

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.

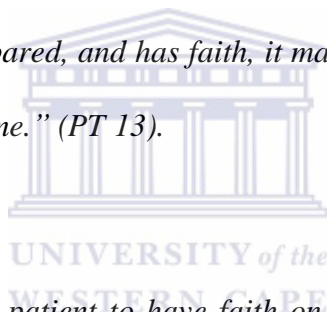
4.5.3 Spiritual aspect

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

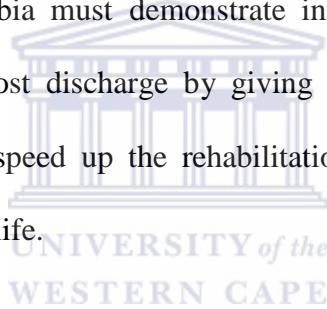
Most researchers agree that the majority of recovery occurs within the first three months post stroke, continue over six month or even longer (Wiles et al.,2002). The same author continued by saying that stroke tends to result in a range of disabilities which have been shown to benefit from rehabilitation 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

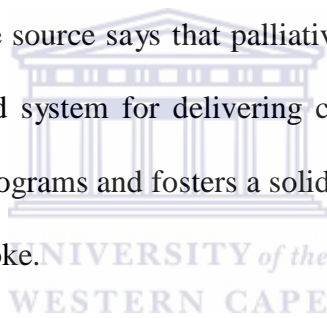
The US National Institute for Health and Care Excellence (2013) stated that despite improvements in mortality and morbidity, stroke patient still need access to effective rehabilitation services. Stroke rehabilitation is a multidimensional process, which is designed to facilitate restoration of or adaptation 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

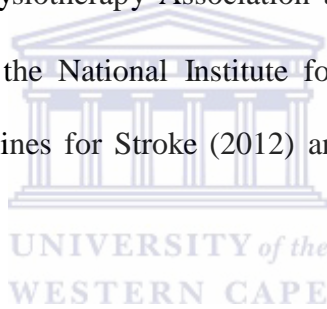
Chapter four highlighted the results and outcomes of the explorative qualitative data collected, and also the discussion of the current study were elaborated. The results were presented clearly in the form of narrative report writing style. Data revealed a comprehensive meaning to finding in the context 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

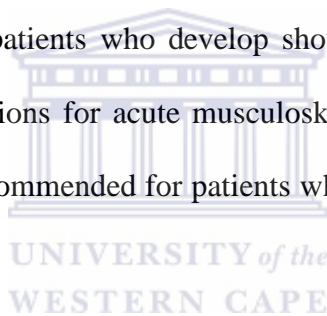
The conventional therapy (early simple interventions) should be provided for stroke patients at risk of, or who have developed contracture. For stroke patients at risk of, or who have developed contractures and are undergoing comprehensive rehabilitation, the routine use of splints or prolonged positioning 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

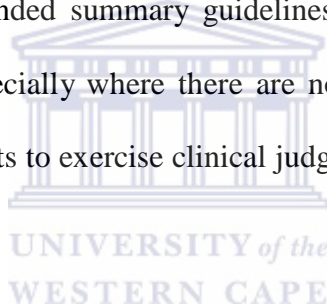
The researcher also recommends that more research could be done both qualitative, quantitative and mixed methods on the same topic in the future. This would capture data and views of physiotherapists in different settings, in order to develop programs that could improve palliative care for chronic and 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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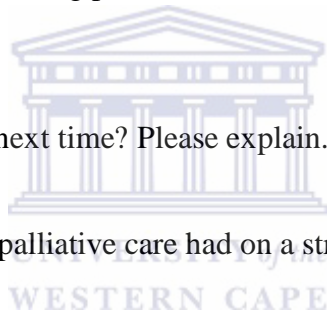


Appendices

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
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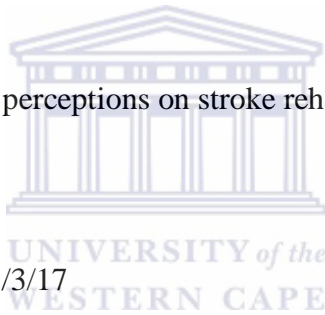
OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

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

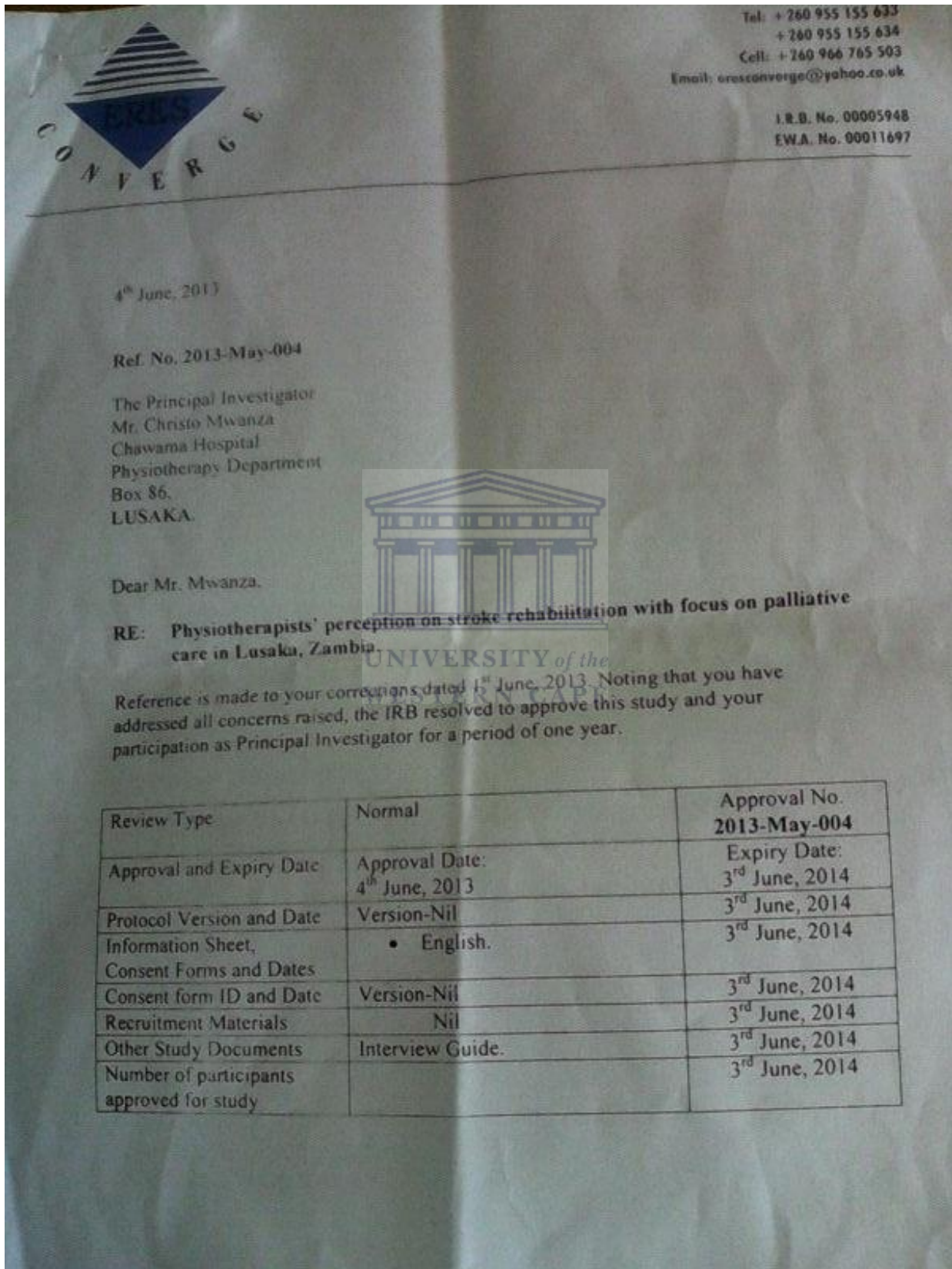
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Appendix D



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

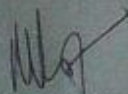
- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended 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

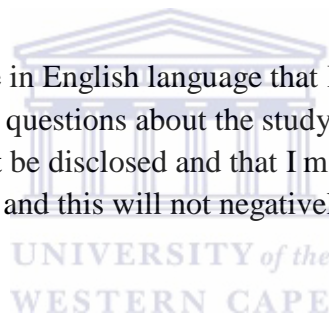
Tel: 0613615462

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.

