

**PHYSIOTHERAPISTS' PERCEPTIONS ON STROKE REHABILITATION WITH
FOCUS ON PALLIATIVE CARE IN LUSAKA, ZAMBIA**

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**A full thesis submitted in fulfilment of the requirements for the Degree of
Master of Science in Physiotherapy
Faculty of Community and Health Sciences
University of the Western Cape**

The logo of the University of the Western Cape, featuring a classical building facade with columns and a pediment, with the text 'UNIVERSITY of the WESTERN CAPE' overlaid in a light blue color.

February 2015

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ABSTRACT

Palliative care is a vague and often confusing term used to describe a type of treatment model for chronic and life-threatening illnesses. WHO describes palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness by: early identification, impeccable assessment, and treatment of pain, physical, psychosocial and spiritual.

The aim of this study is to explore the perceptions of physiotherapists on palliative care in order to contribute to the understanding of the role of physiotherapists to the care of stroke patient in Zambia.

The objectives of this study are to explore physiotherapists' knowledge on palliative care, their perceptions on management of palliative care as well as explore its application in the rehabilitation of stroke patients; and lastly to make recommendations on guidelines based on the outcomes of this study.

Method: an exploratory study, using qualitative design was used. Data collection techniques were in-depth individual interviews and FGDs that consisted of purposively sampling of physiotherapists working; at four selected hospitals and a rehabilitation centre in Lusaka. Audio-recording from the interviews was transcribed verbatim for each session by an independent person. The study employed thematic content analysis for data analysis. The data was classified systematically by means of coding to identify key factors or issues such as concepts, categories, themes and the relationship between them.

Results indicated that all participants in the current study perceived palliative care as a medical care for the chronic and terminal ill patient in whom stroke patient and family will benefit if it is applied in the early stages of the disease trajectory; as well as it does improve the patient and family quality of life. Furthermore they emphasized on multidisciplinary team and holistic approaches in order to achieve all its tenets.

Conclusion: the study had succeeded in exploring the physiotherapists' perceptions on palliative care and contributed to the understanding of the role of physiotherapy to the care of stroke patients in general.

KEY WORDS

- **PHYSIOTHERAPY**
- **PERCEPTION**
- **STROKE**
- **REHABILITATION**
- **PALLIATIVE CARE**



DECLARATION

I declare that “**Physiotherapists’ perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia.**” is my own work, and has not been submitted for any degree or examination in any other University. All the sources it have used or quoted have been indicated and acknowledged by means of complete references.

CHRISTO MWANZA

Signature



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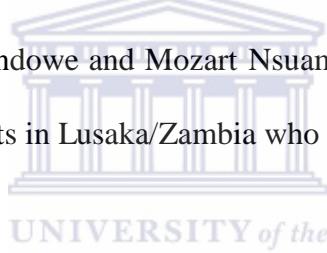
Dr Nondwe Mlenzana

ACKNOWLEDGEMENTS

I would like to give praise and honour to the Almighty God for always being with me, and granting me grace, strength, favour and guidance in my studies.

I would like to express my sincere gratitude to my supervisor Dr Nondwe Mlenzana for the job well done. You provided me with your intellectual, emotional and corrective guidance and support during this long journey of me writing this thesis.

Special thanks goes to Dr Nkandu Munalula for introducing me to palliative care approach, LDHMT management for their invaluable support and confidence shown on me, Mrs Kapoko Ngonwe for transcribing of data, Mrs Rondene Harris for helping me during the data analysis, Mr Francis Mwila, Oswald Nkhondowe and Mozart Nsuami for their support and lastly, I am very grateful to all physiotherapists in Lusaka/Zambia who participated in this study.



A special love and gratitude go to my lovely wife, Chanda Mwanza and children, “Charlotte, Chacri and Christo Junior Mwanza,” as well as my niece, Kaka, for putting up with my absence from home for two years. I am deeply humbled by Chanda’s patience, which saw her enduring alone looking after our three children. I am grateful to my wonderful sister Bienvenue Kutekemene for being there for her financial support when it most needed; my brother Djodjo, B Mwanza and my good friend Morris, Mwala for their assistance and support.

DEDICATION

This full thesis is dedicated to my late, Mom Charlotte Emily Mwamba, for giving me an invaluable educational inheritance as a single mother that I will never be able to repay. May God be with you Mom and may your soul rest in peace in eternity.

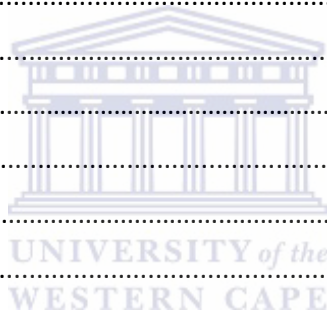
Special dedication goes to Prof Ratie Mpofu who started this project with me but could not have finished it because the time to answer God calling had come. I believe that the Community Health Science Faculty and the entire student body will deeply missed her invaluable intellectual input. May Professor Emeritus Ratie Mpofu rest in peace.



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LIST OF ABBREVIATIONS

ADL: Activities of Daily Living

ACPOPC: Association of Chartered Physiotherapists in Oncology & Palliative Care

AHA: American Heart Association

ASA: American Stroke Association

APCA: African Palliative Care Association

CVA: Cerebral Vascular Accident

CAPC: Centre Advance Palliative care

CFB: Care for Family Business

CPGQPC: Clinical Practice Guidelines for Quality Palliative Care

FGD: Focus Group Discussion

LDHMT: Lusaka District Health Management Team

NICE: National Institute for Care and Excellency

NINDS: National Institute

NCGS: National Clinical Guidelines for Stroke

NSAM: National Stroke Association of Malaysia

NGO: Non Governmental Organisation

PCAZ: Palliative Care Association of Zambia

SFA: Stroke Foundation Australia

SFUSA: Stroke Foundation USA

SAMJ: South Africa Medical Journal

SMNMAC: Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee

TIA: Transient Ischaemic Attack

UN: United Nations

USA: United States of America



UK: United Kingdom

UTH: University Teaching Hospital

WHO: World Health Organisation



CHAPTER ONE

1.0 INTRODUCTION

Chapter one provides the general background, followed by the statement of the problem, research question, aim, specific objectives, and significance of the study, definition of terms and abbreviations and lastly the overview of the organisation of the study.

1.1 BACKGROUND TO THE STUDY

Palliative care is appropriate at any age and any stage of a serious illness, and can be provided together with curative treatment (Morrow, 2007). It is specialized medical care focused on providing patients with relief from the symptoms, pain, and stress of a serious illness whatever the diagnosis (NCP, 2009). Palliative care is perceived as caring for people who have serious illness or life threatening condition (WHO, 2002). It is different from care to cure your illness, called curative care. Palliative care focuses on improving patient quality of life, not just in his physical body, but also in his mind and spirit as well as taking care of his family (NCP, 2009). Palliative care relies on input from the physician, pharmacist, nurse, religious-clergy, physio-therapist, occupational therapist, speech therapist, psychologist, social worker and other health professionals in formulating a plan of care to relieve suffering in all areas of life by addressing physical, spiritual and psychosocial problems that stem from advanced illness (WHO, 2012). Contrary to what most people belief, palliative care is not hospice care only (WHO, 2004). Hospice care is one form of palliative care that is suitable for patients towards the end of their life, especially those with a life expectancy of six months or less following illness prognosis (Morrow, 2007). Palliative care begins at any time of a serious disease more especially at the time of diagnosis process and continues through cure, or until death and then into bereavement (Morrow, 2007). Internationally, little research has been done to explain why palliative care is

not fully incorporated in stroke management compared to other chronic illnesses such as cancer and HIV/AIDS (Addington-Hall & Higginson, 2001).

In Zambia there is no literature regarding palliative care that explains needs for stroke patients. Only seven studies were identified on palliative care for stroke during a systematic review (Lindley & Bernhardt, 2010; Addington -Hall & Higginson, 2001). In one of these studies, palliative care in acute stroke pathway was developed and implemented. The study result revealed improvement in the processes of care based on palliative care standards compared to the conventional care (Lindley & Bernhardt, 2010). According to Beker and Kaufman (1995) stroke patients and their families need better communication, psychological and spiritual care. Palliative care does help patient and family to understand the illness at hands, express freely about it, or decide the desire treatment they may want or not (NCP, 2009). It makes sure that physiotherapists, doctors, nurses, and loved ones understand your goals and thus enable you to be in same level of mutual understanding (NCP, 2009). Despite high levels of mortality and morbidity palliative care needs of people following stroke remain under researched (Lindley & Bernhardt, 2010), and modalities in rehabilitation management become challenging due to the increase prevalence of stroke worldwide. The increasing number of people surviving stroke is leading to a crisis in service provision as the health and community support system struggle to keep pace with demand (Stroke foundation, 2013).

Palliative care for stroke focuses on symptom management and patient needs, as well as family (NCP, 2009). Accessing palliative care as soon as possible will ensure that the symptoms are managed properly and will prepare the patient for what lies ahead (Morrow, 2007). Literature suggests that stroke patients can really benefit from the palliative care approach because most of these patients and families are facing difficulties in communication, psychosocial and spiritual needs that prone palliative care approach (Laakso, 2006). However, the current stroke

management according to the American Heart Association (AHA) and American Stroke Association (ASA) 2013 guidelines; is mostly oriented into physical aspect of treatment; focussing on the acute diagnosis, stabilisation of medical and surgical of stroke as well as in-patient management, secondary prevention of stroke and complication management (AHA & ASA, 2013). Physiotherapy as health care professionals, who aim at improving a patient's quality of life, could play a vital role in administering palliative care treatment on stroke rehabilitation patients. Physiotherapists spend more time than any other health professional with a stroke patient from the time the patient got admission into the hospital ward to fully rehabilitation, and furthermore after rehabilitation process. In this regard physiotherapists could have a significant role through the holistic approach that is prone to the palliative care model. However, the current situation in Zambia is that most physiotherapists rehabilitate a stroke patient following the physical symptom that the patient is presenting, with often inadequate symptom control, spiritual concerns not considered, fears and anxiety unrecognised, and needs of the families not included in the care planning. Therefore research is needed to explore the physiotherapists' perceptions on stroke rehabilitation focussing on palliative care in order to contribute to the understanding of the role of physiotherapists to the care of stroke patient in Zambia. It is also important to know how this approach could be incorporated fully into stroke rehabilitation thus help in adding knowledge in stroke rehabilitation in general.

1.2 STATEMENT PROBLEM

Providing appropriate palliative care for stroke patient in Zambia is a major task for the physiotherapists in practice. In Zambia physiotherapists have been involved in palliative care since 2008 and some of them went for training in 2008. One challenge that they are experiencing is lack of holistic approach to the care of stroke patients. Physiotherapists seem to have mixed feelings about this method of treatment. There is also a perception that palliative care must be

practiced towards the end of a patient's life. It is difficult to implement palliative care due to lack of best practice guidelines as a component towards rehabilitation of a patient with stroke in Zambia. A survey in Canada (Blacquiere et al., 2009), found few guidelines on the provision of palliative care following stroke in general; not specifically applicable to the physiotherapy aspect. Further a formal evaluation in terms of efficacy and effectiveness of palliative care in rehabilitation is still lacking; as well as there is practically no published data regarding palliative care needs for stroke patients in Zambia. Therefore, research is needed to explore what physiotherapists in the world and especially in Zambia understand about palliative care, and how the approach could be incorporated fully into stroke rehabilitation.

1.3 MOTIVATION OF THE STUDY

The motivation came from the researcher passion of palliative care approaches, being one of the few physiotherapists practicing in Lusaka/Zambia who attended the first training on palliative care system which was offered by the Palliative Care Association of Zambia (PCAZ) in 2008. The researcher had the privilege of coordinating the Physiotherapy profession in Palliative Care Project in Lusaka-Chawama Township in which chronically and terminal ill patients suffering from cancer, HIV/AIDS, tuberculosis, CVA/stroke and paraplegia were receiving this kind of treatment model. While coordinating the project, the researcher came into contact with a lot of stroke patients and realised that most of them had difficulties in the areas of physical as well as psychological/emotional well-being and spiritual, and that some of them actually benefited greatly in the palliative care approach. However some of the researcher's fellow physiotherapists were hesitant to or uncertain about how to incorporate it in their rehabilitation process. The researcher was as a result inspired to research on this topic in order to understand the physiotherapists' perceptions on palliative care and how this approach could help in the rehabilitation of a stroke patient.

1.4 RESEARCH QUESTION

What are the perceptions of the physiotherapists regarding palliative care as a component of rehabilitation for a client with stroke in Zambia?

1.5 AIM OF THE STUDY

To explore the perceptions of physiotherapists on palliative care in order to contribute to the understanding of the role of physiotherapists to the care of stroke patients in Zambia

1.6 SPECIFIC OBJECTIVES

- To explore the physiotherapists' perceptions on management of palliative care for patients with stroke.
- To explore the physiotherapists' knowledge about palliative care in the rehabilitation of clients with stroke in Lusaka, Zambia.
- To explore the application of palliative care in the rehabilitation of stroke patients in Zambia.
- To make recommendations on guidelines based on the outcomes of this study.

1.7 SIGNIFICANCE OF THE STUDY

The researcher hope is that the result of this study, will inform the health sector of Zambia about the physiotherapists' contribution to palliative care as a component of stroke rehabilitation as well as adding knowledge to palliative care for stroke in general. Furthermore the result will be evidence-based practice on palliative care and physiotherapy, and could also serve as reference for palliative care curriculum course in the medical and especially in the schools of physiotherapy in Zambia as well as in the world. We are also hoping that the current study will

succeed answering all the specific objectives expected. Lastly this research may be informative to the Palliative Care Association worldwide and in Zambia particularly about the current status of physiotherapy and palliative care; and how to plan further for more activities concerning palliative care and physiotherapy. Significantly, the results of this study may help the Zambia Society of Physiotherapy and the Palliative Care Association of Zambia in formulating a policy proposal for the legislator in order to promote and expand palliative care service in Zambia.

1.9 DEFINITIONS OF TERMS

- **Physiotherapy:** Physiotherapy is a medical profession that assesses, diagnoses, treats, and works to prevent disease and disability through physical means. Physiotherapists are experts in movement and function, working in partnership with their patients, assisting them to overcome movement dysfunctions, which may have been present from birth due to complication, acquired perhaps through accident, disease, injury, or as a result of advance age (Australian Physiotherapy Association, 2013).
- **Perception:** is the ability to take notice of something by using your senses. Taking in your surroundings through sight, sound, taste, touch and smell give the perception of everything around you (Little W., Fowler, H. W., & Coulson, J. 1970).
- **Stroke or cerebrovascular accident (CVA)** is the rapid loss of brain function due to disturbance in the blood supply to the brain. This can be due to ischemia caused by blockage, or a haemorrhage. Thus lead to the brain not to function well and it might result in an inability to move one or more limbs on one side of the body (hemiplegia), inability to understand or formulate speech, or an inability to see one side of the visual field (National Stroke Association of Malaysia, 2013).

- **Rehabilitation:** is a program that helps people recover from mental, physical and social functioning. Some aspects of the program are counselling, exercise programs, emotional and spiritual support (National Institute of Neurological, 2007).

- **Palliative care:** is a treatment model of the discomfort, symptoms and stress of serious terminally chronic illness. It does not replace a patient's primary treatment, but works together with treatment at any point in the patient's care. It does also address psychological, social and spiritual concerns – all to achieve the best quality of life possible for each patient and family (CAPC, 2012).

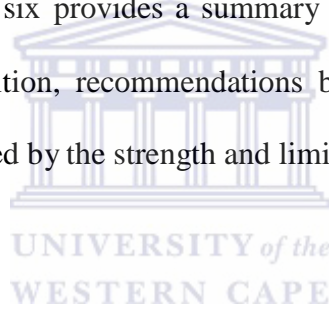


1.10 OVERVIEW OF THE ORGANISATION OF THE STUDY

- Chapter one has highlighted the general background of physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia, palliative care description and importance in stroke rehabilitation has been discussed. Following this part was the problem statement, research question, aim and specific objectives of the study. In addition the significances were also expanded thus providing the research focus of the study. The last section consists of definition of terms and abbreviations.
- Chapter two reviews the relevant literature of palliative care's origin and evolution discussed in the first part of this chapter. There is elaboration on the definition and effects of stroke as well as stroke current facts. The literature reviewed the palliative care for stroke and physiotherapy globally and locally, and lastly any relevant research done on the physiotherapists' perceptions on palliative care in the world.
- Chapter three gives detail to the research setting, research design, study population and sampling, the research instrument used for data collection and the research procedures. The chapter further describes the procedure on how data was analysed and finally ends with the ethics considerations.
- Chapter four reports the results and outcomes of the explorative qualitative data collected, and also result of the discussions of the current study are further examine. The results are presented clearly in the form of narrative report writing style. Data revealed a comprehensive meaning to finding in the context of the literature available in the field as clearly as possible, and analysis and interpretation of the qualitative responses obtained through face-to-face in

depth interview recorded with an interview guide. Two focus discussions were held to get more of insight of the problem. The discussion included the physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia with references to the aim and specific objectives of the study.

- One of the outcomes of this study was to make recommendation on the evidence based guidelines on stroke and palliative care in the Zambian context. In Chapter five, the researcher presents a summary of four evidence based guidelines of palliative care for stroke and physiotherapy sourced from the literature and adjusted it in the Zambia context.
- Final chapter which is chapter six provides a summary of the study and draws conclusion based on the findings. In addition, recommendations based on the main findings of the current study are made; followed by the strength and limitations of this study.



CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

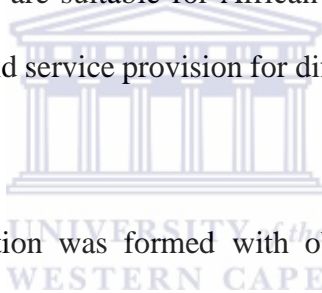
This chapter includes relevant literature of palliative care origin and evolution, definition and effects of stroke, palliative care for stroke and physiotherapy and any relevant research done on the physiotherapists' perceptions.

2.1 PALLIATIVE CARE ORIGIN AND EVOLUTION

The World Health Organization (2012) defined palliative care as treatment aimed at relieving the symptoms associated with serious illness and improving a patient quality of life. Palliative care began in the hospice movement in the mid-1960s; and currently it is used outside of traditional hospice care (Saunders & Baines, 1993). In the 4th century travellers used to rest in the hospices. Further in the 19th century in Ireland and London, hospices for the dying patients were established through church order. (CAPC, 2012). The modern hospice is a new concept that originated and gained momentum in the UK after the founding of St Christopher's hospice in 1967. It was founded by Dame Cecily Saunders and most researchers believe that she is the founder of the modern hospice movement. Their hospice slogan was **“You matter because you are you. You matter up to the last moment of your life, and we will do all that we can to help you to live until you die.”** (Saunders, 1996).

Dame Cecily's pioneering work on the modern hospice movement was later followed by others researchers such as Professor John Hinton who recognized the physical and mental distress of dying in a hospital ward (Hinton, 1999). The hospice movement has grown dramatically in recent years, in the USA, Great Britain, South Africa, Zambia and the rest of Africa.

These services help many patients and their families to cope with the situation of illness at hand. Funding varies from national health services, charity organisations and non-governmental organisations (PCAZ, 2010). The word pall means blanket or holistic care. The word palliative was first used in Canada because hospice means death house and was not acceptable for the new speciality (Addington-Hall & Higginson, 2001). In the 1980s the first hospital based palliative began in the USA at the Cleveland clinic as well as at Medical College of Wisconsin (ACPOPC, 2003). Since then, many other countries in the world have been following the example by opening palliative care unit facilities. In Africa, countries like Cameroon, Zambia, Nigeria, Malawi, Sierra Leone, Botswana, Rwanda, Namibia, Lesotho and Swaziland also joined together to create the African Palliative Care Association with objectives such as training programmes on palliative care that are suitable for African countries; to develop and promote quality standard in palliative care and service provision for different levels of health professionals and care providers (APCA, 2011).



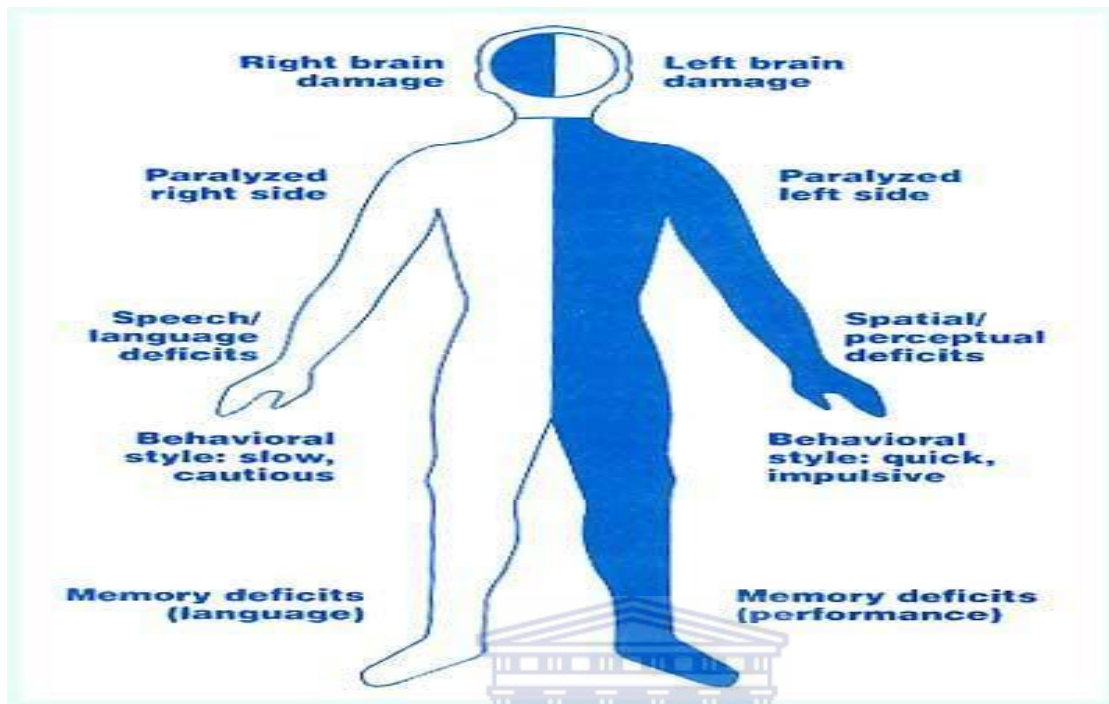
In 2005, Palliative Care Association was formed with objectives to deliver palliative care efficiently through its members, advocate for palliative care givers recognition, support and development in the country (PCAZ, 2010). In 2010 the Palliative Care Association of Zambia conducted a provincial sensitization meeting for palliative care awareness, to sensitize health professional about including palliative care in their district health plans as a key component of health care; and begin to build up constituencies of individual people in need of palliative care services. Radio programs to inform the public were also run (PCAZ, 2010). A palliative care in physiotherapy project was started in Lusaka, Zambia around mid-2010 with a mission to provide physiotherapy services based on palliative care approach to chronically ill patients suffering from cancer, HIV/AIDS, tuberculosis, CVA/stroke and paraplegia in the community. Chawama and Mtendere Townships were selected for the experimental project.

The palliative care in physiotherapy project was initiated by the Centre of Excellence from

UTH with the collaboration of physiotherapists working and based in Lusaka; as an outcome, the community involved appreciated the services offered to them in alleviating their suffering by addressing their physical, psychosocial and spiritual concern that they were facing, Furthermore they wished to have more projects such as this in the future. Currently a wide range of literature is discussing the palliative care extension in other medical condition then cancer (Sonja – McIlfatrick, 2006). To date palliative care is mainly concentrated on cancer disease. In England since 1980 extension of palliative care beyond cancer has been emphasized (NHS Executive, 1996). In 1992, report from the Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee (SMNMAC, 1992), recommended that palliative care principle and provision should be accessible to all patients in need of it. In 1996, the British National health system executive letterhead reinforced this message by saying palliative care can be applied to all chronic diseases (NHS Executive, 1996). In Britain palliative care has been declared as a right for everyone who is dying (NHS Executive, 1996). Illnesses most commonly treated by palliative care are heart disease, cancer, stroke, diabetes, renal disease and Parkinson’s and Alzheimer’s diseases (ACPOPC, 2003). A study conducted in Britain in 2010 by the New England Journal of Medicine revealed that cancer patients receiving early palliative care experienced less depression, improved quality of life and survived 2.7 months longer.

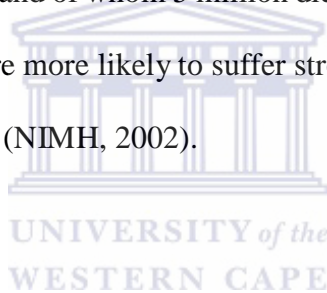
2.2 DEFINITION AND EFFECT OF STROKE

Figure 1: Demonstrating hemiparesis of each side of the body due to brain injury (stroke)



Stroke or cerebro-vascular accident (CVA) occurs when the blood supply to part of the brain is suddenly interrupted or when a blood vessel in the brain bursts, spilling blood into the spaces surrounding brain cells. Brain cells die when they are no longer receiving oxygen and nutrients from the blood or when there is sudden bleeding into or around the brain (Ninds, 2007). The symptoms of stroke include sudden numbness or weakness, especially on one side of the body (refer to Figure1); sudden confusion or trouble speaking or understanding speech; sudden trouble seeing in one or both eyes; sudden trouble with walking, dizziness, or loss of balance or coordination; or sudden severe headaches with no known cause (Morrow, 2007). Stroke may cause problems with thinking, awareness, attention, learning, judgment, and memory (Lindley & Bernhardt, 2010). Stroke patients may have difficulty controlling their emotions or may express inappropriate emotions. Many stroke patients experience depression. They feel numbness and some strange sensations. They experience pain in the hands and feet, and pain may be aggravated by movement and temperature changes. (Ninds, 2007). Two forms of stroke are

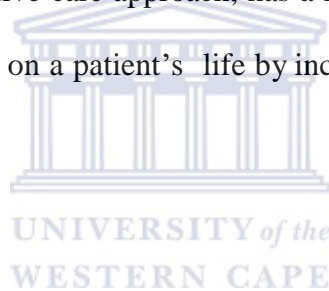
known. One is called ischemic kind where there would be blockage, or obstruction in the blood vessel supplying the brain. Another one is called, haemorrhagic and this refers to bleeding that occurs into or around the brain (Morrow, 2007). A transient ischaemic attack (TIA), happens when the blood supply to part of the brain is blocked or interrupted for a short period. The symptoms are the same as for the stroke illness, but last for a shorter period, and disappear within 24 hours completely (Nice, 2012). Disability that results mostly in stroke patients is the complete paralysis on one side of the body (hemiplegia), and recurrent stroke is frequent; about 25% of people who recover from their first stroke will have another stroke within 5 years (Ninds, 2007). Stroke is the second major cause of death worldwide and the leading cause of long-term disability in adults (Donnan, 2008). According to WHO (2010), 15 million people worldwide have a stroke every year and of whom 5 million die and 5 million become permanently disabled. 25% of men worldwide are more likely to suffer stroke than women and, about 60% of death from stroke occurs in women (NIMH, 2002).



2.3 PALLIATIVE CARE FOR STROKE AND PHYSIOTHERAPY

Physical dimension in physiotherapy includes symptom control, management of physical findings such as mobility, strength, flexibility, endurance, deformity, coordination, balance, gait, breathing, exercise tolerance and energy expenditure (APTA, 2001). Physiotherapy symptom control is applicable in stroke patients with commonest symptoms which require palliative care such as pain, weakness, cough and breathlessness and depression (Kumar & Rajagopa, 1996). The role of physiotherapy into palliative care for a client with stroke is to minimise some of the disease effects, improve the quality of life regardless of their prognosis by helping a patient to achieve maximum potential of functional ability and independence (ACPOPC, 2003). However, there is lack of evidence on palliative care in stroke in general (Lindley & Bernhardt, 2010). Only seven studies identified palliative care needs for stroke during a systematic review and its shows that patients and their family needs are based on better communication, psycho-

and spiritual needs (Lindley & Bernhardt, 2010; Beker & Kaufman, 1995). There is some evidence that rehabilitation intervention improves functional status of palliative care implementation of a massage and exercise therapy program, respiratory physiotherapy techniques and modified manual lymphoedema treatment has been assessed (Kumar & Jim, 2010). The same reference further states that physiotherapy intervention into palliative care for a stroke patient will help to maximize the functional potential of a patient. Africa, in particular, lack literature based evidence on palliative care on stroke. Unlike cancer, stroke is not integrated fully into palliative care. Because the prognosis is difficult, the need for palliative care is often neglected and always comes late in the patient trajectory illness. Therefore physiotherapists as health care professionals whose aim to improve a patient's quality of life if trained in specializing in the palliative care approach, has a role to play in the multidisciplinary team model of making a difference on a patient's life by incorporating it in the early stages of the rehabilitation program.



2.3.1 Rehabilitation

Figure 2: Demonstrating the rehabilitation process of a stroke patient



It has been stated that palliative care and rehabilitation should be integrated into treatment from the moment a life limiting disease diagnostic is made (AHP, Palliative Care Team, 2004). In-patient rehabilitation is always recommended for stroke patients who are fragile, not improving, and still need medical attention but who have some cognitive and physical ability to participate in therapy (Bruce, 2005). Bruce further stated that safely walking without physical help is one form of disability that leads to referral to in-patient rehabilitation. According to the National Institute for Care Excellency guidelines (2013), the stroke rehabilitation team must have the following healthcare with skill in stroke rehabilitation: A medical doctor, nurse, physiotherapist, occupational-therapist, speech and language therapist, psychologist, rehabilitation assistant, and a social worker in helping the patient in very diverse kinds of treatment. Palliative care and rehabilitation services have much in common. Both involve complex interventions from a team of health professionals, and the success of any intervention must usually be judged on a background of improvement, stabilization, or continued deterioration in the person's condition (NICE, 2004). Palliative care does offer a comprehensive management that addresses the many components of discomfort such as physical, psychological or emotional and spiritual that accompanies the stroke patient and provides the best and suitable responsibility of care (CAPC, 2012). Palliative care is a team approach to care and the core team is the same as the stroke rehabilitation team but this time it includes a pastor or religious minister. They spend as much time as necessary with the patient and family; they support every step of the way, not only by controlling the patient's symptoms, but also helping him and the family understand the treatment options and goals (CAPC, 2012). The palliative care rehabilitation team does pay attention to the patients' desire and other needs apart from the physical ones. Therefore, it is cardinal for the rehabilitation team to be alert and sensitive to the patients' needs as well as be able to accept the patient's probability of death as a reality and fact of life; however they should not take away his hope. In the past, rehabilitation was perceived as a treatment which leads to full recovery of a patient. This concept of rehabilitation may seem paradoxical in palliative care system (Kumar &

Jim, 2010). The goal of rehabilitation is to help a stroke patient to reach the highest possible level of independence and to be as productive as possible. Because most stroke patients are in needs of rehabilitation process, each stroke patients are unique in their progress and recovery, nevertheless some may have their functional abilities restored soon after a stroke; but recovery is an on-going process (Ninds, 2007). Stroke rehabilitation is a goal-oriented process that attempts to obtain maximum function in patients who have had stroke and who suffer from a combination of physical, cognitive and language disabilities (Laakso, 2006). According to Waldron et al, palliative care rehabilitation is at its best as the transformation of a dying into living, or the restoration of a patient to a person. Furthermore the same source continues by saying that palliative care rehabilitation focuses on symptomatic relief, rather than treatment of illness (Waldron et al. 2011).

Lastly but not the least, palliative care does also define the patients and family's needs, helping them to cope and adjust with the difficulties at hands (Elizabeth & Higginson, 2004). The rehabilitation is best performed using specific physiotherapy skill in symptom control management. TENS or Heat to reduce pain and discomfort, ultra-sound therapy, incontinence and exercise programs, laser therapy for wound and ulcer, improve and maintenance of mobility and lastly optimise physical function. (Laakso, 2006).

Physiotherapists' knowledge on palliative care is vital on applying its approach on stroke rehabilitation patient through restoration of physical function by evaluating and treating problems with movement, balance and coordination as well as providing counselling to the patient and family on how to cope with the new dimension of the problems that they are facing. Specifically, physiotherapy can contribute to significantly higher function of independence, patient satisfaction and quality of life as well as reducing demand for costly formal in-patient care.

Palliative care in physiotherapy requires basic training in rehabilitation techniques; the integration of rehabilitation professional in a caregiver's team; a profound communication with patient, leading to an effective accompaniment and direct response to the patient's needs and recognition of the patient's functional needs (Marcant & Rapin, 2004). Physiotherapists trained in palliative care should be attentive to patients needs in order to formulate a comprehensive holistic treatment (Addington-Hall & Higginson, 2001).

According to WHO (2012) the World, Africa and especially in Zambia the burden of stroke is likely to increase substantially with the kind of sedentary life that majority of people adopting. The physiotherapists will face a lot of challenges in the rehabilitation process of improving the quality of life of patient therefore a new approach that focuses on palliative care system is needed and if used and incorporated effectively in the management of stroke patients the result will be satisfactory (Laakso, 2006). But the current situation in Zambia is that most physiotherapists rehabilitate stroke patients following the physical symptom that the patient is presenting, with often inadequate symptom control, spiritual concerns not considered, fears and anxiety unrecognised, and needs of the families not included in the care planning. The significance of physiotherapy into palliative care for stroke is to assist the patient improve his quality of life for the rest of his or her days into earth, to be able to take care of his physical, psychosocial and spiritual side for as long as possible (NCP, 2009). This could be an advantageous tool for physiotherapists to incorporate palliative care into rehabilitation system since physiotherapists spend more time with a stroke patient than any other health personnel while treating the patient. Thus will have a positive impact on promoting quality of life through better symptom control management and communication needs, and, together with the patient's family, might be able to find un-met psychosocial needs for help in adjusting to disability and death (Addington & Higginson, 2001).

2.4 RELEVANT STUDIES DONE ON PHYSIOTHERAPY PERCEPTIONS

Provision of care to patients with terminal illness has changed dramatically in all developed countries over the past thirty years as well as an important evolution both in knowledge and provision of services can be acknowledged (Weismann, 2009).

- Sonja – McIlpatrick (2006), in her study demonstrated that the professional health care had difficulty understanding and defining palliative care. She also identified that they had communication difficulties as well as exchange of information and between in-services coordination fragmentation. The main areas of need identified by all participants were psychosocial support, financial concern and inequity in palliative care service provision in general
- Payne and Smith (1999), in their study indicated that there is psychological distress and high levels of strain related to patient care. Life restrictions and limited support were also noted.
- Dahlin and Heiwe (2009) study highlighted that physiotherapy is important as; it does promote independence, pain relief from stress and other symptoms as well as support the patient. However, communication and coordination must improve within the palliative care team, in order to minimize the negative impact of symptom distress on the patient well-being and quality of life.
- In India, Kumar et al, 2011 study revealed how cardinal and effective training does help in adding knowledge, change of attitude and beliefs on the students consequently helping in future practice for an efficient multidisciplinary approach prone to palliative care system. In all these studies, there is a clear indication that palliative care is a treatment that helps reduce the symptoms of a serious illness as well as improve quality of life for both patient and family. Palliative care does not depend on a specific medical condition but rather depends on the patient's need and takes into consideration all patients' care prospective.

- Enguidanos et al, 2013 study indicated that family members report discussions with the in-patient palliative care team results in improved communication and knowledge, which contributes to decision making ability. However, palliative care consultation may be improved by developing stronger protocols for introducing palliative care and by including the attending physician in the process to preclude conflicting, inconsistent information and recommendations.
- Lastly David et al, 2008 study highlighted that the perceived barriers to paediatric end-of-life care differed from those impeding adult end-of-life care. The most-commonly perceived factors that interfered with optimal paediatric end-of-life care involved uncertainties in prognosis and discrepancies in treatment goals between staff members and family members, followed by barriers to communication. Improved staff education in communication skills and palliative care for children may help overcome some of these obstacles, but paediatric providers must realize that uncertainty may be unavoidable and inherent in the care of seriously ill children. An uncertain prognosis should be a signal to initiate, rather than to delay, palliative care.

2.5 SUMMARY OF THE CHAPTER

Literature reviewed relevant literature of palliative care origin and evolution in the first part of this chapter. The definition and effect of stroke were elaborated on including stroke current facts. The chapter has also provided the literature on palliative care for stroke and physiotherapy globally and locally, and lastly concluded with any relevant research done on the physiotherapists' perceptions on palliative care in the world.

CHAPTER THREE

METHODOLOGY

3.0. INTRODUCTION TO THE CHAPTER

The chapter explains in detail the research setting, research design, study population and sampling, the research instrument used for data collection and the research procedures. The chapter further describes the procedure on how data was analysed and finally ends with the ethics considerations.

3.1 RESEARCH SETTING

The study took place in Lusaka, the capital city of Zambia, a country situated in the southern part of Africa with 753,000 square kilometres (UN, 2005). It shares borders with the Democratic Republic of Congo, Tanzania in the north, Malawi and Mozambique in the east, Zimbabwe and Botswana in the south, Angola and Namibia in the west and south west respectively. Lusaka is one of the 10 provinces of Zambia as well as one of the fastest developing cities in Southern Africa with a population of 1.7 million. (Zambia Statistic, 2010). The study was conducted in three big state funded in- patients' hospitals of Lusaka, one in- patients' private hospital and one rehabilitation centre of Lusaka. The researcher chose these sites because they are referral hospitals and they received more stroke patients than others. One private hospital was changed to its subordinate centre where stroke patients receive rehabilitation services. The researcher has given below some brief description of the selected hospitals and rehabilitation centre used in the study.

3.1.1 University Teaching Hospital (UTH)

It is the biggest government funded referral centre as well as a teaching medical hospital of the country, situated in the city centre. It receives patients from all over Zambia for in and out-patient medical services. The UTH has departments of gynaecology and obstetrics, surgery, oncology, urology, neurology, cardiology, maternity, paediatric, internal medicine, orthopaedic, casualty, HIV/AIDS services, physiotherapy and occupational therapy and a well-equipped out-patient department for each department. It has a 2000 beds capacities and physiotherapists, special doctors, surgeons, nurses, occupational therapists, social workers and other health professional employees.

3.1.2 Chainama Hills Hospital

It is one of the state funded hospitals offering both in- and out-patient psychiatric and neurological medical services as well as in-and out -patient physiotherapy services and it also provides training for medical assistant officers, environmental and psychiatric nursing personnel, situated in the east part of the city. It has physiotherapists, psychiatrists, doctors, neurology doctors, psychologists, nurses and other health professional employees.

3.1.3 Mwanawasa Hospital

A very new tertiary facility hospital in the city funded by government, situated in the eastern part of Lusaka, very near to Chainama hills, the Mwanawasa Hospital offers in-and out-patient's medical facilities. It has the departments of gynaecology, neurology, cardiology, orthopaedic, paediatric, surgery, internal medicine and physiotherapy as well as casualty. There are physiotherapists, specialist doctors, surgeons, nurses, pharmacists and other health personnel as its employees.

3.1.4 Care for Business Medical Centre (CFB)

Privately owned, this hospital is, located in the central part of the capital city and provides in- and out-patients medical services (gynaecology, paediatric, cardiology, neurology, internal medicine and surgical), including in-and out-patient's physiotherapy services. It has physiotherapists, specialist doctors, nurses, a pharmacist and other health professional employees.

3.1.5 Kabulonga Church Homes

This is a catholic churches rehabilitation centre for the physically challenged people, located in the central part of the city and it provides in-patients' physiotherapy services for disabled children and out-patients' physiotherapy for adults.



3.2 RESEARCH DESIGN

The researcher applied an exploratory study design, using qualitative methods of data collection. The aims of the exploratory study are to establish the facts, explore topics which are relatively unknown, formulate a problem and develop a hypothesis for further study (Babbie & Mouton, 2001). Although the current study may not be used for the development of a hypothesis, the data related to physiotherapists' perceptions regarding palliative care as one of the rehabilitation components for a stroke patient will be useful to formulate a problem for further study. Furthermore the researcher attempted to understand the physiotherapists in terms of their own meaning of their words that cannot be obtained in a quantitative research method which is one of the major distinguishing characteristics of a qualitative research method (De Vos et al., 2002).

3.3 POPULATION AND SAMPLING

The population of this study included physiotherapists currently practicing in Lusaka. Lusaka has approximately 100 physiotherapists affiliated to Zambia Society of Physiotherapists working in various health facilities in the city. A purposive sample of about 25 physiotherapists in practice, who were willing to participate, were selected from the three government hospitals, one private hospital and rehabilitation centre. The researcher selected physiotherapists who have five years minimum practice on stroke rehabilitation experiences with or without palliative care training and invited them to participate in this study. The first phase of the data collection using face to face in-depth interviews with aid of an interview guide (Appendix A) was done, until saturation was reached at the fourteenth interview. It was focussing on understanding palliative care approach, its effects as well as its application on a stroke patient, physiotherapy participation on palliative care and concluded with suggestions and recommendations. After the first data analysis, senior physiotherapists were invited into two focus group discussions with aid of an interview guide (Appendix B) for the second phase of data collection in order to collect more insight and detailed information on the main palliative care needs of a stroke patient, the barriers to delivering palliative care in Zambia and concluded with additional comment and recommendations. Polit and Hungler (2001) and Brink (2006) describe purposive sampling as a method based on the researcher's judgement about subjects that are typical or representative of the phenomenon being studied in cases where the researcher is particularly knowledgeable about the problem. In such cases the researcher being a physiotherapist from Zambia purposefully chose the participants based on their stroke rehabilitation experience and invited them to participate. The advantage of purposive sampling is that it allows a researcher to select the sample on the basis of his knowledge of the phenomenon being studied. The researcher has chosen specific hospitals to be included in the study because these hospitals receive more patients with stroke illness than others. Furthermore the researcher felt that the participants with a minimum of five years' experience into practice as well as senior physiotherapists because they have got enough skills on

rehabilitation in general and hence will be able to understand the topic of the study.

3.4 INCLUSION CRITERIA

Physiotherapists with a minimum of five years practice experiences with or without palliative care training and senior physiotherapists.

3.5 EXCLUSION CRITERIA

Physiotherapists who are not in full-time practice, and without experience in the fields of stroke rehabilitation and have less than five years experiences in practice.

3.6 DATA COLLECTION

3.6.1 Procedure of the study

The researcher got ethical clearance from the University of the Western Cape Research Grants and Study Leave Committee, Zambia Ethical Research Excellency Scientific Committee and from all relevant authorities of the three in-patients government hospitals, one in-patient private hospital and one rehabilitation centre as well as from the physiotherapists who were willing to participate in the study. Appointments were made with the staff members collectively to explain the aim and objectives of the study. Participants were informed of the purpose of the study, the importance of their participation and their right to withdraw with the interview if they wished to do so. Informed consent form (Appendix C) was given to the participants. The face-to-face in-depth interviews and FGDs were private and took place at a convenient scheduled suitable for the participants. The participants, who took part on the study, were interviewed in English language therefore there was no need for the interpretation during interviews and analysis. The researcher informed the participants that the information gathered will remain confidential; participants were not named during the first phase of data collection and in the second phase

they were given codes to ensure anonymity. Two interview guides each (Appendix A, B) were used during the face-to-face in-depth interviews as well as the two FGDs. The researcher sought permission to record the information using a digital audio recorder. The researcher used probing technique to gather more information following the lead that was emerging from the interviews. The interview was discontinued until a point of saturation. The participants had the privilege to listen, to the recorded information so as to confirm whether it was a true reflection of the interviews; and furthermore made some clarifications. Listening to the recorded information served as member checks and furthermore it was one of the re- searcher possibilities to check the clarity and quality of the recording.

3.6.2 Data Collection

Phase one of data collection techniques was done using face to face in-depth interview with the assistance of an interview guide (Appendix A). Saturation was reached in the fourteenth interviews. Phase two of data collection was done after the first data collection results were analysed with assistance of an interview guide (appendix B). Two focus group discussions of seven and four senior physiotherapists were conducted. The purpose of FGDs was to gain insight into the attitude, perceptions and opinion of participants on a pre- arranged topic (Silverman, 2004). All data was collected in English as it is the official communication language in Zambia. An interview guide (appendix A, B) was used during the in-depth interviews as well as FGDs. The interview guide approach was more structured than the informal conversational interview and; was also flexible in composition (Gall & Borg, 2007). The interviews guide was developed from literature and was based on the research aim and objectives such as exploring the physiotherapists' knowledge about palliative care in the rehabilitation of clients with stroke, exploring their perceptions on management of palliative care and its application in the rehabilitation of stroke patients in Zambia as well as develop guidelines based on the out- comes of this study. Finally it's ensured that the same general areas of information were collected from

each interviewee (Namara, 2009). Before starting the interviewing process, informed consent forms (Appendix C) were given to the interviewees explaining what the purpose of the study was and the time it has taken for the interviews to be completed. The in-depth interviews took approximately 10 to 15 minutes and FGDs took about 40 to 45 minutes. According to Halloway and Wheeler (2002), in-depth interviews had become the most common form of data collection in qualitative research. Interviews provided participants with the opportunity to respond in their own words rather than making them choose from fixed responses, as in quantitative designs (Pelto & Pelto, 1997). The interviews and FGDs were audio recorded and were done in English as well as transcribed verbatim by an independent person. The interviews guide had provided more focus than the conversational approach, but still allowed a degree of freedom and adaptability in getting information from the interviewee.

3.7 TRUSTWORTHINESS

3.7.1 Credibility

Lincoln and Guba, (1985) argue that ensuring credibility is one of the most important factors in establishing trustworthiness, to ensure credibility the researcher adopted an appropriate, well recognised research methods of an exploratory study design, using qualitative methods of data collection. The researcher had purposefully selected physiotherapists practising in Lusaka/Zambia with minimum of five years stroke rehabilitation experiences with or without palliative care training and gather information until saturation was reached. Secondly the researcher made sure to check the quality of the digital audio-recorder prior to the commencement of the interviews. After the interviews were done, the researcher played back the audio recorder in order to confirm if the quality of the sound was good. This was to verify the effectiveness of the recording in order that an independent analyst obtained the same findings in case she wished to analyse the data. The researcher used transcripts and member checking during the interview process and at the conclusion of the study, thus helping to increase credibility as Lincoln & Guba



suggested (1985). During the member checking process, the participants reviewed a summary of the transcript to ensure that data represented their views. The researcher had ensured that his findings were compatible with the participant's perceptions on stroke rehabilitation with focus on palliative care.

3.7.2 Transferability

The researcher had ensured transferability by providing sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to another setting (Marshall & Rossman, 2007). In this study the researcher gave a clear and distinct as well as an accurate description of an exploratory study design, through a qualitative methods of data collection and data analysis that is supported by direct quotations from the interviews were displayed. This approach constitutes "a thick description," which is a condition of transferability (Marshall & Rossman, 2007). Lastly the researcher gave a rich and vigorous presentation of the findings together with appropriate quotations in order to enhance transferability.

3.7.3 Dependability

Dependability has been provided by sufficient descriptive data applicable to another setting (Polit & Hungler, 2001). In this study the researcher achieved dependability by giving adequate information about the participants through the operational data gathering "Verbatim quotes" in the text thus allows the reader to consider the dependability of the study. Lastly the researcher had strived at least to enable a future researcher to repeat the study.

3.7.4 Conformability

Lincoln and Guba (1985) used conformability instead of objectivity and stress the need to ask

whether the finding of the study could be confirmed by another person. According to Miles and Huberman (1994) the researcher had tried to demonstrate that the findings emerged from the data and not their own predispositions. This was achieved through face-to-face in-depth interviews and FGDs with aid of an interview guide (Appendix A, B). The researcher made sure that conformability requirements are met by revealing the findings, conclusions and recommendations being supported by the data collected as well as the researcher's interpretations which are close to the actual responses (Cresswell, 2003)

3.8 DATA ANALYSIS

Marshall & Rossman, (2007) describe data analysis as the procedure that is categorizing, structuring and putting meaning to the mass of collected data. The goal of qualitative data analysis is to produce a detailed and systematic recording of the themes and issues addressed in the interview and to link them together under reasonable exhaustive category system (Burnard, 1991). Digital audio-recorded data from the face to face in-depth interviews and focus group discussions were transcribed verbatim for each session by an independent person. The researcher was reading the transcripts several times to familiarize himself and compare with the recorded data as Neuman (2000) suggested. The data was classified systematically by means of coding to identify key factors or issues such as concepts, categories, themes and the relationship between them. The categories led to the development of patterns and themes within the data (Cresswell, 2003). Contradictions, divergences and convergences were reconciled at the point of data interpretation (Moran-Ellis et al, 2006). For trustworthiness the data were transcribed by an independent person and the researcher had sought the supervisor's opinion during the coding process and the themes and patterns to confirm with two or three participants. The researcher had tried to extract the participants' understanding of the issues under question through face-to-face in-depth interviews and two FGDs of seven and four participants each and it was subjected to in-depth thematic content analysis method to resolve the significant themes and subthemes that

have emerged from the data (Richie and Spencer, 1993). In this regards all relevant and necessary documents of the transcripts were assembled together as one through thematic orientation request and lastly the naming of categories were guided by the literature.

3.9 ETHICAL CONSIDERATION

Permission of the study was sought from the Research Grants and Study Leave Committee of the University of the Western Cape (Appendix D), Zambian Ethics Research Excellency Science Committee (Appendix E). Permissions to conduct the study was obtained from the medical superintendent of the health facilities included in the study (Appendix F). The participants were requested to sign an informed consent form before participating on the study (Appendix C). Anonymity and confidentiality was ensured by the researcher through anonymity and identification of the participants using codes and there was no obvious risk involved in participating in the study. If a participant wished to withdraw from the study for any reason, the researcher was ready to grant him or her opportunity without heart feeling. Data collected and digital audio-recorder was kept confidential by the researcher in a locked cupboard for more than five years. The results of the study will be presented at the Annual General and Scientific Congress of the Zambia Society for Physiotherapists in 2014 and also will be published on the University of Western Cape website and in accredited journals.

3.10 SUMMARY OF THE CHAPTER

The chapter described the research setting where the study was conducted and examine the approach used for the data collection. The study design, study population and sampling, the research instrument used for data collection and the research procedure. Furthermore this same chapter described the data analysis procedures as well as the ethics considerations. The results obtained from the face-to-face in-depth interviews and FGDs are presented in the next chapter combined with the discussion.

CHAPTER FOUR

RESULTS AND DISCUSSION

4.0 INTRODUCTION

In this chapter the results of the study are presented clearly in the form of narrative report writing style. Data revealed a comprehensive meaning to finding in the context of the literature available in the field as clearly as possible, and analysis and interpretation of the qualitative responses obtained through face-to-face in depth interview recorded with an interview guide. Two focus discussions were held to get more insight of the problem. The discussion includes the physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia with references to the aim and specific objectives of the study as well as relevant literature.



4.1 Socio demographic findings

The participants consisted of 25 physiotherapists practising in the five selected hospitals based in the City of Lusaka. There were ten male and 15 females managing stroke patients in their various establishments of work. The qualifications of all physiotherapists in the study were from Diploma level to Master degree in physiotherapy. All of them had five years working experiences and had at least treated a stroke patient before. The majority of the participants had more five years of working experience, followed by more than ten years while the minority of four had more than fifteen years experiences. With regard to the area of practice, most of the participants worked with adults, followed by some with adults and children and lastly few worked with children only. The demographic data is demonstrated in table 4.1. They present a general profile of the participants in the study.

Table 4.1: Demographic Profile of Study Participants

Participants	Gender	Education	Work experience	Area of practice	Names of Institution
1	Male	BSc	10	Adults	UTH
2	Female	BSc	5	Adults	UTH
3	Female	Diploma	10	Adults & Children	Chainama Hills
4	Male	BSc	5	Adults & Children	Chainama Hills
5	Female	MSc	10	Adults & Children	UTH
6	Male	BSc	10	Adults	UTH
7	Female	BSc	10	Adults	Mwanawasa
8	Female	MSc	15	Adults & Children	Churches homes
9	Female	BSc	10	Adults & Children	Churches homes
10	Male	MSc	15	Adults	UTH
11	Male	Diploma	15	Adults	CFB
12	Female	Diploma	5	Adults	CFB
13	Male	BSc	10	Adults	UTH
14	Male	BSc	10	Adults	UTH
15	Male	BSc	5	Adults	UTH
16	Female	BSc	10	Children	UTH
17	Female	Diploma	5	Children	UTH
18	Female	Diploma	5	Adults	UTH
19	Male	Diploma	5	Adults	Mwanawasa
20	Female	BSc	5	Adults	Mwanawasa
21	Female	BSc	5	Adults	Mwanawasa
22	Female	BSc	5	Adults	Mwanawasa
23	Female	BSc	5	Adults	Mwanawasa
24	Male	MSc	15	Adults	UTH
25	Female	BSc	5	Adults	UTH

4.2 DEVELOPMENT OF THEMES

In this study the researcher had predetermined themes developed from the objectives which guided the data collection. Data was analyzed by thematic analysis (Refer to Table 4.2 below). Identification, coding and categorizing of the themes was done (Baumgartner et al., 2002). The predetermined themes as well as categories that emerged from the interviews were developed based upon these specific objectives of the study:

- I. To explore the physiotherapists' perceptions on management of palliative care for patients with stroke.
- II. To explore the physiotherapists knowledge about palliative care in the rehabilitation of clients with stroke in Lusaka, Zambia
- III. To explore the application of palliative care in the rehabilitation of stroke patients in Zambia.
- IV. To make recommendations on guidelines based on the outcomes of this study.

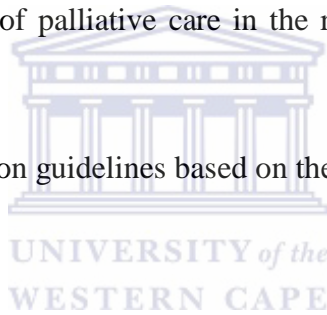


TABLE 4-2: Emerging Themes and Categories.

THEMES	CATEGORIES
1 Understanding palliative care	Care for chronic and terminal ill patient Multidisciplinary team Improve patients' life No idea of what palliative care is
2 Introduction of palliative care	Admission Rehabilitation process
3 Physiotherapy participation in palliative care needs of stroke	Physical aspect Psychological aspect Spiritual aspect
4 Caregivers' roles	counselling Physiotherapy skills
5 Barriers to palliative care	Training Planning and Policy Funding
Suggestion based on standards of palliative care guidelines	

4.3 THEME 1: UNDERSTANDING PALLIATIVE CARE

A total of 25 physiotherapists were asked about what they understand about palliative care and the majority came up with three different definitions. One group said that they understand it to mean care for chronic and terminal ill patients, multidisciplinary team and that it is about improving patients' life. Some of them were confused about what palliative care is and a few had no idea of the concept.

4.3.1. Care for chronic and terminal ill patient

Palliative care is specialized medical care for people with serious illnesses focusing on providing patients with relief from the symptoms, pain, and stress of a serious illness whatever the diagnosis is (Laakso, 2006). It is provided by a team of doctors, nurses, physiotherapists, pharmacists, psychologists, social workers and other health professionals in formulating a plan of care to relieve suffering in all areas of patient's life. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment. The goal is to improve the quality of life of both the patient and the family (WHO, 2002).

Most physiotherapists interviewed understood palliative care as a medical speciality which has to do with caring for people with chronic and terminal illness. These are few responses expressed by the participants about understanding palliative care.

“It is care given to chronic and terminal ill patient.” (PT 8)

“It is care given to very sick patients or those who are terminally ill and it also help in loosening the burden their family faces.”(PT 14)

According to Morrow (2007), palliative care is an area of healthcare that focuses on relieving and preventing the suffering of patients. It is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses, those living with chronic diseases and

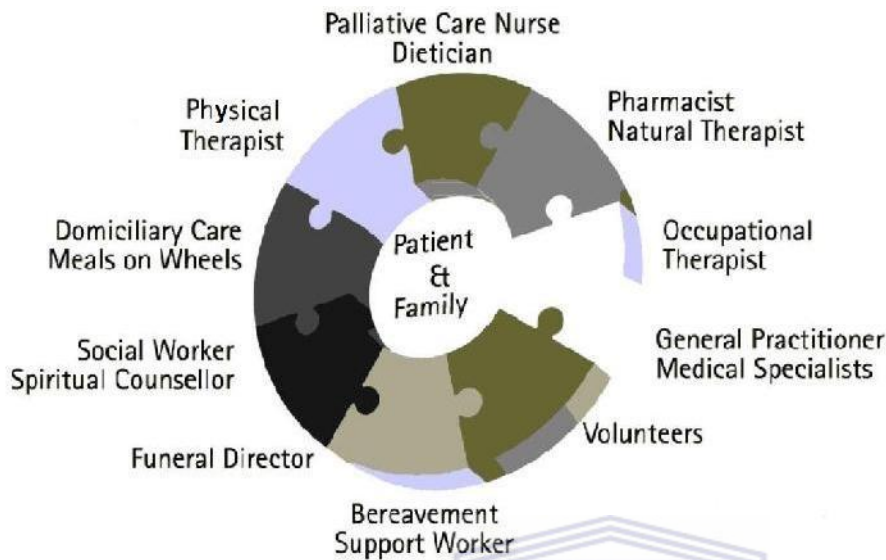
those who are nearing the end of their life. Hourigan and Josephson (2004) elaborated that palliative care means a form of care that recognizes that cure or long-term control is not possible; is concerned with the quality rather than the quantity of life; cloaks troublesome and distressing symptoms with treatments whose primary or sole aim is the highest possible measure of patient comfort (Hourigan & Josephson, 2004). The Australian Submission of Health Reform Committee (2003) stated that palliative care is a specialised treatment of people with incurable illnesses.

The major goals of palliative care are to provide comfort and care for terminally ill patients and their families, and to allow patients to die peacefully in the setting of their choice while receiving all necessary nursing, medical and social care. Before any physiotherapist administered palliative care on a stroke patient; he must have the knowledge and at least have a basic understanding of what palliative care is and what it involved. Thus help on the implementation of the palliative care in Zambia.



4.3.2 Multidisciplinary team for palliative care

Figure 3: Demonstrating Team involved in palliative care



According to the World Health Organisation (2010) palliative care is a multidisciplinary medical specialty that focuses on preventing and relieving suffering and on supporting the best possible quality of life for patients and their families facing serious illness. Few of the informants were able to understand palliative in this way:

“It is a multidisciplinary team of taking care of a patient holistically in the hospital, home or hospice.”(PT14).

“Care of patients who are terminally ill in the area like the physical, spiritual, psychological and emotional.”(PT 3).

Meier & Beresford (2008) stated that multidisciplinary team in palliative care means patient centred care of planning through contributions from all relevant disciplines and is based on a comprehensive assessment of the individual and family. The team works both autonomously and together with individuals, families and caregivers to clarify goals of care and develop a single,

co-ordinated, needs-based palliative care plan (Baldwin & al. 2011). Individual team members work within the evidence base for their specific profession (Baldwin & al. 2011). Mitchell's et al, 2008 highlighted that the benefits of a multidisciplinary approach to palliative care is to increase patient perception that their care is being managed by a team; greater likelihood of the delivery of care in accordance with national standards and clinical practice guidelines. Furthermore the same author concluded that other benefits will be to increase patient satisfaction with care as well as increase access to information, psychosocial and practical support for patients. In Zambia where the study took place, the multidisciplinary approach is not well coordinated on palliative care perspective, as most the informants said it is important that all health personnel's treating the patient have good rapport and communication amongst them. The care must be patient centre by incorporating the physical, psychosocial and spiritual aspect as well as listening and accommodating the patient's needs in the treatment goal.

4.3.3 Improve patients' life

The World Health Organisation (2002) understood palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Some of the respondents understood palliative care as a medical service which does improves patients' life. Here are some of their expressed views:

“Care provided to clients who have incurable illnesses in order to improve their condition and lifestyles” (PT 25).

One revealed that palliative care is

“... an assessment and care given to patients who are bed ridden, who got no help or have negative thought and are in the process of dying in order to improve their life.” (PT 7).

Current expert opinion believed that introducing palliative care after diagnosis for stroke patient is associated with improvement in quality of life, mood and survival (Morrow, 2007); and the same author continued by saying that improvement of a patient’s quality life is the main benefit of palliative care system. Addington-Hall & Higginson (2001) highlighted that there is increasing recognition that the principles of palliative care are important component in the health care services, whether patients are terminally ill or not, and in diseases other than cancer, in order to support multidisciplinary teams in symptom management, improve quality of life and ethical practice. It is evident that the participants in the current study and others re- searchers such as Morrow (2007) and Addington-Hall & Higginson (2001) are agreeing that palliative care in stroke management as it improves the patient and family quality of life by relieving the patients’ suffering and preventing a lot of complications which may arise later in the disease trajectory such as contracture, deformity, patient’s fear for what lies ahead and family psychosocial distress and uncertainty.

4.3.4 No idea of what palliative care is

The findings of the current study revealed also that few out of the participants seem not to understand correctly what palliative care is, or do not have any idea of the palliative care concept.

One simply understood palliative care in this way:

”A drug or medical drug given to a patient; which does not cure the pain.” (PT 12)

And few respondents highlighted in this manner:

”A care that is given to bedridden patients, who have got no help, and they are towards the end

maybe towards dying. So you have to give them that care to send them off.” (PT 10).

According to McIlfatrick (2006) study demonstrated that professional health care workers experienced difficulty in defining the term palliative care, difficulties in communication and information exchange, and fragment co-ordination between services were identify. The current study identified that some of the participants have difficulty in understanding palliative care concept; this could be perhaps due to lack of training as most of them highlighted earlier or lack of experience in the palliative care field.

4.4 THEME 2: INTRODUCTION OF PALLIATIVE CARE

WHO (2002) emphasizes on the need to introduce palliative care in the early stage of any serious illness, even as soon as patient has a diagnosis and begin treatment. There is not a need to wait until a disease is in an advanced stage or in the final months of one’s life. In fact, the earlier stroke patient starts palliative care, the better, because anxiety, depression, fatigue, and pain might set in at the beginning of treatment therefore palliative care model does understand the stresses that a patient and family face; and can help them to cope. According to Frymark et al, (2012) the goals of palliative care into stroke must be short-term and flexible as they might need to change to comply with the changing condition of the patient. It may be necessary to make a renewed assessment every time you meet because the patient’s general condition can vary from day to day. You need to work towards unrealistic goals; but this can be important for the patient to be able to handle his situation. As most of the informants in this study believed and perceived that early introduction of palliative care into stroke will help them in the assessment of the patient, get full history details and make plan of treatment in order to relieve the physical effects, functional impact of pain, psychosocial stress and spiritual need of a stroke patient. The opinion of the informants on the introduction of palliative care brought in-depth discussion with regards to participation in the early stage of admission and in the rehabilitation process.

4.4.1 Admission

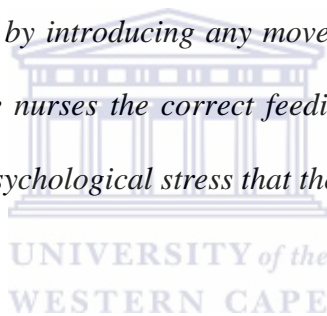
According to Laakso (2006) palliative care should not be limited to the end of life, it must begin much earlier and it can be applied to cancer and other chronic illness such as stroke.

Most physiotherapists interviewed seem to be aware that early intervention in the management of stroke patient will have a positive impact on the patient well-being.

These are some of their views:

“Physiotherapist can start seeing the patient in the ICU until they get better or if any death comes will see them to their homes.” (PT 18)

“Physiotherapy can come in early by introducing any movement or facilitate movement which is already there and can teach the nurses the correct feeding position of a patient in case of dysphasia, and lastly address the psychological stress that the patient and family facing.” (PT1).



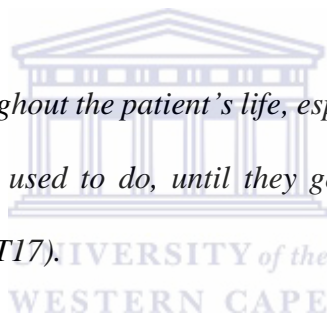
The risk of recurrent stroke is highest soon after the first-ever-stroke happened (Ninds, 2007). Requiring early intervention and appropriate and effective secondary preventive measures will benefit the stroke survivor (SAMJ, 2009). The impact service of physiotherapy intervention on quality of life and function was measured in a study comparing standardised in-patient physiotherapy practice (limited by time and equipment resources) with a well-resourced physiotherapy (Laakso et al, 2003). The results indicated that early intervention and community follow-up, can contribute significantly to the maintenance of functional independence and quality of life among patients receiving palliative care. Association of Chartered Physiotherapists in Oncology and Palliative Care (1993) emphasizes that physiotherapy has a key role to play in the management of clients throughout the stroke journey from diagnosis up to the end stages of the illness. Physiotherapy as a health care profession aimed at improving quality of life can use a variety of techniques to stabilize and improve stroke patient condition in the early stages of

diagnostic process; as well as take responsibility of ensuring that the patient improves functionally so that much of the daily activities become easy done.

4.4.2 Rehabilitation process

Key aspects of rehabilitation process include multidisciplinary assessment, identification of functional difficulties and their measurement, treatment planning through goal setting, delivery of interventions which may either affect change or support the person in managing persisting change, and evaluation of effectiveness (Nice, 2013). Few out of the twenty five informants expressed the view that palliative care must not only be emphasised in the early stages but as well as in the rehabilitation process. These are some of the comments expressed:

“The extent, I think should be throughout the patient’s life, especially in all rehabilitation process and making them to do what they used to do, until they get better as well as preventing the complication which may arise.” (PT17).



Others participants believed that before starting the physical part of rehabilitation it is wisely to prepare the patient’s mind-set first:

“Before the physical comes you have to encourage them spiritually and emotionally to prepare them as well as make them aware about their illness and that prepare and motivate them to take fully in the rehabilitation process.” (PT 11).

One informant highlighted the physical aspect of rehabilitation in this manner:

“Restore the persons’ movements to near as normal, rehabilitate them to near normal and maintain all range of movement in the body. Coordinate as much as possible and ensure that the patient feels; I can go on.” (PT5).

It is crucial that a stroke survivor be referred to a physiotherapist as soon as possible. The sooner physiotherapy starts, the faster the brain relearns normal movements, thus reorganizing the sensory and motor pathways of the brain (Nasam, 2012). The primary benefits of palliative care are symptom management; establishing goals of care that are keeping the patient's values and preferences; consistent and sustained communication between the patient and all those involved in his or her care; psychosocial, spiritual, and practical support both to patients and their family caregivers; and coordination across sites of care (Meier & McCormick, 2013). Rehabilitation of stroke patient focussing on palliative care is a multidimensional process, which is de- signed to facilitate restoration of, or adaptation to the loss of, physiological or psychological function when reversal of the underlying pathological process is incomplete (ACPOPC, 2003). The aims of rehabilitation are to enhance functional activities and participation in society and improve quality of life (Ninds, 2007). The current views of the informants in this study is that the rehabilitation process must be centre through good rapport and communication amongst all health professionals treating the patient, through incorporation of the physical, psychosocial and spiritual aspect as well as listening and accommodating the patient's needs in the treatment goal. Therefore physiotherapists in Zambia can contribute to significantly higher functional levels; improve maintenance of functional independence, patient satisfaction and quality of life if they utilised this palliative care model.

4.5 THEME 3: PHYSIOTHERAPY PARTICIPATION IN PALLIATIVE CARE NEEDS OF STROKE

The National Clinical Guidelines for stroke (2007) identified the palliative care needs in-patient admitted with acute stroke and the result revealed that physical, psychological, religious and spiritual issues were extremely noted, followed by the social as well as end of life concern. The perceptions of all informants concerning this question vary depending to the knowledge and experiences of the individual consequently training Vs non-training on palliative care prospective were noted. Little difference indeed surface: Most informants believed that palliative care need of a stroke patient is the areas of physical, psychological or emotional and spiritual.

4.5.1 Physical aspect

The physical aspect of a stroke patient from the NCGS (2007) survey revealed that 80% of stroke patients have communication problem, 50% reported to have significant problem with weakness, tiredness, being sleep during the day and lastly 50% experiences pain, memory loss, headache, restlessness or bladder problems. The informants perceived that stroke survivors have a lot of physical needs that can benefit through physiotherapy. They highlighted what could be done to help the patient physically in this way:

“...introduction of movement or facilitation of movement which is already there, physiotherapists should take responsibility of ensuring that the patients improve functionally so that much of the daily activities will be done without any or less assistance.” (PT 17).

“Making them start to walk and doing what they used to do before as well as preventing complications which might arise later.” (PT 10).

Stroke patients always have physical disability and stroke is the most frequent cause of adults' onset disability among people (Nice, 2013). The most common disability that leads to referral to in-patient rehabilitation is the inability to walk safely without physical help (Dobkin, 2005). Therefore early intervention is crucial. Every stroke survivor must seek rehabilitation treatment as soon as possible. The sooner rehabilitation starts, the faster the brain relearns normal movements. The longer rehabilitation is delayed, the harder it will be for a stroke survivor to recover his functional independence which includes self-care: using the toilet, dressing, bathing, eating, and mobility (Nasam, 2013). As most the researcher and clinician as well as the informants said stroke tends to result of disabilities which have been shown to benefit from rehabilitation. Physiotherapists in Zambia and in the world can help the stroke patient improve function and gain as much independence as possible and improve his quality of life.



4.5.2 Psychological aspect

The psychological aspect from the National Clinical Guidelines on Stroke (2007) survey revealed that 70% of stroke patient reported “feeling everything’s’ as an effort”; 50% experienced some form of psychological distress such as anxiety, low mood, confusion, poor concentration and loneliness. Most of the participants seem to agree that stroke patients and their family faces a lot of psychological distress therefore addressing these will be cardinal on the re- covering process of a patient. These are some of the views expressed:

” ...dealing with psychological matter makes the patient not to feel abandoned; and he feels that there is someone out there who cares for him, and furthermore it makes it easy for him to accept what has happened and be able to move on beyond the condition....” (PT 1).

“Talking to the patient and family before starting the treatment is to prepare them psychologically and emotionally so that when am doing the physical aspect of treatment the patient will respond.” (PT 6).

Many stroke patients are left to struggle when they leave hospital with the emotional impact of what has happened. A report from England Association of Stroke (2003) revealed that many stroke patients battle with depression, anxiety, relationship breakdowns and suicidal thoughts when they are discharged because they do not get emotional support from health care personnel's and social care services. The England Association of Stroke (2013) survey of 2,700 people affected by stroke reported a pressing need for psychological and emotional support to be seen as important part of recovery as physical rehabilitation. The results found that; only two in ten were given information, advice and support on coping with the psychological aspects of stroke. Almost two-thirds agreed or strongly agreed that their psychological needs were not looked after as well as their physical needs. Although 67% had experienced anxiety and 59% felt depressed, over half of those who responded to the survey did not receive any information, advice or support to help with anxiety or depression. Nearly half said their relationships or contact with friends and families had been put under strain. According to Smith et al, 2013 the psychological effects of stroke can be as devastating as the physical ones because survivors are left grieving for the life and identity that has been taken so suddenly from them. A recent study conducted in Canada on satisfaction with palliative care after stroke revealed that families were satisfied with participation in decision making and least satisfied with psychological/emotion needs (Blacquiere et al.,2013). Therefore it is important that physiotherapists in Zambia as well as in the world pay a serious attention in this area of psychological/emotional trauma that stroke patient encountered and should effectively address this aspect of discomfort to relieve patient suffering as soon as possible by adopting the palliative care model of treatment. Thus help patient and family to rely on their own resources and cope more successfully with the hardships that lies ahead on the road to recovery. Furthermore adequate psychological support is critical as removing stroke patient fear of unknown and help to optimise the symptoms control. Every patient regardless of its level of income, education or self-sufficiency requires psychological support to deal with the challenges poses by stroke disease.

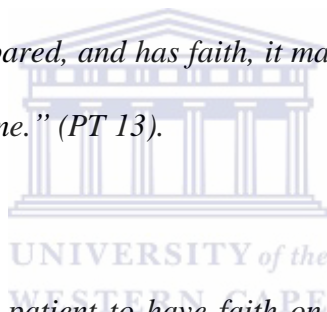
4.5.3 Spiritual aspect

The National Clinical Guidelines of Stroke (2007) revealed that one in every four stroke patients has concern about the religious and spiritual aspect, particularly death and dying issues.

In the current study most of the informants do not feel competent enough to talk about religious and spiritual aspect of a stroke patient. Only two informants out of the twenty five interviewers expressed their views on this matter:

“Before the physical comes in, you need to encourage them spiritually and prepare them for what lies ahead.” (PT 5).

“When the patient is spiritually prepared, and has faith, it makes him be aware about his illness and he will be positive for the outcome.” (PT 13).



“It is always important to tell the patient to have faith on God because some of them lose hope quickly and blame God for their misfortune.” (PT10).

According to WHO (2010) the spiritual care needs is now considered an important aspect of holistic healing practices in palliative care system. However, research is showing that most health care providers do not feel competent or confident in this area of care (Bloemhard, 2006). Many studies declare that people who have a spiritual orientation have a greater resilience in coping with life’s difficulties, especially in the later stages of life (Kirby, Coleman & Daley, 2004). The relational dimension of spirituality involves a deepening of our love, a decentring of the self, to see others as ends in themselves’ which involves not closing off and defending one’s sense of self, but the ability to be being open and vulnerable (Faver, 2004). According to Longaker (1997) Stroke patients need to feel that no matter what their experiences and circumstances are; they must be respected and unconditionally accepted. They need basic human

kindness; the reliable presence of another person, someone who is willing to be in regular contact with them for the duration of their journey through suffering. It is evident that the current study and the literature revealed most health personnel's are not competent enough to discuss with their patients about religious and spiritual care. But it is also essential that physiotherapists in Zambia and in the world give an attention to the spirituals needs of a stroke patient, family or careers; although some physiotherapists may not be comfortable discussing spirituality. Other may not have come to terms with how they feel about their own spirituality, or they may not fully understand what spirituality encompasses. Palliative care approach provides an opportunity for the physiotherapist and the patient to openly talk about their relationship with higher power God. Physiotherapists need to be cognizant of the stroke patient surroundings. For example, the patient may be wearing a cross, carrying a Bible, or displaying other religious symbols in the home or on the body. Making comments about these items may allow for meaningful and needed spiritual discussions with the patient. The physiotherapists could also offer to pray with the patient, family or carers, contact a chaplain or pastor, or provide other spiritual resources, as appropriate.

4.6 THEME 4: CAREGIVERS ROLES

Support for family caregivers is a core function of palliative care and has been advocated since the inception of the modern hospice movement; and now regarded as a requirement for palliative care delivery (WHO, 2010). According to the National Stroke Association (2013) the caregivers role most immediate task may be about the most intimate physical aspect of care, giving baths, helping a loved one eat, get dressed, use the bathroom or even breathe. Others are provision of love and compassion, time of resolving outstanding issues and remembering the good times. Majority of informants perceived counselling and physiotherapy basic skills as vital element support to empower and educate the caregivers in order to speed up the rehabilitation process and improve the patient's quality of life.

4.6.1 Counselling

Farrell (2013) stated that counselling is an important aspect of care because it helps the patient deal and solved everyday activity problem; it does handle and find a new way for the patient to cope and improve his situation. The following statements reflect the informant's views on counselling:

“Counselling makes the patient and family accepts what has happened and be able to move beyond the condition; also it helps the patient feels not abandoned that there is someone cares for him.” (PT11).

“Counselling the patient, family and educating the community at large, to understand that stroke patient is a human being, he got feelings and needs and he has all the human right like anybody else.” (PT3).

The National Stroke Association of Malaysia (2013) understood counselling as listening to stroke survivor in a calm, non-judgmental manner. A study conducted in England on psycho- dynamic counselling after stroke revealed high severities of stress, anxiety and depression post stroke, resulting in themes of grief, loss, attachment, dependency, death anxiety and fear are shown (Bateman & Mikolajczyk, 2012). The basics principles in counselling are that each person has intrinsic worth, is unique, is capable of change, and has strength and responsibility to change, so to act on the belief that 'there is a life after a stroke (Nasam, 2013). Counselling has a lot of benefits to offer a stroke patients and family as most the informants perceived. It is a very important tool in the palliative care system. Counselling does contributes to patient and family understanding the disease complexity, “personality and mood changes” thus help them cope with the disease and live with it consequently avoid denial temptations. Physiotherapists in Zambia must be able to get alongside the patient and their family and spend time presenting options,

answering questions and queering fears. Effective counselling skills are requisite in this area palliative care system. These include appropriate and effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision- making, and communicate with all individuals involved in the care of patients. In this regard effective counselling skills will be an advantage tools for the physiotherapists in Zambia to acquire it through palliative care concept.

4.6.2 Physiotherapy skills

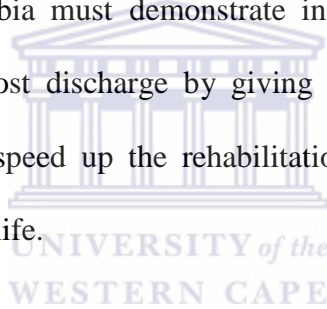
Most researchers agree that the majority of recovery occurs within the first three months post stroke, continue over six month or even longer (Wiles et al.,2002). The same author continued by saying that stroke tends to result in a range of disabilities which have been shown to benefit from rehabilitation in particular physiotherapy. Previous studies providing family physiotherapy skills have shown some benefit for carers in terms of satisfaction with practical information provision (Kalra et al, 2004) emotional support (Lincoln, 2003), mood (Kalra et al, 2004) and improved quality of life (Mant, 2000). As most informants suggested in the current study, it is imperative for the physiotherapists to learn how to teach the caregivers some basic physio- therapy skills in order to complement their effort on providing service and care to their loved one at home upon discharge from the medical facility. The following statements reflect the views of the informants concerning physiotherapy skills:

“The caregivers must learn some basic physiotherapy skills thus will help in caring of the patient at home.” (PT 17).

“Teach the patient’s relatives how to take care of him physically at home and give them some form of psychological counselling as well.” (PT 19).

A Stroke survivor returning home after discharged from the hospital and their carers require support to meet their rehabilitation needs which includes: independence in activity of daily living, exercise and psychosocial support (Joanna et al, 2013). The same author further suggested on the continuity to provide informal rehabilitation support upon discharge, thus may help to address these issues. A recent study identified that rehabilitation practice that addresses and supports autonomy, adaption and social connection may help community- dwelling stroke survivors regain personally valued activities post-stroke (Kubina et al, 2013).

It is evident that caregivers support in term of empowerment of basic physiotherapy skills as most informant said; is the most prominent and reliable factors contributing to positive function and recovery and psychological well-being after a stroke. Carers' are vital health resource therefore physiotherapists in Zambia must demonstrate in the world that caregivers can be engaged in preparation for life post discharge by giving them opportunity in the treatment planning goal. This will help to speed up the rehabilitation process as well as contributing significantly in patient's quality of life.



4.7 THEME 5: BARRIERS OF PALLIATIVE CARE

It is undeniable that anything in society has barriers and; without any exception palliative care has its barriers in providing services. There is little research into barriers to the provision of palliative care in the world and particularly in the African context (Brown, 2011). There were a number of informants who felt that palliative care system in Zambia has barriers related in the three main categories: trainings of physiotherapists, planning and policy in the management and administration of health care and funding were noted.

4.7.1 Training

Assessment of physiotherapists' perceptions on palliative care revealed that informants who received palliative care training rated themselves with adequate knowledge on the topic. Those who do not attend the training perceived their knowledge was not sufficient because most palliative care facts they have, are through the media, internet and personal effort to learn the topic. The informants emphasized lack of palliative care training as one of the barriers of the palliative care system in Zambia. Below are some of the different views expressed by some of them:

“Training could be a barrier if one isn't trained into palliative care and it becomes difficult to apply it; knowledge of palliative care is needed to fully implement its approach into stroke in Zambia since palliative care is a science.” (PT1).

“I think there's need for us physio to be knowledgeable about palliative care because it is a new thing; it just came with the advent of HIV/AIDS, Cancer, so it is quite new in the rehabilitation; currently our knowledge is limited.” (PT 10).

“When we are not competent enough to respond to the needs of the patients because of the uncertainty.” (PT 21).

WHO (2002) recommended that Palliative care should be included in the curriculum of medical, nursing and other health professional students to ensure that health care workers are sufficiently prepared to care for chronic illness in all settings, and are able to train family members and community volunteers. The Clinical Practice Guidelines for Quality Palliative Care (2008) suggested that the primary practitioner’s routine course of providing health care must have the basic elements of palliative care provision (e.g., pain and symptom assessment and management, advance care planning). Dickinson (2006) identified that since 2000 many medical schools in the United States have introduced palliative care education into curricular. The same author also says that the curricula content of entry level programs for health professionals might include a basic understanding of palliative care principles, appropriate intervention, planning and assessment, and the roles of the spectrum of health professionals. Several authors also emphasised importance of educating health professionals in loss and grief during entry level education (Eva et al., 1999).

In Zambia as most respondents highlighted there is a great need to promote higher profile of their profession and skills through education and training opportunities that palliative care offers. Control of pain and symptoms that palliative care system advocates; accessibility, and effective palliative care; and how to develop such services remains to be resolved in Zambia. Palliative care includes components that carry resource and clinical supervision. But these two elements are lacking to sustain quality palliative care in Zambia. Therefore it will be appropriate if all stakeholders in Zambia and the world at large come together to provide means to the Palliative Care Association of Zambia, in order to enable it educates and provides adequate training and clinical support required by the physiotherapists. This will promote skills development for professional care for stroke patients and also facilitates the development of skills for the physiotherapists

working in this field in Zambia.

4.7.2 Planning and policy

Inadequate planning management care and administration as well as the current inefficiency on policy measures were seen as another barrier in palliative care system in Zambia. These are some of the informants' views:

“Ministry of Health have not clearly defined the roles of each profession and I think as physiotherapists, this is where we have a problem. As much as we know that we have a bigger role to play in palliative care in general; there little going on to give us an edge.” (PT 4).

“Some physiotherapists were trained in palliative care and others not that is poor planning, it should keep on rolling so that everyone among us should also have a chance to be trained”.(PT 20).

Some informants emphasize on the policy level inefficiency as a contributing factor as well:

“We need palliative care itself to have a policy and, that policy will define standards of care that benefit the patient. Where we are now; if we are lacking human resources? And so on.” (PT 25).

The World Health Organisation (2002) stated that many countries have not yet considered palliative care as a public health problem and, therefore, they do not include it in their health agenda. Several initiatives have developed but have not been well integrated into the countries national health policies and, therefore, there is not yet a significant impact in the population of patients in need of palliative care. Consequently, there is no doubt that there is a need to advocate worldwide for adequate policy development and effective program implementation in the area of palliative care. At present WHO is developing various activities related to palliative care

and a major emphasis is given to advocating for palliative care as a global public health problem (Sepulveda et al, 2002). Recommendations are tailored to different resource settings; and priority is given to initiatives that are well integrated into the existing health system and related programs such as policy development, education and training, provision of good quality care (WHO, 2002). In this study the respondents lamented on the current weakness in the planning of care, ministry of Health administration as well as current policy in place which does not favour palliative care program in Zambia. As the WHO also advice Zambia should promote awareness among the public and health professionals on palliative care. Zambia Society of Physiotherapy and Palliative Care Association of Zambia must lobby, advocate and collaborate together in order to produce a policy proposal on palliative care which hopefully will be handled to the policy maker or legislator for implementation.

4.7.2 Funding

Apart from training, inadequate planning and policy in place, informants highlighted funding as another barrier which needs attention in order to improve palliative care. These views reflect their perception in this matter:

“Patient comes to us and we also need some follow- up, to check how they behave and stay at home, for us to be able to do that we need transportation (money); thus will enable us to know what has change in their infrastructure at home because life has been changed.” (PT10)

“The money allocate to this palliative care isn’t enough that why the training is no more, if the Ministry of Health can allocate good money for training and research on palliative care that will be great.” (PT 4).

Funding for palliative care services varies. In the UK and many other countries all palliative care is offered free to the patient and their family, either through the National Health Service or

through charities working in partnership with the local health services (ACPOPC, 2003). Palliative care services in the US are paid by national institute of health, by philanthropy, fee-for-service mechanisms, or from direct hospital support. (Gelfman et al, 2013). In Zambia funding varies from the ministry of health, charity organisation and NGOs (PCAZ, 2010). This funding is however not enough to accommodate all. Palliative care needs resources for its implementation in Zambia. Although efforts are made by the government and NGOs much still needs to be done in future in order to sustain palliative care service financially.

4.8 THEME 6: SUGGESTIONS BASED ON STANDARDS OF PALLIATIVE CARE GUIDELINES

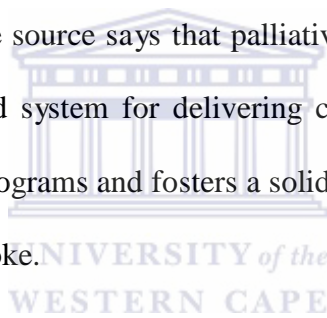
The US National Institute for Health and Care Excellence (2013) stated that despite improvements in mortality and morbidity, stroke patient still need access to effective rehabilitation services. Stroke rehabilitation is a multidimensional process, which is designed to facilitate restoration of or adaptation to the loss of physiological or psychological function when reversal of the underlying pathological process is incomplete (Nice, 2013). In order to achieve these, physiotherapists in Zambia and in the world need to have evidence based guideline to assist them in their clinical reasoning and decision making regarding patients with stroke (Van Peppen et al., 2007). There was a general agreement in the current study by all informants concerning improving palliative care service in Zambia. They suggested having a standard based physiotherapy guidelines on palliative care for stroke as evidence based method of practice as a reference. Some of the informant's highlighted in this manner:

“Once we have a standard will be able to refer to it and check if what we are doing is the correct things.” (PT10).

“I think the most important thing we need to look at is to develop what others call golden standards on palliative care for stroke regarding physiotherapy.” (PT18).

“It will be nice to have a guideline in which we can refer time to time to it, in case we are having uncertainty in delivering palliative care for stroke.” (PT 22).

According to the Clinical Practice Guidelines for Quality Palliative Care (2009) palliative care is growing in response to growth of the population living with chronic and life-threatening illness; and because of increasing clinicians’ interest in effective approaches to the care of such patients. Further asserting the same source says that palliative care is both a philosophy of care and an organized highly structured system for delivering care. The summary guideline is intended to strengthen the existing programs and fosters a solid foundation for the physiotherapists in Zambia on palliative care for stroke.



4.9. SUMMARY OF THE CHAPTER

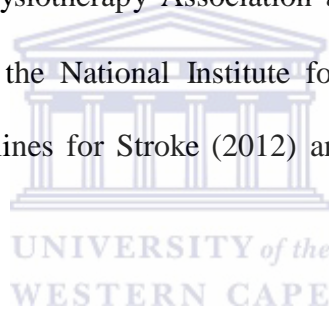
Chapter four highlighted the results and outcomes of the explorative qualitative data collected, and also the discussion of the current study were elaborated. The results were presented clearly in the form of narrative report writing style. Data revealed a comprehensive meaning to finding in the context of the literature available in the field as clearly as possible, and analysis and interpretation of the qualitative responses obtained through face –to- face in depth interview recorded with an interview guide. Two focus discussions were held to get more insight of the problem. The discussion included the physiotherapists’ perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia with references to the aim and specific objectives of the study.

CHAPTER FIVE

RECOMMENDED PHYSIOTHERAPY GUIDELINES FOR STROKE WITH FOCUS ON PALLIATIVE CARE BASED ON THE OUTCOMES OF THIS STUDY

5.0 INTRODUCTION

The researcher recommends summary guidelines as an implementation tool designed to raise awareness and improve health care in line with the evidence for clinical reasoning and practice on palliative care for stroke and physiotherapy. The researcher used four guidelines based on the current study and adjusted it in Zambia context. These are the full Clinical Guidelines for Stroke Management which Australian Physiotherapy Association approved and endorsed in 2010, the recent guidelines from the National Institute for Health and Care for Excellence (2013), the National Clinic Guidelines for Stroke (2012) and the Clinical Practice Guidelines for Quality Palliative Care (2009).



5.1 GUIDELINES FOR PALLIATIVE CARE FOR STROKE IN ZAMBIA

5.1.1 Rehabilitation

5.1.1.1 Use of assessments/measures

The physiotherapists should use assessments or measures that have been studied in terms of validity and reliability and reassess the patients at appropriate intervals.

5.1.1.2 Team work

Doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers should work together with the patient and family as a team, using an agreed therapeutic approach. Furthermore all staff should be trained to place patients in positions that reduce the risk of complications such as contractures, respiratory complications and pressure sores.

5.1.1.3 Goal setting

The goals should be meaningful, measurable (both short- and long-term), achievable and realistic. It setting must include the patient, and the family or carer in the discussion if appropriate

5.1.1.4 Amount, Intensity and Timing of rehabilitation

A structured rehabilitation program will be important to provide as much practice as possible within the first six months after stroke. 45 minutes of active practice daily for a minimum of 3 to 5 days weekly will be suitable for patients undergoing active rehabilitation. Weaker patients, who cannot reach 45minutes, ensure that the sessions still offered 3 to 5 days per week for a shorter time at an intensity that allows them to actively participate. The patients should be encouraged by physiotherapists, with the help of their family and/or friends if appropriate to continue to practice skills they learn in therapy sessions throughout the remainder of the day. Lastly but not the least upper limb mobilisation training should commence as early as possible on a stroke patient.

5.1.1.5 Sensory and motor impairment

The following interventions should be used on stroke patient with body weakness: passive range movement or progressive resistance exercises, electrical stimulation. Specific-sensory training can be done to patients who have sensory loss.

5.2 Physical activity

Sitting: Practice reaching beyond arm's length in sitting with supervision and assistance should be provided for patient who has difficulty sitting.

Standing up: Practising standing up should be undertaken by patient who has difficulty in standing up from a chair.

- ❖ **Standing:** Task-specific standing practice with feedback can be provided for people who have difficulty standing.
- ❖ **Walking:** All stroke patients with walking difficulty should be given the opportunity to undertake tailored, repetitive practice of walking (or components of walking) as much as possible; and one or more of the following interventions can be used in addition to conventional walking training: Mechanically assisted gait (e.g. treadmills), Virtual reality training. Furthermore ankle-foot orthoses, which should be individually fitted, can be used for people with persistent drop foot.
- ❖ **Upper limb activity:** All stroke patients with difficulty using their upper limb should be given the opportunity to undertake as much simple practice of upper limb activity (or components of such tasks) as soon as possible. Interventions which can be used include: constraint-induced movement therapy in selected patients, repetitive task-specific training, mechanical assisted training, mental practice, electrical stimulation, mirror therapy and bilateral training
- ❖ **Wrist joint:** Do not routinely offer wrist and hand splints to patient with upper limb weakness after stroke. Consider wrist and hand splints in patient at risk after stroke (for example, patient that has immobile hands due to weakness and patient with high-tone). Maintain joint

range, soft tissue length and alignment, increase soft tissue length and passive range of movement and finally facilitate function (for example, a hand splint to assist grip or function) aid care or hygiene (for example, by enabling access to the palm).

5.3 Activities of daily living (ADL)

Patients with difficulties in performance of daily activities should be assessed by a physiotherapist. Patients with confirmed difficulties in personal or extended ADL should have specific therapy (e.g. task-specific practice and trained use of appropriate aides) to address these issues. The physiotherapists should advise staff members and the stroke patient and their carer, or family regarding techniques and equipment to maximise outcomes relating to performance of daily activities and sensorimotor, perceptual and cognitive capacities.

5.4 Managing Complications

5.4.1 Spasticity

Interventions to decrease spasticity other than an early comprehensive therapy program should NOT be routinely provided for patient who has mild to moderate spasticity (i.e. spasticity that does not interfere with a stroke patient's activity or personal care). Furthermore stroke patients who have persistent moderate to severe spasticity (i.e. spasticity that interferes with activity or personal care): Electrical stimulation can be used.

5.4.2 Contracture

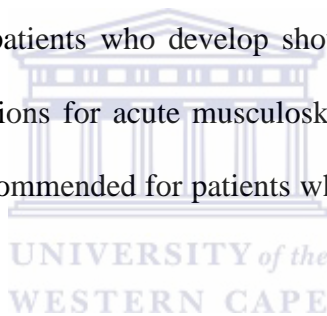
The conventional therapy (early simple interventions) should be provided for stroke patients at risk of, or who have developed contracture. For stroke patients at risk of, or who have developed contractures and are undergoing comprehensive rehabilitation, the routine use of splints or prolonged positioning of muscles in a lengthened position is NOT recommended. Furthermore overhead pulley exercise should NOT be used routinely to maintain range of motion of the shoulder and lastly serial casting can be used to reduce severe, persistent contracture when conventional therapy has failed.

5.4.3 Subluxation

Stroke patients with severe weakness who are at risk of developing a subluxed shoulder, management should include one or more of the following interventions: Electrical stimulation, firm support devices, education and training for the patient, family or carer and clinical staff on how to correctly handle and position the affected upper limb; and for patients who have developed a subluxed shoulder, management may include firm support devices to prevent further subluxation.

5.4.3 Shoulder pain

Stroke patients with severe weakness who are at risk of developing shoulder pain, management may include: Shoulder strapping, interventions to educate staff, carers and people with stroke about preventing trauma and for patients who develop shoulder pain, management should be based on evidence-based interventions for acute musculoskeletal pain. The routine use of the following interventions is NOT recommended for patients who have already developed shoulder pain: Ultrasound.



5.4.3 Swelling of the extremities

Stroke patients who are immobile or mobile and have or do not have swollen extremities, the following interventions are preventive measure and management for the swelling of the hand and foot: Dynamic pressure garments, electrical stimulation, elevation of the limb when resting and continuous passive motion with elevation.

5.4.4 Loss of cardio respiratory fitness

Rehabilitation should include interventions aimed at increasing cardio respiratory fitness once patients have sufficient strength in the large lower limb muscle groups. Patients should be encouraged to undertake regular, ongoing fitness training.

5.4.7 Fatigue

Fatigue therapy is done best when the patient is most alert.

5.5 Address the psychosocial factors

Psychological assessment must include a patients' understanding of disease, symptoms, side effects, and their treatments, as well as assessment of caregiver needs, capacity, and coping strategies; the family understanding of the illness and its consequences for the patient, and also assess the family caregiver capacities, needs, and coping strategies. The physiotherapists must assess emotional functioning in the context of cognitive difficulties in people after stroke. Any intervention chosen should take into consideration the type or complexity of the person's neuropsychological presentation and relevant personal history. Support and educate people after stroke and their families and carers, in relation to emotional adjustment to stroke, recognising that psychological needs may change over time and in different settings. When new or persisting emotional difficulties are identified at the person's 6-month or annual stroke reviews, refer them to appropriate services for detailed assessment and treatment. If physiotherapist is competent enough can manage depression or anxiety in stroke patient who have no cognitive impairment otherwise refers to the appropriate specialists. Stroke survivors and their families or carers should be provided with information and education about fatigue; including potential management strategies such as exercise, establishing good sleep patterns, avoid sedating drugs and too much alcohol. Every stroke patient should be assessed and informed of their risk factors for a further stroke and possible strategies to modify identified risk factors. The risk factors and interventions include: Stopping smoking: nicotine replacement therapy and behavioural therapy, improving diet which is low in fat (especially saturated fat) and sodium but high in fruit and vegetables. Patients should be taught on increasing regular exercise as well as avoiding too much alcohol. Empower with behavioural changes, education and coping strategies techniques.

5.6 Address the spiritual needs

Physiotherapist should have education and appropriate training in pastoral care and the spiritual issues evoked by patients and families faced with life threatening illness. The assessment of spiritual and existential need must be documented. This includes, but is not limited to, life review, assessment of hopes and fears, meaning, purpose, beliefs about after life, guilt, forgiveness, and life completion tasks. Contact the pastoral care ministry and other palliative care professionals facilitator with spiritual and religious skills as desired by the patient and family. If one is not competent enough to assist the patient and family in this area; then they should refer to the appropriate professionals.

5.7 Carer training

Physiotherapists should provide specific and tailored training for carers or family before the stroke patient is discharged home. This should include training, as necessary, in personal care techniques, communication strategies, physical handling techniques, ongoing prevention and other specific stroke-related problems, safe swallowing and appropriate dietary modifications, and management of behaviours and psychosocial issues.

5.8 Palliative care community rehabilitation and follow up service

Physiotherapists should provide comprehensive, experienced multidisciplinary community rehabilitation and adequately resourced support services for stroke patients and their families or carers. If services such as the community based rehabilitation and carers support services are available, then early supported discharge should be offered for all stroke patients with mild to moderate disability. Rehabilitation delivered in the home setting should be offered to all stroke patients as needed. Where home rehabilitation is unavailable, patients requiring rehabilitation should receive centre based care.

5.9 SUMMARY OF THE CHAPTER

This chapter elaborated one of the outcomes of this study which was the development of palliative care guideline on stroke in the Zambian context. The researcher had presented a summary of four evidence based guidelines of palliative care for stroke and physiotherapy sourced from the literature and adjusted it in the Zambia context.



CHAPTER SIX

SUMMARY, CONCLUSION and RECOMMENDATIONS

6.0 INTRODUCTION

This last chapter present the summary, conclusion, recommendations, strength and limitations of the current study. The results of the study have been also highlighted in this chapter. The recommendations are well outlined based on the findings and lastly the strength and limitations encountered during the study are elaborated.

6.1 Summary

The aim of this study was to explore the perceptions of physiotherapists in Zambia on palliative care in order to contribute to the understanding of the role of physiotherapists to the care of stroke patient in countries such as Zambia. However in order to achieve this aim, the study explore (i) the physiotherapists knowledge about palliative care in the rehabilitation of clients with stroke in Lusaka, Zambia; (ii) the physiotherapists' perceptions on management of palliative care for patients with stroke; (iii) the application of palliative care in the rehabilitation of stroke patients in Zambia and lastly (iv) to make recommendations on guidelines based on the outcomes of this study.

An exploratory study design, using qualitative methods of data collection was used in this study. The study population were physiotherapists practicing in Lusaka/Zambia in three inpatients government hospitals, one in-patient private hospital and a rehabilitation centre. The sample of twenty-five physiotherapists practicing in Lusaka/Zambia with minimum of five years experiences on stroke rehabilitation with or without palliative care training. Fourteen in-depth face-to-face interviews with aid of interview guide (Appendix A) were held on the first phase of data collection until saturation was reached. After the first data analysis was done, two FGDs with seven and four seniors physiotherapists each were conducted with an interview

guide (Appendix B) and thus helped to get more insight from the participants in order to contribute in the elaboration of palliative care guidelines for stroke in Zambia. The study employed thematic content analysis for data analysis. The data was classified systematically by means of coding to identify key factors or issues such as concepts, categories, themes and the relationship between them. The categories led to the development of patterns and themes within the data. The results showed that at the time when the current study took place, physio-therapists who attended training on palliative care rated themselves having good understanding and those who did not attend the training had limited knowledge. The insufficient knowledge of the physiotherapists on palliative care has implications on the training programme. The lack of knowledge could be due to the omission of palliative care in the curriculum of the physio-therapy training course in Zambia. Nevertheless all participants perceived palliative care as an important medical care speciality which will benefit the stroke patients if it is applied in the early stages of the illness. They emphasized on the caregiver's roles on counselling and learning of basic physiotherapy skills as compliment efforts for care continuity at home. They identified palliative care barriers in the areas of planning and policy inefficiency, training support and lastly lack of funding. They advocate for the palliative care inclusion into physiotherapy curriculum course in all physiotherapy schools in Zambia and suggested to have palliative care guidelines for stroke as evidence based practise, and lastly, they suggested more palliative care training to be conducted for the in-service physiotherapists.

6.2 Conclusion

The researcher believed that the current study has met its objectives. It is succeeded on exploring the physiotherapists' perceptions, their knowledge and application of palliative care in the rehabilitation of stroke in Zambia. It is evident that physiotherapists who were trained into palliative care have good knowledge and those do not attend the training have limited knowledge. The findings indicated that all participants in the current study have a very positive attitude and good perception towards palliative care model. They perceived it as a medical care for the chronic and terminal ill patient in which stroke patient and family will benefits if it is applied in the early stages of the illness trajectory; as well as it will improve the patients' quality of life. Lastly they emphasized on multidisciplinary team and holistic approaches in order to achieve all its tenets.



6.3 Strength of the study

The informants willingly participated and shared their perceptions on palliative care for stroke. The research is an exploratory study, using qualitative method of data collection which proved to be efficient to understand the topic at hand. The result of the current study recommends the need of palliative care curriculum inclusion in all physiotherapy schools in Zambia. This study will advocate for good planning and policy as well as adequate funding of palliative care activity and lastly the researcher recommends summary guidelines to all physiotherapists, especially in Zambia. The guidelines are sourced from four evidence based guidelines taken from the literature on palliative care for stroke and physiotherapy. The researcher adjusted these four evidence based guidelines in the Zambia context in order to add knowledge of palliative care on stroke in general.

6.4 Limitation of the study

The results of the current study should be interpreted in the light of the following limitations.

- a) First this being a qualitative study, purposive sampling was used to select the physiotherapists practising in Lusaka/Zambia with minimum of five years working experience on stroke rehabilitation trained or not trained in palliative care, and with this kind of in-depth information required a small sample size was preferred. Therefore the study results may be applied only to similar settings.
- b) The comparison of the study results to other studies is made difficult due to the nature of the methodology used in the current study.
- c) Nevertheless the researcher is convinced strongly that the current study has highlighted a lot on physiotherapists' perceptions on stroke with focus on palliative in Lusaka, Zambia.
- d) Additionally the study shed light on palliative care barriers that affect its implementation in Zambia.

6.5 Recommendations

The results of the study will be useful in improving service delivery of stroke patients in need of palliative care in Zambia and elsewhere. In addition, the results will be useful because it recommends summary guidelines on palliative care for stroke focussing on physiotherapy aspect; aimed at enhancing and improving quality of life of a stroke patient and family. These recommended summary guidelines can be used as evidence based practice for palliative care for stroke rehabilitation in Zambia. The results identified barriers into planning and policy, training program and financial resources in the delivery of palliative care services among physiotherapists in Lusaka/Zambia. Considering the results of this study, and the difficulties

physiotherapists experienced in administrating palliative care in Lusaka/Zambia the following recommendations are made:

6.5.1 Educational

There is a need of palliative care as a component medical care speciality should be include in the physiotherapy curriculum course in all our high learning physiotherapy institution in Zambia thus help in adding knowledge, change of attitude and perception on the students consequently helping in future practice for an efficiency multidisciplinary approach prone by palliative care model.

6.5.2 Training

Although the physiotherapists working with stroke patient may know the importance of palliative care, some of them may be lacking palliative care knowledge and skills. Therefore, there is great need for all physiotherapists to undergo special training in palliative care. These can be organised in the form of workshops or seminars that can be held regularly so that they are reminded of this essential requirement of care.

6.5.3 Research

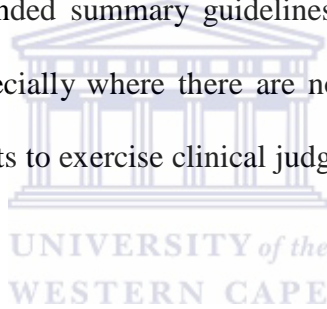
The researcher also recommends that more research could be done both qualitative, quantitative and mixed methods on the same topic in the future. This would capture data and views of physiotherapists in different settings, in order to develop programs that could improve palliative care for chronic and life-threatening illness not necessary stroke. In addition, a similar study with a bigger sample from all Zambian- hospitals should be carried out for comparison, as the results of the current study cannot be generalised since the study was done in Lusaka hospitals only.

6.5.4 Policy

Policy-makers should provide state funded for palliative care activity as a component element of health care, and not as add-on extra therefore it is important that Palliative Care Association of Zambia and Zambia Society of Physiotherapists must lobby, advocate and collaborate together in order to produce a policy proposal on palliative care which will be handled to the policy maker or legislator for implementation. This statutory instrument will help in the development of good planning and policy measures, efficient financial and human resources as well as an effective training program on palliative care in Zambia

6.5.5 Guidelines

There is a need for the recommended summary guidelines on palliative care for stroke and physiotherapy to be in place, especially where there are no palliative care services. It is the responsibility of the physiotherapists to exercise clinical judgement in the management of stroke patient.



6.5.6 Dissemination

There is a need to disseminate this information to the Zambia medical community, especially where they do not have palliative care in order to add knowledge and improve stroke management in general. The researcher is planning to present the results in the next Zambia physiotherapy scientific and annual general meeting 2014; and hopefully the Western Cape University website will do it on a larger scale.

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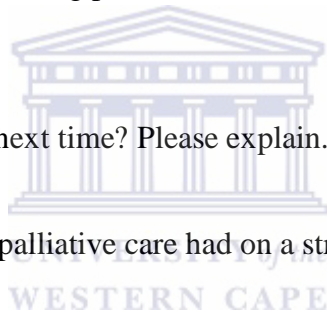


Appendices

Appendix A

INTERVIEW GUIDE (individual interview)

1. What do you understand about palliative care?
2. When do you think palliative care is appropriate to a stroke patient?
3. To what extent do you think your participation as a physiotherapist will be in palliative care? Please explain.
4. What worked well when incorporating palliative care and what doesn't work well? Please elaborate.
5. What would you do differently next time? Please explain.
6. What effect, if any, do you feel palliative care had on a stroke patient?
7. What recommendations do you have for future efforts such as these?
8. Is there anything more you would like to add?



Appendix B

INTERVIEW GUIDE (FGDs)

What do you understand about palliative care?

What are the main palliative care needs of a stroke?

Prompt: physical, emotional, psychological and spiritual

What do you feel are the main palliative care need of a carer caring for a stroke patient?

What are the barriers to delivering palliative care?

What are the barriers (if any) exist which hinder your ability to deliver palliative care?

Probe: personal, relational, organisational

What palliative care services do you think a stroke patient need?

What palliative care services do you think carers of a stroke patient need?

What recommendations do you have for future efforts such as these?

Is there anything more you would like to add?



Appendix C



UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

25 April 2013

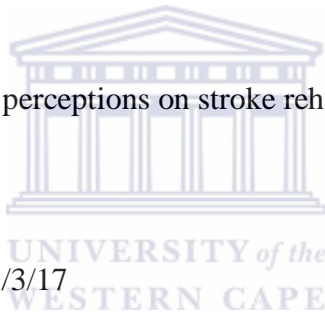
To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by: Mr C Mwanza (Physiotherapy)

Research Project: Physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia

Registration no:

13/3/17



Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer

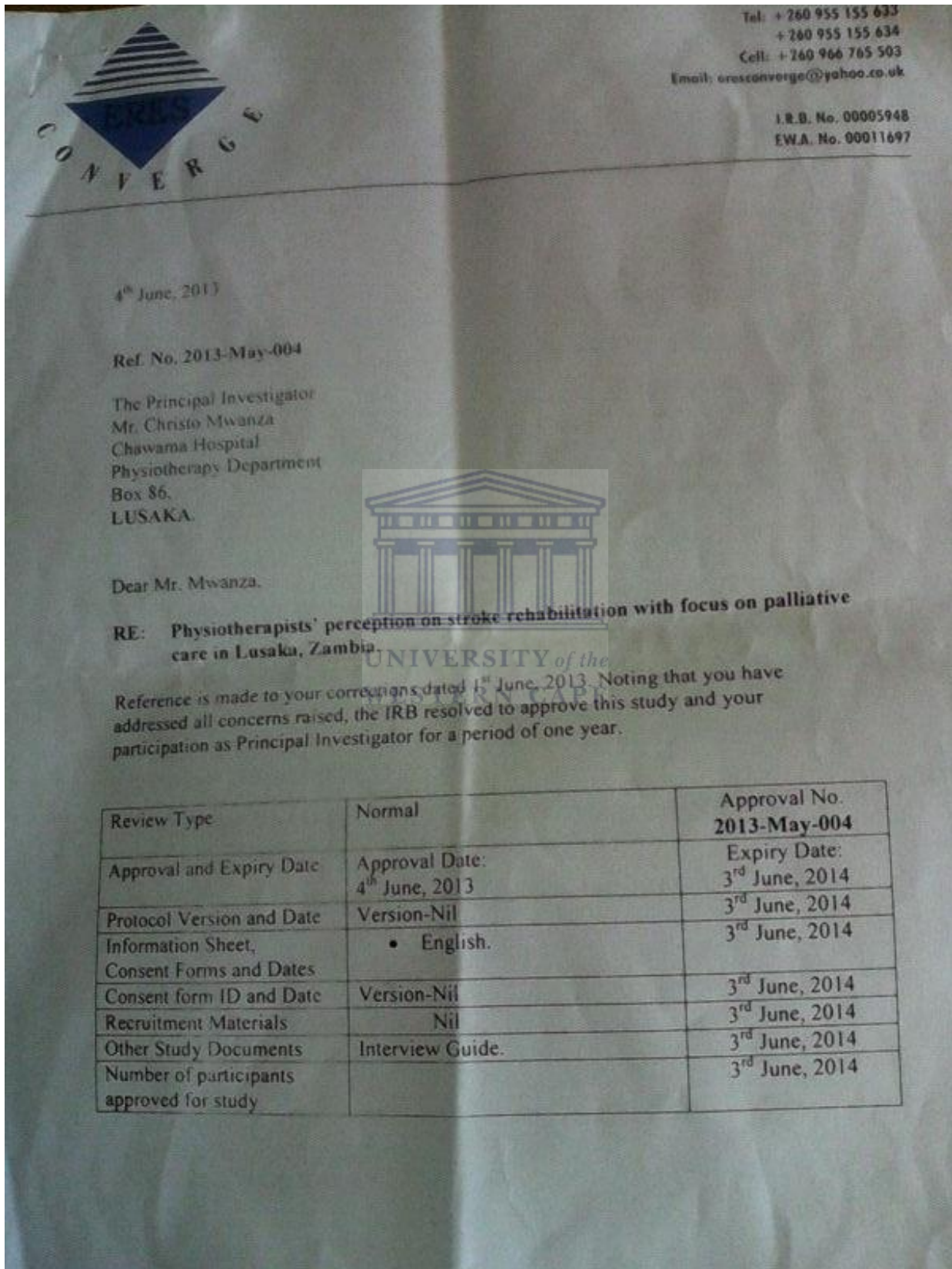
University of the Western Cape

Private Bag X17, Bellville 7535, South Africa

T: +27 21 959 2988/2948. F: +27 21 959 3170

E: pjosias@uwc.ac.za

Appendix D



Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.

Conditions of Approval

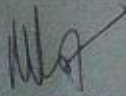
- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labelled "late submissions" and will incur a penalty.
- Every 6 (six) months a progress report form supplied by ERES IRB must be filled in and submitted to us.
- ERES Converge IRB does not "stamp" approval letters, consent forms or study documents unless requested for in writing. This is because the approval letter clearly indicates the documents approved by the IRB as well as other elements and conditions of approval.

Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Yours faithfully,

ERES CONVERGE IRB



Mrs. M.M Mbewe
RNM, DNE, BSc., M.Ed.
ACTING CHAIRPERSON

Appendix E

University of the Western Cape

Physiotherapy department,

P/B X 17,

Bellville 7535,

South Africa.

28 April 2013.

LETTER TO THE INSTITUTION

.....

.....

Dear Sir/Madam,

RE: REQUEST FOR PERMISSION TO DO A RESEARCH



I am a physiotherapy postgraduate student at the University of the Western Cape, South Africa. I am planning to conduct a research on '**Physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia**'.

This is in fulfilment of the requirement for a Master of Science degree in physiotherapy.

I write to ask if you would allow your physiotherapists at this institution to participate in the study and give their views on the subject. The details of the study are explained in the abstract attached to the letter. I am hoping to commence with data collection between 15th May and 15th June 2004. The Senate Research Committee of the Western Cape has approved the study as well as the Zambia Ethics Research Excellency Science Committee.

I look forward to your favourable consideration.

Yours sincerely,

Christo Mwanza (Masters Student).

Supervisor: Dr Nondwe Mlenzana (nmlenzana@uwc.ac.za).

Appendix F

Title: Physiotherapists' perceptions on stroke rehabilitation with focus on palliative in Lusaka, Zambia

University of the Western Cape
Physiotherapy department,
P/B X 17,
Bellville 7535,
South Africa.
27, April, 2013.

LETTER TO THE PARTICIPANT

.....
.....

Dear Sir/Madam,



Re: Request for your participation in a research.

I am physiotherapy postgraduate at the University of the West Cape. I am planning to conduct a research on the above subject in fulfilment of the requirements for a Master's of Science degree in physiotherapy.

The aim of the study is to explore the perceptions of physiotherapists in Zambia on palliative care in order to contribute to the understanding of the role of physiotherapists to the care of stroke patient in countries such as Zambia. The researcher hope is that the result of this study, will inform the health sector of Zambia about the physiotherapists' contribution to palliative care as a component of stroke rehabilitation as well as adding knowledge to palliative care for stroke in general. Furthermore the result will be evidence-based practice on palliative care and physiotherapy, and could also serve as reference for palliative care curriculum course in the medical and especially in the schools of physiotherapy in Zambia as well as in the world. We are also hoping that the current study will succeed answering all the specific objectives expected. Lastly this research may be informative to the Palliative Care Association worldwide and in Zambia particularly about the current status of physiotherapy and palliative care; and how to plan further for more activities concerning palliative care and physiotherapy. Significantly, the results of this study may help the Zambia Society of Physiotherapy and the Palliative Care Association of Zambia in formulating a policy proposal for the legislator in

order to promote and expand palliative care service in Zambia.

I write to ask if you would be willing to participate in this study and give your views on the subject. This will involve audio-recording interviews, the recordings of which will be transcribed and sent back to you for corrections where necessary. Anonymity will be ensured in the reporting of any information you provide to the researcher. Participation is voluntary. Should you feel uncomfortable at any time during the interview you are free to withdraw.

I look forward to working with you and I thank you for your cooperation.

Yours sincerely,

Christo Mwanza (Master student).



Appendix F



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

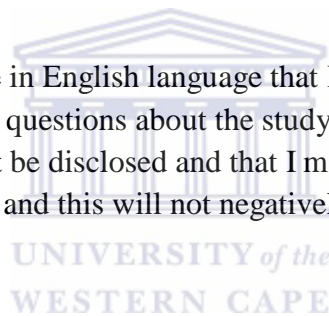
Tel: 0613615462

E-mail: 3202245@uwc.ac.za

CONSENT FORM

Title of Research Project: Physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia.

The study has been described to me in English language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.



Participant's signature.....

Witness.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Dr Nondwe Mlenzana

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-3647/2542

Cell: +27824139016

Fax: (021)959-1217

Appendix G



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: 0613615462

E-mail: 3202245@uwc.ac.za

FOCUS GROUP CONFIDENTIALITY BINDING FORM

Title of Research Project: Physiotherapists' perceptions on stroke rehabilitation with focus palliative care in Lusaka, Zambia.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I agree to be audio-taped during my participation in the study. I also agree not to disclose any information that was discussed during the group discussion.

Participant's signature.....

Witness's name.....

Witness's signature.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact:

Study Coordinator's Name: Dr Nondwe Mlenzana

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-3647/2542

Cell: +27824139016

Fax: (021)959-1217

Chairperson

ERES Converge IRB

33 Joseph Mwilwa Road

Rhodes Park, Lusaka

Tel: + 260955 155 633, Cell: + 260 966 765 503 Email: eresconverge@yahoo.co.uk



Appendix H



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: 0613615462

E-mail: 3202245@uwc.ac.za

INFORMATION SHEET

Project Title: Physiotherapists' perceptions on stroke rehabilitation with focus on palliative care in Lusaka, Zambia.

What is this study about?

This is a research project being conducted by CHRISTO MWANZA at the University of the Western Cape. We are inviting you to participate in this research project because of your work experience on stroke rehabilitation hence you will be able to understand the topic of the study. The purpose of this research project is to explore the perceptions of physiotherapists in Zambia on palliative care in order to contribute to the understanding of the role of physiotherapists to the care of stroke patient in countries such as Zambia.

What will I be asked to do if I agree to participate?

You will be asked to tell us about your understanding of palliative care? What your perceptions on palliative care as a component of stroke rehabilitation? Explain to us how do you incorporate palliative care into clients with stroke? The interview will be audio- recorded and will take approximately 30 to 40 minutes and it will be in English.

Would my participation in this study be kept confidential? This study will involve audio-tapes in order to help the researcher get every detail of the interview. We will do our best to keep your personal information confidential. The recorded information from the interview will only be kept by the researcher and he will keep it under lock where he alone will have access to the key. To help protect your confidentiality, you will not be identified by your name but only codes will be used for transcribing the information on computer. There will be an access password to this information which will only be known by the researcher. After the study is finalized, all the audiotapes used during the study will be destroyed to maintain confidentiality and ensure that they are not used for any other purpose. If we write a report or article about this re- search project, your identity will be protected to the maximum extent possible. There are no known risks associated with participating in this research project.

What are the benefits of this research? The researcher hope is that the result of this study, will inform the health sector of Zambia about the physiotherapists' contribution to palliative

care as a component of stroke rehabilitation as well as adding knowledge to palliative care for stroke in general. Furthermore the result will be evidence-based practice on palliative care and physiotherapy, and could also serve as reference for palliative care curriculum course in the medical and especially in the schools of physiotherapy in Zambia as well as in the world. We are also hoping that the current study will succeed answering all the specific objectives expected. Lastly this research may be informative to the Palliative Care Association worldwide and in Zambia particularly about the current status of physiotherapy and palliative care; and how to plan further for more activities concerning palliative care and physiotherapy. Significantly, the results of this study may help the Zambia Society of Physiotherapy and the Palliative Care Association of Zambia in formulating a policy proposal for the legislator in order to promote and expand palliative care service in Zambia.

Do I have to be in this research and may I stop participating at any time? Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. The researcher will grant you the opportunity without heart feeling.

What if I have questions?

This research is being conducted by Mr **CHRISTO MWANZA** at the University of the West- ern Cape. If you have any questions about the research study itself, please contact:

Supervisor of the Project: Dr Nondwe Mlenzana

University of the Western Cape

Private Bag X17

Bellville 7535

Tel: +27824139016

Email:nmlenzana@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Professor Anthea Rhoda

University of the Western Cape

Private Bag X17

Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee and Zambia Ethics Research Excellency Science Committee.

