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## Relationship between education, personal and social competences and quality of life of adult family caregivers

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### Abstract

Increasingly, lifelong learning is of growing importance and it refers to the constant experiences and needs of individuals adapting to the development of their personal and social skills in relation to the contexts and circumstances in which they are inserted. For this, one of the primary requirements is to be able to enjoy a high Quality of Life. For the family, the diagnosis of disability in children is a particularly significant time consuming energy and mobilizing physical and economic resources, imposing itself as an important event inducing stress. It is an exploratory study with a quantitative data approach. The data analysis was performed using IBM SPSS Statistics (version 25) software. This study has as main objectives (1) to evaluate the QoL of Family Caregivers of Adults with Disability or Intellectual Disability, by identifying the domains and facets of the WHOQOL-Bref most affected; (2) to study the measure of association between some variables related to the care delivery and QoL of Family Caregivers; (3) to evaluate the differences in the indicators of QoL between genders and (4) to evaluate the relationship between the wear associated with the caring of the Family Caregivers and their QoL. N=30 aged 20-57. Instruments: Sociodemographic and Care Rendering Data Sheet, WHOQOL-Bref QoL Scale, and Caregiver's Scale of Attrition. As results this study reveals that the WHOQOL-Bref domains are not significantly affected. It was also verified that there is a negative association between the objective and subjective burnout and the QoL of the Family Caregivers. The scale of personal growth, however, is negatively related to QoL. This study points to the importance of leadership investing in Family Caregivers in the sense of their personal growth and development of social skills.

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## 1. Introduction

### 1.1. Lifelong learning and needs of individuals adapting

Increasingly, lifelong learning is of growing importance and it refers to the constant experiences and needs of individuals adapting to the development of their personal and social skills in relation to the contexts and circumstances in which they are inserted (Antunes, 2008; Peralta, Neto & Marques, 2013; Piccolo & Mendes, 2013; Pires, 2000; Sequeira, 2010; WHO 2000). To the family the development of personal and social skills of its members is very significant for lifelong learning and for personal and social growth in education as a whole Brown, 2011; Carvalho & Carvalho, 2006; Del Prette & Del Prette, 2003; Figueiredo, Guerra, Marques & Sousa, 2012; Fontes, 2016; Gil, 2010; Guadalupe, 2011; Guerra, Lima & Torres, 2014; Lopes & Cachioni, 2012; Masuchi, Rocha, 2012). For this, one of the primary requirements to be able to enjoy a high Quality of Life. For the family, the diagnosis of disability in children is a particularly significant time consuming energy and mobilizing physical and educational resources, imposing itself as an important event inducing stress. All disabled adults require individualized and specialized family care, care that is mostly provided by family members throughout their lives (Ferreira, 2009). The role of caregiver is expected by any parent of a small child, but in the case of a child with chronic illness or disability this may depend on care throughout their life. What was originally planned as a temporary responsibility becomes a permanent, unpaid, demanding occupation that can result in a progressive physical and mental deterioration. There are two types of caregivers, formal caregivers and informal caregivers.

### 1.2. Research design

This study has as main objectives (1) to evaluate the QoL of Family Caregivers of Adults with Disability or Intellectual Disability, by identifying the domains and facets of the WHOQOL-Bref most affected; (2) to study the measure of association between some variables related to the care delivery and QoL of Family Caregivers of Adults with Disability or Intellectual Disability; (3) to evaluate the differences in the indicators of QoL between genders of the sample and (4) to evaluate the relationship between the wear associated with the caring of the Family Caregivers of Adults with Disability or Intellectual Disability and their QoL.

## 2. Method

### Method of the research

It is an exploratory study with a quantitative data approach. The data analysis was performed using IBM SPSS Statistics (version 25) software.

### *2.1. Participant (subject) characteristics*

N=30 Most family caregivers are mostly between 51-60 aged; 80% fem; 20% male, indicating that they are caregivers with some advanced age. Family caregivers of adults with disabilities or intellectual disabilities - who are attending the centers of occupational activities of APPACDM of Santarem. All clients in the representative sample of the study who are integrated into the occupational center social response are moderately or profoundly deficient between 20-57 aged.

### *2.2. Sampling procedures*

The sample was collected with the help of the social service of the institution referred to above, and is therefore a convenience sample. Appropriate authorizations were requested from the Institution's Presidency and Technical Directorate in order to contact family caregivers of adults with disabilities or intellectual disabilities, so that the author could initiate data collection. As criteria for inclusion, family caregivers should be aware of the diagnosis of disability or intellectual disability of the subject they are caring for. This study excluded family caregivers who refused to participate in the research, as well as family caregivers who unexpectedly initiated irreversible disease processes and were not able to consciously respond to the various issues inherent in the instruments applied. The selection of the members of the study was done in conjunction with the coordinators of the valences of the two occupational centers that the institution has, which are deeply knowledgeable about clients with disabilities or intellectual disabilities, and therefore their family caregivers. We opted for a direct approach to family caregivers, both in the institutional environment and in the family environment.

### *2.3. Data Collection tools*

Instruments: Sociodemographic and Care Rendering Data Sheet, WHOQOL-Bref Quality of Life Scale (WHOQOL group, 1994; Portuguese version (Vaz-Serra, Canavarro, Simões, Carona, Gameiro, Pereira, Quartilho & Paredes, 2006), and Caregiver's Scale of Attrition (Montgomery, Bogatta & Bogatta, 2000; Portuguese version (Carona, Faria-Morais, Nazaré & Canavarro, 2008). The first instrument allows to identify the degree of relationship, the time spent in care and the sharing of this task with others, degree of satisfaction with this support, health and opportunities to enjoy, as well as satisfaction with leisure activities. The second instrument evaluates the QoL of family inquired. It consists of 26 issues, two integrate the general facet of quality of life and the remaining 24 facets grouped into four domains: Physical, Psychological, Social Relations and Environment. All 26 questions in the questionnaire have a variance of one to five, to which the caregiver can only signal a response. The third and last instrument evaluates the wear and tear of family caregivers. It consists of three wear subscales (Relation Wear,

Target Wear and Subjective Wear) and a Personal Growth scale or also called Bonuses (positive outcomes).

### **3. Results**

#### *3.1. Statistics and data analysis*

1) From the analysis of the results of the four domains of the WHOQOL-Bref, it can be seen that the areas that are most affected are the areas that concern Physical Health and the Environment. The analysis of each of the 24 facets of the instrument allows to verify that the facets that present statistically significant differences are those that are directly related to their respective domains, they are: physical security and protection; physical environment; economic resources; opportunities to acquire new information / skills; participation in leisure / recreational activities; environment and home; health and social care; transport; pain and discomfort; energy and fatigue; sleep and rest; mobility; activities of daily living (adl); dependence on medication / treatments and work ability.

2) Regarding this objective, the findings show significant correlations between the daily time spent in the continued care of the adult with intellectual disability or disability and all domains of the WHOQOL, and the physical, psychological, environmental and general domains of QoL are more affected. In all domains, with the exception of the Social Relations domain, there is a decrease in the values of the quality of life scale, which leads us to conclude that the greater the daily time spent in care, the smaller the values tend to be of QoL in the physical, psychological, environmental and vice versa (Table 1-6).

In terms of support for continuing care (other than APPACDM), the results show that there are no correlations, this may be due to the fact that the answers focus mainly on the categories of "less than 3 hours and 3" (n=30). This is due to the fact that it is a small number of (non-discriminatory) response categories and the reduced n of the sample. Concerning satisfaction with support in continuing care (in addition to APPACDM), there are positive correlations with all domains, with Social and Environmental Relations having the strongest correlation, concluding that the more high is the satisfaction with the help in the provision of care, the higher values tend to be the values of QoL in the domains of Social Relations and Environment, and vice versa.

Finally, in terms of the frequency and satisfaction with time used in rest, recreation and leisure activities, it is concluded that the higher the frequency and satisfaction with this leisure time, the higher are the values in the field of Psychological health. These variables are important in providing care, possibly avoiding prolonged stress and

facilitating contact with others and experiencing positive feelings. All occupations are important for the existence of balance in occupational life and contribute to an intrinsic growth of the person, in addition to improving their QoL and overall well-being. If one of these occupations is very dominant (eg. care), an imbalance arises, which in the long run can lead to an injurious process leading to occupational deprivation / overload with negative consequences for the health and well-being of family caregivers.

Table 1. Years of Care

Years of Care	Frequency	%
<10	1	3.3
20 – 29	10	33.4
30 – 39	9	30
40 – 49	6	20
>50	3	10
No response	1	3.3
Total	30	100

Table 2. Hours/ Day of Care

Hours/ day of Care	Frequency	%
<3	5	16.7
3 – 6	6	20
>6	19	63.3
Total	30	100

Table 3. Satisfaction with Care Support

Satisfaction with Care Support	Frequency	%
3-More or less	3	10
3.5	1	3.3
4- Satisfaction	7	23.4
4.5	6	20
5-Very	12	40
No response	1	3.3
Total	30	100

Table 4. Resource of psychiatry and mental health services

Resource of psychiatry and mental health services	Frequency	%
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Yes	5	16.7
No	6	20.0
Total	19	63.3

Table 5. Frequency of activities of rest, recreation and leisure

Frequency of activities of rest, recreation and leisure	Frequency	%
Never	5	16.7
Few times	11	36.7
Sometimes	11	36.7
Oftentimes	2	6.6
Ever	1	3.3
Total	30	100

Table 6. Satisfaction with free time

Satisfaction with free time	Frequency	%
1-Very unsatisfied	2	6.7
2- Dissatisfied	3	10
2.5	2	6.7
3- More or less	8	26.6
3.5	1	3.3
4- Pleased	9	30
4.5	2	6.7
5- Very satisfied	1	3.3
No response	2	6.7
Total	30	100

3) Comparing the QoL of both genders, we verified that there are no significant correlations according to the gender of the caregiver, as no domain approaches  $> 0.05$ . The results of the study are in line with international studies, which say that most family caregivers are women (Table 7). According to Ras, Bascuñana, Ferrando, Martínez, Puig and Campo (2006) and Velásquez, López, López, Cataño and Muñoz (2011) the work of women with regard to caring for dependents is understood as a natural function

transmitted from mother to daughter and that women acquire as their role according to the group to which they belong (Molina & Agudelo, 2006).

Table 7. WHOQOL Scale

WHOQOL Scale	T	valor-p	N
1- Physical health	1.140	0.287	29
2- Psychological health	1.867	0.108	27
3- Social relations	-0.546	0.600	28
4- Environment	0.248	0.810	26
QoL General	0.752	0.480	25

4) From the results it is verified that there are significant correlations between the Carer's Wear Scale, the Target Wear Scale and the Subjective Wear Scale, and all WHOQOL-Bref domains (Table 8). The interpretation of the results indicates that the higher the objective, subjective and wear and tear of the caregiver, the lower the QoL values in the physical, psychological, environmental and general QoL domains tend to be. Objective wear refers to the wear and tear that underlies the provision of care and results in the reduction of the time available for leisure and / or rest activities, and which is clearly shown here in the present study. The subjective exhaustion refers to the negative affect that results from the care delivery and that is presented in the study also very affected. Regarding the wear and tear of the relationship, there are no significant correlations between this attrition and the various domains/dimensions of the WHOQOL-Bref, which leads us to conclude that the caregivers' perception regarding the degree of demand and attention of their children it is not excessive or even an exclusive relationship, not giving rise to negative psychological feelings in the caregiver.

Table 8. -p value (WHOQOL, Caregiver wear and Personal growth)

WHOQOL Scale	Caregiver wear	Relationship wear	Target wear	Subjective wear	Personal growth
1- Physical health	0.005	0.128	0.017	0.003	0.274
2- Psychological health	0.005	0.146	0.017	0.000	0.274

3- Social relations	0.058	0.704	0.004	0.023	0.115
4- Environment	0.010	0.221	0.004	0.002	0.093
QoL General	0.004	0.164	0.002	0.000	0.086



#### **4. Discussion**

As results this study reveals it can be inferred that the results underline a low QoL of the Adult Family Caregivers, and also the importance of specific interventions with this population, which has the objective of promoting their well-being and QoL.

The QoL of mothers of adults with intellectual disability or disability is different from the QoL of mothers of healthy children (Eker & Tüzün, 2004). Reflecting on this study, more specifically on the analysis of results, and taking into account the objectives initially established, the following is a summary of the main conclusions drawn. Study reveals that the QoL of family caregivers of adults with intellectual disability or disability is not significantly affected with respect to the domains and facets of QoL of WHOQOL-Bref. Correlations with some variables of care (daily time spent, satisfaction with the sharing of care and frequency and time used in rest, recreation and leisure activities) and QoL of family caregivers of adults with intellectual disability or incapacity.

According to Reis (2007) the QoL of family caregivers of adults with chronic disease (cerebral palsy) present levels lower than those of a homologous group of the general population, as revealed by Tuna (2004) when referring to a study on the adaptation of mothers with children with CP. In this study it is verified that the Physical and Psychological Health domains (self-esteem, negative feelings), translate the wear and tear that is inherent to the task of caring for another person.

These results are in agreement with Monteiro (2002), who states that "in caring for children with chronic illness, caregivers do not require much time and energy, physical and psychological, and the time for these is more limited."

The QoL of family caregivers did not present significant differences between male and female caregivers. The results did not reveal that women's QoL is lower than men's, as the literature reveals, but even if the results were against studies that women see their lives more limited in terms of care delivery. Reservations about the generalization of these results would be necessary, and it can't be generalized that the QoL of the women (N=24) is lower than the QoL of men (N=6) given the reduced "n" of the male group.

The presence of the male figure demonstrates a decentralization of the care of the female figure, and this is confirmed by Crowe and Vanleit (2002) who point out that "women are particularly affected because they are usually the primary caregivers" (p.132). The nature of the woman makes her understand the task of taking care of the other, as a role already intrinsic to her, since the majority of women care for their parents, children, husbands, being always attentive to the environment that involves.

Barrera (2001, quoted by Afanado, Ortiz & Herrera, 2005, p.132) refers to the man as a being who unlike the woman, "is more practical and, in this sense, participates and collaborates in care looking at others aspects that women sometimes do not value".

At the level of attrition, it is concluded that the wearer of the caregiver, objective and subjective affect the values of Physical, Psychological, Social Relations and Environment domains, that is, family caregivers present wear and tear at all levels. Both the scale of wear of the relationship and the scale of personal growth did not present changes, which leads us to conclude that there is no wear and tear on the relationship between the caregiver and the caregiver. Regarding the scale of personal growth, which is the positive psychological state associated with care, it is found that there is no significant correlation with the general facet of QoL, and it is concluded that the caregivers of the study do not draw a positive experience of the act of caring, therefore have lower values of QoL, since the higher the personal growth, the higher the values of QoL tend to be in all domains and the general facet of QoL.

The cross between the 3 scales of the study (WHOQOL, Caregiver Wear and Personal Growth) shows that the Personal Growth scale is not related to any of the other scales and domains / dimensions, similar to the wear domain of the scale of the Caregiver. Regarding the general QoL facet (WHOQOL scale), it is verified that it is significantly negatively correlated with the Caregiver's Scale and with two of its domains, objective wear and tear.

Afanador, Ortiz and Herrera (2005, p. 130), affirm that "the caregiver is subject to permanent stress", encountering physical, mental and / or cognitive limitations that make difficult the normal performance and development of their work. These same authors point out that being a caregiver also implies that there are compromises at the level of establishing "social interactions, perceiving the lack of social support and support of health systems, lack of activity, deconcentration in their tasks, severity of illness care recipient, the amount of care or supervision needed, and alteration of the care-giver relationship".

Over the last few decades, organizations such as the World Health Organization (WHO, 2000) have helped redefine the concept of disability, thus combating the often associated bias and stigma (Macedo, Pereira & Madeira). Until the end of the 20th century, the concept of disability was associated with purely medical criteria. There was no separation between the concepts of disability, which are very different today, due to the WHO, an entity that has been developing of the last decades important contributions to the redefinition of the concept of disability in Portugal, and in the world. Our study confirms that this will be the direction of progress in education for all, in an inclusive educational work that attends to diversity. We recommend studies with higher n with longer samples. So, as guidelines for future studies we consider: the discriminative analysis of the specific impact of different health conditions on the QoL of family

caregivers, promoting the inclusion of parents (family caregivers) in these studies. The size of the sample should be larger in order to obtain the maximum consistency in the results; a simultaneous analysis of multiple determinants of (in) adaptation, as suggested by the theoretical models mentioned in this study, should also be carried out. It is also worth mentioning the importance of longitudinal studies to observe the strength and direction of the dynamic influence of variables.

## 5. Conclusions

This study reveals it can be inferred that the results underline a low QoL of the Adult Family Caregivers, and also the importance of specific interventions with this population, which has the objective of promoting their well-being and QoL. In caring for children with chronic illness, caregivers do not require much time and energy, physical and psychological, and the time for these is more limited. The presence of the male figure demonstrates a decentralization of the care of the female figure. At the level of attrition, it is concluded that the wearer of the caregiver, objective and subjective affect the values of Physical, Psychological, Social Relations and Environment domains, that is, family caregivers present wear and tear at all levels. Both the scale of wear of the relationship and the scale of personal growth did not present changes, which leads us to conclude that there is no wear and tear on the relationship between the caregiver and the caregiver.

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