

Introduction

Qualitative research into the lived experience of disability (Parr, 1997) and factors which facilitate adaptation (Tedeschi & Colhoun, 1998) are needed in order to gain a holistic understanding of disability and promote client centered care. As such there has been a call for more information regarding the factors that promote adjustment and improve quality of life after the onset of aphasia (Holland, 2008). One means of understanding factors that facilitate well-being and positive health involves accessing the personal perspectives of people who have actually experienced aphasia – people with aphasia and their loved ones. Thus researchers have started to explore the concept of ‘living successfully with aphasia’ (e.g., Brown, 2010, Holland, 2006). Reported themes associated with living successfully with aphasia over the long term include: doing things, maintaining meaningful relationships, striving for a positive way of life, and communication (Brown, et al 2010). Similar factors including social support, autonomy and independence and taking responsibility for one’s own continued improvement have been identified as important contributors to successful living (Cruice, Worrall & Hickson 2006; Hinckley 2006; Holland 2006). While this growing body of literature adds to the understanding of the disability of aphasia, the focus of these studies has been on how people live well during the *chronic* phase of aphasia. No existing research describes the experience of people during early stages post onset when the majority of health services are provided.

Methods

In order to identify factors that facilitate successfully living with aphasia during the first year post stroke a prospective mixed method, longitudinal study was undertaken. The study involved the simultaneous collection of qualitative and quantitative data at 3 month intervals over the first 12 months post-onset of stroke. This presentation will focus on the data collected during the first 3 month interval after the onset of aphasia.

Participants

A total of thirteen participants with aphasia, seven males and six females, participated in the study with an average age of 65 years (47-91 years) and Western Aphasia Battery Aphasia Quotient of 76.6 (43.6-99.3). Six participants lived at home, six resided in a rehabilitation facility, and one lived in an aged care facility.

Data collection

Data collection at three months post onset (+/- 2 weeks) included the following: 1) *Western Aphasia Battery* (WAB) (Kertesz, 1981), 2) the *Assessment for Living with Aphasia* (ALA) (Kagan, et al. 2008), 3) the *Successfully Living with Aphasia Rating Scale* (SLARS) (Brown, 2010 et al) and 4) an in-depth qualitative interview to elicit information regarding experiences during the acute recovery period.

The WAB, a comprehensive language test, provided an index of severity and aphasia type to aid in interpretation of data from other data sources. The ALA, a pictographic self-report measure of aphasia-related quality of life, provided a quantitative rating of perceived satisfaction across domains believed to impact life with aphasia. The SLARS, a pictographic 5 point rating scale that asks participants to rate how “successfully” they are living with aphasia, provided an overall quantification of the individual’s perception of life with aphasia and a quantitative score for comparison to the qualitative findings regarding “success” in living with aphasia.

Qualitative interviews were conducted in the hospital or the participant’s residence. Length of interviews ranged from 18 to 100 minutes. Participants completed the SLARS during the interview providing the context for learning more about experiences of life with aphasia since the stroke.

Analysis

Descriptive statistics were derived from the WAB, ALA and SLARS. This data helped to describe the participant sample and identify factors that might impact participant perceptions of life with aphasia (e.g. severity of aphasia). Thus quantitative data contributed to the final interpretation of qualitative themes obtained from interviews.

Data from the interviews were analyzed using thematic analysis following the guidelines outlined by Braun and Clarke (2006). Patterns in the data were derived from coding factors that facilitated or hindered living life with aphasia. Rigor was established by methods of peer review and peer debriefing with co-researchers.

Results

The distribution of the WAB, ALA and SLARS scores for participants at the acute recovery interval can be seen in Table 1. Of the thirteen people that participated in the study six participants rated themselves to be living successfully (rating of 4 to 5), four rated themselves somewhat successful (rating of 3 to 4) and 3 people rated themselves unsuccessful (rating of 1 to 2). It is interesting to note that severity ratings (represented by WAB AQ) did not always coincide with quality of life scores on the ALA and the successful living ratings on the SLARS. In other words, some people with moderate to severe aphasia identified themselves to be living successfully while some people with mild aphasia identified not to be living successfully.

The thematic analysis of interview data resulted in five categories that described the key issues relating to life during the early post onset period. The categories were further grouped into either external or internal factors and included:

External factors

Social Support: *“I think your family and your friends are also a huge help.”* Participants with aphasia stressed the importance of the role of friends and family in providing both practical support (e.g. transport, help with banking, shopping) and emotional support (e.g. encouragement, understanding, someone to talk to).

Rehabilitation and Therapy: *“I was happy because I knew I’d have physio, I’d go to speech. I felt like my speech therapy was working, you know.”* Participants identified the importance of rehabilitation and the role of health professionals during the early stages of their recovery. They felt that therapy helped them improve and that having a good relationship with health professionals was important.

Participation in Meaningful Activities: *“It’s nice really because you do get to do this and do that.”* Many participants discussed the need to have a purpose in life and a sense of feeling valued and this was facilitated through participation in meaningful activities such as therapy, work and hobbies.

Internal factors

Determination and a Drive to Do Things: *“I go and do it... that’s it ...my life can go on.”* Participants felt they were active promoters of their recovery. Through the interviews it became clear that many participants possessed determination to become independent and create meaning in their lives.

Optimism: *“Oh my talking will get better. My talking will get better as it goes.”* Many participants focused on future improvement and spoke about feeling successful about their current situation and what their life will be like in the future.

Discussion and Conclusion

Findings of this research indicate that there are both internal and external factors which facilitate successful living with aphasia during the first three months post stroke. For these participants, severity ratings did not always coincide with ratings of successful living and quality of life. Factors such as social support, rehabilitation, participation in meaningful activities, determination and optimism were identified as important facilitators. These results are similar to findings for chronic stages of aphasia, suggesting that SLPs providing services during the early phases of recovery need to focus on both the communication skills and the external and internal factors that may influence an individual to achieve success and promote positive adaptation.

Table 1: Participant ratings

| Participant | Gender | Age | WAB AQ | ALA QOL score/152 | SLARS score/5 |
|-------------|--------|-----|--------|-------------------|---------------|
| 1 | Female | 57 | 85 | 88 | 3 |
| 2 | Female | 82 | 90 | 93.5 | 4 |
| 3 | Male | 80 | 92.6 | 126.5 | 4 |
| 4 | Female | 49 | 99.3 | 107.5 | 3.5 |
| 5 | Male | 75 | 90.6 | 108.5 | 3 |
| 6 | Female | 67 | 89.9 | 76.5 | 2 |
| 7 | Female | 76 | 43.6 | * | 3 |
| 8 | Male | 49 | 46.5 | 91.5 | 1 |
| 9 | Female | 47 | 75.5 | 111.5 | 4 |
| 10 | Male | 80 | 68.3 | 90 | 4 |
| 11 | Male | 64 | 86.8 | 87 | 5 |
| 12 | Male | 76 | 54.2 | * | 5 |
| 13 | Male | 51 | 73.8 | 83.5 | 1 |

*Participant was unable to complete the ALA

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