Citation: Hilari, K., Cruice, M., Sorin-Peters, R. & Worrall, L. (2016). Quality of life in aphasia: State of the art. Folia Phoniatrica Logopedica, 67(3), pp. 114-118. doi: 10.1159/000440997

Editorial
Quality of life in aphasia: State of the art

Katerina Hilari[a], Madeline Cruice[a], Riva Sorin-Peters[b] and Linda Worrall[c]

[a] City University London, London UK; [b] Speech-Language Pathology, Private Practice, Toronto, Canada [c] The University of Queensland, Brisbane, Australia

Corresponding author address:

Dr Katerina Hilari

Division of Language and Communication Science

City University London

Northampton Square

London EC1V 0HB

United Kingdom

k.hilari@city.ac.uk

This special issue of *Folia Phoniatrica & Logopedica* is on quality of life in aphasia. It includes papers on the quality of life and its relation to education and linguistic performance in older people [Constantinidou, Prokopiou, Nikou, & Papacostas, this issue], on an emerging intervention to improve well being and social participation in people with aphasia [Northcott, Burns, Simpson, and Hilari, this issue], and on speech and language therapists' perspectives on quality of life in adult neurological practice in Denmark [Cruice, Isaksen, Randrup-Jensen, Majken, & ten Kate, this issue]. It also includes the findings of the International Association of Logopedics and Phoniatrics (IALP) international survey on how speech and language therapists/pathologists in 16 countries define quality of life, whether and how they incorporate it in their clinical practice, and how they measure relevant outcomes [Hilari, Klippi, Constantinidou, Horton, Penn, Raymer, et al., this issue]. This editorial will set the scene for this special issue. It will provide a summary of the most established conceptualisations of quality of life, drawing the distinction between the World Health Organisation (WHO) definition of quality of life and the more narrowly focused health-related quality of life. It will highlight what drives clinicians and researchers to consider and address quality of life in clinical practice; and it will summarise what we know about quality of life in aphasia and what we need to explore further in future research.

Quality of life (QoL) is a broad and highly subjective concept that can incorporate all aspects of an individual's life [1]. The World Health Organisation (WHO) [2] defines QoL as:

> *[…] an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in complex ways*

> *by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.*
>
> (WHOQOL Group, 1995, p1405)

Health-related quality of life (HRQL) is a related but narrower term. Rather than encompassing all aspects of life, HRQL is concerned with the impact of a health state, like aphasia, on a person's ability to lead a fulfilling life [3]. It incorporates the individual's subjective evaluation of his/her physical, mental/emotional, family and social functioning [4]. Such definitions of QoL and HRQL are clearly established in the research literature, but little has been known about how treating speech and language therapists interpret and operationalize QoL in clinical practice. Findings from an international study of aphasia therapists [Hilari et al., this issue] illustrate that clinicians report challenges in defining a highly subjective and individual concept, but do agree on a number of domains that reflect QoL. Exploring clinicians' views is important, as some may interpret quality of life more as wellbeing than HRQL as identified in the small-scale study of Danish aphasia clinicians [Cruice et al., this issue].

QoL as a concept in healthcare has gained prominence rapidly over the past decade; this is in part due to the rise of the Patient Reported Outcome Measures (PROMs) movement. Originally initiated in early 2004 by the National Institutes of Health (NIH) Patient Report Outcomes Measurement Information Systems (PROMIS), this movement has resulted in frameworks, item banks and tools to be used in clinical practice. PROMs include QoL and HRQL measures as well as measures of other concepts that are specific aspects of QoL, such as emotional wellbeing, social participation, and life satisfaction. PROMS allow us to better understand and measure the impact of disease on the client's life as a whole [5] and to incorporate the client's perspective in clinical decision-making [6]. Discussing QoL with clients achieves both purposes [7]. Currently there is strong drive internationally to use PROMs in healthcare. Professional bodies across different countries identify enhanced QoL as a key aim of intervention. For example, the American Speech and Hearing Association (ASHA) scope of practice document sets as the overall objective of speech-language pathology services to optimize individuals' ability to communicate and swallow, thereby improving QoL (http://www.asha.org/docs/html/SP2007-00283.html). Similarly, in the UK, the Stroke Clinical Guidelines of the Royal College of Physicians (RCP) set as key aims of stroke and aphasia rehabilitation: to maximise the patient's sense of well being and QoL [8]. In the UK, PROMs have been collected routinely by all providers of NHS-funded care since April 2009, to evaluate the quality of care for four medical procedures; it is a matter of time before this generalizes more broadly in the evaluation of healthcare.

Quality of life in aphasia: where are we now?

In 2003, Aphasiology published a special issue dedicated to QoL. The evidence on what affects QoL in aphasia was emerging at that time, and Worrall and Holland in their editorial [9] raised the need to know more about the extent of the impact of aphasia as opposed to other stroke-related impairments; and the relative effect of the aphasia, i.e., the language impairment on QoL compared to other factors, such as social relationships and activities. Today, we know a lot more about both these areas. 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 impact on preference-based HRQL, even over and beyond cancer and Alzheimer's disease [10]. In terms of the impact of the language impairment and other factors on HRQL post-aphasia, a recent systematic review synthesized the evidence of 14 studies: HRQL was negatively affected by emotional distress/depression, severity of aphasia and communication disability, other medical problems, activity limitations, and aspects of social network and support [11]. Themes drawn from qualitative studies add to these findings. A meta-analysis of qualitative studies identified seven overarching themes related to living successfully with aphasia. These were: participation, meaningful relationships, support, communication, positivity, independence and autonomy, and seeing living successfully with aphasia as a journey over time [12].

These findings have important clinical implications. They suggest that to improve QoL in aphasia, interventions need to focus not just on aphasia and communication, but also on promoting emotional well-being, facilitating activities and strengthening social networks and social participation. People with aphasia report low levels of leisure and other social activities and low satisfaction with them, and reduced social contacts, particularly with friends and their wider social network [13-16]. Targeting these areas in speech and language therapy/pathology interventions is an important area in current and future research (see below; and Northcott et al., this issue). In our continued pursuit of what influences QoL with aphasia, and what makes a difference to target in intervention, we must remember that variables quite separate from stroke and aphasia impact on QoL. As highlighted by Constantinidou and colleagues [this issue], QoL even in healthy aging can be affected by demographic variables such gender and education, as well as depressive symptomatology, necessitating a holistic focus in considering people with aphasia.

Over the past decade, much progress has also been made on the assessment of QoL in people with aphasia. Previously, people with aphasia were often excluded from stroke outcome studies because of their language problems, or proxy respondents were used on their behalf. We now know that, people with aphasia can self-report on their QoL; and a range of valid, reliable and clinically applicable measures have specifically being developed to assess QoL and HRQL with people with aphasia [17-19]. For people with types of aphasia where comprehension is severely affected and reliable yes/no responses might be doubted, and self-report is not viable, we now have some evidence to interpret proxy ratings and estimate their QoL. Research with people with mild to moderate aphasia has shown that using generic measures of HRQL, family members acting as proxy respondents rate the aphasic person's QoL significantly lower than the aphasic person would rate themselves [20]. However, it is possible that using a stroke and aphasia specific measure of HRQL, family members are better judges of their partner's QoL [21]. Based on such proxy ratings, individuals with severe aphasia have been shown to have significantly lower HRQL compared to their general aphasic peers [22]. When considering the general proxy literature, it is clear that multiple factors influence agreement between proxies and patients, and the ideal candidate to report on QoL is the person themselves. This concords with the person-centred approach in SLT practice, and suggests the need to develop differentiated approaches to measuring QoL/HRQL for persons with more severe difficulties, as well as using personalized methods such as Talking Mats™ [23].

Whilst there is increasing interest in QoL assessment, we need to address how QoL and HRQL measures are used in practice and research. Evidence from practice scoping studies demonstrates that QoL and HRQL measures are not systematically incorporated in routine clinical practice, and nor are measures of the factors that predict QoL such as emotional health and social participation [24-26]. Systematic reviews of aphasia interventions, such as the 2010 review of communication partner training [27] and the 2012 Cochrane review of aphasia therapy [28] highlight that QoL is rarely included as an outcome measure in aphasia studies. This issue is investigated further in this special issue, and in particular some of the barriers that exist are discussed [Cruice et al, this issue; Hilari et al, this issue]. Two major barriers are (1) the lack of theoretical, practical and experiential knowledge on the part of the aphasia clinician, and (2) lack of translated QoL instruments, with clear training implications and assessment development or adaptation for the practicing workforce globally [Cruice et al., this issue;

Hilari et al, this issue].

Quality of life in aphasia: where next?

Despite developing ways to assess QoL/HRQL in people with aphasia and understanding better what factors affect QoL/HRQL in people with aphasia, we are still a long way of knowing which interventions produce greater QoL/HRQL gains for them. In terms of principles guiding intervention, Hilari and Cruice [7] advocate a quality of life approach whereby assessment and therapy are structured from the client's perspective after having determined the client's desire for therapy, priorities, standards, and personal aspirations in initial QoL interviews and selecting areas for further assessment based on that. Such an approach is not an alternative or addition to typical approaches such as neuropsychological or functional communication; rather, it is an overarching philosophy that can encompass different approaches and methods depending on what works best for each client at different stages of recovery and life after stroke and aphasia. Additionally, integrating an adult learning approach to treatment can be beneficial. Such an approach can promote quality of life by renegotiating the learner's attitudes and behaviours related to communication to create a more inclusive and integrated understanding of his or her experience living with aphasia . This can be achieved by (a) acknowledging spouses and partners' with aphasia previous learning; (b) using reflective questions; (c) collaborating with couples to set goals and design the programme agenda; (d) explicitly exploring couples' learning styles and diversity; (e) adjusting to the "rhythms" of learning; (f) building on the unexpected; (g) using individualized aphasia-friendly and/or written materials; (h) providing opportunities for practice and coaching support, and (i) using self-evaluation [29]. By making the learning process explicit, this approach also can promote lifelong learning related to communication. Sorin-Peters and colleagues [29, 30] found that incorporating such an approach in communication partner training led to consistently better and broader outcomes that include not just positive changes in communication, but also improvements in emotions and marital relationships.

In terms of specific therapy approaches and interventions to improve QoL and HRQL, there is promising evidence for group therapy in terms of psychosocial benefits [31, 32] and improved social participation and social connection compared with controls [33]; for impairment-based therapy for word finding difficulties, when targeted around an individual's interests [34]; for intensive comprehensive aphasia programs [35]; and for models of community service provision [e.g., 36-39]. Yet, further research in these areas with larger sample sizes and appropriate control groups will increase our confidence in these findings. Encouragingly, a number of randomized controlled trials of intensive aphasia therapy are currently under way around the world, incorporating generic [40] and stroke and aphasia specific HRQL outcome measures [41, 42]. Still, there is a pressing need for interventions that aim to improve HRQL for people with aphasia by specifically targeting factors that affect HRQL, such as depression, communication disability, engagement in activities, and diminishing social networks, to be systematically evaluated. The Communication and Low Mood (CALM) randomized controlled trial of behavior therapy in aphasia [43] is an excellent example of such research, albeit delivered outside the SLT profession and arguably could benefit from interdisciplinary engagement in future iterations. Exploration of approaches newly applied to aphasia in small-scale studies will also move the field forward. The feasibility study exploring solution focused brief therapy as an intervention for five people with chronic aphasia by Northcott and colleagues [this issue] is an example of such recent developments, and suggests encouraging trends in improved mood and communicative participation.

At the same time as developing the evidence base in effective interventions to improve QoL, we need to determine economic benefits, alongside clinical and person-reported benefits. Cost effectiveness in aphasia treatment is a relatively recent development, and typically required for new RCTs. For example, the CALM study reports a positive outcome with a specified cost per point reduction on an emotional health/ depression measure [44]. Most cost effectiveness analyses are prospective, however a recent paper undertook a retrospective cost effectiveness analysis of published single-subject experimental research, analysed according to language outcomes [45]. Within the field, we have a single study that evaluates outcome against HRQL, the economic evaluation of a voluntary sector service [46], and more studies specific to interventions are urgently needed to demonstrate value to client and society.

Finally, the future direction of aphasia interventions needs to be at minimum informed by, and at best driven by the priorities of people who live with aphasia (individuals, families, friends, local communities) and ideally by consensus amongst service recipients, clinicians, researchers, commissioners/ funders, and policy makers. Wallace and colleagues [47] lead this new line of enquiry into core outcome sets (COS) proposing an inclusive consensus-based method for generating agreed priorities for research outcome measurement in aphasia. Such organized consensus approaches are increasingly popular, for example, Pollock and colleagues [48] identified the top ten priorities in stroke research, which include: identifying the best ways of recovering from aphasia; how to help people and families cope with speech problems; helping people to come to terms with the long term consequences of stroke; and improving confidence after stroke. Agreeing on a focus and standardizing QoL/ HRQL or wellbeing measures to be routinely used in clinical practice with people with aphasia will strengthen the field immeasurably.

References

1. Bowling A: Measuring Disease. Open University Press, Buckingham, 1995.
2. WHOQOL Group: The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. Social Science and Medicine 1995; 41: 1403-1409.
3. Bullinger M, Anderson R, Cella D, Aaronson N: Developing and evaluating cross-cultural instruments: from minimum requirements to optimal models. Qual Life Res 1993;2: 451–459.
4. Berzon R, Hays RD, & Shumaker SA: International Use, Application and Performance of Health-Related Quality of Life Instruments. Qual Life Res 1993;2: 367-368.
5. Patrick DL, Erickson P: Assessing health-related quality of life for clinical decision making; in Walker SR (ed): Quality of Life Assessment: Key issues in the 1990s. Dordrecht, Kluwer Academic Publishers, 1993, pp 11– 63.
6. Mayou R, Bryant B: Quality of life in cardio- vascular disease. BMJ 1993;69: 460–466.
7. Hilari K, Cruice, M: Quality of life approach to aphasia**;** in Papathanasiou I**,** Coppens P, & Potagas C (eds.)**:** Aphasia and related neurogenic communication disorders, Burlington, Massachusetts: Jones and Bartlett Learning**,** LLC, 2013, pp233 – 253**.**
8. Intercollegiate Stroke Working Party: National clinical guideline for stroke, 4th edition. London: Royal College of Physicians, 2012.
9. Worrall L, Holland A: Editorial: Quality of life in aphasia. Aphasiology 2003;17: 329-332.
10. Lam JM, Wodchis WP: The relationship of 60 disease diagnoses and 15 conditions to preference-based health-related quality of life in Ontario hospital-based long-term care residents. Med Care 2010;48:380-7.
11. Hilari K, Needle JJ, & Harrison KL: What are the important factors in health-

related quality of life for people with aphasia? A systematic review. Archives of Physical Medicine and Rehabilitation 2012;93:S86-S95.

12. Brown K, Worrall LE, Davidson B, & Howe T: Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. International Journal of Speech-language Pathology 2012;14: 141-155.
13. Cruice M, Worrall L, & Hickson L: Quantifying aphasic people's social lives in the context of non-aphasic peers. Aphasiology 2006;20: 1210-1225.
14. Davidson B, Howe T, Worrall L, Hickson L, & Togher L: Social participation for older people with aphasia: the impact of communication disability on friendships. Topics in Stroke Rehabilitation 2008;15: 325-340.
15. Northcott S, Hilari K: Why do people lose their friends after a stroke? International Journal of Language & Communication Disorders 2011;46: 524-534.
16. Fotiadou D, Northcott S, Chatzidaki A, & Hilari K: Aphasia blog talk: How does stroke and aphasia affect a person’s social relationships? Aphasiology 2014;28: 1281-1300.
17. Doyle PJ, McNeil MR, Mikolic JM, Prieto L, Hula WD, Lustig AP et al.: The Burden of Stroke Scale (BOSS) provides valid and reliable score estimates of functioning and well-being in stroke survivors with and without communication disorders. Journal of Clinical Epidemiology 2004;57: 997-1007.
18. Kagan A, Simmons-Mackie N, Rowland A, Huijbregts M, Shumway E, McEwen S, et al.: Counting what counts: A framework for capturing real ‐ life outcomes of aphasia intervention. Aphasiology 2008;22: 258-280.
19. Hilari K, Lamping DL, Smith SC, Northcott S, Lamb A, Marshall J: Psychometric proper- ties of the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in a generic stroke popu- lation. Clinical Rehabilitation 2009;23:544– 557.

20. 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: 111-129.
21. Hilari K, Owen S, & Farrelly SJ: Proxy and self-report agreement on the Stroke and Aphasia Quality of Life Scale-39. Journal of Neurology, Neurosurgery & Psychiatry 2007;78: 1072-1075.
22. Hilari K, Byng S: Health-related quality of life in people with severe aphasia. International Journal of Language & Communication Disorders 2009; 44:193-205.
23. Murphy J, Tester S, Hubbard G, Downs M, & MacDonald C: Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool. Health & Social Care in the Community 2005;13: 95-107.
24. Rose M, Ferguson A, Power E, Togher L, & Worrall L: Aphasia rehabilitation in Australia: Current practices, challenges and future directions. International Journal of Speech Language Pathology 2014;16: 169-180.
25. Simmons-Mackie N, Threats T, & Kagan :. Outcome assessment in aphasia: A survey. Journal of Communication Disorders, 2005;38: 1-27.
26. Verna A, Davidson B, & Howe T: Speech-language pathology services for people with aphasia: A survey of current practice in Australia. International Journal of Speech-Language Pathology, 2009;11: 191-205.
27. Simmons-Mackie N, Raymer A, Armstrong E, Holland A, & Cherney L: Communication partner training in aphasia: A systematic review. Archives of Physical Medicine and Rehabilitation, 2010;91: 1814-1837.
28. Brady M, Kelly H, Godwin J, & Enderby P: Speech and language therapy for aphasia following stroke. Cochrane Database of Systematic Reviews, 2012;16: 5.
29. Sorin-Peters R: The development and evaluation of a learner-centred training

programme for spouses of adults with chronic aphasia using qualitative case study methodology. Aphasiology, 2004; 18; 951-975.

30. Sorin-Peters R. & Patterson, R.: The implementation of a learner-centred conversation training programme for spouses of adults with aphasia in a community setting. Aphasiology, 2014; 28;6;731-749.
31. Elman R: The importance of aphasia group treatment for rebuilding community and health. Top Lang Disord. 2007;27:300-8.
32. Ross A, Winslow I, Marchant P, Brumfitt S: Evaluation of communication, life participation and psychological well-being in chronic aphasia: The influence of group intervention. Aphasiology. 2006;20:427-48.
33. Vickers CP: Social networks after the onset of aphasia: The impact of aphasia group attendance. Aphasiology. 2010;24:902-13.
34. Best W, Greenwood A, Grassly J, Hickin J: Bridging the gap: Can impairment-based therapy for anomia have an impact at the psycho-social level? International Journal of Language and Communication Disorders. 2008;43:390-407.
35. Rodriguez AD, Worrall L, Brown K, Grohn B, McKinnon E, Pearson C, et al.: Aphasia LIFT: Exploratory investigation of an intensive comprehensive aphasia programme. Aphasiology 2013; 27: 1339–1361.
36. Fink RB, Schwartz MF: MossRehab aphasia center: A collaborative model for long-term rehabilitation. Top Stroke Rehabil. 2000;7:32-43.
37. van der Gaag A, Smith L, Davis S, Moss B, Cornelius V, Laing S, et al: Therapy and support services for people with long-term stroke and aphasia and their relatives: A six-month follow-up study. Clin Rehabil. 2005;19:372-80.
38. Legg L, Stott D, Ellis G, Sellars C: Volunteer stroke service (VSS) groups for patients with communication difficulties after stroke: A qualitative analysis of the value of groups to their users. Clin Rehabil. 2007;21(9):794-804.

39. Mumby K, Whitworth A: Evaluating the effectiveness of intervention in long-term aphasia post-stroke: the experience from CHANT (Communication Hub for Aphasia in North Tyneside). International Journal of Language & Communication Disorders 2012; 47: 398–412.
40. Nouwens F, Dippel DW, de Jong-Hagelstein M, Visch-Brink EG, Koudstaal PJ, & de Lau LM: Rotterdam Aphasia Therapy Study (RATS)–3: The efficacy of intensive cognitive-linguistic therapy in the acute stage of aphasia: design of a randomised controlled trial. Trials 2013; 14: 24.
41. Baumgaertner A, Grewe T, Ziegler W, Floel A, Springer L, Martus P, & Breitenstein C: FCET2EC (From controlled experimental trial to= 2 everyday communication): How effective is intensive integrative therapy for stroke-induced chronic aphasia under routine clinical conditions? A study protocol for a randomized controlled trial. Trials 2013;14: 308.
42. Godecke E, Ciccone NA, Granger AS, Rai T, West D, Cream A, et al.: A comparison of aphasia therapy outcomes before and after a Very Early Rehabilitation programme following stroke. International Journal of Language & Communication Disorders 2014;49: 149-161.
43. Thomas S., Walker M., Macniven J, Haworth H, & Lincoln N: Communication and Low Mood (CALM): A randomized controlled trial of behavioural therapy for stroke patients with aphasia. Clinical Rehabilitation 2013; 27: 398-408.
44. Humphreys I, Thomas S, Phillips C, & Lincoln N: Cost analysis of the Communication and Low Mood (CALM) randomized trial of behavioural therapy for stroke patients with aphasia. Clinical Rehabilitation, 2014 (epub).
45. Ellis C, Lindrooth R, & Horner J: Retrospective Cost-Effectiveness Analysis of Treatments for Aphasia: An Approach Using Experimental Data. American Journal of Speech-Language Pathology, 2014; 23: 186-95.
46. van der Gaag A, & Brooks R: Economic aspects of a therapy and support service

for people with long-term stroke and aphasia. International Journal of Language and Communication Disorders, 2008; 43: 233-244.

47. Wallace S, Worrall L, Rose T, & Le Dorze G: Measuring outcomes in aphasia research: A review of current practice and an agenda for standardization. Aphasiology, 2014; 28: 1364-1384.
48. Pollock A, St George B, Fenton M, & Firkins L: Top 10 research priorities relating to life after stroke – consensus from stroke survivors, caregivers, and health professionals. International Journal of Stroke, 2014; 9: 313-320.