

ORIGINAL REPORT

A QUALITATIVE STUDY OF QUALITY OF LIFE AFTER STROKE:
THE IMPORTANCE OF SOCIAL RELATIONSHIPS

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Background: Stroke is a leading cause of long-term disability in the USA; however, we have an incomplete understanding of how stroke affects long-term quality of life.

Methods: We report here findings from focus groups with 9 long-term stroke survivors and 6 caregivers addressing patients' post-stroke quality of life.

Results: Key themes identified by patients were: social support, coping mechanisms, communication, physical functioning and independence. Role changes in patients were important to caregivers. Much of the discussion with patients and caregivers described specific ways in which the stroke altered social relationships.

Conclusion: These findings are consistent with prior research indicating the importance of social factors to quality of life following stroke. Our findings suggest that measures of stroke-related quality of life should include assessment of social function and social support.

Key words: stroke, quality of life, qualitative analysis, social function.

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Surviving a stroke can be a long-term process that affects many aspects of a person's life. In fact, stroke is a leading cause of significant disability in the USA, with approximately 700,000 people experiencing a new or recurrent stroke each year (1). From the early 1970s to the mid-1990s the estimated number of stroke survivors increased from 1.5 to 2.4 million (2). Of all neurological conditions, stroke may lead to the most long-term disability (3). Ideally, treatment for stroke should improve patients' quality of life (QoL) by reducing the long-term consequences of the event. Measurements of treatment efficacy that rely upon biological or clinical assessments do not always capture dimensions of health that impact the QoL of patients (4–8). Health-related quality of life (HRQL) instruments are designed to measure health status from the perspective of the patient, and usually include the following dimensions: physi-

cal functioning, social functioning, role functioning, mental health, and general health perceptions (9–11). Patient-reported outcomes, such as HRQL, can capture more subtle changes in health than are captured by traditional measures such as life expectancy (4).

Evidence suggests that current HRQL measures are insensitive to important determinants of life satisfaction for survivors after stroke (12–15). In particular, studies investigating determinants of HRQL following stroke suggest that social functioning may be more important than physical functioning in determining QoL (14–16). Unfortunately, generic measures of QoL are often not sensitive to important differences in social functioning and thus, may fail to capture this important dimension of patient's lives (6, 11–13). For example, the social functioning scale in the Short Form 36 health survey questionnaire was found to correlate poorly with a measure of lifestyle activities relevant to the elderly (12).

In order to derive a complete understanding of the dimensions relevant to long-term QoL following stroke, it is essential to understand how patients and those closest to them view the effect of stroke on patients' lives. The current study describes findings from focus groups with stroke survivors and their caregivers, which solicited their perspectives on post-stroke QoL. Focus group methodology was used because it is an effective format in which to generate a variety of ideas in response to open-ended questions (17). We asked participants to talk in an open-ended format about how their QoL, or that of their care recipients, has been affected by stroke. Our main goal was to identify dimensions of QoL that are important to patients after stroke in order to support development of a disease-specific HRQL measure for stroke.

METHODS

Participants

Participants were recruited through flyers posted in various settings, including local patient-centered associations and clinics. Physicians, clinic staff, and members of associations aided in the recruitment process. All patient-participants were screened for the following criteria before participating in the study: age 18 years or older, English-speaking, diagnosed with stroke by a physician, not currently hospitalized or living in an inpatient setting, cognitively able to grant informed consent, and physically able to engage in a 60–90 min round-table discussion.

Caregivers were recruited in a similar fashion and were interviewed separately from patients. Participant criteria aimed to capture a varied sample of participants with respect to symptomatology and age. However, individuals with symptoms such as severe aphasia and chronic fatigue would not have satisfied eligibility criteria for the patient focus group and were not recruited. Participants were recruited and focus groups were conducted in Chicago, Illinois, USA, from October 2005 through March 2006. Participants completed a consent form prior to study participation, and focus groups were completed in 2 hrs. All study procedures were approved by the ethics committees of Evanston Northwestern Healthcare and the Rehabilitation Institute of Chicago.

Five men and 4 women participated in the patient focus group. The mean age of participants was 54.7 years (median 57 years). Eight participants from the patient focus group were African-American and one was Caucasian. The mean number of years post-stroke was 11.9 (range 2–29 years). Four patients were married, 3 were single, and one was widowed (marital status of one patient was unknown).

One man and 5 women participated in the caregiver focus group. Four caregivers' care recipients were their spouses; for one caregiver the care recipient was the mother, and for another caregiver the care recipient was a neighbor. Three caregivers were Caucasian, 2 were African-American, and one was of unknown ethnicity. The mean age of the care givers was 57.2 years (median 60 years). One caregiver's mother and another caregiver's wife were in the patient focus group. The mean age of the care recipients was 65.6 years and the median age was 63 years.

Focus group discussion guide

In the first part of the focus group patients were asked to describe how their QoL had been affected by the stroke, and caregivers were asked to discuss QoL issues for their care recipient. Following the general query, patients and caregivers were asked whether they had experienced changes in specific dimensions of QoL. The QoL dimensions that were covered in the focus group were ones that had previously been identified in the literature (e.g. communication, self-esteem, physical functioning). The moderator only asked about specific dimensions that had not been spontaneously raised in response to the general query. Because we were especially interested in themes that were most salient to participants, in the current study we focus our discussion on themes that emerged in response to the general query about QoL, and note when similar themes emerged during questioning about specific dimensions of QoL.

At the start of the focus group, the moderator briefly explained that the goal of the focus group was to try to understand better the issues of QoL that affect people with certain neurological conditions, such as stroke. Participants were asked to express themselves openly and discuss among themselves, and were told that there were no right or wrong answers to the questions. Occasionally moderators included additional questions or altered the order of questions for the purpose of building rapport with participants as well as to maintain a natural flow of conversation.

Analytic procedures

Audio recordings of the focus groups were transcribed with all personal identifiers removed. Focus group transcript text was imported into QSR N6 (18), a qualitative data analysis and management software package. Two coders (EL and ZB) identified themes independently, compared codes, and resolved disagreements. Analysis was concluded when the coding overlapped sufficiently and the coders agreed that the themes adequately captured the key issues. Coders also indicated whether themes had emerged spontaneously or during explicit probing of specific dimensions. We also indicated whether themes were raised by caregivers or patients.

RESULTS

A majority of themes discussed by participants referred to changes in social relationships that resulted from the stroke. Themes emphasizing social relationships include social support, communication, role changes, and patient independence.

Themes which did not emphasize social relationships, that is, individual-level themes, include coping strategies and physical functioning. Issues related to pain, memory loss and other cognitive problems (with the exception of communication problems), and personality change were probed, but almost never raised spontaneously by either patients or caregivers. The effect of stroke on emotional wellbeing was raised occasionally by caregivers, but never raised spontaneously by patients. Often the comments elicited in response to probing of these dimensions fell into the themes discussed below and those comments are described where appropriate.

The remainder of the results section is organized into 2 main sections: the first discusses themes related to social relationships and the second discusses individual-level themes.

Social relationships

Discussions of social relationships focused on 4 main themes: social support, communication, independence, and role changes. Each of these is discussed below.

Social support

One of the issues most frequently raised by stroke patients was the maintenance of critical social relationships. Our findings suggest that stroke puts severe stress on social relationships and, according to the patients, often results in breaks with significant others, for example, spouses or children. Changes in these relationships have a deep impact on both patients and caregivers. In contrast to patients, caregivers were more likely to mention ways in which the stroke strengthened patient relationships with significant others (i.e. spouses or children).

Patients. Social support was the first theme to be raised spontaneously by patients. The theme of social support captures stories about how friends and family supported or did not support them following the stroke. For patients, the focus of discussion was on people who were not supportive. Many participants told stories about family members who left them or refused to communicate with them after the stroke.

... all the people I worked with... stood by me.But I had an unusual situation, because my daughter, who is a doctor now, she hasn't come to grips. ...she can't look at me like a normal person.

... it's so hard. I have a son in the Navy, and Red Cross notified him, that I had a stroke, and he told them he didn't care about me anymore...So I've had to deal with my own children.

Not only did patients describe experiencing a lack of social support within their own families, but they also cited many cases of friends who had similar experiences. Patients discussed this issue extensively, providing evidence from their own as well as other people's experiences.

... I know about ten couples that they may have a stroke...Do you know (their spouse) left them? They left them high and dry. I had a friend – he had a stroke. His wife left him.

...the same thing happened to my girlfriend. Her husband brought her home...but he eventually, six months later, he

(divorced) her, you know...Now I know I've got a caring husband, a kind husband, a loving husband, but everybody don't have that.

This topic was unique among the themes raised by patients in that people told stories about friends in addition to discussing their personal experience. The extent of discussion generated by the issue of social support reflects its importance to patients.

Caregivers. In contrast to patients, caregivers tended to raise social support issues only in response to specific prompts. Many caregivers reported that their loved ones' stroke brought the family closer together. Less frequently, caregivers mentioned family members who were impatient or angry with the patient after stroke.

Communication

Patients mentioned loss of speech more frequently and with more emotion than other immediate repercussions of stroke, such as physical disability, perhaps because speech problems have a more direct impact on social relationships than do other stroke-related disabilities. Patients reported experiencing extreme emotional reactions because of communication difficulties, and described humiliating experiences that resulted from lack of ability to speak to medical professionals. Problems patients experienced with speech, often from the acute phase of the stroke, remained salient even long after speech had been recovered. Frustration with speech also appeared to be closely related to the difficulty patients experience being dependent on others, a theme discussed below. In contrast to patients, caregivers rarely mentioned speech problems.

Patients. Problems with speech were important to patients and experiences related to communication problems were raised frequently and spontaneously. A number of patients mentioned that their self-esteem or self-confidence was affected by speech problems.

That's what I mean about my self-confidence being affected, because it seems like I'm being judged by my speech.

I hate when people ask me "what did you say", because I won't repeat it. I just won't. If you didn't understand me, then you just didn't understand me. I don't care. I'm not going to repeat it.

Caregivers. Despite the importance of communication problems to patients, no caregiver raised this as an issue until directly probed. Speech issues did not seem to be a major concern among caregivers. Two caregivers mentioned that speech is sometimes more difficult for their care recipients when they are tired or angry, but that generally it is not a problem.

Independence

Patient independence was raised frequently by both patients and caregivers, and their views were often concordant. Patients expressed frustration that caregivers thought they were not able to perform basic tasks, and caregivers expressed frustration that patients did not want help.

Patients. Independence was a critical issue for patients and was closely linked to discussions of social support. Discussions of independence reflected a deep ambivalence among patients. They reported appreciating the support of their family and other caregivers; however they felt very uncomfortable with their dependence on others.

The only thing is that I kind of don't like to have to depend on people to take me places... sometimes you feel like you're dependent, you know, and I don't like that feeling.

...another thing is that I don't put my expectations on anyone...I'm self-sufficient, you know, and every day I take care of myself with just a minimum amount of help. You know, family, you know, they're the first to let you down...I just don't put no expectations on anyone, you know.

Independence issues came up frequently when patients were probed about mood swings. One participant mentioned having strong emotional reactions to family members trying to help him. In some cases, patients described reacting angrily because they felt their caregivers were encouraging their dependence.

...Mood swings...I think mine was usually when my wife would come to help me ...and I would (say) "stop it, go away, let me dress myself, you know...Where did you come from?" "I'm here to help you." "Well, if I don't learn for myself and you keep coming to help me, I can't learn." And that was making me angry, because she kept helping me.

Caregivers. The discomfort patients felt about being dependent created problems for caregivers. Caregivers spontaneously mentioned that their care recipients would not admit to having a reduced QoL, and wanted to believe that their life had not been affected by the stroke. According to caregivers, care recipients commonly deny that they need help and become angry with the person trying to help them.

I believe he feels the quality of life is he's a victim of a stroke, but yet he wants to do things ... to prove that he has no shortcomings because of the stroke. It's just a temporary setback for him. And he wants his life to be as it was, even though it's restricted...he doesn't take help or assistance very well... "leave me alone, I can do it. I might be a little bit slower at doing it, but leave me alone."

Many spouse caregivers talked about how their husbands do not want any help and get angry when they try to help them.

... it's hard for him to accept any help from me or his sons, because well I can do it if you just give me a minute, you know. Or, my guys can do it, you know. I can do it. Don't help me unless I ask you. And that's kind of hard sometimes when you see him struggling. Don't help me... I go and cry... You know, because I feel like he's pushing me away, you know, with his independence. I appreciate it, but then I want to help more than I do.

When probed about cognitive/mental changes in their care recipients, caregivers claimed that patients were reluctant to acknowledge cognitive limitations due to their strong resistance to feeling dependent on others. For example, patients refused help with tasks such as balancing the checkbook and/or became depressed due to their inability to perform those tasks and their consequent dependence on others.

Role changes

Caregivers tended to see the QoL of patients being most deeply affected by role changes. Role changes were also related to issues of dependence and social support. Social roles are altered radically when patients can no longer work. It was apparent from participant discussion that shifts in social roles often challenge relationships that are already stressed by the newly dependent status of the patient. Caregivers seem to view role changes as a problem because patients can no longer engage in their regular activities and often become bored or depressed. Interestingly, patients rarely discussed role changes.

Patients. Patients rarely discussed role changes spontaneously. In the context of other topics, a few patients talked about missing work because it gave them meaning, but other patients said they did not miss work.

Caregivers. Role changes due to the stroke were the most frequently raised theme among caregivers during the open-ended section of the discussion. One of the first topics mentioned by female caregivers was a concern that their husbands (all but one of the caregiver participants was female) no longer had much to occupy their time, and in some cases this led to depression. The topic of patient depression because of inability to work also came up when caregivers were asked about cognitive or personality changes.

That's the one thing I wish my husband could do, find something to do. He wakes up every day, gets dressed at 7:30 in the morning, and has nothing to do.

It depends. I just find – I find him very moody. I mean, just very moody, you know, and most of the time it's depression.

That is most of his problem. (That's) the biggest part of his problem, (he's) depressed because he's not working.

Individual-level themes

Unlike previously discussed themes, the remaining dominant themes, physical functioning and coping, are topics that can be conceptualized as individual in nature, rather than social. For patients, and especially for caregivers, physical limitations were seen to have important and devastating social consequences. However, it is clear from the discussion that patients saw physical limitations as challenges to be overcome by their own individual effort. They believed that it was their job to recover from the physical consequences of stroke, and they developed personal coping strategies in order to do so. Patients firmly believed that having a positive state of mind enabled them to overcome physical limitations. A few patients mentioned seeing their limitations as a personal test. The themes, physical functioning and coping, are discussed below.

Physical functioning

Patients. Patients mainly discussed physical functioning issues that were present during the acute phase of their stroke. The focus of discussions about physical function emphasized how patients managed to overcome physical limitations that resulted

from their stroke. Another way in which patients discussed physical limitations was to express their anger about how physical limitations led to role changes (e.g. lack of a job). For example, one patient explained that he used to do sound recording for churches before the stroke. He lost these jobs after his stroke, but feels that he is still able to do the work and is confused as to why the churches no longer want to hire him.

The following quote illustrates the determined attitude of these participants to “conquer” their physical limitations.

You know, like once you learn how to put your shoes on, your trousers on, maybe your washing of yourself, everything else comes secondary. Even though I've been trying to walk again, now that's a scary part too. You fall so many times you learn to fall without hurting yourself, but once you get up on your feet and you're upright, that's another barrier that you've conquered.

While much of the discussion of physical limitations was aimed toward demonstrating that they were not a barrier, on occasion patients acknowledged that their physical problems placed limitations on what used to be routine activities.

You know, it's aggravating for me, like dressing, you know – like this is okay, as long as I'm dressed like this I can do (it). Like if I want to wear a suit and a tie, I could never dress right because I can't tuck this side my clothes, you know. You know, like that's very frustrating, but as long as I dress this way, I'm good to go. You know, jeans, shorts.

Patients reported learning to adapt to their physical limitations, for example, by learning the kinds of clothes they can manage, and how to do activities like read a book.

Caregivers. Occasionally physical limitations were mentioned spontaneously by caregivers. For caregivers, physical limitations of their care recipients were almost always discussed in the context of how they affected other, usually social, aspects of life. For example, 2 participants mentioned physical limitations as reasons why their care recipient could no longer work, which led to other problems, specifically depression and boredom. Another caregiver talked about the difficulty of knowing when to help the care recipient. The importance of patient independence is illustrated in the quote below.

And if they can do it, it's really a hindrance to them if we jump in, because what happens if we can't be there? I – a lot of times – B can open the car door, but he struggles with it, but after a while we let him do it, because it's good for him, but you wouldn't believe the comments from people that are running over to get the car door, and looking at me going, why can't you help. But there are certain things that they need to do.

Coping strategies

Patients. During the spontaneous portion of the interview, patients commonly discussed their strategies for coping with the impact of the stroke. A commonly reported coping strategy was a persistent emphasis on the positive and de-emphasis on the negative aspects of their stroke.

I don't have no time for no self pity. I just know I can't – there's no room in my life for that to ... You know, you project that nega-

tive energy, you know, that goes out... into the atmosphere... with other negative energy, and it comes back at you...

Participants also reported coping with the stroke by viewing it as a test and framing the stroke in religious terms.

I never would give up on anything, and I'm being tested now to see if I – it's the biggest test I could ever have, my own life...

You can go through anything with the blessing of God... because He's the main doctor.

Whereas many of the other themes were presented by 1 person (and commented upon by others), discussions about coping strategies took place among multiple participants, with each finishing one another's sentences. Coping strategies appeared to be extremely important to patients.

Caregivers. Caregivers rarely commented on how patients coped with, or made sense of, the stroke. Some caregivers discussed the meaning of the stroke for themselves when probed about how the stroke affected family and spouse relationships. Many felt that the meaning of the stroke was to bring their family closer, for example:

... I feel that it really brought him closer to his sons. Because for a minute, before he had the stroke, he was kind of like out there, just wild and crazy, but this, really this turned him all the way around, and so it ... brought his sons together.

DISCUSSION

Our focus group data suggest that maintenance of healthy social relationships may be the most important and salient influence of stroke on QoL, from the perspective of both patients and caregivers. When asked to describe how QoL was affected by the stroke, most of the discussion that spontaneously emerged among focus group participants was related to changes in social relationships. For patients, themes that related to social relationships included social support, especially lack of support from significant others, feelings of frustration resulting from increased dependence on others, and difficulty communicating. Themes related to social relationships that were mentioned by caregivers included emotional problems suffered by patients due to changes in social roles, such as the inability to return to work.

It is not surprising that social relationships emerged as a major determinant of QoL for stroke patients. An important impact of a stroke is a radical shift in social roles. The reactions and behavior of socially significant others impacts the QoL of the stroke survivor. In fact, surviving a stroke is necessarily a social effort. A majority of stroke survivors must depend on others for everyday activities (19). Therefore, social relationships are critical to survival for patients after stroke and become of critical importance to QoL.

Our findings are consistent with research that distinguishes social interaction as an important dimension of health that is essential to rehabilitation (6, 7, 15, 16, 20, 21). For example, King (15) found that social support was one of the primary influences on post-stroke quality of life. Current and previous research findings suggest that HRQL measurements among stroke survivors should include assessments of the quality of

their social relationships. Measures that do not directly address the condition of social relationships may be missing one of the most important dimensions of QoL for patients after stroke.

Common HRQL tools, such as the SF-36, typically measure social functioning with only a few general questions, and often phrase them as to whether physical or mental health cause social limitation. For patients after stroke, the social aspect of QoL may be better captured by a measure of social support or a measure of patients' perceptions of the subjective quality of their social relationships. Furthermore, social functioning may be independent of physical and mental aspects of QoL, or it may play a causal role with regard to physical and mental problems.

In contrast to the other themes, patients discussed physical functioning and coping strategies as personal issues rather than social ones. Patients reported "conquering" physical limitations and managing the stroke recovery process through positive thinking and religious faith. Patients discussed recovery of physical functioning as being under their individual control. Research supports the view expressed by patients that maintenance of a positive attitude is critical to their recovery. Even 2 years post-event, stroke survivors have an elevated risk for depression (22) and depressive symptoms and apathy have been associated with delays in functional recovery (23–25).

Comparison between issues spontaneously identified by caregivers and patients suggests that they see the impact of stroke on patients differently. Caregivers were more likely than patients to mention negative effects of role changes (e.g. negative consequences of not working) and improvements in social relationships, whereas patients were more likely to mention negative changes in social relationships, speech problems, and coping strategies. There are a number of possible explanations for differences in emphasis between caregivers and patients. One possibility is that the experience of care recipients and patients differed, though we have no reason to believe that was the case. Another possibility is that patients are less willing than caregivers to discuss certain factors, such as how role changes affected their lives.

We think the most likely possibility is that patients and caregivers experience the stroke very differently. Caregivers, especially those whose care recipients were spouses, occasionally raised the issue of how the quality of their own lives had been affected by the stroke, mainly due to the changed role and increased dependence of the patient. It is possible that caregiver descriptions of the QoL of their care recipients were highly influenced by parallel changes in their own QoL. This difference in perspectives calls into question the assumption that caregivers can serve as proxies for patients (26). Furthermore, this difference in perspective between patients and caregivers may exacerbate the strain on social relationships that is created by the stroke. Perhaps if patients and caregivers were more aware of each other's perspectives this would help each manage the dramatically altered relationships that occur due to the stroke (27).

Discussion of physical problems during the acute phase of the stroke did not elicit the same degree of emotional reaction among patients as did discussion of communication problems. Speech problems may be more influential on QoL than other physical or cognitive sequelae of stroke because of their direct impact on social relationships.

Limitations

This study was based on findings from 2 focus groups and so the generalizability of the present findings is limited by the size of the sample. Participants of the focus groups are not fully representative of the stroke patient and caregiver population and, thus, our sample may not have captured the complete range of views about how stroke affects QoL. However, the size of the focus group sample does not detract from the clear importance of social relationships for stroke patients' QoL.

Another limitation of the focus group methodology is that, due to the social context of the discussion, some participants may be less likely to vocalize disagreement. Consensus in responses may be lower than it appears in the social context of the focus group. For this reason, focus groups are used to generate hypotheses rather than test them.

The current study was exploratory and the results should be confirmed using quantitative measures in a large representative sample. Because they provide the subjective viewpoint of stroke patients, findings from this study may be valuable input to the creation of quantitative measures of QoL. During the focus group, patients frequently mentioned that medical personnel, even those who are very familiar with stroke, demonstrate little understanding of what it "feels like" to experience a stroke. Furthermore, our data suggest that the perspective of caregivers differs systematically from that of patients. Because QoL is, by definition, a subjective phenomenon, it is critical that stroke QoL measures are informed by the subjective perspective of individuals who have had a stroke. Focus group methodology is an ideal method by which to capture subjective experience.

In conclusion, a strength of this study is that it reflects the views of patients and caregivers on the effect of stroke on QoL when they are given a chance to discuss it in an unconstrained fashion. The themes discussed in this paper were dominant throughout the entire focus group discussion, which included probes of specific dimensions of QoL that are cited in the literature. Thus, we are confident that our findings reflect issues that are important and salient to stroke patients. The present findings suggest that measures of stroke-related QoL should capture the important influence of stroke upon social relationships, including support from others and communication in addition to social function or activity limitation.

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