

### **RESEARCH | PESQUISA**



# Needs of families living with mental illness in Cabo Verde

Necessidades das famílias caboverdianas que convivem com o transtorno mental Necesidades de las familias caboverdianas que convienen con el transtorno mental

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### **ABSTRACT**

Objectives: To characterize the families that use a psychiatric service in Cabo Verde/Africa, regarding socio-demographic issues and the most frequent mental disorders that affect their family members; to identify the needs considered as priorities by the families that live with a person with a mental disorder in this context. Method: Exploratory qualitative study, conducted in 2016, with data obtained from 100 medical records from 2010 to 2015 in a psychiatric service, and interviews with 30 family members. Subsequently, the data were subjected to thematic analysis. Results: The families of people with mental disorders on Santiago Island are poor; the caregivers are predominantly female, single, and resident in the city of Praia. When caring for the ill family member, they face several difficulties, such as the lack of support from health professionals and services and from the social network, in addition to the fact that they do not feel included in the care process and have limited training to take care of the ill family member. Conclusion and Implications for practice: There is a need to recognize the family as a target for care and training aimed at the continuity of care for the ill family member. The study points to the need to review health policies to improve mental health care in primary care.

Keywords: Mental Disorders; Mental Health; Family; Psychiatric Nursing.

#### **RESUMO**

Objetivos: Caracterizar as famílias usuárias de um serviço de psiquiatria em Cabo Verde/África, quanto aos aspectos sociodemográficos e aos transtornos mentais mais frequentes que acometem seus membros; identificar as necessidades consideradas prioritárias pelas famílias que convivem com a pessoa com transtorno mental neste contexto. Método: Estudo qualitativo exploratório, realizado em 2016, com dados obtidos através de 100 prontuários de usuários em um serviço de psiquiatria, no período de 2010 a 2015, e entrevistas realizadas com 30 familiares desses usuários. Posteriormente, os dados foram submetidos à análise temática. Resultados: As famílias das pessoas com transtorno mental na ilha de Santiago são pobres, as cuidadoras são predominantemente do sexo feminino, solteiras e residentes na cidade da Praia. No cuidado ao familiar doente, enfrentam diversas dificuldades, como a falta de suporte por parte de profissionais e serviços de saúde e da rede social, acrescentando, ainda, o fato de não se sentirem incluídos no processo de cuidado e com delimitada capacitação para cuidar do familiar doente. Conclusão e Implicações para a prática: Há a necessidade do reconhecimento da família como alvo de cuidados e capacitação para a continuidade dos cuidados ao familiar doente. O estudo aponta a necessidade de revisão das políticas de saúde, para aprimoramento dos cuidados de saúde mental na atenção primária.

Palavras-chave: Transtorno Mental; Saúde Mental; Família; Enfermagem Psiquiátrica.

#### **RESUMEN**

Objetivos: Caracterizar las familias usuarias de un servicio de psiquiatría en Cabo Verde/África, en cuanto a los aspectos sociodemográficos y a los trastornos mentales más frecuentes que afectan sus miembros; identificar las necesidades consideradas prioritarias por las familias que conviven con la persona con trastorno mental en este contexto. Método: Estudio cualitativo exploratorio, realizado en el 2016, con datos obtenidos a través de 100 registros médicos de usuarios en un servicio de psiquitría, en el período de 2010 a 2015, y entrevistas realizadas a 20 familiares de esos usuarios. Posteriormente, los datos fueron sometidos a análisis temática. Resultados: Las familias de las personas con trastorno mental en la isla de Santiago son pobres, las cuidadoras son predominantemente de sexo femenino, solteras y residentes en la ciudad de la Playa. Con respecto al cuidado del familiar enfermo, enfrentan diversas dificultades, como la falta de soporte por parte de los profesionales, los servicios de salud, y de la red social, agregando además el hecho de que no se sienten incluidos en el proceso de cuidado y con capacitación limitada para cuidar al familiar enfermo. Conclusión y implicaciones para la práctica: hay una necesidad de reconocimiento de la familia como objetivo de cuidados y capacitación para la continuidad de los cuidados al familiar enfermo. El estudio señala la necesidad de revisar las políticas de salud para mejorar la atención de salud mental en la atención primaria.

Palabras clave: Trastorno Mental; Salud Mental; Familia; Enfermería Psiquiátrica.

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### INTRODUCTION

The needs of a human being are defined according to their individual characteristics, which are related to the context in which they are inserted and the historical time in which their life history is built. When a human being belongs to a family that has an individual with mental disorder, the individual characteristics that most influence their needs are the adaptive capacity of the person with the disorder and of the family, the conception of mental illness among its members, the ability of this family to know their own limits as caregivers, the value attributed to the health of its members, and their commitment and complicity.<sup>1</sup>

Contextual aspects that influence the families' needs are the existence or not of specific public policies, the care network, equitable access to health care and the organization of the health system. In general, a network capable of supporting the family helps meeting their health needs and ensures better quality of life for those assisted. In the case of people with mental disorders, the support network is fundamental to their process of reintegration into the family and the community.<sup>1</sup>

The historical time in which the family lives also influences their needs. Throughout their life cycle, the family goes through several phases, beginning their formation with marriage and birth of children, then going on to the adolescence of these children, to the moment when they leave home to study or to work, and later, to the aging of the family members.<sup>2</sup> The moment when mental illness strikes a family can trigger stress and overload, depending on which phase the family is experiencing, as it requires all family members to have greater disposition and ability to deal with the presence of a person with mental disorder in daily family life.<sup>1</sup>

In short, to understand the needs of families living with mental illness, it is necessary to know the context in which they live, their history and their values, beliefs and experiences. In particular, it is necessary to know how the family engages with the mental disorder.<sup>3</sup>

In the context of Cabo Verde/Africa, a middle-income island country, the needs of families of people with mental illness are also determined by the characteristics of each of them, by time, and particularly by the characteristics of the context in which they live. Statistical data from Cabo Verde show that the country has a population of almost 179,909,000 people living in poverty, with 48.5% residing in rural areas and 27.8% residing in urban areas.<sup>4</sup> Also, most of the poor population are women (53%), of whom 51% live in urban areas.<sup>5</sup>

Families who take care of a person with mental illness go through changes in their daily lives, which include changes in routine, damage to their work, changes in financial situation and physical and psychological overload due to the need to take care of other family members (children, teenagers, seniors). In addition, most families do not know how to deal with behavioral changes of the ill family member, especially when their condition involves more marked symptoms such as hallucinations, delusions,

cognitive deficits, mood swings, aggression, and non-adherence to medication.<sup>3,6</sup>

Considering these conditions, this is a vulnerable situation and professionals working in primary care services need to know these families and their needs in order to help and support them, especially in the post-discharge period, when reintegration of the person with mental illness into the community and the family is important to reduce the chances of hospital readmission.<sup>7</sup>

In order to address mental health care needs, Cabo Verde has an Occupational Therapy Center (CTO), located in Ribeira de Vinha, on the island of São Vicente, which works as a day center. As for hospitalization services, the country has mental health wards at the Hospital Central Baptista de Sousa on the island of São Vicente and at the Hospital Regional João Morais, on the island of Santo Antão, and a psychiatry service at the Hospital Dr. Agostinho Neto, Trindade Extension, which is located in the capital of the country and is considered a reference in the national territory. In the other islands of the country, people with mental disorders are initially treated at health centers and police stations, and subsequently referred for specialized evaluation at central or regional hospitals.<sup>8</sup>

It is in this perspective that this study aims to: (1) characterize the families who use a psychiatric service in Cabo Verde/Africa regarding socio-demographic aspects and the most frequent mental disorders that affect their members; (2) identify the needs considered as priorities by the families that live with a person with mental disorder, in this context.

### **METHOD**

Qualitative, exploratory and descriptive study developed with data from two sources. The first were the medical records of 100 people who had been hospitalized in a psychiatry service in the largest island of Cabo Verde/Africa from 2010 to 2015. The second were interviews with 30 relatives of people with mental disorders, selected from the medical records, using as inclusion criteria: being over 18 years old and living in the city of Praia, Santiago Island/Cabo Verde. To preserve the anonymity of the participants, family members were identified by the letter "F" (Family), followed by a number indicating the order of the interviews. Data from both sources were collected in July 2016.

Initially, data were collected from medical records, prioritizing those that allowed identifying a profile in terms of gender, age, civil status, education, occupation/work, number of children, main diagnosis and number of hospitalizations. Subsequently, semi-structured interviews were conducted at the homes of the 30 families, in a previously agreed time and after obtaining the informed consent of the participants.

The interviews were recorded with the agreement of the family member and were later transcribed. The interviews were guided by a script designed specially to address the objectives of this study. The script was divided in five parts. The first and the second were aimed at obtaining data that could characterize the

family member interviewed and the person with mental disorder, respectively. The third assessed the factors that, according to the perception of the interviewee, helped or hindered the relationship with the person with mental illness within the family. In the fourth part, the family member participating in the study was asked about the needs they considered as priorities for the care of the person with mental disorder in the family environment, after hospital discharge. The fifth part of the script investigated the resources and potentialities that, according to the family member's perception, could help the family take care of the person with mental disorder.

The data from the interviews were organized and subjected to thematic analysis. Data analysis began with a pre-analysis for the organization of the collected material, followed by the systematization of the findings through a meticulous reading of the answers obtained in the interviews, and which led to the elaboration of thematic cores.

The study was approved by the Health Research Ethics Committee (CEPAS) of the Federal University of Rio Grande/RGS/Brazil (Protocol 144/2016); by the National Committee of Ethics in Health Research of the Cabo Verde Ministry of Health (Protocol 53/2016) and the Clinical Directorate of the Cabo Verde health institution in which the medical records were accessed (Protocol 1646/HAN716). Since the study was linked to a Brazilian institution, all the recommendations of Resolution 466/12 of the National Health Council, at the time of data collection, were followed.

### **RESULTS**

### Characterization of study participants

The 30 family members who participated in this study were between 28 and 89 years old. Most of the participants belonged to the age groups of 41 to 50 years old and 51 to 60 years old. As for civil status, 21 were single, six married, two widowed and one divorced. Among the families, 25 had one family member with a mental disorder and five had two family members diagnosed with some type of mental disorder. The main caregivers were mothers, sisters, wives and nieces. As for work, six participants had no formal employment; seven were housewives; four were street vendors; three were pensioners; two were retired and eight had various occupations.

Regarding the people with mental disorders who were hospitalized in the Psychiatry service from 2010 to 2015, the information obtained in the 100 medical records examined showed that the age ranged from 19 to 80 years old, with more participants in the age group of 31 to 40 years old. Of the total, 67 were male and 33 were female. Regarding civil status, 82 were single, 8 married, 3 widowed, 1 divorced and 6 records did not have this information. Regarding place of residence, the majority (70) of the patients lived in the city of Praia.

Regarding the main diagnosis, 36 patients were diagnosed with bipolar disorder, 31 with schizophrenia, 27 with alcohol and other drug use disorder, 4 with intellectual disability and psychotic decompensation, 1 with psychotic disorder, and 1 with depression. Regarding the number of hospitalizations, 87 people had been hospitalized from one to eight times, and 13 people had been hospitalized from nine to thirty-three times in the service, between 2010 and 2015.

The needs identified as priorities by the families were grouped considering the characteristics of the person with mental disorder and of the family and the characteristics of the context in which they live. Thus, four categories arose: (1) Need for individualized attention to family and family caregiver; (2) Need for inclusion of people with mental disorders in community health services; (3) Needs related to the family social network; (4) Need to identify and mobilize the potential of the person with mental disorder.

# Need for individualized attention to family and family caregiver

For families  $F_{6}$ ,  $F_{27}$ , family support is fundamental for the recovery of individuals with mental disorders, as it is the essential reference in the insertion and maintenance of the ill person at home. According to  $F_{13}$ ,  $F_{18}$ ,  $F_{23}$ , when this person is discharged from the hospital, the family is not always prepared to assume the role of being a reference and to provide the care they need. This care involves numerous activities, such as feeding, body hygiene, medication administration, outpatient consultations and many others  $F_{\alpha}$ ,  $F_{4}$ .

In this situation, family caregivers emphasize that they need professionals who are able to recognize their challenges and the responsibilities they assume. Participants were unanimous in stating that it is up to the professional to support and train the family member, especially when it comes to knowledge about the signs and symptoms of the disease, the treatment required and the management of crisis.

The same participants stated that these conditions and the burden of the care required by the family member with mental illness, in a reality in which they feel helpless, are predisposing factors for the illness of the family and, especially, of the family caregiver. This is a condition that calls for interventions by the competent entities, which should formulate Public Policies that include the whole family, with a network that provides resolute and efficient support to these families, recognizing their particularities, meeting their needs and reducing the impact that caring for a sick relative can have on their life.

[The professionals] can't explain things well, we don't know what the medications are for. We need better professionals. There is no interaction between caregivers and the professionals who take care of the patient. We don't know what's going on, they just arrive and give the medication. (F.,)

Caring for these patients is complicated. That's why we ask for help in health services. When we have a child

like this we are not okay, they have to take care of the sick person and of the caregiver, we end up being two patients and this is complicated. There should be support for those who care. ( $F_{30}$ )

It is evident that supporting the family and the family caregiver is essential to ensure continuity of care. It is also important to include the family in the process of caring and receiving care, providing effective responses to the needs of the ill family member, of the family and of the family caregiver.

# Need for inclusion of people with mental disorders in community health services

This category includes the needs related to access to health services in the community, which could help families to overcome everyday problems that occur with the return of the person with mental disorder after hospital discharge, sometimes after a long period of hospitalization. Among these problems, families  $F_6$ ,  $F_{17}$ ,  $F_{20}$ ,  $F_{23}$ ,  $F_{25}$ ,  $F_{26}$ ,  $F_{28}$  highlighted family conflicts and the discontinuity of medication, a factor that aggravates the situation and leads to relapse crises and readmission to the only psychiatric hospital in the island, causing a cycle characterized by oscillation between discharge and readmission.

In the city of Praia, the capital of the country, families who have a member with mental illness also face the lack of primary health care services that provide care to people with mental disorders, as they only have psychologic care and the possibility of referral to the psychiatric service located 8 km from the city center, in a region that is difficult to reach and where there is no public transportation.

Participants  $F_2$ ,  $F_5$ ,  $F_6$ ,  $F_{17}$ ,  $F_{20}$ ,  $F_{28}$  report that family members with mental disorders who do not adhere to medication are also resistant to attending scheduled appointments with the doctor, social worker and psychologist, as they fear a referral for another admission to the psychiatric service. In addition, according to  $F_1$ ,  $F_4$ ,  $F_6$ ,  $F_7$ ,  $F_{10}$ ,  $F_{14}$ , when the family member chooses not to take the medication, symptoms such as aggression, agitation, delusions, and affective disorders are more difficult to control and trigger crisis more easily.

I think there should be a place here in the community where I could turn to for help when I need it.  $(F_9)$ 

There should be at least one health unit here in the community that would help us, that was closer than going to the [psychiatric hospital], because we need to pay for two transport fares and sometimes we don't go because we don't have the money.  $(F_{27})$ 

According to  $F_8$ ,  $F_{22}$ ,  $F_{28}$ ,  $F_{30}$ , conflicts between family members aggravate the health status of the ill family member and make them spend less time at home and more time roaming the streets. These conflicts are usually associated with physical and verbal aggression perpetrated by the ill family member. Families  $F_8$ ,  $F_9$ ,  $F_{12}$ ,  $F_{14}$ ,  $F_{15}$ ,  $F_{19}$ ,  $F_{20}$ ,  $F_{21}$ ,  $F_{24}$ ,  $F_{26}$ ,  $F_{26}$ ,  $F_{2}$  refer to aggressiveness

as a factor that makes daily life within the family very difficult, generating fear, insecurity and anguish.

There was a day when I went to work and they called me because she had hit a child, I went to the hospital and found my youngest son there, she hit him with a broomstick and broke his arm. When I got home, I told her that she could not stay here because she was aggressive; everything that is dangerous in here, like knives, I have to hide, because she is aggressive, she picks it up and throws it at people. (F<sub>o</sub>)

Access to health services in the community is a resource for families to meet their difficulties when caring for the sick relative. Therefore, regular follow up of the family member with mental illness and support to the family are priority needs.

## Needs related to the family social network

Families that participated in this study reported that healthy relationships with neighbors and with the community are a fundamental need for social reintegration, as these people know the person with the disorder and try to protect them from abuse or other harms, such as people from other places and sometimes from the same community offering money or alcohol as payment for services. In addition, some family members and neighbors help with medication, as mentioned by  $F_2$ ,  $F_7$ ,  $F_9$ ,  $F_{13}$ ,  $F_{29}$ , and with leisure, providing moments of joy, as stressed by  $F_{10}$ . For families with economic difficulties, neighbors are valuable resources for getting food and water, as reported by  $F_{15}$ ,  $F_{17}$ ,  $F_{25}$ , and considering that water is a problem on the islands.

Participants  $F_1$ ,  $F_2$ ,  $F_6$ ,  $F_{14}$ ,  $F_{20}$ ,  $F_{25}$ ,  $F_{28}$ ,  $F_{30}$  stated that their mentally ill family members have easy access to drugs on the streets, either because people offer it or because they ask for it on the streets. They also often sell personal objects and, with the money they raise, easily buy drugs and alcohol.  $F_{30}$  reports that in the neighborhood where they live, alcohol and drug use is quite common, and access is easy. This is a complicating factor, because besides the problems related to mental illness, the family has to live with the difficulties arising from the use of chemical substances (drugs, alcohol), namely family conflicts and physical violence. Families  $F_6$ ,  $F_9$ ,  $F_{16}$ ,  $F_{23}$ ,  $F_{28}$  report that after the first days or weeks of the return of the family member to their home, they find it very difficult to keep them at home and they often return only at night, to sleep.

He is always in the street and occasionally he comes home and asks for water. One of these days I went there to offer him a papaya, but he did not accept it. He lives on the street, I don't even know how he is. When he left the hospital I managed to take care of him, but he kept fighting with my youngest son, so he left home.  $(F_{2R})$ 

The social support network in the context in which the family and the person with mental illness live was represented in this study in a peculiar way, as an effective means to rescuing

meaningful relationships and pre-existing affective bonds. It has been evidenced that the fragility of the bonds between the ill individual, their family and the community has direct consequences to the care and to the support network they need.

# Need to identify and mobilize the potential of the person with mental disorder

The discourse of the families showed that the negative connotation attached to mental illness influences the identification of the potential of the person with mental disorder and hinders their social reintegration. Families  $F_4$ ,  $F_{10}$ ,  $F_{12}$ ,  $F_{16}$ ,  $F_{20}$  explained that, after receiving a diagnosis of mental illness, the person is usually no longer seen as someone who can perform different activities, such as activities of daily living, work activities and active participation in society. In this context, families  $F_{10}$ ,  $F_{14}$ ,  $F_{16}$ ,  $F_{17}$ ,  $F_{18}$ ,  $F_{26}$ ,  $F_{28}$  cited the need to create conditions that can unleash the potential of people with mental disorders, especially regarding their reintegration into the labor market, as it can promote psychosocial rehabilitation and contribute to the recovery of their autonomy and self-esteem.

She has no family support. Her family didn't support her, her education, they didn't try to help her develop, they always saw her as a sick person who just needs breakfast, lunch and dinner. When I met her I saw that this was a lie, I saw that she is a person that would achieve her goals if we just invested in her... Her family didn't bet on her. So she stayed at home for a long time without leaving, and this contributes to her getting sick.  $(F_{26})$ 

Family members  $F_{16}$ ,  $F_{17}$ ,  $F_{18}$ ,  $F_{26}$ ,  $F_{28}$  also pointed out that community and social institutions should be aware and willing to support the insertion of people with mental disorders in the labor market, offering job opportunities to this group of people.  $F_{14}$  drew attention to how inactivity and the need to feel useful can affect the health of these people.

My daughter talks about committing suicide almost every day, because she can't get a job, here at home she does the dishes and cooks very well... One of those days she told me: Mom, I'll commit suicide because I don't have a job... If at least she had a job opportunity.  $(\mathsf{F}_{_{14}})$ 

I think there should be a center that would help them recover their worth and also help them find a job because they suffer a lot of discrimination. ( $\mathsf{F}_{26}$ )

The unappreciated skills of people with mental disorders when it comes to work activities was pointed out by families  $F_{10}$ ,  $F_{14}$ ,  $F_{26}$  as a factor that also influences the financial burden of the family.

These results allowed recognizing the need for making joint efforts with family, community and employers to recognize and identify the potential of people with mental disorders. The presence of a chronic disease leads to changes in routine and in the previous roles of the individual. However, in the context of this study, there was a sudden loss of autonomy and of identity of the person

with mental disorder, and the non-recognition of their potential generated greater dependence on third parties, especially for health care and financial issues, further aggravating the difficulty of their social reintegration.

### DISCUSSION

The profile of the family members who participated in this study is similar to the profiles found in studies conducted in countries with similar historical and economic context. In the state of Ceará/Brazil, a study conducted in 2016 with informal caregivers of patients from general psychiatric hospitals found that most caregivers were also female (80.9%) and were related to the mentally ill patient (more than 75% were children, spouses and parents). <sup>10</sup> Another study conducted in Portugal with 35 relatives of patients diagnosed with schizophrenia found that female caregivers were more exposed to the objective burden of caring for ill family members. <sup>11</sup>

Data on the socio-demographic characteristics of people who had been admitted to the Cabo Verde/Africa psychiatric service showed that there was a predominance of adult, male and single individuals. Similarly to Cabo Verde, a study conducted in Brazil in three mental health services in the city of Sobral, state of Ceará (CAPS; CAPS-AD; Psychiatric Inpatient Unit in a general hospital) found a prevalence of males, in the age group of 30 to 40 years old. The same authors point out that the objective burden of caring for a family member with mental disorder is greater when the patient is a man. The same authors of the control of th

Regarding the main diagnosis of this study, bipolar disorder is highlighted, followed by schizophrenia and alcohol and other drug use disorder. International studies have shown different scenarios. In two studies conducted in Brazil, one of the main diagnosis is schizophrenia, followed by mental disorders due to substance use and mood disorder. <sup>12,13</sup> In a study conducted at the Dallas County Community Hospital in the United States of America, the main diagnoses were substance use disorders, followed by mood disorders and psychotic disorders, anxiety disorder, and other disorders. <sup>14</sup>

Care for the person with mental illness involves several demands, which are related to individual characteristics, to the context in which they are inserted and to the time in which the sick person and the family live. A study conducted in Santa Catarina/Brazil pointed out that a diagnosis of mental illness in the family has its peculiarities, as the time living with the disease, the degree of evolution, and the relationship of the ill family member with the community where they live can affect the way this process is handled. It also added that each family member may deal with the situation in a different way, according to their personal characteristics and the mechanisms adopted.<sup>15</sup>

In addition, the support of health professionals and their recognition of the need to also provide care to the family is essential to help family members develop adaptation and coping mechanisms. Particularly in the context of Cabo Verde, there is

a deficit in family support services, especially in the period after discharge. In Portugal, a study conducted with families of people with mental disorders showed that multi-family psychoeducational interventions are an effective support to family members, since they reduce the objective and subjective burden of caring for people with mental disorders and of including the family in the care process. <sup>16</sup>

It is also worth noting that the lack of services in Cabo Verde to support families with a person with mental disorder was a concerning factor and a case for greater investment, as it had direct repercussions on the care of the sick relative, such as high readmission rates, due to the lack of preparation of family members and abandonment of medication. In a similar scenario, a study conducted in China added that the care and financial burdens, limited social support and limited support from health professionals are difficulties yet to be overcome, since the needs of families were not met and this had repercussions on quality of life of ill family members and their caregivers. 17 In Brazil, a study showed that the link between community health services and the family, called Family Health Strategy (FHS), focused on guidance, support, recognition of the family as a collaborator and target of care, was efficient, especially regarding adherence to treatment.18

The inclusion of the family in community health services allows nurses to know these families, listen to their concerns and guide them on the whole process of mental illness, which will contribute to a better acceptance and relationship with mental illness. In this perspective, properly oriented and trained family members are the support in the care process of the family member with mental disorder.<sup>19</sup>

Unlike the research mentioned above, in the context of this study, families do not have a community care network that provides assistance to people with mental disorders and their families, especially in the post-discharge period. This is aggravated by the fact that the most important resource available for mental health care is a psychiatric hospital that provides care essentially at times when the sick family member is in a psychotic crisis. In addition, the service is located at 8 km from the city of Praia, in a location that is difficulty to access by public transportation. A study conducted in Ghana showed a reality similar to Cabo Verde, stating that the geographic location and the difficult access to health services associated with factors such as the low priority of mental health in the Health System, the lack of recognition of community health services and lack of knowledge of the family on the efficacy of medication are factors that aggravate the health condition of the family member.<sup>20</sup>

Given this scenario, Cabo Verde's National Health Policy provides guidelines on mental health, advocating for the incorporation of mental illness in the set of essential care measures in primary care and including mental health promotion activities with the families and the community in order to promote prevention, including early diagnosis, to follow-up the patient and his family, and to ensure treatment.<sup>8</sup> Even with these guidelines, there is

still a theoretical and practical gap in relation to a collaborative work with the competent entities, health professionals, family, community and the patients themselves. It should be noted that some locations covered by this research do have primary care services; however, families did not recognize them as a resource, and reported a limited support from professionals of these services in relation to mental health demands.

Furthermore, the country needs to adopt an approach focused on the family and on the community and in which the person with mental disorder can be included. In this sense, outpatient services, if adopted, can be an important instrument to help families and to meet the health needs of the ill person. A study in Timor Leste highlighted the need to combat social exclusion of people with mental illness, investing in family, community and social inclusion, and focusing on the promotion of inclusive health services and systems across sectors.<sup>21</sup>

The social network of the family is another resource that can be used to deal with the mental illness that affects a family member. The person with mental disorder is inserted in a community that contributed to their development and that was the place in which they developed and established significant relationships. A social network and the support offered to the family of the mentally ill person can provide conditions that favor their psychosocial rehabilitation and contribute to their health care.<sup>22</sup>

In this study, the social network was described by families as the fundamental aid and support for maintaining the health of the ill family member, especially when they have moments of crisis, in which they roam the streets and are exposed to social dangers such as drug use. The results of this study show that these families actually need to receive the support of their social network when facing the difficulties of caring for people with mental disorders. As most of the families in the study were poor and faced financial difficulties, the neighbors were pointed as the main partners to help supply some needs, which included food.

The implementation and maintenance of services that support a social network for the care of people with mental disorders is extremely relevant and represent a care strategy in the context and territory where families are inserted. These services contribute to the deinstitutionalization of health care and to a greater integration of these individuals in their community. In addition, they also improve the treatment and survival of people with mental disorders.<sup>23,24</sup> In Portugal, the inclusion of the family in the process of transition of mental health patients from hospital to the community was effective and helped ensuring continuity of care.25 These services are an emerging need in the context of Cape Verde, as families need support so that they can continue to be the protagonists of the care of their ill family member. The impact that these services can have in that context is of paramount importance if we consider that psychiatric reform is not yet a possible reality in this country.

Thus, the results of this study point to the need for changes in the paradigm of care for people with mental disorders and their

families in the context of Cabo Verde and for greater support from health services. Health professionals must know the social support networks of the family and of the ill family member, as this is important knowledge on the meaningful bonds of the caregiver with their community, which can be used in strategies for caring for the person with mental disorder, especially during crisis and after discharge. Moreover, knowing the services that are recognized by families as resources in their territory is fundamental to ensure a more humane and less hospital-centered care.<sup>26</sup>

In addition to these measures, the recognition of people with mental disorders as social beings contributes to the improvement of their health condition. In this study, it was evident that the difficulties in identifying and mobilizing the potential of the person with mental disorders, as well as the few opportunities offered to this group of people, contribute negatively to the recovery of their self-esteem and autonomy. Recognizing the potential and the abilities of people with mental disorders is a necessity for their reintegration into society and into the labor market. The diagnosis of mental disorder usually has repercussions on the person's autonomy. Therefore, rescuing and maintaining social relationships should be part of the care process, as this helps preserving the skills of these subjects and maintaining their position or entering the labor market.<sup>27</sup>

However, very often, people with mental disorders face lack of appreciation of their skills, abilities and potentialities, whether relational or work-related, and are generally discredited by society and by their own family, which then leads to greater financial dependence on third parties. <sup>28</sup> Moreover, a study that addressed the insertion of people with mental disorders in the labor market showed stigmas and prejudiced opinions on the part of employers regarding the work skills of these individuals.<sup>29</sup>

The data from this study were similar the above-mentioned studies, reinforcing the social exclusion of people with mental disorders as they are denied a job opportunity. In the context of Cabo Verde, not including these individuals in the labor market not only impacts their limited autonomy, but also influences the financial condition of their families, who are mostly poor. Thus, a psychosocial rehabilitation with inclusion and reintegration into the family and the society for people with mental disorders favors the recovery of autonomy and promotes the citizenship of this specific group of people.<sup>30</sup> In another context, a study conducted in England and Wales showed anomalies in the benefit system for people with mental disorders, which meant it was more difficult for this group to be able to enter and reach their goals in the job market.<sup>31</sup>

In addition, the recognition of these subjects as social beings, inserted in a family and in a social context, should be the target of investment in order to promote autonomy and independence. Effective care should promote and include people with mental disorders in effective social exchanges, which consequently improves their autonomy and health condition. The participation

of family, community, health services, health professionals and public policies is a crucial part of this process.<sup>21</sup>

### FINAL CONSIDERATIONS

This study revealed the socio-demographic characteristics of families of users of a psychiatry service on the island of Santiago, Cabo Verde/Africa and the needs identified by families as the priorities in the care for the ill family member.

Considering these findings, there is an emerging need to change the approach and perspective of the care for people with mental disorders and their families. Knowing the needs of families who care for their ill family members, as well as their aspirations and potentialities, is important for planning care and for supporting and including the family in the care provided, from health services to health policies.

This study has the potential to support clinical practice, as it allows a theoretical and practical approach to care for the mentally ill and their families. When families who live daily with their ill family member are recognized as direct participants in the care and health-illness process, they can provide crucial information to support the provision of appropriate care in primary care services for the ill family member as well as for the other members.

In addition, this study suggests a review of health policies in order to focus more on mental health care, on primary care, aiming to contribute to the psychosocial rehabilitation of the ill family member and of the family.

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