CARES FOR FAMILIES OF PEOPLE WITH MENTAL ILLNESS

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Summary: Health politics defend that people with mental diseases should be kept within the community. The family is asked to look after these people, without being prepared for that. The family doesn't understand their ill relatives neither the revelation of the illness, dealing as well with guilt, physical and emotional overload, social isolation and frequently economical difficulties. This study allows us to identify the health needs in the families with relatives suffering from mental illness, and develop healthy strategies to overcome the difficulties caused by the illness. Our aim is to promote health in these families. For this investigation we conducted semi-structured interviews within a sample composed by relatives of mental patients. The families feel insecure and don't know what to do, saying it would be important to know how to deal with the ill person and where to turn to in case of family instability. The information allows us to help the family to readjust their new life projects.

KEY-WORDS: Cares; Families; Mental Illness

INTRODUCTION

Commentaries about the family's responsibility upon the becoming ill of one of their members are frequent. In many situations and, apparently more and more, the family, or its absence, is the centre of emotional disruption.

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The aggressions sometimes observed in the families have a different dimension than in other contexts. On the other hand, any family member expects to find in the family the emotional and psychological support to answer the complex demands of today's society.

The family is recognized as the most important group in society and has been suffering changes as time goes by, both in its structure as well as in the performance of its roles and interactions in a community. On the other hand, these interactions interfere with the development of its members within the family, being that the space where the health concept and healthy life habits are acquired.

We verify in everyday life that the cares continue to be centred in the ill person and the family continues to be seen as a supporting system of the ill relative, being responsible for the control of the illness, especially with those who suffer from schizophrenia. In these cases it's frequently the family who mainly cares for people with schizophrenia.

To verify if these study results also apply to the region where we belong to, we decided to do our own study with families of mental illness people. We approached the families during hospitalization of the ill person. We thought it would be the best phase of the living experience of the situation, since they had the problem shared with the health services, and on the other hand had still in their recent memories the difficulties they went through. They were facing as well the fact that the stay in hospital was limited to a quite short period of time (the maximum would be of a month).

We collected information about: i) the way they dealt with the ill, ii) how they faced the illness according to the social environment they belonged to, iii) what information they had to face the moments of greatest emotional tension caused by the illness and which implied necessarily their capacity do adapt to the situation and to integrate themselves in the environment where they lived and iv) what resources they had to deal with the

situation. By resources we understand the information available to interact with the mental patient, the supports they had from the community, such as: big family, neighbourhood, support groups and health services such as: family nurse, ambulatory services, contacts with the services at the hospital where they had been. Thus, the aim of the study is to identify the health necessities in the families of ill people with the possibility of being helped in developing healthy strategies to overcome the difficulties caused by the illness.

The family of the mental patient: short approach

A healthy family is the one which, in a situation of adjustment to a stress situation: (i) is able to give answers to the needs of their members, to deal in an efficient way with the transitions; (ii) is flexible with power distribution; and (iii) keeps the patterns of interaction and the working rules between them and the community where they live in (McCubbin and McCubbin, 1993). Olson *et al*, (1989) consider as well the necessity of maintaining the balance and the cohesion and adaptability, what makes a good communication within the family easier.

The family health concept has been evolving accordingly to the cultural, economical, religious changes and other characteristics of contemporaneous societies.

The promotion of family health refers to activities done by families to make them stronger as a unit. The aim is to regain the health of all members, when for any reason this is threatened (Stanhope & Lancaster, 1999)

Families which have a member with mental illness tend to adapt to the presence of the illness, starting even to restrict their participation in social events due to the prejudice existent in society (Nasi, Stumm and Ildegrandt: 2004) or due to the necessity of caring of the ill person, situations which often are associated to the change of habits in the

family group as well as in the relations with the social group. Usually there is a greater tension, the family seeks isolation, goes less out for walks or other contacts with the outer world, reducing thus their leisure moments (Moreno: 2000).

We can observe that in everyday life mental diseases cause a big impact on the families' balance, since *"these families provide not only physical and emotional support, but support as well the negative impact of discrimination"* (WHO, 2001: 58). When these families are not able to use their adjustment strategies they need external help, *"...available (...) support sources in community"* (Martins: 2002: 139), which allows them to recover the balance.

Literature reveals us that the appearance of the mental illness in a family member causes the family the need of help to deal with *"...the guilt, the overload, the pessimism and social isolation, which come from the suffering that insanity causes, both to them as to the ill person"* (Souza and Scatena, 2005: 174).

They also refer that each family that lives with the metal disease experiences that in a unique way and it's always *"a critical moment of its development cycle"* (Souza and Scatena, 2005: 177).

In 2003 Pereira and Jr., in their study about the dynamics of the relation between mental health services, psychiatric patient and family, tried to identify the difficulties felt by the family dealing with mental illness, showing that the idea that the *"mental disorder is painful for who lives with the illness, and not less difficult for the family that lives with people in this situation"* (Pereira and Jr., 2003: 95).

We know the mental illness is complex because it affects not only the person but the whole, both, in its individuality as in the relation with others. It affects the emotional, social and intellectual behaviour of the ill person. The World Health Organization characterizes it as *"changes in the way of thinking and emotions, or by the damage of*

the social and psychological way of working. It results from biological, psychological and social factors." (World Health Report 2001). It is as well assumed that mental disorders exert a great impact upon the families' balance, since *"these families provide not only physical and emotional support, but support as well the negative impact of discrimination"* (WHO, 2002).

It's necessary to find solutions to help a family finding its emotional balance. It's necessary to search this people so that they may express what they think and how they live with this situation daily.

The mental health report by WHO (2001) refers that the most common disorders, which in general cause severe disabilities, include depressive disorders, disorders due to use of substances and schizophrenia. According to that report, mental and neurological problems match with 30.8% of all lived years with disability, what causes a deep and lasting economical impact, not only for the family, but as well for the community. Not to talk about the low life quality resulting from the lack of support of social necessities and working methods, basics for people with severe mental disorders.

The revision of specialized literature shows that the first systematic trials to relieve the impact of the mental illness overload for the family appeared in 1955. They researched emotional and cognitive problems presented by wifes during the illness of their husbands, to the adjustment of the illness within the family and to the families' dissatisfaction about the available information and the access to health professionals (Marsh: 1992).

Schene *et al.* (1993) reminds us, by doing a revision of the 21 most used instruments to evaluate the impact of a mental disorder in a family that all researchers consider the symptoms and behaviours of the mental patient as being factors of chronic stress, with which the family members should learn to deal. There are various changes in the

family's dynamics, such as: (i) anguish feelings; (ii) financial consequences caused by unemployment or precarious assiduity; (iii) harmed family interaction; (iv) distance between family and social environment; (v) stigma; shame; (vi) little participation in leisure activities; and others.

Method

Sample

The sphere of our study will integrate family members of ill people with diagnostic by a psychiatrist of the hospital entities where the interview will be held and the management of the questionnaires and the nurses of the same places. In the study will be included: (i) family members of ill hospitalized adults, who accept to participate in the study; (ii) families of a ill person in need of specialized psychiatric intervention; and (iii) those who belong to the family of the ill person, that is, live with him/her daily, with affective and economical bonds in common.

Instrument

We used semi-structured interviews with the family members of hospitalized mental illness people, with the aim of receiving answers to the expressed questions. The support guide was done according to the Calgary[3] Model. This Family Evaluation

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[3] The Calgary Family Evaluation Model was developed by two Canadian nurses in the University of Calgary, Wright and Leahey (2002)). It is frequently used to identify difficulties within the family, by allowing doing an evaluation upon: family structure – internal, external aspects and family context; family development – trainees, tasks and bonds and the family's way of working – instrumental and expressive.

Model (MCAF) is organized in a multidimensional way, having three basic categories: structural, development and functional. It presents extended world views, such as post-modernism, feminism and Cognition Biology. The family evaluation has as first step the examination of the structure by the professional that cares of the mental patient, defining its composition, family type, observing losses and family deaths, definition of gender and evaluation of the influence of sex when there are social, cultural or family beliefs regarding the feminine and masculine roles that may cause family tension. The understanding of the social context in which the family is integrated is very important so that the professional may understand the *stress* factors and family resources, being necessary to find out the affective bonds between their members and the social support network.

Procedures

We have randomly chosen three families, which would follow the criterions described previously, to do the interviews.

In order to let them decide freely weather to participate or not in the interviews, they were informed about: aims of the study, time and duration of the interview, the necessity of taping the interview; explanation of confidentiality terms and of possible doubts; the choice of time and space to do the interviews in order not to interfere with their professional, family and social commitments.

The interviews were coded through a letter and a number. At the end of the transcription of the interview's content the tapes will be destroyed.

Ethical principles of voluntary acceptance of each participant were respected, taking into consideration the information about the aim of the study, confidentiality of the information, the freedom of participating in the study, as well as all the remaining requirements of a research process, being here included the corresponding permission of the person, as well as the requirements and corresponding permissions of the places where the data collection was done.

The obtained data was handled with the help of content analysis.

Results

Considering our aims, the analysis of the content of the information of the three families selected for the study made it obvious that these families still consider a mental disorder as something difficult to understand but that causes suffering both, at an individual as well as at a family level.

When families are adapted to the situation of a ill family member, it is expected that they are able to act accordingly and to manage their lives within the normal group and social patterns. The families we found feel insecure, without knowing what to do, expressing that it would be important to know how to deal with the ill person, who to turn to in a situation of instability of the family member. The information allows as well the family to readjust its life projects according to the health limitations or expectations. They feel insecure due to the complexity of the illness, due to the little information they have about its evolution and about how to behave in the face of the expressions of the ill, as we may verify in the following excerpts:

"it's hard to see him like that and not be able to do anything (...) I don't know what I could do" (B1).

"this has been lasting for two years already and I am not able to find a doctor who discovers what his problem is" (C1).

"there was never a doctor who told us that my father had 100% this" (C2).

It seems that the most comfortable situation would be to extend hospitalization *"it would be good that he would stay here a long time to see if he gets completely cured, but this depends (…) depends on the doctor, isn't it?…"* (A1)

Adapting to the disease situation is not easy. Within the interviewed families we could identify a feeling of insecurity and discomfort before the unpredictability of its future and although they keep some expectations, they live with the fear that something may happen. *"the changes of humour (…) he can become very aggressive in five minutes, and that's the greatest problem"* (B2).

"It's unsafe to have a person like that at home because you can't be relaxed for 5 minutes (…) there has to be always someone who is with him 24 hours a day or we cannot have a rest" (C1).

The integration in the social environment is quite easy to achieve when one knows the places and how to behave in them. With the unpredictable behaviours the social adaptation is embarrassing or even not possible. To help families overcoming this difficulty, it should have at its disposal some information about the possible behaviours of the ill person in an instability situation.

Families show not to know what to do because they don't know anything about the illness and about how to deal with their relative: *"No. I was never informed about anything. I don't know"* (A1). And continues: *"Me...what I know is that when he gets aggressive I leave him alone and close myself up in my room (…) or close myself up in*

the house (…) where I am, I am locked up! After a while I come out again and then he's better" (A1). *"Only in the internet… and the psychiatrist talked to me… I have the impression they don't know how to deal with him, either"* (B1).

The son of C makes an interesting parallelism about the information he received when he was diagnosed with an organic disease and its respective cares and the information received as far as his father's illness is concerned: *"As far as my disease is concerned, they called me, my wife and my mother and explained how I should deal with the situation at home, the cares I should take, what I should and what I should not do, they explained everything in details"*, he says *" here the only information we were given was that in case it happens to call an ambulance (...) and avoid the things he can reach. What is difficult because he is a person who takes 10 pills every day"* (C1).

We observed that the interviewed people have difficulties in have affective relationships with others, including those who are close, and the loss of social competences, although sometimes they try to hide it justifying their distance with: *"I think that they are ashamed (...) that their son has a problem"* (B1). *"As family we have never had a big support from the rest of the family (…) as soon as the problem appeared…"* (C2); *"they hide, suppress it (…) in my family they try to suppress it"* (C3); or *"…if they ask me I say he's at the beach"* (A1).

The resources we can use to deal with an unpleasant situation can be internal or external, but need always some learning that is acquired with time. They may learn to deal with the illness and with its implications, leaving many times projects unaccomplished. *"me having my goals, me working and fighting for a better live and having a completely different person next to me (…) it's complicated (...) it's very complicated"* (B1). Being with these ill people at home is a permanent emotional load, which is easily transmitted: *"I have already realized that the illness has no cure (…)*

hospitalization is a relief" (B2), or: *"I don't know how to deal with him"* (C3). With the years, and with the getting conscious that the illness has no cure, it takes the relatives to a feeling of exhaustion *"I feel frustrated because (…) I know he will create expectations again, as the last time he got out, but nothing will happen and then he goes under again (…) exactly the same will happen; thus, in a year or even less he will be here again (…) understand my powerlessness."* (B1)

Extended hospitalization seems to be an alternative found by various relatives: *"My wife wants him to stay here half a year. However, they surly don't want him to stay here half a year as well. Maybe they want to turn him away"* (A2). Some elements refer the importance of divine help, through prayer: *"I ask God for help every day"* (A1).

The support families find, when one of their relatives becomes unstable, at the end of the first decade of the XXI century, are the police forces. With the lack of supervision services of these families the only way of finding the first help, when a ill element has a new crisis, is the "GNR" (Guarda Nacional Republicana – National Republic Guard). *"I went to the guard (meaning GNR)… health delegation and delegate...from one day to the other he took care of the papers and brought him here"* (B1).

If the aim of the family health promotion is to recover the health of all family members, when, for any reason, it is threatened (Stanhope & Lancaster, 1999), then, there is a lot of work to do to help the families of mental illness people.

Discussion and conclusions

After various decades studying the consequences mental diseases bring to families, as the studies of Marsh (1992) show, we can conclude that it is still necessary to insist in the inclusion of the family in the whole process of the taking care.

The relatives are involved with the patient, as such, the therapeutical interventions strategies will have to imply all family elements, who feel that necessity, so that the balance is re-established. In this way it will be easier for the family to adopt behaviours and compatible family interaction patterns with the management of the anxiety the impact of the illness causes. The capacity to involve themselves in the new family roles and functions will get better, the relation quality with the patient will get better as well and they readjust their new attitudes according to the illness.

The current health politics follow the sense that the patients should be kept within the community, but such will only be possible if the family is prepared to deal with them and with the implications of the mental disease. *"...the guilt, the overload, the pessimism and social isolation"* (Souza and Scatena, 2005: 174) are expressions common to all families of our study, as well as social isolation and interpersonal conflicts in the family.

We had the opportunity to observe that the relatives go to the hospitalization services various times, mainly in the following situations: to visit the patient, to talk with the doctor so that he/she gets more information about the patient or when the patient goes to spend the weekend at home. In all the situations the interventions are centred in the patient. When they ask about the evolution of the health conditions of their relative the most frequent answers are: "is doing well", "is getting better". When families address the technicians they expect more than this. These moments can be reserved, as well, for a dialogue centred in the family. A correct intervention next to the family, clarifying symptoms, and reinforcement about the necessity of therapeutical support are important. However, the possibilities of success are greater if they are kept up with strategies to deal with the ill relative, such as avoiding conflicts and depreciative criticism towards the patient, as well as a correct guidance if any alteration is observed in the behaviour of

the patient or if it is predictable that a situation that will cause more anxiety to the patient will happen. Sometimes I feel that if families had the liberty to phone a nurse or one of the doctors in a stress situation, the emotional overload would diminish considerably. These are little interventions that may be useful, since they allow the relative to not feel lonely and to know who to turn to in a moment of crisis.

The family is being cared for when it is helped to understand the behaviours of the ill person, when their effort to care for their relative is acknowledged, when keeping an eye on the behaviours, when cooperating with the therapeutical strategies, but, essentially, listening to them and valuing their difficulties, centring them in the current problems, helping them negotiating solutions or adopting new ways of dealing with problems.

Bibliography

Alarcão, M. (des)Equilíbrios familiares. Coimbra, Quarteto, 2000, p. 212.

Bomar, J. P. (Ed). Nurses and family health Promotion: Concepts, assessment, and interventions (2ª. ed). Philadelphia: W.B. Saunders, 1996, p. 37.

Comissão das Comunidades Europeias (2005) - Livro verde - Melhorar a saúde mental da população: rumo a uma estratégia de saúde mental para a União Europeia.

Comité Económico e Social Europeu (2006) – Parecer sobre o Livro verde - Melhorar a saúde mental da população: rumo a uma estratégia de saúde mental para a União Europeia.

Fawcett, J. - Analysis and evaluation of contemporary nursing knowledge: nursing models and theories. F. A. Davis Company. Philadelphia, (2000).

Fernandes, A - Métodos e regras para elaboração de trabalhos académicos e científicos, Porto Editora, Porto, 1995.

Gubman, G. D.; Tessler, R. C. – The impact of mental illness on families. In: journal of Family Issues, vol. 8, nº 2, 1987, p. 226-245.

Marcia Scazufca. - Abordagem familiar em esquizofrenia. Rev. Bras. Psiquiatr. vol.22 s.1 São Paulo May 2000, 29, p. 228-240.

Marsh, D. T.; Johnson, D. J.– The family Experience of mental illness: implications for intervention. In: Professional Psychology: research and practice, vol. 28, nº 3, 1997. p.229-237.

Marsh, D.T. - *Families and Mental Illness: New directions in professional practice*. New York: Praeger, 1992.

Martins, M. M. F. P. S. - Uma crise acidental na família: o doente com AVC. Formasau: Coimbra, 2002.

Martins, M. S. M. – A família, um suporte ao cuidar. In: sinais Vitais, n.º 50, 2003, p. 52-56.

McCubbin, M.A. - Family stress theory and the development of nursing   knowledge about family adaptation. In S.L. Feetham, S.B. Meister, J.M.Bell, & C.L. Gillis (Eds.) The Nursing Family. New Bury Park: Sage Publications, 1993. p. 46-58.

McCubbin, M. A., & McCubbin, H.I. - Families coping with illness: The resiliency model of family stress, adjustment and adaptation. In, C.B. Danielson, B. Hamel-Bissel, & P.Winstead-Fry, Families, health & illness: Perspectives on coping and intervention. St. Louis: Mosby, 1989.

Minuchin, S.– *Famílias: Funcionamento & Tratamento*. Porto Alegre: Artes Médicas, 1990. p. 25-69.

Minuchin, S; Fishman, H. Ch. Técnicas de terapia familiar. Barcelona, Ediciones Paidos, 1989.

Olson, D. Portner, J. Lavee, Yoav - FACES III. University of Minnesota. St. Paul, 1985.

OMS – Relatório mundial de saúde 2001: nova compreensão, nova esperança Ministério da saúde, Direcção-Geral da Saúde: Lisboa, 2002.

Quivy, Raymond & Campenhoudt, Luc Van. - Manual de Investigação em Ciências Sociais. Lisboa: Edições Gradiva, 1994.

Scazufca, M.- Abordagem familiar em Esquizofrenia. Rev Bras Psiquiatr 2000;22(Supl I):50-2

Schene, A. H., Tessler, R.C. & Gamache, G.M. Instruments measuring family or caregiver in severe mental illness. *Social Psychiatry Epidemiological,* 1994.

Stanhope, M. – *Teorias e Desenvolvimento Familiar*. In Stanhope, M. & Lancaster, J. – Enfermagem Comunitária: Promoção de Saúde de Grupos, Famílias e Indivíduos. 1.ª ed. Lisboa : Lusociência, 1999, p. 492-514.

Relvas, A. P.; Alarcão, M. (coord.)– *Novas formas de famílias*. Coimbra: Quarteto 2002.

Vaz Serra, A. - Stress. Coimbra: Coimbra Médica, 1994.

Wright, L. M.; Leahey, M. – Enfermeiras e famílias, um guia para avaliação e intervenção na família (3ª. ed.). São Paulo, ROCA, p. 117.

Wright, LM. Leahey, M. Enfermeiras e famílias: um guia para avaliação e intervenção na família. 3ª. ed. São Paulo: Roca.2000.

www.saude-mental.net/index.2009.04.07