Parents’ experiences of investigations and interventions by Child Healthcare, Child and Adolescent Psychiatry and Child and Youth Habilitation

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\textbf{ABSTRACT}

This study examines parents’ experiences of support, investigation and treatment from child healthcare/psychiatry and habilitation in children with ESSENCE symptoms (neurodevelopmental symptoms). Data were collected through focus interviews, with 13 parents. A conventional qualitative analysis revealed four main categories: confidence, information, competence and collaboration, affecting parents. While waiting for an investigation parents experience anxiety, frustration, lack of information and confidence and doubts about their parenting ability, which also affects the child. The categories were interpreted using Bronfenbrenner’s bioecological model to illustrate the effects on the family’s interaction with the context. Parents demand a greater insight and participation in the ongoing process and improved collaboration between the various professionals.

\textbf{Trial registration:} Retrospectively registered clinical Trials 2021, PLUSS identifier, NCT04815889.

\textbf{Introduction}

Mental health problems, both internalizing and externalizing, often debut in early childhood and may last throughout adulthood, thereby making early detection and intervention especially important. ESSENCE symptoms (early symptomatic syndromes eliciting neurodevelopmental clinical examinations), is a collective term for all conditions involving early-onset behavioral problems and/or cognitive difficulties). Preschool children with ESSENCE symptoms experience poorer emotional well-being and developmental disabilities with limitations on everyday functioning (Löfstedt, 2018) and increased risk of mental illness later in life (Gustafsson, 2019). Conditions involving early-onset behavioral problems and/or cognitive difficulties lead to consultations with...
a variety of specialists, who often have no close collaboration with each other. Parents to children with ESSENCE symptoms describe a lack of information, difficulties in determining which organization to turn to, feelings of helplessness and frustration, and despair over the lack of structure and routines within the care system (Gillberg, 2010; Strunk, Pickler, Mccain, Ameringer, & Myers, 2014). 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).

**Background**

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 (Gillberg, 2020). About 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 nonspecific 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 (Gillberg, 2010; Hatakenaka, 2018; Hatakenaka & Hirano, 2015).

In particular, small children with externalizing/internalizing behavior are at increased risk of mental illness later in life (Caspi et al., 2014; Egger & Angold, 2006; Gustafsson, 2019; Kendler, Gatz, Gardner, & Pederson, 2006; Kling, Forster, Sundell, & Melin, 2016). Research on early interventions for children with developmental neurological disabilities provides support for the hypothesis that early, targeted interventions can lead to positive effects (Dodge et al., 2015; Gillberg, 2010; Hatakenaka, 2018). 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 (Bondestam, Hansson, Kadesjö, & Zetterquist, 2013; Petersen et al., 2010; Petrenko, 2013). 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 (Carlsson, Miniscalco, Kadesjö, & Laakso, 2016; Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Hatakenaka, 2018).

**Bronfenbrenner’s bioecological model of human development**

Bronfenbrenner’s bioecological model of human development 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 (Bronfenbrenner, 1992; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006). 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 (U. Bronfenbrenner, 1999; Bronfenbrenner & Evans, 2000; Löfstedt, 2018). 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 behavior 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 favorable way. Beyond the mesosystems, factors in the exosystems can indirectly affect a child's environment, e.g. the local healthcare organization and politics. The extreme level of the system, the macrosystem, describes the political, cultural or economic systems at a national level (Gustafsson, 2019).

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 & Morris, 2006) (see Figure 1).

**Child health care in Sweden**

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 (UNICEF, 2018). The health and development of preschool children, i.e. up to six years of age, are regularly monitored through CHC nurses and pediatricians. 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 organization 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 (Govermental, 2020). 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 pediatric clinics or CHC (SKR, 2021).

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 (Gillberg, 2010, 2020; Kazdin, 2008). 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

![Figure 1. Bronfenbrenner’s bioecological model of human development illustrates the child’s interaction with the surrounding environment. With permission from Gustafsson (Gustafsson, 2019).](image-url)
disabilities experience support and efforts from child healthcare, child and adolescent psychiatry and child and youth habilitation.

**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 (WMA, 2013). The respondents’ names were pseudonymised to ensure confidentiality and anonymity.

**Materials and methods**

The study has an exploratory, 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 (Barbour, 2005; Kitzinger, 1995; Polit & Beck, 2017). Participants in a group can be stimulated by one another to remember and have feelings about a topic (Kitzinger, 1995). A focus group should contain five to eight participants so that everyone can express their thoughts within the group (Krueger & Casey, 2015). 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 (Marshall & Rossman, 2016; Patton, 2015).

**Sample**

We obtained the participants by recruiting a convenience sample (Patton, 2015; Polit & Beck, 2017). Parents in Jönköping County, whose children showed developmental delays, behavioral problems and/or early signs of mental illness, i.e. who fulfilled the inclusion criteria for ESSENCE were invited by the professionals specialists at CHC, CAP and/or CYH. 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 specialist (n = 1), a family center’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, assessment by a psychologist.
or physician, communication support, medical treatment and psychological/therapeutic treatment and the Circle of Security a parent intervention in order to promote secure attachment with the child. (Hoffman, Marvin, Cooper, & Powell, 2006),

**Data collection**

The data were generated between August and December 2019 from three focus groups, each with four or five participants. Participants were grouped according to the date and time of the focus group that best met their schedule. The interviews took place at the office of the researcher in the PLUSS project and were audio recorded for later verbatim transcription, performed by two master’s students for specialist nurse in pediatric care. One of the researchers (BMG) acted as a moderator and others (two master’s students pediatric care and employees in the PLUSS model) observed the process and took notes of their initial impressions during the data collection. Saturation in the data appeared already in the second interview, and was further strengthened with a third interview, so no more interviews were conducted. 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. An interview guide with open-ended questions constituted the framework for the session. The open-questions aimed to gather information 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). The questions were designed to gain a deeper understanding of the parents’ experiences, such as What has been important for you? Which support has affected/been most important for your child? What support could have been better for you/your child? What support has been lacking for you/your child? Suggestions for improvement? Other important support? 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 (Patton, 2015).

**Data analysis**

A conventional qualitative content analysis, which means that coding categories are derived directly from text data without beforehand theory guiding the coding, was used to analyze the transcribed text (Hsieh & Shannon, 2005). 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 (U. H. Graneheim & B. Lundman, 2004). In order to emphasize the parents’ opinions, no preconceived codes were used. The researchers (BMG) and the master’s students performed the manifest analysis, starting with reading the transcripts individually several times in order to become familiar with the text and obtain a sense of the whole. In the second step, meaning units related to the topic were selected and condensed (Mile & Huberman, 1994). 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 (Kitzinger, 1994). Then, the condensed meaning units were coded using labels emerging directly from the text, which were compared and abstracted into subcategories. About 5% of the codes were discussed until agreement. Finally, the subcategories were merged into mutually exclusive main categories (Hsieh & Shannon, 2005; Polit & Beck, 2017; U. H. Graneheim & B. Lundman, 2004). An example of how the meaning units, codes and subcategories resulted in one main category is presented in Table 1. The quotes chosen as illustrations for the results were translated into English as the final step in the process. The quotes are taken directly from the participants’ own words and thus strengthen the credibility.

To ensure coding consistency, the second researcher (MS) independently reviewed the coded data, the subcategories and main categories and discussed it with BMG. The latent analysis, conducted by BMG and MSL, comprised interpretation of the revealed main categories in Bronfenbrenner’s bioecological model, as modified by Gustafsson (Gustafsson, 2019), in order to illustrate the effects on the child’s interactions with the surrounding environment. This is explored in the discussion.

Table 1. An example of the analysis process: the relation between meaning units, codes, subcategories and main category.

| Subcategory | Trust | Confidence | Security |
|-------------|-------|------------|----------|
| Codes       | ● not being taken seriously | ● support from others in the same situation | ● feeling of being alone |
|             | ● did not listen to me       | ● existing in an unknown world            |
|             | ● kept trying to calm me down| ● feelings of loneliness                  |
|             | ● kept assuring me that everything was normal | ● feelings of inadequacy                 |
|             | ● they thought I was imagining things | ● feelings of being alienated |
|             | ● I felt something was wrong |                                        |
| Meaning unit | “I felt from the beginning that something was wrong. I felt that early on. Motherhood simply. They thought I was imagining. It felt like they wanted to calm me down. You almost got the feeling of not being taken seriously.”“They did some kind of investigation / – / and it came to the conclusion that it was nothing.” | “we were looking for other people who had it like us. You’re very lonely and searching.”“when you constantly hear that everything is normal, in the end you do not think that what you yourself experience is really true” |

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Results

The analysis revealed four main categories: confidence with subcategories trust and security; information with subcategories consistent, structured, planned and informative; competence with subcategories knowledge, experience and parenthood; collaboration with subcategories responsibility and control, which affected parents’ experiences of the encounter with CHC, CAP and CYH providers. Consistent across all four main categories was the importance of time, i.e. the parents’ experiences of how the process of getting help and support was constantly delayed. The experience that “time just passed” permeates the parents’ story and can be seen as an influence that is present throughout the whole investigation process (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.

/ . . . / 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. / . . . // . . . . // 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)

Confidence

To feel confidence in terms of mutual understanding of each other’s experiences and skills was important for the parents. Feeling trust and security was crucial for the parents’ experiences of treatment in the encounter with child healthcare. When the parents felt that the providers did not take their concerns seriously, it affected their confidence. 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 stigmatizing the child by not contributing to diagnosing deviant behavior. 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.

Loss of security was expressed by most parents as experience 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 criticized. The parents felt that this affected their parenthood.

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, e. g. initiating and inviting to meetings with themselves, preschool and care providers. The feeling that they themselves had to take responsibility to inform the preschool/school, or to mediate contact between organizations, 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 organizations 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.

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 if the parents or the providers 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**

The results are presented in four main categories: confidence, information, competence, collaboration and time, which affected parents’ experiences of the encounter with CHC, CAP and CYH providers. Consistent across all four main categories was the importance of time, i.e. the parents’ experiences of how the process of getting help and support was much too often delayed. The experience that “time just passed” permeates the parents’ story and can be seen as an influence that is present throughout the investigation process.
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 behavior, 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 exosystem, 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). The macro-, exo-, and mesosystems can also be influenced by accident, such as a health emergency. The Covid pandemic had not occurred when these focus groups were performed, so effects on children’s physical and

Figure 3. Interpretation of the revealed main categories in Bronfenbrenner’s bioecological model, illustrating the effects on family interactions with the surrounding environment.
mental health from the pandemic, described by others (Fari et al., 2021; Singh et al., 2020) is not illuminated in the present results.

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 their ability to play and interact socially in context (family and preschool) (U. Bronfenbrenner, 1999). How well the play and social interactions work is affected by the context and the child’s developmental level in relation to age and/or ESSENCE symptoms. Understanding and support from adults in the child’s context are crucial if the child presents ESSENCE symptoms. 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 ability to remain engaged in activity 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 (McWilliam & Bailey, 1992). It can also lead to other children withdrawing from the child, as it becomes difficult to understand their actions and involvement in the play (Sjöman, Granlund, & Almqvist, 2016). In addition, current research shows that, over time, preschool teachers interact socially to a lesser extent with children who are hyperactive (B. M. Gustafsson, Gustafsson, Granlund, Proczkowska, & Almqvist, 2021). With regard to autism diagnosis, it is important that children receive a diagnosis and intervention as early as possible (Bradshaw et al., 2018) so that the meso period does not go by without action. Hence, early detection and efforts in relation to ESSENCE symptoms are essential (Gustafsson, Danielsson, Granlund, Gustafsson, & Proczkowska, 2018).

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 (Reid & Brown, 2008; Reid et al., 2011; Shanley, Reid, & Evans, 2008). Boulter and Rickwood (2013) 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 (2013), in which parents who were awaiting an investigation of autism in their children were interviewed. These parents experienced not knowing when or even if the investigation would be initiated and 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 generally 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 roles have also been demonstrated in previous studies (Connolly & Gersch, 2013; Cunningham et al., 2013).

The difficulties that occur for children with ESSENCE symptoms 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 (Karst & Van Hecke, 2012). Parental education aims to alert parents to techniques that can enable them to deal with their children’s challenging behavior. Bradshaw and colleagues (Bradshaw et al., 2018), 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 behavioral 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 (Zwi, Jones, Thorgaard, York, & Dennis, 2011) and leads to increased self-confidence and a greater sense of control (Connolly & Gersch, 2013). 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 (Meuter, Gallois, Segalowitz, Ryder, & Hocking, 2015).

During the focus groups, it emerged that the support offered differs among 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 symptoms (SBU, 2013). 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 stigmatizing unnecessarily. The assessment of children with behavioral problems requires knowledge of children’s development, diagnoses and symptomatology in order to identify early signs (Egger & Angold, 2006). In order to prevent stigmatization, both in professional activities and in society in general, it is important that investigation, treatment and support take place within a holistic approach (Mastoras, Saklofske, Schwean, & Clime, 2018; Wiley & Vaughn, 2019). The present results reveal a need for primary preventive measures, i.e. structured screening both in mental health and for behavioral problems. Today, there are national guidelines for the early detection of delayed development in children via screening at the age of 2.5 (SKR, 2019). To ensure the offering of more equal support, Swedish national guidelines for neuropsychiatric disabilities are currently being formulated (Socialstyrelsen, 2019a, 2019b). It is also important to take into account environmental aspects, especially risk and protective factors in the micro system, such as negative stressful live events and family-related functions. These play a significant role in the development of the child (Andershed & Andershed, 2015; Menculin et al., 2020). Therefore, collaboration between the different levels of the exosystem is of utmost importance (SKR, 2019).

The results also emphasize how context affects the development of young children. In addition to the child’s relationship to their 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 (U. Bronfenbrenner, 1999; Zeanah & Lieberman, 2016). Collaboration within the exosystem between CHC and the preschool to assess a child’s function and mood is regulated in national guidelines in Sweden (SKR, 2019). Information exchange and practical collaboration are then designed at the macro level with the parents’ consent (Socialstyrelsen,
The parents in the current study, however, demanded more open and accessible cooperation among organizations. 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. The present results confirms a recent national report of the coordination of care for children with mental illness in Sweden. The report emphasizes that lack of coordination and collaboration among caregivers leads to the families feeling abandoned and responsible for coordination and information transfer between levels of care, that the efforts are delayed or not carried out and many meetings and repetitions. Both parents and professionals in child health care called for better communication, professional meetings as a complement to meetings where families participate, better planning and structure (IVG, 2021).

**Limitations**

A critical issue in qualitative content analysis is to select the most suitable meaning units (U. Graneheim & B. Lundman, 2004). In our study, one researcher (BMG) and master students read the text and marked meaning units independently and then compared the markings. Differences were discussed until agreement was reached. To ensure coding consistency, a second researcher (MSL) independently reviewed the coded data, the subcategories and main categories and discussed it with BMG. The latent analysis, i.e. the interpretation of the results into the Bronfenbrenner’s bioecological model, was performed by MBG and MSL, reducing the risk of investigator bias, by the researchers supplementing and contesting each other’s readings, corresponding to reflexivity (Malterud, 2001). To ensure credibility the actual words expressed by the informants were used to the greatest possible extent during all the analytic steps. As the final step a linguistic expert performed the translation of the quotations into English. 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 nonprofit 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.

**Summary**

The results of the current study revealed that parents of a child with ESSENCE symptoms and the child themselves (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. Parents of a child with ESSENCE symptoms in our sample experience 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, collaborations in the exosystem among the various healthcare agencies and the preschool were perceived to have great potential for improvement.

Implications for Practice

It is of the utmost importance to identify and treat ESSENCE symptoms 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 in the macro- and exosystems. By giving parents a greater insight and participation 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 ESSENCE symptoms and development.

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