

Title: The Importance of Social Relationship and Support System after Stroke: A Qualitative Inquiry

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Abstract

Background: Stroke is currently the main cause of neurological disability in Nigeria. The impact of stroke can be devastating, leaving a person with significant residual impairment of physical, psychological, and social functions. The residual physical consequences can pose a significant threat to a survivor's quality of life: yet, we have an incomplete understanding of how stroke affects long-term quality of life.

Objective: To develop a thorough understanding how essential social relationship and support systems are to enabling long-term QOL following stroke.

Methods: This study reports finding from an in-depth interview with 15 stroke patients to understand the importance of social relationship and support system as essential dimensions of long-term quality of life following stroke.

Results: The key themes identified by the patients were: social and instrumental supports, communication, autonomy, social role adjustments, sexual relationship and stigma. A lot of the interviews with the patients consisted of narratives regarding how stroke altered social relationships with families, spouses, friends and significant others.

Conclusion: The finding of this study is consistent with the pre-existing researches attesting the importance of social relationship and support systems after stroke and therefore recommend including assessment of social functions and social support in estimating stroke-related quality of life.

Key Words: Stroke, quality of life, qualitative study

Introduction

Stroke as reported by the WHO is the second commonest cause of mortality globally and the leading cause of severe disability and therefore most common reason for rehabilitation (Geoffrey et al, 2008). The impact of stroke can be devastating, leaving a person with residual impairment of physical, psychological, and social functions (Hackett et al, 2000; Lai et al, 2003). During the sub-acute phase of stroke, when potential for further functional gain is limited, the psychosocial consequences of stroke become increasingly important determinants of health-related quality of life (Katherine et al. 2010; Lyncha et al. 1999). Although about one-third of individuals with stroke may develop post stroke depression, perceived social support may prevent either onset or duration of depressed mood (Salter & Teasell, 2010).

In stroke survivors, social support is believed to affect the quality of patient care and disease outcome, as well as patient's physical and psychosocial well-being (Lyncha et al. 1999; Tsouna-Hadjis et al. 2000). Studies have consistently demonstrated a link between low levels of social support and poor mental and physical health outcomes and have subsequently fuelled the development and evaluation of interventions designed to improve social support for those deprived of this resource (Brenda et al. 2002; Bruwer et al., 2008; Katherine et al., 2010; Lyncha et al., 1999). Apart from disability, psychosocial factors such as emotional responses and social support determine Health Related Quality of Life (HRQOL) in stroke survivors (Owolabi, 2008). In the broadest sense, social support cuts across any process through which social relationships might promote health and well-being (Kolella et al., 2004) and moderates the impact of functional status on well-being (Clarke et al, 2002; Tsouna-Hadjis et al., 2000). Improvement of accessible social support could be an essential plan in mitigating psychiatric distress and averting post stroke depression (Salter et al., 2010). The role of social support as a coping resource, in addition to its association to stressors and

mental and physical wellbeing has generated increased interest in recent years (Bruwer et al, 2008).

In stroke studies, qualitative paradigm underscores the individual's viewpoint of their stroke experience and discovered that stroke survivors describe their losses and improvement according to their subjective interpretation of crucial or important activities in life instead of the standard definition of disability (Clarke, 2009; Gubrium et al., 2003; McKeivitt et al., 2004; O'Connell et al., 2001). Therefore, qualitative study may help us explore how stroke affects wellbeing and thereby understanding the already established importance social relationship and support system after stroke (Clarke, 2009; Curry et al., 2009; Sale et al., 2002). In order to develop a thorough understanding of the important dimensions of essential to long-term QOL following stroke, it's indispensable to understand how the importance of social relationship and support systems to the patients following stroke. This study reports finding from an in-depth interview with patients which inquired their view-point on the importance of social relationship and support systems following their stroke.

Methods

Participants

Participants for this study were recruited from a sample of 233 stroke survivors who took part in an earlier quantitative study examining the determinants of quality of life among stroke survivors. Recruitment began after approval was obtained from the Medical Ethics committee of the University of Malaya (Eth. Comm. /IRB Ref number 830.7), Ministry of Health, Kano State, Nigeria (HMB/GEN/488/11) and Aminu Kano Teaching Hospital Kano, Nigeria (AKTH/MAC/SUB/12A/P3/IV/801). Matching with the concept of theoretical sampling (Clarke, 2009), stroke survivors were purposively selected or sampled according to the factors that were described as essential for QOL after stroke in the quantitative phase. A

total of 15 stroke survivors participated in this study. Owing to the repeated influence of increasing age (Gurcay et al, 2009; Kwok et al, 2007; Nichols-Larsen et al, 2005; Owolabi, 2008), physical and cognitive function (Carod-Artal et al, 2009; Clarke & Black, 2005; Clarke et al, 2000; Gurcay et al, 2009; Kwok et al., 2006; Lynch et al., 2008; White et al., 2008), social support (Bosworth et al, 2000; Clarke et al, 2002; Owolabi, 2008), occupation (Robinson-Smith et al, 2000; Vestling et al, 2003) and education (Aprile et al, 2006; Clarke, 2003; Clarke et al, 2002; Jeong et al., 2012) that have been found to be associated with wellbeing following stroke, thus we stratified the in-depth interview according to these factors to fully explore the findings from different age group on wellbeing following stroke. Participants were excluded if they have severe communication problems (i.e. aphasia) or cognitive impairments that would limit their ability to reveal their subjective experiences. The severity of stroke for each respondent (see table 1) is implied by the scores on the Modified Rankin Scale (MRS) and Barthel Index (BI). The MRS is a clinical measure utilized within international stroke research to assess disability after stroke in terms of global functional independence, and hence evaluate recovery from stroke (Haack et al, 2006; Jennifer et al, 2007) while the Barthel Index assesses the extent of self-reliance in the activities of daily living related to safe care and mobility (Carod-Artal et al, 2009; Haacke et al, 2006; Sangkaew, 2007).

Interview guides

In conducting a qualitative research, the researcher is the primary instrument who collects, observes analyses and interprets the research data. The interview guides as reported by Patton (1987) are commonly used to assist in these processes. The interview guide (appendix 1) has seven open-ended in-depth interview questions, drawn from the findings developed during the earlier quantitative phase by the investigator. Interviews were conducted in Hausa and so the interview guide was translated in to Hausa to use with the consented subjects.

Data collection

Using the interview guide, the investigator carried out an open-ended in-depth interview with the 15 selected stroke survivors in their homes and at a time that was suitable for them. Preparatory works included selection of an appropriate place, contacting the participants prior to the interviews and gaining their consents was ensured before entering the field. The process of conducting the interview was thorough and at the end of the first in-depth interview, we identified where the probing are needed. We did not phrase the questions in the same way each time, or follow the question sequence in a stringent manner thereby enabling discussion to evolve with the study participants. Moreover, interview guide serves as a rough checklist of points for discussion but each interview builds upon the particular issues that were brought about by each respondent. During the in-depth interview, few notes were taken to document something important that needed to be clarified, aid formulate question or as a note if probing was required. During the discussion sessions, participants were encouraged to give their views and probes were used to stimulate discussion whenever there were prolonged pauses during conversation. Interviews commonly concluded between 35 and 70 minutes, and all interviews were audiotaped with the permission of the respondents in order to obtain an accurate record of what was said and transcribed verbatim.

Data analyses

Interviews were conducted in Hausa and taped. Tapes were transcribed verbatim in Hausa and then translated to English. Data analysis of the interviews occurred concurrently and interactively with data collection. The first verbatim transcript examined on Microsoft Word was read many times in order to find the emergence of an intriguing pattern which would clarify the research question, open coded line-by-line for concepts and themes (Charmaz, 2006). A coding system described by Miles and Huberman (1994) which involved scrutinizing through the codes and reflective notes was used to identify connections,

differences and associations between factors. In an iterative process, emergence of identical or related and new concepts was looked for in consequent interviews, sequentially generating comparisons between the coding pattern and interview transcripts (Clarke, 2003; Strauss & Cobin, 1998).

Results

Table 1: Demographic and clinical characteristics of the study participants

Subject	Age	Sex	Stroke laterality	Date of stroke	Date of interview	mRS	BI
XI.	55	F	Left	November 18, 2010	February 27, 2012	3	80
X2.	50	M	Right	January 6, 2011	March 3, 2012	4	58
X3.	55	M	Left	November 19, 2010	March 7, 2012	3	68
X4.	40	F	Right	January 22, 2011	March 9, 2012	4	60
X5.	62	M	Left	December 9, 2010	March 11, 2012	4	75
X6.	35	F	Right	January 12, 2011	March 13, 2012	2	75
X7.	76	F	Right	December 15, 2010	March 15, 2012	5	19
X8.	48	F	Left	November 2, 2010	March 16, 2012	3	85
X9.	52	F	Right	January 11, 2011	March 17, 2012	3	62
X10.	61	M	Left	December 13, 2010	March 21, 2012	4	55
X11.	57	M	Right	January 15, 2011	March 27, 2012	2	82
X12.	52	M	Right	November 8, 2010	April 3, 2012	4	58
X13.	70	M	Left	January 2, 2011	April 7, 2012	4	58
X14.	65	M	Right	December 4, 2010	April 8, 2012	3	88
X15.	54	F	Right	November 24, 2010	April 15, 2012	1	91

Key: **mRS** = Modified Rankin Scale grades as: 0 indicating no symptoms; 1 (regardless of symptoms, no significant disability); 2 denoted as slight disability, 3 as moderate disability, 4, moderately severe disability, 5 means severe disability and 6(dead). **BI** = Barthel Index, The mean BI score of (< 20 was classified as total dependence and demanding “institutional care”; 21-60 as severe dependence; 61-90, moderate dependence; 91-99 as mild independence and 100, fully independent).

Fifteen stroke survivors out of which eight were males and six females were recruited. All of the 15 stroke survivors interviewed were diagnosed with stroke within the past one year and their age ranged from thirty-five to seventy-six years. Eleven of the survivors were married and four were widowed and lived with their children or relatives in a mostly extend family setting. Again, all the participants report being Muslim and belonging to Hausa ethnic group among whom ten are urban and five are rural dwellers. Nine among the fifteen respondents had suffered a left hemispheric stroke as shown in table 1.

The themes emphasizing the social relationships and support systems that emerged from the in-depth interviews include social and instrumental support, communication, dependence, sexual relationship, social roles adjustment and stigma.

Social and instrumental support

Respondents disclosed that they profited from the help of different social supports provided by their friends, spouses, and families and significant others. Social support themes consisted of narratives regarding how families, spouses, friends and significant others supported or did not support the respondents by rendering them emotional, financial and instrumental supports that were essential to them after their stroke. Mr. X2, a 50-year-old politician and businessman regarded the support he received from his brother, family and people around him as what helped him significantly improved as he stated:

- *I am happy with the support I am getting from my brother who is also my close ally, because he is seriously taking care of me with all his knowledge, his wealth and his health..... He all gave them for me... And I thank God, my relatives and the people around because everyone is trying his best for me with all his wealth, prayer and ...coming here to chat with me so as to help me get rid of my sorrows, they all do these things for me.(Mr. X2).*

He also described his stroke as a “lesson or a testimony” that God showed to him to see how he is regarded by the people due to the immense level of supports he received from them as he remarks, “*If not because of this stroke, if I am told this is how I am to the people I can doubt it... I can sincerely doubt it.*” Mrs. X1, who is a 55-year-old widow, narrated how she has improved owing to the emotional and financial supports she received from her children and the people that regularly visited when she recounts:

- *There are people that come to visit me and we sit and discuss.... Some that are willing would even give me money and I would pray for God to bless them. I feel happy.... Everybody feels happy when financially aided and will feel strong since you are helped with what you can use to buy kerosene and other things.... one actually feels happy. (Mrs. X1).*

Respondents also identified family members as rendering them with instrumental supports that were essential to them following their stroke. For participant X6, she found her daughters enormously supportive, remarks,

- *I have a well grown up girls that help me do almost all the home chores. They clean the house... Sweep the house, wash my plates and wash.... toilets, and also put water in the bucket and take it to bath room and even help me wash parts of my body that I cannot do by myself.... They are very supportive... (Laugh).*

Mr. X2, who walks using a walking frame describes it as “everything”, when he comments:

- *You see if not because you told me that you were coming, by now I would have gone out to walk around. I use this walking frame to walk. It's everything for me.... I always pray for a person that invented it. He actually tried a lot.... it helps us a lot. I enjoy it since the day I started using it up till today.... I now use it just as a pilot fly an aeroplane. This is how I walk with this walking frame (laugh).*

In turn, withdrawal of support and not being included in decision making could equally have a detrimental consequence on the survivor's subjective wellbeing. Withdrawal of support was characterized by reduced frequency of contacts with friends and family, especially friends. Respondents disclosed to have been abandoned by their friends and families and this experience of social isolation was the cause of distress in these respondents, due to feeling of loss as reported by the following participants:

- *You see to make the story short, at the moment.... People even consider me dead. They consider me completely dead. I am not even important now. To me, people look at me as completely unimportant and as a burden.... (Sigh) (Mrs. X6).*
- *.. I must be worried.... I must feel worried because, this room would have been full by early morning of everyday but not now. They do not come now because they are tired of me. By Allah people are now tired of me.... (Sigh). Before, I do whatever for them even before the time and now they see me disabled, neglected and not being cared for.... (Crying)(Mrs. X7).*

Communication

Perhaps due to the direct effect of speech problem on social relationship, respondents revealed frustrations and emotional reactions owing to communication difficulties resulting from their inability to effectively communicate. Mrs. X7 reports, "*It hurts when you are asked to repeat what you just said, I find this irritating!*" Frustrations with speech also seemed to be associated with the difficulty some survivors experience in associating with others and thereby affecting their self-esteem. The following participant recounts,

- *You see but if I talk my sound become confused.... my voice shiver and my mouth twist and so I am also worried in this regard.... And you see if I talk for sometimes, my voice diminishes and I find it difficult to freely associate with my friends all the time. (Mr. X12).*

Autonomy

Although appreciated the supports they received from the family, friends, spouses and significant others, some of the respondents felt very uncomfortable with their dependence on others. Perception of being a burden on others was associated with anxiety and a reduced quality of life. One of the participants was simply worried in part as a result of her perception to being a 'burden' to her only child and grandchildren when she stated:

- .. *Even a while ago I cried and cried.... (Sigh)... I cannot do anything. There is nothing I can do rather than to sit down..... And then lie down.... I do nothing. This is only what I do. I do nothing..... by Allah I do nothing. But I am tired about this..... (Crying).... you are only to keep sitting.....becoming a burden on your children I keep burdening them every now and then.... You see I am a burden to them, for we are always on the road to the hospital.... He has not benefited himself and neither do I. that's how we are..... (Pause).* (Mrs. X7).

Social roles adjustment

When asked to describe how they were limited in their social activities and how these affected their quality of lives, launching into biographical accounts of their lives, respondents recounts the challenges they face with respect to their social interaction with people. It was revealing from participant's discussions that social role limitation challenged relationships that are further distressed by their level of restrictions. Survivors no longer engage in their habitual activities and often become bored or depressed. Mrs. X9 who reported that she used to be a very socially active person before her stroke, but she could no longer involve in social events:

- *I am very limited regarding my social interaction with people. You see I cannot now go to people and associate freely especially during social events like wedding ceremony....You see I cannot talk for long time, share food for the people and all*

those things. Associating with my close friend and family becomes difficult.... I cannot roam about, I cannot do it and this worries me a lot..... (Pause).

For respondent X7, her inability to regularly visit her friends and family which is part of her cultural roles is the source of her frustration as she narrates,

- *When a social event arises I cannot associate with people. I don't even go except to delegate one of my children or grandchildren to represent me. I don't have a sound leg and is it not what one uses to walk? And so without a sound leg where do you go? You cannot go to people or visit. By Allah (she swears) you cannot visit and this is simply disgusting!*

Sexual relationship

Six of the respondents recounted the ways upon which the degree to which their sexual functions and relationship was affected following their stroke and demonstrated a decreased sense of wellbeing. For instance, Mr. X5 reported how he was devastated due to the complaints by his two wives over the loss of sexual functions he sustained following his stroke:

- *.... You can't relate with your family (wives) the way you are used to it before your stroke. Because you can do it at any time before, but you now lost the urge and you sometimes cannot even sustain your erection because the nerves are weak..... And your family (wives) always are worried that you don't pay your sexual obligations so this must disturbs one.... I feel worried and devastated..... (Pause) too bad!*

Similarly, Mr. X10, a 61-year-old former bricklayer expressed his frustrations when he lamented over how he was prevented from maintaining a sustained erection following his stroke and the effects it had on his relationship, he stated,

- *You see now I spend 3 months without having sex with my wife because my penis cannot be erect, even if I try and try it's not possible and I am still unable to regain its*

full function.....This is worrying me a lot, quite a lot and my wife is showing her serious worries. (Mr. X10.).

Mr. X3 attributed his decreased sexual functions to be associated to the medications prescribed to him at the hospital which he claimed to have reduced his libido and recounts how seriously the medications affected his sexual relationship with his wife of more than 25 years:

- *Actually these medications seriously reduce one's libido.... because sometimes a person will feel as if he completely doesn't have a penis and this causes worry..... This really affected my quality of life to a large extent since there is nothing like libido and so there is nothing like having sex except that you..... even my wife is more worried because she always wants to see me strong and happy.*

The degree to which the stroke influenced the survivor's quality of life also appeared to rely on the extent to which their physical disabilities affected their sexual relationships. For instance, Mrs. X4, a 40-year-old former tailor remarks, *"The hand is the problem and so you are very limited in that regard, because the hand cannot do anything"*. Similarly, Mr. X11 stated that:

- *..... You see the hand is weak and is making it difficult for me to have sex with my wife. The strength of my erection has also reduced..... But the hand is more problematic in that regard.*

Stigma

Interestingly, two out of the four rural and one out of the ten urban dwellers among the respondents mentioned occasions of being stigmatized by the people due to the disabilities that resulted from their stroke. Mrs. X7, who is bedridden and incontinent, explained how she felt stigmatized by the people following her stroke. She narrates,

- *..... If a person intends to come, he then stops. I realize they run away from me... because of my urine odour..... Urine odour! If not destiny how could a person like me wet at night? It's very annoying indeed. It hurts me a lot... how can a mature person wets her wrapper”.*

Mrs. X8, who is a widow, also reports that, “It hurts when some people became afraid of you. They thought that this is caused by evil spirit... it hurts”. In the same vein, Mr. X12 uttered frustration and felt devastated over the instances he was stigmatized following his stroke, he recounts,

- *Some people run away from me and don't want me to be in their midst, so you see I must be worried..... People show that it's infectious; one can get infected when I know that it's not like that but I disengage from them. If I call a nail cutter to cut my nails, he then tells me that he will not do it..... The barber also tells me that he will not cut my hair..... The barber will not come because he was told that he can get infected, this is why I am very devastated. Even if I sent someone to buy me food, people are afraid of my food container because they feel that the disease may be infectious and I am really worried in this regard..... I can move around before but I cannot go to the midst of the people or their gathering but I follow where there are no people. (Mr. X12).*

He also stated that:

- *If I go out and women see me they run away as if they see a mad man because you know our village people..... So they use to run away and you wonder what they are afraid of.... If I see people running away from me I feel very worried.*

Discussion

The qualitative narratives from the perspectives of the stroke survivors in this study suggest the importance of social relationship and support systems as an essential aspect of long-term stroke-related quality of life. Following their stroke, survivors intimated how stroke altered social relationships with families, spouses, friends and significant others and how they could no longer be the persons they used to be. When asked to narrate how stroke affected their QOL, the majority of the narratives that emerged from the in-depth interviews were associated to the changes in social relationship and support system. The themes identified by the patients included social and instrumental supports, communication, autonomy, social role adjustments, sexual relationship and stigma.

The finding of this study is consistent with the pre-existing researches attesting the importance of social relationship and support systems after stroke (Clarke, 2009; Clarke & Black, 2005; Curry et al., 2009; Sale et al., 2002) and so it's not amazing that social relationship and support system appeared as a main determinant of QOL for stroke patients. The major effect of stroke is role limitation. Launching into biographical accounts of their lives, respondents recounts the challenges they face with respect to their social interaction with people. It was revealing from participant's discussions that social role limitation challenged relationships that are further distressed by their level of restrictions. Our findings revealed that the dynamics of recovery comprises of processes involving both the individual and the surrounding social world and must be collectively considered (Clarke, 2009; Clarke & Black, 2005). Social relationship and support system as reported by Lynch et al (2008), Levasseur & Noreau (2004) are essential to the survival of the patients after and therefore of significant importance to QOL after stroke. Measures of health-related QOL should include assessment of social relationship and support system otherwise, may be lacking in one of the most essential dimensions of QOL for patients after stroke.

Qualitative studies underscore the individual's viewpoint of their stroke experience and discovered that stroke survivors describe their losses and improvement according to their subjective interpretation of crucial or important activities in life instead of the standard definition of disability (Clarke, 2009; Gubrium et al., 2003; McKeivitt et al., 2004; O'Connell et al., 2001). The social components of QOL after stroke may be better captured as such, and may be independent of physical and psychological domains of QOL. Social relationship and support are important in helping stroke survivors engage in adaptive strategies and return to work thereby reporting an improved QOL. Our study suggests that social factors have a buffering or moderating effect in stroke survivors, helping to reduce the adverse effect of the consequent disability on wellbeing. Conversely, withdrawal of support could equally have a detrimental consequence on the survivor's QOL. Some of the narratives illustrated how the detrimental effects of disability following stroke are more obvious in survivors with negative social supports, largely due to reduced ability to adapt to disabilities. Even in certain occasions, some of the respondents uttered frustration and felt devastated over the instances they were stigmatized following their stroke.

The interpretation of this study is limited by the fact that although the participants from different educational and socioeconomic backgrounds were recruited in the study, this study was conducted on participants mainly from urban area as such the findings of this study cannot claim generalizability to all stroke survivors in Kano, Nigeria. The qualitative interviews were also limited to 1 in-depth interview per participant and so may not capture any change over time. If the interviews were to be conducted at different times, the participants may have provided for different answers/narratives to similar questions.

Conclusion

Despite the limitations of this study, the findings of this study permit a more comprehensive understanding of the importance of social relationship and support after stroke. It enabled a more informed interpretation of the underlying reasons why these factors are associated with QOL after stroke explained from the viewpoints of the patients. Our findings therefore further reiterated and reflect on one of the issues that are important and salient to stroke patients.

This study therefore, recommend including assessment of social functions and social support in estimating stroke-related quality of life.

Conflict of interest: The authors report no conflict of interest.

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Appendix

Interview guide

F1: Demographic and Health profile data

Name:

Age:

Sex:

Stroke laterality:

Date of stroke:

Date of interview:

F2: Interview Guide

Interview Guide with probes to used for in-depth interview with stroke survivors

I would like to ask you some questions about yourself. Can you tell me about how has this stroke affected your quality of life?

1. How are you limited in your day-to-day activities and this affect your quality of life?

(Probes: Your ability to sit, stand and walk from one place to another? Activities such as dressing yourself and taking bath? Do household chores? Go shopping and carry things?)

2. How are you limited in your intellectual or cognitive pursuits (e.g. residual memory problems) and how this affects your quality of life?

(Probes: Remember things that people just told you? Solve everyday problems? Remember to do things (e.g. keep scheduled appointments or take medication)? What about perceived change in body image?)

3. How are you limited in your social and recreational activities and how this affects your quality of life?

(Probes: Understand what was being said to you in a conversation? Has your role as a family member and/or friend being affected? Your ability to control your life as you wishes e.g. participating in all ceremonies invited? What kind of social activities and recreation you find relevant? What kind of social and instrumental support do you consider? What about issues related to stigma? What about relationship with husband/wife, does this disease affect that?)

4. How are you limited financially and how this affects your quality of life?

(Probes: Financial hardship either related to income or cost of care and hospital treatment charges? What about personal loss of income or that of a supportive family member?)

5. How are limited in your religious activities and how this affects your quality of life?

(Probes: Your participation in spiritual or religious activities? What about your ability to help others? Praying alone and in congregation? How do physical restrictions and limitations affecting religious activities? What about spiritual and religious resources if applicable?)

6. How are you limited in your career and vocational pursuits and how this affects your quality of life?

(Probes: Your work (paid, voluntary or other)? What about your occupation or source of livelihood? How the feeling of dependency and or loss of job do affected your quality of life? What about the issues of return to work and vocational/job flexibility?)

7. What are the other issues that limit you and how do they that affect your quality of life?