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FACTORS ASSOCIATED WITH THE QUALITY OF LIFE OF THE FAMILY CAREGIVERS OF DRUG-ADDICTED PEOPLE

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ABSTRACT

Objective: To identify the association between sociodemographic, health, and care burden variables on the quality of life of family caregivers of chemically dependent people. **Method:** A cross-sectional study conducted between 2012 and 2013 with 95 family caregivers in a city in northwestern Rio Grande do Sul, Brazil. The following instruments were used: WHOQOL-BREF, Caregiver Burden Scale (CBS), and sociodemographic questionnaire. Data collection was in 2013 and 2014. Multiple Linear Regression was used to identify factors associated with the four WHOQOL-BREF domains. **Results:** Having better self-perception of health, maintaining a good relationship with the addicted person and having formal work were factors associated with better perception of quality of life. The greatest care burden in the environmental, disappointment, and isolation dimensions of CBS; daily use of medications and being female were the factors that most affected the quality of life of family caregivers. **Conclusion:** There are sociodemographic, health, and CBS dimensions that are associated with better or worse perceived quality of life of family caregivers of drug addicts.

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INTRODUCTION

Issues related to chemical dependence on illicit drugs involve the whole society and they have drawn the attention of researchers, politicians, and health professionals regarding the challenges of implementing public policies related to health in Brazil and worldwide (Castro Neto et al., 2016; Dantas et al., 2003; Murthy, 2016; WHO, 2017). In Brazil, the following are considered illicit drugs: marijuana, cocaine, crack, ecstasy, lysergic acid diethylamide (LSD), inhalants, heroin, barbiturates, morphine, *skank*, mushroom tea, amphetamines, chloroform, opium, and others (Dantas, 2017).

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Drug addiction is a complex phenomenon that involves elements of daily life (family, social network, work, leisure, among others), as well as the subjective experiences of people involved with the problem (Marsiglia et al., 2004). Studies have identified that chemically dependent (CD) people have a greater predisposition to violent behaviors to commit and also to be a victim of crimes (Pickard et al., 2013; Rueve et al., 2008), in addition to compromising physical and mental health (Castro Neto et al., 2016; Murthy, 2016) and quality of life (QOL) (Pasareanu et al., 2015). The burden of family members comes from the activities and actions performed as a caregiver and the changes that occur in their social and professional life (Hare et al., 2006). Also, the burden is aggravated by various situations that are encountered in care as

lack of information about the disease and its treatment, strategies for dealing with inappropriate behaviors and crises (Gomes *et al.*, 2009; Hare *et al.*, 2006). These events can overload the family caregiver (FC) and consequently their health, well-being, and QOL (Pasareanu *et al.*, 2015; Marcon *et al.*, 2012a). The Quality of Life Group of the World Health Organization (WHO) Division of Mental Health has defined QOL as "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns" (Fleck *et al.*, 2000). This group developed the WHOQOL-100 instrument to assess QOL, with the collaboration of different countries, from a cross-cultural perspective. The burden is understood as the set of consequences that occur following close contact with a patient, being referred to in the negative sense, that is, in the form of "weight" or "overload," and it is associated with a deterioration of caregiver QOL and higher morbidity (Murthy, 2016). Most of the caregivers, besides having a family bond, an affective bond of commitment, are those who appropriate the responsibility for care, participating, making decisions and behaviors about the cared person (Ortiz *et al.*, 2010). The role of the caregiver goes beyond simply monitoring the daily activities of individuals, whether healthy, sick and/or bedridden, at-risk or fragile, whether at home and/or in any institution in which they need daily attention or care (Brasil, 2009). It is noteworthy that one cannot always choose to be a caregiver, especially when the person cared is a family member or friend. Therefore, before proposing any intervention action along with the FC, it is necessary to know their characteristics, their needs, as well as the care burden. Even with the due importance that this issue has on health policies, in Brazil little is known about the association between care burden and QOL of FC of CD. Thus, the objective of this study was to identify the association between sociodemographic, health, and care burden variables on the quality of life of family caregivers of chemically dependent people.

MATERIALS AND METHODS

This is a cross-sectional analytical study that used a convenience sample. Data collection was performed between June 2013, and March 2014 by the main researcher in a city in the northern region of Rio Grande do Sul, Brazil. All FC ($n = 109$) of CD who were being followed up at the Municipal Mental Health Outpatient Clinic (MHOC) and all (six) Family Health Strategy (FHS) units during the study period were invited to participate in the study, between June 2012 and June 2013 (one year). The MHOC was the only specialist service available in the city at the time, and it had the following professionals: a psychiatrist, a psychologist, a nurse, a nursing technician, a social worker, and a secretary. 95 FC participated in the study. The G*Power 3.1.9.3 program verified the statistical power of the sample ($n = 95$) (Faul *et al.*, 2009). Post-hoc analysis revealed mean effect size (0.50) and statistical power of 99%, with alpha value of 5% of significance. The inclusion criteria established for FC were age ≥ 18 years old, identifying themselves as a FC, the family member that the CD had as responsible for monitoring the treatment in the Units, being a FC for more than three months (considered the minimum time for the caregivers to be able to feel the effects of care), living or residing near the CD. The exclusion criteria adopted were for FC who stopped living in the city and the presence of psychiatric comorbidities (people

informed by the MHOC). Fourteen people were excluded from the study: one for living in rural areas, 11 for having moved to another city, one FC who informed no longer being responsible for care and one caregiver who was also a CD. The medical records of the CD were used to identify the FC of the CD attended the health care services of the city. The interviews were previously scheduled by telephone and conducted at the FC residence in a private environment, without the presence of the CD. The FCs were invited to participate in the research, and at the time of the interview they were informed about the conditions and objectives of the study and the anonymity of the information provided. All participants signed the Free and Informed Consent Form. Due to the low educational level of the participants, the instruments were applied by reading the full questions, without synonyms, interpretations, and explanations and noting the answers following the guidelines of the WHOQOL group (Fleck *et al.*, 2000).

The instruments for data collection were: sociodemographic and health questionnaire with the following closed questions: age (20 to < 40, 40 to < 60, 60 and older), gender, education (uneducated, incomplete elementary school, complete elementary school, complete high school, complete higher education), marital status (in marriage - married, in stable union, cohabiting; unmarried - single, widowed, separated, divorced), formal employment (yes, no), family income (<1 minimum wage (MW), 1 to 3 MW, 3 to 5 MW, 5 MW, and more), family relationship with chemically dependent people (good, regular, poor), self-perceived health status (good, regular, poor), and use of routine medicine (yes, no). The Caregiver Burden Scale (CBS) instrument in the translated version, adapted and validated for Brazil by Medeiros *et al.* (1998) was used to assess the impact of care performed (Medeiros *et al.*, 1998). It consists of 22 questions divided into five dimensions: General Tension, Isolation, Disappointment, Emotional Involvement, and Environment. Values range from 1 to 4, respectively, the greater the impact/burden of care. An overall care burden score or an individual score of each dimension can be obtained. The scores range from 22 to 88 points, and the closer to 88, the greater the burden perceived by the family caregiver. The CBS interobserver and intraobserver reproducibility coefficient was 0.92 and 0.87, respectively (Medeiros *et al.*, 1998). This study showed good internal consistency of the CBS scale. The total scale presented Cronbach's $\alpha = 0.751$ (Nunnally *et al.*, 1994). To assess the QOL of FC of CD, the WHOQOL-BREF abbreviated World Health Organization Quality of Life instrument was used, consisting of 26 questions divided into four domains and two general QOL questions. The domains are: physical health, psychological, social relationships, and environment. The Portuguese version of the WHOQOL instruments was developed at the WHOQOL Center for Brazil (Fleck, 2000). There is no cutoff point for the classification and the closer to 20, the better perception of QOL. The lowest score is 4, and the highest is 20, which was adopted in this study. All WHOQOL-BREF items are based on assessments over the past two weeks and scored on a five-point Likert scale (The WHOQOL Group, 1998). The internal consistency of WHOQOL-BREF with the CD caregivers of this study was considered good ($\alpha = 0.747$) (Nunnally *et al.*, 1994). Data were managed by the *Statistical Package for Social Sciences* program - SPSS® version 21. We used descriptive statistics to describe sociodemographic characteristics, the CBS, and the WHOQOL-BREF instrument. Pearson correlation was

performed between the CBS scale domains (independent variables) and the four WHOQOL-BREF domains (dependent variables). Multiple Linear Regression (MLR) was used to identify factors associated with WHOQOL-BREF domains. The betas coefficients are estimates of the increase or decrease in the dependent variable score for each one-point increase in the independent variable (Alexopoulos, 2010). The MLR models were constructed using the stepwise selection technique, starting from the model in which all $p \geq 0.05$ variables are excluded. A significance level of 5% was adopted, with a confidence interval of 95% (95% CI) for all analyses. This research complied with Resolution 466/12, and it was approved by the Research Ethics Committee with Human Beings of the Federal University of São Paulo (UNIFESP) under the number of Opinion No. 152.041 and CAAE 10269212.5.0000.5505, on 23 November 2012.

RESULTS

It was found in this research that most of the CD were men (83.2%), aged 20-39 years (69.5%), single (56.8%), who had incomplete elementary school (67.4%) and they lived with family members (68.4%). At the time of the research, 59% were not working, 74.7% started using illicit drugs before the age of 20. The most used drug was *crack* (83.1%), followed by marijuana (61.0%), and cocaine (50.5%). However, there used to be a combination of using two or more illicit drugs. It was found that most of the 95 FC were aged between 40 and 59 years (53.7%), were female (85.3%), they lived in union (60.0%), and they had some education (92.6%), and 31.6% had more than eight years of schooling. Just under half (49.5%) of caregivers were formally employed, and approximately 60% earned one to three minimum wages per month, and nearly 1/3 earned less than one minimum wage per month.

Regarding self-assessment of the health condition, most (89.5%) reported that they were between regular to good and slightly more than half of caregivers used some medication daily (50.5%). When asked about the quality of the relationship with the chemically dependent person, 91.6% classified between regular and good. The domains of WHOQOL-BREF that had the highest scores, that is, better perceptions of QOL were the domains of physical health and social relationships. The domain that presented the greatest impairment in QOL was the environment. Regarding the care burden, the general tension dimension was the most impaired, followed by the emotional involvement dimension. The dimensions general tension and disappointment showed an inverse and statistically significant correlation with the four domains of WHOQOL-BREF. The isolation dimension correlated inversely with the psychological, social relationships, and environment domains. The emotional involvement dimension correlated inversely with the psychological domains and social relationships. The environmental dimension correlated inversely and significantly only with the environmental domain of QOL. Although statistically significant, the correlations presented were weak and moderate. Through MLR, it was possible to identify that the variables self-perception of health status ($B = 2.45$; $p < 0.001$), daily medication use ($B = -2.01$; $p < 0.001$), and the environment dimension of CBS ($B = -0.675$; $p = 0.033$) accounted for 48% of the WHOQOL physical domain variance. The psychological domain was explained in 50% by the factors self-perception of health status ($B = 1.43$, $p < 0.001$), CBS disappointment dimension ($B = -1.18$, $p < 0.001$), gender ($B = -1.38$, $p = 0.007$) and quality of the relationship with the CD ($B = -0.742$, $p = 0.014$). The social relationships domain was explained in 15% by the isolation dimension of the CBS

Table 1. WHOQOL-BREF and CBS of FC of CD. City of the northern region of Rio Grande do Sul, Brazil, 2013-2014. (n = 95)

| Instruments | Mean \pm SD | 95% CI |
|-----------------------|------------------|--------------|
| WHOQOL BREF | | |
| Domains | | |
| Physical health | 14.58 \pm 3.36 | 14.10; 15.06 |
| Psychological | 13.80 \pm 2.41 | 13.45; 14.16 |
| Social Relationships | 14.44 \pm 2.57 | 13.95; 14.93 |
| Environment | 12.79 \pm 1.93 | 12.48; 13.10 |
| CBS | | |
| General Tension | 2.72 \pm 0.80 | 2.55; 2.88 |
| Isolation | 2.34 \pm 1.01 | 2.14; 2.55 |
| Disappointment | 2.46 \pm 0.81 | 2.29; 2.62 |
| Emotional Involvement | 2.55 \pm 0.83 | 2.38; 2.72 |
| Environment | 2.20 \pm 0.80 | 2.03; 2.36 |

SD: Standard Deviation; CI: Confidence Interval; CBS: Caregiver Burden Scale.

Table 2. Correlations between CBS and WHOQOL-BREF of FC of CD. City of the northern region of RS, Brazil, 2013-2014 (n = 95)

| Domains | WHOQOL-BREF | | | |
|-----------------------|------------------------------------|------------------------------------|------------------------------------|------------------------------------|
| | Physical Health | Psychological | Social Relationships | Environment |
| CBS Dimensions | | | | |
| General Tension | -0.279 ^a $p = 0.013$ | -0.502 ^a $p < 0.001$ | -0.240 ^a $p = 0.021$ | -0.222 ^a $p = 0.031$ |
| Isolation | -0.019 $p = 0.367$ | -0.360 ^a $p < 0.001$ | -0.343 ^a $p < 0.001$ | -0.321 ^a $p = 0.002$ |
| Disappointment | -0.209 ^a $p = 0.046$ | -0.501 ^a $p < 0.001$ | -0.277 ^a $p = 0.011$ | -0.353 ^a $p < 0.001$ |
| Emotional Involvement | -0.069 $p = 0.504$ | -0.292 ^a $p = 0.004$ | -0.245 ^a $p = 0.026$ | -0.094 $p = 0.365$ |
| Environment | -0.116 $p = 0.264$ | -0.051 $p = 0.620$ | 0.002 $p = 0.987$ | -0.483 ^a $p < 0.001$ |

CBS: Caregiver Burden Scale; ^a Statistically significant ($p < 0.05$).

Table 3. Multiple linear regression of factors associated with QOL of FC of CD. City of the northern region of Rio Grande do Sul, Brazil, 2013-2014. (n = 95)

| WHOQOL-BREF Domains | Associated Factors | B (95% CI) | p-value | Adjusted R ² |
|----------------------|---|-------------------------|---------|-------------------------|
| Physical | Self-perception of health status | 2.45 (1.57; 3.34) | < 0.001 | 0.48 |
| | Daily use of medicines | -2.01 (-3.20; -0.824) | < 0.001 | |
| | CBS Environment | -0.675 (-1.29; -0.055) | 0.033 | |
| Psychological | Self-perception of health status | 1.43 (0.893; 1.96) | < 0.001 | 0.50 |
| | CBS Disappointment | -1.18 (-1.63; -0.739) | < 0.001 | |
| | Gender | -1.38 (-2.37; -0.384) | 0.007 | |
| | Quality of the relationship with the CD | 0.742 (0.157; 1.32) | 0.014 | |
| Social Relationships | CBS Isolation | -0.792 (-1.27; -0.310) | 0.002 | 0.15 |
| | Self-perception of health status | 0.920 (0.189; 1.651) | 0.014 | |
| Environment | CBS Environment | -0.992 (-1.37; -0.604) | < 0.001 | 0.40 |
| | CBS Disappointment | -0.551 (-0.942; -0.160) | 0.006 | |
| | Having a formal work | 0.801 (0.309; 1.294) | 0.002 | |
| | Self-perception of health status | 0.732 (0.264; 1.201) | 0.003 | |

CI: Confidence Interval; CBS: Caregiver Burden Scale.

(B = -0.792, $p=0.002$) and self-perception of health status (B = 0.920, $p<0.014$). The environmental dimensions of CBS (B = -0.992, $p<0.001$) and CBS disappointment (B = -0.551, $p=0.006$) along with formal work (B = 0.801, $p=0.002$) and self-perception of the health status (B = 0.732, $p<0.003$) explained 40% of the WHOQOL-BREF environment domain.

DISCUSSION

This study has identified sociodemographic and health variables and the dimensions of care burden associated with QoL of FC of CD. In general, the FC presented better perceptions of QOL in the physical and social relationships domains. On the other hand, the environmental domain was the most impaired. The results showed that better self-perception of the health status was positively associated with the four domains of QOL. Having a good relationship with the CD was associated with a better perception of QOL in the psychological domain. The FC who had formal work had better perception of QOL in the environmental domain. However, daily medication use was associated with worse perception of QOL in the physical domain. Women had more QOL impairment in the psychological domain. It was identified that greater care burden impairs the perception of QOL in all domains of WHOQOL-BREF. The results showed that better self-perception of the health status was positively associated with the four domains of QOL. It can be inferred that the healthier the FCs feel, the better their perception of QOL. What is observed in practice and corroborated by another author is that FCs neglect care for their health when they are involved in seeking treatment or aid for their family member, and this may cause problems (Belotti *et al.*, 2017). In another study conducted with FC of DC, 53.7% reported having regular or poor health; 31.6% had health problems, with Hypertension and Depression being the most cited (Cosentino *et al.*, 2017). The reality of chemical dependence by a family member causes various difficulties to the family nucleus causing illness of family members and worse perception of their quality of life (Medeiros *et al.*, 2013).

In an investigation conducted with FC of CD using Zarit's caregiver burden inventory, a moderate to severe burden level was found in the researched sample (Sequeira, 2010). In the psychological domain of QOL, the variables that contributed to better perception were: good self-perception of health status and good relationship with the CD. On the other hand, female FC and with greater care burden in the CBS disappointment dimension negatively impaired the perception of QOL.

A study on QOL and care burden in caregivers of CD identified the presence of depressive symptoms in 23.8% of 109 caregivers, emphasizing that these symptoms may affect the caregiver's perception of their QOL impairing the care relationship with the CD (Marcon *et al.*, 2012b). In the multivariate linear analysis of the SF36 domains (Short-Form Health Survey), due to the care burden, the sociodemographic variables and the health variables of the caregiver of the CD, the findings show that the burden scale domains (36.5%), health problems (6.3%), and caregiver gender (2.0%) were the variables that most affected QOL, accounting for 44.9% of their impairment (Marcon *et al.*, 2012b). Other research conducted in India reinforces that chemical dependence often increases conflict, negatively affects family members and overloads families (Mattoo *et al.*, 2013). Evidence of objective and subjective burden in the FC of people with mental disorders was found (Buhning, 2017).

The study of the National Survey of Families of Chemically Dependent People (LENAD FAMILY) found that family members of CD have significantly more physical and psychological symptoms than the average population. However, although very little studied, it is known that the daily experiences lived by the family with a drug-using relative are devastating in the physical, financial, interpersonal, and social aspects. The impact is also on the subjective perspective, causing negative feelings such as tension, stress, worry, stigma, anger, and guilt (Laranjeira *et al.*, 2013). Reinforcing that being a female FC and with greater care burden in the CBS disappointment dimension negatively impairs QOL, it was found in this study that most FCs are mothers, providers, with low-income, and caregivers and who perform the caregiver activity with little support from their social network. Although women assume other social roles, they continue to maintain their traditional historical roles, being responsible for care. This finding is also corroborated by another investigation of family burden among caregivers of chemically dependent people, who found that 39.1% of caregivers had a moderate to severe level of burden. Mothers had a higher level of burden than other FCs with different degrees of kinship (Maciel *et al.*, 2018). FC is the individual who faces along with the CD the situations that drug use/abuse compromises. There is limitation when facing the situation, they live daily with suffering, and they are still in moments of feelings of failure and disbelief concerning the treatment and maintenance of psychoactive substance dependent. But it is this CF that runs after alternatives and actions to prevent or manage daily situations and avoid relapses (Czarnobay *et al.*, 2015). In this study, it

was observed that lapses and relapses are frequent among FC and this is a source of concern for FC. For mothers, in particular, there is the premise that they cannot abandon their familiar CD, that they cannot afford to give up caring. Recent research on family forces in the context of psychoactive substance dependence has found similar results (Claus *et al.*, 2018). The FC, who felt healthy, presented better perception in the QOL social relationships domain. In contrast, the greater burden of the isolation dimension of CBS was associated with worse perception of the QOL social relationships domain. Overloaded caregivers end up feeling isolated in care, not knowing how to ask for help, or refusing to do so because of shame and fear of social stigma (Laranjeira *et al.*, 2013). Another study conducted in India on the burden of care perceived by family members of drug users suggests that to reduce caregiver burden interventions are implemented to strengthen caregiver support systems (Mannelli, 2013). However, a study on the impact of having a female family member with substance use disorders found that 45% of caregivers do not ask for help, putting them at risk for burden (Biegel *et al.*, 2007).

The greater burden of care in the environmental dimensions and disappointment of CBS impaired the perception of QOL in the environmental domain, but the fact that the FC has formal work and feel healthy contributed to a better perception in this domain of QOL. Alcohol and drug use disorders have devastating physical, mental, and socioeconomic consequences, not only for patients but also for their families (Mannelli, 2013; Santos *et al.*, 2016). These results show that taking care of people with chemical dependency can be as or more exhausting for the caregiver as taking care of family members with other chronic diseases or with greater dependence for daily activities. Having an illicit drug addict in the family interferes with almost every aspect of family life, leading to problems or difficulties affecting the lives of family members, causing a huge burden on FCs (Brown *et al.*, 2011; Mattoo *et al.*, 2013). These findings reinforce the need for preventive and intervention actions on the factors that impair the QOL of FC of CD. Preventive actions may be implemented in meetings of support groups to the FC held in the services with the active participation of the multiprofessional team. The interventions may be implemented in individual nursing appointments, where each FC will be carefully received and listened to and he/she will have a humanized and appropriate care to his/her situation and reality experienced. A survey of his/her social support network could also be done at the time, and suggestions could be made to approach those points of the network that most strengthen the FC with the various types of support.

One of the limitations of this study, which suggests further research, is a longitudinal follow-up study to further study the effects on QOL that the activity of being a FC of CD requires and other demographic parameters, other stressors, depressive symptoms, life events, coping, and social support. In the cross-sectional study, it is impossible to establish causal relationships. Another limitation is convenience sampling, which does not allow results to be generalized to all FC of CD. However, although there are limitations, this study clarifies relevant issues, producing evidence to organize and implement health care and education actions for FC; suggesting deepening in the training and professional practice of nurses, broadening the view on the problems arising from chemical dependence.

In terms of practical implications, it is important to investigate the QOL of FC of CD and to deepen the knowledge mainly on the factors that impair the QOL of these people. From this, health professionals who work in primary care and/or other services can promote direct interventions in the factors that impair the QOL of FC of CD.

Conclusion

The FC had lower scores in the WHOQOL-BREF domains when taking daily medications, were female, had a burden on the environmental dimensions of CBS, disappointment of CBS, and isolation of CBS. FCs that reported better self-perception of health status in all domains of WHOQOL-BREF, better quality of the relationship with the chemically dependent person in the psychological domain, and who had a formal job (environment domain) had better perception of QOL. The results show that there may be impairments in QOL and that there is a burden that interferes and changes the QOL of FCs, emphasizing that it is necessary to know their life context and offer the necessary support through health services. There is still an emerging need to organize and implement nursing care, attention of health professionals, and efficient public policies towards family caregivers.

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