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The forum as a friend: parental mental illness and communication on open Internet forums

My Widemalm · Fredrik Hjärthag

Abstract

Purpose   The aim of this study was to identify how daughters or sons to parents suffering from mental illness perceive their situation. The objective was to provide new knowledge based on what they communicate on open Internet forums.

Methods   The sample consisted of forum posts written by individuals who reported that they had mentally ill parents. Data collection comprised 301 comments from 35 forum threads on 5 different Swedish Internet forums, and predetermined inclusion criteria were used. Data were analyzed qualitatively using thematic analysis.

Results   The analysis generated four themes: "Caregiver burden," "Knowledge seeking," "Support from the forum," and "Frustration and powerlessness over health care." The results showed that parents' mental illness affected the forum writers on several levels, and they often felt stigmatized. The writers often lacked knowledge of their parents' mental illness and sought out Internet forums for information and support from peers in similar situations. The psychiatric care given to the parents was a source of dissatisfaction among the forum writers, who often felt that their parents did not receive adequate care.

Conclusions   This study shows that fear of stigmatization and perceived lack of care and support caused forum writers to anonymously seek out Internet forums for information and support from others with similar experiences. The role of social support and the attractiveness of anonymity and availability typical for open Internet forums ought to be considered by health care professionals and researchers when developing new ways for providing support for children or adolescents with a mentally ill parent.

Keywords   Parental mental illness · Internet forum · Stigma · Support

Introduction

Living with a mentally ill parent is complex and challenging [1]. Adults with mentally ill parents have described how, as children, they had been unprepared for the alterations and symptoms their parents displayed during their illness episodes [2]. Furthermore, they described how the families often isolated themselves and, in several cases, how, as children, they had to take on a huge responsibility. As psychiatric outpatient care has become more common in recent years, more parents with severe mental illness also spend more time with their children [2]. Despite this, several studies have shown that these children seldom are informed about the illness and its effects, but that they usually want to receive this information [2–4]. Östman and Hansson [5] showed that the needs associated with having a mentally ill parent were only accommodated in half of the cases in their study, thus indicating the importance for psychiatric care to enhance the focus on all family members in treatment—especially the children.

Having a parent with a mental illness is often associated with feelings of shame and stigma. One study showed that children to mentally ill parents often strive to show that their lives are similar to those of their peers just to avoid stigmatization [6]. In their quest for "normality," the most obvious strategy is to hide the parent's mental illness from others. Hence, children cope with stigma by hiding those

M. Widemalm · F. Hjärthag (✉)
Department of Psychology, Karlstad University,
65188 Karlstad, Sweden
e-mail: fredrik.hjarthag@kau.se

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parts of their lives they think could be viewed as different [6]. Nowadays, it is possible to break the isolation caused by the stigma by participating in supportive Internet forums. In these forums, the recognition and acknowledgement from peers could help reduce feelings of alienation, loneliness, and social isolation [7]. Users of online forums can send messages to each other to give emotional support or to share knowledge and experiences [8]. The opportunity to be anonymous on Internet forums is essential for many of the users. The anonymity promotes users to be open and honest about their situation when writing on the forums and, hence, breaks their isolation without the risk of stigmatization [7, 9]. On an online supportive website, Trondsen [4] investigated the communication between sixteen Norwegian adolescents who had parents with mental illness, and found that the adolescents' everyday lives were deeply affected by their parents' illness. Their communication on Internet forums addressed a number of difficulties and complex challenges that they tried to cope with, and they actively asked for advice, proposed strategies, as well as shared their own ways of trying to deal with difficult and challenging situations [4]. Trondsen and Tjora [10] also showed how online activities could be linked to what happens offline.

Research on having a mentally ill parent has frequently been based on methods using information from the person taken ill or from another adult, whereas the children's own perspective of their situation has often been ignored [1, 3]. However, the recent development of the Internet provides researchers with new methods for both learning more about the problems with parental mental illness and trying different web-based ways to alleviate burden [10]. Web-based forum interventions for relatives, where researchers design and recruit to the forums in a top-down manner, have proved efficient for participants in many different settings and generated important knowledge [10–12]. Nonetheless, research also shows that the level of professional involvement on a forum affects forum activity [13].

To study aspects of parental mental illness using information from open Internet forums with no involvement from the researchers, thus brings a relevant perspective to existing findings. Hence, the aim of this study was to investigate what offspring of parents suffering from mental illness, communicate about on open Internet forums.

Methods

Data for this study were collected on the Internet by searching for publicly available Swedish Internet sites with forums where daughters or sons to mentally ill parents shared their experiences. The forum threads studied were all written in Swedish by persons who stated that their

parents suffered from mental illness. Forum threads active in a time frame of three and a half months were selected, and the data were analyzed qualitatively using thematic analysis [14].

Data collection

Internet forum selection

Publicly available Swedish Internet sites with forums were searched for with the Google search engine using the Swedish words for *forum*, *mental illness*, and *relative*. The search generated about 37,800 results, of which the first 100 results were examined in more detail to determine whether they contained, or were linked to, a publicly available Internet site with a forum. In all cases where a forum was found, further investigation was done in order to search for forum threads written by people who disclosed that they had mentally ill parents. All Internet forums that were found this way were included in the study for further investigation—except forums where questions from anonymous writers only were answered by professionals and closed forums where membership was needed to gain full access. In total, five different Internet sites with forums were finally selected for the study.

Forum threads selection

Further search for relevant forum threads in the five selected Internet forums was then conducted. The search covered forum threads that had been written or active from January 1 to April 17, 2013. A thread was considered relevant if it could be identified as written by a person who, in some way, described herself or himself as having a parent with a mental illness and if the topic, to some extent, dealt with this specific relationship. It was not a necessary criterion that the writer had to know if, or write that, the parent had been diagnosed with a specific psychiatric diagnosis. From one of the five Internet forums specifically directed at children of mentally ill parents, all active forum threads within the given time frame were included in the study. For the other four somewhat broader Internet forums, headlines of all threads were searched for the Swedish words for *relative*, *child*, *mentally ill parent*, *mother*, and *father*. If one or more of these words were found in the headline, the thread was read to determine whether or not the thread could be considered relevant and, thus, included in the study.

Data extraction

When all relevant forum threads had been identified, data were extracted for the study by copying each selected and

complete thread into a transcription document for analysis. The number of threads and comments were noted, as were the number of names or pseudonyms and age, before these data were omitted for reasons of anonymity in the adaption of a uniform transcription.

Sample

In all, 197 different names or pseudonyms were noted among the forum writers in the collected data. Of these forum writers, 29 had stated their age, giving a mean age of 22 years, where the lowest age stated was 13 years and the highest age was 49 years. The final and complete transcription was based on a total of 35 selected forum threads that, in all, contained 301 comments and amounted to 166 pages of text for analysis.

Analysis

A thematic analysis was used according to the steps described by Braun and Clarke [14] to identify, analyze, and report themes from qualitative data.

Step 1: All transcribed material was read through, and patterns in data were sought. No structured coding was done in this initial reading step, but simple notes were written in the margins to record interesting content in relation to what the forum writers communicated about.
Step 2: Initial coding was generated in relation to the purpose of the study. All material was read through again, but this time a systematic initial coding was done on what the forum writers communicated about. This initial coding was done on different post-it notes.
Step 3: In this step, the initial codes from step 2 were used to search for potential themes. Initial codes that seemed to cover similar topics were clustered together into seventeen potential themes (Table 1).
Step 4: A critical review of the seventeen potential themes was conducted in this step. The review was done on two consecutive levels. At the first level, we critically investigated the parts constituting each potential theme in order to determine whether that particular theme seemed valid or not. If a potential theme was considered valid enough at the first level, then, at the second level, all transcriptions were read through in search of a consistent pattern that could further confirm and strengthen the potential theme. At this second level, we also considered whether the potential theme worked in relation to both the entire data set and the purpose of the study. At this step, one potential theme ("To break with the parent taken ill") was omitted, whereas the other sixteen potential themes were kept and reorganized in relation to each other to form the final themes.

Step 5: Here, each final theme that emerged from the previous step was given a definition—based on supporting data—and a name (Table 1). The definition of each final theme hence described the essence of that theme.
Step 6: At this concluding step, the final themes were reported in the results section with their names, definitions, and supporting extracts from the data transcripts.

Results

The analysis generated four themes that describe what the forum writers in the study communicated about on the Internet forums. These themes were called "Caregiver burden," "Knowledge seeking," "Support from the forum," and "Frustration and powerlessness over the health care" and are described with supporting quotes below.

Caregiver burden

The mental illness did not just affect the parents taken ill, but also the forum writers. Many of the writers were exposed to a pressure directly related to their parents' illness—for instance, present symptoms that they did not have the ability to grasp or handle. For several forum writers, this pressure led to different types of stress reactions that affected many areas of their everyday lives, such as education, social networking, responsibilities, and their health.

Some forum writers could not concentrate in school, and their grades dropped. In this situation, they could not get the support they needed from their parents because of their parents' mental illness. "Then, when mum came home after having been in psychiatric care for 2 months, I could hardly look at her, I couldn't forgive her. I stopped going to school, I hated everything, stopped playing soccer."

In situations like this, many forum writers commented that they spent less time with their friends. Instead, they stayed at home with their parents. In some cases, they stayed at home for fear that their parents would harm themselves if left alone; in other cases, they did not have the energy to hang out with their friends. "Several times when I was out, she called me crying and asked me to come home. I wanted nothing more than to be out with my friends and to forget about everything then. But the fear of her doing anything stupid to herself was too strong. At that time I didn't have much leisure time. Always hurried home to make sure that mum was okay."

The amount of responsibility that the forum writers took in everyday life varied depending on the severity of their parent's mental illness as well as on how much responsibility the healthy parent, if present, took in the family.

Table 1 The seventeen potential themes that emerged from the third step of the thematic analysis, and how they in later steps were merged into the four final themes

Potential theme number	Potential theme name	Final theme
1	The forum writer having problems coping with the parents' mental illness	Caregiver burden
2	The forum writer's mental health is affected	
3	The forum writer's everyday life is affected	
4	The forum writer takes great responsibility in the family	
5	Seeks support, advice, and information from others on the forum who are in a similar situation	Knowledge seeking
6	The parent's lack of illness awareness	
7	The forum writer's knowledge of the parent's mental illness	
8	Fear of becoming ill like the parent	
9	The forum writer's feelings about having a parent with a mental illness	Support from the forum
10	Gratefulness for the support given	
11	Does not talk about the parent's illness	
12	Stigmatization	
13	Support from other forum writers	
14	Care and support given to the forum writer	Frustration and powerlessness over health care
15	Care and support given to the parent taken ill	
16	No understanding from the world around	
17	To break with the parent taken ill	(Not included in any final theme)

The seventeenth potential theme was omitted since it was not sufficiently supported by data

Some forum writers described how the healthy parent symbolized stability and took over all responsibilities: "Dad is just like your dad, the mentally healthy one and has always been the stable one…" However, the most common topic among the forum threads was that the writers took over the responsibility for the family when the parent was incapable of doing so due to illness. Forum writers often took responsibility for cooking, cleaning, caring for younger siblings, and caring for the mentally ill parent: "My biggest dream is to move away from home and live on my own because I can take so much responsibility, because it's something you learn after living with a mentally ill parent."

Living with a mentally ill parent is often described as stress exposing, which might be why several forum writers also commented that they themselves suffered from mental distress. The majority of the writers wrote about poorer health in terms of depression, anxiety, sleeping disorders, and so on. According to some forum writers, their poorer mental health was directly caused by growing up with a mentally ill parent and having to endure the behavior the parent displayed as a result of the illness: "3 years ago I had an eating disorder; because of that, and that people around me noticed it and helped me seek help, I realized that a lot of my problems might come from her."

Knowledge seeking

The forum writers were generally troubled and concerned about their mentally ill parent. These worries came from a lack of knowledge about the mental illness their parent suffered from. For instance, some forum writers saw a change in their parent's behavior, but they did not understand why the change occurred. One forum writer whose parent suffered from a psychosis described it as follows: "The first time I'd just turned 15. I'd never experienced anything like this before, so I didn't really understand why I suddenly couldn't recognize my own mother."

Worries about the parent's condition made many of the forum writers seek knowledge about the mental illnesses from other individuals on Internet forums: "Anyone who knows what I can do? Because she has no illness awareness, I don't think there's any other option than compulsory hospitalization. I'm thinking about adding extra emphasis on the fact that she'll soon starve to death." Also, some forum writers' fear of becoming mentally ill themselves was a driving force for them to seek out information about where they could turn for professional help to manage their own life situation: "Hey, is there anyone else who's afraid of becoming ill like their parent? I am EXTREMELY scared of becoming schizophrenic. Want guarantees that I won't get ill, but I know there's no such thing."

The forum writers often searched for knowledge about the mental illness that their parent was suffering from, both in order to understand their parents and to increase their own confidence in coping with their parent's behavior: "I think that my and my brother's lack of knowledge about our father's illness led us to feeling bad individually instead of 'facing the enemy together,' if you know what I mean. I think that we could have had an extra strong relationship if we had known what the problem was and had been able to talk about it."

Support from the forum

The parent's mental illness was a difficult subject for many forum writers to talk about. This was mentioned several times in terms of "the thing you do not talk about." Many kept their feelings to themselves and hid their situation from the world outside: "On the surface I might seem happy, but iťs the inside that hurts. Maybe that's what makes it so hard. No one sees me. I wish everybody understood how this feels. Then life would be easier."

The stigmatization of mental illnesses often restrained the forum writers from seeking support from their social environment. They did not want others to know that their parent was suffering from a mental illness because of fear of being seen as different from their peers. Hence, the illness must be kept a secret within the family.

On Internet forums, the forum writers were more confident to communicate their experiences and share their feelings with peers in similar situations than with someone who did not have a mentally ill parent. In addition, Internet forums also gave them the possibility to be anonymous. These aspects were important for several forum writers who otherwise often thought that they were alone in having a mentally ill parent. Also the possibility to communicate anonymously with others in similar situations was highly appreciated. Many were grateful for the existence of these Internet forums: "Also want to thank for a crazily good site. I was so happy (and touched) when I found it. I recognize myself in so many stories. And now, for the first time, I KNOW that I'm NOT alone."

On the Internet forums, the writers often supported each other. The majority of the forum posts received many responses from other forum participants. For instance, forum writers gave each other hope when life was hard: "Don't give up! You become stronger than you think from this shit. No matter how f***ing bad it hurts, how weak you feel, you shouldn't give up. Keep on fighting—I've done it and believe me, it will get better even if it sometimes feels hopeless." Having the opportunity to help or support others in their struggle with their parents' mental illnesses may also have a positive effect on those trying to help. In some ways the Internet forums seemed to fill the function of a friend: A true friend on a similar journey who listened, supported, and was available for the forum writers at all times.

Frustration and powerlessness over health care

The forum writers often ventilated both the frustration they experienced in regard to the care provided and their frustration with the lack of care that they thought should have been provided for their parent. Many times they had fought hard for their parent to receive adequate health care, and they often felt powerless when they could not control the situation: "After 2 weeks she was sent home, even though she didn't feel ready. I and my sister had to move home and take care of her ourselves. I will NEVER forgive the psychiatric institution for what they did to me and my sister. We literally had to act like 'extra mothers' to our own mother."

Many forum writers who took on responsibility for their parent also experienced feelings of helplessness in relation to health care. They often tried hard to get adequate help for their parent: "The next time they came, there was no room at the psychiatric clinic and they were going to leave her again, so I blocked the door, went down on my knees and cried and begged. Then they took her with them and she had to sleep in the dining room at the psychiatric clinic." The frustration, disappointment, and powerlessness that the some forum writers felt over the health care system and its treatment of their parents, have led to feelings of hate toward psychiatric care: "To allow two children to take care of their own mother?! Totally sick! They really made a tough period even tougher for me. I will never forgive them!"

Discussion

The results of this study show that the stress many daughters and sons experienced from having a mentally ill parent affected their lives significantly. For instance, some forum writers' school grades dropped and their social networks decreased as their responsibilities toward their family increased. In addition, many forum writers often felt alone in their situation, and in the forum threads on the Internet they wrote about the lack of support from professionals in psychiatric care and the social services. Some wrote that they had friends to talk to, but the majority of the writers on the forum threads expressed that they felt completely alone in their situation. This result differs from Pölkki et al.'s [2] study in which children to mentally ill parents stated that they had social support from family and friends. They particularly appreciated the support from their families since the family members were in the same

situation and understood each other [2]. However, the contrasting results of our and Pölkki et al.'s studies might be explained in terms of different sampling procedures and methodologies. The findings of these two studies, when taken together, thus highlight the importance of getting sufficient support—from family, friends, or from Internet forums.

To establish new relations with friends outside the family was problematic since the parents' mental illness was referred to as "the thing you do not talk about" by some writers in the forums. In line with this, Haug Fjone et al. [6] found that children expressed feelings of shame and fear related to having a mentally ill parent. These feelings made it necessary for them to hide their parents' mental illness from the world. The stigmatization of mentally ill individuals thus has a burdening effect on the situation for the children of mentally ill parents [3]. Also Pölkki et al. [2] found that parental mental illness was considered shameful and was therefore kept a secret within the family. Some children were told not to tell anyone else about their parent's illness [2]. Under these circumstances, the possibility of easing their isolation and burden by communicating their situation on Internet forums was of crucial importance for many of the forum writers—as the results of our present study highlight.

Furthermore, we also found that breaking their isolation by communicating on forums was important for many forum writers seeking information and knowledge about their parent's illness. Several forum writers were also worried about their own health and how they themselves could get support. These results are similar to those in a study by Trondsen [4] where adolescents with a mentally ill parent on an online supportive website discussed strategies on how to seek treatment from professionals in order to deal with their own feelings and experiences concerning their parents' mental illness [4]. In retrospect, also adults with mentally ill parents wished that they had had more information regarding their parent's illness and that they, as children, had received professional care [15].

All participants in this study actively sought out Internet forums to find other web users in similar situations as themselves. In some ways, the Internet forum served as a friend with whom the forum writers could vent their feelings and experiences and turn to for knowledge and support. Previous research also shows these beneficial possibilities of Internet forums where personal problems can be discussed anonymously in a unique way without the risk of stigmatization [16, 17]. The anonymity thus contributes to an openness and honesty while protecting the writers against stigmatization. Also, support from people on Internet forums who suffer from the same thing is considered valuable, especially when the need for knowledge was not met by professionals [9].

There are some limitations when studying open Internet forum threads this way. It cannot be controlled for, or guaranteed, that the forum writers really had parents with a psychiatric diagnosis since they were anonymous. Hence, we cannot be sure about the writers' age or sex, how honest they were when writing, or what their motives for writing really were. Research is still scarce, which is why our results should be followed up in future studies using method triangulation to learn more about the role that open Internet forums has for people with a mentally ill parent.

Conclusions

Conclusions from this study are that people with mentally ill parents communicate about the shortcomings they perceive in the professional care and support provided to themselves and their families. It is the perceived lack of support that pushes the writers to seek out Internet forums that could provide both information and support from peers in similar situations. These Internet forums are highly valued by the forum writers and are described as meeting spaces free from stigmatization—which could ease their burden to some extent. This study also contributes with knowledge about how daughters and sons of mentally ill parents perceive their life situation and how they communicate about it on open Internet forums. To conclude, we urge health care professionals and researchers to consider both the role of social support from peers and the attractiveness of anonymity and availability of open Internet forums when developing new support interventions for children or adolescents with a mentally ill parent.

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