

# **Quality of life of the caregivers of people with aphasia**

## **A systematic review**

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Candidatura ao Título de Especialista de

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# Quality of life of the caregivers of people with aphasia: A systematic review

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## ABSTRACT

**Purpose:** Systematic review to identify the factors associated to the quality of life (QOL) of the caregivers of people with aphasia (PWA).

**Methods:** Studies were searched using Medline, Pubmed, Cochrane Library, CINAHL, PsycINFO and Web of Science databases. Peer-reviewed papers that studied the QOL of PWA's caregivers or the consequences of aphasia in caregivers' life were included. Findings were extracted from the studies that met the inclusion criteria.

**Results:** No data is available reporting particularly the QOL of PWA caregivers' or their QOL predictors. Nevertheless, it was possible to extract aspects related to QOL from the studies that report the consequences of aphasia, and life changes in PWA's caregivers. Nine (9) studies including PWA's caregivers were found, but only 5 reported data separately on them. Methodological heterogeneity impedes cross-study comparisons, although some considerations can be made. PWA's caregivers reported life changes such as: loss of freedom; social isolation; new responsibilities; anxiety; emotional loneliness; need for support and respite.

**Conclusions:** Changes in social relationships, in emotional status, increased burden and need for support and respite were experienced by PWA's caregivers. Stroke QOL studies need to include PWA caregivers' and report separately on them. Further research is needed in this area in order to determine their QOL predictors and identify what interventions and referrals better suit their needs.

### Keywords

Quality of life, caregivers, aphasia, consequences

## 1. INTRODUCTION

Most people with aphasia (PWA) see their lives changed forever, as they are faced with a chronic acquired communication disorder. Changes occur at a linguistic and communicative level but also at different levels of daily living and Quality of Life (QOL) (LaPoint, 2005; Pound, Parr, Lindsay, & Woolf, 2001). Stroke and aphasia affect the biopsychosocial integrity of the individuals compromising the participation in activities of daily living, in social activities, the ability to work, and their emotional status (LaPoint, 2005; Pound et al., 2001). The changes may include the loss of communicative partners, participation in less activities, role changes, social isolation, dependency, and the development of depressive symptoms (Ardila, 2006; Berthier, 2005; Jordan & Kaiser, 1996; Patrício, 2007; Währborg, 1991). All these changes are unexpected and have impact on the family and on other social partners (Währborg, 1991; Zemva, 1999). To face all the changes, the psychosocial adjustment of the PWA and their families is very important (Peña-Casanova, Manero, & Bertran-Serra, 1995) .

A comprehensive aphasia treatment goes beyond PWA's impairments, including interventions centred in activities and participation (Brundage et al., 2012) and enrol PWA and their family, caregivers, and friends. Learning about the adjustment of PWA and their families skills is crucial for effective communication (LaPoint, 2005; White, Mayo, Hanley, & Wood-Dauphinee, 2003). Usually, when family members visit the hospital for the first time after the onset of aphasia, they have no knowledge about aphasia and do not know how to deal with the communication difficulties. While the person with aphasia is still in the hospital and after returning home, the families face new challenges in physical, psychological, social and economic areas as a consequence of aphasia (Avent et al., 2005).

A chronically disabled person may often destabilises the family life and disrupts the established balance within the family (Glozman, 2004). For chronically disabled people, the families play a major role in supporting their impaired relative (Glozman, 2004). Caregiving is representative of many situations out of which psychosocial problems may arise (Glozman, 2004; Wilkinson et al., 1997). Three main groups of possible determinants of decreased QOL in caregivers of adults with chronic diseases can usually be identified: clinical; psychological; sociodemographic. More severe impairments are predictive of greater overload and strain for caregivers. Functional disability, severity of the disease, cognitive and behavioural disorders, and impaired social interaction of the care receiver are factors that influence caregivers' QOL. Other variables such as age, gender, educational level, financial status of caregivers and of the person with a chronic disease, the type of relationship, family position of the caregiver, coping strategies,

social support and perception of support availability of the caregivers also influence caregivers' QOL. Older caregivers are more susceptible to overload than younger carers, who suffer more from isolation due to restriction of social and leisure activities restrictions. Male caregivers show a significant increase in depressive symptoms, although, females are significantly more distressed. Caregiver burden is also affected by one's perception of the patient symptoms, by the attitude or emotional response toward caregiving, by the perception of one's adequacy for coping with stressors and by the extent to which caregiving has an adverse impact on one's own life (Glozman, 2004). Concerning particularly people with stroke, caregivers' strain and burden are associated with stroke severity, lower socioeconomic level, caregivers health, amount of required hours of care and a smaller social network (R. E. Rombough, Howse, & Bartfay, 2006).

Regarding PWA, usually the number of relationships decreases and the importance of intra-family relationships increases. The loss or impairment of the ability to communicate is typically devastating and frustrating to both the stroke survivor and his or her primary caregiver and can result in fear, feeling of hopeless and depression (R. E. Rombough et al., 2006). The systematic review of Glozman (2004) referred to a 1978 study that included 97 aphasia caregivers and reported that 47% of the caregivers of PWA needed the help of a psychiatrist and that 76% needed tranquilisers (Glozman, 2004).

Some data is available about the consequences of being close to a person with aphasia, although, the results of these studies have not been systematically analysed. Knowing the impact of such disability in caregivers' lives will help determining suitable interventions and adequate referrals.

The aim of this paper is to compile the data available regarding QOL of PWA's caregivers, identify factors associated to the QOL of PWA's caregivers, and identify predictors of their QOL.

## **2. METHODS**

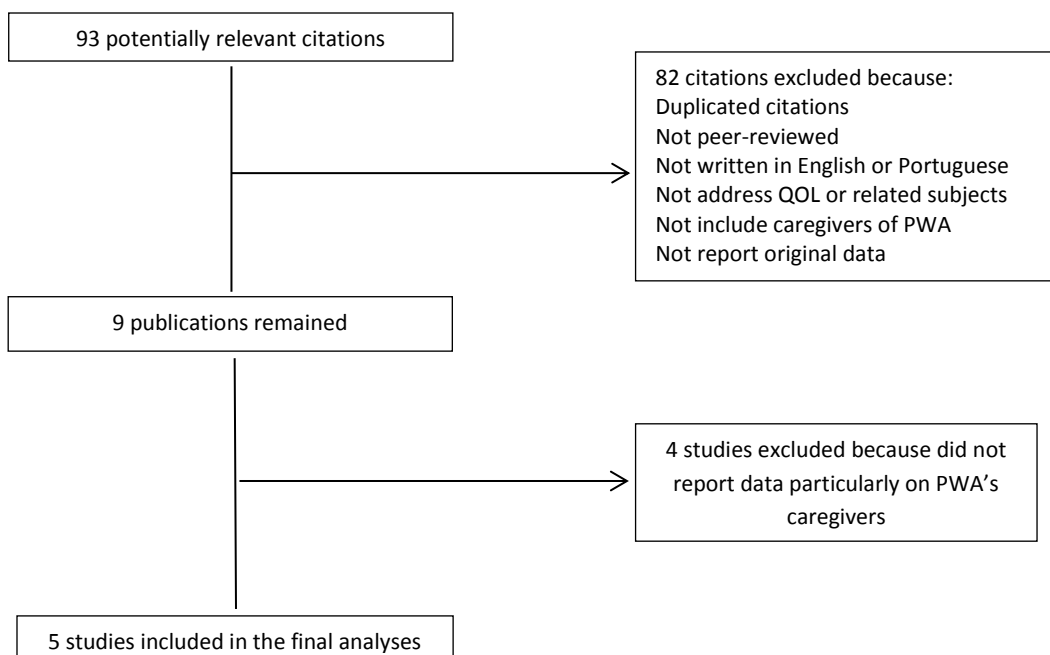
### **2.1. Data sources and search strategy**

A literature review was conducted to identify studies that report data on the QOL of the caregivers of PWA, and their QOL predictors. The following databases were searched: Medline; Pubmed; Cochrane Library; CINAHL; PsycINFO; Web of Science. Studies were considered for review if: published in peer-reviewed journals; published in English or Portuguese; reported original data; participants included adult caregivers of PWA; reported data on factors associated or predictive of PWA's caregivers QOL. No restrictions were imposed regarding study design. No other exclusion criteria were applied. Searches were conducted using the following keywords: "Aphasia" AND

“caregiver” OR “relative” AND “quality of life” OR “well-being” (OR “wellbeing”) OR “life satisfaction” OR “burden” OR “consequences”.

## 2.2. Study selection

A total of 93 potential citations were identified in the initial search. From those, 82 were excluded because: were duplicated citations, were not peer-reviewed, were not written in English or Portuguese, did not address QOL or related subjects on PWA’s caregivers, and did not report original data. Additionally, four (4) more studies were excluded because they did not report data particularly on PWA’s caregivers. Five (5) studies were included in the final analysis (see Fig.1).



Papers meeting the inclusion criteria were coded for aims, country, sample data (caregivers and PWA), methodology, outcome measures and main findings. Two reviewers conducted the coding independently, each using a complete copy of the retrieved paper and summarised the extracted data in a data table. Agreements between the reviewers occurred for 95% of the occasions and the disagreements were solved through discussion.

## 2.3. Data analysis

Because of the aims and methodology of the included studies, statistical procedures for meta-analysis were not performed. A table data and a narrative synthesis (see tables 1 and 2) of the evidence were used.

### 3. RESULTS

According to our literature review, nine (9) papers were found that studied the QOL or related areas of the caregivers of PWA (Bethoux, Calmels, Gautheron, & Minaire, 1996; Choi-Kwon, Kim, Kwon, & Kim, 2005; Denman, 1998; Franzén-Dahlin et al., 2008; Le Dorze & Signori, 2010; Michallet, Tétreault, & Dorze, 2003; Nätterlund, 2010; Nystrom, 2011; White et al., 2003); four (4) of them did not report specific data for this population but for stroke caregivers' as a whole (Bethoux et al., 1996; Choi-Kwon et al., 2005; Franzén-Dahlin et al., 2008; White et al., 2003). The studies that reported PWA's caregivers results only included these subjects in their samples (Denman, 1998; Le Dorze & Signori, 2010; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011). The data of these five (5) studies is reported in the tables 1 and 2.

Across the five (5) studies, the sample size was between 5 and 19 caregivers, and the aims were to identify the consequences and/or needs of those closely related or caring for PWA; no other stroke survivors participated.

The interviewed caregivers were mainly spouses and women with an overall minimum age of 35 years and a maximum of 79 years. Two (2) out of the five (5) studies, reported on the gender of the PWA (the majority were men). PWA's age was reported in the majority of the studies (4/5) and, generally, the minimum age was 25 years and the maximum 88 years. The majority of the studies did not refer to severity and/or aphasia type. Only two (2) studies report on the severity and/or type which were, overall, mild to severe, and expressive, global or mixed type of aphasia. Only one study mentioned the physical disability of the PWA. Michallet et al. (2003) referred that hemiplegia was not an exclusion criteria but didn't characterised what were the physical disabilities of the individuals of the sample (Michallet et al., 2003).

**Table 1:** Sample data

Study	Country	Sample size	Caregivers data			PWA data				
			Relationship to PWA	Gender	Age (y)	Gender	Age (y)	Aphasia severity	Type of aphasia	Physical disability
Nystrom, 2011	Sweden	17	10 Spouses 6 Adult children 1 Parent	11 Women 6 Men	<u>Range:</u> 35-79	11 Men 6 Women	<u>Range:</u> 25-88	NA*	NA*	NA*
Le Dorze & Signori, 2010	Canada	11	Spouses	9 Women 2 Men	<u>Mean:</u> 60.5 <u>Range:</u> 51-68	NA*	<u>Mean:</u> 63.5 <u>Range:</u> 51-76	Mild to severe	NA*	Residual to moderate
Nätterlund, 2010	Sweden	14	7 Spouses 4 Parents 1 Sibling 1 Child 1 Close friend	7 Women 7 Men	NA*	5 Women 9 Men	<u>Mean:</u> 55.6 <u>Range:</u> 28-70	NA*	Expressive	NA*
Michallet et al., 2003	Canada	5	Spouses	4 Women 1 Man	<u>Mean:</u> 65.6 <u>Range:</u> 59-71	NA*	<u>Mean:</u> 68.6 <u>Range:</u> 64-77	Severe	3 global 2 mixed	NA*
Denman, 1998	UK	9	Spouses	6 Women 3 Men	NA*	NA*	N.a.*	NA*	NA*	NA*

\* Not available



The time post onset was mentioned in two (2) studies: Le Dorze & Signori (2010) with an average of six (6) years and eight (8) months; Nätterlund (2010), with a range of two (2) years to eleven (11) years (Le Dorze & Signori, 2010; Nätterlund, 2010).

From all studies, Denman's (1998) was the one with less data on caregivers and PWA (Denman, 1998).

All the studies used qualitative methodology (see Table 2: ). The caregivers were interviewed using a lifeworld approach (Nystrom, 2011), group interview format (Le Dorze & Signori, 2010), conversational form (Nätterlund, 2010) and interview schedule of open-ended questions (Denman, 1998; Michallet et al., 2003).

**Table 2:** Studies aims, methodology and main findings

Study	Aims	Methodology	Main findings
Nystrom, 2011	Identify the consequences of being closely related to a PWA	Qualitative	Life is characterised by: loss of freedom; new form of relationship.
Le Dorze & Signori, 2010	Identify needs, barriers and facilitators	Qualitative	Need of support and respite. Facilitators: availability of close family or friends to provide help. Barriers: organisational.
Nätterlund, 2010	Describe the influence of aphasia on caregivers' life situation	Qualitative	Great changes in life. Loss of friends. Communication problems. Sense of emotional loneliness. Sense of being the one who does most of the chores.
Michallet, Tétreault & Le Dorze, 2003	Identify the consequences of severe aphasia as experienced by spouses of PWA	Qualitative	Changes in lifestyle habits: interpersonal relationships; responsibilities; leisure activities; finances. Spouses experienced: fatigue; anxiety; discouragement; loss of privacy; social isolation; burden. Coping strategies based on the problems or on the control of the significance of them.
Denman, 1998	Identify the needs	Qualitative	Needs: support; information; role change; training; day/respite care

Although the heterogeneity of the studies' aims and outcome measures, some considerations can be made about their findings.

The loss of freedom is frequently felt by close relatives, especially those who live with the PWA; they have to take part as informal caregivers, whether they agreed to it or not (Nystrom, 2011). They feel like all responsibilities lie on them, which could be a source of pressure, stress, irritation, fatigue and exhaustion (Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011).

Role changing happened, the caregivers took over roles that the PWA no longer assumed, and this can also be a source of stress (Denman, 1998; Michallet et al., 2003; Nätterlund, 2010). Financial problems are, as well, a source of stress (Michallet et al., 2003) and because the lack of time to take over all the responsibilities, some carers had to take an early retirement to look after their spouses (Michallet et al., 2003; Nystrom, 2011).

Many communication difficulties were reported (Nätterlund, 2010; Nystrom, 2011). The communication disability is perceived as devastating, as a source of stress and leading to loneliness (Michallet et al., 2003; Nätterlund, 2010). Changes in relationships were manifested in their marital relations, their relationships with family, with friends and with others from their social circle (Michallet et al., 2003). For some caregivers, the loss of friends was described as the hardest part (Nätterlund, 2010). Social isolation was reported not only as a “natural” consequence (others stay apart), but also, in a certain degree, as voluntary by the PWA and/or their caregivers due to the communication difficulties (Michallet et al., 2003).

Caregivers point out a decrease in leisure activities (Michallet et al., 2003) and many report emotional distress (Le Dorze & Signori, 2010; Nystrom, 2011).

Spouses reported decreased sexual desire and some considered divorce, although in many cases it did not happen. A new form of relationship and coping was developed (Nätterlund, 2010; Nystrom, 2011).

PWA’s caregivers showed that they were more concerned about their relative’s everyday well-being than their own needs and life (Nätterlund, 2010).

Regarding needs, caregivers often reported the need for: assistance in taking care of a person with aphasia and day-to-day tasks; information; emotional support for dealing with the consequences of aphasia; support for redefining their roles and their life projects; respite; support to improve interpersonal relationships were also mentioned as a need (Denman, 1998; Le Dorze & Signori, 2010; Nätterlund, 2010).

## 4. DISCUSSION

The concerns about community services centred in caregivers' needs have been developing and many studies were published to report the consequences, needs and QOL of caregivers of disabled people. In Sweden, community services support informal caregivers of stroke victims (Nätterlund, 2010; Nystrom, 2011).

Although many caregivers of chronic disabled people have been studied, less has been done about caregivers of PWA. In this review, five (5) studies were found that look at the consequences of aphasia in caregivers' lives and reported their results separately. As a communication disorder, aphasia impacts the affected person but also their interlocutors, although, the consequences of this impairment in caregivers' QOL has been underexplored.

The studies that report the consequences of chronic diseases in caregivers' lives identify some variables/predictors of their QOL, namely: severity of the impairment; functional disability, cognitive and behavioural disorders, and impaired social interactions of the disabled person; age, gender, educational level and financial status of both; coping strategies, social support, perception of support availability, and type of relationship of the caregiver (Glozman, 2004). Regarding stroke, socioeconomic status, caregivers' health, amount of care hours and social network were additionally identified (R. Rombough, Howse, Bagg, & Bartfay, 2007; R. E. Rombough et al., 2006). The great majority of the analysed studies that included PWA's caregivers did not report these data in detail or did not mention it at all. Functional disability, cognitive and behavioural disorders, educational level, financial status, socioeconomic level, caregivers' health and amount of care hours are not reported at all in these studies. Impairment severity, physical disability and gender of the person with aphasia are reported in few of them. Regarding gender of the caregiver, age and type of relationship are reported in all studies. Although, this data is available, it was only mentioned to characterise the samples and not to determine whether these variables may influence caregivers' QOL or not (Denman, 1998; Le Dorze & Signori, 2010; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011). Thus, concerning these important variables, comparisons cannot be done through all these studies and even among them and studies with more general chronic disease samples.

It will be useful if future research with caregivers of PWA determine and report these data when publishing in order to provide better comparisons among studies, relate variables, and provide a better understanding of the results.

Social isolation was referred in Nystrom's (2011), Nätterlund's (2010) and Michallet's et al (2003) studies, although nothing can be said about its relation to age, as previously reported by Glozman (2004) for people with chronic diseases (Michallet et al., 2003; Nätterlund, 2010;

Nystrom, 2011). Changes in social relationships at many levels were frequently mentioned, which is in accordance with Rombough (2006) regarding PWA (R. E. Rombough et al., 2006).

Increased responsibilities, stress, irritation, fatigue, exhaustion, and emotional distress were reported as consequences of being a close relative or a caregiver of a person with aphasia (Le Dorze & Signori, 2010; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011). Hickey (2011) also mentioned frustration and devastation in his study (R. E. Rombough et al., 2006). The same was observed for people with chronic diseases (Glozman, 2004). These feelings may lead to find help with a psychiatrist, which is in agreement with Glozman's (2004) reported data.

Caregivers of PWA additionally reported role changing, financial problems and decreased leisure activities participation (Denman, 1998; Michallet et al., 2003; Nätterlund, 2010). Chronic disabled caregivers report leisure activities restriction, and financial status influences these caregivers' QOL (Glozman, 2004). Regarding aphasia, we do not know if these variables are significant predictors of caregivers' QOL.

None is known about the influence of the amount of care hours in caregivers' of PWA lives, though, they refer need of support and respite and some had to take an early retirement (Denman, 1998; Le Dorze & Signori, 2010; Michallet et al., 2003; Nätterlund, 2010; Nystrom, 2011), which may have to do with the amount of hours of care. According to Rombough et al. (2006) this variable is associated to strain and burden in caregivers of people with stroke (R. E. Rombough et al., 2006).

Nothing can be said overall about aphasia severity and consequences in caregivers' lives. Only a few studies mentioned aphasia severity and did not explore this data (Le Dorze & Signori, 2010; Michallet et al., 2003).

The availability of others to provide help was identified by PWA's caregivers as a facilitator (Le Dorze & Signori, 2010). The same was previously reported for caregivers of chronic diseases overall (Glozman, 2004).

Methodological characteristics, different aims, and different available data on sample characteristics of the included studies impede cross-study comparisons. Some consequences of living and caring for a person with aphasia were identified, although a life situation as a whole has not been explored. Therefore we don't know if all these changes significantly impact in their QOL or even if some variables are stronger predictors of caregivers' QOL than others. The five (5) reviewed studies highlighted important issues resulting from communication impairment in caregivers, though there might be several issues to consider additionally. Further research is needed in this area. Stroke QOL studies might include PWA's caregivers and report separately their results. From all the consequences of stroke, aphasia is a very particular

one, thus it might be studied in order to better understand the needs and priorities of PWA and their caregivers. As a result, healthcare could be better focused on PWA's caregivers' needs and provide appropriate, relevant and cost-effective interventions and referrals for them. As caregivers are an important source of support and a driving force for PWA's participation in society, caregivers focused programs may reduce the burden of the impairment even for society.

It is important also in Speech and Language Therapy, to understand the impact of aphasia on the caregivers' QOL and on their needs, and use it to determine the aims of the intervention. As these professionals are knowledgeable about communication and aphasia, they might be very important in planning and implementing services that will promote social participation and QOL of all those affected by aphasia (Le Dorze & Signori, 2010).

## **5. CONCLUSIONS**

As a consequence of aphasia, caregivers reported changes in their lives, mainly social isolation, burden, fatigue, anxiety and need of support and respite. These aspects may influence their QOL, although none of the reviewed studies report on the QOL of PWA's caregivers specifically. Thus, no data is available about PWA's caregivers QOL particularly and no predictors of their QOL are known. Healthcare services could benefit from the experience of caregivers to provide adequate services and speech and language therapists could have an important role in designing and implementing PWA's caregivers focused services. More information is needed about the impact of aphasia in caregivers' QOL.

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