Received: 2 April 2024 | Accepted: 21 October 2024

DOI: 10.1111/scs.13310

Scandinavian Journal of Caring Sciences

ORIGINAL ARTICLE

Support needed by parents when a child's mental well-being is threatened—A qualitative study of views of experts-by-experience

Putkuri Tiina MHSc, MAEd, RN, PHN, Senior Lecturer, Doctoral Researcher[1,2] |
Latva-Korpela Irene MHSc, RN, PHN, Senior Lecturer[1] |
Häkkinen Mikko PhD, RN, PHN, Principal Lecturer[1]

[1]Laurea University of Applied Sciences, Vantaa, Finland

[2]Department of Nursing Science, University of Turku, Turku, Finland

Correspondence
Putkuri Tiina, Laurea University of Applied Sciences, Vantaa, Finland.
Email: tiina.putkuri@laurea.fi

Funding information
Opetus- ja Kulttuuriministeriö

Abstract

Background: In situations where a child's mental well-being is threatened, the parents also need support. The available support has been perceived as insufficient by both parents and professionals.

Aim: To explore the views of experts-by-experience of the support needed by parents when a child's mental well-being is threatened.

Methods: A qualitative study with a phenomenological approach was conducted in Finland. The data were collected in six focus group interviews during the autumn of 2022. The participants ($n = 26$) were adult experts-by-experience who had experienced either mental well-being challenges in their own childhood (before the age of 18 years) or experienced the mental well-being challenges of a child from the role of a parent. The data were analysed using inductive content analysis.

Results: The support needed by parents in situations where the mental well-being of their child is at risk consists of support for parenting, support for sharing and support for surviving.

Conclusion: Parents whose child's mental well-being is at risk, need support both for their own well-being and for their ability to support their child's well-being. Support is needed not only from professionals but also from peers.

KEYWORDS

adolescent, child, expert-by-experience, mental health, mental well-being, parent, peer support, qualitative study

INTRODUCTION

Mental health-related problems are one of the most significant global issues [1], and it is noteworthy that the majority of these problems emerge before adulthood [2]. They affect a considerable percentage of families: both children and their parents. It has been estimated that up to 15% of children and adolescents have been diagnosed with a mental disorder [3]. A significantly larger proportion experience various threats to mental well-being; for

instance, in Finland, up to one-third of adolescent girls report considerable anxiety, and only just over half express satisfaction with their lives [4].

The mental health of children and adolescents has often been examined from the perspective of illness, namely mental disorders. However, mental health can also be examined from the perspective of health. A term often used from this perspective is positive mental health or mental well-being. Positive mental health is defined as 'a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community' [5]. Mental disorder and mental well-being are not mutually exclusive; an individual may concurrently experience both mental well-being as well as mental disorders. However, a high level of mental well-being can prevent mental disorders. [5, 6] In this article, we examine the support needed by parents when their child's mental well-being is threatened. The threat to mental well-being is not dependent on the state of mental health, that is, whether the child exhibits symptoms related to mental health or has been diagnosed with mental health problems. The term child refers to a person who is in the position of a child in relation to their parent, and not strictly defined as being based on a specific age limit.

In previous studies, parents have raised various support needs in situations where their child's mental well-being is threatened and also that the support is needed as early as possible [7]. The problems parents face, for instance, are that they may not know where to seek help for their child [7, 8], or they may lack the energy to seek assistance [8]. In addition, they may want information about their child's symptoms and potential diagnosis, as well as ways to help their child [9–11]. Parents have also expressed a desire for training in children's mental health issues, including how to differentiate between normal development and emerging problems [12]. Parents often fail to recognise their child's symptoms in the early stages [13]. Parents need information and concrete advice when trying to help their children with mental health issues [11, 14, 15].

Parents may experience strong feelings of guilt and helplessness regarding their child's mental health issues [9, 10, 13]. Some parents have perceived professionals as either exhibiting a blaming attitude [7] or disregarding their perspective [7, 16]. The response from professionals that parents require, however, is an empathetic attitude and a demonstration of compassion [10]. Parents often feel that they have not been heard or their views have not been valued [16]. The desire of the parents is to have the opportunity to be heard in matters that affect their child [10]. Many parents have found it beneficial to have the possibility to discuss their experiences with peers, that is, people who have gone through similar situations [9, 10, 12, 17]. In addition to sharing their own experiences, parents can also reciprocate by supporting others in peer support groups; an experience the parents found to be essential [9]. Peer support is also needed by parents at an early phase, possibly even before the diagnosis [17].

In summary, parents perceive the support currently provided as insufficient [13], a sentiment shared by many professionals as well [10]. In several recent studies concerning the support needed by parents of children with mental health issues, the informants have exclusively been either the parents [e.g. 9, 10] or the professionals [e.g. 10]. Furthermore, these studies have often focused on specific conditions such as depression [13], eating disorders [9] or obsessive-compulsive disorder [10]. In this study, we aimed to examine the support needed by the parents from both the parent's and the child's perspectives, regardless of the child's diagnosis. Thus, the aim of this study was to explore the views of experts-by-experience on the support needed by parents when a child's mental well-being is threatened.

METHODS

Design

The study was conducted with a cross-sectional, qualitative design and phenomenological approach. The phenomenological approach [18] was applied to achieve in-depth insight into the lived experiences of the participants. In phenomenology, the focus is on the essence and meaning of a phenomenon [18]. In this study, the phenomenon of interest was the support needed by parents in situations where a child faces mental well-being challenges. Participants had personal experience with the phenomenon either from the child's or the parent's perspective.

In phenomenology, it is essential to consider the researchers' pre-understanding of the subject [18]. In this study, the pre-understanding was particularly influenced by the researchers' backgrounds as public health nurses, which fostered a holistic approach to well-being and a focus on health promotion and disease prevention. Beyond their profession and work experience as public health nurses, the research team also possessed relevant expertise and experience in working with families within psychiatric specialised care settings, as well as psychotherapeutic skills. Additionally, the researchers' current roles as nursing educators have influenced their pre-understanding. In hermeneutic phenomenology, the primary goal is not to describe individual experiences but to identify the essential structures of meaning related to the phenomenon

[18]. The researchers' pre-understanding was acknowledged and utilised in the process of interpretation.

Setting, sample and recruitment

This study was conducted as a part of the Research, Development, and Innovation (RDI) project of the Finnish University of Applied Sciences. The overall aim of this project was to develop solutions to the challenges of social exclusion and inequality. In this sub-study of the project, a broader dataset was collected. In this article, it is addressed from the perspective of the support needed by parents. The original plan was to conduct separate interviews for participants representing the perspectives of children and parents. However, this approach was not feasible because many participants had lived experience from both perspectives. As a result, the topic was examined from the perspective of the support needed by the child (reported previously [19]) and from the perspective of the support needed by the parent (reported in this paper).

A convenience sampling was used to obtain adult experts-by-experience who had first-hand experience of either (1) threats to their mental health as a child or adolescent or (2) threats to the mental health experienced by their underaged child. In this study, we refer to an expert-by-experience, as defined by the Central Union for Child Welfare, [20] as a person who, based on personal experiences and peer group discussions, seeks to influence an issue through a common voice of experience. A trained expert-by-experience is a person who has undergone training in order to function as a proficient specialist [21]. Both the trained and non-trained experts-by-experience were invited to be interviewed.

Trained experts-by-experience were preferred as participants because they had both personal experience and broader insights into the topic gained through their training. Additionally, it was assumed that they had processed their own experiences during the training; thus, reducing the risk of emotional distress caused by the interview.

We contacted participants through an association of trained experts-by-experience. In addition, the participants were also accessed through NGOs and social media. Contact information was submitted electronically by those interested ($n=40$) in becoming participants. All registered participants ($n=40$) were sent information about the available interview times. A total of 26 participants attended the interviews.

One of the authors (TP) contacted all those interested by e-mail and asked them to give consent to participate in the study (electronically) and to choose a suitable interview time. In total, 26 experts-by-experience participated. Most of these participants had completed the expert-by-experience training, had experience with the phenomenon from the perspective of a child; the majority had a gap of over 10 years since their personal experience (Table 1).

Data collection

The data were collected in six focus group interviews during autumn 2022. Six focus groups are usually sufficient to achieve saturation; after four focus groups, over 90% of the

TABLE 1 Characteristics of participants ($n=26$).

Characteristics	*n*
Status concerning the expert-by experience training	
• Trained	23
• Non-trained	3
Experience from the perspective of:	
• a child	19
• a parent	3
• both	4
Age (25–68 years)	
• 21–30 years	4
• 31–40 years	9
• 41–50 years	4
• 51–60 years	3
• over 60 years	1
• data missing	5
Time since personal experience	
• under 1 year	3
• 1–5 years	3
• 6–10 years	3
• over 10 years	17

final codes are usually identified [22]. The interviews were conducted remotely. Each author (TP, ILK and MH) conducted at least one interview together with a master's degree student (CF, OR and RS). There were three to seven participants in each group. The interviews lasted from one to one and a half hours.

At the beginning of the interview situation, the interviewers told their professional backgrounds and the participants filled out the electronic background questionnaire. The background information was collected anonymously and was only used to describe the group of participants. Three topics were used to guide the semi-structured interviews (Table 2). There was no pilot interview. The participants received a fee for participating in the interview according to the recommendation of the Association of Trained Experts-by-Experience. [23] The interviews were recorded with the permission of the participants. A third party transcribed the audio recordings as an outsourced service. The transcription consisted of 167 pages (Calibri, font size 12). The interview invitation was accompanied by the Informed Consent Document and the Privacy Statement.

Data analysis

The data were analysed by inductive content analysis with the help of nVivo software. [24] Initially, the transcribed data was read through several times to achieve an understanding of its entirety. Meaningful expressions corresponding to the research questions were extracted from the data. All three authors took part in data coding. We found a total of 149 meaningful expressions from the data. The extracted expressions were reduced and grouped into subcategories based on the similarity of the content. We formed 10 subcategories, which were named to describe the content. The analysis then continued to a more abstract level: the subcategories were further combined into three main categories. [25] An example of the analysis is provided in Table 3. During the analysis, we repeatedly returned to the original material for greater credibility. Additionally, in the early phase of the analysis, the very preliminary results were reviewed with the participants in two separate group meetings to increase credibility. The preliminary results were presented to the participants, and they were asked estimate how well the results corresponded to their initial intention.

Ethical considerations

The research was conducted following the Finnish code for responsible conduct of research [26] and the national guidelines of The Finnish Advisory Board on Research Integrity [27]. In addition, when working with experts-by-experience, specific ethical guidelines [20] were followed. At the beginning of the interview session, participants

TABLE 2 The interview guide.

Topic	Examples of questions
Support provided to children or adolescents	• At what stage do you think support should be provided for a child or adolescent who has mental well-being challenges? Who should offer this support? • In your opinion, what are the strengths of the currently available support? What are the weaknesses?
Support provided to parents	• At what stage do you think support should be offered to a parent whose child is facing challenges in mental well-being? Who should provide this support? • What kind of support would be beneficial for the parent? • In your opinion, what are the strengths of the currently available support? What are the weaknesses?
Peer support for children adolescents or parents	• What do you think is the role of peer support in situations where a child is facing challenges in mental well-being? • In your opinion, what are the strengths of the peer support services currently provided? What are the weaknesses? • What changes do you think would be beneficial in this regard?

TABLE 3 Coding tree.

Meaningful expression	Subcategory	Main category
'If the whole family had been taken into account, perhaps the parents could have been better informed as well'.	Family Work	Support for parenting
'With every diagnosis, there should come psychoeducation for the individual receiving the diagnosis, as well as for the parents'.	Psychoeducation	

were informed about the purpose of the interview and how the data would be used. It was emphasised that the discussions were confidential, and while everyone was encouraged to participate, there was no obligation to do so. There were two interviewers present to enhance the safety of the situation, both of whom had professional expertise in mental health support.

The research plan was discussed in the Human Sciences Ethics Committee of the Helsinki Metropolitan Area Universities of Applied Sciences, which concluded that there was no need for Ethical Approval for the study in the Finnish context. The research was conducted in such a way that the dignity and autonomy of participants were respected. The COREQ checklist [28] guided the reporting.

RESULTS

The support needed by parents in situations where the mental well-being of their child is at risk consists of support for parenting, support for sharing and support for surviving (Figure 1).

Support for parenting

Support for parenting consisted of (1) prevention based on the risk factors threatening the well-being of the child, (2) involving the parents in their child's situation, (3) family work and (4) providing psychoeducation for parents.

According to the interviewees, it is important to provide support as soon as the **risk factors** are detected, and not delay until the actual problems occur. Situations where support was only available after the child had received a diagnosis were seen as problematic. By addressing risk factors, it was thought that it might even be possible to prevent the onset of future mental health problems. The risk factors mentioned in the interviews were, for example, the parent's poor emotional skills, divorce situations and physical punishment. In addition, there was a desire for non-stigmatised support, such as information on factors supporting mental well-being generally to be offered at maternity and child health clinics or parents' evenings at schools. Moreover, it was considered important to intervene in situations through child welfare interventions.

> 'My parents would have needed help, but already when I was very little, to avoid, for example, physical punishment and all the other bad things escalated from it'
>
> (FG1).

Involving parents in their child's situation was seen as crucial. Professionals were needed to involve parents more actively in situations. Involvement included providing parents with information about their child's situation, the opportunity to participate in the child's meetings with a professional, and the opportunity to be heard in their child's case. Without information about their child's situation, it is difficult for a parent to support their own child. The right of non-custodial parents to be involved in their child's affairs was also highlighted. The parents were seen to have essential information about their child, and acknowledging it was also thought to benefit the professional supporting the child. Nevertheless, parental involvement was not intended to jeopardise the child's right to privacy. It was considered important to agree together on what matters were appropriate to discuss with the parents.

> 'Of course, she didn't summarize their conversations to me, that's not what should be done, but I was able to share my concerns with them [...] I thought, the result was really good, that the psychotherapist knew my thoughts and of course knew my daughter's thoughts, so she could do her job much better [...] It's horrible if parents are put aside'
>
> (FG4).

Family work meant discussing the child's situation with parents and siblings and, if necessary, working on the child–parent relationship. Family work was seen as an opportunity, firstly, to identify background factors that threaten the child's mental well-being or, for example,

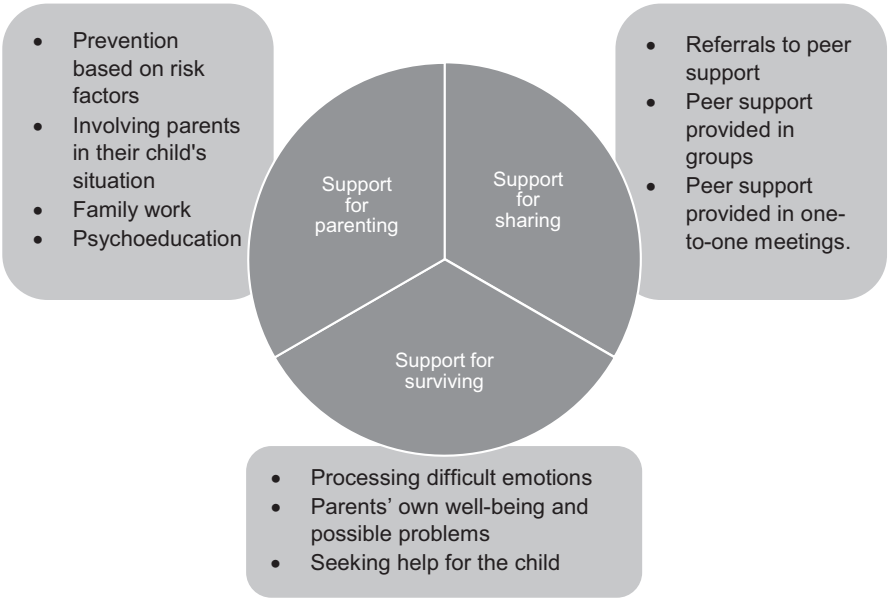

FIGURE 1 The support needed for parents in situations where the mental well-being of their child is at risk.

prevent the relief of symptoms, and, secondly, to offer support to the whole family. Family work was seen as an opportunity to increase the emotional skills of the whole family, support the family members efforts to discuss difficult issues, and help them better understand each other. If a parent is unwilling to participate in their child's meetings for some reason, family work could be the solution.

> 'My parents' line was that they don't understand and don't know what this is about, that it doesn't belong to them, and they have no interest in even finding it out. It would be so important for that parent to make it clear what the situation is, what causes the things, and what they can do about it. The problem should somehow be made so visible to those parents who may be in a situation where they refuse to understand and do not want to understand any part. In my opinion, that would be crucial' (FG3).

Providing **psychoeducation** to parents was considered essential. According to the interviewees, the parent should be provided with information about the situation, possible symptoms or diagnosis, treatment options, and how the situation can affect the life of the child and the whole family. Providing psychoeducation was seen as valuable because parents want to understand how they can help and support their children.

> 'It does not help much if the child, or teenager, is experiencing that turmoil alone without the family being taught about it in any way' (FG1).

Support for sharing

Support for sharing consisted of (1) referrals to peer support, (2) providing peer support in a group form and (3) providing peer support in one-to-one meetings.

When the child's mental well-being is at risk, it was considered paramount to **refer parents to peer support** to share their situation with others who have experienced similar circumstances. Interviewees hoped that professionals would actively refer parents towards peer support provided by third-sector organisations and other providers. Many of the interviewees pointed out that information on the possibility of peer support is rarely available. In most cases, peer support has been found by accident through some means other than professional guidance.

> 'Information can be found, and help is available if you have the energy to search. But it can sometimes be a bit behind a rock. And about organizations, you may only hear about them through someone you know, or when the situation has already progressed very far' (FG6).

The peer support requested was hoped to be made available in traditional **peer support group** settings. Professionals were also requested to participate in facilitating peer support groups together with experts-by-experience. According to the interviewees, peer support groups for those speaking foreign languages should also be available. Online groups enabling anonymous participation were also seen as beneficial. For some parents, the opportunity to simply listen to others' stories without the obligation to share their situation may be a prerequisite for participation. A particular advantage of peer support

in a group form was that it would allow participants to hear each other's experiences.

> 'There are so many supportive stories out there. We've had this situation sometimes and then like this... Parents whose child has just been diagnosed will surely have very heavy thoughts about how to survive. Peer support will help with that.'
>
> (FG6).

Peer support was also needed for parents in the form of **one-to-one meetings**, which could be provided by experts-by-experience working in health care or by NGO actors. In the interviews, it was pointed out that not everyone likes group activities, and the possibility of one-to-one discussion is necessary in these cases.

> 'Only with one person, conversation privately with one person, and not necessarily just in a big group.'
>
> (FG6).

Support for surviving

Support for surviving included support for (1) processing shame and other difficult emotions, (2) addressing the parent's own well-being and possible problems and (3) seeking help for the child.

Interviewees highlighted that parents may need **support for processing difficult emotions**. A parent may experience feelings of guilt or shame about the situation and feel they have failed in some way as a parent when their child is not doing well. In the interviews, it was also highlighted that sometimes the parties offering help to the child may, intentionally or unintentionally, increase feelings of guilt with their comments. For some parents, it may be difficult to accept the child's situation and symptoms. According to the interviewees, support for processing difficult emotions should be offered more actively than is currently the case.

> 'A place where I can call and say, 'We're in this situation' or 'I'm feeling this way,' and ask what I can do so that I don't take it out on my already poorly feeling child'
>
> (FG2).

The interviewees also hoped that it would be possible for parents to receive support for their **own well-being and possible problems**. It was believed that the resources of parents would be reflected in the child's well-being. Interviewees emphasised that no parent should be left alone to cope with a situation where their own child is not doing well. The situation is stressful even without the parent's own problems, and if there are any, they are a further burden for both the parent and the child. These problems can be, according to the interviewees, for example, substance abuse problems or mental health issues. If left untreated, these can make it difficult for the parent to support their child.

> 'Relatives should also receive support for their well-being. Proactively and as early as possible.'
>
> (FG6).

The distress regarding one's own child's well-being can be considerable, but parents may not necessarily know where to **seek help for their child**. They can easily become confused in the service jungle. Centralised service guidance was suggested as a solution, meaning that one person should have control over all the services available to the child and the family. The current situation, where each organisation provides separate service guidance, was not considered optimal. Case management was requested to provide timely information on available services and how to apply for them. Service guidance was also seen as possibly being provided digitally, as long as it functions and can direct the parent to the appropriate service. It was hoped that service guidance would also cover the services provided by the third sector, such as those offered by non-governmental organisations. In addition, information about financial support is also felt to be necessary.

> 'We have tried to seek help, but we've always been told that this is the wrong place, so we haven't been directed anywhere'
>
> (FG2).

DISCUSSION

The aim of this study was to explore the views of experts-by-experience on the support needed by parents when a child's mental well-being is threatened. Our findings indicate that parents need support in parenting, sharing, and surviving. The findings both confirm previous research and enhance understanding of the topic.

Our findings regarding support for parenthood corroborate previous studies. For example, parents' desire for psychoeducation, namely, obtaining information about their child's symptoms and strategies to alleviate them, has also been highlighted also in earlier research by Calaveri et al. [29], by Grennan et al. [9] and Graaf et al. [11]. Moreover,

the need for family work supporting parents' role has been expressed in previous studies, such as in the study by Sowden et al. [10]. In addition to confirming previous findings, our results also reveal novel insights into the topic. Previous studies [e.g. 9, 10, 13] have examined parents' needs for support at the point when a child already has a mental health diagnosis. Support for parents might be beneficial at an early point, before problems escalate to severe levels. When providing support, it is essential to consider the individual needs of families and the potential risk of stigmatisation. Unfortunately, support has often only been considered when the child exhibits symptoms in some way. In contrast, the interviewees in our study emphasised the importance of prevention based on risk factors. It would be both humane and economically sound to support parents early [30], as suggested by our findings, and strive to prevent the onset of mental health issues.

Our results regarding the importance and meaning of sharing, togetherness and peer support are similar to previous studies. It has been shown that peer support between parents has many positive effects in a situation where a child has mental well-being challenges, other disabilities or additional needs [9, 31–33]. Peer support is very meaningful because only a peer can really understand and identify with the situation that parents are dealing with [9, 32, 34]. It has been identified that parents need practical advice on how to act in matters of their child's well-being and how to help their child. Peer support is one source for obtaining advice as well as giving hope for a better future [9, 31, 35].

Our results showed that peer support was desired both in group meetings and in individual appointments. Based on the previous studies, there is not sufficient evidence concerning the effect of peer support whether it is offered in groups or individually. Further research is needed to discover and develop the effect of peer support offered to parents on promoting children's mental health. [29, 31, 36] Typically, parental peer support is offered when symptoms already exist or a diagnosis made instead of concentrating on prevention [29]. In the future, it is worth considering whether peer support for parents could be utilised more effectively at the stage when risk factors are identified, even before symptoms appear.

Our study indicates that parents need support in surviving: for processing difficult emotions, their own well-being, and seeking help for their children. These results are in line with previous studies. For example, parents' feelings of shame and guilt have also been identified earlier [9, 10], as well as the importance of parents' well-being [9, 11]. Graaf and colleagues [11] drew attention to the fact that it is important to take care of parents' well-being even when parents do not have any specific problems of their own. In previous studies, parents have experienced being left alone while seeking help for their children [7, 10]. As participants in our study suggested, having a designated support person to accompany them in the process would be important and could reduce parents' feelings of isolation and having to cope alone.

The results of our study demonstrate the psychological needs of human beings introduced in the self-determination theory presented by Deci and Ryan: competence, relatedness and autonomy [37]. According to this theory, people need a feeling of competence. This can be seen in the results of this study, which indicate that parents need support in their parenting in order to feel competent themselves about supporting their child. Furthermore, the need for relatedness is obvious in our results; parents need the possibility to share their experiences with others who have undergone similar situations. According to the theory, people also need a feeling of autonomy, which involves the desire to participate in decisions concerning themselves and to influence their own lives. This need can be observed in the parents' desire to be involved in their child's issues and to be heard by those in authority. Moreover, the need for support for surviving and coping with problems can also be seen as a need for autonomy; individuals do not want to be tired and passive bystanders in their own lives and the lives of their children but seek resources that allow them active participation.

STRENGTHS AND LIMITATIONS

In this study, trustworthiness has been examined from the perspectives of credibility, transferability, dependability or confirmability. Credibility was increased by the fact that the interviewees were trained experts-by-experience who had a personal, but also a broader understanding of the studied phenomenon. In addition, credibility was increased by the fact that the results of the study were given to the study participants for evaluation. The participants felt that the results described their insights well. As a limitation, many of the participants had a gap of several years since their personal experience. However, the participants noted that the services may have developed in line with their wishes over the years [18, 38, 39, 40].

The fact that some participants had retrospective child perspectives through the lens of a now adult can be seen as a strength or a limitation. The child's perspective provides a more comprehensive view of the phenomenon. However, the support a child wishes for a parent may differ from the parent's preferences. Nevertheless, understanding what support a child would like their parent to receive can be considered valuable when developing services. The preference for participants who had completed experts-by-experience training was intended to provide a

deeper perspective on the topic. However, this may have biased the results, particularly regarding peer support, as many participants were peer supporters.

The credibility of the study was strengthened by cooperation between three researchers in the data collection and analysis. In the analysis of the research material, the NVivo software was used, which helped to structure and manage the extensive material. During the analysis, returning to the original material was made simple with the help of a tool that structured the material [18, 41].

In this study, the transferability was considered by precisely describing the research process, which may be useful to other researchers. The factors described include the data collection and analysis. In addition, the questions in the focus group interview have been described openly. Although qualitative research does not strictly require transferability, the results of this study can be considered a representative description of the thoughts and experiences of the target group [18, 39].

Dependability during the research process was promoted and ensured through reflective dialogue between the researchers. The more careful the researchers are in the reflective examination of their perceptions, the more dependable the research results will be. Despite this, it cannot be completely discounted that the personal views of researchers will influence the results. [18] The analysis concluded that saturation had been achieved. As the analysis progressed, it was observed that the same content began to be repeated in the participants' responses. However, it must be remembered that saturation as a measure of the dependability of qualitative research has its limitations. Since the challenge is to verify saturation from the data other than by describing the saturation observed by the researcher, this can lead to some uncertainty about the matter. [42] The confirmability of the study was strengthened by a detailed description of the research process [18].

CONCLUSIONS

Our results indicate that parents whose child's mental well-being is at risk, need support both for their own well-being and for their ability to support their child's well-being. The results suggest that peer support may be beneficial for at least some parents.

AUTHOR CONTRIBUTIONS

Tiina Putkuri, Irene Latva-Korpela and Mikko Häkkinen were involved in the study design and performed the interviews. All authors performed the analysis and interpretation of data; Irene Latva-Korpela, Tiina Putkuri and Mikko Häkkinen were responsible for the writing of the manuscript. All authors have agreed on the final version of this manuscript.

ACKNOWLEDGEMENTS

We wish to warmly thank experts-by-experience who participated in the study. We also thank the students of the master's degree program at the Laurea University of Applied Sciences who participated in the data collection: Christina Forsberg, Olli Rauhala and Riitta Saarela. The research has been produced as part of the Empowering People towards Socially Inclusive Society RDI-project at Laurea University of Applied Sciences, funded by the Finnish Ministry of Education and Culture.

FUNDING INFORMATION

The study was carried out as part of the Empowering People towards Socially Inclusive Society, VoimaProfi profiling project funded by the Ministry of Education and Culture and implemented by Laurea University of Applied Sciences.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

All study participants provided informed consent. There was no need for Ethical Approval in the Finnish context (TENK 2023).

ORCID

Putkuri Tiina https://orcid.org/0000-0001-7729-1529
Latva-Korpela Irene https://orcid.org/0009-0002-8588-7888
Häkkinen Mikko https://orcid.org/0000-0002-4411-9017

REFERENCES

1. Rehm J, Shield KD. Global burden of disease and the impact of mental and addictive disorders. Curr Psychiatry Rep. 2019;21(2):10. https://doi.org/10.1007/s11920-019-0997-0
2. Solmi M, Radua J, Olivola M, Croce E, Soardo L, Salazar de Pablo G, et al. Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. Mol Psychiatry. 2022;27:281–95. https://doi.org/10.1038/s41380-021-01161-7
3. Dalsgaard S, Thorsteinsson E, Trabjerg BB, Schullehner J, PlanaRipoll O, Brikell I, et al. Incidence rates and cumulative incidences of the full spectrum of diagnosed mental disorders in childhood and adolescence. JAMA Psychiatry. 2020;77(2):155–64. https://doi.org/10.1001/jamapsychiatry.2019.3523

4. THL. Finnish Institute of Health and Welfare. Well-being of children and young people – School Health Promotion study. 2023 Statistical report 50/2023. https://urn.fi/URN:NBN:fi-fe20230913124233
5. WHO. World Health Organization. Mental health (Fact sheet). 2022 [cited 2023 Feb 20]. Available from: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response
6. Keyes CL. Mental illness and/or mental health? Investigating axioms of the complete state model of health. J Consult Clin Psychol. 2005;73(3):539–48. https://doi.org/10.1037/0022-006X.73.3.539
7. Reardon T, Harvey K, Baranowska M, O'Brien D, Smith L, Creswell C. What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies. Eur Child Adolesc Psychiatry. 2017;26(6):623–47. https://doi.org/10.1007/s00787-016-0930-6
8. Kanste O, Halme N, Perälä ML, National Institute for Health and Welfare (THL). Viidesluokkalaisten oppilaiden vanhempien näkemyksiä hyvinvoinnista, palveluista ja kouluyhteisöstä. 2016. [wellbeing, services and the school community as seen by parents of fifth graders. In Finnish]. https://urn.fi/URN:ISBN:978-952-302-622-3
9. Grennan L, Nicula M, Pellegrini D, Giuliani K, Crews E, Webb C, et al. "I'm not alone": a qualitative report of experiences among parents of children with eating disorders attending virtual parent-led peer support groups. J Eat Disord. 2022;10:195. https://doi.org/10.1186/s40337-022-00719-2
10. Sowden E, Robinson D, Lovell K, Bee P, Fulwood A, Lidbetter N, et al. Understanding the support needs of parents of children with obsessive-compulsive disorder: a qualitative descriptive study in the UK. BMC Psychiatry. 2023;23:309. https://doi.org/10.1186/s12888-023-04637-8
11. Graaf G, Kitchens K, Sweeney M, Thomas KC. Behavioral health services outcomes that matter most to caregivers of children, youth, and young adults with mental health needs. Int J Environ Res Public Health. 2024;21(2):172. https://doi.org/10.3390/ijerph21020172
12. Hiscock H, Connolly AS, Dunlop K, Perera P, O'Loughlin R, Brown SJ, et al. Parent perspectives on children and young people's mental health services in Victoria - What's wrong and how to fix it: a multi-site qualitative study. J Paediatr Child Health. 2020;56(7):1114–20. https://doi.org/10.1111/jpc.14835
13. Stapley E, Midgley N, Target M. The experience of being the parent of an adolescent with a diagnosis of depression. J Child Fam Stud. 2016;25:618–30. https://doi.org/10.1007/s10826-015-0237-0
14. Mizzi A, Honey A, Scanlan JN, Hancock N. Parent strategies to support young people experiencing mental health problems in Australia: what is Most helpful? Health Soc Care Community. 2020;28(6):2299–311. https://doi.org/10.1111/hsc.13051
15. Doyle FL, Morawska A, Higgins DJ, Havighurst SS, Mazzucchelli TG, Toumbourou JW, et al. Policies are needed to increase the reach and impact of evidence-based parenting supports: a call for a population-based approach to supporting parents, children, and families. Child Psychiatry Hum Dev. 2023;54(3):891–904. https://doi.org/10.1007/s10578-021-01309-0
16. Hansen AS, Telléus GK, Mohr-Jensen C, Lauritsen MB. Parent-perceived barriers to accessing services for their child's mental health problems. Child Adolesc Psychiatry Ment Health. 2021;15(1):4. https://doi.org/10.1186/s13034-021-00357-7
17. January SAA, Duppong Hurley K, Stevens AL, Kutash K, Duchnowski AJ, Pereda N. Evaluation of a community-based peer-to-peer support program for parents of At-risk youth with emotional and behavioral difficulties. J Child Fam Stud. 2016;25:836–44. https://doi.org/10.1007/s10826-015-0271-y
18. Polit DF, Beck CT. Nursing research: principles and Methods. 7th ed. Philadelphia: Lippincott Williams & Wilkins; 2024.
19. Putkuri T, Latva-Korpela I, Häkkinen M. Alaikäiselle tarjottava tuki mielen hyvinvoinnin ollessa uhattuna—kokemusasiantuntijoiden näkemyksiä. [support provided to child when mental well-being is at risk—perspectives of experts-by-experience. In Finnish]. Kasvun tuki –aikakauslehti. 2023;3(2):32–42. https://doi.org/10.61259/kt.136587
20. Central Union for Child Welfare. Lastensuojelun keskusliitto. Lastensuojelun kokemusasiantuntijuuden eettiset ohjeet. [Ethical guidelines for experts-by-experience in child welfare. In Finnish]. 2021 [cited 2023 Sep 20] Available from: https://www.lskl.fi/julkaisut/lastensuojelun-kokemusasiantuntijuuden-eettiset-ohjeet/
21. Horgan A, Manning F, Donovan MO, Doody R, Savage E, Bradley SK, et al. Expert by experience involvement in mental health nursing education: the co-production of standards between experts by experience and academics in mental health nursing. J Psychiatr Ment Health Nurs. 2020;27(5):553–62. https://doi.org/10.1111/jpm.12605
22. Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. Qual Health Res. 2019;29(10):1483–96. https://doi.org/10.1177/1049732318821692
23. KoKoA. Koulutetut Kokemusasiantuntijat ry. Koulutus- ja palkkiosuositukset. [Training and compensation recommendations. In Finnish]. 2022 [cited 2022 Oct 15] Available from: https://www.kokemusasiantuntijat.fi/koulutus-ja-palkkiosuositukset/
24. Lumivero. Unlock Insights with Qualitative Data Analysis Software. 2023 Available from: https://lumivero.com/products/nvivo/
25. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62:107–15. https://doi.org/10.1111/j.1365-2648.2007.04569.x
26. Finnish National Board on Research Integrity TENK. Finnish Code of Conduct for Research Integrity and Procedures for Handling Alleged Violations of Research Integrity in Finland. 2023 [cited 2024 Feb 20]; Available from: https://tenk.fi/sites/default/files/2023-11/RI_Guidelines_2023.pdf
27. Finnish National Board on Research Integrity TENK. The ethical principles of research with human participants and ethical review in the human sciences in Finland. 2019 [cited 2024 Feb 20]; Available from: https://tenk.fi/sites/default/files/202101/Ethical_review_in_human_sciences_2020.pdf
28. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. IJQHC. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042

29. Cavaleri MA, Olin SS, Kim A, Hoagwood KE, Burns BJ. Family support in prevention programs for children at risk for emotional/behavioral problems. Clin Child Fam Psychol Rev. 2011;14(4):399–412. https://doi.org/10.1007/s10567-011-0100-9
30. McDaid D, Park AL, Wahlbeck K. The economic case for the prevention of mental illness. Annu Rev Public Health. 2019;40:373–89. https://doi.org/10.1146/annurev-publhealth-040617-013629
31. Acri M, Hooley CD, Richardson N, Moaba LB. Peer models in mental health for caregivers and families. Community Ment Health J. 2017;53(2):241–9. https://doi.org/10.1007/s10597-016-0040-4
32. Bray L, Carter B, Sanders C, Blake L, Keegan K. Parent-to-parent peer support for parents of children with a disability: a mixed method study. Patient Educ Couns. 2017;100(8):1537–43. https://doi.org/10.1016/j.pec.2017.03.004
33. Feriante J, Shayani A, Lauer E, Pressman A, Rubin E. Sibling support program: a novel peer support intervention for parents, caregivers and siblings of youth experiencing mental illness. Dent Health. 2022;10(5):908. https://doi.org/10.3390/healthcare10050908
34. Watson E. The mechanisms underpinning peer support: a literature review. J Ment Health. 2019;28(6):677–88. https://doi.org/10.1080/09638237.2017.1417559
35. Acri MC, Craig N, Adler J. An examination of peer-delivered parenting skills programs across New York state. Community Ment Health J. 2018;54(8):1163–71. https://doi.org/10.1007/s10597-018-0269-1
36. Hoagwood KE, Cavaleri M, Serene Olin S, Burns BJ, Slaton E, Gruttadaro D, et al. Family support in Children's mental health: a review and synthesis. Clin Child Fam Psychol. 2010;13(1):1–45. https://doi.org/10.1007/s10567-009-0060-5
37. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55(1):68–78. https://doi.org/10.1037/0003-066X.55.1.68
38. Cope DG. Methods and meanings: credibility and trustworthiness of qualitative research. Oncol Nurs Forum. 2014;41(1):89–91. https://doi.org/10.1188/14.ONF.89-91
39. Stahl NA, James RK. Expanding approaches for research: understanding and using trustworthiness in qualitative research. J Dev Educ. 2020;44(1):26–8. http://www.jstor.org/stable/45381095
40. Lincoln YS, Guba EG. Naturalistic Inquiry California: Sage Publications. 1985 https://doi.org/10.1016/0147-1767(85)90062-8
41. Bazeley P. The contribution of computer software to integrating qualitative and quantitative data and analyses. Res Sch. 2006;13(1):64–74. [cited 2024 Feb 20]; Available from: https://psycnet.apa.org/record/2007-09345-006
42. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893–907. https://doi.org/10.1007/s11135-017-0574-8

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Tiina P, Irene L-K, Mikko H. Support needed by parents when a child's mental well-being is threatened—A qualitative study of views of experts-by-experience. Scand J Caring Sci. 2024;38:1061–1071. https://doi.org/10.1111/scs.13310