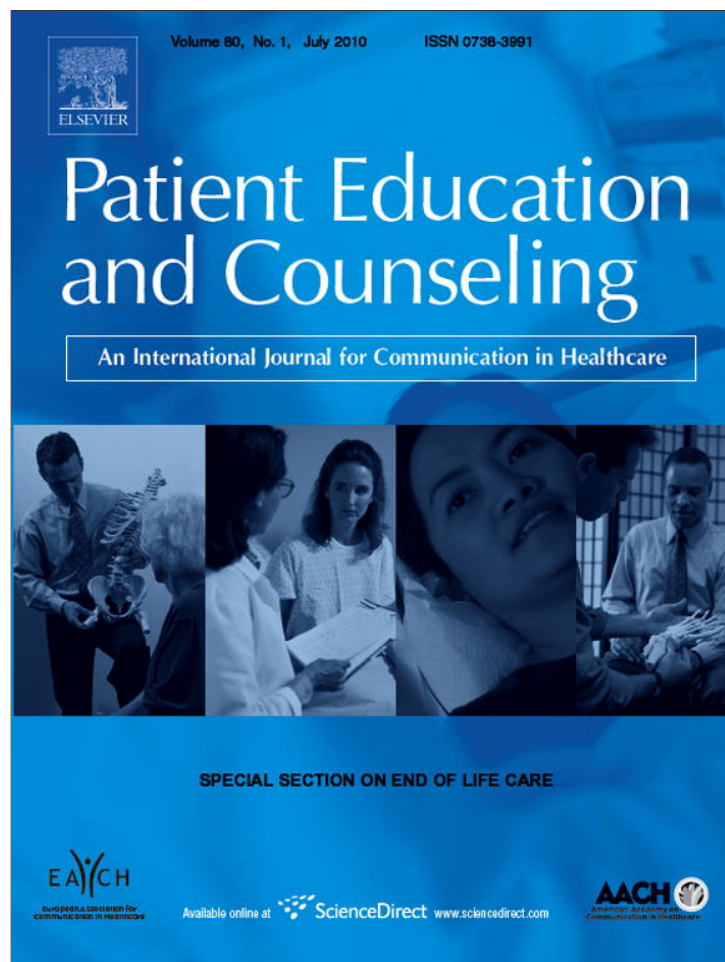


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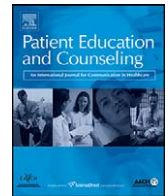
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Mental Health

The relationship between mental health workers and family members

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ARTICLE INFO

Article history:

Received 3 June 2009

Received in revised form 3 September 2009

Accepted 7 September 2009

Keywords:

Family members
Mental health care
Communication

ABSTRACT

Objective: To study the relationship between family members and mental health care workers to learn more about the support available to family members of mental health patients.**Methods:** Eighteen interviews were conducted with family members, seven with professionals and two with patients. Observations were performed at a long-term hospital ward and at family and client council meetings.**Results:** Family members perform an important carer role which greatly affects their lives. They need support from mental health professionals in order to cope. However, communication between mental health care workers and family members is problematic. Family members report a lack of information, consultation and support.**Conclusion:** Family members and mental health care workers frame the role of family members in the care process differently.**Practice implications:** Since the role of family members in the care process can be beneficial for all actors including the mental health patient it is important that mental health professionals acknowledge this and provide support to family members. Considering relatives as fellow carers (reframing their role) could be the way to do this.

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1. Introduction

Informal care such as traditionally provided by family members or close friends has become an important subject on the policy agenda of many Western countries [1]. Family members are expected to care for their sick family members or relatives with disability and many of them do [2]. In mental health care informal care is also very important. Because of the policy of de-institutionalization in this sector family members have to take on more caring tasks than before [3–9]. They can assist in the diagnostic process and take on several caring tasks [5,10–14]. Since mental illnesses can be unpredictable – patients who become psychotic, threaten to kill themselves or wander the streets at night – family members also have to deal with crisis situations [10,15]. The fact that mental health care patients do not always acknowledge that they are ill and the subsequent difficulty in finding professional help for the patient, further complicates matters for family members of mental health patients compared to family members of relatives with a somatic condition [10,15].

The literature shows that the active role of family members can have positive effects on patients [3,16–18]. Their activities may also provide significant cost benefit to government where the alternative would be greater requirement for paid services. The active role of family members of mental health care patients fits into the broader trend of active citizenship: of giving citizens more responsibilities to solve societal problems. One of these responsibilities is to care for each other, to be able to accommodate the increase in the demand of health care and to control health care costs [19]. However, Tonkens argues that citizens need support in order to be able to play that role. If people are simply expected to become active they may not be up to the task or suffer from problems of overload [19]. The fact that the burden of care for family members of mental health care patients is high has been amply discussed in the literature [5–9,11,12,14,20–22]. The effects can be substantial and include reduction of social contacts and social life, less time for themselves, revision of career and retirement possibilities, changing family relationships, feelings of guilt, stress and grief [6–15,20,22,24–27].

To enable family members to play their active role and to limit the negative effects of caring family members need support. Professional mental health care workers may be an important source for support, since they are acquainted with psychiatric diseases and therapeutic possibilities in general, they know the patient and they probably meet his or her family members on a

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regular basis. Thus, it is important to pay attention to the relationship between family members and mental health care workers to see whether they do indeed support family members so as to enable them to play their active role. In this study we explore the ways in which family members experience their contacts with mental health care professionals.

2. Methods

The study was conducted using a multi-method design. Such a design enables researchers to compare different data, thus allowing for cross-fertilization and triangulation. On the one hand one may get ideas and information from one method which one would not have acquired by other methods. On the other hand one can use the multi-method approach to check whether data collected by one method (say by interviews) can also be witnessed if one uses another method (say observation) [28]. In order to maximize the chances of cross-fertilization we used two research methods simultaneously, viz. semi-structured interviews and observation. We conducted semi-structured interviews with 18 family members of mental health patients in the Netherlands. Our interviewees included parents, siblings, partners and a daughter of a patient, all of them family members of patients with severe and long-term conditions (most often schizophrenia, sometimes with an additional diagnosis of autism, or an eating disorder, in two cases manic depression and in three cases the diagnosis remained unclear even though the patients had been in contact with the mental health care sector for a long time). The family members we interviewed were all actively involved with the patient. Respondents were contacted through Ypsilon, an organization for family members of patients with schizophrenia and psychotic episodes ($n = 14$) and through the family council of a mental health hospital in the Netherlands ($n = 4$). We worked with a topic list in order to ensure that core areas were covered but respondents were given the opportunity to relate their individual stories. Our topic list was composed after a literature search on the subject of family members in mental health care. The topic list consisted of some general background questions such as the relation to the patient, the diagnosis of the patient, the medical (psychiatric) care the patient was currently receiving and how much contact there was with the patient. We further asked what kind of care family members provided for the patient and how having a severely afflicted mental health patient as a family member affected their own lives. We then asked about their experiences with professional mental health care workers: how did they communicate with them about the patient and did they receive support from them. The interviews were recorded on tape and fully transcribed, except for two on the respondents' request. In these two cases extensive notes were taken by the interviewer at the time of the interview.

In addition, we interviewed other parties involved in the care of mental health patients: a mental health patient, who sat on a patient council of a mental health hospital, a patient who was active in a patient organization, two social workers, four psychiatric nurses and the assistant of the family council, to probe their feelings and ideas on the contacts between family members and professionals.

During the same period we performed observations at a long-term care ward of a mental hospital during 1 week, and we observed four meetings of the hospital's family council and two meetings of the client council. During these observations extensive notes were taken by the researcher concerning family contacts and the experiences with and opinions of health care workers and family and client council members concerning this subject.

We performed a content analysis on the interviews and observations. Two researchers independently analyzed the inter-

views and the observation notes. After seven interviews a preliminary analytical scheme was composed, which was refined after analyzing the other interviews. We analyzed the data on the following subjects: (1) carer activities, (2) effects of carer activities, (3) receiving information from professionals, (4) providing information to professionals, (5) consultation with professionals about the care of the patient and (6) support needed and provided.

To accomplish further triangulation we presented our preliminary findings at an Ypsilon conference at which family members were present, at a schizophrenia conference for mental health care workers and at a symposium of a mental health care institution where both family members and mental health care workers were present. In addition we sent our preliminary research report to Ypsilon and a mental health hospital for comments. If either of these audiences would have informed us that our findings were incorrect, one-sided or biased according to their own experience, we would have searched for additional data (more interviews and more observations). However, the conference audiences as well as our contacts at Ypsilon and the mental health hospital informed us that our findings looked very plausible and familiar to them.

This type of research does not require consent from an ethics committee in the Netherlands. We asked our respondents permission to use quotations from their interviews, on the basis of anonymity, to which all of them agreed.

3. Results

In this section we will first describe the caring activities of family members. We will subsequently describe the experiences of family members with their contacts with mental health workers. An overview of the experiences of our respondents concerning their contacts with mental health care professionals can be found in Table 1.

3.1. Caring for a family member suffering from a psychiatric condition

All of the family members we interviewed ($n = 18$) performed carer activities. Family members report that they are often the ones to notice that there is something wrong, that their family member needs help and try to convince their family member to find this help. At a later stage they take care of the patient's finances, perform domestic tasks, provide daytime activities and check the patient's medication. Moreover many respondents ($n = 16$) report having to deal with their family member who engages in dangerous behavior (wandering the streets at night) or exhibits suicidal behavior. Family members also try to represent the interests of the patient when the patient cannot (temporarily) do this ($n = 17$), they help to formulate his or her care needs for instance. According to one of our respondents, things would have ended badly for her husband if she would not have done so:

I fear for people who do not have this support from their family, in case of my husband: he could have been dead now, or vegetating in a nursing home or something, [without me] he would have ended it himself. (wife of husband with a psychiatric condition)

In addition to taking care of the patient family members report of worrying about the patient ($n = 17$), about the care he/she receives, about his/her future, but also about themselves and the rest of their family. Family members talk about a mourning process whereby they have to say goodbye to the family member they knew and get another family member in return. This also affects the relationship they have with the patient. Furthermore, family members often experience physical or mental problems due to their caring activities ($n = 15$).

Table 1
Contacts with professional mental health care workers.

Respondent	Experiences with mental health care professionals
1. Mother of a stepson with a double diagnosis (psychiatric disorder and drug addiction)	Very bad, lack of information sharing and consultation. Has filed several formal complaints.
2. Husband of a wife with manic depressive illness	Very bad in the past, lack of information sharing and consultation. Is satisfied with current health care professional although still experiences problems in contacts because of autonomy of the patient.
3. Wife of a husband with a psychiatric disorder, diagnosis unclear	Variable, both positive and negative experiences. Has to be proactive in contacts herself.
4. Mother of a son with manic depressive illness	Mostly positive, although she experiences some problems expressing her concern about son's current condition.
5. Brother of a sister who had a severe psychiatric disorder and had been institutionalized for over forty years	Mostly negative, lack of information sharing and consultation. Had to be proactive himself to get information.
6. Mother of a son with schizophrenia	Variable, both positive and negative experiences.
7. Father of a son with schizophrenia and autism	Variable, both positive and negative experiences.
8. Mother of a son with schizophrenia and autism	Variable, both positive and negative experiences.
9. Mother of a daughter who suffers from psychoses and has an eating disorder	Variable, little contact with professionals, lack of information and consultation.
10. Mother of a son with schizophrenia	Very bad experiences in the past, lack of information and consultation. Has now established a good relationship.
11. Mother of a daughter with an undiagnosed psychiatric disorder	Mostly negative, lack of information and consultation.
12. Wife of a husband with schizoaffective disorder	Mostly negative, lack of information and consultation.
13. Daughter of a mother with schizophrenia	Variable, both positive and negative experiences in the past. There is now a good relationship.
14. Sister of a brother with schizophrenia	Variable, both positive and negative experiences. Has to be proactive in contacts herself.
15. Mother of a son with schizophrenia	Variable, both positive and negative experiences. Has to be proactive in contacts herself.
16. Mother of a son with schizophrenia	Variable, both positive and negative experiences.
17. Sister of a brother with schizophrenia	Is not primary carer for her brother and therefore has little contact with health care professionals.
18. Mother of a son with schizophrenia	Variable, both positive and negative experiences.

Given all these caring activities and their effects, contacts between professional mental health workers and family members are important, both for the patient and for the relatives, to be able to effectively care for the patient and to learn how to cope. So what kind of interaction with professionals do relatives need to enable them to play their active role?

3.2. Information

One of the things our respondents highlighted is that they need information about their loved one's mental health status, the professional care he/she receives as well as general information about the condition the patient is suffering from and the functioning of the mental health care system. All respondents mentioned a lack of information (*n* = 18). One respondent explains what information family members need but often do not get. According to her health care professionals should make an appointment to:

(...) provide general information and to agree on certain things. What is someone's role going to be (...), how are the tasks going to be divided [between mental health workers and family members]. (Mother of a son with schizophrenia)

For a long time the husband of a patient did not know what was wrong with his wife and consequently was unaware that her 'weird' behavior was a result of her illness. At the first ward where she stayed, he was not given any information:

Never had a conversation, never saw a leaflet. Then she went to a different ward. After about three months we got a leaflet: this is what you can expect given your wife's diagnosis. (Husband whose wife suffered manic depression)

Not being informed about the diagnosis was not reported by other respondents. They did report on not getting other information they needed such as information concerning the current condition of the patient, what the treatment would entail, what the role of the family should be, or whether the patient was expected to come home for the weekends. Family members did not receive such information as a matter of course:

A good relationship with family members of the patient is not a given. The relationship is not bad exactly, but you have to keep asking for information yourself. (...) there is no structure in the hospital that keeps you posted. (Brother of a sister who had been institutionalized for forty years)

Other respondents recognized that it was not routine practice to inform them about the patient, although many of them happened to meet professionals that did provide them with (some of the) information they needed (*n* = 15). Apparently it depended on the individual professional whether family members received information about the patient or not. The social workers we interviewed have dealt differently with the subject of informing family members over the years. In the past they did not inform the patients' family because of the privacy of the patient. Now they feel they should inform family members:

In the past I told [a relative] of a patient: I'm sorry. When you ask how [the patient] is doing I cannot answer (. . .). These days I changed my opinion on that subject somewhat. (. . .) I say to the patient: I am going to give information in general terms to let your sister know you're alive and you're not in trouble, otherwise your sister is worried and I don't want that. (social worker)

So the subject of informing family members is dealt with differently in practice by health care professionals. However it is clear that it often raises problems, since many family members feel they do not receive the information they need.

3.3. Consultation

Consultation between family members and professionals about the care of the patient is also difficult. Consultation between professional and informal carers can be important to gear their activities to one another. It is also important when the patient is incapable of representing his/her own interests. In that case relatives can advocate for the patient. However, family members often feel that they are not consulted enough ($n = 18$).

I have experienced when I wanted to visit my sister on ward A, that she had been moved to ward B. There was no consultation, it just happened. It also happened that she was lost for a while and then you hear the following day that your sister was lost. (Brother of a sister who had been institutionalized for forty years)

During our observations we saw another family member who had not been consulted about a transferral of her brother to another bungalow in advance but had only been informed about it afterwards. She made an appointment to complain about this:

During the break the sister of one of the patients came by. She called because she was very angry about what had happened. It was clear that she was still unhappy with the situation. (. . .) The cleaning woman later told the observer that this woman was right. 'What if your father is in a nursing home and suddenly he is moved, then you'd want to know!', she said indignantly. (Observations 15-12-2006)

A husband described how he had not been consulted about the decision to discharge his wife although discharge meant that he would have to take care of her again:

They just told me: your wife is coming home earlier. That's the only information I got. (. . .) and we were not ready for that, as a family, and my wife was nowhere near ready. But you had to comply, whether you wanted to or not. (Husband of wife with manic depression)

In order to be heard and consulted family members felt that they had to take the initiative themselves. One had to be assertive, to proactively and repeatedly contact health care professionals, in order to be acknowledged and to be able to represent the interests of the patient:

You just have to be assertive, you should not let them walk all over you, and then you accomplish much more. (Mother of a son with schizophrenia)

Again there are differences between mental health care professionals. Several family members also report positive encounters ($n = 13$). However, in general, consultation between family members and mental health care workers seems to be a problem.

3.4. Information for professionals

Contacts between health care professionals and family members are not only important because family members can represent the interests of the patient or provide care for the patient. It is also important because family members know a great deal about the patient.

Information about the patient that family members felt was important for the care provided by professionals was not always taken on board ($n = 18$). However, there were examples where family-professional communication was satisfactory according to family members, which meant that the importance of the information that family members have about the patient was recognized ($n = 13$). One of our respondents related a positive experience whereby the nurse had followed up on a lack of contact since the information she could provide was helpful to the nurse:

I call his nurse regularly because I feel that it's important that she knows what he's like. And when I don't call for some time she calls me and says: 'I haven't heard from you for a while and I really like to hear from you because you know so much about him'. (Mother of a son with schizophrenia and autism)

However, some respondents also had different and less positive experiences. One mother told us how she had been excluded from her son's care, and the far-reaching consequences that had:

They said that it [involving me] would not be good for his treatment. The consequence was that they started working with too little information, which resulted in a faulty diagnosis. Then he attempted suicide for a second time and a third. (Mother of a son with schizophrenia)

A father thought that it was important for him and his wife to talk with the professionals alone about their son, but this was not easy:

It is in his best interest that we do not mince our words for once. And when he's in the room you can't do that. And then I believe privacy is sometimes misused. (Father of a son with schizophrenia and autism)

Other respondents reported on experiences that could be placed between these two extremes. They were listened to but they had to work very hard to be heard.

Many family members ($n = 12$) report that mental health care workers point out that the privacy and the autonomy of the patient prohibits contacts with family members. However, they often feel that the privacy legislation is misused in order to avoid contacts with family members.¹ During our observations we saw mental health care workers making important decisions for patients without informing their family. This also happened when patients were clearly mentally incompetent due to their illness. Although mental health care workers make these decisions with the

¹ In the Netherlands the Psychiatric Hospitals (Compulsory Admissions) Act (*Wet BOPZ*) regulates decisions concerning compulsory care. In this act it is stated that patients can only be admitted or treated against their will when they are considered a threat to themselves or others. In other situations mental health care patients can legally make decisions concerning their treatment themselves. The Guardianship Act (*Wet Mentorschap*) makes it possible to appoint a legal guardian for mental health care patients who can take decisions concerning the patients' care, when a judge has decided that the patient is mentally incompetent. This does not happen often in mental health care, however (www.vilans.nl), in practice there are therefore cases, as are described in our article, where patients have difficulty making their own decisions and representing their own interests without there being a legal guardian to take decisions on their behalf. In those cases health care professionals and family members may not see eye to eye on who should represent the patient's interests.

patient's best interest at heart, it is obvious that the autonomous patient making informed decisions is not always the patient that mental health care workers deal with in practice. This makes the argument that family members cannot be informed, consulted or listened to because of the patients' autonomy a questionable one. It raises the question who should represent the interests of the patient and what the role of involved family members should be.

3.5. Support for family members

Information exchange and consultation about the patient is important for family members to enable them to play their carer role. However, aside from this family members need support directed at them to be able to cope with their carer role. This could prevent that family members get physical or mental problems themselves due to the burden of caring for their sick relative. Some respondents did not receive any support at all ($n = 6$). Others did, but sometimes in a way that they did not find very helpful ($n = 3$). Two spouses reported that when they finally got some attention they were given the advice to get a divorce.

Supporting family members does not necessarily have to involve difficult or time-consuming procedures. First and foremost family members seek acknowledgement and some understanding ($n = 8$):

When I visit my sister and she doesn't want to see me, then I like a nurse who is there for me and says: 'Hey, yesterday she was doing a lot better', or whatever. (...) I want someone in the hospital who calls me every six months, if necessary: 'How are you doing?' That's 5 or 10 minutes' work. (Brother of a sister who had been institutionalized for forty years)

Other family members need more support. For example, several of our respondents had followed a psycho-education course ($n = 4$). Others had help from a psychologist. Although such help was available, family members had to pursue it actively themselves.

4. Discussion and conclusion

4.1. Discussion

One of the limitations of this study is that we conducted interviews with a limited number of family members ($n = 18$), most of whom were contacted through Ypsilon, a family organization. It is possible that people that are in contact with or join such an organization are more critical than other family members. However, the different presentations of our research showed that the problems described in this article are indeed widespread in mental health care. Furthermore, although this study was performed in the Netherlands, there are signs that the problems outlined in this article are not typical only for the Dutch situation. The relationship between mental health care professionals and family members is problematic in other countries as well [5,6,8,9,12,14,24,29,30]. This means that family members do not receive the institutional support they need to fulfill their carer role.

Although it is often pointed out that the autonomy of the patient prohibits mental health care workers to inform family members, privacy regulation does not have to stand in the way of keeping family members posted [31]. Of course there can be legitimate reasons for a difficult relationship between individual mental health care professionals and the patients' family. It is possible that family members contribute to or even partially cause the development of mental illness [32,33]. It is also possible that patients explicitly ask their physician not to inform their family. However, these possibilities do not explain the difficult relationship between health care providers and family members in general.

Caring for a mentally ill person will remain difficult to some degree regardless of the course of action health professionals take. However, the problems relatives experience do not solely have to do with the severity of the patient's illness [15]. They are also partly caused by the way society and especially health care professionals relate to relatives. The concept of framing rules introduced by Hochschild can be enlightening to analyze the difficult relationship. Framing rules are rules according to which we ascribe meaning to situations [34]. Karp argues that the strong emphasis in the U.S. on individualism causes problems for family members who care for a mentally ill person. Caring for the patient is framed solely as the family's responsibility, which leads to problems of overload [15]. In the Netherlands, as in other countries, the problem seems to be slightly different. Health care professionals frame their own role towards patients and family members differently than family members tend to do. Health care professionals in mental health care frame their own responsibilities and tasks solely towards the (autonomous) patient. Patients' family members do not have a part in that relationship. Family members feel that they are closely related to the patient, that it is their responsibility to care for the patient. Family members frame themselves as fellow carers to professionals and feel that they should be included in the professional care process. Family members may be quite right in this. In modern health care one of the dominant paradigms is patient centered care [35]. However, the patient does not stand alone; his social context is also important [36]. In mental health care the focus on the patient seems especially strong, due to the anti-psychiatry movement in the 1960s and 1970s [37,38]. Since that period it is felt that mental health care patients need to be empowered [38]. Patient autonomy has become an important concept to ensure this empowerment. Mental health care professionals referring to the autonomy of the patient to explain why they cannot share information with family members show that these ideas have become ingrained in the culture of mental health care. Yet by referring to their role as informal carers, family members feel that they are entitled to information and support from health care professionals, which they need to fulfill this role. Thus, different framing rules lead to tensions between the family rights' perspective family members adhere to and the patients' rights perspective that has become dominant among professionals in mental health care [15,39].

4.2. Conclusion

On the basis of our study we conclude that the relationship between health care professionals and family members of mental health patients is problematic. All of our respondents have had negative experiences in the contacts with mental health care workers. Although many of them also reported on positive contacts, the general picture is gloomy. Family members find that this difficult relationship causes problems with regard to information exchange, consultation and support. This troubled relationship is a problem when family members are expected to fulfill their carer role. When they are not well enough equipped with information and support this becomes difficult. Although patient centeredness is a very important concept in health care [23,35,40], when focused on too much and in consideration of other factors it can lead to undesirable results, such as neglecting the social network around the patient in the case of mental health care.

4.3. Practical implications

This study shows that it is important to improve the contacts between mental health care workers and family members of patients who take care of the patient often for as long as they live.

Practitioners should provide information to family members, they should treat them at least partly as fellow carers, consult with them when necessary and support family members to enable them to play their carer role. The fact that health care professionals already deal with the subject of autonomy and patient laws differently [41], shows that changes are possible. Some training for professionals may be necessary to reframe their perception of the role of family members.

Funding

The authors wish to thank Meerkanten Geestelijke Gezondheidszorg for financing this research project in celebration of the 120th anniversary of their hospital and the 30th anniversary of their Family Council.

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