

BAS British Aphasiology Society

Therapy Symposium 2012
6th - 7th September 2012

Assessing quality of life in aphasia The benefits and limitations of the WHOQOL-Bref in therapy planning for aphasia in Portugal

Brigida Patricio^{1,2}, Luis M. T. Jesus^{2,3}, Madeline Cruice⁴, Andreia Hall⁵
abp@eu.ipp.pt; lmtj@ua.pt; m.cruice@city.ac.uk; andreia.hall@ua.pt

¹Escola Superior de Tecnologia da Saude do Porto (ESTSP), Instituto Politecnico do Porto, Porto, Portugal
²Institute of Electronics and Telematics Engineering of Aveiro (IEETA), University of Aveiro, Aveiro, Portugal
³School of Health Sciences (ESSUA), University of Aveiro, Aveiro, Portugal
⁴School of Health Sciences, City University, London, UK
⁵Department of Mathematics, University of Aveiro, Aveiro, Portugal

BAS British Aphasiology Society

Therapy Symposium 2012

Overview

- Background
 - Quality of life (QOL) definition
 - QOL of people with aphasia (PWA)
 - QOL of caregivers
- Method
- Results
- Discussion
- Conclusions

London, September 2012

Quality of Life

“Individual’s perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns.”

(WHO, 1998)

- QOL domains:
 - physical
 - psychological
 - level of independence
 - social relationships
 - environment
 - personal beliefs/spirituality

London, September 2012

Quality of life in people with aphasia

- Chronic acquired communication disorder
- Biopsychosocial impact:
 - Participation in activities of daily living
 - Social activities, social isolation
 - Ability to work
 - Emotional status (depressive symptoms)
 - Role changes
 - Dependency from others
 - Proper and others

London, September 2012

Quality of life in people with aphasia

- Methodological challenge
- Self-reported instruments (suitability)
- Proxies-reported data
- Used instruments:
 - SAQOL-39;
 - SF-36;
 - Dartmouth COOP Charts;
 - How I Feel About Myself Well-being Scale;
 - WHOQOL-Bref;
 - Psychosocial Well-being Index;
 - Aachen Life Quality Inventory;
 - Open-ended questioning methods.

London, September 2012

Quality of life in people with aphasia

- PWA are dissatisfied with their lifestyle (Hinckey, 1998)
- PWA have worse QOL than:
 - Non-brain injured people (Ross & Wertz, 2002)
 - General population (Ribeiro & Mansur, 2008)
 - Healthy people (Manders et al., 2010)

London, September 2012

Quality of life in people with aphasia

- Domains most affected by aphasia
 - Communication (Bose et al., 2009, Lata-Caneda, 2010)
 - Social relationships (Ross & Wertz, 2003)
 - Psychosocial (Bose et al., 2009 , Lata-Caneda, 2010)
 - Socialization/activities (Bose et al. 2009)
- Domains less affected by aphasia
 - Physical (Lata-Caneda, 2010 , Manders et al. 2010)

London, September 2012

Quality of life in people with aphasia

- Gender, marital status, educational level, type of stroke and language impairment are not associated to QOL
- No agreement about age and time post stroke association to QOL
- Social support, verbal communication, people around and socializing are important to PWA's QOL
- Emotional status, cognition, communication ability, functional limitation, and activity level are associated to QOL;

(Bose et al., 2009; Cruice et al., 2003; 2006, 2010; Engell et al. , 2003; Hilari et al., 2003; Hinckey, 1998; Manders et al., 2010; Ribeiro & Mansur, 2008; Ross & Wertz, 2002)

London, September 2012

Quality of life in PWA's caregivers

- Some studies included PWA's caregivers but most did not examined the impact of the communication impairment
- Poorer physical and mental health (White et al., 2003)
- Diminished QOL (White et al., 2003)
- Changes in patients's emotions, communicative capacities, loss of autonomy, the need for patience and tolerance, the changes in lifestyle – Stressful factors (Zemva, 1999; Michallet, Tétreault & Dorze, 2003)

London, September 2012

Quality of life in PWA's caregivers

- Consequences in communication, interpersonal relationships (social isolation), leisure activities and finances (Zemva, 1999; Michallet, Tétreault & Dorze, 2003)
- Correlation between PWA's and their caregivers' QOL (Carleto & Caldana, 2011)
- Most affected domains (Carleto & Caldana, 2011):
 - Physical
 - Environment
- Need to accept changes for successful living (Cruice, Worrall & Hickson, 2006)

London, September 2012

Research questions

- What is the QOL of PWA?
- What is the QOL of their caregivers?
- What variables are correlated with their QOL and Social relationships?
- What are the QOL domains most affected by aphasia in both groups?
- There are differences in the results of WHOQOL-Bref Social Relationships domain and the same domain of WHOQOL-100?
- Can the data provided by WHOQOL-Bref be helpful for therapy planning?

London, September 2012

Method

- Cross-sectional descriptive study
- Participants: 7 PWA (with at least 3mths post stroke and good auditory or written comprehension)
7 Caregivers (living with the PWA)
255 adults from general population [details not reported here]
- Instruments:
 - WHOQOL-Bref (PWA and caregivers)
 - WHOQOL-100 Social Relationship Domain (PWA and caregivers)
 - Demographic data sheet (PWA and caregivers)
 - Center for Epidemiologic Depression Scale (PWA and caregivers)
 - Lisbon Aphasia Assessment Battery (PWA)
 - Language Modified Mini-Mental State, Portuguese version (PWA)
 - Communication Disability Profile, Portuguese version (PWA)

London, September 2012

Method

- WHOQOL-Bref:
 - Self administered or interviewer assisted
 - 26 items (Social relationships domain has 3 items)
 - Comprehensive (all important domains and items)
 - Sensitive (relative importance of the domains)
 - Cultural relevance (cross-culturally comparable)
 - Subjective assessment approach (satisfaction)

London, September 2012



WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

http://www.who.int/substance_abuse/research_tools/whoqolbref/en/

Method

- Procedures:
 - 4 Portuguese hospitals
 - Testing occurred at the Speech-Language Therapists' (SLT) office (interviewed assisted instruments) and at people's home (self-administered instruments)
 - Participants were encouraged to inform the SLT if they need any assistance

London, September 2012

Results

PWA and Caregivers demographic data

		PWA (N = 7)		Caregivers (N = 7)	
		n	%	n	%
<i>Gender</i>	Male	3	42.9	3	42.9
	Female	4	57.1	4	57.1
<i>Educational Level</i>	Illiterate	1	14.3	0	0.0
	1-4 years	2	28.6	0	0.0
	5-6 years	0	0.0	1	14.3
	7-9 years	1	14.3	2	28.6
	10-12 years	3	42.9	4	57.1
<i>Socioeconomic Status</i>	High	1	14.3	1	14.3
	Medium	1	14.3	1	14.3
	Medium-low	3	42.9	3	42.9
	Low	2	28.6	2	28.6
<i>Age</i>	Mean ± SD	55.9 ± 9.2		52 ± 12.6	
	Min-Max	45-79		27-57	

London, September 2012

Results

PWA stroke and aphasia data

		n	%
<i>Speech-Language Therapy</i>	Currently	4	57.1
	Past	3	42.9
<i>Motor Impairment</i>	Hemiparesis	4	57.1
	No impairment	3	42.9
<i>Aphasia Diagnostic</i>	Anomic	3	42.9
	Conduction	2	28.6
	Broca	1	14.3
	Transcortical motor	1	14.3
		<i>Mean ± SD</i>	<i>Min-Max</i>
<i>Aphasia Coefficient</i>		66.2 ± 17.0	47.9 – 85.4
<i>Time Post-Stroke (months)</i>		27.1 ± 29.0	4.0 – 48.0

London, September 2012

Results

Overall QOL and domains results

	Control Group	PWA	Caregivers
	<i>Mean ± SD</i>	<i>Mean ± SD</i>	<i>Mean ± SD</i>
Overall QOL	3.9 ± 0.6	2.3 ± 1.4	3.4 ± 0.5
Bref Physical	4.0 ± 0.5	2.7 ± 1.0	3.6 ± 0.6
Bref Psychological	4.0 ± 0.5	2.8 ± 1.1	3.5 ± 0.5
Bref Social Relationships	3.9 ± 0.6	2.4 ± 1.1	2.9 ± 0.7
Bref Environment	3.7 ± 0.5	3.1 ± 0.9	3.2 ± 0.7
100 Social Relationships	3.9 ± 0.6	2.8 ± 0.9	3.1 ± 0.7

London, September 2012

Results

Comparing overall QOL of PWA and Caregivers

PWA and Caregivers

	Overall QOL
Z	-2,032a
Asymp. Sig. (2-tailed)	0.042

a. Based on negative ranks.
b. Wilcoxon Signed Ranks Test

- Significant differences between the QOL of PWA and their caregivers

London, September 2012

Results

PWA's Overall QOL and Social Relationships correlations

		Spearman's rho		
		Overall QOL	Bref Social Relationships	100 Social Relationships
Age	Correlation Coefficient	0.393	0.418	0.364
	Sig. (2-tailed)	0.383	0.35	0.423
	N	7	7	7
Time Post Stroke	Correlation Coefficient	0.524	0.346	0.346
	Sig. (2-tailed)	0.227	0.448	0.448
	N	7	7	7
Emotional Status (CES-D)	Correlation Coefficient	-.954**	-.873*	-.873*
	Sig. (2-tailed)	0.001	0.01	0.01
	N	7	7	7
Cognition (LMMSE)	Correlation Coefficient	0.35	0.302	0.208
	Sig. (2-tailed)	0.442	0.51	0.655
	N	7	7	7

** . Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

London, September 2012

Results

PWA's Overall QOL and Social Relationships correlations

		Spearman's rho		
		Overall QOL	Bref Social Relationships	100 Social Relationships
Aphasia Severity	Correlation Coefficient	0.356	0.327	0.327
	Sig. (2-tailed)	0.434	0.474	0.474
	N	7	7	7
Activities (CDP)	Correlation Coefficient	-.954**	-.873*	-.873*
	Sig. (2-tailed)	0.001	0.01	0.01
	N	7	7	7
Participation (CDP)	Correlation Coefficient	-.869*	-.780*	-.826*
	Sig. (2-tailed)	0.011	0.039	0.022
	N	7	7	7

** . Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

London, September 2012

Results

Caregivers' Overall QOL and Social Relationships correlations

		Spearman's rho		
		Overall QOL	Bref Social Relationships	100 Social Relationships
Age	Correlation Coefficient	0.444	0.523	0.073
	Sig. (2-tailed)	0.319	0.228	0.877
	N	7	7	7
Time Post Stroke	Correlation Coefficient	0.15	0.018	-0.108
	Sig. (2-tailed)	0.749	0.969	0.818
	N	7	7	7
Emotional Status (CES-D)	Correlation Coefficient	-.755*	-.771*	-.918**
	Sig. (2-tailed)	0.05	0.043	0.004
	N	7	7	7

** . Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

London, September 2012

Results

Caregivers' Overall QOL and Social Relationships correlations

		Spearman's rho		
		Overall QOL	Bref Social Relationships	100 Social Relationships
Aphasia Severity	Correlation Coefficient	-0.334	-0.464	-0.029
	Sig. (2-tailed)	0.518	0.354	0.957
	N	6	6	6
Activities (CDP)	Correlation Coefficient	-0.73	-0.582	-0.595
	Sig. (2-tailed)	0.063	0.17	0.159
	N	7	7	7
Participation (CDP)	Correlation Coefficient	-0.736	-0.596	-0.827*
	Sig. (2-tailed)	0.059	0.158	0.022
	N	7	7	7

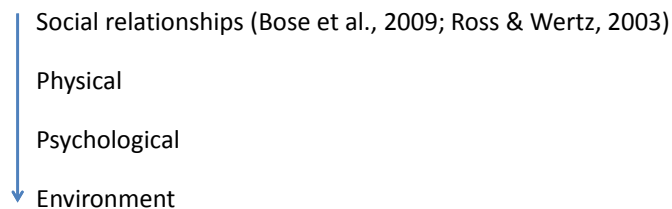
** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

London, September 2012

Discussion

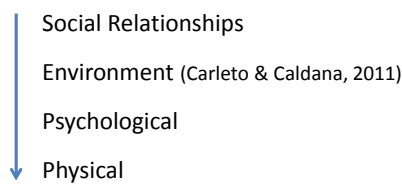
- PWA have worse QOL than general population (Ribeiro & Mansur, 2008)
- PWA classify their QOL as “bad” (Hinckey, 1998)
- PWA’s most affected domains:



London, September 2012

Discussion

- Caregivers have diminished QOL (White et al., 2003) – worse than general population but better than PWA
- Caregivers classify their QOL as “neither good nor bad”
- Caregivers’ most affected domains:



London, September 2012

Discussion

- QOL correlations:
 - Emotional status – PWA and caregivers
 - Activities - PWA
 - Participation - PWA

↓
Improvement in these areas may increase PWA's and/or caregivers' QOL

Important to integrate in aphasia therapy
Referral to other professionals

London, September 2012

Discussion

- WHOQOL-Bref seems to be suitable for PWA
- Challenges/reflection points:
 - Good auditory and/or written comprehension
 - Need for interviewer assistance
 - Sexual life question
 - Need to repeat or rephrase the questions
 - Bias introduced by interviewers?

London, September 2012

Conclusions

- PWA characterize their QOL as “bad”
- Carers characterize their QOL as “neither good nor bad”
- WHOQOL-Bref seems to be a good measure to capture PWA’s and their caregivers’ QOL

London, September 2012

Future

- General population data will be presented on ISOQOL conference in October, 2012, in Budapest
- Collect more data from PWA and caregivers (N = 50)
- Identify QOL predictors for PWA and their caregivers
- Determine if WHOQOL-Bref social relationships domain is suitable for PWA

London, September 2012

References

- Bose, A., McHugh, T., Schollenberger, H., & Buchanan, L. (2009). Measuring quality of life in aphasia: Results from two scales. *Aphasiology*, 23(7), 797 - 808.
- Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation*, 13(1), 14-24.
- Carleto, N. G., Caldana (2011). *Qualidade de vida dos pacientes afásicos e de seus familiares*. Mestrado Tese de Mestrado, Universidade de São Paulo.
- Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, 17(4), 333-353.
- Cruice, M., Hill, R., Worrall, L., & Hickson, L. (2010). Conceptualising quality of life for older people with aphasia. *Aphasiology*, 24(3), 327-347.
- Engell, B., Hütter, B.-O., Willmes, K., & Huber, W. (2003). Quality of life in aphasia: Validation of a pictorial self-rating procedure. *Aphasiology*, 17(4), 383-396.

London, September 2012

References

- Lata-Caneda, M. C., Piñeiro-Temprano, M., García-Armesto, I., Barruego-Egido, J. R., & Meijide-Failde, R. (2009). Spanish adaptation of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39). *European Journal of Physical and Rehabilitation Medicine*, 45(3), 379-384.
- Manders, A., Dammekens, E., Leemans, I., & Michiels, K. (2010). Evaluation of quality of life in people with aphasia using Dutch version of the SAQOL-39. *Disability and Rehabilitation*, 32(3), 173-182.
- Michallet, B., Têtreault, S., & Dorze, G. L. (2003). The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology*, 17(9), 835 - 859.
- Hilari, K., Byng, S., Lamping, D., & Smith, S. (2003). Stroke and aphasia quality of life scale-39 (SAQOL-39): Evaluation of acceptability, reliability and validity. *Stroke*, 34, 1944-1950.
- Hinckley, J. J. (1998). Investigating the predictors of lifestyle satisfaction among younger adults with chronic aphasia. *Aphasiology*, 12(7-8), 509-518.

London, September 2012

References

- Ribeiro, C., & Mansur, L. L. (2008). *Avaliação da qualidade de vida em pacientes afásicos com protocolo específico SAQOL-39*. Mestre em Ciências, Faculdade de Medicina da Universidade de São Paulo, São Paulo.
- Ross, K., & Wertz, R. (2002). Relationships between language-based disability and quality of life in chronically aphasic adults. *Aphasiology*, 16(8), 791 - 800.
- Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, 17(4), 355-364.
- Zemva, N. (1999). Aphasic patients and their families: wishes and limits. *Aphasiology*, 13(3), 219 - 224.
- White, C. L., Lauzon, S., Yaffe, M. J., & Wood-Dauphinee, S. (2004). Toward a model of quality of life for family caregivers of stroke survivors. *Quality of Life Research*, 13(3), 625-638.
- WHO (1998). Health Promotion Glossary. Geneva: World Health Organization.

London, September 2012

Brigida Patricio

abp@eu.ipp.pt

brigidapatricio@gmail.com

Thank BAS for support funding

London, September 2012

