

The Socio-Economic Impact of Stroke on Households in Southern Zambia

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ABSTRACT

The World Health Organization (WHO) defines stroke as 'the neurological deficit of cerebral vascular cause that persists beyond twenty four hours or is interrupted by death within 24 hours'. In Livingstone, Zambia, more than 30% of stroke victims indicate socio-economic problems. The study aimed at assessing the socio-economic impact of stroke in households in Livingstone district. A total of 50 households were conveniently selected from the Physiotherapy and Community Based Rehabilitation registers of Livingstone General Hospital. Self administered questionnaires and Focus group discussions were used to collect quantitative and qualitative data respectively. The data was analyzed using SPSS and content analysis. The social impacts on the victim were depression, difficult to get along with, resentment, apathy, needy, separation, divorce, general marital problems, neglect on the part of the victim and fear. In families, there was low moods and apathy in households. The study also revealed an association between period of stroke and relationship changes ($p < 0.001$). Gender and family relationship changes were highly associated ($p < 0.001$), as more females than males experienced relationship changes. The economic impacts were loss of employment, reduced business activity and loss of business on the part of the victim. Economic activities like food provision, payment of school fees, accommodation

were affected as a result of stroke, and this led to financial insecurities in households. The study also showed that the incomes lost were mostly salaries, followed by businesses. Most of the victims experienced economic challenges after stroke with a few of them were receiving economic assistance. The activities forgone by stroke households were food provision, housing, and education in order to accommodate the stroke situation in the households. The results of the study show that stroke has considerable socioeconomic impact on households which can deter the victims' development as well as the household and the nation at large.

INTRODUCTION

Stroke is a non-communicable disease of socio-economic importance. The World Health Organization (WHO) ¹ defines stroke as 'the neurological deficit of cerebral vascular cause that persists beyond twenty four hours or is interrupted by death within 24 hours'. The risk factors of stroke are varied, and include hypertension, advanced age, previous stroke or TIA (Transient Ischaemic Attack), diabetes, increased cholesterol levels, estrogen containing forms of hormonal contraception, migraine with aura and thrombophilia and severe rare disorders ². The Framingham study revealed cardiovascular diseases, obesity and cigarette smoking to be highly associated with stroke ³. The clinical care of stroke is long and costly, qualifying stroke to be a chronic condition, hence the social and economic

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Key words: Stroke, household, socio-economic, impact, Livingstone

consequences, with the direct costs diverting the scarce family and societal resources to medical care⁴. Stroke, which affects mostly the productive age group, leaves about 65% of its victims disabled, leads to increased loss of manpower both at individual and national levels⁴. With the changing lifestyles, the incidence of stroke is increasing, and thus, 28 million people are estimated to die in 10 years time, just in Africa, due to Non communicable diseases, largely stroke⁵. The incidence of stroke is showing an increasing trend in Zambia⁶, due to hypertension, diabetes, advanced age and increased cholesterol levels. With the advent of HIV/AIDS, the dimension of stroke especially in patients between 20-40 years is increasing (Unpublished observations). Livingstone district, of Southern province, Zambia has not been spared by this increase⁷. Stroke, being a chronic condition, has considerable socio-economic impact on households which could be aggregated to national impact.

The study aimed at assessing the socio-economic impact of stroke on households in Livingstone, Zambia. Specifically, the study aimed at determining the relationship and role changes in households due to stroke, to verify lost incomes in households due to stroke, to verify opportunity costs in households due to stroke, to assess victims' willingness to form a stroke support group in Livingstone district. There is need to analyze the socio-economic impact of stroke on households in Zambia, for the magnitude of the problem to be documented officially. As the initial impact of the disease manifests at the individual level, the assessment would therefore start on this micro level of analysis. Although the prevalence of stroke is showing an increasing trend in Zambia, its socio-economic impact has never been evaluated (Unpublished observations). The study helps households in Livingstone district, to see the impact of stroke and motivates them to form a support group to enrich them both emotionally and psychologically. This study can be used as a reference by the Ministry of Community development and Social welfare and the Zambia

Association for the Physically Handicapped for the inclusion of stroke victims in their programs.

METHODS

A cross sectional study design was used to collect quantitative data using a self administered questionnaire targeting the stroke victims. Focus group discussion of spouses and caregivers was used to collect qualitative data. The study was conducted in Livingstone district, Southern province of Zambia. Livingstone district has a population of over 103, 288 and 18, 000 households²². Livingstone General Hospital has in place a Community Based Rehabilitation programme spearheaded by the Zambezi paramedical centre, offering rehabilitation services to the physically and mentally challenged in the community. More than 50 stroke patients are registered in the hospital register and in the Community Based Rehabilitation register. The study consisted of households who have stroke victims, in Livingstone district thereby the target population being victims of stroke, and their spouse or caregiver or guardian. Case definition of stroke in this study was weakness on one side of the body with a history of hypertension, TIA, diabetes, high cholesterol levels or any other risk factors of stroke following cerebral vascular accident.

Sample size was calculated as follows;

With more than 50 stroke victims in the Hospital and CBR register, the formula below was used, $n = z^2 PQ / d^2$

Where z is the degree of freedom at 95% confidence interval being 1.96

P is the target proportion required being 30% (Being the indication for socio-economic problems). Fifty (50) stroke victims answered the questionnaire, 20 spouses or caregivers or guardian participated in the Focus group discussion and these were conveniently picked.

In this study, the dependent variable was stroke and the independent variables were relationship changes, family role changes, lost income and opportunity costs.

Operationalizing variables

<i>Variable</i>	<i>Operational definition</i>	<i>Indicator</i>
Family relationship changes	Social relationship changes due to stroke	Marital problems, separation, divorce, abandonment, family problems, apathy, neglect
Family role changes	Changes in family roles due to the impact of stroke	family provider, dependency, assisted
Types of income lost	Income lost due to the impact of stroke	Employment termination, Business termination
Opportunity costs	Costs forgone due to stroke	Reduced food, accommodation quality, clothes, unpaid school fees, others

Impact of stroke

Social impact

Most of the respondents reported to have had change in their family relationships (Table 2),

After data collection, coding was done and responses were entered into a computer package, Statistical Package for Social Sciences (SPSS). Data was analyzed using Statistical Package for Social Sciences. Qualitative data from Focus group discussion was analyzed using *content analysis*. Chi square test for association of variables was used. Pretesting of the tools was done before use in the field to test validity and reliability. Identified shortcomings of the tool were corrected in order to answer the objectives of the study. Participants of the pretest were excluded from the sampling frame.

Ethical consideration

Ethical clearance for the study was obtained from The Research Ethics Committee of the University of Zambia, School of Medicine. An informed consent form was prepared according to the Research Ethics Committee guidelines which were issued to the participants in order to guarantee voluntary participation, confidentiality and maintenance of privacy for all participants in the research. Only those who volunteered to participate were included in the study. Written permission to conduct the study was sought from Livingstone General Hospital Management.

RESULTS

Demography

The majority of the victims were females (56%). The majority were in formal employment (48%) followed by those in self employment while dependants were the least (Table 1). Most of the respondents had had stroke for three years or more.

of these the majority were females (Table 3). A significant relationship between change in family relationship and gender of the victim was observed which increased with time ($p < 0.001$) (Table 4). The association was observed between the period of stroke and the relationships changes ($p < 0.001$). Table 5 shows the different types of changes experienced by those who had some changes in their relationship due to stroke. Table 6 shows percentages of family role changes. Female victims experienced more family role changes as compared to their male counterparts but there was no significant relationship between family role change and gender observed ($p \text{ value} = 0.2$). Table 7 shows the type of family role changes for those who experienced change in roles, with 63.6% of the respondents reduced to dependency. The majority experienced abandonment, followed by apathy and neglect. Of those who were married, the majority had change in marital relationships (Table 8). Table 9 shows the types of changes in marriage from marital problems to neglect and other unspecified problems. No association was observed between change in marital relationship and gender ($P \text{ value} = 0.413$). Of those who were either divorced or separated, the majority (52%), pointed to stroke as a contributing factor (Table 10).

Economic impact

Of the total stroke victims, only 38.5% of them retained their occupational status of which the majority were males (60%) (Table 11). However, no association was observed between retention of occupational status and gender ($p \text{ value} = 0.318$). Most of the respondents had lost salaries and businesses (Table 12). Table 13 shows the type of activities affected following stroke of which feeding

was the most affected at 43.6%, followed by education at 33.3%. Of the economic adjustments made in households, housing was the most negotiated, followed by School fees and food consumption (Table 14). The males made more adjustments in feeding, clothing and other unspecified adjustments while the females made more adjustments in school fees and accommodation.

Table 1: Occupational status before stroke

Status	Percentage
Dependant	22
Formally employed	48
Self employed	30
Total	100

Table 2: Change in family relationship

Presence of Change in relationship	Frequency	Percentage
Change in relationship	34	68
No change	16	32
Total	50	100

Table 3: Change in Family relationship with gender

Presence of change	Male	Female	Percentage
Change in relationship	16	52	68
No change in relationship	27	4	32
Total	44	56	100

Table 4: Change in family relationship with period with stroke

Period of stroke	Change in relationships (%)	No change in relationships (%)	Total
Below 3 years	22%	26%	48.0%
3 years and above	46%	6%	52.0%
Total	68%	32%	100%

DISCUSSION

The majority (68%) of the victims reported changes in their social relationships as a result of stroke. The social relationship changes could have been caused by the psychological sequelae of stroke in terms of social and emotional which can lead to depression and anxiety, changes in identity and personality process and this is potential for social isolation on the part of the victim him/herself⁸. The residual

Table 5: Type of family relationship changes

Type of change	Percentage
abandonment	32.4
Apathy	23.5
Neglect	23.5
Other	20.6
Total	100

Table 6: Presence of family role changes

Family role change	Male (%)	Female (%)	Total (%)
Present	36%	52%	88.0%
Absent	8%	4%	12.0%
Total	44%	56%	100%

Table 7: Type of family role changes

Victim role change	Percentage
Victim dependant	63.6
Victim assisted	36.4
Total	100.0

Table 8: Presence of change in marital relationship

Status	Male	Female	Total
Change in marital relationship	5	2	7
No change in marital relationship	3	3	6
Total	8	5	13

Table 9: Types of change in marital relationship

Type of change	Male	Female	Total
Marital problems	2	1	3
Neglect	1	1	2
Other (unspecified)	2	0	2
Total	5	2	7

Table 10: Stroke as a contributor changes in marital relationships

Stroke as a contributor To stroke	Frequency	Percentage
Yes	13	52
No	12	48
Total	25	100

Table 11: Retention of occupational status after stroke

Retained occupational status	Male	Female	Total
Retained	9	6	15 (38.5%)
Not retained	11	13	24 (61.5%)
Total	20 (51.3%)	19 (48.1%)	39 (100%)

Table 12: Types of Income lost following stroke

Lost income	Male	Female	Total
Salary	6	8	14
Business	4	3	7
Other	1	2	3
Total	11	13	24

Table 13: Type of activities affected

Type of activity affected due to stroke	Percentage (%)
Education	33.3
Assistance to family members	18.0
Food	43.6
Other	5.1
Total	100.0

Table 14: Economic adjustments

Economic adjustment made	Male	Female	Total
Reduced food consumption	5	4	9
Reduced school fees	4	6	10
Accommodation	3	8	11
Clothing	3	1	4
Reduce support to family	1	2	3
Other	2	0	2
Total	18	21	39

disability itself can also pose a threat to relationship ties due to the immobility of the victim and hence lack of socialization⁹.

The findings show familial relationship changes happened with time. For instance, the majority (67.6%) of those who had familial relationship changes experienced these changes in 3 years and more. There was an association between period of stroke and familial relationship changes with the P-value of 0.003. More female respondents (76.5 %) experienced the familial relationship changes as compared to their male counterparts. There was a strong relationship between sex and relationship

changes with the P-value less than 0.001. The types of relationship changes which included apathy, abandonment, neglect and others unspecified, were categorized from the victims' point of view. The majority of females, experienced abandonment as a relationship change. This could be due to female gender role of care giving in societies, because in their absence, less care is given resulting in abandonment¹⁰. Some were shown apathy and neglect while a few had unspecified changes. Concerning multidisciplinary management of stroke, there is need to address the issue of social withdrawal and familial relationships targeted at family care givers to alleviate familial relationship changes¹¹.

Family role changes were also noted in this study. The majority of the respondents were reduced to either dependency (63.6%) or to be assisted (36.4%) by family members. This is possible as there is presence of residual disability making it impossible for victims to return to their normal positions⁹.

Marital relationship changes were also observed. More males, compared to females, experienced change in marital relationships following stroke. The co-morbidity, general health status with psychological factors are the determinants of post stroke sexual dysfunction¹². Victims with sexual dysfunction may end up with marriage problems, as sex, which a very important part of marriage is not assured in such cases. Sexual dysfunction is as a result of muscular imbalance making sexual intercourse difficult for stroke victims¹³. There is evidence to the fact that spousal relationship altered significantly in terms of sexuality, sexual desire and function following stroke¹⁴. As a result of lack of duties expected in matrimony, from affection to intimacy, and when the victim is unable to offer or to be offered, this could bring strains on a marriage. The relationship changes in marriage due to stroke could have led stroke to be a contributing factor to either divorce or separation as shown in Table 10 where the majority accused stroke as the cause for their marital breakdown. Due to disability, stroke survivors experienced profound, complex and multifaceted difficulties in many areas of their spousal

relationships, which were distressing to both them and their spouse. This study is further supported by the fact that there is sexual impairment in both the victim and spouse and this calls for multi-dimensional evaluation of stroke patients and provides new challenges for stroke rehabilitation¹⁵. All these changes have an impact on the daily lives of spouses and affect their quality of life¹⁶.

The results showed that only 38.5% (less than half) respondents who were either formally employed or self employed, retained their occupational status following the stroke. The remaining were either severely disabled to work or to do business again. This is really a hit on the labour market because the majority could not do their former job or the employer could not keep them following a long sick off and hence laid off as being a liability to the company. In this study, more males retained their occupational status and had more stable jobs with higher education levels than their female counterparts, consistent with UNICEF country level statistics¹⁷.

Incomes are lost after stroke as the victim may be disabled, hence may not retain their previous occupation. In this study, more females lost income than the males, as they were not educated enough to have job security after being absent from work. The incomes lost, could help sustain families economically by bringing development to households and the nation at large. Such losses are termed as "health related set back to development"¹⁸. The economic change is present in 78% of the respondents in this study; hence the impact is very considerable. This goes with the activity affected requiring finance parallel to unretained status.

The findings names the activities affected namely payment of school fees for their children, assistance to family members, food and other unspecified activities. Food and education were most affected and yet these are what are needed for household growth and development as these are the basis for any development, be it at household or national level. In this case it can be said that the affected families' development has been deterred by stroke.

The economic adjustments made following stroke were reduced food consumption, challenges in paying school fees, reduced accommodation standards and clothing and reduced support to the family. More males adjusted food supply while more females' adjusted accommodation and a considerable number of males and females adjusted education. The difference could have been that more males owned their own houses than females but both had children's education to consider. These adjustments are the opportunity costs of stroke because the households had to forgo proper accommodation, food and education just to deal with stroke. These adjustments made, can hinder a household and nation to progress. At the moment, Zambia has no social system to support disadvantaged individuals after stroke. Those organizations offering assistance are non-governmental with special interest. As a result of the absence of social support system, the respondents' willingness to form a support group was very overwhelming. All the respondents yearned for a support group where they could support, encourage and build one another. Concerning Non Communicable Diseases, it was concluded that "if nothing is done to reduce the risks of chronic diseases, an estimated US\$84 billion of economic production will be lost from heart diseases, stroke and diabetes"¹⁹ in some stated low and middle income countries, like Zambia. This will require the effort of health policy makers to take non-communicable diseases seriously even under restrictive budgets and the burden of communicable diseases, and challenge two related myths that Non Communicable Diseases are not a significant cause of mortality and morbidity and that they are diseases of the affluent not important to developing countries²⁰. For such suggestions to be in place, mediation need to take place and this can only be done with a body like a stroke support group of which willingness to form a support group in Livingstone was 100% from the victims.

Implications of the study

The study findings have shown that stroke has considerable impact on victims and households

socially and economically, which can deter the victim's development as well as the household and the nation at large. This implies that if stroke is unchecked, social relations could be affected making the society socially unfit for any kind of progression or development. A socially sick society may be followed by increased depression, family breakdowns resulting in delinquency, reduced family ties²¹. Since a nation is comprised of societies, a socially sick society leads to a socially sick nation. A socially sick nation will be deterred in development because citizens will fail to see reason let alone progression. This goes for the same with the economy. A condition which affects the productive population puts households at risk of economic setback. Finances are required for all types of activities and development and with the economic impact as a consequence of stroke, the labour force is affected which is the main factor of development, hence consequences at both the household and national level. The study has demonstrated that the socio-economic consequence of stroke is considerable, and thence a deliberate policy on stroke should be put in place.

Stroke is a non-communicable disease and can be prevented. Prevention can be in schools, workplaces and communities. The highest parameter of prevention is knowledge empowerment through education. Health education can be achievable through the media and Information Education Communications. Management of stroke in Zambia has concentrated more on physical rehabilitation, whilst social rehabilitation has been left out. Social rehabilitation therefore needs to be included in a multidisciplinary management of stroke because there are multi-dimension effects following stroke. Occupational therapy needs to be promoted in Zambia alongside Physiotherapy as it focuses mainly on the occupation of the victim and addresses some other social facets as well. With excellent Occupational therapy, the economic impact of stroke can be reduced. Community based interventions in the management of stroke would be favourable if the impact of stroke is to be reduced. This would be appreciated more because the victims would be rehabilitated taking into consideration the

environment and surroundings with social aspects. It can be expected that under strong social ties and networks, even the economic impact of stroke is lessened.

CONCLUSION

Stroke has considerable socioeconomic impact on households and as a result, stroke victims need support in order to alleviate the impact of stroke on individuals and households. It is common knowledge that stroke affects adult individuals, who are assets to their families as well as the nation. The myth is that stroke is for the affluent nations but literature review has shown that the burden is increasing in the low and middle income countries of which Zambia is found. The study findings in Livingstone, Zambia show that its impact is very considerable and its impact is felt on more than half of its victims. The findings also show that the impact of stroke goes way beyond daily living and extends into the victims' welfare and development. According to this study, social impacts such as depression, neglect, apathy, separation, divorce on the individual part, and low moods in households are the sequelae of stroke and hence the impact is considerable. While the study has revealed economic impacts such as the loss of employment, reduced business activity and entire loss of business on the individual's part, these impacts can extend to households in that caregivers may need to let go of either job or business in order to care for the victim. In addition, the opportunity cost of stroke has been highlighted with activities such as food provision, accommodation and education having to be forgone in order to accommodate the stroke situation in the family.

ACKNOWLEDGEMENTS

Sincere and utmost gratitude goes to the following for their contribution and support towards this Dissertation:

The faculty of Public Health, school of Medicine, University of Zambia for the patience, constructive comments and advice rendered, without whom this study could not have been a success.

Marjory Mwansa Mambazi Mwang'u for being the research timekeeper and keeping the study on track.

Ministry of Health for sponsoring the Master of Public Health at the University of Zambia.

Livingstone General Hospital, for the assistance given physically and morally.

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