



Expressions used by family members to share experiences of living with mental illness*

Expressões utilizadas por familiares ao relatarem experiências de conviver com o adoecimento mental

Expresiones utilizadas por familiares al relatar experiencias de convivir con la enfermedad mental

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ABSTRACT

Objective: To identify the expressions used by families to describe the experience of living with mental illness. **Methods:** This research analysis of the accounts of family members is conducted using the *software, Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte* (ALCESTE), which contains methodology for analyzing qualitative data that is adapted to any area of research in which text-based material is to be reviewed. **Results:** The analysis provided by ALCESTE formed four classes grouped two by two: Class 2 - onset of illness, and Class 4 - start of treatment, Class 1 - living, and Class 3 - everyday. **Conclusion:** The moments described by family members were identified by expressions, words and terms used in their narrations. The principle contribution of this study was to bring the language of families used to describe the moments of illness through a methodology of analysis that is more distant from the researcher.

Keywords: Family/psychology; Schizophrenia/nursing; Psychiatric nursing; Interviews as topic

RESUMO

Objetivo: Identificar as expressões usadas por familiares para descrever a experiência de conviver com o adoecimento mental. **Métodos:** Trata-se de pesquisa que realizou análise dos relatos de familiares por meio do *software Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte* (ALCESTE), contendo metodologia de análise de dados qualitativos que se adapta a qualquer domínio de investigação, em que se pretenda tratar material textual. **Resultados:** A análise realizada pelo ALCESTE forneceu quatro classes agrupadas duas a duas: Classe 2 -- início da doença e Classe 4 -- início do tratamento; Classe 1 -- convivência e Classe 3 -- cotidiano. **Conclusão:** Os momentos descritos pelos familiares foram identificados por expressões, palavras e termos usados pelos mesmos em suas narrações. A principal contribuição deste estudo foi trazer a linguagem dos familiares para descrever os momentos do adoecimento por meio de uma metodologia de análise mais distante do pesquisador.

Descritores: Família/psicologia; Esquizofrenia/enfermagem; Enfermagem psiquiátrica; Entrevistas como assunto

RESUMEN

Objetivo: Identificar las expresiones usadas por familiares para describir la experiencia de convivir con la enfermedad mental. **Métodos:** Se trata de una investigación realizada con el análisis de los relatos de familiares por medio del *software Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte* (ALCESTE), utilizando metodología de análisis de datos cualitativos que se adapta a cualquier dominio de investigación, en la que se pretenda tratar material textual. **Resultados:** El análisis realizado por el ALCESTE proporcionó cuatro clases agrupadas de dos en dos: Clase 2 -- inicio de la enfermedad y Clase 4 -- inicio del tratamiento; Clase 1 -- convivencia y Clase 3 -- cotidiano. **Conclusión:** Los momentos descritos por los familiares fueron identificados por expresiones, palabras y términos usados por los mismos en sus narraciones. La principal contribución de este estudio fue traer el lenguaje de los familiares para describir los momentos de la enfermedad por medio de una metodología de análisis más distante del investigador.

Descritores: Familia/psicología; Esquizofrenia/enfermería; Enfermería psiquiátrica; Entrevistas como asunto

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INTRODUCTION

Schizophrenia is a chronic mental disorder that affects both patients and their relatives. Patients may be so incapacitated that they experience serious hindrances in their responses to the demands of everyday life and reality. Patients are particularly vulnerable to stressful situations, and they exhibit an increased risk of suicide⁽¹⁾. The experience of having a schizophrenic family member has been compared to a journey through a storm⁽²⁾.

A visit to the doctor is necessary when the behavior of the affected individual worsens. Upon entering the mental healthcare system, the family has to learn a new language – the language spoken by health caregivers. For the illness to be understood and treated, the conventional common sense of the family must be adjusted to this new language.

The language of illness includes a lexicon of words and notions shared by patients and professionals, and it must enable both parties to understand one another. Families learn new words and notions as they construct their history and experience with mental illness⁽³⁾.

One study⁽⁴⁾ sought to understand the meaning of care for parents of children who had been diagnosed with schizophrenia in a therapeutic community. A hermeneutic phenomenological approach was used to interpret the meaning of the experiences that were narrated in transcribed interviews. Eight relatives of six patients were interviewed, and five themes were identified: 1) *Living with sadness, anguish and constant worrying*: when parents have difficulties identifying the symptoms of the disease, they consider uncommon behaviors to be representative of typical adolescence, and the establishment of a diagnosis is reported as a shock; 2) *Living with guilt and shame*: parents feel guilty about the disease, and they feel ashamed for their child's odd behavior; 3) *Relationship with nurses/caregivers, comfort and difficulties*: the nurses did not exhibit an interest in sharing information or cooperating with the parents; however, the nurses cared well for the patients; 4) *Coping with difficulties*: accepting the disease and hoping for a better life for their child were useful tools for facing difficulties; 5) *Hope for a better life for their child*: the narratives noted hope as the power that sustained the search for resources that would improve their child's life, and relatives explicitly strove to keep hope alive.

Studies on the family's experience of mental illness contribute to the understanding of the suffering that is inherent in the experience and in the strategies developed by families to cope with it.

AIM

The aim of this study was to identify the expressions used by relatives to describe their everyday experiences with mental illness.

METHODS

This study describes the lexicon used by relatives to describe their everyday experiences with mental illness at the following moments: the onset of the disease, the onset of treatment, their lives together and their everyday lives. The analysis of the relatives' narratives was performed with the software *Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte* (ALCESTE, Lexical Analysis of a Set of Text Fragments by Context), which comprises a large number of statistical tests to analyze textual data. With a calculus foundation, the software considers rules of vocabulary distribution to perform a lexical analysis of words in a set of texts, independently from their source of production⁽⁵⁻⁷⁾.

ALCESTE is a method of qualitative data analysis that can be adapted to any research domain involving textual analysis, especially regarding lexical composition and thematic structure⁽⁶⁾.

In this study, the textual material was derived from 24 interviews with relatives of schizophrenic patients. The interviews were collected in the context of the following research projects: "Family adaptation during the first five years after the diagnosis of schizophrenia", which was approved by the Research Ethics Committee of the Clinics Hospital of the Ribeirão Preto Faculty of Medicine (HCRP), University of São Paulo (USP), Protocol HCRP n° 9800/2007; "Family adaptation after the initial impact of the first five years after the diagnosis of schizophrenia", which was funded by FAPESP (Fundação de Amparo à Pesquisa do Estado de São Paulo/São Paulo Science Foundation) and approved by the Research Ethics Committee of the Teaching Healthcare Center of the HCRP, USP, Protocol HCRP n° 230/2007; and "Redefining family identity: trajectories of families after the diagnosis of schizophrenia", which was funded by FAPESP and approved by the Research Ethics Committee of the Clinics Hospital of the HCRP, USP, protocol HCRP n° 9801/2007.

The textual material was prepared as prescribed by the software ALCESTE. Each interview was defined as an initial context unit (ICU), and the software analyzed 24 ICUs. The preparation of the material required the identification of a set of variables at the onset of each ICU. The variables included the age and sex of the patient and the participating relative, the duration of the disease and the relative's relationship with the patient. This set of variables became a *corpus* of analysis, which is considered a textual set that is centered on a given theme. This study established the *experience of caring* among relatives who live with a schizophrenic family member as its theme.

ALCESTE analyzes data in four stages⁽⁵⁻⁷⁾:

Stage A – The software recognizes the ICUs and splits them in equal-size text parts called "elementary

context units” (ECUs); the software groups occurrences of words together according to their roots and calculates the frequencies of these reduced forms.

Stage B – The matrices of the data are calculated, and the ECUs are classified. The set of ECUs is distributed as a function of the frequency of the suggested forms. The application of a descending hierarchical classification method results in a definitive classification.

Stage C – The software displays the Dendrogram of Descendent Hierarchical Classification, which indicates the relationships between the classes and supplies the elements that describe each class according to their characteristic lexica and the variables in the command-line.

Stage D – Continuing from the previous stage, the software selects the most characteristic ECUs in each class, which allows for the contextualization of the most significant lexica for each class.

This study was submitted to the Research Ethics Committee of the Ribeirão Preto School of Nursing – University of São Paulo. Informed consent was waived because the interviews had been previously approved by the Ethics Committee and were completed after informed consent had been granted. Therefore, further informed consent was not needed to analyze the interviews.

RESULTS

Operation A1 (*corpus* reading) supplied the number of lines that had been denoted with an asterisk (24). The software divided the *corpus* into 24 ICUs, or interviews.

Operation B1 selected the ECUs, or text fragments, and calculated the data; the words were reduced to their roots, which resulted in 1,193 analyzable words (with a frequency that was equal to or greater than four), 221 tool words and 42 variable words (with asterisk). The 1,193 analyzable words occurred 41,385 times.

Operation C1 (intersection among classes) divided the *corpus* into 1,507 ECUs, from which 1,045 (69.3% of the total) were attributed to one class in two descendent hierarchical classifications (DHC) with different-sized ECUs.

The four classes that were generated by the Descendent Hierarchical Classification (Figure 1) encompassed specific semantic contexts; each semantic context was labeled with a heading, and the name of the *corpus* was defined as “caring experience”. The classes were grouped in pairs that corresponded to four different moments: Class 1: Life together, Class 2: Onset of disease, Class 3: Everyday life and Class 4: Onset of treatment. Class 1 is related to Class 3, and Class 2 is related to Class 4, as they refer to complementary moments.

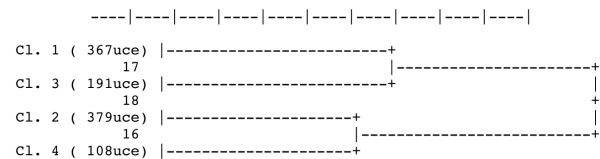


Figure 1: Descendent Hierarchical Classification – Dendrogram of Stable Classes.

Words and terms appeared in the sequences of the groups of classes (DHC) according to the trajectories reported by the relatives. In Class 2 (Onset of disease), the following terms were used: “*the disease began*”, “*(he/she) fell ill*”, “*illness*”, “*history of disease*”, “*odd behaviors since childhood*” and “*before the disease*”. The following terms in Class 4 (Onset of treatment) were used: “*(he/she) changed*”, “*hospitalizations*”, “*hospital discharge*”, “*hospital*”, “*treatment*”, “*neurologist*”, “*doctor*”, “*remedy*”, “*day-hospital*” and “*primary care center*”. For Class 1 (Life together), the software grouped “*happy*”, “*difficult*”, “*future*”, “*hope*” and “*schizophrenia*”, and for Class 3 (Everyday life), it grouped “*care*”, “*alone*”, “*now we understand better*”, “*concern*” and “*the patient only talks to me*”.

DISCUSSION

The information reported by relatives and represented by the words in Class 2 (Onset of disease) indicate a variety of facts related to the onset of the disease and a variety of altered behaviors, such as with sensorial perception, emotions, thought, communication and one’s relationship with oneself and with other people.

The onset of the disease was represented by two different narratives. According to one, the relatives described patients as quiet, isolated since childhood and with few friends, but they thought these behaviors were common in children or reflected traits of the patients. According to the other narrative, patients changed their behaviors, became more irritated and nervous, began to isolate themselves, began locking themselves inside their bedrooms, slept too much or not at all and became aggressive.

In one study, the parents narrated the history before the disease with sadness, as their children had been happy and had had many friends, but they started to isolate themselves after the disease⁽⁴⁾. According to another study, the initial changes in the patients’ behaviors were described as alterations in their mood and relationships⁽⁸⁾.

Aggressiveness was a significant phenomenon in this study. Relatives mentioned that patients were quarrelsome and eventually hit them or strangers; sometimes it was necessary to call the police to control the situation. Some patients were unable to remember

how they had behaved after the fights. Others wept and asked to be forgiven for the aggressive behavior that they were unable to control.

Some studies have reported about parents who were assaulted by their children. Violent behavior was quite frequent and was directed against property, relatives or the patients themselves. Episodes of crises, even when nonviolent, were traumatizing. Not surprisingly, the parents reported high levels of stress because of feelings of frustration, powerlessness and low self-esteem ⁽²⁻⁹⁾.

Another study found that the two main symptoms reported by relatives were isolation and aggressiveness. Families start wondering whether there is something wrong with the patient only when social isolation intensifies and patients' aggressive responses to simple questions increase ⁽⁸⁾.

In the study by Mohr and Regan-Kubinski ⁽¹⁰⁾, the parents reported that there was one particular moment when they started to realize that something was not well with their child. They described that particular moment as the beginning of a nightmare. Muhlbauer ⁽²⁾ reported the process of living with mental illness as a journey through a storm. At the beginning of the journey, the family saw the onset of a storm in the patient's change of behavior.

The family finds itself within a critical situation; the exacerbation of the patient's behavior triggers a discussion on whether it is a developmental stage or mental illness. Thus, the family starts seeking professional counsel to try to understand the problem.

Hospitalization was the primary measure that was adopted to start treatment and to change medication. In some cases, hospitalization was non-voluntary and was performed at the emergency care level. Patients became aggressive and nervous because they did not want to be admitted to the hospital, and sometimes the police had to be called.

This fact was evident in one study ⁽¹¹⁾ in which acute schizophrenia episodes led to families' frequent visits to the healthcare system; at times, these visits culminated in the first hospital admission, and in others, it was the beginning of pharmacological treatment. In some cases, the prescribed medication was refused by patients, and in others, the medication did not help.

After being introduced to healthcare service, the family must face another problem: they must understand what the problem is with their loved one. The family must learn about mental illness and its treatment in a new language. At that moment, the relatives try to make their language and knowledge converge with the healthcare professionals, and they attempt to learn the words and notions that the healthcare professionals use to explain the disease ⁽³⁾.

The words in Class 4 (Onset of treatment) represent the family's learning process. The family describes the trajectory that it experienced with the patient, the visits to the many services and healthcare professionals, the difficulties adapting to medications, the need for hospitalization during crises or to adjust medication and the patient's refusal to comply with the prescribed pharmacological treatment.

Many authors have reported that the care for patients with schizophrenia should be a combination of medication and a holistic approach, such as socio- and psychotherapy, which should also be offered to family members ⁽¹²⁻¹⁶⁾. However, only the medication approach was reported by the families in these studies, indicating that medication is important for controlling symptoms. Even in instances when patients are undergoing psychosocial rehabilitation, both relatives and patients believe the process is only possible because of medication.

In the last three decades, the psychiatric reform movement achieved profound changes in the approach to psychiatric assistance. The hospital- and doctor-centered model was replaced by a comprehensive community-based network of services. However, the community-based approach has not fully fulfilled its goals ⁽¹⁷⁾.

This movement seeks to transform the notion of mental illness and to build a network of novel services, such as spaces for sociability, exchange and the production of subjectivity. These services are meant to be more than an alternative; they are meant to replace the traditional therapeutic model to provide a better quality of life for the mentally ill ⁽¹⁸⁾.

One study found that the medications most frequently used by patients are second-generation antipsychotic agents, which are effective at suppressing both the positive and negative symptoms of schizophrenia and can reduce its cognitive alterations. Antipsychotic agents are associated with a very low incidence of extrapyramidal adverse effects. Therefore, they represent a drug alternative that affords a better quality of life for patients ⁽¹⁶⁾.

Another study observed that together with the onset of treatment, the improvement of symptoms and knowledge of the disease, the family subjects the patient to indirect supervision. The family experiences constant tension between overprotectiveness and stimulating a higher degree of independence in the patient. Overprotection results from families' continued fear of relapses and with them, the stormy acute episodes ⁽²⁾.

When medication is adjusted, patients improve and begin to perform activities they had forsaken as a consequence of the disease. This improvement raises the hope ⁽³⁾ of a return to normal life.

Classes 1 and 3 represent the family's progress in learning how to live with the patient and the ongoing family situation. The words in Class 1 indicate the difficulty the family has in coping with the disease, its symptoms and the associated problems they must face. However, after some years of living together, the relatives learn to recognize when the patient is not well, and the understanding and acceptance of the disease make life together easier. For these reasons, some families become happier over time.

Relatives ponder and compare the onset of the disease to the present moment. They report that they needed more information in the beginning and that if they had had this information earlier, their lives might have involved less suffering. However, time allows for better understanding and acceptance of the disease, and the role of health caregivers, such as nurses in terms of education, is crucial for improving families' everyday lives. While the present moment remains difficult, the relatives report that it is much better than the past; they indicate that the family is now more united and understands the disease better than before, which makes everyday life easier. Some relatives state that despite the problems they have to face, they are happier now than at the onset of the disease.

Some studies have shown that the search for knowledge and the process of learning about the patient's disease makes families learn to characterize the signs and symptoms of the disease. Thus, they succeed in organizing tasks and duties by rearranging the functional operation of the family ^(2,9,19).

Relatives' search for information about schizophrenia occurs frequently and is said to be necessary for their ability to cope with the disease. They want to know more about the disease, and they want to better understand what the family is going through. One study observed that the recognition and acceptance of the disease makes all of the difference; treatment is understood as necessary and essential for improving the quality of life for patients and their relatives ⁽²⁰⁾.

Nurses and other health caregivers can reduce the negative consequences of schizophrenia for patients and relatives, as they can provide information and education about the disease. Education enhances the family's understanding and provides realistic expectations about schizophrenia and the patient, which leads the family to provide better care ⁽²¹⁾.

Some relatives in this study reported feeling tired. As they had distanced themselves from friends and other relatives and had experienced much trouble, they did not want to talk about the subject. They attributed their own illness and difficulties addressing problems to their relative's disease.

A study of schizophrenic patients' relatives pointed to three types of family overload: financial, daily routine and physical or emotional illness. Furthermore, their leisure activities and social relationships were changed ⁽²²⁾.

The hope for a cure motivates the family to fight their ill family member's disease; this hope can be a working tool that helps the family move forward. Later, the relatives realize that a cure might never happen, but this does not hinder them from wishing for the best possible quality of life for the patient ⁽²³⁾. Acceptance of the disease and hope for a better quality of life for the patients proved to be useful for overcoming difficulties ⁽⁴⁾.

Suffering and insecurity are constant throughout the stages of treatment and perspectives about the future. Relatives, especially older ones, express concern about how the patients would survive if they became disabled, were unable to provide care or died ^(2,24). Issues related to the future, such as who would be in charge of the patient, are a source of concern for relatives ⁽²⁵⁾.

The words selected in Class 3 (Everyday life) show that the relatives are also worry when they have to leave the patient alone; they worry about something happening or the patient needing to take medication. Therefore, they organize their everyday lives to ensure supervised care and to never leave the patient home alone. Most caregivers are mothers who report that patients are currently able to help at home and that their social relationships are intimately linked to the patients. Mothers and caregivers report that the patients talk the most with their mothers, who devote considerable time to their care.

Fear and insecurity induce the relatives to provide supervised care, assert control and assume responsibility for helping and protecting the patient in an attempt to avoid relapses. Therefore, they supervise medication, avoid leaving patients home alone, constantly observe patients' behavior and try to control patients' routines ⁽²⁶⁾.

The negative symptoms of schizophrenia, such as emotional dullness, apathy, anhedonia and social isolation, lead to relatives constantly stimulating the patients to do something. Relatives tell the patients that they cannot sleep and stay at home doing nothing. Although the family may understand the disease better than they once did, this type of behavior makes everyday life difficult.

Life with a mentally ill individual poses serious difficulties for families. For example, families must cope with the difficulties of everyday tasks, household disorganization, a reduction of the family income, exhaustion, family tension and relationship conflicts ⁽²⁷⁾.

The concern for patients' wellbeing might be constant for families that are consistently making decisions

to provide them with relief. Care seems to constitute the essence of mutual relationships in the context of everyday life, and it is considered to be a priority that is more important than any other matter in life ⁽²⁴⁾.

The relatives in charge of the patient's care are concerned with and pay special attention to the proper administration of medication, and they assume the responsibility of complying with the schedule and doses of drugs; these relatives fear that patients who are left to themselves will make improper use of the drugs and may risk their lives ⁽²⁷⁾.

Mental illness affects the family life and the emotional atmosphere, and it creates tension and anxiety related to family duties, which results in damaging effects on family functioning and dynamics. The family becomes fragile, and its internal and external relationships become seriously impaired. However, the family also emerges as a place of warmth, affection and care, even despite the contradictory feelings and frustrations that are inherent to the objective and subjective duties. The family reflects on its motivation, lifestyle and pre-established values before the disease. Life is observed from another perspective, and many values acquire new meaning ⁽²⁴⁾.

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CONCLUSION

The moments described by relatives were identified through the expressions, words and terms they used in their narratives. The main contribution of this study is to bring attention to relatives' language that alludes to their experiences with the illness using an analysis method far from the subjective perceptions of the investigator.

The results show that the family begins by noticing changes in the patient's behavior, and they seek professional counsel that leads to pharmacological treatment. After adjusting to the medication, patients improve, and the family starts fearing that they will not take the medication properly. The family then offers supervised care, sometimes preventing the patients from going out or being home alone. These tendencies that are awakened by the onset of the disease become incorporated into the family's routine.

The need for information, especially at the onset of the disease, manifested patently in this study. The relatives reported that better knowledge about schizophrenia and its consequences helps their understanding and acceptance of the disease, which ultimately helps them cope with the patient and the disease.

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