Information needs, care difficulties, and coping strategies in families of people with mental illness

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ABSTRACT

الأهداف: لتحديد الاحتياجات من المعلومات، وصعوبات الرعاية وآليات التعامل مع أفراد الأسرة المصابين بمرض عقلي.

الطريقة: في هذه الدراسة المستعرضة الوصفية تكونت عينة من 134 من المرضى الذين عولجوا في وحدة الطب النفسي للتدريب في جامعة جمهوريت ومستشفى الأبحاث في سيواس، تركيا خلال الفترة ما بين يناير ومايو 2011م. جمعت البيانات عن طريق الإستبيان، وحللت وصفياً عن طريق اختبار مربع كاي chi-square.

النتائج: قرر أن 79.1% من أفراد الأسرة كانوا على دراية حول هذا المرض. تبين أنهم واجهوا صعوبات في التواصل مع المريض وضمان الامتثال للأدوية وإدارة الغضب وأنهم استخدموا استراتيجيات المواجهة النفسية والاجتماعية.

الخاتمة: تشير نتائج دراستنا إلى أن الوصول إلى المعلومات الطبية من تلقاء نفسها ليست كافية لمقدمي الرعاية للأشخاص الذين يعانون من مرض عقلي وضرورة تطوير المواقف الإيجابية في التعامل مع المرض وأعراضه. وفي هذا الصدد، نوصي الممرضين وغيرهم من المهنيين الصحيين بتقديم الدعم الطويل المدى وبرامج الاستشارة لأفراد الأسرة.

Objective: To determine information needs, care difficulties, and coping mechanisms of family members of people with mental illness.

Methods: In this descriptive cross-sectional study, the study sample consisted of the families of 134 patients who were treated in the Psychiatric Unit of Cumhuriyet University Training and Research Hospital in Sivas, Turkey between January and May 2011. Data was collected by a questionnaire and analysed descriptively, and by chi-square testing.

Results: It was determined that 79.1% of family members were knowledgeable of the patients' illness. It was found that they experienced difficulties in communicating with the patient, and in ensuring drug compliance and anger management and that they used psychological and social coping strategies.

Conclusion: Our results indicate that access to medical information on its own is not sufficient for carers of people with mental illness, and the necessity of developing positive attitudes when dealing with the illness and its symptoms. We recommend that nurses and other health professionals offer long term support and consultation programs to family members.

The responsibility of the care of mental health patients has been shifting from the hospital to the community. Families are a vital part of patient care.[1] Seventy-five percent of all patients discharged from psychiatric hospitals live with their families.[2] Families work in cooperation with mental health professionals in the care and treatment of people with mental illness.[1] At the same time, families are a valuable resource in the gathering of relevant patient-related information necessary for effective treatment.[1] Mental illness has a negative impact on the lives of sick individuals and their families.[3-5] People with a mental illness and their families experience problems such as deterioration of relationships within their social circles, lack of self-sufficiency, decreases in activity levels, inability

to fulfil their roles as spouses or family members, and unemployment.[3-11] Family members experience significant difficulties in care giving and are often at a loss as to how to cope. Huang et al[6] identified caregivers' coping strategies as: accepting the situation, seeking information about the illness, keeping occupied at the workplace, and denying the existence of the illness. Eaton et al[7] found communication with people within the immediate family or community to be a vital coping strategy. Family members who experience serious problems and have significant difficulty coping express the need for more information regarding the illness and to actively participate in the treatment of their relative.[4,8-11] A study conducted determined that establishing effective communications with health professionals, drug therapy, and side effects of medications are among the most common concerns of family members.[12] Rummel-Kluge & Kissling[13] determined that family members want not only information on the illness, but also on symptom control and relapse-prevention. In their study conducted in Taiwan, Sung, Hixson and Yorker[14] found that people with mental illness and their families mostly needed information regarding psychiatric medications and management strategies for general problems. In a study conducted with family members in China,[15] Chien and Norman[15] reported that the most important educational needs of family members concern illness, early signs of illness, medication, and coping with unpredictable and aggressive behaviour people with mental illness may display. Despite the results of these studies; treatment, care, and support requirements of family members are often not adequately met.[10,16] Studies conducted in the USA by Gasque-Carter & Curlee[1] and in Australia by Shankar and Muthuswamy[2] found that mental health professionals generally did not include family members in the treatment of people with mental illnesses, that interaction between family members and mental health professionals was poor, and that the mental health professionals gave them very little information on the illness. In addition, another study, determined that families viewed the education provided to them as vague and inadequate for care giving.[1]

In order to achieve enhancement of their role in the rehabilitation of people with mental illnesses, families need to have their burdens lightened through emotional, social, and financial support, as well as education and skills-training.[1,6,17,18] Reid, Lloyd, and de Groot[18] found that addressing the education and support requirements of family members significantly contributed to their satisfaction of, and participation in treatment, and promoted a positive perception of mental health professionals. Information requirements, healthcare

difficulties, and coping strategies of patients' families have been very clearly defined in the international literature.[1,2,6,7,12,15] In line with these requirements, in various countries, family-centered services are provided to meet the families' needs and to support them.[2,3,4,11] In many countries are aimed to reduce costs of hospital care, the frequency of hospitalization, and the need for support in crisis through family-centered training and support programs.[2] In Turkey, the information and counselling services provided to families of people with mental illnesses remain inadequate. Family-centered services within the framework of community health have been initiated in recent years. However, these are available only in some large cities and are limited in number and effectiveness.[19,20] In order to plan and implement family-centered education and support services within the public health framework in Turkey, it is important to determine information requirements, healthcare difficulties, and coping strategies of families of people with mental illnesses. Determination of this requirement is critical in the establishment of the content of family-centered services, which is a recent issue on the agenda in Turkey. Such studies will contribute to the establishment of information and consultancy services for families. Therefore, this study aims to determine the information needs, care challenges, and coping strategies of family members of people with mental illnesses.

Methods. *Study design and participants.* This descriptive cross-sectional study was conducted between January and May 2011. During the study period, there were 456 admissions to the Inpatient Psychiatry Department of Cumhuriyet University Training and Research Hospital. The study sample consisted of the family members of 134 people with mental illnesses who were treated in the psychiatric unit of Cumhuriyet University Training and Research Hospital in Sivas, Turkey and met the study inclusion criteria. Study inclusion criteria were: being 18 years old or above; being a family member of a psychiatric patient diagnosed at least one year prior to the study and still receiving treatment; being able to fill out the questionnaire and giving voluntary informed consent to participate in the survey. One family member per patient was interviewed. The participants were first-degree relatives who resided in the same house as the people with a mental illness.[1,3,6,7,12]

Setting. The Inpatient Psychiatry Department of Cumhuriyet University Training and Research Hospital provides health services to the population living in the neighboring cities of Tokat and the Central Anatolian region of Turkey. The psychiatric clinic is open 24

hours a day, 7 days a week. The Inpatient Psychiatry Department of Cumhuriyet University Training and Research Hospital has 25 beds and 8 wards where 7 nurses and 8 doctors work. In the clinic, except for patients who have significant difficulty in self-care or who are believed to be at high risk of harming themselves or others, any patient is provided treatment. Each year, more than 700 patients are discharged from the clinic depending on the number of people hospitalized. Information and counselling services are not offered to families on a regular basis. Instead, information concerning the illness and medications is provided upon the request of family members.

Data collection instruments. Data was collected with a questionnaire designed by the researchers based on existing literature. The theoretical framework of the instrument was compiled as follows: "The Educational Needs Questionnaire" developed by Meuser et al[12] was taken into account for the section on information requirements. The section on coping strategies was based on the classifications of Huang et al[6] resulting from their literature review on this subject as well as relevant information in the literature.[6,21,22,23] The questionnaire assesses individual characteristics of family members, difficulties they experience, and the needs they have concerning information and support for illness management and coping strategies. The instrument comprised 14 questions in 4 sections. The first section consisted of questions concerning demographic characteristics (5 questions), the second section was regarding knowledge of the illness (3 questions), the third section was regarding difficulties of care giving (3 questions), and the fourth section was designed to identify coping strategies (3 questions). The questions regarding demographic characteristics were closed-ended, multiple-choice questions (your gender: male/female, your education: elementary/high school, are you employed: yes/no, and so forth). Questions regarding the disease knowledge were yes/no, multiple-choice closed-ended and open-ended questions (Are you knowledgeable about the patient's disease? If yes, who did you have get the information from? and so forth). Questions in the third and fourth sections were open-ended questions (what type of information do you need in the care of your patient? Please indicate; what difficulties do you have most when providing care for your patients? Please indicate; how do you cope with the challenges you face in your patient care? Please indicate, and so forth). Regarding family members' disease knowledge, their knowledge level of the diagnosis of the disease was assessed. This assessment included the following: what the disease is, its causes,

symptoms, treatment, medications used, prognosis, and the importance of health checks. The expert opinions of 3 academics were obtained with regards to content validity.

The validity and comprehensibility of the questionnaire were tested in a pilot study with a sample group of 20 family members. During the pilot study, content validity of the questionnaire was investigated, and similar questions were excluded. Questions in the questionnaire comprise the basic variables studied. All the questions were understandable. The form was administered on a one-on-one basis in a private interview room during the hospital visiting hours. The survey questionnaire took approximately 15-20 minutes to complete.

Data analysis. The Statistical Package for Social Sciences version 15.0 (SPSS Inc., Chicago, IL, USA) was utilized. Data were analyzed by using descriptive statistics. The families' knowledge levels, source of the information, information they need, challenges faced while providing healthcare, and coping strategies in providing healthcare were determined with percentage distribution, and knowledge levels on demographic characteristics, information requirements, difficulties experienced with coping strategies were compared using the chi-square test. Values were expressed as percentages. The percentage was calculated in the presence and absence group by Pearson's Chi-square test. The limit of statistical significance was set at $p < 0.05$.

Ethical considerations. The study protocol was approved by the Research Ethics Committee of Cumhuriyet University. The study was conducted according the Principles of the Helsinki Declaration. Before the questionnaire was applied to the family members, institutional permission was obtained from the hospital and informed verbal consent was obtained from all the family members who participated in the study. The family members were specifically informed regarding their entitlement to information regarding the study, voluntary participation, privacy issues, their right to refuse to divulge information, and to terminate their participation at any time.

Results. *Sociodemographic characteristics.* The participants' mean age was 42.74±13.54. Of the subjects, 26.9% were within the 18-30 age group, 52.2% were female. Forty-seven percent were primary school graduates, 44% were employed, and 76.1% had an income around the national income per person

Information levels of the families. The level of knowledge of the family members regarding the illness is shown in **Table 1**. It was determined that 79.1%

of the family members were informed regarding the illness. There was no statistically significant association between the variables such as gender, age, employment status and income level of the family members, diagnosis, and duration of illness of people with mental illnesses in terms of knowledge regarding the illness ($p>0.05$). However, it was found that those with higher educational levels were more knowledge of the illness compared with those with lower educational levels ($x^2=11.37$; $p=0.02$).

Information requirements of the families. The areas that family members needed counselling for better management of patient care are shown in **Table 2**. Female or unemployed family members needed more information than others on how to manage the anger of their sick relatives ($x^2=4.80$; $p=0.022$). Family members in the 18-25 age group needed more help than older subjects regarding where to get information from ($x^2=18.61$; $p=0.005$). There were no statistically significant differences between information requirements and education or income levels, length of time spent care giving, the type of mental illness diagnosed, and duration of the illness ($p>0.05$).

Difficulties experienced in caring. The difficulties experienced by family members in providing care to individuals with mental illnesses are presented in **Table 3**.

Coping strategies of families. Coping strategies of family members are depicted in **Table 4**. Female or unemployed family members used emotional coping mechanisms (crying) more than other participants ($x^2=24.52$; $p=0.000$). Those with lower levels of education tended to use emotional (crying) ($x^2=12.93$; $p=0.012$) and behavioral (blaming others) ($x^2=10.73$; $p=0.030$) methods to cope, while those of higher educational levels tended to use cognitive (problem solving) methods more often ($x^2=9.57$; $p=0.048$). No statistically significant differences were found in the coping strategies of family members and the type of illness diagnosed and the duration of the illness ($p>0.05$).

Discussion. In this descriptive study, the investigators used a questionnaire to determine the status of family members of people with mental illnesses regarding difficulties in care giving, coping with illness, and accessing relevant information. The findings are discussed under the following 4 headings: information levels, information requirements, difficulties experienced in caring, and coping strategies of family members.

Information levels of the families. Family members frequently compile information on the illness and its consequences.[1,10] In this

study, most of the family members were knowledgeable of the illness. This finding could be considered as having positive connotations. On the other hand, a significant finding of the current study is that almost one quarter of the family members did not have any relevant information. In order to enhance the active role families play in rehabilitation, it is imperative that families should be armed with information of the illnesses they are dealing with. This is supported by another noteworthy finding reported in a number of studies: family members are unsatisfied with the amount of illness education they receive and also require more information on the workings of the health system.[1,24,25] It was determined in the current study that approximately half the family members who had illness-related information had received this information from doctors; while only 4.7% had received the information from nurses. This finding may be interpreted as an indication that nurses do not adequately fulfil their educative role or are not sufficiently aware of these responsibilities. Nurses do carry the responsibility of informing family members of the condition suffered by

Table 1 - Knowledge levels of family members of people with mental illness regarding the illness of their relatives (N=134).

Knowledge levels pertaining to the illness	n	(%)
Has information on the illness		
Yes	106	(79.1)
No	28	(20.9)
Person/s who provide illness information (n=106)		
Doctor	60	(56.6)
Nurse	5	(4.7)
Doctor and Nurse	18	(17.0)
Self-researched	23	(21.7)

Table 2 - Counselling requirements of families regarding patient care of patients with mental illness.

Issues that require counselling*	n	(%)
Approaching an aggressive patient	78	(58.2)
Ensuring drug compliance	64	(47.8)
Coping with side effects of medicines	60	(44.8)
Communication with the patient	58	(43.3)
Information on the illness	55	(41.0)
Information on the symptoms	51	(38.1)
Where to receive help when needed	50	(37.3)
Distinguishing the symptoms	43	(32.1)
Whom to seek help from when needed	41	(30.6)

*Expressions are multiple. The percentages are calculated according to number "n"

Table 3 - Mental illnesses patient care difficulties experienced by families (N=134).

Difficulties experienced in care giving*	n	(%)
Approaching aggressive patients	76	(56.7)
Being unable to maintain regular administration of medications	67	(50.0)
Difficulty communicating with the patient	59	(44.0)
Self-harming behaviors of the patient	48	(35.8)
Suicidal thoughts expressed by patient	41	(30.6)
Patient hearing voices	38	(28.4)
Risk of patient harming others	23	(17.2)

*Expressions are multiple. The percentages are calculated according to number "n"

Table 4 - Families' strategies for coping with illness in mental health patients (N=134).

Coping strategies*	n	%
Psychological coping strategies		
Cognitive		
Acceptance	58	(43.3)
Making plans to find solutions to the problems	53	(39.6)
Behavioural		
Concentrating on work in order to ignore the problems	34	(25.4)
Keeping away from people	16	(11.9)
Blaming others for the problems	7	(5.2)
Emotional		
Crying	40	(29.9)
Repressing the problem, sharing with no one	29	(21.6)
Becoming angry-shouting	24	(17.9)
Social coping strategies		
Seeking help from immediate circle (relative, neighbor)	64	(47.8)

*Expressions are multiple, the percentages are calculated according to number "n"

the patient. This study revealed a significant association between the level of formal education of the family members, and the amount of illness information they acquired. Consistent with the findings of the current study, Chien and Lee,[26] and Wei et al[27] determined that family members with higher educational levels were more effective in determining their own needs. This may be indicative of the fact that people who are better educated are more aware of their needs and are also better able to access information.

The information requirements of families. Often, the treatment, care, and support needs of families of people with mental illnesses are not completely met.[10,16] Families tend to seek more information of the disease from mental health professionals.[3,8] In the current study, family members reported that the information

they most needed was related to issues of side effects of medication, communicating with and managing the anger of people with mental illnesses, as well as ensuring drug compliance. This indicates that accessing information necessary to cope with symptoms has the highest priority among the families. It is safe to say that long-term counselling would also be useful in order for family members to develop positive attitudes toward their sick relatives. In a study involving people with schizophrenia, it was found that patients themselves were not satisfied with receiving general information regarding their illnesses and its treatments, but they also required practical advice on coping with their own symptoms.[28] While Sung et al[14] determined that patients and their families needed information mostly regarding strategies for the management of general problems; Ascher-Svanum et al[29] found that family members needed information on crisis management tactics. Moreover, Chien and Norman[15] report that developing skills in coping with unpredictable and aggressive patient behavior is among the most important educational needs of family members. These results are consistent with the findings of the current study. Unlike other study findings,[6,12,13,30] the need for information regarding illnesses and their symptoms is not as highly rated in the current study. This may have stemmed from the fact that a large majority of the participants in our study said they had information on the disease. However, we also found that the subjects did not know where and from whom they could receive help when needed. This finding is consistent with previous reports,[1,12,31] and is an indication of communication problems between mental health professionals and family members. Therefore, it is important for mental health experts to establish professional rapport with family members. In the current study, the female, or unemployed participants reported more need for information on managing patient anger than did the remaining participants. The fact that 79% of the female participants were unemployed may be an indication that female family members experience difficulty controlling angry behaviour. Those in the 18-25 age group felt more need for information on where to seek help than did the older participants. This may be attributable to their lack of experience.

Difficulties experienced in caring. It was determined that the difficulties experienced in care giving are concomitant with the need for information: dealing with aggressive behaviour, timely administration of medication, and communication difficulties. This finding is significant as it indicates that lack of sufficient information can lead to more difficulties in giving care. Tel and Terakye[32] indicate the tasks of ensuring that the

patient takes medication and sleeps regularly, maintains communication and basic daily self-care are some of the main challenges that face family members. Tel et al[33] found patients' refusal to take medication and to attend medical checkups to be major difficulties experienced by families. Consistent with the literature, the findings of this study indicate that communication problems and the timely administration of medication are common difficulties experienced by caregivers. Drug compliance is the biggest challenge to families as it is closely associated with the risk of repeated hospitalizations. Identifying the difficulties involved in it, and educating family members on this undertaking is an important care function, and nurses are the health-care professionals best suited to perform this function.

Coping strategies of families. Coping is defined as the behavioural or cognitive response of an individual or family to a life event. Understanding the coping dynamics of family members who live with a person suffering from serious mental illness is essential in providing effective support.[6,34] Studies indicate that the most frequently used coping methods of family members of individuals with mental illness are physical, psychological, and social strategies.[6] The current study has found that family members utilize psychological and social coping strategies, but not physical coping methods. Psychological coping strategies include cognitive, behavioural, and emotional strategies. Cognitive coping strategies include positive thinking, acquisition of knowledge, and problem-solving techniques. Behavioural coping strategies include action-oriented pursuits to keep busy and interests that divert attention. Consistent with a study conducted by Huang et al,[6] this study determined that almost half the family members used "accepting the situation," "problem solving," "keeping oneself occupied," and "getting angry" as coping methods. Emotional coping strategies include crying, becoming upset, or stressed.[6] It was found in the current study that family members used methods of coping such as "crying," "internalizing," and "not sharing with anyone," "getting angry," and "getting away from people." These findings indicate that the participants did not know how to cope with the difficulties they experienced. There is a large body of literature supporting the fact that family members experience difficulties in coping with mental illness,[6,9,10,18] and this finding alone demonstrates the necessity of providing professional consultation by nurses and other health professionals to support and enhance the coping strategies of families. According to Gavois et al,[35] families develop better skills in coping with the burden of caring for people with mental illness when health professionals offer emotional support

and empathy along with illness information. One of the most important coping strategies for family members of individuals with mental illness involves a strong social support network. Social coping strategies include seeking support from family or friends, seeking community resources and professional help, accessing services that provide respite care, spiritual support, education, and self-help groups.[6,23] In the current study, requesting help from family members, close friends, and neighbors were identified as the most important coping strategies. This finding may be attributable to cultural values and the survival of the extended family structure in Turkish society. Consistent with our findings, Eaton et al[7] determined that the most common coping method used by family members is to seek contact with close acquaintances. Huang et al[6] categorized the social coping strategies of family members as religious, seeking social support, and seeking professional support. None of the participants of the current study referred to religious and professional support as social coping strategies. While Huang et al,[6] and Eaton et al[7] indicated that religious support is a very important social coping strategy; only 2 participants of the study conducted by Huang et al[6] reported having received professional support. As in this study, many research findings show that family members receive little or no professional support.[1,2,6] As Lau,[36] and Eaton et al[7] also stated; one possible reason might be that fear of the stigma of mental illness can impede the seeking of psychiatric help. Hence, educating the public on modern psychiatry and its importance is essential. In this regard, nurses are at a very important juncture in improving the level of professional support. It was determined in this study that consistent with the results of a study by Eaton et al,[7] female family members who are not employed tend to use emotional coping methods (crying) more often. Seventy-nine percent of female participants of the current study were not working. In Turkish society, display of emotions by males is unwelcome and is considered to reflect a personality weakness. The findings may be attributable to this cultural trait. Also in line with Eaton et al,[7] we found that the participants with lower educational levels used emotional (crying) and behavioural (blaming others) coping strategies while those with higher levels of education tended to use a cognitive method (solving the problem) more often. Based on this finding, it would be safe to say that educated participants used their cognitive and intellectual skills, accessed information resources more readily, and found it easier to learn how to cope with difficulties in a positive manner.

Study limitations. Data was collected with a survey questionnaire developed by the investigators who based

it on existing literature. It was tested for validity and comprehensibility and used to collect descriptive verbal responses from individual participants. However, the questionnaire has not been tested for psychometric properties. This is the first study on this topic that was conducted in this hospital. As such, its purpose was to determine the existing status. In-depth analysis of the association between families' information needs, and coping skills with the individual characteristics and psychiatric conditions was not undertaken. This study provides general information regarding the information needs and coping skills of family members of people with mental illness. Research was conducted in one Turkish hospital with the participation of family members of its inpatients and as such, cannot be used to formulate generalisations about similar families across Turkey.

In conclusion, this study indicates that most participants received information on the illness, and that it was mostly provided by physicians. These findings highlight the inadequacy of illness education on its own, and the necessity of counselling to assist family members in developing positive attitudes and behaviour patterns, as well as in symptom management. Several studies carried out on the issue revealed that thanks to family intervention practices, difficulties experienced by patients' relatives while they provide healthcare decreased, they were able to cope with stress better, there were positive changes in family functions, patients' compliance with drug regimen and control appointments improved,[32,37-39] and the recurrence of the disease and re-hospitalization decreased.[40] These studies also revealed that although the first results of family intervention counseling appeared after the first 6 months, the best results were obtained at the end of 2 years.[39,40] Therefore, we recommend that nurses and other health professionals offer long term support to, and consultation programs for, family members regarding symptom-control and developing positive approaches. Education is an important variable affecting information levels and coping strategies. Therefore, nurses and other health care professionals may give priority to providing information and counseling services to family members with lower educational levels. Our findings indicate that while family members used psychological and social coping strategies, they did not seek professional support to cope with the illness. In the light of these results, we recommend that mental health centers should facilitate easier access to professional help and implement programs to enhance communication between family members and nurses as well as other health care professionals. The results of this study can be used to offer information and consulting counseling services to families, and to conduct interventional studies to evaluate the effectiveness of such services. Further studies can be conducted to investigate the association of the information needs of families with their coping strategies and care giving difficulties, as well as to identify the factors which influence these. Such studies would contribute to the establishment of information and counseling services for families.

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SUPPLEMENTS

* Supplements will be considered for work including proceedings of conferences or subject matter covering an important topic.

* Material can be in the form of original work or abstracts.

* Material in supplements will be for the purpose of teaching rather than research.

* The Guest Editor will ensure that the financial cost of production of the supplement is covered.

* Supplements will be distributed with the regular issue of the journal but further copies can be ordered upon request.

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