PERCEPTION OF SCHIZOPHRENIC´S RELATIVES: LEXICOGRAPHIC ANALYSIS THROUGH IRAMUTEQ

PERCEPÇÃO DOS FAMILIARES DE PESSOAS COM ESQUIZOFRENIA: ANÁLISE LEXICOGRÁFICA ATRAVÉS DO IRAMUTEQ

PERCEPCIÓN DE LOS FAMILIARES DE PERSONAS CON ESQUIZOFRENIA: ANÁLISIS LEXICOGRÁFICO A TRAVÉS DEL IRAMUTEQ

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ABSTRACT

Objective: To know through graphic lexicography, the most frequent vocabulary by the perception of schizophrenic's relatives. **Method:** Descriptive study with a qualitative approach, developed with five family members of a municipality in the extreme north of Brazil, in the Franco-Brazilian border region. Data were obtained through individual interview, processed in the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* IRAMUTEQ software and the word cloud, Descending Hierarchical Classification were analyzed through the dendogram and Correspondence Factor Analysis. **Results:** The most common word was "no", in which it dismantled the sense of negativity of the disease, which demonstrates a rejection on the part of the familiar. **Conclusion:** Based on this, IRAMUTEQ was found to be a valuable tool in the search for this vocabulary and, from this, the knowledge of the perception of those involved in this study, being surrounded by feelings of devaluation and factors in which family life is difficult, since there is difficulty in associating and understanding the behaviors resulting from the disease.

Descriptors: Perception; Schizophrenia; Family; Family Nursing; Mental Health.

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RESUMO
Objetivo: Conhecer através da lexicografia gráfica, o vocabulário mais frequente por meio da percepção dos familiares de pessoas com esquizofrenia. **Método:** Estudo descritivo de abordagem qualitativa, desenvolvido com cinco familiares de um município do extremo norte brasileiro, na região da fronteira franco-brasileira. Os dados foram obtidos por meio de entrevista individual, processados no software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ) e analisados a nuvem de palavras, Classificação Hierárquica Descendente, através do dendograma e Análise Fatorial de Correspondência. **Resultados:** A palavra mais comum foi "não", no qual desmontou o sentido de negatividade da doença, o que demonstra uma rejeição por parte do familiar. **Conclusão:** A partir disso, percebeu-se que o IRAMUTEQ é uma ferramenta valiosa na busca deste vocabulário e, a partir disso, o conhecimento da percepção dos envolvidos neste estudo, sendo rodeadas de sentimentos de desvalia e fatores nos quais dificultam o convívio familiar, pois, há dificuldade em associar e entender os comportamentos resultantes da doença.
Descritores: Percepção; Esquizofrenia; Família; Enfermagem de Família; Saúde Mental.

RESÚMEN
Objetivo: Conocer a través de la lexicografía gráfica, el vocabulario más frecuente por meio de la percepción de los familiares de personas con esquizofrenia. **Método:** Estudio descriptivo de abordaje cualitativo, desarrollado con cinco familiares de un municipio del extremo norte brasileño, en la región de la frontera franco-brasileña. Los datos fueron obtenidos por medio de una entrevista individual, procesados en el software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ) y analizados la nube de palabras, Clasificación Jerárquica Descendente, a través del dendograma y Análisis Factorial de Correspondencia. **Resultados:** La palabra más común fue "no", en el cual desmontó el sentido de negatividad de la enfermedad, lo que demuestra un rechazo por parte del familiar. **Conclusión:** A partir de eso, se percibió que el IRAMUTEQ es una herramienta valiosa en la búsqueda de este vocabulario ya partir de ello el conocimiento de la percepción de los involucrados en este estudio, estando rodeadas de sentimientos de desvalorización y factores en los que dificultan la convivencia familiar, hay dificultad en asociar y entender los comportamientos resultantes de la enfermedad.
Descriptores: Percepción; Esquizofrenia; Familia; Enfermería de Familia; Salud Mental.

INTRODUCTION

Schizophrenia is a psychic, chronic and disabling disorder that affects the socialization of the patient. It is a disease affecting the lives of individuals, families and caregivers. Therefore, this mental illness causes a major challenge for the entire family unit, often associated with lack of pathology, as well as the burden arising from the symptoms of the mental disease.[1]

The act of caring for people with schizophrenia requires the families and caregivers a physical, psychological, social and economic support, since the disease

directly affects these spheres, generally leading to a stressful experience.[2]

Thus, studies concerned with uncovering the feelings, perceptions and experiences of people with schizophrenia and their families are increasingly common today. A recent research[3] pointed out that living with this disease is to live trapped in the dark and with interrupted dreams, as much for those sickened and the ones surrounding them, implying the sense of termination of life projects planned before.

Therefore, the identification of the disease in its early stage is essential for the best therapeutic and prognostic outcome. Mental disorders represent a challenge; however, in most of these disorders there is only control, not cure, which will help the patient to be inserted into society, as it helps their families to better understand and cope with problems related to the relative's disease, thus resulting the least impairments possible.[4-5]

A study of relatives of people with schizophrenia showed that there are major changes in routine and there is a reduction of pleasure and fear of getting sick. The prospects for the future are important overload factors. Thus, one can show that care of users with schizophrenia directly impacts the lives of all involved with the disease.[6]

Based on the description above and reflecting about family interventions, a study[7] pointed out that the family burden in the acute phase of the disease can be reduced from the effectiveness of the interventions of the nurse, specialist in mental health, within that context. The family approach results in mobilizing himself as a therapeutic resource, to establish a supportive relationship with both the person with schizophrenia, as with his family in need of care.

Then, the aim of this study was to know, through the graphical lexicography, the most common vocabulary through the perception of relatives of people with schizophrenia in a city of the extreme northern Brazil, in the Franco-Brazilian border region.

METHOD

It was a descriptive-exploratory study, with qualitative approach, carried out in a city of the extreme northern Brazil, in the Franco-Brazilian border region. Data collection occurred in the period from July to September 2017, through individual interviews with five family members of people with schizophrenia who attend the Psychosocial Care Center - CAPS I.

For data production, it was used a semi-structured interview guide with

questions related to perception of family members about the one who has schizophrenia. At first, it was conducted a survey of the patients who have the disease, from the medical records, along with the help of the professionals of the service. Secondly, the researchers visited the homes of the potential participants, when it was explained the research objectives, inviting them to participate in the study. Therefore, those who accepted participating read and signed the Written Informed Consent Form (WICF). Then, the interviews were carried out, which were recorded in audio equipment. Each interview lasted an average of 40 minutes, inside homes, in order to ensure greater privacy. After collection, the interviews were transcribed in full and reorganized in a compatible way to the processing.

For analysis, one used the software IRAMUTEC (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*). Furthermore, the software used the lexical analysis for identification and reformulation of text units, which turn into Initial Context Units (ICU) and Elementary Context Units (ECU), which are identified by the number of words, average frequency and number of hapax (frequent words). The vocabulary research was done with the words being reduced, based on their roots (stemming), with the dictionary being created from the reduced forms and identified the active and supplementary forms.[8]

In this study, the following steps were used: 1) recording and transcription of the interviews, thus creating the corpus, which was placed in single file, following the precepts of IRAMUTEC; 2) The corpus was prepared after repeated readings, excluding information not aimed to achieve the objectives of the study. Then, it was made the decoding of the variables (subject, gender, occupation and origin); 3) analysis carried out by the software that generated the data and that will be described in this study: word cloud, Descending Hierarchical Classification (DHC) through the dendrogram and Factorial Analysis of Correspondence (FAC).

The study was registered in Brazil platform under the number of the Certificate of Presentation for Ethical Appraisal (CAAE): 68577017.1.0000.0003 and approved under opinion number: 2.108.232

RESULTS

In this study, the software recognized the separation of the corpus in

04 texts, although there were conducted five interviews. Therefore, one *text* was automatically deleted by the program itself, maybe due to the fragility of speech or excess of words.

The number of distinct forms was 754, with 3454 the number of occurrences. From the sample of different words, the software deemed important and analyzed 443 with a frequency equal to or greater than 3. Based upon the above data, the program used as a parameter to divide the corpus into text segments, classifying them according to their respective vocabularies. Thus, the corpus was divided into 82 segments of texts analyzed from a total of 102, which had a utilization level of 80.39% of the total of the study, which were designated in Descending Hierarchical Classification (CHD). The time the software spent for data generation was 16 seconds.

The results were presented in three aspects: word cloud, Descending Hierarchical Classification, through the dendrogram and Factorial Analysis of Correspondence (FAC).

As for the characterization of the participants, it can be easily seen in Table 1.

Table 1 - Characterization of the subjects involved in the research. Oiapoque, AP, Brazil, 2017

Subject	Gender	Age (Years)	Marital status	Place of birth	Religion	Profession	Kinship	Diagnosis time (Years)	Treatment time (Years)
subject 01	F	40	Married	Pará	Evangelical	Autonomous	Sister	16	5
subject 02	F	68	Stable union	Macapá	Catholic	Merchant	Mother	15	6
subject 03	F	54	Married	Minas Gerais	Evangelical	Home	Wife	29	28
subject 04	F	60	Widow	Oiapoque	Catholic	Retired	Mother	32	6
subject 05	F	59	Married	Macapá	Catholic	Retired	Mother	10	5

The word cloud groups and organizes the words graphically because of its frequency and, therefore, the simplest lexical analysis, however, generates a key and interesting graphic as enabling rapid identification of the key words of a corpus. Thus, this graphical analysis is generated from the interviews, highlighting the words that appear more over the speeches. In this study, the cloud was: (Figure 1).

Figure 1 – Word cloud, organized based on IRAMUTEQ software, Oiapoque, AP, Brazil, 2017

This denial can also be seen in the words of the interviewees:

But it´s been a long time she goes beyond the barriers of patience because you get to the point of exploding because the thing has gone over the top a lot, it makes you want to give up (Subject 03)

I do not know where one takes the strength of a schizophrenic, he has a terrible force, when he's mad like that I do not argue if I'm ordering and he does not want I do not insist you know? I leave him, I leave and then he comes (Subject 01)

From this very point, one can see that the word "stay" is highlighted, showing that the family tends to be obliged to take care of the patient with schizophrenia, since he needs constant care, which takes time and makes him to have careful attention. It makes the relative to be more present, not doing other activities in his daily routine life.

He was quiet was a healthy, strong boy he used to play, just had trouble to study in learning, look there are times that I, we get tired, right many years that I have to fight (Subject 01)

Until today he has a problem, he does not go out and we do not as well, right? He does not go out and when he goes out

it is because he has to go to CAPS to take the prescription (Subject 02)

What draws attention in the word "be," which also reflects this need for attention from the patient, which causes that connection between what can be expressed by another word such as "look", depicts the same impression in the previous words.

Then he is undergoing treatment with her, they give prescription for him right? I am the one who gives him the medications (Subject 04)

It is heavy only for me and I take care of me too because I have high blood pressure problems, I have diabetes and I take care of myself too, right? I have to take care of myself right? But I also have her to take care of (subject 05)

The word "medicine" appears in a secondary form, since the patient needs to take medication at a certain time, which creates a familiar routine with respect to this dosage, given that the patient does not have autonomy with regard to his drug administration routine, due to the limitations that his illness causes him in. This way, one may see that the family member tends to have a routine in which this activity tends to be redoubled.

The medicine is strong, look, when he takes it looks like he sleeps standing, sleeps sitting he has said to me (subject 02)

He still takes medicine as the doctor said that those who do not take that they can make something to themselves, they may even kill themselves (Subject 01)

I am who accompany her medicines [...] it is for that uneasiness, that agitation and at the same time it is soothing (Subject 03)

In the class organization of the perceptions of relative's schizophrenics, six semantic classes were revealed related to each other through the Descending Hierarchical Classification (Figure 2).

These classes were generated derived from the corpus processing by IRAMUTEQ software that provided full report and, after the reading and analysis in depth, based on the speeches of the interviewees.

Figure 2 - Descending Hierarchical Classification, organized based on IRAMUTEQ software, Oiapoque, AP, Brazil, 2017
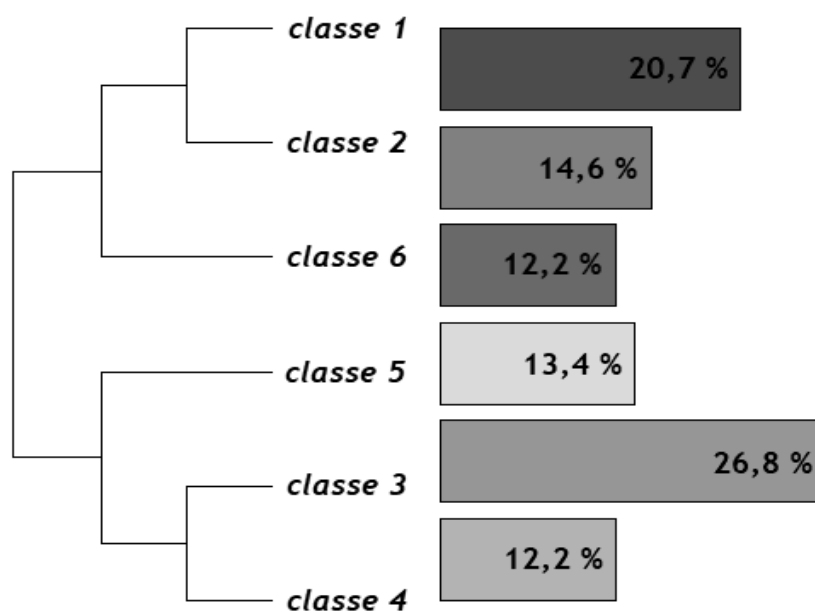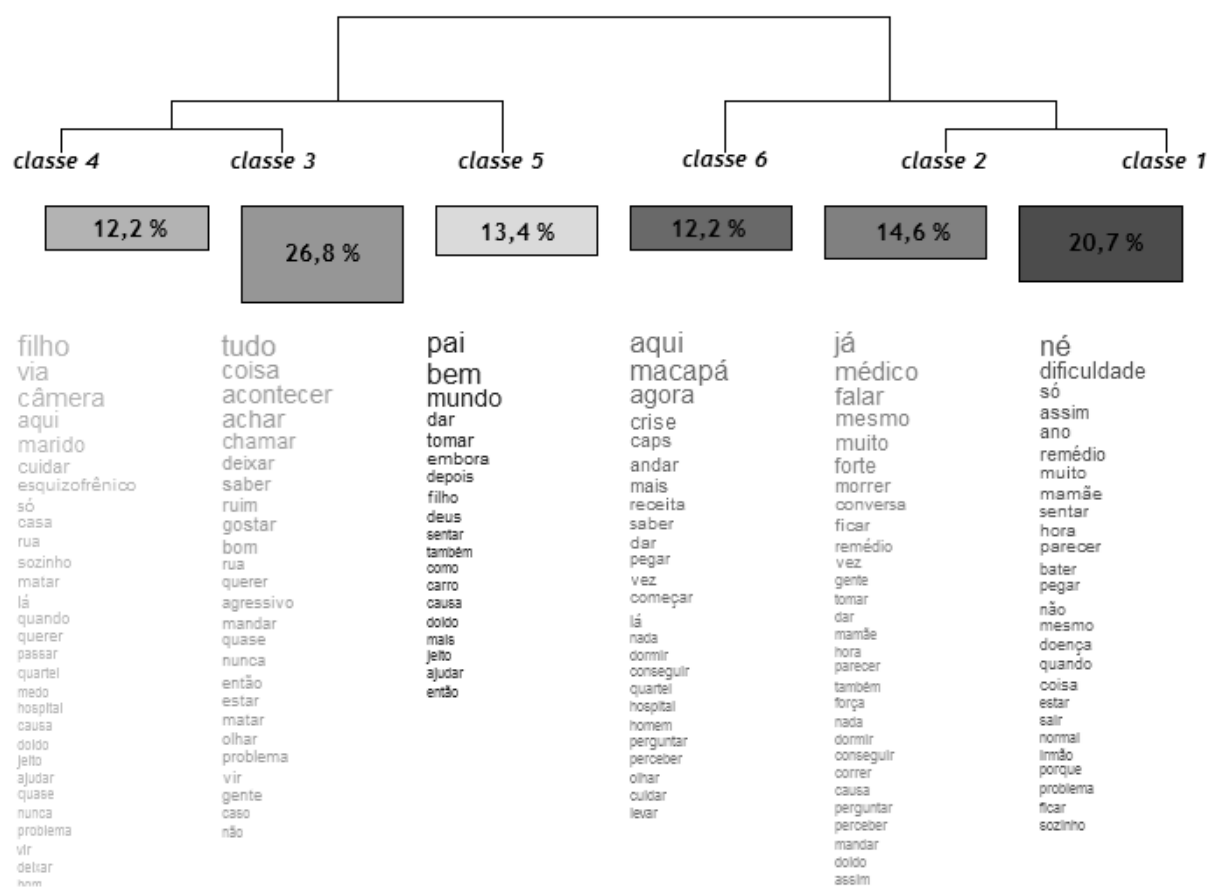

For the construction of the dendrogram (Figure 3) words with frequency equal to or greater than the average frequency were considered. Each class is described by the most significant words (more frequent) and by its respective associations with the class (chi-square).

Figure 3. Dendogram organized based on IRAMUTEQ software, Oiapoque, AP, Brazil, 2017

classe 4	classe 3	classe 5	classe 6	classe 2	classe 1
12,2 %	26,8 %	13,4 %	12,2 %	14,6 %	20,7 %

classe 4	classe 3	classe 5	classe 6	classe 2	classe 1
filho	tudo	pai	aqui	já	né
via	coisa	bem	macapá	médico	dificuldade
câmera	acontecer	mundo	agora	falar	só
aqui	achar	dar	crise	mesmo	assim
marido	chamar	tomar	caps	muito	ano
cuidar	deixar	embora	andar	forte	remédio
esquizofrênico	saber	depois	mais	morrer	muito
só	ruim	filho	receita	conversa	mamãe
casa	gostar	deus	saber	ficar	sentar
rua	bom	sentar	dar	remédio	hora
sozinho	querer	também	pegar	vez	parecer
matar	agressivo	como	vez	gente	bater
lá	mandar	carro	começar	tomar	pegar
quando	quase	causa	lá	dar	não
querer	nunca	doido	nada	mamãe	mesmo
passar	então	mais	dormir	hora	doença
quartel	estar	jeito	conseguir	parecer	quando
medo	matar	ajudar	quartel	também	coisa
hospital	olhar	então	hospital	força	estar
causa	problema		homem	nada	sair
doido	vir		perguntar	dormir	normal
jeito	gente		perceber	conseguir	irmão
ajudar	caso		olhar	correr	porque
quase	não		cuidar	causa	problema
nunca			levar	perguntar	ficar
problema				perceber	sozinho
vir				mandar	
deixar				doido	
bom				assim	

This dendrogram illustrates the partitions made in the corpus, to obtain the final classes. In performing reading from left to right, as recommended by the IRAMUTEQ, one identified that a priori there was a division of the main corpus with the emergence of two segments.

Next, one of the segments generated in the first step is subdivided again, giving rise to class 5. From the branch of the previous step, there was subdivision the branch, giving rise to classes 3 and 4.

When one observers the other segment of the corpus, it is clear that at a first time there was the formation of class 6, which is subdivided, appearing classes 1 and 2.

This way, the analyzable words were distributed in the six classes of this study, as follows: class 1, with 17 segments of text, corresponding to 20.7%; class 2, with 12 segments of text,

corresponding to 14.6%; Class 3, with 22 text segments, totaling 26.8%; Class 4, with 10 segments of text, scoring 12.2%; Class 5, with 11 text segments, corresponding to 13.4% and, finally, with Class 6, with 10 text segments, scoring 12.2%.

In performing the Factorial Analysis of Correspondence (FAC), IRAMUTEQ allowed visualization in the form of a factorial plane the oppositions resulting from the DHC, as shown in Figure 4.

Figure 4 - Factorial Analysis of Correspondence, organized based on IRAMUTEQ software, Oiapoque, AP, Brazil, 2017
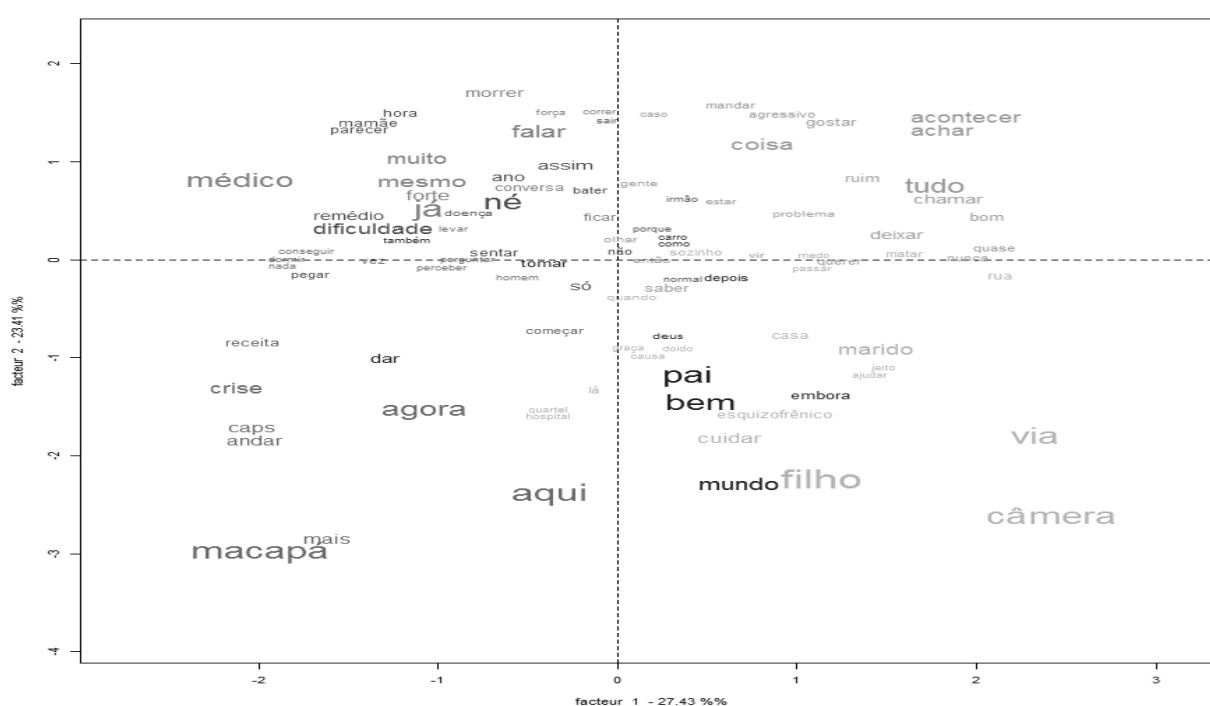
DISCUSSION

It can be seen from the data that the family members are female. Therefore, these are the women who exercise care act. Caring has its delineated path for survival of peoples.[9] Family is, therefore, a support bracket, embracement and love of the sick beloved one and it is necessary to understand his role, which is essential for the progress of treatment, so as to prevent the illness of family members involved in the act of caring.[10]

Regarding the figures, in the word cloud, the words are positioned at random in such a way that they frequently appear larger than the others, demonstrating their

prominence in the research analysis corpus.

For appropriate action, in this study, after the processing steps, the meanings of words in the speeches of the family were interpreted. Thus, the word "no" had the sense of negativity of the disease, which demonstrates a rejection by the family's relative with regard to the patient with schizophrenia.

In this sense, it is possible to say that in patients who are affected by schizophrenia or any other mental disease, a disruption of their normal activities occurs and some of them need to be performed by others, which leads to a serious rejection by the caregivers/relatives.[2]

Thus, it is up to the relatives to care for of the affected family member, promote contact between the patient and the existing health services; deal with crisis situations, deciding when the management is possible at home and when to seek emergency help. It is worth saying that adjustments should be made in the daily routine, so that this family member can continue to exercise his ordinary life activities, with less wear, improving both his own quality of life and the one who is cared.[11]

According to a researcher from this area, the relatives mentioned they are the ones that deal with the treatment most, in addition to medication, which is considered extremely important because, although the use of psychotropic drugs is essential to controlling the psychotic symptoms of schizophrenia, it is known that the use of strategies that combine medication and psychosocial interventions increases the possibility of recovery and can optimize the results. This way, it is up to the relative to deal with this medication routine, which generates a rejection by the relative to have this 'obligation'.

It is possible to see the word "also" appearing as a form of consent to the secondary research questions, since this tends to have a characterization of lack of arguments and question escape. Agreeing does not always undergo a matter of acceptance, but of submission to something previously stated. Therefore, one can see that the relative often uses the word 'also' in order to agree, giving leak to that inquiry made.

Comparing the findings of this research with other investigation one realized that the experiences, perceptions and feelings of family members who live with schizophrenics are varied. This study[13] concluded that caregivers have a

good relationship with the patient, although, they are unaware of the condition itself, which contributes significantly to the quality of life of patients with schizophrenia. It also states that it is necessary to recognize the family with a g weakened patient, who ignores the new reality and who adapts himself according to the needs arising, experiencing all stages, overcoming traumas and anxieties together with the beloved one, in the pursuit of his health.

Another finding showed that relatives feel anguish at diagnosis, conforming themselves with passing times, with some showing a hope of healing. In addition, the concern and care were common in the statements of the respondents. It further states that the live experiences with a family member with mental illness mark their lives in profound ways and that the family is the fundamental building block of human relationships.[14]

Another research has pointed narratives with experiences of guilt, repression of emotions, attachment to the past, that is, before the illness with an emphasis on healthy characteristics linked to guilt, emotional overload, besides marks, redefining the need for attention to people with mental disorders.[15]

Still comparing the findings of this research with previous ones, data were found showing that the relatives experienced conflicts permeated with anguish, uncertainty, fatigue, depression, so, seeking to reframe the existence from the feelings experienced.

The relatives realized living with schizophrenic family members as something uncomfortable, in which they had to abandon their own destiny, stating melancholy and sense of abandonment, causing the rejection of the beloved one. However, they live mixed feelings because, while they feel distressed by the disease, they are relieved to have them close and sharing joys and sorrows, causing them to seek ways to deal with the disease and mitigate the suffering.[16]

Other impacts generated in the lives of the relatives were: fearful situations, aggressiveness, fatigue, stress and worry resulting in physical and mental strain, as well as social and psychological damage that hinder family living with the beloved sick one. It also shows the family as a fundamental link in the support, embracement and rehabilitation of people with schizophrenia.[17]

Therefore, the family relationship becomes troubled, most of the time, as there are changes in routine, coupled with

the denial of the experienced situation. However, when the family assimilates diseases the interpersonal relationships tend to stabilize. Another fact that makes life difficult for families is prejudice, moving the family from social interaction established before, hampering the caregiver's social life.[18]

However, another study showed that feelings of respect, empathy and patience are paramount and essential between patient with schizophrenia and the caregiver, emphasizing communication as vital to the strengthening of the relationship built over time, highlighting the family as part of schizophrenia treatment.[19]

Finally, another research aimed to understand the burden of caring for schizophrenia from the perspective of the relatives found loneliness, anguish and fear in the care process that involves a family member, highlighting that professionals need to plan the therapeutic practice, giving importance to the feelings and weaknesses regarding the overburden of the process of caring.[20]

Therefore, the perception of the relatives about people with schizophrenia are varied, once permeated the need for an interactive relationship between the family and the sick one. In this sense, the health team needs to work this triad (patient-family-health team) more deeply and lasting.

In this aspect, the nursing stands out, playing a key role in mental health through a holistic view, having a wide knowledge with precipitates predisposing and perpetuating factors. It tends to perform care that covers the ethical, cultural, social and psychotherapeutic aspects, focused on the patient, family and community, working for the patient, respecting his needs, difficulties and uniqueness, valuing his citizenship.

CONCLUSION

The word "no" as meaning of refusal and negativity content was the most frequent being the IRAMUTEQ a valuable tool in pursuit of this vocabulary and, from that knowledge, the perception of those involved in this study, being surrounded by feelings of worthlessness, such as sadness, worry, fear and suffering, factors that hinder family life, as it is difficult to associate and understand the behaviors resulting from the disease.

With this study, it was possible to understand the importance of listening to reports of daily living of the relatives of schizophrenics, in which the relatives

interviewed were able to show their feelings and frustrations, through their suffering and impaired quality of life. However, they were welcomed, respected and valued. The relatives' perception is differentiated in relation to schizophrenia, but the concern with the care is the same.

IRAMUTEQ enabled a careful look from the material collected by quantifying the words presented most and allowing for greater empowerment around the qualitative research. It is highlighted the importance of further studies with this software that analyze various aspects in the material produced.

In short, this study proved to be important in order to enhance the speeches of the people who are directly involved in this care process. Although, it presents as limiting the isolation of the city, with lack of resources, essential services to the Psychosocial Care Network, being the negativity presented here about the disease something that might not be generalizable to other family members of other realities. Therefore, it is not a sufficiently large and representative sample, requiring further studies in different areas of the country. However, it points out a potential to be a pioneer in the study of mental health in the Brazilian frontier region on this subject, being a remote area with less access to medical resources and health care, then providing information about the feelings and perceptions of stress situations experienced by the relatives of people with schizophrenia.

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