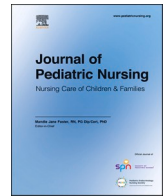




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Parenting a child with Down syndrome: A qualitative study on parents' experiences and behaviors from a self-determination theory perspective

Eline N. Desimpelaere^{a,*}, Lana E. De Clercq^a, Bart Soenens^b, Peter Prinzie^c, Sarah S.W. De Pauw^a

^a Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, B-9000 Ghent, Belgium

^b Ghent University, Department of Developmental, Personality and Social Psychology, Henri Dunantlaan 2, B-9000 Ghent, Belgium

^c Erasmus University Rotterdam, Department of Psychology Education & Child Studies, Burgemeester Oudlaan 50, 3062 Rotterdam, the Netherlands

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ABSTRACT

Purpose: Raising a child with Down syndrome (DS) brings unique challenges to parents' psychological functioning. Extensive quantitative research has shown that these parents tend to experience higher levels of parental stress and lower well-being. However, a more in-depth and balanced insight is essential to fully grasp the complexity of parenting a child with DS. To address this gap, this study uses a qualitative approach to explore the experiences and behaviors of parents raising a child with DS.

Design and methods: By adopting the Self-Determination Theory as a comprehensive theoretical framework, this study attends to both opportunities and challenges for parents' psychological needs of autonomy, relatedness, and competence, and provides insights into how they support the psychological needs of their child with DS. Eleven in-depth interviews were conducted with parents of a child with DS (aged 4 to 23 years).

Results: Through thematic analysis, six themes of parental experiences and three themes of parenting behaviors were distinguished.

Conclusions: The findings indicated that parents experience many opportunities for need satisfaction, predominantly in their need for relatedness. However, raising a child with DS also involves challenges for the parents' family relationships, personal freedom, professional ambitions, and feelings of competence. Regarding their parenting behaviors, parents considered stimulating independence, tuning into the child's mental world, and being patient as essential practices when raising a child with DS.

Practical implications: This study provides important clues to promote parents' well-being as well as their engagement in need-supportive parenting practices towards their child with DS.

Introduction

Parents raising a child with Down syndrome (DS) must accommodate a child who is cognitively, physically, and behaviorally different from peers (Hodapp et al., 2019). Even though children with DS are typically portrayed as 'cheerful' and 'humorous' (Corrice & Glidden, 2009), families of a child with DS still face multiple challenges related to the child's intellectual disability, health, and psychosocial development (Cuskelly et al., 2008; De Clercq, Prinzie, Swerts, et al., 2022; Van Gamen-Oosterom et al., 2011). Decades of research have established that these parents experience higher levels of stress than parents raising children with neurotypical development (Fucà et al., 2022; Phillips

et al., 2017), leading to an increased risk for mental health problems (Gau et al., 2008). Moreover, families including a child with DS often report increased financial burden and greater caregiving demands, with siblings experiencing disadvantages due to time constraints, parental emotions, and assuming caretaker roles (Mulroy et al., 2008; Plant & Sanders, 2007). As such, the family quality of life tends to be lower in these families in comparison to families with neurotypically developing children (Brown et al., 2006).

Whereas most research in prior decades has predominantly focused on these negative consequences, the literature within this domain has also engendered a persistent discourse surrounding the 'Down syndrome advantage' (e.g., Corrice & Glidden, 2009). This concept postulates that

* Corresponding author at: Ghent University, Faculty of Psychology and Educational Sciences, Department of Special Needs Education, Henri Dunantlaan 1, B-9000 Ghent, Belgium.

E-mail address: Eline.Desimpelaere@UGent.be (E.N. Desimpelaere).

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these families in particular encounter fewer adverse effects and demonstrate more positive overall adaptation when compared to families raising children with other developmental disabilities. The notion of this advantage is rooted in the belief that children with DS possess a more positive personality profile (e.g., Stoneman, 2007), which contributes to enhanced family functioning, improved parental relationships, effective coping strategies, reduced divorce rates, and lower stress levels compared to families of children with other developmental disabilities (Hodapp, 2007; Hodapp et al., 2001, 2019). Although this advantage has historically been critiqued due to its stigmatizing effect and risk to underestimate the struggles faced by these families, contemporary research has shown a growing interest in further unraveling the strengths and adaptation within these families. As such, a couple of studies indeed showed that many families respond with resilience to 'a change of plans' and that the experience of including a child with DS in the family resulted in positive consequences for both individual family members and the family as a whole (Van Riper, 2007). For instance, many parents reported that they experience personal enrichment by raising a child with DS (Pillay et al., 2012; Povee et al., 2012; Skotko et al., 2011a), and 88% of siblings in a large-scale study believed that they were better people because of their sibling with DS (Skotko et al., 2011b).

To date, almost everything we know about the experiences of families including a child with DS is based on quantitative research. Qualitative research is much more limited, yet highly important to grasp the richness of the parenting process and the uniqueness of the family context in which this process typically occurs (Cuskelly et al., 2008). As such, adopting a qualitative approach offers immense potential in providing a nuanced understanding of the opportunities and challenges inherent to raising a child with DS. Nonetheless, for a thorough exploration of these opportunities and challenges, it is essential to recognize that they emerge from a complex interplay of parent, child, and contextual characteristics (Taraban & Shaw, 2018). In this regard, turning the attention to parents' individual psychological functioning becomes meaningful. According to Belsky (1984), parents' psychological functioning is the most important determinant of parenting, exerting direct and indirect influences (Belsky, 1984; Belsky & Jaffee, 2015; Taraban & Shaw, 2018). Hence, focusing on this determinant by conducting a qualitative exploration of parents' experiences and behaviors would not only offer a nuanced understanding of the parenting process, but also yield important insights to inform parent and family support.

Nevertheless, to systematically capture these parents' experiences and behaviors in a balanced manner, the incorporation of a suitable conceptual framework is essential. One framework that has proven to be valuable to capture parents' lived experiences is the Self-Determination Theory (SDT; De Clercq, Prinzie, Swerts, et al., 2022; Dieleman et al., 2018; Dieleman, Van Vlaenderen, et al., 2019; Ryan & Deci, 2000, 2017), a broad theory on motivation and social development that is applied increasingly to research on parenting (Joussemet et al., 2008; Soenens, Deci, & Vansteenkiste, 2017; Soenens, Vansteenkiste, & Beyers, 2019). This macro-level theory postulates three basic psychological needs that are essential to understand both individuals' positive adjustment and their risk for psychosocial difficulties: *the need for autonomy* (i.e., the need to experience self-direction and psychological freedom), *relatedness* (i.e., the need to feel loved and connected with others), and *competence* (i.e., the need to feel effective in one's actions and capable of solving problems) (Chen et al., 2015). These basic psychological needs are considered as essential nutrients for psychological growth, integrity, and well-being (Deci & Ryan, 2000). Whereas satisfaction of these needs contributes to psychological health, need frustration (which manifests in experiences of pressure, social alienation, and failure) leads to maladjustment and even risk for psychopathology (Vansteenkiste & Ryan, 2013).

A substantial body of SDT-related research in neurotypical populations has shown that parents' degree of support for their children's psychological needs is important for children's psychosocial

development (Soenens, Deci, & Vansteenkiste, 2017). Specifically, SDT distinguishes between three dimensions of need-supportive parenting behavior that each appeal primarily - but not exclusively - to one of the child's basic psychological needs. The first dimension is *autonomy support*, which refers to parenting behaviors that promote the child's volitional functioning by recognizing the child's perspective, offering choices, encouraging initiative, and supporting dialogue (Joussemet et al., 2008; Soenens et al., 2007; Soenens, Deci, & Vansteenkiste, 2017). The second dimension is *relatedness support*, referring to a warm and sensitive approach through which parents convey their love and emotional availability towards their child (Davidov & Grusec, 2006; Soenens, Deci, & Vansteenkiste, 2017). The third dimension is *competence support*, often described as structure, which includes parenting practices that foster the child's sense of competence by communicating clear expectations and consistent guidelines, and scaffolding support to their child's capacities and needs (Soenens, Deci, & Vansteenkiste, 2017). These need-supportive dimensions of parenting can be contrasted with three need-thwarting dimensions, involving controlling parenting (e.g., intrusive parenting behavior), cold parenting (e.g., lack of interest, or even rejection of the child), and chaotic parenting (e.g., inconsistent rules) (Joussemet et al., 2008; Soenens, Deci, & Vansteenkiste, 2017). Need-thwarting parenting increases the child's vulnerability for maladjustment, including risk for internalizing or externalizing behaviors (Soenens, Deci, & Vansteenkiste, 2017; Soenens, Vansteenkiste, & Beyers, 2019).

Much like children's psychological needs impact their well-being, these needs play a key role in parents' affective functioning and quality of parenting as well. Several studies in the general population have shown that the degree to which parents experience need satisfaction or -frustration affects the way they behave towards their children (Mabbe et al., 2018; Van der Kaap-Deeder et al., 2019). Parents experiencing more need satisfaction were found to have more energy and psychological availability, resources that are needed to engage in need-supportive parenting strategies towards their child. Conversely, need frustration depletes parental energy and engenders a more self-centered attitude, which may elicit tunnel vision and increase the odds of parents relying on need-thwarting parenting behaviors (de Haan et al., 2013; Mabbe et al., 2018; Van der Kaap-Deeder et al., 2019). Similar findings were obtained in atypical populations such as parents of children with autism spectrum disorders (ASD) or cerebral palsy (CP). Although SDT-based research indicates that raising a child with ASD or CP affects parents' psychological needs in a unique way (Dieleman et al., 2018; Dieleman, Van Vlaenderen, et al., 2019), the degree to which parents' needs were satisfied or frustrated was found to play a similar role in the quality of parenting (Dieleman et al., 2021; Dieleman, Soenens, et al., 2019).

Despite the relevance of SDT to better understand parental functioning in the general population, and the increasing application of this theory in a few specific parent groups of children with developmental disabilities, the study of need-related experiences and behaviors in parents of children with DS is still in its infancy. In the past decades, a vast amount of research in this field has mainly focused on the topic of 'parental stress' to capture these parents' experiences (Cuskelly et al., 2008). However, parental stress can be considered a surface-level manifestation of parents' deeper and more fundamental need-based experiences (Van der Kaap-Deeder et al., 2019). For instance, the additional caregiving demands and the presence of behavioral problems in a child with DS, factors that challenge parents' needs for autonomy and competence in particular, have been identified as major predictors of stress in these parents (Fucà et al., 2022; Phillips et al., 2017). Similarly, findings concerning adaptation in these parents can also be interpreted through the lens of SDT. For instance, nearly all parents in the study of Skotko et al. (2011a) reported that they love their child with DS and are proud of their accomplishments, which indicates satisfaction in their need for relatedness and competence. A limited number of qualitative studies also showed that a child with DS facilitates the formation of new

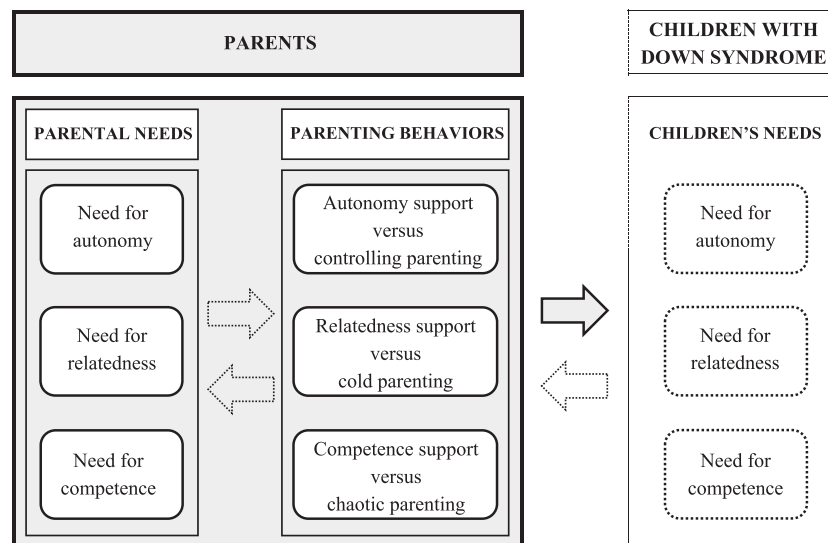


Fig. 1. Conceptual framework to analyze parental experiences and parenting behaviors based on SDT.

friendships and brings the family closer together (Farkas et al., 2019; Joosa & Berthelsen, 2006; Povee et al., 2012), which points towards opportunities for relatedness satisfaction.

Parenting a child with DS not only affects parents' own psychological needs but also requires efforts from these parents to adapt their parenting practices. To date, however, research on parenting behavior in this parent population has remained scarce and inconclusive. For example, a quantitative study by Phillips et al. (2017) indicates that mothers of children with DS engage in a more permissive parenting style (i.e., providing relatedness support in the absence of structure) and less in an authoritative parenting style (i.e., an approach combining relatedness support with structure and autonomy support), and are more likely to ignore misbehavior than mothers of neurotypically developing children. In sharp contrast, Daunhauer et al. (2017) concluded that mothers of children with DS tend to combine a highly structured approach with controlling communication, thereby behaving more directly (i.e., providing close guidance in the child's activities) and intrusively (i.e., limiting the child's potentially initiated actions) towards their child.

In addition to these inconsistent findings, it has remained largely unexamined how parents adjust their parenting behavior to support the basic psychological needs of their child with DS. One relevant exception is the qualitative study of Gilmore et al. (2016), which examined how parents support the need for autonomy in their child with DS. This focus on autonomy support in research is not surprising, given the numerous opportunities for housing and employment for people with intellectual disabilities created in recent decades (Docherty & Reid, 2009). In this regard, parents try to stimulate the independence and development of basic everyday skills in their child with DS as much as possible, using a variety of strategies such as encouraging the child to try before asking for help or breaking tasks up into smaller, manageable steps (Gilmore et al., 2016). However, despite these efforts, their capacity to support autonomy in their child with DS is often jeopardized by a range of family, contextual, and child characteristics. For instance, mothers indicated that directiveness is sometimes necessary when siblings need attention, time is limited, or the child's safety cannot be guaranteed. Additionally, the lack of interest to be involved in an activity, communication problems, fine motor and sensory difficulties, or the short attention span of a child with DS often interfere with autonomy-supportive parenting behavior (Gilmore et al., 2016). Despite this focus on autonomy support in research, relatedness and competence support could also be regarded as relevant in the context of raising a child with DS. For instance, recent cross-disability research has

indicated that relatedness-supportive parenting behavior is associated with beneficial outcomes in a child with DS (De Clercq et al., 2019). However, to gain a better understanding of how these need-supportive parenting practices manifest when raising a child with DS, a more in-depth exploration is needed.

Therefore, this study aims to provide a more comprehensive understanding of parental experiences and behaviors by adopting the SDT as a conceptual framework (see Fig. 1, Ryan & Deci, 2000). Specifically, the first objective is to examine how these parents' experiences relate to their basic psychological needs of autonomy, relatedness, and competence. Here, we aim to present a balanced insight into both the opportunities and challenges for parents' basic psychological needs, thereby surpassing the predominant focus of previous research on the negative consequences for parents' well-being (e.g., Gau et al., 2008). The second objective is to explore how parents support the psychological needs of their child with DS, to provide a more profound understanding of how these parents adapt to challenges within their parenting practices.

Method

Procedure

Parents of children with DS were recruited through social media announcements, parent support groups, and youth associations for children with disabilities that distributed the invitation for participation in this study. Parents who wanted to participate were requested to contact the researcher and received additional information about the study. To participate in this study, parents had to meet the following criteria: (1) having at least one child with a formal diagnosis of DS and (2) being a primary caregiver of the child with DS. No specific age range for the child with DS was predetermined to capture a broad range of parental experiences and behaviors across different ages. Using this maximum variation sampling method, we assembled a diverse sample of participants, encompassing varied profiles in terms of gender, age, education levels, and the characteristics of their children with DS. This approach facilitated a more comprehensive understanding of parents' experiences and behaviors (Suri, 2011). Data collection was diligently continued until code saturation was reached (i.e., the point where no additional issues emerged and the codebook began to stabilize; Hennink et al., 2017).

Parents could choose to participate in the interview alone or with their partner. Prior to the interview, the researcher elaborated on the purpose of the study. An explanation of SDT was provided (Ryan & Deci,

Table 1

Demographic characteristics of participants.

Information of the parent and family structure					Information of the child with DS			
Participant (age)	Marital status	Education level	Number of children		Gender	Age	School situation	Additional diagnosis/health problems
1. Mother (53) & Father (55)	Married	M&F: Higher education	3		Boy	23	Special secondary education	Heart problem
2. Mother (37) & Father (41)	Married	M: Secondary education F: Higher education	3		Boy	14	Regular secondary education	Obesity
3. Mother (39) & Father (47)	Cohabiting	M&F: Secondary education	5		Boy	4	Special primary education	None
4. Mother (50)	Divorced	Higher education	2		Boy	19	Special secondary education	None
5. Mother (33) & Father (42)	Married	M&F: Secondary education	2		Girl	5	Special primary education	Eye problems
6. Mother (50)	Married	Higher education	2		Boy	16	Special secondary education	Hypermobility
7. Mother (43)	Cohabiting	Higher education	2		Girl	6	Special primary education	Heart-, thyroid-, and knee problems
8. Father (48)	Divorced, new partner	Higher education	5		Girl	13	Regular secondary education	Autism Spectrum Disorder
9. Mother (45)	Married	Higher education	4		Girl	18	Special secondary education	Heart problem
10. Mother (52) & Father (47)	Cohabiting	M: Secondary education F: Higher education	2		Girl	14	Regular secondary education	None
11. Mother (48)	Single	Higher education	2		Girl	10	Regular primary education	None

2000), clarifying that each of the basic psychological needs (i.e., need for autonomy, relatedness, and competence) and the three dimensions of need-supportive parenting behavior (i.e., providing autonomy, relatedness, and competence support) would be addressed during the interview. To maximize standardization within this qualitative study, semi-structured interviews were conducted. General questions about their parental experiences and need-supportive parenting behaviors were asked in the first part of the interview (e.g., “Can you describe how you raise your child with DS?”), whereas the second part specifically addressed the satisfaction or frustration of their basic psychological needs (e.g., “Has the birth of your child with DS affected your relationship with your partner?”) and their strategies to support the needs of their child with DS (e.g., “What do you do to ensure that your child feels comfortable?”). A more detailed overview of how these SDT concepts were integrated into the interview guideline is provided in the Supplementary Material (Table 1). However, this interview guideline was handled flexibly, allowing parents to introduce other topics they deemed important for their parenting experiences. During the dyadic interviews, the researcher was careful to include the perspectives from both parents by using prompts such as: “How do you feel about that?”, to prevent the potential risk that one of the partners dominated the discussion. All interviews were conducted between November 2019 and February 2020, took place at the parents' homes, were digitally recorded, and ranged in duration from 48 to 117 minutes.

Participants

In total, 11 interviews were conducted with parents of children with DS. In five interviews, both the mother and father participated, in five other cases only the mother participated, and in one interview only the father. All participants had a Belgian nationality and were aged between 33 and 55 years ($M = 45.6$ years). Most of the informants were married or cohabiting. In each situation, the parent or the couple had multiple children. The children with DS (five boys, six girls) were aged between 4 and 23 years ($M = 12.9$ years). In 10 cases, the child with DS was living permanently at home. One child was in boarding school during the week (interview 9). Four children had medical problems that varied widely in severity, with a heart problem as the most common condition. In most cases, the child or the parents received professional support, such as

school support, speech or physical therapy, and/or support at home. Only in two situations, no professional support was received at the time of the interview. More demographic characteristics are summarized in Table 1.

Analysis

The data analysis was conducted according to the six-steps approach of Braun and Clarke (2006; Clarke & Braun, 2013), using the software program Nvivo. In the first phase, the first author familiarized herself with the data by transcribing the data and by repeatedly reading the transcripts while noting comments and identifying relevant patterns. Given that the individual parent was the unit of analysis, particular emphasis was placed on differentiating individual experiences and behaviors between partners in dyadic interviews. In the second phase, line-by-line coding was applied to the transcripts, yielding an extensive list of codes. This coding process was underpinned by a semantic approach, as the initial codes were rooted in the explicit or surface-level meanings present within the data (Braun & Clarke, 2006; Clarke & Braun, 2013). Although the coding process predominantly followed a theory-driven framework based on SDT (Dieleman et al., 2018; Ryan & Deci, 2000), flexibility was maintained to include elements that might not align precisely with SDT and to gain a broad perspective on parents' experiences and behaviors. Subsequently, the compiled list of initial codes underwent a thorough review by the second and last author (both possessing substantial expertise in SDT), to ascertain the alignment of most codes with the SDT framework. As a third step, these initial codes were clustered into potential themes and subthemes, and all data relevant to each potential (sub)theme was gathered. In the fourth step, this pattern of codes within (sub)themes was discussed with the second and last author, to ensure the congruence of the (sub)themes with the initial codes and the entire dataset. During this process, each member of the research team evaluated whether this pattern accurately represented parents' experiences and behaviors from an SDT perspective. Specifically, less important themes were removed, while other themes were specified or generalized. After a thorough evaluation of this (sub)theme pattern, the first author proceeded to code additional data that may have been missed in earlier coding phases. In the fifth step, the research team defined and refined (sub)themes, capturing the essence of the content

within each theme and subtheme. Lastly, in the sixth phase, a final structure was created (depicted in Fig. 2), while a concise yet nuanced narrative for each (sub)theme was written and associated quotes were discussed within the research team (Braun & Clarke, 2006; Clarke & Braun, 2013). Irrespective of the steps described, the analytic process was not linear, but involved loops going back and forth between the different steps (Howitt, 2016).

In this process of data analysis, we implemented a range of procedures aimed at ensuring qualitative rigor. For instance, to enhance reflexivity within this study, the first author kept a reflexive journal throughout the research process to record reflections but also to use the practice of writing as a tool for deepening reflexivity (Braun & Clarke, 2013, 2021, 2022). Moreover, to mitigate the potential influence of the authors' own beliefs and hypotheses on the data analysis, the first author engaged in frequent discussions with the second and last authors during the analytical phases. This collaborative effort served to acknowledge and manage any assumptions while preventing misinterpretations of the data (Braun & Clarke, 2006, 2013; Meyrick, 2006). Furthermore, our adherence to the different stages of analysis prescribed by Braun and Clarke (2006) contributed to the transparency and transferability of our study. In addition, we presented the transcribed interview to each participant and gave them the chance to add information or to comment on the interview to ensure the credibility of the results (Braun & Clarke, 2022).

Ethical considerations

This study received ethical approval from the Institutional Review Board of the host university (nr. 2015/70) and adhered to the ethical standards outlined in the Declaration of Helsinki. Written informed consent was obtained from all participants, which emphasized that participation was voluntary, that they could withdraw at any time, and that the data would be processed confidentially.

Results

In the thematic analysis, six themes of parental experiences and three themes of parenting behaviors were distinguished. Each of these themes

comprised multiple subthemes, which are represented in Fig. 2. The distribution and frequency of each theme and subtheme across the individual participants and the interviews can be found in the Supplementary Material (see Table 2).

Parents' need-related experiences in raising a child with DS

The analysis of parents' experiences revealed that raising a child with DS involves both challenges and opportunities for parents' psychological well-being. Three themes were identified that relate directly to the psychological needs central to SDT: opportunities and challenges for parents' (1) need for relatedness, (2) need for autonomy, and (3) need for competence. We also identified three other themes concerning (4) coping with the diagnosis, (5) adjusting the vision on one's personal life, and (6) worrying about the child's future. The identified themes in parental experiences are depicted in the left panel of Fig. 2.

Opportunities and challenges for parents' need for relatedness

A first important set of experiences could be framed as opportunities and challenges for parents' need for relatedness. Although most parents indicated that their child with DS impacted their social life and often challenged relationships within the family, they also experienced a lot of opportunities to satisfy their need for relatedness by feeling closely connected with their child with DS, their family, and their broader network.

A warm relationship with the child. In the interviews, parents frequently expressed their unconditional love for their child with DS. Conversely, eight parents also reported that their child with DS expresses his or her love for the parent very openly. In this way, taking on extensive and prolonged care for their child with DS gives parents a lot of satisfaction in return.

Father: You get a lot of gratitude from him. That is enormously satisfying. Mother: Those little things are wonderful to hear. He says all the time: "I love you so much", and he really means it. Or when he calls you on the phone, he starts with "Hello sweetheart". (Interview 1)

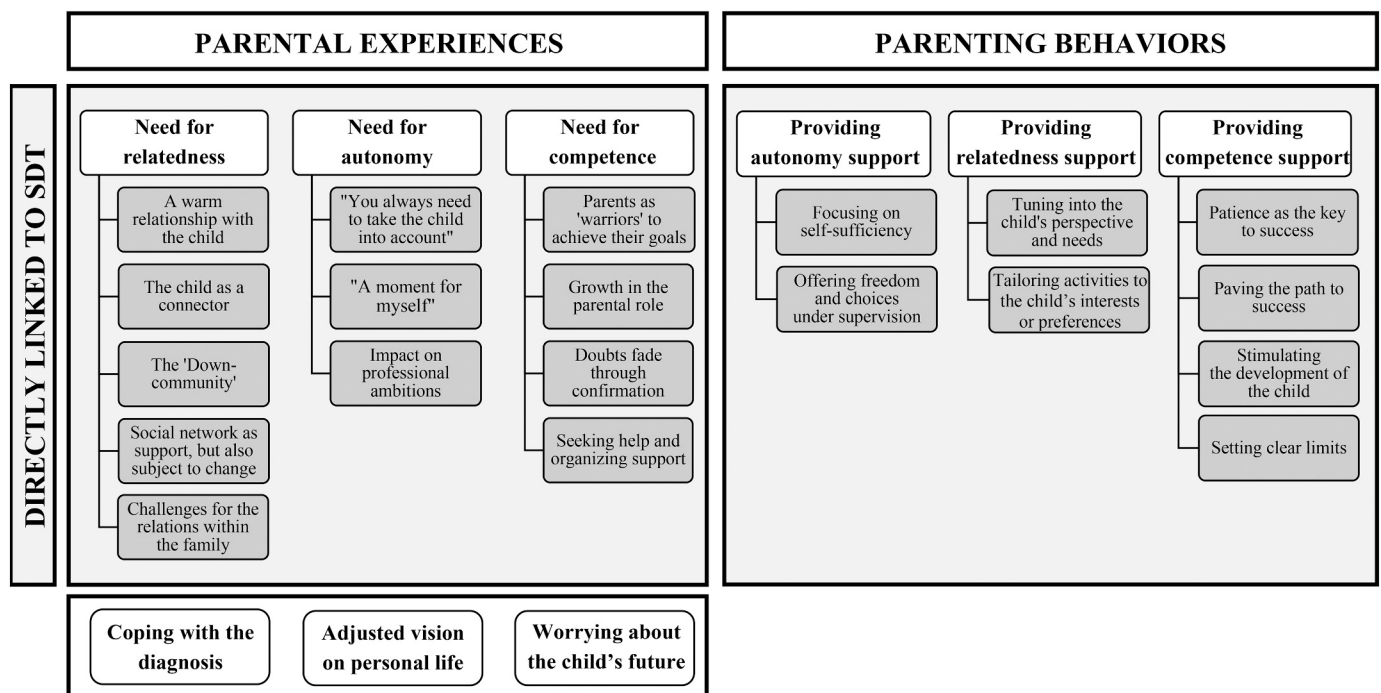


Fig. 2. Overview of the parental experiences and parenting behaviors when raising a child with DS.

The child as a connector. Seven parents stated that their child with DS promotes a closer bond within the family through, for instance, the collective care for the child. Parents also described the strong relationship between siblings and the child with DS. In addition, parents noted that their child with DS allows them to expand their social network with people they otherwise would not have met. Some parents have formed a support network for their child with DS, which has led to meaningful connections with others.

She (child with DS) undoubtedly facilitates connection. Even if it is just, at certain points, we need to take extra care of each other. The fact that the older siblings sometimes must stay at home to help us out, creates a bond. Their sister can always rely on them. (Interview 8)

The 'Down-community'. An additional opportunity to satisfy the need for relatedness is the possibility to join support groups for parents of children with DS or intellectual disabilities. In these groups, parents can share their positive and negative parenting experiences. Because of their common experiences, they seem to understand each other better. Additionally, some mothers (but almost no fathers) united online on social media (e.g., Facebook) with other parents of children with DS. Whereas some parents used these groups to share experiences and to not feel alone in coping with the challenges of parenting a child with DS, others made use of these groups to ask for advice.

It is nice when you can talk to other parents because they know... you only need half as many words, because they are in the same situation. You can talk to 20 people and they can say "yes, I understand", but only someone who is in the same situation really knows what you are talking about. (Interview 6)

Social network as support, but also subject to change. Almost all parents stressed the importance of having a strong social network for emotional support. Since these parents often have concerns or frustrations in their parenting role, they felt the need to express their feelings to a close friend or family member frequently. In addition, parents mentioned that they needed a strong network to provide them with practical support in caring for their child with DS. Receiving such practical help made parents feel supported and empowered.

Conversely, 11 of 16 participants reported that their child with DS had a significant impact on the formation of their social network. For example, some parents lost friends because they found it difficult to cope with a child with DS, while some acquaintances became close friends. Remarkably, this did not lead to frustration in the need for relatedness in any of the parents, as they experienced their current network as more valuable. However, it is important to note that hurtful reactions from others about the child with DS strongly affected them. These reactions often lingered for a long time and led to feelings of anger in these parents.

When he was born, our aunt said to us: "Down syndrome will grow out of him". Then you must be able to cope with such reactions. (Interview 1)

Challenges for the relations within the family. Raising a child with DS also had a substantial yet varying impact on the partner relationship. Whereas five parents indicated that they became closer as a couple because they could find support and comfort with each other on difficult moments, four parents reported a negative effect because they have less time to spend as a couple. In addition, parents mentioned challenges in their relationship with the other children in the family. The child with DS often struggled with medical problems at birth, which negatively influenced the parents' relationship with their other children. Even after these early years, parents reported that they are more preoccupied with

the child with DS. They often feel guilty towards their other children because less time is spent with them. Nonetheless, many parents make a conscious effort to strengthen their relationship with their other children. For example, some parents referred to activities they do with their other children without the presence of the child with DS, such as an annual 'pampering day'.

He (sibling) was never angry when we were a bit busier with her (child with DS). But when he became older, he started to say: "Hey, hello, I am still here too!" (Interview 10)

Opportunities and challenges for parents' need for autonomy

A second area of experiences could be framed as opportunities and challenges for parents' need for autonomy. Parents noted that raising a child with DS had an enormous impact on both their personal and professional freedom. However, although it takes more effort to always have a plan for the child with DS, these parents generally manage to maintain a sense of self-direction and take some quality time for themselves.

"You always need to take the child into account". Parents indicated that they feel restricted in their personal freedom due to their child's specific needs and constant need for supervision. Especially when the child reaches adolescence, these parents did not experience an increase in their personal freedom. Because they did not want to leave their child home alone (for safety reasons), it often took a lot of planning and organization to do something together with friends, to pursue hobbies, or to engage in an activity as a couple. They always needed to have a plan for the child with DS, which made it difficult or even impossible to take impulsive decisions. However, despite these challenges, many parents still managed to do the activities they wanted.

Although he is almost an adult, it feels exactly like having a little kid. Either you bring the child with you, or you must find a babysitter. (Interview 1)

"A moment for myself". Because a child with DS often requires more time, care, and energy, parents experienced the need to take some time for themselves on a regular basis. Therefore, many parents intentionally scheduled enjoyable activities for themselves without the presence of their child with DS. For instance, some parents sent their child to a youth movement or school daycare during holidays to take some time for themselves.

Wednesday morning, that is my morning. Then, I do not plan any school meetings or anything like that. Sometimes I just sit on the couch for three hours watching series, or I go for a long walk or have breakfast with a friend. Or sometimes I just enjoy grocery shopping without the kids. (Interview 11)

Impact on professional ambitions. Raising a child with DS often poses challenges to the professional career of at least one parent in the family. In seven families, one parent - in each case the mother - had to reduce time in paid work during the first few years of the child's life (mainly due to medical issues of the child). Even as the child with DS grew older, parents continued to face practical challenges in balancing their job with their caregiving responsibilities. For example, transportation to school or therapy, or regular trips to the hospital with the child for medical checkups, forced parents to adjust their work schedules. Given that these caregiving activities were mostly shouldered by mothers (with two exceptions in our interviews), mothers elucidated most impact on their professional trajectories. Six mothers mentioned that they had to give up their professional aspirations, such as pursuing a second degree or seeking a higher position within the company. Altering these ambitions was experienced differently, with some parents feeling more

comfortable than others.

Quitting my job (i.e., running a daycare) was difficult because I really liked doing that. Suddenly, I had so much time to spare. When she (child with DS) is at school, I am just sitting here... (Interview 10)

Opportunities and challenges for parents' need for competence

A third set of experiences relates to opportunities and challenges for parents' need for competence. Despite occasional doubts on their capacities as a parent, most parents felt strengthened in their parental role through personal growth, confirmation, and by responding with empowerment to barriers in society.

Parents as 'warriors' to achieve their goals. Throughout the parenting process of their child with DS, parents occasionally faced barriers in various domains of life. For instance, some parents got frustrated by the financial and legal provisions related to the care of their child, whereas other parents struggled to find a suitable childcare center, a babysitting service, or a dance school for their child with DS. In addition, parents who chose a regular school for their child faced many challenges, as they gradually found out that not everyone supports inclusive education. Despite these difficulties, parents demonstrated resilience and empowerment. Hence, 14 parents mentioned situations in which they advocated for their child's participation opportunities or took on different roles to advocate for their child's rights, such as joining a user council to give their child a voice, educating themselves on reading and communication methods to advise paramedics, or becoming leaders or core members of parent support groups.

The latest example is the new system of the government. As a parent, you very often hit a wall and you have to fight for your child. (Interview 1)

Growth in the parental role. Even though many parents aimed to raise their child 'as normal' as possible, all parents acknowledged that raising a child with DS required adjustments to their parental role. Over time, parents learned to empathize with their child's perspective and how to deal with the behavioral difficulties of their child (e.g., by using humor). In addition, parents gained a better understanding of their child's capabilities, adjusted their expectations, and gradually applied adapted parenting strategies.

I cannot say that raising him is asking too much of me right now. However, I have grown so much in this... If someone had to take over my parenting role, they would probably say: "wow, that is so spicy!" But it is not like that overnight. Little by little you grow into this role and you learn to understand his world. You learn to know his weaknesses and how you can turn them around. (Interview 4)

Doubts fade through confirmation. Despite the finding that parents generally felt competent when raising their child with DS, seven participants reported that they occasionally doubted their parental role, their parenting practices, or the choices they made for their child. Parents sometimes wondered: "Are we doing the right thing?" In this regard, some parents experienced confirmation from their environment as helpful. These parents (predominantly fathers) noted that friends, family, or others appreciated or complimented the way they accommodated their child, which contributed to their feelings of competence.

I find it very hard to assess her behavior. For example, is this behavior because she is so young at the social-emotional level? Or is this just because she is not in the mood and being stubborn? (Interview 11)

Seeking help and organizing support. To strengthen their feelings of

competence, both mothers and fathers searched for information about the development of a child with DS or organized professional help. Almost all parents received support at home during the child's first years of life. During regular home visits, professionals explained the delay in development and gave practical advice to the parents. This allowed parents to see that their child was still making progress, which increased their sense of accomplishment. Even during childhood and adolescence, some parents often consulted professionals in the child's school or rehabilitation center when they had questions about the child's development or doubts about their parenting practices.

You had someone who came to reassure you (refers to support at home). You know, her progress is slower than in other children, but then they say: "Waw, she can do this already!". (Interview 11)

Coping with the diagnosis

A fourth salient theme in the parental experiences concerns coping with the diagnosis. All parents experienced receiving the diagnosis of DS during pregnancy or shortly after birth as a drastic event. Many parents referred to this experience with a metaphor: "this was really a bolt from the blue" or "that happens to you like a ceiling falling down". At that moment, parents needed to let go of their aspirations and dreams and were overwhelmed with uncertainty. Although receiving the diagnosis deeply affected all parents, their experiences differed according to the moment when they received the diagnosis. Half of the parents were not informed about the diagnosis before birth and experienced a pregnancy without worries. In the other cases, there was a suspicion or a diagnosis before the child was born. Regarding prenatal screening, parents' opinions are clearly divided. Parents who knew about the diagnosis were happy to be able to prepare themselves and to inform their network before the child was born. Conversely, parents who were not informed about the diagnosis expressed a sense of relief in being spared from this decision-making process, as any choice would entail distressing emotions. Although most parents admitted uncertainty about what choice they would have made, one couple recounted the scenario in which the mother would have leaned towards abortion, whereas the father would be inclined towards preserving the pregnancy.

A mourning process. I went through all those different steps. When you become a parent, you have this kind of dream image of your child in college or university and so on. You are in the euphoria of the moment and then suddenly it is like: 'Bam! Nope, that is not going to happen.' (Interview 2)

Even though parents experienced a period of intense emotions after receiving the diagnosis, they were able to subsequently respond with resilience. After a few days, weeks, or months, many parents experienced a turning point at which they decided to look forward. Since then, they gradually discovered that their child with DS also brings lots of positivity. However, this did not mean that parents had fully accepted their child's diagnosis. Although all parents mentioned positive aspects about their child, they also frequently referred to the tough and hurtful confrontations with the child's disability.

That is what hurts the most, the moments when, for example, nephews and nieces of his age went to college, or when they graduated. Those are the moments that you think: he (child with DS) is 23 now, he might have had a job or a girlfriend, or he might have been living on his own already. (Interview 1)

Adjusted vision on personal life

A fifth theme in the parental experiences focused on positive life changes. Many parents perceived their child with DS as an enrichment in their lives. Parents indicated that the child with DS taught them invaluable life lessons, for instance, to take a more positive perspective, to be more conscious in life, to enjoy in the moment, and to appreciate simple things in life. Because parenting a child with DS goes along with

good and bad days, parents also learned to plan day by day and not look too far ahead in the future.

When it is spring, he is going to look outside in the morning and say: "the sun is shining, so I am happy today." And actually, life can be that simple. I sometimes wonder why we are rushing around... rushing around in this and in that... It learns you to put things in perspective. (Interview 6)

Worrying about the child's future

A final theme relevant to 15 of 16 parents involves worries about the child's future. Almost all parents worried about the continuity of care and the future professional career of their child with DS. For instance, parents questioned: "What if we pass away? Who will take care of the child?" In this regard, parents emphasized that they did not want to burden the sibling(s) with taking care of the child with DS. Additionally, the transition to adulthood was a major concern for parents. Specifically, parents stressed that they want their child to have a meaningful way to spend their days after graduating from school and expressed their concerns about the housing possibilities for the child. They wondered, "Will my child be able to work? Where will my child live when he/she is an adult?" Notably, political factors played a substantial role in these concerns. Due to long waiting lists for financial support in Flanders (Belgium), many parents worried if they will be able to pay for their child's care in the future. However, some parents tried to be proactive in addressing these concerns. To provide the child with a housing option, two parents started a housing project, while other parents already planned or carried out renovations to their house to create a home for their child. One mother built a farm next to her house, thereby hoping that the child will be able to work there in the future.

Because we are getting older, we started this housing project. What if we are no longer here? We are still young, but hey, we also do not know what life will bring. We do not want his siblings to have to take care of him in their own household on weekends. That is why we started this housing project. And to ensure that they will not be financially responsible for him. (Interview 1)

Need-related parenting behavior in raising a child with DS

Next to parents' experiences, this study focused on parents' parenting practices that are perceived as essential in raising their child with DS. Consistent with SDT, three types of parenting behaviors were identified, namely providing autonomy support, relatedness support, and competence support. These identified (sub)themes are shown in the right panel of Fig. 2.

Providing autonomy support

To ensure that the child with DS will function as independent as possible in the future, parents considered providing autonomy support as one of the most important parenting practices. The analyses revealed two different strategies to facilitate their child's autonomy.

Focusing on self-sufficiency. Nine parents reported that fostering the self-sufficiency of their child with DS is one of their main parenting goals. Parents want their child to function as autonomously as possible, to have more comfort in the future for both their child as well as for themselves. From an early age on, many parents invested a lot in training the child to read and write, in order to promote their child's autonomy later in life. Even as the child grew older, some parents tried to leave their child regularly home alone for a short period. Other parents created a network of contacts for their child and taught him/her to ask for help. Several parents also encouraged their child to do day-to-day activities independently, such as going to the supermarket alone.

I try to make her as independent and self-sufficient as possible. And to teach her that... if things do not work out, she should try other ways of making them work. I want her to know that she should not be afraid to ask for help if something does not work out. (Interview 11)

Offering freedom and choices under supervision. Another parenting strategy to support autonomy is to offer freedom and choices. However, parents realized that they cannot do this in the same way as with their other children. Parents indicated that their child with DS had not yet internalized certain values and norms. As a result, the child's autonomy always went hand in hand with guidance and watchful care from the parent. Additionally, parents let the child make his or her own decisions, but often gave advice or guided the decision-making process.

We want as much independence as soon as possible, just like with our other children. But with her, you always need to have some supervision from a distance. That changes over the years because she becomes more independent, so you can also give her more and more freedom. But you must check it again and again. With other kids from her age, you expect that they have internalized a number of things and started doing them spontaneously, but with her, that is not always a certainty. (Interview 8)

Providing relatedness support

A second set of practices revolved around supporting relatedness in the child with DS. Relatedness-supportive parenting comprised two subthemes and was characterized by parents' attunement to the child.

Tuning into the child's perspective and needs. Twelve parents referred to parenting behaviors in which they try to attune to the child's perspective and needs, by empathizing with the mental world and aligning with the social-emotional or cognitive level of their child. This often led to adjustments in their parenting behaviors. For instance, when their child was functioning at a lower level, parents knew that their child was worried and they needed to clarify the context for the child. Moreover, because having abstract conversations is often more difficult for a child with DS than for peers, parents tried other ways to involve their child in the conversation.

You cannot approach her on her chronological age, but you must approach her on her mental age. So, we automatically adapt to that. You cannot have conversations with her like with other thirteen-year-old children, but then you just do not do that. You need to do something else. (Interview 8)

Tailoring activities to the child's interests or preferences. Seven parents referred to activities that the child loves or correspond to his/her specific interests. For example, one couple noted that they regularly plan a trip to the cinema with their adolescent child with DS to watch a movie that is adapted to the child's cognitive level. Two couples reported that their child with DS likes to spend time with the family, so they schedule a time to come together with the whole family every week. Other families only go to vacation destinations where the child feels comfortable. However, some parents indicated that they do not undertake any additional or special activities adapted to their child with DS, but always try to ensure that each family member enjoys joint activities.

His brother will go to the cinema with his friends to movies like Star Wars, but we will not ask friends of M. (child with DS) to go watch a movie for little kids with him. That is something that we will do with him because those friends have already grown out of that stage. (Interview 2)

Providing competence support

The third parenting dimension in raising a child with DS could be labeled as providing competence support and consisted of four parenting strategies.

Patience as the key to success. Because their child with DS learns and develops more slowly, parents needed to adjust their expectations. Whereas many parents perceived the achievement of developmental milestones with their other children as a spontaneous and self-evident process, almost all parents indicated that this was/is not the case with their child with DS. Parents often needed to put in months of effort to reach a milestone, which taught them to appreciate the small steps of progress in the child's development. Therefore, 10 parents described raising a child with DS with the word 'patience'. Even when the child stagnates or regresses in its development, parents noted that patience is essential to avoid frustration in parenting.

What comes naturally with another child does not come naturally with him. Another baby can roll over or can do this and that... But with him, we had to go to the physiotherapist for three months. It all takes much longer. So, you learn to pay more attention to details and be more quickly satisfied. (Interview 6)

Paving the path to success. Many parents tried to create a nurturing environment where their child felt confident and competent. In terms of education, parents opted for regular or special education by assessing where the child will flourish and thrive the most. Parents who chose regular education often provided support to the teacher or adapted learning materials to meet their child's needs. In terms of leisure, parents searched for a suitable hobby in which the child could be proud of him- or herself. In general, parents tried to formulate achievable goals and expectations according to the capacities of the child. Some parents also broke down broader goals into smaller subgoals to make them more manageable and to foster experiences of success in the child.

Now, when she rides a bicycle, she can cycle straight without turning. But she can cycle straight ahead! Although the overall goal has not yet been achieved, she can do already something. (Interview 10)

Stimulating the development of the child. Even though all parents recognized the disability of their child and the associated challenges, they tended to focus on their child's abilities. As such, parents provided a wide range of learning opportunities, tried to involve their child in many conversations, and stimulated the child's development as much as possible. For example, some parents used specific methods to train their child in reading or communicating (e.g., speaking with the support of gestures), whereas other parents gave feedback on the pronunciation of certain words or tried to trigger communication skills in their child by asking questions.

I trained myself in this reading method which claimed that anyone can learn to read. And effectively, that was quite amazing, but she could read better than she talked. But this took a lot of time and effort on my part. Every morning and evening, I practiced a few words with her. (Interview 9)

Setting clear limits. Parents noted that their approach to set limits to their child with DS differed from their approach to their other child(ren). For instance, some parents still used 'standing in the corner' as a disciplinary measure with their child with DS, which they no longer did with their other child(ren) at adolescent age. In addition, as it takes more time for a child with DS to internalize rules, and because they also need clarity, parents were inclined to be consistent in their parenting behavior and to not allow exceptions.

We cannot say to her: "Look, me and daddy are busy, so today you can watch a lot of TV. But not tomorrow. How is that going to look to her? 'Oh, today, I seem to have done something right, I do not know what... But hey, I can watch TV! From now on, I can watch TV all the time!' And then tomorrow: 'Why am I not allowed to turn on the TV? Am I being punished? Have I done something wrong? But I have not done anything wrong!' Then, she becomes frustrated and aggressive. So, you cannot do that. You must be consistent. It is the same as raising little kids. With her, it stays in that stage. (Interview 9)

Discussion

Extensive quantitative research has shown that parents raising a child with DS are at increased risk for parental stress and reduced well-being compared to parents of neurotypically developing children (Cus-kelly et al., 2008). Although these findings suggest rather one-sidedly that raising a child with DS is challenging, they do not provide an in-depth insight into the multi-layered nature of this parenting process. This qualitative study aimed to advance the understanding of parental experiences and behaviors in the context of raising a child with DS, thereby relying on SDT as comprehensive framework.

Parents' need-related experiences in the context of raising a child with DS

By integrating both positive and negative experiences within the framework of SDT, the current study adds a balanced insight to the literature. Specifically, this study showed that parenting a child with DS brings along multiple opportunities and challenges for parents' need for relatedness, autonomy, and competence. First, this study revealed that parents of children with DS have many opportunities to satisfy their *need for relatedness*. For instance, parents experienced a warm relationship with their child with DS and noted that their child facilitates the connection within the family and their network, which is in line with previous findings (Farkas et al., 2019; Povee et al., 2012; Skotko et al., 2011a). Although previous studies identified family and friends as important sources of emotional support, the present study revealed that parents also benefit from their network for practical support in the care for their child with DS. In addition to feeling connected with their child, their family, and with their broader network, another opportunity for parents' relatedness was the strong connection to the 'Down-community'. Many parents experience great positivity and support from other parents raising a child with DS because it feels like 'a shared adventure' (see also Farkas et al., 2019).

In contrast to these opportunities, parents also mentioned challenges in fulfilling their need for relatedness. For example, parents in this study stated that their child with DS impacted the formation of their social network, something they did not necessarily perceive as negative. Instead, they often experienced their current network as more 'authentic', which contradicts the assumption of Hodapp et al. (2019) that this intimate circle of social support can feel suffocating. Although losing some friends did not lead to lasting relatedness frustration, parents did report some need-frustrating experiences within the family. As the child with DS placed higher emotional, financial, and physical demands on the parent, this often added pressure on the relationship with their partner and with their other children. As such, results of this study confirm previous findings indicating that parenting a child with DS can pose threats to the partner relationship (Hodapp et al., 2019; Povee et al., 2012) and can enhance marital stress (De Clercq, Prinzie, War-reyn, et al., 2022), even though some parents mentioned that they became closer as a couple. Regarding their other children, parents in our sample believed that they received less attention and were often assigned the role of caretaker. Although only a limited number of siblings in a study by Skotko et al. (2011b) indicated that they experience these caregiving tasks as a burden, further research is needed to better understand the impact on the parent-sibling relationship.

Second, the results indicated that raising a child with DS implicitly threatens parents' *need for autonomy*. Almost all parents experienced a burden on their personal freedom as they always need to take the child into account. This finding aligns with previous research by Povee et al. (2012), indicating that family life in this population often lacks spontaneity. Moreover, this finding corroborates previous cross-disability research (De Clercq, Prinzie, Warreyn, et al., 2022), which showed a higher degree of role restriction in parents of children with DS compared to parents of neurotypical children. In addition, parents expressed limitations in their professional ambitions due to difficulties in combining caregiving responsibilities with their job. In most families in our sample, the mother had to reduce working hours or adjust her professional ambitions. Although some mothers expressed regrets about altering these ambitions, other mothers stressed the positive effects of this decision. This finding is reminiscent of Brown et al.'s (2006) observation that 58% of parents raising a child with DS feel satisfied with their professional career, compared to 89% of parents raising children without a disability. However, despite these challenges in personal freedom and professional ambitions, parents in our sample did not experience complete autonomy frustration. They were still able to carry out desired activities and managed to regularly take a moment for themselves to promote their own need-satisfying experiences. This is a promising finding, given that these parents have less time for themselves due to the high demands of their child (O'Mullan Wayne & Krishnagiri, 2005; Sari et al., 2006). Since engagement in hobbies and leisure activities was found to be essential in this parent population to maintain feelings of self-direction (O'Mullan Wayne & Krishnagiri, 2005), practitioners should encourage parents to regularly plan some leisure time to foster their adjustment. One tool that may also be helpful in this regard is LifeCraft, an online prevention program that was developed recently to foster individuals' awareness of their own psychological needs and encouraging people to seek activities and contexts that are need-conducive (Laporte et al., 2022). Because this program was found to be effective in terms of increasing people's need satisfaction and mental health, an interesting avenue for future (applied) research could be to examine whether this program also strengthens the resilience of parents raising a child with DS.

Third, this research sheds light on opportunities and challenges for parents' *need for competence*. The results confirm previous work showing that parents raising a child with DS often face barriers in society and struggle with discrimination against their child in schools, daycares, and the wider community (Farkas et al., 2019). Remarkably, almost all parents in our sample responded to these confrontations with empowerment and resilience. Consistent with Van Riper's (2007) findings, parents take on new roles, such as a tutor in class, parent group leader, advisory board member, or member in associations to advocate for the rights of persons with special needs. Parents fight for what they believe is important for their child, which is in line with the metaphor of the parent as a 'warrior' identified in narrative research among parents of children with special needs (Van Hove et al., 2009). A second opportunity for these parents to experience competence satisfaction is by noticing growth in their parental role. Over time, parents gradually learn to empathize with their child's perspective and adjust their expectations accordingly. This finding meshes with Gilmore and Cuskelly's (2012) conclusion that mothers' feelings of competence increase between early childhood and adolescence of children with DS. In our study, fathers also expressed this growth in their parental role. However, at certain points in time, parents inevitably doubted their parenting capacities. To cope with these doubts, parents experienced the positive feedback from friends, family, or others about their parenting approach as helpful. Many parents also referred to professionals of home support services who acknowledged their efforts or professionals who helped them when they had questions, to promote their feelings of efficacy. This finding underscores the importance of identifying and acknowledging parents' strengths and efforts to foster their feelings of competence and to help parents persevere in difficult times.

In addition to the three themes directly related to SDT, *coping with the diagnosis* was also identified as a relevant theme in parental experiences. When parents received their child's diagnosis, they were shocked and overwhelmed with intense emotions. In line with previous findings among parents of children with DS (Nelson Goff et al., 2013) and parents of children with other disabilities (such as ASD or CP; Dieleman et al., 2018; Dieleman, Van Vlaenderen, et al., 2019), initial reactions primarily included grief, fear, mourning, denial, and anger. However, parents indicated that after a certain time, they tried to take a more positive perspective and accepted the situation. Notably, since that moment, parents began to realize the positive aspects of DS. Although this process could not be structured within the need for relatedness, autonomy, or competence, it can be linked to another concept central to SDT, that is, the process of internalization (Ryan & Deci, 2017; Soenens & Vansteenkiste, 2011). According to SDT, internalization represents the process through which values, beliefs, commitments, and behaviors are increasingly brought into alignment with the self. This process allows people to identify with their commitments and to fully endorse them. Hence, by accepting the child's diagnosis, parents might accept their identity as a parent of a child with DS more and align this identity within themselves. Given that people who fully endorse their identity have more need-satisfying experiences, parents who accept the diagnosis may experience more opportunities for need satisfaction (Soenens & Vansteenkiste, 2011). At least, this process might explain why parents only began to see the positive aspects of DS after a certain period of time. However, it is important to note that these signals of internalization do not mean that parents have fully accepted the diagnosis. Although Hodapp et al. (2019) stated that emotions are most intense after birth, parents noted that events and milestones in their child's later life can also evoke strong reactions. Practitioners should be aware that coping with the diagnosis is a difficult, long-term process, waxing and waning across time.

The controversial topic of prenatal screening was inherently part of parents' coping process. In this study, parents who received a prenatal diagnosis were happy to be prepared before birth, whereas parents who got a postnatal diagnosis felt lucky to have never faced the choice to terminate the pregnancy. These results confirm previous studies suggesting that prenatal screening has both advantages (e.g., allowing informed decisions) and disadvantages (e.g., increasing social stigma) (Kellogg et al., 2014; Nelson Goff et al., 2013). Because many parents in our study worried that the routinization of prenatal testing will lead to a loss of diversity in society, they stressed the importance of a nondirective counseling process where balanced information is provided and both the challenges as well as the value of raising a child with DS are discussed openly. Unfortunately, even in recent years, some parents feel pressured to terminate their pregnancy by societal values, friends or family, or by clinicians when the fetus is diagnosed with DS (Crombag et al., 2020; Korenromp et al., 2007; Lou et al., 2020).

Even though raising a child with DS can be a challenging lifelong process, parents also described it as an enriching experience. Parents reported that raising a child with DS has led to an *adjusted vision on their personal lives* through a shift in their priorities and identity-related values. Although this can be the result of internalization (Soenens & Vansteenkiste, 2011), this might also be an expression of parents' search for need-satisfying experiences. By reevaluating these priorities and values, parents may proactively seek to create more opportunities for need satisfaction. For instance, by realizing that they always need to take their child with DS into account, parents have learned to plan day-by-day to experience more autonomy satisfaction.

A final theme concerns parents' *worries about the child's future*. Even though almost all parents expressed concerns about the child's future care, services, or financial support, this theme is hardly addressed in quantitative research. Moreover, this finding extends the qualitative study by Pillay et al. (2012) that identified mothers' concerns about the level of functioning of their child with DS. In the present study, parents' major concerns related to the continuity of care and the transition to

adulthood in terms of employment and housing. Parents did not want the child's care to be taken over by siblings, and therefore, some parents proactively sought information or started their own projects to provide the desired future opportunities for their child. However, in their search and initiatives, parents were often confronted with political uncertainty, waiting lists, or difficulties to obtain financial support, causing them to worry about whether they will be able to pay for the care provided. Hence, while policymakers should address this uncertainty and encourage initiatives with financial support, healthcare providers should inquire not only about parents' acute problems but also their long-term worries.

Need-related parenting behavior in raising a child with DS

Next to parents' experiences, this study shed light on how parents adapt their behaviors to their child's needs. While these parents also referred to strategies that are used across the mainstream parent population (e.g., being warm towards the child), some practices appeared to be unique to raising a child with DS. We identified three themes that relate directly to the need-supportive practices as posited by SDT (Soenens, Deci, & Vansteenkiste, 2017) and represent strategies to nurture their child's need for autonomy, relatedness, and competence. However, it is important to note that there is not a simple one-to-one association between one of the parental need-supportive dimensions and satisfaction of the child's corresponding need (Soenens, Deci, & Vansteenkiste, 2017). In fact, each dimension of need-supportive parenting is to some extent relevant to satisfaction of each need. For example, when parents attend to the child's perspective (a practice framed as relatedness support in this study), a child with DS likely not only feels loved and cared for but also deeply understood in terms of personal interests and preferences (an experience reflecting satisfaction of the need for autonomy). Although there are complex interrelationships between the different dimensions of need-supportive parenting, for the sake of simplicity of presentation we assigned each parenting theme to one of the three dimensions of need-supportive parenting.

The limited research on *autonomy-supportive parenting* in the context of raising a child with DS has focused primarily on promoting self-sufficiency or independence (Docherty & Reid, 2009; Gilmore et al., 2016). Although independence is also an important goal in neurotypical development, parents in our sample considered this as one of their main parenting goals. In line with the study by Gilmore et al. (2016), parents in our study referred to many strategies to promote the development of independent skills in their child as much as possible. This encouragement of self-sufficiency was considered to be beneficial for their child but ultimately also for parents' own well-being and need for autonomy in the future. Next to promoting independence, parents try to support the child's autonomy by offering freedom and choices under supervision. There is indeed more to autonomy support than merely encouraging independence. Autonomy-supportive parenting is also about creating conditions where children can take initiative, explore options, and participate in decision-making, thereby experiencing a sense of volition and authenticity (Soenens et al., 2019). Parents' provision of freedom and choices in our study is consistent with the finding of Docherty and Reid (2009), indicating that parents gradually give responsibilities to their child and describe themselves as 'gate-keepers'. Although Gilmore et al. (2016) showed that mothers of children with DS between three to seven years usually offer choices with a restricted range of options and sometimes only provide 'guided choices', parents in our study indicated that they also use these strategies with their older children with DS, even at adolescent or adult age.

A second set of adaptations in parenting behavior revolved around *relatedness-supportive parenting*. In past decades, multiple scholars have attempted to examine responsiveness within observational designs, thereby analyzing interactions between the parent and child with DS during free play (Daunhauer et al., 2017). Although most of these studies suggest that the degree of responsiveness in parent-child

interactions does not differ across parents of children with or without DS, the present study adds to the literature by allowing an in-depth exploration of responsiveness in these parent-child dyads. As such, we identified specific adaptations in how parents convey their desire to nurture their child and offer comfort to their child with DS. For instance, being responsive in the relationship with their child with DS required parents to attune to the child's perspective and social-emotional or cognitive level, or to tailor activities to the child's interests or preferences.

A final set of behaviors referred to strategies to *support the child's need for competence*. Although parents described several practices commonly identified in general populations (e.g., providing consistent guidelines) (Soenens, Deci, & Vansteenkiste, 2017), they stressed the importance of scaffolding their support and expectations to their child's capacities and needs. For instance, parents indicated that their child's developmental delay urged them to be satisfied with small steps of progress and to have lots of patience to avoid frustration. Additionally, parents pave the path to success by creating environments where the child feels competent. In line with the findings of Gilmore et al. (2016), parents search for the most appropriate school and leisure activity, break down larger tasks into manageable steps, and formulate goals according to the child's capacities to help them achieve success. Furthermore, parents support the child's need for competence by actively stimulating their development. According to the qualitative study of Docherty and Reid (2009), parents seem to be more driven to anticipate the next stage of development when interacting with their child with DS in comparison with their other children. Moreover, by acknowledging that it takes more time for the child with DS to internalize rules, another important practice was to set clear limits. Parents noted that they cannot afford any exception to the rule and sometimes need to apply strategies that do not correspond to the child's chronological age. Overall, parents displayed an impressive capacity for calibration, thereby adjusting both their strategies for cognitive stimulation and their disciplinary measures to the child's level of competence.

Parental need-related experiences and behaviors on universal, cross-disability and disability-specific levels

Considering all of the themes raised by parents of children with DS in this study, a striking observation is that some of these themes are rather universal in nature whereas other themes are more specific to particular groups of parents. In terms of *universal themes*, parents share a common desire to see their children thrive, and they often face similar challenges in parenthood. The finding that parents in our sample struggle with balancing work and family responsibilities, doubt their parenting practices at certain points in time, or stimulate self-sufficiency as much as possible, can be considered as universally prevalent experiences and behaviors among all parents (Bornstein, 2019; Soenens, Deci, & Vansteenkiste, 2017).

However, other parental experiences are more unique to raising a child with special needs and should be considered from a *cross-disability level*. Parents of children with special needs face specific challenges in parenting that may pose additional threats to their psychological needs. For example, this study revealed that the increased pressure on family relationships and the limited flexibility due to the extra demands in time and care contribute to parents' relatedness and autonomy frustration, which is consistent with findings from qualitative studies examining need-related experiences among parents of children with ASD or CP (Dieleman et al., 2018; Dieleman, Van Vlaenderen, et al., 2019). In line with these studies, parents in our sample felt also worried about the child's future and perceived coping with the diagnosis as a difficult process. Despite these challenges, it is important to note that positive experiences and adaptive parenting behaviors can also be generalized across disabilities. For instance, the finding that parents create opportunities for success, seek for help, and adjust their vision on life, aligns with findings among parents of children with ASD (Dieleman et al.,

2018).

Importantly, this study also identified themes that appear to be very unique to parenting a child with DS and, therefore, are situated at the *disability-specific level*. In our study, parents referred to specific opportunities for their need for relatedness, such as the child fostering connections within the family and the benefits of a 'parent community', that were not reported in other SDT-based research among parents of children with special needs (Dieleman et al., 2018; Dieleman, Van Vlaenderen, et al., 2019). Parents also emphasized the importance of supervision and patience as essential parenting behaviors. Although these findings warrant further inquiry, they do suggest that parents have unique experiences and strategies when raising a child with DS.

Practical implications

The present findings have multiple practical implications. First, this study revealed several opportunities for parents' need satisfaction, which point towards important targets for parent support. For example, multiple parents referred to the 'Down-community' as a valuable source of support. As having a strong social network appears to be one of the critical factors for resilience in families of children with disabilities (Peer & Hillman, 2014), practitioners should encourage parents to join associations or parent support groups to connect with other parents of children with DS. This study also highlighted the value of online parent support groups, which may be particularly useful given the time demands of caring for a child with special needs, and therefore could be an interesting avenue for enhancing parents' sense of relatedness. In addition, parents stressed the importance of confirmation to strengthen their feelings of competence. This suggests that healthcare workers should not only focus on problems but also acknowledge parents' undertaken efforts and adopt a strengths-based approach.

Second, this study also identified challenges for parents' psychological needs. For instance, parents noted that having a child with DS can strain family relationships. Therefore, practitioners should always adopt a family-oriented approach that addresses not only the relationship between the parent(s) and the child with DS but also the partner relationship and the relationship with siblings. Especially during the child's early years when frequent hospitalization may be necessary, healthcare providers should encourage parents to regularly engage in family activities to strengthen family connections. Caregivers could also help to organize (specialized) care, such as respite or after-school care, to give parents more room to invest in their relationship with their partner or other children, or to take more time for themselves, which might enhance their need for autonomy and relatedness.

Third, this study showed that, even when there are no acute problems, this does not mean that these parents do not need support and reassurance. Parents indicated that coping with the diagnosis is a life-long, yet difficult process. While professional parent support is typically provided during the child's early years, parents also encounter strong emotions and various challenges during the child's later developmental stages. Especially the continuity of care and the transition to adulthood of their child are major concerns for these parents. As they often feel alone in their search for information and solutions, a support or healthcare system that offers guidance or counseling throughout each developmental phase of the child would be beneficial in addressing these worries.

Finally, this study contributed to the understanding of how parents can support the psychological needs of their child with DS. Practitioners should acknowledge that specific adjustments in parenting behaviors are crucial and should therefore encourage the use of these need-supportive parenting practices. For instance, healthcare providers should help parents to better understand their child's perspective to promote relatedness-supportive parenting behavior or should highlight the importance of offering freedom and choices under supervision to promote autonomy satisfaction in the child with DS.

Limitations and directions for future research

When interpreting these findings, several limitations should be taken into consideration. First, the recruitment procedure required parents to contact the researchers themselves, which might have caused selection bias. Additionally, parents who were recruited through a parent support association might have had a more adaptive profile than other parents of children with DS. Second, due to the wide variation in parents' socio-demographic backgrounds (in terms of employment, marital status, and educational level) and the wide child age range, we obtained a heterogeneous sample. However, this sample did not differ in terms of nationality. Hence, it remains unclear to what extent the identified themes can be generalized to other (sub)samples. Future research could therefore recruit samples within socio-demographic niches (e.g., specific child age ranges) or diverse countries, to better understand how certain factors (e.g., family socio-economic status, number of children in the family, culture) may affect parents' perspectives. Third, even though six fathers participated in this study (one alone and five together with the mother), most of the information was offered by mothers. It might be an interesting avenue for follow-up research to interview mothers and fathers separately to identify similarities and differences in their parenting experiences and behaviors. In addition, the current study included both single-parent and dyadic interviews, which may have affected the findings. Despite the substantial advantages of dyadic interviews (Bjørnholt & Farstad, 2014; Taylor & de Vocht, 2011), it is plausible that specific themes might have remained unnoticed due to parental hesitance in sharing experiences not previously discussed with their partner or stemming from conflicting viewpoints, which could have influenced the credibility of the data. Although no major differences in content and coding were found between dyadic and single-parent interviews, and no (sub)theme in this study was exclusive to either dyads or single participants in this study, future research could further explore variations in experiences and behaviors between these two interview formats.

Finally, the current study focused on parents' experiences and behaviors separately, which does not allow us to draw conclusions about the interplay between the (sub)themes. However, according to SDT and previous research among neurotypical and atypical parent populations (Dieleman et al., 2021; Dieleman, Soenens, et al., 2019; Ryan & Deci, 2017), parents' psychological needs and their parenting behaviors are highly intertwined. Moreover, while this study explored how parents' behaviors relate to their child's needs (see Fig. 1), it is important to note that the opposite direction of effects is equally plausible. Empirical research in neurotypical populations has convincingly demonstrated that the child's psychosocial development and parenting behavior reciprocally affect each other (Pinquart, 2017a, 2017b). However, bidirectional associations between parents' needs and behaviors, as well as the reciprocal effects with children's behaviors, remain understudied in the current literature on parenting a child with DS. Hence, future research would do well to disentangle this complex interplay by adopting a multi-method (e.g., observations, diary study) and prospective longitudinal design, in order to further improve the understanding of parents' functioning when raising a child with DS.

Conclusion

By relying on the framework of SDT, this qualitative study offered an in-depth insight into parents' experiences and behaviors when raising a child with DS. Although parents experienced opportunities to feel closely connected with the child with DS, with their broader network and the 'Down-community', many parents also indicated that raising a child with DS involves challenges for the family relationships, personal freedom, professional ambitions, and their feelings of competence. Additionally, coping with the diagnosis, the adjusted vision on their personal life, and worries about the child's future also appeared to be relevant themes in parents' experiences. Next to parents' experiences, this study yielded new insights into how parents of children with DS

adjust their parenting behaviors to support the child's needs. For instance, parents offer freedom and choices under supervision, attune to the child's mental world, and scaffold their expectations to the child's capacities. The results of the present study provide important clues to promote both the parental well-being and need-supportive parenting of children with DS.

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Ethics approval

Approval was obtained from the ethics committee of the Faculty of Psychology and Educational Sciences at Ghent University (nr. 2015/70). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent

Informed consent was obtained from all individual participants included in the study.

CRediT authorship contribution statement

Eline N. Desimpelaere: Investigation, Formal analysis, Writing – original draft. **Lana E. De Clercq:** Formal analysis, Writing – review & editing. **Bart Soenens:** Writing – review & editing. **Peter Prinzie:** Writing – review & editing. **Sarah S.W. De Pauw:** Conceptualization, Formal analysis, Writing – review & editing.

Declaration of Competing Interest

The authors have no competing interests to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jpedn.2023.10.021>.

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