Parents experience a sense of guilt when their newborn is diagnosed small for gestational age, SGA. A grounded theory study in Sweden

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Abstract

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Background: To become a parent of a child who is born small for gestational age can lead to challenges in addition to the newly acquired parenting role. There is currently a lack of knowledge regarding parents’ experiences of having a child born small for gestational age.

Purpose: The purpose of this study was to describe the experience of becoming a parent of a child small for gestational age

Design and method: A qualitative inductive approach was chosen with grounded theory as a method, a strategic selection was used and individual interviews with open questions were performed.

Results: The results showed that the parents expressed guilt over the child’s size and focused on the ability to nourish their child to keep their unexpectedly small child alive. An experienced concern about the child’s food intake could be seen throughout the entire interview material and the need for information was great. A common experience of the parents was that constant feeding of the child dominates their lives.

Conclusion: The conclusion is that the unexpectedly small size of the child awakens the parent’s instinct to provide life-sustaining care and the parents need increased support and more information around the child’s condition. This requires well-trained professionals, because parents to children born SGA often harbour feelings of unpreparedness and guilt.

Practice implications: Increased understanding and knowledge about the parents’ experience of having a child born SGA, healthcare services can optimize the potential for better attachment between parent and child as well as offer appropriate support.

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Introduction

There are two common definitions of being born small for gestational age (SGA); one is birth weight and/or length below the 10th percentile and another is birth weight below –2 standard deviations for gestational age. In Sweden, where the study was performed, the last definition is used and 2.6% of the children are born SGA (The National Board of Health and Welfare, 2020). SGA means “too small at birth for age” and the small fetus might have difficulty handling the stresses entailed by birth. The risk for acute respiratory problems increases and hypoglycemia is 15–20 times more common in cases of extreme growth inhibition. The risk increases in combination with asphyxia and is the most elevated during the first three days of life. Other newborn complications found with SGA include hypothermia, polycythemia, coagulation issues as well as nutritional challenges (Huebler, 2013).

Knowledge around the causes of SGA is well documented. Tobacco use (Baba et al., 2012; Kvalvik et al., 2016), alcohol- or drug-abuse, heredity, mental illness, socioeconomic status, malnutrition in the mother, as well as maternal diseases such as diabetes, preeclampsia, or kidney disease are primary risk factors (Zabransky, 2013).

Children born SGA are at greater risk for delays in speech and language development as well as worse verbal and non-verbal memory, concentration, and memorization. They also have higher risk of dyslexia and/or dyscalculia as compared with their peers born at typical normal weight for gestational age. Also, neuropsychiatric disabilities such as
Attention Deficit Hyperactivity Disorder, depression, anxiety, and worsened abilities are three times as common among this group of children, which offers them compromised opportunities to succeed in society (Haverkamp, 2013). In a long-term perspective, intrauterine growth restriction can also constitute a risk factor for heart- and vascular disease as adults (Ibáñez et al., 2006; Kajiser et al., 2008), diabetes type 2 (Baird et al., 2005), high blood pressure (Albery & Soothill, 2007), as well as reduced insulin sensitivity (Ibáñez et al., 2006). Research also indicates that there might be a correlation between low birth weight, catch-up growth, and metabolic syndrome (Nobili et al., 2008).

The period of pregnancy has shown to be a vulnerable time for both becoming mothers and fathers (Åsenhed et al., 2013; Göbel et al., 2020). Previous research has charted the experience of stress among parents but has primarily focused on the mothers. Recently published research concluded that if a pregnant woman experienced a negative emotional status, this could lead to a maternal dissatisfaction after birth (Göbel et al., 2020). However, the last decade there has been an increased interest for fathers and the period of pregnancy has shown to be a transition period even for the becoming father (Åsenhed et al., 2013).

The transition to motherhood has shown to be characterized by vulnerability (Erfina et al., 2019). Becoming a mother is a period of various feelings like unreadiness, and aloneness, (Barclay et al., 1997; Rogan et al., 1997) but also feelings of being vulnerable and confused (Barclay et al., 1997; Erfina et al., 2019). During the last ten years there has also been a growing interest concerning experiences of becoming a father and the result showed that becoming a father was like “an emotional roller coaster”. The father’s experiences were feelings of both exclusion during visits to the midwife at the antenatal clinic but also a confusion regarding how to support their partner (Åsenhed et al., 2013).

There exists a fair amount of research regarding the experience of parents of premature children including the relationship between increased psychological ill health and low birthweight (Howe et al., 2014; Singer et al., 1999; Singer et al., 2010). Becoming a parent of a premature or severely ill child involve feelings such as chaos and trauma that can lead to stress, grief, anxiety or depression (Boykova & Kenner, 2012; Lefkowitz et al., 2010; Purdy et al., 2015). For example, in cases where the child needed to stay at the neonatal intensive care unit (NICU) after birth, both parents showed symptoms of stress such as acute stress disorder, posttraumatic stress disorder and additionally mothers showed symptoms like postpartum depression (Lefkowitz et al., 2010). In a study by Ballantyne et al. (2017) parents describe a feeling of unpreparedness regarding parenting at a distance, feelings of stress and a need for support. These feelings came from not being informed or involved in decisions due to insufficient communication with different healthcare professionals.

In Sweden, visits to the Maternity Health Care (MHC) and Child Health Care (CHC) are free of charge and after the child is born the parent that care for the child at home receive remuneration from the Swedish Social System (Swedish Social Insurance Agency, 2021). Both MHC and CHC have different kinds of parental programs aiming to give the parent support and by that give the child an opportunity to develop an attachment while growing up which is considered a wellness factor and offers the child tools to get through difficulties in life (Piotrowska et al., 2017). Therefore, it is important to identify risk and protective factors since disturbances in the mother–child bond increase the risk of negative consequences for child development (Cuijiltis et al., 2019).

Becoming the parent of a child who is SGA can entail a number of experiences (Glaser, 1998). During the interview memos were written and why, always forming the foundation during the processing of the material in order to achieve a satisfactory structure of the analysis (Charmaz, 2006). Then commenced an interview consisting of an open-ended main question as well as a few supplementary questions, this to support those interviewed in freely relating their experiences (Glaser, 1998). During the interview memos were written down. All interviews were recorded and transcribed verbatim. The data collection was initially open-ended without pre-understanding and gradually hypotheses emerged during this process. The data analysis was influenced during the work with the data collection. This allowed the authors to use the guidance of possible questions
which were received during the analyses. Thereby, the process could support and develop a theory which led to emergence of a core problem (Glaser, 1998).

Data analysis

The analysis and gathering of data were conducted in parallel and were allowed to influence each other according to this. All parts of the material were read multiple times and open coding was conducted in order to find characteristics and concepts in the text. The codes are grounded in the data and the concepts emerged from the data and formed categories (Glaser, 1998) (Fig. 2). Memory notes, so called memos, were used to remember thoughts and perceptions of the material, both at the time of the interviews and during the processing of data. The data collection proceeded until a point at which the material reached theoretical saturation and no additional information to the

![Diagram](image-url)

**Fig. 1.** Overview of study participants.

![Diagram](image-url)

**Fig. 2.** Analysis structure following grounded theory.
categories was added. Then the axial process started and relations between concepts and categories and between concepts and characteristics took place. Subcategories were related to categories hypothetically and verified in the text, and categories were compared to explain variations in different dimensions. This process was the beginning of a theoretical model. The focused process followed, and the theoretical code was the main focus. Categories were related to each other; saturation was searched for and a main category was decided Glaser (1998).

A core category was then selected which expresses the main experiences from the participants perspective. The first two authors carried out the analysis together and all memos have been read by both. Recordings of interviews were then compared to each other and discussed by the two first authors in order to establish trustworthiness. In addition, a test interview was conducted before the start of the study, with one for the study relevant person who had given birth to child born SGA three years previously. This interview gave the authors some experience interviewing as well as a hint as to what could be expected to come up with subsequent respondents. This laid the groundwork for some of the themes in the interview material which could be further illuminated through additional open-ended questions. In their experiences as pediatric nurses for many years, the authors have a certain preunderstanding of the focus parents of small children might have during the newborn period. Nonetheless, they entered into the study with an open mind.

Results

The result gave a core category and five main categories. Overall, the result showed that the parents were focusing on nutrition and the ability to nourish their child in order to keep their child alive. They expressed feelings like guilt, questions like “why did this happen?” and reflections like lack of information and the quality of care, or more exactly insufficient care from the CHC. The core category “Feelings of guilt” and five main categories: “The child is unexpectedly small”, “Constant feeding”, “Reflecting over responsibility”, “Thinking about cause and effect” and “Connecting the family” as well as twelve sub-categories, emerged from the data and formed a theoretical model (Fig. 3).

The child is unexpectedly small

To become the parent of a child with a growth restriction is described as an experience of shock. To be entirely unprepared for the child to be so small and therefore not live up to expectations one had contributes to an immediate sense of worry and insecurity. The same feeling is described by the mother who was informed while still pregnant; “My pregnancy took a completely different course when we were told that they were small”. 

Well, but just this, that we didn't receive any…is it a diagnosis? It is? Well, yeah, they didn't tell us that. 

[(Father 1)]

This lack has resulted in a need to seek out information on one's own in order to manage the situation, which in turn has increased parents' worrying.

[(Father 1)]

Once I realized that she had a diagnosis that had a name, that's when I got this form to fill out from social security that said diagnosis SGA, so then I googled that of course and I saw there's something called growth restriction and I thought that sounded pretty scary.

[(Mother 6)]

The lack of previous experience in relation to be a first-time parent is expressed in the sense of not having anything with which to compare the new parenting situation; however, it is felt as reassuring to receive information that the child is doing well. The insight that the child is small is reinforced in encountering other, normal-sized, babies in the

Fig. 3. Theoretical model of “Feelings of guilt”. The model shows the division of the study’s twelve subcategories which first evolved. The five main categories that emerged from the subcategories which developed into the core category.
delivery ward and later in daily life. The reactions of others also serve as constant reminders of the child’s small size:

> I thought my mom would have a shock when she saw them...when she called and I told her the measurements after they were born, she said that she was just praying to God that they would survive because they were so terribly small.

[(Mother 1)]

This feeling is described by some as guilt, sadness, and challenging, but by others as nothing they think about or are affected by. The common experience some time after the newborn stage is that the parents’ anxiety has been reduced and that the child’s size is not seen as something negative, but even in some cases as an advantage in everyday situations such as carrying.

### Constant feeding

In terms of care requirements, the single most touched upon topic revolves around thoughts surrounding the child’s food intake. This topic was seen as so central that one’s own well-being is set aside in favor of the child’s, with the reflection on this not taking place until after the fact. A sense of responsibility in the mother appeared primarily after coming home, when she perceived her own responsibility as far as breastfeeding. She is the one expected to produce nourishment and ensure the child’s nutritional intake at the breast. Mothers described the experience as “I feel like she cannot be allowed to lose a single gram”, “I thought she was going to die every time she threw up”, and “I have to make her survive”. Smoothly functioning breastfeeding was seen as having a positive effect on the level of anxiety relating to the child’s nutritional status. The by caregivers mandated high frequency of feedings contributes to a feeling of being tied up, where every hour of the day and night seem scheduled.

> Well, it was more like you had times. Life depended on his food clock, basically. There just could not be that much time between feedings and yeah... well, I had to constantly wake him up and yeah, that was a hassle. And then the supplemental feeding was not that much fun either.... Feeding with a cup, you know...it took a lot of time.

[(Mother 4)]

This affects both emotional well-being in the form of stress and physical in the form of fatigue. In cases of supplemental feeding there is a sense that lack of knowledge has contributed to difficulties managing. The fathers, however, feel that supplemental feeding gives them a sense of participation and the mothers expressed a feeling of equality and having their burden shared.

### Reflecting over responsibility

Good treatment from care personnel, despite heavy workloads and a notably stressful work situation, has generated a sense that care was good, primarily in the context of basic assistance and support with the newborn child. Those parents who were receiving care along with their child at the maternity ward experienced unease that the family was separated already the first night when the father according to the clinic policies was not allowed to stay at the unit. The experience of neonatal care is described as ‘incredibly secure’ as they are experts on the small child and his or her needs, “Neo was the child’s world” and “at the maternity ward it was more about me” are expressions that illuminate this. Nonetheless, there is the feeling of not wanting to be a bother, which led to the parents not asking for help to be near their child, as they felt the premature children had a greater need for the caregivers.

They said, pick them up, pick them up as much as you can. But each time we were going to do that, we had to ring the bell so that they could unplug the cord and the tube and after a while we just felt like we were totally in the way. Even if we weren’t, it just felt like we were in their way. There were other babies on that floor who had more life-threatening issues than our little one.

[(Mother 6)]

One insight that surprised the parents was the lack of reliability in the intrauterine measurements in connection with prenatal visits at the MHC, where the estimates of the fetus’s size in no case aligned with reality.

> Well, yeah, I was kind of shocked and thought how could they miss that? Because all through the pregnancy at the check-ups they would say he is doing well, and everything is fine and so on.

[(Mother 5)]

A wish, especially among the mothers that primary caregivers during pregnancy had been more alert to early signs of growth restriction emerges. Encounters with the CHC are described as follow-up on child’s weight with good continuity; however, interviewees stressed the lack of concrete advice regarding interventions surrounding the child’s state of health. A notable lack of knowledge in CHC staff regarding children born SGA is a recurring theme among the parent respondents.

Experiences diverge regarding coming home with the small child. “My sense was that it was one hundred thousand percent my responsibility to make sure she survived”, ‘autopilot – I have to function now’, “it was when I came home that I truly started feeling that this is my child”, “very wonderful to be home” are expressions that bear witness to this. Feelings varied from increased anxiety to a feeling of safety. Parents express thoughts that the entire focus is on the child’s well-being and also wish for being offered follow-up regarding their own well-being and psychosocial health.

The general and most tangible experience of the encounter with healthcare is the lack of knowledge and information in the staff around the growth restricted child. This wish is expressed by the parents as consisting of more information and explanations around the child’s condition, diagnosis, causes, feeding, and future. Furthermore, there is a sense of inadequate cooperation around the information offered both between staff on the same unit and between different care units. A higher degree of cooperation is requested.

### Thinking about cause and effect

The experience of feeling guilty and to blame oneself for the child being so small is brought up repeatedly by the mothers in the study, “I feel that it’s my fault”, “what I felt was guilt and a bit of a guilty conscience”. The feeling that during the pregnancy, they should have realized that something was not right is a recurring thought even long after the announcement that the child was small. Thoughts about one’s own responsibility in drawing healthcare providers attention to abnormalities that in retrospect appear as signs that the child would be abnormally small are expressed in ponderings such as “as a woman, was the one carrying her and didn’t react”, “The whole time, the feeling that I should have raised the alarm somehow”, “The whole time, people asked me about my small belly and whether there was actually anything in there”. The impression of having had the power to have made a difference are constantly recurring. After thoughts about what might have caused the child’s condition to vary according to the birthweight, where the parents of the smallest children in the study wondered about this fact to a larger extent.

Anxiety and worry about becoming a parent again with the risk of giving birth to another growth restricted child is expressed in thoughts
such as “I feel really scared about becoming pregnant again”, “...will want to follow-up on everything when it comes to the growth issue” and “I think it’s really scary”. In contrast, there is the sense that it would be interesting if the next child was small and safer because of the experience gained with the first child and being a bit better prepared.

Connecting the family

All parents in the study felt that their connection to the small child is good and that a strong emotional feeling of togetherness appeared early after delivery.

I felt in a way right away that she is my daughter and I liked her so much and you really felt like you would do everything for her and you thought about her having a good upbringing and all such feelings. When they get to be a few months old and are looking around and you make a different kind of connection then it’s so charming whenever she smiles or laughs or whatnot and when you’ve been away for just a moment and come home and you’re met with this huge smile from her then you really feel....I mean, you get such positive energy from it.  

[(Father 3)]

Even if the child is seen as fragile due to small size, closeness is important and feels natural.

...I don’t know if it was because she was sort of small, that it made it extra important somehow, but for me it felt totally natural that she gets to be close all the time and somehow that has been a given.  

[(Mother 5)]

In cases where the family has been separated, both mother and child after delivery or when the father must leave the hospital at night, it is felt as hard to lose the proximity to the child and partner. Nonetheless, the mothers expressed confidence that the child was well cared for by the father when the mother needed care elsewhere in the hospital. The common feeling among parents is that the relationship of the couple has not been negatively impacted by having a child born SGA.

I guess it didn’t really affect between us more than that we were both worried because it was this with, a lot of keeping time, it was extreme, your whole life was about, like setting the alarm, and then breastfeeding and supplemental feeding. Well, it was a huge focus and maybe it is for all parents there in the beginning, but it was even more of a focus for us.  

[(Mother 3)]

Support in close relations, such as friends and the rest of the family, contributes to a feeling of security, especially if there is previous experience within the family with low-weight child. When there is a lack of family nearby, respondents experienced a feeling of loss not to have anyone to turn to and bounce ideas off.

Discussion

The aim of this study was to describe the experience of becoming a parent of a child born SGA and our result showed that even if the child was born healthy, the parents often harbour feelings of unpreparedness and guilt. The analysis demonstrates the parents’ all-encompassing instinctive goal of helping the small child to survive. Experienced anxiety around the child’s size and nutritional intake can be seen as permeating the entire data material. A common experience among parents in our study was that caring for the small child dominates their entire daily lives, for good and for bad.

Feelings of guilt

Jackson (2008) writes that when the announcement about the child’s irregular weight reaches the parents, it is experienced as an upheaval and a traumatic experience. This is in line with the result of this study. To not receive an explanation regarding the child’s condition nor a diagnosis leads to severe anxiety. In the parents’ encounter with healthcare around the small child, the lack of information is most notable. One core category grew out of categories that had been created out of open-ended interviews, “Feelings of guilt”. Fear of subsequent pregnancies can be viewed as a good indication that care for these families is not optimal and that more attention is called for at all levels of care.

The feelings of guilt and bad conscience that is expressed by mothers in this study could point to a tradition of gender roles between the parents, possibly unconscious. As none of the interviewed fathers expressed this feeling, there is reason to believe that this is the case. Self-blame was primarily expressed by mothers who had become parents of the very smallest children in the study, which could indicate what has been previously discussed regarding the degree of anxiety in relation to the child’s size (Singer et al., 1999). The present results showed that fathers experienced a greater overall serenity as compared to the mothers over the child’s size. People’s reactions to the child’s small size did not seem to affect the fathers as much as it did the mothers and for the fathers it was not relevant to make comparisons with other children of the same age. Perhaps these results would have been different if not all the respondents had been first-time parents. As in previous research (Singer et al., 1999), respondents reported diminished psychological ill health as children grew and became bigger in size, which might indicate that the child’s size is in direct proportion to the degree of worry and instinct to protect.

That all parents, both mothers and fathers, reported good bonding with their child is interesting and must be seen as an important result since research have concluded that it is important to identify risks and protective factors since a lack of bonding could be negative for the child (Cuijlits et al., 2019). Bonding is a prerequisite for the child’s attachment and can be considered as a wellness factor that offers the child tools to get through difficult situations in life (Piotrowska et al., 2017).

The feeling of being unprepared has also been described in studies of full-term infants, becoming a mother can be a state of vulnerability and a loss of control (Barclay et al., 1997; Cuijlits et al., 2019; Rogan et al., 1997). Other studies have described parents with children born premature or staying at the NICU due to other complications and both mothers and fathers experience different kinds of severe stress (e.g. Boykova & Kenner, 2012; Lefkowitz et al., 2010; Purdy et al., 2015). It also seems that being a parent for the first time is a challenging period for most parents.

Becoming a parent of a child born SGA and perceptions of support from healthcare professionals

The need for knowledge and information is great; and here healthcare professionals plays a big role and has an important function to fill. Korukcu et al. (2017) have shown that nurses are able to help the mother to cope and to facilitate her transition into motherhood. For this, cooperation between MHC and CHC is vital and our result showed that it is not just information that is lacking but also a lack of continuity. The parents described an experience of everyone saying different things, both the healthcare personnel in the same units as well as a lack of communication between for example maternity care and MHC. A higher degree of knowledge in staff should thus raise the level of information, for instance through shared guidelines for caring for this patient category, as is pointed to in the study by Ballantyne et al. (2017). An integrated maternity and neonatal unit are also requested by the respondents, as well as a web-based information compendium based in science, which parents can use for their own research. This is in line with the study
by Ballantyne et al. (2017) were parents expressed a feeling of not being informed or involved. Fathers have also experienced being excluded from e.g. visits to the MHC (Åsenhed et al., 2013).

Our study showed that most mothers felt that support and help from healthcare personnel in basic care protocols has been good, in terms of breastfeeding, and the satisfaction in being able to nourish one’s child has felt reassuring. In cases of supplemental feeding, both at the maternity ward, neonatal ward and/or at home, a sense of teamwork and equality are expressed. The common assessment of care in general turns out to be good, except for the lack of adequate information mentioned previously. In cases where growth restriction was verified by ultrasound measurements have still not resembled reality. Thus, all the parents questioned the reliability of measurements. Like the perceived lack of knowledge in in-patient care regarding children born SGA, respondents perceived an even greater lack of knowledge within MHC. Here as well guidelines regarding treatment protocol for this diagnosis could be beneficial (Ballantyne et al., 2017). To provide good care for these families a pediatric nurse must have proper education and relevant knowledge in order to decrease the potential negative feelings these families as pediatric nurse must have proper education and relevant knowledge in order to decrease the potential negative feelings these families are expressed. The common assessment of care in general turns out to be good, except for the lack of adequate information mentioned previously. In cases where growth restriction was verified by ultrasound measurements have still not resembled reality. Thus, all the parents questioned the reliability of measurements. Like the perceived lack of knowledge in in-patient care regarding children born SGA, respondents perceived an even greater lack of knowledge within MHC. Here as well guidelines regarding treatment protocol for this diagnosis could be beneficial (Ballantyne et al., 2017).

Limitations

Even if we presume that experiences of becoming a parent are, in some sense generic, one limitation could be that our population were all Swedish born, which meant that there was a limitation in ethnic diversity. Certain variations in the experiences of the parents have emerged tied to the child’s size, even though the selection of participants could be seen as adequate. Another limitation could be that the sample size might considered to be small but according to GT interviews should continue until saturation is reach. One potential limitation that needs to be highlighted is that a number of the interviews were conducted over the phone, while also these phone interviews consisted of open-ended questions with the parents’ own narratives at the center; it is likely that the results were not affected by the method.

Conclusion

The conclusion is that the unexpectedly small size of the child awakens the parent’s instinct to provide life-sustaining care and the parents need increased support and more information around the child’s condition, throughout the chain of care. Better support and information could help parents manage their situation and thus further promote and elevate quality of life. Professionals have a significant role to support parents and children born SGA and the support should not only include teaching parents how to feed and care for the infant, but also help parents with debt relief. This is especially challenging and requires well-trained professionals, because parents to children born SGA often harbour feelings of unpreparedness and guilt.

Credit authorship contribution statement

Charlotta Dykes: data collection; data analyse writing the manuscript &. Carola Hellman: data collection; data analyse writing the manuscript. Eva-Lotta Funkquist: supervision, reviewing the manuscript. Ann-Cathrine Bramhagen: Study design, supervision and reviewing the manuscript.

Declaration of Competing Interest

The authors have no conflict of interest to declare.

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