# **Quality of Life for Caregivers of Elderly Patients** with Dementia and Measurement Tools: A Review

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#### Abstract

Dementia is a multifactorial syndrome that requires high levels of care, which are provided by informal structures, mainly the family. However, support from the family caregiver comes at a cost, with high levels of burden, psychological morbidity, poor physical health, social isolation and financial difficulties. The purpose of this review article is to depict the quality of life for family caregivers of people with dementia, based on existing studies, the relation with the burden of caregiving and its implications. The necessity dictated the review, results from the fact that the findings from the various studies will show the extent to which affected the quality of life of caregivers and the different factors associated with it, serving as catalysts to planning strategies for its maintenance or improvement, but will also provide reliable data for social policy makers for similar interventions. The review focused on studies and reviews concerning the quality of life and the physical and mental burden (in relation to the quality), of informal caregivers of aged dementia patients, residing in the community. Caring for a patient with dementia causes burden and therefore deteriorates the quality of life of caregivers. Several common factors were found to be associated with it giving more weight to each of them in the various studies. Multicomponent interventions which provide a range of services to the families of people with dementia, based on the variety and differentiation to their problems, they can prevent, or minimize the deterioration of the quality of life.

**Keywords:** Dementia caregiver; Caregiver Quality of life; Community care; Alzheimer Caregiver; Family Caregiver; Caregiver well-being; Caregiver Interventions.

## **1** Introduction

Through the studying of the bibliography it is understood that providing for a family member with dementia is a stressful process with negative effects on both physical and mental health of the caregiver affecting the quality of their life<sup>1,2,3,4</sup>. Moreover, the burden resulting from the management of cognitive, behavioral and psychological symptoms of dementia (BPSD),

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which is demanding and challenging<sup>5,6</sup> is even greater than that of people who take care of patients with chronical diseases, whose role has been described as"36 hours day"<sup>7,8,9</sup>.

Several factors such as social, economic, demographic, environmental, and the existence of social support networks, limited access and use of health services, severity of the disease, behavioral disorders, hours of care, social isolation, family cohesion, possibly affect the health of dementia caregivers<sup>10,11,12,13</sup>.

This review raises two researchable questions:

- 1. What is the assessment of quality of life for caregivers of patients with dementia based on existing studies and what the concept of "quality of life" means for them?
- 2. What is the relationship between quality of life for dementia caregivers and the burden of care?

## 2 Methods

A search was performed in OVID MEDLINE and PubMed for studies published between 1999 and 2014. Reference lists were also checked for relevant studies. No language limits existed and foreign papers were also translated. Also, the search was extended to international journals such as: Alzheimer Disease and Associated Disorders, Aging & Mental Health, International Journal of Geriatric Psychiatry, Social Science and Medicine etc.

Searched articles were mainly in English, but Spanish, Greek, Italian and other articles that regarded the quality of life were also included. These articles related to studies and reviews (critical reviews and meta-analyses) relevant to the matter being investigated. Keywords and their combinations were used, with conjunctive and disjunctive relationship between them (and - or): «Dementia caregiver» «Caregiver burden», «Caregiver Quality of life», «Caregiver Health-related quality of life», «Community care», «Alzheimer Caregiver», «Family Caregiver», «Caregiver well-being», «Caregiver Interventions».

The selection (Inclusion) criteria for articles were studies dealing with quality of life of family caregivers of patients with dementia in the community, which provide most of the care and support the patients, that is to say were the main caregivers, regardless of gender, age, years of care, kinship, severity of dementia and ethnicity. Furthermore articles regarding the burden of care and its effects on physical and mental health of caregivers were researched, as well as articles concerning measurement tools (questionnaires) of quality of life, that were used in each study.

The exclusion criteria have been articles before 1999, articles to which there was no access to the full text, double registrations, the studies concerning formal (paid) caregivers and patients in nursing homes.

More than 648 articles were searched in total. 440 of them were excluded initially based on the title. Out of the remaining 208, 119 were rejected due to no full texts. Of the 89 studies that were included in the final review, 42 are directly or indirectly related to the Quality of Life, while 47 studies and reviews related to the burden of the consequences of care in physical and mental health, as well as the Quality of Life Measurement tools used in the aforementioned 42 studies (Figure 1. Flow Diagram).

## 2.1 Definition of Dementia

Dementia is not a single disease, but a term used to describe symptoms such as impairments to memory, communication and thinking (decreased concentration and judgment, orientation

problems in space and time, behavioural problems etc.), with Alzheimer's disease being responsible for more than half of the cases and the most common.<sup>14</sup>.

Nowadays dementia is a public health problem, because of the increasing global population aging. 35,6 million patients worldwide live with dementia, while it is expected be increased to 65,7 million by 2030 and 115,4 million by 2050<sup>15</sup>. In Greece it is estimated that patients number 200.000, according to the Alzheimer's Disease and Related Disorders of Athens, and the number is expected to exceed 600.000 by 2050.

## 2.2 Care at Home

In the vast majority the demented patients are cared for at home by family members, spouses, children, etc. Daily problems such as personal care (personal hygiene, medicine, movement), emotional support, mobility reduction, but also more complex issues (use of health services, medical appointments, medicine prescriptions etc), managing financial and legal issues, etc., are dealt by the caregivers<sup>5</sup>. They must also be on standby 24 hours a day and protect the elderly against potential risks (high risk of falls, fractures, risk of suicide, etc.)<sup>16,17</sup>.

## 2.3 Family Caregiver - Family Care

The term "family caregiver" is attributed to people from the close or distant family environment, who care for patients which are unable to cope with daily requirements. Family care differs from the formal (the employed) to the fact that is unpaid, based on ties of affinity and emotional connection of the caregiver and of the care recipient, the time limits are not defined, and the services that are offered are varied in order to serve the specific needs of the patient<sup>9</sup>.

In the United States 75 to 80 % of people with dementia who live in the community are cared for by family and friends<sup>7</sup>. In 2007 approximately 10 million Americans took care of demented patients, while in 2010 they amounted to 15 million. The largest percentage of caregivers of these patients are women, wives and daughters<sup>18,19,20</sup>. In Greece, the family maintains the responsibility of care even when professional caregivers are employed for a few hours. The percentage of patients living in the community was estimated at 98 % <sup>21</sup>.

## 2.4 Costs of Dementia - "Financial Caregiver Burden"

The cost of dementia is high. The direct cost, including direct expenditure, medical visits, medicine, nursing care, institutional care, was estimated at 604 billion dollars worldwide. The indirect costs incurred significantly caregivers and include the hours of informal care, care expenses (transportation, use of health services), loss of income from them which reduce their hours of work or resign from their work, were estimated at 251 billion<sup>14</sup>.

The contribution of caregivers is extremely important and this is because the financial cost of care would have been enormous for the countries if families had not undertaken this task<sup>7</sup>.

## 2.5 Burden of Family Caregivers

Burden is the multidimensional biopsychosocial reaction to the demands of care in relation to the personal time, the social roles, the physical and emotional states, the economic and supportive resources of caregivers, well as the other multiple roles that they have to fulfill<sup>22</sup>. The burden of dementia caregivers is higher compared to the burden of caregivers of elderly people with other chronic diseases, and their role has been characterized as the "day of 36

hours"<sup>6,9</sup>. High levels of burden are confirmed by several studies<sup>19,20,23,24</sup>. In the study of Papastavrou et al., (2007) to Cypriots caregivers the 68,02 % were highly burdened, but also in a recent study in Greek population, moderate to severe burden was presented at the 41,61 % and severe burden at 14,29 % of caregivers<sup>20</sup>. In a study of Badia Llacha et al., (2004), in 268 Spaniards caregivers, 46,5 % had moderate to severe and 34,7 % severe burden<sup>23</sup>. Much of this arises from the management of cognitive and behavioral symptoms of dementia (BPSD), which is demanding and challenging<sup>8,25</sup>.

Severity of dementia, deterioration in functional ability and level of the patient's daily activities<sup>25,26,27,28</sup>, the type of dementia<sup>29</sup>, the depression of the caregiver<sup>30</sup>, as well as poor communication with family, lead to high burden<sup>28</sup>. The burden has been associated with shorter time for institutionalization of patients<sup>7</sup> and premature mortality for caregivers<sup>31</sup>.

So indisputably the emotional, psychological, but also practical burden of caregivers is high, which results in the deterioration of physical and mental health<sup>32</sup>.

#### 2.6 Effects on Mental Health

Several studies have shown that caregivers have an extremely high risk for the development of emotional disorders such as major depression and anxiety disorder<sup>3,30,33,34</sup>. In a review of Brodaty et al., (2009) the percentages of depression ranged between 23% and 85%, and anxiety between 16% and 45%. Serious psychiatric problems, behavioral disorders, QOL of patients, reduced functional ability, the level of dependency, the perception of income inadequacy<sup>35</sup> were associated with depression of caregivers in several studies<sup>27,25,36</sup>. The caregivers with psychological morbidity and higher stress is more likely to have poor physical health and higher mortality risk<sup>32,37</sup>.

#### 2.7 Effects on Physical Health

There is an increased risk of developing cardiovascular problems, vulnerable immune system, higher chances of chronic diseases (diabetes, arthritis, kidney failure, anemia), more medical visits and medication use, reduced participation in preventative health behaviors, poor quality of sleep<sup>2,4,32</sup>. The poor sleep quality, is directly linked to depression, poor quality of life, cardiovascular disease<sup>32,38</sup>, strokes<sup>39</sup>.

#### 2.8 Definition of Quality of Life (QOL)

It is difficult to give a definition of "Quality of Life". This assessment is complicated and includes the evaluation of objective levels of health status, filtered by the subjective perception and expectation of the individuals themselves. Despite the different definitions, most authors consider that QoL is the combination of physical function, work, socioeconomic status, network supporting, housing, income, self-esteem, life satisfaction, happiness, and health<sup>40</sup>.

The Health-related Quality of Life (HRQOL) may be defined as the functionality in the physical, emotional and social dimensions of life with the aggregation of wellbeing, as estimated by each person. Therefore, the QOL in addition to a broad sense, is subjective and changeable, with multiple dimensions and characteristics that makes it rather impossible to accurate quantification and measure it<sup>40,41</sup>.

## 2.9 Assessment and Measurement Tools of the QOL

The HRQOL identified through the researchers' efforts to create assessment systems and metric instruments of physical, mental and social well-being, the parameters that constitute health<sup>42,43</sup>. The tools for measuring QOL typically include assessments of emotional wellbeing, social wellbeing, and physical fatigue, and often is estimated indirectly with scales for mood or depression, but also specific instruments include measures of family, spiritual, and financial status. Some authors have also used qualitative<sup>10,44</sup> or mixed methods (Quant + Qual)<sup>45</sup> to describe the QOL (Table 1).

## 2.10 Quality of Life (QOL) for Family Caregivers

There is a close relationship between Burden and QOL. The increased burden of care leads mainly to a degradation in QOL of both the caregivers and their patients<sup>23,28,46,47,48,49,50</sup>.

It has been confirmed that poor QoL of caregiver as a result of poor mental and physical health, is a predictor of increased use of health care services by the same, as well as the institutionalization of the patient<sup>7,14,25,51,52,53,54</sup>. In a review of 42 studies of Luppa et al., (2008), the institutionalization of the patients and the decision to disengage from the care was associated with the severity of dementia and secondarily with QOL and Burden<sup>51</sup>.

Caring for a spouse with dementia, is associated with lower levels of life satisfaction, decline of mental health and wellbeing<sup>47,55</sup> higher burden, while it has been found that QOL of the caregiver especially when he's companion, is much worse than that of the patient 1. Pinquart, et al., (2011) has also analyzed the patient-caregiver relationship in a meta-analysis of 168 studies<sup>56</sup>.

Spouses caregivers reported more depressive symptoms, higher burden and lower levels of mental well-being. The high levels of psychological distress among spouses are mainly explained by the high levels of care. Further in a longitudinal study of two years of Bond et al., (2003), also for spouses caregivers, mostly women, found that the institutionalization of the patient and the disengagement from care had a positive effect on their mental health and well being<sup>57</sup>.

Mental health is one of the key elements and an evaluation index of health-related Quality of Life (HRQoL), with women being predominate in a poor HRQoL<sup>33,52,58,59,60</sup>. In the study by Thomas et al, (2005), in 1410 caregivers in the majority women (n = 834 women) and spouse (n = 1.009), these showed lower QoL and higher vulnerability. It seemed to be more vulnerable in the management of patients than men. They complain less, have been trapped in their social role that they are expected to provide care, have different coping strategies, are more demanding concerning the quality of care, using fewer services for assistance at home and be relatively more exposed to the aggressive behavior of male patients<sup>60</sup>.

Symptoms of depression by the caregivers are an important<sup>33,59</sup> if not the strongest predictor of emotional exhaustion and demoting of their QOL<sup>61</sup>. Based on this, Takai et al. (2011) suggest that interventions which incorporate strategies for reducing symptoms of depression may have positive effects <sup>62</sup>.

In other studies, were associated with QoL years<sup>29,33,63</sup> and the hours of care<sup>11,23,47,50,52,64</sup>. However, a lower QOL in the study of Riedijk et al, (2006) was associated with shorter duration of dementia FTD (frontotemporal), in comparison with Alzheimer's disease<sup>29</sup>. In the study of Badia Llacha et al., (2004), the commitment of time, more than eight hours a day in the 72,1% of cases and more than 20 hours in the 39,6%, adversely affected the QOL of caregivers<sup>23</sup>.

The impairment of cognitive function<sup>1,28</sup>, the severity of the patients' behavioral disorders<sup>12,25,33,52,63,65,66</sup>, severity of dementia in general<sup>12,26,63</sup>, but also poor QOL of patients<sup>33,52</sup>, associated with a negative experience of care and are important predictors of degradation caregiver's QOL. However, in the study of Kurz et al., (2003), in 207 caregivers in Belgium, better QOL was observed in those who take care of patients with severe than with moderate dementia<sup>34</sup>.

The functional disability of the patient and the dependency arising from it, are associated with negative experience of care and have negative effects on QoL, burden, depression and satisfaction with care<sup>27,48,65</sup>. Caregivers of patients with both functional and cognitive impairment experienced higher burden and poorer QOL than those who take care of patients with only one impairment-symptom in 276 female-spouse caregivers, aged 78-83 years old, to the study of Tooth et al., (2008)<sup>67</sup>.

In a study of Rosness et al., (2011), for QOL and depression of caregivers of patients with early onset dementia, it appeared that the QoL was associated positively with increased age of caregivers but also awareness by patients of their condition<sup>68</sup>.

The QOL of caregivers was affected by individualized pharmaceutical and other treatments of dementia. Psychosocial and pharmacological interventions in 421 patients in the United States (CATIE-AD study) that reduced the symptoms (mainly behavioral problems) and improved their QOL, resulted in a decreased burden and improved wellbeing of the caregiver<sup>25</sup>. Caregivers of patients received rivastigmine and galantamine in the study of Thomas et al., (2005) reported a better QOL compared to caregivers of patients receiving other therapy<sup>60</sup>.

The excessive involvement in care can reduce the time that the caregivers have for themselves, disrupt their personal and social life, and consequently, degrade their  $QOL^{5,44,63}$ .

Poor communication with the family, and family conflict are another two variables that affect QoL in several studies<sup>28,63</sup>. The help and support from family, unity and cooperation, is an important factor to support and improve QOL and relieve from high burden. Even with no material support, the presence of the family is of fundamental importance for the *"moments of discouragement and sadness"*<sup>44</sup>.

Low income was associated with worsening of QOL in several studies<sup>5,63</sup>, while the financial government support and assistance from another person, who will share the tasks of care, could relieve enough caregivers<sup>10,44</sup>.

The diagnosis of dementia causes forced adaptation of the whole family, in order to cover the specific patient needs for their living<sup>63</sup>, while multiple simultaneous changes-transitions (new tasks, decision making, changes in relationships, increase negative feelings, thoughts for the future) affect caregivers. Transition is the process in which a new situation is incorporated in the life of the caregiver, while relevant studies show a correlation between it and the QOL<sup>69</sup>. Caregivers who understand and realize that the evolution of the disease had influence in their lives, but also those who searched information and assistance to cope with the changes in it, had higher overall QOL. Thus, interventions which encourage them to actively work to search for information and assistance can be a way to help them address these changes<sup>45</sup>. They describe the *"hope"* as a means of keeping them from sliding in desperation, one psychosocial source, an important factor in their QOL, which helps them face the challenges of care and be able to respond to various changes of the disease<sup>45,69</sup>.

In the study of Vellone, et al., (2008), at the heart of the notion of QOL for caregivers was freedom, peace - serenity, good financial status while the good health and lower dependence of the patient as well as more help in care could improve it<sup>10</sup>.

The needs and expectations of caregivers in the study of Amieva et al., (2012) focused on two important aspects of care: on the information about the disease and on learning of skills

for improving the management of everyday life of the patient. The authors suggest that among the available support programs, programs that provide information, education, and practical guidance for improving daily life should have an important position<sup>70</sup>.

Another major factor associated with QoL and emphasized from caregivers is the understanding and awareness from society. Most people do not know what Alzheimer's disease and dementia mean, and often express behaviors that indicate they do not understand the difficulties of caregivers and their families, thereby make them feel isolated and abandoned<sup>44</sup>.

Limited access and use of the official services, stigma of dementia, lack of information and awareness, financial barriers, especially in distant rural areas, leading to worse OOL<sup>13,44</sup>.

In the study of Arango-Lasprilla et al., (2010) in 99 Colombian caregivers, limited access or absence of services and the lack of financial support were associated with worse QoL.

Governments in developing countries probably do not give priority to psychological support services, respite care services, financial assistance, educational materials, etc., because of high maintenance costs<sup>13</sup>.

In contrast in the study of Manninen, et al. (2003), although it took place in a rural area of Finland, the QOL of 77 caregivers were relatively close or slightly better than the general population, with slightly higher levels of anxiety and depression from the control group. One possible explanation for the differences between this study and other studies is probably the use of QOL assessment tools as well as the relatively limited access to services for caregivers of other countries, so that their QOL appeared reduced. In the above study, the majority of patients were receiving at home social and healthcare support and assistance services. More than 54% of the patients used nursing services at home, 37% received help at home from social services, 30% received some other social benefit with most popular (73%) meals provision. A percentage of 42% of caregivers received a refund from the municipality, while 25% from public social insurance (KELA)<sup>71</sup>.

Factors that seem to improve the QOL of caregivers include providing support, information, education in skills in problem solving, and in the management of anxiety. Moreover, the regular provision of interdisciplinary home care can moderate the harmful effects of informal care. The interdisciplinary psycho educational interventions in the family, but also the respite care services where the patient's care is temporarily undertaken by official services, allows some rest to the informal caregivers, reduces burden and improves the QOL<sup>6,7,14</sup>. But even simple interventions such as participation in a clinical visit<sup>73</sup>, and also multicomponent, adapted to the particular needs and the individual profile of caregivers as shown in the study, of Belle et al. (2006), for 642 caregivers in the US (of different nationalities), may positively affect their QOL. In the intervention group were treated depression of caregiver burden, social support and the patient's behavioral problems, for a period of six months. The QOL was improved, and the burden and depression were significantly reduced<sup>74</sup>.

In contrast, the intervention of Coen et al. (1999) which was designed to assess the effects of a training program for caregivers in their QOL, Burden and wellbeing,, certainly increased their knowledge about dementia, but did not result in significant improvements in the above areas. The increased patient behavioral problems, was the most important factor to demote the QOL of 110 caregivers. But the short-term access to a voluntary service of "friendship" and emotional support seemed to improve wellbeing, stress levels, depression and QOL in general, in the 15 months period randomized controlled trial (BECCA trial) of Charlesworth et al., (2008), in 236 caregivers in the UK<sup>36</sup>.

## **3** Discussion

The measurement of the caregiver's QOL is an important, challenging and a growing area of dementia research. Usually QOL measurements are focused on patients. However, the assessment of QOL, but also the burden of the caregiver to which is closely related, is equally important, particularly if the patient is still living in the community<sup>63</sup>.

As has been shown, Dementia and Alzheimer's disease should not be considered exclusively a health problem but a social problem as well. This is because they do not concern only the patient, but the whole family as well, whereas placing a patient under professional institutional care can significantly burden the country's budget<sup>58</sup>.

The complexity of the treatment, the continuous commitment of the person who cares, the inadequacy of social services, consequent effects from emotional and interpersonal relations, direct and indirect costs of care, have a significant effect on the social, psychological and physical integrity of the caregiver.

Care is considered to be very demanding, especially in emotional involvement while the continuous commitment to it leads to physical and mental health problems, burden and degradation of QoL<sup>29,34,47,52</sup>. However the maintenance of caregivers' QOL is an essential ingredient in the care process which in turn may influence the quality of care provided.

Caring for a person with dementia includes many aspects that may not be detectable by the parameters of various questionnaires. Some of the reasons that could explain the differences in QOL but also the different factors that influence it, among the various studies, include the time spent on care, caregiver-patient relationship, caregiver gender, tool-questionnaire which is used, medical management of the patient, particular problems, access to available services, cultural differences<sup>13</sup>.

The findings of the various studies and different factors that connect caregivers with their QOL, can help in the design of strategies to maintain or improve it, adapted to the different needs and specific problems. It is crucial that interventions be able to reduce the strong effect that the patient has on caregiver and take into account individual physical, psychological and financial aspects of both<sup>74</sup>.

Institutional state agencies, companies and associations active in the field of dementia, the volunteer movement, associations of patients with dementia, health professionals, families, could be the main axles around which it rotates every effort to better quality of life for caregivers. The creation of community care programs, financial assistance and social support to families, but also to improve existing structures and their expansion in the region as to be accessible in remote areas, will contribute to saving resources that are lost from the early institutionalization of patients with dementia but also the unnecessary morbidity of their family caregivers<sup>44</sup>.

## 4 Conclusions

Caring for people with a progressive degenerative disease, such as dementia may negatively influence the quality of life of family caregivers in many ways.

As there is still no treatment that can stop the progress of dementia, all agree that the reduction of the negative consequences of caring for those who provide it, constitutes a main goal in its management.

So the more time family caregivers remain healthy, the more they will maintain their quality of life and will be able to better care for their favorite people.



Figure 1: Flow Diagram

Study	Assessment and Measurement Tools of the OOL	Fields-Areas
McMillan &	COoL-Index	One of the first tools developed specifically for the OOL
Mahon, 1994 <sup>75</sup>	- <b>2</b> · · · · · ·	of caregivers is the McMillan and Mahon's "Caregiver
,		Quality of Life Index" with 4 domains of the physical,
		mental, social and economic dimensions of the QOL
Vickrey et al.,	CGQOL 80-item Measure	Investigating dimensions of the QOL on various aspects
2009 <sup>11</sup>	-	of care. It includes 80 questions in 10 areas: assistance
		with BADLs, assistance with IADLs, personal time, role
		limitation because of care, family participation,
		requirements of care, restlessness, caregiver emotions,
		spirituality, faith and benefits of care.
Thomas et al.,	The questionnaire for QOL	It includes 20 items, 4 sectors with the negative aspects
2002a <sup>78</sup>	dementia caregivers developed	of care (skills for dealing with the difficulties of the
	in the PIXEL study (Scale of	disease, environment, psychological perception of the
	caregivers' Quality of life):	situation, risk perception), without addressing positive
		aspects, such as allowances, spirituality, faith. Disregards
$C_{max} = EO_{-1000}^{77}$	$E_{\rm resc} O = 1 (E O - 5 D)$	It studies the physical social and amotional mental
010up EQ, 1990	EuroQot(EQ-5D)	dimension through five sectors (mobility self-care
		performing routine activities pain - distress anxiety:
		depression).
Saxena &	World Health Organization	Short version assessing OOL of WHO. It examines four
Orley,199778	Quality of Life -BREF	sectors with 26 items: physical, mental health, social
	(WHOQOL-BREF).	relationships, environment.
Ware et	Medical Outcomes Short Form-	General measure of health status with 36 questions that
al.,1994 <sup>79</sup> ; Ware	36 Health Survey (SF-36) кал	evaluates eight dimensions: physical functioning,
et al., $1996^{80}$	SF-12.	physical pain, general health, energy / vitality, social
		functioning, emotional role, mental health. These shaping
		Summarized measurements in two summary scales,
		physical and mental health. (Physical Component
		score (MCS)) It is a reliable measuring instrument
		approaching the basic dimensions of OOL
Jovce et al	Scale for the assessment of	Appropriate to use in patients with dementia and their
2003 <sup>81</sup>	individual OOL - Schedule for	caregivers, with comparison between the 2 groups.
	the Evaluation of Individual	Besides qualitative also allows and quantitative
	Quality of Life (SEIQoL).	measurement and it can by assessing the effects of
		interventions to be used for monitoring of changes to the
		QOL. It measures level of functionality in 5 self-defined
		aspects of life and the relevant importance given to them.
		Responses are classified into one of the generally
		acceptable aspects of the QOL: Cognitive, Emotional,
Novelli et al	Quality of Life Evaluation Scale	General assessment scale of the OOL adepted to
$2005^{82}$	jn Alzheimer's Disease (COdV-	Brazilian culture with 13 areas: physical health mood
2005	DA) Caregiver Version	humor housing memory family marriage friends
	Dirij, curegiver version.	work ability, possibility of leisure, and other activities.
Van Weel et al	COOP/WONCA. Dartmouth	A general questionnaire of the OOL, which measures six
1993 <sup>83</sup>	Primary Care Cooperative	dimensions: physical status, feelings, daily activities,
	Information Functional Health	changing to a health and general health.
	Assessment/ World	
	Organization Project of	
	National Colleges and	
	Academics (COOP/WONCA).	
Kaplan et al., 1998 <sup>84</sup>	Quality of Well-Being Scale	Questionnaire of Mental and Physical Wellbeing

 Table 1: Assessment and Measurement Tools of the QOL

Herth, 1992 <sup>85</sup>	Herth Hope Index (HHI-hope).	Used to evaluate hope and includes 12 items
Frank et al., 2004 <sup>86</sup>	Health Utilities Index Mark 2 (HUI - 2).	Health utility index. It measures the overall health status and HRQOL of individuals, populations, but also clinical teams. This index looks for association of the HRQOL with eight parameters (vision, hearing, speech, mobility, skill, insight, emotion, pain-distress)
Logson et al., 1998 <sup>87</sup>	The questionnaire UWMC / ADPR / QOL: Quality of Life in Alzheimer's Disease: Patient and Caregiver Report (QOL- AD).	Evaluates 13 areas of life: physical health, energy, mood, conditions of life, memory, family, marriage, friendships, personality, ability to housework, ability for fun, financial situation and how they feel about their lives in general
Goldberg, 1972 <sup>88</sup>	General Health Questionnaire.	The 28 questions deal with: depression, anxiety, social functioning, physical symptoms
Cohen et al., 2000 <sup>89</sup>	Qualitative Method	Qualitative approach with Open-Ended Questions (Hermeneutic Phenomenological Approach)

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