





'I have cried a lot': a qualitative study on children experiencing severe parental illness

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Scand J Caring Sci. 2021

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Abstract

Background: A considerable body of research has explored implications of severe parental illness on children. However, less is known about what children and adolescents with a severely ill parent experience as the most challenging.

Aims: To describe what children with a severely ill parent experience as their most difficult challenge.

Methods: A qualitative descriptive design with a manifest content analysis was used on data from a cross-sectional, multicenter study on children of patients in five Norwegian Health trusts. Data consisted of written textual responds from 238 children (age 8–18) to one open-ended question in a self-report questionnaire.

Results: The overall theme concerning the children's most difficult challenge was named 'the drama of life

unfoldment', reflecting the parental illness' impact on themselves, their relationships with others, and their life circumstances. The subthemes consisted of: Children's experiences of difficult thoughts and feelings; negatively impaired relationship with parents, friends and others; and challenging life events and obstacles in welfare.

Conclusions: The most difficult challenge experienced by the children with a severely ill parent implies life unfoldment challenges and include negative personal and relational impact, challenging life events and obstacles in welfare.

Keywords: severe parental illness, challenge(s), adolescents as relatives, family, well-being, children as next of kin, children as relatives, parental mental illness, parental substance abuse, parental physical illness.

Submitted 8 July 2020, Accepted 8 November 2020

Introduction

This study concerns children and adolescents (henceforth called children) affected by severe parental physical or mental illness or substance abuse (henceforth called severe parental illness) and difficult challenges the children may face. Severe parental illness may be experienced as dramatic and influences the whole family (1–7).

Family well-being is crucial for children's well-being (8, 9) and severe parental illness put children at risk for adjustment difficulties and psychosocial problems (10–12). The effect of severe parental illness on family well-

being and children is complex (7, 10). However, in addition to children's early experiences, the importance of family distress and children's emotion regulation has been identified as fundamental in child development (13). Although the facilitating environment for children is strained during times of adversities (5, 14–16), adversities may also imply brief periods of not damaging stress which may increase resistance to later stress (17). For example, developmental benefits have been reported as a result of meeting, and successfully coping with, challenges (18). Thus, the parenting role and parents' capacity to safeguard and regulate emotions during times of adversities are fundamental to children's health and well-being (19).

When a parent becomes severely ill, his or her parenting role and capacity to perform developmental support to the children may be jeopardised (12, 20, 21).

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Comparing symptomatology between children with either parental depression or physically illness, and those having healthy parents, Hirsch et al. (22) suggested that the experience of parental disability or distress in the family affected the development of symptoms in adolescence. Threats to the family (such as stigma and loss) (19, 20, 23), family role distribution and child daily hassles (stresses and strain of daily life) (24) are of significant importance (7). Furthermore, child stress response from parental illness may represent a discrete, negative and uncomfortable life event (25, 26). The loss of a healthy parent, periods of chronic stress, separation during hospitalisations, compassion with the ill parent and fears about being abandoned are some experiences children with a severely ill parent have in common (27–29). Aside of that, children may experience losing their parent's emotional and physical availability for periods as well as any sense of normality in their own lives (30, 31).

Another strain put on these children is during hospital visits to their parent. In- or outpatients clinics are often described as unfamiliar surroundings where the children sought information but instead were overseen by the health personnel (32–36). A parent's hospitalisation might be a frightening experience to a child since it means separation, worsening of the illness, or scary surroundings for a child. Notwithstanding, it may also involve relief due to distance from the disease (37).

Common to children who have parents with severe illness is to reach for normality, to try to avoid stigma and to take increased responsibility, at home and for the ill family member (4, 38–41). A study of adolescents of parental multiple sclerosis showed that their main concern was to preserve control in an uncertain everyday life by 'balancing needs' through reflecting, adjusting, taking responsibility and seeking respite (42). These findings are in line with international reviews of qualitative research (37, 43–47). Although there are similarities in children's experiences across parental illness groups, studies have also found differences. For example, one study found that children of parents with substance abuse may experience greater levels of social exclusion while experiencing similar negative impacts of care as their caring peers (48).

Results from a Norwegian cross-sectional, multi-informant, multicenter study on children as relatives showed that the parents, health professionals and teachers did not adequately capture the children's challenges as the children themselves described them (49). We thus wanted to extend the understanding of children's experiences when having a severely ill parent. Specifically, the aim of this study was to describe children's experience of the most difficult challenge when having a severely ill parent.

Methods

Design

The present study is a sub-study with a qualitative descriptive design suitable to analyse written answers to open-ended questions included in a questionnaire.

The primary study

The overall objective of the primary study was to explore the experiences of children when one of their parents had a severe illness, their perceived need for support, and to what extent they received support from health-care services (20, 50–55). A total of 534 children aged 0–18 years of patients from departments of physical illness (cancer and neurology), mental illness and substance abuse and their families in five hospitals across Norway were included. One child per family was randomly selected to participate. Statistical analysis of data showed no significant differences between children with parental physical illness, mental illness or substance abuse aged 8–18 ($N = 246$) concerning health-related quality of life (56) and positive and negative outcomes of caring activities (52). The present sub-study ($N = 238$) used data from this multicenter study (49).

The present sub-study

The present study explores responses to the following open-ended question included in the children's questionnaires in the primary study: 'Please respond to the following question in your own words: What do you think is the most difficult challenge related to having a severely ill parent?' The question was posed at the end of the survey, after the children had answered questions about sociodemographic factors, support received, their knowledge of their parent's illness, family issues, and validated instruments about mental health issues, quality of life and traumatic life events.

Participants

Inclusion criteria referred to children of patients undergoing treatment at in- and outpatient clinics in the specialised healthcare services, who were providing care for a biological or adoptive child at a minimum of every second week. Participants had to understand and read Norwegian language. In families with more than one child, one was randomly selected. Of 246 participating children between 8 and 18 years in the primary study, 238 children responded to the question selected for the present study. Sociodemographic characteristics of the sample are shown in Table 1 (data from the primary study).

Table 1 Children's and patients'/parents' characteristics

Variable	Total M (SD)	Physical illness M (SD)	Mental illness M (SD)	Substance abuse M (SD)
Children's characteristics (N)	246	140	76	30
Age (year)	12.45 (2.85)	12.74 (2.61)	11.97 (3.05)	12.33 (3.32)
Gender (% female)	56.9%	56.4%	60.5%	50%
Family demographics (N)	238/165	135/102	75/43	28/20
Ill parents' age (year)	42.62 (5.81)	44.25 (5.61)	40.08 (5.17)	41.57 (5.85)
Ill parents' ethnicity (% Norwegian)	93.3%	94.8%	88%	100%
Ill parents' gender (% female)	72.7%	71.1%	85.3%	46.4%
Ill parents' education	43.7%	54.8%	32%	21.4%
High				
Middle	40.8%	34.8%	48%	50.0%
Low	15.5%	10.4%	20%	28.6%
Single-parent family (%)	17.2%	11.9%	20.0%	35.7%
Family income per year (NOK)	820 366.8	1 009 031.8	618 000.0	452 785.7
Very high	30.3%	39.3%	24.0%	3.6%
High	24.8%	28.9%	22.7%	10.7%
Middle	17.6%	15.6%	14.7%	35.7%
Low	16.0%	11.1%	21.3%	25.0%
Very low	11.3%	5.2%	17.3%	25.0%

Unless otherwise noted, estimates are mean (standard deviation; SD). Data from the primary study.

Definitions.

Parent with severe illness: A patient with severe physical illness (cancer or neurological disease defined as severe by a panel of experts (MDs)), mental illness or substance abuse, receiving treatment from the specialised healthcare services.

Child of patient with severe illness: A biological or adopted child aged 8–18 years of a parent with severe illness.

Specialised healthcare services: Public hospitals which provide treatment at in- and outpatient clinics within the fields of physical and mental illness, and substance abuse.

Data collection

Data were collected from May 2013 through January 2015. Study personnel were available for the children if technical or any other support was needed. The younger children (8- to 9-year-olds) with less reading and writing skills sometimes asked for help to read the questions, but answered themselves with their own words which they were encouraged to by the study personnel. The questionnaire was filled in on online tablets, transferred via Internet and stored at an approved database. All families were offered two cinema tickets as compensation for the time used in filling in the questionnaires.

Data analysis

Based on research described in the background section, we considered the children as one unified group and thus analysed their reports as a whole. Another reason for not separating or making comparisons between the three illness groups was that the sub-groups differed in size (see Table 1). Since the answers were overall short, and we could not ask in-depth questions, we chose to bring out general features and experiences as a whole, which can help to shed light on some important experiences that children and young people may have with parents' illness or substance abuse problems. In the reading, we also found more similarities than differences in the statements. This applied both across the parents' disease groups and the children's age groups. Although there will be a need to go into more depth on such possible differences in further research, it is also an advantage to know general features that healthcare professionals should be aware of in clinical practice.

Based on the variety in length in responds, from longer explanations to short answers, consisting of a few sentences or words, we found it appropriate to perform a manifest analysis. Notwithstanding, the material in total was rich in content, coming from 238 children. Hence, we conducted a qualitative inductive, manifest content analysis, guided by the descriptions of Elo and Kyngäs (57). In accordance with Elo and Kyngäs (*ibid.*), we kept close to the children's statements throughout the analysis process. We used Guba's (58) four criteria (i.e. Credibility, Dependability, Transferability and Confirmability) to ensure trustworthiness. Credibility was strengthened with the use of open-ended question, allowing informants the freedom to express their own views. Dependability was ensured by having all participants answer the same, open-ended questions. Furthermore, an account of the process was described which establishes an 'audit trail' (*ibid.*). In the *preparation phase* (57), we considered all children's answers to the open-ended question as being the unit of analysis. The research group (AF, EK, MH,

BW) read the text several times and agreed that the data in total was both rich and sufficient in content to explore the aim. The research group repeatedly tested our insight and understanding of the material against the informants' statements and also included deviant statements from the informants. The open coding was discussed until all aspects of the content were covered. Throughout the analysing process, individual and mutual understandings were discussed until agreement was reached. In the *organizing phase* (ibid.), the research group performed a condensation of each meaning unit. The research group then made an initial grouping with descriptive codes, followed by the process of creating mutually exclusive themes and sorting out emerging subthemes (AF and BW). To ensure rigour, we assessed inter-rater reliability in the process of identifying themes where we separately (AF, BW, EK and MH) came up with suggestions and discussed until we reached agreement. The two levels of themes were named according to our understanding of their content (AF and BW with input from EK and MH). The research group went back and forth between the levels of themes. Whenever in doubt of the placement of a meaning unit, AF and BW separately went back to the original texts and then discussed the excerpts to secure reliability of the thematic interpretation (ibid.). Finally, the pattern of levels showed in the findings was established (AF and BW with approval from EK and MH). At the end, a main theme was named (AF and BW). In the *reporting phase* (ibid.), AF with input from BW described the various thematic levels (main theme, themes and subthemes) and also included some excerpts to secure trustworthiness of our analysis. Transferability was established by the description of data collection, the informants and the analysing process (58). Confirmability (ibid.) was attained by comparing the understanding of the findings with other studies and included in the discussion section. Moreover, the possibility of having preconceived notions with regard to the material was thoroughly discussed within the research group, which was balanced in terms of professional experiences.

Ethical considerations

Written informed consent was obtained from both parents and children, and parents additionally consented for children between 8 and 16 years of age. Children and families were offered referral to helping agencies if needed/wanted.

The study was conducted according to the principles of the Helsinki Declaration (59) and approved by the Regional Committee for Medical and Health Research Ethics (ref. 2012/1176 A), and the local Data Protection Officer at each participating Health Trust. All authors certify responsibility of this paper. Quotations used in the manuscript are unidentified.

Results

The main theme, unravelled from the children's descriptions of their most difficult challenge associated with their parent's condition, was summarised and conceptualised as descriptions of 'Drama of Life unfoldment'; a shivering, emotional or unexpected series of events or set of circumstances. The content and connections between the subthemes, themes and main theme are described in the following and pictured in Table 2.

Drama of life unfoldment

The main theme 'Drama of Life unfoldment' revealed three themes: 'Impact on themselves', 'Impact on relationships' and 'Impact on life circumstances' of which each consisted of various subthemes. The content of the subthemes is sometimes overlapping, reflecting that human experiences, conceptions and emotions are interwoven, as is life itself. The main theme, themes and subthemes are illustrated in Table 2.

Impact on themselves

The theme 'Impact on themselves' included children's descriptions of how the most difficult challenge when having a parent with severe illness influenced themselves, how they were *thinking and feeling* and how *demands and responsibilities* changed. Many children described how this represented strains on a cognitive level, for others on an emotional level, and for some, it represented strain on their functional level.

Thoughts and feelings

This subtheme revolves around different demanding thoughts and difficult emotions the children describe. They were concerned about the parent's condition and worried about the future, which they described as disturbing, causing attention problems at school and elsewhere as well as sleeping problems and thoughts about

Table 2 The main theme, themes and subthemes

Main theme	Drama of life unfoldment		
Theme	Impact on themselves	Impact on relationships	Impact on life circumstances
Subtheme	Thoughts and feelings	Parents and family	Hard moments and periods related to the illness
	Demands and responsibility	Friends and others	Social support and welfare

their insecure situation. They also struggled with thoughts about how to help the parent and the family. Feelings of anxiety, anger and guilt were prominent.

Thoughts

'I get easily overstretched' (girl, 17) is a noteworthy quotation for this subtheme. Thoughts about the parent's condition can be illustrated by quotations like: 'I'm afraid she is going to die' (girl, 10); 'thinking about his pain and that he is not well' (girl, 11). The load of balancing various considerations was characterised as a strain by many: 'The huge load ... that I feel that everything has happened to mommy. Generally speaking, that mom has not been ill just once but several times. I think this has been very unfair' (girl, 13). Worries for the future were expressed like: '...thinking about what is going to happen if my mom dies' (boy, 14).

Attention problems were expressed by others, such as 'to be concentrated at school, and also a little at home' (girl, 10). Sleeping problems were also described as very challenging: 'I am thinking a lot about it and cannot sleep' (boy, 11). Some expressed despair because they were unable to help their ill parent or did not know what to do about the situation: '(to figure out) what am I going to do' (girl, 12), and 'I don't know how to respond' (boy, 15). Statements like 'bad thoughts' (girl, 11) and '... just to think about it' (girl, 8) exemplify how their parent's illness had a negative impact on their cognition. A statement like '... I get tired, and quarrel a lot with my parents' (girl, 14) shows how the most difficult challenge emerged into behaviour. Others expressed that it had been difficult mentally.

Feelings

Many children expressed how their own emotional reactions were most challenging to them. Experiences like feeling emotionally blocked, lonely, sad, angry, guilty, frightened and deprived were striking. This can be illustrated by statements like: 'It's sad and difficult to see my father very ill' (boy, 14), and 'to keep calm and to be in peace with myself' (boy, 17). They expressed that their parent's condition bothered them, and inner turmoil and feelings of loneliness, fear for the future, anxiety and anger were expressed. One child did put it like this: 'Loneliness, and fear for the future' (boy, 17). Another expressed it like this: 'I have been a bit frightened' (girl, 8). Sadness was described in different ways by many of the children. Statements like 'I have been crying a lot because he has been to the hospital' (girl, 10) and 'I am sad' (girl, 9) are examples of that. Sadness was also something that was difficult to overcome: 'The hardest about this is [to try] not to be sad' (girl,

14). Anger could be exemplified by statements like 'My temper has been short, and that has been difficult' (girl, 16), 'Problems with anger' (girl, 14) and 'Easily frustrated' (boy, 12). Others described a sense of guilt: 'I always feel it's my fault' (girl, 16).

Demands and responsibility

The other sub-theme concerned the children's descriptions of strains emerging from demands and expectations from themselves and others to act or to be responsible in certain ways. For example, many had to shoulder an increased load of duties. This could be to care for siblings; making breakfast, bringing them to school or kindergarten and comforting them when they had a hard time. This could be particularly demanding when not having anyone (adult) to receive own support or comfort from. One child described that: 'The most difficult challenge is that I have to get up early in the morning, all alone, wake up my siblings, and make breakfast and lunch for them, and so on' (boy, 15). Some described that they had to take care of many tasks in the household that parents normally do: 'I have to help more at home' (boy, 14) and 'I have to be more in charge' (girl, 15).

Impact on relationships

This theme contained children's descriptions of the most difficult challenge associated with how their parent's illness influenced their relationships. This included descriptions of how the parent's condition influenced on their relationships with their *parents and family* and with *friends and others*.

Parents and family

This subtheme consisted of statements like 'I find it very difficult to relate to dad when he is ill' (boy, 15); 'That he cannot play with me' (girl, 10); and 'The hardest thing is that I can never know for sure when dad is getting well again' (boy, 13), which show how the relationship with the ill parent was influenced. Many children experienced the most difficult challenge being when the ill parent changed attitude and became unpredictable or in a bad mood: 'I find it very hard to relate to dad when he is down. He is very unpredictable and I never know when his mood will turn' (girl, 17); 'When he gets tired and I notice he is tired of everything' (boy, 14); and 'When she locks herself in for days' (girl, 13). Even the relation to the well parent was experienced as hard by some: 'When mom is drinking and dad is ill, and she is the one putting me to bed' (girl, 8).

For other children, less shared family and social activities compared to before the parent became ill were most challenging. This was exemplified by statements like '....

when we could not go on holiday together' (girl, 12), '... that dad was not able to do the same things as me and my mom' (girl, 13), and 'We are not able to do all the things we used to do before my father got ill' (boy, 17). Others experienced quarrelling and an unpleasant atmosphere at home: '(I) become tired quickly and (I am) arguing a lot with (my) parents' (girl, 14); 'That they get more tired and angry' (girl, 11); 'That I'm not seen, and there is a lot of arguing' (girl, 17); and 'It's also hard when you know she's sick, so it's like a bad mood throughout the home' (boy, 15).

Friends and others

This subtheme contains descriptions of difficulties with sharing thoughts with friends and others: 'I have experienced it hardest not to talk to my friends about it, but at the same time I feel that is the easiest' (girl, 15) and 'I think it's hard to share the topic with others, thus I keep it all to myself' (boy, 16). Some experienced that the most difficult was to not getting understanding or support from others: 'It's harder for them at home and for others to understand and help out' (girl, 12).

Some experienced that the most difficult challenge was restrictions in their own leisure time: '---it is strange not to have friends with me at home anymore' (girl, 11).

Impact on life circumstances

The theme 'Impact on life circumstances' comprised children's descriptions of the impact the parent's illness had on the context they were living in. This included how children described the most difficult challenge as hard periods and moments related to the illness, and circumstances related to welfare.

Hard moments and periods related to the illness

Many children described various moments (life events) related to the parent's illness as their most difficult challenge. Such events could be the moment when they got the message that the parent had a severe illness: 'To get the message that my dad will not get well and that he is going to die of the disease' (boy, 16). For some, it could be the moment when treatment started, while others described the duration of treatment that the parent had to go through as most difficult to handle. We found descriptions of treatment periods which led to the parent being sad and tired, in pain, having low energy, or showing increased irritability and anger. Lack of information, unpredictability and the uncertainty of not knowing what may happen were for others experienced as the most difficult: '... I did not understand anything, and I did not get any information about what happened and what was going to happen...' (girl, 17), and 'The hardest has been not to know for certain how this will turn out,

and to experience that an illness can occur so sudden and change so much in so short time...' (girl, 17).

Some children described periods when the parent was admitted to hospital as being the most challenging: 'Not having anyone there for me in the same way. Knowing that your parent is sick and not at home. Just the fact about that in a way' (boy, 15). Others stated that not being able to stay in touch with the parent during longer periods in hospital as their worst experience: 'The hardest was when dad had to stay at the hospital for a longer period' (girl, 10). The long distance to hospital could also be difficult: 'To keep in touch when she is admitted to a hospital far away' (girl, 11).

Some described periods of worsening of the illness as being the hardest part: 'The hardest is to see mom be sad, or worse' (girl, 16); 'Hardest is when he has strong headache and is very tired' (girl, 13); 'That he quickly gets tired or sad when he has a bad day. That he struggles with simple things like walking or moving' (girl, 17); and 'That my dad sometimes has to lie down relaxing all day' (boy, 12). Others experienced periods when parent lost functions as the most difficult challenge, like not being able to bicycling, walking, running or dancing.

Some experienced moments of reminders of the illness in everyday life, like hearing the parent talk with others about the illness, were the most difficult challenge: 'To hear my dad talk with others on the phone about cancer' (girl, 12).

Social support and welfare

This subtheme consisted of children's descriptions of how these challenging life circumstances affected their safety and security at large. These children described a profound impact on everyday life concerning their residence, home environment and economy. Descriptions comprised experiencing increased problems at home by simply stating 'It is more difficult at home' (girl, 12), while others pointed out extreme consequences like the possibility of losing their home or having to leave home: '... but the hardest thing was that I had to leave my home' (girl, 14). Such statements were both related to the possibility that the child welfare services could take over custody, but also the family's financial situation. Regarding the latter, we found that the financial situation was described as being most difficult for many of these children: from the possibility of losing their social security network due to having to move, to statements about the economic situation in general without further details: '...lack of money' (girl, 15); 'Money and food' (boy, 17); and simply: 'Economy' (boy, 17).

Discussion

The aim of this study was to describe children's experience of the most difficult challenge when having a

severely ill parent. The results indicate experiences addressing a spectrum of shivering, emotional, unexpected events (stressors) putting strain (tension) on themselves, their relationships and their life circumstances which in our opinion constituted a fundamental life change in ways that may inflict with life unfoldment if the tension is not resolved. Rose & Cohen (46) stated a decade ago that children's experiences of difficult thoughts, feelings of uncertainty, shame and isolation, demands and responsibility might form their identity. While previous research has described similar implications of severe parental illness on children and adolescents with a severely ill parent (31, 60–64), our findings are of particular importance in the context of what children and adolescents in their own words describe as the most difficult challenge.

The first theme, 'Impact on themselves', revolved around challenges with a *negative impact* addressing strains and tensions related to various thoughts and feelings characterised by distress and the load of demands and responsibilities. Our findings showed that the children found it challenging to handle their ever-present thoughts about their ill parent's pain and struggle, their own worries about the future, and in particular what to do if the parent should die. Hardship associated with loss of, or separation from, a healthy parent, compassion with the ill parent and fear of being abandoned have previously been reported (27–29). These and other related challenges described by the children in the present study have been found in research with children from similar parental illness groups as in our study (62, 63, 65, 66). Some children were exhausted by such disturbing thoughts, others could not sleep or concentrate, while others felt overstretched or in a terrible mood (64). Furthermore, to experience difficulties with feelings like sadness, anger, fear and guilt, which are well-known experiences among children with a severely ill parent (36, 64, 66, 67), was a difficult challenge for many. Loneliness and the feeling of being deprived in the situation have also been reported previously as challenging for children (29). The description of a struggle to keep calm and to be in peace with oneself concurs with Mordoch & Hall (62) and is a reminder of what the situation with a severely ill parent may cost emotionally. These findings are consistent with what previous studies (62, 65, 68) and personal report (69) have revealed children with severely ill parents have considered as very hard, a burden and interruption in their lives. Among others, adolescents interviewed on how they managed living with a parent experiencing heavily chronic noncancer pain endured hardships, distanced themselves, lamented losses and held back on revealing their authentic selves (63, 65). Trondsen (38) explored experiences in everyday life based on observation of young people with a mentally ill parent in an online self-help group, finding

children describing difficult emotional and practical challenges to handle. Fear and loneliness were pointed out, and words like the worst and particularly challenging were used (*ibid.*). Furthermore, Martinsen et al. (36) reported that young next of kin in mental health care described frightening experiences at home when they had been afraid and felt insecure, like screaming and quarrelling or witnessing suicide attempts or self-harm. They often felt upset and depressed, angry and irritable, or introvert and silent (*ibid.*).

The second theme, 'Impact on relationships', revolved around the tension and strains the children and young people experienced related to their *relationships*. In our opinion, our findings indicate that these children might experience a kind of existential loneliness: they did not find anyone of whom to share their experience of being in a severely difficult situation, which affected their whole being. Existential loneliness despite the presence of others is also previously described (40, 70). The experience of less availability of significant others in times where comfort and support were crucial is also indicated by others (21, 63, 71). Our findings show that this estrangement could be explained by not being able to find a way to express their emotions in ways that others could understand (i.e. friends and siblings), in order to protect others (i.e. the other parent, other adults) from having to deal with their emotional or practical strains, or to protect themselves from shame and stigma (i.e. from parental substance abuse) (64). The emphasis on not wanting, or not being able, to share their innermost thoughts, is in line with previous studies (63, 64). Similarly, Trondsen (38) also reported that it could be particularly challenging to confide in someone about family issues and personal experiences, and the feeling of being overlooked in the family. While familial and social support could be an important asset in these circumstances, our findings show that to reach out in order to gain support seems difficult for these children and young people. Similarly, Rose and Cohen (46) reported that children with severe parental illness did not feel that their friends could understand why they were unable to go out and socialise, leaving them with a sense of being 'different' as well as 'invisible'. Another finding was that, although family routines could be upheld, they often appeared in a different way than usual. Our informants experienced a change in their own and/or the parents' attitudes, and a strange affective quality and disputes in the family inflicted the home with a strange atmosphere (21, 31, 36, 62, 64, 66, 67, 72).

The third finding was addressing *contextual challenges* as a result of the parent's illness. The focus of the accounts here was on the shocking news or longer periods of distress related to the parental illness and social insecurity. In these children's descriptions, the first message about the severe parental illness, treatment periods, periods

when the parent was in hospital, and times of worsening of the illness were particularly tough for them. Uncertainty in terms of unpredictable behaviour from their parents, and of their own present and future situation can be understood as an ever-present insecurity. We understand this in line with Trondsen (38), regarding children's descriptions of unpredictability and instability related to severe parental illness. Social insecurity was also highlighted by our informants, considering threats against basic residential, nurturing and nourishing needs. Such threats seem comparable to other studies (38, 46). Furthermore, the findings in our study are also in line with Trondsen (38) in signalling children being alone in an 'emergency alert mode' and Pedersen and Revenson (7) noting that children of severely ill parents occupy a dual role as a primary provider of emotional and instrumental support to the ill parent and so as a family member who needs support in the face of a major and often long-lasting life-stressor. Similar to what others have reported, life events mentioned in our findings have the character of overwhelming traumatic experiences (31, 62, 65, 66, 73–75). These facts may indicate an experience of lack of control (7) which must be an additional burden in these young people's situation.

Despite that the impact of severe parental illness on children's health is complex (13), the results are a reminder of the parents' and other significant persons' role in safeguarding and regulating children's emotions during times of adversities (13, 19, 22). This is pivotal, as developmental benefits may evolve if children get support in meeting and successfully handle challenging thoughts, feelings and demands, difficulties in relationships, scaring and dramatic life events and losses in welfare (13, 17, 18, 25, 26). Children's well-being is dependent on family well-being (8, 9), and thus, health personnel should have focus on identifying if patients have children, and if so, make sure their children's and family's well-being is taken care of. Family distress and children's emotion regulation have been identified as fundamental in child development (13), and thus, a family focus in treating patients who are parents is requested. There is a need for the children to have access to secure adults in periods when parents are not available and they are losing their parents' emotional and physical availability (29, 30). Patients that are parents must be offered support and guidance in their parenting functioning by professionals if needed. Children need to be informed about the illness according to their developmental age and assured that their ill parent is treated well and taken care of by the specialised healthcare services, the general practitioner and public services in the community. Severely ill parents should get practical help in their home in periods of adversities, and financial support if needed to secure children's social security and basic needs (18, 19, 22, 23). Grove et al. (76) identified several key aspects of

interventions that young people of parents with a mental illness wanted: (i) how to cope with their parents' illness, (ii) psycho-education and information about what a mental illness is and associated hereditary risks, (iii) support from school through a generalised programme about mental health, (iv) confidential and/or anonymous support, (v) the involvement of healthcare professionals and (vi) talking with their parent about mental illness. The results of the present study add to this that the kind of interventions young people of parents with a mental illness want also reflect what children with a parent with severe physical illness and substance abuse may need.

There are a number of limitations applied in interpreting the findings. First, parental medical condition other than illness group (physical, mental or substance abuse) was not collected at the time of the survey, and diagnoses and information on severity of the illnesses were thus not available for interpretation. On the other hand, it might be strength that, instead of assuming that, for example statements regarding a demanding financial situation belongs to one particular group, this will show that the difficulties that these children describe, seems common across groups. The age range of the informants was wide, which may have had an impact on the possibility to bring out nuances in the analysis. Further, we did not have the opportunity to pose following up questions.

This study was performed in Norway. Healthcare service provision differs across countries, which should be taken into account in terms of the transferability of the results. However, children's experiences related to parental illness will have transfer value despite any differences in health services and other relevant contexts.

In-depth interviews with children of different age groups and parental illness groups about their most difficult challenges should be performed to further explore the results of the present study. Internationally, over the past decade there has been substantial focus on children's needs when parents are ill. Several countries have introduced national guidelines for the health services on this. However, evaluations on whether these guidelines are followed remains, as well as whether these guidelines meet the children's needs. Further qualitative research is needed concerning what children with a severely ill parent perceive as helpful support as well as randomised, controlled implementation studies on the effect of such support for the children, families and the health services, respectively.

In conclusion, this study's results indicate that the most difficult challenge experienced by children with a severely ill parent implies life unfoldment challenges and include negative personal and relational impact, challenging life events and obstacles in welfare. The findings emphasise that the characteristics of their most difficult challenges in times of emergency, often faced with the

threat of death, may affect their unfolding in life if they do not receive the necessary support to release the tension these challenges imply.

Acknowledgements

The authors are grateful to the participants who shared their experiences. We also wish to thank Akershus University Hospital, VestreViken Hospital Trust, Sørlandet Hospital HF, Stavanger University Hospital, Rogaland A-senter and Nordland Hospital Trust for their assistance in recruitment of participants for the study. We are also grateful to those who assisted us in the data collection. We are grateful to the Regional Center for Child and Adolescent Mental Health Eastern and Southern Norway for technical support in collection of data and to Barns-Beste (the Norwegian Competence Network for children as next of kin) for their initiative to and support during the study.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication

of this article: The study was funded by The Norwegian Research Council [grant number 213477/H10]; The Norwegian Directorate of Health [grant number 12/7937]; and the participating Health Trusts.

Conflicts of interest

The authors declare that there is no conflict of interest.

Author contributions

TR, BW, EKK, EK and AF made substantial contributions to conception and design. EKK, EK and BW acquired the data. AF, BW, EK and MH did the analysis and interpretation of data. AF and BW drafted and revised the manuscript. EK, EKK, MH and TR revised it critically. All authors gave final approval of the version to be published. Each author has participated sufficiently in the work to take public responsibility for appropriate portions of the content. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

References

- Weimand BM, Hedelin B, Hall-Lord ML, Sallstrom C. "Left alone with straining but inescapable responsibilities:" relatives' experiences with mental health services. *Issues Ment Health Nurs* 2011; 32: 703–10.
- Foster K. 'You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness. *J Clin Nurs* 2010; 19: 3143–51.
- Hall M, Sikes P. "It would be easier if she'd died": young people with parents with dementia articulating inadmissible stories. *Qual Health Res* 2017; 27: 1203–14.
- Werner A, Malterud K. Children of parents with alcohol problems performing normality: a qualitative interview study about unmet needs for professional support. *Int J Qual Stud Health Well-being* 2016; 11: 30673.
- Lander L, Howsare J, Byrne M. The impact of substance use disorders on families and children: from theory to practice. *Soc Work Public Health* 2013; 28: 194–205.
- Phillips F, Lewis FM. The adolescent's experience when a parent has advanced cancer: a qualitative inquiry. *Palliat Med* 2015; 29: 851–8.
- Pedersen S, Revenson TA. Parental illness, family functioning, and adolescent well-being: a family ecology framework to guide research. *J Fam Psychol* 2005; 19: 404–19.
- Newland LA. Family well-being, parenting, and child well-being: Pathways to healthy adjustment. *Clin Psychol* 2015; 19: 3–14.
- Bronfenbrenner U. Ecology of the family as a context for human development: research perspectives. *Dev Psychol* 1986; 22: 723–42.
- Chen CY-C. Effects of parental chronic illness on children's psychosocial and educational functioning: a literature review. *contemporary school. Psychology* 2017; 21: 166–76.
- Pakenham KI, Cox S. The effects of parental illness and other ill family members on the adjustment of children. *Ann Behav Med* 2014; 48: 424–37.
- Stein A, Ramchandani P, Murray L. Impact of parental psychiatric disorder and physical illness. In *Rutter's Child and Adolescent Psychiatry*, 5th edn (Rutter M, Bishop D, Pine D, Scott S, Stevenson J, Taylor E, Thapar A eds), 2008. Blackwell Publishing Ltd, Oxford, UK, 407–20.
- Sroufe LA, Coffino B, Carlson EA. Conceptualizing the role of early experience: lessons from the Minnesota longitudinal study. *Dev Rev* 2010; 30: 36–51.
- Arestedt L, Persson C, Benzein E. Living as a family in the midst of chronic illness. *Scand J Caring Sci* 2014; 28: 29–37.
- Stoeckel M, Weissbrod C, Fogarty CT, Mauksch L. Growing up with an ill parent: an examination of family characteristics and parental illness features. *Fam Syst Health* 2015; 33: 356–62.
- Kieffer-Kristensen R, Siersma VD, Teasdale TW. Family matters: parental-acquired brain injury and child functioning. *NeuroRehabilitation* 2013; 32: 59–68.
- Rutter M. Resilience as a dynamic concept. *Dev Psychopathol* 2012; 24: 335–44.
- Rutter M. Pathways from childhood to adult life. *J Child Psychol Psychiatry* 1989; 30: 23–51.
- Myrvoll LR, Lund K, Kufås E. Foreldre med psykiske problemer. Om å styrke muligheter for vekst og redusere belastninger for barn og ungdom. *Tidsskrift for psykisk helsearbeid*. 2004; 1: 35–48.

- 20 Weimand B, Birkeland B, Ruud T, Høie M. "It's like being stuck on an unsafe and unpredictable roller-coaster": experiencing substance use problems in a partner. *Nordisk Alkohol Nark* 2020; 37: 227–42.
- 21 Forrest G, Plumb C, Ziebland S, Stein A. Breast cancer in young families: a qualitative interview study of fathers and their role and communication with their children following the diagnosis of maternal breast cancer. *Psychooncology* 2009; 18: 96–103.
- 22 Hirsch BJ, Moos RH, Reischl TM. Psychosocial adjustment of adolescent children of a depressed, arthritic, or normal parent. *J Abnorm Psychol* 1985; 94: 154–64.
- 23 Hafting M, Gullbra F, Anderssen N, Rortveit G, Smith-Sivertsen T, van Doesum K. Overcoming clinician and parent ambivalence: general practitioners' support of children of parents with physical or mental illness and/or substance abuse. *Front Psychiatr* 2018; 9: 724.
- 24 Leinonen JA, Solantaus TS, Punamaki RL. Parental mental health and children's adjustment: the quality of marital interaction and parenting as mediating factors. *J Child Psychol Psychiatry* 2003; 44: 227–41.
- 25 Compas BE. Stress and life events in childhood and adolescence. *Clin Psychol Rev* 1987; 7: 275–302.
- 26 Masten AS, Neeman J, Andenas S. Life events and adjustment in adolescents: the significance of event dependence, desirability, and chronicity. *J Res Adolesc* 1994; 4: 71–97.
- 27 Pfeffer CR, Karus D, Siegel K, Jiang H. Child survivors of parental death from cancer or suicide: depressive and behavioral outcomes. *Psychooncology* 2000; 9: 1–10.
- 28 Phillips F. Adolescents living with a parent with advanced cancer: a review of the literature. *Psychooncology* 2014; 23: 1323–39.
- 29 Melcher U, Sandell R, Henriksson A. Maintaining everyday life in a family with a dying parent: teenagers' experiences of adapting to responsibility. *Palliat Support Care* 2015; 13: 1595–601.
- 30 Davey MP, Tubbs CY, Kissil K, Nino A. 'We are survivors too': African-American youths' experiences of coping with parental breast cancer. *Psychooncology* 2011; 20: 77–87.
- 31 Phillips F. The experience of adolescents who have a parent with advanced cancer: a phenomenological inquiry. *Palliat Support Care* 2015; 13: 1057–69.
- 32 Walczak A, McDonald F, Patterson P, Dobinson K, Allison K. How does parental cancer affect adolescent and young adult offspring? A systematic review. *Int J Nurs Stud* 2018; 77: 54–80.
- 33 Werner A, Malterud K. Encounters with service professionals experienced by children from families with alcohol problems: a qualitative interview study. *Scand J Public Health* 2016; 44: 663–70.
- 34 O'Brien L, Anand M, Brady P, Gillies D. Children visiting parents in inpatient psychiatric facilities: perspectives of parents, carers, and children. *Int J Mental Health Nurs* 2011; 20: 137–43.
- 35 MacEachnie LH, Larsen HB, Egerod I. Children's and young people's experiences of a parent's critical illness and admission to the intensive care unit: a qualitative meta-synthesis. *J Clin Nurs* 2018; 27: 2923–32.
- 36 Martinsen EH, Weimand BM, Pedersen R, Norvoll R. The silent world of young next of kin in mental health care. *Nurs Ethics* 2019; 26: 212–23.
- 37 Yamamoto R, Keogh B. Children's experiences of living with a parent with mental illness: a systematic review of qualitative studies using thematic analysis. *J Psychiatr Ment Health Nurs* 2018; 25: 131–41.
- 38 Trondsen MV. Living with a mentally ill parent: exploring adolescents' experiences and perspectives. *Qual Health Res* 2012; 22: 174–88.
- 39 Haug Fjone H, Ytterhus B, Almvik A. How children with parents suffering from mental health distress search for 'normality' and avoid stigma: To be or not to be ... is not the question. *Childhood* 2009; 16: 461–77.
- 40 Wong M, Ratner J, Gladstone KA, Davtyan A, Koopman C. Children's perceived social support after a parent is diagnosed with cancer. *J Clin Psychol Med Settings* 2010; 17: 77–86.
- 41 Trondsen MV, Tjora A. Communal normalization in an online self-help group for adolescents with a mentally ill parent. *Qual Health Res* 2014; 24: 1407–17.
- 42 Mauseth T, Hjalnhult E. Adolescents' experiences on coping with parental multiple sclerosis: a grounded theory study. *J Clin Nurs* 2016; 25: 856–65.
- 43 Dam K, Hall EO. Navigating in an unpredictable daily life: a metasynthesis on children's experiences living with a parent with severe mental illness. *Scand J Caring Sci* 2016; 30: 442–57.
- 44 Morris JN, Martini A, Preen D. The well-being of children impacted by a parent with cancer: an integrative review. *Support Care Cancer* 2016; 24: 3235–51.
- 45 Razaz N, Nourian R, Marrie RA, Boyce WT, Tremlett H. Children and adolescents adjustment to parental multiple sclerosis: a systematic review. *BMC Neurol* 2014; 14: 107.
- 46 Rose HD, Cohen K. The experiences of young carers: a meta-synthesis of qualitative findings. *J Youth Stud* 2010; 13: 473–87.
- 47 Chikhradze N, Knecht C, Metzger S. Young carers: growing up with chronic illness in the family – a systematic review 2007–2017. *J Compassionate Health Care* 2017; 4. <https://doi.org/10.1186/s40639-017-0041-3>
- 48 Moore T, McArthur M, Noble-Carr D. Different but the same? Exploring the experiences of young people caring for a parent with an alcohol or other drug issue. *J Youth Stud* 2011; 14: 161–77.
- 49 Ruud T, Birkeland B, Faugli A, Hagen A, Hellman A, Hilsen M, Kallander EK, Kufås E, Løvås M, Peck GC, Skogerbø Å, Skogoy BE, Stavnes K, Thorsen T, Weimand BM. *Barn som pårørende – Resultater fra en multisenterstudie Lorenskog*. 2015, Akershus Universitetssykehus, Norway.
- 50 Kallander EK, Weimand BM, Becker S, Van Roy B, Hanssen-Bauer K, Stavnes K, Faugli A, Kufås E, Ruud T. Children with ill parents: extent and nature of caring activities. *Scand J Caring Sci* 2017; 32: 793–804.
- 51 Birkeland B, Weimand BM, Ruud T, Høie MM, Vederhus JK. Perceived quality of life in partners of patients undergoing treatment in somatic health, mental health, or substance use disorder units: a cross-sectional study. *Health Qual Life Outcomes* 2017; 15: 172.

- 52 Kallander EK, Weimand B, Ruud T, Becker S, Van Roy B, Hanssen-Bauer K. Outcomes for children who care for a parent with a severe illness or substance abuse. *Child Youth Serv* 2018; 39: 228–249.
- 53 Birkeland B, Foster K, Selbekk AS, Hoie MM, Ruud T, Weimand B. The quality of life when a partner has substance use problems: a scoping review. *Health Qual Life Outcomes* 2018; 16: 219.
- 54 Kallander EK, Weimand BM, Hanssen-Bauer K, Van Roy B, Ruud T. Factors associated with quality of life for children affected by parental illness or substance abuse. *Scand J Caring Sci* 2020. <https://doi.org/10.1111/scs.12868>
- 55 Skogoy BE, Ogden T, Weimand B, Ruud T, Sorgaard K, Maybery D. Predictors of family focused practice: organisation, profession, or the role as child responsible personnel? *BMC Health Serv Res* 2019; 19: 793.
- 56 Hagen KA, Hilsen M, Kallander EK, Ruud T. Health-related quality of life (HRQoL) in children of ill or substance abusing parents: examining factor structure and sub-group differences. *Qual Life Res* 2018; 28: 1063–1073.
- 57 Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs* 2008; 62: 107–15.
- 58 Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. *Educ Commun Technol J* 1981; 29: 75–92.
- 59 World Medical Association. World Medical Association Declaration of Helsinki ethical principles for medical research involving human subjects. *JAMA* 2013; 310: 2191–4.
- 60 Bogosian A, Moss-Morris R, Bishop FL, Hadwin J. How do adolescents adjust to their parent's multiple sclerosis? An interview study. *Br J Health Psychol* 2011; 16: 430–44.
- 61 Bostrom K, Nilsagard Y. A family matter—when a parent is diagnosed with multiple sclerosis. A qualitative study. *J Clin Nurs* 2016; 25: 1053–61.
- 62 Mordoch E, Hall WA. Children's perceptions of living with a parent with a mental illness: finding the rhythm and maintaining the frame. *Qual Health Res* 2008; 18: 1127–44.
- 63 Umberger W, Martsof D, Jacobson A, Risko J, Patterson M, Calabro M. The shroud: ways adolescents manage living with parental chronic pain. *J Nurs Scholarsh* 2013; 45: 344–54.
- 64 Tinnfält A, Eriksson C, Brunberg E. Adolescent children of alcoholics on disclosure, support, and assessment of trustworthy adults. *Child Adolesc Soc Work J* 2011; 28: 133–51.
- 65 Buchwald D, Delmar C, Schantz-Laursen B. How children handle life when their mother or father is seriously ill and dying. *Scand J Caring Sci* 2012; 26: 228–35.
- 66 Wangensteen T, Bramness JG, Hals A. Growing up with parental substance use disorder: the struggle with complex emotions, regulation of contact, and lack of professional support. *Child Fam Soc Work* 2018; 24: 201–8.
- 67 Wangensteen T, Hals A, Bramness JG. Creating meaning to substance use problems: a qualitative study with patients in treatment and their children. *J Subst Use* 2020; 25: 1–5.
- 68 Thastum M, Johansen MB, Gubba L, Olesen LB, Romer G. Coping, social relations, and communication: a qualitative exploratory study of children of parents with cancer. *Clin Child Psychol Psychiatry* 2008; 13: 123–38.
- 69 Macy MA. Through the eyes of child: reflections on my mother's death from cancer. *J Pain Palliat Care Pharmacother* 2013; 27: 176–8.
- 70 Karlsson E, Andersson K, Ahlström B. Loneliness despite the presence of others – adolescents' experiences of having a parent who becomes ill with cancer. *Eur J Oncol Nurs* 2013; 17: 697–703.
- 71 Bartfai Jansson K, Anderzen-Carlsson A. Adolescents' perspectives of living with a parent's cancer: a unique and personal experience. *Cancer Nurs* 2017; 40: 94–101.
- 72 Haugland BSM. Recurrent disruptions of rituals and routines in families with paternal alcohol abuse. *Fam Relat* 2005; 54: 225–41.
- 73 Lunde I, Myhre Reigstad M, Frisch Moe K, Grimholt TK. Systematic literature review of attempted suicide and offspring. *Int J Environ Res Public Health* 2018; 15: 937.
- 74 Grimholt TK, Lunde I, Frisch Moe K. Barn som pårørende etter selvmordsforsøk. *Tidsskrift for Norsk psykologforening* 2019; 56: 20–7.
- 75 Eide T, Faugli A, Kufås E, Mjøsund NH, Eilertsen G. Mental health as perceived by Norwegian adolescents living with parental somatic illness: living in an earthquake zone. *Int J Qual Stud Health Well-being* 2020; 15: 1783064.
- 76 Grove C, Reupert A, Maybery D. The perspectives of young people of parents with a mental illness regarding preferred interventions and supports. *J Child Fam Stud* 2016; 25: 3056–65.