

A qualitative analysis of child and family complaints related to child mental health services

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Abstract

Problem: Little is known about issues of patient-reported problems, in particular within psychiatric services for children with mental ill health. Child and family complaints related to child mental health services can be analyzed and discussed in light of the universal human right to health and healthcare. Therefore, the aim of this study was to analyze child and family complaints related to child mental health services.

Methods: A retrospective, descriptive design was used. Child and family complaints were analyzed with a qualitative thematic analysis.

Findings: The findings were described in three themes describing lack of access to care, inadequate communication between services and children with mental ill health and their families, and lack of clarity of who is responsible for care, leading to neglect of children's needs. These issues place a huge responsibility on parents or relatives.

Conclusion: Better communication within mental health services, and better collaboration with other services such as school and social services, could limit children's suffering. Healthcare services with named professionals who specialize in child mental health and provide continuity in care, are required. General human rights principles should guide planning and care of children.

KEYWORDS

children and adolescents, human rights, mental health

1 | BACKGROUND

A significant number of children and adolescents suffer from mental ill health (Polanczyk et al., 2015; Vasileva et al., 2021). Among mental health problems, depression is a leading cause of disease worldwide (Malhi & Mann, 2018). Due to the increasing needs of mental healthcare, children and adolescents with mental ill health are treated both in hospital and outpatient mental healthcare services (Koet et al., 2022). However, there are barriers to accessing specialist services and to treating mental ill health in children (O'Brien

et al., 2016). Research from the perspective of families and children on these services is scarce. To understand the challenges and barriers in mental healthcare services for children with mental ill health, we performed a study to explore the meaning of patient complaints from children and their families in contact with specialist psychiatric services for children with mental ill health. This study is part of the research project *Human Rights and Patient Complaints*, where patient complaints are analyzed and discussed in light of the universal human right to health and healthcare. The comprehensive project addresses both in and outpatient mental healthcare services for adults as well as

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for children. An analysis of patients' complaints on adult mental healthcare services have been reported elsewhere (Sundler et al., 2022).

Reporting and dealing with patient complaints can be useful to assess the perception of patients' rights (Karačić et al., 2021). Patient complaints are important to understand patient satisfaction or dissatisfaction (Hogg et al., 2018; Semyonov-Tal, 2021). Moreover, complaints reported by patients or their significant others are important indicators of quality in healthcare services (Thi Thu et al., 2015) and may provide directions for healthcare improvements (Mirzoev & Kane, 2018). Healthcare services can learn from patients' and families' experiences reported in complaints to provide safer and more person-centered care (Van Dael et al., 2020). A greater commitment to addressing complaints should give insights into aspects of healthcare that traditional quality and safety reporting systems fail to capture (Gallagher & Mazor, 2015). One advantage of dealing with patient complaints is facilitating healthcare providers' preparedness to effectively manage and improve patient care (Thi Thu et al., 2015). Complaints by patients in psychiatric hospitals in Israel underscores the link between voiced complaints and patient satisfaction (Semyonov-Tal, 2021). Research also points to the importance of the behavior and attitudes of service providers in patient care (Hogg et al., 2018).

Everyone—child, adult, and older person, has the right to the highest attainable standard of health. This integral human right is described in detail in the United Nations convention (United Nations Committee on Economic, Social and Cultural Rights, 2000). While a life free of illness and disease cannot be guaranteed, everyone has the right to equity and equality in healthcare. Of Sweden's approximately 10.2 million inhabitants (Statistics Sweden, 2020a), just over 2 million are under the age of 18 (Statistics Sweden, 2020b), the age limit that separates children from adults (United Nations Convention on the Rights of the Child UNCRC, 1989). In Sweden, where this study was conducted, the rights of children in need of healthcare are regulated by a variety of laws such as The Health and Medical Service Act (2017); and The Patient Act (2014), and most recently, The UNCRC, which became Swedish law in 2020 (UNCRC as law in Sweden, 2020).

Promoting good mental health for all is a prioritized area both nationally and on a regional level, and there is an agreement that strategies need to be preventative and sustainable (The Public Health Agency of Sweden, 2019). Five nationally identified areas of focus for mental health are suicide prevention and health promotion, accessible early services, the individual's right to participation, integration of services for vulnerable groups and leadership and organizations that use evidence-based methods. Particular goals for children are similar, but with the addendum that parents be offered support and that all children are to leave school with pass grades (The Public Health Agency of Sweden, 2019).

In Sweden, patients and their relatives have the legal right to make comments or complaints about their care (The Act on Support for Complaints against Health care, 2017). Complaints are made to the Patient Advisory Committee (PAC) that exists in each county and

municipality. The primary task of PACs is to assist patients and their relatives with problems arising from public healthcare services, help them with information and to have their complaints answered by the healthcare service in question. PACs are legally obliged to exist but are independent and impartial bodies without any authority to make medical judgments or dole out punishments. They review documented reports and any written correspondence about a patient's or a relative's concern. Swedish PACs assist patients or relatives with complaints related to publicly financed in and outpatient services.

2 | PURPOSE

Complaints are important indicators of quality in healthcare services. Understanding the issues and details of patient complaints may provide directions for healthcare improvements, and in particular, for children with mental ill health. Children benefit from early and targeted interventions in healthcare, often with long-lasting positive effects. However, very little is known about the impact and issues of patient-reported problems related to child mental health services. Therefore, the aim of this study was to analyze child and family complaints related to child mental health services.

3 | METHODOLOGY

3.1 | Design

A retrospective study with a descriptive qualitative design was used to explore patient complaints made to a PAC in Sweden. The data were analyzed using qualitative thematic analysis (Sundler et al., 2019).

3.2 | Setting and sample

As part of the comprehensive study, a sample of patient complaints collected from a PAC in a healthcare region in the West of Sweden was analyzed. The services in this region provide healthcare and medical treatment for over 1.7 million people. The region operates 17 hospitals, 121 healthcare centers, and 170 public dental care centers. Subcontracted private centers provide some of the care.

A purposeful sampling of patient complaints on healthcare services made in the region in 2017 revealed 434 complaints related to children. Complaints about child psychiatric services specifically counted for 75 of the 434 complaints related to children. A narrative written by a child or relative was included in 47 of these complaints and formed the base for the present study. Girls were the focus of 24 of the complaints, 22 complaints related to boys and one of unknown gender. The majority of children, $n = 31$ (66%) were between 10 and 19 years of age and from both country ($n = 32$) and urban ($n = 15$) environments. Researchers accessed data that had been anonymized with the help of a legislative controller at the actual PAC which

provided the data to the researchers. The inclusion criteria were: patient complaints made in 2017, including a written account of a complaint by a patient or a relative and sent by mail or e-mail to the PAC or the transcription of a telephone call made by a patient or relative to the PAC. Primarily relatives made complaints, with only three complaints made by children themselves. The 47 child complaints extracted from the sample were used for the in-depth qualitative analysis in the present study.

3.3 | Data analysis

A qualitative thematic analysis was performed (Sundler et al., 2019). The objective was to identify and describe patterns of meanings within the content of the complaints. The first step of the analysis involved carefully and repeatedly reading the complaints to get an overall sense of what was predominant in and characteristic of the data. In the second step, a more systematic reading of the data focused attention on identifying meanings in the data and understanding patterns in the text. Step three involved the data being grouped as different meanings, and patterns of meanings were identified, condensed, and arranged in initial themes. In the fourth step, the authors attempted to delve deeper into the data, reflecting on the details of the complaints to allow new insights to emerge. Themes and subthemes emerged from this reflective process. The emerging themes were reviewed, discussed, and further refined by the researchers. The analysis involved an iterative movement between the whole data and the emerging themes, going back and forth between original data with reflection. Finally, the analysis yielded three themes and nine subthemes that were used to organize and describe the findings. The researchers remained cognizant of the voice of the child in their analytic process, even when adult relatives were telling the child's story in complaints. Quotations have been selected to identify complaints and help illustrate themes.

3.4 | Ethical considerations

This study was approved by the Regional Ethics Committee in Gothenburg, Sweden (DNo. 951-15), complies with the ethical principles in The Declaration of Helsinki and follows the Swedish

Ethical Review Act (The Ethical Review of Research Involving Humans Act, 2003, p. 460) which regulates research involving humans. Data were provided by the PAC in accordance to Swedish ethical standards of research and EU General Data Protection data. The PAC anonymized the data so that none of the names or other personal information of patients, relatives, nurses, or other persons in the complaints were shared with the researchers. In Sweden, patient complaints are considered public property after being anonymized, but for research studies ethical approval is of course, still required and has been acquired. Thus, all participants were treated with respect for autonomy, beneficence, nonmaleficence, and justice.

4 | RESULTS

Patient complaints related to child mental health services are described based on three themes and nine subthemes, see Table 1.

4.1 | Problems related to lack of access to care when a child suffers from mental ill health

Difficulties of not getting access to healthcare services as needed were reported in the complaints for children suffering from mental ill health. Uncertainty on who was responsible for the child's healthcare was described and problems related to continuity in care. Long waiting times to services were reported, which for some children were linked to school refusal problems and increased mental ill health.

4.1.1 | Lack of insight on who or what service is responsible for the child

The process of investigation and treatment involved several instances such as the neuropsychiatric team, doctors, nurses, and social services. However, who or what service had the main responsibility for the child was described as uncertain. This uncertainty placed extra responsibility on the child's family who needed to be the ones holding the various aspects of the child's care together. Repeated contact,

TABLE 1 The results as presented by themes and subthemes.

Themes	Problems related to lack of access to care when a child suffers from mental ill health	Inadequate communication between services and children with mental ill health and their families	Lack of clarity of who is responsible for care led to neglect of children's needs
<i>Subthemes</i>	Lack of insight on or what service is responsible for the child	Lack of communication led to feelings of not being taken seriously	Responsibility for the child's care is unclear due to lack of continuity and teamwork
	Long waiting times with no clear alternative plan	The way in which communication took place was sometimes problematic	Deficient interprofessional communication about the child's care and follow-up
	Exacerbation of school refusal problems for children with mental ill health	Requested updates to perceived mistakes in the patients' health records	Inadequate follow-up on care planning, drug treatments and side effects

often unsuccessful, with the various actors involved in the child's care created a feeling of helplessness for the child and family.

"The doctors at the health center sent a referral to child mental health services ... who have sent it back. Then the referral was sent to specialist pediatric outpatients, who send it back to the health center who say they can't take care of this problem." [34]

Periods of transition were especially vulnerable to lack of contact between mental health services and the child. Transition between child and adult services, between the child's school and neuropsychological services, between child services and rehabilitation, and between all of the aforementioned services and social services was problematic. The lack of clarity in who was responsible had led to referrals and appointments delayed or missed. For instance, uncertainty on what services were responsible for a child when being transferred from child to adult services resulted in nobody being responsible for the child's care at that time:

"My child has been in the queue for a neuropsychiatric investigation for almost two years now, or so we thought after our last doctors visit. During that time, she would be transferred to adult services, which would not affect the waiting time for the investigation. Last autumn, after a year of waiting, I contacted the adult mental health services to check when we would get a time and was told that there was no written referral and my child had no right to a place in the queue for investigation. I rang outpatients several times and in the end, they wrote an incident report but they had not even contacted me or adult services. Now my child is in the queue to adult services but they haven't taken the two years she's already stood in the queue into account." [39]

4.1.2 | Long waiting times with no clear alternative plan

Not knowing how long the child needed to wait for investigating mental ill health issues was a recurring theme. Complaints question the relevance of the region's guarantee to be seen within a specific period and the right to choice of care services, for children with mental health issues. After long waiting times without a result, families wished to get permission to proceed to contact services in other regional health boards or private clinics.

"I have referred to the care guarantee several times at children's services but to no avail- to the children's psychiatric unit, to the psychologist, then the secretary, then the head of the unit a few times, and now to

you at PAC. My child should be investigated according to the care guarantee and to Swedish law. I demand an immediate offer of an investigation by a private healthcare provider care." [21]

4.1.3 | Exacerbation of school refusal problems for children with mental ill health

Complaints include those from children not attending school, so-called school refusal children. Everyday life, and in particular school, did not work for these children while they are waiting for investigation or continued care. This resulted in the child remaining at home for an unspecified amount of time, which also affected the child's family as parents or relatives needed to be at home with the child. Waiting for investigations meant that children lacked the help and support needed to manage school and everyday life and for many, this waiting increased their mental health issues.

"The child has many difficulties in everyday life but the biggest ones are isolation and school refusal. We are worried ... the longer we wait for the investigation to be done, the longer it takes before the child can sort out her life and get help with her difficulties Now, she doesn't even go to school." [32]

4.2 | Inadequate communication between services and children with mental ill health and their families

The complaints reported on problems in communication with child psychiatric services. Care and treatment were not always suited to the child's actual needs and situation. It might be that the care offered was not suitable and, therefore, not carried out. One such example was when the child received a time for the psychologist but was too unwell to keep the appointment. Another was when the child was offered group sessions with other children, which is unsuitable for many children with mental ill health.

4.2.1 | Lack of communication led to feelings of not being taken seriously

Lack of clear communication led to lack of insight and understanding on decisions made by the services. Children and families were left wondering what the next step was and with whom. Lack of communication was described within and between different services such as school, social services, the psychologist, and the family.

Lack of communication with healthcare staff contributed to children with mental ill health feeling that they were not taken seriously by the services. It is possible that child and family had felt

they had not been treated well in personal meetings with staff or that parents felt they are made feel guilty because of their worry for the child. Parents reported feeling like a bother when they talked to healthcare professionals about their child:

"I've tried to speak to the staff but they just wave our worries aside." [40]

"They said we weren't to burden them with small stuff." [29]

4.2.2 | The way in which communication took place was sometimes problematic

Unreturned telephone calls and questions that went unanswered caused frustration and worry for parents. Children and parents felt they lacked enough information or clear decisions on the child's continued care and treatment. Parents had trouble understanding information healthcare staff gave them. Alternative ways of communicating were requested such as via email where both written information and the name of the person sending the email would be visible, as opposed to the invisibility a telephone call was experienced as:

"They have installed a system whereby one rings to an answering service, leaves a message and they are to ring back the next day at the latest. It doesn't work at all." [42]

4.2.3 | Requested updates to perceived mistakes in the patients' health records

Parents described how the child's medical records had erroneous content about the child's diagnosis and treatment and this negatively affected present care. Parents pointed out that incorrectly written record entries affected the child's schooling and insurance policies. Some complaints describe how staff have broken the confidentiality law when they have informed the school about the child's health and situation. Requesting the health services rewrite the medical records entries was futile and resulted in frustration.

"I want corrections made to entries in the medical records; there are lots of mistakes in it." [28]

4.3 | Lack of clarity of who is responsible for care led to neglect of children's needs

Complaints describe inadequate staffing resources within all categories of the child psychiatry services. Lack of a named and informed

team of carers led to children and families missing out on necessary care, information, or follow-up.

4.3.1 | Responsibility for the child's care is unclear due to lack of continuity and teamwork

An insufficient number of both nurses and doctors led to the child and family experiencing problems in continuity in care and lack of teamwork. Dissatisfaction was expressed when children had to meet different people each time in their meetings with child psychiatric services—for example, when they did not have a named doctor, they met different ones each time.

"Doctors move on, we meet new ones that are not updated on the child's problems and in some cases their Swedish is so poor that we have difficulty in understanding what they are saying." [32]

The child's family wondered who was responsible for the lack of staffing resources or changes in the organization of services that resulted in no one taking responsibility for the child's care.

4.3.2 | Deficient interprofessional communication about the child's care and follow-up

Other complaints related to the family not been informed about changes to the child's medicines, not receiving information on when the child's investigations would be done or when treatment would start. Deficiencies in teamwork and collaboration between all instances and professions take a central place in complaints.

"My child attends a therapist at the child mental health service but the type of therapy does not suit the child. She has several different problems we need help with but have not met any doctor. Why doesn't she get to see a doctor and a dietician?" [33]

4.3.3 | Inadequate follow-up on care planning, drug treatments, and side effects

Children who had previously been investigated and started treatment lacked follow-up in care planning and drug use. Complaints described children that had no one to give feedback to on drug side effects or to get prescriptions renewed. The child's relatives had tried to contact services for weeks to get a prescription renewed:

"For several weeks now we have asked them to fix a new prescription for me as my tablets are almost finished and the capsules are giving me side-effects ...

they say that they are going to do it but nothing has happened ... one's prescription should be administered as soon as possible and not be promised without result ... one shouldn't have to wait this long. This is not OK." [20]

Complaints describe children's psychiatry service in relation to lack of follow-up on drug treatment, often despite the fact that side effects of treatment had previously been reported. Planned blood tests and basic medical controls such as pulse and blood pressure measures were forgotten:

"Nobody knows how she is or about the follow-up ... blood-tests and vital signs were supposed to be done weekly at the health center but my child has been forgotten, right in the middle of the introduction of a narcotic substance, without adequate follow-up. When the nurse finally rang back she promised to write an incident report—but nothing has happened." [41]

5 | CONCLUSION

5.1 | Discussion of the results

This study reports on problems and unmet healthcare needs of children with mental health illness. Complaints related to child mental health services in a large region in the West of Sweden, describe a group of children and young people with mental ill health who have difficulty in accessing health services when needed. The findings describe the uncertainty experienced by these children and young people and their families about who is responsible for the child's care and indeed, what the plan of care is. The findings further indicate that there is inadequate communication from the services to the family, within services themselves and with other actors such as school and social services. This means the child and the care they require are at risk of being forgotten or ignored. The burden of responsibility placed on parents or relatives to access, communicate with, and see that their child receives adequate care is huge.

The lack of or long delays in accessing specialized mental health services highlighted in this study caused prolonged suffering. Children and families expressed dissatisfaction and suffering from unmet healthcare needs. There problems with access to treatment and care for children and adolescents with mental ill health (Reardon et al., 2017). Lack of available resources seems to limit the availability of specialist or suitable psychiatric services for children with mental illness. Attention needs to focus on how to facilitate better access and increased resources and providers of mental health services for children (O'Brien et al., 2016). According to the parents in the present study, problems with access to care prolonged the child's suffering.

Increased availability of suitable services for children with mental ill health is warranted (Reardon et al., 2017).

The children and families in the present study exposed suffering from inadequate encounters with healthcare professionals. The analyzed complaints emphasize the child's vulnerability when suffering from mental illness. Parents and family play an important role in caring for children, and in particular, providing security for the child. Contact with new people at each health service contact can increase the vulnerability of the child. In vulnerable situations, the behavior and attitudes of service providers become imperative to decrease unnecessary suffering and increase patient satisfaction (Hogg et al., 2018). Developing trusting and supportive relationships with professionals is significant (Reardon et al., 2017). Nurses are part of the team of professionals providing psychiatric care. Their relationship with the child and the family is pivotal to support and guide the child. Children are already vulnerable and even more so when in need of healthcare (Sahlberg et al., 2020). Problems related to lack of adequate communication within and between services led to children being unable to attend school. Further requirements are necessary to prevent and promote the mental health of children and adolescents. In particular, better communication within organizations such as school, social services, and mental healthcare services. Also, better and earlier collaboration between these various instances that affect the child's school going and everyday life. Hence, psychiatric nurses have an important role in developing meaningful and supportive relationships and to collaborative with those involved.

This study raises awareness of the importance of the child's perspective in care, by focusing on complaints related to children's care from the children themselves or from their relatives. In the complaints, mainly adult voices were heard, and the voice of the child themselves was limited. While family may tell part of the child's story, the voice of the child still needs to be acknowledged. A problem in modern society is that children are seldom seen as competent and active members of society in their own right (Bergnehr & Zetterqvist Nelson, 2015). Human rights should be taken into account in every situation where children are in need of healthcare at all levels, including mental health services. We need to rethink and create real change in healthcare so that children are active participants with the right to have their voices heard in matters that affect them. Every care encounter needs to meet the child's needs to achieve the principles of the UNCRC. Leading principles are about treating all children equally (Article 2), to make children's best be governed in all decisions concerning children (Article 3), children's inherent rights to life, survival, and development (Article 6), and children's rights to express their views and have it taken into account (Article 12). Positive experiences when receiving healthcare are necessary to increase sustainability in healthcare for children. There is always a risk that children's needs and wishes are based on an adult's perspective of what is best for the child when the child is exposed to healthcare (Sahlberg et al., 2020), also referred to as the adult having a child perspective. Young children's voices are often missing in research but should be heard (Coyne et al., 2016).

5.2 | Strengths and limitations

A limitation of the study is the relatively small number of complaints. From a sample of 75 complaints related to child mental health services only 47 of these complaints were included. The remaining complaints did not include a narrative written by a patient or a relative. The inclusion and exclusion of complaints were discussed together with the legislative controller at the PAC. Complaints written by personal at the PAC were excluded as these reports were short and not as detailed in their descriptions as needed for a qualitative study like this. Still, the complaints analyzed were detailed and rich in their descriptions, which is a strength of this study.

Another limitation of the study is the fact that a child's relative made the majority of complaints on behalf of the child, thereby giving another adult perspective rather than the child's own perspective. Children with mental health problems are vulnerable, but still capable and competent. Research as well as societal issues should acknowledge children experiences and listening to children's perspective (Sudarsan et al., 2022). The child's own perspective is seldom looked for in healthcare services or in research, which is a limitation in this study as well. Children's possibilities to demand their rights in healthcare is difficult and the child's complaint may not have become known otherwise. Even if most complaints in the present study were made from an adult perspective, this contributed to important insights on children's view. Still, the view of the child needs to be acknowledged, and there is a need to improve how to acknowledge the voice of children in vulnerable situations.

All complaints were made to the PAC by healthcare users who could express themselves verbally or in text in Swedish, which excludes users without Swedish. Very little is known about Swedish psychiatric healthcare users with other mother tongues than Swedish.

5.3 | In summary

The findings of the present study expose a major challenge for vulnerable children with mental ill health and their families in accessing child mental health services. Lack of timely care from well-functioning services results in greater ill health and suffering in the long term. An important issue to recognize is the particular vulnerability during the time for transition from child to adult services. The experiences shared in this study show that the general principles of the UNCRC seem to be endangered in caring for children needing and accessing psychiatric services, and that more attention needs to be directed to those principles when planning and performing care with children in healthcare encounters.

Accessible child mental health services with good inter-professional collaboration, clear communication with child and family, and continuity in care from named professionals would make the child's right to health and development possible and encourage them to have a meaningful everyday life. However, this would require that services be run for and by patients in collaboration with health

services rather than on and to patients. Understanding the issues and details of patient complaints may provide directions for healthcare improvements.

Nurses, as critical healthcare professionals, are important in providing comprehensive healthcare services and supporting children suffering from mental ill health and their families. This study address needs for timely care from well-functioning services that provide continuity in care and better communication and collaboration to support and help these children. The findings are important to help nurses' awareness of the vulnerability of children with mental health illness and their families. This study highlights the vital role nurses play in supporting and guiding these children and their families.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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