Background

There is little published evidence in aphasiology of what quality of life is like for people who have aphasia, and even less about whether family and friends share those same views. Despite this, there is an ever-increasing need in speech pathology for clinicians to understand and provide intervention in the context of the broader life quality issues for people with aphasia, and a frequent reliance on family members and others to provide that information when people with aphasia are unable to communicate their views.

Because there is almost no explicit QoL-focused research based on insiders' perspective in aphasia, little is known about how people with aphasia interpret their QoL, and what contributes to and detracts from the quality in their current lives. Studies have explored how people with aphasia and their family hold differing perceptions of the impact of aphasia (Le Dorze & Brassard, 1995; Zemva, 1999), however there is also little known about family members' specific views on QoL and whether these also differ. A recent study provides some insight into the behaviours of proxies and participants with aphasia on quantitative measures (Cruice, Worrall, Hickson, & Murison, 2005). This study found that proxies rated global and physical aspects of QoL significantly lower than their aphasic counterparts, rated some aspects possibly adequately, and had no systematic pattern of rating social aspects of QoL. It is not known whether these biases apply in qualitative studies of QoL, and thus this paper seeks to address the important question of to what extent can we rely on the qualitative views of proxy respondents when it comes to understanding aphasic people's QoL.

Methodology

Participants with aphasia self-selected their proxies, and were simply instructed to choose someone who knew them well and could answer questions about their QoL. Proxies met the following inclusion criteria: lived independently; spoke English as first language; negative history of cerebrovascular or neurological disease; were not currently taking medication for clinical depression; and had regular contact of some form with the participant with aphasia which was more frequent than monthly.

Twenty-three women and seven men took part in this project. Proxies comprised 17 spouses, nine children (primarily daughters), two friends, one sibling, and one daughter-in-law. They had a mean age of 58 years (range 27-82yrs), and an average of 12 years education (range 5-18yrs). Proxies knew participants on average 39 years (range 2-70). Twenty-seven proxies had daily contact with participants, two had weekly, and one had fortnightly contact. In terms of type of contact, 22 proxies lived with participants, five phoned, and three visited.

Proxies were generally interviewed in their partners' homes using six open-ended questions, in a semi-structured interview with the primary author. The first five questions were drawn from existing gerontological research (Farquhar, 1995), and a sixth question specifically targeting communication was added. Proxies were instructed to respond to the question as they thought their aphasic counterpart would respond, not as they thought the person should respond. Responses to the questions were not timed and respondents were instructed to provide as little or as much information as they wanted. Proxies' responses were audiotaped or sometimes recorded on-line, and transcribed by the primary author. Using content analysis, a research assistant read each response and categorised a word or a group of words as a unit of data. Related units of data were then coded as concepts (Patton, 1990). Across the

data, like concepts formed a category, and definitions for each category were written and held consistent across both the aphasic participant and proxy data.

Results

Data is represented visually as a computerised mind-map for each of the questions, and proxies' data is placed in context of their aphasic partners as matched concepts between proxy and aphasic responses. For ease within this submission, the data is reported descriptively.

One third of proxies described their aphasic partners' QoL in terms similar to the participants, within three discrete categories of 'quite good', 'average/okay', and 'not good'. Proxies did not identify three further categories derived from the aphasic data:- 'really good', 'changing quality of life' and 'used to be good/ changed quality of life'.

Approximately half of the proxies were accurate in identifying 'people' and 'activities' as that which gave their aphasic partners quality in life. These were the main themes from the second question, and whilst this appears positive, aphasic participants had a further 22 concepts relating to mobility, home, communication, support from others, positive outlook, and other, that proxies didn't identify.

A little more than half of the proxies identified that an 'inability to do activities' took quality away from their aphasic partners' lives, and one third of proxies identified the 'inability to communicate verbally'. Proxies largely failed to mention other issues which were raised by the aphasic participants, namely impairments, dependence, the stroke, poor health, other, and 'nothing'.

Proxies found it difficult to identify the same reasons as their aphasic partners as to what would improve the aphasic person's quality of life. One third identified 'better verbal communication', however as few as one fifth identified 'ability to engage in activities' and 'better use of body parts/ functioning'.

Proxies were better at identifying what would make their partners' life quality worse. All proxies identified an 'inability to do things', half of the proxies identified 'another stroke', and some proxies also identified a 'loss of speech, people, and mobility' as important to their partners. Proxies did not identify the loss of impairment to body parts, personal accident (fall), poor health or 'other' as impacting on their partners' lives.

In response to the final question, more than half the proxies accurately identified the negative impact of difficulties in communicating verbally on their partners' lives. However, only two proxies interpreted the impact in a positive way, compared to twelve aphasic participants, with proxies failing to recognise the verbal and non-verbal communication strengths of their partners.

Discussion

Few proxies shared the same views on QoL as their aphasic partners. At the best of times, half of the proxies accurately identified what mattered to their partners, and this revolved around people, activities, and verbal communication. Proxies were unable to identify some of the smaller categories derived from the partners' data. It is difficult to interpret the findings in the context of previous research given the infancy of this field, and the data analysis is not yet complete (70 more hours being conducted). Further

analysis is exploring the characteristics that may account for the proxy matches described, as well as analysing what proxies' views are when they 'mis-match' with their aphasic partners.

Limitations of the study are recognised as possible misinterpretation of the data, wherein checking with the members would have been helpful, and the issue that proxies' and participants' responses were not probed. This data collection occurred within a much larger study of communication and QoL, and the richness of the data only became apparent once data collection was part way completed.

In summary, up to half of the proxies shared some of the same views on QoL as their aphasic partners, which is insufficient in both scope and depth for clinicians and researchers to rely on family and friends' views in QoL evaluation as substitutes for their aphasic partners' views.
(1195 words)

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Background
Almost fifty years have elapsed since Eisenson (1959) suggested that right-hemisphere brain damage (RBD) can lead to communication disorders. Prosodic, lexical-semantic, discourse, and pragmatic deficits have since been reported to occur in RBD individuals (Code, 1987; Joanette, Goulet & Hannequin, 1990; Tompkins, 1995; Myers, 1999). Although such communication deficits have since been described at length, there is growing evidence that they are not present in

all RBD individuals, nor do they express themselves the same way in such subjects. Surprisingly few studies have looked directly at the question of the incidence and the clinical profile of communication deficits following RBD. Some years ago, Joanette, Goulet and Daoust (1991) reported a preliminary study with this goal, based on the use of three tasks: word naming, sentence completion and story narration. The results revealed that of the 33 RBD individuals tested, four had overall performance similar to those of matched control participants, confirming that RBD does not always impair communication abilities. Conversely, nine RBD individuals were impaired on all tasks. However, the most interesting result was that the other 20 participants exhibited poorer performance on one or two tasks only, yielding distinctive—and even contrasting—profiles of communication deficits. This study offers only a partial exploration of possible communication profiles since the tasks did not cover all the components of communication that can be affected following RBD. Myers (2005), in a similar attempt to explore clinical profiles after RBD in eight participants, also emphasized the lack of comprehensive published instruments to evaluate all aspects of communication that could be affected in RBD individuals and thus was unable to clearly identify distinctive profiles. Few batteries for evaluating communication skills in RBD individuals exist (e.g. Bryan, 1989, 1995; Halper, Cherney, Burns & Mogil, 1989; Benton & Bryan, 1996), and these have been found to have theoretical and methodological limits (Eck, Côté, Ska & Joanette, 2001). Recently, a standardized battery in French was introduced, allowing for the evaluation of prosodic, lexical-semantic, narrative and pragmatic abilities (MEC Protocol; Joanette, Ska & Côté, 2004). Thus, the goal of this study was to contribute to the description of distinctive clinical profiles of communication impairments following RBD by using the MEC Protocol in an unselected group of individuals with RBD in different specialized post-CVA rehabilitation units in order to (a) estimate the proportion of RBD individuals with communication impairments, and (b) contribute to the description of the different profiles of communication deficits that can be seen following RBD.

Methodology

Participants – Twenty-eight French-speaking individuals with a right-hemisphere (RH) lesion participated in this study. Participants ranged in age from 26 to 90 and had between 5 and 18 years of education. All participants had suffered from a single vascular brain lesion, ascertained by a CT or MRI test, without any other neurological history, with the exception of three individuals who had experienced transient RH ischemia. None of the participants had any psychiatric disease or drug addiction. Participants corresponded to unselected incoming patients admitted to a stroke rehabilitation unit, and were not selected on the basis of the presence or absence of communicational impairments.

Tasks

Communication battery – The MEC Protocol (Joanette, Ska & Côté, 2004), a recently published test battery, allows one to assess four components of verbal communication that are

often reported to be impaired among RBD individuals:

1   Prosodic component: five tasks investigate emotional and linguistic prosody in both expressive and receptive modalities.

2   Lexical-semantic component: three oral naming (verbal fluency) tasks and one semantic judgment task evaluate this dimension.

3   Discourse component: a story retelling task allows one to evaluate the production and comprehension of narrative discourse.

4   Pragmatic component: interpretation of idiomatic and active metaphors and of indirect speech acts evaluate this communication aspect.

Procedure – All RBD participants were evaluated using the MEC Protocol during two to three 45- to 60-minute sessions. Five experienced speech-language pathologists contributed to the evaluation of communication abilities. The 14 tasks were presented to each participant in the same order. Since participants' answers were audio-recorded, any doubt regarding scoring could be resolved through consensus by at least two evaluators.

Results

All participants' communicative performance on the 14 tasks was first described in terms of the MEC Protocol's standardized scoring procedure using "alert points" (generally the 10th percentile based on control participants' results obtained during the normalization, considering age and education). Moreover, a hierarchical cluster analysis was then used to allow for the identification of sub-groups of RBD participants with similar performance, based on all 14 tasks of the MEC Protocol. To take into account both age and education factors, a z score was calculated for every task completed by each participant as a prerequisite to the hierarchical cluster analysis. Following the sub-grouping, a deficit for a given task was considered to characterize a given sub-group if more than 50% of the members of the group had a z score below –2 and if the overall mean z score of the group was below –1.5. The hierarchical cluster analysis allowed the identification of four clusters. RBD participants in the first group showed severe impairments in all four language components, while the second group was characterized by a relative preservation of discourse abilities. The third group was composed of only two participants who had severe lexical-semantic deficits, while the fourth group of participants did not show any abnormal results with reference to the MEC Protocol's normative data. The analysis of the brain lesion in each participant included in these four sub-groups did not allow to identify a specific lesion site associated with a specific communication profile. Age and education were fairly evenly distributed among the four sub-groups, except that older and less educated participants were over-represented in the fourth sub-group in which RBD participants were most similar to normal participants. No factor other than the RBD itself seems to be responsible for the formation of the four sub-groups.

Discussion

The use of the MEC Protocol in conjunction with a cluster analysis allowed an exploration of the possible communication profiles in the RBD population. Despite the overall heterogeneity, it was possible to identify sub-groups of RBD participants who shared a common communication disability profile. Though the limitations of this study did not allow to identify a relationship between a given communication profile and a given lesion site, lesion site and extension probably relate to the different profiles reported. It is also possible that age and communication style may represent confounding factors. Further studies will have to better control for these factors as well as basic cognitive deficit profiles such as the presence of an inhibition or attentional deficit. Despite these limits, this study represents a further attempt to describe clinical profiles of communication deficits following RBD. This could eventually guide clinicians in planning and adapting their interventions with this underserved clinical population.

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