How can the general practitioner support adolescent children of ill or substance-abusing parents? A qualitative study among adolescents

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ABSTRACT
Objectives: To explore significant experiences of adolescents as next of kin that the general practitioner (GP) should identify and recognize.

Design: Qualitative study with focus-group interviews.

Subjects and setting: Three focus-group interviews were conducted with a total of 15 Norwegian adolescents each with an ill or substance-abusing parent. The participants were recruited from existing support groups.

Results: The adolescents’ days were dominated by unpredictability in their family situation and their own exhausting efforts to keep up an ordinary youth life. Mostly, they consulted GPs for somatic complaints. In encounters with the GP, they wanted to be met both as a unique person and as a member of a family with burdens. Their expectations from the GP were partly negatively formed by their experiences. Some had experienced that both their own and their parent’s health problems were not addressed properly. Others reported that the GP did not act when he or she should have been concerned about their adverse life situation. The GP may contribute to better long-term psychosocial outcomes by ensuring that the adolescents receive information about the parent’s illness and have someone to talk to about their feelings and experiences. In addition, the GP may help by supporting their participation in relieving activities.

Conclusion: Burdened adolescents seek a GP most often for somatic complaints. The GP has a potential to support them by taking the initiative to talk about their life situation, and by recognizing their special efforts.

KEY POINTS
• Little is known about how a general practitioner can support adolescents with ill or substance-abusing parents.
• Adolescents experience unpredictability in life and strive to find balance between their own needs and the restrictions caused by parental illness.
• In encounters with adolescents having ill parents, the GP should take the initiative to talk about their family situation.
• The GP may help them by recognizing their experiences and struggles, give information, offer talks and support coping strategies.

Introduction
More than 13% of children growing up in Norway have a parent who suffers from severe mental illness or substance abuse.[1] International reports using broader definitions of mental illness estimate that up to one in five children grow up with a mentally ill parent.[2] A German study found that about 4% of all children have a parent with severe physical illness.[3] Children with ill parents have special challenges and needs compared to children with healthy and well-functioning parents.[4–8] The problems ill parents face may affect their parenting abilities in different ways. At least periodically, most of these parents have a reduced capacity to give the basic support their children need.

Children who are next of kin are at risk of developing psychosocial problems and poor health,[9–11] although some children exposed to adverse childhood experiences grow up healthy and well-functioning.[11–13] Family dysfunction is one factor associated...
with psychosocial problems among the children in families with a mentally ill parents or a parent suffering from cancer.[5,8] In addition, a number of studies assume an association between insecure or disorganised infant attachment states and severe psychopathology and low maternal sensitivity towards the infant's signals and needs.[13,14] There is a “dose–response” relationship between the burden of adverse childhood experiences and the risk of negative health and social outcome. Included in these described adverse childhood experiences are having a parent with mental illness, having an alcoholic parent, experience violence, or experience sexual, mental or physically abuse.[9,10] Protective factors that can reduce the impact of risk factors are mostly not disorder-specific, e.g. care by the other parent, the child’s own problem-solving skills, and social support by family, friends or teachers.[15]

It is important to prevent children and adolescents with ill or substance-abusing parents from acquiring their own problems and illnesses, not only from an individual patient and family perspective, but also from a public health perspective.[10] The potential for involving the general practitioner (GP) in this work has received little attention. Targeting youths with special needs may be challenging.

Researchers argue that the primary health care system should be more youth-friendly in order to reach adolescents.[16,17] In a review of young people’s perspectives on youth-friendly care, respect for the young person, trust and continuity of care were emphasized.[16] Adolescents often do not disclose sensitive topics to carers unless prompted.[18,19] Negative life experiences increase the likelihood that adolescents will seek help from primary carers.[20] We may therefore assume that adolescents as next of kin to some extent seek their GP. The challenge is how to address their family situation in these encounters. Frederiksen et al. claim that recognition is a central aspect in creating a good GP–patient relationship.[21] There is a need for more knowledge about how recognition could be enacted in the context of adolescents as next of kin.

Schibbye, a psychologist, has developed a theory about recognition in clinical settings.[22,23] She describes how recognising behaviour is expressed at a practical level as listening, understanding, acceptance, tolerance and confirmation. These types of behaviour are interlinked. Listening is active and focused, and it necessitates receptiveness and willingness to let oneself be moved. Understanding entails entering the other person’s world of experiences. To understand the other person, one must approach corresponding feelings in oneself and assess the other person’s feelings, but simultaneously retain one’s own field of experiences, always remembering that the other person’s experiences belong to him or her. Acceptance and tolerance imply that we accept the other person’s right to his or her feelings; we tolerate these feelings and let them be. Confirmation deals with authorising the validity of these feelings, trying to understand them, and then returning them as understandable and reasonable, given the other persons’ starting point. We used Schibbye’s theory of recognition as a theoretical support in the analysis of this study.[24]

In a previous study, we explored GPs’ experiences with and views on supporting children with parents suffering from mental illness, substance abuse or severe somatic disease.[25] In the current study, we approached a sample of young persons who were next of kin to parents with serious illnesses or substance abuse. The aim was to explore significant experiences of adolescents as next of kin that the GP should identify and recognize.

**Methods**

Due to scarcity in the literature, we had few hypotheses in advance, and chose a qualitative approach to answer the research question. We recruited participants from support groups for adolescents with parents who suffer from mental illness, substance abuse or cancer. This was a practical way to reach the target group and to ensure that the participants had someone to talk to after the interview about the topics that had come up. The group leaders received invitation letters, then informed the group members and asked about their interest in participating. Informed consent was obtained from the participants. The Regional Committee for Medical Research Ethics approved the study. We conducted three focus-group interviews with 15 participants aged 16–25 years (Table 1).

**Data collection**

The focus-group interviews were conducted from May 2013 to March 2014, each lasted approximately 90 minutes. The interview guide was designed to elicit a conversation between the group members about the following topics: everyday life, including living with a parent who has problems, their supporting network and their experiences from encounters within the health care system, including GPs. The discussions were led by a GP, the first author (FG). The last author (MH), a child and adolescent psychiatrist, participated as a moderator, and another GP and co-author (TSS) was an observer. We conducted three interviews, one with each target group. We decided to await a preliminary analysis to evaluate whether we had enough...
information to elucidate the research question. We found that the material included varied experiences from the three target groups sufficient to develop new knowledge according to our aim.

**Analysis**

The interviews were audiotaped, de-identified and transcribed verbatim. Data were managed using NVivo 9 software. Analysis was supported by Schibbye’s theories on recognition,[22] focusing on experiences presented by the participants which might indicate how recognition could be enacted in encounters with a GP. We used systematic text condensation [26] to analyse the interviews. During the first phase, we read the material to get an overview, and identified some preliminary themes. In phase two, we identified meaning units and organized them in code groups. In phase three, we agreed on some overarching codes with sub codes, and made condensates of the content of the sub codes. We then summarized the condensates into new descriptions and concepts according to the aims of the study. We then ended up with three final categories: Living with unpredictability, The struggle for an ordinary adolescence and Experiences and expectations from encounters with the GP (Table 2). In the end, we searched in the meaning units to find citations to illustrate the results. This work was done in

Table 1. Participants’ characteristics.

<table>
<thead>
<tr>
<th>Group Nr</th>
<th>Parent’s problem</th>
<th>Participants girls/boys</th>
<th>Age (years)</th>
<th>Having parents living together</th>
<th>Live now with ill parent*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Substance abuse</td>
<td>4/1</td>
<td>16-17</td>
<td>0</td>
<td>3 (2 part-time)</td>
</tr>
<tr>
<td>2</td>
<td>Mental illness</td>
<td>4/1</td>
<td>16-18</td>
<td>1</td>
<td>1 (1 foster care)</td>
</tr>
<tr>
<td>3</td>
<td>Cancer</td>
<td>4/1</td>
<td>17-25</td>
<td>0</td>
<td>0 (all ill parents dead)</td>
</tr>
</tbody>
</table>

*Many participants do not live with their ill parent now, but they told about experiences in the period when they still were living with them.

Table 2. Process of analysis.

<table>
<thead>
<tr>
<th>Preliminary themes</th>
<th>Codes with sub codes</th>
<th>Final categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is helpful</td>
<td>What is helpful</td>
<td>Significant experiences of the adolescents that the GP should identify and recognize.</td>
</tr>
<tr>
<td>Relationship to parents</td>
<td>Burdens</td>
<td>Living with Unpredictability</td>
</tr>
<tr>
<td>Consequences of parental illness</td>
<td>-stress symptoms, health complains</td>
<td>The struggle for an ordinary adolescence</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>The GP</td>
<td>Experiences and expectations from encounters with the GP</td>
</tr>
<tr>
<td>Role of helpers</td>
<td>-conversation partner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-expected to do proper work</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-advise and give information</td>
<td></td>
</tr>
</tbody>
</table>
consultation with other experienced researchers in our network to validate the results and find alternative interpretations.[27]

Results

The participants experienced a serious impact on their daily lives due to their parents’ conditions. They strived to keep up an ordinary youth life despite unpredictability and burdens at home. Their experiences from encounters with GPs were mostly limited to their own somatic complaints and their impression of how their parent’s needs were met.

Living with unpredictability

Unpredictability in daily life was a central issue for the participants. They often worried about what condition the ill parent would be in when they returned home from school. Everyday planning was hard. This 17-year-old girl with a mentally ill mother gave an example of how this uncertainty had formed her way of acting in social settings:

Always when I enter a room, such as at home, there are many questions coming to my mind: How should I behave right now? How is Mum? How is Dad? Is the atmosphere good or bad? What can I say, what can I not say? I always have this sensation – it is really stressful.

Many of the participants were troubled by feeling of guilt. These feelings often were a result of parental instability. The adolescents struggled to support their parents; however, they sometimes felt that they did too little, or they felt frustrated or anger. An 18-year-old girl with a mentally ill mother gave an example of how this uncertainty had formed her way of acting in social settings:

All my life I have been working with my feelings of guilt. And it’s all about my mum. I have to deal with it when she is down. Then I am thinking – it is my fault. And she can say: ‘Yes, it is your fault.’ And suddenly she says: ‘No, it is my fault!’ It is very hard to cope with her inconsistent mood.

These experiences of ambivalence and unpredictability seemed to pervade their world view. This was especially apparent among those with parents suffering from mental illness or alcohol and drug abuse, but were also seen among those with physically ill parents.

The struggle for an ordinary adolescence

The participants talked about how the situation at home influenced their lives. “It affects us in all aspects of life”, said one 16-year-old boy with a depressed mother. However, the youths also provided examples of what they experienced as helpful: they wanted to be treated as ordinary adolescents without stigma and without being pitied, and many expressed a need for a timeout when they did not have to think about illness and problems. Some had friends who did not know about their parents’ problems at all. One 16-year-old girl living with a father with schizophrenia stated:

I just wanted to have a free space with them, my friends, where nobody knew about my dad. I found that relaxing. I didn’t want to be pitied for living with him; I just wanted to be seen as an ordinary girl.

The same was stated by a 17-year-old girl whose father died from cancer:

While he was ill, only three or four of my friends knew he had cancer, but after he died, everybody knew it. In a way I wanted to keep it secret. I did not want to say he was ill, for me it was good that only a few knew about it.

The continuous struggle to find a balance between one’s own wishes and needs and the burdens and boundaries in everyday life was a theme that permeated the participants’ statements. They wanted to be treated as ordinary youth even though some needed special arrangements in their daily lives. One moment, they would leave home to have free time; in the next, they would come home to do extra work to help their parents. A girl of 17 with a physically ill mother said:

It turns out that I do not speak so much with my mom because she often has no strength to mingle with us. And often I cannot bring friends home, because she is so sensitive to sounds and ... it can cause great pain to her and stuff. And therefore I must help more at home, too.

The children had to cope with their parents’ good days and bad days and with their own ambivalent feelings for their parents, including pity, anger and guilt. Many stated that they currently managed this balance, but in the past, some of them had experienced collapses such as falling ill, needing support from child care services or moving into foster care. However, the participants emphasized how much effort and energy this continuing balancing act demanded. An 18-year-old girl with a mentally ill mother told us:

It is so lovely to talk to some adults who can tell you that this is NOT how you should live. You should not do the dishes after a huge dinner that you didn’t eat. That is not how a life should be for a kid. You should be out playing, because it is sunny outside. That kind of information is so incredibly important.
Experiences and expectations from encounters with the GP

The participants told about their own health problems, such as headache, stomach pain, muscle pain, anxiety and depression. In addition, many had concentration issues, restlessness and problems at school. A girl of 16, who lived alone with her father with serious mental illness, said:

So when he was ill, it affected me too. I started getting ill because I could not stand it…. I got really sick. When I was brought to a doctor, it turned out that I had anorexia…. But then I got help.

Their experiences from encounters with their GPs about their own health problems ranged from a feeling of being taken seriously to a feeling that their concerns were being downplayed. It was important, some said even vital, to have someone who knew about their problems, someone to talk to about their burdens. They mentioned the healthy parent, a teacher, a friend, a family member, a support group or someone from the health care system, i.e., the GP. An 18-year-old daughter of a mother with bipolar disorder told about experiences of being met as unique by her GP:

The physician is seen as one who fixes medicine, and then you leave. That was the way I used my GP as well, until I found the doctor I use now. She spends time on me. Although I must sit waiting for a long time in the waiting room, it is worth it. Because she actually sits down and says, ‘Hey, you have got a haircut, you look great!’ And things like that.

The participants also wanted the doctor to use their authority and to react if they were concerned about the children’s care, as this girl of 18 having an alcoholic mother expressed it:

My mum is an alcoholic, and when I was young and lived with her, she was almost always drunk. Everybody should have seen that I could not live there. At that time, my mum and I visited our GP together, and the GP should have alerted someone. Because that should be a doctor’s job.

When they talked about experiences with the GP, they often referred to their parents. Several participants told stories about delayed diagnoses of cancer and psychiatric disorders in their parents. An 18-year-old girl told about her relief when her mother was diagnosed with bipolar disease:

My mother’s GP must have been rather bad. He refused to give her an assessment. My mother said: ‘There is something wrong with me.’ Then she was told that she was maybe a bit hyperactive, otherwise only creative and lively. But that she had to try to commit suicide to get an assessment is too much! At that time she was 47! … In the hospital, they found that she had bipolar disorder and something with the personality. Then I thought: ‘Oh – is this my life?’ I didn’t know she was ill.

Knowledge about their parent’s condition and expected course was often incomplete, which caused worries and worsened the uncertainty. They thought the GP could relieve some of these by supplying relevant information, either directly to the young person or by giving information and advice to other close family members. This is illustrated by a 22-year-old girl who had lost her mother to cancer:

When we were at home, I could wish that the GP had dropped by and told us a bit more about the course of the illness. Because my mother was at home the last week before she died. And we didn’t know what to expect the next day … like that she didn’t talk the last two days. That would be good to be prepared for.

In summary, their stories about themselves and about their parents were interlinked as two aspects of the same topic: the need to be met both as a unique person and as a member of a family with burdens.

Discussion

The results have given us knowledge about important elements for the GP to bear in mind during encounters with young people as next of kin, when the goal is to address their challenging family situation with a recognizing attitude. From our results we see how their sometimes exhausting efforts to keep up an ordinary youth life and the unpredictability in the family situation dominated their everyday lives. Their expectations for the GP were sometimes negatively formed by their experiences that both their own and their parent’s health problems were not addressed properly, or that the GP did not act when he or she was concerned about their adverse life situation.

Strengths and weaknesses

We recruited participants from well-established support groups for children as next of kin. This means that our participants and their situations were known to the health and social care system. Studies in the field have revealed that this is not the case for many adolescents with ill or substance-abusing parents.[28,29] Our participants, therefore, probably have more experiences from encounters with health and social service providers, but else it is no reason to believe that our participants’ experiences differ from adolescents as next of kin in general. They told much about living with ill parents before they got help.
Although we were unknown to them, the setting was known, and the participants seemed relaxed. The interviewers were GPs and a child and adolescent psychiatrist. This probably influenced the participants’ accounts from their meetings with doctors, but they gave examples of both good and bad experiences from encounters with a GP. We interviewed groups of young persons from families with different types of illnesses or abuse problems. There are more shame and stigma associated with mental illness and substance abuse compared to physical illness, and the different parental problems may give children different challenges and needs. However, some problems are common, because all children at least sporadically experience a lack of parental support from the affected parent. Our results thus describe some core experiences that might be transferable to adolescents as next of kin more generally. It turned out to be more difficult to recruit to these focus groups than we had expected. The leaders of the support groups we contacted were initially positive, but obstacles emerged, like the group did not start or the time schedule did not suit. Most participants were girls; however, the boys provided the same information as the girls. Caution should be taken with regard to transferring the results to adolescent boys and children younger than 16 years.

Findings in relation to other studies

In the following discussion, we will focus on two aspects: the impact of some core experiences in need of recognition in the GPs’ encounters with these adolescents, and how GPs can support psychological resilience.

Our participants said they contacted their GP about their own health problems. Negative life experiences increase the likelihood that adolescents will seek help from primary carers, at least for somatic health problems.[20,30] This means that to some extent, these young people are already within the reach of their GP. These encounters may be an opportunity to talk about other concerns as well, but the adolescents have to be prompted.[18,31] Our participants told how unpredictability had formed their world view. That may imply that they meet the GP with a withdrawn or hesitant attitude. They do not know what will come and have learned through life to wait before they respond. This can easily be misinterpreted by the GP as rejection or no interest in the topic. Another misinterpretation may be that they do not want to expose their family situation; it might be more important to perform as an ordinary youth. A video study of doctor–patient encounters suggests that the doctor too often lacks curiosity in the patient’s life situation and ends the consultation before exploring these aspects.[32] Adolescents as next of kin will be especially vulnerable to this kind of behaviour from the GP.

These experiences of being invisible to the helpers are described in several studies of young caregivers.[29,33] Either the helpers do not see their burdens or the youths actively hide their caring burdens out of loyalty to their parents or for fear of the professionals interfering and splitting up the family. Their experiences and expectations for the GP are closely connected to their evaluation of how the GP had addressed their parent’s situation. The sometimes exhausting ambivalence and balancing between adversities and ordinary life that our participants told about seem to characterize these families [34] regardless of parental illness. In Norway, the family members may be enlisted with different GPs, and very often these GPs do not know the patient’s situation at home.[35] Thus, the probability is high that the youth’s family situation, which often is a premise for understanding the problems the youth present with, is unknown for the GP.

Other studies have documented that children as next of kin (as a group) are at risk;[10,13] still, some children exposed to adverse childhood experiences grow up to be healthy and well-functioning adults; these are so-called “resilient children”.[12,13,36] According to Masten,[36] “psychological resilience” describes an individual’s ability to achieve good outcomes in spite of serious threats to adaptation or development. In a qualitative study among children of drug- or alcohol-addicted parents, the participants expressed three ways that a health worker could help them strengthen their resilience: by providing a venue in which to express their feelings, by providing education and information and by showing them that they can make their own lives better than their parents’ lives.[12] A study among children whose parents suffered from cancer showed that the factors that positively affected the children’s adjustment included good information about the illness and a culture of sharing feelings at home.[19] The results of these two studies agree with our findings. Our participants expressed the need for information about their parents’ illnesses, and they coped better with their difficulties if they had someone to talk to. In addition, they emphasized the importance of having arenas free from their families’ adversities.


Meaning of the study; implications for clinicians

When adolescents as next of kin consult GPs, we may assume that the GPs often do not know the adolescents’ family background. The adolescent may show an awaiting attitude, easily misinterpreted by the GP as rejection, an impression that might be enhanced by the importance for them to perform as an ordinary youth. However, it is mandatory to create an atmosphere for a talk about the youth’s everyday life, because his or her health problems and life situation are closely connected to the parent’s health.

According to Schibbye,[22,23] a recognizing attitude from the GP would be to sense these feelings of uncertainty and ambiguity and the patient’s need to be met as an ordinary youth. The GP can facilitate a trustful relationship by listening actively, asking open questions about everyday life, and by giving the youth confirmation that it is allowed to have ambivalent and contradictory stories and feelings. This requires the doctor to take time to await answers, accept their stories and give reactions when concerned about their care. The health problem that brings the youth to the GP, often a somatic complaint, may initially seem limited and simple. However, engagement and time is required, and often several consultations. Within the frame of a trustful relationship, the GP can help strengthen the youth’s resilience by supporting their engagement in relieving activities and by offering talks about health problems and life situation. In addition, the GP can give information about their parent’s situation in agreement with the parent.

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Ethical approval

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