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Searching for What Really Matters: A Thematic Analysis of Quality of Life among Preschool Children on the Autism Spectrum

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Abstract:	Quality of life (QoL) is an essential measure when assessing health interventions. Most early interventions for autistic preschoolers evaluate the effects on autism symptoms. However, researchers increasingly believe that good interventions should also improve the QoL of these children. Domains of QoL among autistic preschoolers have also not previously been researched. We interviewed autistic adults to explore early childhood experiences that made their lives satisfying. Our data revealed four major themes: interests, environmental regularity, perceptual differences and social interactions. This study provides the first insights on aspects of life important to autistic preschoolers. Findings will contribute to developing items for a measure of QoL among this population.
Response to Reviewers:	We would like to thank both reviewers for their feedback and further constructive comments. We hope that the changes suggested by the second reviewer will meet your expectations. Only new additions to the original manuscript appear in yellow. Reviewer #2 1. I still think the justification for use of a retrospective qualitative study that relies on memory could be further enhanced. There were only a few sentences added in the introduction. I think this warrants at least another paragraph in the introduction of your paper. You provide additional information but I would actually recommend taking it a step further and adding a whole paragraph on the general importance of retrospective qualitative research. Within this paragraph, you can provide descriptions of studies that used this in the past to enhance your justification to use this approach. You can also

add in information/research on memory to support the importance. I think this is best placed in the paragraph before the last paragraph which should identify the purpose of the current study and the questions that you are attempting to answer.

We have added in the introduction a paragraph on the importance of retrospective qualitative research. We have also added some of the information originally included in the discussion. Finally, we have modified the last paragraph of the introduction by restating the main purpose of our study and our research question (page 5, lines 4-25).

2. Page 5, Lines 21-23: I would suggest rephrasing this sentence to something like, "Participants were included if they self-reported having a diagnosis on the Autism spectrum and if they spoke and understood French well enough to participate in an interview."

Done (page 6, lines 11- 13).

3. The additions to the Discussion are helpful but need further organization to make the points clear about: 1) memory function; 2) Use of alternative data sources and 3) age of responders. Some of this information should be in future research, as you need to provide a clear justification for your findings in the discussion. Some of it also could be moved up to the Introduction in the recommended additional paragraph.

We have changed the organization of these points in the discussion, and added references in the "future research" section (page 19, lines 1- 5).

**Searching for What Really Matters: A Thematic Analysis of Quality of Life Among
Preschool Children on the Autism Spectrum**

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Abstract

Quality of life (QoL) is an essential measure when assessing health interventions. Most early interventions for preschool children on the spectrum evaluate the effects on autism symptoms. However, researchers increasingly believe that good interventions should also improve the QoL of these children. Domains of QoL among preschool children on the autism spectrum have also not previously been researched. We interviewed adults on the spectrum to explore early childhood experiences that made their lives satisfying. Our data revealed four major themes: interests, environmental regularity, sensory differences and social interactions. This study provides the first insights on aspects of life important to pre-schoolers on the spectrum. Findings will contribute to developing items for a measure of QoL among this population.

Keywords : autism spectrum disorder, children, preschool, quality of life, thematic analysis

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1 **Abstract**

2 Quality of life (QoL) is an essential measure when assessing health interventions. Most early
3 interventions for autistic preschoolers evaluate the effects on autism symptoms. However,
4 researchers increasingly believe that good interventions should also improve the QoL of these
5 children. Domains of QoL among autistic preschoolers have also not previously been
6 researched. We interviewed autistic adults to explore early childhood experiences that made
7 their lives satisfying. Our data revealed four major themes: interests, environmental
8 regularity, perceptual differences and social interactions. This study provides the first insights
9 on aspects of life important to autistic preschoolers. Findings will contribute to developing
10 items for a measure of QoL among this population.

11 **Key words:** autism spectrum disorder, children, preschool, quality of life, thematic analysis

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1 Autism spectrum can vary depending on symptom severity, development stages, and
2 chronological age (American Psychiatric Association [APA], 2013). Therapeutic, re-
3 educational and psycho-educational interventions have been targeting the fundamental
4 characteristics of autism for many years (National Institute for Health and Care Excellence
5 [NICE], 2013), without significantly being able to modify these variables (Sandbank et al.,
6 2020). It has therefore been suggested interventions should also focus on quality of life (QoL)
7 (Bieleninik et al., 2017). This is considered as the “gold standard” for health interventions
8 (Ikeda et al. 2014). Moreover, families and autistic people are seeking interventions to
9 improve their QoL (McConachie, Livingstone et al. 2018; Pfeiffer et al., 2016).

10 There is no unified theoretical basis for the concept of QoL (Clark et al., 2015).

11 Factors of QoL differ depending on authors (Feldhaus & von Ossietzky, 2015). The only
12 consensus is that QoL is a multidimensional and subjective concept that includes personal
13 appraisal, functional assessment, and social indicators (Schalock, 2004). Many studies use the
14 definition of QoL proposed by the World Health Organization: “individuals’ perception of
15 their position in life in the context of culture and value systems in which they live and in
16 relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1995, p.11).

17 QoL levels among autistic people are lower than typically developing individuals
18 regardless of age (Ayres et al., 2017; Ikeda et al., 2014), despite the fact that autistic adults
19 report their QoL in social domain as higher than their parents estimates (Hong et al., 2016).
20 Several studies have therefore sought to determine factors that can improve the QoL of
21 autistic people (Chiang & Wineman, 2014). Reported factors include the quality of social
22 interactions (Deserno et al., 2017; Mason et al., 2018), quality of sleep (Deserno et al., 2019),
23 perceived stress (Bishop-Fitzpatrick et al., 2017), anxiety (Adams et al., 2019), depression
24 (Lawson et al., 2020), psychiatric comorbidity (Knüppel et al., 2018; Park et al., 2019), and
25 the severity of repetitive behaviors (Moss et al., 2017).

1 Few studies have examined the QoL of autistic children under the age of six (Chuang
2 et al., 2014). Studies assessing the QoL of autistic children do not generally distinguish
3 between age groups (Table 1). An exception is Chuang et al. (2014), who include children
4 aged 36-70 months. This makes it difficult to draw conclusions regarding the QoL in a
5 specific age group. However, comparative studies show that autistic preschoolers have a QoL
6 lower than typically developing children, or children with other chronic conditions (Table 1).
7 These studies mainly use PedsQL 4.0 to measure the QoL by interviewing the parents and not
8 the children (Table 1). Another disadvantage of this research is the use of generic tools not
9 adapted to the child's condition (Ayres et al., 2017; Clark et al., 2015).

10 The lack of data concerning the QoL of autistic preschoolers is problematic for at
11 least two reasons. First, the variety of early interventions targeting children under the age of
12 six has increased considerably over the past decade (French & Kennedy, 2018; Wainer et al.,
13 2017). Currently, there exists little knowledge on whether these early interventions could be
14 more beneficial than harmful (Bottema-Beutel, Crowley, Sandbank & Woynaroski, 2020;
15 Dawson & Fletcher-Watson, 2020), or how they impact QoL (Pfeiffer et al., 2016; Reichow
16 et al., 2018). This is a concern as these early years are crucial for determining many
17 children's current and future well-being (Franchini et al. 2018). Second, criteria for assessing
18 QoL differ depending on chronological and mental age (Eiser & Jenney, 2007; Rodary,
19 2000). Measures need to be specific to a child's developmental level to evaluate QoL (Nathan
20 et al., 2004), especially among young children (Fekkes et al. 2000; Schepers et al. 2017).

21 When trying to assess an individual's QoL, it is important to consider how they
22 perceive their experiences to better understand their difficulties (Turner et al., 2007). It is
23 particularly difficult to interview very young children about their subjective experiences,
24 regardless of whether they are typically developing (Coghill et al., 2009; Matza et al., 2004)
25 or autistic (Hong et al. 2016; Stokes et al., 2016). We also lack reliable methodology to

1 collect data of subjective experiences among autistic people without oral language (Tesfaye
2 et al., 2019; Kirby et al., 2015).

3 It is possible to interview verbal autistic adults on their personal experiences (DePape
4 & Lindsay, 2016). However, retrospective reports remain problematic given the
5 reconstructive nature of the human memory (Barusch, 2011), and its unreliability (Brogger,
6 Eagan, Eide, Bakke & Gulsvik, 2004), which could lead to recall bias (Hassan, 2005).

7 Among the general population, the ability to remember life events from childhood decreases
8 with age (Lindsay et al., 2004). This bias can even be accentuated when remembering
9 stressful events (Colman et al., 2016). The explicit memory of autistic people seems to be
10 preserved, however memory skills for personal memories involving emotions are also likely
11 to be impaired (Ullman & Pullman, 2015). Autistic people may present an altered
12 autobiographical memory regardless of their age (Bruck, London, Landa & Goodman, 2007).

13 However, retrospective studies are best suited for constructing the sequences of significant
14 events (de Vaus, 2011). Qualitative studies using long-term retrospective recalls generally
15 provide a similar quality of reports than those provided by short-term recalls (Beckett, Da
16 Vanzo, Sastry, Panis & Peterson, 2001). Furthermore, salient retrospective life history data
17 does not appear to produce bias (Jivraj, Goodman, Ploubidis & Oliveira, 2020). Validity of
18 retrospective recall of autistic adults' interviews may be preserved given that this population
19 is able to express their feelings or personally significant past events using highly specific
20 facts and detail (Zukauskas, Siltan & Baptista, 2009). The proficient memory skills of these
21 individuals can also facilitate first-person accounts of their childhood experiences (Volkmar
22 & Cohen, 1985).

23 The primary aim of this study was to conduct a thematic analysis of semi-structured
24 interviews with verbal autistic adults about early childhood experiences that made their lives
25 satisfying, to determine what matters to enhance preschool autistic children's QoL.

1 **Method**

2 Guidelines provided by O'Brien et al., (2014) were used for reporting qualitative
3 research while preserving the flexibility of various methods.

4 **Recruitment and participants eligibility**

5 Recruitment was carried out on a voluntary basis using clinical partners, charities,
6 care services and centers specialized in autism located in the Paris region of France.

7 Gradually recruitment via social networks was also implemented. Recruitment ceased when
8 we reached data saturation (Blanchet & Gotman, 2010).

9 This study was proposed to adults with a diagnosis of ASD or Asperger Syndrome,
10 according to international classifications (DSM-IV-TR, DSM-5 or ICD-10). Participants who
11 were not able to write and speak in French were not included in this study. **Participants were
12 included if they self-reported having a diagnosis on the autism spectrum and if they spoke
13 and understood French well enough to participate in an interview.**

14 **Sample characteristics**

15 Ten autistic adults were interviewed. Five interviews were conducted remotely: four
16 by telephone and one by video call. Three interviews were conducted in a public place, and
17 two at the participant's home. Interviews lasted between 17 and 44 minutes (with an average
18 of 31 minutes). Participants were diagnosed with ASD (n = 8) or Asperger Syndrome (n = 2)
19 according to the DSM-IV-TR classification criteria, and some had an associated condition (n
20 = 4). These associated conditions were diagnosed late (during adulthood for 9 participants
21 and adolescence for 1 participant). We are therefore unable to know whether these conditions
22 were present when they were preschoolers. Their average age was 39 years. Half of
23 participants lived with a partner. Eight participants had at least one child, of which two had
24 an autism-related diagnosis. The majority of participants were employed (n = 7) and had a
25 bachelor degree education level (n = 7). Sample characteristics are presented in Table 2.

1 **Procedure**

2 This research was approved by the *Comité d’Ethique pour les Recherches*
3 *Comportementales et en Santé* of the *Université Paris Descartes*. Participants who met
4 inclusion criteria were contacted by email. An information letter was then sent to interested
5 participants.

6 An individual interview was organized with those who agreed to participate in the
7 study. Interviews were carried out at their convenience: at home, in a public place, or
8 remotely by telephone or videophone call. All participants signed a consent form. They also
9 completed a socio-demographic and diagnosis information form.

10 We conducted semi-structured interviews, which is the most widely used method to
11 collect first-person perspectives of autistic individuals (DePape & Lindsay, 2016). Firstly,
12 participants were asked a general question about important elements that made life satisfying
13 or unsatisfying before the age of 6 (Table 3). Secondly, the interviewer explored themes
14 specific to autism developed from the literature (Table 3) if they were not addressed
15 spontaneously (Romelear, 2005). Questions were adapted specifically to each participant
16 depending on the words they used during the interview. Nevertheless, the same topics were
17 addressed among all participants. According to Feldhaus and von Ossietzky (2015), using the
18 term “life satisfaction” renders the concept of QoL more understandable for verbal autistic
19 people. We therefore favored sentences such as “what elements were important to make your
20 life satisfying when you were younger than 6 years old” / “what was not satisfying in your
21 life when you were under the age of 6”. If participants had difficulty answering questions, we
22 specified the following: “If you have difficulty remembering your life before the age of 6, it
23 does not matter, just think about your childhood in general”. However, during the interviews,
24 participants were reminded of the importance of trying to remember life events from the
25 preschool period. Interview instructions were pre-tested among two participants. They said

1 instructions were clear and one of them requested questions to be repeated to ensure he
2 understood what was expected of him.

3 Interviews were recorded with participants' consent and then verbatim was
4 transcribed anonymously.

5 **Analysis**

6 A thematic content analysis was performed following Braun and Clarke's (2006)
7 guidelines. Data analysis followed these steps: (1) becoming familiar with the data via
8 repeated readings, (2) generating initial codes by summarizing interview elements to
9 represent participants' descriptions as accurately as possible, (3) organizing codes into
10 potential themes and sub-themes, i.e. coherent and meaningful patterns relevant to quality of
11 life (4) refining identified themes and sub-themes, as well as checking that they match both
12 the coded extracts and the full data-set, (5) defining themes to determine their features,
13 writing a detailed analysis of each theme, and giving a concise and informative name for each
14 theme.

15 To improve study strength and reliability, analysis was independently performed by
16 two of the authors (JL & AP) (MacPhail et al., 2016). Differences in findings were discussed
17 until consensus among all authors. The analysis was performed under the supervision of KL,
18 a researcher specialized in qualitative research. Interviews were analysed using NVivo
19 Version 12© software for qualitative textual analysis to refine themes and improve the
20 intercoder agreement. According to Viera and Garrett (2005), a value of k (Cohen's kappa
21 coefficient) between 0.61 and 0.80 is considered significant and indicates that the coding
22 performed by two researchers is highly similar. A satisfactory inter-rater agreement among
23 the ten coded interviews was obtained for this analysis ($k = 0.77$).

24 **Results**

25 **Themes**

1 Four major themes emerged from the data (Table 4). Elements impacting participants'
2 life satisfaction at preschool age were related to (1) interests, (2) social interactions, (3)
3 perceptual differences and (4) environmental regularity.

4 ***Theme 1: Interests***

5 All participants discussed their areas of interest, such as activities, games or topics
6 they particularly appreciated when they were young children. For example, seven participants
7 said they were attracted to written language: “I was captivated by reading” (Geraldine).
8 Interests influence quality of life in three ways:

9 **The importance of interests (1.1)**

10 Nine participants frequently sought their interests or devoted themselves to them, as
11 illustrated by this extract from Felicity’s interview: “I had a specific interest in dogs, wolves
12 and I like to collect cards; I know all about dog breeds (...) I was completely focused on it”.

13 **Satisfaction associated with interests (1.2)**

14 Nine participants felt either positive emotions when interests were available or
15 negative emotions when they were unattainable, as Igor specifies: “I always liked being
16 around things I appreciated, to be calm, isolated and focused on the passion of the moment”.
17 Or Edward: “whatever family circumstances, or other, that prevented me from... I classified
18 them as harmful and disturbing”.

19 **Sharing interests (1.3)**

20 Participants expressed their need to share interests with other people (n =5), or keep
21 them to themselves (n = 4). One participant (Danielle) mentioned these two aspects: “At
22 times, I wanted them to participate, I told them that, but not all the time. Only when I wanted
23 them to”.

24 ***Theme 2: Social interactions***

1 All participants spoke about their social interactions. This theme refers to their
2 experiences and needs when interacting with their entourage (family, peers, professionals).
3 Six sub-themes emerged from the analysis, five of which could impact participant's QoL
4 during childhood (sub-theme 2.6, "awareness of one's differences", is not addressed as it
5 does not answer the research question).

6 **Respect specific characteristics (2.1)**

7 This sub-theme refers to the way others respect or do not respect the participant's
8 different behaviors. Kindness and flexibility were mentioned, as well as how this made the
9 participant's lives more satisfying. Conversely, a lack of flexibility could make participants'
10 lives less satisfying. All participants mentioned this sub-theme. For Edward: "My family had
11 great respect of my, I would call it my autistic life - but at that time I called it my tranquility
12 for concentrating on the passions that drove me". For Helene: "I remember times when I
13 asked my loved ones, or when I told them what we were going to do this day and that day and
14 the other day. But I was not supported during these personal attempts (...). I don't think my
15 needs were obvious enough to my loved ones. I don't think they realized that I needed it".

16 **Solitude (2.2)**

17 Seven participants spoke about needing and searching solitude, as well as associated
18 positive benefits or emotions. For example, Alan: "I played with toys, like Playmobil, but
19 always on my own. Even when I went to my cousins, who were my age, I preferred to let the
20 two of them play together, and I would isolate myself and play alone". Four participants
21 reported the benefits of solitude. Such as Edward, who could concentrate better alone: "I
22 could isolate myself from the outside world (...) The main reason was for concentration".

23 **Hostility (2.3)**

24 Seven participants experienced hostile behaviors from their entourage and emotional
25 responses. This could include physical or emotional abuse, feeling judged, mockery or

1 rejection. Feeling excluded was reported by six participants. Danielle referred to her
2 experience of rejection as: “The impression of being rejected, that was very difficult. Even
3 with other children, sometimes it was very hard for me, very, very hard. And sometimes
4 when I came back from school, I cried because it had gone wrong, because I had been
5 rejected, it was very hard, it was difficult to experience”.

6 **Communication difficulties (2.4)**

7 Participants had difficulties: understanding what others expected of them;
8 understanding the behaviors of others; making themselves understood; expressing
9 themselves. Seven participants mentioned these difficulties, for Felicity: “(...) my
10 relationship with my mother and sister who didn’t understand. And since they didn’t
11 understand me, I didn’t feel like I belonged there”. Or even Bérangère: “I also had a big
12 problem, that is to say I didn’t understand what I was being asked. I had no idea what was
13 expected of me”.

14 **Emotional bonds (2.5)**

15 Participants discussed their emotional closeness to others, as well as their friendships
16 during early childhood. Nine participants sought and needed emotional bonds. John
17 considered “having friends, getting along with my friends too” as an important element for
18 life satisfaction during early childhood. For Cecile it was “feeling loved by my parents,
19 because I don’t think there was anyone else around me who mattered”. On the other hand,
20 five participants demonstrated a disinterest or dislike for emotional bonds with peers. This
21 was the case for Alan: “I’ve always preferred to be surrounded by adults and have
22 conversations with them rather than children who didn’t interest me”. Almost half of the
23 sample (n = 4) stated they had very few friends during early childhood: “I never really had
24 any friends, the only friend (laughs), I don’t like to say this, it’s sad, but (crying), the only
25 friend I really had was a little girl who was rejected, a little bit like me” (Geraldine).

1 ***Theme 3: Perceptual differences***

2 Participants were sensitive or insensitive to certain stimuli depending on the low-level
3 perceptual system. This could lead them to either avoid stimuli or seek certain sensations,
4 which could impact their QoL when they were younger. All participants spoke of their
5 sensory differences. They are organized into the following sub-themes:

6 **Auditory avoidance or attraction (3.1)**

7 Nine participants reported an auditory avoidance for all types of sounds: social sounds
8 “The noise of general chatter in the classroom could disturb me. Quite violently sometimes”
9 (John); or non-social sounds: “I remember hating shops, for reasons that seemed obvious to
10 me on a sensory level with all the noise” (Helene). Auditory perception provided positive
11 experiences for two participants, including Igor: “At the time it was CDs or cassettes that I
12 listened to, always the same ones, many times (...) sometimes it was just an intonation I liked
13 to listen to (...). It was a nice sensation”.

14 **Visual perception (3.2)**

15 Among the four participants mentioning visual perception, most (n = 3) expressed an
16 aversion to light, either artificial (n = 2) or natural (n = 1). For Alan: “Everything neon or
17 similar has always been a problem for me”. Cecile evoked an aversion to seeing movements:
18 “Other people’s sudden or fast movements, were like an assault. It’s not the sounds that
19 necessarily harmed me, but the gesture”.

20 **Mouth sensitivity (3.3)**

21 Six participants mentioned sensitivity to food or non-food items textures or taste.
22 Avoidant behaviors to food were mentioned by six participants, as Bérangère explains: “I had
23 big problems with the texture of certain foods (...). I preferred to go up to my room, go back
24 to school hungry, but there were things that just didn’t agree with me. You could leave me at
25 the table until everyone was gone, I would resist until the end”. One participant presented a

1 sensory need to chew materials throughout childhood: “I was often searching for sensations, I
2 also needed to chew things (...). I tended to, and still tend to, suck things (...). It’s true that at
3 the time it was mostly clothes, but it was a little bit of everything, it could go as far as
4 cardboard” (Igor).

5 **Tactile perception (3.4)**

6 Five participants testified to the unpleasantness of being touched by other people.

7 This is what Bérangère told us: “I had very long hair at the time, I cried every day when my
8 mother combed my hair because it wasn’t nice, nobody could touch my hair”.

9 **Olfactory perception (3.5)**

10 Olfactory perception was reported by four participants, which led some to avoid
11 odors. Danielle for example expressed this when she was confronted with certain chemical
12 smells: “Chemical smells attacked me, sometimes I was so focused on them that I couldn’t do
13 anything else”. Whereas in other situations, participants sought odors associated to positive
14 emotions. For Cecile: “People are surprised, they often see me smelling a book, smelling an
15 object (...). And it’s something that I’ve done since I was a little girl, and makes me feel safe.
16 Even sniffing people, so I do it discreetly (laughs), because, let’s say it’s not very socially
17 acceptable, but I’m extremely sensitive to smells”.

18 One participant also experienced incomfort to some temperatures. This is not
19 presented in more detail as it was not experienced by the majority of participants.

20 **Theme 4: Environmental regularity**

21 This last theme refers to the regularity of behaviors, life events, or the participant’s
22 environment. Expressed by all ten participants as either habits, rituals, or reference points.

23 Two sub-themes specify how this regularity could be important for the participant’s life
24 satisfaction before the age of six:

25 **Recurrence (4.1)**

1 Eight participants needed environments to stay the same, and certain behaviors or
2 events to be repeated. This recurrence was associated with positive emotions, for example
3 Geraldine: “Each evening, it is as if my grandmother understood that I needed this ritual,
4 each evening she invented stories (...) and I remember that one of my rituals was to turn her
5 hair, it was something that reassured me”.

6 **Predictability (4.2)**

7 Eight participants needed to be able to predict events. This was the case with Igor: "It
8 is true that when there were unforeseen events, it was quite complicated for me".

9 **Discussion**

10 The objective of this qualitative study was to identify areas of QoL important to autistic
11 children under the age of six. Semi-structured interviews were conducted with autistic, verbal
12 adults. Four major themes were revealed: interests, environmental regularity, perceptual
13 differences and social interactions.

14 In general, QoL measures should account for an individual’s concerns (WHOQOL
15 Group, 1995) and interests (Schalock & Parmenter, 2000). Compared to typically developing
16 individuals, autistic people are particularly motivated to engage in their interests (Anthony et
17 al., 2013). This is strongly correlated to positive affects (Grove et al., 2016), such as well-
18 being (Author et al., 2000), enthusiasm, pride or joy (Winter-Messiers, 2007). Interests
19 among autistic people promote social inclusion (Plimley, 2007), help them develop academic
20 skills (Wood, 2019), or symbolic play skills (Porter, 2012). They can also help improve their
21 QoL, whether they are adults (Jordan & Caldwell-Harris, 2012) or children (Tavernor et al.,
22 2013). Focusing on strengths and interests is also recommended for good practice by many
23 countries when caring for autistic children and adolescents (NICE, 2013 for example). Access
24 to interests not only relieves negative emotions, it is intrinsically motivating for autistic
25 individuals (Grove et al., 2016). However, the positive aspects of interests can be

1 counterbalanced by certain challenges. Some interests can be deemed invasive (Author et al.,
2 2000). They can be linked to functional impairments (Turner-Brown et al., 2011) or a
3 deterioration of well-being if the interest is very intense (Grove et al., 2018). Participants in
4 this research evoked both the positive and negative aspects of interests. Finally, the majority
5 of participants expressed a particular interest for written language during childhood, which is
6 consistent with previous work demonstrating intense early interests for written material
7 among autistic children (Author et al., 2018).

8 Predictable routines are an important factor for improving the QoL of autistic children
9 (Epstein et al., 2019; Pfeiffer et al., 2016). Sudden, unanticipated changes can cause
10 challenging behaviors (Epstein et al., 2019). Even though autistic individuals may seek
11 predictability and uniformity as a way to cope with anxiety created by different perceptual
12 experiences (Ashburner et al., 2013), this search could also be related to the way they process
13 information (Goris et al., 2019). Indeed, in this study, certain accounts highlight the positive
14 affects linked to being repeatedly exposed to certain stimuli.

15 Unsurprisingly, our analysis revealed a major theme regarding perceptual differences.
16 Atypical responses to perceptual input are now considered a regular characteristic of autism
17 (Sapey-Triomphe et al., 2017; Taylor et al., 2018) and are included in diagnostic criteria
18 (APA, 2013), albeit in a simplified and unsatisfactory, “sensory” form (Author, 2019).
19 Sensory overload is a factor shown to make daily lives difficult for autistic adults
20 (McConachie, Mason et al., 2018) and children (McConachie, Livingstone et al., 2018).
21 Three qualitative studies of interviews with adults (Robertson & Simmons, 2015; Smith &
22 Sharp, 2013) and children (Kirby et al., 2015) reported that some aspects of perceptual
23 experiences can be judged as both problematic and enjoyable by autistic participants. Our
24 results also revealed both the positive and negative aspects of perceptual experiences on QoL,
25 even if our participants mostly had aversive experiences. Auditory and taste were the sensory

1 modalities most cited by participants. Auditory is also presented in the findings of the three
2 qualitative studies mentioned above. As for mouth sensitivity, Meral and Fidan (2015) show
3 food related problems could indeed be an important predictor of QoL among autistic children.
4 Finally, our results argue in favor of the hypothesis that perceptual differences are among the
5 main characteristics of autism present from an early age (Green et al., 2012; Marco et al.,
6 2011). It should not, however, be considered as summarizing the increased importance, role
7 and autonomy of autistic perception (Author, 2019).

8 Social interactions and various sub-themes constitute the last theme discovered via
9 our analysis. Autistic children enjoy spending time alone to relax or pursue their interests
10 (Epstein et al., 2019; Tavernor et al., 2013). However, this data should be interpreted with
11 caution, as solitude among autistic people can also be associated with negative emotions
12 (Mazurek, 2014). It is also difficult to know whether the quest for solitude is chosen or a
13 behavior that is forced upon them because of their autistic characteristics, especially with
14 regards to perceptual differences. Even if some aspect of perceptual input (eg: rotatory
15 objects, written codes) are actively searched for (Author et al., 2017), some other can trigger
16 avoidance and isolation (Smith & Sharp, 2013). Ashburner et al. (2013) show autistic people
17 can sometimes use avoidance to adjust to their different perceptual experiences. This can
18 generate strong feelings of anxiety. Seeking solitude could also be a way of avoiding hostile
19 social interactions.

20 Although the participants in this study present characteristics that facilitate their social
21 inclusion (no speaking impairments), hostile social interactions was identified as a sub-theme
22 in our study. Autistic children can be victims of bullying or exclusion, which can negatively
23 impact their QoL (Epstein et al., 2019). This hostility may explain the aversion of some
24 participants towards their peers, or the reason they had few friendships when they were
25 children. While being understood could make lives of autistic children and adults more

1 satisfying (Epstein et al., 2019; McConachie et al., 2018). When mothers recognize and
2 accept the special needs of their child, challenging behaviors decrease (Singh et al., 2006).
3 Bishop-Fitzpatrick et al. (2016) show a low level of "maternal criticism" to be a predictor of
4 good QoL for autistic people when they reach adulthood.

5 Even though autistic people seek solitude, we should not underestimate their desire to
6 socially connect like their typically developing peers (Egilson et al., 2019; Epstein et al.,
7 2019). Our results tend to confirm these findings also among young autistic children.
8 However, communication difficulties expressed by participants in this study can make
9 creating relationships more difficult and therefore moderate the effect of social participation
10 on their QoL (Bishop-Fitzpatrick et al., 2017). These communication difficulties are more the
11 result of reciprocal issue than an inherent deficit in the child's skills (Morisson et al., 2019;
12 Sasson et al., 2017). Difficulties could therefore be reduced during interactions with peers
13 who are themselves autistic (Heasman & Gillespie, 2019). In the end, it is likely that the
14 apparent need for solitude is endured rather than chosen among autistic children.

15 This study has several limitations. First, this study only focuses on autistic people
16 with good language skills. This prevents us from drawing conclusions about QoL for profiles
17 without oral language. Second, this research is limited by only using a hedonistic view of
18 QoL. We do not explore elements referring to a person's future, which allows them to build
19 deeper gratifications, or "eudemonism" (Gasper, 2010). It would be interesting to know how
20 an individual's short-term childhood life experiences can impact their QoL in the long term
21 (Cribb et al., 2019; Pickles et al., 2020). This distinction is important, since short-term
22 satisfaction linked to avoiding experiences can ultimately lead to the deterioration of mental
23 health (Pahnke et al., 2014). Third, the ability for young autistic children to decide what is
24 important for their QoL can be challenged (Robeyns, 2016). It is suggested that the
25 determinants of QoL of young children be discussed with the child's parents (Egilson et al.,

1 2017). Fourth, a typically developing comparison group would reveal whether QoL
2 determinants differentiate between samples (Ritchie & Lewis, 2003). Fifth, the current
3 diagnostic criteria of autism favour heterogeneity, which question the generalizability of
4 results obtain in individuals with a specific range of values of the clinical specifiers
5 “language” and “intelligence” (Author et al., 2020). Finally, elements determining life
6 satisfaction before the age of six were collected among autistic adults. The data is therefore
7 retrospective and likely to generate biases as participants were required to remember past life
8 events. Although a large majority of participants were able to focus in detail on the preschool
9 period, two participants presented difficulties answering questions about this time, and
10 focused more on their childhood in general. It should also be noted that participants with an
11 autistic child could compare themselves, which would bias their recall.

12 To obtain more reliable data, interviews could be conducted with younger autistic
13 people. In this case, it is recommended develop a partnership with parents when collecting
14 subjective perspectives from autistic youth (Teachman & Gibson, 2013) to maximize their
15 participation (Stafford, 2017). It has also been suggested to elicit information with close-
16 ended questions (Bruck et al., 2007), adapt communication style by emphasizing simple
17 language without stylistic devices (Harrington, Foster, Rodger & Ashburner, 2014), and
18 provide more meaning (Karkhaneh et al., 2010). The current study recruited and began
19 interviews with 5 verbal autistic adolescents. Despite our parents’ consultations and our
20 adaptations (e.g. preparation prior to the interviews, using close-ended questions), adolescent
21 interviews did not provide useful information related to our research question (partly due to a
22 perceived lack of motivation among participants). Consequently, we kept only the adults’
23 extracts for data analysis.

24 Future research looking at the first-person perspectives of autistic youth should using
25 other methodologies, such as those advocated by Tesfaye et al. (2019) (e.g. Talking Mats,

1 Photovoice or questionnaires). Gulec-Aslan, Ozbey & Yassibas (2013) also suggest
2 interviews should be supported by additional documents (for example, written documents by
3 mothers collecting their experiences and feelings since pregnancy). The notion that memory
4 is reconstituted suggests that the past is constantly reinvented, which underscores the
5 importance of verification (Barusch, 2011). Collecting information from multiple sources
6 appears to be a useful method to minimize recall bias among general population (Hassan,
7 2005), and to gain a comprehensive understanding of the lived experience of autistic youth
8 (Tesfaye et al., 2019). For example, triangulating interview data from parents and
9 professionals provide better understanding about the daily life of autistic youth (Preece &
10 Jordan, 2010).

11 Finally, developing a specific measure to assess the QoL of autistic preschoolers
12 should be a priority for researchers (McConachie et al., 2015). Tools for measuring the QoL
13 in the field of autism have already been developed by professionals (Billstedt et al., 2011).
14 However, the creation of such a tool should favor a participatory research strategy (Turner et
15 al., 2007) by involving autistic people (Fletcher-Watson et al., 2019; Taylor, 2017). Such an
16 approach has already been used to develop a scale to measure the QoL of adults
17 (McConachie, Mason et al., 2018) or autistic children over six (Ikeda and al., 2016). The
18 results of this paper will be used to develop specific items for a measure of QoL among
19 autistic preschoolers. The collected data will be cross-checked and completed via future
20 collaborations with parents and experts.

21 **Conclusion**

22 Despite these limits, this study offers insights on the life experiences of autistic
23 preschoolers belonging to the verbal. To our knowledge, this is the only qualitative research
24 to date focusing on aspects of life important to autistic children under the age of six. It
25 provides important updates to consider for improving their QoL, particularly by being more

1 tolerant of their different behaviors and choices. This study is part of a larger research
2 project, which aims to develop a QoL measure for autistic preschoolers, which is a current
3 priority in research (McConachie et al., 2015). Our methodology also involves consulting
4 with experts in the field, as well as parents of autistic preschoolers. Such a tool would enable
5 clinicians and researchers to evaluate the actual impact of early interventions currently
6 available on QoL.

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1 **Table 1**

2 Characteristics of studies examining the QoL of autistic preschoolers

Source	Country	Participants and comparison	a) QoL measures b) Rater	Results of QoL differences (p-value)
Azad et al 2020	USA	476 children and adolescents ¹ (5-17 years; ASD ^a)	a) PedsQL ^b 4.0 b) Parents	
Chuang et al 2014	Taiwan	36 children ¹ (36-70 months; Autism, AS ^c , or PDD-NOS ^d)	a) TNO-AZL Preschool children Quality of Life, Chinese version (TAPQOL-C) b) Parents or professionals	
Delahaye et al 2014	USA	86 children ² (4-12 years; Autism, AS, or PDD-NOS) Comparison with normative QoL data of typically developing children.	a) PedsQL 4.0 b) Parents	<0.0001 (comparison with normative sample)

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Jahan et al 2015	Bangladesh	149 children and adolescents ¹ (2-18 years, 33.6% younger than 6 years, 57% 6-12 years, 9.4% 12-18 years; ASD).	a) PedsQL 4.0 b) Mothers	
Kose et al 2013	Turkey	102 children and adolescents ² (3-18 years; Autism, AS, or PDD-NOS), Comparison group: 39 typically developing children	a) PedsQL 4.0 b) Mothers	<0.001 (comparison with TDC ^e group)
Kuhlthau et al 2010	USA	286 children and adolescents ² (2-17 years 9 months; Autism, AS, or PDD-NOS). Comparison with normative QoL data of TDC or	a) PedsQL 4.0 b) Parents	<0.001 (comparison with TDC sample) <0.001 (comparison with chronic health conditions)

1			children with	sample)	
2			chronic health		
3			conditions		
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7	Kuhlthau et al	USA	4910 children and	a) PedsQL 4.0	
8			adolescents ¹ (2-18	b) Parents	
9	2018		years; Autism,		
10			AS, or PDD-		
11			NOS). Cross-		
12			sectional and		
13			longitudinal study		
14			(2008-2015),		
15			2722 participants		
16			(follow-up 4.7		
17			years).		
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34	Meral & Fidan,	Turkey	379 children,	a) KIDSCREEN	
35			adolescents and	27-SV	
36	2015		adults ¹ (1-28	b) Mothers	
37			years; ASD)		
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43	Oztürk et al	Turkey	102 children and	a) PedsQL 4.0	<0.01
44			adolescents ² (3-18	b) Mothers	(comparison with
45	2016		years; Autism,		children with
46			AS, or PDD-		ADHD, asthma,
47			NOS) 40 children		and TDC)
48			with ADHD ^f ,		
49			without conduct		
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disorder.
44 asthmatic
children without a
psychiatric
disorder.

Comparison
group: 39 TDC

Flor et al 2017 USA 1347 children and a) PedsQL 4.0
adolescents¹, 2- b) Parents
17.5 years
(Autism
Treatment
Network, ATN).
DSM-IV
diagnosis

Sikora et al USA 3066 children and a) PedsQL 4.0
2012 adolescents¹ (2-17 b) Parents or
years 9 months, professionals
56.6% aged
between 2-5
years; Autism,
AS, or PDD-
NOS).

1 ¹ Cross-sectional Study

2 ² Comparative study

- 1 ^a Autism Spectrum Disorder (ASD)
 - 2 ^b Pediatric Quality of Life Inventory (PedsQL)
 - 3 ^c Asperger Syndrome (AS)
 - 4 ^d Pervasive Development Disorder Not Otherwise Specified (PDD-NOS)
 - 5 ^e Typically Developing Children (TDC)
 - 6 ^f Attention-Deficit/Hyperactivity Disorder (ADHD)
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Table 2

Participant characteristics

Adult	Fictitious	Age	Diagnosis	Associated	Relationship	Number	Education	Employment	Narrative
	names	Gender	Year	diagnosis	status	of	level	status	period
			Provided by			children			
1	Alan	42	ASD ^a	Dyspraxia	Divorced	1	Master	Self-employed	Preschool
		Male	2017						
			Psychiatrist						
2	Bérangère	39	ASD	/	Single	/	Bachelor	Employed	Preschool
		Female	2017						
			Psychiatrist						
3	Cecile	42	ASD	/	Partner	1	Bachelor	Employed	Preschool
		Female	2017						
			Psychiatrist						

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QUALITY OF LIFE OF CHILDREN ON THE SPECTRUM

4	Danielle	29	ASD	ADHD ^b	Partner	1	Upper	Unemployed	Preschool	
		Female	2018				secondary			
			Psychiatrist							
5	Edward	51	ASD	ADHD	Partner	2	Master	Employed	Preschool	
		Male	2017							
			Psychiatrist							
6	Felicity	46	ASD	Prosopagnosi	Partner	2	Master	Employed	Childhood	in
		Female	2018	a					general	
			Psychologist							
7	Geraldine	46	ASD	/	Divorced	4	Upper	Self-employed	Preschool	
		Female	2014				secondary			
			Psychiatrist							
8	Helene	29	AS ^c	/	Divorced	1	Upper	Self-employed	Preschool	
		Female	2010				secondary			
			Screening							
			centre							

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QUALITY OF LIFE OF CHILDREN ON THE SPECTRUM

9	Igor	42	ASD	/	Partner	1	Bachelor	Unemployed	Childhood	in
		Male	2015						general	
			Screening							
			centre							
10	John	23	AS	/	Divorced	/	Bachelor	Student	Preschool	
		Male	2010							
			Screening							
			centre							

^a Autism Spectrum Disorder (ASD)

^b Attention-Deficit/Hyperactivity Disorder (ADHD)

^c Asperger Syndrome (AS)

Table 3

Interview schedule

General question

What elements were important for your life to be satisfying when you were under the age of 6 years old? What was unsatisfactory in your life when you were under the age of 6?

Specific themes

1. Special interests: access to activities of interest or developing skills related to interests

2. Inclusion: accepting differences / level of knowledge of autism in different care services

3. Support: social partners / professional services

4. Sensory aspects

5. Predictability

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Table 4

Themes and sub-themes

1. Interests*1.1. The importance of interests**1.2. Satisfaction associated with interests**1.3. Sharing interests*

2. Social interactions*2.1. Respect specific characteristics**2.2. Solitude**2.3. Hostility**2.4. Communication difficulties**2.5. Emotional bonds**2.6. Awareness of one's differences*

3. Perceptual differences*3.1. Auditory**3.2. Visual**3.3. Mouth**3.4. Tactile**3.5. Olfactory*

4. Environmental regularity*4.1. Recurrence**4.2. Predictability*

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