Research Topic

To investigate the Need for Palliative care in Cerebrovascular Accident (stroke) patients at Ladysmith Regional Hospital

Part of fulfilment: MPhil degree course in Palliative Medicine at University of Cape Town

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Declaration:

I, the undersigned Dr. Mohammed Jamil Hossain, hereby declare that the contained of this dissertation is my personal research work and that I have not previously submitted it, in its entirety, or in part, at any University for a degree.

Signature:

Date: 09 May 2016

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Abstract

This research study explores the need for palliative care by the patients who are recovering from stroke after an acute event. Stroke survivors need comprehensive care for their physical, psychosocial, spiritual well-being and additional support. The comprehensive total care in all aspect of physical, social and spiritual well-being can only be offered by the holistic approach of palliative care focusing, as it does, on the rehabilitation for stroke survivors to improve their quality of life.

A literature review was conducted to investigate how palliative care can help to change the quality of life for stroke survivors. There has been little research on the topic of providing palliative care to stroke patients in South Africa. This research study explores the need and understanding of palliative care management for a stroke survival.

The aim of the study is: "*To investigate the Need for Palliative care in Cerebrovascular Accident (stroke) patients at Ladysmith Regional Hospital*". The objectives of the study were:

1. To identify the holistic care needs of stroke patients.
2. To describe the care provided to stroke patients.
3. To identify the gaps in the care requirements of stroke patients.

The study site was Ladysmith Regional Hospital, in UThukela District in Kwa-Zulu-Natal province, South Africa. This is a cross sectional study using mixed methods-both quantitative and qualitative-interviewing patients, and family members of patients who had suffered from a cerebrovascular accident.

For the quantitative study, the data-collection tool was the SS-QOL (Stroke Specific Quality of Life) which was used as a questionnaire administered both in English and isiZulu languages as a structured interview with stroke patients. For quantitative data analysis, there are 12 variables in SS-QOL questionnaires and three factors were used to analysis the data. From those variables three factors were identified to assess the functional capability of a stroke survival and how severe the disabilities. Data collection was carried out by the PI with the help of research assistant nurses.

For the qualitative study, an interview guide was designed to collect data related to the daily activities of stroke survivors and to elicit the patient’s experience of stroke and care needs. The qualitative data were analysed thematically and five themes emerged: 1) the life changing effect of the stroke; 2) the impact on quality of life after stroke; 3) holistic care needs; 4) loss of independence; 5) spiritual aspects of patient’s experience.

From the results of quantitative data analysis by using SS-QOL tools, it was identified that the physical, emotional and social dysfunctions were the major concern of the participants after survive from acute stroke.

The result of qualitative data analysis, it was found that patients’ quality of life was poor and they needed assistance from different health care team. It was observed in the study that the integration of palliative care with the rehabilitation programme can deliver a better service to the stroke patients with residual disabilities and morbidities.

Conclusion

More research is required about the need of palliative care for stroke survival. It is important to have effective, patient-centred palliative care services together with rehabilitation in place for stroke patients and by which patient can improve their quality of life with residual disabilities. Early transition for palliative care management is better for a stroke survivor.

Heath workers should be alert to the need of palliative care by a patient after survival from acute stroke. There is a need to advocate for home based care to be provided to the patient after discharge from hospital.

Chapter 1

Introduction

This research study explores the need for palliative care for patients who are recovering from a stroke after an acute event. Very few studies have been conducted on the topic of providing palliative care to stroke patients in South Africa.

In this dissertation, Chapter one describes the Introduction and background to the research study, Chapter two describes the literature review from relevant publications chapter three describes the study methodology, Chapter four describes the results of the research study and Chapter five describes the discussion, conclusions and recommendations of this research study.

Stroke is one of the foremost causes of disability worldwide. Relatively good progress in medical science has been made for the prevention and therapeutic management of stroke but less has been done to identify the need of physical, social and spiritual well-being for stroke survivors.

This study addresses the gap between current practise the understanding of the necessity of palliative care for stroke-survival. This includes care for the last days in life as an important aspect of stroke management for patients with severe cerebrovascular accident. Research suggests[1] that integration of palliative care and rehabilitation programmes provide good outcomes for stroke management in general.

Stroke mortality rates remain high[2] in spite of modern therapeutic treatment and facilities for stroke management throughout the world. There is a concern that palliative care management[3] is not recognizing as specialist care in the developing world. There are few hospices and few palliative care trained health workers available especially in rural areas of developing countries. Even in South Africa palliative care is not a recognize speciality in the health sector. In some rural areas in South Africa, there is no hospice facility available[4] and health care teams rely on home based care only which is mainly delivered by relatives or paid caregivers.

1.1 Background

As described by Clark, "*stroke has been recognized for a long time* as a disability for a patient (*it features as "apoplexy" in the writings of Hippocrates*)".[5] Many patients need long-term treatment from multi-disciplinary health professional team. Cerebrovascular accident (CVA) is one of the most common conditions in adults admitted to the medical wards for their treatment and the most common cause of adult morbidity.[6]

Long-term management of cerebrovascular accident or stroke is a serious concern in health sector not only in South Africa but in every country in the world. Even those who survive an acute event experience significant problems or difficulties because of the complications of stroke together with the residual disabilities.

Stroke survivors and their relatives face major challenges both in the initial period and in the long-term since the management decisions or options are complex. Family members experience the problem of uncertainty about the long-term management, therefore most of the time they seek for considerable amount of mental support, access to financial support from social worker. In spite of major impact of the consequences of stroke in personal and social life of a patient, it is difficult to determine how long a patient needs the active management or care after an acute event.[7]

Stroke survival and management is a major concern in any country of the world. In developing countries with financial constraints and lack of infrastructure the suffering of stroke patients are more significant. The provision of palliative care for stroke survivor and their family members may result in clinical benefit in all aspects by improving their quality of life.[8]

Health care teams should be vigilant to identify the need for palliative care for patients who survive after an acute stroke and for those patients who are acutely ill with a poor prognosis. It is also important to discuss the palliative care plan with the relatives or caregivers.

It is suggested that initiation of palliative care into the management plan for stroke patients, may benefit the patient in the long term with a positive impact on their residual disabilities and co-morbidities. Integration of palliative and therapeutic management can deliver an improved service to stroke patients and their family members.[9]

Palliative care is a relatively new specialist discipline available in many developed countries throughout the world. Initially palliative care was developed to care for cancer patients at the end of their lives but it has developed to include care for different illnesses and can be applied early in the course of a chronic illness. In the case of a poor prognosis, clinicians can withdraw or reduce ineffective treatments, medications or decide it is inappropriate to initiate resuscitation efforts. Patients still receive active care in the form of interventions to ensure physical comfort and emotional support while they are dying.

There is also a need for community-based stroke research with evaluation of severity of stroke, accurate stroke statistics as well as the consequences of stroke, in order to help us to improve appropriate management besides prevention plans.[10]

1.2 Epidemiology

The prevalence of stroke related disability in South Africa is already higher than any other chronic illness. It was estimated that there are about 6 million people with hypertension, 7 million smokers and 3–4 million diabetic patients in South Africa are at risk of cerebrovascular accident.[7]

It is reported that more than 100 000 people each year suffer a major stroke in the United Kingdom and that stroke has become a top NHS priority in the past few years.[11] In rural South Africa, the prevalence is high but the exact figure is unknown. The crude estimated prevalence for South Africa is estimated to be 243/100 000.[7]

South Africa has a substantial burden of HIV/AIDS and there is a need to face the burden of preventing the upcoming problem of the complications due to chronic diseases such as hypertension, diabetes mellitus and AIDS.

1.3 Mortality

Cerebrovascular accident is the second commonest cause of death globally[12] with two-thirds of these deaths occurring in developing countries of the world, including sub-Saharan Africa (SSA). The main concern is not only related to the high mortality rate after cerebrovascular accident or stroke but the fact of those who survive almost 50% patients live with different morbidities.[7] Stroke is still one of the commonest causes of death in elderly populations in South Africa and it has been found that 7.9% of deaths secondary to stroke occur between the ages of 35-64 years.[13]

The incidence and mortality of stroke in developing countries are likely to increasing in upcoming years, as the populations going through what has been describes as the "*health transition*"[14] with the proportion of lifestyle illnesses and non-communicable diseases increasing in the developing world and replacing communicable diseases as the main source of morbidity and mortality.

Sub-Saharan Africa remains the only major area in the world where the burden of infectious disease still outweighs the burden of non-communicable disease.[7] Stroke or cerebrovascular disease mortality is high at present in South Africa. According to the WHO (World Health Organization) data published in May 2014 stroke death in South Africa reached 39, 4999 or 7.06 % of total deaths.[15]

It is still difficult to determine the cause, extent and the consequence of cerebrovascular accident in the different races in South Africa, because of the very insufficient research work and of statistical data. Research describes that approximately 30% of stroke survivors die usually within the first month of life after having had a stroke.[16]

In 1992, Steyn *et al.*[17] found that 24.5% of the deaths of all South Africans were attributed to chronic diseases of life style. Life style modifications are very important to reduce the mortality from chronic diseases. It was found that half of the patients who have had a stroke survive for another five years sometimes with other morbidities and with the residual disabilities.

1.4 Rehabilitation and palliative care

Rehabilitation (Rehab) and palliative care have emerged as two important parts of comprehensive medical care for patients with advanced disease such as who experienced CVA; the relationship between the two components are important and there is possible role of rehabilitation interventions in the care of patients with residual disabilities after surviving stroke.[18] Rehabilitation programmes comprises physiotherapy, speech therapy and occupational therapy and clinical experience confirms that the application of the fundamental principles of rehabilitation medicine improves the care for stroke survivors. Through rehab care, physical function can be maintained to lessen dependency on others and reduce the burden of care for the caregivers.

There is little published literature in South Africa to describe the need for palliative care for stroke survivors although Connor and Bryer provided a comprehensive overview of the problem of stroke in South Africa. [19] Even though most of these patients would qualify for palliative care which can be delivered by multi-disciplinary team in terms of the World Health Organisation's definition of palliative care "*To improves the quality of life of patients and their families facing the problems associated with life threatening illness, treatment of pain and other problems, physical, psychosocial and spiritual.*"[20]

After survival from stroke, many patients suffer from residual disability and need rehabilitation to improve their physical function. In addition those patients suffer from psychosocial or social problems, palliative care play an important role to improve their well-being. "*Palliative care is a holistic approach and by involving the multi-disciplinary team to enhance good quality of life, dignity in death as well as support for the family-including bereavement care*".

Furthermore, rehabilitation can help patients to regain their functional ability while they are admitted in hospital and as an out-patient. Stroke rehab also contributes to regain the capability to self-care so that a stroke patient can live independently depending on the extent of their recovery. The rehabilitation process is best achieved by means of multi-disciplinary care by health care professionals who must have ample knowledge and understanding of the precise concerns facing by stroke survivors.

In South Africa, outpatient rehabilitation therapy is difficult to continue for a stroke patient. Sometimes, patients are not able to come for their follow-up at out-patients because of financial difficulties. [4] Consequently, wherever essential and available rehabilitation services are required, in-patient management would be the preferred choice. In-patient rehabilitation facilities in the public sector are available at most of the state hospitals, community health clinics and these are usually located in towns or in township.

There is a rising awareness of the value of palliative care management in patients who are affected by non-malignant diseases, including stroke.[8] Palliative Care Australia describes that stroke patients requiring "*palliative care often present with complex and challenging needs in terms of physical care, as well as family*" and caregiver concerns. Palliative care and rehabilitation together can deliver the adequate care to the stroke patient.

A palliative care management plan needs to be designed about the requirements and difficulties of each individual while remaining cost effective. A clinician can easily determine or assess the needs of a patient with stroke morbidity by taking good history from the patient and the family members.[21]

The palliative care plan can help to improve quality of life, especially those patients living with different morbidities. This can be provided by a holistic approach of palliative care that considers the physical, psychological and spiritual aspects of treatment.

1.5 Integration of Rehabilitation and Palliative care

Palliative care and rehabilitation share common goals to improve the patient's quality of life. Both disciplines have a multi-disciplinary model of care, which act to improve patients' levels of function and comfort.

By combination of both disciplines, an improved more comprehensive service can be delivered to a stroke survivor to improve the quality of life more effectively. The elements of rehabilitation that are used in managing stroke survivors include physiotherapy, speech, therapy and occupational therapy. Palliative care can also provide additional resources in ensuring management of physical symptoms, psycho-social support and spiritual care.

Palliative care for stroke survival can provide pain relief and can provide psychological as well as spiritual support. Those patients who develop depression or anxiety after surviving stroke can benefit from palliative care counselling. Social worker can also arrange financial support for stroke survivors.

Palliative care includes the evaluation and management of bodily functions, social, emotional as well as spiritual needs. Families and care-givers also get support from palliative care personnel. This support is obtainable during the patient's illness as well as providing bereavement care.

In some stroke patients, intact areas of the brain might be capable to execute functions that were lost when the cerebrovascular accident transpired. Patients experience residual disability according to the areas involved during stroke and those disabilities can be improve with functional outcome by using rehabilitation programme.

Physiotherapy includes by means of physical exercise and other physical resources such as neurologically stimulating activities, therapeutic exercises to benefit the patients to regain the power for using their arms, legs and trunk, as well as to avert muscle stiffness in patients with permanent disability.

Speech therapy can help the stroke patients those who cannot talk and assist them in expressing themselves. Speech therapy also helps to get stimulation of the swallowing reflex and assists patients with swallowing problems caused by stroke.

Occupational therapy helps the patients to regain their self-governing functions in addition to learn the basic skills, such as buttoning a shirt, preparing a meal and bathing.

Rehabilitation is an aim orientated processes to facilitate regaining full function (as far as possible) in patients who have had a cerebrovascular accident and who suffer from combination of physical, intellectual and speech problems. In the presence of difficulty with speech or depressive symptoms, there is significant dependence on the family caregiver with challenges to the patient, caregiver and the rehab team.

1.6 Problems facing stroke survivors

A high level of quality rehabilitative and supportive care is needed by individuals who present with a diagnosis of CVA in order to optimize their outcomes and to minimize the personal long-term burden of the disease. Beside functional disabilities many patients may be fearful of dying. Patients may experience of depression and psychologically distress because of their disabilities.

The prognosis following a stroke is related to the severity of the cerebrovascular accident and in which area of the brain has been damaged due to stroke either infarction or haemorrhage. A significant number of patients sometimes regain the functions back to a near-normal state with negligible clumsiness or difficulty in speaking in the long run.

However many stroke patients live with long-lasting disabilities, such as paralysis of limbs, speech difficulties, or not being able to control passing urine and stool. A number of patients become unconscious after an acute stroke and die following a severe cerebrovascular accident due to extensive brain damage. Patients those who lose their consciousness for long time may need artificial feeding and other management by the rehabilitation team.

1.7 Planning patients' care at an advance stage

Palliative care is a holistic, patient cantered approach which improves the quality of life for patient and their family members from the moment of diagnosis of a life threatening illness. If brain damage has been severe or extensive after a cerebrovascular accident with impairment of cognitive function, family members are left with a very difficult situation to take decisions on behalf of patient for the comprehensive management plan.

It is sometimes advisable to limit further active medical management especially for patients who are unconscious with prognostic factors. It is very important for the health professional to discuss the patient's concern and prognosis with their family members/caregivers.

Sometimes patients may have advance directive in place which can guide decision-making and health care team should respect the "Living Will or advance directive. The management plan may include Do Not Resuscitate (DNR) orders; or "Allow Natural Death". Although these decisions are never easy, discussions about preferences for care that may have been held within families and documented in an advance directive help to guide the discussion.

Stroke patients those who survive from acute event often have permanent disability such as dysphasia or dysphagia and they may need ongoing help by rehabilitation team. Patients with stroke can survive with different morbidities such as cognitive deficiency or physical disability which are improved by rehabilitative services and others by palliative care.

1.8 Social isolation

Once patients are discharged from hospital after surviving acute stroke, many of them lives with morbidities such as physical disability, speech problem and they may become socially isolated for those problems.

A hospital palliative care team would support and train family members to care for the patient at home and community-based palliative care would continue to support families in providing care to a stroke survivor. In addition palliative care provides psychosocial and spiritual support counselling to families, as well as to the patient.

1.9 Hospice care for stroke survivors:

It is difficult to determine when a patient is eligible for hospice care who has suffered a severe stroke. But families frequently ask the health care team a lot of questions about their loved one’s prognosis. *Will they recover? How long will it take? Is it time for hospice or home based care?*

A stroke can be a devastating event and a certain number of patients die before any intervention taking in place. It can cause pain and suffering for the patient, as well as the family. Recovery from a stroke depends upon how much damage was done in the area of brain. Part of the trouble in making the determination is because a person who has suffered a stroke may be debilitated but not dying.

Those patients who survive the initial stroke may die later from complications such as a pulmonary embolism, a chest infection or aspiration pneumonia. There are two primary categories that may help the health care team to make the determination when patient will be eligible for hospice care; firstly for patients in the acute stage of a stroke and secondly for patients in a chronic phase.

The Gold Standards Framework in the UK suggested that patients with neurological problems following survival from stroke and progressive physical or cognitive deterioration, problems with swallowing or speech problems, or other distressing symptoms such pain require palliative care. This care or service can be provided by hospice or in a care home depends on the resources available in the particular situation.[22]

In general, most of a patient's recovery occurs during the first three months after a stroke. Hospice can provide comfort measures for the patient controlling distressing physical symptoms and emotional and spiritual support to both the patients and the families. The hospice may have specific criteria that determine admission to hospice service.

1.10 Applying the principles of palliative care in managing stroke patients

Palliative care is defined by the WHO (World Health Organization) and it can be delivered over several months including at the end of life. The definition of "Palliative Care" by the World Health Organization (2002) is:

"An approach that improves the quality of life of patients and their families facing the problems 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"[20]

Palliative management aim to improve quality of life for those who are the terminally ill patients and suffering from progressive advanced diseases. The Canadian Heart and stroke website[23] describes the palliative care as "*focusing on:*

Managing pain and distressing symptoms: *Modern medical treatment and associated therapies such as acupuncture, warm massage and physiotherapy can be used to manage symptoms related with pain, fatigability and distressing breathing problem.*

Managing disability: *Many patients with stroke experience the effect of disability and depending on others to take care of them. Home based care support services can provide meal preparation, cleaning services, and transportation. Patients may also receive assistive devices such as wheel chair that could help them to mobilize themselves.*

Psychological, social and spiritual support: *Depression and anxiety are common in patients after survival of stroke. Social support, spiritual and psychological counselling can be provided to improve their quality of life. Bereavement support may help the families to cope through their grief.*

Family support: *Empowering with information to the family members can help on how to care for their relatives after survive from stroke or what to expect and plan for victim at the end of life care*."

1.11 Conclusion

In South Africa, there is a national drive to improve the quality of life in all clinical areas, including that for stroke patients. Stroke care should integrate the multi-disciplinary team working together side by side which includes palliative care and rehabilitation programme to provide comprehensive care.[24]

The requirement for palliative care management does not depending on a particular medical diagnosis. It was originally developed to care cancer patients but is applicable to any. The provision of palliative care depends on the patient's need. The role of family/caregivers for the stroke patients is also important and there is a need to explore ways to support the caregivers. Palliative care for stroke patients can be offered at the hospital while patient still admitted in the ward and later after discharge from the hospital.

Sometimes patients can be discharged to a hospice or on home based care. It is also important to discuss all the issues together with the patients, relatives and caregivers. Effective palliative care can contribute to the rehabilitation of stroke patients as well as providing care for patients whose condition progresses and results in death. In stroke patients with substantial disabilities, attention must be given to decreasing the load of care for the family members and helping the patient to be as independent as possible.

Chapter 2

Literature Review

2.1 Introduction

A literature search was conducted by using Pub Med, of the following journals SAMJ (South African Medical Journal), CME (Continuous Medical Education), Lancet, BMJ (British Medical Journal), JAMA (Journal of American Medical Association), Palliative Medicine, BMC Palliative care and Journal of Palliative Medicine. Journals were selected for relevant articles such as stroke and palliative care, stroke morbidities and mortality, stroke rehabilitation, hospice and home based care for stroke patients.

The goal of reviewing the literature was to identify the aspect of palliative care relating to for stroke survivors, recognizing that the outcomes after a cerebrovascular accident result in significant levels of mortality and morbidity. There are limited studies on palliative care services for stroke patients and the ways in which such services could be provided to stroke patients especially in the South African setting.

The literature search found that only a few relevant papers were published on investigation of the need of palliative care for stroke patients. There is much research and publication on stroke prevention, management and rehabilitation but very little published research on palliative care services delivered to stroke patients.

Following key words were used to guide the literature search: “Barthel;” “*activities of daily living*;” “*disability evaluation*;” and “*stroke or cerebrovascular*,” linked to palliative care. The use of rehabilitation programme for a stroke survival in conventional medical practise is necessary to improve the quality of life from residual disabilities. Berthel index is used to assess the rehabilitation programme after stroke.[25] Dorothea W. Barthel was adapted this tool to measure the functional impairment and the functional evaluation can be done by using Barthel Index.[26]

Meiring *et al.*[27] state: "*As in many other places, care of stroke victims in South Africa leaves much to be desired*". Ideally, all cases should be admitted to a stroke unit where rehabilitation can proceed at a pace commensurate with the individual's potential for improvement. In South Africa, especially in the provincial hospitals, regional hospitals and academic teaching hospitals, the pressure of beds is high and admission for too short a time for adequate rehabilitation. Patients belonging to one ward are often boarded out in other wards of the hospital. Thus, all but the sickest patients may be discharged early, to make room for the new admissions. Stroke patients may sometimes be discharged with feeding tube or catheter in situ and the relative or caregiver does not know how to maintain the sterilization properly.

The study was conducted in Conradie Hospital, Cape Town and in Grahamstown and found that it would have been possible to discharge many patients into the community had community support existed in their area. This observation is equally true of stroke patients. The provision of good stroke care in the older age group is practically synonymous with the elements of good geriatric care because many of the same goals prevail. The study indicates that rehabilitation and re-establishment of self-worth is possibly even more important in the younger stroke patient.

2.2 Epidemiology

There is little high-quality epidemiological data on stroke and particularly on the effect of the health transition on stroke, both in South Africa and in Sub-Saharan Africa in general. Connor describes that South Africa's multi-ethnic population provides the opportunity to compare the nature of stroke (pathological stroke types, ischaemic stroke subtypes, risk factors and the causes of stroke) in populations at different stages of the health transition.[28] In describing the MEDUNSA stroke bank data, Joubert explains that studies investigating the incidence of stroke in South Africa were carried out in urban black South African populations (Kalafong n=212 and Medunsa n=304) before the HIV era.[29]

In 1992, Steyn *et al.*[17] found that almost 24.5% of deaths of all populations in South Africa were attributable to chronic diseases of life style. Strokes were the second commonest cause 7.2% of all deaths and 7.9% of deaths of persons were between 35-64 years. The authors identify the poor socio-economic conditions may lead to late presentation of 'silent' illness such as hypertension and diabetes so that these are only recognised when CVA occurs. Hypertension & diabetes are under-treated but stroke is treated when the patient presents with this serious complication of under-treated chronic disease of life styles in South Africa.

In reviewing chronic diseases of lifestyle Steyn *et al*[17] comment that South Africa has a significant burden of disease resulting from Chronic Diseases of Lifestyle (CDL) and with limited resources, has poor prevention strategies, in common with many resource constrained countries, the health system focuses on managing acute illness rather than chronic diseases.

In addition, Connor and Bryer[19] describe that stroke adds significantly to the burden of disease in South Africa and that people with stroke in South Africa have high requirements for help with activities of daily living, more so than those in developed countries. The South African Stroke foundation has taken on the responsibility of creating awareness of stroke prevention amongst South African communities. The authors made to mention neither of palliative care needs nor of palliative care services for stroke patients.

A publication by Rossouw *et al.*[30] examined the association between median head of house hold income level, all causes and selected causes mortality for Coloureds and Whites in the greater Cape Town area for the age group of 35-74 years. Although CVA or stroke mortality showed no consistent relationship to income, the high CVA mortality in the coloured population was consistent with a high prevalence of hypertension (27% of males and 31% females) and there is a high level of smokers amongst this population.

2.3 Palliative care consultation

In 2009, Blacquiere *et al.*[31] found that 10% of palliative care consultations with severe stroke patients centred on matters directly correlated to non-natural way of giving fluid or artificial nutrition. In this study shown that, the archives of 104 patients who passed away from acute stroke over a two-year period were retrospectively examined. The numbers of patients were involved in this research was good and the patient’s management at stroke care unit, decision for delivery of palliative management choices, and treatment usage were matched efficiently. Family concerns about the palliative care practice were also considered in this study.

2.4 Stroke survivors and residual disability

In a study, Creutzfeldt *et al.* [32] stated that survival after stroke differs, according to the degree of the brain that is affected and extent of residual disability after an acute stroke. Due to the sudden onset, relatively short time of treatment, as well as the frequent linguistic difficulties of patients it is sometimes very difficult for a clinician to do a meaningful assessment and to guide decisions at the end-of-life. It is important for patients living with long term disabilities to be involved in decision-making. This is especially difficult when patients are on life sustaining treatments such as tube feeding or artificial ventilation.

In Creutzfeldt's study, it was found that the most frequent and incapacitating post-stroke complications are speech problems, pain in the body, spasticity, and paralysis of both upper and lower limbs. The magnitude of disability and onset of illness is unpredictable, and pain is often very severe, interfering with rehabilitation participation. It was observed in this study that patients with stroke who had severe difficulties to swallow were offered artificial feeding, whether or not they were waiting for palliative care team to review their care. Patients who benefited most were those who were sent early for palliative care after an acute event.

2.5 Integration of Rehabilitation and Palliative care

In 2010, Wee *et al.*[33]establish that the current collected works describing on palliative care for stroke survivors is inadequate, generally concentrating on management of stroke at acute stage or in last days of life. In her study, Wee established that problems such as pain and dyspnoea remain predominant in management of acute stroke and which need immediate attention to give them relief. The care-giving to those patients is a huge burden for families often over a long period of time.

Analysis of Wee's study found that comprehensive discussion about stroke and rehabilitation was mentioned which could be very beneficial for stroke patients. Caregivers were included in this study and the need for rehabilitation was discussed with the family of the patients. Overall, the study reported that there was a need for both rehabilitation and palliative care for these stroke survivors.

The authors highlighted that palliative care and comfort at the end stage of life could be delivered to stroke survivors as well as their relatives, nevertheless the approach by which stroke management as well as palliative care services ought to link with one another remains uncertain.

In 1990, Dewar *et al.*[6] investigated the outcome of critical stroke in 219 elderly patients were hospitalised. Patients were admitted in a Durban-based provincial hospital with a diagnosis of severe stage of stroke for the periods of 1 January 1983 to 31 December 1984 were included in the study. Patients with stroke were investigated by retrospective case review and household follow-up. A structured rehabilitation programme was not utilised. Age, sex and side of weakness have no significant relation to functional outcome scores.

However, poor mental ability, depression and urinary incontinence caused low functional status scores. The authors found that there was a very high degree of social isolation - 12 patients (34%) never left their homes and 11 (31%) were unable to use telephones. Most of the patients were assessed at a mean of 30 months after their stroke. The level of functional recovery in those patients who eventually lived was considered to be good so no rehabilitation neither palliative care was provided.

From the Dewar study it was illustrated that there is no single measure that could suffice to increase the quality of life and functional capability of stroke survivors in South Africa. However, there is a need for supportive community-based health services to empower patients to continue the care at their own homes and communities rather than to be institutionalized.

Hankey *et al.*[34] conducted studies in Australia and reported that of those who survived after acute stroke almost 40% of patients were disabled, or dependent on other people for their care, especially family members. Stroke patients need multi- disciplinary management as problems can lead to long-term disabilities. Regular care, such as physiotherapy, nutritional advice, speech therapy, occupational therapy is essential from multi-disciplinary health workers, so that the appropriate care can be delivered to the stroke survivors.

2.6 Palliative care and stroke

The literature from Guy *et al.* [35] revealed that a need for assistance with end-of-life care was the most common reason for referral to palliative care service which the investigators say or recommends *"a more traditional view of palliative care, as being synonymous with terminal management"*. There is in contrast to the WHO definition which states that "*palliative care is applicable early in the course of the illness"*.[36]

In 2010, Holloway *et al.*[37] described a systematic review on the role of palliative care for patients with acute stroke and the timing of providing palliative care service that there were few referrals for consultations. The author commented that it is not easy to predict the functional recovery of patients after survive from acute stroke and while people think there is a chance of recovery, palliative care services are not consulted so many patients die without receiving the benefit of palliative care.

Analysis from Holloway's study has found that an increasing number of deaths following severe stroke are due to withdrawing life support. The authors describe that variation in decisions making regarding the withdrawal of active treatment "*suggests the possibility of unnecessary prolongation of suffering"*. This was not a conclusive study to describe evaluation of treatments for stroke patients. During the transition period, it was reported that patients who were likely to die should have been included in this study on palliative care. It is noted that many studies on palliative care have a high attrition rate due to death of participants. Holloway's research shows that dysphagia, specifically difficulty or inability to swallow to be assessed on the first swallow evaluations, influence early transition to palliative care for stroke patients.

Holloway's study determined "*the predictors of an early transition"* to the palliative care service among patients with "*acute ischemic stroke after involvement of middle cerebral artery distribution"*. This information might be very useful for the early identification of palliative care need and to document the aims of a care plan, assisting patient with decision making and improving their quality of life. This was conclusive research with well substantiated recommendations to determine the transition period to palliative care for the stroke patient.

Stevens *et al*.[11] in an appraisal of international publications identified seven documents that recognized the need for palliative care for stroke survivors. The author reflects that there is extraordinary level of mortality and morbidity after stroke, as well as inadequate provision for palliative care.

The authors describe that there are many issues during the last year of life experienced by stroke patients encompassing physical, psychological or spiritual problems. The studies that were reviewed the psychological impact on care givers and those who were providing the palliative care service to the stroke patients. The study revealed the psychological morbidity and caregiver burden and the importance to assist in providing appropriate support to the family members or caregivers.

Anderson *et al.* [38]described "*that caring for a stroke patient has a detrimental effect on the physical and social health of the* caregivers and *they also highlighted the fact that the use of a positive coping* mechanism *contributed to a better psychological outcome*".
They recommended that "*palliative care should be integrated early into the care trajectories of people with life-threatening illnesses, such as stroke*". However, the guidance which was published mainly focuses on end-of-life care and there is inadequate evidence about long-term requirement for palliative care management of acute stroke patients and families. The author presented a comprehensive publication for the initiation of palliative and acute stroke care.

Burton and Payne[9] describe a study on the integration of the palliative care needs of patients and family. "*Data was collected on 191 patients and they reported palliative care needs. Out of 191 participants 53 were interviewed to identify their experiences with patients and family members and in group interviews with 29 staff members from three United Kingdom stroke services.*" The study identified cognitive and behavioural mechanisms to integrate palliative care with stroke care. Both clinical and service factors impact whether such patients should receive palliative care.

A qualitative study published by Gardiner illustrated that good quality palliative care is advocated for patients where there was doubt to recover those patients from acute stroke. The study was conducted to "*explore the perspectives of health care personnel regarding the provision of palliative and end stage of life care in the UK stroke units*"; focused groups and individual were interviewed held with 66 health professionals working in UK specialist stroke care units.

Thematic analysis identified that palliative care was a significant element of stroke care to their quality of life. However, there was uncertainty about the time of initiation of palliative care for stroke patients and concerns were identified regarding the combination of acute stroke care and palliative care.[39]

2.7 Hospice care and stroke

There is not enough literature or published papers found on hospice care for stroke patients. Residents at old age homes sometimes express preference to be treated at hospice after discharge from hospital. In South Africa hospices mainly care for patients with HIV, chronic diseases and cancer.[40]

Javier *et al.*[41] discussed hospice and palliative care management for patients who live disabilities after an illness. The study found that patients functional disabilities can be improve significantly through hospice care and states that *"Hospice can help provide comfort care for patients disabled by a stroke*". Javier explains that the hospice care team creates an individual plan for the patient and family that help to meet the physical, emotional and spiritual needs of the whole family. In particular hospice can manage the pain and symptoms stroke patients experience due to immobility. This is a very comprehensive study all the benefits from palliative rehabilitation at hospice was discussed.

Amanda du Preez *et al.*[42] describes that hospice care not sufficiently used for the management of with stroke. The authors mentioned predictors of hospice enrolment for stroke survivors and describe the socio-demographic situation of the patient at hospice enrolment. This retrospective study shows that over all enrolment for hospice were 23% of stroke survivors in 30 days after an acute attack.

In the Halcyon hospice, USA; website[43] it was described there are many hospices provide care for stroke patients to improve the quality of life. There is a criteria that physician should certify the patient before get admitted in to hospice. The hospice describes that, when considering eligibility of hospice admission for stroke patients *"the physician will be looking* *for symptoms such as weight loss, an inability to maintain hydration and a history of aspiration. Hospice can provide comfort measures for the patient and emotional and spiritual support to the family* members".

Hospice is a specialized health care, supportive in nature, provided to a dying person. A holistic approach is often taken, providing patients and their families with legal, financial, emotional, or spiritual counselling in addition to meeting patients' immediate physical needs. Care may be provided in the home, in the hospital, in specialized facilities or in specially designated areas of long-term care facilities. The concept also includes bereavement care for the family.

2.8 Home based care and stroke

Hillier *et al.*[44] describes that rehabilitation for the stroke survivors was offered mainly in hospital inpatient, outpatient or day care ward. After discharge from hospital, a health care team can offer this service to a stroke survivors at their actual place of residence as home based care service. Home based care programmes are also cost effective. In Hillier's study it was revealed that there was significant effect in favour of home based care for stroke rehabilitation. The authors found that rehabilitation offered at home, improves the quality of life and daily activities of a stroke survivor.

Home based care management for stroke survive patients help significantly to improve quality of life, especially for those patients who live longer with different morbidities. Patient's relatives or caregivers need to be informed or trained sufficiently, so that they can look after their patients at home.

Wasserman *et al*.[45] describes a comparison between hospital and community based management or rehabilitation for stroke patients in rural South Africa. The authors recommended development of a model for Home-based care management for stroke patients. It was found that the recovery from functional activities with residual disabilities improving with the community-based stroke care.

2.9 Care givers

A literature review on the topic of palliative care was conducted by Stevens, Payne, Burton, Addington-Hall, and Jones and indicates that there is a little evidence on patients' and families' preferences with regard to palliative care.[11]

Teno *et al.*[46] also identify that models of palliative care developed for cancer patients may not be applicable or appropriate for those who survive after acute stroke. The fact that there is a prolonged length of illness in stroke means that carers particularly require additional support especially as they are likely to be older than in the situation of caring for cancer patients.

Ebrahim *et al.* [47]describes in his publication that it is important to assess the impact of stroke on family carers. Most of the caregivers described that their role had an adverse influence on their lives. This study also recommended extra supports for family/caregiver and further research to identify methods of deliver suitable support in the community.

2.10 Conclusion

More clinical research should be encouraged for the health care personnel in particular regarding stroke care management together with the need of palliative care. An understanding about stroke management is dynamic and it can reinforce all clinical practice. By doing new research stroke physicians can keep themselves up-to-date with the need of care for comprehensive stroke management. The UK Stroke Research Network co-ordinates research for stroke patients and which has shown the increase numbers of stroke patients are to participating in clinical research.[48]

Sydney and Feldman suggest that integration of palliative care with the rehabilitation programme[1] can provide better service in stroke management. Focusing on comprehensive palliative care management for a stroke survival together with rehabilitation, total team includes palliative nursing, clinical psychologist, physical therapy, occupational therapy, speech and language therapy.

Rationale for the study

Given the complex clinical, psychological and social problems facing patients and family members following a cerebrovascular accident, it is proposed that palliative care should be incorporated into stroke care management plan.

Many of the studies reviewed recommend that further research is needed to assess the input and expertise of palliative care clinicians in stroke care and what palliative care expertise would be of benefit to patients. It is observed that by integration of rehabilitation together with palliative care a better service can be delivered to the stroke patients.

In this study plans to assess the needs for patients with stroke in a South African district hospital, in order to review the services offered and identify gaps in care. The study investigates whether there is any importance for palliative care in the management of patients with stroke at the hospital.

Aim

'To investigate the Needs for Palliative care in Cerebrovascular Accident or stroke patients'

Objectives

1. To identify the holistic care needs of stroke patients.
2. To describe the care provided to stroke patients.
3. To identify the gaps in the care requirements of stroke patients.

Chapter 3

Methodology of study

3.1 Study design

This research work is a cross sectional study using mixed methods-both quantitative and qualitative-interviewing patients, and family members of patients, who had suffered from a cerebrovascular accident.

3.2 Study site

The study site was Ladysmith Regional Hospital, which is situated in the UThukela District in Kwa-Zulu-Natal province, South Africa.

3.3 Study population

Stroke patients admitted to medical wards, and who had attended the MOPD (Medical Outpatient Department) at Ladysmith Regional Hospital over 4-month period from the month of April to July 2013, and the members from family who were involved in their care at home.

3.4 Selection of participants

Inclusion criteria:

- Both male and female patients.
- Age: 40 years onwards.
- Those who survive from stroke incidents.
- Family members of these patients.

Exclusion Criteria:

- Age over 80 years.
- Debilitated and very sick patients.

3.5 Sampling

All patients meeting the inclusion were invited to take part in the study and those who were meeting exclusion criteria excluded in the study.

3.6 Sample size

Quantitative study: Using the calculation for a single proportion and based on the study by Williams *et al.*[49] 52% stroke patients had had problems on the SS-QOL and it was expected that a similar proportion of patients would be found. This calculation has a precision of 10% with a sample size of 68, and a 90% confidence level.

The average number of admissions of stroke patients in medical wards per month is 10 to 12 and MOPD consultations amounted to approximately 8 to 10 per month; therefore in 4 months' time approximately 70 to 75 patients will be eligible for the study. It is uncertain as to the total number of possible stroke patients so, consequently, the statistical calculation has been done using infinite population size.

Assumptions:

Precision = 10.00 %
Prevalence = 52.00 %
Population size = infinite

90% Confidence Interval specified limits [42% -- 62%]
(These limits equal prevalence plus or minus precision)
Estimated sample size: n = 68

Qualitative study: Patients with speech capacity and family members of aphasic patients were included for purposive sampling. It was estimated that 10 patients out of total 72 participants would provide qualitative data and that recruitment would continue to data saturation.

Estimated sample size: n=10

3.7 Data-collection process

3.7.1 Data-collection tool

Quantitative study: The data-collection tool was the SS-QOL Scale, which was used as questionnaire administered as a structured interview with stroke patients. This SS-QOL tool was developed in the USA. This is a consistent and effective tool for measuring self-reported quality of bodily health, set equal to amongst people with mild to moderate stroke.
The "Stroke Specific-Quality of Life (SS-QOL)" Scale is an effective tool for measuring and to evaluate the quality of life in patients after survival from an acute stroke.

The SS-QOL questionnaires were available in the website and there was no permission needed to use those questionnaires as tools to identify the patient's quality of life after surviving stroke. These were used in few other countries as well and there was validity of questionnaires. It has been validated in Denmark[50], Turkey[51], and the Netherlands[52], although not in South Africa. From the previous research articles it is revealed that the "Stroke Specific Quality of Life Scale (SS-QOL)" is an appropriate tool to check the quality of life after survival from stroke.

The questions were simple and related to the daily activities of life after survive from stroke. Questionnaires were used for SS-QOL tool interpreted and translated into isiZulu language for the participants by the research assistant nurse. Even a set of questionnaires was in isiZulu language for isiZulu speaking participants specifically. All four research assistant could speak and understand both isiZulu and English.

The research assistants were qualified professional nurse both from MOPD as well as from Medical ward. Research assistants were trained by PI how to do correct interpretation and not to deviate from the original questions. Simple terms were used to explain the questionnaires to the participants.

Answered questionnaires are options to score such as 5 ("no help needed/no trouble at all/strongly disagrees"), 4 ("a little help/a little trouble/moderately disagree"), 3 ("some help/some trouble/neither agree nor disagree"), 2 ("a lot of help/a lot of trouble/moderately agree"), and 1 ("total help/could not do it at all/strongly agree"). Stroke Specific Quality of

Life scales offer score for each domain as well as a total score, with higher scores indicating restored functions.

Qualitative study: An interview guide was designed which includes a questionnaire and an information sheet to elicit the patient's experience of stroke and care needs. The questionnaire was designed in discussion with the research supervisor and drawing on the literature regarding the experience of stroke and the researcher's experiences in stroke care. There were six open ended questions in the interview guide questionnaires which reflect the daily life needs for a stroke patient.

3.7.2 Recruitment of the nurses

All together four nurses were recruited as research assistants for the data-collection and assisted in interviewing the participating patients. These research assistant nurses were helping the PI for interpretation of language from isiZulu to English where ever necessary.

The research assistants were professional nurses fluent in the isiZulu and English language of the patient population. They were trained by Principal Investigator (PI), in research ethics and in the study protocol as well as in the processes of accurately administering questionnaires and conducting in-depth interview.

3.7.3 Recruitment of participants

All stroke patients attended to at Ladysmith Regional Hospital for the periods of four months, from April to July 2013, were invited to participate in the study. The research study was explained to them in presence of their accompanying family member(s). Potential participants were given the opportunity to ask questions and it was explained that should they choose not to take part in the study or chose to remove from the study, their care would not be compromised and they would still receive the standard management plan for stroke patients in the hospital.

Participants were asked to give their written consent after the information sheet had been read out to them in their preferred language to both the patient and family members. For participants who were not able to read or write, witnessed oral consent was obtained.

Participant’s information sheet and consent form had been translated to isiZulu, so that the information and consent was in their language of preference.

All participants taking part in the research were told about qualitative data collection interview participation and convenience sampling was used to recruit 10 participants for the qualitative interviews and the interview process was explained to obtain voluntary informed consent.

3.7.4 The data collection procedure:

Data collection was carried out by the PI using the structured questionnaires translated into isiZulu with assistance from the research assistants as interpreters. A set of SS-QOL questionnaires for quantitative data collection were translated and formatted in isiZulu language for use in the data collection process.

The PI asked the questions in English and the research assistant used the isiZulu translations to ask the questions of isiZulu participants. The answers provided by the patients or relatives were noted by research assistant and at the same time, the research assistant interpreted all the answers in English to the PI for documentation. After finish each patient interview, the PI and research assistant verified the answers of respective questionnaires together.

There were a few patients or family members who chose to withdraw from the interview process, this was accepted. Depending on the reason for stopping the interview, such as tiredness, an opportunity to complete the interview was offered at a later stage, especially if the participant had indicated that he or she would like to complete the interview later. This ensures that the data were collected from patients who were low functioning, as well as those who were high functioning after the cerebrovascular event. Attention was paid to non-verbal responses, as well as to verbal responses.

When patients were interviewed in the ward, two research assistant nurses were present which ensured double checking of the interpretation. Agreement with the interpretation was given importance while interviewing the participants. The research assistant immediately translated the answers for the PI and the answers were documented in the questionnaires tool.

The in-depth interview for qualitative data collection was audio taped following consent from the participant. These participants were interviewed at MOPD consultation room with research assistant. Ten participants were interviewed over the course of the data collection period. After each interview, the PI and research assistant listened to the recorded audio tape together and transcribed the interview into English.

Participants were encouraged to describe their experiences in an unhurried way, with the opportunity to stop the interview, and to resume at a later time if the patient were to request to do so, or was invited to do so by the research assistant; for example, if the patient expressed or exhibited fatigue. Some patients were unable to answer the questions, due to confusion, loss of speech, or tiredness and those questions were answered by their family members in presence of patients in the consultation room.

3.7.5 Confidentiality and data storage

Confidentiality was strictly maintained at all times by all members of the research team. Study databases were password-protected. Names were not used and the questionnaires were marked with numbers. Master copy of the names and study number kept separately.

The questionnaires and the study databases were used for the study numbers only; therefore, there was no chance of any loss of confidentiality. The questionnaires were stored in locked cupboards, when not in use. All the study databases were password-protected. Answered questionnaires were kept in a locked cupboard and the collected data were stored in Microsoft excel personal computer password-protected.

3.7.6 Data analysis

The quantitative data were analysed statistically. The questionnaires were comprised three Sections: Section 1/A contained the Demographic details; section 1/B had the Medical and other history of the patient: and section 1/C comprised the Functional assessment scales, known as SS-QOL scales.

Altogether 12 areas of questionnaires' were subdivided into three groups according to the protocol for SS-QOL as follows:

Physical functions: Energy, Mobility, Self-care, Upper extremity function (UEF), Vision, Language, work.

Social function: Family role, Social role.

Emotional functions: Mood, Personality, and Thinking.

There are 12 variables in SS-QOL questionnaires therefore 3 factors were used to analysis the data and from three factors patients' functional capability were revealed in result. Factor analysis is a statistical technique used to identify factors that statistically and encompasses generating one or more unobserved independent variables that correlate with the observed measures. Commonly used in survey research and other applications, factor analysis can be measured a data reduction technique because it reduces a large number of variables that often correspondence to a smaller number of factors.

Significance and reliability of data collected from SS-QOL scores were measured by using Cronbach's alpha. Before summated scores (calculated as either the sum or the average of responses to a set of items) can be analysed it has to be determined whether they are reliable.[53] The statistic used for this is Cronbach's alpha. The recommended interpretation intervals are: 0.60 to 0.69 acceptable; 0-70 to 0.79 good; 0.80+ excellent.[54]

The qualitative data described from the in-depth interview were analysed through a process of thematic analysis. The following steps were used in the analysis of qualitative data: 1) immersion in the data – the transcripts were read and re-read to ensure 2) familiarisation with the data. During this period the PI held back from analysis and simply focused on getting to know the data; 3) identifying the topics or issues that seemed important to the participants and highlighting these in order to refer to them in collating the qualitative data; 4) coding the emerging themes and subthemes to organise the data.

The PI identified the themes and sub-themes from the completed questionnaires for the analysis of data thematically by inductive coding. In the research paper themes and sub-themes were written in descriptive manner with the quote from participants. David and Thomas describe that "*the general inductive approach provides an easily used and systematic set of procedures for analysing qualitative data that can produce reliable and valid findings*".[55]

3.8 Ethical considerations

Ethical approval of the research work was obtained from HREC (Human Research Ethics Committee) at UCT and reference number was 588/212. Thereafter, ethical approval was obtained from Provincial Heath Department (Ref: HRKM 089/13) and also from the facility where the study was conducted, respectively.

Special ethical considerations were borne in mind that the study participants were a vulnerable population and needed particular attention and respect. Some patients could not manage to talk or communicate well, because of dysphasia therefore, the questions were directed to the caregivers in presence of patient following the study protocol. These care givers were most commonly the family members.

Attention was given to non-verbal responses and any signs of tiredness or distress. The participants were given the opportunity to withdraw from the study under these circumstances, as well as the opportunity to continue the interview at a later stage should they wish to do so. During data collection procedure 4 patients out of 72 stopped the interview but chose to complete the interview later.

Chapter 4

4.1 Quantitative analysis:

Demographic results:

A total of 72 participants were interviewed of whom 31(43%) were male and 41(57%) female patients who had a stroke. The participants' ages ranged from 40 to 80 years and majority were 50 to 60 years of age. Majority of the participants were married and had family size of 4-5 persons. It also reveals that the majority of participants were black African population. Participants were interviewed both at MOPD and in patient ward.

Table 1: Demographics of patients

Variable	Category	Frequency n	and %
Gender	Male	32	44%
	Female	40	56%
Marital status	Single	3	4%
	Married	33	46%
	Widow/Widower	26	36%
	Others	10	14%
Age	40 – 50	15	21%
	50 – 60	24	33%
	60 – 70	18	25%
	70 – 80	15	21%
Ethnicity	African	65	91%
	Indian	4	5%
	Coloured	2	3%
	White	1	1%
Family size	Single	0	0%
	2-3	12	17%
	4-5	24	33%
	6-7	22	30%
	7 and up	14	20%

Figure 1: Comparison of gender and age from all participants.

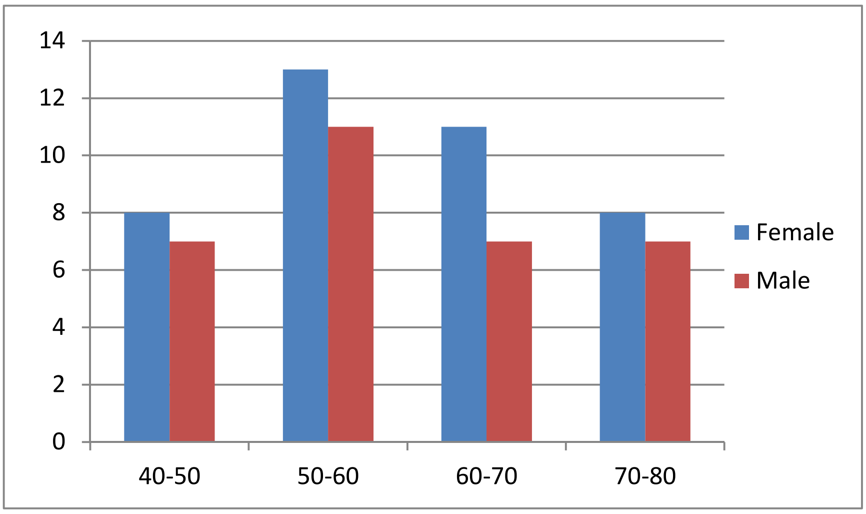

Figure 1, show that most of the participants were female and majority of patients were between 50 to 60 years of age.

Co- morbidity:

The main co-morbidities reported among all participants, hypertension 58(81%) and diabetes 28(61%). Some patients also had both hypertension and diabetes.

Table 2: Co-morbidities for participants

Variable	Category	Frequency n and	%
Hypertension	Yes	58	81%
	No	14	19%
Diabetes	Yes	28	39%
	No	44	61%

Few participants were suffering from other chronic diseases as well, such as arthritis, epilepsy and HIV diseases. It was found that majority of the patients were suffering from hypertension before they had a CVA.

Table 3: Psychological level of participants

Variable	Category	Frequency	
		n	and %
Anxiety	Yes	26	36%
	No	36	44%
Depression	Yes	36	44%
	No	26	36%

Out of 72 patients 26 have been suffering from anxiety and 36 patients were suffering from depression

Table 4: Other history

Variable	Category	Frequency	
		n	and %
Spiritual belief	Yes	68	94%
	No	4	6%
Knows about palliative care	Yes	8	11%
	No	64	89%
Seen by other doctor	Yes	70	97%
	No	2	3%

The majority 68 (94%) of the participants responded that they do have a spiritual belief. Few patients (8 out of 72 participants) had knowledge about palliative care. Most patients had also seen by other doctor before at MOPD during their previous consultations for post-stroke management.

Stroke Specific Quality of Life Scale (SS-QOL):

The results identified that which functional disabilities are mostly affected and influencing their daily activities in life. Participants were more concern about their physical functional disabilities and which influence patients’ daily activities in life. Participants were also psychologically distressed, with some participants expressing their concern with tears in the eyes.

From the findings of SS-QOL questionnaires’ it was also revealed that how severe the residual disabilities were after surviving stroke and how the patients were coping with those morbidities. All the findings are stipulated with statistical manner in tables and figures. Both descriptive statistics and dimensional statistic were used to explain their functional capability from mild to severe in nature. Because of their functional disabilities Social and Emotional factors both were affected.

Table 5: Descriptive statistics: D.P. Social role to F. Total (n = 72)

	Mean	S.D.	Minimum	Quartile 1	Median	Quartile 3	Maximum
D.S.Soc Role	1.60	0.58	1.00	1.15	1.40	2.00	3.00
D.S.Fam Role	1.93	0.63	1.00	1.33	1.67	2.33	3.33
D.P.Mobility	1.95	0.52	1.00	1.67	2.00	2.00	3.00
D.P.Energy	2.01	0.67	1.00	1.67	2.00	2.33	4.00
D.P.Work	2.13	0.56	1.00	2.00	2.00	2.33	4.00
D.P.UEF	2.14	0.55	1.00	1.60	2.00	2.40	3.60
D.P.Self care	2.24	0.59	1.00	1.80	2.00	2.60	3.80
D.E.Mood	2.56	0.78	1.00	2.00	2.60	3.20	4.40
D.E.Personality	2.62	0.89	1.00	2.00	2.33	3.33	4.67
D.P.Lang	3.26	1.68	1.00	1.80	3.00	5.00	5.00
D.E.Thinking	3.76	1.06	1.33	3.00	3.84	5.00	5.00
D.P.Vision	4.21	1.26	1.00	3.38	5.00	5.00	5.00
F.Social	1.77	0.53	1.00	1.27	1.70	2.15	3.00
F.Physical	2.56	0.55	1.56	2.18	2.60	2.94	3.89
F.Emotional	2.98	0.77	1.44	2.32	2.95	3.56	4.58
F.Total	2.44	0.55	1.34	1.97	2.42	2.83	3.73

In table 5, describes the mean and the range of functional disability of the participants.

Table 6: Frequency Distributions of functional disability: D.P. Social role C to F. Total. C(n = 72)

	Very/Severe		Moderate		Mild / None	
D.S.SocRole.C	64	89%	8	11%	0	0%
D.P.Mobility.C	62	86%	10	14%	0	0%
D.P.Energy.C	57	79%	14	19%	1	1%
D.S.FamRole.C	56	78%	16	22%	0	0%
D.P.Work.C	56	78%	15	21%	1	1%
D.P.UEF.C	55	76%	16	22%	1	1%
D.P.Selfcare.C	49	68%	22	31%	1	1%
D.E.Personality.C	39	54%	23	32%	10	14%
D.E.Mood.C	34	47%	29	40%	9	13%
D.P.Lang.C	31	43%	6	8%	35	49%
D.P.Vision.C	16	22%	2	3%	54	75%
D.E.Thinking.C	12	17%	16	22%	44	61%
F.Social.C	65	90%	7	10%	0	0%
F.Physical.C	32	44%	37	51%	3	4%
F.Emotional.C	24	33%	26	36%	22	31%
F.Total.C	42	58%	27	38%	3	4%

Table 6, shows the frequency distribution functional disability from very severe to none.

Figure 2: Stacked bar chart - Dimensions

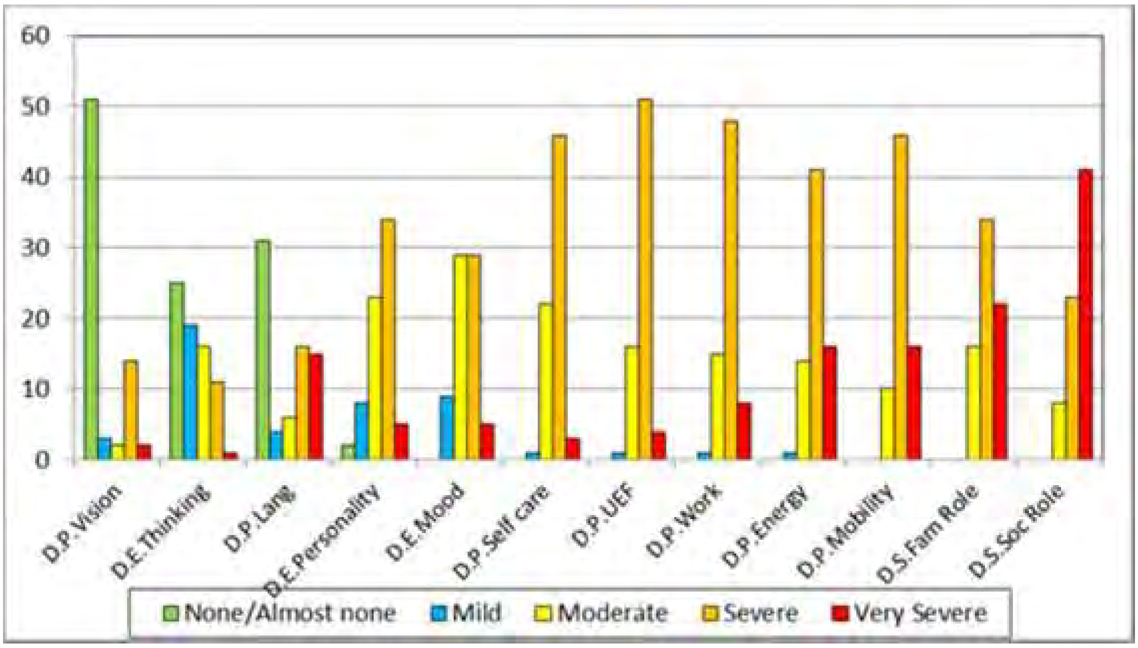

Figure 2 shows the severity of functional disability of participants for SS-QOL survey.

Figure 3:

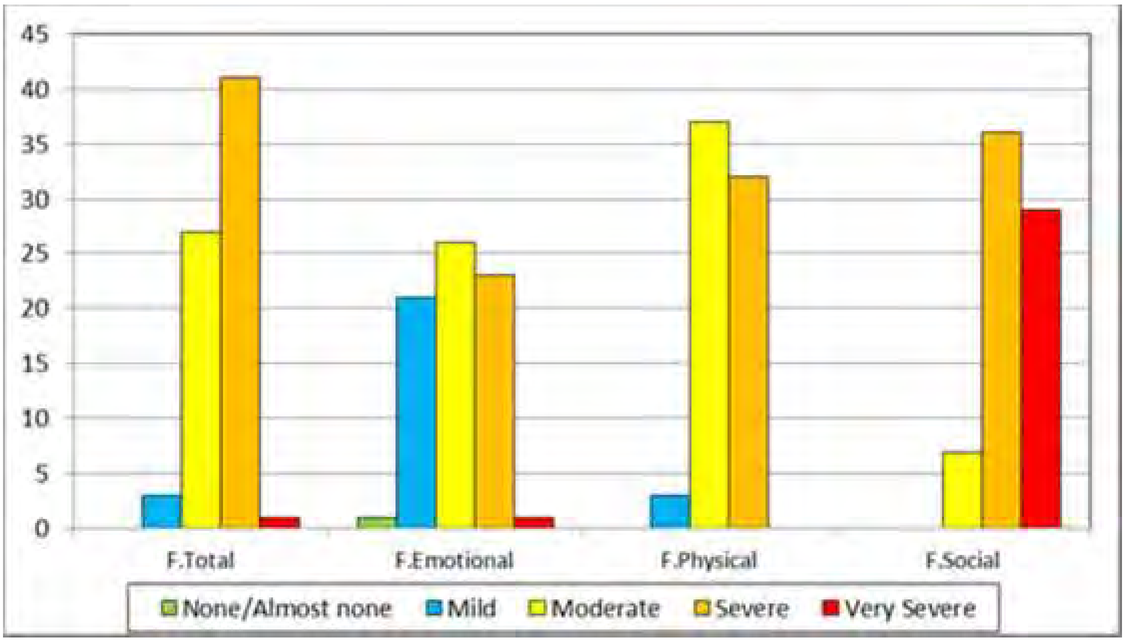

Figure 3, it shows that 41% patients out of 72 participants had severe total functional disability that is physical, emotional and social. Thirty two percent of patients had severe physical functional disability and 33% patients had severe emotional functional disability after survival from stroke.

Table 7: Inferential Ranking of Dimensions(n=72)

					95% Conf.Interval	
Dimension	**Rank**	**Significance Group**	**Mean**	**SD**	**Low**	**High**
D.S.Soc Role	1	1	1.60	0.58	1.46	1.73
D.S.Fam Role	2	2	1.93	0.63	1.79	2.07
D.P.Mobility	2	2	1.95	0.52	1.83	2.07
D.P.Energy	2	2	2.01	0.67	1.86	2.16
D.P.Work	5	3	2.13	0.56	2.00	2.25
D.P.UEF	5	3	2.14	0.55	2.01	2.27
D.P.Self care	5	3	2.24	0.59	2.10	2.38
D.E.Mood	8	4	2.56	0.78	2.38	2.74
D.E.Personality	8	4	2.62	0.89	2.41	2.82
D.P.Lang	10	5	3.26	1.68	2.87	3.65
D.E.Thinking	11	6	3.76	1.06	3.52	4.01
D.P.Vision	12	7	4.21	1.26	3.92	4.50

Table 7 shows the statistical analysis inferential ranking of the 12 dimensions of functional disabilities. The mean and standard deviation was calculated to determine the statistical significant of different dimensions.

Table 8: Inferential Ranking of Factors (n=72)

					95% Conf.Interval	
Factor	**Rank**	**Significance Group**	**Mean**	**SD**	**Low**	**High**
F.Social	1	1	1.77	0.53	1.65	1.89
F.Physical	2	2	2.56	0.55	2.43	2.69
F.Emotional	3	3	2.98	0.77	2.80	3.16

Table 8, reveals that the social functions are affected more than the emotional functions.

Table 9: Pearson Product Moment Correlations – Between the factors (n = 72)

Factor	**F. Emotional**	**F. Physical**	**F. Social**
F.Emotional	-	**.653**	**.760**
F.Physical	**.653**	-	**.697**
F.Social	**.760**	**.697**	-

Pearson Product Moment Correlations - Dimensions (n = 72)

Correlations are:

Statistically significant at 0.05 level for n = 72 if |r| >= .232

Practically significant if |r| >= .300

Table 10: One-sample t-Test (d.f.=71) Classification of Dimensions

Dimension	Mean	SD	H_0	t-value	p-value	Cohen's d	Category
D.S.Soc Role	1.60	0.58	≠ □ 2.51	-13.36	<.0005	1.57	Severe
D.S.Fam Role	1.93	0.63	≠ □ 2.51	-7.86	<.0005	0.93	Severe
D.P.Mobility	1.95	0.52	≠ □ 2.51	-9.22	<.0005	1.09	Severe
D.P.Energy	2.01	0.67	≠ □ 2.51	-6.37	<.0005	0.75	Severe
D.P.Work	2.13	0.56	≠ □ 2.51	-5.83	<.0005	0.69	Severe
D.P.UEF	2.14	0.55	≠ □ 2.51	-5.73	<.0005	0.68	Severe
D.P.Self care	2.24	0.59	≠ □ 2.51	-3.88	<.0005	0.46	Severe
D.E.Mood	2.56	0.78	≠ □ 2.51	0.56	.578	n/a	Severe or Moderate
D.E.Personality	2.62	0.89	≠ □ 2.51	1.05	.297	n/a	Severe or Moderate
D.P.Lang	3.26	1.68	≠ □ 2.51	3.79	<.0005	0.45	Moderate
D.E.Thinking	3.76	1.06	≠ □ 3.49	2.20	.031	0.26	Mild/ Almost none
D.P.Vision	4.21	1.26	≠ □ 3.49	4.84	<.0005	0.57	Mild/ Almost none

In table 10, sample t-Test was done for classification of different dimensions of functional disabilities. The dimensions from above table show most of them were statistically significant with a p-value of < .0005.Sample size was adequate to statistically analysis of the data.

Table 11: One-sample t-Test (d.f. =71) Classification of Dimensions variables

Factor	Mean	SD	H_0	t-value	d.f.	p-value	Cohen's d	Category
F.Social	1.77	0.53	≠ □ 2.51	-11.95	71	<.0005	1.41	Severe
F.Physical	2.56	0.55	≠ □ 2.51	0.79	71	.433	n/a	Severe or Moderate
F.Emotional	2.98	0.77	≠ □ 2.51	5.23	71	<.0005	0.62	Moderate

Table 11 shows that both social and emotional factors p-value <0.0005 are significantly compromised.

Summary:

The SS-QOL survey identified physical, emotional and social dysfunctions were the major concern of the participants. The severity of dysfunctions also stipulated in the SS-QOL survey.

This study detects the different levels of patients need and where to focus care after survive from stroke to improve their quality of life. The questionnaires used had satisfactory core reliability with Cronbach's α coefficients greater than 0.60 for all scales and greater than 0.70 for five.[56]

Measures of reliability were acceptable in this study; Cronbach's α correlation coefficient was more than 0.60 for all scales. The patients' functional abilities are diminished and this correlated with the limitations in performing activities for daily living.

4.2 Results (Qualitative analysis)

The interview guide was designed to elicit the patient's experience of stroke, post-stroke complications and the care needs. Ten patients (n=10) were recruited to participate in the qualitative study out of total seventy two (n =72) participants for the whole study.

It was found that all ten participants could speak and understand English and they were interviewed during their follow-up consultation in presence of family members or the care givers at MOPD (Medical Out Patient Department).

Thematic analysis developed the following themes: The first theme dealt with the life changing effect of the stroke. The second theme dealt impact on quality of life after stroke. The third theme dealt with holistic care needs. The fourth theme dealt with loss of independence after surviving from a stroke. The fifth theme dealt with spiritual aspects of patient's experience.

Table 12: Table of themes and sub-themes developed in data analysis

THEME ONE	THEME TWO	THEME THREE	THEME FOUR	THEME FIVE
1.Life changing	**2. Impact on quality of life**	**3. Holistic care Needs**	**4. Loss of independence**	**5. Spiritual aspects**
1.1 Experiencing the effect of disability	2.1Experiencing Bad quality of life	3.1 Understanding a holistic care approach	4.1 Isolation	5.1 Spiritual Concerns
1.2 Awareness about Post-stroke disability	2.2 Hope for good quality life		4.2 Loss of physical ability	

THEME ONE

1. Experiencing the change of life after survival an acute stroke:

After recovering from the acute event of stroke, most of the patients experienced a residual disability, such as difficulty in walking, difficulty in using their hands, difficulty in speaking. Because of all these disabilities, their life style might change abruptly and which influence the quality of life.

Most patients were dependent on other people such as their care givers or family members because of their disabilities. During interview process, it was noticed that patients may feel isolated from others, for example their family members and friends, which can lead to emotional and mental health problems.

1.1 Experiencing the effects of a disability

During interview it was identified that most of the participants were worried about their post-stroke complications. Many participants expressed their concern during the interview about the effect of the residual disabilities and which has changed their life style as well. Participants expressed their views with lots of emotion as follows:

"After surviving from stroke, I could not manage to talk properly with people because of slurred voice."(Interview: Participant 4)

"My life has been changed a lot since I have been suffering from disabilities after surviving stroke such as cannot speak properly and feel weak at the left side of the body, cannot walk without support."(Interview: Participant 5)

"I could not manage to walk because my one side of the body was paralysed; it was a very difficult situation for me." (Interview: Participant 7)

1.2. Awareness about post-stroke disability

During the interview, it was found that patients were interested to know about the post stroke complications and disabilities and how they can overcome or recover from those disabilities. A few participants had significant awareness of the post stroke complications but most patients had very little knowledge of the complications patients experience after surviving a stroke.

"I did not know that after stroke; still people can suffer with disabilities and which takes even longer time to recover. I was told and explained by the doctor about my disabilities while I was admitted in the ward." (Interview: Participant 5)

“Well, I could not manage to do daily activities on my own. But the doctor who attended me in medical ward explained everything about the disabilities and complications, people get after survive from stroke.’’ (Interview: Participant 7)

<u>THEME TWO:</u>

2. Effect of quality of Life

After surviving from stroke, patients were experiencing the problems associated with residual disabilities and which were influencing on their quality of life as well as daily living. Many participants expressed their concerns and described that they were feeling that current disabilities are the main problems. This was reflected during the interview as follows:

“After surviving from stroke and my daily living was bad with disabilities, my life was horrible. I could not manage to go out for a while after get discharged from hospital. This is not a life.” (Interview: Participant 10)

“I could not manage to socialize with the friends and relatives; it was really painful for me.”(Interview: Participant 6)

2.1 Experiencing poor quality of life

After surviving stroke patients expressed that they experienced poor quality of life and the difficulties adjusting to this. Some patients were concern about the pain in their limbs and the pressure sores.

“I was experiencing pain and tingling in my legs, which was unbearable.” (Interview: Participant 7)

“Due to lack of mobilization I had few pressure sores and it was very painful at times.” (Interview: Participant 9)

“I could manage to socialize with people and friends like before. I was even having difficulties to talk with friends and relatives over telephone.”(Interview: Participant 8)

2.2 Hope for good quality of life

A few patients were very optimistic and hopeful to get back their normal life again. The patients observed that with the help of the rehabilitation programme, they are slowly improving from their disabilities. Participants experiencing the improvement of physical disability and regain a good quality of life after recovering from acute stroke with a residual disability**;** however, few participants have expressed their hope that they would recover completely.

"My husband was told by physiotherapist, how to continue daily exercise to improve the physical power and strength of muscles. Gradually I am getting the power back. I am optimistic about the physiotherapy which is really helping me." (Interview: Participant 7)

"One of my family members was told by physiotherapist how to continue the daily exercise at home to improve the physical power and strength of muscles." (Interview: Participant 9)

"Gradually, I am getting some power back because of attending rehab department at hospital for physiotherapy, but still I need to carry on more." (Interview: Participant 2)

THEME THREE:

3. Holistic care needs

During the interview with the participants it was identified that majority patients need help from different allied health workers such as physiotherapist, speech therapist, clinical psychologist and social worker.

Participants complained of not only physical functions but they mentioned financial, emotional and social problems as well.

"Always I needed help to dress myself and to prepare my food. Also I needed help to mobilize myself. Anyway almost for everything I needed help throughout the day. Because of attending physiotherapy treatment I am getting my power back slowly."(Interview: Participant 5)

"I need financial supports for my family because the money I get from disability grants not enough and I was sent to social worker". (Interview: Participant 2)

"I was told by physiotherapist can help me to do certain exercise to get my physical strength and power of muscles back."(Interview: Participant 3)

"I was getting speech therapy from my speech therapist and which was organized by my doctor while I was admitted in medical ward." (Interview: Participant 8)

3.1 Understanding a holistic care approach

Participants expressed their views about the care received from multi-disciplinary health workers such as physiotherapist, speech therapist and social workers. Few participants mentioned how they received counselling from the clinical psychologist. There was also appreciation the role of social workers in addressing concerns about financial problem.

"I could do lot of things on my own before stoke attack, even talk could not properly, doctor organized speech therapist for my speech difficulties."(Interview: Participant 1)

"People could not understand me what I am trying to express. Fortunately I was attended by speech therapist and which helping me lot recover from speech problem." (Interview: Participant 5)

"Most of the time I get frustrated, sometimes people are busy and difficult to get help. Doctor in the ward organized counselling by clinical psychologist at hospital."(Interview: Participant 10)

"Social worker organized social and disability grant for me and the money, I get from grant is helping my family a lot."(Interview: Participant 5)

THEME FOUR:

4. Loss of independence

Participants expressed their concern that they were now depending on someone to do their daily activities in life. Following quotes were documented from participants:

"I cannot walk and do things on my own like before; almost for everything I have to depend on someone." (Interview: Participant 5)

"Due to the weakness of one side of my body, I could not manage to walk without support and obviously I cannot do the daily activities. I was always depending on other people." (Interview: Participant 6)

"I was depending to family members for my daily activities, even for feeding, wearing cloths" (Interview: Participant 7)

4.1 Isolation

Participants experienced the pain of isolation from close friends after surviving a stroke. It was frustrating for stroke survival patient to cope with isolation and contributed to poor quality of living for a patient.

"Most of the time I am alone at home with the maid, after I was discharged from hospital. Before stroke I could drive a car and was able to go out when I needed, but now I cannot." (Interview: Participant 5)

"My children are always busy with their own life." (Interview: Participant 3)

"I was feeling isolated from friends and relatives. I could not manage to visit them whenever I wanted." (Interview: Participant 4)

"I was missing my social life, friends and relatives whom I used to visit and feeling lonely most of the time." (Interview: Participant 6)

4.2 Loss of physical ability

From the findings of the interview of participants, it was noticed that the loss of physical abilities after surviving stroke was affecting their daily life. Participants mentioned that the physical functions are coming back gradually after receiving treatment.

"I cannot do the daily activities. Almost for every little thing I needed help from others." (Interview: Participant 8)

"I cannot do my daily life activities and the way I used to do before. Especially I would like to prepare food myself and I used to do shopping own my own, but without help things are impossible for me now."(Interview: Participant 4)

THEME FIVE:

5. Spiritual aspects

The majority of participants interviewed expressed their spiritual concerns and described the role of their faith in coping with the illness.

'My husband takes me to church every week. I was always thinking after surviving stroke that if I die now what will happen to my family. The time I spent in church I feel very relax and get more strength in mind. I have started to think positive after I have started going to church again."(Interview: Participant 2)

"I used to go at church with my wife, but it is difficult for me to attend church regularly. My priest visited me at home and gave me lot of spiritual support." (Interview: Participant 4)

5.1 Spiritual concerns

Patients with diagnosis of stroke and after surviving from acute stage may think of dying and become psychologically upset about current living condition. Spiritual wellbeing can give a person peace of mind and people then exude calm confidence, happiness, and tolerance.

The majority of participants had spiritual belief and expressed faith in different religions. During interview participants mentioned that spirituality is giving them mental comfort.

"I like to pray to God and he can help me to get better as quick as possible. There was a fear in my mind about death. My family was taking me to church every week. The time I spent in church I feel more strength in mind."(Interview: Participant 7)

"I had a fear of death after stroke. Local mowlana (Muslim priest) from mosque was coming to my house sometimes and I got lot of spiritual support from him."(Interview: Participant 5)

Summary:

From the interview and discussion with the participants it was noticed that majority of the patients lacked of knowledge about post stroke complications and morbidities after surviving a stroke.

Participants' accounts and expressed their concern with the current care they are getting and they were concerned about their life style and loss of independence. It is evident from the interview data that stroke survivors have to carry on life with disabilities but they need assistance to improve quality of life. Participants expressed the hope that multidisciplinary health team could help them to improve gradually from their residual disabilities and morbidities.

Stroke has many different effects. These includes physical changes that can be seen and recognise more easily but there can also be hidden effects, such as emotional changes. As described by the Stroke Association in the UK, "*changing emotions often lead to a change in behaviour which may signify that all is not well*" with the patient.

Chapter 5

Discussion

5.1 Palliative care and CVA

Palliative care is *'an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, proper assessment, and the treatment of pain and other problems: physical, psychosocial and spiritual'*.[20]

This study highlights the impact on physical, emotional and social functions determined Stroke Specific Quality of Life of stroke survivors. It also considers their personal experiences described in individual interviews. The SS-QOL survey conducted in this study helps in understanding the psychological and social impact of the illness as well the physical needs and impact on activities of daily living. SS-QOL survey identified that physical, emotional and social dysfunctions were all major concerns of the participants.

From the SS-QOL questionnaires after analysis the answers, it was found that many patients had severe total functional disability that is physical, emotional and social. The qualitative interviews also highlighted the reliance on spiritual support. The goal of palliative care for stroke survivors would be to restore functional capacity back to normal as best as is possible by involving a multi-disciplinary team including rehabilitation programme: and also to reduce the suffering those patients whose condition does not improve or deteriorates, in addition to providing family support. The literature review found that a number of authors identified the need for support of family carers.

Many of the issues addressed through palliative care are interdependent and can interact to improve outcomes. For example, effective treatment of emotional distress improves not only anxiety or depression but it may also result in better physical and social functions which make the patient more energetic. There is always a greater motivation to comply with medical management recommendations all major strokes with morbidities.

Functional disabilities may lead to dependence on a wheelchair or sometimes the need for residential care with the help of rehabilitation team. A severe stroke can place a great burden on the coping abilities of care givers and family, as well as on the patients themselves. Frustration is a common response to problems with all the disabilities after a stroke. Losing one's independence is hard to accept. It is easy to imagine needing someone's help to bath or to tie a shoe lace: and trying to complete even simple tasks can be very frustrating and humiliating. Therefore many patients required counselling by clinical psychologist.

In this research study, patients expressed their view about the benefit of counselling by clinical psychologist. During qualitative data collection interview, the majority of the participants expressed their concern about quality of life, psychological upset and spiritual thinking.

As described by Wee *et al* [33] effective palliative care can be delivered to stroke patients by a holistic approach to those who need it, including physical, psychological, social, and spiritual well-being. One of the significant findings from this study is that the knowledge of palliative care among patients, care-givers and family members was not adequate and it is necessary to empower potentials users with the knowledge about palliative care and stroke related complications for the patients. From literature review, it was found that the multi-disciplinary approach of palliative care together with rehabilitation programme could improve the quality of life among stroke survivors with their residual disability.

Moreover, substantial research is necessary to investigate the management of stroke patients for those who live longer after recovering from acute stroke. Stroke patients need additional care beyond routine rehabilitation and the support that can only be offered by palliative care with multi-disciplinary team, focusing as it does, on the rehabilitation and improvement in quality of life.

Palliative care teams consist of professionals from different discipline such as physicians, palliative care specialists, physiotherapists, social workers, psychologists, counsellors including spiritual counsellors, dieticians and other allied health workers. This approach addresses the physical, emotional and social dysfunctions that were the major concern of the study participants as reflected in SS-QOL survey.

5.2 Palliative care and post stroke psychological problems

From SS-QOL survey significant prevalence of severe emotional disability was found. During the interview with patients those who reported about psychological problem, such as depression, anxiety and which was related with the life style changes after survive from stroke.

Emotional distress was identified through the SS-QOL questionnaires asking about mood and personality. It is important to diagnose correctly and treat the patient with significant anxiety and depression, while adequately addressing other common concerns such as "*demoralization, grief, social role, and family conflict*". This requires skilled assessment and psychological support by the clinical psychologist, social workers and non-clinical people such as a priest.

5.3 Palliative care and post stroke disability

Stroke patients need to aware about their possible complications which can give them disability. The health care team should provide adequate support and to empower the patient and the family by providing information about stroke complications. The majority of the surviving patients live with the morbidities from post stroke complications; as well as weakness or paralysis, some patients may also experience trouble with speaking or understanding of speech, headaches, inappropriate behaviour, memory difficulties, visual problems and emotional problems.

Stroke is one of the diseases where most of the survivors suffer from disabilities after survival and sometimes, patients feel they are a burden to their family members because of their disability, dependence and extra medical cost. When someone in family is the bread winner and becomes disabled because of stroke complication, then they also worry about being a financial burden on their own family.

During the interview with patients and family members it was reported that family members are very willing to care their love one. With support from palliative care team, family members can also take the responsibility to look after patients well -in order to improve their quality of life.

5.4 Palliative care and rehabilitation

In this study the SS-QOL survey, confirmed that a high proportion of participants after stroke have poor quality of life due to severe impairment of physical function: and most of them were depressed about their life, especially those who had low score on the Stroke Specific Quality of Life scale questionnaires. This confirms findings from other studies such as Hankey's study[34] reporting disability and dependency in stroke patients in Australia

Effective rehabilitation programme is essential for good outcome and gradual recovery to get back physical functions after acute stroke. There is need of integration of palliative care and rehabilitation to deliver the best quality service to a patient after surviving stroke.

After surviving acute stroke, many patients suffer from residual disabilities and for that reason, patients need rehabilitation. This can be offered to a patient by holistic approach and by involving a multi-disciplinary team. Many patients mentioned their disabilities like limitation of physical, psychological and social activities after surviving from a stroke. For these patients the holistic approach of palliative care can be offered to patients by a palliative care team but not by an individual, such as a physiotherapist, a doctor or a nurse.

In this study, the majority of the patients underwent three to four sessions of rehabilitation therapies and most of the times it was twice in a week. The type of rehabilitation therapy most commonly used was physiotherapy and psychological counselling.

It was observed throughout the study that rehabilitation alone cannot provide quality care to a stroke survive patient. When physiotherapy and speech therapy were offered to the patients by the doctor, patients were happy to accept the therapy, in addition to any other rehabilitative therapy that was needed. Thereafter, patients expected to receive help from such rehabilitation programmes.

5.5 Palliative care and spiritual values

The concept of spirituality is often misunderstood. Spirituality can be defined as *"spiritual needs are the needs and expectations that human beings have to find meaning and purpose in life; such needs maybe specifically religious but even people who have no religious faith or who* *are not members of an organised religion have belief systems relating to meaning and purpose"*[57] Despite the clinical management of patients with stroke, there was a need to identify the holistic approach of palliative care to support patients and family members encompassing spiritual care.

After surviving acute stroke, some patients start thinking about or develop a fear of death, recognising they might have died from this event. During interview with the participants of this study, 20% patients spoke about the fear of death. Spiritual counselling can help stroke patients to explore the issues raised by these fears and to bring some comfort to the patients.

Because of existing functional disabilities only few participants in this research were attending their religious places for pray and this was a concern. Patients received the counselling from respective religious priest of different religions even at their home. A patient's spiritual distress may be more than fears about dying. Existential concerns of meaning, purpose and connection, can all affect spiritual well-being and require spiritual counselling.

5.6 Benefits of palliative care to stroke patients

Palliative care can help with communication and may improve relationships at different levels, including those between patients and family members and between patients, family members and health care team. It is important to document, as appropriate, discussions with the patient, family and other care-providers to ensure a good flow of information within and between organisations involved in service delivery. The palliative care team must also be skilled in the care of stroke patients.

Palliative care can be initiated as early as possible during the illness and which can give comfort to the patient. However many health professionals believe that the palliative care mainly focuses on the end of life. This view may be re-enforced by studies such as Bacquiere's[31] which focused on artificial feeding. There is lack of evidence about how the palliative care needs of acute stroke patients and family members should be addressed. This was also identified by Wee *et al* [33].

If palliative care is focused only on the end-of-lie and is seen as failure on the part of the clinical team, there are barriers to the development of new insights to integrate the palliative care with other treatment modalities. Burton proposes that *"shift in thinking is required which acknowledges the potential benefits of earlier integration of palliative care*[9]*"* for patients for the stroke survivors with different morbidities as described by Anderson *et al*[38] and Stevens *et al*[11].

5.7 Limitations of the Study

A major limitation of the study is that not all participants could speak and express their views directly. Therefore, close family members were interviewed on behalf of many of the participants. Interviewing the relative or caregivers rather than directly interviewing patients may have led to some information being omitted in the collection of data.

There may also have been information lost by the researcher by using research assistants as interpreters in data collection as most of the participants could not speak any English. This limitation was anticipated and addressed during training of the research assistants. Special consideration was given to the fact that the researcher was also the clinician providing care to the patients and that this may have introduced elements of bias, in particular, social disability bias and interview bias.

This study was done at Ladysmith Regional Hospital and the patients who were admitted in the ward and attending MOPD (Medical Outpatient Department). So the study is completely hospital based and does not include the assessment of the need of palliative care for stroke patients at community level.

Conclusions and Recommendations

Conclusion

The study identified the holistic care needs of stroke patients and through patient interviews assessed the care currently provided to stroke patients at Ladysmith Regional Hospital. It is clear that there are gaps in the provision of holistic care to stroke patients and it is proposed that the integration of palliative care and rehabilitation can provide better service to stroke patient.

Rehabilitation is an important part of stroke management and by which health professional intends to maximize a patient's functional ability. But rehabilitation alone cannot deliver the effective care to stroke patients, therefore integration of rehabilitation and palliative care is necessary.

Recommendations

There are a number of recommendations that result from considering patient experiences and care needs following a stroke. Family members provide the most care for stroke patients and there is necessity to involve the family members in the care of stroke patients. It was found that families may suffer from social, emotional and physical burden. It is difficult for family carers to combine caring with their other work and life commitments and need both social and emotional support.

It is very important to ensure and give support to the families, throughout the illness, but especially upon diagnosis, if there are behavioural issues, deterioration in health, admission to hospital or care home , and at the end of life. It is necessary to communicate properly with patient or the care givers about the management plan and should be document adequately.

It is suggested that to integration of the palliative care into the management plan together with other management plan for stroke patients, which may benefit the patient in the long term with a positive impact with their residual disabilities and co-morbidities. Integration of palliative care, rehabilitation and therapeutic management can deliver an improved service to stroke patients and their family members.

Effective communication in palliative care service identifies and aims to address all needs of the patient, family and the health care provider (such as psychological, spiritual, social, cultural and physical issues). It can be considered for stroke survival to provide psychosocial and spiritual support where needed.

Stroke patients who may be aware of their condition may need emotional support from the health professionals for coping. Spiritual care-giving for stroke patients should include an assessment of spiritual practices, the patient’s wishes and needs regarding spiritual care and support from the patient’s faith community

Additional research to explore how best palliative care service can be delivered at different stages of the ‘stroke journey’ and the natures of the illness trajectories after survive from stroke would assist in improving care for stroke patients.

Appendices

Appendix 1

Information Sheet

"To investigate the Need for Palliative care in Cerebrovascular Accident or stroke patients at Ladysmith Regional Hospital"

Thank you for giving your time to hear about our study. This information sheet tells you about a study that you may wish to participate in. You are allowed to ask any questions rise in your mind during or after completion of the study from the clinical team, from the researcher, or by using the telephone numbers at the end.

This information sheet is for you to keep. Thank you for thinking about whether you want to participate in this study. Please take your time to make a decision.

Purpose of the study:

We are looking at patient's care needs after having had a stroke, and how these needs are helped by the different services available at the hospital or even in our community, to which patient can have access.

How to take part in the study:

You are invited to take part in the study: but you do not have to agree to take part. If you are interested to participate, you will have the freedom to withdraw from the interview at any time during the interview process. Even your care will not be affected if you like to withdraw yourself from the study. There is a need to sign a consent form, which shows that you have agreed to participate in this study. You can take your time to think about whether you would like to participate and you may want to talk it over with your family, friends or someone in your care team.

What does the study involve?

The study involves answering questions put to you from a questionnaire by the doctor or the nurse (research assistant) conducting the study. The questions are about you and your health - after experiencing stroke. The interview will take approximately 30 minutes.

Benefits of the study:

There are no direct benefits to the study for participants will be interviewed using these questionnaires find that they are good points for discussion about on one's health needs after a stroke. The anticipated benefits are to be found in identifying people's care needs, and in trying to meet those needs.

Risks of the study:

Although many people find it useful to discuss these questions, there may be a risk that a question causes distress. If any of the questions cause you to feel distressed in anyway, you are free to withdraw from the study, and will still receive your usual care. In addition, a counsellor will be available to assist you. If you become tired during the interview, we will stop the interview. You can complete the interview at another time if you wish, or we can stop the interview altogether - and not bother to finish it.

Confidentiality about the study and participants:

All the information which we collect during the interview will be kept strictly confidential at all times by all members of the research team. Study databases were password-protected. Names were not used and the questionnaires were marked with numbers. Master copy of the names and study number kept separately.

We also ask your permission to interview a family member that you nominate on your care. The information you have shared with us will not be disclosed to your family member, unless this is requested by you.

How will I know about the results of the study?

At the end of the study, a report will be sent to the Medical Manager of Ladysmith Regional Hospital, and to those people who took part in the study.

Who is organizing the research?

If you need to talk to anyone about this research, you can contact the following people.

If you have any questions about the study:

Researcher's name: **Dr. Mohammed Jamil Hossain**
Contact telephone number: **0734761621**
Email: **mj_hossain@hotmail.com**

If you have any questions about your human rights, or of any ethical issues about the study:

Research Ethics Committee
University of Cape Town
E 52, Room 24, Old Main Building,
Groote Schuur Hospital, Observatory
Telephone: 021 406 6338

Appendix 2

Consent form designed for the patient

To investigate the Need of Palliative care for Cerebrovascular Accident patients at Ladysmith Regional Hospital

1. I confirm that I have read and understand the information sheet.

2. I understand that my participation is voluntary, and I have full freedom to withdraw at any time, without giving a reason, without my care being affected.

3. I agree to participate in this research.

4. I agree to my family member(s) or caregiver ………………………………….to

   be present at the interview.

Name of the patient_______________________

Signature _______________________Date _____________

Researcher: Signature ___________________ Date: _______________

Witness:
Name ____________________________ Signature _____________________
(Professional nurse from research team)
Date _______________

Appendix 3

Consent form designed for family member or care giver on behalf of patient

To investigate the Need of Palliative care for Cerebrovascular Accident patients at Ladysmith Regional Hospital

1. I confirm that I have read and understand the information sheet.
2. I understand that my participation is voluntary and I have full freedom to withdraw at any time, without giving a reason and the care of my will not be compromised.
3. I agree to participate in this research.

Close Family member or the care giver's name_______________________

Signature _________________

Date ____________

Researcher: Signature ___________________

Date: _______________

Witness:
Name ____________________________Signature _____________________
(Professional nurse from research team)
Date: _______________

Appendix 4

Questionnaires that were used for the data collection tool

STUDY NUMBER: ☐ ☐ ☐

To investigate the Need for Palliative Care in stroke or CVA patients: Quantitative Study

Section 1/A Demographic details

1. Date of admission or seen at MOPD: dd____ / mm_______/ yy___________

2. Gender: M ☐ F ☐

3. Marital status: Single ☐ Married ☐ Widow/Widower ☐ Others ☐

4. What is your country of origin (country of birth)?

1. SA ☐ 2. Non South African ☐

5. What is your Ethnic group?
1. African ☐ 2. White ☐ 3. Coloured ☐ 4. Indian 5. Other ☐

6. What is your year of birth? ☐ Do not know ☐

What is your age? ☐

7. What is your current employment status?
Employe ☐ 3. Social grant (disability) ☐

Unemployed ☐ 4. Other ☐

8. Are you a shift worker? Yes ☐ No ☐ N/A ☐

9. What is your family size?
Single ☐ 2-3 ☐ 4-5 ☐ 6-7 ☐ More than 7 ☐

Either from patient or family member Section 1/B Medical history

1. Suffering from Hypertension: yes / no (if yes as follows)

Yes ☐ No ☐
Less than 5 years ☐ More than 5 years ☐

2. Suffering from Diabetes Mellitus: yes / no (if yes how many years as follows)

Yes ☐ No ☐
Less than 5 years ☐ More than 5 years ☐

3. Any other chronic illness? Yes ☐ No ☐

4. Stroke history: (previous stroke if any)? Yes ☐ No ☐

5. Psychological impact for stroke?

Depression ☐
Anxiety ☐
Others ☐

6. Any spiritual belief? Yes ☐ No ☐

7. Any concern as a family member or caregiver? Yes ☐ No ☐

8. Knowledge about palliative care approach? Yes ☐ No ☐

9. Have you consulted with any other health practitioner? Yes ☐ No ☐

Section 1/C, Stroke Specific Quality of Life Scale (SS-QOL)

Scoring: Each question, participant can score with the following key

Total help - Couldn't do it at all - Strongly agree 1
A lot of help - A lot of trouble - Moderately agree 2
Some help - Some trouble - Neither agree nor disagree 3
A little help - A little trouble - Moderately disagree 4
No help needed - No trouble at all - Strongly disagree 5

Energy

1. I felt tired most of the time. ____
2. I had to stop and rest during the day. ____
3. I was too tired to do what I wanted to do. ____

Family Roles

1. I didn't join in activities just for fun with my family. ____
2. I felt I was a burden to my family. ____
3. My physical condition interfered with my personal life. ____

Language

1. Did you have trouble speaking? For example, get stuck, stutter, stammer, or slur your words? ____
2. Did you have trouble speaking clearly enough to use the telephone? ____
3. Did other people have trouble in understanding what you said? ____
4. Did you have trouble in understanding the words you wanted to say? ____
5. Did you have to repeat yourself, so that others could understand you? ____

Mobility

1. Did you have trouble walking? (If patient can't walk, go to question 4 and score questions 2-3 as 1.) ____
2. Did you lose your balance when bending over to or reaching for something? ____
3. Did you have trouble climbing stairs? ____
4. Did you have to stop and rest more than you would like, when walking or using a wheelchair? ____
5. Did you have trouble with standing? ____
6. Did you have trouble getting out of a chair? ____

Mood

1. I was discouraged about my future. ____
2. I wasn't interested in other people or activities. ____
3. I felt withdrawn from other people. ____
4. I had little confidence in myself. ____
5. I was not interested in food. ____

Personality

1. I was irritable. ____
2. I was impatient with others. ____
3. My personality has changed. ____

Self-Care

1. Did you need help preparing food? ____
2. Did you need help eating? For example, cutting food or preparing food? ____
3. Did you need help getting dressed? For example, putting on socks or shoes, buttoning buttons, or zipping? ____
4. Did you need help taking a bath or a shower? ____
5. Did you need help to use the toilet? ____

Social Roles

1. I didn't go out as often as I would like. ____
2. I did my hobbies and recreation for shorter periods of time than I would like. ____
3. I didn't see as many of my friends as I would like. ____
4. I had sex less often than I would like. ____
5. My physical condition interfered with my social life. ____

Thinking

1. It was hard for me to concentrate. ____
2. I had trouble remembering things. ____
3. I had to write things down to remember them. ____

Upper Extremity Function

1. Did you have trouble writing? ____
2. Did you have trouble putting on socks? ____
3. Did you have trouble buttoning buttons? ____
4. Did you have trouble zipping a zipper? ____
5. Did you have trouble opening a jar? ____

Vision

1. Did you have trouble reaching things because of poor eyesight? ____
2. Did you have trouble seeing things off to one side? ____

Work/Productivity

1. Did you have trouble doing daily work around the house? ____
2. Did you have trouble finishing jobs that you had started? ____
3. Did you have trouble doing the work you used to do? ____

TOTAL SCORE ____

SS-QOL questionnaires in isiZulu language

Amandla:

1. Uzizwaukhathelengasosonkeisikhathi?
2. Kumelengiphumuleosukwiwi?
3. Ngiyakhathalangingakwaziukwenzaengifunaukukwenza?

Imisebenzivasekhaya:

1. Angikwaziukuhlanganyelanomndeniwamisizithokozise?
2. Ngizizwangiwumthwaloemndeniniwami?
3. Ukugulakwamikuphazamiseukuphilakwami?

Ukukhuluma:

1. Unenkingayokukhuluma? Okunjengokuthi, Uyabambeka, Uyangingizanoma uyanensa.
2. Unenkingayokukhulumakahleocingweni, abanyeabantubanenkingaukukuqonda okushoyona?
3. Ngabeunenkingaukuqondaamagamaofunaukuwasho?
4. Ingabekudingekauphindaphindeukuzeabantubakuqondeokushoyo?

Ukuhamba:

1. Ngabeunenkingaukuhamba?
2. Ngabeunenkingaukumauzimeleleumakukhonaokucoshayonomaokuthathayo?
3. Ngabeunenkingayokuhambaezitebhisini?
4. Ngabekudingekaumeuphumuleizikhathiezinningiumauhambanomausebenzisaisihlaloes ihambayo?
5. Ngabeunenkingayokuma?
6. Ngabeunenkingayokwehlaesihlalweniesihambayo?

Ubuwena:

1. Ngangisheshaukucasuka?
2. Ngangingakwaziukubekezelelaabanye?
3. Ubuminabashintsha?

Ukuzenzela:

1. Ngabewawudingausizoukuzenzelaukudla?
2. Bewudingaukufunzwanjengokusikelwaizkuluizicucyezincanezokudla?
3. Ngabeubudingaukusizwaukugqoka. Njengokufakaizicathulonomaamasokisi, nokufasa, izikinobhonomaukukhuphulauziphu?
4. Ngabeubudingaukusizwaukuzigeza?
5. Ngabeudingaukusizwaukuyaendliniencane?

Impiloyokuzihuanganisanabanye:

1. Bengingasakwaziukuzikhiphanjenudbangangithanda?
2. Ngangikwenzaengikuthandayonokuzivocavocaisikhathiesifishane?
3. Bengingasakwaziukubonaizihlobozaminjengobangangithanda?
4. Ucansiangisaluthokozelinjengakuqala?
5. Ukugulakwamikwayiphazamisampiloyami?

Ukucabancia:

1. Kwakunzimakimiukugxilaentweni?
2. Nganginenkingayokukhumbulaizinto?
3. Bekumelengibhalephansiizintoukuzengizikhumbule?

UkusebenzisaIzingalo:

1. Ngabeubunenkingayokubhala?
2. Ngabebewunenkingaykugiqokaamakosi?
3. Ngabebewunenkingayokufasaizinkinobho?
4. Ngabeubunenkingayokwenyusauziphu?
5. Ngabeubunenkingayokuvulaujekeukubonakwamehlo?
6. Ngabeubunenkingayokufinyelelaentweningenxayokungaboni?
7. Ngabeubunenkingayokubona into ngeceleelilodwa?

Ukufezaimisebenza:

1. Ngabeubunenkingayokwenzaimisebenziyasendlini?
2. Ngabeubunenkingayokuqalaizintooziqalile?
3. Ngabeubunenkingayokwenzaimisebenziojwayeleukuyenza?

TOTAL SCORE ____

Appendix 5

Questionnaires for in-depth interview

1. Would you please tell me the ways in which your life has changed since you had a stroke?

2. What kind of help do you need to get through the days and the nights?

3. What special help do you need for physical care?

4. What special help do you need for emotional support?

5. What special help do you need for spiritual support?

6. What other help would be useful to you and your family?

Appendix 6

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Faculty of Health Sciences Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za
www.health.uct.ac.za/research/humanethics/forms

15 March 2013

HREC REF: 588/2012

Dr MJ Hossain
c/o Dr L Gwyher
Pallative Medicine
Public Health & Family Medicine

Dear Dr Hossain

PROJECT TITLE: TO INVESTIGATE THE NEED FOR PALLIATIVE CARE IN CEREBROVASCULAR ACCIDENT (STROKE) PATIENTS AT LADYSMITH PROVINCIAL HOSPITAL

Thank you for addressing the issues raised Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year till the 28 March 2014.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

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HEALTH
Department:
Health
PROVINCE OF KWAZULU-NATAL

LADYSMITH PROVINCIAL HOSPITAL
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Email: bongani.mabaso@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Dr B.A. Mabaso
Telephone: 0833384747
Date: 25/04/2013

Dr Mohammed Jamil Hossain
Family medicine

RE: PERMISSION TO CONDUCT RESEARCH AT THE HOSPITAL

You are hereby granted permission to conduct research on TO INVESTIGATE THE NEED FOR PALLIATIVE CARE IN CEREBROVASCULAR ACCIDENT (STROKE) PATIENTS AT LADYSMITH HOSPITAL, KZN.

Please note the following:

1. Ensure that you adher to all the policies, procedures, protocols and guidelines of the Department of Health KZN with regards to this research
2. This research will only commence once this office office has received confirmation from the Provincial Health Research Committee in the Department of Health KZN
3. Please ensure the office of the CEO before you commence your research
4. Ladysmith Provincial Hospital will not provide any resources for this research
5. You will be expected to provide feedback on your findings to the hospital

Thank you.

25/4/2013

DR. B.A. MABASO
Senior Manager: Medical Services
Acting CEO

PROVINCIAL HOSPITAL
2013 -04- 25
PROVINSIALE HOSPITAAL

uMnyango Wezempilo. Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

health
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Health
PROVINCE OF KWAZULU-NATAL

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Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM 089/13
Enquiries : Mr X Xaba
Tel : 033 – 395 2805

Dear Dr MJ Hossain

Subject: Approval of a Research Proposal

1. The research proposal titled **'To investigate the need for palliative care in cerebrovascular accident (stroke) patients at Ladysmith provincial hospital'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at Ladysmith Hospital.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 14/07/2013

---

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

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