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GRUPO DE SUPORTE À FAMÍLIA DA PESSOA COM DOENÇA MENTAL GRAVE: ESPAÇO DE PARTILHA NA ADVERSIDADE

GROUP OF SUPPORT TO THE FAMILY OF RELATIVES OF PATIENTS WITH SEVERE MENTAL ILLNESS: SPACE OF SHARING IN ADVERSITY

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RESUMEN | Objetivo: compreender as condições e contexto que levam os familiares de doentes com doença mental grave a participarem no grupo de suporte num Hospital Psiquiátrico. **Método:** Estudo qualitativo, segundo *Grounded Theory*. Participantes-familiares de doentes que frequentam o Hospital de dia. **Procedimentos:** sessões de grupo áudio-gravadas, entrevistas a membros da equipa de saúde, questionário aos familiares, notas de campo de incidentes críticos. **Resultados:** as condições e contexto que fazem com que os familiares se reúnam no grupo de suporte é a aliança na adversidade devido ao estigma da doença mental que devasta a vida das pessoas doentes e suas famílias em todas as dimensões do seu quotidiano pelo que o grupo de suporte constitui um porto de abrigo. **Conclusão:** no grupo os familiares partilham aprendizagens, estratégias e aprendem a gerir o quotidiano incerto. Esta é uma estratégia relevante para melhorar o cuidado profissional que é dado as pessoas com doença mental grave e seus familiares em casa.

Palavras-chave: Cuidador familiar; doença mental grave; grupo de suporte

ABSTRACT | Objective: to understand the conditions and context that lead the relatives of patients with severe mental illness to participate in the support group in a Psychiatric Hospital. **Method:** Qualitative study, according to Grounded Theory. Participants - family members of patients attending day hospital. **Procedures:** audio-taped group meetings, interviews with members of the health team, family members' questionnaire, critical incident field notes. **Results:** The conditions and context that make the family members in the support group is the alliance in adversity due to the stigma of mental illness that devastates the lives of sick people and their families in all dimensions of their daily lives, so the group is a shelter. **Conclusion:** in the group the family members share learning, strategies and learn to manage uncertainty in everyday life. This is a relevant strategy to improve the professional care given to the people with severe mental illness and their families at home.

Keywords: Caregivers; Mental Disorders; Support group

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INTRODUCTION

The advances made in psychiatry in the treatment of people with mental illnesses have allowed, in the last fifty years, for a decrease in the number and duration of internments, by allowing the ill person to be closer to the community and their family. The latter has been gaining a greater importance and being considered a relevant resource in the rehabilitation of people with Severe Mental Illness (SMI), given the scarcity or even absence of other support structures (Gonçalves-Pereira et al, 2012).

Family is a fundamental partner in the assistance and support of its members when one of them suffers from a SMI. This is defined as a situation that due to its characteristics and progress of the clinical picture, affects in a prolonged and continuous way the person and their family work (Kuipers, Leff, & Lam, 2006). The health-illness transition experienced by family can lead to greater dysfunctionality and vulnerability (Meleis, 2010). The family must know in advance the difficulties it will face with the diagnosis of a SMI in one of its members, for which they need professional help. This transition will be gruelling and time-consuming, whether due to the stigma associated with it or the complex and difficult management of the behaviours of the ill person in their daily lives.

The life of a person with a SMI is one of extreme suffering as well as that of their family, which change their whole dynamic in a way that is not always healthy. It is therefore necessary to find intervention strategies that allow, from the start, for the follow-up, support and guidance of these families, where the psychosocial interventions have proven useful, namely through support groups (Gonçalves-Pereira et al, 2012; Torres Lima & Guerra 2014).

The diagnosis of a severe mental illness creates a situation of increased vulnerability in the midst of a family, for there are factors they have no control over, be they of endogenous, social or environmental origin. The family members of patients with SMI live, in their private lives, with a family member whose behaviours they do not understand which escape their control and make them fear for themselves and for the afflicted person. As such, the family is exposed to living in a stressful environment prolonged by the unpredictable reactions which are triggered by factors it does not understand, such as a lack of cooperation in treatment. Family and friends are avoided in order to abstain from fleshing out a diagnosis which is denied. Although the hope for improvement is always maintained, the continuous setbacks are slow in showing any sign which can provide them with optimism (Levy-Frank, Hasson-Ohayon, Kravetz, & Roe, 2011).

According to the National Commission for the Restructuring of Mental Health Services (2007-2016), whatever form the professionals' intervention takes the relationship with family members is essential. This requires a good inter-relationship with the patients, family members and professionals, who must adopt a systematic attitude based on attention, understanding, availability, posture capable of stimulating communication and consolidating an empathic alliance, trustworthiness, mutual respect, hopefulness and an interlinking of goals between professionals, ill person and family caregiver. The objective is to promote a group environment through which family members can support each other. Instilling hope is a necessary ingredient in psychotherapy. It is important for therapists to directly reinforce the potential of a group approach and to emphasise the positive results that the participation in support groups confirm (Figueiredo & Charepe, 2010).

Many other therapeutic interventions are certainly utilised when nurses and other elements of the team seek to aid the ill to deal with the transition that comes from dealing with a SMI. These situations demand a healthcare service intervention, particularly in regards to Nursing for, according to Meleis (2010), such transitions if not supported, might generate further dysfunctions which will lead to new illnesses. The power of families is not the same as that of the technical staff, being much more impactful. The power of family associations é one of a kind, and irreplaceable. Family and institutional objectives must coincide and be guided in the perspective of what is best for the ill person.

According to the plan for restructuring the Mental Health services (2007-2016), the family members of people with SMIs must be considered essential in providing care for mental health. This is because the presence of family members is considered in the treatment provides comfort and tranquillity to both, helping keep the ill person within their family.

However, in the growing accountability of families of people with SMI there is a bigger picture in which they lack basic information or skill training which will allow them to care for their family member with SMI. Without these competences, caregiving turns into an overload that they might not be able to handle adequately, eventually compromising their own health (Nirmala, Vranda & Reddy, 2011).

If many of the difficulties of these families are well known, the survival dynamic which is adopted and the learning which occur from their experiential knowledge are still enigmatic. Besides, if there is research on psycho-educative interventions, the same does not happen in relation to support group interventions with a less formal working system which is adjusted to the possibilities of the healthcare organizations. It is therefore important to stimulate, bring into the spotlight and to support the activities that they carry out, so that they start to take place in a more organized, systematic and efficient manner (Grácio, Gonçalves-Pereira & Leff, 2016).

As such, in a Psychiatric Hospital in Lisbon (CHPL) a support group with a work methodology has been created, with two sessions per month, focused on the support and guidance of family members of people with SMI. Evidence in other similar realities suggests efficiency in this kind of intervention for the family members of ill people (Grácio, Gonçalves-Pereira, & Leff, 2015; McFarlane, 2016).

This article aims at allowing us to understand which are the conditions and context that make family members of people with SMI participate in the CHPL support group.

METHODOLOGY

Qualitative study, according to Strauss and Corbin's grounded theory (1998). The participants were the family members of patients with SMI (24), which attended the Lisbon's Psychiatric Hospital support group. We chose this approach as it was our intention to understand he ways of thinking, feeling and acting of the family caregivers for people with SMI when faced with their daily difficulties. In particular, we aimed at understanding the situation that led the family members of people with SMI to participate in CHPL's support group, which implied answering the questions: What? How? Where? Why? (Strauss and Corbin, 1998).

Data collection instruments

Data has been collected between March of 213 and March of 2015 through the non-participative observation of 12 support group sessions, documented through audio recording, field notes relative to each group session including the conviviality periods and open questions questionnaires (24) to each of the group's participants. To identify the participants, numbers and letters were used. In the coding of the recorded audio sessions the abbreviation RG was used, following the respective numbering and in the coding of questionnaires the abbreviation RI was used, following the respective numbering. Two in-depth interviews to the group's facilitator were also audio recorded, along with two informal interviews to the psychologist, due to her being the member of the healthcare team that had the most regular presence, in order to clarify aspects relative to the dynamic of the group. The analysis of all this data was undertaken through the method of constant comparisons.

Context of the study

The support group takes place at the CHPL since 2009, where it began at the Day Hospital. In 2014 the group switched over to the Psychiatric Clinic V service – with no changes regarding the group's guidance philosophy having occurred, which still takes place to this day. The support group gathers twice per month, from 13h30m to 15h30m.

The healthcare team includes the nurse specialized in mental health, which coordinates the sessions, a psychologist, and more irregularly a psychiatrist and a social worker. The entire healthcare team keeps a discreet profile and very limited intervention. The duration of each family member's place in the group is unlimited. There was an average attendance of 7 family members per session.

Ethical principles

The project was approved by the Ethics Board of the institution where this intervention takes place. Every family member was given information regarding the study and their rights. They gave informed consent to participate, accepting, in writing, the presence of a researcher in the group session as well as audio recording.

The healthcare staff and the Administration of CHPL have authorized the identification of the service and institution where this study took place.

Data analysis

We made use of the principles of Grounded theory (Strauss & Corbin, 1998), with the data analysis having been characterized by the constant comparison of similarities and differences regarding what was observed and said by the participants, in other words, between the codes and the categories, allowing the researchers to carry out what is called a theoretical sampling. This is directed by the data analysis, guiding the researcher in the process of sampling selection and gathering of relevant data in order to create and refine the categories.

The questions guiding the data collection and analysis were the following:

What meaning did the family members of patients with SMI attribute to the process of being in the group?
What makes them stay in the group? And how do they express it?
Why are they in the group? And what do they emphasise in it?

The coding process encompassed three levels: open, axial and selective coding (Strauss & Corbin, 1998).

Open coding is considered the first level of coding and is undertaken as the researcher collects the data. It consists in coding each sentence, using as many codes as necessary, in order to assure a thorough analysis of the transmitted information. The researcher will try to bring out the concepts implicit in the data in order to build the categories, their qualities and dimensions, as is illustrated in the following figure.

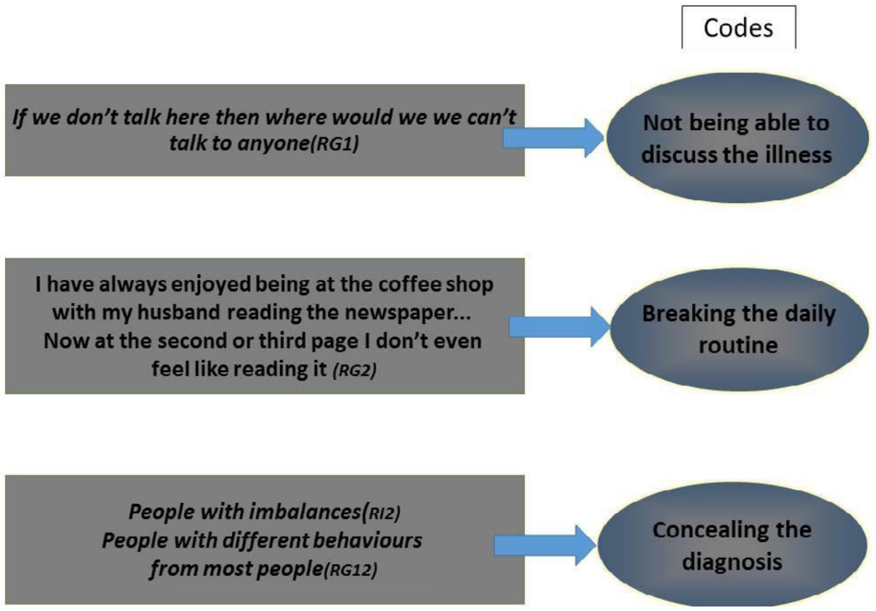

Figure 1. Open Coding diagram (Source: the authors)

Axial coding is the second level of coding and consists in identifying the substantive codes, names as such due to containing the substance of data, which are constantly compared and grouped, in according to a logical orientation, aiming at identifying categories and sub-categories and relate them, based on their properties and dimensions. Thus, we identified categories and subcategories, grouped them and categorized them in ever more abstract terms, aiming at formulating explanations regarding the phenomenon based on the answers to the questions: What makes the family members go to the support group? (What?); Faced with that situation, how do they act? (How?); Where do they do it? (Where?); Why do they do it? (Why?), as is illustrated in the following figure.

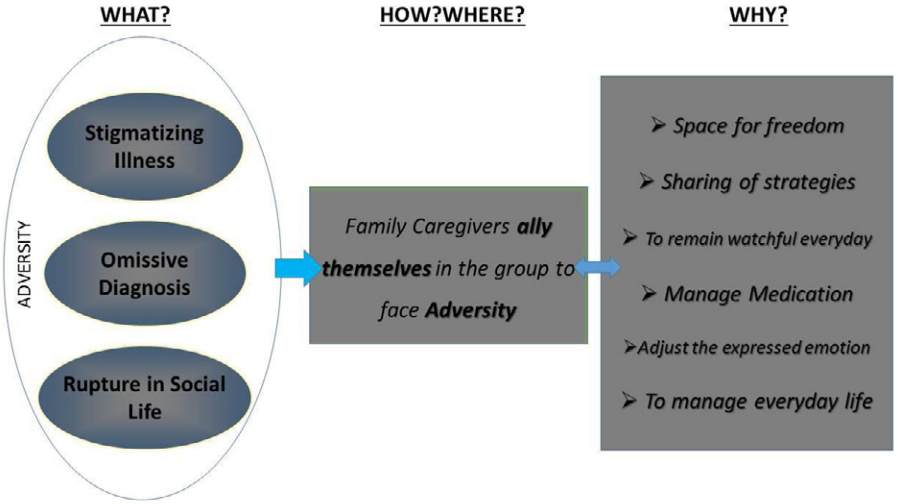

Figure 2. Diagram of a stage of axial coding (Source: the authors)

Selective coding is the third level of coding and consists on the integration of categories in order to build the theoretical structures, in other words, the central category around which the other categories will regroup and integrate (Strauss & Corbin, 1998). As such, coding and the utilisation of analytical memos (descriptions by the researcher as the data analysis is processed and that reveal thoughts, interpretations that lead towards new questions and directions in data collections) allowed to manage the concepts, integrate the categories, aiming at the saturation of each of them and the surfacing of the central category which resulted in alliance in adversity, allowing the creation of the explanatory theoretical structure of the process in study, as is explained in the results chapter.

The validity of the findings was undertaken by three elements of the healthcare team, but mostly we mobilised the researchers' reflexivity on the data, with the writing of memos being a very useful used methodological strategy (De La Cuesta & Carmen, 2015).

Another strategy employed was to confront the findings with the family members who participated in the study and saw themselves reflected on them. As Leininger (2005) mentions, one of the criteria for validity of qualitative studies is the meaning in context. This criterion is based on the contextualization of ideas and experiences inherent to a situation or in the whole environment, data that becomes comprehensible within the holistic contexts or that have a special meaning in regards to the participants.

RESULTS

The findings show that joining and participating in the group comes from the great suffering that the confrontation with the SMI causes in families, who faced with such an adversity ally themselves around a group dynamic in order to go on with their daily lives. The support group becomes a true safe haven (Gomes, et al, 2017). In figure 3 the explanatory theoretical structure of this process is represented.

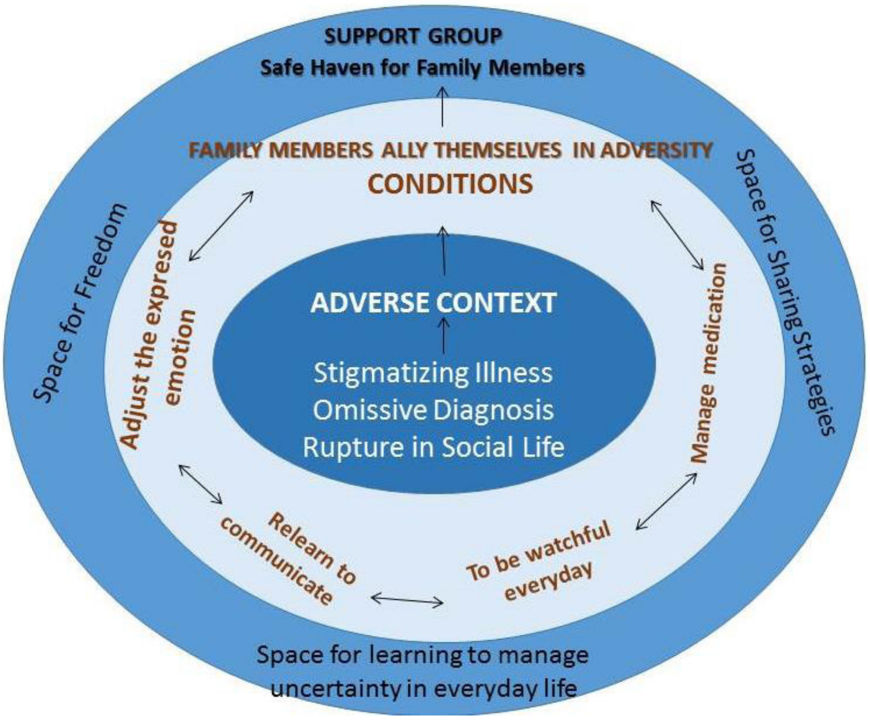

Figure 3. Diagram for the explanatory theoretical structure of the conditions and context of the support group for relatives of people with SMI (Source: the authors)

The illness transforms and makes almost unrecognisable the afflicted, deteriorating the family life through the avoidance of dialogue amidst the family, as well as the avoidance of social contacts, and may even cause a rupture in the family derived from the stigma that still hangs over mental illness.

The mental illness stigma leads to omit the diagnosis by the family, not being named even when institutionalisation has occurred. The euphemisms used people with imbalances; people with different behaviours from most people (RG3) show the denial and difficulty in accepting the disease. The suspicion and cover up before family and friends further enhances isolation and suffering.

The lack of understanding of mental illness thus leads to an avoidance of social contacts, which leads to a rupture in the family's social life, mainly in regards to the family caregiver due to the their central role in daily life, sometimes even leading to an abandon of self-care and other family roles. The following excerpt shows how the disease changed he leisure habits of a family caregiver "... I have always enjoyed being at the coffee shop with my husband reading the newspaper… now at the second or third page I don't even feel like reading it (RG2).

The family caregiver, due to the continuous and all-consuming role that is demanded of them daily suffers from high levels of strain when faced with the variety of problems and feeling they have to deal with. These processes can result in positive transformations as well as lead to a backtracking and strain in the caregiver's development, according to the mobilization of available internal and external resources.

The risk of exhaustion of the family caregiver exists, for there are days that are very difficult to manage due to not knowing what to do, metaphorically stated as thus: sometimes days seem to be very dark (RG5). The group is a resource seen as very positive by all family members. It is a space for sharing, safe haven for the family members of the person with severe mental illness. By being able to hear about cases identical to their own they realize they are not alone. Phenomena occur in the context of the support group that have an identification effect by acknowledging the similarities in behaviours that exist in other families. This makes the families feel helped, though everyone is different here are several behaviours that are common due to the underlying disease. A family member said: by coming to this group I see that I am not alone, there are many people living these equally distressing moments (RG10). To not be alone in the suffering process minimizes solitude, comforts and diminishes the feeling of exclusion.

The support group is also a place of teaching, for the participants also have contact with other family members more experienced than them, who have figured out several solutions. As such, they work as role models for the new arrivals, for whom everything is new, unknown and frightening. A family caregiver mentioned their lack of knowledge in order to be able to manage the situation they experienced as something troubling and weird in their life, and said: when you live the problem so intensely and are very involved, everything looks like a very big deal (RG10).

The support group has a mostly educational purpose for a family member that start attending it. As they integrate further, it becomes a sharing space, where they have the possibility to talk and be heard without judgement, as everyone in it is experiencing identical problems. To this purpose, a family member said: I have also had this and that doubt previously, it's curious that even so there is so much similarity (RG12). It's in the dialog and in the sharing of experiences that the family members, in close contact with each other, can become aware of strategies and ways of communication to deal with their family member. The support group also helps to envision solutions, as it allows the belief that there are different ways to act and ponder other solutions, especially when they feel less optimistic. The fact that they see others with hope makes them feel even more comforted.

In this space they relearn to communicate. The measuring of words and how to use them in the right moment and in the right way requires a certain continuous learning process, which generates strain in the daily life. The fear of causing a crisis in their ill family member is a heavily underlined subject, though it comes up inevitably in what's said, which might mean the seriousness and failure associated with the question, to a point where mentioning it becomes hard. Thus, the learning to communicate might help to achieve some behavioural stability. The family caregiver learns mostly through being aware of the mistakes they made, though it is still a slow and hard learning process.

Adhering to medication is the biggest hope the family member has for the illness to become more stable. On the other hand, medication is often rejected by the ill person, for they feel that it alters their essence. In this context, the family member closely watches as the medication is ingested, and helps the ill person to not forget to take them. Medication is a resource that demands effort from the family members, as they must commit in order for the patient to not stop taking them regularly.

For the medication to take its effect the absence of alcohol must be respected, a question that is often misunderstood and misinterpreted by the patient. Friends are often not aware of the alcohol's effect on medication and do not contribute to avoid its respective consumption, reason why the family caregiver will often seek to separate them from the ill family member.

Medication alters the ill person and provokes in the family a love-hate relationship regarding treatment. This relationship comes from the double role that medication has in itself. If on one hand it does help to stabilize the signs and symptoms of the illness, on the other hand it will also have negative effects, as it changes a person's behaviour, making them sometimes more apathetic.

One of the biggest struggles that the family caregiver experiences is knowing just exactly how to act. How vigilant should they seem, how much should they correct, what questions to pose, how to be aware of the proper time to speak out, knowing when an awkward silence should be broken, the permanent doubt on the best behaviour to take all make the daily life a constant source of hesitation and indecision. The family caregiver has difficulties in knowing whether they have been invasive, if they're allowed to question, what is the best way and moment to do so, whether doubt should be held on to or wait for the answer to naturally appear. These situations are what make the daily life always disturbing, highly stressful and quite unpredictable. Uncertainty is express as thus: after every action we take, we are always left with a kind of remorse, a guilt, because we either demand too much or too little (RG5),.

The family caregiver-ill person interrelationship has the particularity of being a two-person changing process, in the way that they both change: the family member and the person with severe mental illness, who articulate and influence each other mutually in the process of managing the condition. A family caregiver mentions: It took me many years to change a little bit,… he is now also changing or I automatically make him change, or we are both changing… (RG8).

Before these adverse contextual conditions, the family members of those afflicted with SMI ally with each other in the support group to face the adversity. In this group they find a space for freedom and sharing of strategies which they discover at the same time the develop their own process for emotional management, where it is imperative that resilience is fostered and encouraged, for it is fundamental to adjust the expressed emotions. The support group is thus revealed as an effective safe haven, for everyone there is an equal, competent/incompetent in the struggle of dealing with this grave problem, in which everyone has their moments of uplifting and discouragement, as well as moments of success and failure.

DISCUSSION

Hesitations and difficulties regarding the facing of the SMI diagnosis and the stigma that follows along with it, along with the complexity of the adjustments for the most adequate medication and the effort in adhering to the therapy in the long run in order to stabilize the disease, are some of the elements of the indescribable difficulty within the management of this chronic disease. The physical and psychological wear is inevitable, and its mitigation is an achievement constructed daily through managing the symptoms of the SMI.

The daily life is the reflex of a good or inadequate management of the daily life, for it is in it that the importance of life is reflected. The daily life is what is closer to someone's heart, the mot invisible part of them, hidden, dissimulated and, however, so important in the perception of the true meaning of existence (Crespo, 2006). Family, due to its traditional role, has major role in accompanying and supporting its members in their own safety, taking responsibility for the continuation of the therapeutic process of one of their own. However it cannot be abandoned in this process of caregiving and intricate symptom management that characterize the SMI, with the support groups being just a tiny parcel of the help that these families are entitled to. Family members can keep finding strategies to manage the uncertainty in their daily lives often by trial and error, but such a situation is akin to abandonment by the Healthcare System, as this is something that can't and shouldn't be the family's responsibility (Grácio, Gonçalves-Pereira, & Leff, 2016).

The support group, with a specialized professional intervention, exerts a "therapeutic effect" on its members, as Torres, Lima & Guerra mention (2014), since their formation isn't spontaneous, and occurs between people that have a family member with SMI in common and have the conditions to help each other. The support group is a synergetic strategy that intervenes on an educational and emotional support level, for it allows the family caregiver to vent, share and adhere to a daily life management and, above all, to be understood. In this context, it is important to highlight the role of the nurse specialising in mental health as a group coordinator. He sees the family as an integral part of the process of supporting the ill person, with the family involvement as a partner to healthcare something to be wished and aimed for. Guidance for the families is made though the development of interventions that allows the stimulation of learning and personal transformation, personally and upon others. As such, in the group several themes are approached such as alternatives to deal, manage the impact of the mental illness on the family member and on the family. From these we highlight: information regarding the clinical picture and possibilities for treatment, symptoms, diagnosis and prognosis, medication and how to deal with crisis episodes, namely more adequate strategies and necessary procedures. Relevance is given to the dealing with realistic expectations. We highlight, still, the support network present in the family and the community (Gomes et al., 2017).

However, we realised that the guidance given to families within the group happen only occasionally. And if the afflicted person is given support and guidance before and after they are discharged, the same does not happen to the families. The inexistence of structured programmes aimed at preparing a responsible and safe hospital discharge creates dynamics marked by great stress amidst the family, with the support group being a most useful resource, but ultimately lacking for the amplitude of the problem of dealing with someone with a SMI at home (McFarlane, 2016). As such, it is important to change the ideas of family healthcare that still prevail, mostly focused on a client's needs and satisfaction, and we must move towards an idea of care focused on the patient and their family, and their potential for development. In this latter idea, we would believe and recognise the ties of the familial connection with the Healthcare System, and that the outcome of such a connection would result in the creation of a support and guidance role for managing symptoms and promoting well-being. However, we also recognise the harmful effects that this can have on the caregiver and on the family, which might overload if not properly helped.

The fact that the ill person is absent from this group allows the family members to express the problem that otherwise would be repressed, though this option can be seen as negative by the ill people due to feeling left out and eventually threatened. The presence of other family members, as the study revealed and is confirmed by the literature, creates an environment for understanding and he observations and remarks can be made in a more sincere and convincing way than they would, should the interaction be only with professionals (Fisher et al., 2015).

The aid, support and guidance of the clients in their life transitions, particularly the transition of a disease such as a SMI, are the practical domain of nursing, It is important to look at a family that has in its midst a family member with this illness as a great and indispensable ally and a partner in healthcare, for their life and health projects are interconnected with the ill family member's recovery project (Gomes, 2016).

CONCLUSIONS

This study has highlighted that understanding the SMI is a chronic disease, and not as an unsurmountable and ruthless problem, or even a fatality, demands a long learning process from the family caregiver and the family itself. This necessity derives from the weight of the stigma that metal illness represents still today in society and is lived by the family, which limits their dialogue with family members and friends.

The existence of broader social systems, such as the support group, can help the family improve communication between itself and family members and friends, since communication with a person with SMI is a highly complex area. The necessity to verbalize negative emotions and to receive emotional support is, effectively, eased by the freedom and respect dynamics and found in the support group. In fact, the space for freedom and the opportunity for the sharing of emotions and strategies allows for a unique learning by accepting the SMI as a chronic disease. The weight of the social stigma that still lasts is slowing being abated.

The support group allows the family caregivers to release themselves from social stereotype through the intensity of sharing. It provides help for the family members, with the relearning that acknowledges different ways of acting, motivating, helping, allowing, believing and accepting. To accept their ill family member as a special member of their own family and recognising in them the fragility and dignity inherent ot every person is a very long road indeed. Society needs to free itself from prejudices, in the sense of seeing someone with a SMI as a complete human being. Aiming at perfecting the still lacking answer to the families of people with SMI, it seems relevant to promote the maintenance and development of these support groups.

The working of the support group such as the one mentioned here can be a stimulus for, in different contexts where the support towards families is made in a more informal fashion to restructures itself and allows for work dynamics that provide more awareness to the work developed to help families. However, in the sense of stimulating these groups, we propose improvements in their working with more systematized evaluations before and after the planned intervention and consistent with the needs for guidance and support of each family.

CONFLIC OF INTERESTS

No financial, legal or political conflict, involving third parties (government, companies and private foundations, etc.) has been declared for no aspect of the work submitted (including but not limited to subsidies and financing, executive advice, trial design, manuscript preparation).

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