Quality of Life Scales For Evaluating Neurogenic Communication Disorders

Michelle M. Diatte, B.A. ♦ | R. Ding, Ph.D., CCC-SLP ❖

Department of Communication Sciences & Disorders

Elmhurst College, Elmhurst IL

♦ Corresponding author ❖ Faculty mentor

INTRODUCTION

Quality of life is impacted greatly when a person receives a diagnosis of one of the neurogenic disorders (e.g., aphasia, Traumatic Brain Injury) or neurodegenerative disorders (e.g., Parkinson's Disease, dementia) previously described. Communication is affected during the disorders, but manifests in different ways. Before communication can be treated properly, it is important to know what the person with the neurogenic disorder wants and needs out of treatment. Reflecting on the person's life before the diagnosis was received, and what daily living skills and functions are important for a person to keep, is how therapy should be designed. Using the proper quality of life scales helps during the evaluation process to find this information. Without the proper quality of life scales, the person's needs and the way he would like to communicate may be misinterpreted. Using this information, the research question was formulated: What are the valid and reliable quality of life scales for evaluating a person's overall communication considering the diagnosis of a neurogenic or neurodegenerative disease? It is hypothesized that the health-related QoL (HRQoL) scale will be one of the main scales that is reliable and valid for all neurogenic disorders.

BACKGROUND OF QUALITY OF LIFE

When a person loses the ability to communicate effectively, the person loses an aspect of Quality of Life (QoL). QoL is defined as an individual's feelings of well-being as it relates to emotional state, physical functioning, psychosocial attitudes, or a combination of these factors (Pallavi, Perumal, & Krupa, 2018). More specifically, the World Health Organization (WHO) describes QoL as an individual's "perceptions of their position in life in the context of the culture and value systems where they live and in relation to their goals, expectations, standards, and concerns" (Ross & Wertz, 2003, p. 355). The ability to communicate is a factor of high importance related to QoL and the psychosocial adjustment in society (Bose, McHugh, Schollenberger, & Buchanan, 2009). QoL is subjective because it is the individual's perception of how he thinks he is functioning in the world.. The assessment of QoL requires an individual's subjective evaluation of his life situation. To measure QoL in different populations, a combination of generic and specific measures is needed (Ross & Wertz, 2003). When correlating the specific neurogenic or neurodegenerative disorder to QoL, many of the disorders use a framework or scale that is significant to the disorder. There are multiple dimensions, however that encompass the overall framework of QoL. The dimensions consist of physical, psychological, interpersonal, happiness, financial, and spiritual. These dimensions are then interpreted and constructed to fit the QoL scale or evaluation for the specific disorder (LaPointe, 1999).

RESEARCH QUESTION

What are the valid and reliable quality of life scales for evaluating a person's overall communication considering the diagnosis of a neurogenic or neurodegenerative disease?

It is hypothesized that the health-related QoL (HRQoL) scale will be one of the main scales that is reliable and valid for all neurogenic disorders.

METHODS

Design: Systematic review of literature

Data sources for intervention: CINHAL, PubMed, MEDLINE, and Web of Science

Inclusion Criteria: The searches were limited to the English language and studies were conducted on human participants. Studies had to include a neurogenic disorder in relation to an interview, scale, or questionnaire.

Search Terms: (1) "quality of life," "quality of communication," "questionnaires," "health-related quality of life," "aphasia," "Parkinson's disease," "Traumatic Brain Injury," and "dementia." **(2)** The following keywords were combined to find the most relevant articles: "quality of life and aphasia," "quality of life and Parkinson's disease," "quality of life and Traumatic Brain Injury," and "quality of life and dementia."

Initial Yield: 124 articles, found between the years 2002-2018

Articles Identified for Final Analysis: 28

RESULTS OF RESEARCH QUESTION

Most of the disorders researched for this paper used specific scales with questions geared toward specific symptoms, signs, and difficulties that the person would encounter when living with the specific neurogenic or neurodegenerative disorder. When it relates to the specific neurogenic or neurodegenerative disorder, the quality of life scales designed specifically for that disorder is used. There was overlap of scales found because all the disorders commonly rated communication as affected by QoL. It was found that when related to aphasia, the Quality of Communication Life Scale (QCL) and WHOQOL scale was more commonly used. Regarding , Parkinson's Disease (PD) and Traumatic Brain Injury (TBI) the HRQOL scale was used between the two neurogenic disorders. However, all the disorders, aphasia, PD, TBI, and dementia, used the HRQOL scale as a basis to shape the specific QoL scale so it targeted the neurogenic or neurodegenerative disorders' significant characteristics. Most of the studies also conducted an interview with the person with the disorder and a family member or close communication partner. This way, both the family member and the person with a neurogenic or neurodegenerative disorder could rate how the disorder has affected him.

FINDINGS: QUALITY OF LIFE SCALES COMMONLY USED FOR ALL DISORDERS

The most common scale used among all disorders was the HRQOL scale. This scale was used to compare QoL to communication partners and overall gather information about how a person with a health condition may rate their own QoL. The HRQOL scale was used most frequently in studies involving people with PD. The HRQOL scale was used in accordance with a disorder-specific scale as well. The HRQOL is the basis and first scale that is presented to the person with the disorder because it can then be compared to the scores of the other scales used.

For example, Mcauliffe (2016) paired the HRQOL scale with the Communicative Participation Item Bank (CPIB) and found the scores to be moderately correlated. Because there is correlation between other communication scales and disorder-specific scales, there may not be a need to use many different instruments when assessing QoL. However, it most likely will still be necessary to use a disorder-specific scale because there are different domains that are rated such as: emotional, psychological, social, cognitive, and daily life domains that the HRQOL scale does not focus on. The HRQOL scale has a main focus on the patients' overall health and well-being. Table 1 shows which studies with a specific disorder used the HRQOL scale.

Parkinson's Disease	Traumatic Brain Injury	Dementia
Galeoto (2018)	Norup (2015)	Sopina (2018)
	Formisano (2016)	
Karlstedt (2018)		
Mcauliffe (2016)		

FINDINGS: QUALITY OF LIFE SCALES COMMONLY USED FOR EACH DISORDER

APHASIA

	Pallavi (2018)	Fucetola (2015)	Bose (2009)
Subject	Participants consisted of 24 adults who were 29-57 years old. 12 adults had aphasia.	130 PWA due to neurological illness and who were at any point in the recovery process Consisted of both fluent and nonfluent aphasia types.	19 participants with aphasia from ages 27-79 years old. PWA had to be a minimum 6 months post-stroke.
Design	Comparative Study.	Sample of population.	Both scales were given to the control group and PWA group.
Major Findings	Significantly lower in socialization/activities domain because they restrict themselves from social activities due to impairments related to motor and communication skills.	Only rated QoL depending on if PWA could use expressive language. Nonfluent aphasia participants had lower communication scores.	Linguistic variables correlated with psychosocial, communication, and socialization/activities (subdomains of QoL).

PARKINSON'S DISEASE

	Galeoto (2018)	Karlstedt (2018)	Parveen (2016)
Subject	104 participants. Participants received a diagnosis from Movement Disorder Society.	51 patients with mild to moderate PD.	20 individuals with Study used a self-reported diagnosis of PD.
Design	Sample of population. Test-retest-test design.	Cross-sectional design. Sample of population.	Comparative Study.
Major Findings	Clinicians can use the PDQ-39 in healthcare and rehabilitation services to help understand a person with PD's rating of quality of life regarding communication and mobility.	Non-motor speech symptoms had a larger negative impact on the patient's HRQoL than motor symptoms.	Speech and motor related QoL activities were rated similarly for person with PD and the associated neurotypical proxy.

TRAUMATIC BRAIN INJURY

	Cohen (2019)	Cohen (2018)	Bertisch (2017)
Subject	132 parents and 115 children with a 6-month follow-up from the initial sampling.	385 participants with TBI ages 18-85 years old.	134 parent-child participants. Children all sustained TBI.
Design	Sample of population and survey.	Study used an interview format with scales.	Sample of population.
Major Findings	Emotional function, anger, and anxiety ratings had a strong correlation between TBIQOL and PROMIS.	TBIQOL and PHQ-9 assessed similar cognitive and emotional constructs. TBIQOL identified if the patient had more psychological differences (e.g., increased anxiety, depression, cognitive impairments).	Both PROMIS and TBIQOL rated headaches and fatigue measures, peer relations, and anxiety.

DEMENTIA

	Resnick (2018)	Sopina (2018)
Subject	137 patients with dementia who lived in nursing home. All participants were 55 years or older. Participants had a moderate-severe cognition impairment.	115 patients with dementia. 45% were widowed and 43% were married.
Design	Scales and Interviews were used.	Scales and baseline data from a 1-year follow-up was used.
Major Findings	A significant relationship between QoL and depression symptoms for late-stage dementia was found.	QUALID and the non-dementia-specific instrument's QoL ratings increased from baseline after exposure to intervention.

DISCUSSION

The HRQOL was the most used scale because it can be used as a self-reported rating scale or a scale rated by the communication partner. It can also be compared to a more disorder-specific rating scale to determine what QoL factors are overall affected because of health and what factors are affected with symptoms correlating to the specific disorder. Overall, when reviewing a comparative study, no matter the disorder, it was found that the person with a neurogenic or neurodegenerative disorder always had a lower QoL rating compared to a normed, age and gender matched person. Majority of the studies used at least one other mode of collecting information such as organizing observations, conducting an interview, partaking in treatment sessions, or collecting a survey for the participants in the study and/or their communication partners (Pallavi, Perumal, & Krupa, 2018). Whether it was aphasia, PD, TBI, or dementia, all the individuals with a neurogenic or neurodegenerative disorder rated their QoL lower than a typical individual. The main concern for the population of neurogenic or neurodegenerative disorders is the difficulty these people face functioning in society and communicating with others. Rating QoL 'low' on health-related or specific QoL scales means that no matter the disorder, when a person is diagnosed, one of the main considerations is the need to analyze QoL and how a person's daily living may change due to the diagnosis.

LIMITATIONS

The impact on QoL varies across domains, depending on the individual. Some of these domains are physical abilities, emotional health, and communication (Pallavi, et al., 2018). There is also overall limited data for QoL and dementia because majority of the QoL scales collected are based on a familiar communication partner rating the person with dementia. Because the communication partner or caregiver is rating the person with dementia, there may be some limitations that arise. Factors to consider is the level of frustration or exhaustion the communication partner or caregiver faces. If these feelings are present, QoL scores for the person with dementia may be rated lower than they should be. Considering all the disorders and QoL, the support system the person has may affect overall QoL scores as well. Another limitation seen over all studies collected was that of a small sample size with lack of differentiating severity levels and a diverse population.

FUTURE RESEARCH

Future research should consider using a larger, diverse, sample size when collecting data on QoL for dementia, aphasia, PD, and TBI. Future research should also focus on collecting data on QoL scales for aphasia, PD, TBI, and dementia over time. The length of the follow-up period for data collection would be based on the specific disorder. For example, PD patients will have a longer follow-up period with longer intervals because it is a slower progressing disease. All patients of the neurogenic disorders would benefit from this type of data collection because, whether the person's functional levels are improving or declining, the state of these disorders is constantly changing. Depending on the patients' support system, therapy, emotions, and rate of recovery, the progression of the disease may drastically change the way QoL is rated. If scores change significantly or are inconsistent, further actions, such as interviews and observations, can be used to determine the person's QoL and ability to function. It would also be helpful to see if the score changes because there may also be an underlying psychological disorder present that can be identified and treated. With the information collected, it would be beneficial to aim to help the person with the neurogenic or neurodegenerative disorder and their families find social outlets and support groups to help cope with the disorder and enhance overall QoL.

REFERENCES

Bose A, McHugh T, Schollenberger H, & Buchanan L. (2009). Measuring quality of life in aphasia: Results from two scales. *Aphasiology*, *23*(7/8), 797–808. Retrieved from http://proxy.elmhurst.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=105397942&site=ehost-live&scope=site

LaPointe, L. (1999). Quality of life with aphasia. *Seminars in Speech and Language*, *20*(01), 5-17. doi:10.1055/s-2008-1064005

Mcauliffe, M. J., Baylor, C. R., & Yorkston, K. M. (2016). Variables associated with communicative participation in Parkinson's disease and its relationship to measures of health-related quality-of-life. *International Journal of Speech-Language Pathology, 19*(4), 407-417. doi:10.1080/17549507.2016.1193900

Pallavi, J., Perumal, C., Krupa, M. (2018). Quality of communication life in individuals with Broca's aphasia and normal individuals: A comparative study. *Annals of Indian Academy of Neurology, 21*(4), 285-289.

Ross, K. B., & Wertz, R. T. (2003). Quality of Life with and without aphasia. *Aphasiology, 174*, 355-364. doi:10.1080/02687030244000716

Author Disclosure: M. Diatte does not have any financial or non-financial relationships to disclose pertaining to the research. R. Ding does not have any financial or non-financial relationships to disclose pertaining to the research.