

Meeting Unmet Needs of Families of Persons with Mental Illness: Evaluation of a Family Peer Support Helpline

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Abstract Family members of persons with mental illness experience multiple stressors stemming from the burdens of caring for the ill family member. A potential source of help for this population is a family peer support helpline. Knowledge, however, is lacking about the types of help offered in such a service and its benefit for this population. In a study conducted in Israel, 800 calls made by family members of persons with mental illness to a family peer support helpline were analyzed utilizing an instrument developed for the family peers' evaluation of the calls. In addition, researchers conducted 77 follow-up interviews with callers who agreed to be interviewed. The findings indicate the importance of the life experience, flexibility and anonymity of the family peers in providing types of help that are complementary to the help provided by formal services. The most frequent categories of support provided were emotional support, information and advice. This help could assist family members of persons with mental illness with their care-giving role, as well as provide them with an alternative source of help if they experience difficulties with professionals. It could also serve as a catalyst in encouraging them to establish and maintain contact with the formal mental health services. Recognizing and supporting the contribution of a family peer support helpline would encourage its development within the range of services available for this population.

Keywords Helpline · Mental illness · Family peer · Families

Introduction

With deinstitutionalization a reality and with shorter hospital stays, many families have become primary caregivers of persons with severe mental illness (SMI). Families of persons coping with SMI experience a variety of stresses (Jewell et al. 2009; Pratt et al. 2007). Even when persons with SMI are not living at home, families are important sources of emotional and financial support, and often assist them with advocacy and housing (Brent and Giuliano 2007). Families may experience, however, deficits and gaps in the services available to them to cope with the stressors that stem from the caregiving role. Studies indicate that families have repeatedly stated that they need, but do not get, information about the relative's illness and treatment, assistance with managing illness symptoms and support for their own anxieties and depressed moods (Hummelinck and Pollock 2006; Rose et al. 2004). One of the services that may help families of persons with SMI with their unmet needs is a telephone helpline operated by family peers. Family peers are family members who are current or former parents/caregivers of a family member with mental illness. They serve as peers who support and coach caregivers with a family member coping with mental illness (Wisdom et al. 2011).

Lefley (2009) conceptualized three different types of stressors that a family may experience: situational, societal and iatrogenic. Situational stressors involve both objective and subjective burdens stemming from the caregiving roles of family members. Societal stressors include stressors that stem from societal attitudes such as stigma, cultural

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attitudes and general societal neglect of the needs of persons with mental illness and their families. Iatrogenic stressors involve an approach by professionals in which they emphasize parental causation of the mental illness and overlook the reality of burdens the family faces. This may lead to behaviours such as failure to provide information and support to caregivers and rejection of the families' involvement in treatment.

Family Peer Support Helpline

One of the most significant features distinguishing the family peer support helpline from professional mental health services pertains to the anonymity of both the callers and those who provide the service. A telephone helpline can ensure confidentiality, anonymity and accessibility (Cruz et al. 2001). Attention has been given to the relationship between anonymity and help-seeking behaviour. Whereas conditions of full identifiability have inhibitory effects on help-seeking behaviour, anonymity adds to the sense of security on the part of the help seeker (Nadler and Fisher 1986). Telephone helplines can serve populations that may not seek help from the formal mental health services for a diversity of reasons, including the stigma associated with mental illness or geographical locations in which there is limited access to mental health services.

Another feature differentiating between a family peer support helpline and professional mental health services is that this type of helpline, while falling within the scope of helping services, tries to avoid a professional image by using non-professional volunteers. Family peers providing help is an initiative focusing on the strength of shared experience and support provided by the peers, and is an adjunct to rehabilitative treatment. Combining crisis theory with self-help, family peers construct a relationship between equals that is based on the power of shared experience (Lane 1998).

Family peers bring unique strengths to their work. Among these are life experience, the development of successful coping techniques, and familiarity with successful resource strategies (Ingram et al. 2008; Leggatt 2002; Paulson 1991; Scharer 2005). Mowbray and Moxley (1997) note that family peers are able to provide services that are not always suggested by the formal services such as information about their rights and alternative treatment approaches. However, Leggatt (2002) notes that despite the potential importance of such programs for family members of persons with mental illness, they have not been subjected to evaluation and knowledge is limited about their contribution.

To contribute to a knowledge base about this kind of program, research evaluating the type of help provided to family members of persons with mental illness who called

a family peer support helpline has been conducted in Israel. The objectives of this research were to determine the areas of help provided and to evaluate how recipients perceived the help they were given.

Operation of the Family Peer Support Helpline

A family peer support helpline designed to help family members of persons with mental illness was established by a self-advocacy organization of persons with mental illness or family members of persons with mental illness. The organization is operated by them without any professional involvement, and it provides a number of other services to its recipients of help (such as supplying written information needed for coping with mental illness).

Those operating the helpline are volunteers who are primarily family peers. They received training about how to provide help to callers from two parents who developed and implemented guidelines based on the knowledge they acquired during their involvement in the helpline since its inception, as well as from their own life experiences. They included guidelines about ways to provide helpful support, including presenting basic active listening and engagement skills, suggesting constructive ways of sharing personal experience, and advising them about how to navigate the mental health system and resolve conflicts with mental health professionals. In addition, the guidelines related to skills needed to respond to crises and to conflicts with the family members with mental illness, and provided information and details, for example, about possible rehabilitation services and about the course of the mental illness and its potential impact. These guidelines are in line with the guidelines delineated in 'family-family' support programs in US (Rodriguez et al. 2011; Wisdom et al. 2011).

The volunteers who fulfilled the role of family peers were mentored throughout the first several months of volunteering by the two parents who developed the guidelines and who had also been active providers in the helpline. Two volunteers from a group of volunteers who served as family peers responded to callers each day for 6 h. Phone calls to the helpline were anonymous and anyone could call. Families were not limited in the number of calls they could make, thus it was not known how many times a family member called. In a limited number of cases, based on the callers' requests and their agreement, the volunteers provided practical advice, such as helping the caller to connect with and receive help from treatment and rehabilitation services. Because only two volunteers responded to calls each day, it was not possible to match the type of mental illness of the ill family member of the callers with the type of mental illness of the son/daughter of the family peer providing help. Callers learned about the existence of the helpline and services it provided via written

information distributed to mental health services, services for families of persons with mental illness and the electronic media.

Methodology

This study focuses on evaluation of the calls made by family members of persons with mental illness to a family peer support helpline. All the phone calls of family members of persons with mental illness to the helpline during a period of 2 years were evaluated by the family peers. Follow-up interviews were conducted with callers who agreed to reveal their identity and be interviewed.

A semi-structured instrument designed for this study to determine the areas of help provided during the phone calls was completed by the family peers after each call. In addition to this evaluation, follow-up interviews were conducted using an open-ended instrument with callers who agreed to reveal their identity and be interviewed about how they perceived and evaluated the help they received.

Instruments

The semi-structured instrument included four categories, each category containing items describing more specifically the type of help provided, as well as an open-ended question for information not specifically mentioned in the structured items. The family peers marked those items in each category that described the type of help they provided. The four categories were: (a) emotional support (three items, e.g., provision of encouragement and support, provision of hope), (b) advice about how to cope with difficulties the family members encounter (five items, e.g., coping with issues related to the relationships with the person with mental illness, the relationships with professionals), (c) specific information (12 items, e.g., information about mental health services, about the mental illness of the family member), (d) connecting with rehabilitation and treatment services (eight items, e.g., residential services, vocational services, medical/psychological help, assistance with applications for benefits).

The instrument also included a background section that could be completed without compromising anonymity, including the caller's gender, his/her relationship to the person with mental illness and the living situation of the person with mental illness,

The instrument utilized for the follow-up interviews contained open-ended questions. It included the following items: (a) whether the phone conversation was helpful and what was helpful, (b) whether any change occurred in the situation about which they called and, if yes, what was the

nature of the change, and (c) what they thought about the fact that the help was provided by family peers, i.e., other family members of persons with mental illness.

Procedures

The instrument utilized to evaluate the phone calls was based on an instrument developed by one of the family peers who based it on content analysis of written summaries of the help provided during 350 phone calls not included in the study. The categories and items included in the instrument were developed further for the purpose of this study. The face and content validity of this instrument were examined via a pilot test conducted with 30 phone calls. The family peers received training about how to complete this instrument from the principal investigator. They confirmed that the instrument accurately reflected the types of help they provided in the helpline.

Each family peer, after responding to a phone call made by a family member of a person with mental illness, completed the instrument developed for this study. It took them a few moments to complete the evaluation of the types of help provided in the phone call. The family peers indicated in the background section only the background information that they were able to discover without asking for identifying information.

Since the phone calls to the helpline were anonymous, each of the callers was asked at the end of the conversation whether he/she would agree to participate in a follow-up interview to assess his/her subjective perception of the assistance he/she received. Only those who agreed to participate and, consequently, reveal their identity were contacted 3 months after their phone call. Thus the sample of participants in the follow-up interviews, $n = 77$, was a convenience sample of those who felt comfortable enough to reveal their identity. They were interviewed by a member of the research team who is also a parent of a child with mental illness. The length of each interview was between 15 min to about half an hour.

The data gathered from the semi-structured instrument completed by the family peers after each phone call were analyzed quantitatively. The analysis focused on each of the four main categories included in the instrument and the items in these categories.

A qualitative method of data analysis, using the grounded theory as a guiding framework, was utilized to analyze the data collected from the follow-up interviews. The themes and categories were not determined before the data collecting stage, but were identified as the data were analyzed (Janesick 1994; Miles and Huberman 1994).

To address possible concerns about the reliability of this analysis of the data, two university based researchers who were not involved in the helpline conducted the qualitative

analysis. In addition, the classification of the themes and categories was examined by two staff members of the helpline. Inter-rater reliability indicated 90 % agreement among the researchers and assessors of the analysis. This research was approved by the human subject committee of the university where the principal investigator is employed.

Results

Family Peers Evaluation of Phone Calls

All the phone calls made to the helpline during a period of 2 years were evaluated. Eight hundred calls were made during this period, most of them by women ($n = 638$, 80.4 %). The majority of the calls were made by parents of persons with mental illness ($n = 483$, 60.8 %). Other calls were made by their spouses ($n = 45$, 5.7 %), their siblings ($n = 133$, 16.8 %), their children ($n = 35$, 4.4 %) and other relatives ($n = 60$, 7.6 %). Because of the anonymity, in a small number of calls, the caller did not identify his/her relationship to the ill family member.

The area of help marked most frequently by the family peers in their analysis of the help they provided in the phones calls was that relating to the emotional support category. The three specific types of emotional support provided were: provision of an opportunity for catharsis ($n = 596$, 74.5 %), provision of support and encouragement ($n = 574$, 71.8 %) and provision of hope about the callers' ability to cope with difficulties ($n = 464$, 58 %).

The second most frequently marked category was defined as provision of advice (see Table 1). The items most frequently cited within this category were: suggestions made by the family peers based on their experience about how to cope with difficulties in the relationships with the family member with mental illness and with difficulties in the relationships with professionals (psychiatrists, psychologists, social workers and physicians). Other areas included suggestions about how family members could deal with the way they feel about themselves because they have a family member with mental illness, and suggestions about how to deal with difficulties in their relationships with other family members who are not coping with persons with mental illness. The item cited with the lowest frequency related to suggestions made by staff members about ways of coping with stigma.

Within the third category, provision of specific information, the item marked most frequently was that of requests for specific information about services that provide psychological treatment for the person with mental illness (see Table 2). Other items that were frequently cited related to requests for information the callers felt they needed for the care of their family member (e.g.,

Table 1 Advice about how to cope with difficulties ($N = 800$)

Subject of coping	Frequency	%
Issues concerning the family member with mental illness	287	35.9
Relationships with professionals	247	30.9
Feeling about the self	194	24.3
Relationships with other family members (excluding the person with mental illness)	141	17.6
Stigma	55	6.9

The % of each of the items is based on $N = 800$, the number of phone calls analyzed. Because the evaluators could mark more than one item within each category, the numbers and % cannot be combined

Table 2 Specific information ($N = 800$)

Type of information	Frequency	%
Services which provide psychological treatment for the person with mental illness	280	35
About the mental illness	154	19.3
The eligibility criteria according to the law for rehabilitation services	149	18.6
Medications and medical treatment	117	14.6
Self help and support groups	105	13.1
How to act during periods of emergency	106	13.3
Rehabilitation services	81	10.1
Psychological treatment for family members (not for the person with mental illness)	80	10
About other rights of persons with mental illness (other than the eligibility criteria for rehabilitation services)	76	9.5
Dual diagnosis	23	2.9

The % of each of the items is based on $N = 800$, the number of phone calls analyzed. Because the evaluators could mark more than one item within each category, the numbers and % cannot be combined

information about the mental illness of the family member, the rights for provision of rehabilitation services according to public law, medications and medical treatment). Two of the items related to the needs of the callers or other family members who are not coping with mental illness. Information about self help and support groups, ranked fifth in this category; information about psychological treatment for family members, ranked eighth in this category.

Items included in the fourth category, requests for practical help in connecting with rehabilitation services, were marked with less frequency than the other categories (see Table 3). The items cited most frequently by the family peers were: help with the process of receiving approval for governmental rehabilitation services, help with finding a rehabilitation service for the family member with mental illness, and help with submitting applications for benefits.

Table 3 Connecting with rehabilitation services ($N = 800$)

Type of help	Number	%
Receiving governmental approval for the eligibility of rehabilitation services	64	8
Finding a rehabilitation service for the family member with mental illness	55	6.9
Help with submitting applications to the social security office	54	6.8
Help in receiving treatment services for the family member with mental illness	38	4.8
Help with finding adequate employment for the family member with mental illness	27	2.2
Help with seeking legal advice	23	2.9

The % of each of the items is based on $N = 800$, the number of phone calls analyzed. Because the evaluators could mark more than one item within each category, the numbers and % cannot be combined

Follow-up Interviews

Qualitative analysis of the follow-up interviews conducted with 77 family members who called the helpline revealed that the four types of help they perceived to be helpful were: (a) providing emotional support ($n = 29$, 37 %), (b) providing help in overcoming barriers and difficulties encountered when receiving help from the mental health services ($n = 29$, 37 %), (c) providing information needed for helping the family member with mental illness ($n = 22$, 28.5 %), (d) helping them learn specific coping strategies ($n = 20$, 26 %).

It should be noted that analysis of each of the types of help mentioned in the open-ended interviews by the callers corresponded to the categories or items that were revealed in the qualitative analysis of the follow-up interviews. Therefore, the content of the follow-up interviews provides support to the content validity of the structured instrument.

Interviewees emphasized significance of the immediacy and accessibility of receiving help via the phone conversation. They also noted the understanding expressed by the staff: "I was in emotional turmoil and the support and encouragement of the family peer helped me to function." "The family peer understood what is going on with me and gave me a lot of information and support; it is good to speak with people whom I don't know personally." In addition, they mentioned how significant it was, when they had been in crisis situations, that the family peer did not leave them alone but provided them support: "I'm coping as a mother of a son with schizophrenia; each time that my son is being hospitalized, you were there for me...you were always listening, being supportive and providing hope." "The family peers did not leave me alone; they provided me support until the end of the hospitalization process of my brother."

The second type of help they cited related to overcoming the barriers and difficulties in receiving help from the mental health services. The interviewees noted that the phone conversations helped them to learn how to deal with the formal helping systems: "I received guidance in the phone conversation about how to be more practical, to prepare a list of questions for the psychiatrist about medications and their side effects." "Our son is in supported housing and the phone conversation helped us in our interaction with the professional staff; we received important suggestions about how to collaborate with the staff there and about the need to be less critical of them." Interviewees also related to the empowering effect of the conversations: "The conversation gave me confidence to continue and fight for my rights."

The respondents emphasized that the phone conversations served as a catalyst for them to connect with rehabilitation services. They said that, especially in those situations in which they were in a quandary about contacting the professional services or they had difficulties in finding helping resources that will meet their needs, they received practical help from the family peer. Several components were cited as catalyzers for seeking help: the family peer enhanced their motivation and awareness of the need to seek help; a specific recommendation given about a helping resource motivated them to contact that resource; and a suggestion they received to join a support group for parents served as a catalyst to seek additional helping resources. "Since my son is not cooperating and is not willing to receive help, after the phone conversation, we understood that we need to help ourselves and to join a support group, as suggested to us in the conversation."

As for the third type of help, providing information and advice needed for helping the family member with mental illness, the interviewees noted that the family peer helped them to overcome the dilemmas and conflicts that are embedded in receiving help with the difficult situations they face. As one of the interviewees noted: "With your encouragement I decided to hospitalize my son with coercion; without your help my situation would have been very difficult." "After many years of coping with my brother who is not willing to receive help and to help him, we understood that we cannot go on in this way; we sought help and my brother was taken out of our home; this was done following the phone conversation to the helpline."

The fourth type of help related to advice received about learning specific coping strategies. The interviewees mentioned that they learned, for example, how to perceive the problem of the ill family member and cope with it, and how to develop a better sense of control over their own lives. "During the time that we called the helpline, all our family members had been anxious and there had been many question marks; no one had been able to help the other. The

conversation gave us a different perspective on our lives, how to divide the problem into small components and to cope with it in stages.” “The strategies that I acquired with your guidance enabled me to maintain harmony at home, to cope successfully with the subject of medications and to convey to my son their significance in preventing the next hospitalization. I do have control over our lives and I’m not scared anymore.”

As part of their coping strategies, they related to receiving concrete information about the rights for rehabilitation services for the family member with mental illness and about how to file requests for receiving rehabilitation and treatment services. They also stated that they received information that helped them to understand the meaning of the illness and the processes that one may experience while coping with the illness. “I received written information from the helpline that helped me understand the complexity of the illness, and increased my awareness of the disability and its meaning.”

A different question in the interview was whether or not the respondents felt that there was any significance to the fact that the helpline was operated by family peers. The answers indicated that the respondents felt that a person who has been in their place can understand how they feel and give the assistance needed, along with encouragement, empathy and hope. Emphasis on the phrase “understanding their situation” was dominant in their answers. “Persons who have not been there do not understand what I have been experiencing.” “They understand what I’m experiencing and I feel that help comes from very deep inside.” The sense of being understood that they received from the family peer providers during the phone conversation enabled many of them to develop a feeling of trust that was expressed during the interviews. “I felt accepted, that I’m being understood and I felt an immediate trust toward the person in the helpline.” Such feelings enabled them to speak without feeling criticized. “There was no criticism about my decision to take my son out of home.”

Discussion

The findings suggest that the helpline may make a unique contribution to the services available to family members of persons with mental illness as they confront ongoing stressors and burdens in their daily lives. The life experience of the family peers was an important characteristic of the helpline, which was for the family members a complementary service available within the range of existing formal services. As reported in the follow-up interviews, the respondents indicated that the emotional support received from the helpline, especially during times of crises, and the sense of being understood by family peers were

distinctive features of the helpline. Interviewees also emphasized the value of receiving advice about how to cope with their family member with mental illness from persons whose experience might be similar to their experience.

The most frequent types of help provided by the family peers reveal the callers’ unmet needs. The emotional support provided in the helpline could be understood, for example, in light of the ongoing difficulties families of persons with mental illness may experience along with the limited support they may receive from the formal mental health services. It is worth noting that the second largest category of family members who called the helpline was siblings of persons with mental illness (the largest category was the parents), a population whose needs are especially overlooked by the formal professional services.

Another common type of help offered in the helpline was provision of information relating to the treatment and rehabilitation of the ill family member (e.g., help about service availability and eligibility). This corresponds to studies conducted with parents of children with mental illness who reported that there is a scarcity of information being provided to them by formal services (Hummelinck and Pollock 2006; Rose et al. 2004). Acquiring adequate information about, for example, the specific nature of the mental illness and how to cope with it, and about the effects of medications might be a way to help family members overcome iatrogenic stressors resulting from not receiving adequate information from professionals (Lefley 2009) or not being in any kind of contact with professionals.

The relatively large number of phone calls evaluated may provide a basis upon which to draw some conclusions about how a family peer support helpline may respond to some unmet needs of family members of persons with mental illness. However, this study is an evaluation of one helpline and on the nature of help it provided, and so its generalizability might be limited. The findings rely primarily on the family peers’ evaluation of the help they gave to the callers, although the responses of the callers who agreed to be interviewed showed that the type of help they said they needed was in line with the type of help that was provided.

The study did not examine dilemmas and conflicts which may arise from provision of help by family peers. One could question, for example, whether or not there should be any limits on the type of information, advice, or consultation the family peers supply. Can they decide to provide any type of information they think is relevant for the callers? Should they avoid certain topics, such as medications, which may require special training? Another possible limitation is that there was no examination of what effect utilizing the varying life experiences of the family peers might have had. Nikkle et al. (1992) noted, for example, that there might be a tendency of some family

peers to generalize their own experiences to the to the life situations of those calling for help. A future study should also examine the possible limits of a family peer support helpline.

Summary and Conclusion

The family peer support helpline is a service that could provide an accessible, flexible and anonymous resource for helping family members of persons with mental illness. These components could be especially significant for this population because of the multiple stressors they may experience along with the limited opportunities they may have to discuss their own subjective sense of burden in their ongoing contact with formal services (Pratt et al. 2007).

The helpline should be viewed as one type of service along the continuum of the range of formal and informal services family members of persons with mental illness may need. It is a service complementary to the formal services available and provides for needs which are not generally met by the formal services. It can also serve as an important alternative source of help in cases in which family members experience difficulties with professionals, as well as a catalyst helping them to establish contact with formal mental health services in situations in which callers receive assistance about how to overcome iatrogenic stressors.

Because of the complementary and alternative functions the helpline fulfils, development of a family peer support helpline within the range of services needed for this population should be encouraged. At the same time, there is a need to continue and develop knowledge about the potential contribution of the helpline, as well as the limitations of its provision of help.

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