PEER-REVIEWED RESEARCH

Lack of clear framework impedes work with children of sick parents

Healthcare personnel who work with parents who are mentally ill or have substance abuse problems are uncertain about their role. The support that the children receive can therefore be haphazard.

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ABSTRACT

Background: According to the Norwegian Institute of Public Health, 290 000 children are living in families where at least one of the parents has a moderate alcohol abuse problem or mental illness. Research conducted over several decades has shown clear links between mental illness or substance abuse in a parent and impaired mental health in children. Several reports and studies also demonstrate shortcomings and difficulties in the work aimed at children of sick parents. In 2010, new legislation was introduced to ensure that children of sick parents in the specialist health service are better taken care of.

Objective: To investigate the perceptions and experiences of healthcare personnel who have a special responsibility for the work with children of sick parents.

Method: Through in-depth interviews, the study investigated healthcare personnel's perceptions of working with children of sick parents. The data were analysed using systematic text condensation.

Results: The informants identified a number of practical challenges in their daily work, including difficulty in getting parents to understand how their mental condition affects their children. The healthcare personnel also reported that they have trouble motivating parents to receive help with the parenting role. They face major challenges in the work with children of sick parents, where lack of time to perform statutory tasks is highlighted as a key factor.

Conclusion: The study indicates that healthcare personnel who work with children of sick parents need a clearer framework for their work and more time to carry out the work.

A clear link has been demonstrated between mental illness or substance abuse in a parent and impaired mental health in children (1–5). There is a risk that the parents' mental or substance abuse problems affect how they function as a parent, thereby having a negative impact on the environment in which the children grow up (1, 3, 6).

According to the Norwegian Institute of Public Health (1), children of parents with a mental illness or substance abuse problem have almost a 100 per cent greater risk of experiencing adverse events in their childhood home than children who do not grow up with such parents.

The increased risk of the children experiencing adverse events depends on the severity of the problem, the severity of the parents' psychopathology and the age of the children when the problems first arose. It also depends on whether both parents are sick (1, 4, 6). Depression has been shown to impair parents' ability to understand the children's signals, their need for safety and their parents' presence (1, 2, 6).

«Approximately 290 000 children in Norway have at least one parent with a moderate mental disorder or substance abuse problem.»

Other mood disorders and substance abuse problems can create unpredictable parental behaviour that scares the children (4, 5). A negative emotional climate of frequent conflicts can develop in the home (7). Such factors create sustained stressors, which in turn have a negative impact on brain development and increase the chance of developing learning difficulties, behavioural problems and impaired physical and mental health later in life (8).

Calculations from the Norwegian Institute of Public Health (1) show that approximately 290 000 children in Norway have at least one parent with a moderate mental disorder or substance abuse problem. Being able to provide preventative and support measures for families where the parents have substance abuse problems and mental disorders is therefore a high priority (9, 10).

Government focus and new legislation

We have gradually gained more knowledge about the extent of atypical development and the increased risk of this in children of parents with a mental illness or substance abuse problem. The Ministry of Children and Equality initiated an investigation into the follow-up of these children. This resulted in three reports (11–13), which all concluded that despite the knowledge about risk factors, the healthcare provision for these children was haphazard, unpredictable and disjointed.

The reports resulted in the government's focus on funding in the period from 2007 to 2010. The focus was aimed at initiatives in competence development and administration, in addition to long-term support through measures and early-stage intervention to help the children (14). Towards the end of the focus period, new legislative acts were passed, which entered into force on 1 January 2010: in general, section 10a (15) of the Health Personnel Act and section 3-7a (16) of the Specialist Health Services Act.

These laws define the patients' children as children of sick parents and impose a requirement for all departments in the specialist health service to have dedicated healthcare personnel with a child welfare role who have responsibility for fostering and coordinating healthcare personnel's follow-up of minors. The laws are intended to complement each other, and aim to ensure that these children are identified at an early stage. Their purpose is also to ensure that processes are initiated to give the children and parents the tools they need to better master their situation (10, 14).

Shortcomings in work with children of sick parents

After the end of the focus period and when the new legislation was implemented, recent surveys indicate that the work with children of sick parents is still subject to shortcomings. In a review from 2012 (14), the Norwegian Directorate of Health points out that only a limited number of children and young people have used the measures that were introduced after the focus period.

Inadequate registration of the patients' children shows that implementing the new legislation in clinical practice is taking longer than intended (17, 18). Earlier studies highlight barriers in the work with children of sick parents and failings in the interaction between different agencies (19–22).

A Norwegian multicentre study indicates lack of cooperation and coordination as an existing problem (22). One of the main findings in this study is that the specialist health service only partly adheres to the legislation on children of sick parents.

The purpose of our study is to gain more knowledge about the perceptions of healthcare personnel who have a responsibility for children of sick parents in relation to the process of identifying families' needs and initiating support.

Method

Design and sample

The study has a qualitative research design. We used an exploratory method (23) in order to understand and describe how those who work with patients and their children perceive and understand their work. By attempting to set aside their own existing knowledge of the subject, the authors sought to study the informants' experiences, and hence generate knowledge about the field (23).

We searched for informants with experience in working with children of sick parents. The inclusion criteria were as follows: holding a position of responsibility and personal experience in working with children of parents with a mental illness or substance abuse problem. A total of seven informants formed the knowledge base. Five of the informants were personnel with a child welfare role in accordance with the new legislation from 2010, while two of the informants had previous experience of working with children of sick parents.

Part of the sample was assembled using the 'snowball method' (24). By asking each informant about other potential informants with experience from such work, the first author learned of other professionals within county 1. For county 2, we received contact details from the health trust's research department about relevant informants in line with the inclusion criteria.

We invited the informants personally via an information e-mail and a subsequent telephone call. Of those invited, one declined the invitation to take part. The sample consisted of four women and three men aged 38–65, made up of qualified specialist nurses, nurses, social educators and special needs teachers.

Informants from adult psychiatric wards and outpatient clinics were included. Four informants had over five years of experience working with children of sick parents, while one had two years of experience.

Data collection

We conducted the data collection through individual in-depth interviews of personnel from four different workplaces in Central Norway. A semi-structured interview guide with a phenomenological approach provided a framework for the interviews (24).

The interview guide had four main themes: 1) how is the daily work, 2) experiences with child and parent contact, 3) experiences with and perceptions of arranging support, and 4) perceptions of support reaching where needed. The interview form was flexible and allowed for follow-up questions with a view to gaining a more in-depth understanding.

The interviews were conducted by the first author at the informants' workplace during their working hours. The first author interviewed the informants in a suitable meeting room or in their office. She used a tape recorder, and all the interviews were transcribed immediately afterwards. The interviews lasted from 45 to 85 minutes.

Analysis

We used Malterud's (25) systematic text condensation method to analyse the text. The form of analysis is a descriptive, cross-sectional analysis through four stages of decontextualisation and recontextualisation. The first two steps have a phenomenological foundation. The latter two also use interpretation and the hermeneutical circle through an analytical journey between the whole and its parts until a new understanding is developed.

In the first step, we read through all the transcribed interviews in their entirety, focusing on listening to the narrative. In step two, we used a computer program for qualitative analysis, MAXQDA 11. Most of the text was categorised into meaning units with different codes based on how the statements answer the problem.

In the third stage, we condensed the meaning units within each theme into shorter sentences with the same meaning content. Similarities and differences in the informants' perceptions were then identified. In the final step, we summarised the condensed text in parallel with returning to the raw material and examining the whole from which the text sequence was extracted.

Ethics and data protection

The study was approved by the Norwegian Centre for Research Data (NSD) and the research and development departments at Nord-Trøndelag Regional Health Authority and St. Olavs Hospital. We invited the informants personally, so that no one other than those conducting the study would know the identity of the participants. In order to ensure confidentiality, we deleted the audio recordings after the informants approved the transcribed text.

We endeavoured to anonymise place names or other specific factors that might be recognisable. The consent form and encryption key were kept separately from the data material and stored in accordance with applicable guidelines.

Results

Lack of information on time use

The informants lacked a clear specification of how much time they should dedicate to their work with children and their families. The personnel with a child welfare role who were nurses and social educators reported that their new ‘post of responsibility’ was prioritised above their normal work as a nurse or social educator: ‘There’s no specific time set aside. It’s just something that needs to be done in addition.’

The personnel with a child welfare role had no reduction in ordinary duties. Nor had they received any guidance on how long they were expected to spend on duties in their child welfare role: ‘It’s hard to say how much time is spent on the child welfare part of the job. Management has given no indication of how long we should spend on it.’

In addition to the practical challenges of finding enough time, the informants stated that they were uncertain about the expectations in terms of the depth and scope of the work. For example, they were unsure how hard they should try or how long they should endeavour to motivate the parents.

The personnel with a child welfare role who were nurses and social educators said that they were already busy in their positions as nurses and social educators, and that the added responsibility presented major challenges in terms of prioritisation: ‘Actually, it’s quite a lot of extra work, you have several patients and therefore numerous tasks. So, there can sometimes be a bit too much, and then I think the children get less attention. Or not less attention, but there just isn’t enough time.’

The ward personnel in particular felt the time constraints. Staff at the outpatient clinic were more inclined to feel that they had time to talk to their own patients about their children. However, they pointed out that only having an overview of their own patients was a challenge, and that it was difficult to arrange meetings with other personnel with a child welfare role: ‘It’s actually a bit of an isolated position.’

The parents shied away from seeking help

All of the informants in the study found that the parents were often hesitant to talk about the situation at home, the children and their role as parents. One reason could be that many parents do not have knowledge about and an understanding of how their own disorder affects their children: ‘They often believe that the children don’t understand or don’t know. But children know more than we think.’

One informant told of an example where a mother claimed to be a better mother when she was high than when she was sober. The informants also said that many parents believe that the children do not notice if they cry or have a moderate drug habit.

Some informants described how the work was ‘difficult to progress’, and that it could therefore stagnate: ‘I try to arrange meetings at the family centre or some such thing. Sometimes they don’t turn up. As if they don’t have a need.’

The fear of child welfare services was another reason why the parents were hesitant to talk about their children. Consequently, patients often quickly brushed aside questions by saying that everything was fine: ‘Some parents say that the children are doing well, and that’s the end of it. But then it turns out that they may have been through quite a lot.’

> **«It’s usually those who aren’t worried about their children who are the most difficult to have contact with.»**
>
> Informant

The parents’ fear and hesitation were a major challenge for all of the informants. Some also found that the parents’ reticence to talk prevented them from procuring further support for the family. Additionally, it was often difficult to assess which cases were serious enough to warrant reporting their concern to the child welfare services.

Several of the informants said that it was not the patients who worried most about their children who caused them the most concern. Those who were most worried were open to seeking help and changing the situation. One informant described it as follows: ‘It’s usually those who aren’t worried about their children who are the most difficult to have contact with. And then it’s a case of if they’re aware of it, they’re terrified of revealing something.’

Some informants described the situation as follows: ‘Those kinds of concerns play on my mind after I get home from work.’ Others described how they had to spend a long time reassuring the parent and gaining their understanding before the parent opened up and wanted to discuss the situation surrounding the children and possible support.

Challenges in the interaction with other support agencies

The informants who had a child welfare role in addition to their position as an occupational therapist and outpatient clinician had minimal cooperation with other agencies in the support work for children of sick parents: ‘We can provide brochures about the primary health service measures, but it’s only giving out a brochure, not direct contact with the local authority. So, it’s really left up to the parents to make contact.’

At the information meeting where families can ask questions, parents are given good guidance on how to chat with their children and how to seek further support. However, it is primarily the parents who need to take the initiative to contact other support agencies.

Several informants reported that there is seldom more than one information meeting, and that they lose track of whether the family is receiving further follow-up. It transpired that when they have direct contact with another agency, it is mainly in the form of a report of concern to the child welfare services.

Several informants said that despite having positive experiences working with parents and children of sick parents, they feel that they have little insight into how the support functions operate outside their own department.

One informant felt that the support work lacked a holistic approach: ‘I feel in a way that we’re at the core of things at the hospital, and then there’s this large apparatus scattered about externally. I don’t even know what they all do. It’s like a bit here and a bit there, where is the big picture?’

Another informant said the following: ‘It’s like we’re sitting on our own islands, without really knowing what’s going on on the other ones.’ Only one of the informants reported a close dialogue with support agencies outside the department, where these agencies were actively used. The informant said the following: ‘It depends on how you ask and how well you explain about the parent. It takes time.’

The informant further explained how achieving a good cooperation requires a close dialogue with local support agencies. The person also explained how time-consuming it is to establish good contact and how close cooperation will be almost impossible for someone who is also working on a ward or has set patient hours during the day.

Discussion

In this study, all healthcare personnel with a child welfare role performed their statutory duty to report whether the sick patient has children, but the healthcare personnel face a number of challenges in their work.

According to the Norwegian Directorate of Health (10), the purpose of the new legislation is to ensure that the children are identified at an early stage and that processes are initiated to give the children and parents the tools they need to better master the situation when a parent becomes seriously ill. Identifying children of sick parents requires extensive efforts that not only involve registering the number of children with sick parents, but also mapping the child’s life situation and need for support (9, 10, 14).

No clear timeframe

The informants reported that it is often healthcare personnel with a child welfare role who conduct the information meeting with parents and children. In addition, they are responsible for guiding and following up other healthcare personnel, keeping their knowledge up to date and maintaining an overview of relevant support services (10). Although supervisors and guidelines encourage personnel to allow time and space to become familiar with their role, informants said that this was not feasible in practice.

The reason is that the child welfare role is in addition to other regular tasks they have. This additional responsibility corresponds to the findings in another study (26) and partly explains the informants' feelings of uncertainty about the time they are expected to spend on the work. When the child welfare role does not have a defined timeframe, the workload in the department will impact on how much time the employee has available for her work with the children.

Earlier studies show that the level of healthcare personnel's involvement in the focus on children is determined by random factors. Variations occurred due to, for example, the age, gender and level of education of healthcare personnel (18, 19). The variations in focus on the child perspective in combination with undefined timeframes for the work had a detrimental effect. These factors create a synergy and result in a child receiving haphazard support.

Insufficient guidance

The implementation of the child and family perspective in adult psychiatry requires moving the spotlight from being individual-oriented to being family-oriented (20). The informants expressed a desire to succeed in the work, and when they felt they had not done enough for a family it played on their mind at home. In order to succeed, good communication from management is important when new tasks are to be included in the daily work (27).

Either the work tasks must be understandable and clear in practice, or the employee must know how much time is to be given to the new task. The informants reported a lack of guidance. For example, how much time was it sensible to spend on the work and how could they ensure they had enough time.

This lack of guidance corresponds to findings from the multicentre study (22) and may indicate a shortcoming in the implementation at management level. Uncertainty about time use will also create uncertainty about the scope and depth of the work.

Unclear home situation complicates the work

The informants talked about the challenges they face with regard to parents who deny that they need help, and the feeling that these are actually the ones who are most likely to need help. The healthcare personnel were concerned about these challenges. Children can sometimes help to hide how much a parent is struggling out of loyalty (28). Both children and parents may feel a sense of shame and that they are being stigmatised for being different, and this will exacerbate their unwillingness to talk about their home situation (29, 30).

It is therefore not possible to tell by looking at a child whether they have a good or difficult home situation, and time needs to be spent talking with the family to find out if there is a need for further support. Healthcare personnel must be given the opportunity to map risk factors and protection factors in order to assess whether further follow-up is needed. Several informants talked about how the support grinds to a halt when parents do not recognise a need for help.

> **«Their uncertainty about how much time they are to spend on the tasks also makes them unsure of the extent to which they should map the children's situation.»**

These findings correspond to findings from other studies (20, 21). According to Maybery and Reupert (21), the fact that the patients themselves do not acknowledge that a problem exists represents a barrier in the work with children of sick parents. Their uncertainty about how much time they are to spend on the tasks also makes them unsure of the extent to which they should map the children's situation. For example, has the situation been sufficiently mapped when the parent answers that the children are doing well, or should the healthcare personnel continue to ask questions?

They are also unsure as to whether they provide adequate information to parents and children. Can anyone get enough information in one hour? By no means least, uncertainty about time use also causes uncertainty in the healthcare personnel as to whether they should continue to motivate the parent to participate in support measures even when they declined the initial offer of help. Such uncertainty can make the parents' reticence to talk about the home situation a real obstacle to providing support for the children.

Not everyone uses the measures

We know from the countless and serious potential harmful effects we see in children who have lived with parents who are mentally ill or have a substance abuse problem (1) that it is vital to get more of these children to participate in preventive interventions (14, 30–32). In recent years, a number of support programmes and services aimed at children of parents with a mental illness or substance abuse problem have been established.

According to Kallander et al. (14), there are nevertheless only a limited number of children and young people who have used the measures that were introduced after the focus period. Possible reasons may be too much faith in child welfare services as a primary measure, limited user involvement and lack of interaction with children of sick parents (14).

These three factors correspond to the challenges described by the informants. The informants have a certain overview of the primary healthcare services, but have no contact or any cooperation with these support measures. When the healthcare personnel with a child welfare role initially refer the parents to another municipal authority, it is mainly the child welfare services that are contacted, which is of concern to many parents.

Personnel lack a clear framework

Healthcare personnel who are responsible for ensuring the children's need for information is met and for providing the necessary follow-up report time constraints in their daily work and are uncertain how much time they can devote to these important tasks. This uncertainty indicates that they lack a framework for the work. If the desire for user involvement is to be fulfilled, it will be necessary to spend time talking with the parents in order to establish the appropriate level for further support.

The healthcare personnel will also need more time to stay abreast of developments in the field and familiarise themselves with local support programmes (10). They will need to consult with other professionals in relevant situations that raise concerns. The informants felt isolated in their role of responsibility, which is a further indication that the framework for the work is not clear enough.

> **«Time is also a crucial framework factor for achieving a sense of security and understanding, and a good alliance that entails direct contact with the patient.»**

A coordinated effort requires having time to take telephone calls and participate in meetings with other parties involved in the support work. Time is also a crucial framework factor for achieving a sense of security and understanding, and a good alliance that entails direct contact with the patient. This can be vital to whether the parents let their children or family participate in a preventive intervention (33).

The lack of defined timeframes for this work can be one reason why the informants felt there was little chance of providing further support outside the specialist health service. Time constraints can also be the reason why relatively few families are transferred to other support measures outside the specialist health service (14). Studies have shown that support services are used to a greater extent when personnel are able to allocate time to working with families (22, 34).

Methodological considerations and limitations

The sample represents a limited number of informants, and we cannot therefore draw general conclusions. The in-depth interviews gave us a deeper understanding of the informants' challenges in the workplace. The study shows that informants from different workplaces have a variety of similar experiences. What the informants have described can therefore be transferred to the same practices in other places where work is carried out with children of sick parents.

Conclusion

The results of our study reveal the challenges that healthcare personnel face in their work with parents who are mentally ill or have substance abuse problems. The informants appear to be genuinely interested in helping families who need support in caring for their children, but they encounter obstacles when parents are reticent to talk about the children and their parenting role.

In their efforts to hold informative talks with the children or provide other support, informants describe a challenging situation that often involves guiding parents to understand their own disorder and how they can affect the children. Staff in wards and at outpatient clinics already have a busy working day. Several informants reported that when they have no clear guidelines on how much time they can or should spend on their work with children it creates uncertainty.

While some informants managed to gain parents' confidence and understanding to the extent that they accepted further follow-up of the family, others felt that their efforts were not successful, even though they had identified a need for further follow-up. The sum of these conditions indicates that the work aimed at children lacks a clear framework and that the support given to children of sick parents is haphazard.

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