DATA COLLECTION WITH FAMILY CAREGIVERS OF DEPENDENTS OF ILLICIT PSYCHOACTIVE SUBSTANCES: EXPERIENCE REPORT

RESUMO
Objetivo: relatar a experiência, a partir da coleta de dados, sobre qualidade de vida e sobrecarga do cuidado sentido por cuidadores familiares de pessoas dependentes de substância psicoativa ilícita. Método: estudo descritivo, tipo relato de experiência, realizado com 95 cuidadores familiares que procuraram os serviços públicos de saúde de Palmeira das Missões/RS em 2012/13. Resultados: os cuidadores familiares, na maioria, eram mulheres, mais da metade, mães, com idade média de 47,4 anos, com baixo nível de escolaridade (Ensino Fundamental incompleto). Conclusão: constatou-se a necessidade fundamental de escuta manifestada pelas cuidadoras. O estudo demonstrou que cuidadores familiares vivenciam problemas, tais como econômico, de interação familiar e social, legal, adoecimento físico e psíquico, e sofrer violência por parte do dependente durante o processo de reabilitação psicossocial, levando-os a dificuldades de enfrentamento e de resolução adequada dos problemas emergentes advindos deste cuidado. Descriptors: Cuidadores; Substance-Related Disorders; Nursing.

RESUMEN
Objetivo: relatar la experiencia, a partir de la coleccion de datos, sobre la calidad de vida y sobrecarga del cuidado sentido por los cuidadores familiares de dependientes de sustancia psicoactiva ilicit. Método: estudio descriptivo, de tipo estudio de caso, llevado a cabo con 95 cuidadores familiares que buscaron los servicios de salud pública de Palmeira das Missões/RS en 2012/13. Resultados: los cuidadores familiares, la mayoría, eran mujeres, más de la mitad, madres, con edad media de 47,4 años, con bajo nivel de escolaridad (Educación primaria incompleta). Conclusion: se constató una necesidad fundamental de escucha manifestada por las cuidadoras. El estudio demostró que los cuidadores familiares viven problemas, tales como económico, de interacción familiar y social, legal, adolecimiento físico y psíquico, y sufren violencia por parte del dependiente durante el proceso de rehabilitación psicosocial, llevándolos a dificultades de enfrentamiento y de adecuada resolución de los problemas emergentes de este cuidado. Descriptores: Cuidadores; Trastornos Relacionados con Sustancias; Enfermería.

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INTRODUCTION

This research deals with perceived impressions during the collection of data from a research that investigated the quality of life (QoL) and overload of the family caregiver of an illicit psychoactive substance dependent individual (DSPAI). Quality of life (QoL) is a human knowledge and involves many meanings that encompass notions, experiences and values of individuals and collectivities. These meanings reflect the historical moment, the social class and the culture to which individuals belong. It is understood as an overload the set of consequences, problems, difficulties or adverse events that occur in the sequence of close contact with a patient, being referred to in a negative sense, that is, in the form of “weight” or “burden”, and still, it is associated with the deterioration of the quality of life of the caregiver and the greater morbidity. Chemical dependence refers to a complex phenomenon involving elements of daily life (family, social network, work, leisure, among others), as well as to the subjective nature experiences of the people involved with the problem. It is observed that the family also resents due to the illness of one of its members. The quality of life of the family member who interacts most with the chemical dependent, often assuming the role of caregiver and also responsible, consequently it changes, changing the way you live.

The use of drugs (licit and illicit) has been happening very early and the supply is in all environments and social environments, a configuration often overwhelming for the individual and their families. Its use has a direct and indirect relationship with several health problems of adolescents and young people, especially traffic accidents, aggressions, depressions and conduct disorders, along with risk behavior in the sexual area and transmission of human immunodeficiency virus for the use of injectable drugs and other health problems arising from the components of the substance ingested and the administration routes.

A family caregiver of an individual who is dependent on an illicit psychoactive substance (DSPAI) is defined as the person in the family or next person who is responsible for the care, treatment follow-up, encouragement, limitation, active participation in all phases of life, family in search of rehabilitation, involving commitment, patience, respect and affection.

In this study, it was understood that family caregivers of dependents have unique and collective life experiences, experienced in the family structure, and these experiences reflect in their quality of life and also in the overload of perceived care. The consumption of licit and illicit drugs is considered a public health problem, since it affects the life of the consumer subject, as well as the quality of life of their relatives is modified. Future plans sometimes have to be postponed because a whole change in family structure occurs. The drug user may sometimes be the main provider of family support, and the chemical dependence, consequently, may generate disorganization and instability, causing changes in the subjects’ quality of life. “It is possible to affirm that chemical dependence affects not only the substance user, but also the relatives who live with it.”

Based on the above, the objective of this study is:

- Report the experience, from data collection, on quality of life and overload of care felt by family caregivers of people dependent on illicit psychoactive substances.

MÉTHOD

A descriptive study, an experience report, that describes the experience during the data collection on the occasion of quality of life (WHQOQL-BREF) and Caregiver Burden Scale (CBS) research, perceived by family caregivers of DSPAI who sought the public health services for one year (Municipal Ambulatory of Mental Health and Family Health Strategy Teams). It should be taken into account that the DSPIs that did not seek the public health services of the municipality did not participate in the research.

Data collection was carried out between March 2013 and October 2013 in Palmeira das Missões / RS, Brazil. It was an epidemiological investigation with transversal design that used the sample for convenience. However, this report, addresses qualitative data expressed by family caregivers that were not included in the quantitative study. The research was approved by the Committee of Ethics in Research with Human Beings of the Federal University of São Paulo (Unifesp) under the number CAAE 10269212.5.0000.5505 and Opinion CEP 152.041.

In Palmeira das Missões / RS, there was no service offered by the Psychosocial Care Center (CAPS) in 2013. The outpatient follow-up was offered by the Mental Health Clinic of the municipality, where there was a multi-professional team (Nurse, Psychiatrist, Psychologist, Nursing Technician). The hospitalization, for treatment in chemical...
dependency, occurred in hospitals of the surroundings, with which the municipality maintained an agreement. There was also a Therapeutic Community. The vast majority of hospitalizations in hospitals or clinics were made by the Unified Health System (SUS), as well as referrals to Therapeutic Communities.

- **Preliminary remarks**
  - The protocol application time ranged from 50 minutes to two hours.
  - Most of the caregivers contacted accepted to participate in the study, although it was sometimes necessary to reschedule the interview due to behavior that indicated resistance or a desire not to participate. Even so, at the insistence of the investigators, the interviews were obtained.
  - The interviewer took the precaution of asking the family caregiver to talk in a place where the person with a chemical dependency could not hear the conversation, as she might be uncomfortable responding to certain questions are present. However, few (two) chemical dependents made a point of staying together, with the consent of the caregiver, but did not manifest during the interview, remaining silent.
  - The Term of Consent had to be, at times, exhaustively explained, when the caregivers were asked to sign it. Two of the family caregivers were slow to understand that their acceptance or refusal would not affect their life or that of the person with the chemical dependency they took care of, opting to sign after the interview was completed with their prior approval.

### RELATED EXPERIENCE

Data collection was organized in order to explain the purpose of the research; to obtain free and informed consent; to fill out the socio-demographic, economic and health survey of the family caregiver; explain the history of the family member's chemical dependence; verify the construction of the social support network (Ecomapa); complete the WHOQOL-BREF quality of life instrument and Caregiver Burden Scale's perceived care overload.

It was a challenge to carry out this investigation because of the difficulty of telephone contact to mark the interview; find the address in streets and neighborhoods where house numbers were confusing and did not follow a logical sequence; difficult access; Insecurity in certain neighborhoods. 95 family caregivers of DSPAI were interviewed. The majority, were women, with a mean age of 47.4 years, more than half mothers, with low level of education (incomplete elementary school), married or living in union. The predominant occupation was taking care of the home, followed by domestic/day care. Nearly a third lived on less than one minimum wage. The National Survey of Families of Chemical Dependents (LENAD FAMILY) presented women (66%) as responsible for the treatment of alcohol and/or illicit substance dependents, in addition to being the majority of respondents (80%). Of these women, 46% are mothers who suffer a strong negative impact and feel “overloaded to take care of the dependent child and to be responsible for the care of the family.” 8-4 The family assumes, for the most part, guilt due to the family member being chemically dependent, leading to experiencing stressful situations and the manifestation of illnesses.9

The majority (90.5%) of family caregivers took care of only one dependent, however, eight caregivers who cared for two DSPAIs and a parent who cared for three were interviewed. More than half cared for 24 hours. Care is expressed not only to meet physical needs, but to encourage the individual not to use drugs, to provide emotional help, aiming to maintain tranquility in the environment, adequate communication, sensitive listening, because the situations experienced by the user of drugs, in search of rehabilitation, is complex and difficult.

Most DSPAIs were men, and more than half were in the age group between 20 and 39 years. A result similar to this research found that 60% of the chemical dependents belonged to the same age group.11 What is expected for this age group is that individuals are committed to their school education (concluding high school and entering higher education ) and working on various fronts of the world of work. Two-thirds of them had not completed Elementary School. With regard to professional occupation, most of them worked with hard labor, such as mason and general services. At the time of the survey, 59% were not engaging in any professional activity. The most commonly used drug was crack (83.1%), however, there used to be a combination of using two or more illicit drugs. The greater proportion of male users confirms the tendency of the massive presence of men in drug-dependent care services.8,12 Different studies explain that low education among drug addicts is associated with drug involvement and its consequent dependence, making it more difficult to enter the labor market due to lack of professional qualifications.12,4 With regard to crack, the vast majority of users are
young, single, of low socioeconomic class, and male.

More than half lived with their families and had children, that is, in reality, depended emotionally and economically on their families. Therefore, growing up in a family that has a chemical dependent is always a challenge, especially, when it comes to the direct contact of children and adolescents with this reality. Children of dependents are at increased risk for psychiatric disorders, development of physical-emotional problems and school difficulties. Among psychiatric disorders, they present an increased risk for the consumption of psychoactive substances when compared to children of non-drug addicts; it is also a group with a greater chance for the development of depression, anxiety, conduct disorder and social phobia.  

♦ Housing conditions

Housing conditions varied, but, most resided on a paved street. The residences were mostly wooden or mixed, some masonry, with few rooms and with a scarce network of urban equipment that provided adequate sanitation, comfort, and support services. The difficult access to few residences was observed, with the presence of garbage in the surroundings, as well as the circulation of loose domestic animals in the courtyards of the houses and in the streets; in addition to the presence of areas of drug trafficking near the residences. It was found, in a residence, that the caregiver was a wheelchair, lacking the necessary adaptations in the environment so that it had the minimum access to all the rooms of the house, or, was also a person dependent on care.

♦ Impressions perceived during data collection

There was an expressive number of separations from the husband or partner, and the responsibility of taking care of the children, even grandchildren, assumed by the woman. Some referred that the father was alive, but, they could not count on his support to help take care of the son with dependence of illicit psychoactive substances.

Many family caregivers took advantage of the interview time to vent their condition, sometimes even relating things from a distant past, involving their life history. Many cried when talking about their past and present situation. However, it was observed that there were family caregivers who expressed themselves as if they did not care about the situation and some showed dismay at the situation experienced. Such manifestations reinforced the impression that the life story, for many, was punctuated by suffering, disappointment, as well as by accommodation with the situation experienced. This denotes a feeling of hopelessness that nothing would change or improve. A need for important listening on the part of the caregivers, who demonstrated that they did not have anyone to talk about their problems and confrontations was noticed.

Some of the stories were quite complex, permeated by family disruption, domestic and family violence, loss of ties, poor social support network, low socioeconomic status, self-care deficiency and health problems referenced by family caregivers, especially, in hypertension and depression. The moment was taken to promote guidelines for self-care and health. Mothers, mainly, reported difficulty feeding themselves adequately (inappetence), and that they did not sleep because their relative DSPAI spent the night in the street and they were worried about what could happen to him/her. A fact similar to that found in another investigation, where the problem most faced by the family were the many sleepless nights because the drug user spent whole nights in the street, being subject to risks.

During the interview, a caregiver (father) reported that, given the situation, he provided money for his child to acquire the drug, an attitude adopted after several times when the child took objects from the home and exchanged/sold them for drugs, a fact further aggravated by financial difficulty in replacing the stolen utensils. In the face of extreme situations, people end up not knowing how to correctly discern what is right or wrong. This caregiver also reinforced the feeling of being trapped inside his own home, since everything that had value, including food, was locked in a room.

Other family caregivers reported that the situation was so unsustainable due to evidence of frequent lapses/relapses, constant thefts of family assets, that they were no longer able to care for, because they had to move to hide from the dependent, consequently leaving the DSPAI person. When reflecting on this, it seems that these caregivers presented with fragility, depression, disorientation, emotional instability, feeling of impotence, a picture probably caused by the experience of being a caregiver of a person dependent on illicit psychoactive substances.

More than half of the caregivers, when initially approached, demonstrated with the following argument:
It's my child, I have to take care of him, I cannot turn my back on him, I have to take care of him!

The vast majority have become users and/or dependent on drugs in adolescence. It is noted that this care is solitary and painful, since most of them do not have support from other relatives or even from the father of the child. Although they had other sons and daughters, they reported that they had difficulty accepting the problem of chemical dependence of their brother (or their sister). Chemical dependence has an important impact on the interpersonal and social affective relationships identified in the separations, withdrawals and isolation between the dependent member and their relatives and vice versa. It is difficult for parents to coexist with a dependent child, since, with the drug use, conflicts often emerge among family members.

Feelings of loneliness, isolation, and hopelessness were acutely felt in the wives and companions, as they were compounded by concern for the support of the family and children and almost no effective social support network. Younger caregivers were at risk of feeling more isolated and more socially constrained, as in the case of their partners, there were more social and leisure opportunities in this age group. They reported that they did not feel supported, mainly, by mothers of the spouses/companions, who were conniving with the problem or blamed them for being dependent. At the time of collection, most of their spouses were prisoners on suspicion of being involved in drug trafficking, theft, violent fighting. The real reason for the imprisonment of these people, was not sought by legal means, since it is not the focus of this investigation.

It was observed that family caregivers sought care and professional treatment of their relative's chemical dependence when physical symptoms affected their activities of daily living, resulting in abandonment of studies / employment, separations, deviations from conduct, acts of violence and subtraction of goods and objects from the home and other residences. This delay in identifying and/or admitting to the problem further aggravates it. Drug use/abuse means that the user does not remain employed, then steals things from the home and sells them or exchanges them for the drug. This situation makes the family vulnerable by feeling powerless, leading them to choose between working or caring for the drug user 24 hours a day.

The encounter with these family caregivers showed a universe permeated by feelings such as emotional suffering, feelings of helplessness and loneliness when they discovered that their family member was dependent on drugs, but even in the evidence of this, they left to seek help in the health services when they could no longer deal with the problem and/or with the individual drug user.

Family caregivers experience many events during the psycho-social rehabilitation process of their relative, ranging from economic and legal problems, lack of family and social interactions, physical and psychic illness, violence in their various forms of presentation, leading them to the difficulties of coping with and adequately resolving the problems that arise from this care. But most of them still cared for their relative.

Studies with family caregivers of dependents of illicit psychoactive substances are still scarce in national scientific production, although there are significant numbers of articles with caregivers in different health contexts or in other areas. It is understood that if we worked with a small portion of the population, faced with the large contingent that faces such a reality in Brazil, it is also not a situation of easy resolution, because it deals with a multi-causal origin problem of unequal contexts.

This report clarifies important issues related to family caregivers of persons dependent on illicit psychoactive substances, producing evidence for the organization and implementation of care and health actions. And to identify and know these caregivers, with the aim of reducing the negative impact caused by caring for people dependent on illicit psychoactive substance, valuing preexisting resources in the community and seeking to understand the dynamics of different people, different families and different cultures.

CONCLUSION

The practice of the researchers of this study has shown that, for the recovery of the chemical dependence, it is necessary to change habits of life, that is, a whole reorganization in the way of living. Family caregivers need to be supported and advised that lapses and/or relapses can occur in the course of treatment and that this is part of psychosocial rehabilitation. It is observed that, when the family member receive adequate care to be able to take care of their chemical dependent relative, he feels more security to face the problem.
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