

Received: 11.05.2012
Accepted: 28.03.2013

A – Study Design
B – Data Collection
C – Statistical Analysis
D – Data Interpretation
E – Manuscript Preparation
F – Literature Search
G – Funds Collection

QUALITY OF LIFE IN APHASIA COMMUNITY GROUP MEMBERS: A SOCIAL MODEL OF CLINICAL TREATMENT

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SUMMARY

The purpose of this article is to provide speech-language pathologists with information about aphasia community group outcomes, with a focus on quality of life (QoL) factors. This article will also describe the social model of aphasia treatment as it relates to QoL and discuss the ways in which QoL may affect clinical outcome. The authors will also summarize predictive factors of QoL in people with post-stroke aphasia and briefly describe the assessment scales used to measure health-related QoL in communicative disorders. Participation in aphasia community groups helps to resolve the common complaint of social isolation and help improve psychological well-being through social interaction. It seems that improving quality of life in people with aphasia significantly depends upon building a stable and long-term social support network.

Key words: functional communication, social interaction, aphasia community outcomes

INTRODUCTION

Aphasia community group members inform researchers and clinicians with the status of their rehabilitation – not only in terms of speech or motor impairments, but also in terms of how they perceive their quality of life (QoL). QoL can be defined 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 concern” (World Health Organization, 1995). Social participation is an important factor in the social model of aphasia treatment, because it mediates social isolation—a commonly reported problem in people with aphasia. The application of QoL research to social models of aphasia treatment will be fundamental in unraveling the psychosocial, cultural and environmental impact on clinical outcomes in aphasia. The development of QoL assessment tools can be traced back to the early 1980s (Flanagan 1982), with QoL research in aphasia emerging in the early to middle 1990s (Pachalska 1991; Bech 1993; Sarno 1997). This paper will examine the aphasia community group as a social method of treatment, with special consideration for QoL factors implicated in clinical outcomes.

THE SOCIAL MODEL OF APHASIA TREATMENT

The National Aphasia Association (NAA), which was founded in 1989, surveyed persons with aphasia and their caregivers and identified increased social isolation as one of the most frequent consumer complaints. The NAA then took as one of its mandate to create “community groups” across the country. According to Elman (2007) the increase in aphasia group programs across the country in the past 20 years has been one of the most notable changes in the management of aphasia in the United States. Social programs in clinical intervention usually serve an extension of the traditional medical model of treatment.

In speech-language pathology, the typical outpatient course of treatment for those individuals with aphasia has been reduced over the years due to the limits placed on insurance sponsorship. As a result, many patients with aphasia seek resources in the community to continue their care when health care funding has expired. These resources may consist of modified treatment programs, including speech/language remediation services delivered at low cost at academic facilities. This is one major reason why individuals with aphasia are joining community groups.

An additional thrust to the community group movement has been the trend to employ a “social model” of aphasia management. Many prominent aphasiologists now focus on increasing the involvement of the aphasic individual in his or her social environment and subscribe to the social and life-participation approaches to aphasia (Chapey, et al 2001; Simmons-Mackie 2001; Hilari et al. 2003; Pachalska & MacQueen 2001). These writers and clinicians have borrowed notions from the World Health Organization International Classification of Function (www.who.int/classifications/icf/) and the SF-36 Health Survey Scoring (www.SF-36.org) which pertain to activities related to participation in life, placing

at the center, re-engagement in life by strengthening daily participation in activities of the individual's choice. This includes attention given to the creation of supportive environments, e.g. joining community activities, dealing with strangers and the community at large, maintaining friendships, primarily from the standpoint of reducing the emotional pain which is thought to interfere with social and emotional adjustment.

The social and life-participation model suggests that the primary task of the post-stroke patient, after the medical stability is re-gained, is the renegotiation of social identity within a social context (Grochmal-Bach et al 2009; Pachalska 1991. Astrom et. al. (1992) identified the importance of a social network for patients with chronic conditions and found that individuals that are three years status post stroke have more psychiatric symptoms and depression than other elderly persons (1992). It stands to reason that individuals with communication disabilities are more vulnerable to the effects of social isolation since conversation with others is the primary way people connect with one another and thereby maintain an active social life and connect with one's community. Shadden and Agon (2004) state that the primary focus of support groups in aphasia is the renegotiation of social identity which they maintain is an integral part of the coping process (see also: Pachalska 1991). Research shows that the social model has important implications for QoL in people with aphasia. Providing an evidence-based quality of life approach to community group activities focuses aftercare on the main goal of psycho-social well-being.

QUALITY OF LIFE RESEARCH ON APHASIA

QoL research on aphasic individuals in community groups helps to explain how QoL relates to outcome. For instance, a study by Vickers (2010) found that people with aphasia are susceptible to both a reduction in social networks and social isolation. Notably, aphasics who attend aphasia community groups report increased social participation and a sense of social connectedness (Vickers, 2010). These are two important factors which may help to improve quality of life in people with aphasia.

Quality of life and predictive factors

QoL research may help improve the clinical management and outcome of aphasia patients. Understanding the predictive factors of QoL in post-stroke aphasia can also help clinicians and researchers develop the appropriate intervention programs (Hilari et al., 2003). For instance, Cruice et al. (2003) noted that functional communication ability is linked to QoL. In addition, emotional health was a mediating variable, while physical health had an effect on life participation. Previously, King (1996) had identified three predictive factors of QoL in long-term post-stroke survivors, including: depression, social support and functional status.

Ross and Wertz (2003) stated “Therapy that focuses on situation-specific communication and societal participation appears to be most appropriate for enhancing the [QoL] of people with chronic aphasia.” The authors also affirm that the “social approach to managing aphasia is designed to improve the quality of life (QOL)”. Ross and Wertz (2003) also identified three domains of quality of life which is particularly important to aphasics, compared to non-aphasics, including: level of independence, social relationships, and environment. In addition, Hilari et al. (2003) found that poorer health-related QoL was associated with “[i]ncreased distress, reduced involvement in activities, increased communication disability, and comorbidity” in people with chronic post-stroke aphasia.

INTERNATIONAL QOL RESEARCH

Some noteworthy QoL research has been conducted in foreign populations, including Indian, Chinese and German patients with Aphasia. Raju et al. (2010) used the World Health Organization QoL-BREF to assess QoL in 162 hospital-based patients. They found that QoL in Indian post-stroke survivors was associated with anxiety, depression, and functional dependence. Delcourt et al. (2011) administered a 35-item quality-of-life questionnaire (QOL-35) designed specifically for use in Chinese populations. They found that the level of disability at hospital discharge and level of income were predictive factors in health-related quality of life in post-stroke Chinese patients. Engell et al. (2003) administered the Aachen Life Quality Inventory (ALQI), to assess QoL in German patients with post-acute and chronic aphasia. They found that patient reports depended on both the type and severity of impairment.

SUMMARY OF PREDICTIVE FACTORS

In summary, predictive factors for quality of life in individuals in aphasia include the following:

- functional communication ability
- social support
- emotional health
- physical health
- gender
- age
- recreational involvement
- comorbid disorders

The social model of aphasia treatment would be particularly useful in tackling some of these issues. Factors contributing to quality of life, such as social interaction, life participation, renegotiating social identity and emotional release, can be addressed within the context of a support group.

QUALITY OF LIFE MEASURES: A BRIEF REVIEW

The authors will briefly review two quality of life measures that have extensively used for assessing QoL in people with communicative disorders, including The Quality of Communication Life Scale (ASHA-QCL; Paul et al., 2005) and The Assessment for Living with Aphasia (ALA) (Kagan et al., 2007).

The Assessment for Living with Aphasia (ALA) (Kagan et al., 2007) is a self-report quality of life measure addressing life activities, identity, language and environment. Items are “rated on a 0-4 scale in line with ICF scoring, however, 0.5s are inserted in between to create a 9-point numerical scale” (Kagan et al. 2008, 273). It uses a pictographic approach and provides both quantitative and qualitative data from the patient’s perspective. This measure reportedly has high psychometric reliability and validity, and has been piloted several times (Kagan et al., 2008).

The Quality of Communication Life Scale (ASHA-QCL; Paul et al., 2005) is a self-report measure used to assess quality of life in individuals with communication disorders. It consists of 8-items rated on a 5 point vertical visual analog scale without numbers but with graphic representations at the end points to indicate positive or negative responses (Babbit and Cherney, 2010). The QCL examines the effect of adult neurogenic communication disorders on psychosocial, vocational and educational domains, as well as the overall quality of life. It is short, requiring approximately 15 minutes to complete, but is considered a valid measure for the above stated purpose.

COMMUNITY GROUPS: A PATIENT-CAREGIVER INTEGRATED APPROACH

Patient support groups and caregiver support groups are typically separate communities that form to address their own issues in managing aphasia. Understandably, the patient and caregiver perspective will differ on the challenges of coping with communicative disorder. It is the opinion of the authors that establishing an integrated patient-family group will provide clinicians an opportunity to evaluate group communication in a more typical context, and to be able to instruct caregivers on how to interpret and respond to the needs of their disabled partners. Instructing both patients and caregivers on effective communicative and coping strategies would also help to improve quality of life on both an individual and familial scale.

CONCLUSION ON APHASIA COMMUNITY GROUPS AND QOL

Participation in aphasia community groups helps to resolve the common complaint of social isolation and help improve psychological well-being through social interaction. It seems that improving quality of life in people with aphasia significantly depends upon building a stable and long-term social support network.

ACKNOWLEDGEMENT

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