Parents' Experiences of Investigations and Interventions by Child Healthcare, Child and Adolescent Psychiatry and Child and Youth Habilitation

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Abstract

Background: ESSENCE (early symptomatic syndromes eliciting neurodevelopmental clinical examinations) is a collective term for all conditions involving early-onset behavioural problems and/or cognitive difficulties. These lead to consultation with a variety of specialists, who often have no close collaboration with each other. Parents experience frustration about the lack of cooperation between care providers, and helplessness and despair over the lack of structure or routines within the care system. The aim of this study was to elicit parents' experiences of support and interventions from child healthcare, child and adolescent psychiatry and child and youth habilitation.

Method: An explorative, qualitative design taking an inductive approach. Data were collected through semi-structured focus group interviews, with 13 parents of children with behavioural and/or ESSENCE problems. Firstly, a conventional analysis of the interviews was performed. Then the revealed categories were interpreted using the bioecological model to illustrate the effects on the child's interaction with the surrounding context, i.e. micro-, meso-, exo- and macrosystems.

Results: The analysis revealed four main categories: *confidence, information, competence and collaboration*, affecting parents' experiences of the encounter with child healthcare, child and adolescent psychiatry and child and youth habilitation providers. Consistent across all four themes was the importance of time, i.e. the parents' experiences of how the process of getting help and support was constantly delayed.

Conclusion: While waiting for an investigation of ESSENCE problems, parents experience anxiety, worry, frustration, lack of information, lack of confidence and doubts about their parenting ability, which also affects the child. They experience a lack of competence among care staff when their concerns about their child's development are not taken seriously, and demand a comprehensive approach regarding investigation and treatment. Collaboration within the exosystem between the various professionals involved is perceived to have great potential for improvement.

Trial registration: Retrospectively registered clinical Trials 2021, PLUSS identifier, NCT04815889.

Background

Preschool children with mental illness risk experiencing poorer emotional well-being and developmental disabilities, with limitations on everyday functioning (1) and increased risk of mental illness later in life (2). Conditions involving early-onset behavioural problems and/or cognitive difficulties lead to consultations with a variety of specialists, who often have no close collaboration with each other. Parents or caregivers of children with ESSENCE problems (early symptomatic syndromes eliciting neurodevelopmental clinical examinations, a collective term for all conditions involving early-onset behavioural problems and/or cognitive difficulties) experience a lack of information, difficulties in determining which organisation to turn to, feelings of helplessness and frustration, and despair over the lack of structure and routines within the care system (3, 4). This paper focuses on parents' experiences of

investigation and interventions for their preschool children from Child Healthcare (CHC), Child and Adolescent Psychiatry (CAP) and Child and Youth Habilitation (CYH).

The total frequency of early (before school start) identifiable difficulties that later lead to neuropsychiatric / developmental neurological disabilities is estimated at 10% of the population (approximately 13% of all boys and 7% of girls) (4). Approximately half of these children are estimated to have appeared at some point during their first years for examination at a healthcare clinic (with a doctor, speech therapist or psychologist). Some are subsequently given a diagnosis, and others are assessed with a non-specific developmental abnormality without any diagnosis. Examples of diagnoses that are covered by the ESSENCE concept are ADHD (attention deficit hyperactivity disorder), ASD (autism spectrum disorder), language disorder, motor coordination disorder, Tourette's syndrome and other tic conditions. Frequently, there is also comorbidity within the ESSENCE concept (4-6).

In particular, small children with externalising/internalising behaviour are at increased risk of mental illness later in life (2, 7-10). Research on early interventions for children with developmental neurological disabilities provides support for the hypothesis that early, targeted interventions can lead to positive effects (4, 5, 11). There is an urgent need for research to improve evidence-based knowledge about the best ways to manage children, especially preschool children, with mental illness (12-14). Because parents know their children, and therefore pay early attention to any problems in their child's development, it is important to take their concerns seriously and involve them early on in the diagnostic process (5, 15, 16).

CHC in Sweden takes a public, preventive, supportive, health-oriented and psychosocial approach to ensuring preschool children's health, safety and development, based on Article 24 of the Convention on the Rights of the Child (17). The health and development of preschool children, i.e. up to six years of age, are regularly monitored through CHC nurses and paediatricians. The CHC nurse also coordinates contact with primary healthcare and psychologists, dietitians and speech therapists. CAP consists of interprofessional teams that investigate and treat children and adolescents with mental health conditions and disabilities and support their parents. Parents can apply to the organisation on their own or be referred from other care providers, e.g. CHC. A strengthened care guarantee has been in place for CAP since 2009. This means that children should not have to wait longer than 30 days for an initial assessment and an additional 30 days for an in-depth investigation or treatment (18). CYH offers habilitation support and interventions that will promote the development of children's functional abilities and skills. The interprofessional efforts in child and youth habilitation comprise the whole family, including siblings and relatives. Referrals of children and parents to child and youth habilitation are usually made by paediatric clinics or CHC (19).

Bronfenbrenner's bioecological model

Bronfenbrenner's bioecological model provides an understanding of a child's development over time within different microsystems, such as the family, peer group and teachers in preschool. The model involves synergistic interconnections between proximal processes, personal characteristics and context

(20-22). Proximal processes include reciprocal interactions with other people, such as family, relatives, teachers in preschool and friends, and objects and symbols in the immediate environment, i.e. the microsystems in which the child is participating here and now, such as play (1, 22, 23). For example, hyperactivity can affect proximal processes by disrupting the child's ability to engage in an activity for an extended period of time. A child's development is also affected by genetic factors and the context of the microsystem. Interactions between the microsystems and mesosystems then affect both the child's behaviour and their developmental and health outcomes. Therefore, the offer of support from the exo- and macrosystems to the parents and child becomes important for the child's opportunity to develop in the most favourable way. Beyond the mesosystems, factors in the exosystems can indirectly affect a child's environment, e.g. the local healthcare organisation and politics. The extreme level of the system, the macrosystem, describes the political, cultural or economic systems at a national level (2).

Time is also an important aspect as most children's development improves over time. Time is linked to all the system levels and is described as micro, meso and macro time. Micro time describes what is happening here and now in the proximal process. The meso period refers to the extent to which processes take place in the child's context over the course of days, weeks or years. The macro context focuses on changing expectations within cultures over time, within and across generational boundaries (Bronfenbrenner and Morris 2006) (see Figure 1).

Taken together, collaboration between different child healthcare providers for preschool children with developmental neurological disabilities is crucial in the early identification and initiation of support for both the child and their parents (4, 24). In order to improve processes and identify and support preschool children's overall needs in all systems, the project Mental Health, Learning, Development, and Collaboration for Young Children (PLUSS) model was launched 2019 in Jönköping County in Sweden and retrospectively registered in Clinical Trials 2021, PLUSS identifier, NCT04815889. The present study is part of PLUSS with the purpose of exploring how parents of preschool children with developmental neurological disabilities experience support and efforts from child healthcare, child and adolescent psychiatry and child and youth habilitation.

Methods

The study has an explorative, qualitative design and takes an inductive approach. To obtain a wealth of information in an efficient manner, we used focus group interviews in order to take advantage of the group dynamics (25-27). Participants in a group can be stimulated by one another to remember and have feelings about a topic (26). A focus group should contain five to eight participants so that everyone can express their thoughts within the group (28). We assumed that a group of participants with similar experiences would feel comfortable, secure and stimulated by each other to remember situations and encounters with CHC providers (29, 30).

Sample

Parents in Jönköping County, whose children showed developmental delays, behavioural problems and/or early signs of mental illness, i.e. who fulfilled the criteria for ESSENCE, were asked by the PLUSS researcher about participation in connection with visits to CHC, CAP and/or CYH. We obtained the participants by recruiting a convenience sample (27, 30). A total of 13 women participated. They were aged 31–45 years, 12 lived with partners, and one was single. A majority (n=11) were employed and two were studying. They were mothers of three girls and 10 boys aged 4–6 years (n=5) and 7–9 years (n=8). Six described developmental neurological problems in a close relative, and experience of contact with, primarily, a speech therapist (n=9) and CYH (n=8), CAP (n=4), child and adolescent medicine (n=1), a family centre's sociologist (n=2), and social services (n=2). The support they were offered mainly consisted of investigation (n=10) and information (n=9), so-called guiding interaction and the Circle of Security (31), assessment by a psychologist or physician, communication support, medical treatment and psychological/therapeutic treatment.

Data collection

The data were generated between August and December 2019, from three focus groups each with four or five participants. The interviews took place at the office of the researcher in the PLUSS model and were audio recorded for later verbatim transcription. One of the researchers (BMG) acted as a moderator and others (students at advanced level and employees in the PLUSS model) observed the process and took notes of their initial impressions during the data collection.

To start with, all participants filled out a questionnaire providing sociodemographic data about themselves and their child. After repeating information about the study, the moderator led the interview. Open-ended questions about the parents' experiences of information, accessibility, support and opportunities for improvement in their contact with CHC, CAP and CYH (when they seek help for their child) in contact with constituted the framework for the session. The order of the questions was adapted by the moderator to fit with the flow of the group conversation, and probes like "What do you mean by that?", "Can you explain more?" and so on were used to add more depth to the answers. The focus groups lasted between 90 and 110 minutes and ended with the participants answering an open-ended item on the questionnaire in order to evaluate their experience of taking part (30).

Data analysis

A qualitative conventional content analysis was used to analyse the transcribed text (32). Each focus group was regarded as one unit of analysis. As a first step, the analytical process focused on the manifest content, i.e. the visible and obvious outcome (33). In order to emphasise the parents' own wording, no preconceived codes were used. The analysis started with the researchers reading the transcripts individually several times in order to become familiar with the text. Meaning units related to the topic were selected and condensed (34). To take advantage of the focus group nature of the data, we looked for meaning units not only in single participants' opinions but also in opinions voiced within the

group during the discussion (35). Then, the condensed meaning units were coded using labels emerging directly from the text, which were compared and abstracted into subcategories and mutually exclusive main categories (27, 32, 33). An example of how the codes and subcategories resulted in one main category is presented in Table 1. The quotes chosen as illustrations for this article were translated into English as the final step in the process. The latent analysis comprised interpretation of the revealed categories in Bronfenbrenner’s bioecological model, as modified by Gustafsson (2), in order to illustrate the effects on the child’s interactions with the surrounding environment. This is explored in the discussion.

Table I

An example of the analysis process: the relation between codes, subcategories and the main category.

Main category	Confidence	
Subcategory	Trust	Security
Codes	<ul style="list-style-type: none"> • not being taken seriously • did not listen to me • kept trying to calm me down • kept assuring me that everything was normal • they thought I was imagining things • I felt something was wrong 	<ul style="list-style-type: none"> • support from others in the same situation • existing in an unknown world • feelings of loneliness • feelings of inadequacy • feelings of being alienated

Ethics

The present study is part of an ongoing project by the County Council of Jönköping and the municipalities, the so-called PLUSS model. The PLUSS model was approved by The Ethics Committee for Human Research at the Faculty of Health Sciences, Linköping University (No. 2019 – 04839). Informed consent was obtained in written and verbal form from the respondents in accordance with the Declaration of Helsinki (36). The respondents’ names were pseudonymised to ensure confidentiality and anonymity.

Results

The analysis revealed four main categories: *confidence, information, competence and collaboration*, which affected parents’ experiences of the encounter with CHC, CAP and CYH providers. Consistent across all four themes was the importance of time, i.e. the parents’ experiences of how the process of getting help and support was constantly delayed (Figure 2).

Time passes

A major feature of importance was the time aspect, which permeates all parts of the process. The parents expected quick feedback relating to the promised care guarantee, and when this was not forthcoming it created great frustration and anxiety.

Yes, it's like you have a guarantee of 90 days and then you should be contacted, but then it's almost just a registration. You get there, get enrolled and then you have to wait another eighteen months for an investigation. I think I collapsed when I discovered there are a lot of people in line....so much waiting. (FG 3)

"The hardest part was probably like the time between, the wait before the investigation I thought was the worst. You didn't know what to expect":::// "It took almost two years and we hadn't expected that. It was really tough!"// "The uncertainty makes you almost a horrible person, I feel. But I somehow needed to vent, get someone to bark at and blame." (FG 1)

Parents felt that the delay in starting an investigation for their child, despite their expressed concerns, could lead to serious consequences for the child.

With M, it didn't become an acute situation until he went to preschool class. We'd tried to stop him from starting preschool class via CHC and had met paediatricians at CHC with whom we had a very long conversation. And they thought it was nothing because they had done, yes, we don't know what they really did in preschool, but they did some kind of investigation /—/ and it came to the conclusion that it was nothing. / / the consequence was that M had to go to preschool class, which was terrible for him because then he went a year and it was set that he would start first class and /.../ he didn't because it didn't work. /.../ He was very sad, he was completely devastated and felt cheated. /.../ And then we think that it's taken so long, we raised this seven years ago. /.../ (FG 4)

/.../ you as a parent want it to have happened yesterday. It's all about children's development. As long as we don't receive that help, his development will stand still. (FG 4)

Confidence

Feeling trust and security was crucial for the parents' experiences of treatment in the encounter with child healthcare. Confirmation of the parents' concerns by CHC staff, as well as support for the child and parents, were described as decisive for how the encounter was experienced. In several cases, parents described how the CHC nurse had not taken them seriously when they expressed their concern that their child was not developing normally. The parents also described how CHC staff have difficulty seeing the whole picture surrounding the child, and that they seemed more interested in weight and height growth curves. The assurance that everything was normal only created more anxiety, frustration and loneliness for the parents. In addition, it was difficult to get a referral to the CAP for further assessment.

"... it was this feeling that something wasn't right. It was this way with his language, his gaze, he could sit for hours in one place while my other children were everywhere in the house, and I said that." // "You've had such mischievous children, so you're not used to it." // "When I spoke, it felt like they thought I was imagining it and it felt like they wanted to calm me down." (FG 1)

In opposition to their desire for confirmation that their child was in need of extra support and further investigation, some parents experienced that CHC staff wanted to avoid stigmatising the child by not contributing to diagnosing deviant behaviour. Some parents felt that their fear was also reflected in more anxiety in their child. Those parents who experienced that their concerns were taken seriously in the encounter with CHC felt more secure and calmer, even later in the process when their child was referred and examined by CAP.

Most parents experienced loneliness in their situation. They expressed a need to find support from other parents in similar situations to share feelings, thoughts and experiences of having a child with developmental neurological problems and/or cognitive difficulties. There was experience from specialist care. Furthermore, participants described feelings of inadequacy and sadness over the fact that parenthood had not turned out as they expected, saying that it felt like being in an unknown world.

"A support group where you can sit, talk and vent everything. Find what you're looking for ..." // "... we were looking for other people who had it like us. You're very lonely and searching." (FG 2)

Information

The parents expressed a desire for more consistent, structured and useful information, planning, feedback and available support, especially in the early stages. Information about planning was related to expectations of quick feedback and that the process would start immediately. They requested hints about where to find information and how to get in contact with support groups. They related the lack of information to feelings of shuttling between hope and despair, and expressed a desire to have someone to turn to with questions, which would have made the uncertainty they experienced easier to deal with. One option was to search for information on the internet or via other social forums in order to understand and manage the situation. There were suggestions to provide an online flow chart of the care process for a preschool child from CHC to a specialist, and where exactly their child was in that flow. Most of the parents expressed dissatisfaction with the parental education offered, as it did not meet their expectations. A majority of the parents in the focus groups did not have Swedish as their first language and thought that it was difficult when interpreters were included in parental training. It became difficult, disruptive and time-consuming.

The parents experienced frustration and irritation when the professionals were not prepared and felt that their contribution about the child was decisive for the diagnosis created. *"I've been so upset about the investigation process, it feels like I have to diagnose my own children"* (FG 1).

Once a diagnosis was established, the parents experienced a significant improvement in the provision of information and a more structured follow-up and support, especially in contact with CYH.

After the diagnosis, you were very well taken care of by the habilitation. At the habilitation, I thought you felt you could breathe out and you got the information you needed. (FG 3)

Competence

Differences in competence could occur, depending on which childcare provider the parents had been in contact with. The parents expressed this in terms of lack of professional knowledge and experience, with CHC and preschool staff being particularly criticised.

"We picked it up very early on at CHC, but they don't listen there. I feel that it's a question of competence"....//..."Now that his investigation is complete, he has a pretty serious problem, so I can easily think that it's a question of competence. That those at CHC and those at preschool don't have the competence to see this."(FG 3)

The parents also experienced a lack of resources within CHC. for example: *"Had there been more psychologists who could have done investigations, they would have come closer faster and received help"* (FG 2). Not being believed and being given the same advice over and over again caused feelings of powerlessness and doubts about their parenting ability and perception of their child, especially for first-time parents. *"When you're constantly told that everything is normal, in the end you don't believe that what you yourself are experiencing is really true"* (FG 2).

Collaboration

The parents described a lack of collaboration between different healthcare providers, which forced them to take responsibility themselves, and to control and act as a coordinator within the care system. The feeling that they themselves had to take responsibility to inform the preschool/school, or to mediate contact between organisations, was perceived as stressful. Furthermore, they described experiences of preschool/school attendees declining invitations that came from parents. *"We sometimes say [that we're] the liaison centre. That's the way it is, because you have to keep all the balls in the air"* (FG 3).

The parents also described difficulties in achieving a functioning collaboration, due to different organisations for CHC, the preschool/school, CAP and CYH, and said that current legislation means that collaboration can only take place with the parents' consent. This caused concern that children were not receiving the help and support required for them to have the opportunity to develop and meet their knowledge goals. The fear that something about their child would be missed led to parents feeling the need to have control over everything that concerned their child's existence.

Another difficulty is that the support offered to children and their parents is not equal, but depends entirely on where the family lives. The experience of being forced to take control over everything around their child created a lot of stress for all the parents. The participants described having difficulty letting go of control and trusting that the staff would do what was required in the situation their child was facing.

An exception was the contact with CYH, which was perceived as positive and providing more cohesive care, involving an approach that included a holistic view of the child's needs.

The habilitation has been gold for us there, I think you can breathe a sigh of relief. You meet with respect, people who listen and have experience. Absolutely great security, I would say, where the needs are, the help you get. (FG 2)

You should try to keep everything together because we've changed staff, changed in preschool class, first, second and now third as well, so we start every single year with new staff and then you have to pull everything together over and over again. You would like to have only one person with whom you would have contact. (FG 3)

In addition, parents experienced that collaboration between CAP and school was affected by who sent the invitation.

CAP sends the application for education directly to the school and to us /.../ it's not us who convey that contact or that information, but CAP does. (FG 2)

/.../ I invited the school, then I asked the assistant why they didn't come, the assistant said that the principal wanted her to take time off instead. (FG 1)

I think it's easier for the school to say no if the invitation comes from a parent than if the invitation comes from the habilitation. (FG 3)

As a result of the constant experience of having to control everything around their child, some parents described having developed a mental illness, which led to long sick leave, with financial consequences for the family.

Interpretation And Discussion

According to Bronfenbrenner's (1979) bioecological model, a child is part of various microsystems, such as the family, preschool and peers. These different microsystems interact with each other. How well they work together affects the child's behaviour, development and health. The interaction between these systems is defined as the mesosystem. According to this model, individuals are also affected by their exosystems; one such example is external support for parents. Interpreting the parents' experiences in the present study by means of the bioecological model shows that the healthcare system (exosystem) affects the family (microsystem) in terms of increased stress, worry, anxiety, loneliness and frustration over long waiting times, poor communication and inadequate information. The ecosystem, in turn, is

affected by the macrosystem of laws and policy regulations that reinforce the care guarantee. These results demonstrate the need for a holistic perspective to improve the preschool child's development and health, and also the parents' health and quality of life. Parents need to feel trust and security in their care contacts (see Figure 3).

Throughout the results, the time aspect for both the family and the child emerges as an important component. The child is in the present within the proximal process, that is, in his/her ability to play and interact socially in context (family and preschool) (23). How well the play and social interactions work depends on the child's developmental level in relation to age and/or ESSENCE problems. Understanding and support from adults in the child's context are crucial if the child presents ESSENCE problems. However, parents feel that this support and understanding may be lacking for a long time if the CHC does not acknowledge the child's need for support and investigation. The meso period extends to days, weeks and even years, during which the parents are worried and stressed and try to signal their need for investigation and support. This delay has a great impact on the child's commitment and social contacts. For example, hyperactivity and impaired impulse control can make it difficult for a child to remain active in their play, which in the long run affects learning (37). It can also lead to other children withdrawing from the child, as it becomes difficult to understand their actions and involvement in the play (38). In addition, current research shows that, over time, preschool teachers interact socially to a lesser extent with children who are hyperactive (39). With regard to autism diagnosis, it is important that children receive a diagnosis and intervention as early as possible (40) so that the meso period does not go by without action. Hence, early detection and efforts in relation to ESSENCE problems are essential (41).

The results of this study reveal that parents and children become "victims" in macro time, despite political efforts in the macro system to increase the accessibility of healthcare. These parents' experience of long waiting times in public child psychiatric care and a complicated path to investigation is supported by previous studies (42-44). Boulter and Rickwood (45) interviewed parents about their experiences of seeking help for children with mental health problems. The results show that the emotional impact on the families was significant, and that the parents found it difficult to cope with their children's difficulties. They also described a desire for help in dealing with feelings of frustration, guilt, stress, anxiety and fear, which also affected the child. This is consistent with what emerged from parents' experiences of a long wait, uncertainty, frustration and symptoms of stress in this study.

The parents in the current study stated that the long waiting time would have been easier to handle if they had been given the opportunity to follow their child's investigation process more easily. This is in line with a previous study by Connolly and Gersch (46), which interviewed parents who were awaiting an investigation of autism in their children. These parents experienced not knowing when or even if the investigation would be initiated and that they lost valuable time that could have been used in a better way to help their children. The parents described it as being as though they had lost their children and they felt a great deal of concern for their children's future during the waiting period. Parents whose children had undergone an investigation could, however, testify that their children developed despite the parents' feeling that they had missed out on early interventions.

The present study also highlights the importance of parents being offered support and information while waiting for, and during, the investigation process, in order to improve the environmental factors for the child. The parents also wondered about how caregivers in healthcare interact with each other. They suggested some form of web-based flow process to enable them to understand the efforts being made within the exosystem. Being able to follow the process from referral to the beginning of the investigation would have made them better able to accept the wait. It would also have made the role of the CHC psychologist more understandable and what is involved in the specialist level of healthcare. Furthermore, the wishes and suggestions of the parents were to be given useful professional tips by healthcare personnel to make everyday life easier while waiting. The desire for support explaining how parents can handle their children's problems, information about the children's difficulties and the opportunity to develop their parental role have also been demonstrated in previous studies (46, 47).

The difficulties that occur for children with ESSENCE problems and the challenges these entail have been shown to increase the mental and physical health problems of the parents compared to parents of children who develop normally (48). Parental education aims to alert parents to techniques that can enable them to deal with their children's challenging behaviour. Bradshaw and colleagues (40), for example, showed that parental education was a support for parents of young children with ASD and also led to an indirect improvement in the children's behavioural problems. Research has also shown that parental education reduces parents' stress, increases their confidence in their own ability to handle difficult situations with the child (49) and leads to increased self-confidence and a greater sense of control (46). It is very important that the education offered to these parents is of high quality and adapted to the parents' needs. In the present study, however, the parents expressed dissatisfaction with the education offered within the exosystem. The parents wanted more time for discussion and exchange with other parents in similar situations. Suggestions for improvement that came from the parents were that the education should be better adapted to the participants, among other things because it is not uncommon for parents to have a neuropsychiatric diagnosis themselves. Another aspect that the parents put forward was that, if there is a need for interpreters, parents who speak the same language should have their own group meetings, because it is difficult to maintain focus and absorb information when interpretation is in progress. This is in line with the finding that functioning communication between healthcare personnel and the patient and relatives is a prerequisite for good care (50).

During the focus groups, it emerged that the support offered differs between municipalities and regions in the macro system, which is probably because Sweden's municipalities and regions themselves are establishing available support for parents and children with ESSENCE problems (51). A consequence might be that the support offered to children and parents is not on an equal level, because it depends on where in the country the family lives. Also, the parents in the present study experienced ignorance in the encounter with care staff at CHC, which can be interpreted as healthcare staff lacking knowledge and/or being afraid of stigmatising unnecessarily. The assessment of children with behavioural problems requires knowledge of children's development, diagnoses and symptomatology in order to identify early signs (8). In order to prevent stigmatisation, both in professional activities and in society in general, it is important that investigation, treatment and support take place within a holistic approach (52, 53). The

present results reveal a need for structured screening both in mental health and for behavioural problems. Today, there are national guidelines for the early detection of delayed development in children via screening at the age of 2.5 (54). To ensure the offering of more equal support, national guidelines for neuropsychiatric disabilities are currently being formulated in Sweden (55, 56).

The results also emphasise how context affects the development of young children. In addition to the child's relationship to his/her parents/primary caregivers within the microsystem, there is also a network of family relationships, i.e. the mesosystem. Everybody concerned affects the child's development and adaptation in one way or another (23, 57). Collaboration within the exosystem between CHC and the preschool to assess a child's function and mood is regulated in national guidelines in Sweden (54). Information exchange and practical collaboration are then designed at the macro level with the parents' consent (58). The parents in the current study, however, demanded more open and accessible cooperation between organisations. They expressed a desire to not always have to be involved in all the collaborations that take place around the child, as they already felt that they were sufficiently stressed.

Limitations

The limitations of the present study might include that the results are based only on mothers' experiences, although they mostly referred to "we", i.e. including the father, in their experiences. Also the study was performed in a Swedish context, i.e., in the context of a mainly non-profit healthcare system with a homogeneous approach. This is also a strength, because the respondents were all basing their experiences on a similar context. The small groups might also have affected the interactions between participants.

Conclusions

The parents of a child with ESSENCE problems and the child him/herself (the microsystem) are affected in different ways while waiting for an investigation by the healthcare system (exosystem), which is governed by the macrosystem's economy, laws and policies. Due to long waiting times before the investigation begins, the parents experience anxiety, worry, frustration and doubt about their parenting ability, which also affects the child. The parents also experience shortcomings in information during the waiting period and demand better collaboration and a unified approach from the various actors in healthcare. There is a lack of competence among care staff which means that parents' concerns about their child's development are not taken seriously. The child is affected both in mesotime and in the here and now in the proximal process (microtime). When the child does not receive help with his/her problems in mesotime, development can be adversely affected. In conclusion, collaboration in the exosystem between the various healthcare agencies and the preschool was perceived to have great potential for improvement.

Clinical implications

It is of the utmost importance to identify and treat ESSENCE problems in young children at an early stage in order to prevent suffering and mental illness in both childhood and adulthood. A holistic view is needed, taking into account everything that affects the preschool child's development and health, as well as the parents' health and quality of life. The waiting time until diagnosis and treatment could be shortened and facilitated for both child and parents, mainly by means of improved routines and collaboration between caregivers. By giving parents a greater insight into the ongoing investigation and an opportunity to follow the flow, greater security and understanding is created while waiting. Parents need to be able to feel trust and security in their care contacts. They also want contact with parents in a similar situation for conversation. Healthcare professionals need training on treatment and children's mental health and development.

Declarations

Ethics approval and consent to participate

The present study is part of an ongoing project by the County Council of Jönköping and the municipalities, the so-called PLUSS model. The PLUSS model was approved by The Ethics Committee for Human Research at the Faculty of Health Sciences, Linköping University (No. 2019 – 04839). Informed consent was obtained in written and verbal form from the respondents in accordance with the Declaration of Helsinki (36). The respondents' names were pseudonymised to ensure confidentiality and anonymity.

Consent for publication

Patient consent for publication, not required.

Availability of data and materials

Data are available from the author Berit M Gustafsson upon reasonable request.

Competing interests

No competing interests.

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Authors' contributions

BG conceived the idea for the article, led the focus groups and analyzed the material. BG and MSL designed the study and drafted the manuscript. Both approved the final submitted version.

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Figures

Figure 1

Bronfenbrenner’s bioecological model illustrates the child’s interaction with the surrounding environment. With permission from Gustafsson (2).

Figure 2

Parents' experiences of their encounters with child healthcare (CHC), child and adolescent psychiatry (CAP) and child and youth habilitation (CYH).

Figure 3

Interpretation of the revealed categories in Bronfenbrenner's bioecological model, illustrating the effects on family interactions with the surrounding environment.