



To Investigate the Need for Palliative Care in Cerebrovascular Accident (Stroke) Patients at Ladysmith Regional Hospital

Mohammed Jamil Hossain*

Department of Pediatric Hematology-Oncology, University of Santo Tomas Hospital, Manila, Philippines

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.

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.

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 in 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

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.

90% Confidence Interval specified limits [42% --62%]

(These limits equal prevalence plus or minus precision)

Estimated sample size: n = 68

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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

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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 [7], Turkey [8], and the Netherlands [9], 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 surviving 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.

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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.

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 finishing 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 provide qualitative data for the study. These were identified through the interviews and care needs. The interviews were conducted in isiZulu and the answers were stored in a database for analysis.

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

Table 2: Co-morbidities for participants.

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

Table 3: Psychological level of participants.

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%

Table 4: Other history.

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, describes the mean and the range of functional disability of the participants.

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

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

Figure 3 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 shows the statistical analysis inferential ranking of the 12 dimensions of functional disabilities. The mean and standard deviation was calculated to determine the statistically significant of different dimensions.

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

(Table 9) Pearson Product Moment Correlations-Dimensions (n = 72)

Correlations are Statistically significant at 0.05 level for n = 72 if $|r| \geq .232$

Practically significant if $|r| \geq .300$

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

Table 12 shows 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.

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 surviving from stroke to improve their quality of life. The questionnaires used had satisfactory core reliability with Cronbach's coefficients greater than 0.60 for all scales and greater than 0.70 for the [12].

Measures of reliability were acceptable in this study; Cronbach's 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.

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 Outpatient Department).

Thematic analysis developed the following themes: the first theme dealt with the life changing effect of the stroke. The second theme dealt

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

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	

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

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.

Discussion

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.

This study highlights the impact on physical, emotional and

