to develop context specific programmes and opportunities to enable the caregivers to have satisfying leisure. These programmes should be cost effective and practical due to financial and time constraints.

- Caregivers also need to be educated on the benefits leisure provides and how to manage their personal and working time to be able to make time for leisure. Caregivers also need to be made aware of possible facilities and opportunities in the community and they should be enabled or assisted to have access to it.

References

Bedini, L.A. & Guinan, D.M. 1996a. If I could just be selfish: caregivers' perceptions of their entitlement to leisure. *Leisure science*, 18(3):227-239.

Bedini, L.A. & Guinan, D.M. 1996b. The leisure of caregivers of older adults: implications for CTRS's in non-traditional settings. *Therapeutic recreational journal*, 30(4):274-288.

Cordes, K.A. 2013. Applications in recreation and leisure for today and the future. 4th ed. Urbana, IL: Sagamore.

Dunn, N.J. & Strain, L.A. 2001. Caregivers at risk: changes in leisure participation. *Journal of leisure research*, 33(1):32-55.

Dupuis, S.L. 2000. Institution-based caregiving as a container of leisure. *Leisure sciences*, 22(4):259-280.

Dupuis, S.L. & Smale, B.J.A. 2000. Bitter sweet journeys: meanings of leisure in the institution based context. *Journal of leisure research*, 32(3):303-340.

Fodness, D. 1994. Measuring tourist motivation. *Annals of tourism research,* 21(3):555-581.

Guha, S. 2009. Motivational push factors for visiting re-enactment sites. San Jose, CA: San Jose State University. (Thesis - PhD).

Heintzman, P. & Mannell, R.C. 2003. Spiritual functions of leisure and spiritual well-being: coping with time pressure. *Leisure sciences: an interdisciplinary journal*, 25(2-3):207-23.

Mannell. R.C. 1999. Leisure experience and satisfaction. (*In* Jackson EL. & Burton, T.L., *eds*. Leisure studies: prospects for the twenty-first century. State College, PA: Venture. p. 235-248).

OECD. 2009. Society at a glance 2009: OECD social indicators. Paris: OECD. http://dx.doi.org/10.1787/soc_glance-2008-en. Date of access: 23 Jun. 2016.

Schryer, E., Mock, S.E., Hilbrecht, M., Lero, D. & Smale, B. 2016. Use of leisure facilities and wellbeing of adult caregivers. *Leisure sciences*, 38(1):17-33.

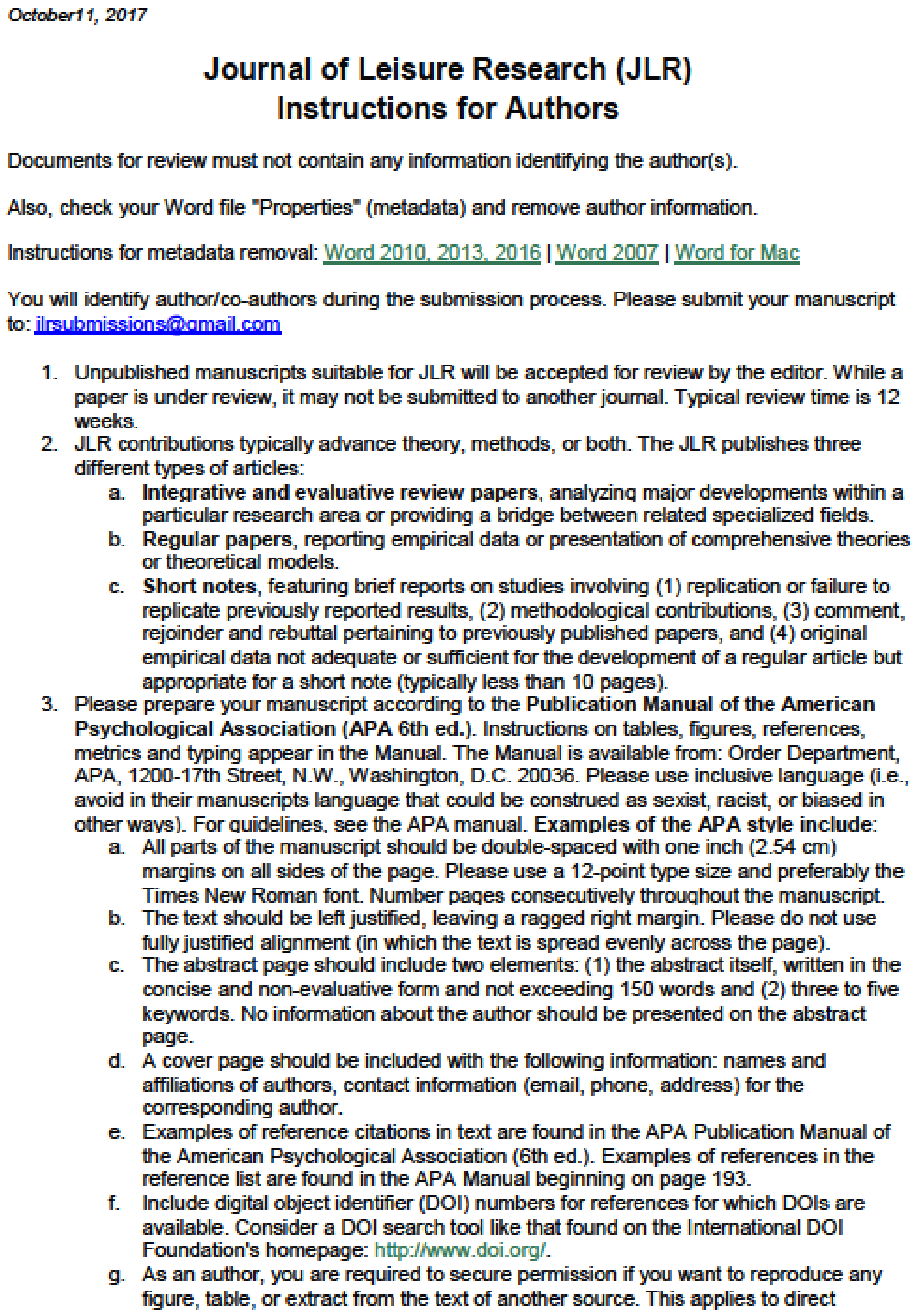
Schuz, B., Czerniawski, A., Davie, N., Miller, L., Quinn, M.G., King, C., Carr, A., Elliott, K-E.J., Robinson, A. & Scott, J.L. 2015. Leisure time activities and mental health in informal dementia caregivers. *Applied psychology: health and well-being,* 7(2):230-248.

Uren, S.A. & Graham, T.M. 2012. Contextual elements of palliative caregiving in a low-income community. *South African journal of psychology*, 42(1):61-70.

Wahl, S. & Newmark, R. 2009. The self-perceived quality of life of staff caring for adults with intellectual disabilities. *Journal of humanities*, 49(2):289-306.

Wood, S. & Tirone, S. 2013. The leisure of women caring for people harmfully involved with alcohol, drugs, and gambling. *Journal of leisure research*, 45(5):583-60.

ANNEXURES A: JOURNAL OF LEISURE RESEARCH GUIDELINES



October11, 2017

Journal of Leisure Research (JLR)
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    a. **Integrative and evaluative review papers**, analyzing major developments within a particular research area or providing a bridge between related specialized fields.
    b. **Regular papers**, reporting empirical data or presentation of comprehensive theories or theoretical models.
    c. **Short notes**, featuring brief reports on studies involving (1) replication or failure to replicate previously reported results, (2) methodological contributions, (3) comment, rejoinder and rebuttal pertaining to previously published papers, and (4) original empirical data not adequate or sufficient for the development of a regular article but appropriate for a short note (typically less than 10 pages).
3. Please prepare your manuscript according to the **Publication Manual of the American Psychological Association (APA 6th ed.)**. Instructions on tables, figures, references, metrics and typing appear in the Manual. The Manual is available from: Order Department, APA, 1200-17th Street, N.W., Washington, D.C. 20036. Please use inclusive language (i.e., avoid in their manuscripts language that could be construed as sexist, racist, or biased in other ways). For guidelines, see the APA manual. **Examples of the APA style include**:
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    b. The text should be left justified, leaving a ragged right margin. Please do not use fully justified alignment (in which the text is spread evenly across the page).
    c. The abstract page should include two elements: (1) the abstract itself, written in the concise and non-evaluative form and not exceeding 150 words and (2) three to five keywords. No information about the author should be presented on the abstract page.
    d. A cover page should be included with the following information: names and affiliations of authors, contact information (email, phone, address) for the corresponding author.
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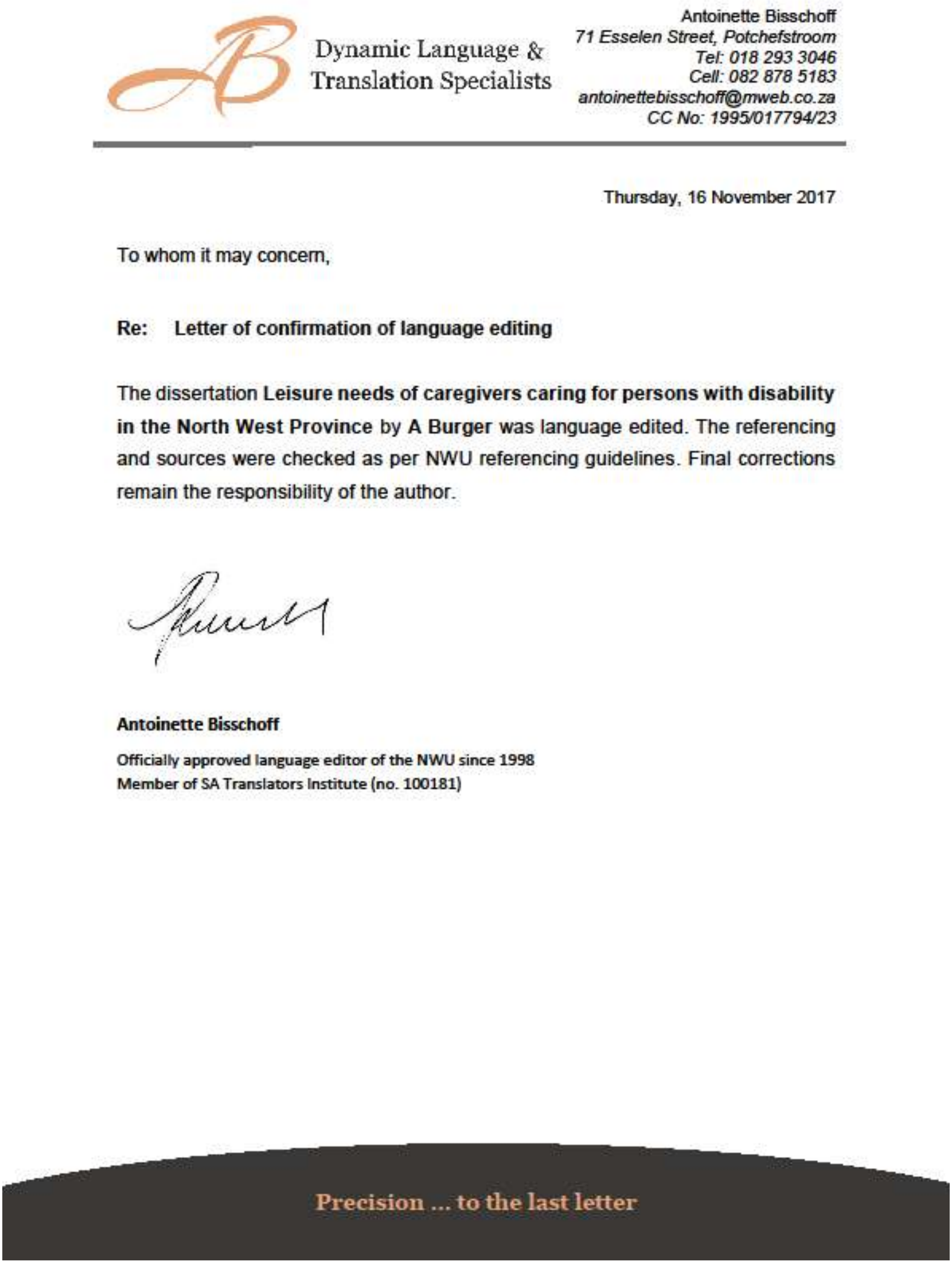
ANNEXURES B: LANGUAGE EDITING



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Thursday, 16 November 2017

To whom it may concern,

Re: Letter of confirmation of language editing

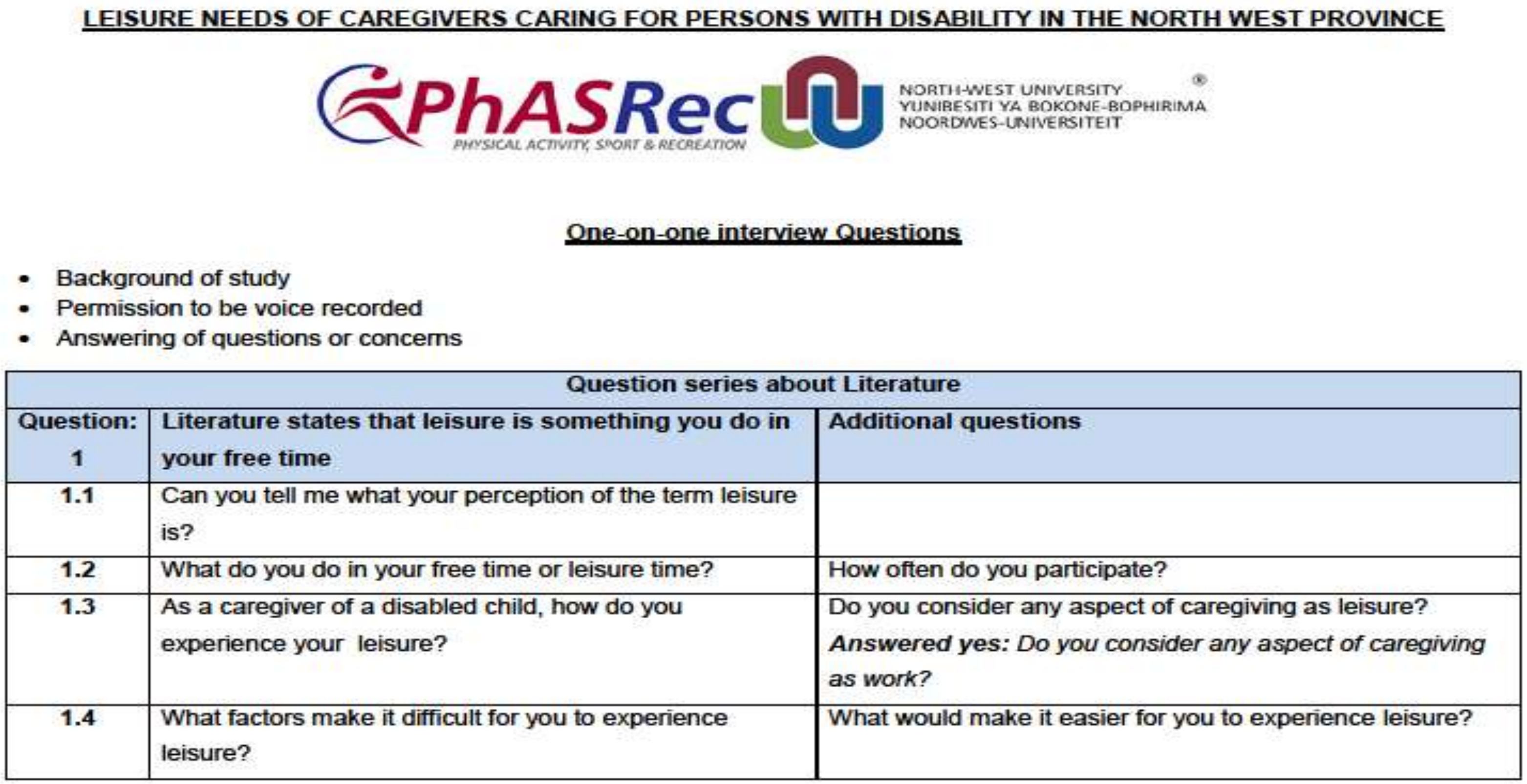
The dissertation **Leisure needs of caregivers caring for persons with disability in the North West Province** by **A Burger** was language edited. The referencing and sources were checked as per NWU referencing guidelines. Final corrections remain the responsibility of the author.

Antoinette Bisschoff

Officially approved language editor of the NWU since 1998
Member of SA Translators Institute (no. 100181)

Precision ... to the last letter

ANNEXURES C: INTERVIEW SCHEDULE



LEISURE NEEDS OF CAREGIVERS CARING FOR PERSONS WITH DISABILITY IN THE NORTH WEST PROVINCE

PhASRec
PHYSICAL ACTIVITY, SPORT & RECREATION

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

One-on-one interview Questions

- Background of study
- Permission to be voice recorded
- Answering of questions or concerns

Question series about Literature

Question: 1	**Literature states that leisure is something you do in your free time**	**Additional questions**
1.1	Can you tell me what your perception of the term leisure is?	
1.2	What do you do in your free time or leisure time?	How often do you participate?
1.3	As a caregiver of a disabled child, how do you experience your leisure?	Do you consider any aspect of caregiving as leisure? ***Answered yes:*** *Do you consider any aspect of caregiving as work?*
1.4	What factors make it difficult for you to experience leisure?	What would make it easier for you to experience leisure?

Question: 2	**Literature states that there are many consequences of leisure participation**	**Additional questions**
2.1	What impact does participating in leisure have on you?	
Question: 3	**Literature states that caregivers experience the need for leisure**	**Additional questions**
3.1	What needs do you experience as a caregiver that can be satisfied through leisure?	
3.2	What would make it possible for you to fulfil these needs?	
Question: 4	**Literature states that caregiving has an impact on the leisure of caregivers**	**Additional questions**
4.1	How does your caregiving role and responsibilities have an impact on your leisure?	

- Closing statements
- Conclusions
- Answering of questions or concerns

End, thank you

ANNEXURES D: INTERVIEW

Interview 10 / Participant 10

09 September 2016

09:55

		Codes/notes /memo
P:	Ke shap.	00:02
R:	Ke Shap! Okay.	
P:	Ke shap.	
R:	So, / [p] let's just do this and [recorder sound] there we go.	
P:	/ [Clearing throat]	
R:	Okay [name].	
P:	Hhm? [Giving attention]	
R:	Let's just put these papers here. [Moving of papers] So we spoke a lot about the, [p] or not that much but [p] uhm we talked a little bit about the leisure, free time activities [p] okay. now uhm [clearing throat] [p] uh the the smart people from the university, [p] they say that leisure [p] is something that you do [p] in your free time, the time you have available after your responsibilities.	
R/T:	[Explaining in S]	
P:	Hhm.	
R/T:	Ehh [explaining in S]	
P:	Hhhhm. [Listening]	
R/T:	[Explaining in S]	
R:	Okay.	
R/T:	[Explaining more in S]	
P:	[Responding in S]	
T:	[Speaking in S] [Laugh]	
P/T:	Eh free time really [clearing throat] …	
P:	Is too short	
P/T:	Is too short ja.	
R:	Hhhhhhm.	
P/T:	Because uhh [p] th- there are many things [p] that one would like to do, to attend to marriages (xxx), to work with people (xxx) people, to [p] to attend to death cases, and a lot of those things, but with the type of work that we have [p] free time really [p] you can't use it for the things that you want to do,[p] / or it [p] it's a very little, for instance i- if (4x) I want to attend to anything [p] I'll have take [p] to request for leave, for instance if they [p] they give me leave from [p] ten o'clock am, I've got to be back at work by ten o'clock there // [p] the next day.	
R:	/ That you want to do? // Sho. [p] Okay. Hm, I hear what you're saying. Uhm [name] [p] while we are just in the beginning of the interview, I forgot to tell you that I would just like you to know, I think you are comfortable, but I would just like you to know that the questions I'm asking you is uhm just like having a normal conversation, and uhm [p] for in case you were wondering [p] there's no wrong or right answer to	

	the questions. So I'm, like you are already (ex)plaining to me	
P:	Hm.	
R:	I'm just here to come here from you what is your experiences here at the centre, so I would just like to make sure that you know that [p],	
P:	Hm.	
R:	and u- ja.	
R/T:	[p] Ja [explaining in S].	
P:	Hhhm.	
R/T:	[Explaining in S]	
P:	[Responding in S] [Loud voice of child screaming and people speaking]	
T:	Eh.	
P:	[Responding in S] [Caregiver speaking loud in background]	
T:	Hm.	
P:	[Responding in S]	
T:	Hm.	
P:	[Responding in S] [Caregiver speaking loud in background]	
T:	Ehh. [Listening]	
P:	Ehh.	
P/T:	Eeh just I'll regard this, (that?) or this the same as uh something happening about my child. You don't just take your child and dump him to school and say it's a matter of school teaching (xxx), you must also assist the teacher with the education of my child. It is the same for you [p] that whilst you're doing your masters here I'm going to, I'm prepared to help you, because I know [p] I'm helping to help so that you can help others.	04:55
R:	Okay okay. Thank you very much. What is it in English, thank / you? Ag in tswana?	
T:	/ Eh [p] eh eh "kaleboga".	
P:	Eeh. Hm. [Agreeing]	
R:	Kaleboga. Thank you. / [Laughing]	
P:	/ [Laughing]	
R:	Okay so [p] let's get back, you said that the centre you don't have time for funerals, for weddings [p] uhm stuff like that y-, and if you have to go you must take leave neh.	
P:	Hm.	
R:	Uhmm [p] are those the type of things that [p] you regard as free time activities?	
R/T:	[Explaining in S]	
P:	[Responding in S]	
T:	[Short interruption in S]	
P/T:	Just to see through during my free time, [p] free time I will go do certain responsibilities within the family. For instance, I have my of kids attending school [p] and then uhh i- it's good to be around them and vigilant [p] uh as they grow sometimes some of them will go, you know, like (xxx) sneak out at night. I need to be there to see that so that I can / (reprimand?) them and (bail?) them, [p] and then uhhh [p], but but because of this type (I have?) no time towards those things there are other things I've got to do to mend and tend to the house uhh [p], so during that [p] free time when you get there y- [p] sometimes you find [p] the bigger ones have going to work. So you hardly [p interact with	07:48

	anybody with that free time // over things that you really have wanted to do.	
R:	/ Yeeees. // Hhhhhhhm. [Wait until T finish speaking] Yeeees. So you have a big need for interaction with your children? [Confirming/asking]	
R/T:	[Explaining in S] [People speaking in background]	
P:	Hhm.	
T:	Yess? [Giving opportunity for P to speak]	
P:	[Responding in S] … / ……… [p] ….	
P/T:	/ Yes it’s [p] it’s it’s important.	
P:	Hmm.	
P/T:	During my free time I should be able to [p] to identify the needs [p] of [p] of the very same chil- children.	
R:	Okaaay. And then I would also assume if you say that, that you sometimes sacrifice your own needs to attend to the needs of your children?	
R/T:	[p] [Explaining in S] … / …	
P:	/ Ehh. [p] [Responding in S] … // …	
P/T:	// Okey. Eh just to (that) (xxx) not the same as [p] us in the past.	
R:	Just say what is not the same?	
P/T:	Uh it’s modern [p] children [p]	
R:	Modern children.	
P/T:	Are not the same as we were / (xxx) was parent, I mean, children. Uhh they actually instead of being reprimanded they rather reprimand YOU [p] as a parent. And as I said there’s just little time, you know, sometimes you get home, you find the other one is not there. You cannot th- the (xxx) time.	
R:	/ Hhhhm.	
T:	But I’d like to redirect this question back to to re-answer it about (you?) / [p] sacrifice (your?) [p] for. It has not been // answered.	
R:	/ Okay, [p] so … // Ja. It was not really a question, it was uh a statement, something I [p] I picked up through what you said, so it was more like something I (3x) uhm [p] “opgemerk” [p]	
T:	Ja.	
R:	Uhm [p] what is that in English?	
T:	Uh f- noticed.	
R:	noticed	
T:	Hm	
R:	that you sacrifice your time for the children here, and for your children at home. So you sacrifice your own needs for the [p], to that.	
R/T:	Ja. [Explaining in S] … / …	
R:	/ Leisure needs. [Wait until T finish speaking] Hhhm.	
P:	[Responding in S]	
T:	I must repeat ag- it again.	
R/T:	[Start explaining in S]	
P:	[Short response]	
R/T:	[Explaining in S]	
P:	[Responding in S]	

P/T:	Eh [p] the, [p] eh eh uh the (3x) uh the free time what you do about it, th- uh-ma- uh [p] [researcher] says [p] you've got leisure t-, free, you've got free time yourself. And that free time that you have, [p] instead of using it for your own [explaining further in S]	
P:	Hm.	
R/T:	[Explaining in S] … / … [p]	
P:	/ [Responding in S] =	
P/T:	= Yes it does // benefit them and not me.	
R:	// Hhhm. [Long p] Aaaah. Ookay. Uhh [name], [p] I would like to know from you [p] what leisure, what free time activities [p] would you cons- sider as so- u-. or can you give me examples of activities that one would do in their free time [p] for themselves [p] that they like.	
R/T:	[Explaining in S] … / …	
P:	/ [Sigh]	
R:	I'm not speaking about the children, I'm speaking about in general for people. What activities would you consider as / (something?)?	
R/T:	/ [Explaining in S] [Children voices in background]	
P:	[Responding in S]	
T:	Eheh.	
P:	[Responding in S]	
P/T:	When I'm not at work	
R:	Yess. [Listening]	
T:	Eh.	
P:	[Responding in S] [People speaking loud in outside]	
T:	[p] Ja.	
P:	[Responding further in S]	
T:	Hm. [Listening]	
P:	[Responding in S] [Laugh]	
T:	Shap, [speaking in S] when I'm interrupting you [p]	
P:	Hm.	
T:	it's not that I'm stopping you. I'm trying to cover [explaining in S] just for a moment [p] let's have a breath so that [explaining in S] … / …	
R:	/ Just to remember what you want to say.	
T:	Ja, because otherwise I'm going to forget many things that you say and she wants them here.	
P/T:	Free time, [p] is free time that is [p] my free time and where I do things out of my own volition / because I'm away of work. But first thing, for instance if I'm home, because it's my free time, I like to [p] to mend my vegetable garden for instance.	
R:	/ Ah. [Wait until T finish speaking] Aahhh to work in your // vegetable garden.	
P/T:	// Ja, and the next thing that comes best to me, to my mind, is a- attending to my own children.	
R:	Aaahhh. [Listening]	
P/T:	And then comes the question of, you get invited in the village and societal, you know, issues and events, [p] you need to go there [p] and we so- a social person as well.	
R:	A social person?	
P/T:	Ja.	

R:	Hhhhm.	
T:	Yes. =	
R:	= Okay. Well uhm, [p] do you think uhm [p] that people can experience leisure [p] in [p] different [p] sph- spheres of work? Like can they experience it after, during, or before work? What is your opinion?	
R/T:	[Explaining in S] [Children making sounds in back ground]	
P:	[p] [Responding in S]	
P/T:	Repeat.	
P:	[Responding in S]	
P/T:	Eh okey, she wants me to repeat / what I'm saying.	
R:	/ Okay.	
R/T:	[Explaining in S]	
P:	Eh.	
R/T:	[Explaining in S]	
P:	Uhum.	
R/T:	[Explaining in S]	
P:	After.	
P/T:	Uhm [p] after.	
P:	[Responding in S] come [p] tomorrow morning, (xxx) going to work / [responding in S].	
R:	/ Hhhm.	
T:	Hhhm.	
P:	Eh.	
P/T:	You know (xxx), as I as I said free time whe- [p] eh when you get it, my own, my own free time I want to get [p] home, and this body gets exhausted, / I want to really rest [p] uh body rest so that // when I come back to the job the next day [p] I'm I'm fresh again.	
R:	/ [Laugh] Hhm. // Yeees. [Wait until T finish speaking] Hhhhm. [p] /// Okay	
T:	/// Yess.	
R:	Now, this free time of you neh, when [p] do you have time to do that? Like, you said you work twenty four hours, [p] seven days a week, then you have one day off. Uhm, [p] tell me more about the different uhm off days [p] or weekends you have. Tell me about all the the breaks or off times you have, and when your able to do what [p] things [p] for yourself. [Children making loud sounds throughout conversation]	
R/T:	[Explaining in S] I mean that leisure time you speak of, what do [p] (xxx) speak about the the shift or something like that [Children making loud sounds throughout conversation]	
R:	Yes yes.	
T:	Ja, can we make it clear to her?	
R:	Yes, you can explain again.	
R/T:	[Explaining in S] out of seven days [p] [explaining further in S]	
P:	Hhm.	20:22
R/T:	Out of three months [explaining in S] weekend, (ja?) Friday, Saturday, Sunday.	
P:	Ehh.	
R/T:	[Explaining in S] annual leave [explaining further in S].	
P:	Hhm.	

R/T:	[Explaining in S] one day weekend off [p] [explaining further in S] [people shouting out loud in background]	
P:	Hmm.	
R/T:	[Explaining in S] one by one, because I mean it, let us take it one by one.	
P:	Aaah yahh.	
R:	/ Hm.	
T:	/ [Speaking in S] one.	
P:	Ah one day [p]	
T:	Yes	
P:	[Responding further in S]	
T:	Aah.	
P:	[Responding in S]	
T:	Uhum. [Listening]	
P:	[Responding in S] … [sigh], weekend off	
T:	Okay, let’s take (xxx) that one, ja.	
P/T:	Thi- this one (we are?) one day off.	
R:	Yes, when / you have one day off?	
P/T:	/ (one of seven?). Yah. [Yes] [p] uh that’s just the right one for me, [p] because I’ll get home and get rested, because it’s only one day, because I cannot go here and there, but // the main thing is I shall have managed [p] to rest well.	
R:	// Hhhhm. [Wait until T finish speaking] Hhhhm. [Listening]	
P/T:	(After which?) …	
T:	Let’s take the second one.	
P:	[Responding in S] [Children voices in background]	
T:	[p] Ehh.	
P:	Eh. [Responding in S]	
P/T:	W- we (had?) long-, we (had?) three day weekend off	
R:	Hhhm.	
P/T:	Eh [p] e- uh uh resting is also part of that	
R:	Yeeees.	
P/T:	(xxx) you’ve got enough rest,	
R:	Hhhm. [Listening]	
P/T:	and then y-yo- you are able to say for instance, (you?) may have been invited by mister (Mlovalho?) or something [p] for the wedding ceremony [p] stuff (that?) we’re able to [p] to honour such invitations,	
R:	Okay.	
P/T:	And then you also have [p] in our, in our society, we have got weddings, (when you’re?) are invited [p] you definitely wish to attend [p] / to all those invitations, and then you also have other societal obligations [p] where you you team up as members of the community to contribute towards a certain [p] eventuality and so forth. You need to interact with other people for such.	
R:	/ Hhhhm. [Wait until T finish speaking] Okay.	
T:	(Alright?)	
R:	I would like to know [p] if there’s a weekend where there are no weddings or societal obligations? What on those small occasions when there’s nothing big going on like a wedding or a party, what do you like to do in your free time when there’s nothing of that, on a weekend like that? Something that you do for yourself for the pleasure of it, [p] something you would like to	

	do uhm [p] it, ja, just for / yourself.	
R/T:	/ [Explaining in S]	
P:	Hm.	
R/T:	Ehh. [Explaining in S]	
P:	[Short sentence in S]	
R/T:	Yehh.	
P:	[Responding in S]	
T:	Yeh.	
P:	[Responding in S]	
P/T:	Ja on such weekends you say “hoo” well what a bonus, because in deed you may actually even, I I mean, u- manage [p] to [p] to, I I mean, to vist- to make long visitation, visitation of of long (xxx), like for instance faraway places like Mafikeng / where one would go and visit relatives or friends for one or two days, and also there is also leisure, part if my leisure time spending for [p] resting.	
R:	/ Hhhm. [Wait until T finish speaking] For resting? [Laugh] And what do you do when you visit your friends or relatives like with Mafikeng? What do you guys like to do together [p] when you visit each other?	
P:	[Responding in S] … // ……. // …….[Child sounds in background]	
T:	// Ja. // Ja.	
P/T:	You see uh [clearing throat], that weekend uh is just by mere visitation to (really?) far away friends and so forth, it’s not only physical [p] resting, it’s also mental rest,	
R:	Mental // rest?	
P/T:	// because you are there, and then you maybe [p], you know, spoil (xxx) entertainment, to say let’s go to [p] to a restaurant and and / there then you [p]	
R:	/ To a restaurant?	
P/T:	Ja, you maybe, you’ll be entertained (and) through [p] you know, a host and so f-, // your host would definitely entertain you this way or the other and (3x) that’s /// also mental reach, [p] rest.	27:11
R:	// Aaaah. /// Okay. [long p] That’s that’s good! That’s very good to hear. And uhm, [p] okay, so [p] when you have that one day off neh, [p] you said when you have a long weekend off, like three weekends, it’s a mental rest to go visit family. So when you have that one day off, what do you do for rest on that day? Is it als-, what types of rest do you do? [Laugh]	
R/T:	[Explaining in S]	
P:	[Laugh] [Responding in S]	
R/T:	Hhhm. [Explaining in S] [High children voices in background]	
P:	[Responding in S] [High children voices continue]	
T:	Ja.	
P:	[Responding in S]	
P/T:	No indeed when I’m home you (3x) comprehend that.	
P:	Hhhhhm.	
T:	Yes.	
R:	Okay so what did she say about the house and the cleaning?	
P/T:	Oooh obviously there you will, now (xxx) I [p] I clean the house.	
R:	You clean the house [p]	

T:	Yehh. [Yes]	
R:	and you watch TV / (xxx)?	
T:	/ And I watch TV and uh …	
R:	And the children?	
P:	[Responding in S] [Children voices in background]	
T:	Jaa	
R:	/ Aaah.	
P:	/ [Responding in S] … // ……….. I'm already ouma.	
T:	// Hhhm.	
R:	[Laughing] Ouma?	
P:	Eh ja. [Responding in S].	
P/T:	Ja (xxx) sometimes when I get home they are not e-, they are not even there because it's one day, they've gone to school, / [p] but they'll be happy when they come back from school, // they f-n- [p] and they and I'm there and I'm there for them and they, they are happy, they sit around. =	
R:	= / Aah. // And you're there. [Wait until T finish speaking] Aaaah. [Laugh] Ookay. So [p] uhm [p] when you have leave [p] that is normally a long time, normally. So, when you take leave, those thirty days neh,	
P:	Hm.	
R:	what do you like to do when you're on leave? Except for responsibilities, but like [p] what do you like to do for free time activities, for fun, for yourself?	
R/T:	Hm. [Explaining in S] [Child making very loud sounds]	
P:	[Responding in S] [Children making very loud sounds]	
T:	[Laughing]	
P/T:	How I wish during those long days that I really had money, and enough money, so that I could take, you know, leave and go to the coast or just Cape Town and just go there and relax.	
R:	Aaaaaah! Lovely, and what would you like to do if you go relax in Cape Town?	
P:	To stay and see [p] the / seeee or whatever [responding further in S] … forget the work and // [p] the children way way way [p] and going to rest.	
R:	/ Sight	
T:	// [Laughing]	
R:	Yeeeees.	
P:	When I came in from the (xxx) or Cape Town I'll be FRESHHH!	
R:	You're refreshed?	
P:	Fresshh / [p] fresh fresh fresh!	
R:	/ When you come back?	
T:	Ja.	
P:	Yeh.	
R:	Okay, so you said you'd like to site see, explore? [p] (When you're?) there. [Very loud children voices]	
P:	I I, I like, I like outing. [Very loud children voices continue]	
R:	Outings, [p] [Very loud children voices]	
P:	Hhm. [Yes]	
R:	Entertainments? [Very loud children voices]	
P:	Entertainments.	
R:	Ookay okay. So [p] [caregivers speaking loud outside] okay, but when you do not, [p] okay you said money is a problem, /	

	because you don’t always have the money for // that.	
P:	/ (xxx). [p] // Hm.	
R:	So [p] uhm [children making funny sounds] [p] let’s say [p] on an, [p] okay you don’t, you’re not able to do that, but what do you do when you have your leave?	
R/T:	Ja, [explaining in S].	
P:	Hm.	
R/T:	[Explaining in S] [Caregivers and children voices in background]	
P:	[Responding in S]	
T:	Hm.	
P:	[Responding in S] ….. [loud scream from outside and continues chats] …. [children voices] …	
P/T:	No it’s it’s, no in such days uh (5x) long days it’s [p] apart from resting you are able to [p] to to go around, such people like us who have got illnesses of this nature and that nature, you (3x) really need [p] to rest, and you can do that by visiting people,	
R:	Hm.	
P/T:	interacting in society, and learning and gaining information about this and that, because you have not been there,	
R:	Hm.	
P/T:	[p] but the main thing is to inter-mingle with other people of society	
R:	Hmmm.	
P/T:	And to learn from them and what the developments are (around you?), because you’re affected by those. [Child making loud continuous screaming sounds]	
R:	Yes. So you want to catch up when you have the free time? [Child making loud continuous screaming sounds]	
P:	Yes.	
R:	Okaaay [p] okay. And you see that as [p] as something you do out of your own will, because you want to do it and you like to do it, It’s free time activities, leisure for you? [Child making loud continuous screaming sounds]	
P:	[Indicating yes through facial expression]	
R:	Ookay. Okay. So, when you do that [leisure activities], when you interact with the people, you catch up, you’re in the community, you learn new things, [p] uhm [p] how do you experience that? [p] How does doing that [p], being busy doing that make you feel? What experience is it? [Child making loud continuous screaming sounds]	
R/T:	[Explaining in S]	
P:	[p] [Responding in S]	
T:	[Laughing] Yes!	
P:	[Responding in S] … / … [Caregivers speaking loud outside]	
T:	/ [Clearing throat]	
P/T:	Hm. No uh [wit sigh] when I’m [p] I’m home [p] on long weekends and interacting with [p] with people you [3x, p] really gain a lot of knowledge, because whilst, for instance I’m [p] I’m married in [p] Rustenburg (xxx), the rural areas away from here, [p] but most of the time I’m here, [p] so there is a lot that I’m missing, [p] knowledge [p] that that affects me and other people / so (so that’s) part of society. So when I go there [p] and meet here and there i- I’m I’m I’m, I get well informed, // [p] and and get to know how involved in, in-in things of my own society.	

R:	/ Hhhm. // You get well informed? [Confirming/listening] [Wait until T finish speaking] Okay, and how does it make you feel when you get informed and you gain information? What feeling is, how does it feel when you know [p] I'm involved, I gain new information, I'm [p] busy. How, what, how does that make you feel?	
R/T:	[Explaining in S] … / … [p]	
R:	/ If you could just [p] sorry, [p] if you could describe it in a few words.	
R/T:	[Explaining in S]	
P:	[Responding in S]	
P/T:	Yes, uh that's [p] that's that's a feeling, when I do that, because I [p] I've I've lack knowledge before I interacted, and I'm here, I'm well informed, I'm becoming part of society, I'm well informed and I feel I I I'm (xxx) I'm moving the same pace with everybody else.	
R:	Hm.	
P/T:	And and uhhh [p] you get satisfied by that.	
R:	Is, it brings you satisfaction?	
T:	Hm.	
P:	Hhm.	
P/T:	/ Because of knowledge.	
R:	/ Okay. [p] Personal satisfaction. And uhm [clearing throat] [p], but [p] I would like to know [p] more that the satisfaction. That feeling you have [p] when you're busy doing it? [p] Neh. When when I'm with my f- family for instance, [p] and I spend time with them [p]	
P:	Hm.	
R:	I feel energized. Okay. So what type of d- word [p] uhm can you say, what feeling do you have when you're doing that?	
R/T:	[p] [Explaining in S] … / …	
P:	/ [Word or short sentence in S] [p] eh.	
R/T:	Eehh neh. [Explaining in S]	
P:	[Responding in S] [Child's voice outside]	
T:	Hm.	
P:	[Responding in S]	
T:	Hm.	
P:	[Responding in S]	
P/T:	You see / what	
P:	/ [continue responding in S]	
P/T:	When (3x) we interact with people, (xxx) explained, people that, who (I have?) not been living with [p] for quite some time, and when you join them and (xxx) this, and they inform you well, you you catch up the things that have been outstanding, then you no longer have a void in your heart, / because you're fulfilled, ja [p] ja [p] uhh you are no longer empty. [Children voices in background]	40:12
R:	/ A void? [Wait until T finish speaking] Aaaah.	
P/T:	So you are // fulfilled, you know, and you don't go along with maybe (xxx) [p] fear or or doubts [p] as to how people react and respond to your [p] predicament, because you are part of them and you do what the (set?) is doing. [Children voices in background]	

R:	// It fulfils you? [Wait until T finish speaking] Hhhm. [Listening]	
T:	Ja.	
R:	And you said something about free, feeling free, what did she say, you say about?	
P/T:	Free [p], you yeh [p] you you, you feel free (xxx) you are free from guilt (xxx). =	
R:	= Free from guilt? [Confirming]	
P/T:	And fear.	
R:	And fear? [Confirming]	
T:	Jaa.	
R:	/ Oookay.	
P/T:	/ After, and fear [p] for victimisation, because if you don't comply in societal norms [p] people (xxx) you.	
R:	Aaah.	
T:	Jaaa.	
R:	Oookay.	
P/T:	But this time you are part of them and then you feel free and so on. =	
R:	= So it's a experience, a a free experience? Uhm, almost a experience of relief uh rel- [p] release of (xxx) yes. Okay, and uh you said, okay you have those three days off sometimes neh?	
P:	Hhm.	
R:	Every [p] quarter almost. You said you like to rest in that time, you like to uhm sometimes watch TV or clean house, or when you get invited to a wedding uhh you, you would go there. Uhm [p] let's start with, with the house. When you like to clean the house [p] and uhm watch tv, [p] how does that make you feel? How do you experience it when you busy doing it? [Children voices in background]	
R/T:	[p] [Explaining in S]	
P:	[Responding in S]	
T:	Hm.	
P:	[Responding in S]	
T:	Hmm.	
P:	[Responding in S]	
P/T:	Ja [clearing throat] [p] ja when I'm there, when you, when you get engage in cleaning your house [p]	
R:	Hhhm.	
P/T:	yehh, [p] that is manual (xxx).	
R:	It is?	
P/T:	Manual, something you / use work, I mean, you use your body to do this and that.	
R:	/ Manual? [Wait until T sentence is finish] Hm.	
P/T:	And then it also serves as uh, [p] as an exercise, you know, exercising the [p] the body (xxx).	
R:	Yeees.	
P/T:	So, when you exercise you youuu [p] you get some fitness of some sort, because you also (xxx). But then when you see switch off and you go to a TV [p] that's another [p] type of a [p] a a, let me put it as an escape.	

R:	/ Escape?	
P/T:	/ Because your, you've got a mental [p] uhh fresh, I mean, a uh a, I won't say revival, you are concentrating on something [p] on tv [p] which may be educative [p]	
R:	Educative.	
P/T:	Or sometime it's informative, that's in terms of news, but the focus is taken away from allll this and that, the [p] the // daily things, now you are really (xxx), also it takes away from the hus, (harsh?), and uh you know, [p] of life, // now you are here in another world and you, and you feel refreshed as well, because you are resting // away [p] from the daily [p] yess.	
R:	// All the other things. // (xxx). // Yees. So it's a very refreshing experience and / relieving experience?	
P/T:	/ So [p] ja.	
R:	And how does it feel when your body get exercise? How do you feel when you clean the house and you get that exercise, your body is working? How do you feel when you do it? [p] What does it make you feel like?	
R/T:	[Explaining in S] [Many chatting voices outside]	
P:	[Responding in S] [Many chatting voices continue outside]	
P/T:	Uhum. / Well [p]	
P:	/ [Responding in S]	
T:	Hmm.	
P:	[Responding in S] [Many chatting voices outside]	
P/T:	Well [p] my my, wh- as (5x) I clean and go on with my cleaning chores, because I'm involved, I'm involve in my body and my body parts, I'm also uh uh engaged in my mind and in a way [p] ehh eh eh th- that eh [p] you you [p] you relief it, because you cannot always say now I got free time, we are going to (visiting?) there [p] and sit in there all the time, to say I [p] I'm (xxx). So as you work and you work, and you look at TV and so forth, and you work [p] the mind also work and uh…	
R:	Hhhm.	
T:	/ Hhhm.	
R:	/ It keeps the mind // busy and and of /// [p] from the daily things? [Confirming] Okaay. Uhm, a- a- and what would you call that experience of keeping the mind busy? If you could ss- call it one thing, what would you say is that? What do you call that when your mind [p] is [p] busy?	
T:	// Hhm. /// Hhm.	
R/T:	[Explaining in S] … / … [p]	
	/ Can you describe it in a word?	
R/T:	[Explaining in S] =	
T:	= Can you rephrase the question?	
R:	Yes, uhm so so when you're busy, [p] and you're working and you're mind is also working, it it's keeping your mind busy, it's thinking of things, it's taking your mind of uh off from your daily routines uhm [p] what [p], if you could describe that in a word, what would it be?	
R/T:	[Explaining in S] … / [p]	
R:	/ How would you // describe it?	
R/T:	// [Explaining in S]	
P:	/ [Laughing]	

R:	/ [Laughing]	
R/T:	[Explaining in S]	
P:	[Long p]	
R:	Just tell her it's not uh uh diffic-, I'm not trying to make a difficult question, I'm just asking her what she would personally [p] call that [p] experience of her mind k- keeping busy.	
R/T:	[Explaining in S] [Many voices in background]	
P:	[Speaking in S] … / …	
T:	/ [Explaining in S] ja.	
P:	[Responding in S] … // … [Children voices in background]	
P/T:	// Eh ja [p] you you [p] you really feel free and light in all respects.	50:04
R:	Aaaaah. Okay okay okay. And when uhm, when you get invited to a wedding or a funeral [p] or any sort of a party or a get together [p] uhm, [p] what type of experience is that for you? What feeling do you get when you get together with people at a and, at an occasion like a wedding or a party or a funeral?	
R/T:	[Explaining in S]	
P:	Hhm. [Listening]	
R/T:	[Explaining in S]	
P:	[Responding in S] [Caregivers speaking loud in background]	
P/T:	Ja [clearing throat] pe- people of our calibre [p] and (xxx) are invited to [p] a our ceremony such as (xxx) (wedding?), you don't just in there and attend to sit. You know you [p] you'll definitely be giving, you're prepared to give a helping hand.	
R:	Hhm.	
	But since there, you may be requested in the family to say, can you do salad for us, can you make gavy- gravy for us, can you make me stew meat, so there your involvement / in the whole scenario are part of it.	
R:	/ Aaaaah. [long p] And you enjoy to be involved with that party neh?	
P:	Yees.	
R:	Okay, and how does it make you feel when you're involved?	
P:	/ Ah. [With sigh]	
R:	/ Like I just asked you, you said when you clean the house, you feel relieved and light, now what do you feel when you're involved with the party? [Children voices in background]	
P:	[Responding in S]	
P/T:	I feel energetic	
P:	/ [Responding in S] [p]	
R:	/ Energetic?	
P:	Ja. [Responding in S] [Children voices in background]	
P/T:	Eh you you see that else, or whilst you are helping, give a helping hand and uh, you know, uh time to fill up spaces here and there as requested [p] you really feel [p] your human worth / when (you know?) you are being appreciated and so forth and uh [p] I'm a meaningful person.	
R:	/ Aaaaaah. [Wait until T finish speaking] Ookay, you feel like you [p] add some meaning to something?	
P:	Hm.	
R:	Okay. And then, I just want to know one last thing. When you	

	spend time with your children neh, / you say you sometimes spend time with them or you help them with things, [p] I also want to know from that, what [p] how do you experience that? What feeling do you have when you do that? How does it make you feel?	
P:	/ Hm. [Wait until R finish speaking] [p] [Responding in S] … // … [Child moaning in background]	
T:	// [Laughing]	
P/T:	Well I uh, when I'm home and you know, [p] children are there, because eh uh [p] (xxx) uh uh homely personality to your kids (xxx) for love, they come and they're free, they hold you by (nose?), kiss my eh, they (xxx), uh you know they (xxx), they nag you sometimes, but they [p], because of love, they come / to uh [p] they cover your, cover you all over and sometimes kiss you all, I mean, in your // face all over and you are pleased with them, you feel relieved as [p], you you just feel relieved. /// [p] Hm. Ja.	
R:	/ Huhm. // Aaaaaaah. /// Ooooh! It's it's so sweet.	
T:	Hhhhm.	
R:	[Laughing] Ookay. I want to ask you [name], do you consider any [p] part [p] of your caregiving role [p], caregiving responsibilities or job here, [p] as leisure? As something that you like to do when you and you do it out of your f- uh [p] for for the pleasure of it? It's not, is there anything about you role here that's not work for you?	
R/T:	[Explaining in S]	
R:	Any specific thing that you have to do here?	
R/T:	[Explaining in S]	
P:	[Responding in S]	
P/T:	There's // nothing.	
P:	// [Responding in S] Eh ja.	
P/T:	There's / nothing.	
P:	/ There's [p] nothing.	
P/T:	There's nothing, everything that I do [p] I regard as work.	
R:	You regard as work. Okay. Now you spoke about a lot of fun things and free time activities neh.	
P:	Hm.	
R:	Let's start again with that one day when you like to clean the, maybe rest and you clean house, you spend time with the children, maybe watch a little TV, [p] is there anything about [p] your [p] your circumstances here, and your role and responsibilities as a caregiver that sometimes make it difficult for you [p] to do those [p] those leisure things, those uh activities on that off day [p] uhm [p] ja.	
R/T:	/ [Explaining in S] [p]	
R:	/ Is [p]	
R/T:	[Explaining in S]	
P:	Hm.	
R/T:	[Explaining in S]	
P:	[Responding in S] [Loud children voices]	
P/T:	Ye- yes it does have an impact, sometimes when [p] when you leave, uh when you go on let leave or whatever, and then	

	knowingly [p] that you leave someone here at the centre like miss m- m- like uh [p] uh uh [Manager] or one of the kids [p] you, it haunts you there, because you know what [p] what the progress is or what is been happening [p] with the people, (being?) ill persons that you left behind.	
R:	Hhhhm. [Listening]	
T:	Hhhm.	
R:	Okay, [p] so you feel guilty about it or it just makes you feel worried?	
T:	Hhm. [Yes]	
P:	[Responding in S]	
P/T:	Yes, [clearing throat] the work [p] will impact on even in your free time or leisure time [p] such as it was there[p] or (anywhere?) in your leisure, time you get a call [p] uhh and they reported uh [p] serious illness or death case [p] within the the / centre. It (4x) worries you.	
R:	/ Hhhm. [p] Aaah. Okay.	
T:	Hm.	
R:	Hm. What would make that thing [p] easier for yo-, what would make it easier [p] for you to enjoy that free time experience more? [p] So you said [p] uhm the fact that you worry when your [p] on [p] free time, you worry [p] about the children and sometimes you get a call about a death or something which is also not good. What would make it easier for you as a caregiver [p] to enjoy that free time?	
R/T:	[Explaining in S] … [Papers moving] ….	
P:	[Responding in S] [Loud voices and shouting]	
T:	Uhum.	
P:	[Responding in S]	
P/T:	Well [clearing throat] (when [p] one?), [p] to make things better, what I would do is for instance, when I get such a call or information it's for me [p] to keep up, I mean, to pick up the phone and make a follow up with the [p] centre or institution.	01:01:35
R:	Follow up?	
P/T:	Ja, follow up [p] about the [p] fate [p] or the condition of the person affected.	
R:	Hhhhmm.	
P/T:	And because at time, and then sometimes you may actually [p] know, I mean, information as to where [p] he or she is at that time. Maybe (if it's?) at the hospital [p] you could make a visitation to the hospital to see / [p] just to say "hi" and g- [p] and and when [p] when [p] one wishes uhm, [p] that's what one could do.	
R:	/ Hhhhm. [Wait until T finish sentence] // Hhhm.	
P/T:	// Because after doing that [p] you, when you, you no longer anxious and fearful, you'll be well informed and uh [p] you'll be at ease.	
R:	Okay. Would that make it easier for you to better experience and enjoy your free time that you have?	
P:	Ja.	
R:	Okay. Okay, so uhm [clearing throat], when you participate in leisure neh, tha- the-the smart people say that caregivers, o- or let's say that uhm [p] when you participate in leisure, [p] free	

	time activities, [p] uhm [p] there are specific [p] things that happened to you. It has specific consequences or effects on you okay. But that's just the statement. Uhm, what I want to know about that is uhm what positive, [p] like benefits, [p] or negative, disadvantages, things can hap-, does happen to you when you participate in leisure? [p] So let's start with uhm [p] the (3x) [p] uhm [p] the one day off where you clean your house, you watch TV, you spend time with your children neh, [p] what positive things, which means [p] almost like benefits, or negative things like, almost like disadvantages, are there when you participate in those things?	
R/T:	[Clearing throat] [Explaining in S]	
P:	Hm.	
R/T:	[Explaining in S] [Caregivers speaking in background]	
P:	[p] [Responding in S]	
T:	[Explaining in S]	
P:	[Responding in S]	
T:	Uhum. [Listening]	
P:	[p] [Responding in S]	
P/T:	I don't grasp it uh quite proper.	
R:	Okay. Uhm [p] what outcomes do you get from from participating in leisure? U- [p] it can be positive or negative neh, so uhm if I can give and example. When I participate in leisure, [p] free time activities, I like toooo go running in my free time. When I go running [p] the outcome of running or the effect that running has on me [p] is it improve my health, it strengthens me, and [p] it gives me a, maybe for instance a uh better fitness. Okay. That's the outcomes, the effect that running has on me. And it maybe clears my mind. So that is the effect that leisure has on me. So what is the effect [p] that [p] resting, cleaning house, watching TV, spending time with your children have on you?	
R/T:	[Explaining in S] … / …………….. // [p]	
P:	/ Hmm. // Hm.	
R/T:	[Explaining in S] [Loud voices vin background]	
P:	Hm.	
R/T:	[Explaining in S] … / ……... // …… [children making loud sounds outside]	
P:	/ Hm. // Hm. [Wait until T finish speaking] [p, with sigh] [Responding in S]	
T:	Uhum. [Listening]	
P:	[Responding in S]	
T:	Hm.	
P:	[Responding in S]	
P/T:	Okey. / No [p] it [p] it (3x) is too (way?), in one day sometimes [p] you learn [p] at the [p] (married/burried?) family where there's death, and there are problems, and there are intricacies and short comings, [p] that in it's way also [p] you make it, you feel it and it's it stresses you.	
P:	/ [Word in S]	
R:	Okay and that is the negative impact that / leisure have on you?	
P/T:	/ Ja. [p] But at same time the same scenario whether it's with marriage or [p] death case where there is happiness and (order?) and	01:09:05

	everything, uh you [p] you feel less stress, you are, you become less, I mean, stress-free .	
R:	Hhhhhm.	
P/T:	Sometimes you (xxx) even near the death case, people is nice, they're communicating, there are [p] there are laughter's here and there and there's peace and harmony.	
R:	Hhm. =	
P:	= So [p] also uh it's it's a two [p] way, two-way house.	
R:	Okay okay. And uhm when you uhmm [p] like when you hou- clean house and watch TV, or you spend time with your children, you do any sort of rest for activity uhm what impact does that have, or let me state it differently. As a caregiver here [p] is uhmm [p] how does your free time activities like the watching the tv and spending time with your children, or uh cleaning the house, how does that [p] impact you positively or negatively [p] as a caregiver of the centre?	
R/T:	[Explaining in S]	
P:	Hmm.	
R/T:	[Explaining in S]	
P:	[Responding in S] … / …	
T:	/ Hm.	
P/T:	Well [p] the work that I'm doing here for instance, du- during my free time or leisure time when I [p] when I go [p] home and I'm trying to [p] to enjoy my free time and my leisure time,	01:12:15
R:	Hm?	
P/T:	The [p] the (3x) uh it doesn't have a negative impact	
R:	Uhum. =	
P/T:	= Except when you have gone home [p] knowingly [p] that you have left the centre with some things that don't go right.	
R:	/ Okay.	
P/T:	/ That you have left you know.	
R:	Okay.	
P/T:	Hhmm.	
R:	But I would also like to know it the other way around. When you participate in leisure neh, [p] when you spend time in your free time activities, all the fun activities, you go out with family, [p] or whatever you do in your free time, how does spending [p] uhhm time on rest and spending time in your free time [p] impact your caregiving here?	
R/T:	[Explaining in S]	
P:	Ehh.	
R/T:	[Explaining in S]	
P:	Ehh.	
R/T:	[Explaining in S]	
P:	Boiketlo.	
R/T:	Eh [Explaining in S]	
P:	Eehh.	
R/T:	[Explaining in S]	
R:	Just, let's start with positive. / Just [p] positive.	
R/T:	/ [Explaining in S]	
P:	[Responding in S]	
T:	Hhm.	
P/T:	Eh [p] negatively [p] two u- two sided answer from your question.	

	When I'm home with my [p] that little leisure time, and uh having left here at th- the work s- or the centre [p] some part of the work completed [p], then I'm there [p] "ooh" I become anxious, it [p] whilst I'm there to say "ooh ooh" by the way something's outstanding what is my boss going to say, [p] and it it haunts me, because there's something during my "tjaila" time when I knocked off [p]	
R:	Jaaa.	
P/T:	my work was not complete when I left here.	
R:	Hhhmm.	
P/T:	So it was outstanding.	
R:	Yeeees.	
P/T:	And then I've got to account. So when I'm busy with my leisure time when it goes into my mind that there's something outstanding, it begins to haunt me.	
R:	Hhhm.	
T:	Hm	
R:	Okay and the other [p] side of it. when you participate, [p] when there's nothing here that haunts you neh, [p] you go home [p] with a free heart, you go and spend time in the community, with your children, you clean the house, you go and have some fun time, free time neh, [p] when you have the opportunity to freely do that and it makes you feel good and everything, how does it impact your work here?	
R/T:	[Explaining in S]	
P:	Hhm.	
R/T:	[Explaining in S]	
R:	/ How [p]	
R/T:	/ [Explaining in S] [p]	
R:	Ja, how is your leisure time good for your work?	
R/T:	[Explaining in S]	
P:	Hhmm.	
R/T:	Eh [Explaining in S] … / …	
P:	/ [Response in S] [p] eh [Responding in S]	
R/T:	Eh.	
P:	Eh.	
R/T:	[Explaining in S]	
P:	[Responding in S]	
T:	Ehh.	
P:	[Responding in S] [Children continuously making loud sounds and caregivers speaking now and then]	
P/T:	Well when I'm out there and having no, I mean, knowing that there is nothing outstanding in terms of my task and work, I [p] I I quite enjoy my work there because there's nothing that haunts me.	
R:	Okay [clearing throat] uhh you [p] enjoy you're your time in your leisure [p], because there's nothing at work that haunts you? Okay, I would like to know w- uhm how does [p] spending leisure time [p] benefits [p] your work? [p] Do you understand what I mean, / I want to know, when I I [p] my work is to do [p] uhmm [p] interviews today, [p] now if I go running [p] my running benefit's the way I uhm influence the way I give interviews, maybe running gives me some new energy and a refreshed	

	mind, now I’m able to do my interview better [p] uhm, [p] but for you it’s different, how does your leisure time that you do [p] benefit your way of // working?	
T:	/ Ja.	
R/T:	// [Responding in S]	
P:	Hm	
R/T:	[Explaining in S]	
P:	Hm.	
R/T:	[Responding in S] [Loud voices in background]	
P:	[Responding in S]	
P/T:	Okay, / (xxx) briefly [p] eh having there have rested well, and interacted, [p] the benefit of that is that I come now more [p] refreshed when I come to work	
P:	/ [Responding in S] [p]	
R:	Hhmm. Okay, and when you’re refreshed at work uhm [p] what uh uh what part of your work do you do then uhm, how does u- [p] being refreshed help you to [p] uh at work? What makes [p] when your refreshed, how does it make your work easier? [Children voices outside]	
R/T:	[Explaining in S]	
P:	To concentrate [responding in S]	
P/T:	No as I said, when I come back from there I’m refreshed and now less less [p] I mean s-, (xxx) less stressed, because I have nothing outstanding at my work.	
R:	/ Yess.	
P/T:	/ So when I come here I can concentrate with vigour.	
R:	You can concentrate, // that’s wonderful. Okay. [p] Uhm [clearing throat] so now you told me the benefit’s and the the positive things and the negative things that leisure could have [p] uhm could impact [p] have an impact on you. Now what [p] something else I’d like to know is, the smart people at the universities always say that caregivers [p] of children with disabilities [p] experience a need for leisure. So we spoke a lot about that and in the beginning you said / [p] you have a need [p] to interact neh, and you said when you have a need to interact you get involved in the community [p] uhm you visit family or you’re in- involved at weddings and stuff neh. Uhm, [p] what other needs do you also have [p] that gets satisfied through your leisure time?	
T:	// Hhhm.	01:20:32
P:	/ [Coughing]	
R/T:	[Explaining in S]	
P:	[Speaking in S]	
R/T:	[Explaining in S] not necessarily rest [p] [explaining further in S]	
P:	[Speaking in S]	
R/T:	[Explaining in S]	
T:	Uh (we have?) made the statement, uh put the direct question [p] otherwise (xxx) have / (xxx).	
R:	/ Okay, so (3x) uhm the question is uhm // uhm [clearing throat] that that uh [p] let me just ask again [p] think again [p] what needs do you experience [p] as a caregiver [p]	
T:	// Yes. [Wait until R p] Ja.	

P:	Hm	
R:	that can be met through doing those things? [p] Do you know what I mean?	
P:	[Loud coughing] [p] / [Loud coughing]	
T:	/ Leisure [p] on leisure. Can you re-[p]take the original q- // [p] question?	
R:	// Okay. [p] So we said that [p] you uh you li- [p] you had a need for interaction. And by [p] uh with that need you get involved in the community or you go to parties or whatever neh.	
P:	Hm.	
R:	Now I want to know is there any other needs [p] that you have that can be seti- satisfied through different sorts of leisure? Like let's start with cleaning the house and tv neh.	
P:	Hm.	
R:	What needs do you have [p] that makes you, that forces you to go and clean the house and watch TV?	
R/T:	[Explaining in S]	
P:	Hm.	
R/T:	[Explaining in S]	
P:	Hm.	
R/T:	[Explaining in S] [Loud voices outside]	
P:	[Word in S]	
T:	[Word in S]	
P:	[Responding in S]	
T:	Ehh.	
P:	[Responding in S]	
P/T:	Ja, rather these these needs that are primary and so forth, so that they (xxx) accomplished and be fulfilled, the driver is the money.	01:24:04
R:	Ookay, / uhm need [p]	
T:	/ [Laugh]	
P/T:	Money.	
R:	for for [p] fulfilment?	
P/T:	Ja needs, I mean uh money, needs for fulfilment / [p] can only be attained through money.	
R:	/ Okay. [long p] Need [p] for [p] money.	
T:	Hm.	
R:	Yeees. Okay. And there was something else you said fulfilment and something else? [p] You said uh you spoke about uhm [p] it's fulfilling and something?	
P/T:	Ja, it's it's through money uh I said (xxx) the [p] the major driver [p]	
R:	Is / the …	
P/T:	/ towards fulfilment [p] of these needssss [p]	
R:	Ooh.	
P/T:	Is the // money.	
R:	// Okay.	
P/T:	Because when you have it [p] you'll be able to do a, b, c, d [p] for satisfaction. You'll buy a cold drink for the children and you give them an, you enhance their entertainment and then they (laugh?).	

R:	Hhhm.	
P/T:	But you (leaves?) the drivers, so there are many other issues that you can satisfy [p] / when you have.	
R:	/ Hhhm. [p] Okay.	
P/T:	To make your family more happier you need money to do that.	
R:	Hhhm. / Okay.	
T:	/ Hhm.	
R:	Uhm [clearing throat] is there anything else as a caregiver of this centre neh, [p] that uhm [p] sometimes feel that can also [p] make it more difficult for you to to have your leisure time, [p] except for money?	
R/T:	[Explaining in S]	
P:	Hhhm. [With sigh]	
R/T:	[Explaining in S]	
P:	Hm.	
R/T:	[Explaining in S]	
P:	[p] [Responding in S]	
P/T:	You mean [p] something that can uhhh [p] uh uh what do you, change or better this establishment? This centre?	
P:	/ [Word in S]	
R:	/ Yes in a way, but specifically that can make thing easier for YOU.	
P/T:	No, [p] uh yes, yes and no.	
R/T:	[Explaining in S]	
R:	So in a sense it's going to uhm make things in the establishment better if w-, if things can be made better for you.	
R/T:	Ja, [Explaining in S].	
R:	So what would you specifically like [p] uhm [p] that can be made easier for you too [p] to experience / (leisure?)?	
R/T:	/ [Explaining in S]	
P:	[Responding in S] … // … [p]	
R/T:	// [Explaining in S] …. [p] …..	
P:	[Responding in S]	
P/T:	[p] Uhm [p] whilst the, the question is being [p] answered or not answered indirectly, the thing is [p] uhm as a volunteer [p] you actually have no benefits, [p] (like others, for instance?) have housing allowance, medical allowance, or (med?) benefit, [p] this and that, and then uhh [p] / as a volunteer here youu you you get out here ultimately empty handed.	
P:	/ [Speaking in S].	
R:	Hhhm.	
P/T:	But I'll want to redirect the question back to you. =	
R:	= Hm.	
T:	Can you we get the direct question so that we get a direct answer.	
R:	Ja, so what about the uh uhm the structure here, how things work, the way things are organised here, can make it easier for youuu [p] to [p] have that leisure time [p] or to experience your leisure time?	
R/T:	[Explaining in S]	
T:	Can you put it eh directly to us, answer directly as to say, [p] under these circumstances [p] things should be this way, that's	

	what (we?) asking.	
R:	And we would mak-, you would have more available, / or you can enjoy your leisure. //	
T:	/ Jaa. // Hm.	
P:	[Long p] [Responding in S]	
P/T:	I’m still saying [p] when there is no money / [p] there is nothing you can do.	
R:	/ Hhhm. [Wait until T finish sentence] Okaay. And you also said that sometimes when you go home [p] or on holiday [p] you f-, you you [p] your, you worry back [p] about the children or you feel guilty about something. [p] Uhhm, what can be, what changes can be made so that when you go away you don’t need to worry about the children even if they are sick?	
T:	Just ask the same question again.	
R:	Okay. When [p] you explained that sometimes what it make it difficult for you to experience your leisure or to fulfil those leisure needs is when you worry back about a child maybe that is sick here, or about work or something here. Uhm, [p] what in that context can [p] uhmm can be changed around here to help you not to go back and worry about things / (xxx).	
R/T:	/ [Explaining in S]	
P:	Hhm.	
T:	Ehh. [Explaining in S]	
P:	[Responding in S] [Chatting voices in background]	
T:	[Question in S]	
P:	Eeeh. [Yes]	
T:	Hhm.	
P/T:	Uhm [p] Ja, I think it’s a [p] indirect answer which is good anyway. That the problem is that you’ll remember or recall that I work, the type of work [p] I do s- specialised work and I’m [p] I’m (the only?) one doing it. And when Bettie sais where are you, come and collect money s-, there’s no other one as an assistant.	10:33:35
R:	Hhhhhm.	
P/T:	But she then goes on to say [p] if (xxx), because there is no money enough [p] to hire people [p] for instance if there (were?) somebody for instance uh wh- where we could be working together [p], but I think (let’s just say), the answer is in there (inevitably?).	
R:	Ja.	
P/T:	// You’ve you’ve, / if it could be [p] hhm.	
R:	// Ja. / I heard what yo- what you’re saying. So	
T:	Hhm. So I /// try to	
R:	/// Yess. [p] So ca- can I ask you, would the fact that if there is more people or money to pay more people [p] make it easier for you [p] for everyone here, to be able to maybe have more free time [p] or to be able to experience their free time as fun?	
R/T:	[Explaining in S]	
P:	[Responding in S]	
P/T:	Yes our our burden / [p] or weight of work, spade of work [p]	

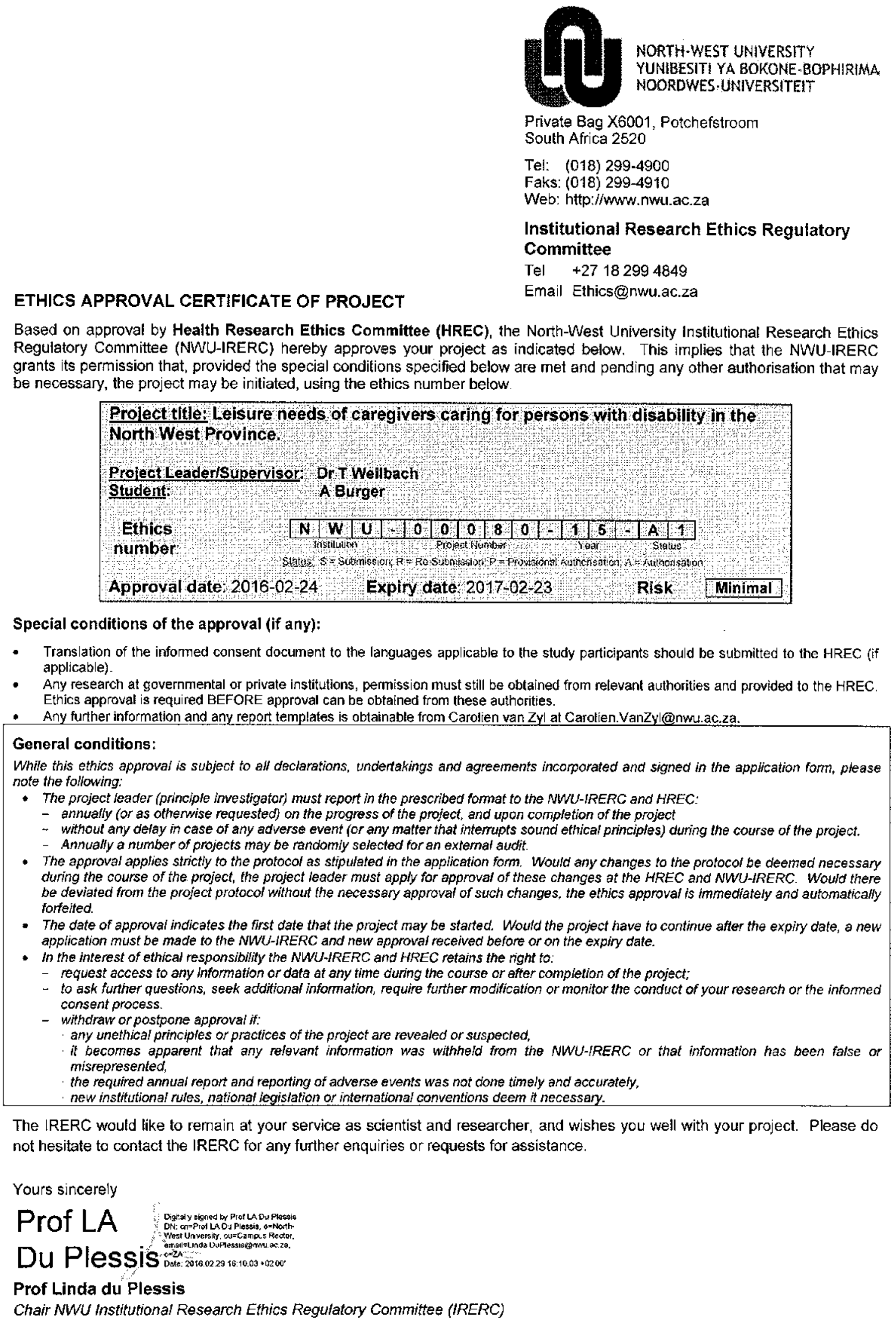
	would definitely diminish.	
R:	/ Hhhhmm. [Wait until T finish speaking] Hhhm.	
P/T:	or decrease.	
R:	Okay okay. Hum. So uh lastly I would like to know, you said that uhh you do different things with the children in in (your?) form about uhm [p] washing the children and doing different chores here neh. Uhm how does your role as a caregiver,[p]all these jobs you do with them, washing the children, feeding them, uhm cleaning them, picking them up and doing different things neh, [p] uhm [p] what impact does that have on you physically or mentally?	
R/T:	[Explaining in S]	
P:	[Question in S]	
T:	Eh yeh. [Yes]	
R/T:	[Explaining in S]	
P:	[Responding in S] [Shouting in background] [p]	
T:	[Speaking in S]	
P:	[Responding in S]	
P/T:	Yes, (xxx) actually if you're question perhaps was put differently, as to the impact on my body / [p] I would say yes here and there I get tired and whatever pains, [p] but as for mentally and spiritually, because of the passion I have for this work [p] it's no impact what so ever on me. =	
R:	/ Hhm. [Wait until T finish sentence] = Hhhm. Okay, now what I would like to know from that is [p] uh you said it sometimes gets to you a little bit physically, but mentally it's actually good for you. How does that [p] impact your leisure time? Let's start with the [p] physically that sometimes influence your body. How does the effect that it have on your body [p] impact your leisure time sometimes?	
R/T:	[Explaining in S] [Many people speaking and children crying in background]	
P:	[Responding in S]	
P/T:	I I don't know, uh perhaps I'm a, because I'm a different type of a person [p] exhaustion [p] not when I'm at work. / Uhh maybe because of our upbringings that we're use to work a lot, but really to be honest with you, o- uh o- I I don't really feel eh uh exhaustion, [p] I can't complain that u- I'm exhausted from work.	
R:	/ Hmm. [Wait until T finish speaking] Okay, but you said something about uh uh pain, or so-, it might have an influence you.	
P:	[Speaking in S]… / ……	
R:	/ The the [p] work. [p] What is that?	
P/T:	Ag uhm maybe yes indeed it is like another person, just to pick up and so forth, it will, it will have a slight impact, but because I'm aging and // it is just maybe because of aging, but otherwise [p] I can never // say I'm feeling this fatigue // and what what.	
R:	// Oooh. // Ookay. // Yes. [p] So p] you don't really have any uhm, [p] I I u- just struggle to remember exactly what you said when I asked you physically [p] how does it have an impact like certain pains, or wha- how	

	specifically?	
R/T:	[Explaining in S] … / …….	
P:	/ [Sigh] [Speaking in S] [p] [Wait until T finish speaking] [Responding further in S]	
P/T:	No, to be honest with you, maybe because of other factors like the [p] the chronic illnesses like sugar and uh and high blood.	
R:	Ooooh.	
P/T:	Ehh, but / it does have an impact, but not from the caregiving exhaustion.	
R:	/ But that's not from the caregiving? [p] Oookay okay okay. So the positive things that you say, eh the the work here, it's actually mentally good for you cause you work with the children and you love the work. Uhm, [p] that positive way, that positive thing about your work, [p] does that u- [p] impact your leisure in any way positively? [Children sounds]	
R/T:	[Explaining in S] [Children sounds]	
P:	[p, with papers moving] Ehh. [Responding in S]	
P/T:	Honestly eh eh uh I always get astonished when even younger people begin to complain and say "oooh"	
R:	Hhhm. =	
P/T:	= at this age what's going to happen when your of my age then [p] when you begin to complain? So naturally [p] I I'm not a person who [p] complains about hard work or something.	
R:	Okay so so [p] what you would say the positive thing about your caregiving role here a- and your responsibilities [p] which you quite experience quite positively is that when you go home, [p] you are astonished [p] about how other people might complain? So it makes you feel [p] actually that you appreciate uh [p] is, [p] would it say that you appreciate more what you have [p] or what you ca- [p] are able to do?	
T:	Uhm, can you put your question straight again?	
R:	Okay. So uhm you said that, that the work is actually mentally a positive thing for you neh. [Stating and confirming]	
P:	Hhm. [Yes]	
R:	Uhm [p] that positive thing, [p] when you go, okay now you work here and you experience everything here, and mentally it's [p] good for you, you see things and you help the children. Now you go home neh, you go have leisure, or you go out in the community or with family. [p] What you experience here positively [p] how does that impact your leisure time positively?	
R/T:	[Explaining in S] … / ……..	
P:	/ Hhum. [Wait until T finish speaking] [Responding in S] …. // ……………	
P/T:	// With [long p]. With the same vigour that I'm off here when I go / on my leisure time at home, I can tell you just a continue, [p] it's just continuous, I do [p] I do work much the same as I do here. I'll get to my yard [p] and my yard (xxx), spade and mend everything at home.	
R:	/ Hhm. [Listening] [Wait until T finish speaking] Okay, and you said that uhm sometimes when you come from here you see that other people complain a lot, what other people is that? [p] People from outside the centre?	
R/T:	[Explaining in S]	
P:	[Responding in S]	

P/T:	I don’t remember talking about complaining people.	
R:	Oooh okay no. Then I [p] I wrongly understood you. [Laughing]	
T:	/ [Laughing]	
P:	/ [Laughing] // [Responding in S]	
R:	// Okay.	
P/T:	Ja I only spoke about things such as obstacles, how obstacle [p] would impact on you [p] here at work [p] when I’m at my leisure time. That’s what I was saying.	
R:	Oooh okay. Okay. How the obstacles here impact your leisure time? And what obstacles are that [p] and how do they impact your leisure?	
R/T:	[Explaining in S]	
P:	[Responding in S]	
T:	Hm.	
P:	[Responding in S] [Children laughing in background]	
T:	Hm.	
P:	Eehh.	
P/T:	Uh for instance eh whether I actually want to s- uh to to (xxx),when I’m at home or at my leisure time,	01:46:29
R:	Hmm.	
P/T:	and I’m there and then something [p] nasty for instance having happened here at work [p] (par?) an individual, [p]	
R:	Hm.	
P/T:	then I’ll [p] apply my (xxx), but when when so and so did this, what did actually go [p] in this persons mind, because (it’s cause?) something of a (havoc?) or something un- distasteful.	
R:	Hm.	
P/R:	So that type of a thing / [p] is the thing that (you’d?) // [p] that I’m referring to.	
R:	/ Okay. [p] // So what your saying is [p] is if you have a bad experience with someone specific here and you go home, it would make you wonder about [p] why did this happen or why, what was this person /// feeling or thinking?	
P:	/// Hhhhhm.	
R:	Okay, and then you you cannot enjoy that time at home [p] / sso much that you [p] (want to?).	
P:	/ [Responding in S]	
P/T:	Yes you, you [p] you you do actually try to interrogate to say but how come that [p] such a normal person, what really co-, what what was going in his mind or // [p] what can be in mind that a person should be able to do such a thing.	
R:	// In his mind? [Wait until T finish sentence] Okay okay. And that makes it difficult for you too? Okay, well I think you told me a lot of things today [name], it was really interesting to hear from you. It was, it was really a pleasure to talk to you. It, I enjoyed it and you gave me so much information. Thank you very much for that.	
P:	/ Hm.	
R:	/ Uhm, do you have any questions? [p]	
R/T:	[p] [Explaining in S] … / …	
P:	/ [Responding in S]	
T:	[Laughing]	

P:	[Responding in S] [p] you must come and tell me [p] this is my (certificate?).	
R:	I [p] will I / will I will, I’m going to be so happy that day!	
T:	/ [Laughing out loud] You [p] you had it all, you had it all! It was pleased to work with you.	
P:	Hhm.	
R:	Jaaaa.	
P/T:	But please I wish you well, go there, you must come back here and say [p] I did get my masters and / (xxx).	
R:	/ Oh I will really [p] try to remember and do that, because that day is going to be a glorious day.	
T:	Ja, you (are/aren’t?) going to forget.	
R:	Nooo.	
P:	[Speaking in S] … / …	
T:	/ Standard.	
R:	Hhhmm.	
P:	Yes, [Speaking in S].	01:49:22
	Pause [next recording of participant ten]	00:00
P:	[Speaking in S] [Child moaning or screaming in background]	
P/T:	You see, I I’ll say [p] I’m not [p] I’m not literate, [p] I went to up to standard eight, [p] because of the difficult, you know, times [p] for person who could (take?), [p] but other challenging (thing?) is [p] the children of today don’t like school, [p] schooling	
R:	Hhhhhmm.	
P/T:	so when a person young, or from the youth like you [p] a- are interested [p] in education [p] uhh I feel [p] to be, to do, to encourage [p] / that person, because most of them go for, you know, what they call joy and drinks and drugs.	
R:	/ Hhhhm. [Wait until T finish sentence] Ja.	
P/T:	So It’s encouraging that people of that age [p]	
R:	Okay.	
P/T::	are keen for education.	
R:	Okay.	
T:	/ Hhm.	
P:	/ Hhm.	
R:	That’s very good to hear.	
T:	So she speaks to (now?) as a mother now. [Laughing]	
P:	Hhm.	
R:	Aaahhhh! [Laugh]	
P:	[Responding in S]	0:55

ANNEXURES E: ETHICS APPROVAL CERTIFICATE



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ETHICS APPROVAL CERTIFICATE OF PROJECT

Based on approval by **Health Research Ethics Committee (HREC)**, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby approves your project as indicated below. This implies that the NWU-IRERC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: Leisure needs of caregivers caring for persons with disability in the North West Province.

Project Leader/Supervisor: Dr T Wellbach
Student: A Burger

Ethics number:

N	W	U	-	0	0	0	8	0	-	1	5	-	A	1
Institution					Project Number					Year			Status	

Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Approval date: 2016-02-24 **Expiry date:** 2017-02-23 **Risk** **Minimal**

Special conditions of the approval (if any):

- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HREC. Ethics approval is required BEFORE approval can be obtained from these authorities.
- Any further information and any report templates is obtainable from Carolien van Zyl at Carolien.VanZyl@nwu.ac.za.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- *The project leader (principle investigator) must report in the prescribed format to the NWU-IRERC and HREC:*
  - *annually (or as otherwise requested) on the progress of the project, and upon completion of the project*
  - *without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.*
  - *Annually a number of projects may be randomly selected for an external audit.*
- *The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the HREC and NWU-IRERC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.*
- *The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-IRERC and new approval received before or on the expiry date.*
- *In the interest of ethical responsibility the NWU-IRERC and HREC retains the right to:*
  - *request access to any information or data at any time during the course or after completion of the project;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the project are revealed or suspected,*
    - *it becomes apparent that any relevant information was withheld from the NWU-IRERC or that information has been false or misrepresented,*
    - *the required annual report and reporting of adverse events was not done timely and accurately,*
    - *new institutional rules, national legislation or international conventions deem it necessary.*

The IRERC would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the IRERC for any further enquiries or requests for assistance.

Yours sincerely

Prof LA
Du Plessis

Digitally signed by Prof LA Du Plessis
DN: cn=Prof LA Du Plessis, o=North-West University, ou=Campus Rector, email=Linda.DuPlessis@nwu.ac.za, c=ZA
Date: 2016.02.29 16:10:03 +02'00'

Prof Linda du Plessis
Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)