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Expertise-by-Experience in Child and Family Services: Professionals' Perspectives on Experiential Knowledge

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Abstract

This study analyses child and family service professionals' perceptions of expertise-by-experience. Group and individual interviews with professionals were analysed. The analysis yielded three main dimensions of experiential knowledge: supportive peer knowledge; contested knowledge, in which education and talking among peers in small groups helps experts-by-experience to locate the limits of their knowledge before publicly disclosing their inner thoughts; and emotional knowledge, which is based on shared experiences of emotional challenges and vulnerability. The results support the call for a critical appraisal of experiential knowledge. The increasing demand for experiential knowledge means that clarity on what kind of experiential knowledge is required and who can best represent it is necessary. In the child and family services contexts, the question of what constitutes experiential knowledge remains crucial. The results also indicate that collective analysis could help professionals tackle the challenges and demand for intersectional and heterogeneous knowledge.

Keywords

Expertise-by-experience, Experiential knowledge, Child and family service professionals

Introduction

Expertise-by-experience is one of the many concepts used to describe service users' involvement in the production of services (Tambuyzer et al., 2014). In the social and health care services context, it refers to, e.g., families, parents and children who are or have been clients of those services and thus represent individuals or groups who share common experiences of social and health issues. As stated by McLaughlin (2009, p. 1111), expertise-by-experience refers to a special kind of knowledge that is "rooted in an individual's experiences of using services." It also refers to experiential knowledge beyond immediate service user experiences (Pösö, 2018, p. 112).

Research on expertise-by-experience has focused on, e.g., experiential expertise (Näslund et al., 2019; Palukka et al., 2021), identity construction (Jones & Pietilä, 2020; Mayer & McKenzie, 2017) and empowerment (Ewalds Mulliez et al., 2018; Lindström & Toikko, 2021). In performing their role, experts-by-experience are expected to be active

and distanced from professional control. In institutional contexts, questions of power, such as who defines the positions of lay experts and in what ways they can influence service delivery, are commonly present. However, experts-by-experience often receive special training programmes, or they may work as paid employees, meaning that lay expertise is also cultivated and institutionalised. (e.g., Tambuyzer et al., 2014, p. 142; Jones & Pietilä, 2020, p. 810; Lindström & Toikko, 2021.)

Expertise-by-experience has been widely utilised and studied in the mental health and addiction (recovery) service contexts (Edwards et al., 2018; Rosenberg & Hillborg, 2016; Tambuyzer et al., 2014). Patient involvement in hospitals and the roles of lay health workers have also been extensively studied (e.g., Solbjør & Steinsbekk, 2011). However, only a few studies have addressed the questions of lay expertise in the context of child and family services (e.g., Larkins et al., 2014; Hackett et al., 2018; Lucas, 2019; Pösö, 2018). Cortis (2007) found that services better meet the needs of children and families when user-defined performance indicators are used. Hamilton Schilling and colleagues (2021) concluded that to ensure the acceptability and effectiveness of interventions and services important for adolescents, they should always be involved in the related design processes and decision-making. Lucas (2019) emphasises that service-user involvement in developing early intervention settings in children's social care is all about building confident partnerships with children, as it is much more than just asking minors to join in.

This study analysed how child and family service professionals perceive the expertise-by-experience of their clientele and how they understand the knowledge they possess. The focus is on professionals' perceptions and understandings of lay expertise and how it has been adopted in child and family services. The qualitative analysis is based on a dataset comprising 25 individual and 10 group interviews conducted in one Finnish region among professionals in public social or health care organisations or third sector organisations. The research was part of the VerKo project, aimed at developing service users' participation in cooperation with service providers.

Expertise-by-experience and experiential knowledge

Although the concepts of expert-by-experience and expertise-by-experience are widely used, no consensus exists on their meanings. The object and focus may be either oneself or other service users, and the aim is to collaborate with professionals and the services they provide (Jones & Pietilä, 2020; Meriluoto, 2018; Noorani et al., 2019). The involvement of experts-by-experience refers to their participation in different forums when services are being evaluated and/or planned. Experts-by-experience may be co-workers acting alongside professionals as, e.g., a client developer or educator. They may also take part in decision-making processes when resources are distributed. (Lindström & Toikko, 2021.) In such roles, the level of involvement is deeper than the provision of occasional service user feedback or participating in one's own processes as a client.

It is worth remembering, however, that even in the very same organisation the services providers, organisation leaders and service users may have different views about what expertise-by-experience should include and how lay (lived) experiences should be understood. (Bennetts et al., 2011; Tambuyzer et al., 2014; McLaughlin, 2009.) It can be argued that expertise-by-experience is contextual and, hence, limited to specific situations. However, experiential knowledge is not solely an individual asset or cognitive capacity: it is also socially situated and constructed. Experiential knowledge is one form of collective knowledge, as it emphasises the lived experiences of individuals and challenges the dominance of formal knowledge (education, qualifications and research). (Beresford,

2013; Gillard et al., 2020.) Collective knowledge formation is not only about acquiring new knowledge but also about making active efforts to enrich existing knowledge and develop practices. Expertise-by-experience is also essentially about developing expertise horizontally, i.e., sharing knowledge with others. (Hakkarainen et al., 2012.)

According to Blume (2017), we do not know enough about the mechanisms of *how* people's experiences become valuable for other people. Consequently, it is important to ask how experiential knowledge is used and whose lay experiences are considered to constitute "knowledge". Blume suggests that it is important to be aware of the possibility of competing claims, as experts-by-experience are not a homogeneous group. Noorani and colleagues (2019, p. 224) emphasise the heterogeneity of experiential knowledge. The relevant question then is, whose knowledge is considered important and why? Rabeharisoa et al. (2014) describe expertise-by-experience as a form of evidence-based activism which can take the form of a collective inquiry in which service users with their experiential knowledge and professionals with their scientific and professional knowledge join forces. However, redistribution of professional power is not an easy task. As Fox (2008, p. 43) have stated, "Bottom-up shifts in power must complement top-down implementation." In their research among people with a history of crime and substance abuse, Lindström and Toikko (2021) noticed that informants questioned their status as experts-by-experience, mostly because of the power imbalances in the service system. They found it difficult to criticise the service system and the professionals, and thus were unable to use their experiential knowledge in the way they would have wanted. In relation to children, it is also a question of adult authority and power in generational relations as children's role and status is usually dominated by adults (e.g., Cuevas-Parra & Tisdall, 2018; Punch, 2020).

Gillard et al. (2020, p. 42) highlight the intersectionality of experiential knowledge: it is socially situated and cannot be separated from who people are. Knowledge is gendered, classed, racialised etc., and it should not be regarded only as counter-professional discourse. This notion is also important for research, which has underlined the possibility for conflict between professional and experiential knowledge. However, the heterogeneity of knowledge (Noorani et al., 2019) and how professionals understand and consider the rich reserve of experiential knowledge, especially in child and family services, have been far less researched and hence form the topic of this article. Moreover, whereas most studies have addressed the perspectives of experts-by-experience, this study focuses on how professionals understand the role of experiential knowledge in service development (see, e.g., Itäpuisto et al., 2021; Kirkegaard, 2020.)

Research design

Data and method

The dataset consists of group and individual interviews collected between May 2019 and February 2020 in one region in Finland. The interviewees worked as professionals and managers in child and family service organisations in the health and social sectors and in non-profit organisations. The aim of the data collection was to recruit a group that (1) was geographically representative, (2) included a variety of professionals from different organisations, and (3) also included individuals who were interested on the topic but had only little experience in working with experts-by-experience.

Group interviews. 36 frontline professionals took part in ten group interviews. Each group contained two to six participants. The participants were recruited through contact persons who were already participating in the project development group. Participants'

occupations were representative of those commonly found in child and family services, such as social workers, doctors, preschool teachers, psychologists, occupational therapists, service counsellors, practical nurses and social counsellors. Six (6/10) group interviews were conducted with participants working in the non-profit sector (social services), one (1/10) was conducted with participants working in the public healthcare sector and three (3/10) with participants from inter-organisational groups representing both non-profit and public sector actors in social and healthcare services. Apart from one organisation in which three separate interviews were held, only one group interview was conducted in each organisation. Each interview was conducted by two members of the research group. The duration of the interviews ranged from 1 hour 33 minutes to 1 hour 59 minutes. In the results section, the group interviews are referred to by the abbreviation GI along with information on whether the interviewed professionals represented social services, healthcare or NGOs. Group interviews that included multiple professionals are referred to as “Network”.

Individual interviews. 25 managers were interviewed via telephone. To recruit participants for these interviews, managers of child, youth and family services were contacted directly. Eight (8/25) of the interviewed managers worked in the non-profit sector, ten (10/25) in public social services and seven (7/25) in public healthcare services. Each individual interview was conducted by one member of the research group. Interview duration ranged from 37 to 90 minutes, with the majority lasting approximately 45 minutes. In the results section, the individual interviews are referred to by the abbreviation II along with information on whether the professionals represent social services, healthcare, or NGOs.

All the interviewed professionals were interested in discussing expertise-by-experience, but not all had experience of performing concrete actions with experts-by-experience. However, these professionals were in the minority (two professionals in one NGO and four managers). In the interviews, expertise-by-experience was mainly discussed in relation to adults and parents, such as how experts-by-experience worked to support parents’ well-being and parenthood in children’s wards in hospitals and in organising and running peer support groups. Examples of how the professionals had worked with children, including descriptions of how young experts-by-experience worked alongside professionals and how they had acted as coordinators in online chat discussions and facilitators in peer support groups were provided in five (5/10) group interviews and six (6/25) interviews with managers. However, none of the healthcare sector managers had concrete experiences of working with children.

In Finland, research with human participants must comply with the guidelines of the Finnish National Board on Research Integrity (TENK, 2019). In this study, however, ethical review was not required either by law or the TENK guidelines. The policies of each organisation were followed in the process of applying for research permission. Only one of the organisations required a formal application. Each interviewee individually gave their informed consent at the beginning of the interview. No other type of personal information was collected. All the interviews were transcribed verbatim by a research assistant. At the same time, the data were anonymised by removing all possible personal information, such as names of participants, organisations and places.

The interview framework comprised four themes. Two concerned interviewees’ familiarity with the terms and conceptualisations of peer support and expertise-by-experience and their use in the interviewee’s own organisation. The other two concerned the interviewee’s skills and knowledge on peer support and expertise-by-experience, and the leadership

and management of this work in their organisation. Finally, the potential and risks inherent in the use of peer support and expertise-by-experience were discussed.

The concepts used in interviews were “expertise-by-experience”, “experts-by-experience” and “peer support”, as these concepts are generally used in Finnish organisations and service contexts (e.g., Rissanen, 2015; Toikko, 2016; Meriluoto, 2018). The interviewees were also encouraged to use concepts that they preferred and to critically evaluate and express their own thoughts. In the final interview data, although a variety of terms were used, the analysis focused on the concepts of expertise-by-experience and experts-by-experience, as they were the main concepts used by the interviewees. The discussion around these terms was rich in all the interviews. Peer knowledge was analysed when it was discussed in relation to being an expert-by-experience, since providing peer support and being an expert-by-experience are interrelated phenomena.

Analysis

Data were analysed using qualitative content analysis (Elo & Kyngäs, 2008; Silverman, 2009). The research question addressed in this article is: how do child and family service professionals discuss the experiential knowledge of experts-by-experience?

The analysis started with summarising the data and extracting all parts where the term expertise-by-experience was mentioned in the dataset. Discussion on experiential knowledge was present in all the interviews. The first round of the analysis showed that experiential knowledge was considered to be the main element of expertise-by-experience, and hence the analysis focused on analysing talk where experiential knowledge was discussed in the child and family service contexts.

In the second round of the analysis, the parts of the data where the question of experiential knowledge was discussed were classified into different themes. Three main themes were identified in the interviews. First, the professionals discussed lay everyday knowledge as one key feature of expertise-by-experience. This was discussed in relation to other service users and in relation to professional knowledge. This theme is named peer knowledge. Second, the interviewees discussed how lay knowledge and lived experiences should be critically evaluated by experts-by-experience themselves and by professionals. In the analysis section, this theme is named contested knowledge. Third, the professionals engaged in lively discussion on the emotional aspects of experiential knowledge and the trustworthiness of experts-by-experience. This theme was named emotional knowledge. The three themes are not mutually exclusive, although each provides a different perspective on expertise-by-experience. All three themes are discussed next.

Results

Peer knowledge

Experts-by-experience, acting as peers, share knowledge, guide others and provide lay support. The core of peer knowledge is that peers identify similar life events among themselves and can thus relate to each other's experiences. In the child and family service contexts, peer knowledge is mainly connected to everyday family life and the different needs and circumstances of children and their parents. The professionals discussed how service users may have special expectations of experts-by-experience and may criticise them if their needs are not met. One example is given where service users claimed that the experience of drug or alcohol abuse is not enough if the expert-by-experience invited by the professionals to discuss and support the service users is not also a parent or, especially, a woman and a mother of young children and thus also of having experienced pregnancy.

H3: They were disappointed, I mean they could talk about substance abuse and recovery and so on, but if you do not have any experiences of also being a mother of small children and being pregnant, there is a clear lack of shared experiences and peerness. (GI10, NGO)

In another example, the healthcare professionals discussed a case where an older expert-by-experience was assigned to work with the young parents of small children in a children's hospital ward. This was also given as an example of experiential knowledge that was not considered beneficial; on the contrary, the parents felt that the expert-by-experience had "very old-fashioned and confusing ideas of what it means to be a parent." These examples illustrate the socially-situated nature of the peer knowledge that should include elements of sameness and a certain amount of similarity among peers.

Some healthcare professionals considered peer knowledge as important in cases of children with illnesses or other diagnoses. The social services professionals also pondered on peerness in relation to child protection services or being in care. In these social and healthcare circumstances, peerness meant powerful and empowering experiences of sameness.

H3: In school we have small children who might be confused or frustrated with, e.g., ADHD or Asperger, or some other situation. For these children it is very important to see other, older children in the same situation, so they realise that they are not the only ones and that it is possible to cope with it in the future. (GI5, healthcare)

In contrast to this, two health care managers, who had no experience of working with children as experts-by-experience, stated that "this has gone too far," giving an example of a public discussion in which child experts-by-experience had criticised child welfare and mental health services in public forums. The professionals argued that a hasty conclusion had been drawn based on the experiences of "these sick children," who in fact had serious problems in their lives and who first and foremost needed professional help (Kiili et al., 2021). By this, the managers meant that children cannot be considered as responsible actors, and hence their experiences cannot be considered relevant when, e.g., developing services or providing support for others. This line of argument was not presented in relation to adult experts-by-experience, which demonstrates the power of age and generational position. The healthcare professionals did not regard children as reliable sources of information and children's own words were not facing value. On the other hand, in some of the interviews, children were mentioned as having valuable peer knowledge simply because they are children. What makes children's knowledge unique is that their peer experiences are also related to their generational position of being a child or a young person (Punch, 2020; Cuevas-Parra & Tisdall, 2019). Peerness in the case of children is a generational position to which adults lack access. Only children know what it is like to be a child at that moment and have child-specific challenges in life. Adults and professionals cannot relate to these experiences in the same way other children can.

Although the interviewed professionals valued peer support and the experiential knowledge that peers can share with each other, they also debated the different challenges presented by peerness, especially when experts-by-experience are specifically in the role of providing support for other service users, organising peer support groups and co-working with professionals. Experiences of exhaustion and of having excessive responsibilities towards peers were considered major challenges for all individuals acting as experts-by-experience, especially minors. The social-service professionals, in particular, argued that children and young people are still in the process of forming their identity. It was not

desirable for their identity to be too strongly connected to the role of being an expert-by-experience, as that occupies only one part of their life and should not become too much of a burden (also Hamilton Schilling et al., 2021).

You can call this as an identity project where the young people identify as the developers of the service system. ... But you need also safe adults who set the limits and ask relevant questions, so that the young people don't break down. (II5, NGO, social services)

This requires that professionals are able to assess when acting as lay expert is an excessive burden on an expert-by-experience and to discuss this with that individual. Professionals should also recruit service users who meet the core criteria, such as service needs, age, generation and gender, for the right kind of peer knowledge. The above examples illustrate that peer knowledge is socially situated, time- and place-bound and intersectional. Peer knowledge is important, but it should be the right kind of experiential knowledge, incorporating the heterogeneity of knowledge and intersectionality of people's everyday lives and circumstances (also Faulkner & Thompson, 2021; Gillard et al., 2020; Noorani et al., 2019).

Contested knowledge

Contested knowledge is a form of lay experiential knowledge that becomes challenged when it is critically evaluated by experts-by-experience themselves, other service users and professionals. Experts-by-experience should first talk among peers in small, confidential peer support groups. This strategy was recommended by the professionals because, by talking to others, experiences are "put into words" and thereby become contested. The professionals thought that experts-by-experience should first disclose their personal experiences and then learn to distance themselves from these (also Jones & Pietilä, 2020). This contesting process is especially important before experts-by-experience present themselves in public arenas, such as professional conferences, print media or social media platforms. One's own experiences should first be "talked out" in order for one to accept them because "you need to be at peace with yourself before you can cope with others."

H1: If the motivation of the expert-by-experience is to provide therapy for themselves by running a peer support group and hasn't processed their own situation, it will turn into

H2: Self-care

H3: I mean you need to be in balance with yourself. (G1, network)

Uncritically shared and uncontested experiences present a risk to the wellbeing not only of experts-by-experience themselves but also that of other service users. This was specifically emphasised in the case of experts-by-experience who were minors, as all the professionals from all the different organisations clearly stated that children should not participate in public arenas. Being an expert-by-experience was considered a learning process in which adult professionals can guide and support children in how to use the experiential knowledge they have. The social service professionals reported advising children not to publish their personal histories and thus avoid being identified. Instead, to protect their anonymity, professionals recommended that they construct composite stories combining the perspectives of several children. In the case of adults, the professionals did not stress the risks posed by publicity but instead emphasised the importance of contesting and being "at peace" with one's own experiences.

Contesting one's own lived experiences "in the right way" is not an easy task. One way of getting it right is through education given by professionals. Most of the interviewed professionals considered education not only an important element of becoming an expert-by-experience but also a right. Education was especially emphasised in relation not only to organisational rules and regulations but also ethics, as experts-by-experience are likely to hear confidential stories from other people. Professionals' responsibilities included the prevention of possible malpractices, such as making confidential information public. Experts-by-experience, whether children or adults, needed to be educated in these responsibilities.

You need to have education before you can act as an expert-by-experience and use that title, yes. (II6, healthcare)

Education is their right, no matter what their situation or age (GI4, NGO)

Education shapes lay knowledge into contested knowledge which can then be used, for example, in lobbying, in the public arena and in developing services. This knowledge cannot be impulsive, fragmentary, or unclear (see also Jones, 2018). When using contested knowledge, experts-by-experience should also understand their limits, as professional interventions, decisions, and plans are not their responsibility: "At the end, it is our responsibility, how things work, we as professionals are responsible." Residing within contested knowledge are the ideas of progress and development: knowledge becomes ennobled when experts-by-experience, with the help of peers and education, have the time and possibility to process it. Social-service professionals especially emphasised the problem of representation, as they saw a model in which one person represents the voices of others as tokenistic, "it can be a problem if we just hear one or two voices when developing services." From the professionals' perspective, this also means that contested knowledge must measure up to the criteria organisations set for experts-by-experience, such as collective use of multiple voices, which can generate a robust corpus of experience-based knowledge (Noorani et al., 2019), and adopting ethical guidelines, which are considered important in child and family services, especially when working with minors.

Well, professional secrecy is something that applies to all age groups, however when you work with children it's especially important and we have discussed this a lot. (GI4, NGO)

However, the professionals rarely viewed experts-by-experience as partners in formulating ethical guidelines; instead, this was regarded as a professional responsibility (see also Kiili et al., 2021). This was done together with the experts-by-experience in only one organisation, where the professionals took a very positive stance on this practice. Shared assessment on such issues as how experiential knowledge is used and by whom was discussed in relation to the possibilities and risks associated with the experts-by-experience.

We are responsible. We have formulated ethical guidelines together so that we do not forget these things, ... part of our responsibilities is to make sure that our collaboration is safe and ethical all the time. (GI16, NGO social services)

While experts-by-experience occupy the position of knowledge owners, how their knowledge is used was seen as the responsibility of professionals. However, the interviewed

professionals did not offer critical assessments of what happens to experiential knowledge when it is contested, e.g., through education

Emotional knowledge

Emotional knowledge is based on shared experiences of vulnerability and emotional challenges. For this reason, experts-by-experience should be reliable but also be aware of their own fragility in order to be able to hear and work with the emotional knowledge provided by others. Working with emotional knowledge should not form yet another unpleasant experience either for the experts-by-experience or for others, as “all our actions are aimed at strengthening their wellbeing and giving empowering experiences to all.” Reliability is essential component of emotional knowledge-building. The interviewees portrayed trustworthiness as important attribute of experts-by-experience.

As professionals, we must have a strong sense of this person being a good peer support person or expert-by-experience, I mean I must think that I can trust them, they have sharp ideas and that they will perform well, for myself I don't care about their education, they can be a construction worker or whatever, the main thing is that I can trust them. (GI, network)

In some interviews, experts-by-experience were described as emotion workers. Shared experiences are especially shared on the level of emotions, as peers know “how others feel” and share emotions in a trusting relationship with each other. These emotional experiences are something professionals do not or are not expected to have. One interviewed professional emphasised that besides “cognitive knowledge” professionals can use the emotional knowledge of experts-by-experience when working together.

If there is somebody present, who has gone through the same process it helps me when working with the service users, I mean there's somebody telling me about their own experiences of how it felt and what was happening. (GI4, NGO)

Although emotions are strongly present in the child and family service contexts, they can be a challenge for professionals. In one group interview, it was suggested that experts-by-experience can bring emotions into the work context in a manner that is not considered suitable for professionals. For example, professionals rarely shed tears in the work context, as this would be considered unprofessional. For experts-by-experience it is acceptable, even expected, to weep together with service users. Controlling one's emotions is considered as part of professionalism, whereas for experts-by-experience, emotions are way of connecting, as when they share emotions people can get “on the same wavelength”. This was considered especially important in the case of minors. In one group interview, the social-service professionals described young service users as generally rather passive, but when young experts “start talking, you could cut the air with a knife, their whole demeanour sharpens up and they start focusing. It is emotionally important for them.” Emotions are “important advantage which we (professionals) do not have.” Thus, for experts-by-experience, it is important to learn what constitutes an appropriate amount of emotional expression as they are expected to exercise some emotional control to be able to work with others (see also Näslund et al., 2019).

Discussion

According to the child and family services professionals interviewed in this study, experts-by-experience have a rich repertoire of experiential knowledge that plays an

important role in service development and delivery. The analysis of the interview data yielded three main dimensions of experiential knowledge: peer knowledge, contested knowledge and emotional knowledge.

The criteria for what constitute the right kind of experiential knowledge are set not only by professionals but to some extent also by service users, especially in the case of peer knowledge. In child and family services, experiential peer knowledge is gendered, generational, and context specific. In this study, the generational position of children and parents and the generation-specific knowledge they have and use in relation to other service users was considered important. Gendered and context-specific knowledge was, for example, discussed in relation to the mothers of young children, who also had a history of substance abuse. Our data indicate that experiential knowledge and peer knowledge are not connected solely to service contexts that professionals tend to consider important. In the case of substance abuse, the issue of young motherhood was considered the most important factor influencing the quality of peer knowledge. This illustrates the importance of seeing substance abuse issues through questions of parenthood, motherhood and family, and not purely in terms of the individual's drug use and personal recovery. These cases exemplify the need for intersectional peer knowledge (also Gillard et al., 2020).

Experiential knowledge should be contested. Moreover, it must not be impulsive or unclear. On the contrary, it must be structured, acceptable and relevant for both the professionals and other service users (see also Jones, 2018; Meriluoto, 2018; Lindström & Toikko, 2021). By talking with peers and through education, lay knowledge becomes contested. The professionals underlined the ethical use of experiential knowledge and the importance of educating experts-by-experience in ethical issues. However, knowledge is also linked to power. Research has shown that educating experts-by-experience may result in the inclusion only of voices that comply with the organisation's views, meaning that expertise-by-experience loses its critical purpose (Lindström & Toikko, 2021; Meriluoto, 2019) and becomes co-opted by the professionals. This could mean that while professionals see experts-by-experience as providing lay experiences, they only allow lay criticism of practices up to a certain point. Interviewed professionals especially emphasised children as vulnerable human beings, whose lay expertise was conditional upon adults' actions (also Kiili et al., 2021). Based on the results, it is vital to ask how experiential knowledge can be used so that it does not create new hierarchical positions among service users and/or between professionals and experts-by-experience. Hence, it is valid to ask not only whose knowledge is valued (Blume, 2017) but also what kind of experiential knowledge is considered acceptable and what this means in relation to the heterogeneity of knowledge and the demand for intersectional awareness. (Noorani et al., 2019; Gillard et al., 2020; Näslund, 2020).

Experiential knowledge is emotional, as service users utilise their personal experiences and the emotional connotations of these as a resource when collaborating with peer service users and professionals. Emotional experiences can be deeply personal and sensitive. While the professionals valued the emotional resources that experts-by-experience have, they did not explicitly discuss what it means to use emotional experiences. Liz Brosnan (2019) asked what the emotional costs for service users are when they enter professional spaces. Citing the concept of emotional labour (Hochschild, 1979), she emphasises the importance of recognising these costs, which often remain invisible to the more powerful actors, such as professionals.

The professionals interviewed for this study recognised the value of emotional knowledge but did not directly contemplate its costs for experts-by-experience. They spoke indirectly

about ethical and safe encounters and professional responsibilities in ensuring the well-being of all stakeholders, stances which can also be related to the recognition of emotional work by experts-by-experience. However, the emotional aspects should be discussed and studied more explicitly and systematically. In mental health research, it has been proposed that experts-by-experience could benefit from external support from a supervisor independent of the organisation who could help them in reflecting on the question of emotional labour (Faulkner & Thompson, 2021).

The findings also clearly indicate the need to discuss minors as experts-by-experience. Although not all the interviewed professionals had worked with children as experts-by-experience, they all had opinions and insights on the matter that were based on their professional knowledge. The professionals considered children to have unique everyday knowledge which they recognised as valuable primarily in their relations with peers. Hence, how such knowledge is used largely remained the responsibility of professionals. Much emphasis was placed on their generational position as minors and on protecting them from harmful experiences and less on their experiences, interests and capabilities as experts-by-experience. This finding indicates the need to consider the experiences and interests of children as experts-by-experience and the social realities within which they live (also Kiili et al., 2021; Cuevas-Parra & Tisdall, 2018).

Limitations

This research has its limitations. While the interviewed professionals were interested in expertise-by-experience and eagerly discussed it, they did not represent the full spectrum of the professionals working in child and family services. In relation to minors, especially, the opinions of some were based solely on their professional knowledge as they had never actually worked with child experts-by-experience. A further limitation is that the interviews were conducted in just one province of Finland.

Conclusions and implications for practice and research

This study corroborates the need for a critical appraisal of experiential knowledge, both in practice and in research, and the need to critically evaluate the concepts of experts-by-experience and expertise-by-experience. As the demand for experiential knowledge increases, it is vital to be clear about what kind of experiential knowledge is needed and who are best suited to represent it (see also Näslund, 2020; Blume, 2017). The research findings prompt the question whether expertise-by-experience is mainly being developed according to professionals' perceptions and standards and is thus losing sight of its critical purpose (Lindström & Toikko, 2021; Meriluoto, 2019). Noorani et al., (2019) consider that experiential knowledge is robust when it is analysed collectively by service users. Collective analysis could help professionals tackle the challenges related to the demand for intersectional and heterogeneous knowledge. Particular attention should be given to methods of how collectively analyse and transfer the experiential knowledge to others in a democratic way. At the same time, it is vital to honestly and openly discuss the possibilities and constraints different organisations have for implementing expertise-by-experience. For example, in child and family social services, the anonymity of clients and other stakeholders, and professional secrecy, are important. This needs a strong commitment to co-development and to collective structures that should not be designed *for* but together *with* experts-by-experience, also with those who are minors. Resources for developing inclusive and collective participation structures are needed, both in research and practice

References

- Bennetts, W., Cross, W. and Bloomer, M. (2011). Understanding consumer participation in mental health: Issues of power and change. *International Journal of Mental Health Nursing*, 20, pp. 155–164. <https://doi.org/10.1111/j.1447-0349.2010.00719.x>
- Beresford, P. (2013). From ‘other’ to involved: user involvement in research: an emerging paradigm, *Nordic Social Work Research*, 3(2), pp. 139–48. <https://doi.org/10.1080/2156857X.2013.835138>
- Blume, S. (2017). In search of experiential knowledge, *Innovation: The European Journal of Social Science Research*, 30(1), pp. 91–103. <https://doi.org/10.1080/13511610.2016.1210505>
- Brosnan, L. (2019). The Lion’s Den’: The Epistemic Dimensions of Invisible Emotional Labour in Service-User Involvement Spaces. *Journal of Ethics in Mental Health. Special Theme Issue VI: Disordering Social Inclusion: Ethics, Critiques, Collaborations, Futurities. JEMH Open Volume 10*, pp. 1–16. <https://jemh.ca/issues/v9/theme6.html>
- Cortis, N. (2007). What do service users think of evaluation? Evidence from family support. *Child & Family Social Work*, 12(4), pp. 399–408. <https://doi.org/10.1111/j.1365-2206.2007.00495.x>
- Cuevas-Parra, P., and Tisdall, E. K. M. (2019). Child-Led Research: Questioning Knowledge. *Special Issue Childhood and Society, Social Sciences*. 8(2), pp. 44. <https://doi.org/10.3390/socsci8020044>
- Edwards, M., Soutar, J. and Best, D. (2018). Co-producing and re-connecting: a pilot study of recovery community engagement, *Drugs and Alcohol Today*, 18(1), pp. 39–50. <https://doi.org/10.1108/DAT-09-2017-0054>
- Elo, S. and Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62, pp. 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Ewalds Mulliez, A.-P., Pomey, M.-P., Bordeleau, J., Desbiens, F., Pelletier, J.-F. (2018). A voice for the patients: Evaluation of the implementation of a strategic organizational committee for patient engagement in mental health. *PLOS ONE* 13(10): e0205173. <https://doi.org/10.1371/journal.pone.0205173>
- Faulkner, A., and Thompson, R. (2021). Uncovering the emotional labour of involvement and co-production in mental health research, *Disability & Society*, <https://doi.org/10.1080/09687599.2021.1930519>
- Fox, J. (2008). The Importance of Expertise by Experience in Mental Health Services, *International Journal of Leadership in Public Services*, 4(4), pp. 39–43. <https://doi.org/10.1108/17479886200800035>
- Gillard, S., Foster, R., and Sweeney, A. (2020). Experiential knowledge in mental health services, research and professional education. In (eds.) McLaughlin, Beresford, Cameron, Casey and Duffy: *The Routledge Handbook of Service User Involvement in Human Services Research and Education*. Routledge, pp. 41–53. <https://doi.org/10.4324/9780429433306>
- Hackett, C. L., Mulvale, G., and Miatello, A. (2018). Co-designing for quality: Creating a user-driven tool to improve quality in youth mental health services. *Health Expectations*, 21(6), pp. 1013–1023. <https://doi.org/10.1111/hex.12694>
- Hakkarainen, K., Lallimo, J. and Toikka, S. (2012). Kollektiivinen asiantuntijuus ja jaetut tietokäytännöt. *Aikuiskasvatus* 32(4), pp. 246–256. <https://doi.org/10.33336/aik.94003>
- Hamilton Schilling, S., Carreño, A., Tapia, E., Mascayano, F., Pitronello, R., Santander, F., Jorquera, M. J., Soledad Burrone, M. and Alvarado, R. V. (2021). Experts by Experience: Qualitative Evaluation of Adolescent Participation in the Development of a Technological Intervention to Prevent Youth Suicide in Chile. *Frontiers in Psychiatry*, 11. <https://doi.org/10.3389/fpsy.2020.522057>
- Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. *American Journal of Sociology*, 85(3), pp. 551–575. <https://doi.org/10.1086/227049>
- Itäpuisto, M., Kiili, J., Malinen, K., Moilanen, J. and Punna, M. (2021). Perhe- ja lapsityön ammatilliset asiantuntijuudet kokemusasiantuntijuuden kontekstissa. *Janus: sosiaalipolitiikan ja sosiaalityön tutkimuksen aikakauslehti*, 29(3), pp. 212–228, <https://doi.org/10.30668/janus.96981>
- Jones, M. (2018). Kokemustiedon määrittelyt ja käyttö julkisen terveydenhuollon kontekstissa. In J. Toikkanen and I. A. Virtanen (eds.) *Kokemuksen tutkimus VI: kokemuksen käsite ja käyttö*. Rovaniemi: Lapland University Press, pp. 169–90. <http://lauda.ulapland.fi/handle/10024/63420>

- Jones, M. and Pietilä, I. (2020). Personal perspectives on patient and public involvement – stories about becoming and being an expert by experience. *Sociology of Health & Illness*, 42(4), pp. 809–824. <https://doi.org/10.1111/1467-9566.13064>
- Kiili, J., Itäpuisto, M., Moilanen, J., Svenlin, A.-R. and Malinen, K. E. (2021). Professionals' views on children's service user involvement. *Journal of Children's Services*. 16(2), pp. 145–158. <https://doi.org/10.1108/JCS-10-2020-0069>
- Kirkegaard, S. (2020). The Everyday Drama of Coproduction in Community Mental Health Services: Analyzing Welfare Workers' Performance as the "Undercover Agent". *Symbolic Interaction*. 43(3), pp. 428–451. <https://doi.org/10.1002/SYMB.478>
- Larkins, C., Kiili, J. and Palsanen K. (2014). A lattice of participation: reflecting on examples of children's and young people's collective engagement in influencing social welfare policies and practices. *European Journal of Social Work*, 17(5), pp. 718–736. <https://doi.org/10.1080/13691457.2014.928269>
- Lindström, J. and Toikko, T. (2021). Survival stories as access to society. People with history of a crime as experts by experience, *Nordic Journal of Criminology*, 23(1), pp. 3–22. <https://doi.org/10.1080/2578983X.2021.1918435>
- Lucas, S. (2019). The assembly of active participation by parents of children subject to a multi-agency model of early intervention in child and family services. *Child & Family Social Work*. 24(4), pp. 529–536. <https://doi.org/10.1111/cfs.12633>
- Mayer, C. and McKenzie, K. (2017). '... it shows that there's no limits': the psychological impact of co-production for experts by experience working in youth mental health. *Health and Social Care in the Community*, 25, pp. 1181–1189. <https://doi.org/10.1111/hsc.12418>
- McLaughlin, H. (2009). What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next? *The British Journal of Social Work*, 39(6), pp. 1101–1117. <https://doi.org/10.1093/bjsw/bcm155>
- Meriluoto, T. (2018). Making experts-by-experience – Governmental ethnography of participatory initiatives in Finnish social welfare organisations. University of Jyväskylä, JYU Dissertations. <https://jyx.jyu.fi/handle/123456789/60096>
- Meriluoto, T. (2019). 'The will to not be empowered (according to your rules)': Resistance in Finnish participatory social policy. *Critical Social Policy*, 39(1), pp. 87–107. <https://doi.org/10.1177/0261018318764322>
- Noorani, T., Karlsson, M., and Borkman, T. (2019). Deep experiential knowledge: reflections from mutual aid groups for evidence-based practice, *Evidence & Policy: A Journal of Research, Debate and Practice*, 15(2), pp. 217–234. <https://doi.org/10.1332/174426419X15468575283765>
- Näslund, H., Sjöström, S., & Markström, U. (2019). Delivering experiential knowledge: Repertoires of contention among Swedish mental health service user organisations. *Nordic Social Work Research*, 10(4), pp. 369–381. <https://doi.org/10.1080/2156857X.2019.1583599>
- Näslund, H. (2020). Collective Deliberations and Hearts on Fire: Experiential Knowledge Among Entrepreneurs and Organisations in the Mental Health Service User Movement *VOLUNTAS – International Journal of Voluntary and Nonprofit Organizations*. <https://doi.org/10.1007/s11266-020-00233-6>
- Palukka, H., Haapakorpi, A., Auvinen, P. and Parviainen, J. (2021). Outlining the role of experiential expertise in professional work in health care service co-production, *International Journal of Qualitative Studies on Health and Well-being*, 16(1). <https://doi.org/10.1080/17482631.2021.1954744>
- Punch, S. (2020). Why have generational orderings been marginalised in the social sciences including childhood studies? *Children's Geographies*, 18(2), pp. 128–140. <https://doi.org/10.1080/14733285.2019.1630716>
- Pösö, T. (2018). Experts by Experience Infusing Professional Practices in Child Protection, in Falch-Eriksen, A. and Backe-Hansen, E. (eds) *Human Rights in Child Protection*. Palgrave Macmillan, Cham, pp. 111–128. <https://doi.org/10.1163/15718182-02704012>

- Rabeharisoa, V., Moreira, T., & Akrich, M. (2014). Evidence-based activism: Patients' users' and activists' groups in knowledge society. *BioSocieties*, 9(2), pp. 111–128. <https://doi.org/10.1057/biosoc.2014.2>
- Rissanen, P. (2015). Toivoton tapaus? Autoetnografia sairastumisesta ja kuntoutumisesta. *Kuntoutussäätiön tutkimuksia* 88. Helsinki. <http://hdl.handle.net/10138/157106>
- Rosenberg, D., and Hillborg, H. (2016). Systematizing Knowledge of User Influence – A Study of User Advisory Boards in Substance Abuse and Mental Health Services. *Social Policy & Administration*, 50(3), 336–352. <https://doi.org/10.1111/spol.12113>
- Silverman, H. I. (2009). Qualitative Analysis In Financial Studies: Employing Ethnographic Content Analysis. *Journal of Business & Economics Research (JBER)*, 7(5). <https://doi.org/10.19030/jber.v7i5.2300>
- Solbjør, M. and Steinsbekk, A. (2011). User involvement in hospital wards: Professionals negotiating user knowledge. A qualitative study. *Patient Education and Counseling*, 85(2), pp. e144–e149. <https://doi.org/10.1016/j.pec.2011.02.009>
- Tambuyzer, E., Pieters, G. and Van Audenhove, C. (2014). Patient involvement in mental health care: one size does not fit all. *Health Expectations*, 17(1), pp. 138–150. <https://doi.org/10.1111/j.1369-7625.2011.00743.x>
- TENK (2019). Finnish Advisory Board on Research Integrity. The ethical principles of research with human participants and ethical review in the human sciences in Finland. TENK 3/2019, https://tenk.fi/sites/default/files/2021-1/Ethical_review_in_human_sciences_2020.pdf
- Toikko, T. (2016). Becoming an expert by experience: an analysis of service users' learning process. *Social Work in Mental Health*, 14(3), pp. 292–312. <https://doi.org/10.1080/15332985.2015.1038411>