

Communal Normalization in an Online Self-Help Group for Adolescents With a Mentally Ill
Parent

Marianne V. Trondsen¹ and Aksel Tjora^{1,2}

¹ University Hospital of North Norway, Norwegian Centre for Integrated Care and
Telemedicine (NST), Tromsø, Norway

² Norwegian University of Science and Technology, Department of Sociology and Political
Science, Trondheim, Norway

Corresponding Author:

Marianne V, Trondsen, University Hospital of North Norway, Norwegian Centre for
Integrated Care and Telemedicine (NST), P.O. Box 35, N-9038 Tromsø, Norway

Email: marianne.trondsen@telemed.no

Abstract

Although implications of parental mental illness are well documented, most children of mentally ill parents are left to manage their family situation with limited information and support. We explore the role of a Norwegian online self-help group for adolescents (aged 15 to 18) with a mentally ill parent. Through in-depth interviews with 13 participants, we find that the online self-help group provides “communal normalization” by which participants, through communication in the forum, make sense of everyday experiences and emotions arising from having a mentally ill parent. We identified three main aspects of this process, recognizability, openness, and agency, all of which are important for the adolescents’ efforts to get support, to be supportive, and to handle everyday life situations better. Communal normalization might provide resources for significantly improving the participants’ life situations, and could demonstrate similar potential for users in other situations characterized by stigma, loneliness, silence, and health worries.

Keywords

adolescents / youth, at-risk; Internet; in-depth interviews; mental health and illness; parenting; self-help

In this article, we explore the role of an online self-help group in managing everyday life for adolescents with a mentally ill parent. The study is related to research demonstrating that online self-help groups provide useful arenas for coping with various challenging life situations through the disembodied, mutual exchange of knowledge, experiences, and emotional support (Bar-Lev, 2008; Hinton, Kurinczuk, & Ziebland, 2010; Sandaunet, 2008b). The Internet is also found as a valuable communication tool in relation to stigmatizing conditions (Berger, Wagner, & Laurence, 2005). As young people are the most ardent Internet users (Andreassen et al., 2007), online health services tailored to youth groups have increased. These services provide help for various sensitive topics that young users find hard to obtain otherwise (Suzuki & Calzo, 2004). Adolescents are often reluctant to consult health care providers because of worries about confidentiality, shame, and stigma (Prior, 2012; Suzuki & Calzo, 2004).

Parental mental illness leads to a range of practical and emotional implications for children's everyday lives (Gladstone, Boydell, Seeman, & McKeever, 2011). Thus, this issue has become a subject of increasing concern in research, policy, and practice across Western countries. Mental illness is among the leading causes of ill health and disability worldwide. Recent estimates suggested that 37% of Norwegian children (0–18 years) have a parent with a mental illness (Norwegian Institute of Public Health, 2011). These children represent a significant risk group for developing mental illness or behavioral problems themselves, based on genetic, psychological, and social impacts (Beardslee, Versage, & Gladstone, 1998; Rutter & Quinton, 1984).

Children with a mentally ill parent often struggle with challenges such as difficult emotions, social isolation, additional care-giving responsibilities, financial hardship, and disruptions because of unpredictability of parents' illness-related behavior (Gladstone et al., 2011; Mordoch & Hall, 2008; Trondsen, 2012). They also suffer the burden of negative

attitudes, shame, and stigma of mental health problems (Fjone, Ytterhus, & Almvik, 2009), especially “courtesy stigma” (Goffman, 1963), i.e., stigma on behalf of others. In addition, most children in such families are left with limited information related to their parent’s mental illness, and formal resources for managing the situation (Mordoch, 2010). Few prevention and intervention programs, such as support groups, provide direct support based on the children’s own needs or strategies for managing the difficulties children face (Gladstone, 2010). A major hindrance to such programs is also that teenagers are particularly difficult to reach (Drost, Cuijpers, & Schippers, 2011).

A recent literature review of children’s experiences of parental mental illness concluded that new peer support interventions must be developed (Gladstone et al., 2011). Because the Internet is a medium for information and social contact commonly appreciated by adolescents, online interventions are expected to be effective tools in providing health care for those with mentally ill parents (Drost et al., 2011). However, the body of research on online self-help groups has focused primarily on services for adult users and for adult caregivers of a child/partner suffering from illness.

Studies of caregivers have demonstrated that online peer support from others in similar situations is a valuable resource (Gage & Panagakis, 2012; Gundersen, 2011). However, because of variations in disease, phases of sickness, contact with health care providers, and other contextual aspects, more research is needed to determine the usefulness of online information and support for caregivers (Gage & Panagakis, 2012). Moreover, children’s and adolescents’ perspectives are often different from those of adults (Mordoch, 2010). Studies of online support interventions for children and adolescents living with parental mental illness are nearly nonexistent (Drost et al., 2011).

In this article, we draw on a qualitative study of a Norwegian online self-help group for adolescents (aged 15 to 18) with a mentally ill parent. The overall aim of the study was to

explore the potential role of online self-help groups in supporting adolescents with mentally ill parents. In the online forum, the participants discussed various difficulties related to a parent's mental illness and how the participants were coping with these difficulties in the family (Trondsen, 2012). Drawing on in-depth interviews with the group participants, in this article, we explore the meaning of the online self-help group in adolescents' actual lives.

Perspectives on the Internet and Health

Over the past few decades, several studies have examined and debated various facets of the Internet's influence within the context of health care, addressing the implications for patients, clinicians, the medical encounter, and the structure of health care delivery (Broom & Tovey, 2008; Gage & Panagakis, 2012; Henwood, Wyatt, Hart, & Smith, 2003; Nettleton, Burrows, & O'Malley, 2005). Nettleton et al. (2005) classified the various responses to the proliferation of Internet-based health information as (a) "celebratory," (b) "concerned," and (c) "contingent" approaches.

Some researchers have viewed the increased lay use of the Internet for health purposes in almost celebrating terms, because of the supposed potential for transforming and recalibrating the power relations between patients and health professionals (Nettleton et al., 2005). They have suggested that lay use of the Internet provides pluralism and democratization, and establishing ground for an empowered lay expertise as a resistance to biomedical dominance (Hardey, 1999; Radin, 2006).

Others, however, especially within the medical profession, have been more skeptical about lay use of the Internet. In this perspective, there has been emphasized that online health information is of poor quality, and too often promoting potentially risky alternative care and therapies (Crocco, Villasis-Keever, & Jadad, 2002; Kiley, 2002). Hirji (2004) suggests that laypeople have insufficient expertise to assess the quality and reliability of Internet-based information. Others have shown laypeople's acceptance of unhealthy attitudes in some online

forums, such as proanorexia identities (Gavin, Rodham, & Poyer, 2008) and self-harming behavior (Whitlock, Powers, & Eckenrode, 2006).

Those who take a middle position contend that the empowering potential of the Internet and “Internet dangers” are overstated (Nettleton et al., 2005). These authors suggest that people’s use of the Internet for health purposes is contingent on their own needs in particular situations. Rather, the use (and nonuse) of the Internet in relation to everyday health practices and offline contexts is complex (Andreassen, 2011; Broom & Tovey, 2008; Henwood et al., 2003; Kivits, 2009; Nettleton et al., 2005; Sandaunet, 2008a).

Our study follows in this latter tradition. We explore how Internet use is embedded in a wider everyday context, as one of many sources of information and support, and with significant potential relevance for life as such. Accordingly, the research design includes everyday experiences of adolescents with a mentally ill parent, moving into the details of how participation in an online forum is related to “offline” experiences.

Study Design

In this article, we draw on in-depth interviews of adolescents with a mentally ill parent to explore how a web-based discussion forum designed for this particular group might provide support. The article is part of a larger qualitative study that includes observation and interviews in which the overall aim was to explore the potential role of online self-help groups for adolescents with a mentally ill parent (for more details, see Trondsen & Sandaunet, 2009; Trondsen, 2012). In this project, we drew on an action research framework. Action research describes methods that are participatory and grounded in experience, to pursue practical solutions to issues of pressing concern to people (Reason & Bradbury, 2006). The key objectives are improvements in practice and increased knowledge, with the researcher performing a dual role, as implementer and evaluator.

In the project, an online self-help group for adolescents with a mentally ill parent (aged 15 to 18) was established in December 2005 through collaboration between the Norwegian Centre for Telemedicine and a hospital in Norway. The self-help group was hosted by an existing, national web site run by this hospital, for children and youths with mentally ill parents. The web site includes various services available to everyone: information pages, an open access forum, and a question-and-answer service in which health professionals respond to questions sent by users of the web site.

Participation in the self-help group was open only to adolescents (aged 15 to 18) who had assented to participate in the study. The forum was designed as a password-protected, user-directed list server (news group), in which the participants were anonymous and used nicknames. It represented the first Norwegian online self-help group for adolescents initiated by a public health care provider. Using the action-oriented study, the hospital intended to test this type of forum before setting it up as a regular service. A revised version of the online self-help group was established as a permanent forum available to all adolescents (aged 15 to 18) with a mentally ill parent, after the study period was completed at the end of 2007.

The study participants were self-recruited through invitations on web sites for youths, mass media announcements, posters at schools, and health personnel. The study was approved by the Regional Committee for Medical Research Ethics in Norway and Norwegian Social Science Data Services. Participants had to sign a written consent form before they were allowed to enter the study. In addition, participants under 16 years of age had to provide signed permission from one parent. As part of the effort to organize the service appropriately, a reference group consisting of mental health clinicians was established as a “safeguard” according to ethical guidelines. If problems related to the participants’ activity in the self-help group required a professional response, the reference group could provide support in collaboration with the forum moderator.

The first author acted as moderator during the study period (2006–2007), with a clinician as comoderator. Based on recommendations (Sandaunet, 2008b; Till, 2003), the moderator acted as an administrator, and ensured that all communication was in accordance with the very strict Norwegian rules of privacy and confidentiality. The moderator also communicated to the forum how the service could represent a safe space and supportive community for the participants. However, to adhere to the self-help ideal in which conversation is supposed to be governed by the participants, the moderator did not introduce topics or respond to discussions that were raised (for more details, see Trondsen & Sandaunet, 2009).

Sixteen adolescents (aged 15 to 18) from various parts of Norway participated in the online self-help group during the study period. The group started with only 4 participants, but new members were welcomed throughout the entire study period. Although the participants were self-recruited with no restrictions on gender, there was only one male user. The preponderance of female participants resonates with previous findings that women are more active online users in health matters than men (Andreassen et al., 2007; Drost et al., 2011).

The parents of the participants suffered from severe mental illnesses, such as bipolar disorder, experienced psychotic periods, and attempted suicide. Although not all of the participants knew their parent's exact diagnoses, the parents had been mentally ill for years, were incapable of working, and were taking medication, were undergoing psychological therapy, or were hospitalized. None of the participants lived alone with their mentally ill parent; instead, they lived in dual-parent families, in single-parent families with the healthy parent, or on their own.

All participants had access to a computer at home. During the 2-year study period, about 600 messages were posted in the forum. The messages were distributed across 72 self-

defined topics, or “threads” (cf. Trondsen, 2012, for an online observation study of the web interaction).

Our analysis is based on in-depth interviews with 13 (all girls) of the 16 participants in the online self-help group. Three of the participants were out of reach; 2 of them had dropped out of the forum. The interviews were conducted face-to-face by the first author in 2007, in a suitable location near each participant’s home. The interviews lasted between 1.5 and 3 hours, and were digitally recorded and transcribed. The quotations used in this article are translated from Norwegian and depersonalized.

Beginning with an open exploration of the participants’ experiences of their lives with a mentally ill parent and perceptions about the online self-help group, the participants were encouraged to “tell their story” in the way they chose. In the last part of the interview, a semistructured interview guide was applied to explore relevant issues that had not emerged earlier in the interview. The questions concerned the participants’ “offline lives”: family situation, social network, contact with health professionals, impacts of the parent’s mental illness, and need for support. In addition, attitudes toward and experiences of participation, communication, and the issues discussed in the online forum in the context of the participants’ everyday life were raised. The interviews were shaped in the interplay between the interviewer and the interviewees, and situated in a local collaborative context (Holstein & Gubrium, 2003).

The interviews were analyzed through an inductive, issue-focused approach, in which specific issues, events, or processes (Weiss, 1994) are identified across the participants. Our aim was to explore types of issues raised during the interviews, aiming at identifying the roles of the online self-help group in supporting adolescents in managing everyday life with a mentally ill parent. As an issue-focused analysis implies focusing on emerging topics (and

not on individuals) interview data from some participants might contribute more to the analysis than data from others.

According to Weiss (1994), four distinct analytical processes are involved in an issue-focused approach to interview material: coding, sorting, local integration, and inclusive integration. However, these processes alternate, as we read and reread the interview material and its codes, throughout the analysis. First, we coded the transcribed interviews in themes or “meaning units” (Weiss, 1994), linked to exploring the adolescents’ experiences of the forum. Then we sorted collections of the excerpts that dealt with the same issue from all the interviews. Local integration means that we summarized the material and organized the main topics, to bring coherence and meaning to the excerpt materials and corresponding codes (Weiss, 1994). Finally, we developed a framework that included all the analyses, and identified and categorized three core topics that recurred in the adolescents’ presentations of the role of the online self-help group.

Analysis

During our analysis of the interview data, we identified three aspects of social processes that evolved through communication within the online self-help group: (a) recognizability (recognizing each other’s similar experiences), (b) openness (discussing issues that had been kept secret), and (c) agency (retaining independent active steps toward plans and ambitions). In the following section, we discuss these processes further.

Recognizability

All the participants emphasized that meeting other adolescents with a mentally ill parent was a crucial aspect of the online self-help group. Before joining the group, they had a sense of being “the only one in the world” with a mentally ill parent, and most had never met others in a similar family situation. Moreover, the adolescents had a common experience of being left

alone with the practical and emotional implications of their parent's mental illness. One participant explained that just knowing others in a similar situation made her feel less alone:

When I came to the forum and found out about all the others who were in exactly the same situation as me, I didn't feel so alone anymore. There were actually other people in the world having a horrible time, just like me, and it felt very good to know that, because I was feeling so incredibly lonely with those feelings.

In addition, several of the adolescents stressed the importance of the group consisting of peers at their own age. One stated:

We are in the same life situation; you go to school, you get grades, you're in a class situation, you're supposed to be "trendy," you're under the same pressure, and so on, and at the same time you have a parent who is mentally ill.

She continued: "I wouldn't have wished to join the forum if there had been a bunch of psychologists sitting there who were supposed to help me." Another girl underlined the value of sharing her story with her "online peers" in contrast to her other friends, because they genuinely could understand her experiences: "There were some people who understood it, who read it. You don't get that with friends who have grown up with healthy parents. They can't really put themselves in your situation, the way someone who has been there can."

The participants emphasized that recognizing others' experiences and feelings as similar to one's own was particularly helpful. It provided a sense of being "normal," despite an unusual family situation. The adolescents expressed that they often felt different from their friends, and they were constantly worrying about their own reactions, feelings, and thoughts of not being normal. One girl illustrated this by referring to conversations with her classmates, in which she often had a feeling of being "abnormal." When her friends easily

chatted and laughed lightly about boys, clothes, music, and movies, she was paralyzed by heavy worries about her mentally ill mother and incapable of engaging in the conversations. Reading in the forum about others' similar experiences allowed her to be calmer and to stop worrying so much about not being "normal."

The participants were aware of their status as an at-risk group with an increased chance of becoming mentally ill themselves; consequently, they expressed a deep fear of inheriting their parents' illness. One adolescent said she joined the online self-help group during a period when she was dejected and worried that her sadness could be a sign she was developing the same disease as her manic-depressive parent. She pointed out that entering the forum had been a great relief:

I had wondered: Is this right? Is it normal? So I felt good to get confirmation that I am not alone in my situation, that many people are struggling with the same things, and all my reactions are normal. It was a relief that there wasn't anything wrong with me after all.

By comparing herself with the others, she concluded that she was still "normal," with similar emotional reactions as others whose parents were mentally ill.

Recognizing others' thoughts and emotions as similar to one's own was emphasized by several participants as crucial in learning to handle the fear of being mentally ill. Another aspect that came through in our analysis was the openness maintained in the communication in the forum.

Openness

In the interviews, all participants emphasized that the online self-help group provided an arena in which they could address issues left unspoken in other social contexts. In daily life, nearly all experienced silence and lack of information about the illness and its consequences,

from parents, relatives, other adults, or health professionals who knew about their parent's illness. Moreover, the adolescents kept their parents' illness secret from their friends, or at least very seldom told any about their experiences and emotions in detail. The majority of the participants said they had never described personal experiences as thoroughly as they did in the forum.

Although the participants shared information about medical, legal, and practical issues in the forum, they particularly valued the space the forum provided for talking openly about emotions related to their parents' mental illness. One girl characterized herself as a person who rarely talked about her family situation to others and used the group to share her thoughts when emotions were too overwhelming: "In a way, I have sort of got rid of the feelings much more. I mean, because I have never talked very much about it, so it has been good to get it all out." Another girl explained she wrote in the forum when:

Your feelings boil over and then it's just: "OK - get it out . . ." Often it really feels wonderful, because there are some things you have actually wanted to say for such a long time, but there has never been anyone you feel you can tell, or the right moment to say it. It's just a relief to get it off your shoulders.

All the participants perceived the online group as a safe space for sharing feelings and thoughts that they were ashamed of and hid in other settings. One said she especially appreciated the support and acceptance of her emotions in the forum. She was relieved when she discovered that others had guilty feelings similar to hers. She said:

I had a guilty conscience because I was feeling sad and angry about all the stuff with Mom. . . . To read that they had the same feelings as me: anger, sadness, and so on, was good. Because when I felt as angry as hell, I felt at the same time that I wasn't allowed to be angry.

Some of the adolescents had received support from health professionals or had participated in face-to-face groups. However, they regarded the Internet features as stimulating emotional openness. One explained that her frequent face-to-face consultations with a health professional were useful, but she underlined the online forum's availability at all hours as particularly helpful for dealing with her emotions whenever she was affected by them.

Another adolescent said she also valued this flexibility and gave an example of a family situation in the middle of the night. She was very upset and sad and could not sleep because she heard her mentally ill mother crying and screaming. To handle the situation, she wrote a message in the forum about the episode and her painful feelings. She said later in the interview: "That was the time it was most helpful for me to write in the forum. . . . After all, it's when you feel sad that you need this opportunity."

The participants also emphasized that anonymity was an important premise for openness, such as one girl said:

I haven't talked about the illness and its consequences in such a depth as in the forum. This is the first time I've been so honest about it, and it's wonderful to speak out to people who don't know who I am.

The lack of peers in everyday life who know about the parent's illness seems to be a major problem. One adolescent said she would not share with any of her friends the parts of her life influenced by her mother's mental illness because none of her friends knew about the problems. She worried about saying anything that could give her friends a bad impression of her mother or herself.

The forum's text-based format also stimulated openness about emotions and experiences the participants did not talk about in other settings. One of the adolescents stated, "Often it's easier to write down what you are feeling in a way, and not to sit there and see the reaction of the other person straightaway." Although not all the participants found it easy to write about their feelings, they appreciated the written communication, because it gave them valuable access to others' emotions and experiences. The increased level of openness for discussing issues related to having a mentally ill parent also influenced how participants dealt with their everyday lives outside the Internet forum.

Agency

Communication in the group supported a more active approach to managing family situations, and gave hope for future prospects. Most of the participants in our study lacked information about their parent's mental illness, which was a source of concern, fear, and frustration. Thus, they appreciated the information circulating in the online group addressing mental disease, treatment, health care services, and various practical issues. One participant explained that knowledge obtained from the self-help group motivated her to manage the consequences of her mother's mental illness: "I understood more about what an illness like that involves, and I saw how the others handled things. I understood then, that it is possible to cope with matters, instead of just suppressing them."

Not only factual information but also other participants' stories, support, and advice based on experiential knowledge were important in stimulating agency. Through sharing experiences, the participants became role models for each other. They did not only share "sunshine stories", give support and advice. Reading about others' expressions of sadness, pain, and difficulties could also give hope and strength, as illustrated by one girl:

I thought it was sad. At the same time, I thought it was wonderful that they were managing so well when they seemed to be in such a horrible situation. It's not as

though everyone who is having a terrible time will go and kill themselves; they manage well in spite of it, and it's a burden they have, but they live normal lives all the same, and they are strong and resourceful people. That really does motivate you. Therefore, I shouldn't be any worse off than that, as it were.

Many of the participants worried about developing the same mental illness as their parent. One girl said that all the indications of normality she could find in the others' stories were valuable sources for her own sense of hope of living an ordinary life in the future. She found hope in reading about others who were also afraid of becoming mentally ill:

They seemed quite normal; after all, it was just that they had a terrible situation. Then I thought, "Oh my God, they are never going to be mentally ill like that." . . . I felt it was less likely that I would also become like my mom . . . Because [one of the participants] had a boyfriend – I felt that I too had a chance to get a boyfriend, friends, and live a completely normal life. Just minor things like that; good details that she mentioned by the way meant a lot to me. At least it gave me hope, and I thought that I could have a normal life too.

Moreover, by discussing strategies for managing their parents' mental illness in a long-term perspective and in immediate situations, the participants helped each other keep up their spirits. One girl stated that she was deeply sad because of disparaging and hurtful remarks from her mentally ill mother, who blamed her for their family problems. When the girl described this in the forum, she received a response from another girl that was crucial for dealing with the situation and improving her relationship with her mother:

She wrote something that really helped me; it helped me enormously just then. This was the only thing that helped. Before I read that message, I was sitting in tears and crying. I was devastated. Exactly what she said helped me. That was the reason I

could handle it, I think. . . . What she said was something I hadn't thought of. People come up with some pearls of wisdom. Thank heavens she wrote that!

Thus, the adolescents' use of the online self-help group to share experiences, emotions, thoughts, and advice contributed to reframing their situation from hopelessness to hope for their future and stimulating more active managing of their family situation.

A recurring aspect emphasized by the participants was how communication in the group led them to reflect and gain knowledge about managing daily life with a mentally ill parent. Furthermore, communication with other forum members lowered the threshold of talking about their parent's mental illness with people in their everyday social networks. One girl explained how participating in the group stimulated her to be more open and explicit about her family experiences to people outside the group:

I had kept it secret that my mom was ill. It was one of my biggest secrets, and only my closest friends knew about it. . . . Some things are easier to talk about now. Two years ago, it was absolutely unthinkable that I would talk with friends and people I knew as openly as I have done in the forum.

For another girl, communicating in the online self-help group motivated her to consult her mother about difficult and sensitive issues related to her mother's mental illness, which she had never done before. For instance, she felt guilt, and that she was responsible for her mother's depression, but she had never dared to tell her mother about either this or other feelings related to her mother's illness. Inspired by others' experiences of talking with their parents, and with the support from the forum, she finally told her mentally ill mother about her own feelings and experiences related to the illness:

In a way, it was a combination of how people in the forum understood the way I felt and just accepted it exactly the way it came out, that it was OK, and that I read that it had gone well with those who had told their parents. So then, I dared to tell her. . . . It did really help a lot, to speak up, clear up the misunderstandings. Because after I had talked to her, I understood that her problems didn't have anything to do with me. . . . The forum was a very important part of making it possible for me to dare to talk to her and get it cleared up, and have a better relationship with her.

The discussions in the online self-help group encouraged several participants to more actively seek help and support from health professionals. One even contacted the Child Protective Service because of her particularly difficult family situation. Another girl initiated contact with a health visitor at school for further help, after she had participated in the group for several months. She emphasized that communication with her peers in the forum was crucial for her to take this initiative to get professional support:

It made it possible for me to ask for help at school. Yes, because I knew I had to talk to someone, but it was as though through the forum I became absolutely certain about that. . . . It pushed me out of it a bit, it did.

This example illustrates how communicating in the forum stimulated the adolescents' agency to manage the implications of their family situation with parental mental illness. In the following discussion, we synthesize the three aspects of social processes that evolved through the online self-help group in, to suggest the concept of communal normalization.

Discussion: Communal Normalization

A major problem for adolescents with mentally ill parents is the feeling that their everyday life experiences were completely different from their friends' experiences. The experience of

out-of-the-ordinary lives related to stigmatizing situations left the participants alone with their difficulties. As Fjone et al. (2009) observed, children and youths with mentally ill parents often “struggle hard” to present themselves as “normal” and equal within their peer group, to avoid stigmatizing situations. Simultaneously, these children and youths often feel lonely in their efforts to cope with the implications of their parents’ mental illness (Trondsen, 2012). Postings and discussions in the forum made it clear, however, that these experiences are not unique. Other adolescents shared them. For instance, through participating in the forum, one girl realized that the “problems [her mother] had, did not have to do with [her].”

Similarly, the participants mentioned that they had been deeply worried about becoming mentally ill like their parents (Trondsen, 2012). Discovering other adolescents with the same worries was a great relief. Recognizing others’ feelings and reactions were similar to one’s own implied a communally based normalization of personal life and experiences notwithstanding the abnormal family situation. As Gladstone (2010) suggested in a study of a support group for children with mentally ill parents, the participants’ identification with others normalized their experiences and validated their perceptions.

The forum provided a medium for what we term “communal normalization.” Participants make sense of their experiences and emotions related to having a mentally ill parent. In the previous analysis, we identified three characteristics of this process: (a) recognizability (recognizing each other’s similar experiences), (b) openness (discussing issues that had been kept secret), and (c) agency (retaining independent active steps toward future plans and ambitions).

Goffman provided concepts of normalization involved in maintaining an interaction order in public space, such as “saving face” (1955) and maintaining “civil inattention” (1971). Whereas saving face identifies processes of maintaining one’s dignity by avoiding focusing on interactional failures or negative attributes, civil inattention is a term for

distancing oneself from (obtrusive) interest in others in public. Normalization strategies toward embarrassing incidents or delicate issues might include lowering one's voice (Linell & Bredmar, 1996) to avoid attracting attention or emphasizing normal aspects within abnormal circumstances (Clarke, 2002).

In our case, however, normalization is about redefining what is experienced and perceived as abnormal as being normal for members in a specific community. Furthermore, when we regard normalization as a communal process, we emphasize that communication about the normality of abnormal family situations is the core of this concept. The forum established a "communication community" (Delanty, 2003), in which normalization was developed communally through the act of communication, thus through communal normalization.

By providing a space for participants to be explicit about difficult emotions and out-of-the-ordinary experiences, to recognize them based on the participants' own experiences, and to accept frustration and anger, the forum provided an arena for openness in emotions and reactions that the participants withheld in other social situations. As the forum was based on anonymous postings and maintained for and by adolescents with mentally ill parents only, normalization was developed within the safe space of the online community over time.

As noted elsewhere (Tjora, 2011; Rettie, 2009), Goffman's concepts of interaction order must be revised, or at least refined, when analyzing mediated communication, such as the type found in the forum studied in this article. Based on specific inclusion criteria (being an adolescent with a mentally ill parent) and anonymity, an interaction order providing communal attention (rather than civil inattention) to the out-of-the-ordinary individual experiences developed in the forum. One adolescent mentioned that the forum gave her an opportunity to talk about things that she had "wanted to say for a long time," but they were too sensitive or stigmatizing to bring into everyday face-to-face situations.

Recognizability and openness through exchanging experiences, advice, and support between peers in the forum are aspects of communal normalization processes. These aspects formed the basis for further reflection and inspiration for each participant to take a more active role in managing her own situation, and thus growing a sense of hope for a brighter future. The way the forum produced agency outside the forum to inspire participants to communicate more openly with their peers about mental illness in the family and to initialize professional assistance was one of the more important findings in our study. The forum connected “life online” with problems and solution in participants’ everyday social life within school and family.

In light of new perspectives within the sociology of childhood, in which children and youths are viewed as active and competent social actors in constructing their own lives (James, Jenks, & Prout, 1998), we found the adolescents’ participation in the forum was a significant strategy for managing their everyday lives with a mentally ill parent. Building on this approach, children are viewed as influencing, as well as being influenced by, their social environments. Childhood is situated within various contexts (James et al., 1998). Thus, a focus on children’s and youth’s agency, a “capacity of individuals to act independently” (James & James, 2008, p. 9), is important in this approach. Through the online self-help group, the adolescents created an arena for communal normalization, in which they extended agency based on peer support and recognition. Extended agency resulted in a lower threshold to talk to family, friends, and professionals about their situation. The adolescents also took a more active role in managing their everyday lives with a mentally ill parent.

Fear of stigma and the risk of being ascribed an “illness identity” are widely accepted arguments for understanding adolescents’ nondisclosure and non-help-seeking in mental health issues (Prior, 2012), which also explain our participants’ reluctance to talk about their parents’ mental illness to friends or to seek support from professionals. However, Prior

(2012) has shown young people are active agents in constructing their positions as counseling service users to overcome stigma. By normalizing their difficulties, they might avoid the potential “illness identity” in exchange for a problem-solver subject position, from which accessing help becomes possible (Prior, 2012).

Accordingly, we found that, through the processes of recognition and openness in the forum, the adolescents became active in constructing a position in which they extended their agency to talk to someone outside the forum. The process of communal normalization formed the basis for informal and professional support within the participants’ environments, far beyond the online group itself. Based on recognition and openness, the participants’ agency is shaped, reshaped, and extended, enabling novel strategies to manage everyday life with a mentally ill parent.

The concept of “biographical disruption” (Bury, 1982) is often used to explain the experience of chronic illness. However, as Harden (2005) emphasized in a study of parents with a mentally ill child, disruption of life is also significant for caregivers to a person with a chronic illness. Their perceptions and experiences as parents are disrupted because of their child’s mental illness. They try to make sense of the illness by reconstructing their past, present, and future experiences (Harden, 2005).

Similarly, we showed that living with a mentally ill parent represents major consequences and disruptions in daily life, challenging adolescent life experience and identity. Communal normalization, through recognizability and openness in the forum, stimulated active steps toward managing the family situation and regaining hope for the future. The participants’ communication in the forum became a communal resource for reconstructing previous disruptions and conceptions of the role as an adolescent with a mentally ill parent. Through communal normalization, the participants reoriented and repositioned their identity and experiences, which stimulate agency to manage current and

future everyday life. From ascribing themselves with a potential abnormal or mental illness identity, they changed the definition of their family situation to being less out-of-the-ordinary.

Reframing biographical disruption from an individual to a contextual level stimulates an extended agency to manage life, for instance, by talking with family, friends, or health professionals. In accordance with the contingent approach in other Internet studies (Nettleton et al., 2005), the everyday context of people's Internet use must be considered. Using the Internet as an "everyday helper" might be relevant only in specific situations, or made sense of in relation to particular experiences (Kivits, 2009).

Consequently, the adolescents' creation of a space of communal normalization must be understood in the context of everyday life, offline as well as online. The Internet is not only about access to what but also access to whom (Walther, 2004), i.e., other individuals who are potential supporters. The adolescents in our study escaped being "the only one in the world" with a mentally ill parent by "meeting" others in a similar situation. Experiences of out-of-the-ordinary lives, loneliness, lack of openness, risk of stigma, and worries about their own mental health were all made sense of through communal normalization in the forum.

Early in the article, we referred to Nettleton et al.'s (2005) classification of different responses to the proliferation of Internet-based health information as "celebratory," "concerned," and "contingent." Our study has a wider application than studying online health information. We were concerned with how the participants in our study experienced in their everyday life having a parent with mental illness and how a specific web-based support group made a difference in coping with "offline" experiences as well. Although our findings support previous findings of people's use of the Internet as contingent on particular needs and conditions in their everyday lives (Andreassen, 2011; Kivits, 2009; Sandaunet, 2008a), our main contribution is detailing social processes between the online and offline.

The Internet has been around for 20 years, and has become salient in people's everyday lives, at least in the Western world, during the last 10–15 years. Thus, the Internet is a significant part of society, and not just a communication medium for specific applications. In a more general sense, our findings point toward social research that cuts the boundaries between the online and offline; social processes (as identified in this article) run across such merely technical carriers.

Concluding Remarks

The participants in our study lived their everyday lives with a risk of stigma, shame, and blame related to their parents' mental illness (courtesy stigma) and their fear of future mental health problems. They also experienced uncertainty arising from the lack of information and openness from family, networks, and health professionals about mental illness (Trondsen, 2012). Although a sense of normality is important for most adolescents in general, it is critical for those with mentally ill parents (Fjone et al., 2009). The online interaction not only contributed to direct relief and hope but also promoted agency in the daily "offline" lives of these young people.

Our study is limited to an analysis of users of one online forum for adolescents with a mentally ill parent. They were recruited on a voluntary basis; as a result, the number of participants is limited, and only girls were active users. We cannot conclude that communal normalization processes will occur in all support forums, as legitimate themes, discussions, and types of communication in web-based forums are formed through the actual interactions over time (cf. Sandaunet, 2008b). Given this limitation, however, our study has a more general application. It demonstrates the potential of web-based interaction to assist people risking stigma in experiencing their everyday life as less out-of-the-ordinary and more normal.

As suggested by Scambler and Kelleher (2006, p. 227), health-related social movements can have “mobilizing potential” through users’ discussion of experiences and the development of an “alternative collective sense of identity.” Although the web forum studied here was initiated through a top-down “involvement process” (Tjora & Sandaunet, 2010) by health service providers, we identified web-based mobilization by communal rationality within the life world of the participants. Communal normalization is first and foremost the participants’ sense of normalization, i.e., normalization for self, self-situation, and self-identity, rather than about any change in the broader community. Therefore, although such a service does not challenge the fundamental structure of health services, it provides great potential of agency for certain groups of people experiencing their everyday life lives on the margins of normality.

Acknowledgments

We thank all the participants in the study. Thanks also to Graham Scambler, Sissel H. Eriksen, Amy Holtan and the anonymous reviewers for their constructive comments on earlier versions of this article.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The first author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Northern Norway Regional Health Authority funded the research and the authorship.

References

- Andreassen, H. K. (2011). What does an e-mail address add? - Doing health and technology at home. *Social Science and Medicine*, 72(4), 521–528.
doi:10.1016/j.socscimed.2010.11.026
- Andreassen, H. K., Bujnowska-Fedak, M. M., Chronaki, C. E., Dumitru, R. C., Pudule, I., Santana, S., . . . Wynn, R. (2007). European citizens' use of E-health services: A study of seven countries. *BMC Public Health*, 7(53). doi:10.1186/1471-2458-7-53
- Bar-Lev, S. (2008). "We are here to give you emotional support": Performing emotions in an online HIV/AIDS support group. *Qualitative Health Research*, 18(4), 509–521.
doi:10.1177/1049732307311680
- Beardslee, W. R., Versage, E. M., & Gladstone, T. R. G. (1998). Children of affectively ill parents: A review of the past 10 years. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37(11), 1134–1141.
- Berger, M., Wagner, T. H., & Laurence, B. C. (2005). Internet use and stigmatized illness. *Social Science and Medicine*, 61(8), 1821–1827.
doi:10.1016/j.socscimed.2005.03.025
- Broom, A., & Tovey, P. (2008). The role of the Internet in cancer patients' engagement with complementary and alternative treatments. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 12(2), 139–155.
doi:10.1177/1363459307086841
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167–182. doi:10.1111/1467-9566.ep11339939
- Clarke, V. (2002). Resistance and normalization in the construction of lesbian and gay families: A discursive analysis. In A. Coyle & C. Kitzinger (Eds.), *Lesbian and gay psychology* (pp. 98–116). Oxford, England: Blackwell.

- Crocco, A. G., Villasis-Keever, M., & Jadad, A. R. (2002). Analysis of cases of harm associated with use of health information on the Internet. *Journal of the American Medical Association*, 287(21), 2869–2871. doi:10.1001/jama.287.21.2869
- Delanty, G. (2003). *Community*. London, England: Routledge.
- Drost, L. M., Cuijpers, P., & Schippers, G. M. (2011). Developing an interactive website for adolescents with a mentally ill family member. *Clinical Child Psychology and Psychiatry*, 16(3), 351–364. doi:10.1177/1359104510366281
- Fjone, H. H., Ytterhus, B., & Almvik, A. (2009). How children with parents suffering from mental health distress search for “normality” and avoid stigma. To be or not to be . . . is *not* the question. *Childhood*, 16(4), 461–477. doi:10.1177/0907568209343757
- Gage, E. A., & Panagakis, C. (2012). The devil you know: Parents seeking information online for paediatric cancer. *Sociology of Health and Illness*, 34(3), 444–458. doi:10.1111/j.1467-9566.2011.01386.x
- Gavin, J., Rodham, K., & Poyer, H. (2008). The presentation of “pro-anorexia” in online group interactions. *Qualitative Health Research*, 18(3), 325–333. doi:10.1177/1049732307311640
- Gladstone, B. M. (2010). *“All in the same boat”: An analysis of a support group for children of parents with mental illnesses* (doctoral dissertation). University of Toronto, Canada.
- Gladstone, B. M., Boydell, K. M., Seeman, M. V., & McKeever, P. D. (2011). Children’s experiences of parental mental illness: A literature review. *Early Intervention in Psychiatry*, 5(4), 271–289. doi:10.1111/j.1751-7893.2011.00287.x
- Goffman, E. (1955). On face-work: An analysis of ritual elements of social interaction. *Psychiatry: Journal for the Study of Interpersonal Processes*, 18(3), 213–231.

- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Goffman, E. (1971). *Relations in public: Microstudies of the public order*. London, England: Lane.
- Gundersen, T. (2011). "One wants to know what a chromosome is": The Internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder. *Sociology of Health and Illness*, 33(1), 81–95. doi:10.1111/j.1467-9566.2010.01277.x
- Harden, J. (2005). Parenting a young person with mental health problems: Temporal disruption and reconstruction. *Sociology of Health and Illness*, 27(3), 351–371. doi:10.1111/j.1467-9566.2005.00446.x
- Hardey, M. (1999). Doctor in the house: The Internet as a source of lay health knowledge and the challenge of expertise. *Sociology of Health and Illness*, 21(6), 820–835. doi:10.1111/1467-9566.00185
- Henwood, F., Wyatt, S., Hart, A., & Smith, J. (2003). "Ignorance is bliss sometimes": Constraints on the emergence of the "informed patient" in the changing landscapes of health information. *Sociology of Health and Illness*, 25(6), 589–607. doi:10.1111/1467-9566.00360
- Hinton, L., Kurinczuk, J., J., & Ziebland, S. (2010). Infertility, isolation and the Internet: A qualitative study. *Patient Education and Counseling*, 81(3), 436–441. doi:10.1016/j.pec.2010.09.023
- Hirji, F. (2004). Freedom or folly? Canadians and the consumption of online health information. *Information, Communication and Society*, 7(4), 445–465. doi:10.1080/1369118042000305593

- Holstein, J. A., & Gubrium, J. F. (2003). Inside interviewing: New lenses, new concerns. In J. A. Holstein & J. F. Gubrium (Eds.), *Inside interviewing: New lenses, new concerns* (pp. 3–30). London, England: Sage.
- James, A., & James, A. (2008). *Key concepts in childhood studies*. London, England: Sage.
- James, A., Jenks, C., & Prout, A. (1998). *Theorizing childhood*. Cambridge, England: Polity Press.
- Kiley, R. (2002). Does the Internet harm health? Some evidence exists that the Internet does harm health. *British Medical Journal*, *324*(7331), 238–239.
- Kivits, J. (2009). Everyday health and the Internet: A mediated health perspective on health information seeking. *Sociology of Health and Illness*, *31*(5), 673–687.
doi:10.1111/j.1467-9566.2008.01153.x
- Linell, P., & Bredmar, M. (1996). Reconstructing topical sensitivity: Aspects of face-work in talks between midwives and expectant mothers. *Research on Language and Social Interactionism*, *29*(4), 347–379. doi:10.1207/s15327973rlsi2904_3
- Mordoch, E. (2010). How children understand parental mental illness: “You don’t get life insurance. What’s life insurance?.” *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, *19*(1), 19–25.
- Mordoch, E., & Hall, W. A. (2008). Children’s perception of living with a parent with a mental illness: Finding the rhythm and maintaining the frame. *Qualitative Health Research*, *18*(3), 1127–1144. doi:10.1177/1049732308320775
- Nettleton, S., Burrows, R., & O’Malley, L. (2005). The mundane realities of the everyday lay use of the Internet for health, and their consequences for media convergence. *Sociology of Health and Illness*, *27*(7), 972–992. doi:10.1111/j.1467-9566.2005.00466.x

- Norwegian Institute of Public Health. (2011). *Barn av foreldre med psykiske lidelser eller alkoholmisbruk: Omfang og konsekvenser* [Children of parents with mental illness or alcohol abuse: Extent and consequences]. *Report 2011:4*. Oslo, Norway: Norwegian Institute for Public Health.
- Prior, S. (2012). Overcoming stigma: How young people position themselves as counselling service users. *Sociology of Health and Illness*, *34*(5), 697–713. doi:10.1111/j.1467-9566.2011.01430.x
- Radin, P. (2006). “To me, it’s my life”: Medical communication, trust, and activism in cyberspace. *Social Science and Medicine*, *62*(3), 591–601.
doi:10.1016/j.socscimed.2005.06.022
- Reason, P., & Bradbury, H. (2006). Introduction: Inquiry and participation in search of a world worthy of human aspiration. In P. Reason & H. Bradbury (Eds.), *Handbook of action research* (pp. 1–14). London, England: Sage.
- Rettie, R. (2009). Mobile phone communication: Extending Goffman to mediated interaction. *Sociology*, *43*(3), 421–438. doi:10.1177/0038038509103197
- Rutter, M., & Quinton, D. (1984). Parental psychiatric disorder: Effects on children. *Psychological Medicine*, *14*(4), 853–880. doi:10.1017/S0033291700019838
- Sandaunet, A.-G. (2008a). The challenge of fitting in: Non-participation and withdrawal from an online self-help group for breast cancer patients. *Sociology of Health and Illness*, *30*(1), 131–144. doi:10.1111/j.1467-9566.2007.01041.x
- Sandaunet, A.-G. (2008b). A space for suffering? Communicating breast cancer in an online self-help context. *Qualitative Health Research*, *18*(12), 1631–1641.
doi:10.1177/1049732308327076

- Scambler, G., & Kelleher, D. (2006). New social and health movements: Issues of representation and change. *Critical Public Health*, 16(3), 219–231.
doi:10.1080/09581590600986440
- Suzuki, L. K., & Calzo, J. (2004). The search for peer advice in cyberspace: An examination of online teen bulletin boards about health and sexuality. *Applied Developmental Psychology*, 25(6), 685–698. doi:10.1016/j.appdev.2004.09.002
- Till, J. E. (2003). Evaluation of support groups for women with breast cancer: Importance of the navigator role. *Health and Quality of Life Outcomes*, 16(1), 1–6.
- Tjora, A. (2011). Invisible whispers: Accounts of SMS communication in shared physical space. *Convergence*, 17(2), 193-211. doi: 10.1177/1354856510394604
- Tjora, A. & Sandaunet, A.-G. (2010). Digitale pasienter: En introduksjon og leseanvisning [Digital patients: An introduction and reading guide]. In A. Tjora & A.-G. Sandaunet (Eds), *Digitale pasienter [Digital patients]* (pp. 13-25). Oslo, Norway: Gyldendal Akademisk.
- Trondsen, M. V. (2012). Living with a mentally ill parent: Exploring adolescents' experiences and perspectives. *Qualitative Health Research*, 22(2), 174–188.
doi:10.1177/1049732311420736
- Trondsen, M., & Sandaunet, A.-G. (2009). The dual role of the action researcher. *Evaluation and Program Planning*, 32(1), 1–20. doi:10.1016/j.evalprogplan.2008.09.005
- Walther, J. B. (2004). Language and communication technology. Introduction to the special issue. *Journal of Language and Social Psychology*, 23(4), 384–396.
- Weiss, R. S. (1994). *Learning from strangers. The art and method of qualitative interview studies*. New York, NY: Free Press.

Whitlock, J. L., Powers, J. L., & Eckenrode, J. (2006). The virtual cutting edge: The Internet and adolescent self-injury. *Developmental Psychology*, 42(3), 407–417.

doi:10.1037/0012-1649.42.3.407

Bios

Marianne V. Trondsen, MA, is a PhD candidate at the Norwegian Center for Integrated Care and Telemedicine, University Hospital of North Norway, Tromsø, Norway, and in the Department of Sociology, Political Science and Community Planning, University of Tromsø, Tromsø, Norway.

Aksel Tjora is a professor of sociology in the Department of Sociology and Political Science, at the Norwegian University of Science and Technology, Trondheim, Norway, and an adjunct professor at the Norwegian Centre for Integrated Care and Telemedicine, University Hospital of North Norway, Tromsø, Norway.