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Perspectives of Quality of Life by People with Aphasia and Their Family: Suggestions for Successful Living

Madeline Cruice, Linda Worrall, and Louise Hickson

Understanding the client's perspective is essential for good practitioner care in rehabilitation after stroke, and nothing is more relevant than enquiring directly about our clients' quality of life to inform our management. Relatively little is known about how older people with aphasia consider the quality of their current lives, and this article seeks to explore this issue. Four women's accounts of their life quality are presented, as well as their husbands' or daughter's accounts of their lives. Their stories share some common elements. Who you love or share your life with; where you live; feeling independent and/or in control; and engaging in satisfying activities mattered to these women's life quality. The impact of aphasia varies across the cases, and the need to accept change for successful living is illustrated in all accounts. **Key words:** *aphasia, family, interviews, quality of life*

The provision of services that meet the needs of the service user is becoming more important in today's health care systems, particularly with respect to stroke, which is considered the leading cause of disability in Western countries. This user focus is increasingly demonstrated in documentation and government initiatives. For example, in the United Kingdom, the second edition of the *National Clinical Guidelines for Stroke* is prefaced with the opinions and experiences of stroke patients and carers, and examples of patients' and carers' perspectives are interspersed throughout the document.¹ However, to understand the needs of the stroke patient, one needs an understanding of the lived experience of stroke, which means going beyond the "objective measurement of function," which is so "central to rehabilitation,"^{1(p37)} and seeking the perspective of the individual.

This article describes the perspectives of four older individuals with stroke and aphasia on what gives them quality in their lives. The interviews contributed in part to a much larger research project that endeavored to demonstrate a link between communication and quality of life for older people regardless of whether they had an aphasic language impairment or not. Some of this research has already been published, for example, how essential social and emotional support, social activ-

ity, and psychological well-being was to people with aphasia² and whether family members or friends could adequately answer questions about someone else's quality of life on their behalf if they had aphasia.³ However, people's perspectives on whether they thought they had quality in life and, as such, were living successfully have not been published and are the focus of this article.

Method

Thirty people with aphasia were recruited through a number of sources in Australia (metro-

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politan hospitals, university aphasia groups, and stroke groups), and each had given ethical approval for the study. People were visited in their homes. Although these visits were clearly research agreements, the presence of the researcher in someone's home altered the dynamic. Participants felt comfortable and relaxed in their homes, and therefore their responses reflect the context in which they were interviewed. Each person was interviewed individually by the primary author, who is a speech-language pathologist, and their responses were tape-recorded or handwritten if the person requested not to be taped.

The quality of life interviews were structured around six questions that were asked in the same order: (1) How would you describe the quality of your life, and why do you say that? (2) What gives you quality in life? (3) What takes quality away from your life? (4) What would make the quality of your life better? (5) What would make the quality of your life worse? (6) Does communication have an impact on the quality of your life, and, if yes, how? The first five questions had been used before in researching older Londoners' quality of life⁴ and the sixth was written specifically for this research. People with aphasia also invited a significant other to participate in the research as their proxy respondent (a person who could answer for them if they were unable to). Questions to these people were slightly rephrased. For example, "How would [name] describe the quality of her life, and why would she say that?"

This article focuses on four people – Rose, Joan, Maude, and Fran – and their significant others as appropriate. They were selected because they illustrate the theme of living successfully with aphasia after a stroke. Their responses to the questions are reported in their entirety. Before and after each story is a brief commentary that provides some context for the reader and emphasizes specific features in the story. All names have been changed to protect people's privacy and confidentiality.

Rose's story

Rose was 81 years old, recently married, and living with her new husband in a self-contained unit (independent living) within a retirement village. She had 7 years of schooling and worked as a

shoe sales assistant during her life. Her husband had been a clerk. At the time of the interview, she had been living with the stroke and aphasia for 3.5 years and had met her husband at an aphasia group coordinated by a hospital outpatient rehabilitation service 2 years previously. Rose's communication was characterized by fluent speech but significant difficulties in saying the names of words and a significant hearing impairment, however she accommodated this well by using hearing aids. Her hearing loss appeared to have little impact on her conversation during the interview. Rose's perspective on her quality of life is as follows.

Rose thought quite positively about her quality of life:

Well I think it's really wonderful really. . well because um well. . Ron'sss here ffirst with me, and then because there's I think it's so wonderful that I was ah so terrible you know when I was sick and now I'm I'm so much so much better, you know. Yes, ...and I think it's just wonderful that that I'm happing happing with Mark with er Mark, isn't that poor darling....[Rose laughs at her calling her current husband by her previous husband's name.] It's um Ron yes so... it's I think it's really wonderful that we've got together and and having such a lovely time, you know.

Rose discussed being happy where she lived as giving her life quality:

[already said Ron and having such a lovely time with him] well that are there's my have my house you see and um...and I had to had a look about it there, and it was good there, but if I thought about another say another ah five years or or like that, I'd say, oh I'd have to get a bit of that and I'd have get more that, and so thing, and so I thought it was really better to have it away at the moment, 'cause it was really good there you see, and so I thought I was able to to have the house there, and so now when we can go here together with Ron. Well he was here anyhow, but I think that this is wonderful, because if it's not so well at all we can tell you what ah you know down at the bottom they can tell us you're not so well....We have a little thing at the for church ah for night and for day too... [referring to buzzer]. [So you're happy where you're living?] Yes, yes.

Language difficulties appeared to be a main concern for Rose in terms of taking quality away from her life:

Oh well um well perhaps the main thing really is the ah word the words, you know, and ah even that I think is wonderful, that because I couldn't tell you anything, you know so yes, I think that is really about the main main thing.

She saw being rid of those difficulties as the sole necessity for improving her life quality:

Oh just give me some better words!! No no we don't want them all, because I I know what it is, it's just how to do that. Yeah yeah because otherwise I think ah you know really a bit just so lovely.

Rose described the following as making her life quality worse:

Oh...well I I don't ah ...the only thing that I could be would be that anything would be happen for Ron together or um...yeah no, and even then even if I have to go well I know the Lord will know when time, you know, and that's no worry because I know about that Lord you see, so ah so really it's just Ron would be the only thing would be... terrible. ...too quickly I know that we can go sometime, but we don't time...we just have the happy time.

Finally, Rose's response here indicated just how much of an impact communication had on her life:

Ah it ah...perhaps there is one one thing, you see, now um Ron is alright because I'll say to her... to him, "Ron, how you can...how would you be able to do like this here?" to to for somebody that I could tell them, you know. And and I used to be able to do that you see, now now I can't do that it's um, I don't I know exactly what I know want to do but I can't have the thing, you know. I can't tell you any at the moment, can you. I just want wanted to show you. [Rose went and got a letter from the Queensland Ladies Baptist Fellowship.] I can't tell you, like I used to get right across ah round the ah.. .week...ah no what's the word Queensland [used to travel around Queensland] you see and I'd go to these er...people and I'd tell you about something or what what the Lord would like to have, and all this sort of thing, and um...now I couldn't tell you how to do of that. Yes I I can know I know what I want to tell them, but I can't in the words, you see, that's the words thing.... Not not so much that but be able to put it in here, in wh because you see, you have to look to, I used to have them all put them down here, and do it first you see, and then I'd two bits off here to tell you of that you know just a bit of the here sort of thing, and you see that's the sort of thing...so that's the thing that's one of the things that gets a bit hard with me, but I don't know if it's a terrible thing, because I can't still tell you about a thing...this is what I want to see, you see... but I can't get the words of the whole thing to do that.

Commentary

In listening to Rose's account, one can see three elements (two major, one minor) that contribute to her living successfully. First, Rose's story is full of joy in her relationship and shared experiences

with her new husband who also has aphasia. Incidentally, her husband felt similarly when he answered what he thought Rose would say concerning what gave her quality in life. Here is an excerpt from his interview:

Good, hm..get marry me! [laugh] Well is ah think we talked about that, and that ah think ah think get married before successfully, bombs [unintelligible word] for me, so I don't know. You know in the old days, Rose was alone more or less, and ah one daughter in [name of city], and ah...visit once a week, and the rest of the week alone, long time partner dies and the same thing here.

Second, there is contentment in her living arrangement. Rose is very satisfied with her decisions regarding the sale of her house and moving in with Ron, who was already established in the unit, and she has peace of mind, because she is able to easily call for support or care from within the unit in the retirement village. Third, one infers that good or stable health is enabling them to live successfully. At the start of her story, Rose mentions how her health is much improved, and she also makes a comment on whether anything should happen to Ron (it's also clear from her story that she's also referring to the death of her husband). She is troubled by her difficulties with the "words thing"; however, this is not about being embarrassed or restricted by her speech, but rather it is about not being able to put words together to share with others (e.g., not being able to discuss the Bible with others). Still, this does not overshadow that fact that her life was "really wonderful really."

Joan's story

Joan was 80 years of age, had 9 years of schooling, and had spent her life occupied with the duties of her house in the roles of wife and mother. She and her husband, Tom (a tool maker during his working life), had known each other for 70 years. At the time of the interview, she had been living with the stroke and aphasia for 2 years and 3 months. Her story is as follows.

Joan described the quality of her life as follows:

Oh dear, now I gotta think...well I'm alright, okay, we do everything together. Everything's okay. I don't know what I'd do without my husband, cause he helps a lot. I do most of the, he does the work the ones I can't do, but I do the cooking I like. I like to cook. Some things I can't always

remember but I do it, do it my way. I get my husband to help me with the bed and I do the washing.... So we do alright.

She noted the following as giving her life quality:

Oh well, going out and seeing my daughter and my grandchildren, um... speaking to my son ...lives in Singapore, he was a good son too...but he had to go there for wa work...but he always thinks of you, so that gives me quality.

Joan thought the following took quality away from her life:

Things that um...well I don't stay ta taste as well, things that I cook is not the same...but I got used to that now...um... I have a shower that's alright I manage...I can't walk so good yet and I can't swim yet...um now what...speaking to other people. Especially when I can't remember them...their names sometimes... all those people yesterday I didn't remember their names but when I got to use them, I knew who they were but still I didn't remember them all.

She described what would make her life quality better:

To speak better I think that would be wonderful ...and remembering...I think I could do most of the things then ...and reading of course...I can read but it's slowly, it makes me cross so I leave it. I do a little bit every morning so that it goes into my head.

She also described what would make her life worse:

I wouldn't like to lose my husband, because I ...wouldn't be able to get about....

Finally, Joan perceived an impact of communication on her life:

Well yes, well it's good to speak to people...mostly yeah...well I used to lot of painting...used to have the place to myself to help other people...to do everything now, I can't do it now. I thought I'd be able to go back and then I had that funny stroke and I didn't know what it was, so I never came back. I was doing when I had the first stroke the big stroke but since I had this operation I haven't be able to do it. I s'pose cause I'm...I can't stay there too long. Oh I can't stand too long. I'm alright when I'm walking, but standing to pain....

Commentary

Joan's story does not shine with successful living as does Rose's, yet her account provides several insights into how she manages and adjusts successfully to her life. There are many positives in Joan's life that give her quality: she has a support-

ive, helpful husband and acknowledges this, she maintains her relationships and communication with her immediate family, and she is out of her home visiting and socializing with others. She is successfully managing the everyday activities of the household, albeit with the help of her husband, and she continues her interest in cooking. Joan has also successfully adjusted to the changes in doing some household tasks differently ("do it my way") and her taste of food, both of which are important given the frequency with which they occur in her daily life. It is clear though that several things are holding her back from the life she wants: mobility and pain affecting her walking and re-suming previous interests of swimming and painting class; memory affecting her capacity to do things independently and remember people's names socially; and communication affecting her speech and her reading. There is also a sense of perseverance in Joan's story, namely her determination to read every day despite the challenge, which creates a sense of hopeful living. This is more clearly evidenced in her husband's account of her life quality.

Joan's life according to Tom

Tom thought that Joan would describe her life quality as follows:

Well um...different to what it prior to her operation... although not at the top of the line, you know she's stepped up from what it was originally, she's three quarters of the way there. Well the ah the only way she could get better, to confidence in herself and the willpower to get on with it, which she did right from the very first, while she was in hospital and of course since she's been out.

He thought she'd say the following in giving her quality of life:

As long as she can go out in the garden...um...she does like meeting people ...er...especially family, and er... close friends...er...she is not one for having items to give her quality of life. As long as she can get out and around, she's quite good. Better than I would be, I think.

In terms of what takes quality away from her life, Tom said:

As long as she can move around and ...that's most important." [prompt – What would she say takes away quality from her current life?] All due to the ah...getting better from the stroke really, ...well it bothers her because she's

not regained full mobility that she had before...but ah...she's never depressed about it.

Tom thought Joan would say the following about what makes her life quality better and worse, respectively:

Well ah...wish complete recovery really. She aim, will aim for that all the time...what she talks about and what she does, you know, she exercises and do anything that will help. Doesn't lay down with the problem. Just to be immobile be the worst thing to happen, yes.

Briefly, Tom agreed Joan would see an impact of communication on her life:

Um...she likes to communicate, and talk to people that's for sure. Yes ah...That's the most important thing.

Commentary

Tom's account agrees with Joan's in that he identifies that her relationships with family and others, being social and talking with others, enable her to have the success in her life that she currently does have. Furthermore, his account provides more examples of her hopeful and determined approach to her situation and her good attitude about what has happened. Although it is generally accepted that having aims or goals to strive for is a positive and desirable thing, the desire to return to a prestroke state is slightly alarming, as complete recovery so seldom occurs. Whether Joan wants a complete recovery, or whether she would be satisfied with "managing swimming" again and "managing standing long enough" to resume going to her painting class, we don't know. Finally, Tom's account of what impacts on Joan's life is reasonably similar to Joan's, however he describes it actually as "mobility," whereas she interprets her mobility in the form of activities and dependence.

Maude and John's story

Maude was 78 years old, had 11 years of schooling and training, and worked as a clerk telephonist during her life. She and her husband, a postmaster with 13 years of schooling and training, had known each other for 53 years. She had been living with her stroke and aphasia for the same length of time as Joan, that is, 2 years and 3 months. Maude and John were chosen for this article for two rea-

sons: to demonstrate how perceptions of quality of life or living successfully can depend on whose version of the story is sought, and to illustrate an unfulfilled and thus unsuccessful life. John's account of Maude's quality of life is presented first.

John said:

I s'pose considering her disability, I think she's considers her life the quality of life s'pose ah quite good, she doesn't seem to press for anything like that. Oh yes I think she ah yes takes an interest in things.

John thought the following would be what gave Maude quality in her life:

Stable marriage, no financial worries, very pleasant place to live here, isn't it?

He said the following took quality away from her life:

Well of course that's the disability of course, isn't it...the disability and that ah not being able to move ah get around as much as she can and not being able to do the things she normally did do.

He thought the following would make her life quality better or worse:

Better health, take the stroke away that would be the ah that would improve the quality of her life of course. Yes I s'pose actually having another stroke or having another setback.

John thought communication did impact on Maude's life:

Oh yes not being able to speak fluently, not being able to make herself understood at times, and not being able to complete sentences, they would be the main things. I know she set it all clear in her mind but it just doesn't come out. That's the biggest impact, and I mean lack of mobility, another big problem.

Maude's description of her quality of life and why she'd say that and what gave her life quality was:

Mm...well ...mm...ah...well I ah...well it I I used to ah...you know do everything but now I can't, so I have to, you know, take it as it comes. [prompt – Would you say it is good... wonderful.... um?] It's as good as it can get. See, I can't garden, I can't do anything, I can't cook, but um...but ah...mm.

[prompt – What are the important things?] Oh kids I suppose, ...particularly ah you know the ah...the ah son in Brisbane. He's married he's not married and he comes up....[prompt – Anything else in your life that you value, that gives you a lot of joy?] Oh like music but because I

can't play that the now I have to use the ah ... not the TV the other thing... [meaning radio] I can see it. I go ga...I can ah tour the yard...but I can't garden you know, see.

Maude said the following took quality away from her life:

Mm... [Not being able to garden?] yeah, and can't play the piano, can't sew and I can't cook and I can't do anything. I can't speak, see.

She thought the following would improve her future life quality:

Ah, get rid of the stroke! No, my my have used, I can speak, I couldn't speak, and ah... ah...you can say the quality would be better bett than the stroke. You can't get it!

She thought the following would worsen it:

Getting a stroke, the third one!

Finally, she saw a clear impact of communication on her life:

Oh yes, you can't speak or you can't write or can't do anything, see, I used to go to ah Red Cross and I can't do that. Can't do anything. I can't speak anything. I find ah words and you thinking, what could I say and how how can you say it.

Commentary

Even though both Maude and John both use the word "good" to describe her life quality, there is a clear difference of opinion, and John's account is both more positive and less emotional than Maude's. John describes what she has (stability in relationship, finances, living arrangement, care), whereas Maude describes what she's lost or can't do (cooking, gardening, and playing piano) and this continues throughout her story (sew, speak, write, or volunteer for Red Cross). John seems to recognize the same issues as Maude in terms of affecting her quality of life, but he describes the aphasia as "the disability" and refers to "mobility," and Maude describes these in a more functional sense, such as the skills or activities that she can no longer do.

There is little that gives Maude enjoyment, let alone success, in her life now. Visits from her son are a source of quality in her life, as are her remaining interests in music and the garden. However, she cannot pursue her interests as she used to; she has to listen to piano music on the radio and walk around the garden instead. It is clear that these are

poor substitutes for previously satisfying activities, as she continually reiterates her loss of them, as well as other activities. Maude mentions twice that she "can't do anything" now, indicating an overwhelming sense of inability to function in everyday life. Finally, despite having clearly sufficient speech and language to articulate her perspective during the interview, Maude still perceives a significant loss or change in her speech and writing.

Fran's story

The final story on living successfully (or degrees thereof) with stroke and aphasia is that of Fran. Fran's story was specifically chosen for two reasons: to illustrate the huge discrepancy that can exist between one person's objective perception of someone's life (here, the speech-language pathologist researcher's assessment data) and Fran's subjective perception of her life, elaborated in further detail by her daughter Ruth's account; and to illustrate the need for personal growth to be living successfully at any age.

Fran was 68 years of age, with 11 years of schooling and training, and had worked as a nursing assistant during her life. Her daughter Ruth took part in the research as Fran's significant other. Ruth was 35 years old, had spent 18 years in schooling and education, and was working as a social worker. At the time of the interview, Fran had had the stroke and aphasia 13 months ago and was currently living with Ruth and her family.

Fran's story according to the data

On paper, Fran had every reason to have the best quality of life possible. Compared to the other three people in this article, she was the youngest participant; she had the mildest aphasic language impairment, so mild it wasn't deemed impairment by the test's criteria (she scored an overall 95.2 on the Western Aphasia Battery⁵ and the cutoff is 93.8); she had the highest functional communication skills score (89/100 on the Communication Activities of Daily Living Second Edition test⁶); and she had the largest social network numbering 40 people, naming 23 of them as being very important in her life. However, none of these assessments recorded her perception of her abilities. The

only suggestion of dissatisfaction was her self-reported low mood on the Geriatric Depression Scale⁷ (15-item version) where she scored 6/15, indicating mild depression. Her story comes to light in her responses to the quality of life interview questions, as seen below.

Fran described her quality of life as:

Average, got good friends and very good family, like, I do things with my friends...went to [a] play with friends, scrabble with friends...table tennis...I like the company out at the [name of aphasia group]...lovely place to live in [name of suburb]...go on my scooter ride on the [She continued after a moment.] Yeah I do what I can, yeah, I love gardening...that's the thing I miss most...have emotional highs and lows more than I did.

Fran said the following gave her life quality:

"I s'pose ah... Ruth and the baby and Jenni and her kids and my friends you know, and going to the play or whatever, there's a lots of goods things going on around in [name of suburb]. Yeah, these things...discussion groups, also I was member of ah Australian for reconciliation..and they vite me to come with them to...One of the things that makes my life enjoyable is my scooter. I can go on that right around to [name of nearby place] and past there...it's very nice to have.

She talked about what took quality away from her life:

I guess the feeling of ah helplessness, the little things you have to can't do for yourself. There's some things that you just can't do...and I s'pose being able to play table tennis meant a lot to me, and being able to speak Indonesian meant a lot to me those things I can't do, so I have to try to other things.

Fran reflected on what she thought might improve her life quality:

Oh...that's hard...well ah yes maybe before too long I'll move into a little house, low set, a very handy one and maybe I'll cope by myself, you know.

She expressed the following as worsening her life quality:

If I had another stroke yeah. If I had a bad fall and had a broken leg, I would have to go into a nursing home and I wouldn't like that very much.

Last, she saw a clear impact of communication on her life:

Yeah I was a good talker but not so good now. Sometimes particularly if I'm tired you know I can't say anything, I can't get anything out. But it's a lots better than it was. I guess I I don't talk too much like I used to, maybe it's a

good thing...I even made speeches for ah against land mines and things like that.

Commentary

Relationships and activities with friends and family feature highly in Fran's life, as does her physical independence with her scooter to travel about the local area. Many of her activities are social and dependent on language (going to a play, playing Scrabble, being invited to attend discussion groups), some of which she continues to do and some she cannot, such as learning an additional language and giving speeches. Her passion for language and subsequent self-expression would suggest why her aphasia has had the impact it has on her life. She enjoys living in a stimulating area; however, in terms of her living arrangement, she would live a more successful life if she regained her independence and her own space. Aside from Indonesian, she has lost a further significantly meaningful activity in not being able to play table tennis. Fran's story suggests she was someone who was interested in continued growth and personal development throughout her life, and indeed she says she is trying new things now to replace her Indonesian and sporting loves.

Fran's life according to Ruth

Ruth's account of her mother's life quality is included here as she elaborated further on some of the finer details. Ruth's response to this first question was as follows:

Now since the stroke? I think it varies a fair bit from day to day with mum, varies a bit from day to day. She gets down and thinks it's a bit hopeless, and then she gets about and out, and she's taken on new things. She does get, you know sometimes she gets a little defeated, in the face of things. You know the other day she came home from the computer course in tears because she couldn't understand and there wasn't anyone else there to help her, and she takes it on.

Ruth reiterated what her mum had said regarding what gave Fran life quality:

Friends she enjoys that...her scooter...and she gets out on that a fair bit... that's given her independence, she seems to like the grandchildren round...um she plays scrabble with people....

Ruth thought the following took quality away from her mother's life was:

The fact that she's not mobile as much as she'd like to be. She finds that frustrating and it does stop her from doing gardening, things like that. And the speaking is a big one, she feels like she can't communicate what she wants to say...so um I mean she can communicate heaps more than what she used to be and heaps more than what other people do, but she still feels like she can't...oh her writing too, that's the other thing too, hand writing she's got a typewriter but it's not the same, her poetry...that's affected.

Ruth thought her mum would say the following about future better and worse life quality:

If she could walk better than what she does, ...yep if she could use the right hand more and be able to talk more fluently and be able to express herself more emotionally and her ideas more succinctly. If she had another stroke, that would and she does think about that I think. I think eventually she's thought about getting her some little place that would make it better if she's up to it, so...but in terms of worse, another stroke or ...I don't know, if people weren't so caring and supportive.

Ruth described the following as the impact of communication on her mum's life:

Yeah the Indonesian language that she was learning, she can't do that, that was a major interest of hers...um it's just now the number of interests that she had, that now she can't ... although she can still read books and that's good, she can do that and type on the typewriter...sometimes I think with communication, because she's not able to express her feelings so well, it can lead to misunderstandings with people around, with us or whatever.

Commentary

Ruth is very much in tune with her mother's perception of her quality of life and adds further details, especially in describing Fran's emotional responses to situations. Living successfully is about enjoying being with friends and the grandchildren and having independence. However, Ruth also recognizes her mother's losses in activities and how her altered communication impacts her mother's life. Aspects of Ruth's account can be interpreted through a successful ageing framework. The processes of assimilation, and more so accommodation, are theoretical explanations for why some people may adjust well to ageing. These processes may equally be applied to the onset of a disability in late adulthood, such as stroke and aphasia. In Ruth's account, there is evidence of assimilation ("efforts to sustain current activities/ interests by, for example, using aids or adaptations"^{8(p12911)}) when she refers to

her mother using a typewriter for her poetry rather than hand writing, yet it is not having the desired positive impact, because it isn't satisfying her mother. Similarly, there is evidence of accommodation ("efforts to replace current activities with equally valid new ones"^{8(p12911)}) when she talks about her mother taking on new things. Although Ruth doesn't elaborate on what these are specifically, one suspects that the computer course represents a new activity. This new activity constitutes a positive influence in Fran's life; however, with Ruth's account of her mother's experience of the situation, it clearly adds emotional distress because her mother is unable to experience success or support in the new endeavor.

Ruth also acknowledges a considerable change in her mother's communication, comparing Fran's current status to a previous state, and she also compares her mother favorably against other people presumed to have aphasia. While both comparisons are usually associated with helping people positively adjust to their new lives, this is not the case with Fran. Ruth recognizes that her mother's perception of her own communication outweighs any other judgment. Ruth's account also presents her mother as someone who was a passionate communicator, with whom it was important that she engaged emotionally with people and expressed herself through poetry. Difficulties in communication now lead to misunderstanding and inadequate expression of self, which has been noted previously in aphasia research.⁹

Discussion

These four stories of quality of life shed light on what living successfully can mean for older people with aphasia after a stroke. Four key components are highlighted here. The first contributor to living successfully is the positive experience of sharing one's life with others through intimate relationships with a spouse, connecting with immediate family and grandchildren, and through friendships. The process of sharing can be carried out by living with others, visiting family, socializing, playing with grandchildren, and sharing tasks. A second key component that is highlighted in these stories is satisfaction with the physical arrangement in which one lives, that is, enjoying living

with others, living by oneself, or having support on hand if it is required. A third component is a feeling of independence or being in control of one's life; this includes being able to live alone, to travel independently, and to do the things you want to. It also includes not feeling helpless and managing one's responsibilities. A fourth essential element for living successfully is being able to take part in activities that are meaningful and personally rewarding, at a level or standard that is satisfying. Known as activity theory, this last component is especially important, because individuals derive self-esteem and self-worth from involvement in activities.¹⁰ Activities are crucial for the subgroup of a population who are no longer occupied by work. These four components are not specific to people with stroke and aphasia; they feature in other research that investigates the quality of life of elderly people who are normally ageing without stroke or aphasia.⁴

These accounts indicate the importance of accepting change in one's health and functioning. A better sense of life quality is noted by comparing current function to a time immediately post stroke or by comparison with others who are less able. Conversely, dissatisfaction can arise when current function is compared to prestroke functioning, as the person has not accepted the irreversible change caused by the stroke. Also important to the four individuals sampled here is acceptance of their current life with stroke and aphasia by assimilating changes in skills and abilities by participating in activities differently and by accommodating strengths and weaknesses in pursuing new activities in place of old activities.⁸

Furthermore, the pursuit of new activities and interests contributes to personal growth and development in life.¹¹ For Fran, learning Indonesian represented more than a hobby with which to fill her time; it was something that enriched her life and who she was. Danish researchers Ventegodt, Andersen, and Merrick¹² categorically state that quality of life is connectedness and development, as well as having purpose in life. These needs were evident for all four women with aphasia in this article.

These personal accounts of life quality also illustrate the significant impact of altered physical and communication functioning. Changes in physical status and mobility affect a continuum of

activities of daily living, from basic or instrumental tasks such as showering and walking to leisure pursuits such as gardening, swimming, and playing the piano. The impact of aphasia on these women is similarly profound in affecting life quality. Clearly all four women were able to communicate with their loved ones and friends, albeit to differing levels of satisfaction, and indeed they were chosen for this article because their residual language skills permitted them to articulate their thoughts on their quality of life. However, these women made it clear that aphasia affected their speaking, reading, and writing at a basic or instrumental level; their ability to put their thoughts into words for self-expression (poetry and general conversation); their pursuit of leisure and personal development activities (learning a second language, poetry, discussing the Bible); and the experience of learning of new skills (computer course).

The cases presented in this article, despite some limitations, have implications for stroke rehabilitation. First, professionals working in stroke rehabilitation need to seek the perspective of their patients or clients in what it means to have quality in life and thus to be living successfully with stroke and aphasia. Only then can we align our involvement with the client and their family and our options for intervention with *their* priorities and goals, leading to as satisfying outcomes as possible. A second implication concerns the role of the speech-language pathologist (SLP). The four accounts demonstrated that people were able to articulate their thoughts, reflect on the issues, and offer valuable insights in an interview format with an SLP. Hence, the SLP has a dual role in the stroke team and broader community in supporting people with more severe aphasia in understanding and expressing their views so that they can participate in these discussions about their lives and in training other professionals in the stroke team to a level of competency where they can facilitate the involvement of people with aphasia in discussions. A third implication is the need for coordinated multiprofessional and multiagency involvement to enable people to live successfully with stroke and aphasia. For example, there is a clear need for counseling to help people deal with loss and change in abilities and

activities; psychologists, social workers, occupational therapists, and SLPs need to work together as an integrated service.

Finally, there are far bigger questions about the goal of stroke rehabilitation. Rose, Joan, Maude, and Fran were between 1 and 4 years poststroke with aphasia and were no longer on caseloads in hospital rehabilitation services. Whose role and responsibility is it to identify their needs and wishes to live successfully and to provide appropriate services? Should hospital rehabilitation services focus solely on functional and instrumental activities of daily living and community rehabilitation services focus on leisure and personal development? Can more community rehabilitation services be funded to provide these opportunities? Do professionals working in stroke rehabilitation have a role in working with and training general community agencies who provide leisure opportunities?

There are several limitations in this article that need to be identified and that will subsequently form the foci for future research. First, the views are not representative of people with severe and moderate-severe aphasia after stroke. The views of people with more significant physical disabilities and aphasic impairments, especially the receptive type, need to be investigated to understand the full spectrum of life with stroke and aphasia. Although it is difficult to facilitate understanding and expression of people with more severe aphasia, it is not impossible (e.g., Murphy¹³ and Talking Mats at <http://www.talkingmats.com> – a low tech communication framework). Second, for this article, 4 of 30 participants were selected to report their interviews as full stories; however, larger samples with a thematic analysis of case data are needed to establish what it means to be living successfully for the wider community of people with stroke and aphasia. Third, the four stories do not include men's views on living with stroke and aphasia. It is important to note that in these stories John and Tom described their wives' difficulties as pertain-

ing to mobility and "the disability" (i.e., aphasia), whereas the women used words pertaining to skills and activities. Future research should explore whether men and women cope differently with change and thus are likely to have different outcomes in living successfully with the changes brought about by stroke and aphasia. Fourth, people were accepted for this study if they were 55 years or older, and all four women in this article were retired. Therefore, the views of younger people are needed to understand the impact of stroke and aphasia on working life, as well as on identity, self-worth, and families in earlier stages of development.¹⁴

Conclusion

Living successfully with stroke and aphasia means perceiving quality in life, which in turn depends on a number of factors that include having positive experiences in sharing one's life with others, being content with one's living arrangements, having independence and control over aspects of one's life, engaging in meaningful and personally rewarding activities (especially leisure), dealing with loss and change, and continuing to grow personally. Leisure activities were particularly identified as being essential to successful living in these four individuals. This preliminary study suggests areas for further research and cites the need for more integration and expansion of scope in stroke rehabilitation service provision. Perhaps in the not-too-distant future we will see the findings of such research taken seriously. For example, occupational therapists could do home visits to teach people how to garden safely following a stroke, and speech language pathologists could coordinate book clubs to help people re-engage with their love of reading. We need to do whatever it takes for us to meet our goal of facilitating people with stroke and aphasia to have quality in their lives.

REFERENCES

1. Royal College of Physicians. *National Clinical Guidelines for Stroke*. 2nd ed. Prepared by the Intercollegiate Stroke Working Party. London: Author; 2004.
2. Cruice M, Worrall L, Hickson L, Murison R. Finding a focus for quality of life with aphasia: social and emotional health, and psychological well-being.

- Aphasiology*. 2003;17(4):333–353.
3. Cruice M, Worrall L, Hickson L, Murison R. Measuring quality of life: comparing family members' and friends' ratings with those of their aphasic partners. *Aphasiology*. 2005;19(2):111–129.
 4. Farquhar M. Elderly people's definitions of quality of life. *Social Sci Med*. 1995;41(10):1439–1446.
 5. Kertesz A. *The Western Aphasia Battery*. Austin, TX: PRO-Ed; 1982.
 6. Holland A, Frattali C, Fromm D. *Communication Activities of Daily Living Second Edition*. Austin, TX: PRO-Ed; 1999.
 7. Sheikh J, Yesavage J. Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. *Clin Gerontol*. 1986;5:165–172.
 8. Lundh U, Nolan M. Aging and quality of life 2: Understanding successful aging. *Br J Nurs*. 1996; 5(21):1291–1295.
 9. Brumfitt S. Losing your sense of self: what aphasia can do. *Aphasiology*. 1993;7(6):569–574.
 10. Reitzes D, Mutran E, Verrill L. Activities and self-esteem: continuing the development of activity theory. *Res Aging*. 1995;17(3):260–277.
 11. Ryff C. Happiness is everything or is it? Explorations on the meaning of psychological wellbeing. *J Pers Social Psychol*. 1989;57:1069–1081.
 12. Ventegodt S, Andersen N, Merrick J. Quality of life philosophy I. Quality of life, happiness, and meaning in life. *Sci World J*. 2003;1(3):1164–1175.
 13. Murphy J. Enabling people with aphasia to discuss quality of life. *Br J Ther Rehabil*. 2000;7(11):454–458.
 14. Hinckley J. Investigating the lifestyle satisfaction of young adults with chronic aphasia. *Aphasiology*. 1998;7/8:509–518.

RECOMMENDED RESOURCES

National Aphasia Association. *Aphasia fact sheet*. 1999. Available at: <http://www.aphasia.org/NAAfactsheet.html>. Accessed October 10, 2005.

Speakability. *Aphasia information*. 2005. Available at: http://www.speakability.org.uk/Pages/Aphasia_%20Information/Aphasia_Information.htm. Accessed October 10, 2005.