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Meaning-making amid existential uncertainty: A hermeneutic phenomenological study of parents of children with trisomy 18

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Abstract

Advances in medical care have transformed the management of trisomy 18 while posing increasingly complex ethical and psychosocial challenges for parents. This study aimed to explore and interpret the lived experiences of parents of children with trisomy 18. Semi-structured interviews were conducted with 25 parents of children with trisomy 18. Data were analyzed using a hermeneutic phenomenological approach based on van Manen's "Phenomenology of Practice." Three themes emerged: (1) Existential uncertainty about the child's future, (2) Ambivalence between social isolation and recognition of the child, and (3) Living a meaningful life through the child's enduring presence. Although parents experienced profound existential distress, interactions with their children enabled them to reexamine the values that mattered most and reconstruct their identities. These findings suggest that parents' experiences cannot be understood solely in terms of suffering. Meaningful parent–child interactions fostered ongoing meaning-making that was not constrained by the child's lifespan and continued beyond the child's death, providing new insights for family-centered care.

Key words: trisomy 18, parents, hermeneutic phenomenology, meaning-making, family-centered care

Introduction

Trisomy 18 (Edwards syndrome) is a chromosomal abnormality characterized by the presence of an extra copy of chromosome 18 [1]. Its incidence is approximately 1 in 3,500–8,500 live births, with a male-to-female ratio of 1:3 [2]. The mortality rate associated with trisomy 18 reaches 75%–95% within the first year of life, reflecting its poor prognosis due to multiple major congenital anomalies affecting the cardiovascular, respiratory, gastrointestinal, skeletal, and other organ systems [3] [4] [5]. Traditionally, invasive life-sustaining treatment has often been withheld as part of postnatal management [6]. However, advances in medical technology have enabled some children with trisomy 18 to survive for more than 10 years, with reports of long-term survivors achieving slow but steady psychomotor development and leading enriched lives with access to healthcare and education. These developments marked the beginning of a paradigm shift after the year 2000. In recent years, survival among children with trisomy 18 has improved significantly following surgical interventions and neonatal intensive care, particularly among those with congenital heart disease or esophageal atresia [7] [8] [9]. However, in Japan, regional disparities in support systems remain, and decisions regarding whether to pursue active treatment are often left to individual medical institutions. Furthermore, since the introduction of noninvasive prenatal testing in 2011, prenatal screening for chromosomal abnormalities, including trisomy 18, has become highly accurate. Consequently,

51 the scope of ethical decision-making has expanded to the prenatal period, further increasing the
52 complexity of care.

53 With rapid advances in genetic medicine, parents are now required to make decisions on
54 behalf of their children at multiple stages—from prenatal diagnosis and delivery to neonatal
55 care and home-based treatment [10]. This process involves increasingly complex ethical
56 considerations, including maternal well-being, delivery-associated risks, balancing the benefits
57 and burdens of treatment, uncertainty regarding prognosis and disability, differing values
58 concerning life-sustaining treatment, and diverse family contexts [11]. Meanwhile, access to
59 professional support, including counseling and decision-making assistance, remains limited
60 [12]. Previous studies have primarily examined parental decision-making regarding life-
61 sustaining treatment, prenatal diagnosis, and the perceived quality of life of children with
62 trisomy 18 [13] [14], providing important insights into treatment choices and caregiving
63 challenges. However, these studies have largely focused on specific decisions and difficulties
64 faced by parents and less is known about parents' experiences of living with their child and the
65 meanings they derive from these experiences. A deeper understanding of parents' lived
66 experiences beyond decision-making and caregiving challenges is therefore essential to
67 understanding the broader meaning of raising a child with trisomy 18. Accordingly, this study
68 aimed to explore and interpret the meanings embedded in the lived experiences of parents of

children with trisomy 18.

Methods

Design

This study was guided by the philosophical ideas presented in Heidegger's (1962) "Being and Time." Heidegger argued that human beings, by virtue of their existence, interpret the people and things around them, assign meaning to their experiences, and define their identities—an idea that forms the basis of hermeneutic phenomenology [15].

Hermeneutic phenomenology seeks to uncover fundamental dimensions of lived experience that are often overlooked or unexplained. This objective aligns with the purpose of the present study, which was to investigate the lived experiences of parents caring for children with trisomy 18 and to gain a deeper understanding of the meanings they attribute to those experiences.

However, phenomenological research is inherently complex because of its relatively unstructured approach. Therefore, we adopted van Manen's "Phenomenology of Practice," which provides practical methodological guidance. Although van Manen did not advocate fixed phenomenological or interpretive methods, he argued that researchers should be guided by

methodological principles. His approach encompasses four lifeworld existentials: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality)[16] [17].

Study participants and setting

Participants were parents of live-born children with trisomy 18. Parents whose child had died were included; however, those whose child had died within the previous 6 months were excluded for ethical considerations. Parents whose pregnancy did not result in a live birth were also excluded.

Recruitment was conducted on a national scale. We contacted the representative of a nationwide parent-led support organization for families of children with trisomy 18, to explain the study purpose and methods both verbally and in writing and to obtain permission to recruit participants through the organization “Team 18”. Following approval, an invitation describing the study was posted in the organization’s members-only Facebook group. Parents who wished to participate completed a Google Forms questionnaire by scanning the QR code provided in the study information document. All participants received a written explanation of the study purpose and procedures, and written informed consent was obtained. For participants who preferred online interviews, the study was explained verbally, and a consent form, together with

a stamped return envelope, was mailed to their home address. Participants were asked to sign and return the consent form to the researchers affiliated institution before the interview.

Data collection

Data were collected through semi-structured interviews using an interview guide (Table 1). Data collection was conducted between February and May 2024. Of the 28 parents who initially expressed interest in participating, three subsequently withdrew because of changes in their child's health condition or family circumstances. Consequently, 25 parents participated in the study.

All interviews were conducted in quiet locations that ensured privacy. For participants who brought their children, interviews were conducted in settings where the child could be comfortably observed. Childcare was prioritized throughout the interview, and interviews were paused whenever necessary. To minimize participant burden, each participant was interviewed only once. All interviews were conducted by the lead author, a female researcher (PhD) with extensive experience in perinatal care as a midwife and formal training in qualitative interviewing.

Demographic information collected included family composition, parents' current age, parental age at the time of the child's diagnosis of trisomy 18, timing of diagnosis, gestational

age at birth, and birth weight. During the interviews, participants were encouraged to speak freely, allowing their narratives to unfold naturally with minimal interruption. With participants' consent, all interviews were audio-recorded using a digital voice recorder (Sony IC recorder, ICD-TX660: Sony Corp., Tokyo, Japan) and transcribed verbatim. Furthermore, nonverbal observations (e.g., speech rate, pauses, facial expressions, and other notable observations), together with the researcher's reflections, emotions, and impressions during the interviews, were documented as field notes.

Table 1. Interview guide

Q1	Can you describe a situation related to your child, and how you felt at that time?
Q2	What changes have you observed in your daily life and interactions with others, and how do you feel about these changes?
Q3	How has your child's presence influenced your values and feelings?
Q4	What meaning has your child's presence brought to your life?

Data analysis

Data were analyzed using van Manen's hermeneutic phenomenological approach [16] [18]. Van Manen's interpretive phenomenological methodology seeks to develop a phenomenological text that begins with lived experience and conveys its essential meaning as reflectively experienced by participants. The analytical process was informed by the practical guidance for nursing research provided by Errasti-Ibarrondo et al. [19].

First, all interview transcripts were read repeatedly to gain an overall understanding of the participants' lived experiences. Narrative summaries (crafted stories) were then developed for each participant while preserving the context of their original accounts. Subsequently, these narratives were divided into meaning units, and the meaning units were compared across participants to identify patterns of meaning. Related meaning units were grouped into subthemes, which were then further integrated into overarching themes. Finally, through iterative reflection on the themes, the lifeworld existentials, and the researchers' interpretations, a comprehensive understanding of the phenomenon was developed. The lead author read all interview transcripts and conducted the preliminary analysis. The preliminary interpretations were then shared and discussed with the other researchers of this study. The four lifeworld existentials served as heuristic guides for reflection rather than predetermined analytical

148 categories.

149 Throughout data immersion, we adopted an open and reflective stance consistent with the
150 phenomenological attitude. To become more open to the meanings embedded in the parents'
151 lived experiences, we sought to suspend immediate judgments and remained attentive to
152 participants' descriptions of the phenomenon. Throughout the analysis, we remained reflexively
153 aware of our premature judgments and continuously examined how these might shape our
154 interpretations. Finally, all members of the research team engaged in discussions to enhance
155 analytical rigor and achieve consensus regarding interpretation of the phenomenon.

156 **Ethics approval and consent to participate**

157 This study received approval from the Ethics Review Board of Kanazawa University
158 (Approval no. 111108-1; September 8, 2023) and was conducted in accordance with the
159 principles of the Declaration of Helsinki (2013) and relevant research ethics guidelines. All
160 participants received written and verbal explanations regarding the study purpose and
161 procedures. Participation was entirely voluntary. Participants were informed that they could
162 withdraw from the study or revoke their consent at any time without penalty, that their
163 anonymity would be protected, that the data would be used solely for this study, and that any
164 information that could potentially identify them would be modified to protect confidentiality

without altering the essential meaning of the data. Participants did not receive any financial compensation.

Interpretive rigor

Interpretive rigor was established by ensuring credibility, confirmability, and communicability [20]. To enhance credibility, we established rapport with participants and created a private environment that facilitated open reflection on their experiences. During data analysis, participants' verbal narratives were interpreted alongside nonverbal observations and contextual information.

Researchers with expertise in midwifery and mental health nursing engaged in ongoing discussions throughout the analytical process to achieve a shared understanding of the phenomenon. Interpretative rigor was further enhanced by considering van Manen's (2014) [16] six evaluative criteria for phenomenological research: descriptive richness, interpretive depth, distinctive rigor, strong and adhesive meaning, experiential awakening, and evocative epiphany. A summary of the findings was shared with the participants (member checking). Participants confirmed that the interpretations reflected their experiences and did not misrepresent their narratives. The reporting of this study was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Results

Participant characteristics

The study included 25 participants (16 mothers and 9 fathers) from 19 families. Of these 19 families, both parents participated in six families, whereas only one parent participated in each of the remaining families. The mean (± standard deviation) maternal age at the time of the trisomy 18 diagnosis was 36.8 ± 4.7 years, whereas the mean paternal age was 39.8 ± 4.3 years. The mean birth weight was 1,894.2 ± 416.0 g. Regarding the children's current living status, 47.4% were receiving home care, 5.3% were hospitalized, and 47.4% were deceased. The mean interview duration was 112.8 min. Table 2 summarizes the characteristics of the participants.

Main findings

Three themes emerged from the lived experiences of parents of children with trisomy 18: (1) Existential uncertainty about the child's future, (2) Ambivalence between social isolation and recognition of the child, and (3) Living a meaningful life through the child's enduring presence (Table 3).

198 **Table 2. Participant characteristics**

(N = 25 participants from 19 families)

Variable	Category	n
Mothers (n = 16)		
Maternal age at diagnosis (years)	<30	2
	30–34	2
	35–39	7
	≥40	5
Fathers (n = 9)		
Paternal age at diagnosis (years)	<30	0
	30–34	1
	35–39	4
	≥40	4
Timing of diagnosis		
	Second trimester	4
	Third trimester	6
	After birth	9
Gestational age at birth		
	32+0–36+6 gestational weeks	2
	37+0–41+6 gestational weeks	16
	≥42 gestational weeks	1
Birth weight (g)		
	1000–1499	4
	1500–2499	13
	≥2500	2
Child status		
	Receiving home care	9
	Hospitalized	1
	Deceased	9

Note. Data are presented as number of participants (n). Some participants belonged to the same family; therefore, the total number of participants exceeds the number of families (n = 19).

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Table 3. Themes and Subthemes

Themes	Subthemes
Existential uncertainty about the child's future	Collapse of future vision
	Desire for a slight possibility
	Living on borrowed time
Ambivalence between social isolation and recognition of the child	Social isolation due to stigma
	Seeking social recognition of the child
	Building a wall around oneself
Living a meaningful life through the child's enduring presence	Reconstructing self-identity
	Enrichment of life through the child's presence
	Weaving a continuing narrative of the child's presence

Theme 1. Existential uncertainty about the child's future

All parents were informed by healthcare professionals of their child's poor prognosis at the time of the trisomy 18 diagnosis. Consequently, their child's very existence became uncertain, leaving parents overwhelmed by confusion and anxiety. This uncertainty extended beyond concerns about prognosis and survival, encompassing the future of their child, themselves, and their families. As a result, they lived suspended between a faint glimmer of hope and profound uncertainty.

Subtheme 1-1. Collapse of future vision

This subtheme reflects parents' experiences of having their vision of the future shattered.

The expectations they had once taken for granted regarding life with their child were abruptly disrupted. Anticipating their child's shortened lifespan while living under constant time constraints, often without sufficient opportunity to reflect on the meaning of their experiences, imposed a considerable emotional burden.

Parents described being suddenly confronted with what they perceived as a cruel reality beyond their control. As a result, they experienced a loss of the future they had envisioned for their child and family. Their distress reflected not only the prospect of an altered future, but also difficulty imagining what their child's future might look like.

> *"I was told that, because it is a genetic disorder, there is nothing that can be done with current medical technology. I was told that rather than causing the child suffering, we should leave it up to fate. I felt as if my baby had not even been born yet, and the world had come to an end." (Participant B)*

Subtheme 1-2. Desire for a slight possibility

This subtheme reflects parents' persistent search for even the slightest possibility that their child might have a future despite recognizing the life-threatening nature of trisomy 18. This search became a means of sustaining hope while learning to live with the uncertainty surrounding their child's future. Parents carried the overwhelming responsibility and fear of

making life-and-death decisions that would shape their child's life course. Nevertheless, they continued searching for any possibility that might preserve their child's life. However, the rarity of trisomy 18 and the limited opportunities to connect with other families who had undergone similar experiences made this process particularly challenging.

"Life expectancy, fate, and poor prognosis; that was all the information I was given. There was no hope anywhere I looked. However, I had no choice but to keep searching. In the end, all decisions had to be made with limited time left to live." (Participant A)

Subtheme 1-3. Living on borrowed time

This subtheme describes how parents lived each day with the constant awareness that the time they could spend with their child was limited and that separation was inevitable. For these parents, the birth of their child simultaneously signified both a beginning and an awareness of an approaching end. Mothers who received the diagnosis prenatally experienced not only profound uncertainty but also the fear of losing their child before birth. Parents were fully aware that their time spent with their child might be limited. Across these participants, living with the possibility of separation generated a persistent sense of anxiety, vigilance, and emotional tension.

"Even if I just go home for a little while, I can't help worrying that something might

happen to my baby during that time. I'm constantly chasing away something that feels like it's trying to take my baby's life. I'm always in a hurry, feeling anxious."

(Participant U)

"If something happens because I let my guard down, I'll regret it for the rest of my life. I rarely had a night of uninterrupted sleep." (Participant M)

Theme 2. Ambivalence between social isolation and recognition of the child

Parents were often reluctant to speak openly about their child due to concerns about stigma and misunderstanding, which led them to restrict their social interactions. Some had experienced rejection or a lack of understanding from close friends, family members, and even siblings, further reinforcing their tendency to withdraw socially as a means of self-protection. At the same time, they wished for their child to be recognized and valued as a unique individual, creating a tension between protecting themselves from potential hurt and seeking acknowledgment of their child's existence.

Subtheme 2-1. Social isolation due to stigma

This subtheme focuses on parents' experiences of feeling hurt and isolated by comments and behaviors rooted in social stigma and limited understanding of trisomy 18. Some parents

even experienced painful rejection from family members whom they had expected to be sources of support.

> *"My mother-in-law told me to give up and move on to another pregnancy. I felt as though my decision to give birth to this child had been denied, and it was deeply heartbreaking." (Participant T)*

> *"On social media, I even received comments from anonymous users saying that providing treatment for children like mine was a waste of the country's healthcare resources." (Participant F)*

Subtheme 2-2. Seeking social recognition of the child

This subtheme describes parents' desire for their children to be recognized and accepted by society. Parents longed for their child to be acknowledged as a unique individual with inherent meaning and value and to be accepted as a member of society through relationships with others. They hoped that every life would be equally valued and celebrated and that their child would be recognized in the same way as other children through simple acts such as being called by name and having others listen to stories about them.

> *"Their lives may be short, but no life is more valuable than another. My baby may leave this world without ever knowing anything beyond the hospital, but even so, I*

hope that, just like other children, she will be accepted as a member of society and called by name by those around her." (Participant D)

Subtheme 2-3. Building a wall around oneself

This subtheme demonstrates how parents distanced themselves from others by building a protective wall around themselves. They withdrew from social relationships because they found it difficult to speak openly about their pregnancy or the birth of their child, were uncertain how to respond to well-intentioned congratulations and expressions of concern and feared being misunderstood or hurt by others' prejudices. Consequently, they increasingly detach themselves from those around them.

"I received messages from friends who knew I was pregnant, such as 'Was the baby born healthy?". I have not been able to reply to any of them or keep in touch with anyone." (Participant A)

"My parents kept pressing me, asking, 'What are you going to do about our child's treatment?' I cut off contact with my parents for a while." (Participant X)

Theme 3. Living a meaningful life through the child's enduring presence

Through their relationships with their child, parents confronted the finiteness of life and gradually came to view their own lives through new meanings and values. As they shared

296 moments of joy and sorrow with their child, the child's presence became deeply embedded in
297 their everyday lives. Even after the child's death, the relationship did not simply end with
298 physical separation. Parents continued to experience the meaningful presence of their child in
299 their lives, maintaining emotional bonds that continued to shape how they understood
300 themselves and their lives. Thus, the significance of the child extended beyond the time they
301 spent together and became woven into the ongoing narrative of the parents' lives.

302 ***Subtheme 3-1. Reconstructing self-identity***

303 This subtheme focuses on parents' experiences of letting go of the roles and values they had
304 built over time and reconstructing their identities according to new values. As they had changed
305 their work and daily roles to accommodate their child's circumstances, many experienced
306 identity conflicts. Their identity reconstruction did not proceed smoothly from the outset.
307 Rather, despite the conflicts and traumatic experiences they faced, parents witnessed their
308 children striving to live to the fullest despite their fragile bodies. This observation brought about
309 new insights and changes in their parents' values.

310 *"When I thought about the future, I felt depressed, and I envied others, which made*
311 *me feel negative. However, when I saw my weak little child desperately trying to*
312 *open his eyes, I realized what was truly important to me. From that moment on, I no*

longer had any doubts. Now, all I want is to spend this moment with my child."

(Participant K)

Subtheme 3-2. Enrichment of life through the child's presence

This subtheme describes how parents gained new perspectives on life through their child's presence, which enriched their lives. By engaging deeply with their children's lives, some parents changed careers or embraced new challenges, resulting in significant changes in their lifestyles and personal values. Previously abstract concepts such as "happiness" and "love" became tangible and deeply meaningful. Recognizing the preciousness of the finite time they shared with their child, parents became determined to live their lives more fully.

"When you look at the world from a place where there is nothing, realize that everything exists. I am very happy to be able to say 'good morning.' That's all I really need. I am very grateful to be able to feel this way and to have met so many kind people." (Participant B)

"Perhaps because their growth is slow, even the slightest reaction makes me feel incredibly happy. Just having this child here is enough. That is a miracle."

(Participant L)

Subtheme 3-3. Weaving a continuing narrative of the child's presence

This subtheme focuses on how parents wove the story of their child into the ongoing narrative of their own lives. Even after the child's death, parents continued to assign meaning to their child's existence by integrating that story into their own life narratives. Although their children's lives were physically small and fragile, their existence held immense significance for their parents. Even after their death, the children continued to exert a profound influence on their parents' lives. Parents continued to care for and think about their child, living their daily lives guided by new values. Their focus was not on the length of time spent together but on how that time was spent. Thus, children continued to exist within their parents' lives through memories, narratives, and ongoing emotional engagements.

> *"She is a big presence. It's always in my heart. (omitted) When I make an important decision, I always ask her questions. It's strange, but it's like a voice that's different from me, and the answers to my questions come back from her." (Participant S)*

> *"He is not physically present anymore, but the image I have of him sometimes grows up. I put a spoon in the coffin, but I keep worrying whether he will be able to eat. Others may laugh at my concern." (Participant O)*

Discussion

This study explored the lived experiences of parents of children with trisomy 18. The findings revealed that parents lived with profound existential uncertainty and social isolation; however, through interactions with their children, they gradually reconstructed their identities and developed enduring meanings that extended beyond the child's lifespan. These findings suggest that the experiences of parents raising a child with trisomy 18 cannot be understood solely in terms of suffering or caregiving burden. Rather, the child's presence and the ongoing parent–child interactions played a central role in shaping how parents interpreted their experiences and reconstructed the meaning of their lives.

The first key finding was that parents had been living with profound existential uncertainty since receiving their child's diagnosis. Most parents who receive a prenatal diagnosis of trisomy 18 are informed that fetal or infant death is highly likely [21]. In our study, participants experienced uncertainty not only regarding their child's prognosis and survival but also regarding their own future and family life. The greatest source of distress was not simply raising a child with severe disabilities, but living with the persistent possibility of losing their child and the inability to envision a future together. This finding highlights the unique existential challenges faced by parents of children with life-threatening genetic conditions, in which hope

and uncertainty coexist throughout the child's life course.

Despite this uncertainty, parents were not merely passive recipients of difficult circumstances. Rather, through ongoing interactions with their children, they gradually reconstructed their identities and values. Even subtle developmental changes, small responses from their children, and ordinary moments shared together became sources of joy and profound meaning. Parents reexamined what was important in their lives and redefined concepts such as happiness, love, and family. This process of identity reconstruction is consistent with previous findings among parents who experienced child loss, in which reflection on their child's life and death contributed to changes in self-understanding and identity [22]. Similarly, parents of children with life-threatening illnesses have reported personal transformation through caregiving and bereavement experiences [23]. These findings also resonate with Bernard's model of parent–child interaction [24], which emphasizes the reciprocal influence between parents and children through ongoing engagement. In this context, the child was not merely the recipient of parental care but an active participant whose presence contributed to parental growth and meaning-making.

Another key finding was the tension between social isolation and the desire for recognition of the child. Due to stigma and misconceptions surrounding trisomy 18, many parents

381 experienced the devaluation of their child's life and withdrew from social relationships as a
382 means of self-protection. At the same time, they strongly desired their child to be recognized as
383 a unique individual with inherent value. Previous studies have primarily focused on parental
384 decision-making regarding treatment choices and the challenges associated with raising a child
385 with trisomy 18 [13] [14]. The present findings extend this understanding by demonstrating that
386 parents' experiences are also shaped by broader social contexts, including whether their child's
387 existence is acknowledged and valued by others. Recognition from healthcare professionals,
388 family members, and society may therefore play an important role in affirming not only the
389 child's identity but also the parents' experiences of parenthood.

390 A notable finding of this study was that the meaning of the child's existence continued
391 beyond the child's death. Parents maintained an ongoing connection with their deceased
392 children through memories, narratives, and emotional engagement, suggesting that the parent–
393 child relationship was not limited to physical presence. These experiences are consistent with
394 the concept of continuing bonds, which views bereavement not as the termination of a
395 relationship but as a transformation of the relationship with the deceased [25]. Continuing bonds
396 have been reported to support identity reconstruction and meaning-making after bereavement
397 [26]. The present study provides additional insight into this understanding by showing that,
398 among parents of children with trisomy 18, the child's influence on parental identity and values

may continue throughout the parents' lives, regardless of the length of time they shared together.

Taken together, these findings provide a broader understanding of parenting a child with trisomy 18 by illustrating how parents navigate existential uncertainty through ongoing meaning-making. As illustrated in Figure 1, parent–child interactions may serve as an important context in which parents reinterpret their experiences, reconstruct their identities, and develop enduring meanings despite uncertainty and social stigma. These findings suggest that family-centered care may benefit from recognizing the significance of parents' meaning-making processes and the value of parent–child interactions beyond conventional outcomes such as survival or functional development. Supporting families of children with life-threatening genetic conditions requires attention not only to medical decision-making and caregiving challenges but also to the meanings emerging through parents' and children's shared lives.

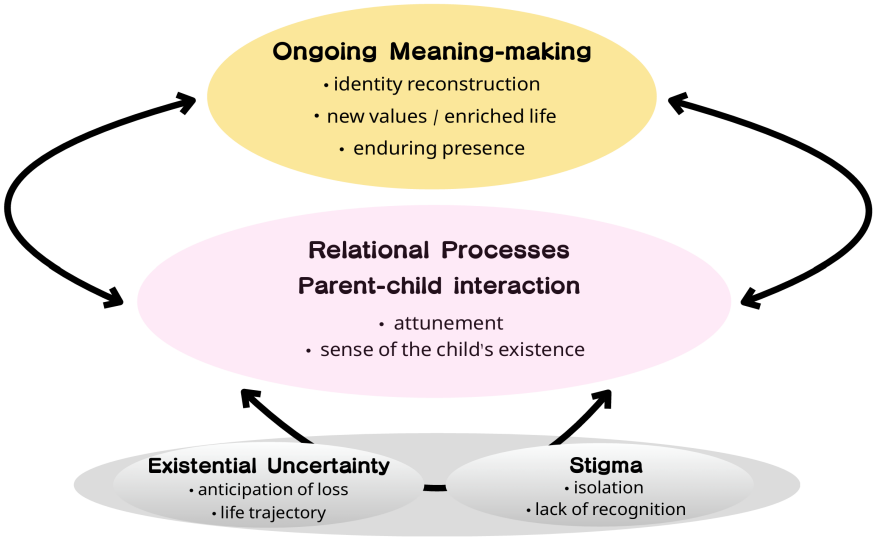


Fig. 1. Interpretive schema of the lived experiences of parents of children with trisomy 18.

Limitations

This study has several limitations. First, medical systems and treatment approaches for children with trisomy 18 and their families vary across regions in Japan. Therefore, parents' experiences may have been influenced by the specific healthcare and social support contexts in which they lived. Second, the children's clinical conditions and survival status varied considerably among participants, including both parents of living children and bereaved parents. Although this diversity allowed exploration across different stages of the child's life course, it may have influenced the meanings described by participants. Third, all participants had experienced childbirth; therefore, the experiences of parents who chose termination of

pregnancy or whose child died before birth were not captured. Future research should explore a broader range of parental experiences to further understand the diverse meanings associated with having a child with trisomy 18.

Conclusions

Despite profound existential uncertainty and social isolation, parents gradually reconstructed their identities through interactions with their children and engaged in ongoing meaning-making. This ongoing meaning-making was not constrained by the child's lifespan but continued beyond the child's death, reflecting the enduring presence of the child in parents' lives. These findings suggest that family-centered care may be strengthened by recognizing parents' ongoing meaning-making and fostering meaningful parent–child interactions while acknowledging each child as a unique individual.

Declarations

Consent for publication

Not applicable.

Availability of data and materials

The qualitative data generated and analyzed during the current study are not publicly available due to privacy and ethical considerations but are available from the corresponding author upon reasonable request.

Competing interests

The authors declare no conflict of interest.

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Author contributions

K.M. conceived and designed the study; K.M. recruited and interviewed study participants; K.M. and Y.O. transcribed the interview data verbatim; K.M. conducted the initial analysis; Y.O., K.T., K.N., and M.T. conducted member checking; K.M. wrote the manuscript; K.T. supervised the overall structure of the manuscript.

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Figure Legends

Figure 1. Interpretive schema of the lived experiences of parents of children with trisomy 18. Relational processes between parent and child fostered ongoing meaning-making despite existential uncertainty and stigma, leading to identity reconstruction, new values, and the child's enduring presence beyond death.

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