

The silent world of young next of kin in mental health care

Abstract

Background: Young next of kin to patients with mental health problems are faced with many challenges. It is important to focus on the special needs of children and adolescents as next of kin to ensure their welfare and prevent harm.

Research questions: We aimed to investigate young next of kin's need for information and involvement, to examine the ways they cope with situations involving coercion related to the treatment of their relative, and to identify ethical challenges.

Research design: We conducted a qualitative study based on semi-structured, individual interviews.

Participants and research context: Seven young next of kin aged 14-22 participated in the study. The informants were recruited from a regional hospital trust in Norway.

Ethical considerations: The study was approved by the National Data Protection Official for Research and based upon informed consent and confidentiality.

Findings: The adolescents wanted more information and described a need for increased interaction with their sick relative at the hospital. They struggled to keep their relationship with their relative intact, and they described communication problems in the family. Coercive treatment was perceived in a negative way.

Discussion: The study finds that there are ethical challenges at stake for young next of kin and their families other than those that are often emphasized by traditional health care, which often focuses on the individual patient's rights. These challenges are related to the young next of kin's needs for interconnectedness and for the preservation of relationships as well as challenges related to family communication and the need for information.

Conclusion: The study finds a need for more family-oriented perspectives in both mental health care practices and health care ethics.

Key words: COPMI, sibling caregivers, mental health care, family support, ethics, family ethics.

Introduction

Mental health problems raise difficult and complex challenges for families and may disrupt the lives of children and adolescents. Young next of kin differ from adults in terms of their increased vulnerability and dependence on their parents. Because they are considered minors, they have no formal representational role in relation to their relative and thus are easily overlooked. Research shows that young next of kin to parents or siblings with mental health issues face many challenges and difficult situations during a vulnerable time in life.¹⁻⁵ Health care personnel have a moral obligation to support young next of kin in improving their quality of life and life-course.

Since the 1990s, there has been increased attention to young next of kin to psychiatric patients in research and policy in Europe, the US, and Australia.⁶⁻⁹ For instance, in 2010, Norway added a new paragraph of law that obliges health personnel to attend to and safeguard the minor children of patients.¹⁰

International research shows that young next of kin are faced with many challenges that affect their emotional and physical health as well as their educational life.¹¹⁻¹⁵ Some young next of kin report experiences of a lost childhood with enormous responsibilities at home.¹⁶⁻¹⁷ Previous research also reveals that siblings experience subjective burdens and stress due to the mental health problems of their brother or sister¹⁸⁻²⁰ and notes that mental health problems influence family relations and family

interactions.²¹⁻²³ A review of the literature shows that many children and adolescents have insufficient information about the status of their ill family member.¹²⁻¹⁴ Several studies have found that mental health services seem to have partly failed to meet children and adolescent's needs for information and involvement.²³⁻²⁵

In addition to the difficulties of dealing with the mental illness itself, another challenge involves exposure to coercion (i.e., involuntary admission and hospitalization, forced medication) in mental health care, either directly as a patient or indirectly as next of kin. The use of coercion is a controversial clinical and moral practice that produces various ethical dilemmas.²⁶ Research has shown that coercion has consequences for both the patient and the patient's next of kin.²⁷⁻²⁹ However, little previous research has examined how children and adolescents as next of kin experience and address situations involving coercion. To our knowledge, no studies have explicitly examined the views and experiences of young next of kin in relation to the use of coercion. However, some studies address the impact of the hospitalization of a close family member on young next of kin, including their encounters with 'locked wards', implicitly describing involuntary admissions.³⁰ Many of these children and adolescents have an unmet need for information and support.^{14,24} The use of coercion reflects the seriousness of the mental health problems, and the coercive situations may be dramatic events with serious effects on the people involved and their families.

Systematic and sufficient support of children and adolescents whose family members are involuntarily committed or who experience other types of coercive measures might be especially important.³¹⁻³²

Internationally, the principles presented in the UN Convention on the Rights of the Child have contributed to an increased focus on children and adolescent's rights to be involved and to have a voice in matters that influence their own situations.³³ This study aims to help to provide such a voice to young next of kin, including children or siblings, who have experienced situations in which coercion has been used against an ill parent or sibling. For our interview-based qualitative study, we identified the following research issues:

First, how do children and siblings of psychiatric patients experience situations involving coercion, such as involuntary hospital admissions and hospitalization, in relation to the treatment of their close relative? Do they have specific needs for coping with these situations? Second, what are their wants and needs in relation to obtaining information and being involved in the treatment of their relative? Finally, we aim to identify and discuss ethical challenges in supporting young next of kin.

Materials and Methods

The study is part of a large-scale project in Norway called “Mental health care, ethics and coercion”, which was conducted from 2011–2015. Inspired by discourse ethics³⁴ the project aimed to explore ethical challenges in relation to the use of coercion and participation as seen from the perspectives of *all* stakeholders, including young next of kin. We conducted a qualitative study based on semi-structured, individual interviews.³⁵⁻³⁷

Participants

The first author interviewed seven young next of kin ages 14–22 years, including three males and four females. Four were brothers or sisters of an ill family member, and three were children of a mentally ill parent. The informants were recruited through psychiatric wards where a family member was receiving treatment in a regional hospital trust in Norway. The criteria for inclusion were being a child or sibling of a patient who had experienced coercion in the psychiatric ward. **An exclusion criterion was an increased vulnerability of the young next of kin. In the recruitment process, there were parents who refused to allow us to interview their child because of this consideration.**

Originally, the project was intended to address young next of kin from 12–18 years of age. However, similar to other researchers, we experienced significant

challenges in reaching these adolescents.^{9,38} As a result of these challenges, the age span was expanded to include young people in their early 20s. Ultimately, we included seven participants in the study. **Because of the difficulties of the recruiting process, there was neither the time nor the economic resources to continue the data collection in order to recruit more participants. However, the intention of the study was not to reach full saturation of data but rather to initiate knowledge generation on a previously little-explored field.** Several possible reasons for difficulties in recruiting this population include cumbersome consent procedures, therapists and parents' concerns about putting too much stress on the youth, and the reluctance to provoke bad memories for some potential informants.

Data collection

We used semi-structured interviews (lasting 50–90 minutes each) to collect data from June through October 2014. **The first writer collected the data.** The interview questions covered the experience of being a young next of kin and asked for the informants' experiences and perceived challenges. Using an explorative approach, we asked for the informants' own experiences in relation to coercion and in relation to information and involvement, as there was little previous knowledge on this subject. All interviews were recorded on audiotapes and transcribed by an assistant.

Analysis

The analysis was conducted through collaboration with the co-authors following systematic text condensation.³⁶⁻³⁷ The analysis proceeded through the following stages: (1) reading all the material to obtain a general impression of the whole; (2) identifying units of meaning that represented different aspects of the participants' experiences of being a young next of kin and coding for these; (3) condensing and abstracting meaning units within each coded group; and (4) summarizing the contents of each coded group to generalize descriptions reflecting the most important aspects of the informants' experiences related to being a young next of kin. To ensure the reliability of the analysis, the interviews were examined by the co-authors, and excerpts were included in the results section. The interviews were read and interpreted independently by the co-authors, and the findings were subsequently discussed. **If there was disagreement or uncertainty concerning the interpretation, we went back to the original transcripts to see the quotes and the text condensations in context, and then further discussed the material until we reached agreement.** In the last analytical stage (4), we assessed the relevance of our findings by comparing them to existing empirical studies and theories.

Research ethics

In accordance with Norwegian law, the study was formally evaluated by the Regional Committee for Medical and Health Research Ethics, which deemed the study outside of their scope of responsibility because it was regarded as 'health service research.' Thus, the study was instead assessed and approved by the National Data Protection Official for Research³⁹ and the local research committee at the participating hospital trust.

Both the informant and the informant's relative had to give written informed consent. If the informant was under 16 years old, his or her parents had to provide consent. **The relative who was ill received oral and written information about the study from his or her therapist or other related health care personnel in the first place. Furthermore, the relative asked the young next of kin if he or she wanted to participate.** Information letters that included a formula for giving consent were sent to the participants and their relatives. All respondents gave written voluntary and informed consent. **The data were anonymised and confidentiality was maintained.**

Results

The adolescents were deeply affected by the situation in their family and described challenges and difficulties both at home and at the hospital. Their experiences could be classified according to three main topics: (1) coercion and the hospitalization of the close family member; (2) contact with the health care system as a young next of kin; and (3) the impact of the mental illness in the family on the adolescent as a young next of kin and on the family as whole. Based on this categorization, we present the findings in three sections as outlined below.

Hospitalization and coercion

The word coercion – it seemed to never be mentioned

The informants spoke about concrete experiences related to the involuntary hospitalization of their close family member. Although coercion exhibited a powerful force on the informants' experiences as young next of kin, coercion was never a theme that was addressed or explicitly discussed with them: "The word coercion seemed to never be mentioned!" one informant exclaimed. None of the informants had received any special information about their relative's involuntary hospital admissions and the basis for the admission. With the exception of one informant, none of the informants

had any knowledge of whether their relative had been subjected to other coercive measures in the hospital.

Negative drama

Although coercion was not discussed with the young next of kin, they surely perceived the effect of coercive treatment on their relatives' bodies. The participants reported that hospital admissions and the use of police force in the transport of their family members to the hospital were often experienced as negative and brutal acts. One informant mentioned a situation in which his father was brought to the hospital by the police in a way that could lead people in the neighborhood to believe that his father was a criminal:

"... it's not fun to see your father being handcuffed and dragged out....And there are many other blocks around us, so that when the police car stops outside there for about ten minutes and then my dad is dragged out of the house in handcuffs and into the car, people don't think, 'He is sick.' Rather, they think, 'Wow, what the hell has he done?' and that he is a criminal".

Meetings with closed doors

Other informants noted the consequences of an involuntary hospital admission and the subsequent restrictions in relation to visitation. For example, the family member could not come home when he or she wanted, and they could not spend time together inside or outside the hospital grounds without being watched by staff. One informant, a 15-year-old boy with an older brother who had been in and out of the hospital in recent years, said that one of the things that bothered him most when his brother was in the hospital was that it was difficult for them to be together like they used to because hospital personnel were watching them much of the time.

“... Yes, we are allowed to go out, but there is always someone behind, walking with us all the time.... It's a little strange. In a way, you don't manage to talk about anything you want as long as there is an unknown person there”.

Many of the informants described the closed feeling of the hospital, with locked doors and tiny, unwelcoming rooms for visitors, as being associated with “rooms of coercion”. They said that they experienced the staff as distant and rarely available, and this seemed to trigger an unease and uncertainty related to the care of their admitted family member.

Inducing feelings of ambivalence and guilt

The informants reported feelings of ambivalence and guilt in connection to the involuntary hospitalization of their relative. One informant said that he felt guilty when his father was medicated against his will at the hospital because the informant was the one who had called for help, which led to his father's admission to the hospital: "I felt some guilt when he got medication against his will, and it was me that called the doctor in the first place, nagging them".

Contact with health care services during involuntary hospitalization

Lack of information

All of the informants felt that they had received little or no information from the health care personnel about their family member's disease or diagnosis, and they knew little about what was happening at the hospital. They all stated that they had little insight into the patient's treatment plan and that information was given exclusively to the parents. None of the informants had any contact with the therapist or with personnel at the hospital other than greeting them when they came to visit. They claimed that they had many unanswered questions regarding the disease and follow-up of their family member:

“No one from X hospital has done that; that is, informed me or something. No, they have not....They have not mentioned anything to me. They have not spoken to me really. The only thing they have said to me is "hello" and "goodbye". So it's not more than that”.

Being involved is being together

The informants' experience of being involved in their family member's treatment and follow-up related to the informant's ability to come visit and spend time with their family member at the hospital.

“Being involved in terms of being able to gather with the family or just being with him and seeing him. Still be my brother... know that, yes ... he is not totally out of Pakistan in a way....There should be more focus on the family being together”.

Many of the informants said they were seldom able to visit their family member at the hospital, but they wanted to be there more often. Contact with the sick family member was important to them. They wished that they had been encouraged by the staff at the hospital to visit more often and that the hospital had been more suitable for visitation. They particularly described the visiting rooms, which they found unpleasant—“the most miserable you can imagine”—and poorly suited for spending time together.

Many of the informants called for more opportunities to spend time together as siblings and a family, such as sharing a meal or watching a movie.

One informant, a 15-year-old girl whose sister developed acute psychosis one year earlier, said that she missed her sister in everyday life, and it was important to see her regularly: “No, I will not keep more distance or something like that Although she is sick... I just love her, and she's as fond of me and all that”.

Impact on the self and on the family

Having a difficult time

The informants explained that it was difficult to be next of kin. They discussed frightening experiences at home when they had been afraid and felt insecure. These situations involved screaming and quarreling or situations when they had witnessed suicide attempts or self-harm. Several of the informants used expressions such as “hard”, “tough” and “rotten” to describe their situation.

“I was very scared then, so I was lying under the bed saying nothing.... I ... I did not know what to do, in a way”.

Several of the informants reported that their mental health was negatively affected by the situation at home. They often felt upset and depressed, angry and irritable, or introverted and silent.

Silence in the family

Many informants described a lack of communication within the family about the illness and the treatment of the sick family member. They stated that the family did not talk about these issues and that they also failed to talk with each other about how they perceived the situation with the sick family member at home:

“What has been the greatest problem in our family is that we have not talked about it at all. Although it has had such a strong impact ... Instead, we have tried to hide from each other, and, in a way, run away from it“.

Several respondents felt that they were alone with their experiences and thoughts. After the family member was admitted to the hospital, it became completely silent at home. One informant described this silence as a feeling of "aloneness" in the family that was harsh and cold.

Altered relations

Experiences of altered relations with the sick family member were a central theme among the informants. Many informants stated that they felt that their relationship with the sick family member had deteriorated. They used terms such as “an increased barrier” between them to describe the feeling of being more separated and distant from each other:

“It was such a barrier, in a way. Because we had a story, but it was just there, we did not talk about it. And it became really that separated”.

Although some of the informants did not feel that the relationship with the sick family member had deteriorated, they described difficulties being together when the family member was ill and hospitalized and their struggles in maintaining the relationship. They wanted to be together as before, but this was difficult due to the family member's illness and symptoms as well as the practical circumstances surrounding the admission.

Discussion

Giving a voice to the young next of kin

This study has provided insights into the thoughts and experiences of young next of kin. However, the study included a small number of informants because of

difficulties related to the recruitment process, as described above. Despite the small number of participants, the collected material was rich in data, offering varied and detailed information about the topics we aimed to investigate.

Few studies have focused on talking to the young next of kin themselves. More often, the parents or the professionals are asked about their views regarding the needs of young next of kin.^{40,41} One reason for this may be the difficulties involved in recruiting children and adolescents. Another reason may be the ethical consideration of not exposing children to unnecessary distress. Underlying this view is an assumption that it may be hurtful for the children and youth to talk about their experiences. In contrast to this view, the young next of kin we interviewed all expressed a sense of relief that someone had finally asked them about their experiences, thus making the interview process a positive one for them. Our experience was that the barriers we encountered in reaching these young next of kin were not due to their own unwillingness but to others' concerns that it would not be good for them. By giving voice to the young next of kin, this study contributes to an emerging field of research in which children and adolescents are included in studies to improve health care services for psychiatric patients and their families.

It also highlights an important research ethical insight, namely, the importance of giving voice to those who are seldom heard and recognized. To give a

voice to these young next of kin, who do not have a formal representational role in relation to their parents or siblings in their contact with the health care system but who nevertheless may be deeply involved in a relative's illness, is of ethical importance, as previous research and this study confirm that children and adolescents with mentally ill parents or siblings face many difficulties. As we have seen from this study, a lack of information and involvement may increase the suffering of the young next of kin by increasing their worries and feelings of being alone and isolated. Research has shown that interventions to prevent mental disorders or psychological disturbances in children of parents with mental disorders are effective⁶ and in this regard is obtaining information and being involved as a young next of kin of vital importance.⁷

Another understanding of involvement

An interesting finding in our study is that the young next of kin discussed an understanding of what it *means* to be informed and involved that differed from the usual understanding of these terms. In the literature, 'involvement' often entails involvement in decision-making and active participation in the planning and evaluation of care and thus focuses on the next of kin's role of representation and right to contribute to the decision-making process.⁴² In this understanding of the term, young

next of kin can easily be overlooked because they are minors and have no legal representational role. For the young next of kin in this study, however, ‘being informed and involved’ seemed to involve being seen and recognized by the health care personnel as a participant in the care of their family member—not in terms of making decisions but in terms of being able to spend time with the ill family member at the ward unit and having the opportunity to talk about their own experiences and to receive information about the patient. In their understanding of involvement, the possibility of actually *being together* as family members is important. In this regard, the young next of kin give themselves an active role, and they also have needs that should be met by health care personnel.

Repairing and preserving relationships

These adolescents want more information, and they want to be with their ill family member. **Being away from their family members matters to them, even though their parent or sibling is mentally ill, and being separated may cause relational damage, as we have seen from this study. The study shows how young next of kin struggle to maintain their relationship with their ill family member. They often experience negative changes in their relationship with their parent or sibling, raising the question of how to preserve these close relationships to prevent**

relational harm. This reflects an important ethical challenge among the young next of kin, namely, the ethical challenge of preserving and repairing relationship within the family. That is, the relationships between parents and children and between brothers and sisters are significant, and working to prevent these relationships from breaking down as a consequence of illness is of clinical and ethical importance.⁴³

We may approach this ethical challenge of preserving and repairing relationship within the family from the perspective of *family ethics*.^{44,45} The needs of the young next of kin call for a perspective that takes into account the *whole family*, and they express a need for a family perspective in relation to the treatment and follow-up of their ill family member.⁴⁶ The ethics of families differ from traditional health care ethics, which are typically patient-centered and individualistic, with a focus on the individual patient and his or her right to make autonomous choices. Traditional health care ethics do not embrace the vulnerability and needs of the next of kin. Furthermore, an ethical perspective that focuses on individual representation and decision-making does not capture what is really at stake: the importance of a family being together.

From a family ethical perspective, it is important to acknowledge how serious illness interferes with family functioning. Focusing exclusively on the patient and his or her needs and rights without taking the family perspective into account may damage

the family and its tasks and functions. This was evident in our data. The informants reported altered and sometimes damaged relationships with their close family members, communication problems within the family, and problems connected to the nurturing or caring functions of the family.

The negative effects of coercion

The use of coercion in mental health care represents a major ethical issue that raises many ethical challenges, and in this study we asked for the experiences of young next of kin who were witnesses to coercive treatment of a close relative. We found that coercion had a negative impact on the young next of kin, both intra-psychically by inducing feelings of stigma, ambivalence, and worry, and relationally by negatively affecting their relationships with their family members. This finding indicates that communicating coercion to young next of kin is important. However, in our study we found the opposite, namely, that coercion was highly *under-communicated*, being seldom or never thematized to the young next of kin either by health care personnel or by the family members.

Protect or inform?

Therefore, it is important for health care personnel to contribute to these families rather than leaving them alone, both in terms of providing essential information to the young next of kin, including information about coercive treatment, and in terms of helping family members to communicate with each other. **However, this further raises an ethical dilemma for health care personnel regarding how to balance the amount of information and exposure to the locked wards at the hospitals with the risk that the young next of kin might become afraid when faced with frightening situations and information. Thus, personnel may experience a dilemma between informing and protecting, where informing the young next of kin may be difficult due to the desire to avoid inflicting harm, as talking about mental illness may be hurtful. Withholding information from the young next of kin may represent a form of paternalistic practice, often reflecting a discomfort or lack of competence among personnel in terms of dealing with these issues rather than a well-founded decision not to inform the young next of kin.**

The literature presents different views of this topic, noting both positive and negative consequences of young next of kin's involvement in the care of their close family members.^{13,24,30} Nevertheless, previous studies highlight the importance of individual judgements and cooperation with the youth in relation to where to "draw the line" of involvement and distance.²¹ Our study shows that protecting young next of

kin is not equivalent to *not* informing them. That is, even though the young next of kin in our study received no formal information, they were still informed in terms of what they had witnessed at home prior to the hospital admission and afterwards as well as from their experiences at the hospital, meeting the staff, and experiencing the environment. All of this informal information influenced them. Being met with a “paradoxical” silence¹⁴ from the personnel, even if this silence was intended to “protect” them, increased their concerns and induced a feeling of loneliness. However, it is important to note that the amount of information and the way it is managed must be adjusted to the age and specific situation of each young next of kin.

Conclusion

The study demonstrates a need for more family-oriented perspectives in mental health care and in relation to the handling of coercive treatment to meet the needs of young next of kin and their families. It also highlights a need to evaluate the organization of psychiatric wards to promote a more family-friendly approach.

Furthermore, the study finds that there are ethical aspects at stake for young next of kin and their families other than those that are emphasized by a traditional health care ethics approach that focuses on the individual patient’s rights. This finding indicates a need for a wider ethical perspective in psychiatric health care that also

includes a family ethical perspective. These are ethical challenges related to the young next of kin's needs for interconnectedness and being together with their sick family member. These challenges are connected to the preservation and reparation of relationships, to family communication, and to the need for information with which to better comprehend their family member's situation.

Declaration of Conflicting Interests

There are none conflicting interests.

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