

Children as next of kin and the general practitioner

A qualitative study about the general practitioner's
opportunities to help

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Scientific environment

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My primary supervisor was Marit Hafting, Regional Research Centre for Child and Adolescent Mental Health West, Uni Research Health, Bergen, Norway.

My co-supervisors were Tone Smith-Sivertsen, Research Unit for General Practice, Uni Research Health, Bergen, Norway, and Guri Rørtveit, Department of Global Public Health and Primary Care, University of Bergen, Norway.

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Gullbrå, January 2017

Frøydis Gullbrå

Abbreviations

GP General practitioner

CME Continuing medical education

Abstract

Background and aims: Children whose parents suffer from mental illness, substance abuse, or severe somatic disease are at risk of developing psychosocial problems and a variety of health complaints. These children often remain invisible in the healthcare system. Most parents will first visit their general practitioner (GP) if they are in need of healthcare, and the GP often meets the entire family and provides continuity of care. This doctor is therefore in a unique position to also help the patient's children. This thesis focusses on the GP's role with regard to children as next of kin. Specifically, the research aimed to identify the types of help that GPs can provide, as viewed from the perspective of three groups: children with parents who are ill or are substance abusers, ill parents, and lastly, GPs.

Materials and Methods: After deciding on a qualitative approach, we invited GPs, adolescents, and ill parents to interviews regarding the ways in which a GP could provide help for children as next of kin. We performed focus group interviews with the GPs and adolescents, and semi-structured interviews with the ill and substance-abusing parents. The data were analyzed using thematic content analysis or systematic text condensation.

Results: Children living in families with an ill or substance-abusing parent experienced unpredictability in their daily life, and often had own health problems. Despite good intentions, the parents did not always manage to create a good and predictable everyday life for their children. Both parents and adolescents stated that they wanted their GP to acknowledge the fact that they are striving to lead a normal everyday life. However, they would simultaneously find it helpful if the GP recognized that their situation carried extra burdens due to parental illness. The children or adolescents did not visit their GP frequently, and if they did, it was mostly for somatic complaints. They welcomed a discussion of their home situation with the GP in these consultations. They found it difficult to raise the issue of their home situation by themselves, even if they were in need of support and required information about the parent's situation. Several expressed a need to be prompted by a helper they

trusted. The parents expressed the same need for help in order to gain support and assistance in informing their children, but were also sometimes reluctant to address the home situation with their GP. The GPs stated that they were in a position to identify children in need of support and to advise their parents. This research found that the structural frameworks of general practice, with short consultations and the focus on the presenting patient, were significant barriers, as was the GPs' fear of placing extra burdens on struggling patients.

Conclusions: GPs are in a good position to support children as next of kin, but often miss the opportunities to act. A good starting point may be to recognize a parent's honest intentions to make a good life for their children, and to consider the children and adolescents as ordinary youths in a challenging life situation. Within a trusting patient-doctor relationship, the sensitive topic of how a parental illness might affect the children in a family can be discussed, and a GP can provide support and advice, to adolescents or parents, based on the needs identified. It is usually important for the GP to participate in a multidisciplinary collaboration to ensure appropriate support and care for the families with the greatest burdens.

Norsk samandrag

Bakgrunn og mål: Barn som har foreldre med psykisk sjukdom, rusmisbruk eller alvorleg somatisk sjukdom, har ein auka risiko for å utvikle psykososiale problem og ulike typar helseplager. Desse barna blir ofte usynlege i helsevesenet . Når helseplager oppstår, er det ofte fastlegen foreldre først oppsøker om dei har trong for helsehjelp. Fastlegen kjenner ofte heile familien og følger familien over tid, og skulle difor vere i ein god posisjon til å sjå barna, og sørge for at dei også får nødvendig oppfølging. Denne avhandlinga fokuserer på fastlegen si rolle i høve barn som pårørande. Konkret vil prosjektet prøve å identifisere korleis ein fastlege kan hjelpe, sett frå perspektivet til tre grupper: barn som har sjuke eller rusmisbrukande foreldre, sjuke foreldre og fastlegar.

Materiale og metode: Vi valte ei kvalitativ tilnærming og inviterte fastlegar, ungdom med sjuke foreldre og sjuke foreldre til intervju. Tema var korleis ein fastlege kan hjelpe barn som pårørande. Vi utførte fokusgruppeintervju med fastlegar og ungdom, og semi-strukturerte individuelle intervju med sjuke og rusmisbrukande foreldre. Data blei analysert ved «thematic content analysis» eller systematisk tekstkondensering .

Resultat: Barn som har vakse opp i familiar med ein sjuk eller rusbrukande forelder, opplevde ofte ein uforutsigbar kvardag, og dei hadde ofte eigne helseplager. På trass av gode intensjonar, klarte ikkje alltid foreldra å skape ein trygg og god kvardag for barna sine. Både foreldra og ungdommane uttrykte at dei ynskte at fastlegen skulle anerkjenne deira forsøk på å skape ein normal kvardag, og på same tid forstå at dei var i ein situasjon med ekstra byrder på grunn av sjukdom/rus hjå ein forelder. Desse ungdommane var ikkje ofte innoft fastlegen, og då helst med fysiske plager. Dei ynskte gjerne at fastlegen i konsultasjonen tok opp heimesituasjon med sjuk forelder. Dei fann det sjølv vanskeleg å ta opp dette temaet, også om dei kunne ha behov for støtte og informasjon om den sjuke forelderens sin situasjon. For å snakke om dette trengte dei å bli invitert til det av ein hjelper dei hadde tillit til. Foreldra uttrykte same behov for råd i høve det å støtte og informere barna, men var også nokon gonger reservert i høve til å ta dette opp med fastlegen. Fastlegane uttrykte at dei var i ein god

posisjon for å identifisere barn i risiko og for å rådgi foreldre. Rammene i allmennpraksis med korte konsultasjonar og hovudfokus på pasient tilstades, var viktige hindringar i dette arbeidet. Det same var fastlegen si frykt for å gi ekstra byrder til foreldre som streva.

Konklusjon: Fastlegen er i ein god posisjon for å hjelpe barn som pårørande, men går ofte glipp av moglegheitene til å handle. Eit godt utgangspunkt kan vere å anerkjenne foreldra sine gode intensjonar om å skape ein god kvardag for ungane sine, og å forstå at ungdommane har behov for å bli møtt som vanlege ungdommar med ein utfordrande livssituasjon. I ein tillitsfull relasjon kan sensitive tema som korleis foreldre sin sjukdom påverkar barna, bli tatt opp. Fastlegen kan gi støtte og råd, både til foreldre og ungdom, basert på dei behov som er avdekka. For dei tyngst ramma familiane kan det vere viktig at fastlegen deltek i tverrfagleg samarbeid for å sikre nødvendig hjelp.

List of publications

- I Gullbrå F, Smith-Sivertsen T, Rortveit G, Anderssen N, Hafting M.
To give the invisible child priority. Children as next of kin in general practice. A qualitative study among general practitioners.
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1. Background

Severe health problems in parents influence the lives of their children. This study addressed the ways in which general practitioners (GPs) can help children with parents who are ill or who are substance abusers from the perspective of GPs, parents, and children.

In this introduction, I describe some basic needs for children, I define to which group of children our research related, and provide an overview of their situation. I also describe how primary care and general practice is organized in Norway, providing examples of some frameworks and tools that give the premises for how a GP can help.

1.1 Children's living conditions and needs

The living conditions and wellbeing of children vary, both in rich countries and definitively between rich and poor countries, and there are a variety of contributory factors. In a 2016 news report, UNICEF presented an overview of the inequalities in child wellbeing in some rich countries [1]. According to this report, no country made clear progress in reducing the gap between child health problems in the group with lowest socioeconomic status and those in the middle group from 2002–14; the gap actually increased in many countries.

Difficult living conditions and a variety of adverse experiences in childhood give rise to numerous health and social problems, both during childhood and in later life. A large American cohort study, namely, the Adverse Childhood Experience (ACE)-study [2], found that children experiencing abuse or household dysfunctions have a greater risk of poorer adult health, both physical and mental. The same results were found in a longitudinal cohort study carried out in New Zealand, the Dunedin study [3], and in a Norwegian study conducted in 2015 [4]. These studies confirmed a graded increase in health risk behavior and poor health with increasing numbers of adverse childhood experiences. The risk of early death and psychosocial problems is also increased [5,6].

Fellitti et al. [2] suggested that the increased risk is a product of genetic vulnerability and environmental factors.

All children have basic needs and the right to grow up as healthy, fully developed adults. Child-rearing or parenting is a process in which parents or other caregivers promote and support the physical and emotional, as well as social and intellectual development of a child. Where children grow up in families, the parents are normally the primary individuals fulfilling these needs. In addition to physical care, nutrition, and protection, emotional needs must be met in order for a child to grow up healthy. Three dimensions of the parent-child relationship that have been greatly assessed in research are warmth, behavioral control, and autonomy support [7,8]. Of course, distribution of these dimensions varies between families, and the central questions that arise are: what is required to fulfill the children's needs for care and support? What is the minimum with regard to not putting them at too high a risk? Houghugh and Speight [9] showed an understanding of what lies in "good enough parenting", and placed the emotional needs in the following three categories: "1) love, care, and commitment; 2) consistent limit-setting; 3) the facilitation of development". A child must receive all these aspects of good parenting over time in order to develop into a mature, emotionally stable grownup [9]. Parental illness may influence parenting abilities. First, the parent's sensitivity to the children's signals and needs is essential for the children's normal development, and this capacity may be reduced when the parents' minds are occupied by illness and problems [10-12]. Second, children with ill parents often get more caregiving experiences than children from families with healthy parents. In an Australian study from 2015 [13], no difference in these extra caring experiences between parents with substance abuse, mental illness, or somatic illness was found. Positive family functioning can be a protective factor when a child experiences adverse experiences [5]; for example, positive parental factors may promote resilience in adolescents with depressed mothers [14]. Previous studies have shown that parental and family functioning are more strongly associated with adolescents' mental health than are illness-related factors [7,8,12,15]. Thus, parenting abilities play an important role when it comes to outcomes for children and adolescents experiencing different types of problems while growing up.

1.2 Children as next of kin

According to the factors outlined above, children growing up with parents who are ill or who are substance-abusers may have an increase in vulnerability with regard to social and health problems of their own. They may have a genetic risk for transgenerational transference of illness, they may experience reduced parental capacity from their main caregivers, and they may have experienced other adverse experiences as a result of their parent's problems. Many of them have unmet needs, and they have become "invisible" in the healthcare system [16]; those who provide healthcare for the ill parent easily forget them. These children are also often referred to as "young carers", because they take on extra responsibilities at home, caring for their ill parent and/or siblings, or take on a greater number of household responsibilities [13,17]. Meeting their special needs can be regarded as an important measure in health promotion and disease prevention.

In Norway, as in many other parts of the world, the living conditions and health risks of children as next of kin have received increasing attention in recent decades. In order to secure their rights as next of kin to patients with mental illness, substance abuse, or severe somatic illness, new law paragraphs were introduced in Norway in 2010 [18]. Paragraph § 10a was introduced to the Health Personnel Act, according to which all health personnel treating patients in one of the aforementioned three groups should inquire whether they have children younger than 18 years of age, and make the necessary effort to ensure that they receive information and follow-up [18]. A new paragraph has now also been included in the Norwegian Regulation Concerning Patient Records, and states that health personnel should note in a journal whether a patient who suffers from mental illness, severe somatic illness, or substance abuse has children [19].

When considering the term "next of kin", we normally think of a relative that assumes responsibility for an ill person, or has rights to inherit after a person is dead. In this research project, we used the term "children as next of kin" to mean children with an ill or substance-abusing parent. Such children have no legal responsibilities for their ill

parent, and have the same legal status as other children. More specifically, we understand the term children as next of kin as being children aged 0–18 years, with at least one parent suffering from mental illness, substance abuse, or severe somatic disease. The severity of the illness should be of a nature that affects the parent’s daily functioning or parenting abilities. The term is defined in this manner in the new law paragraphs in Norway, and, in delineating our research project with regard to what is relevant in the context of these paragraphs, we used the same definition.

1.2.1 Prevalence of children as next of kin

Norwegian data on the number of young people (0–18 years) living in families in which a parent is suffering from mental illness, substance abuse, or severe somatic disease are sparse. According to a 2011 report from The Norwegian Institute of Public Health, 23.1 % of all children aged 0–18 years constantly live with at least one parent with a mental illness that can affect daily functioning (moderate or severe disease) [20]. The same report estimated that approximately 6.5% of all children live with a parent who abuses alcohol at a level that influences daily functioning [20].

A report from the Netherlands estimated that approximately 17% of Dutch children under the age of 18 years have a parent with a mental illness [21]. This report is only available in Dutch, but has been referred to in articles written in English [22].

A Canadian study from 2009, reported that around 12.1% of children under 12 years of age lived with a mentally ill parent [23], and an Australian study concluded that up to 20% of children lived in families in which a parent had a mental illness [24].

A UK study published in 2009 [25] indicated that 6% of children under the age of 16 years lived with a dependent drinker. Approximately 3.6% of these children lived with a problem drinker who also used drugs, and 4% lived with a parent in whom problem drinking co-existed with mental illness. A US population study published in 2013 [26] revealed that 22% of adult Americans had at least one biological parent with an alcohol use disorder.

With regard to somatic disease, a German study estimated that 4.1% of the population aged 4–18 years had a parent with severe somatic disease [27]. It defined these

conditions as “a currently existing serious physical disease in one or both parents, which can be classified as life-threatening and/or having a severe impact on a patient’s quality of life” [27]. Cancer was the most prevalent diagnosis. A Norwegian study conducted in 2012 [28], found that 4% of children aged 0–25 years had, or had had, parents who had been diagnosed with cancer, and a Finnish Birth Cohort study [29] found that 6.6% of the children studied had had experience of a parent suffering from cancer during the 21-year follow-up.

In sum, the reports we have cited showed that approximately 20–30 % of all children experience having a parent with severe somatic disease, severe mental illness, or substance abuse. The estimated incidence of children living with an ill parent varied, and we may assume that the numbers are uncertain. However, the number of children who constantly live with ill parents, or parents with substance abuse issues, is extensive.

1.2.2 Impact of parental illness on children

There is much scientifically documented knowledge regarding the associations between parental illness and adverse outcomes in their children. In recent years, research has also focused on interventions and the implementation of new strategies. The following sections will summarize what is known of the impact of different parental illnesses and substance abuse on children.

Parental mental illness

Rutter et al. [30] were the first to describe the children of mentally ill parents as one group, and not as related to a specific psychiatric diagnosis. They concluded that the risk of the development of problems in these children was a combination of genetic vulnerability and environmental factors. Mental illness in parents often influences parenting; however, the influence of the illness may vary and some individuals can carry out good parenting, even with a severe mental illness [31]. Children with parents suffering from a mental illness often have living conditions that are characterized by a greater number of conflicts and less cohesion in the family [22,32]. A mental illness sometimes makes a parent less responsive to their child, and such children may

experience anger and emotional lability from their ill parent. There is also greater social isolation, poor economic status, and a higher number of single parents among families in which there is a parent with a mental illness [31]. Previous studies have shown that children with mentally ill parents often experience serious disruption in their daily life. This may result in more parenting tasks for the children, many of whom assume the responsibility of carer of the house and their siblings, and sometimes of their ill parent [33,34]. Children living in these circumstances, as a result of parental mental illness, are at risk of acquiring their own problems, although most of them do well. The risk is related to how parenting is carried out and to environmental factors [22,35], but genetic factors also play a role [36,37]. The children are at risk of their own mental health and psychosocial problems, as well as cognitive delays [2,30,38]. They often feel lonely and experience instability in their daily life [39]. The risk of their own problems, and the type of these problems, may be related to the severity and expression of the parental illness, and the child's age at the time of the illness (if it is a periodic illness) [24]. For example, severe depression in a mother in the first year of a child's life can result in attachment problems, particularly if no other carer is available [31,36]. Children who are exposed to adverse experiences, such as having a mentally ill parent, are also at risk of poorer physical health [2,36], and those who grow up with a mentally ill parent are also at risk of dysfunction and mental illness in adult life [36,40]. Some studies have found gender-related differences in the risk to these children. The daughters of depressed parents are more vulnerable to internalizing problems, while male offspring are at higher risk of externalizing problems [36]. If depression in a parent is treated, and the parent's functioning improves, this may have a positive effect on the child [35]. However, this is not always the case for young children. Van Doesum et al. [41] and Murray [12] showed that when a mother is feeling less depressed, it does not mean that the quality of mother-infant interaction improves. Children with mentally ill parents request more information and an understanding of their parent's illness [42]. In a review of qualitative studies of children's experiences with mentally ill parents, Gladstone et al [33] also identified a need for further psychoeducation for the children. In children, intelligence and cognitive skills are important factors in the prevention of their own

problems [43]. Many children growing up with mentally ill parents do not develop impairments, thus the outcome depends on a balance between the number of risk factors in the child's environment and the presence of protective factors [36,44,45].

Children of substance abusers

Children of alcohol abusers have an increased risk of negative experiences in childhood, such as neglect, violence, economic problems, and social isolation, in addition to the break-up of the family and high levels of conflict at home [46,47]. These children are also at higher risk of physical and sexual abuse [48,49]. Such adverse childhood experiences may have a negative impact on the child's later psychosocial adaptation and health; they are themselves at risk of alcohol and drug addiction [26,48,50]. Children growing up with alcoholic parents more often have teenage pregnancies, and are more likely to be unemployed [47]. In childhood, they more frequently perform poorly in school [51,52], and are at higher risk of attention and conduct problems [53]. They are also at higher risk of developing mental health problems, both as children/adolescents and in adulthood [48,54-56]. In addition to health problems, they are at risk of social distress, low self-esteem, and problems with close relationships in adulthood [57]. In a Norwegian qualitative study conducted in 2016 [58], the adult children of alcoholics described healthcare system needs that were not met during their childhood. As children, they strove to live as members of a normal family, thus hiding their needs for professional support [58]. Some protective factors that can lower children's risk of acquiring their own problems have been identified. A close bond with a caring adult in childhood, and a good support network may act as protection [31]. In addition, a positive parenting style and engagement in activities may also be protective, as well as the child's own temperament [59], and positive opportunities at times of life transition can be helpful [46]. Continuing family cohesion and harmony in the face of the misuse and its related effects (e.g., domestic violence, and serious mental health problems), can also act protective against their own problems [46].

Severe somatic illness in parents

With regard to parents with a somatic illness, the majority of previous research has been conducted in parents with cancer and the impact of this on their children. There have been fewer investigations of the impact of other somatic diseases, but some research has been carried out in families in which a parent has multiple sclerosis [60,61]. The children of parents with cancer experience a great change in family life and have an extra stress load [62]. They take more care of their families and are more mature than their peers [62,63]. They often think about death, they fear the death of the ill parent, and they often have less support from their parents, as one is ill and the other (if present) must frequently take care of the one who is ill [64]. These children often feel alone, and they struggle with feelings of grief and anger [65].

Children of parents with severe somatic disease are at risk of psychosocial maladjustment [27] and mental illness [66]. With regard to parents with cancer and multiple sclerosis, significant correlations have been found between emotional distress in the parents and psychological difficulties in their adolescent children [67,68]. A German multicenter study conducted in 2014 [69], found that the strongest predictor of emotional and behavioral problems in the children of parents with cancer was general family dysfunction. A 2007 review [70], showed that family function and parenting varied in families in which a parent had cancer, and was correlated with psychosocial functioning in the children. It has been found that girls appear to experience more internalizing problems than boys during a cancer illness in the family [15].

Parental coping appears to protect the child from the adverse effects of a parent's somatic illness [68]. Previous studies and reviews have suggested that children with parents who have cancer require age-appropriate information about the illness, support for communication about the situation, and help to participate in normal childhood activities [63,71].

1.3 Correlations between risk and protective factors in disorder transmission – a theoretical model

Resilience is described as a person's ability to adapt to different adverse experiences [72-74], although no clear definition has been provided [75]. The term is highly used in psychology, in the field of child and adolescent development [75]. Masten [73], asserted that resilience refers to "a class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development". The reduction of risk and the promotion of resilience can be a way of strengthening the members of families in which there is a parental illness, including the children. This may result in a better outcome, despite difficult living conditions. The resilience can be viewed as a process, and different factors contribute to its expression. Hosman et al. [76] developed a model that explains the transmission mechanisms of mental illness in families, including risk and protective factors (Figure 1). This model is based on extensive research in this field, in addition to clinical and preventive practice, which includes research on several mental illnesses, as well as substance abuse. The framework is useful for understanding disorder transmission, and it visualizes areas relevant for interventions or research. In creating this model, Hosman et al. discovered some risk factors, such as poverty and isolation, which are common to different parental conditions, and others that are more disorder-specific, such as genetic and biochemical factors. The model also highlights some protective factors that are unrelated to disease, for example, positive social support, and enables us to assess how different factors contribute to the risk, resilience, and outcome for a child with an ill parent.

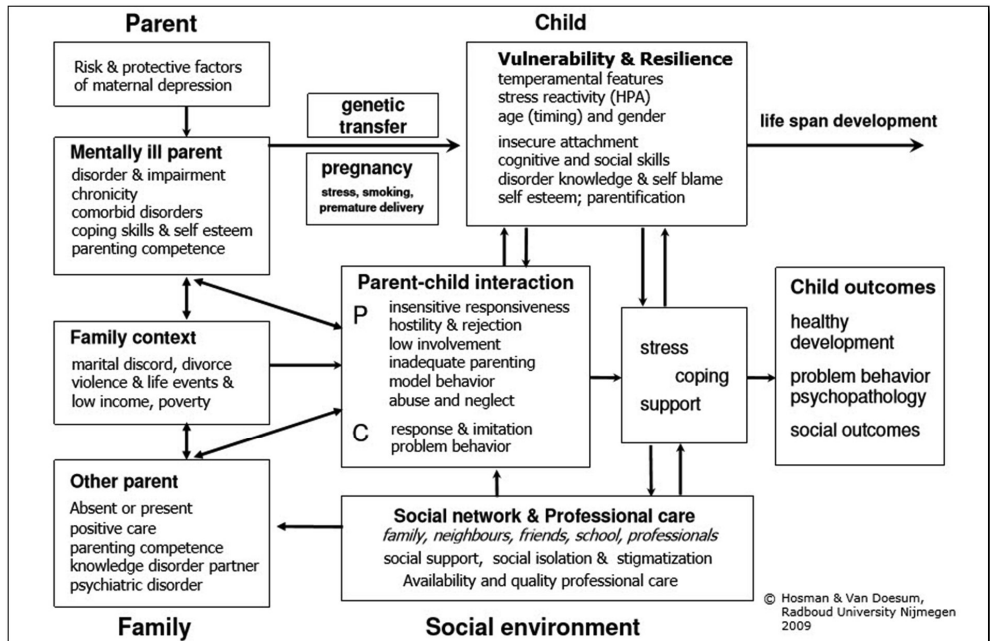


Figure 1. A Transgenerational Model of Mental Health [76]

In order to influence the outcome for a child, early identification of children at risk is important, as is the provision of support for the families that need it. This is a task for mental healthcare, *inter alia* secondary care units caring for ill parents, but also for primary healthcare and the GP. For most people in Norway, the GP represents the first contact with the healthcare system. Hence, the GP has an opportunity to identify problems and needs at an early stage, and provide support.

1.4 Children as next of kin in primary care

1.4.1 Primary care and general practice in Norway

Primary care is characterized by the delivery of coordinated and comprehensive health services [77]. The European GP organization, Wonca Europe, has regularly released documents explaining the role of general practice in healthcare [78]. General practice provides open access for people with all types of health-related problems, and the GP is often the first medical contact within the healthcare system. GPs cooperate with others in the primary care setting, giving the patients coordinated care, and also act as gatekeepers and coordinate entrance into secondary care by referrals. General practice also has the ambition to provide longitudinal continuity of care [78].

General practice is an important part of the healthcare system in Norway. The municipalities are responsible for primary healthcare, while the government is responsible for secondary care and hospitals. The primary healthcare system includes services from GPs, rehabilitation, and mental health services at the municipality level, as well as well-child clinics, school nurses, and child protection/child welfare [79].

In Norway, a patient list system is operational in general practice. Almost all citizens are enlisted with a personal GP, which facilitates continuity of the doctor-patient relationship. The GP list system is among the most popular public services in Norway [80]. Most Norwegian GPs have a contract with the municipalities and work on a self-employed basis, commonly in group practices consisting of two to six GPs. They are usually not co-located with other personnel in the primary care setting, and this can make multidisciplinary collaboration challenging. In 2013, a new regulation relating to a Municipal Regular GP Scheme (“Fastlegeforskriften”) [81] was launched, which specified the duties and responsibilities of GPs in Norway, and in January 2012, a new health reform, the Norwegian Coordination Reform (“Samhandlingsreformen”) [82] was established. One goal of this reform is to ensure improved coordination of services, both within the primary health service and between primary and secondary care. The reform focuses on preventive care, and places greater responsibility for healthcare on the municipalities. However, while these new regulations place higher

expectations on Norwegian GPs, extra resources are not allocated. Many GPs experience work overload and capacity problems in attempting to meet all expectations [83]. The same problems with work overload were highlighted in a report by NHS England, which revealed that GP workload grew hugely in England during the last 5 years [84].

1.4.2 Important elements in consultations concerning children as next of kin

GPs primarily work at their offices, in which they receive patients for consultations. Each consultation is usually time-limited, so it is important to have an effective patient-doctor communication method, in which the patient is permitted to raise important matters, while feeling safe and comfortable.

1.4.2.1 The patient-centred consultation model

Levenstein et al. described a model for the doctor-patient relationship that is suitable for general practice [85]. This patient-centred consultation model is widely used in general practice, is taught to numerous medical students in Norway and other countries [86], and has been designed to enable an understanding both of the patient as a person and of the disease. According to this model, the doctor must address two agendas in a consultation - the patient's agenda and the doctor's agenda. In order to elicit the patient's agenda, the physician must attempt to enter the patient's world, and help the patient by creating a supportive atmosphere, so that this individual can express and share his or her thoughts, feelings, and understanding of his/her symptoms and situation. The doctor's agenda is to gain an understanding of the patient's symptoms in relation to the diagnosis and risk factors, and to recommend treatment and prevention procedures. Following an exploration of the two agendas, the doctor and patient discuss and agree on actual treatment or actions. This model allows for an understanding that surroundings, other human beings, and previous experiences may all influence the patient. Transferred to a situation with parental illness, the doctor's agenda will be to gain knowledge of the illness, ascertain the prognosis, and improve their general knowledge of the situation for the children and their risks of later health problems. However, in order to reach the stage that enables discussion and agreement on actual treatment and actions, including an initiative concerning the children, the GP

must explore the patient's individual agenda. This implies *inter alia* the patient's (here the parent's and/or the children's) understanding of their own situation, the impact of the parent's illness on their family, and their expectations and hopes for the consultation.

Ridd et al. [87] described a framework for a good doctor-patient relationship, as viewed from the patient's perspective. The authors distinguished between the dynamic factors that develop or maintain the relationship, and the depth of that relationship. The depth is a product of the dynamic factors of longitudinal care and consultation experiences, and encompasses what the patient considers to be mutual knowledge, trust, loyalty, and respect between themselves and the doctor.

1.4.2.2 Trust

Trust is a core component of a good doctor-patient relationship [88]. A patient-centred consultation model is based on the patient's trust in the doctor [89]. To trust a person is to give this person power; Fugelli described personal doctoring as being like sharing power [89]. The patient knows his or her life, as well as his or her symptoms and what lies behind them, while the doctor knows the best medicine. To share information and merge is to share power [89]. However, the doctor-patient relationship is unequal when it comes to power. Trusting the doctor means that the patient must give the doctor a possibility to use power, and hopefully, this power will be used to benefit the patient [90]. A trusting relationship might be a good base for sharing adverse experiences and sensitive topics [91], so such a relationship is of particular value for patients in adverse life situations. In his James Mackenzie Lecture in 2000 [89], Fugelli claimed that evidence from previous research has indicated that the majority of patients still trust their personal doctor, whereas confidence in the healthcare system is under strain [89,92], but we cannot take this trust for granted. Skirbekk [93] described trust as a dynamic phenomenon, and claimed that a patient gives their doctor a mandate of trust that may vary with different situations. This mandate may be open, meaning that the doctor is permitted to address broad aspects of the patient's life situation, or it may be more restricted to certain issues. When the doctor is given a broader mandate of trust it implies that the patient relies on the doctor's good intentions, and that he/she knows what is best for them in the long run, although it may

currently be painful to raise the issue. This trusting relationship, and its genuine limits, is usually implicit or taken for granted [94]. Neither the doctor nor the patient discuss it in their consultations. Occasionally, there may be a mismatch, particularly if the doctor does not realize the limits of the mandate of trust he/she has been given, and this can lead to mistrust on behalf of the patient. In addition, it is highly possible that the doctor does not realize that the patient is providing a broader mandate, for example, to address the children's situation in a consultation with an ill parent.

1.4.2.3 Recognition

Several general practice studies have claimed that an attitude of recognition from the GP is frequently a prerequisite for the patients to share their stories [95-97]. Psychologist Anne Lise Schibbye [98] outlined the concept of recognition in therapeutic relationships from a philosophical and theoretical background. Her point of departure was the Hegelian concept of mutual recognition, after which she made a connection to psychoanalytic theory via the concept of intersubjectivity, involving affect attunement and sharing. She claimed that therapy is far more than recognition, and that "it is basic to the clinical attitude with which we should meet our clients" [98]. On the practical, clinical level, she described recognition as a mutual, subject-to-subject relationship between a therapist and a client, the essence of which is a basic mutual respect for the other person as an authority of his/her experiences. In the clinical setting, recognition behavior is expressed as listening, understanding, acceptance, tolerance, and confirmation [99]. Listening and understanding entails actively entering the person's world of experience and allowing oneself to be moved. The therapist must approach and assess their own feelings, and must simultaneously be aware of the other person's ownership of his/her experiences and corresponding feelings. Acceptance and tolerance imply that the therapist tolerates the patient's feelings, and confirmation means the validation of these feelings - conveying to the patient that they are understood, given the patient's situation.

As previously stated, the GP is the first contact in the healthcare system for most people. Having knowledge of their patients' situations, and using a longitudinal continuum of care and consultations, the GP has a good opportunity to recognize, and

react to, illness and problems at an early stage. This is important for children in families where a parent has an illness, but it requires the GP to use the occasion to explore the topic. However, GPs have a heavy workload, and these children may be overlooked [85]. Several different studies have found that while there are good opportunities, there is room for more family-focused practices in primary care [100,101].

2. Aims of the study

The overarching aim for the three sub studies in this project was to acquire knowledge of how GPs can meet the special needs of children of ill and substance-abusing parents. These children's own health is at risk, and they also risk developing psychosocial problems. Thus, it is important preventive measures to identify children in need of support, to ensure they get information regarding the parent's situation and follow-up, if required. But how should this be carried out in everyday general practice?

The research had the following specific aims:

- * To explore GPs' thoughts and experiences with regard to addressing the specific needs of children with ill and substance-abusing parents
- * To explore the significant experiences of adolescents with ill and substance-abusing parents that the GPs should identify and recognize
- * To identify important factors for the GPs to bear in mind during consultations with ill and substance-abusing parents, to enable GPs to provide appropriate support for the children.

3. Design, Materials and Methods

This project was part of a research project in which the aim is to establish knowledge regarding how GPs in Norway can support children with parents experiencing mental illness, substance abuse, or severe somatic disease (children as next of kin).

Specifically, the project aimed to identify the types of help that GPs can provide, as viewed from the perspective of the following three groups: burdened children, ill or substance-abusing parents, and GPs. This will lay a scientific foundation for the development of specific tools and guidelines as to how GPs can aid such children when the perspectives of the children and their parents are integrated.

The research project consisted of five sub studies:

- 1 An interview study of GPs
- 2 An interview study of children with ill or substance-abusing parents
- 3 An interview study of parents with mental illness, severe somatic illness, or substance abuse
- 4 A web-based survey of all GPs in Norway. The results from the first three sub-studies were used as background for the questions. The aim was to obtain knowledge of what GPs consider to be a good and feasible service to children as next of kin within the frameworks of general practice, and how this corresponds with the expectations that adolescents and parents have expressed in the previous sub studies.
- 5 The development of tools and guidelines to help GPs in the follow-up of children as next of kin. This will be based on the results of the previous four sub-studies.

Sub studies 1–3 formed the basis of my PhD, and only these will be further described. I will describe the strategies I used to explore the issues and how I collected, processed, and analyzed my empirical data. The three sub studies described will be referred to as GP study, Child study, and Parent study, accordingly.

During the research process, I took numerous decisions of methodological significance with regard to how to perform the study. The current chapter relates how I carried out the project and why I made the choices I did. My ambition is to make the research

process as transparent as possible. In order to secure intersubjectivity between reader and researcher [102], the research process was conducted, and is now presented, in a manner that allows the reader to follow the procedure and to see that the results are trustworthily underpinned, which means it is also transparent.

3.1 Choice of method

As described above, we wanted to obtain a differentiated description of the participants' experiences, wishes, and advice, to form a basis for new knowledge relating to how a GP could help children as next of kin. We decided that a qualitative approach was most suitable, due to our research question [103]. Qualitative methods involve systematic collection, processing, and interpretation of material from conversation, observation, or written text [104], and are used to gain understanding of a phenomenon as experienced from those involved [105]. These methods may be particularly useful in areas that have previously been little researched, with few hypotheses to trace, as well as in areas in which we want to explore «how», not «how many» or «how often», as was the situation in our research area.

The empirical data in two sub studies, the GP study and the Child study, were obtained from focus group interviews, while the Parent study data were collected via individual, semi-structured interviews.

Focus group studies, as used in our first two studies, are suitable for collecting data when we want to explore common experiences, particularly when the research topic is restricted. A focus group study is a carefully planned discussion on a topic, and is designed to encourage a variety of opinions. The moderator introduces topics for discussion and is responsible for creating a non-threatening and non-judgmental atmosphere, to encourage the participants to freely share their viewpoints [105]. Interaction between the participants is a core element in focus group discussions [106]. Several persons – typically 4–10 - are interviewed at the same time, and the group dynamic leaves room for associations and remembrance. In turn, this may lead to more

stories – and deliberations on the participants’ own perspectives [103,107].

Participants may react to each other’s stories, with recognition or reflections [106].

Individual semi structured interview was the data collecting method we used in the Parent study. This method is suitable when the theme is sensitive [108], as it might have been for these parents, to discuss experiences concerning how their illness might have affected their children. It also gives an opportunity for more in-depth sharing of, and reflections on, topics advanced by the researcher, even if the issues are sensitive [103].

The evaluation of whether the sample was sufficiently large and varied to allow elucidation of the aims of the study, was carried out step-by-step, during the data collection. The evaluation of the information power [109] depends on sample adequacy, data quality, and variability of relevant issues. We changed the interview guides and the samples to some extent during the research process. When we decided that the information power of the empirical material was optimal, we stopped the data collection.

There are different ways of analyzing qualitative data, and a variety of strategies can be used, and again this is dependent on the research questions that guide the inquiry. In the first interview (the GP study), we used the analytic method of thematic content analysis, as described by Braun and Clarke [110]. This is believed to be a straightforwardly described process of a thematic cross-case analysis of qualitative data [110]. During my PhD education, I was presented for Systematic text condensation, as described by Malterud [102], and found this method’s use of condensates helpful. We chose this method in the two last studies. Both methods have a structured and well-defined analysis procedure, and are suitable for use by an inexperienced researcher [102,111]. The specific procedures, and how we used them, are described in detail below.

Table 1. Summary of materials and methods:

	GP study	Child study	Parent study
Data collection	Focus group interviews	Focus group interviews	Individual semi-structured interviews
Participants	27 GPs	15 adolescents	12 parents
Parental problem		5 mental illness 5 substance abuse 5 somatic illness (cancer)	9 mental illness 2 substance abuse 3 somatic disease
Analysis	Thematic content analysis	Systematic text condensation	Systematic text condensation

3.2 Recruitment and participants

3.2.1 The GP study

We did not expect the current subject to be a frequent issue in general practice. We therefore chose to invite experienced GPs to participate in the study, to ensure that they had some relevant cases to discuss. In order to strengthen the external validity to ensure transferability of the results, we wanted both male and female doctors, doctors from rural districts and from urban areas, and GPs with an academic background or bureaucratic (community health or trade union) experience.

In such a manner, we obtained a purposive sample, with participants representing a variation of experiences concerning care for children as next of kin [108]. We recruited participants from already existing GP groups - groups organized within Norwegian continuing medical education (CME) for GPs. We sent an invitation email

to the leaders of different groups in our network in Western Norway (Appendix 1). Four groups were invited, and all of them agreed to participate. Following acceptance, all individual participants received an invitation email in which we asked them to come along with experiences whereby they had been a GP for an ill parent in a situation where the illness might have affected their parenting ability. We eventually had four groups with a total of 27 participants - 10 women and 17 men, 14 from countryside settings and 13 from urban areas.

Table 2. Overview of participants in the GP study

	Group 1 (Urban)	Group 2 (Rural)	Group 3 (Urban)	Group 4 (Rural)	Total
Number of participants	5	5	9	8	27
Men/women	5/0	4/1	9/0	0/8	18/9
Age (yrs.)					
<i>Mean</i>	56	56	58	46	54
<i>Range</i>	53–60	51–63	52–65	38–55	38–65
Time in gen. practice (yrs.)					
<i>Mean</i>	21	26	26	14	22
<i>Range</i>	11–33	24–28	15–30	6–25	6–33

3.2.2 The Child study

In this sub study, we initially wanted a purposive sample [106], and sought participants with different backgrounds, from both rural and urban areas, with different parental problems, and across a range of ages. Children or adolescents with ill or substance-abusing parents were our target group, and were recruited from existing support groups for children as next of kin. We contacted them by email or phone via a variety of lay organizations running groups for children/adolescents with parents with cancer or mental illness, or with substance-abusing parents. We gave the group leaders

written information regarding the study via email, and asked them to inform their groups and invite the participants to a group interview (Appendix 2). It emerged that it was difficult to recruit from these groups, and it took much longer than we had expected. Many organizations had problems recruiting participants to the groups themselves, and several planned groups were cancelled. In addition, we experienced that in groups where it was necessary to obtain parental consent, some of the parents did not want their children to participate. They told the leaders that they thought their children had enough worries and wanted to protect them. These recruitment difficulties meant that we eventually had a less varied sample than we had planned, that is, we obtained a convenience sample [106]. However, we succeeded in recruiting participants with the relevant parental problems. All the groups were in urban areas, and we eventually included only adolescents and young adults. We conducted a preliminary analysis of the interviews immediately after they were performed. Initially, we had recruited a group of children aged 6–11 years who had parents with cancer, but they had little relevant information to share, since they had had few experiences with their GP, and few thoughts as to how a doctor might help out. Therefore, we decided not to include the data from this group and conducted a new focus group interview with young people with parents with somatic diseases. They had numerous experiences to share, and brought rich material to the study. We ultimately included 15 participants in the study, only three of whom were boys (Table 3).

Table 3. Overview of participants included in the Child study

	Group 1	Group 2	Group 3
Parent's problem	Substance abuse	Mental illness	Cancer
Participants	4 / 1	4 / 1	4 / 1
Girls / Boys			
Age (years)	16–17	16–18	17–25
Having parents living together	0	1	0
Currently living with ill parent *	3 (2 part-time)	1	0 (all ill parents had died)

**Many participants were not living with their ill parent when the study was conducted, but they told us about experiences from the period when they still were living with them.*

3.2.3 The Parent study

In this sub study, we asked GPs to help in recruiting parents with an illness or substance abuse of a severity that could influence their parenting ability. We prepared an invitation letter and response letters, and pre-stamped return envelopes for potential participants (Appendix 3). The GPs were asked to find relevant patients and to ask them if they wanted to participate (Appendix 3). If they were interested, they were given the envelope containing the relevant information and consent letter. Those willing to participate returned this directly to me – without involving their GP. In addition, they provided their phone number, and I called them to arrange a time and location for the interview. The GP should not know whether the patient returned the letter.

We first asked the participants in the GP study to recruit relevant patients from their own list of patients. We then included GPs in our personal network of GP colleagues to help us with further recruitment. Other GPs in Western Norway were also visited and asked to recruit participants. We aimed for a purposive sample [106], and wanted parents from all three categories; mental illness, somatic disease, and substance abuse.

We asked the GPs to recruit appropriate patients, and they gave an information letter to those who were interested. This recruitment was more difficult than we had expected, and it took an extra 6 months to recruit all the participants we needed. It emerged that the sample was skewed with regard to parental problems and gender. In total, we interviewed 12 parents, three men and nine women, and we again ultimately had a convenience sample [106].

Table 4. Overview of the participants (N=12) in the Parent study

Gender	Female	9
	Male	3
Illness of parent	Mental illness	8
	Somatic illness	4
	Substance abuse	2
Employment	Full employment	0
	Part-time	2
	No employment	10
Number of children in the families (N=28)	1–2 children	6
	3–4 children	6
Live with the other parent	Yes	6
	No	6

3.3 Data collection

3.3.1 The GP study

We conducted four focus group interviews. These were all carried out as part of an ordinary meeting in the CME groups, and took place at their usual meeting places - two in private homes and two in offices. Two researchers were present in all the interviews; FG acted as moderator leading the interviews, MH was an observer who introduced comments and follow-up questions, and took notes. The interviews focused on the discussion of experiences that the participants described. They were encouraged to share their stories and to discuss their experiences of being a doctor for ill parents, and their opportunities to help the children in these families. A short interview guide was developed as a checklist for the moderator through the interviews, and covered the following topics: sharing of thoughts related to relevant cases in which the GPs had been involved, experiences of talking to parents and children about the impact of parental health problems, and experiences concerning collaboration regarding children at risk. In some of the interviews, some participants had little experience in this field, for example, some primarily worked with elderly people. These participants contributed less to the discussions. The interviewers were observant of these phenomena, and involved all participants, when appropriate, to ensure that they all made a contribution. Otherwise, the discussions proceeded in an uncomplicated manner, and were mainly between the participants without the involvement of the researchers. The participants recognized each other's experiences, and new stories emerged. The interviewer occasionally posed some questions, based on themes from the interview guide. The interviews were all digitally audio recorded and transcribed verbatim. After conducting the four interviews, we decided that we had sufficient material to illuminate our research topic, and that no more interviews were required. We considered that the material had sufficient information power [109].

3.3.2 The Child study

In order to obtain information from children with ill or substance-abusing parents, we decided on focus-group interviews as the method of data collection. As described above, we invited already established support groups for children as next of kin. We began the interviews by describing the study and its procedures, and the participants then signed a consent form (Appendix 2). Three researchers participated in two of these interviews; FG and MH acted as moderators, while TSS acted as an observer. In the groups of children of parents with a somatic illness, two researchers were present; FG as a moderator and MH as an observer. An interview guide was developed to ensure that all topics were addressed (Appendix 2). During construction of the interview guide, we obtained valuable input from researchers in our network, including psychologists and an academic with experience of child protection services. This enabled us to formulate satisfactory questions that were relevant to the adolescents and children we interviewed. The guide covered the following topics: everyday life, network and support, use of healthcare, and the needs experienced by the participants. The moderators took turns in questioning and commenting on the youths' experiences and thoughts. The participants shared experiences, thoughts, and wishes, and appeared to be fairly relaxed in the situation. They commented on one another's thoughts and opinions, and while some participants talked more than others in all groups, this was not in such a manner that they dominated the group session. The interviewers attempted to maintain a friendly atmosphere, and endeavored to include everyone - occasionally providing direct encouragement to those who were less vocal. They addressed possible misunderstandings between themselves as interviewers and the participants, to ensure that the material enabled maximum validity of the participants' experiences and opinions. After including a second support group for children of parents with somatic illness, consisting of adolescents and young adults, we found that we had sufficient material to elucidate our research question. All interviews were digitally audio recorded and transcribed verbatim.

3.3.3 The Parent study

In this sub study, we chose individual semi-structured interviews as the method of data collection. We wanted to interview the ill parent, in order to explore the field from their perspective. The same researcher, me, a GP, conducted all interviews. I used an interview guide (Appendix 3) that helped ensure that the discussion remained on-topic, thereby enabling exploration of all subjects that we had evaluated as relevant prior to beginning the study. We had created this to cover the following topics: daily life, consequences of illness, experiences with healthcare providers (particularly GPs) and other support, and how the children were coping. After the first interviews, we made slight adjustments to the guide to include more specific topics related to the GP's role, in order to obtain a greater amount of data relevant to the aim of the study. In one case, a mother had recently died of cancer, and the father came along for the interview. We decided to include this interview, as this father shared many experiences that were relevant to the ill parent. The parents chose where the interview took place, whether that be in their home or at an office. All participants appeared to be fairly relaxed in the interview situation, and they shared thoughts that also elicited emotions. This sometimes resulted in short breaks. However, despite a reminder of their right to withdraw, all participants completed the interviews. The interviews lasted from 50–90 minutes, and were all digitally audio recorded and transcribed verbatim. After the 12th interview, we considered that the material had enough information power [109] for the purpose of our study.

3.4 Analysis

We used a thematic cross-case analysis to analyze our empirical data, using an editing analysis style, as described by Crabtree and Miller [112], whereby we arranged meaningful units of text in categories according to the material, and searched for patterns that connected the categories. Theoretical perspectives supported the analysis to varying degrees [113], but it was not theory-driven in terms of having the codes and categories predetermined according to an existing theory [112].

Both thematic content analysis and systematic text condensation are rooted in the phenomenological hermeneutical research traditions [103]. Using these procedures, we explored the phenomenon; the experiences and thoughts the informants shared, in order to gain knowledge directly from them. Furthermore, we interpreted what they said, that is, searched the meaning behind the human expression. We continuously compared the text-fragments chosen for our codes and categories with the stories and experiences that each participant provided, and also with the full dataset in each sub study, to ensure that our results were rooted in the empirical data and in accordance with them. In other words, we attempted to follow principles from the hermeneutical circle [105].

Two to three researchers collaborated on the analysis, supplementing and discussing one another's initial categorization to obtain a richer analysis [104]. All co-authors of each article that resulted from this research participated in discussions on the categories and themes presented.

3.4.1 The GP Study

In the GP study, we used thematic content analysis, as described by Braun and Clarke [110]. This method involves searching a data set to find repeated patterns of meaning. According to the level of analysis, we chose themes on a semantic level, that is, we referred to the participants' descriptions of the topic discussed without making an interpretation [110].

The empirical material consisted of transcripts of the four focus group interviews and field notes taken during the interviews. We received analysis input from the co-authors and researchers in our network, by presenting and discussing preliminary data in research meetings.

We used the following steps in conducting the analysis:

1. *We familiarized ourselves with our data*

During transcription of the interviews, I obtained a first impression of both content and meanings. Both MH and I read and reread all of the material with an open mind to

acquire an overview, a first impression. We noted preliminary ideas regarding the relevant themes in the data.

2. We generated initial codes

We thoroughly read all of the material and identified aspects of the data that were relevant to the aim of the study. We organized the interesting text sequences (meaningful groups) under different codes, using NVivo 9 software.

3. We searched for themes

In this step, we worked through the codes from step 2 and examined whether any of these could be merged with, or placed in, more overarching themes. Thus, we established some preliminary themes. Some codes were ultimately preliminary themes, with other codes becoming sub themes of these, while other codes were discarded, as they did not fit.

4. We reviewed themes

We examined every text-segment under each theme developed in step 3, and reviewed these to determine whether they appeared to form a coherent pattern. We discarded any extracted data that did not fit, or placed them in another, more relevant, theme. In cases where the content under a preliminary theme did not form a coherent pattern, we sought to replace the segments that did not fit or created new themes. We then reviewed every theme in relation to the data set, to assess whether our themes reflected the information provided in all interviews, in relation to the research question. We found that the themes worked at this level.

5. We defined and named themes

In the final step, we identified the essence of every theme, to determine what aspects they each contained. We again examined every data extract in each theme set, to obtain an overview of what each theme captured. We evaluated each theme in relation to the study objectives, which resulted in two overarching themes, namely, opportunities and barriers. The refined categories became sub-themes that fell under the two overarching themes.

Table 5. Examples of an analysis of two text segments

Phase 2		Phase 3	Phase 4	Phase 5
Text segments	Initial codes	Preliminary category	Refined category	Final theme
« But in that situation, the help we got from the health visitor was good. He was in the first or second class, and after the father had died, the health visitor went to the school to talk to the class and followed-up with him and some of his mates.»	Well-functioning collaboration with health nurse.	Cooperation with others to help children as next of kin	Multi-disciplinary collaboration	Opportunities
"I had my hands full with this dad. It was so demanding, I talked to him several times a week in long consultations. So for me to lift my eyes above the horizon and try to see if there's something else out there, it's almost inconceivable "	The patient was the subject of the entire focus of the consultation.	The children do not come into the visual field.	Lack of time and capacity – barriers within the frames of the consultation	Obstacles

3.4.2 The Child and Parent studies

In both of these studies, we used systematic text condensation [102] as the analytic procedure, and our empirical material was the text from the transcribed interviews. We used a stepwise analysis in the following manner:

1. A complete impression – from chaos to themes

We (FG and MH) read all of the transcripts in their entirety with an open mind, to obtain a complete impression. During this reading, we attempted to set aside our preunderstanding, so that our results were generated entirely from the data alone. We both identified preliminary themes according to our research questions during this first

reading. We then discussed these preliminary themes and agreed on some that we used in our subsequent analysis.

In an example from the Child study, we reached the following initial and preliminary themes in the initial analysis, following negotiations:

- That which is helpful
- Relationship to parents
- Consequences of parental illness
- Coping strategies
- The role of helpers

2. Identification and determination of meaning units – from themes to codes

Using these themes as a background, we systematically read through all of the interviews, to identify meaning units that were relevant to our research topic. A meaning unit is a text fragment that expresses knowledge of what we want to explore [102]. To some extent, the interviews were open discussions between the participants, and the text contained topics that were not relevant to the aim of our research; these were discarded. We used the themes established in step one as headings, and coded each meaning unit accordingly. We sorted the coded meaning units into code groups, using NVivo software as a tool. This process implies decontextualization, namely, removing parts of text from their original context to group them with other text fragments with a similar meaning. We discussed the different code groups, re-sorted some meaning units, and modified some units, which resulted in a greater number of headings with a higher level of consistency.

Table 6. An example of analytic coding and subcategorization from the Child study:

Preliminary themes		Code groups with sub codes
That which is helpful		That which is helpful -understanding -relieving activities
Relationship with parents		Burdens -stress symptoms, health complaints -unpredictability -emotional ambivalence toward parent
Consequences of parental illness		The GP -conversation partner -expected to work properly -advice and information
Coping strategies		
The role of helpers		

3. Condensation – from code groups to meaning

When we began this step, we had numerous meaning units coded under different code groups. In this step, we first sorted the meaning units within each code group into different subgroups, each representing different aspects of this code group. From each subgroup, the content was summarized in a shorter text, a condensate. This was written in a first-person format, to remind us that what we expressed here was extracted from the participants' voices. We then found an authentic quote to illustrate the major points of the subgroup.

Table 7. Example from the Parent study

Code group and sub code	Condensate	Quote
Economical and practical worries -In need of information about other support services	<p>When I became ill, my family had needs for help other than those we had previously had. I wish someone could see the whole family, including the kids, and advise us. Tell us what support services exist, or where to get help.</p> <p>A brochure would have been nice. Nothing came automatically. I sort of had to find out everything by myself. I really struggled with that, it was hard to find (....).</p>	<p><i>“Once the doctor knows that we have children, there should be an alarm ringing and telling them: ‘Okay, now these kids need to be protected’. The doctor should tell the parents: ‘I have some advice for you, and some helpers you can contact, and here are the phone numbers’, a brochure to hand out or other stuff – I think that could be very helpful.”</i></p>

4. Synthesizing – from condensation to descriptions and concepts

In the final step, we recontextualised the material. We put together the content of the condensates in each code group and rewrote this in an analytic text, summarizing our main findings. This text was written in the third person. We again evaluated every subgroup, and ultimately made decisions on the final subgroups and headings. The analytic text of every final subgroup was compared to the entire transcript, to ensure that our synthesis reflected the original material. In the Child study, in accordance with our theoretical support [99], we finished with final categories that reflected significant

experiences of the adolescents and young adults that the GP should identify and recognize:

- Living with unpredictability
- The struggle for an ordinary adolescence
- Experiences and expectations from consultations with the GP

In the Parent study, we ultimately had two final categories:

- The importance of appearing as a normal family
- In need of professional support

We observed that these categories represented a dual message from these parents to their GPs.

3.5 Ethical considerations

Previous research has confirmed that children as next of kin are often invisible in the healthcare system, and do not receive attention from professionals in the community [17,61,100]. These children may have a stressful everyday life and are at risk of developing health and social problems. Prevention of transgenerational transfer of problems is an important measure to take, and is an ethical obligation for policymakers, governmental agencies, and other relevant professionals. The conducting of research on this topic to develop science-based knowledge in the field is of high ethical value.

We presented the study protocols from all sub studies to the Regional Committee for Medical and Health Research Ethics, Western Norway. As the GP study did not involve patients, the committee did not consider the project to be within their mandate, so it was not necessary to gain approval from them. Shared patient-stories were anonymously presented. We sent written information detailing the interview study to

all of the invited GPs. At the beginning of each group interview, we informed them that they could withdraw any information provided without giving any reason for doing so.

The Child study received ethical approval from the Regional Committee for Medical and Health Research Ethics, Western Norway (2012/2248). The children were invited via a group leader, to whom we sent information about the study to share in advance. The interviews took place during an ordinary group meeting, and those members not interested in participating were offered an alternative arrangement. At the beginning of each interview, we shared information about the meeting, and the participants then signed a consent form. With regard to those younger than 16 years of age, their parents had signed a consent form in advance. The group leaders were present during the interviews, to enable them to follow-up with the participants afterwards if difficult questions or feelings arose during the interviews.

The Parent study received ethical approval from the Regional Committee for Medical and Health Research Ethics, Western Norway (2013/2336-3). The participants were recruited by their own GPs, who gave them letters providing information about the study and asked them if they were interested in participating. Those who agreed to participate submitted a signed consent form. At the beginning of each interview, they were given oral information about the study and the purpose of the interview. The interviews ended with debriefing questions about how they felt about sharing information regarding the topic. They were given the opportunity to contact their GP if they needed someone to talk to after the interview. No one expressed such a need.

4. Summary of results

Paper 1

Gullbrå F, Smith-Sivertsen T, Rortveit G, Anderssen N, Hafting M. To give the invisible child priority. Children as next of kin in general practice. A qualitative study among general practitioners. Scand J Prim Health Care 2014; 32(1):17-23

How do general practitioners view their role as helpers of children with ill or substance-abusing parents? The objective of this study was to explore GPs' experiences in helping children as next of kin of parents with substance abuse, mental illness, or severe somatic illness. A total of 27 experienced GPs participated in focus-group interviews during 2011, and the data were analyzed using thematic content analysis.

The GPs experienced both opportunities and barriers with regard to helping children as next of kin. They could be in a good position to identify children at risk, particularly those GPs working in small communities, those who make house calls, and who work with health visitors. When these children were identified, the GP could help them via the provision of information and advice to their parents on how to support them and how to inform them of illness or substance abuse. To a lesser extent, many of the GPs talked to the children themselves. Participation in collaboration with professionals in the healthcare system in the communities around these families was viewed as another way to support these children. The barriers that the GPs faced included the constraints imposed by the consultation framework. Limited time and an entire focus on the patient could be a reason why the children's situation was not discussed during consultations. Some GPs believed that addressing the children's situation in a consultation with ill parents might lead to mistrust, or result in more feelings of guilt in, and greater burdens for, parents who were already struggling. The results of this study show that GPs appear to be in a position to support children as next of kin, but that they frequently face barriers that prevent them from providing this support.

Paper 2

Gullbrå F, Smith-Sivertsen T, Rortveit G, Graungaard AH, Hafting M. How can the general practitioner support adolescent children of ill or substance-abusing parents? A qualitative study among adolescents. Scand J Prim Health Care 2016; 34(4):360-367

The objective of this study was to explore significant experiences of adolescents with ill parents, of importance for the GP to identify and recognize.

The empirical material consisted of transcripts of three focus group interviews with 15 Norwegian adolescents with ill or substance-abusing parents. We performed a cross-case analysis, using systematic text condensation, and a theory on recognition in clinical settings inspired our analysis.

We found that the parent's illness had a substantial impact on these children's lives. They experienced unpredictability in daily life and described feelings of ambivalence toward their parents. However, they wanted to have an ordinary life, and wished to be treated as ordinary young people. Therefore, our informants struggled in balancing their own needs with the influence of their parent's illness. Many had their own health problems, such as symptoms of stress, muscle pain, or abdominal pain. The experiences with a GP were mostly limited to their own somatic complaints and their impression of how their parent's needs were met. They rarely initiated a discussion of the situation at home with the GP. Many wanted more information about their parent's condition, and they welcomed it if the GP discussed this. Their health problems and life situation were closely connected to that of their parent's. In order to help these adolescents, the GP should consider them as ordinary youths, while recognizing their situation, and thus create a suitable atmosphere for a discussion of their everyday life. They most frequently visit their GP for somatic complaints, and the doctor might use these opportunities to also discuss their family situation. The GPs can help by encouraging their engagement in activities that provide relief and by offering to discuss their life situation. In addition, the GP can provide information about their parent's health problems, with the agreement of the ill parent.

Paper 3

Gullbrå F, Smith-Sivertsen T, Rortveit G, Anderssen N, Hafting M. Ill and substance-abusing parents: How can the general practitioner help their children? A qualitative study. BMC Family Practice 2016;17:154

The aim of this study was to explore how a GP could offer help to the children of ill or substance-abusing parents from the perspective of the parents themselves. We conducted 12 individual interviews with parents with severe somatic disease, mental illness, or substance abuse. The data were analyzed by systematic text condensation.

An overarching finding was that the ill parents presented themselves as coping parents, while simultaneously expressing a need for support with regard to parenting. They strived to make an ordinary everyday life for their children, and gave many examples of how they managed as parents. For them, it was important that the GP and others in the healthcare system acknowledged this. For many parents, several different health professionals were involved, and they stated that they found it was helpful for them that they cooperated well and shared information. It was perceived as important that the children had good information about their parent's illness. In order to provide this information the parents sometimes needed advice. In some instances, they wanted others to provide their children with the information; the GP was mentioned as important in this regard. In addition, they expressed a need for their children to have someone with whom they could talk about their experiences, someone from whom they could receive support. We found that the GP was welcome to address parenting and the children's situation in consultations with the ill parents. The GP should be aware, and should take the time to discuss not only the first spontaneous story about an ordinary day, but also to explore their concerns about their children and the need for support. The trusted GP might then be in a good position to give advice about parenting and ensure specific follow up for the children, to provide information about support services, and to participate in collaboration with others in the healthcare system, with regard to the children.

5. Discussion

5.1 Methodological and ethical considerations

When the research questions have been clarified, the researcher must choose a suitable method with which to explore the area he/she wants to investigate, and identify the tools that could provide answers to the questions. Evaluating the quality of qualitative inquiry, can be done in different ways, and Stige et al [121] describe the evaluation more as an ongoing process and a reflexive attitude than based on checklists. Malterud [104] proposed relevance, validity and reflexivity as suitable concepts to bear in mind for this process, and Brinkmann and Kvale [105] argue that validation permeate the entire research process in interview studies. Malterud [103,104] argue that to evaluate the validity of the findings, it may be practical to divide the concept into internal validity; did the study investigate what it intended to - and external validity; in what contexts are the results applicable? We use the concept as described by Malterud [104] in the further description of validity. Numerous factors may affect the internal and external validity of the results, and, to make an evaluation, the research process must be clearly and transparently described, which I hope to have accomplished in the Methods section. I will now discuss factors concerning validity issues, including the researcher's role and try to demonstrate the reflexivity that has accompanied the research process.

5.1.1 Internal validity

In order to achieve satisfactory good internal validity, the method used in a study must elucidate what the study intends to explore [104]. That mean the research question must guide all methodological choices. In addition, information power [109], depending on sample adequacy, data quality, and variability of relevant issues, is an aspect of internal validity. This influences the potential of the available empirical data with regard to providing access to new knowledge by means of analysis and theoretical interpretation. In this subsection, I will discuss to what extent our methodological choices contributed to the internal validity of the results, especially concerning design, sampling, the quality of the interview data and the analysis.

We aimed to explore the experiences and ideas of GPs, ill parents, and children as next of kin with regard to how the GPs might help the children of ill parents. We decided that the use of qualitative methods to answer our research questions appeared to be appropriate [104] (see Chapter 3), and we chose to gather the GPs', children's and parents' experiences across parental difficulties. There are obvious differences in living with an substance-abusing parent, a mentally ill parent, or a parent suffering from cancer, both with regard to stigma and to everyday living (see Chapter 1), and it is of course differences in being a patient with parental responsibilities depending of which types of problems you have (substance abuse, etc).

In our study, we focused on what these groups of children have in common concerning their need for support (see Chapter 5.2.2). It could also be interesting to explore differences between these groups of children, but that would have been a different research question and it would have required a design other than the one chosen for this study.

A prerequisite for internal validity in an interview study is the intersubjectivity between participant and interviewer. Does the interviewer capture the real meaning of what the participants say during the interview? This depends inter alia on the atmosphere during the interview and on the interview technique, whereby the interviewer ensures that he/she has an adequate understanding by active inquiry.

In the *GP study* and the *Child study*, we used focus group interviews for collecting data from discussions on preselected topics, and the data were generated in interaction between the participants. In order to produce fruitful discussions, it is important to establish an atmosphere in the group where the participants feel comfortable, and can easily share thoughts, meanings, and diverse views [114]. Elements that can affect the data gathered are whether the participants have the same background, whether they have prior knowledge of each other, and group dynamics [114]. If the participants already know each other, and are used to discussing similar topics, it may be easier to share thoughts and experiences. In our studies, both the GPs and the adolescents knew each other well, and appeared to freely discuss the themes explored, and the group dynamics seemed productive.

In focus group interviews, we run the risk of someone not having the courage to express their opinion if it is not in accordance with that of the majority of the group. It may therefore be easier to glean their genuine meaning and hear of their adverse experiences in an individual interview [114]. Therefore, we used this method for data collection in the Parent study (see Chapter 3.1).

In the *GP study*, we recruited established CME groups to the focus group interviews, and this was partly for practical reasons; we could meet a group of doctors who already had a scheduled meeting. I (FG) was the moderator in all focus group interviews, and my main supervisor, MH, was the secretary. In the interviews, we wanted to explore how the GPs contributed in relation to children with ill parents, and, to a lesser extent, to hold general discussions of best practice. Therefore, the participants were asked to share experiences from practice in the focus group, relating how they approached the family, particularly the children, when they had been the GP for a family with parental problems. It was difficult to ascertain whether their stories represented accurate descriptions of what had occurred, but discussions of experiences resonated with the rest of the group.

The participants knew each other well, were used to discussing medically related issues and seemed to have a relationship of trust. This might have promoted sharing all kinds of experiences. They acknowledged one another's experiences, both when they were success stories and when they were descriptions of failures [106]. However, they could also have had an established group dynamic, whereby some were dominant, and this hierarchy could have affected the communication [114]. Undergoing an interview by a GP and a child-and-adolescent psychiatrist might have influenced what they related, and the opinions they expressed about the issue [115,116], inter alia focusing on success stories more than on failures. When the goal was to identify how a GP may contribute to helping children as next of kin, we believe that we gained relevant information from these focus group interviews, despite this possible bias in the interview situation. Due to my field knowledge from general practice and the generally relaxed atmosphere during the interviews, we also saw the intersubjectivity between the participants and the interviewers as being good. The use of focus group interviews

allowed us to obtain rich and varied material, exploring different ways in which the GPs viewed their role in helping children as next of kin [109]. As we interviewed only 27 GPs, it was not possible to explore all support strategies, but we did obtain material with sufficient information power to enable a satisfactory analysis to obtain relevant results [103]. The data quality was fairly good and the sample was sufficiently large and varied to elucidate the aims of the study.

In the *Child study*, we also used focus group interviews for data collection. We performed four focus group interviews, but three interviews with adolescents were ultimately included; we did not obtain information relevant for the project in one interview with young children with parents with cancer, so we decided to exclude that interview (see Chapter 3.2). Maybe another approach would be more useful in this age group, for example, the use of drawing, pictures, or videos [105].

The participants included were fairly similar with regard to age, ability to reflect, and the participation. We interviewed one group of adolescents with a mentally ill parent, one group with a substance-abusing parent, and one group in which the participants had a parent suffering from cancer (in fact, all of them had lost their parent to cancer). Irrespective of whether the adolescents had parents with different problems and experienced different burdens because of the parental illness, they had common challenges on which we focused in the analysis. All interviews were led by the same researcher, using an interview guide as a reminder of the themes to discuss. Thus, the foundations were laid for obtaining data from each interview in the same manner. Not only did we acquire data on the same themes [114], but also on themes we did not in advance realize were relevant. In the interviews, we paid particular attention to creating a friendly atmosphere, and we attempted to avoid the use of leading questions, to which young persons are especially vulnerable [105]. Before beginning the study, we were already aware that children and adolescents with an ill parent often find it difficult to talk about the illness, both with the parent and with others [39,117,118]. This is particularly apparent with regard to mental illness and substance-abuse problems. Children in these families often do not feel comfortable talking about the issues to others outside the family, due to shame and stigma [119]. However, the fact

that they were interviewed in group settings, in which they already knew each other and were familiar with talking about these topics, might have moderated this effect. In order to obtain further information on this sensitive topic, individual interviews might have been useful. It may be easier to share sensitive matters with one person, as long as this person is trusted [103,105]. In our interviews, we obtained rather sparse information relating to concrete somatic complaints and issues that were potentially relevant to these children, such as their thoughts on the heredity of illness. However, with this exception, we obtained rich material relating to these adolescents' everyday life and their experiences with healthcare. We therefore determined that the material had sufficient information power for our purpose. In addition, the rapport between us and the participants appeared to be good; the mutual understanding, or intersubjectivity, seemed fairly good.

In the *Parent study*, the participants were recruited by their GPs. These GPs were in our extended network, and included those participating in the GP-study. In this manner, we expected patients who were familiar with their GP to be included, meaning that there was a good chance of obtaining rich material with numerous experiences. We had expected most participants to have a good relationship with their GPs, and that the interviews would provide less information about adverse GP experiences. We used individual semi-structured interviews for data collection.

All participants gave relevant, comparable data that fitted with the data obtained from the other parents interviewed. An interview guide was used to ensure that the same topics, relevant to the study aims, were explored in every interview. However, we found that the guide was sufficiently flexible as to allow for the discussion of relevant topics that we had not been aware of in advance. A GP as the interviewer might have influenced the information they gave about the healthcare system, particularly GPs [120], avoiding adverse experiences. Nevertheless, they provided much relevant information as our focus was how the GP could help their children [104]. The participants seemed relaxed during the interviews, and although the topics sometimes evoked emotions and they had to take a break, they all evaluated the interviews as a good experience in the end. Maybe my background as a GP who frequently have

sensitive talks with my patient, created a secure atmosphere? I therefore evaluate the intersubjectivity between me and the participants as fairly good.

The results of a qualitative study rely also on the type of data analysis that is conducted. We used a thematic cross-case analysis to analyze our empirical data. In the first interview, we used thematic content analysis, as described by Braun and Clarke [110], and in the other two, we used systematic text condensation, as described by Malterud [102]. Other methods are also appropriate for cross-case analysis of qualitative data, such as Grounded Theory. However, the latter focuses more on developing new theories and models [103,105], and, as the goal of our study was more to develop descriptions, we found that method less useful. Narrative analysis [103] might have been a relevant method, particularly in the GP study, whereby the GPs shared numerous previous practice experiences. Since the aim was to explore the GPs actions toward helping families and children as next of kin, and we condensed information from several participants, we found that a cross-case analysis was the most useful. During the analysis, we sought to ascertain commonalities relating to GPs' possibilities of helping children with a parent with mental illness, substance abuse, or severe somatic illness. There are obvious differences between these groups, in terms of needs and challenges, which were not addressed in our studies as indicated in the start of this subsection.

5.1.2 External validity/transferability

External validity addresses the extent to which the results of a study are relevant in settings beyond the study context [104]. The concept of external validity or transferability is connected to the samples giving empirical data to the studies. In the Child and Parent studies, we ultimately had a convenience sample, with less variation concerning important participant qualities.

In this subsection, I will discuss the possible relevance of our results in settings outside the study context, particular in GPs' consultations with ill parents and their children, and clarify the limitations of the results that arose from the sampling difficulties.

In the *GP study*, we used purposive sampling of participants who had different experiences, but who simultaneously had sufficient knowledge of children as next of kin; therefore, we attempted to balance the shared backgrounds and diverse experiences [106]. We interviewed GPs from the west of Norway, but I assume that GPs from other parts of the country share the same experiences.

In the *Child study*, we had difficulties recruiting participants, meaning that we ultimately recruited a convenience sample. All of the participants had joined established support groups for adolescents with ill parents. For various reasons, they had all been identified as children as next of kin in need of support, and had been given the opportunity to join a group. In addition, they were willing to participate in our study; maybe they were particularly interested in the topic. This might have affected their opinions, especially with regard to the benefit they gain from support groups. Only a minority of the adolescents in the target group take part in support group; therefore, the results of this study may not be applicable to all children of ill parents. However, the adolescents interviewed related experiences of their daily life and of support they had received before joining the group. Their descriptions of their everyday lives may be transferable to many adolescents in similar situations, but they probably had more experiences of the support services than do children as next of kin in general. All groups were concentrated in urban parts of Norway, although some of the participants lived in districts that are more rural. Adolescents and children living far from the big cities in Norway do not have the same opportunities to join support groups. Therefore, rural children/adolescents might have experiences and challenges that we did not capture in this study. Most participants were girls, only three boys participated. The boys often confirmed the girls' statements in the interviews, and there were few gender disagreements. However, boys might have specific experiences that were not captured in our interviews. I have presented the results and discussion in terms of children in general although most participants were girls. The fact that gender fundamentally and pervasively organizes the life worlds of not only girls and boys, but also their ill or substance abusing parents and their GPs, suggest that gender might have been an interesting angle in the project. I have chosen to specifically look at common features regarding children as next of kin, and have not utilized gender as an

analytic approach. The results of this study must be generalized with particular caution to more rural settings and to gender aspects.

In the *Parent study*, we interviewed parents with a variety of illnesses. Unfortunately, it was difficult to recruit participants for this study. We do not know if this was because the GP did not ask their patients, or deliver the relevant information, or if it was because the patients did not return consent letters. In addition, we do not know how many of those patients who were invited by the GPs actually agreed to take part. Most of the participants were women with mental illness. The provision of different instructions to the recruiting GPs, whereby every GP was asked to recruit one particular group of participants, could have resulted in a more varied sample. However, given the recruitment problem we experienced, such a strategy would likely have made recruitment even more difficult. Eight participants had mental illness, two had substance abuse, and four had somatic disease (one participant had a combination of mental illness and substance abuse and one participant had a combination of somatic disease and mental illness). Few participants had substance abuse, and the results must be generalized with great caution to that group. In addition, we interviewed few ill fathers, so our results may not give an accurate picture of this group's situation.

In these studies, we have investigated how children having ill parents can receive help from their GP. Children with other unfavorable experiences during childhood may have similar challenges. Our results may to some extent be relevant in those settings as well, for instance when a parent is in prison, sudden death of a parent, children experiencing conflicting divorces, children living in poverty etc. Also for these groups of children issues of balancing needs towards adverse experiences, might constitute serious challenges.

5.1.3 Reflexivity

All research is influenced by the researcher conducting the study. Both personal and professional experiences and preferences may have an impact on choice of aim and method, during the collection of data and in the analysis. The researcher cannot avoid

this, but must conduct a continuous self-reflection on how personal matters may influence the research process [103,121,122]. As an experienced GP, specialist in general practice and with 15 years as practicing GP, I have an extensive knowledge of Norwegian general practice. I have met numerous patients, and I have gradually got to know many families. My own experiences, often aware of shortcomings, and frequently with concerns for burdened families, contributed to my decision to join this research project. I am familiar with the patient-centred consultation model, and know from experience that a long-term relationship with continuity of care can open the door to the discussion of sensitive topics during consultations [87]. With this knowledge and experience, I entered the research position. This may have been both a strength and a limitation: my experience meant that I was more capable of understanding the situations the GPs described in the interviews, and made it easier to generate follow-up questions; however, there is a risk of having preconceived ideas in such situations, and of not paying attention to new perspectives or knowledge [104].

There will always be a power-imbalance in research interviews, where the researcher asks the questions and leads the discussion [105,123]. It is important that the participants obtain sufficient information regarding the purpose of the study and their role in the interview. As explained, we provided all of the participants with written information, and we also gave a short introduction at the beginning of each interview, to ensure that all of them understood the setting.

The challenges of being a GP, exploring the GP's position to help via interviews, was borne in mind throughout the entire research process [103,120], while creating the interview guide, performing the interviews and during the analysis of the material. We purposely had a multidisciplinary research group and research network. In addition to academics with a general practice background, the group and network included academics with experiences in preventive psychology, child and adolescent psychiatry, and child protection services. These people were involved at all levels of the research process to ensure broad, but relevant, perspectives, and to guard against professional and personal preferences and prejudices. The same researcher, me, carried out the interviews in all studies, which may be viewed as problematic in that the researcher is

biased, but which could also be considered an advantage. This makes possible a continuous checking of relevance – bearing in mind information from the other groups. It can be expected that the influence of the “researcher-as-instrument” [124] will be the same in all interviews. Two to three individual researchers, to support each other and to gain a more critical evaluation [104,121], were engaged in the start of the analysis, and were invited to take part with comments and discussions throughout the further process.

5.1.4 Ethical considerations

According to Brinkmann and Kvale, ethical consideration must be given throughout the entire research process [105]. They hold that, in particular, attention should be paid to four items; informed consent, confidentiality, consequences, and the role of the researcher.

Informed consent: All participants signed a form whereby they agreed to participate and agreed to publication of the results. We attempted to make the text in the information letter easy to read, avoiding medical language, to ensure that the participants understood it. At the beginning of the interviews, the participants were again informed of the purpose of the study and the interview procedure, and they were given an opportunity to clarify questions. They were informed that they could withdraw from the interview at any time, without any questions or consequences.

Confidentiality: The participants were ensured that the results would be anonymized such that their confidentiality was assured. In the GP study, the participants were asked to relate experiences from practice, whereby they had been a doctor for an ill parent. The experiences were related without names, so that no patient could be identified. All participants agreed on keeping the patient stories in the group. The participants also shared personal meanings, reflections and experiences on their own behalf, and the agreed-upon confidentiality included this. In the two focus-group studies, we emphasized the shared responsibility of maintaining confidentiality of the content of the interviews. During transcription of the interviews from all sub studies, we gave the participants numbers instead of names when referring to them, to ensure

confidentiality. In addition, any references to third persons were carefully scrutinized and rephrased to secure anonymity for these third parties.

Consequences: When performing a qualitative interview study, the researcher often gets close to the participants, and when discussing sensitive themes, as in the present study, there is a risk of stressful emotional reactions [108]. This was particularly relevant to the Child study and the Parent study.

When conducting research on children and adolescents, particular attention to ethics is required [125]. The present study also involved a sensitive theme; how the illness of a parent may affect the daily life of their children. Thorough consideration prior to the interviews contributed to the decision to interview the children in groups. Inviting established support groups for children as next of kin meant that the adolescents were familiar with talking about the challenges of parental illness. However, it was possible that our focus group interview could have evoked feelings regarding, and reflections on, their life situation. In order to ensure available support afterwards, we arranged for the local group leader to be present through the entire focus-group interview.

In the Parent study with individual interviews, I aimed at paying particular attention to the participants, trying to balance the depth of questioning according to their reactions and willingness to share. Individual interviews about the themes in these interviews may evoke painful emotions such as shame and uneasiness. None of the participants wanted to end the interview, although they needed breaks throughout.

Recruitment to the Parent study was carried out via GPs in our network and in the surrounding areas. In knowing us, some GPs might have felt pressure to recruit potential participants. It is also possible that some participants felt that they should participate because their own doctor asked them to help a colleague; however, they had been told that the GP would receive no feedback from us if they did not want to participate (see Appendix 3).

The role of the researcher: As a researcher, you might be in a position of power over the interview subject, and, if not conscious of this, you can push someone to share

more of their experiences and thoughts than he/she wants, thus entering a patient's private zone. I was aware of this during the interviews, and attempted to avoid it. In addition, before the interviews, the participants were given information regarding their rights to share only what they wanted to. They were also informed that they could withdraw any information given. All interviews were performed by an experienced GP. In addition, MH, a child and adolescent psychiatrist, participated in the GP study and in the Child study. In some of the focus group interviews with adolescents another GP, TSS, also participated. Setting aside our usual role as a doctor and helper in favor of being a neutral and safeguarding researcher was challenging, and we had to remind ourselves of this change in role during the interviews. This possibility to confuse roles was specially challenging, both for participants and interviewer in the individual interviews with the parents.

5.2 Discussion of results

5.2.1 Summary of results

These three studies enabled us to ascertain that GPs are in a position to identify and ensure help for children as next of kin, but that they frequently did not manage to do so (GP study). The adolescents and the parents wanted to be recognized as ordinary young people and competent parents, respectively. However, they also described stressful life situations in which they needed advice and support. They welcomed the GP to explore the family situation during consultations, and to ensure relevant support for the children if required (Child and Parent study). The GPs' participation in collaboration with other healthcare professionals appeared to ensure the best total care for the families and children with the greatest burdens (Parent study).

5.2.2 Children of ill parents – a group with both common and diverse hallmarks

During this research process, we faced questions from fellow researchers and reviewers as to whether it is appropriate to treat substance abuse, psychiatry, and severe somatic illness in parents as one group, when wanting to address their children's possible problems and risks, as we did in our studies. In this subsection, I will discuss this in relation to our results and to evidence from published research.

In the Child study, we found that the adolescents with ill and substance-abusing parents all had a daily life that was permeated by uncertainty and stress. The same has been found in other studies, for example, in a Dutch study of children with parents with mental illness [22], as well as in studies of children of parents with cancer or substance abuse [46,126,127]. In the Parent study, we found that many GPs did not pay attention to their patient's children, meaning that many needs were probably not met. In an interview study conducted in Iceland, Bjorvinsdottir [61] described the same phenomenon among children with a parent with multiple sclerosis. In an interview study conducted in adults with an alcoholic parent [58], Werner and Malterud described how these individuals had unmet needs that had not been recognized during their childhood. This allows us to see that children of parents facing different problems experience the same challenge of being overlooked and having unmet needs. Another common challenge across different parental illnesses is that some of the children have extensive caring burdens in taking responsibility for their parents, siblings, and the household [13,34,61,128]. The same increased level of caregiving and stress has been found in studies conducted in children of parents with different illnesses [13,129]. In a 2015 Australian study, no difference was found in these extra caring burdens, irrespective of whether the parent suffered from substance abuse, mental illness, or somatic disease [13].

In studies of different parental difficulties, many children and adolescents have expressed a need for more information about their parents' conditions [71,130]. The identified lack and importance of age-appropriate information about parental illness has been found in other qualitative studies conducted in adolescents with mentally ill

parents [39] and in children with a parent suffering from cancer [118]. We found the same in our Child study. The adolescents often talked about how more information about their parent's illness and prognosis might have stopped them from worrying so much, and stated that they would appreciate the opportunity of someone with whom to talk about the problems at home. In a 2016 Norwegian study, Werner [131] found that adults who had grown up with alcohol-abusing parents did not have opportunities to talk about the problems at home in consultations with healthcare professionals. These results are in accordance with those of our Parent study, whereby the participants were aware of their children's information needs and wished that they could be offered someone with whom to talk. In a review, Gladstone et al [33] found that children with mentally ill parents were often aware that something was wrong with their parent, even if the parent had attempted to hide their illness-related problems. This finding parallels the results of our Child study, and also those of a qualitative study by Trondsen [39], whereby adolescents stated that they had detected mood changes in a parent long before they were informed of his or her mental illness. Antonovsky developed a theory regarding sense of coherence [132], and found that an understanding of why adversities are happening around you may help you to view them as meaningful in the actual context. This understanding of meaningfulness promotes improved health and resilience, underpinning the importance of ensuring that children have information about their parent's illness, and the significance of an opportunity to talk about the problem, irrespective of parental problems.

The adolescents we interviewed in the Child study also expressed a need to be viewed as ordinary, like other adolescents, and they strived to find a balance between their own needs and the influence of their parent's illness. A Norwegian study of children of parents with alcohol problems [58] revealed similar findings, and parallel results were also found in a qualitative study of children with mentally ill parents [133].

In addition to common difficulties for children facing different parental problems, there are common factors that may reduce the risks. Various studies, both on parents ill with cancer [68,118] and children exposed to adverse childhood experiences [5], have found that positive family functioning, with open, friendly communication, can be

protective with regard to children's own mental health. This was also found in an interview study, whereby 50 children in families with parental alcohol abuse were asked about their views of resilience [134]. It has been found that a support network outside the family and participation in leisure activities are also protective for children with parents having different problems [15,46,76]. This is in accordance with our findings in the Child study.

As described, there are many common challenges and risk factors, protective factors, and needs across different parental illnesses. However, parents with the same diagnosis may have different parental abilities, and children growing up with the same illnesses in the family may have very different living conditions and outcomes [31,67,69]. It appears that the risk these children face is a consequence of unfavorable environmental factors to a great extent, but genetic vulnerability may also play a role [34,135,136]. Children in other circumstances may have similar challenges in their childhood to children with an ill parent. For example, children with parents in major conflicts or children with imprisoned parents, children experiencing sudden death in the family, children with ill siblings, or children living in poverty. As mentioned in the introduction, the comprehensive ACE study [2] investigated different negative childhood experiences, and found a graded relationship between exposure to these experiences and risk of poor health as adults. A Norwegian study also found that a self-reported difficult childhood presented a risk of poor health later in life [4]. This supports the theory that unfortunate childhood conditions, both as a result of parental illness and of other reasons, is a common risk factor with regard to children developing their own problems.

What is the relevance of these common hallmarks for the GP? Due to the prevalence of severe somatic disease, mental illness, and substance abuse in parents caring for children, a GP does not see many of these families every week. An important factor for the wellbeing of all children in these families is good developmental conditions in their childhood and the parent's ability to ensure these. Meeting parents with the same attitude, recognizing their ambitions to be good parents, and possessing knowledge of relevant, common challenges and needs for these families may be valuable. Similarly,

it may be valuable to meet adolescents (or children) growing up in families with an ill parent when understanding their wishes to be ordinary and treated in the same way as their peers, and knowing that they may have burdens related to the parent's function. On this basis, a GP can explore their individual challenges and suggest measures based on every family's needs. Having a common approach toward these different parental problems may be a starting point with regard to giving attention to these vulnerable children.

5.2.3 What opportunities does a GP have, within the frames of general practice, to make a difference for these children?

Irrespective of all the knowledge of the health risks faced by children with ill parents, few studies have described the GP's role toward children as next of kin [101,137]. In the GP study, the GPs described numerous experiences of ill parents they had met, where they had seen children in need of follow-up, but had missed the opportunities to act.

The time frame in general practice represent a challenge in terms of which subjects to be explored in each consultation. Most GPs in Norway work in clinics or health centers, receiving a new patient every 15th or 20th minute. General practice has a holistic ideology, attempting to meet the patients as whole persons, and not treating only a single medical problem [78]. However, these time constraints in the consultations are a barrier to how much it is possible to explore at one time, and require the GP and the patient to prioritize. This can make it difficult to explore the children's situations in the family, whether it is the ill parent or a child/adolescent who is presenting. An advantage for GPs is that they often have a long-lasting relationship with their patients, and it is possible to explore these subjects through a series of consultations, given a situation in which they are aware that the children are not in danger of serious maltreatment. The continuity of care can compensate for the time constraints associated with single consultations [138]. Another barrier to exploring the children's situation is the worries the doctor may feel with regard to adding extra

burdens to the struggling patient. Therefore, they sometimes avoid addressing their children's situation. This avoidance has also been observed in other contexts, for example, in the psychiatric ward [131,139,140], and is a reason why many children are not paid any attention. This may be a more universal challenge, and connected to cultural taboos [131]. Doctors, like the rest of the population, have barriers with regard to discussing sensitive, stigmatizing matters. However, professionals do not fulfil their obligations, both ethically and legally, if they do not explore these themes [18].

In the GP study, some GPs problematized the limited information they may have about their patients' everyday lives. They stated that they only had a peephole into their reality when they meet a patient for a short consultation in their office. The patient can omit to relate difficulties and unfortunate situations for their children. Without other input, the GP must rely on what the patient says. Some of the participants in our GP study who worked in rural areas told us that they could observe these children in different settings in the community, for example, at the football ground, at social arenas in the community, or at school. They stated that they had a good overview of these families, from which they assessed the situation for the children. However, it may have been that these GPs did not recognize important things that were happening, if they saw, for example, a child's enthusiasm at joining the local football team, and from that concluded that the child was okay. Home visits [141,142] may be a better way of exploring the environment in which the children grow up, but it is time-consuming, and only used infrequently in a Norwegian GP practice.

The patient list system ensures continuity of care and promotes good knowledge between patient and doctor. If all members of a family are on the same doctor's list, this system will promote knowledge of the entire family over time. However, if the family members are enlisted with different GPs, the list system may represent a barrier to seeing the entire family. When the parents do not live together, they frequently have different GPs. If the child of an ill parent is on another doctor's list, this may mean that the ill parent's GP does not feel responsible for the child, and the child's GP is not aware that the child has an ill parent. Therefore, he or she may not be identified as a child as next of kin. In the Norwegian Regulations on patient records [19], a paragraph

states that information about patients' children should be noted in their record if the illness might affect their parenting abilities. Similarly, there is a paragraph stating that information about a parent's illness should be noted in the children's records if the illness might affect parenting. If these notes are made in the files, it will be easier to remember the children's situations when in contact with both ill parents and the children or adolescents.

The participants in the GP study stated that they often cooperated with other professionals in the healthcare system to support children as next of kin. This was viewed as an effective way of giving help and sharing information. In the Parent study, some participants appreciated the fact that the GP took part in multidisciplinary meetings, as it meant that he/she was then fully aware of their family situation. A study of children of parents with MS [143] reached a similar conclusion and recommended greater cooperation between healthcare actors in primary care. In the 2011, World Psychiatric Association guidance relating to severe mental illness in parents [31], the importance of collaboration between different services supporting the families was highlighted, as was pre-birth in situations involving severe mentally ill mothers. It is important to have knowledge of the extended healthcare system, including local services, such as support groups or similar, as this gives the GP a better opportunity to provide advice or referrals. It may also make it easier for the GP to raise the subject of children as next of kin, as he or she knows where to seek help if required. When a child as next of kin needs follow-up, other professionals can frequently offer support and the GP needs to know on whom they can rely.

5.2.4 The consultation- the point of departure

Most GPs in Norway meet their patients for consultations at their office. How can the GP use these meetings to assess the situation and initiate help for children of struggling parents? Our studies enabled us to identify some relevant factors in the consultations between the GP and ill parents or adolescents that could help both of these groups to accept an invitation from the GP to talk about the difficulties at home.

Capturing the dual stories

Both in the Parent study and in the Child study, the participants described the ambivalent situations in which they lived. The parents wanted to be acknowledged as being caring and responsible, and striving to make an ordinary everyday life for their children. In our Parent study, we found that being a good parent was important for their identity and self-respect, due to the feelings of normality and social belonging that it engendered. However, they simultaneously revealed worries about their children and their need for help with regard to giving them adequate information and support. It may be important for the GP to first acknowledge their intentions and efforts to be good parents, after which it may be appropriate to open up a discussion of their worries or needs concerning their children. In order to reach a position to obtain the entire stories, the GP must be aware that there may be a story with two sides to capture, and not focus only on the first spontaneous description of a well-functioning everyday life. In that manner, the doctor will arrive at a better overview of the family's entire situation, and be in a better position to help. A 2011 Norwegian study found that doctors rarely addressed the personal aspects of a patient's condition in consultations at a hospital setting [144], so we can observe this challenge to explore different aspects of a person's illness at various levels in the health system.

The adolescents in the Child study wanted to be treated as ordinary youths, but they also wanted to be recognized as part of a family with burdens. They stated that they did not often see the doctor, and when they did, it was primarily for somatic complaints. These same trends have been observed in other studies of struggling adolescents [145-147]. For the adolescents, it was difficult to discuss the home situation with the doctor, and the GP had to take the initiative with regard to whether it should be discussed. This is in accordance with the results of an Australian study [145], in which, although youths expressed a willingness to talk about sensitive topics with their doctor, they had to be prompted to do so [145,148]. A study from Norway [149] found that busy GPs give less priority to adolescents. This can lead to delay and less experience on the topic from the GP. Thus, young people are at risk of not being seen for various reasons. It may therefore be useful to conduct an assessment of the home situation as a natural part of the assessment of an adolescent's complaints.

The Importance of trust

In both the Parent and the Child studies, the participants welcomed the GP to discuss their situation at home. The parents were recruited by their GP and appeared to have a relationship of trust with them; other studies have shown that trust is an important prerequisite for sharing sensitive topics in consultations [150,151]. As described by Skirbekk et al [93], the patient gives the doctor a mandate of trust, and if the situation for the children is to be explored in consultations with ill parents, the parent must give the GP a mandate of trust that is sufficiently wide as to include an exploration of that topic. Trust is often not explicitly stated [94], and it can be difficult for the GP to know how wide the mandate is. There might be a mismatch between what the GP thinks the parent would tolerate in a discussion of how their illness affects their children and what the parent actually wants. One option for the GP is to take a chance and ask if it is okay to talk about the patient's children [94]. The parent then either agrees or disagrees, and the topic is mentioned in a nonintrusive way. It has been found that parents with mental illness, or living in adverse conditions, do not seek help for parenting because they are afraid of being judged as bad parents, or may have concerns about custody [152,153]. In order for a parent to open up to a discussion of parenting, he or she must trust the GP, and the GP must address the topic with due respect. Adolescents are particularly concerned about confidentiality and trust [154]. In order for a GP to develop an attitude of recognition, it may be helpful to explore the subject in a sensitive and trusting atmosphere. Many of the GPs interviewed in the GP study were scared to explore the subject, as they were afraid that the alliance might be disrupted. This fear may be overestimated, weighted against what the interviewed children and parents expressed.

The patient-centred consultation model – a useful tool

In the patient-centred consultation model [85], the physician works with two parallel agendas. He or she seeks to understand the patient's expectations, background, and feelings, and, in negotiation with the patient try to combine this with the results of his/her examination and general knowledge of illnesses and contexts to assess differential diagnoses or explanations of symptoms and problems. In meetings with ill parents, it may thus be useful to bear in mind this knowledge of common parenting

challenges and children's needs across different parental problems. GPs often use their experience and general knowledge in the assessment of patients, as described in a Danish study [155], in which GPs stated that they could identify children undergoing emotional stress by using their experience and a sense of "this is not normal".

However, in the actual meetings, the GP should treat every presenting patient as an individual, and consider everyone with an open-minded, listening attitude, without preconditions, and attempt to identify measures that are based on this family's special needs.

In the patient-centred consultation model, the patient sets the agenda for the consultation, and in order to introduce another topic, agreement must be reached with the patient. In a relationship of trust, this can be done in a caring and supportive manner, encouraging ill parents to discuss challenges in daily life. Thus, according to what is described above, the patient-centred consultation model can be a very good tool to use when meeting with ill parents, in order to explore the situation for their children. Similarly, it can also be effective when discussing daily stressors with adolescents leading difficult lives.

6. Conclusion

The children of parents with illness and substance-abuse issues may be at risk of distress in daily life, and of health and social problems during childhood and later in life. It is important for health and social services, including GPs, to make steps to prevent this transgenerational transmission of problems by ensuring support for these children and their families.

This study revealed numerous opportunities for a GP to identify and help children as next of kin, on certain premises and within certain limitations. Within a relationship of trust, the sensitive topic of how a parental illness might affect the children in the family can be discussed, and a GP can provide support and advice both to adolescents and to parents, based on the needs identified. One important factor in achieving this relationship appears to be to recognize the parents' genuine intentions to make a good life for their children, and the children and adolescents' need to be evaluated as ordinary youths in a challenging life situation.

Parental problems represent challenges for children, and difficulties in maintaining parenting with sufficient developmental support appears to be a recurring factor in different settings. Some parents can manage this, if necessary, after receiving advice on how to do so. Some children need support from outside the family. When assessing families and children in need of support, maybe it is most appropriate for the GP to identify and explore the overall parenting abilities in the consultations with these parents. The impact on the parental abilities appears to be more important for the evaluation of the child's situation than for the specific diagnosis.

In order to advance a change for the better for the children and their families, the GP must know relevant professionals and services available, in order to share roles and responsibilities. This often means that she/he must take part in multidisciplinary networks that are based around the child and their family.

7. Further research

This research has raised at least three appropriate questions for future investigation.

- The adolescents' health worries and health complaints were not fully explored in this study. To elaborate further, a study using individual interviews with adolescents could be useful.
- From our extended research project, we have planned to develop advices and tools for GPs in their work with children as next of kin. Implementation research on these tools could give us knowledge whether these measures could make a difference for children as next of kin.
- The GPs view health nurses as an important resource and support in helping children as next of kin. We know that the interaction between health professionals at the municipality level is less than wanted. How is this cooperation working with regard to children as next of kin? Can it be improved?

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Papers

Paper I

I



ORIGINAL ARTICLE

To give the invisible child priority: Children as next of kin in general practice

A qualitative study among general practitioners

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Abstract

Objective. To explore general practitioners' (GPs') experiences in helping children as next of kin of drug-addicted, mentally ill, or severely somatic ill adults. These children are at risk of long-term mental and somatic health problems. **Design.** Qualitative focus-group study. **Setting.** Focus-group interviews were conducted in western Norway with a total of 27 GPs. Participants were encouraged to share stories from clinical encounters with parents who had one of the above-mentioned problems and to discuss the GP's role in relation to helping the patients' children. **Results.** The GPs brought up many examples of how they could aid children as next of kin, including identifying children at risk, counselling the parents, and taking part in collaboration with other healthcare professionals and social workers. They also experienced some barriers in fulfilling their potential. There were time constraints, the GPs had their main focus on the patient present in a consultation, and the child was often outside the attention of the doctors, or the GPs could be afraid of hurting or losing their vulnerable patients, thus avoiding bringing up the patients' children as a subject for discussion. **Conclusions.** Norwegian GPs are in a good position to help children as next of kin and doctors make a great effort to support many of them. Still, support of these children by GPs often seems to depend not on careful consideration of what is best for the patient and the child in the long run, but more on short-term convenience reasons.

Key Words: Child of impaired parent, children as next of kin, disease prevention, family health, focus group, general practice, general practitioner, health promotion, Norway, qualitative research

Introduction

Children whose parents are suffering from mental illness, substance abuse, or severe somatic disease are at risk of developing psychosocial problems, psychiatric diseases, and somatic diseases [1–3]. Several reports have addressed these children's special needs [4–8]. In order to secure their rights, new law paragraphs were launched in Norway on 1 January 2010 [9]. According to these laws, healthcare personnel treating patients in one of the aforementioned three groups should enquire whether they have children younger than 18 years of age, and make the necessary effort to ensure that the children receive adequate information and follow-up [9,10]. It is challenging

for healthcare professionals to include the children while treating the parents [11].

According to a report from 2011, 115 000 children in Norway, or 10%, live with one or both parents with severe mental illnesses and 30 000 or 3% with one or both parents with severe substance abuse [7]. Some 15 000 children or 1% have a parent or sibling with cancer, or live with grief after the death of close family members [6]. Norway has a registered list system for general practice, and almost all inhabitants are listed [12]. On a standard general practitioner (GP) list of 1200 persons, there are approximately 39 children with these kinds of burdens.

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Children whose parents are suffering from mental health illness, substance abuse, or severe somatic disease are at risk of developing poor health and psychosocial problems. Meeting their special needs is important for health promotion and disease prevention.

- GPs are in a good position to identify children as next of kin, support parents in their parenting role, and take part in the multidisciplinary network.
- Lack of time and capacity problems are barriers for GPs in fulfilling this potential.
- GPs' fear of jeopardizing the relationship with their patients represents an important barrier to introducing the children's situation in consultations with the parents.

According to McWhinney, to succeed in building a relationship with the parents in order to meet the individual's and his/her child's needs, communication ought to be patient-centred [13]. The patient-centred approach has been shown in several studies to enhance communication between patient and doctor [14,15], and the method is taught to medical students in all Norwegian medical schools.

GPs are potentially in a unique position to identify at-risk children and to ensure that they are adequately followed up, either in their own practice or by referring them to relevant health personnel and the child welfare system in the community. Despite this opportunity, little is known about how GPs can contribute to this important aspect of preventive care. This study explores GPs' thoughts and experiences with handling the special needs of these children in general practice.

Material and methods

A qualitative approach was chosen because we wanted to explore the participants' thoughts and

experiences. The scope of the question is rather narrow and focused, and therefore focus-group discussions were chosen as the method for collecting data [16]. The potential of the group interview is to create a situation where the informants discuss the topics between them and in that way open up to new knowledge.

Data collection

Participants. We wanted to elicit the experiences of GPs with a certain amount of exposure to the research topic. One inclusion criterion was that the GP should have had at least five years in general practice. We invited established continuing medical education groups of GPs in western Norway by mail to the interviews. The four invited groups, a total of 27 GPs (Table I), all agreed to participate. We wanted a strategic sample [17] of informants with respect to gender and rural vs. urban practices.

Method

Focus groups. Group members were encouraged to bring their own stories of clinical encounters with parents who had mental illness, substance abuse, or severe somatic disease. The discussions were led by the first author (FG) with the last author (MH) as a moderator.

The interviews were conducted from February to June 2011, each lasting approximately 90 minutes. During the fourth interview, few new themes were brought up, and we concluded that we had sufficient material for satisfactory analysis.

The main topics for the focus groups included the following:

1. The sharing of thoughts related to actual cases the GPs had been involved in.
2. Experiences regarding talking to parents in the target groups about how their illness might affect their children.

Table I. Overview of the informants.

	Group 1 (Urban)	Group 2 (Rural)	Group 3 (Urban)	Group 4 (Rural)	Total
Number of informants	5	5	9	8	27
Men/women	5/0	4/1	9/0	0/8	18/9
Age (years)					
Mean	56	56	58	46	54
Range	53–60	51–63	52–65	38–55	38–65
Time in general practice (years)					
Mean	21	26	26	14	22
Range	11–33	24–28	15–30	6–25	6–33

3. Experiences regarding talking to children about their parents' health problems.
4. With whom did they collaborate regarding children at risk?

The informants knew each other well and engaged in the discussions of the stories and the questions with reflections, associations, and opinions.

Analysis

The four focus-group interviews were audio-recorded and transcribed by FG. To manage the data, NVivo9 computer software was used. The material included reflections and case stories. There were seven stories concerning parental problems of abuse, 15 about somatic disease, and 23 about psychiatric disease.

We used thematic analysis [18] to elaborate our results through the following steps:

1. We read through the whole material, obtaining an overview.
2. We identified aspects in the data relevant to the study and coded for relevant patterns or themes.
3. The codes from phase 2 were sorted and condensed into more overarching themes.
4. These themes were reviewed, refined, and validated in relation to the whole data set.
5. Lastly, we defined and decided on the final themes.

The analysis was done in ongoing discussions with the members of our research group, other researcher networks, and GPs with field competence by presenting preliminary results in meetings and courses. This was done to find alternative interpretations of the data and validate our results so far [19,20].

Results

Two major themes emerged through our analysis:

- Opportunities: what GPs said they could do to help children as next of kin.
- Barriers: what the GPs said were limitations in helping children as next of kin.

Opportunities

Identifying children at risk. Some of the GPs, especially those working in small communities, described how well they knew the family, how they might be familiar with the extended family and social

networks, and how they used this information to evaluate whether or not the children were at risk:

“As a doctor in rural districts, you know how many kids your patients have. You know how old they are, you know who their friends are and you know their grandparents. You also know which sports teams they belong to. You get a good overview of the entire family when you’ve worked a few years.”

Other GPs pointed out how their knowledge about the child was restricted to what the adult told them in a consultation. Many significant things might happen in a child’s everyday life that the GP does not know, including troublesome conditions in the child’s environment:

“You may not know how people are when they’re not in your office. There they are in a fairly solemn location, and they behave nicely like they’ve learned. We can’t see deviant behaviour, that is easy to hide from a GP.”

The informants said that it was easier to become aware of the children during house calls. Home visits were most often performed when the problem was severe somatic disease or sudden death. They also stated that the threshold for remembering the children’s condition often was lower when they worked in preventive health services for children and adolescents.

The GP could be in a good position to identify children at risk, but awareness of the children largely depended on the conditions the GP worked under. Awareness seemed to be easier for those working in small communities, who do house calls, and who work together with health visitors.

Supporting the patients in the parenting role. The informants stated that generally they informed and advised either the parent with problems and/or the healthy parent on how to talk to their children and help them. They spoke to a lesser extent with the children themselves and some wanted more education and tools to make conversations with children easier. Some described following up on teenagers with an individual talk. Several informants actively called on families during acute crises, such as sudden death, and could then also speak with the children. One GP spoke of her role in the case of a drug-abusive father’s death due to an overdose:

“The mother had asked me for advice on how to inform her son about the father’s drug problem. She had told her son that this was an illness and a drug abuse problem, and then the

father died of an overdose. Afterwards I gave advice on how to tell the son about the death and why it happened. Naturally, I also visited their home a few times after he died and talked with the little 7–8-year-old boy. It was not easy!”

Many of our informants expressed confidence in relation to informing and advising parents, but they were more uncertain about talking directly to the children.

Multidisciplinary collaboration. Most of the GPs recounted how they took part in multidisciplinary meetings in addition to much informal local cooperation regarding patients. In meetings concerning children the doctors said they sometimes had an important role as the parents’ supporter. Several spoke about well-functioning division of tasks, especially with health visitors and GP colleagues. From the same example above, death due to overdose:

“In this case, too, we had good support from the school nurse. After the father died, she came to the school and informed the class, and afterwards she followed up the son and some of his friends. Hence, the role of the school nurse is vital.”

By collaborating with other health professionals, the GPs could help children as next of kin. Some of the informants, however, said that they were seldom involved in inter-disciplinary cooperation, and some spoke about negative experiences, in particular with the child welfare services.

Barriers

Lack of time and capacity – barriers within the framework of the consultation. Most of the informants worked in busy general practices with brief consultations, and they saw most of their patients in the doctor’s office. Many of the GPs described it as difficult to bring in the children’s situation and their legal rights within the framework of an ordinary consultation. It was usually the patient who introduced the subject of the consultation, and the possibility for the GPs to bring in other topics was perceived as limited. The informants spoke about time and capacity limits, as illustrated here:

“In that family there were children who were affected by the father’s alcohol abuse, but how I could help the children I could not imagine. I spent plenty of hours with that man, long consultations every week about his problems.

This theme, to see and help the patient’s children, gets lost in all other things we have to do.”

Some also stated that they purposely omitted addressing the children’s situation because they were afraid of being left with too much work on their hands that they did not know how to handle. The doctor’s feeling of responsibility for the actual children was often unclear because the family members might be on the lists of various GPs.

FG: “Does the general practitioner already have so many tasks that this becomes difficult to handle during the workday?”

GP: “I think that’s a good point, especially in a situation where the rest of the family is not on your list. Then you think there are other people involved who will take care of them. This can be people you don’t know and whom you have never seen.”

In some of the stories the GPs mentioned informal contact between colleagues concerning the target families, but in many cases it was evident that no GP actually took responsibility for the child at risk.

The frameworks within general practice in terms of consultations and the list system can leave the children invisible when parents are in contact with their doctor.

Doctors are afraid of hurting and losing their patients. Some GPs said they avoided addressing the children’s situation in consultations with ill parents. They were afraid the patient would leave their list and choose another GP, and that this would be a disadvantage for both the patient and his or her family. Some were also afraid that introducing this theme would increase feelings of guilt and make the burden greater on parents who were already struggling. One doctor expressed it thus, when asked about how to thematize the children’s situation:

“It is difficult, because then it’s as though I am also saying that her problem is her children’s problem. Then I am putting the blame on her, and here she has come to get help for herself. I am just placing one more burden on her shoulders, I should think.”

The doctors appeared to be confident in their supportive role in cases of acute illness. They said that helping a family in a crisis, children and adults alike, was a natural part of the tasks a patient would expect their GP to undertake. The GPs seemed more uncertain that parents with mental health and substance

abuse problems accepted that giving support to their children was a natural task for their GP.

Discussion

The aim of our study was to investigate how Norwegian GPs support children as next of kin and their families. The results showed that they might be in an important position to support the children, but often missed the opportunity to act.

The working conditions in Norwegian general practice can represent barriers to the support of these children. Three issues – the invisible children, the trustful but limited relationship, and the under-utilized consultation – form the basis of the following discussion.

The invisible child

Within the framework of the consultation it seems to be difficult for the GP to become aware of and help the child of a patient with problems. If the GP does not know the family situation, the doctor gets to know only what the patient tells her or him. In Norway, the children are usually not registered in their parents' dossier. It is easy for the patient to hide or forget to bring up information about their children. And if the GP does not ask, important information about the child can be missed. This is especially apparent when the child has a different GP than the parent. It seems easier to address the issue when the doctor leaves the office for home calls or works in collaboration with others in the municipal health service, such as the health visitor. The same findings were found in a study of GP services for children and young people with mental health difficulties [21].

A doctor–patient relationship with limitations

Several previous studies have shown that trust is a key factor in the doctor–patient relationship [22,23], and patients often have great confidence in their GP. Patients have reported that a trusting relationship can make it easier to bring up sensitive themes [24]. This has also been found with battered women, who have to be convinced of loyalty from their physicians before they admit to having been abused [25]. In our material we had reports from experienced doctors, some of whom had practised in the same community for a long time. These GPs had a long-term relationship with their patients and had prime conditions for building trusting doctor–patient relationships. Nevertheless they told stories of where they did not rely on the alliance. Some GPs were

afraid of giving the patient even more burdens by increasing feelings of guilt and shame. Helping children as next of kin might introduce a sensitive theme for the patient. In general practice the doctors often have to address sensitive topics, such as concerns about the patients' weight or alcohol abuse [26]. Even if the GPs consider lifestyle changes important, several studies report that follow-up is deficient. Doctors often explain that they will not jeopardize the relationship by bringing up such a sensitive topic, which is similar to our findings [27–29]. Fear of interrupting the therapeutic alliance is also found to be a barrier to psychiatric work being family focused [11].

The under-utilized consultation

In the patient-centred consultation model, the physician strives to interpret the patient's illness and problems within his or her own frame of reference, and the patient plays an active role in the consultation [13]. According to McWhinney, frames of reference for the patient also include the family situation. This implies the doctor needs to thematize the family, including the children. When avoiding introducing the children's situation at all, the GP does not utilize the possibilities given by the consultation model. However, the patient-centred method is not always sufficient for the GP to do his or her job, since the method implies that the child is not included as part of the consultation unless the patient follows up the issue. Even if the parent does not welcome a conversation about the child's needs, the GP has an ethical and legislative requirement [9] to address his or her concerns and ask for the parent's consent to ensure that the child get adequate information and follow-up.

Methodological discussion

We established a strategic sample with spread based on the selection criteria, but all groups turned out to be skewed concerning gender. We do not think this influenced the discussions in ways that distorted the results significantly.

The participants were recruited from established groups, and they knew each other well. It might be that the doctors wanted to tell more success stories and speak less about the times they did not contribute or failed [30]. This trend might have been strengthened by the fact that FG is a GP and MH a child and adolescent psychiatrist [31]. However, since our primary goal was to find out how GPs may contribute, we believe the results are valid for this purpose [16]. We wanted a sample of experienced GPs, and age and time in practice is therefore higher

than average among GPs. Our results therefore cannot be generalized to young, more inexperienced GPs without reservations.

Conclusion

Norwegian GPs may be in a good position to support children as next of kin, but they also face barriers in doing so. The children easily remain invisible in the GP's consultation with their parents. Time constraints as well as fear of jeopardizing the patient-doctor relationship may cause the GP to hesitate in bringing up this sensitive theme. From the experience in this study it seems as if support from the GP to a child who is burdened as next of kin depends often not on careful consideration of what is best for the patient and the child in the long run, but more on short-term convenience reasons.

Implications and further research

It is an important preventive mental health task for the GP to identify, inform, and ensure follow-up for children as next of kin. The present study introduces hypotheses that might be useful in the development of tools and guidelines for GPs to perform these tasks. To further enquire about the possible role of GPs, information is also needed from the perspective of the parents and the children.

Ethical approval

According to the Regional Committee for Medical and Health Research Ethics, Western Norway, the Act does not apply to this project.

Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of the paper.

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Paper II

II



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

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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.

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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

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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

Table 1. Participants' characteristics.

Group Nr	Parent's problem	Participants girls/boys	Age (years)	Having parents living together	Live now with ill parent ^a
1	Substance abuse	4/1	16-17	0	3 (2 part-time)
2	Mental illness	4/1	16-18	1	1 (1 foster care)
3	Cancer	4/1	17-25	0	0 (all ill parents dead)

^aMany 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.

Preliminary themes		Codes with sub codes		Final categories
				<i>Significant experiences of the adolescents that the GP should identify and recognize.</i>
What is helpful	→	What is helpful -understanding -free place	→	Living with Unpredictability
Relationship to parents	→	Burdens -stress symptoms, health complains -unpredictability - emotional ambivalence toward parents (fault / anger / compassion)	→	The struggle for an ordinary adolescence
Consequens of parental illness	→		→	
Coping strategies	→	The GP -conversation partner -expected to do proper work -advise and give information	→	Experiences and expectations from encounters with the GP
Role of helpers	→		→	

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

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 said:

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 alcohol-abusive 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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Paper III

RESEARCH ARTICLE

Open Access



Ill and substance-abusing parents: how can the general practitioner help their children? A qualitative study

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Abstract

Background: Severe illness among parents may interfere with their parenting. Children having ill or substance-abusing parents are at risk of own health problems and psychosocial difficulties. The health care system should identify families in need of help and provide the help needed. For ill parents, it can be difficult to seek help and advices for their parenting. The aim of this study was to identify important factors for the general practitioner (GP) to bear in mind during encounters with ill and substance-abusing parents, to enable the GP to provide appropriate support for the children.

Method: A qualitative approach was chosen and the data material was semi-structured individual interviews with 12 parents with mental illness, substance abuse or severe somatic illness. The participants were recruited through GPs in Norway, and the interviews were performed in 2014. We used systematic text condensation for analysis.

Results: It was important for the participants that the GP was oriented about their family and children's situation. They wanted to be regarded as competent parents in ordinary families; however, they were aware that their illness affected their parenting. They expressed a need for advice about how to inform the children of their illness and talk to them about their challenges, and, if necessary, utilize helpers who could inform the children and talk to them directly. There were often many agencies involved, and it was important that the helpers cooperated and shared information. In addition, the parents were in need of information about support services.

Conclusion: Ill parents in this study conveyed a double message to their helpers. They wanted to be considered as responsible and well-intended parents who wished the best for their children. At the same time they needed support in parenting. The GP should take the time to listen to the parents' first spontaneous description about an ordinary daily life (while realising that it may not necessarily be an accurate report), then explore their worries and needs of support.

Keywords: General Practice, Family health, Parenting, Child of impaired parent, Qualitative research

Background

When parents suffer from severe somatic disease, mental illness or substance abuse, it may influence the caregiving of their children [1–4]. The impact of their problems on the children's well-being depends on the specific situation of the family, i.e. whether there are other caregivers available to meet the children's needs, or whether there

is access to a support network [5]. Reports on the help-seeking behaviour among seriously ill parents regarding parental problems indicate that parents with substance abuse problems and mental illness are reluctant to seek such help. For some, this is because they are afraid of losing their parental rights [6, 7]. Studies from the UK and Norway have found that parents with serious mental health problems often do not receive help in order to support their children [1, 8, 9]. Children of seriously ill parents are at risk of developing their own psychosocial and health problems [10–12]. Hence, children and families at risk should be identified so their needs

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can be recognized and support can be ensured [13, 14]. There seems to be a knowledge gap regarding factors that may facilitate ill parents seeking help and advice for their parental role in a strained situation. There are social and psychological differences and differences in the needs of families with a somatic ill parent compared to families with a mentally ill parent or a parent with substance abuse, not the least due to different types of shame and stigma related to this variety of family situations. Still, children in these families face some similar burdens and challenges [15, 16], since they all live with a parent that in the vast majority of cases will struggle to meet their children's needs – at least periodically [2, 17]. Because of this, “children as next of kin” are often dealt with as one group, i.e. concerning legal rights [18] and support.

In Norway, almost all inhabitants are listed with a general practitioner (GP). This doctor is usually the first step into the health care system for everyone. She or he follows the patient during their illness and is the gateway to other areas of the health care service. Hence, a GP is in a good position to identify ill parents in need of support in taking care of their children. Several studies have explored what needs these children may have [19–22], but studies concerning the GP's facilitating role for the family are few. The GP may lessen the burdens for the families, including the children, in long-term strained situations. The point of departure for the GP who is engaged in the children's situation is to address the children's special needs with the parents, and eventually get the parents' consent to initiate specific follow-up. However, studies have shown that often there are barriers for health personnel to implement this, both in general practice and in hospitals [14, 23, 24]. GPs who considered these children as their responsibility still reported that they either forgot to address the children's needs, or they were afraid of hurting their vulnerable patients, and possibly increase the parent's feeling of guilt and shame [14]. Thus, it may be challenging for GPs to address the children's situation in encounters with their parents. The GP has knowledge about the children's risk and special needs, but, in the encounters with their parents, they also need to have insight into the parents' perspective, according to the patient-centered clinical consultation model (McWhinney et al's [25]). This is the prevailing consultation model taught at medical schools in Norway. It claims that to decide on how to meet the patient's problem in a useful way for the patient and the family, the GP has to integrate his bio-psycho-social knowledge about the problem with the patients' perspective, i.e. the patients' worries and expectations for the consultation. In the encounter, the GP finds a joint agreement together with the patient on how to deal with the issue of concern. In this consultation model, the physician

strive to interpret the patient's illness and problems within his/her own frame of reference, and the patient plays an active part in the consultation [26]. In several studies, the patient-centred approach has been shown to enhance the communication between patient and doctor [27]. Therefore, in the present study, we explored the meaning of the illness for the parents within the realms of the impact of the illness on their own and their children's everyday life, and their thoughts, feelings and expectations for the GP concerning their children. The aim of this study was to identify important factors for the GP to bear in mind during encounters with ill and substance-abusing parents, to enable the GP to provide appropriate support for the children.

Methods

The study design is a qualitative analysis of individual semi-structured interviews. We chose a qualitative approach because there were few hypotheses to trace, and we wanted to explore the participants' thoughts, feelings, expectations and experiences [28]. Individual interviews are appropriate in a situation like ours, when the subject investigated is sensitive [29].

Data collection

GPs participating in a previous study [14] and GPs in our professional network were asked to recruit patients to the study. The GPs received invitation letters for patients with information and reply forms. They were asked to give these to relevant patients in their practices with the following inclusion criteria: (1) a patient suffering from a mental illness, substance abuse or severe somatic disease; (2) being a parent to one or more children younger than 18 years; and (3) having an illness of sufficient severity to interfere with parenting. If they wanted to participate, the patients returned the reply form with signed consent to the research team. As we do not know how many letters were handed out, we do not know how many that refused to participate. We included participants for a purposive sample with variation in parental problems, gender and rural vs urban residencies. The first author, a female GP, performed the interviews, which were conducted in an office or in the participant's home according to the participant's choice. Each interview lasted 45–70 min. The interviews were conducted on the basis of an interview guide developed by the research team. This was used as a support to make sure our core topics were discussed in all interviews. In accordance with McWhinney and Freeman's [25] perspective, the five core topics were: 1) how the illness might affect their daily life, 2) how it might influence their children, 3) what kind of help was needed for the children, 4) their experience with their own GP, and 5) how the GP might support them in parenting. All informants were interviewed only once, and the interviews were

audiotaped, de-identified and transcribed verbatim by the first author. The transcripts were not returned to the participants for comments. We did preliminary analysis during the data collection, and after 12 interviews, we experienced few new relevant themes coming up, and concluded that we had material with sufficient information power for the purpose of the study [30]. From this empirical data, we could achieve a reliable analysis.

Data analysis

Data were managed using NVivo 9 software (QSR International, Melbourne, VIC, Australia). We performed a cross-case analysis and used systematic text condensation [31] as an analytical tool (Fig. 1). Starting the analysis, we read the material to get an overview. During this reading, we identified some preliminary themes that were relevant for the aim of the study. In step two, we identified meaning units throughout the material and sorted them into four code groups negotiated from the preliminary themes. In step three, we explored the content of these codes and found them comprising different nuances; thus, we split each code group into sub-codes. We made condensates of

the content from all sub-codes, and these condensates formed the basis of the results. Finally, the essence of the codes was merged into two overarching categories: the parents' need of being seen as competent parents and their need of competent helpers. During this last step, we found that the concept of a 'double message' was a central topic for the communication between the patient and the helpers. During the analysis, we continuously went back to the full transcripts to evaluate our codes and sub-codes in the context of the interviews [32]. The analytic work was done by FG and MH, in discussion with the other co-authors and experienced researchers in our network to validate the results and find alternative interpretations [33].

Results

Participant characteristics

The sample consisted of three men and nine women (Table 1). Two had addiction problems, four suffered from somatic disease and eight had a mental illness. In total, they cared for 28 children. Two of the participants worked part-time, the others were unemployed. Only half of them lived with the other parent. One participant

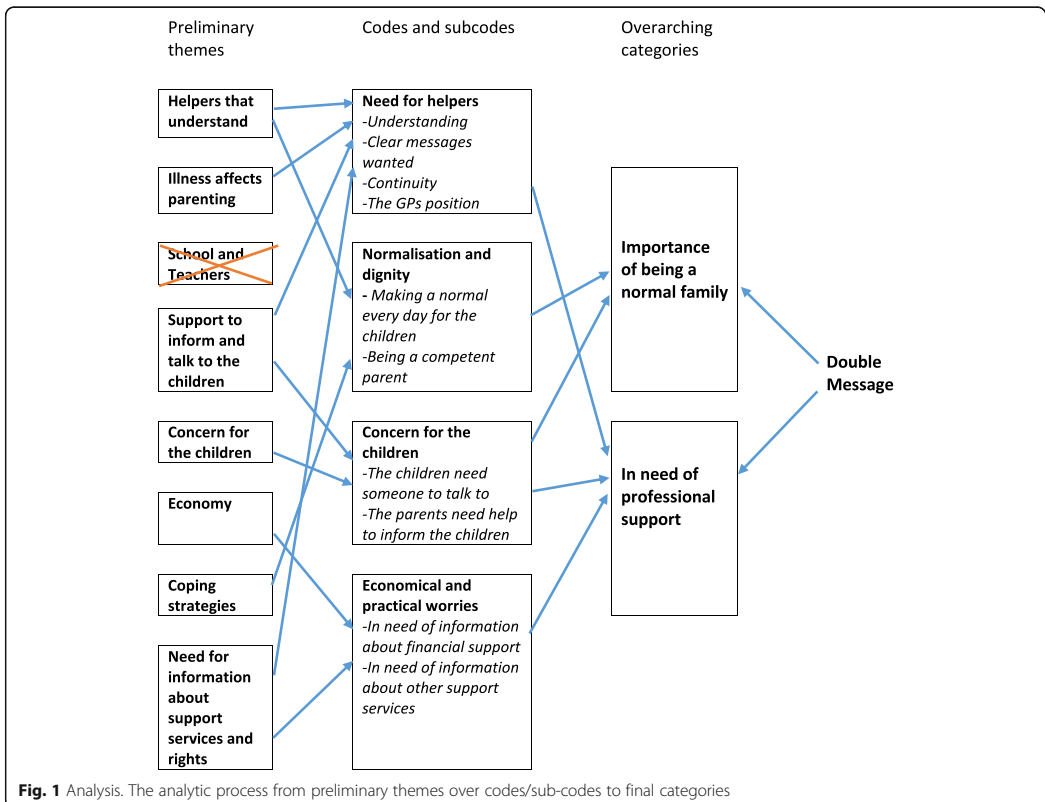


Fig. 1 Analysis. The analytic process from preliminary themes over codes/sub-codes to final categories

Table 1 Participants' characteristics

Interview	Gender	Parental problem	No of children	Employment	Live with the other parent of their children
1	Female	Addiction problems	3	Part-time	No
2	Female	Addiction problems (+ mental illness)	1	No	Yes
3	Male	Somatic disease	4	No (sick leave)	Yes
4	Male	Mental illness	3	No	No
5	Female	Mental illness	3	No	No
6	Female	Mental illness	2	No	Yes
7	Male	Somatic illness	1	No (sick leave)	No (wife dead of cancer)
8	Female	Mental illness	2	No	Yes
9	Female	Mental illness	2	Part-time	No
10	Female	Mental illness (+somatic illness)	3	No	Yes
11	Female	Somatic illness	3	No	No
12	Female	Mental illness	1	No	Yes

was a healthy father of an eight-year-old boy where the mother had recently died from cancer. Although he was not himself ill, we included him in the study, as he had relevant experiences.

One overarching finding was that the participants presented themselves as coping parents, but at the same time, they expressed a need for parenting support. On the one hand they expressed knowledge about the impact of their illness on family life, and, in spite of this, how they managed to support their children in everyday life. On the other hand, they expressed uncertainty and concern for the children, and that they were in need of help to secure good care for them. This represented a double message: 'we are coping, but we still need support'. Most of the participants spoke about a long-term, trustful relationship with their GP, and nobody mentioned any adverse experiences. It was important to all participants that the GP knew about their illness, the family situation and their children. It was also useful that the GP was informed about what kind of help they received, both for themselves and for their children, even if the GP was not very involved in the support for the family. In addition, some parents explicitly wanted advice in parenting matters, including how to inform their children of their illness, professional support for the children and information about the support services available.

The importance of being an ordinary family

The analysis of the material from our talks revealed that it was vital for these parents to be recognized as responsible parents.

Making everyday life normal for the children

The participants strived to make an ordinary everyday life for their children, or at least as ordinary as possible. They wanted their illness to take as small a part as

possible in their children's lives. In addition, being able to master family life was a message both to themselves and to those around them that they were coping despite their problems. A substance-abusing mother living with a husband and a son expressed it like this:

For the last six months, a woman from the child protection has been coming home to me twice a week to take urinary tests. In addition, she does an inspection in our home. I wanted it that way. I want these people to come home to me, to let them see that we manage just as well as our neighbours, despite my problem.

When they were asked about daily life, most of the participants told similar stories about the routines in their homes; regular meals, afternoon moments doing homework with their children, the children participating in leisure-time activities, etc. In addition, fixed routines seemed to be helpful when the illness caused challenges.

Being a competent parent

Parenthood was seen as a sign of normality and social belonging and was, therefore, important for their identity and self-respect. In addition, some were afraid of being judged as incompetent parents with the risk of losing their children. They gave many examples of how they managed well as parents. Some told about specific strategies during relapses or variations in their level of functioning due to illness in order to protect their children. A father of three children in a family where both parents had bipolar disorder said:

Now I think we are beginning to cope quite well with the situation, really. We have got our own strategies for many situations that are special for us. For example, if my wife gets very depressed, the deal is that she should see a therapist. In addition, she will

have time to recover. The agreement is that she must not let it affect the children (that she is depressed). It is better that she withdraw for a while. It is the same with me; if something occurs or if a symptom shows, we have strategies to handle it. It works very well.

In need of professional support

To be able to secure the quality of life they wanted for their children, most of the participants said that it was important for them to have professional support from helpers that knew their situation, including the social and family setting. All participants stated that the doctor was an important person, but their involvement could vary. They appreciated that the GP had a good knowledge of the family and the support services, and worked as a referring authority.

Counselling and support from a helper close at hand

Many participants had a trusting relationship with one professional helper. This helper often provided a continuity of care and had a strong personal involvement. It was important for the parents to have easy access to these helpers when they needed support. Many of them mentioned the GP as one of these helpers, but for some it was a cancer nurse, a psychologist or a family therapist. The father of an eight-year-old boy, where the mother had died recently of cancer, expressed their experience like this:

Support from the GP, a cancer nurse or health visitor is really important. To have helpers genuinely interested in helping you and not just doing a job because it is their duty to do so. You tell more to a person you know and trust than to a person you see only once. These helpers have been there through all the illness. It started with the GP; the GP has been there all the time and it is there you go if new troubles come up.

From a trusted helper, the parents could tolerate more direct speech, and accept alternative viewpoints and corrections. A strong and trustful alliance also made it easier to involve the children's situation in the talks. Some informants expressed that they wanted individualised and concrete advices concerning their children's situation. If they had a trusted helper from another profession, the ill parents' need to talk with the GP about the children was less. However, all informants welcomed the GP to ask about their children. An ill father of four with cancer explained it like this:

I am very pleased with my GP, but the only thing he has done concerning my children is to help referring them to the Child and Adolescent Psychiatric Ward. I talk about my children's situation with a cancer nurse in the community. That is enough for me now.

Many ill parents, especially those with drug addiction or severe mental illness, received support from different professions. For them, close cooperation between the helpers was important. Scheduled multidisciplinary meetings were mentioned as an effective way of sharing information. By participating in these meetings the GP obtained valuable information and could contribute with information based on his or her knowledge about the ill parent and the family. A mother who had a personality disorder and was the solo parent of two children said:

My GP is very active participating in collaborative meetings. Then she gets more information about my situation – more than if she just sees me at her office. In those meetings, we talk about almost everything. It is of great importance that the GP participates in these meetings. Otherwise, she would have had no insight. I am not that often at the GP's office.

The children's specific needs for information and emotional support

The children's need for information about their parents' problems was an ambivalent topic for many of the participants. In hindsight, some parents realized that the children should have been better informed. Some felt it was difficult to know when the best time to inform them was, and they were not sure what information was relevant to share. Some thought it might be best for the children not to know so much about illness and problems. From the participants' perspective, a helper close by seemed to be the best person to discuss what information to share and how to do it. This helper could also give the children information directly about the parents' situation, but most preferably together with the parents. A father with bipolar disorder and three children expressed it like this:

Our experience is that the kids have to trust someone very much to be able to talk about the influence of the illness. It is difficult for someone outside the family to get that role. [...] I am trying as best as I can, and if there is something I do not manage to explain, I can ask my GP about it. Then maybe I can give a better answer. My GP use to be very good finding the right pictures for explanation.

Many participants said that their children had emotional worries. Some became aware of this in hindsight. The children generally seemed to be reluctant to start talking about the illness or problems at home. They had to be prompted. The parents wanted the children to be offered help to talk about their experiences. Often, the parents, if necessary with counselling from a trusted helper, could be the best conversation partner, but sometimes

people outside the family were needed. This could be a helper close by, a teacher, the parents' psychologist or the GP (among other options). A mother with severe chronic back pain, living with a husband and three children explained it this way:

[...] because all kids get worried when the mother stays in bed all day, and when they peep into the bedroom she is lying there crying with pain. Of course, my kids got worried. They were terrified. They thought that I would die. They did not see the difference whether I laid there not being able to move because of back pain, or if I had cancer. For them there was no difference. I did not manage to sense their worries. I was staying in bed all day trying to gather strength so that I could do half an hour's homework with them after school. That was all the energy I had.

Information about support services – a task for the GP

Often, the families and the children were in need of special support. The children could benefit from participating in support groups or other initiatives directed towards the children of ill parents. The ill parent often did not have surplus energy to search for information about services by themselves. They wanted their GP to take the initiative and ask questions about what the family needed. Some parents said they received such information too late. Many of these families had financial problems that affected the children in various ways; for example, what leisure activities they could join in with. The participants stressed that information about financial support was important. A mother with bipolar disorder and two children told us:

It is important that the GPs have knowledge about where they can recommend us to get help when it comes to the children. Once the doctor knows that we have children, there should be an alarm ringing telling them: 'Okay, now these kids need to be protected'. The doctor should tell the parents: 'I have some advices for you, and some helpers you can contact, and here are the phone numbers', a brochure to hand out or other stuff – I think that can be very helpful.

Discussion

It was important for the participants to be regarded as competent parents in ordinary families; however, they realised that their illness affected their parenting. They expressed a need for advices about how to inform their children of their illness and how to talk to them about their experiences. In some cases, helpers who could inform the children and talk to them directly were wanted. Parents needed information about the available support services.

Discussion of the methodology

In the interviews, we addressed the sensitive theme of how parental illness may affect children. In this situation, parents may want to present themselves with a higher degree of mastery than they actually have, concealing the real problems at home. We can assume that we only get a glimpse into their real lives [34]. However, our goal was not to get insight into the participants' actual situation. We wanted to learn from these parents about how the GP could meet their expectations in order to give tailored help both for the parents and their children. For that purpose, the interviews contained relevant information.

The interviewed parents had different conditions; mental illness, somatic complaints, and some suffered from substance abuse. However, it was a common challenge that their parenting might be compromised and their children would have some difficulties that they didn't share with their peers [2, 15, 16]. Performing a cross-case analysis, we aimed to explore how to meet these common challenges. There were few informants with substance-abuse problems, and only three of the twelve informants were male. Concerning these groups, our results must be transferred with care. The participants all contributed with information and reflections on the five main topics in the interview guide.

Most of the participants meant that the GP was an important person for them, and no one mentioned any bad experiences with their GP. This might be related to the fact that they were recruited from GPs and the interviewer was a GP. Probably, not all ill parents experience the same importance of the GP as our informants, and other ill parents might have more adverse experiences. However, our aim was to explore how the GP could meet their expectations for a GP, thus the positive experiences that were reported gave relevant information.

Discussion of the results

Many of the participants spoke about long-term relationships with their GPs and of many good experiences. Some told explicitly about their relationships with GPs who knew their history, their family and their living conditions. These were GPs that offered regard and care, and whom they trusted. This is in accordance with Ridd et al.'s [35] framework for good doctor–patient relationships seen from the patient's point of view. The authors distinguish between dynamic factors that develop or maintain the relationship and the depth of the relationship. The depth is a product of the dynamic factors of longitudinal care and consultation experiences, and encompasses what the patients consider to be mutual knowledge, trust, loyalty and regard between the patient and the doctor. A recent study [36] found that the depth of the doctor–patient relationship, as Ridd et al. [35] define it, is associated with more topics raised by the patient and more discussion on emotional and psychological

issues in consultations. Skirbekk et al. [37], in their studies of patients' consultations with GPs, interpret trust as the patient's implicit willingness to accept the physician's judgement in matters of concern to the patient. They concluded that in order for the patient to bring psychosocial topics into the encounter, the doctor must achieve a rather open mandate of trust. Our participants considered the relationship with their GP to be good and trustful, and from the abovementioned literature, we may assume this facilitated a talk about the children's situation in the parent's encounters with the GP. Thus; these participants can teach us some factors of importance for the GP to bear in mind during the encounters with ill and substance-abusing parents when the aim is to help their children. In the following subsections, we discuss three issues from what we consider to be of specific interest for the GP during encounters with these parents.

The double message

The interviewed parents spoke about an ordinary everyday life together with their children, but many also talked about circumstances due to their condition that affected their children. On one hand, they said they managed ok; on the other hand, they asked for help. In a previous sub-study, we conducted focus group interviews with adolescents who had ill parents [38]. The stories align well with the stories from the informants in the current study. The adolescents stressed that they took part in ordinary activities just like their peers, but they also told of constraints, duties and obligations caused by parental illness. This ambivalence or balancing act seems to characterize these families regardless of the nature of the parental illness [39]. The GP needs to be aware that there may well be a double message and not immediately take the often first spontaneous answer about ordinary everyday life as being entirely factual. 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 [40]. If the GP recognizes the patient with these sometimes contradictory stories of their lives, it can lead to a shared understanding of the situation, which may contribute to a patient–doctor relationship where the children's situation is a natural topic [35, 41].

Ill parents want to talk to a trusted GP about their children

Our participants wanted their GP to bring up the situation concerning illness, parenting and the home situation. Unless prompted, they might not talk about this at all. Adolescents, as next of kin, tell the same story [38, 42]. Thus, it is important that the GP take the first step to bring up the topic when appropriate. In an interview study we performed with GPs, they spoke about the barriers against bringing up this topic [14]. Professionals' resistance against introducing the theme about how the children are

doing is also documented in other studies [24, 43]. From the present study, it seems that GPs' fear of touching on the sensitive topic of how patients are coping with parenting is overestimated. All the interviewed parents, having a relationship of trust with their GP, were keen for this topic to be introduced by the GP.

Support from a GP concerning parental tasks

All children have basic needs that parenting must address. Illness and substance abuse can interact with these, making parents less able to notice and give their children what they need [1–3, 13]. Relevant links between parental major depressive disorders and offspring psychopathologies are suggested to be the level of parenting skills and how the children cope [44]. Parenting skills are thus an important topic in this setting. For marginalized parents, parenthood can be of significant importance because, among other things, it gives a sense of belonging to ordinary social life [45]. This is in accordance with our results.

Good parenting (positive expressed emotions, support from co-parents) is found to correlate with resilience in youth having a depressed parent [46]. For children, it may be valuable if the GP opens the conversation about parenting in their encounters with the parents, gives advice and refers to special services if needed. The GP must maintain a balance between supporting the parents in challenging parental roles, and securing good care for the children. The GP needs to be able to tell if the parenting is not good enough and be prepared to report to child protection if necessary.

Conclusion

From the information the parents gave, the GP is welcome to bring up parenting and the children's situation during their encounters. Ill parents have a double message to GPs: they want to be recognized as responsible and well-intended parents wishing the best for their children, and they need support in parenting. The GP should be aware of and take the time not only to catch up the first spontaneous story about an ordinary everyday family life, but also to explore the parents' concerns about their children and the level of support needed. Then, the trusted GP can be in a good position to give the parents advice about parenting and ensure follow-up of the children if needed, give information about support services and participate in collaboration with others in the health care system concerning the children.

Gaining more information from substance abusive parents and parents with adverse experiences with their GP might be an interesting aim for further research.

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Availability of data and materials

All audio tapes and transcripts are stored in secure, password protected storage at the University of Bergen. Completely de-identified transcripts from the interviews could be made available to interested persons/organisations on request to the corresponding author at froydis.gullbra@uib.no.

Authors' contributions

MH and GR conceived the study. FG collected the data, transcribed the interviews and made the first analyses together with MH. TSS, GR and NA gave input during the analyses. All authors made critical revisions on the drafts and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent to participate

This study received ethical approval from the Regional Committee for Medical and Health Research Ethics, Western Norway (2013/2336-3). The participants were recruited by their GPs who gave them information letters about the study and asked for their interest in participating. Those who accepted submitted signed consent for their participation.

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Appendix 1
GP study

Barn som pårørende – kva kan fastlegen bidra med?

Invitasjon til å delta som informant i forskingsprosjekt.

Utgangspunktet for forskingsprosjektet er ei endring i helsepersonellova (§10a) som pålegg helsepersonell å sørge for at barn som pårørende får nødvendig informasjon og oppfølging. Fastlegen vil ha ei viktig rolle i å identifisere og hjelpe desse barna. Vi vil undersøke korleis erfarne allmennlegar tek hand om denne gruppa, og håpar å kunne hauste erfaringar og synspunkt frå smågrupper.

To av oss vil gjerne invitere oss med på ei av dykkar smågruppesamlingar og gjere et gruppeintervju. Tema vil vere kva de som fastlegar har av erfaringar med å ivareta barn som pårørende (barn som har foreldre med alvorleg somatisk sjukdom, psykisk sjukdom eller rusmisbruk).

Gruppesamtalen vil vare om lag 60-90 minutt. Den vil bli tatt opp på band og analysert av oss i etterkant.

Vi ynskjer gjerne at alle tenkjer over en historie/kasuistikk på forhand. Ta då utgangspunkt i ein alvorleg sjuk pasient (psykisk sjuk, alvorleg somatisk sjuk eller rusmisbrukar) i foreldre-alder. Har denne pasienten barn? Følgjer du opp desse barna? Kva tenkjer du kunne vore gjort for barna?

Vi veit at mange kjenner på liten erfaring på området, men vi håper ikkje det vil vere til hinder for at de vil vere med å diskutere temaet.

Smågruppa kan notere "barne-og ungdomspsykiatri" som tema for denne delen av gruppemøtet.

Dersom de finn dette interessant, ynskjer vi at de tek kontakt med Frøydis Gullbrå (frogull@online.no) for nærare avtale om tid og stad . Vi kjem gjerne på ei av dykkar fastsette samlingar.

Ta gjerne kontakt om de ynskjer meir informasjon om prosjekt eller gruppeintervju.

Med venleg helsing

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Appendix 2

Child study

II

Hvordan kan fastlegen hjelpe barn som pårørende?



Vil du gi litt av din tid for at vi skal finne ut dette?

Vi inviterer ungdommer som har erfaring med kreft /psykisk sykdom/rusproblem hos foreldre til å delta i en studie som undersøker hvordan fastleger kan hjelpe barn/ungdom som har noen med kreft/psykisk sykdom/rusproblem i familien.

Det handler om en samtale i gruppe, der alle som vil delta fra deres gruppe er samlet. Det vil ta ca 45 minutt-1 time. Vi er to-tre forskere/ leger med, og vi ønsker da å høre hva ungdommene tenker kan være til hjelp for dem når noen i familien er syk. Intervju vil foregå i

Det vil være til stor hjelp for oss om du vil delta i dette!

Vedlagt ligger mer informasjon om studien.

Vil du takke ja til denne invitasjonen kan du gi en melding til:

Frøydis Gullbrå, frogull@online.no / 90959808 innen Vi trenger ditt navn og en mail-adresse.

Nærmere informasjon vil bli gitt om tidspunkt for gruppeintervjuet.

Vennlig hilsen

Frøydis Gullbrå, allm.medisinsk forskningsenh, Kalfarvn 31, 5018 Bergen. frogull@online.no

Og

Marit Hafting, BUP, Voss sjukehus, 5700 Voss. Marit.hafting@uni.no

Spørsmål om deltaking i forskingsprosjektet

”Barn som pårørende og fastlegen”

Bakgrunn og føremål

Barn og ungdom som har opplevd å ha sjuke foreldre kan ha det vanskeleg, og ein del barn fortel at dei ynskjer meir informasjon og hjelp enn dei har fått.

Vi ynskjer å finne ut korleis barn og unge som har opplevd å ha sjuke foreldre har det, kva dei treng hjelp til og kor det er lettast å få hjelp. Nesten alle i Norge har ein fastlege. Vi lurar på kva barn og unge trur fastlegen kan hjelpe med. For å få svar på dette, har vi spurt om å få snakke med deltakarar i gruppetilbudet..... Invitasjon blir gitt til ungdom som har hatt tilknytning til dette tilbudet.

Gruppeleiar for har stilt seg positiv til invitasjonen. Difor får du spørsmål via denne gruppa om å vere med i intervjuet.

Kva inneber studien?

Vi vil intervjuer dei frå Treffpunkt som ynskjer vere med. Vi er fastleger eller barn-og ungdomspsykiater. Vi vil snakke med alle samla. Vi ynskjer å høyre litt om korleis det har vore å ha alvorleg sjuke foreldre. Vi vil høyre kva som gjer livet godt å leve, og kva som er vanskeleg. Kor er det hjelp å få når det trengs? Kan fastlegen brukast til noko? Gruppesamtalen vil vare om lag 45 minutt. Den vil bli tatt opp på band og analysert av oss i etterkant.

Mogelege føremoner og ulemper

Det er heilt frivillig om du vil seie noko du sjølv har opplevd. Det går an å seie noko om kva ein trur kan vere til hjelp, og korleis det kan vere å ha sjuke foreldre, utan å seie akkurat korleis det er heime hjå deg.

Kva skjer med informasjonen du har gitt?

Det som blir sagt i samtalen blir tatt opp på band, og forskarane skriv deretter dette ned i eit dokument. Kvar person som seier noko får ein kode, og det er denne koden som blir brukt i dokumentet. Koden knyter personen til det han/ho fortel gjennom ei namneliste. Det er kun forskarane som har tilgang til namnelista og berre desse som kan finne tilbake til personen. Det vil ikkje vere mogeleg å kjenne deg att i resultatane av studien når desse vert skrive om. Bånda og utskriftene av dei vert sletta når prosjektet er avslutta, seinast juni 2016.

Frivillig deltaking

Det er frivillig å ta del i studien. Du kan kva tid som helst og utan å gje opp nokon grunn trekkje deg frå å delta. Du kan delta vidare i Treff. Dersom du ønskjer å delta i gruppeintervjuet, kan du ta med samtykkeerklæringa på siste side til intervjuet.

Dersom du seinare ønskjer å trekke deg eller har spørsmål til studien, kan du kontakte Marit Hafting, marit.hafting@uni.no / 9955 0315 eller Frøydis Gullbrå, frogull@online.no /90959808

Meir om studien –

Barn som pårørende i møte med fastlegen

Intervjua av barne/ungdomsgrupper er del av eit større prosjekt, som her blir kort skildra:

Barn av pasientar med alvorlege helseproblem er sårbare og utsette. Dei siste 10-15 åra har det i Noreg vore sett fokus på desse borna, spesielt born av rusmisbrukarar og psykisk sjuke. Stortinget har vedtatt lovendring i helsepersonellova (§10.a og §25) og spesialisthelsetenestelova (§3-7a), med verknad frå 01.01.2010. Dette skal sikre born av psykisk sjuke, alvorleg fysisk sjuke og rusmisbrukarar rett til informasjon og oppfølging der det er nødvendig. Fastlegen har gjennom lovendringane fått ei nøkkelrolle i oppfølging av desse borna. Mange av foreldra har første møte med helsetenesta hjå fastlegen, og denne legen følger også pasient og familie over tid. Det har tidlegare blitt gjort lite undersøkingar på korleis desse borna blir ivaretatt hjå allmennlege/fastlege.

Forskningsprosjektet er 5-delt:

- **Vi undersøker korleis erfarne fastlegar identifiserer og ivaretek desse borna.** Vi spør kva erfaringar dei har på området, og kva moglegheiter og avgrensingar dei ser i fastlegerollen. Datainnsamlinga vart gjort våren 2011, gjennom fokusgruppe-intervju av fastlegar. Artikkelen vert sendt til eit vitenskapleg tidsskrift vinteren 2013.

- **Kva erfaringar har sjuke foreldre med fastlegen i høve oppfølging av born?** Her ynskjer vi informasjon frå foreldre med alvorleg psykisk eller fysisk sjukdom, eller rusmisbruk. Korleis tenkjer dei at fastlegen kan hjelpe borna deira? Kva behov ser dei ? Kva opplever dei vil vere god oppfølging frå fastlegen si side. Datainnsamling vil bli gjort gjennom enkelt-intervju av foreldre antakeleg våren 2014.

- **Kva erfaringar sit barn og ungdom med?** Vi ynskjer å få informasjon frå dei som har forelder med alvorleg sjukdom eller rusproblem. Kva opplever dei er god livskvalitet. Kor kan ein få hjelp om det trengs. Vi vil høyre deira erfaringar med fastlege/allmennlege, om dei har opplevd hjelp derifrå. Vi ynskjer å høyre kva oppfølging og støtte dei meiner fastlegen kan gi. Informasjon vil bli innhenta gjennom gruppe-intervju av etablerte grupper for barn som pårørende vinteren/våren 2013.

Føremålet med studien er å skildre dei ulike aktørane sine erfaringar og deira ynskje og råd for oppfølging av desse borna.

- **Spørreskjema til fastlegar.** Etter desse intervjua er gjort vil vi sende spørreskjema som handlar om barn som pårørende til alle fastlegar i Norge.

- **Hjelpemidler** I siste del av vårt prosjekt vil vi oppsummere det som er kome fram med å lage nokre hjelpemidler / tilrådingar til fastlegar som dei kan bruke i sitt arbeid med barn som har sjuke foreldre.

Forskergruppa er:

Prosjektleder Marit Hafting (RKBU, Uni helse),

Frøydis Gullbrå (Allmenntmedisinsk forskningsenhet, Uni helse),

Tone Smith-Sivertsen (Allmenntmedisinsk forskningsenhet, Uni helse),

Guri Rørtveit (Allmenntmedisinsk forskningsenhet, Uni helse),

Norman Anderssen (Allmenntmedisinsk forskningsenhet, Uni helse)

Personvern

Opplysningar som vert registrert om deg er namn og alder, i tillegg til lydopptak av det som blir sagt i gruppeintervjuet.

Lydopptaka blir kryptert og lagra elektronisk på ein slik måte at dei ikkje er tilgjengelege for andre enn personell med løyve og knytt til prosjektet. Lydband, namnelister og utskrifter vert sletta når prosjektet er avslutta, seinast juni 2016.

Rett til innsyn og sletting av opplysningar

Dersom du seier ja til å vere med i studien, har du rett til å få innsyn i kva opplysningar som er registrert om deg. Du har vidare rett til å få korrigert eventuelle feil i dei opplysningane vi har registrert. Dersom du trekkjer deg frå studien, kan du krevje å få sletta opplysningar, med mindre opplysningane alt er brukt i vitskaplege publikasjonar.

Økonomi

Studien er finansiert gjennom forskingsmidlar frå Norges forskningsråd og Helse -Vest

Informasjon om utfallet av studien

Deltakarane har rett til å få vite resultat av studien. Dersom de ynskjer dette kan de få tilsendt publiserte tekster eller artikler. Dette kan de få ved å kontakte Marit Hafting, marit.hafting@uni.no / 9955 0315 eller Frøydis Gullbrå, frogull@online.no /90959808

Samtykke til deltaking i studien

Eg har lese informasjonsskrivet og er villig til å ta del i studien

(Signert av prosjektdeltakar, dato)

Eg bekreftar at eg har gjeve informasjon om studien

(Signert, rolle i studien, dato)

Intervjuguide ungdomsgruppe

-Innledning: Vi er leger, og det er viktig for oss å vite noe om hvordan barn og ungdom har det når deres foreldre har psykiske vansker / har problem med rus / har kreft. Derfor har vi spurt denne gruppen om vi kunne få komme hit og snakke med dere.

Presentasjonsrunde: først intervjuere, deretter barna.

Forsknings spørsmål	Aktuelle intervju spørsmål (hovedspørsmål i kursiv + event. tilleggsspørsmål)
Hverdagslivet	<i>For det første lurer vi på hvordan dere har det de vanlige hverdagene?</i> Vi vet at dere går i denne gruppen fordi dere har en mor eller far med <i>psykiske vansker/ rusproblem/ kreft</i> , stemmer ikke det? Hvordan er hverdagen din? Hva er styrken i din familie? Er det noe som er positivt ved at foreldre er syke? Hva er det verste ved at mor eller far har problemer? Er det en spesiell dag eller spesiell ting du kommer på? Hvordan hadde du det før du kom med i dette gruppetilbudet? Kunne det blitt fanga opp at du kunne ha bruk for dette tidligere?
Nettverk	<i>Vi lurer på hvem dere har som kan støtte dere når dere har det vanskelig (- mor/far, familie, lærer, venner, nabo, trener osv) ?</i> Hvem kan du snakke med om det som er vanskelig? Hvem kan hjelpe deg? Hvem gjør deg glad? Hvem vet at mor eller far har psykiske problemer? Har noen ertet dere eller sagt noe negativt? Hva skjedde da? Er det viktig å ha noen å snakke med? Hvorfor er det viktig å ha noen å snakke med?

	<p>Vi har snakket med ungdommer som har foreldre som har alkoholproblem /ruser seg, og noen av dem sier at de ikke tar med venner hjem, hvordan er det for dere?</p> <p>Hva blir evt konsekvensene av at dere ikke tar med venner hjem?</p> <p>Hvordan går det med vennskapene når dere må skjule.</p>
<p>Helsetjenesten</p> <p>Egen helse</p>	<p><i>Vi er fastleger og treffer barn daglig i jobben vår. Vi lurte derfor hva slags erfaringer dere har med helsepersonell slik som fastleger og helsesøstre?</i></p> <ul style="list-style-type: none"> - Alle i Norge har en fastlege. Kjenner du din fastlege? -Har du vært til fastlegen med helseplager eller bekymringer? -Fysiske plager? -Er du oftere syk enn dine kamerater/ enn andre? -Er det andre i fam som har lignende plager som din syke mor/far? -Har du snakket med fastlegen om mors/fars sykdom? -Kan du komme på noe bra fastlegen har gjort for din familie? - Vi er fastleger, kan dere gi oss noen råd når det gjelder å hjelpe barn og familier der foreldrene har psykiske vansker? -Har du snakket med helsesøster om problemene til mor eller far? -Tror du helsesøster kan være til hjelp for barn/unge som har det vanskelig? <p>Har du hatt kontakt med andre i helsevesenet ? (sosialteneste? Barnevern? Støttekontakt? Psykisk helsevern?)</p> <ul style="list-style-type: none"> –Hva trenger du mest hjelp til nå? -Hva mangler du, hva har du behov for? -Er du redd for selv å bli rammet av det samme som din mor eller far? -Hva skal til for at dere får tillit til en profesjonell hjelper? -Hvordan er det for dere at leger/lærere/andre som vet om situasjonen hjemme spør deg om hvordan det går?
<p>Informasjons- behov</p>	<p><i>Barn/unge som har foreldre med psykiske vansker har sagt at de ønsker å vite mer om hva som skjer med mor eller far. Stemmer det for dere?</i></p>

	<p>Husker du når du fikk greie på hva mor eller far sliter med?</p> <p>Hvordan fant dere ut at mor eller far var syk?</p> <p>Husker du hvem som fortalte deg dette?</p> <p>Hvem ville du aller helst få slik informasjon fra?</p> <p>Hva vil du ha informasjon om?</p> <p>Hvordan tror dere det er for foreldrene deres å snakke med dere om dette? Trenger de hjelp?</p> <p>-Tror dere foreldrene har noen bekymring for dere?</p>
<p>Mestring</p> <p>Tanker om fremtid</p>	<p>-Hvordan håndterer du situasjonen du er i?</p> <p>-Hvilke råd vil du til gi andre som kommer i samme situasjon som deg?</p> <p>-Hvilke råd vil du gi til fastleger?</p> <p>- Hvordan vil ditt liv se ut når du blir voksen?</p>
<p>Tanker som oppstår underveis</p>	<p><i>Nå har vi snakket sammen en stund, og ofte dukker det opp ting underveis som vi ikke har spurt om. Er det noe mer dere vil si?</i></p>

Appendix 3
The Parent study

Invitasjonsbrev foreldre

Spørsmål om deltaking i forskingsprosjektet

”Barn som pårørende og fastlegen”

Kunne du tenke deg å bruke 40 minutt på eit intervju?

Vi vil gjerne høyre di meining om kva familier treng av hjelp når mor eller far er sjuk eller har rusproblem. Vil du vere med, kan du sende inn vedlagt svarbrev i frankert konvolutt, så kontaktar vi deg.

Bakgrunn og føremål

Dette er eit spørsmål til deg som forelder om å vere med i ein vitskapleg studie om korleis fastlegen kan hjelpe barn og familiar når ein eller begge foreldre er sjuke eller har rusproblem. Legen din meiner at du er mellom dei som kan ha slike utfordringar og samstundes er forelder for barn under 18 år. Det er grunnen til at du får denne invitasjonen. Gjennom eit intervju med deg ynskjer vi å høyre dine erfaringar med fastlegetenesta og om du har råd til fastlegar om korleis dei kan hjelpe.

Regionalt kompetansesenter for Barn og Unges psykiske helse Vest (RKBU Vest) og Allmenmedisinsk forskningsenhet, begge Uni Helse, er ansvarleg for studien.

Kva inneber studien?

Dersom du ynskjer å delta i studien skal du underteikne samtykkeerklæringa som ligg vedlagt denne informasjonen. Vi vil ta kontakt med deg for å avtale ein stad for eit intervju. Det kan vere heime hjå deg eller på eit offentleg kontor. Ein forskar som også er fastlege vil då møte deg og stille nokon spørsmål. Vi vil høyre kva utfordringar du ser i det å vere forelder samstundes som du er sjuk. Kor er det hjelp å få når det trengs? Kan hjelp kan familien ha bruk for? Kan fastlegen hjelpe med noko? Intervjuet vil vare om lag 30-40 minutt. Det vil bli tatt opp på band og analysert av oss i etterkant.

Mogelege føremøner og ulemper

Studien inneber eit intervju, der du må bruke ca 40 minutt på ein samtale med ein forskar. Du får då høve til å dele dine erfaringar og kome med råd som kan bli til nytte for fastlegar og liknande familiar som din i etterkant. Du bestemmer sjølv kor mykje du vil fortelje av personleg art. Det går an å seie noko om kva ein trur kan vere til hjelp, og korleis det kan vere å ha sjukdom samstundes som ein er forelder, utan å seie akkurat korleis din situasjon er.

Kva skjer med informasjonen om deg?

All informasjon som du gir, skal berre brukast slik som det er skrive om i føremålet med studien. Alle opplysningane vert behandla utan namn og fødselsnummer eller andre direkte opplysningar som kan gjera at dei vert kopla til deg. Ein kode knyter deg til det du fortel gjennom ei namneliste. Det er berre personell med løyve og knytt til prosjektet som har tilgang til namnelista og berre desse som kan finne tilbake til deg. Det vil ikkje vere mogeleg å identifisere deg i resultatata av studien når desse vert publisert. Banda og utskriftene av dei vert sletta når prosjektet vert avslutta, seinast juni 2016.

Frivillig deltaking

Det er frivillig å ta del i studien. Du kan kva tid som helst og utan å gje opp nokon grunn trekkje samtykket til å delta i studien. Dette vil ikkje få konsekvensar for den vidare behandlinga du får i helsevesenet. Dersom du seinare ønskjer å trekke deg eller har spørsmål til studien, kan du kontakte

Marit Hafting, marit.hafting@uni.no / 9955 0315 eller
Frøydis Gullbrå, frogull@online.no /90959808

Meir informasjon om studien finn du i Vedlegg 1

Meir informasjon om personvern, rett til innsyn og økonomi finn du i Vedlegg 2.

Samtykkeerklæring er vedlagt.

Kva gjer eg no?

Vil du *ikkje* vere med på studien, treng du ikkje gjere noko.

Dersom du *vil vere med* i studien, ber vi deg underskrive samtykkeerklæringa som ligg vedlagt og sende den til oss i posten. Du vil deretter snarleg bli kontakta av oss med vidare informasjon.

Venleg helsing
Prosjektansvarlege

Frøydis Gullbrå
Fastlege i Modalen
Forsker III, Allmenntmedisinsk
forskningsenhet i Bergen
Uni Helse
E-post: frogull@online.no
Telefon 90959808

Marit Hafting
Overlege, barne-og ungdomspsykiatrisk
poliklinikk, Voss
Forsker II, Regionsenter for Barn og
Unges Psykiske helse / Uni Helse

Vedlegg 1 -Meir om studien –

Barn som pårørende i møte med fastlegen

Intervju av sjuke foreldre er del av eit større prosjekt, som her blir kort skildra: Barn av foreldre med alvorlege helseproblem kan ha ekstra belastningar fordi omsorgspersonar er sjuke. Dei siste 10-15 åra har det i Noreg vore sett fokus på desse borna. Stortinget har vedtatt lovending i helsepersonellova (§10.a og §25) og spesialisthelsetenestelova (§3-7a), medverknad frå 01.01.2010. Dette skal sikre born av psykisk sjuke, alvorleg fysisk sjuke og rusmisbrukarar rett til informasjon og oppfølging der det er nødvendig. Fastlegen har gjennom lovendingane fått ei nøkkelrolle i oppfølging av desse borna. Mange av foreldra har første møte med helsetenesta hjå fastlegen, og denne legen følgjer også pasient og familie over tid. Det har tidlegare blitt gjort lite undersøkingar på korleis desse borna blir ivaretatt hjå allmennlege/fastlege.

Forskningsprosjektet er 5-delt:

- **Vi undersøker korleis erfarne fastlegar identifiserer og ivaretek desse borna.** Vi spør kva erfaringar dei har på området, og kva moglegheiter og avgrensingar dei ser i fastlegerollen. Intervju gjort våren 2011, gjennom fokusgruppe-intervju av fastlegar. Artikkelen er innsendt til eit Vitenskapleg tidsskrift.

- **Kva erfaringar har sjuke foreldre med fastlegen i høve oppfølging av born?** Her ynskjer vi informasjon frå foreldre med langvarig psykisk eller fysisk sjukdom, eller rusmisbruk. Korleis tenkjer dei at fastlegen kan hjelpe borna deira? Kva behov ser dei ? Kva opplever dei vil vere god oppfølging frå fastlegen si side. Datainnsamling vil bli gjort gjennom enkelt-intervju av foreldre.

- **Kva erfaringar sit barn og ungdom med?** Vi ynskjer å få informasjon frå dei som har forelder med alvorleg sjukdom eller rusproblem. Kva opplever dei er god livskvalitet. Kor kan ein få hjelp om det trengs. Vi vil høyre deira erfaringar med fastlege/allmennlege, om dei har opplevd hjelp derifrå. Vi ynskjer å høyre kva oppfølging og støtte dei meiner fastlegen kan gi. Informasjon vil bli innhenta gjennom gruppe-intervju av etablerte grupper for barn som pårørende.

Føremålet med studien er å skildre dei ulike aktørane sine erfaringar og deira ynskje og råd for oppfølging av desse borna og familiene.

- **Spørreskjema til fastlegar.** Etter desse intervjuar er gjort vil vi sende spørreskjema som handlar om barn som pårørende til alle fastlegar i Norge.

- **Hjelpemidler** I siste del av vårt prosjekt vil vi oppsummere det som er kome fram med å lage nokre hjelpemidler / tilrådingar til fastlegar som dei kan bruke i sitt arbeid med barn som har sjuke foreldre.

Forskergruppa er:

Prosjektleder Marit Hafting (RKBU, Uni helse),

Frøydis Gullbrå (Allmenntmedisinsk forskningsenhet, Uni helse),

Guri Rørtveit (Allmenntmedisinsk forskningsenhet, Uni helse/ Universitetet i Bergen),

Tone Smith-Sivertsen (Allmenntmedisinsk forskningsenhet, Uni helse),

Norman Anderssen (Allmenntmedisinsk forskningsenhet, Uni helse)

Vedlegg 2

Personvern

Opplysningar som vert registrert om deg er namn og alder, i tillegg til lydopptak av det som blir sagt i intervjuet.

Lydopptaka blir kryptert og lagra elektronisk på ein slik måte at dei ikkje er tilgjengelege for andre enn personell med løyve og knytt til prosjektet. Lydbånda og utskriftene vert sletta når prosjektet vert avslutta, seinast juni 2016.

Rett til innsyn og sletting av opplysningar

Dersom du seier ja til å vere med i studien, har du rett til å få innsyn i kva opplysningar som er registrert om deg. Du har vidare rett til å få korrigert eventuelle feil i dei opplysningane vi har registrert. Dersom du trekkjer deg frå studien, kan du krevje å få sletta opplysningar, med mindre opplysningane alt er brukt i vitskaplege publikasjonar.

Økonomi

Studien er finansiert gjennom forskingsmidlar frå Norges Forskningsråd og Helse-Vest.

Informasjon om utfallet av studien

Deltakarane har rett til å få vite resultat av studien. Dersom de ynskjer dette kan de få tilsendt publiserte tekster eller artikler. Dette kan de få ved å kontakte Marit Hafting, marit.hafting@uni.no / 9955 0315 eller Frøydis Gullbrå, frogull@online.no /90959808

Svarbrev foreldre

*Denne sida skal du sende inn i vedlagt svarkonvolutt
dersom du ynskjer å delta i studien*

Samtykke til deltaking i studien

Eg har lese informasjonsskrivet og er villig til å vere med
i studien «Barn som pårørende og fastlegen».

(Signert av prosjektdeltakar, dato)

Namn (tydeleg) _____

Fødselsdato: _____

Telefon der vi kan nå deg: _____

Intervjuguide Foreldre

Forsknings spørsmål	Aktuelle intervju spørsmål (hovedspørsmål i kursiv + event. tilleggsspørsmål)
Innleiing	<p><i>I denne studien vil me undersøkje korleis fastlegar kan hjelpe barna i familiar der ein av foreldra er sjuk (eller har rusproblem). Her kan det vere ulike meiningar. Vi spør for å få fram så mange ulike vinklingar som mogleg, og me stiller alle dei same spørsmåla.</i></p> <p><i>Aller først, kan du seie noko kven som er i din familie.</i></p>
Kvardagslivet	<p><i>Kan du først seie nokon kvardagens rutiner i din familie.</i></p> <p><i>Kva er styrken i din familie? Kva tenkjer du familien din får godt til?</i></p> <p><i>Kven tar seg av de daglege oppgåvene heime når du er dårlig?</i></p>
Implikasjon / konsekvens av sjukdom	<p><i>Merkar barna dine at du er sjuk eller har vanskar, trur du?</i></p> <p><i>Har du hatt bekymringar for barna dine?</i></p> <p><i>Korleis taklar barna situasjonen?</i></p> <p><i>Får barna andre roller enn elles når du er sjuk (oppgåver etc)?</i></p>
Helsetenesta	<p><i>Kan du fortelje om dine erfaringar med fastlegen, når det gjeld hjelp til barna dine?</i></p> <p><i>Opplever du at fastlegen din engasjerer seg i din situasjon, og i din familie? Er det andre som er engasjert</i> Har du snakka med fastlegen om barna dine?</p> <p><i>Har fastlegen tatt det opp?</i></p> <p><i>Kunne fastlegen gjort noko meir eller noko anna?</i></p> <p><i>Har du eller barna dine snakka med helsesøster?</i></p> <p><i>Trur du helsesøster kan være til hjelp for barna når foreldre er sjuke?</i></p> <p><i>Har du eller barna dine hatt kontakt med andre i helsevesenet? (sosialteneste? Barnevern? Støttekontakt? Psykisk helsevern?)</i></p> <p><i>Kva skal til for at du får tillit til en profesjonell hjelper?</i></p> <p><i>Er barna dine meir sjuke enn andre barn? Trur du det evt kan ha samanheng med at du er sjuk?</i></p> <p><i>Tenkjer du det er greitt at fastlegen også spør om korleis det går med ungane, når ein vaksen kjem dit med sitt? Er det innafor det som det er naturleg at ein lege spør om?</i></p>

<p>Nettverk</p>	<p><i>Vi lurer på kven utanom helsevesen de kan ha hjelp frå når det trengs (- mor/far, familie, lærar, vener, nabo, trenar osv) ?</i></p> <p>Kven veit at mor eller far er sjuk?</p> <p>Opplever de at nokon ynskjer hjelpe?</p> <p>Tenkjer du det viktig at barna har nokon å snakke med om det som er vanskeleg? Kvifor er det evt viktig å ha noen å snakke med?</p> <p>Har du som forelder andre å snakke med om barna og deira situasjon?</p> <p>Er det viktig for deg?</p>
<p>Informasjon</p>	<p><i>Fleire barn og unge som har foreldre med sjukdom har sagt at dei ynskjer å vite meir om kva som skjer med mor eller far. Trur du det stemmer for dine barn?</i></p> <p>Har du snakka med barna dine om din sjukdom/dine vanskar?</p> <p>Syns du nokon skulle snakke med dei?</p> <p>Kunne du hatt bruk for meir hjelp til å informere? F.ex råd om kva ein bør seie til barna om sjukdom og korleis gi informasjon?</p> <p>Nokon reiser heim, på heimebesøk, for å ha slike samtaler. Kunne du tenkt deg det for din familie?</p> <p>Kven kunne vore best til å gi deg som forelder råd?</p>
<p>Mestring Tankar om framtid</p>	<p><i>Korleis meistrar du og familien den situasjonen de er i no?</i></p> <p><i>I beg snakka vi litt om korleis kvardagen er heime hjå dykk. Eg har lyst å kome litt tilbake dit, no mot slutten. Kva skulle du ønske hadde vore annleis for deg og barna dine?</i></p> <p>Kunne de hatt bruk for anna hjelp enn den de har fått?</p> <p>Har du råd å gi til fastleger – når det gjeld å følgje opp familiar der ein vaksen er sjuk/ har problem?</p>
<p>Avslutning</p>	<p><i>Mot slutten, korleis har det vore å svare på desse spørsmåla?</i></p> <p>Synest du det har vore vanskeleg å snakke om dette temaet?</p> <p>Er det slik at du no i ettertid tenkjer du kunne ha bruk for nokon å snakke med om dette? Er det tankar/ kjensler som har kome opp?</p> <p>(Etter avtale kan vi kontakte fastlege eller andre. Informant kan også ta kontakt med oss i ettertid, så kan vi formidle hjelp.)</p>

