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9 Aphasia

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Introduction

Aphasia is a language disability caused by organic damage to the brain, most commonly a stroke. It can affect all language modalities, i.e. speaking and expressing oneself, understanding what other people say, reading and writing. It may also affect non-verbal communication modalities such as gestures. It is estimated that about a third of people who suffer a stroke have aphasia early post-stroke (Engelter, Gostynski, Papa, Frei, Born, et al., 2006), while 15% remain aphasic in the long term (Wade, 1994).

More often than not, aphasia does not occur in isolation. People may have other stroke-related disabilities, such as mobility problems, difficulties with activities of daily living and self-care, and cognitive decline. In a survey of stroke outcomes across western Europe, at one year post-onset, 55% of stroke survivors were still dependent in basic activities of daily living (Wolfe, Tilling, Rudd, Giroud & Inzitari, 2004). The prevalence of cognitive impairment has been estimated at 35% at one year post-stroke (Patel, Coshall, Rudd & Wolfe, 2003). People with aphasia (PWA) may also have other communication problems, such as dyspraxia. Communication may be further compromised by reduced hearing and vision, which typically affect people of older age.

Aphasia has a profound impact on all aspects of people's lives. Chapter 16 of this book illustrates this through the voices of people with aphasia themselves. In this chapter, the research evidence on how aphasia impacts on a person's emotional wellbeing, relationships, social participation and quality of life is presented. The impact on the family is also highlighted. Before considering all this, issues around the assessment of wellbeing and quality of life in PWA are raised. The chapter finishes with drawing clinical implications.

Challenges in assessing the impact of aphasia

Assessing wellbeing and quality of life with PWA is not without challenges. PWA may have difficulty understanding the questions that interviewers ask them or the items on questionnaires. They may also have difficulty finding the words they want to use and expressing their responses. As a result of this, until the late 1990s, stroke studies focusing on psychosocial outcomes either excluded PWA or included only people with mild aphasia. Some studies used proxy data for PWA. This is understandable for people with severe aphasia, but analyzing proxy data together with self-report data can be misleading. There tend to be significant differences in proxy and self-report assessments of functional status and quality of life after stroke (Knapp & Hewison, 1999; Sneeuw, Aaronson, de Haan & Limburg, 1997) and aphasia (Cruice, Worrall, Hickson & Murison, 2005), especially when generic tools for quality of life are used.

In the field of aphasiology, a lot of progress has been made in addressing these issues. From a qualitative paradigm, interviewing techniques, such as semi-structured and structured interviewing, and ethnographic approaches, such as participant or non-participant observation, analysis of artefacts, for example, diaries or published personal accounts, have been used to evaluate the impact of aphasia on people's lives (Cruice, Hill, Worrall & Hickson, 2010; Hinckley, 2006; Parr, Byng & Gilpin, 1997; Parr, 2007).

From a quantitative paradigm, measures specifically for use with people with aphasia have been developed, such as the Visual Analogue Self-Esteem Scales (VASES; Brumfitt & Sheeran, 1999), the Quality of Communication Life Scale (Paul, Holland, Frattali, Thompson, Caperton & Slater, 2004) and the Communication Disability Profile (Swinburn & Byng, 2006). Scales for other groups have also been adapted for use with PWA, such as the Stroke and Aphasia Quality of Life scale (SAQOL-39; Hilari, Byng, Lamping & Smith, 2003; Hilari, Lamping, Smith, Northcott, Lamb & Marshall, 2009) and the Community Integration Questionnaire (Dalemans, de Witte, Beurskens, van den Heuvel & Wade, 2010a).

Ways to facilitate PWA complete self-reported measures have been researched. These include modifying the presentation of scales to make them more aphasia-friendly – key words in bold, large font (minimum 14), few items per page, practice items, lead-in questions and, where appropriate, use of pictures – and administering the scales in an interview format with an interviewer who can facilitate the communication of PWA (Hilari & Byng, 2001; Townend, Brady & McLaughlan, 2007; Worrall, Rose, Howe, Brennan, Egan et al., 2005).

Last but not least, research on proxy and self-report agreement on quality of life scales between PWA and their proxies has shown that agreement is generally poor when generic scales are used (Cruice et al., 2005), whereas it is better when stroke- and aphasia-specific scales, such as the SAQOL-39, are used (Hilari, Owen & Farrelly, 2007).

The approaches identified here may facilitate the assessment of the impact of aphasia on people's lives, yet they have their limitations. Qualitative approaches are hard to implement in clinical practice; and in the case of ethnographic approaches involve value judgements linking an observed behaviour or artefact to what the person with aphasia may feel about it, which is problematic. Using scales and questionnaires, even adapted for PWA, raises questions about whether the most relevant questions are asked for each individual. Each method has its limits but it is important to remember there is no perfect way of assessing wellbeing and quality of life for people with communication disabilities. We need to be aware of the strengths and limitations of each approach and interpret findings accordingly. In the light of this, using the tools and the methods identified above, a substantial body of evidence is emerging on the impact of aphasia on people's lives. This is synthesized below.

Emotional wellbeing

Emotional wellbeing is commonly affected after stroke. A conservative estimate is that 33% of people with stroke suffer depressive symptoms at any time during follow-up (Hackett, Yapa, Parag & Anderson, 2005). Such symptoms affect people's response to rehabilitation and, thus, long-term functional outcomes and quality of life. For PWA, the prevalence of depression is even higher, with 70% being depressed at three months post-stroke and 62% at one year (Kauhanen, Korpelainen, Hiltunen, Maatta, Mononen et al., 2000). In this study, although the overall prevalence of depression decreased from three months to one year, the prevalence of major depression increased from 11% to 33%.

Identifying what factors predict low mood is important in order to detect those at risk for depression and target intervention appropriately. In a recent review, the most consistent variables associated with depressive symptoms after stroke were physical disability, stroke severity and cognitive impairment (Hackett & Anderson, 2005). Fewer studies explored social factors, but when considered together – living alone, place of residence, social support and social isolation – these were also important. However, in most of the studies included in this review (17 out of 20), PWA were excluded.

PWA were included in two recent studies that systematically evaluated predictors of emotional distress after stroke. In the first study, people were assessed one and six months post-stroke. Expressive aphasia and dependence in personal activities of daily living (ADL) predicted distress at one month post-stroke. Stroke severity, expressive aphasia and distress at one month post-stroke predicted distress at six months (Thomas & Lincoln, 2008). In the second study, people were assessed within two weeks of their stroke and then three months and six months later. Stroke severity was the strongest predictor of distress early on, whereas social factors predicted distress at three and six months post-stroke. The baseline factors that predicted distress at six months were levels of distress, loneliness and low satisfaction with one's social network (Hilari, Northcott, Roy, Marshall, Wiggins et al., 2010). In this study, though aphasia was not a predictor of distress at any time point, still, at three months post-stroke, people with aphasia were significantly more likely to suffer from emotional distress (93%) than people without aphasia (50%). These two studies highlight that emotional distress and depression are persistent problems impacting on PWA's lives.

Social wellbeing

Two areas are considered in this section: social participation and social support.

In terms of social participation, i.e. involvement in social life situations, PWA perform fewer social activities than non-aphasic controls and derive less satisfaction from them (Cruice, Worrall & Hickson, 2006). PWA also feel less engaged in their social activities and less integrated (Dalemans, de Witte, Wade & van den Heuvel, 2010c) and are at risk of social isolation and exclusion (Parr, 2007). A recent study looking at factors associated with social participation in PWA found that age, gender, functional activities of daily living (ADL) and aphasia severity were the strongest predictors (Dalemans, De Witte, Beurskens, van den Heuvel & Wade, 2010b). Return to work is also a major issue. For the majority of people, there is no return to work at all after stroke and aphasia; and return to work is often characterized by reduced hours, return to another job or return to the same job with modifications (Dalemans, de Witte, van den Heuvel & Wade, 2008).

Social relationships and social support are also affected. People are at risk of losing their friends after a stroke (Astrom, Asplund & Astrom, 1992) and this is even more the case for those who have aphasia (Davidson, Howe, Worrall, Hickson & Togher, 2008). In a study of 83 people with chronic aphasia, 64% reported that they saw their friends less than before the stroke, and 30% reported having no close friends at all (Hilari & Northcott, 2006).

Maintaining social networks is important after a stroke as friendships can be a protective factor for older people. A meta-analysis of studies on factors affecting wellbeing in later life suggested that contact with friends is associated with higher subjective wellbeing (Pinquart & Sorensen, 2000). Friends-based social networks have also been shown to enhance survival in the elderly (Giles, Glonek, Luszcz & Andrews, 2005).

Using in-depth qualitative interviews, Northcott and Hilari (in press) explored why people lose friends after stroke. The main reasons given were: loss of shared activities; reduced energy levels; physical disability; aphasia; unhelpful responses of others; environmental barriers; and changing social desires. The participants who experienced the most extensive loss of friends were those who described a sense that they were 'closing in' on themselves leading to a withdrawal from social contact. Those with aphasia experienced the most hurtful negative responses from others and found it more difficult to retain their friends unless they had strong supportive friendship patterns prior to the stroke (Northcott and Hilari, in press).

Health-related quality of life

Health-related quality of life (HRQL) reflects the impact of a health state, in this case aphasia, on a person's ability to lead a fulfilling life. It incorporates the individual's perception of and satisfaction with his/her physical, mental/emotional, family and social functioning (Bullinger, Anderson, Cella & Aaronson, 1993; Berzon, Hays & Shumaker, 1993).

Aphasia has a profound impact on quality of life. A recent population-based study of people living in long-term care facilities in Canada (n=66,193) compared the impact of 60 diseases and 15 conditions on caregiver-assessed preference-based HRQL. After adjusting for age, sex and other diagnoses, aphasia exhibited the largest negative relationship to preference-based HRQL, even over and above cancer and Alzheimer's disease (Lam & Wodchis, 2010). People with aphasia themselves report significantly worse HRQL than non-aphasic stroke controls (Hilari, 2011); and compared to healthy controls they report worse quality of life, particularly in terms of level of independence, social relationships and access to aspects of their environment (Ross & Wertz, 2003).

In terms of the impact of the severity of aphasia, individuals with severe aphasia have significantly lower HRQL compared to their general aphasic peers (Hilari & Byng, 2009). Two studies used both measures of functional communication and language impairment to explore their relative impact. They found that impaired functional communication, and to a lesser degree language impairment, predicted worse HRQL and wellbeing in PWA (Cruice, Worrall, Hickson & Murison, 2003; Hilari, Wiggins, Roy, Byng & Smith, 2003).

A recent systematic review explored the factors associated with or predictive of poor HRQL in PWA post-stroke. This review comprised 14 studies (three qualitative and 11 quantitative reports). The qualitative studies included a total of 98 participants with aphasia and the quantitative studies 742 PWA. Emotional distress/depression, extent of communication disability and aphasic impairment, presence of other medical problems and activity level were the predictors of HRQL emerging from quantitative studies. Social factors also emerged as important. Themes drawn from qualitative studies included looking to the future/having a positive outlook, verbal communication, body functioning, and people and social support, and supported these findings. They also added to them, by identifying adaptation of personal identity and development of a collective identity, and working to remove the barriers that people with aphasia face as ways to reduce aphasic disability and live successfully with aphasia (Hilari, Needle & Harrison, in press).

Impact on the family

A large proportion of disabled stroke survivors live at home and they are primarily supported by informal carers, i.e. their family or, in some cases, friends. A review of studies on the quality of life of informal carers highlighted that they suffer from reduced HRQL and high levels of stress, anxiety and depression (Rombough, Howse, Bagg & Bartfay, 2007). Looking at what happens as time passes (from admission to hospital to three years after stroke), it has been reported that burden decreases but harmony in the relationship and social relations also decrease. Moreover, although carer depression decreases initially post-stroke, it increases in the long term (Visser-Meily, Post, van de Port, Maas, Forstberg-Wärleby & Lindeman, 2009).

Studies on factors affecting carer burden and quality of life identified advancing age and anxiety in patients and carers, high patient dependency and poor family support as main predictors of poor carer outcomes, which could be reduced by carer training (McCullagh, Brigstocke, Donaldson & Karla, 2005). A review of qualitative studies corroborates these findings by identifying lack of information and training and also lack of emotional support to manage distress, feeling undervalued or trapped and lacking freedom as main challenges for carers. It also adds to these findings by highlighting role and relationship changes, such as having to give up paid employment and having to adjust to the new role of being a carer, as main themes identified by the carers (Greenwood, Mackenzie, Cloud & Wilson, 2009).

Studies focusing specifically on the needs of carers of PWA are scarce. One study compared carers of PWA to carers of non-aphasic stroke survivors and found that carers of PWA perceived greater difficulty with tasks and had more negative stroke-related outcomes than carers of non-aphasic survivors. Communication with the person with aphasia was rated as most upsetting and difficult by carers in the aphasic group, followed by managing behaviours (Bakas, Kroenke, Plue, Perkins & Williams, 2006). Two qualitative studies on the challenges that spouses/family members of PWA face raised as main concerns:

1. changes in family/marital life, such as worrying for the person with aphasia and understanding their needs, profoundly changed marital life, dependence on the help of other people and the loss of spare time (Zemva, 1999); and
2. the need for support and respite and the lack of available services (Le Dorze & Signori, 2010).

In summary, carers of people with stroke and aphasia suffer from anxiety, depression and reduced quality of life. Their marital and family relations change, their role in the family changes and their financial circumstances also change. They identify as main challenges the need for training and information and for support and respite.

Clinical implications

Hilari and Cruice (in press) advocate a quality of life approach to intervention for aphasia, which structures assessment and therapy from the client's perspective, having determined their desire for therapy, priorities, standards, and personal aspirations from initial quality of life interviews. Such an approach is not an alternative or addition to, for example, neuropsychological or functional communication approaches. It is more of an overarching philosophy that encompasses different approaches and methods depending on what works best for each client, at different stages of recovery and life after stroke and aphasia (Hilari & Cruice, in press).

To date, few interventions have specifically focused on improving the impact of aphasia on people's lives. There is promising evidence for group therapy for PWA, in terms of psychosocial improvements after therapy (Elman & Bernstein-Ellis, 1999; Ross, Winslow, Marchant & Brumfitt, 2006) and improved social participation and social connection after therapy compared to controls (Vickers, 2010). There is also preliminary evidence that impairment-based therapy for word-finding difficulties, when carefully targeted around an individual's interests, can produce changes not just in the therapy room but also on what people do in real life and on how they feel about it (Best, Greenwood, Grassly & Hickin, 2008).

Yet, other programmes that are generally thought to lead to broader benefits for the lives of PWA do not always have the evidence base to support such assumptions. Simmons-Mackie, Raymer, Armstrong, Holland and Cherney (2010) reviewed the literature on the effects of communication partner training on PWA and their communication partners. They found that communication partner training is effective in improving communication activities and/or participation of the communication partner and is probably effective in improving communication activities and/or participation of persons with chronic aphasia when they are interacting with trained communication partners. However, there was insufficient evidence to make recommendations related to the impact of partner training on psychosocial adjustment, or quality of life for either the person with aphasia or the communication partner. There is a pressing need for such outcomes to be systematically evaluated in relation to interventions.

In terms of service provision for PWA, some models of community service have been evaluated in terms of psychosocial outcomes for PWA and their families, but lack of appropriate controls limit the validity of their findings. These services include the York-Durham Aphasia Centre in Canada (Hoen, Thelander & Worsley, 1997), the MossRehab Aphasia Centre in the US (Fink & Schwartz, 2000), and in the UK the Volunteer Stroke Service groups (Legg, Stott, Ellis & Sellars, 2007) and Connect, the communication disability network (van der Gaag, Smith, Davis, Moss, Cornelius, et al., 2005).

Interventions for carers also need to be considered. In the UK, a large randomized controlled trial looked at the effectiveness of training carers in reducing the burden of stroke in carers and patients. They compared conventional care mainly involving stroke education, encouragement to attend therapies and help with accessing services (control group), with conventional care plus training in basic nursing and facilitation of personal care (intervention group). In the intervention group, a higher proportion of disabled stroke survivors achieved independence at an earlier stage; both stroke survivors and their carers reported better quality of life and less anxiety and depression; and the cost of stroke care was reduced (Karla, Evans, Perez, Melbourn, Patel et al., 2004). A review of intervention studies for stroke carers concluded that counselling programmes appeared to have the most positive outcomes (Visser-Meily, van Heugten, Post, Schepers & Lindeman, 2005). Such programmes should be made routinely available to stroke survivors and their families in order to reduce the personal, societal and economic burden of stroke.

Conclusion

Aphasia has a profound impact on people's lives. Communication, which is crucial in all domains of people's lives, is affected by aphasia and leads to high levels of emotional distress and depression, reduced HRQL, reduced social participation and the loss of friends. Interventions that aim to improve the impact of aphasia on people's lives by specifically targeting factors that affect HRQL – depression, communication disability, engagement in activities, and diminishing social networks – need to be systematically evaluated.

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