

# Parents' Need-related Experiences and Behaviors When Raising a Child With Autism Spectrum Disorder

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## ARTICLE INFO

### Article history:

Received 15 January 2018

Revised 17 May 2018

Accepted 13 June 2018

### Keywords:

Autism spectrum disorder

Parenting

Need-related experiences

Self-determination theory

Qualitative research

## ABSTRACT

**Purpose:** Research suggests that parenting a child with autism spectrum disorder (ASD) brings about major challenges to parents' own psychological resources. Considered through the lens of Self-Determination Theory (Ryan & Deci, 2017), parents rearing a child with ASD particularly face challenges to their psychological needs for autonomy, competence, and relatedness. In turn, these challenges potentially jeopardize parents' capacity to attune to their child. This qualitative study aims to advance insight into (the interplay between) parents' experiences and parenting behaviors when raising a child with ASD, thereby using SDT as a framework to understand how these experiences and behaviors relate to the psychological needs for autonomy, relatedness and competence.

**Design and Methods:** Fifteen parents of children with ASD, aged 6 to 17, participated in an interview concerning their behaviors and experiences in raising their child with ASD.

**Results:** Four sets of parental behaviors and five sets of parental experiences were identified, with the majority being relevant to the psychological needs postulated by SDT.

**Conclusions:** The findings of this study provide (1) a deeper understanding of the threats and opportunities for the well-being of parents of children with ASD, (2) an in-depth insight into how these parents adjust their parenting behaviors to their child, and (3) an understanding of how parents' need-related experiences and parenting behaviors are dynamically intertwined.

**Practical Implications:** By structuring how parents perceive threats and opportunities when raising a child with ASD within the SDT-framework, important targets for parent-support are identified.

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## Introduction

Parents rearing a child with an autism spectrum disorder (ASD) experience elevated levels of stress and are at risk for various psychosocial difficulties (Hayes & Watson, 2013). In addition, these parents have to accommodate their parenting behaviors in diverse ways towards the ASD-related vulnerabilities of their child (van Esch et al., 2018). However, it remains largely unclear how these parents' affective experiences (i.e., what parents feel) relate to their parenting behaviors (i.e., what parents do). As parenting is a highly complex process, scholars have called for more systematic qualitative research to gain deeper insight in this complex of parent-child interactions, particularly when raising a child with ASD (Cridland, Jones, Caputi, & Magee, 2015). This qualitative study aims to advance the understanding of the interplay between

parents' experiences and parenting behavior by applying the framework of the Self-Determination Theory (SDT; Ryan & Deci, 2017), a motivational theory prominent in current, mainstream research on parenting.

### Need-related Experiences in Raising a Child With ASD

Extensive quantitative research has shown that parents of children with ASD face a variety of difficulties, such as decreased self-efficacy, elevated levels of stress, physical and mental health problems, decreased marital satisfaction, and financial burden (Karst & Van Hecke, 2012). However, a few qualitative studies demonstrated that some parents of children with ASD also report positive experiences in spite of all the challenges (DePape & Lindsay, 2014). For instance, parents report feeling empowered, having improved coping strategies, and becoming closer as a family (DePape & Lindsay, 2014).

In order to understand the full range of experiences encountered by parents rearing a child with ASD, it is important to adopt a framework attending to both challenges and opportunities in the parenting process.

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A macro-level theory such as SDT can help to structure the wide variety of experiences encountered by parents of a child with ASD. More particularly, considered through the lens of SDT, both the psychosocial difficulties faced by parents of children with ASD as well as their positive experiences are likely to revolve around three basic psychological needs: the need for autonomy (i.e., the need to experience self-direction), relatedness (i.e., the need to feel connected with others), and competence (i.e., the need to feel effective in accomplishing goals) (Deci & Ryan, 2000). While satisfaction of these needs is essential for people to feel well, frustration of these needs increases risk for ill-being (Ryan & Deci, 2017).

As such, these psychological needs can help to better understand both the dark and the bright sides of parents' functioning (Vansteenkiste & Ryan, 2013). For instance, the findings concerning financial difficulties and lack of leisure time could be interpreted as restricted opportunities for satisfaction of the need for *autonomy* (Meirsschaut, Roeyers, & Warreyn, 2010). The decreased levels of marital satisfaction and feelings of being isolated from friends and family might indicate *relatedness* frustration (Woodgate, Ateah, & Secco, 2008). In addition, parents report low levels of self-efficacy and feelings of hopelessness, signaling issues with parents' need for *competence* (Ooi, Ong, Jacob, & Khan, 2016). The SDT framework also allows for the identification of possibilities for need-satisfying experiences. The finding of the qualitative review study of DePape and Lindsay (2014) documenting that raising a child with ASD may also enrich parents' personal lives (e.g., feeling empowered) can be interpreted in the framework of SDT as satisfaction of competence and autonomy. Moreover, the finding that some parents report strengthened marital and family relations indicates relatedness satisfaction (Bultas & Pohlman, 2014; Myers, Mackintosh, & Goin-Kochel, 2009).

#### *The Relation Between Parents' Own Need-related Experiences and Parenting Behavior*

Parenting a child with ASD does not only challenge parents' own psychological needs, but also requires several adaptations in their style of interacting with their child. In a recent qualitative interview study, van Esch et al. (2018) found that parents of early adolescents with ASD adjust their parenting strategies at multiple levels, including the way they show affection, their communication style and their responses to undesirable behaviors. Although van Esch et al. (2018) argued that parents' feelings are likely involved in the way parents adjust their parenting behaviors, this interplay between parental experiences and behaviors remains largely unexamined.

The framework of SDT allows for a better understanding of this interplay, because it states that the basic psychological needs for autonomy, relatedness, and competence are not only important for parents' personal well-being, but also for their way of interacting with their child (Ryan & Deci, 2017). A growing body of research on typical development shows that when parents' own needs are satisfied, they are able to relate to their children in a constructive way and have sufficient energy and openness to attune to their children's psychological needs (i.e., need-supportive parenting) (Mabbe, Soenens, Vansteenkiste, van der Kaap-Deeder, & Mouratidis, 2018; Van der Kaap-Deeder et al., 2017). In contrast, when parents experience need-frustration they are more at risk for dysfunctional ways of interacting with their child and are more likely to engage in maladaptive parenting behaviors (i.e., need-thwarting parenting) (de Haan, Soenens, Deković, & Prinzie, 2013; Dieleman et al., 2018; Mabbe et al., 2018).

Specifically, SDT identifies three types of parenting that either support or thwart children's psychological needs (see Fig. 1). Need-supportive parenting is specified by autonomy support, structure and relatedness support (Ryan & Deci, 2017). Autonomy-supportive parenting refers to parents' promotion of their child's volitional functioning by, for instance, providing choice, conveying a meaningful rationale when choice is restricted, recognizing the child's perspective and stimulating initiative (Joussemet, Landry, & Koestner, 2008). When parents provide structure, they facilitate mastery in their child by, for instance, providing clear and consistent guidelines, scaffolding expectations according to the child's capacities, and offering informational and non-critical feedback (Grolnick, Deci, & Ryan, 1997). Relatedness-supportive parenting refers to behavior that conveys parents' interest in and love for the child and makes children feel connected with their parents by being responsive, affectionate and engaging in joint activities with their child (Soenens, Deci, & Vansteenkiste, 2017). In contrast, need-thwarting parenting involves controlling parenting (e.g., guilt-induction or threats of punishment), chaotic parenting (e.g., unpredictable rules), and cold parenting (e.g., lack of interest). Fig. 1 offers a conceptual presentation of the presumed (bidirectional) associations between parental needs, their parenting behavior (i.e., need-nurturing versus need-thwarting parenting) and child outcomes (i.e., child's needs and psychosocial adjustment) according to SDT. The current study focuses on the left panel of the figure and aims to advance insight into (the interplay between) parental needs and parenting behavior when raising a child with ASD.

In sum, SDT-based research in the general population has shown that, when parents experience need-satisfaction, they are better able to support their children's psychological need for autonomy, relatedness and competence, whereas parents who experience frustration of

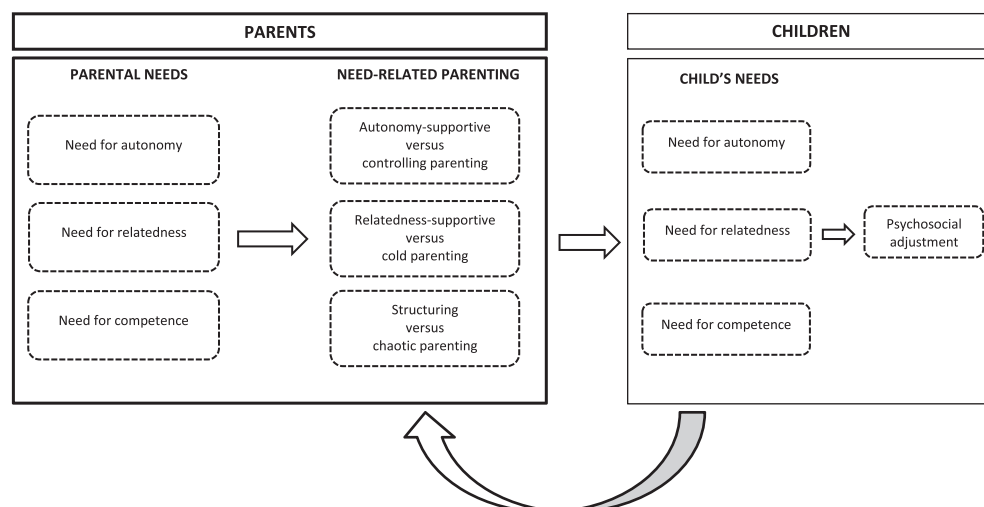


Fig. 1. Conceptual model presenting associations between parental needs, need-related parenting behavior, and children's needs as assumed in SDT.

their own psychological needs are more likely to rely on behaviors that thwart their children's needs. In parents of children with ASD, the relation between parents' need-related experiences and parenting remains understudied. To date, only one quantitative study has addressed associations between parents' needs-based experiences and parenting among parents of adolescents with ASD (Dieleman et al., 2018). This study revealed that parents of adolescents with ASD who are confronted with challenging externalizing child behavior report lower feelings of parent-child relatedness, lower parental competence, and a decreased sense of psychological freedom. These experiences of decreased psychological need satisfaction, in turn, related to more controlling parenting. However, much more in-depth research is needed to explore the interplay between parents' own experiences and parenting behaviors in a challenging context as raising a child with ASD (Cridland et al., 2015).

Therefore, this qualitative study aims to advance insight into (the interplay between) parents' experiences and parenting behaviors by interviewing parents on their experiences and behaviors in raising a child with ASD. SDT is then used as a conceptual lens to capture richness and complexity in parents' lived experiences, relating these experiences and behaviors to the psychological needs for autonomy, relatedness and competence.

## Method

### Procedure

Parents of children with ASD were recruited by placing announcements on Belgian websites providing information regarding ASD. Parents who wanted to participate could contact the researchers via e-mail or phone. In order to participate, families had to meet three inclusion criteria: the child (1) had received a formal diagnosis of ASD, (2) was aged between six and eighteen years, and (3) had no formal intellectual disability ( $IQ < 70$ ). Using convenience sampling strategy, all families who met the inclusion criteria were included in the study. To verify the ASD diagnoses, parents provided the diagnostic reports. These reports were reviewed by a multidisciplinary expert team. In the cases ( $n = 4$ ) where the original ASD diagnosis was not made by a multidisciplinary diagnostic team, using the Autism Diagnostic Observation Schedule (ADOS-2, Lord et al., 2012) and/or the Autism Diagnostic Interview-Revised (Rutter, LeCouteur, & Lord, 2003, 2008), we invited the children to the university for the administration of an ADOS-2 (Lord et al., 2012) by a trained researcher. All four children scored above the ASD cut-off (i.e., total score  $\geq 7$ ).

Parents participated in a semi-structured interview focusing on their personal perspective on raising a child with ASD. Parents were free to participate alone or with their partner. Prior to the interview, parents received information about the study and informed consent was obtained from all participants. All procedures performed were in accordance with the ethical standards of the institutional research committee. To increase standardization, an interview schedule, consisting of general questions about parents' feelings and parenting behaviors, was developed. First, parents were asked to describe their parenting behavior in general and the strategies that they experience as being important (e.g., "What do you do to make your child feel happy?"). Second, parents were asked how they experience raising a child with ASD and how their life was affected (e.g., "How has autism influenced your life?"). The interview schedule was handled flexibly and individual topics were followed by probes.

### Participants

A total of 15 Belgian parents of children with ASD (7 girls, 11 boys), aged between six and seventeen ( $M = 10.6$ ), participated in this study. In families with multiple children with ASD ( $n = 2$ ), the interviews focused on all the children with ASD. In 10 cases, only the mother participated, in the five other cases, both parents took part. In 14 families, the

child with ASD was permanently living at home. One child (case 3) was in boarding school during the week. Most of the parents reported that they and/or their children received support via a psychologist, support-at-home, support-at-school, or other. In two cases (case 5 and 13), support was no longer needed, and one family (case 3) was on the waiting list for support-at-home. More demographic characteristics are summarized in Table 1.

### Analysis

Each interview was digitally recorded and lasted between 57 and 175 min ( $M = 103$  min). The verbatim transcripts were analyzed in accordance with the principles of thematic analysis (Braun & Clarke, 2006) using the software program NVivo (QSR International, 2012). Because this study aimed to adopt SDT as a conceptual lens to capture parents' experiences and behaviors, the data-analysis relied on theoretical or deductive thematic analysis (Braun & Clarke, 2006). Nevertheless, the generic questions on parents' feelings and behaviors also allowed to explore additional themes, unrelated to the theoretical concepts central in SDT, that were important in order to more fully understand parents' experiences and parenting behaviors.

First, the first two authors (with one author having a theoretical background in SDT and the other not), read the interviews while noting comments (i.e., familiarizing with data). Next, the first two authors both generated initial codes, which were discussed and compared, resulting in a list of codes. In a third step, the initial codes were clustered into potential themes and sub-themes. In a fourth step, the themes were reviewed by evaluating whether all codes within a theme formed a coherent pattern and by evaluating whether the themes form an accurate representation of parents' experiences and behaviors. Less central codes were removed and a final structure of parents' behaviors and experiences was created (see Fig. 2). Finally, the themes and their underlying relations were defined. To ensure that the findings represented parents' perspectives, member checks were conducted by discussing the final list of themes with two mothers (case 1 and 2).<sup>1</sup>

In order to ensure qualitative rigor, we incorporated procedures addressing credibility and dependability. Credibility was addressed through data triangulation by using multiple researchers for data-analyses, and by conducting two member checks. We addressed dependability by composing a research team that included trained researchers with diverse personal and professional backgrounds (i.e., the team included both researchers with and without a theoretical background in the SDT). The group process, in which all researchers discussed and reflected upon the codes until consensus was reached, reduced personal biases in the data analysis.

## Results

The analyses resulted in four themes of parenting behavior and five types of experiences, which were highly intertwined with each other. Each of these behaviors and experiences comprised multiple subthemes (see Fig. 2). Moreover, the behaviors and experiences are embedded in a specific context and are subjected to changes throughout time. First, we will describe the four parenting behaviors and the five themes of experiences. Next, we will address their interplay, thereby taking into account the context and the temporal process.

<sup>1</sup> Three participants representing three different demographic groups (i.e., a single parent, a parent who was married, and a couple) were randomly invited for a member check. Because the couple did not have time to participate, we conducted the member checks with the two other participants. Since both participants, who differed in their demographic background, child gender and age of the child, could recognize themselves in the final themes and did not add additional themes, no additional member check was conducted.

**Table 1**  
Demographic characteristics of participants.

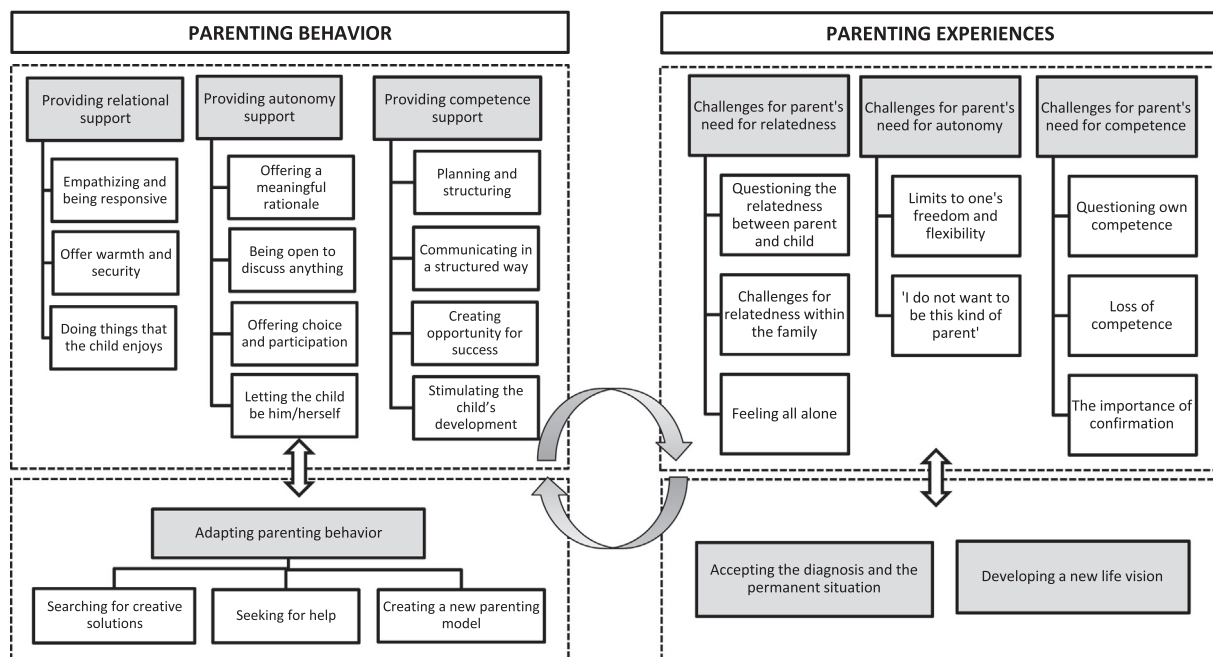
Parent information & family structure						Child information				
Participant (age)	Marital status	Education level <sup>a</sup>	Employment status	Number of children	Gender	Age	School situation	Age at diagnosis	Additional diagnoses	
1. Mother (42)	Divorced, co-habiting with new partner	Higher education	Full-time	2	Girl	17	Regular secondary education	4	None	
2. Mother (43)	Married	Higher education	Housewife & Teacher of son	1	Boy	14	Home schooled by mother	13	None	
3. Mother (42)	Co-habiting	Higher education	Part-time	2	Boy	11	Special primary education	5	None	
4. Mother (36) and father (40)	Married	M&F: Higher education	M: Part-time F: Full-time	2	Boy	7	Special primary education	5	None	
5. Mother (36)	Single	Secondary school	Full-time	1	Boy	9	Regular primary education	8	None	
6. Mother (43) and father (45)	Married	M&F: Higher education	M: Part-time F: Part-time	3	Girl	14	Regular secondary education	12	None	
7. Mother (42)	Divorced	Higher education	Full-time	2	Girl	13	Regular secondary education	8	AD(H)D	
8. Mother (38)	Married	Higher education	Part-time	1	Girl	8	Special primary education	8	Dyspraxia	
9. Mother (36) and father (38)	Married	M&F: Higher education	M: Part-time F: Full-time	2	Boy & Girl	12 & 6	Both special primary education	Boy: 8 Girl: 6	Boy: Learning disorder Girl: DCD	
10. Mother (47) and father (46)	Co-habiting	M: Higher education F: Secondary school PhD degree	M: Part-time F: Part-time	2	Boy	11	Special primary education	6	None	
11. Mother (39)	Married	PhD degree	Full-time	1	Boy	10	Special primary education	6	None	
12. Mother (41) and father (43)	Married	M&F: Higher education	M: Housewife F: Full-time	2	Girl	12	Regular primary education	9	Learning disorder	
13. Mother (46)	Married	Higher education	Part-time	4	Triplet boys	8	Special primary education	4	None	
14. Mother (50)	Married	Secondary school	Housewife	2	Girl	12	Regular secondary education	12	Dyspraxia	
15. Mother (43)	Single	Higher education	Part-time	1	Boy	10	Regular secondary education	5	Dyspraxia	

<sup>a</sup> Higher education = college or university.

### Parenting Behavior in Raising a Child With ASD

Parents indicated four types of parenting behavior as essential in raising a child with ASD: (1) Providing relational support, (2) Being

autonomy supportive, (3) Competence supportive behavior, and (4) Adapting parenting behaviors. The first three of these behaviors can be related directly to concepts central in SDT because they are concordant with the three parenting types nurture children's psychological



**Fig. 2.** Parenting behaviors and parent's experiences in raising a child with ASD.



needs for relatedness, autonomy, and competence (Fig. 1). The fourth parenting type, adapting parenting behavior, focuses on how parents modify their more general parenting strategies (e.g., searching for support related to parenting) and their parenting philosophy to the context of raising a child with ASD (e.g., adjusting their expectations).

#### *Providing Relational Support*

When asked what parents perceive as important for their child with ASD, one of the most important practices that was reported by all parents was providing love and affection. This parenting theme comprises three subthemes.

##### *Empathizing and Being Responsive*

All parents described that they continuously and consciously try to empathize with the mood, feelings or thoughts of their child, in order to adapt their behavior to their child's needs. This consisted of both pro-active and reactive practices. In order to prevent their children from being overstimulated or overwhelmed, parents proactively tried to avoid stressful situations. When children did experience stressful situations, parents reactively focused on staying calm and offering tranquility.

[She takes in a lot of stimuli, but in the evening, she is exhausted. You put her in bed, and she sleeps. Then I think 'her head has got not a second of rest'. So, it is really our job to create that rest. (Mother 8)]

##### *Offering Warmth and Security*

The second subtheme of providing relational support is making the child feel secure and loved. Parents tried to attain this by being present (when needed), and by expressing their unconditional love. Even though this is important for all children, there does seem to be an autism-specific component in this theme. Parents indicated that their child with ASD has a high need for them to be physically present in all situations (e.g., during sport activities) in order to warrant safety.

[The school is on walking distance from here, but he held my hand! Halfway, I tried to let go because I thought 'someone of 12 years does not have to walk hand-in-hand with his mother'. But he held my hand until we reached the school's entrance! Only then, he let go of my hand. Well, as a mother I felt flattered. And I had to be at school when the bell rang, and if I was not there, it was a disaster. (Mother 2)]

##### *Doing Things That the Child Enjoys*

The third component of providing relational support involves organizing or doing activities that the child loves or that correspond to his/her specific interests.

[Right now, he is a little bit obsessed with workshops about games. And he wanted to go there again. Then he starts to whine and whine. So, I made an appointment, and that is fantastic for him. Going there, with mum to the city, eating an ice-cream... (Mother 3)]

#### *Providing Autonomy Support*

A second set of practices revolved around supporting autonomy. Providing autonomy support comprises four subthemes.

##### *Offering a Meaningful Rationale*

One way how parents offered autonomy support was by giving clarifications or rationales. Parents noted that they did this because of two reasons. First, children with ASD have less insight in the causes and consequences of actions. By explaining why they do certain things, parents

tried to help increase their child's understanding of the world. Second, children with ASD have a need for clarity and honesty. Not knowing why certain things happen, can cause distress.

[I literally express my reasoning to him, explaining exactly why I changed a rule or something. Like 'if we do activity A now, then we have more time later because I didn't think this through. If we do activity B first, like planned, then this and that won't work. So now I decided to do activity A first'. And then it works. Then he stays quiet for a bit, and he thinks 'yes but...'. But yes, then it works like that. Sometimes, I literally have to explain my line of thought. (Mother 13)]

##### *Being Open to Discuss Anything*

When offering autonomy support, parents also tried to create an open atmosphere, in which their son/daughter felt safe to talk about his/her thoughts and to ask any question. Some parents told this explicitly to their children and other parents created a daily moment to talk about what happened during the day.

[In the evening, my husband or I go lay together with him in bed for 20 min and then he can talk about his day and ask three questions and those are sometimes the most ridiculous questions. Last night, he asked 'how come dragons were invented?'. That was his problem during the day, and if you give it some attention then he is happy because he feels heard. That is important. (Mother 11)]

##### *Offering Choice and Participation*

The third subtheme that could be framed as autonomy support encompasses offering choice and including the child in decision making. Parents indicated that, when children actively participate in creating rules or making plans, they understand the reasoning behind them better, and will be more motivated to follow them.

[He prefers that we just treat him like a grown-up. That he can have a say as well and that he also can make choices and so on. Then he is happy. (Mother 11)]

##### *Letting the Child Be Him/Herself*

The fourth subtheme under the umbrella of autonomy support refers to allowing the child to be him/herself. Parents expressed concerns that their child has to push him/herself on a daily basis in order to keep up with the society or to prevent exhibiting certain behaviors (e.g., stereotypes). As such, parents believed that their child should be able to be completely him/herself at home.

[It's very important to give your child space at home, so he can be himself, even with the negative aspects. The safety that they get from home, that is very important. At home, they can go crazy and they can be completely themselves. (Mother 10)]

#### *Providing Competence Support*

The third important parenting dimension that was brought up by parents, could be framed as competence support. In the analyses, we found four different strategies that parents use to facilitate their child's competence.

##### *Planning and Structuring*

Parents tried to plan and structure their family life as much as possible, thereby balancing their child's need for routine and their own need for autonomy. To do so, they used different techniques, such as following a daily routine, announcing upcoming events timely, visualizing the environment, and consistently following rules. Parents avoided changing plans or rules, ambiguous situations or surprises.

[We have a blackboard with a day schedule and we notice that on moments when he is having a difficult time, when things are different - like outings with school, long weekends, or something, that is always difficult for him - then we notice that this brings him peace. (Mother 4)]

Although all parents stressed the importance of planning and structuring, eight parents also mentioned flexibility as a vital dimension. They indicated that they consciously promote flexibility by deviating from the routine, because they want to prepare their children for 'real life', which will never be as structured as their family life. Parents tried to promote this flexibility when they felt that both they and their child are in a good 'state of mind'.

[From time to time, we add something to create some flexibility. He also has to learn that not everything is always in accordance with the structure that we agreed upon, and that life is full of unexpected events. (Mother 3)]

#### *Communicating in a Structured Way*

The second subtheme that we framed as competence support is communicating in such a way, that there is no ambiguity about the message. Parents adjusted their communication by consciously thinking about when to announce things, by asking concrete questions, and by giving explicit instructions. Parents avoided using merely non-verbal communication but communicated verbally in a short and to-the-point manner.

[Be very clear and do not make ambiguous agreements. (Mother 7)]

#### *Creating Opportunity for Success*

The third way in which parents tried to be competence-supportive was by fostering their child's possibilities to succeed. Parents created circumstances in which their child had more chances to succeed at tasks by informing their environment about their child's autism-specific characteristics, by identifying positive behaviors, or by giving positive feedback. A number of parents explicitly mentioned the strengths of their child's autism characteristics (e.g., have an eye for detail). Parents also adjusted their expectations in line with their child's skills, so that it was more feasible for the child to meet these expectations.

[You also learn to understand 'ok, we cannot expect this from D., he simply does not have those capacities or possibilities, we still have to teach him that'. (Mother 4)]

#### *Stimulating the Child's Development*

The fourth component that we distinguished within competence support is stimulating the child's development. Parents used diverse autism-specific or general techniques to stimulate different developmental skills, such as problem-solving, self-reliance, and self-insight. Stimulation of social development appeared to be an especially important and delicate task for parents. They tried to foster their child's social understanding by clarifying social situations or emotional reactions, by teaching social skills, or by facilitating social interactions (e.g., inviting children at home).

[We have had to tell her 'people sometimes just chat'. At school when there was a group of people, she literally stood next to them. Those were things we saw. So we said, 'you have to join them'. But then she said, 'but I have nothing to say'. 'But if you join them, maybe you hear something and you can join the conversation'. And then she joined the group, instead of standing next to it. But we did have to teach her that. (Father 6)]

Although parents found it important to stimulate their child's social development, most of them also stressed the importance of taking the specific difficulties and sensitivities of the child into account.

#### *Adapting Parenting Practices*

Next to the behaviors that could be framed directly as need-supportive practices according to SDT, we retained a fourth dimension focusing on parents' more general adaptation process. Almost all parents indicated that "typical parenting strategies" do not apply to a child with ASD, forcing them to seek different practices. Three subthemes of adaptation were distinguished.

#### *Searching for Creative Solutions*

Specific autism-related difficulties (e.g., hypersensitivity) required creative solutions from parents. Even common situations (e.g., starting a hobby) required different strategies than those used for typically developing children. Parents indicated that this search for creative solutions can be tiring. Moreover, the solutions sometimes worked only temporarily.

[Lot of the problems are ordinary things. It's just the normal upbringing. I mean, these are things that other people, colleagues of mine, also experience with their children. But the solutions that they use, do not work for me at all. They just do not work with my son. They are just temporarily useful, or too easy, or they do not take into account his anxiety. (Mother 11)]

#### *Seeking for Help*

The second subtheme within this adaptation process concerns the search for help. Parents distinguished between looking up information and bringing in external support. Parents valued receiving information about ASD, because it helped them to understand certain behaviors as well as to search for solutions. Parents indicated that doing everything alone is hard and that it is important to solicit support from family, friends or professionals. Although acknowledging the need for help was difficult, parents perceived most external support as helpful.

[We have psychiatrists, psychologists, many conversations... Sometimes it is a lot, but ultimately, it all helps. (Father 10)]

#### *Creating a New Parenting Model*

By going through the process of searching for creative solutions and seeking for help, parents created a new parenting model, that is, they created adjusted expectations towards themselves and towards their child, and they started to rely on adapted parenting practices.

[Raising a child with autism or without autism is completely different. The rules that apply to the one child, do not apply to the other. It really is totally different. It changes all your ideas about parenting. It's like starting from scratch again. (Mother 10)]

Although this model was unique for each parent, one specific theme recurred in almost all interviews ( $n = 11$ ), relating to the use of punishment as a disciplining technique. Most parents indicated that their child with ASD did not learn from punishment, possibly because children do not link the punishment to their own actions or, because their behavior was not intentional. As such, parents tried to limit the use of punishment by preventing specific situations or by giving their child time and space to express their negative emotions.

#### *Parents' Need-related Experiences in Raising a Child With ASD*

As raising a child with ASD is anything but straightforward, all parents described experiencing different types of challenges that profoundly affected their life. In total, we retained five themes of important experiences. Three of these experiences could be directly related to the psychological needs central to SDT and were framed as: Challenges for parents' own need for (1) relatedness, (2) autonomy,

and (3) competence. We distinguished also two other themes of experiences. One experience was closely intertwined with the acceptance and consequences of the ASD diagnosis: (4) Accepting the diagnosis. The fifth experience, (5) Developing a new life vision, indicated that raising a child with ASD also creates positive opportunities.

#### *Challenges for Parents' Own Need for Relatedness*

Parents experienced different challenges for their own need for relatedness. Raising a child with ASD did not only impact the relationship with that child, but also with the partner, other children, family, and friends. This experience comprises three specific challenges.

##### *Questioning the Relatedness Between Parent and Child*

The relatedness with their child with ASD was an important yet complex theme for parents, as they often experienced conflicting signals. Sometimes parents felt little connection with or little reciprocity from their child. The child expressed little affection or seemed to be stuck in 'a world of his/her own' and parents felt like they did not have a genuine connection with their child.

[I had a period in which I felt like I was taking care of a robot, that there was nothing in it for me. I had the feeling that she drained me, and that I got nothing from her. (Mother 1)]

On other moments, parents did feel closely connected with their child. Sometimes, parents felt like they had to search more actively for these signs of relatedness, or they experienced the signs as being atypical. However, when parents discovered these (atypical) signs, most of them indicated that they felt a real sense of relatedness to their child.

[At 22 pm we go to bed and my husband always has to put him in his bed. But he always comes to lie with me for two minutes. To hug for a bit. On the one hand that is a habit, but on the other hand it is also love. Well, that's what I think. (Mother 2)]

##### *Challenges for Relatedness Within the Family*

Raising a child with ASD also severely impacted parents' relatedness with other family members, such as their partner. As the child with ASD required a lot of attention and adjustments, parents had little time to spend together as a couple. Disagreements on how to handle parenting situations, might also strain feelings of relatedness. Some parents, on the other hand, reported a strengthened relationship. The difficulties forced these parents to consult each other more and to work as a team. The impact of having a child with ASD on the siblings was also a very salient theme for parents. Parents realized that the child with ASD needed more attention or adjustments but felt conflicted because they wanted to give every child their best.

[I think that, in your relationship, you have to talk a lot with each other. You both really have to be there. (Mother 3)]

##### *Feeling All Alone*

A third theme within challenges for parents' relatedness refers to relationships with people outside the family. Some parents felt all alone and felt little relatedness in their broader social network. They became more isolated because raising a child with ASD limited their time for friends and family or because their friends and family did not understand their situation. Although some parents consciously decided to no longer invest in these relationships, most of them experienced this as a real loss.

[But we have become more and more on our own. Yes. Because they do not understand it. (Mother 9)]

#### *Challenges for Parents' Need for Autonomy*

A second important experience refers to challenges for parents' need for autonomy. Parents felt that raising a child with ASD controlled all aspects of their life and had an enormous impact on their personal, family, social, and professional life. Certain child characteristics forced parents to behave in a certain way or prevented parents from behaving in a volitional way. This experience consists of two specific challenges.

##### *Limits to One's Freedom and Flexibility*

Because the children with ASD had specific needs and required adapted support, parents felt restricted in their personal, social, and professional functioning. They were less able to make time for their own hobbies, friends, and interests. Parents were often the only people that the child trusted in or relied on. The permanence of the ASD-related challenges and the fact that nobody could take over parents' role, even for very specific or temporary things, created a lot of pressure on parents.

[I have said it a lot during the past years: when you have a child with autism, you have to be the perfect mother. (Mother 7)]

Parents sometimes felt forced to 'stick with the schedule', because changing it would cause distress in their child. Because of these limitations, many parents felt like they gave up a lot, in order to provide the best care for their child with ASD.

[So everything is very structured. The more structure, the more you limit your own freedom as well. (Mother 3)]

Although most parents experienced 'sticking with the schedule' as a limitation towards their own freedom, some parents mentioned that they found it positive because it made their personal life more structured.

##### *'I Do Not Want To Be This Kind of Parent'*

Next to giving up a part of their autonomy in the personal, social, and professional domain, parents also indicated that they sometimes (re)act in non-volitional ways as a parent due to mainly two causes. First, some children with ASD required specific adjustments (e.g., communicating in a direct way), which did not come naturally, or which was not in keeping with parents' vision on parenting. Second, some children with ASD exhibited very challenging behaviors, forcing parents to react in a way that they did not want. Sometimes, parents lost control and reacted in a harsh way (e.g., giving a slap). Some parents also felt like they had to 'give up' their own parenting principles, because their child's behavior made it too difficult to sticking to these principles.

[With D., I feel sometimes that he forces you into a role as a parent, that you actually do not ... what you do not want to become. Sometimes I really have the feeling 'I do not want to be this kind of mother'. Sometimes I get so angry or he pushes me so much, that this provokes you so hard that you think 'I do not want to react like this towards my child', but still he gets you that far. (Mother 4)]

#### *Challenges for Parents' Need for Competence*

A third important area of experiences could be framed as challenges for parents' need for competence. Although most parents indicated that, at a certain point, they felt insecure about their competencies as a parent, a wide variety of experiences was reported. We identified three specific subthemes related to parents' need for competence.

### *Questioning Own Competence*

From early on, most parents noticed that certain parenting practices did not work as expected or that certain expectations were unattainable (cfr., adapting parenting behaviors). This made parents doubt themselves. Although receiving a formal diagnosis took away a part of the doubt, parents continued to doubt their own competencies from time to time (e.g., during a transition period).

[In the long turn, you also start to doubt about yourself as a mother, in particular when it is your first child. You think: 'I cannot do this, my child is demanding because of me...' (Mother 1)]

### *Loss of Competence*

Some parents did not only question their own abilities, but completely lost their sense of competence as a parent. These parents were overwhelmed and felt like they could no longer handle the situation.

[We have sat here crying too, that it is so bad that you just sit and cry. You can't... I see that my child is suffering at that moment, so I can't be angry. The child is suffering, otherwise, he would not do that and you just can't help at that moment, and sometimes it is too much and I just sat there literally crying when it happened. (Mother 9)]

### *The Importance of Confirmation*

The third subtheme involved recognition from the environment. In a context of insecurity, parents strongly needed the environment to recognize their efforts and to confirm their competencies. This recognition could take away feelings of guilt and strengthen parents' competence. Getting informed about ASD and receiving autism-specific support helped some parents to realize that they were not doing 'so bad after all'.

[It did me really well that they said that...officially... and it did me so well, the feeling 'I am not doing so bad with O.'. I still can remember this really well. (Father 6)]

### *Accepting the Diagnosis and the Permanent Situation*

Next to the challenges for parents' relatedness, autonomy, and competence, we retained a fourth experience concerning the acceptance of the diagnosis. Accepting the diagnosis of their child was described as a difficult, but imperative, process. On the one hand, parents felt relieved to have an explanation for the experienced difficulties. The formalization of the diagnosis gave parents recognition for the adaptations that they made. On the other hand, parents also realized that their child might require lifelong adaptations. This realization was experienced as a loss of aspirations, hopes and dreams. Although most parents were resilient and focused on the future (cfr., adapting plans for the future), parents did indicate that accepting the permanent condition of the diagnosis was anything but easy.

[Trying to accept it. That your child has that. Because it is a disability, in the end. And that is not easy to accept. I still did not accept it completely. (Mother 10)]

### *Developing a New Vision on Life*

In addition, we retained a fifth experience that focused on positive life changes. Most parents in our study explicitly stated that raising a child with ASD has also been a positive, rewarding experience. Parents mentioned personal enrichments such as having a changed view on social interactions, being more conscious in life, living more in the moment, and having a more down-to-earth view on life. Because parents noticed that their son/daughter experienced a lot of stress, many parents shifted their priorities and started to value their child's happiness

more than anything. Their only priority was having a happy child, even if this required making adjustments, giving up expectations, or receiving criticism. Things such as accomplishing good grades, having a wealthy lifestyle, or aspiring big ambitions became less important.

[F: And I think that, this might be stated a bit bluntly, that as a father of a child with a disability, you have a richer life than... Inwardly... How do I say that? M: A rich inner life. F: Yes, your mental life. That you just have a richer inner life because all ballast is thrown overboard. (Mother and father 12)]

### *About the Interplay Between Parenting Behavior and Parents' Experiences Within a Specific Context and Time*

The interviews clearly indicated that parents' behaviors and experiences were highly intertwined. For example, parents indicated that they chose to adopt certain specific parenting practices (e.g., planning what to eat) in order to satisfy specific needs of the child (e.g., need for predictability). Although most parents highly valued these adaptations because they improved their child's well-being, parents indicated that some of these adaptations conflicted with their own need experiences. For instance, although parents described the implementation of structure as an important strategy to satisfy their child's need for competence, they often experienced it as a limitation of their own need for autonomy. Sometimes, parents gave up part of their own needs in order to be as need-supportive as possible. Of course, there could also be a positive interplay: when parents adapted their behavior to their child's needs, parents felt more connected with their child. Moreover, parents' behaviors and experiences were bidirectionally related: parents' behaviors did not only impact their own need-related experiences, but these experiences also related to parents' behaviors. When parents, for instance, doubted their own competence, they started to seek for help.

Moreover, parents' behaviors and experiences were embedded in a specific context. Two contextual factors, influencing parents need-related experiences and behaviors, were mentioned: child characteristics and reactions from the broader community. One of the most important child characteristics that impacted parents' experiences and behaviors was the physical invisibility of ASD. On the one hand, parents valued this invisibility because their child experienced less stigmatization. On the other hand, parents sometimes felt that people around them did not understand the impact of raising a child with ASD because it was invisible at first sight. In addition, reactions from people in the broader context (i.e., both unknown people and acquaintances) can create additional hardships (e.g., people stating that they could 'fix' the child by parenting differently). However, other parents indicated that the people in the broader context could also be an important source of support. Feeling understood or noticing small acts of support was a salient experience for parents, which strengthened them to continue when life was hard.

The stories of parents were also strongly embedded in a specific time frame. When parents talked about their experiences as a parent of a child with ASD, a process of ups and downs unfolded naturally. Throughout time, parents experienced several moments of despair, in which they did not know what to do and in which they felt disconnected from everybody. These 'downs' were followed by moments of hope and renewed energy, in which parents found the right approach. When the next period of adversity hit again, parents tried to understand what changed and how they could overcome this new challenge. Most parents were aware of this process and tried to prepare themselves for the next difficult period.

## **Discussion**

Abundant research has shown that parenting a child with an ASD is a challenging experience, increasing the risk for parental stress and



reduced well-being (Hayes & Watson, 2013). In addition, parents are required to adapt their parenting behaviors in diverse ways (van Esch et al., 2018). Nevertheless, there is a lack of in-depth qualitative research investigating how the parenting behaviors and the experiences of these parents relate to each other. Accordingly, this qualitative study relied on SDT to provide an in-depth examination of (the interplay between) parents' need-based experiences and rearing behavior in the context of raising a child with ASD.

In total, four themes of parenting behavior and five themes of experiences were identified as essential for understanding parents' behaviors and need-based experiences when raising a child with ASD. The majority of the themes, both at the level of parenting behaviors and at the level of parents' own experiences, could be directly related to the needs for autonomy, relatedness, and competence posited in SDT. We found 3 themes that were not directly related to SDT, but did also capture an important part of the specific situation raising a child with ASD. Interestingly, these themes can also be aligned to SDT, as described further. Overall, SDT proved to be a comprehensive and meaningful framework to capture the richness of parents' lived experiences and behaviors in raising a child with ASD.

#### *The Interplay Between Need-related Experiences and Parenting Behavior*

A first important finding is that, in line with theories on parenting (e.g., Abidin, 1992) and SDT-based research in typically developing children (e.g., Mabbe et al., 2018), the interplay between parents' need-related experiences and parenting behaviors is complex and reciprocal. Although the interview focused on parents' behaviors and experiences separately, the results indicated clearly that you cannot understand the one without taking the other into account. Parenting behaviors and need-related experiences impact each other in both adaptive and maladaptive ways.

Parents indicated that they continuously adjust their parenting behaviors to their child's (autism-specific) characteristics, which can strongly undermine parents' own psychological needs. Parents reported, for example, that adapting to their child required reducing (or even giving up) their career aspirations (resulting in autonomy frustration) or their social life (resulting in relatedness frustration). Clearly, need-frustration can also affect parents' behaviors or reactions towards their child. Some parents indicated that they experienced so much need frustration that it caused them to react in a rather harsh way. The finding that parents sometimes felt pushed into harsh reactions corresponds with quantitative studies showing that negative child behavior can lead to need-frustration in parents, which, in turn, leads to negative parenting behavior (de Haan et al., 2013; Dieleman et al., 2018). At first glance, this reliance on harsh reactions might seem contradictory to parents' reported tendency to avoid punishment as a disciplinary technique (cfr., subtheme 'creating a new parenting model'). Both behaviors can, however, be differentiated based on their intention. The use of harsh reactions, as a consequence of need-frustration, is rather a reactive form of control in which parents lose their self-control and respond in an over-reactive way to stop the unwanted behavior of their child immediately. Often, these harsh 'outbursts' are followed by feelings of remorse. By contrast, the use of punishment as a disciplinary technique is a more proactive and intentional form of control in which parents consciously use certain strategies (e.g., prohibiting the child to do something fun) in order to shape their child's behavior towards more adaptive or desirable outcomes. When relying on these strategies, parents are not losing control and do not experience these high levels of need-frustration. So, although parents deliberately decide not to use punishment because it is not successful in shaping their child's behavior, the experience of need-frustration can still, at some moments, push them to react harshly towards their child.

At the same time, we also found evidence for an adaptive interplay between parenting behaviors and need-related experiences. For instance, adopting specific parenting practices, such as searching for

creative solutions, could create new opportunities for competence satisfaction (e.g., because parents experience that they found an effective solution) or for relatedness satisfaction (e.g., because parents grew closer together by working as a team). Similarly, parents' need-related experiences can foster change in their parenting behaviors. When parents, for instance, feel like they are not being the parents they would like to be (i.e., a desire for more autonomy satisfaction), they might try to adapt more to their child. As another example, experiencing relatedness with their child can prompt parents to empathize with their child more and to be more responsive to his/her specific characteristics.

In sum, this study yielded new insights in how parents of children with ASD adjust to the child's (autism-specific) characteristics while simultaneously trying to care for their own psychological needs. It also provides further support for the SDT-based notion that parents' own need-related experiences are dynamically intertwined with the quality of parenting, a notion that had not been tested with a qualitative design in the context of raising a child with ASD.

#### *An In-depth Insight in Parenting Behaviors When Raising a Child With ASD*

This study also allowed for an in-depth understanding of how parents adjust specifically to their child's (autism-specific) characteristics. In line with recent findings obtained by van Esch et al. (2018), the themes identified in this study strongly reflect parents' attempts to adjust to their child's characteristics.

Three parenting themes were related directly to the need-supportive practices as described by SDT (Ryan & Deci, 2017, see Fig. 1). More specifically, they represent strategies used by parents to nurture their child's need for relatedness (i.e., the need to feel connected with others), autonomy (i.e., the need for self-direction), and competence (i.e., the need to feel effective in accomplishing goals). Yet, each of these practices proved to have specific manifestations unique to raising a child with ASD. Although parents mentioned the importance of supporting the child's autonomy and described several practices commonly identified as autonomy-supportive practices in general populations (e.g., providing a rationale, offering choice, encouraging dialogue) (Grolnick et al., 1997; Joussemet et al., 2008; Soenens et al., 2017), some autism-specific adaptations were mentioned. For example, parents indicated that their child's need for clarity urged them to offer a rationale more often. In line with studies indicating that parents of children with ASD exhibit high levels of warmth and maintain close relationships with their child (Hoffman, Sweeney, Hodge, & Lopez-Wagner, 2009; van Esch et al., 2018), parents in this study also stressed the importance of making their child feel loved (i.e., relational support). In line with the findings of van Esch et al. (2018), parents described autism-specific adaptations in how they expressed their love and affection. Parents felt, for example, that their child with ASD has a strong need for them to be physically present. In addition, being empathic and responsive required parents to take into account their child's ASD-related vulnerabilities (e.g., choosing activities that fit with the child's sensory difficulties). A final set of behaviors refers to strategies satisfying children's need for competence. The finding that parents offer structure by using daily routines is in line with previous empirical studies identifying the importance of structure for children with ASD (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Interestingly, some parents intentionally deviated from this structure in order to encourage flexibility.

In addition, parents reported to adjust their parenting behaviors on a more general or philosophical level. Parents described that 'typical parenting strategies' are not sufficient for their child with ASD, forcing them to search for creative solutions, to reach out for help, and to create a new parenting model. These findings corroborate research identifying problem-focused coping and social support seeking as major coping strategies in parents of children with ASD (Lai & Oei, 2014). Although this theme of adaptation of one's view on parenting is not inherently tied to one of the needs identified in SDT, it is indirectly relevant to

parents' support for children's needs. Indeed, by going through this adaption process, parents learn how they can nurture their child's need for autonomy, relatedness and competence, while taking into account his/her ASD-related vulnerabilities or sensitivities. For example, learning that punishment is not effective to stop or prevent a child from posing unwanted behavior (e.g., running away during swimming lessons), can allow parents to seek for the roots of this behavior (e.g., abundance of stimuli) and to find better solutions that better match the child's needs (e.g., using earplugs) at that moment.

#### *Need-related Experiences in Parents of Children With ASD*

The third important finding of this study concerns its nuanced insight in parents' need-related experiences while raising a child with ASD. More specifically, the current study adds to the literature concerning experiences in raising a child with ASD by integrating both positive and negative experiences while structuring them within the SDT framework.

The identified experiences indicate that raising a child with ASD implies a modification of fundamental life-goals, values, and aspirations. In other words, raising a child with ASD has profound implications and affects not only the parenting role but also parents' identity more generally. More specifically, this study identified challenges to parents' own psychological needs for autonomy, relatedness and competence. First, the challenges for parents' need for autonomy are in line with studies reporting high levels of restriction in different life domains (Hoffman et al., 2009; Myers et al., 2009). Parents stress the dominance of the ASD in their role as a parent and feel like the care for their child with ASD completely takes over their lives for an undefined period of time. Similar findings have been reported in qualitative studies with parents describing ASD as 'the center of their lives' (Myers et al., 2009) or stating to be 'drowning' in autism (Woodgate et al., 2008). Second, corroborating research on closeness in ASD (Hoffman et al., 2009), this study shows that accommodating the need for relatedness between the parent and the child with ASD is complex, and can alternate between feeling closely connected and feeling completely disconnected. Moreover, results confirm previous work showing that raising a child with ASD also poses threats for parents' relatedness with their partner, other children, friends, and family (Woodgate et al., 2008), even though some parents also mentioned a strengthening of the partner relationship (Myers et al., 2009). Third, the challenges for parents' need for competence show how the specificity of raising a child with ASD can cause parents to doubt themselves and can sometimes lead to a complete loss of trust in their own parenting abilities. These findings mesh with studies reporting decreased levels of parental competence or self-efficacy in parents of children with ASD (Hoffman et al., 2009; Meirsschaut et al., 2010).

In addition to these challenges for the parents' psychological needs, the acceptance of the diagnosis and its permanent situation is found to be essential for parents' experience of raising a child with ASD. In line with previous qualitative work (DePape & Lindsay, 2014), accepting the diagnosis is also described as an important yet difficult process. The diagnosis confronts parents with mixed emotions and coming to terms with it is a long-term process. Although this long-term process does not directly and specifically reflect one of the three needs identified in SDT, it can be linked to another concept central to SDT, that is, the process of internalization. According to SDT, internalization refers to the process through which values, beliefs, commitments and behaviors of a person become personally endorsed, align with the self, and reflect own preferences and sensibilities (Ryan & Deci, 2003; Soenens & Vansteenkiste, 2011). With increasing internalization, people identify more strongly with their commitments and wholeheartedly endorse their commitments. When parents accept their child's diagnosis and its permanency, they might have identified themselves with the identity as being a parent of a child with ASD (i.e., recognizing the meaningfulness and relevance of the identity) or even integrated this identity

within their self (i.e., the identity is also aligned with other values and goals). Because internalization lays the foundation for need-satisfying experiences (Ryan & Deci, 2017), parents who accept the diagnosis might experience more opportunities for need-satisfaction. In contrast, parents who continue to struggle with the acceptance of the diagnosis may more often appraise challenges encountered during the parenting process as a threat to their own psychological needs.

Despite the discussed hardships, we found that most parents reported that raising a child with ASD also provided positive experiences. In line with previous studies (e.g., Bultas & Pohlman, 2014), parents describe experiencing personal enrichments such as a shift in priorities, values and their view on life. This finding suggests that raising a child with ASD can be stressful, yet at the same time also enriching even at the level of deeper identity-related values and lifestyles. Considered from an SDT-perspective, this new life vision might arise from two different processes. One possibility is that the development of a new life vision is a result of internalization of the (assigned) identity as a parent of a child with ASD. When parents experience this identity as meaningful and a reflection of who they are (i.e., identification) or integrate this identity with other values and goals (i.e., integration), they are able to behave and to make commitments consistent with this identity (e.g., having more respect for the uniqueness of each individual). The new life vision might also be an expression of parents' search for need-satisfying experiences. By shifting their priorities, adapting their values and changing their view on life, parents may proactively seek to create more opportunities for psychological need satisfaction. So, initial experiences of need-frustration (e.g., lack of freedom and flexibility; questioning own competence) while raising a child with ASD might prompt parents to make changes in their behavior, priorities, and values in order to create more opportunities for need-satisfaction (e.g., focusing on family life and by working part-time; following a specialist course on ASD and helping other parents).

#### **Practical Implications**

The present findings have a number of practical implications. First, this study identified several challenges for parents' psychological needs, which represent important targets for parent-support. Parents expressed a need for support about parenting-related issues and personal issues such as social isolation. Second, this study identifies opportunities for improving need-satisfaction through parent-support. Parents stressed, for example, the importance of positive feedback, suggesting that health-care workers should not only identify problems but should also acknowledge parents' strengths and undertaken efforts. Concerning parents' need for relatedness, this study shows that interventions should not only focus on the relation between the parent (s) and the child with ASD, but should also include other family members (e.g., siblings). The findings also highlight how little personal time these parents have and how few people, if any, they can rely on to take care of the child. This finding underscores the importance of investing in specialized (respite) care and in creating social support networks. Third, this study is one of the first to structure the experiences and behaviors of parents of children with ASD within the framework of SDT (Deci & Ryan, 2000). As previous SDT-based interventions have shown the positive impact of fostering need-satisfying experiences (Weinstein, Khabbaz, & Legate, 2016) and of encouraging parents to engage in need-supportive parenting (Joussemet, Mageau, & Koestner, 2014), parents of children with ASD might also benefit from applying principles of SDT.

#### **Limitations and Directions for Future Research**

When interpreting the results, some limitations need to be taken into account. First, the recruitment procedure required parents to contact the researchers themselves, which might have caused selection bias. Although a sample size of 15 has been identified as sufficient for

an interview study with this scope (Braun & Clarke, 2013), a second limitation concerns the heterogeneous sample of parents and children with ASD. Because the socio-demographic background of the parents (in terms of employment, marital status, and educational level) was quite heterogeneous, it remains unclear to what extent the identified themes can be transferred to more specific subsamples or whether specific themes might appear in specific subsamples. As children were aged between six to seventeen years, parents might be confronted with diverse challenges, relating to diverse experiences and parenting behaviors. Future research could, therefore, address this by recruiting larger subsamples within socio-demographic niches (e.g., divorced parents, children within a specific age group). A third limitation is that, even though we managed to include five fathers (participating together with the mother), most information was offered by mothers. It might be interesting to interview mothers and fathers separately in order to examine differences and similarities. In addition, the current study included both single-parent interviews and dyad-interviews. Although we did not find differences in the themes reported in single-parent interviews and in dyad-interviews (i.e., each subtheme was endorsed by at least two dyads and there was no subtheme that was only endorsed by dyads or by single participants), it might be interesting for future research to include more dyads and to examine differences in need-related experiences and parenting behaviors between partners. Fourth, although this study examined the interplay between parents' experiences and behaviors, the qualitative design does not allow one to draw any conclusion about the direction of effects. In order to do so, longitudinal or experimental research is needed. Finally, although parents indicate to use similar need-supportive parenting behaviors as parents of typically developing children, findings do suggest some autism-specific adaptations. Therefore, more research is needed to examine to what extent SDT can help guiding parents of children with ASD to support their children's psychological needs.

## Conclusion

This qualitative study, relying on SDT as an integrative framework, offered an in-depth examination of (the interplay between) parents' need-related experiences and parenting behaviors in the context of raising a child with ASD. By relating both experiences and behaviors to the psychological needs for autonomy, relatedness and competence, the findings provided a deeper understanding of the challenges and opportunities for parents' well-being and offered greater insight into how parents of children with ASD adjust to their child's characteristics.

## Acknowledgments

This research was funded by grants from the Marguerite-Marie Delacroix Support Fund (GV/B-202) and the Fund for Scientific Research Flanders (FWO) (12B4614N and 11X6516N). The authors wish to thank all the participating families for sharing their experiences. In addition, the authors wish to thank prof. Herbert Roeyers for his help with reviewing the diagnostic files and Rashida El Kaddouri, Chloé Bontinck and Ellen Demurie for administering the ADOS-2.

## Declaration of Interest

None.

## References

- Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of Clinical Child Psychology*, 21, 407–412. [https://doi.org/10.1207/s15374424jccp2104\\_12](https://doi.org/10.1207/s15374424jccp2104_12).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706qp0630a>.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage Publication.
- Bultas, M. W., & Pohlman, S. (2014). Silver linings. *Journal of Pediatric Nursing*, 29, 596–605. <https://doi.org/10.1016/j.pedn.2014.03.023>.
- Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2015). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews. *Journal of Intellectual and Developmental Disability*, 40, 78–91. <https://doi.org/10.3109/13668250.2014.964191>.
- de Haan, A. D., Soenens, B., Deković, M., & Prinzie, P. (2013). Effects of childhood aggression on parenting during adolescence: The role of parental psychological need satisfaction. *Journal of Clinical Child & Adolescent Psychology*, 42, 393–404. <https://doi.org/10.1080/15374416.2013.769171>.
- Deci, E. L., & Ryan, R. M. (2000). The “what” and “why” of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, 11, 227–268. [https://doi.org/10.1207/S15327965PLI1104\\_01](https://doi.org/10.1207/S15327965PLI1104_01).
- DePape, A., & Lindsay, S. (2014). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, 25, 569–583. <https://doi.org/10.1177/104973231452455>.
- Dieleman, L. M., De Pauw, S. S. W., Soenens, B., Mabbe, E., Campbell, R., & Prinzie, P. (2018). Relations between problem behaviors, perceived symptom severity and parenting in adolescents and emerging adults with ASD: The mediating role of parental psychological need frustration. *Research in Developmental Disabilities*, 73, 21–30.
- Grolnick, W. S., Deci, E. L., & Ryan, R. M. (1997). Internalization within the family: The self-determination theory perspective. In J. E. Grusec, & L. Kuczynski (Eds.), *Parenting and children's internalization of values: A handbook of contemporary theory*. New York: Wiley.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629–642. <https://doi.org/10.1007/s10803-012-1604-y>.
- Hoffman, C., Sweeney, D., Hodge, D., & Lopez-Wagner, M. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 24, 178–187. <https://doi.org/10.1177/1088357609338715>.
- Joussemet, M., Landry, R., & Koestner, R. (2008). A self-determination theory perspective on parenting. *Canadian Psychology*, 49, 194–200. <https://doi.org/10.1037/a0012754>.
- Joussemet, M., Mageau, G. A., & Koestner, R. (2014). Promoting optimal parenting and children's mental health: A preliminary evaluation of the how-to parenting program. *Journal of Child and Family Studies*, 23, 949–964. <https://doi.org/10.1007/s10826-013-9751-0>.
- Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15, 247–277. <https://doi.org/10.1007/s10567-012-0119-6>.
- Lai, W. W., & Oei, T. P. S. (2014). Coping in parents and caregivers of children with autism spectrum disorders (ASD): A review. *Review Journal of Autism and Developmental Disorder*, 1, 207–224. <https://doi.org/10.1007/s40489-014-0021-x>.
- Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism diagnostic observation schedule* (second edition). Torrance, CA: Western Psychological Services.
- Mabbe, E., Soenens, B., Vansteenkiste, M., van der Kaap-Deeder, J., & Mouratidis, A. (2018). Day-to-day variation in autonomy-supportive and psychologically controlling parenting: The role of parents' daily experiences of need satisfaction and need frustration. *Parenting: Science and Practice*, 18, 86–109. <https://doi.org/10.1080/15295192.2018.1444131>.
- Meirsschaut, M., Roeyers, H., & Warreyn, P. (2010). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions. *Research in Autism Spectrum Disorders*, 4, 661–669. <https://doi.org/10.1016/j.rasd.2010.01.002>.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heart ache”: Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670–684. <https://doi.org/10.1016/j.rasd.2009.01.004>.
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, 745–762. <https://doi.org/10.2147/NDT.S100634>.
- QSR International (2012). *NVivo qualitative data analysis software (version 10)*. QSR International Pty Ltd.
- Rutter, M., LeCouteur, A., & Lord, C. (2003–2008). *Autism diagnostic interview – Revised*. Los Angeles: Western Psychological Services.
- Ryan, R. M., & Deci, E. L. (2003). On assimilating identities to the self: A self-determination theory perspective on internalization and integrity within cultures. In M. R. Leary, & J. P. Tangney (Eds.), *Handbook of self and identity* (pp. 253–272). New York: Guilford Press.
- Ryan, R. M., & Deci, E. L. (2017). *Self-determination theory: basic psychological needs in motivation, development, and wellness*. New York: Guilford Publications. [https://doi.org/10.1007/978-94-007-0753-5\\_2630](https://doi.org/10.1007/978-94-007-0753-5_2630).
- Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism. *Autism*, 15, 373–389. <https://doi.org/10.1177/1362361310386505>.
- Soenens, B., Deci, E. L., & Vansteenkiste, M. (2017). How parents contribute to children's psychological health: The critical role of psychological need support. In M. L. Wehmeyer, T. D. Little, S. J. Lopez, K. A. Shogren, & R. Ryan (Eds.), *Handbook on the development of self-determination* (pp. 171–187). New York: Springer.
- Soenens, B., & Vansteenkiste, M. (2011). When is identity congruent with the self? A self-determination theory perspective. In S. J. Schwartz, K. Luyckx, & V. L. Vignoles (Eds.), *Handbook of identity theory and research* (pp. 381–402). New York: Springer.
- Van der Kaap-Deeder, J., Soenens, B., Mabbe, E., Dieleman, L. M., Mouratidis, A., Campbell, R., & Vansteenkiste, M. (2017). *From Daily Need Experiences to Autonomy-Supportive*

- and Psychologically Controlling Parenting Via Psychological Availability and Stress. (Submitted for publication).
- van Esch, L., O'Nions, L., Hannes, K., Ceulemans, E., Van Leeuwen, K., & Noens, I. (2018). Parenting early adolescents with Autism Spectrum Disorder before and after transition to secondary school. *Advances in Neurodevelopmental Disorders*, 2, 179–189. <https://doi.org/10.1007/s41252-018-0058-4>.
- Weinstein, N., Khabbaz, F., & Legate, N. (2016). Enhancing need satisfaction to reduce psychological distress in Syrian refugees. *Journal of Consulting and Clinical Psychology*, 84, 645–650. <https://doi.org/10.1037/ccp0000095>.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18, 1075–1083. <https://doi.org/10.1177/1049732308320112>.
- Vansteenkiste, M., & Ryan, R. M. (2013). On psychological growth and vulnerability: Basic psychological need satisfaction and need frustration as a unifying principle. *Journal of Psychotherapy Integration*, 23, 263–280. <https://doi.org/10.1037/a0032359>.