Journal of Autism and Developmental Disorders (2022) 52:2098–2111
https://doi.org/10.1007/s10803-021-05097-3

ORIGINAL PAPER

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

Jérôme Lichtlé[1] · Kristopher Lamore[1] · Amandine Pedoux[1] · Naomi Downes[1] · Laurent Mottron[2] · Emilie Cappe[1]

Accepted: 16 May 2021 / Published online: 31 May 2021

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 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

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

There is no unified theoretical basis for the concept of QoL (Clark et al., 2015). Factors of QoL differ depending on authors (Feldhaus & von Ossietzky, 2015). The only consensus is that QoL is a multidimensional and subjective concept that includes personal appraisal, functional assessment, and social indicators (Schalock, 2004). Many studies use the definition of QoL proposed by the World Health Organization: "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1995, p.11).

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

Few studies have examined the QoL of autistic children under the age of six (Chuang et al., 2014). Studies assessing the QoL of autistic children do not generally distinguish between age groups (Table 1). An exception is Chuang et al. (2014), who included children aged 36–70 months. This makes it difficult to draw conclusions regarding the

✉ Emilie Cappe
emilie.cappe@u-paris.fr

[1] Université de Paris, LPPS, 92100 Boulogne-Billancourt, France

[2] Autism Center of Excellence, Hôpital Rivière Des Prairies & CIUSSS du Nord, Université de Montréal, 7070, boulevard Perras, Montréal, QC H1E1A4, Canada

Table 1 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)
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 children with chronic health conditions	a) PedsQL 4.0 b) Parents	< 0.001 (comparison with TDC sample) < 0.001 (comparison with chronic health conditions sample)
Kuhlthau et al 2018	USA	4910 children and adolescents[1] (2–18 years; Autism, AS, or PDD-NOS). Cross-sectional and longitudinal study (2008–2015), 2722 participants (follow-up 4.7 years)	a) PedsQL 4.0 b) Parents	
Meral & Fidan, 2015	Turkey	379 children, adolescents and adults[1] (1–28 years; ASD)	a) KIDSCREEN 27-SV b) Mothers	
Oztürk et al 2016	Turkey	102 children and adolescents[2] (3–18 years; Autism, AS, or PDD-NOS) 40 children with ADHD[f], without conduct disorder 44 asthmatic children without a psychiatric disorder Comparison group: 39 TDC	a) PedsQL 4.0 b) Mothers	< 0.01 (comparison with children with ADHD, asthma, and TDC)
Flor et al 2017	USA	1347 children and adolescents[1], 2–17.5 years (Autism Treatment Network, ATN). DSM-IV diagnosis	a) PedsQL 4.0 b) Parents	
Sikora et al 2012	USA	3066 children and adolescents[1] (2–17 years 9 months, 56.6% aged between 2–5 years; Autism, AS, or PDD-NOS)	a) PedsQL 4.0 b) Parents or professionals	

[1] Cross-sectional Study

[2] Comparative study

[a] Autism Spectrum Disorder (ASD)

[b] Pediatric Quality of Life Inventory (PedsQL)

[c] Asperger Syndrome (AS)

[d] Pervasive Development Disorder Not Otherwise Specified (PDD-NOS)

[e] Typically Developing Children (TDC)

[f] Attention-Deficit/Hyperactivity Disorder (ADHD)

QoL in a specific age group. However, comparative studies show that autistic preschoolers have a QoL lower than typically developing children, or children with other chronic conditions (Table 1). These studies mainly use PedsQL 4.0 to measure the QoL by interviewing the parents and not the children (Table 1). Another disadvantage of this research is the use of generic tools not adapted to the child's condition (Ayres et al., 2017; Clark et al., 2015).

The lack of data concerning the QoL of autistic preschoolers is problematic for at least two reasons. First, the variety of early interventions targeting children under the age of six has increased considerably over the past decade (French & Kennedy, 2018; Wainer et al., 2017). Currently, there exists little knowledge on whether these early interventions could be more beneficial than harmful (Bottema-Beutel et al., 2020; Dawson & Fletcher-Watson, 2021), or how they impact QoL (Pfeiffer et al., 2016; Reichow et al., 2018). This is a concern as these early years are crucial for determining many children's current and future well-being (Franchini et al. 2018). Second, criteria for assessing QoL differ depending on chronological and mental age (Eiser & Jenney, 2007; Rodary, 2000). Measures need to be specific to a child's developmental level to evaluate QoL (Nathan et al., 2004), especially among young children (Fekkes et al. 2000; Schepers et al. 2017).

When trying to assess an individual's QoL, it is important to consider how they perceive their experiences to better understand their difficulties (Turner et al., 2007). It is particularly difficult to interview very young children about their subjective experiences, regardless of whether they are typically developing (Coghill et al., 2009; Matza et al., 2004) or autistic (Hong et al. 2016; Stokes et al., 2016). We also lack reliable methodology to collect data of subjective experiences among autistic people without oral language (Tesfaye et al., 2019; Kirby et al., 2014).

It is possible to interview verbal autistic adults on their personal experiences (DePape & Lindsay, 2016). However, retrospective reports remain problematic given the reconstructive nature of the human memory (Barusch, 2011), and its unreliability (Brogger et al., 2004), which could lead to recall bias (Hassan, 2005). Among the general population, the ability to remember life events from childhood decreases with age (Lindsay et al., 2004). This bias can even be accentuated when remembering stressful events (Colman et al., 2016). The explicit memory of autistic people seems to be preserved, however memory skills for personal memories involving emotions are also likely to be impaired (Ullman & Pullman, 2015). Autistic people may present an altered autobiographical memory regardless of their age (Bruck, London, Landa & Goodman, 2007). However, retrospective studies are best suited for constructing the sequences of significant events (de Vaus, 2011). Qualitative studies using long-term retrospective recalls generally provide a similar quality of reports than those provided by short-term recalls (Beckett et al., 2001). Furthermore, salient retrospective life history data does not appear to produce bias (Jivraj et al., 2020). Validity of retrospective recall of autistic adults' interviews may be preserved given that this population is able to express their feelings or personally significant past events using highly specific facts and detail (Zukauskas et al., 2009). The proficient memory skills of these individuals can also facilitate first-person accounts of their childhood experiences (Volkmar & Cohen, 1985).

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

Method

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

Recruitment and Participants Eligibility

Recruitment was carried out on a voluntary basis using clinical partners, charities, care services and centers specialized in autism located in the Paris region of France. Gradually recruitment via social networks was also implemented. Recruitment ceased when we reached data saturation (Blanchet & Gotman, 2010).

This study was proposed to adults with a diagnosis of ASD or Asperger Syndrome, according to international classifications (DSM-IV-TR, DSM-5 or ICD-10). Participants who were not able to write and speak in French were not included in this study. 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.

Sample Characteristics

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

Table 2 Participant characteristics

Adult	Fictitious names	Age Gender	Diagnosis Year Provided by	Associated diagnosis	Relationship status	Number of children	Education level	Employment status	Narrative period
1	Alan	42 Male	ASD[a] 2017 Psychiatrist	Dyspraxia	Divorced	1	Master	Self-employed	Preschool
2	Bérangère	39 Female	ASD 2017 Psychiatrist	/	Single	/	Bachelor	Employed	Preschool
3	Cecile	42 Female	ASD 2017 Psychiatrist	/	Partner	1	Bachelor	Employed	Preschool
4	Danielle	29 Female	ASD 2018 Psychiatrist	ADHD [b]	Partner	1	Upper secondary	Unemployed	Preschool
5	Edward	51 Male	ASD 2017 Psychiatrist	ADHD	Partner	2	Master	Employed	Preschool
6	Felicity	46 Female	ASD 2018 Psychologist	Prosopagnosia	Partner	2	Master	Employed	Childhood in general
7	Geraldine	46 Female	ASD 2014 Psychiatrist	/	Divorced	4	Upper secondary	Self-employed	Preschool
8	Helen	29 Female	AS[c] 2010 Screening centre	/	Divorced	1	Upper secondary	Self-employed	Preschool
9	Igor	42 Male	ASD 2015 Screening centre	/	Partner	1	Bachelor	Unemployed	Childhood in general
10	John	23 Male	AS 2010 Screening centre	/	Divorced	/	Bachelor	Student	Preschool

[a] Autism Spectrum Disorder (ASD)

[b] Attention-Deficit/Hyperactivity Disorder (ADHD)

[c] Asperger Syndrome (AS)

Procedure

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

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

We conducted semi-structured interviews, which is the most widely used method to collect first-person perspectives of autistic individuals (DePape & Lindsay, 2016). Firstly, participants were asked a general question about important elements that made life satisfying or unsatisfying before the age of 6 (Table 3). Secondly, the interviewer explored themes specific to autism developed from the literature (Table 3) if they were not addressed spontaneously (Romelear, 2005). Questions were adapted specifically to each participant depending on the words they used during the interview. Nevertheless, the same topics were addressed among all participants. According to Feldhaus and von Ossietzky (2015), using the term "life satisfaction" renders the concept of QoL more understandable for verbal autistic people. We therefore favored sentences such as "what elements were important to make your life satisfying when you were younger than 6 years old" / "what was not satisfying in

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
Special interests: access to activities of interest or developing skills related to interests
Inclusion: accepting differences / level of knowledge of autism in different care services
Support: social partners / professional services
Sensory aspects
Predictability

your life when you were under the age of 6". If participants had difficulty answering questions, we specified the following: "If you have difficulty remembering your life before the age of 6, it does not matter, just think about your childhood in general". However, during the interviews, participants were reminded of the importance of trying to remember life events from the preschool period. Interview instructions were pre-tested among two participants. They said instructions were clear and one of them requested questions to be repeated to ensure he understood what was expected of him.

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

Analysis

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

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

Results

Themes

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

Theme 1: Interests

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

Table 4 Themes and sub-themes

Interests
The importance of interests
Satisfaction associated with interests
Sharing interests
Social interactions
Respect specific characteristics
Solitude
Hostility
Communication difficulties
Emotional bonds
Awareness of one's differences
Perceptual differences
Auditory
Visual
Mouth
Tactile
Olfactory
Environmental regularity
Recurrence
Predictability

The Importance of Interests Nine participants frequently sought their interests or devoted themselves to them, as illustrated by this extract from Felicity's interview: "I had a specific interest in dogs, wolves and I like to collect cards; I know all about dog breeds (…) I was completely focused on it".

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

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

Theme 2: Social Interactions

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

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

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

Hostility Seven participants experienced hostile behaviors from their entourage and emotional responses. This could include physical or emotional abuse, feeling judged, mockery or rejection. Feeling excluded was reported by six participants. Danielle referred to her experience of rejection as: "The impression of being rejected, that was very difficult. Even with other children, sometimes it was very hard for me, very, very hard. And sometimes when I came back from school, I cried because it had gone wrong, because I had been rejected, it was very hard, it was difficult to experience".

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

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

Theme 3: Perceptual Differences

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

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

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

Mouth Sensitivity Six participants mentioned sensitivity to food or non-food items textures or taste. Avoidant behaviors to food were mentioned by six participants, as Bérangère explains: "I had big problems with the texture of certain foods (…). I preferred to go up to my room, go back to school hungry, but there were things that just didn't agree with me. You could leave me at the table until everyone was gone, I would resist until the end". One participant presented a sensory need to chew materials throughout childhood: "I was often searching for sensations, I also needed to chew things (…). I tended to, and still tend to, suck things (…). It's true that at the time it was mostly clothes, but it was a little bit of everything, it could go as far as cardboard" (Igor).

Tactile Perception Five participants testified to the unpleasantness of being touched by other people. This is what Bérangère told us: "I had very long hair at the time, I cried every day when my mother combed my hair because it wasn't nice, nobody could touch my hair".

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

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

Theme 4: Environmental Regularity

This last theme refers to the regularity of behaviors, life events, or the participant's environment. Expressed by all ten participants as either habits, rituals, or reference points. Two sub-themes specify how this regularity could be important for the participant's life satisfaction before the age of six:

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

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

Discussion

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

In general, QoL measures should account for an individual's concerns (WHOQOL Group, 1995) and interests (Schalock & Parmenter, 2000). Compared to typically developing individuals, autistic people are particularly motivated to engage in their interests (Anthony et al., 2013). This is strongly correlated to positive affects (Grove et al., 2016), such as well-being (Author et al., 2000), enthusiasm, pride or joy (Winter-Messiers, 2007). Interests among autistic people promote social inclusion (Plimley, 2007), help them develop academic skills (Wood, 2019), or symbolic play skills (Porter, 2012). They can also help improve their QoL, whether they are adults (Jordan & Caldwell-Harris, 2012) or children (Tavernor et al., 2013). Focusing on strengths and interests is also recommended for good practice by many countries when caring for autistic children and adolescents

(NICE, 2013 for example). Access to interests not only relieves negative emotions, it is intrinsically motivating for autistic individuals (Grove et al., 2016). However, the positive aspects of interests can be counterbalanced by certain challenges. Some interests can be deemed invasive (Mercier et al., 2000). They can be linked to functional impairments (Turner-Brown et al., 2011) or a deterioration of well-being if the interest is very intense (Grove et al., 2018). Participants in this research evoked both the positive and negative aspects of interests. Finally, the majority of participants expressed a particular interest for written language during childhood, which is consistent with previous work demonstrating intense early interests for written material among autistic children (Jacques et al., 2018).

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

Unsurprisingly, our analysis revealed a major theme regarding perceptual differences. Atypical responses to perceptual input are now considered a regular characteristic of autism (Sapey-Triomphe et al., 2017; Taylor et al., 2018) and are included in diagnostic criteria (APA, 2013), albeit in a simplified and unsatisfactory, “sensory” form (Mottron, 2019). Sensory overload is a factor shown to make daily lives difficult for autistic adults (McConachie, Livingstone, et al., 2018; McConachie, Mason, et al., 2018) and children (McConachie, Livingstone, et al., 2018; McConachie, Mason, et al., 2018). Three qualitative studies of interviews with adults (Robertson & Simmons, 2015; Smith & Sharp, 2013) and children (Kirby et al., 2015) reported that some aspects of perceptual experiences can be judged as both problematic and enjoyable by autistic participants. Our results also revealed both the positive and negative aspects of perceptual experiences on QoL, even if our participants mostly had aversive experiences. Auditory and taste were the sensory modalities most cited by participants. Auditory is also presented in the findings of the three qualitative studies mentioned above. As for mouth sensitivity, Meral and Fidan (2015) show food related problems could indeed be an important predictor of QoL among autistic children. Finally, our results argue in favor of the hypothesis that perceptual differences are among the main characteristics of autism present from an early age (Green et al., 2012; Marco et al., 2011). It should not, however, be considered as summarizing the increased importance, role and autonomy of autistic perception (Mottron, 2019).

Social interactions and various sub-themes constitute the last theme discovered via our analysis. Autistic children enjoy spending time alone to relax or pursue their interests (Epstein et al., 2019; Tavernor et al., 2013). However, this data should be interpreted with caution, as solitude among autistic people can also be associated with negative emotions (Mazurek, 2014). It is also difficult to know whether the quest for solitude is chosen or a behavior that is forced upon them because of their autistic characteristics, especially with regards to perceptual differences. Even if some aspect of perceptual input (eg: rotatory objects, written codes) are actively searched for (Jacques et al., 2018), some other can trigger avoidance and isolation (Smith & Sharp, 2013). Ashburner et al. (2013) show autistic people can sometimes use avoidance to adjust to their different perceptual experiences. This can generate strong feelings of anxiety. Seeking solitude could also be a way of avoiding hostile social interactions.

Although the participants in this study present characteristics that facilitate their social inclusion (no speaking impairments), hostile social interactions was identified as a sub-theme in our study. Autistic children can be victims of bullying or exclusion, which can negatively impact their QoL (Epstein et al., 2019). This hostility may explain the aversion of some participants towards their peers, or the reason they had few friendships when they were children. While being understood could make lives of autistic children and adults more satisfying (Epstein et al., 2019; McConachie, Livingstone, et al., 2018; McConachie, Mason, et al., 2018). When mothers recognize and accept the special needs of their child, challenging behaviors decrease (Singh et al., 2006). Bishop-Fitzpatrick et al. (2016) show a low level of "maternal criticism" to be a predictor of good QoL for autistic people when they reach adulthood.

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

This study has several limitations. First, this study only focuses on autistic people with good language skills. This prevents us from drawing conclusions about QoL for profiles without oral language. Second, this research is limited by only using a hedonistic view of QoL. We do not explore elements referring to a person's future, which allows them to build deeper gratifications, or "eudemonism" (Gasper, 2010). It would be interesting to know how an individual's short-term childhood life experiences can impact their QoL in the long term (Cribb et al., 2019; Pickles et al., 2020). This distinction is important, since short-term satisfaction linked to avoiding experiences can ultimately lead to the deterioration of mental health (Pahnke et al., 2014). Third, the ability for young autistic children to decide what is important for their QoL can be challenged (Robeyns, 2016). It is suggested that the determinants of QoL of young children be discussed with the child's parents (Egilson et al., 2017). Fourth, a typically developing comparison group would reveal whether QoL determinants differentiate between samples (Ritchie & Lewis, 2003). Fifth, the current diagnostic criteria of autism favour heterogeneity, which question the generalizability of results obtain in individuals with a specific range of values of the clinical specifiers "language" and "intelligence" (Mottron & Bzdok, 2020). Finally, elements determining life satisfaction before the age of six were collected among autistic adults. The data is therefore retrospective and likely to generate biases as participants were required to remember past life events. Although a large majority of participants were able to focus in detail on the preschool period, two participants presented difficulties answering questions about this time, and focused more on their childhood in general. It should also be noted that participants with an autistic child could compare themselves, which would bias their recall.

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

Future research looking at the first-person perspectives of autistic youth should use other methodologies, such as those advocated by Tesfaye et al. (2019) (e.g. Talking Mats, Photovoice or questionnaires). Gulec-Aslan, Ozbey & Yassibas (2013) also suggest interviews should be supported by additional documents (for example, written documents by mothers collecting their experiences and feelings since pregnancy). The notion that memory is reconstituted suggests that the past is constantly reinvented, which underscores the importance of verification (Barusch, 2011). Collecting information from multiple sources appears to be a useful method to minimize recall bias among the general population (Hassan, 2005), and to gain a comprehensive understanding of the lived experience of autistic youth (Tesfaye et al., 2019). For example, triangulating interview data from parents and professionals provide better understanding about the daily lives of autistic youth (Preece & Jordan, 2010).

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

Conclusion

Despite these limits, this study offers insights on the life experiences of autistic preschoolers. To our knowledge, this is the only qualitative research to date focusing on aspects of life important to autistic children under the age of six. It provides important updates to consider for improving their QoL, particularly by being more tolerant of their different behaviors and choices. This study is part of a larger research project that aims to develop a QoL measure for autistic preschoolers, which is a current priority in research (McConachie et al., 2015). Our methodology also involves consulting with experts in the field, as well as parents of autistic preschoolers. Such a tool would enable clinicians and researchers to evaluate the actual impact of early interventions currently available on QoL.

Acknowledgements The authors would like to thank all the study participants (autistic people and parents), and Zoé Chiron, psychology intern, who participated in the transcription of the interviews.

Author Contributions JL, the principal investigator of the study, recruited participants, collected data and participated in writing and

proofreading the article. KL participated in the data processing, analysis and writing the article. AP participated in the data processing and analysis. ND participated in writing and proofreading the article. LM participated in proofreading the article; he is the co-supervisor of Jérôme Lichtlé's doctoral thesis. EC participated in the data processing, analysis and writing the article; she is the supervisor of Jérôme Lichtlé's doctoral thesis.

Funding This research had no funding, it was conducted as part of a PhD thesis.

Declarations

Conflict of interest The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication for this article.

References

Adams, D., Clark, M., & Simpson, K. (2019). The relationship between child anxiety and the quality of life of children, and parents of children, on the autism spectrum. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-019-03932-2

American Psychological Association. (2001). *Publication manual of the American Psychological Association* (5th ed.). . APA.

Anthony, L. G., Kenworthy, L., Yerys, B. E., Jankowski, K. F., James, J. D., Harms, M. B., & Wallace, G.L. . (2013). Interests in high-functioning autism are more intense, interfering, and idiosyncratic, but not more circumscribed, than those in neurotypical development. *Development and Psychopathology, 25*(3), 643–652. https://doi.org/10.1017/S0954579413000072

Ashburner, J., Bennett, L., Rodger, S., & Ziviani, J. (2013). Understanding the sensory experiences of young people with autism spectrum disorder: A preliminary investigation. *Australian Occupational Therapy Journal, 60*(3), 171–180. https://doi.org/10.1111/1440-1630.12025

Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2017). A systematic review of quality of life of adults on the autism spectrum. *Autism, 22*(7), 774–783. https://doi.org/10.1177/1362361317714988

Azad, G. F., Dillon, E., Feuerstein, J., Kalb, L., Neely, J., & Landa, R. (2020). Quality of life in school-aged youth referred to an autism specialty clinic: a latent profile analysis. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-019-04353-x

Barusch, A. S. (2011). New understanding of memory poses challenges for retrospective research. *Journal of Gerontological Social Work, 54*, 751–754. https://doi.org/10.1080/01634372.2011.633481

Beckett, M., Da Vanzo, J., Sastry, N., Panis, C., & Peterson, C. (2001). The quality of retrospective data: an examination of long-term recall in a developing country. *The Journal of Human Resources, 36*(3), 593–625. https://doi.org/10.2307/3069631

Bertelli, L., Piva Merli, M., Rossi, M., Lassi, S., Bianco, A., & Colangelo, J. (2013). Quality of life in pharmacological intervention on autism spectrum disorders. *Advances in Mental Health and Intellectual Disabilities, 7*(1), 40–48. https://doi.org/10.1108/20441281311294684

Bieleninik, L., Posserud, M. B., Geretsegger, M., Thompson, G., Elefant, C., & Gold, C. (2017). Tracing the temporal stability of autism spectrum diagnosis and severity as measured by the Autism Diagnostic Observation Schedule: A systematic review and meta-analysis. *PLoS ONE*. https://doi.org/10.1371/journal.pone.0183160

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood a population-based study. *Autism, 15*(1), 7–20. https://doi.org/10.1177/1362361309346066

Bishop-Fitzpatrick, L., DaWalt, L. S., Greenberg, J. S., & Mailick, M. R. (2017). Participation in recreational activities buffers the impact of perceived stress on quality of life in adults with autism spectrum disorder. *Autism Research, 10*(5), 973–982. https://doi.org/10.1002/aur.1753

Bishop-Fitzpatrick, L., Hong, J., Smith, L. E., Makuch, R. A., Greenberg, J. S., & Mailick, M. R. (2016). Characterizing objective quality of life and normative outcomes in adults with autism spectrum disorder: an exploratory latent class analysis. *Journal of Autism and Developmental Disorders, 46*(8), 2707–2719. https://doi.org/10.1007/s10803-016-2816-3

Blanchet, A., & Gotman, A. (2010). *L'entretien: L'enquête et ses méthodes* [The interview: Survey and methods]. Paris, France: Amand Colin.

Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2020). Research Review: Conflicts of Interest (COIs) in autism early intervention research–a meta-analysis of COI influences on intervention effects. *Journal of Child Psychology and Psychiatry*. https://doi.org/10.1111/jcpp.13249

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brogger, J., Eagan, T., Eide, G. E., Bakke, P., & Gulsvik, A. (2004). Bias in retrospective studies of trends in asthma incidence. *European Respiratory Journal, 23*, 281–286. https://doi.org/10.1183/09031936.03.00041103

Bruck, L., & Landa & Goodman, . (2007). Autobiographical memory and suggestibility in children with autism spectrum disorder. *Development and Psychopathology, 19*, 73–95.

Chiang, H. M., & Wineman, I. (2014). Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders, 8*(8), 974–986. https://doi.org/10.1016/j.rasd.2014.05.003

Chuang, I. C., Tseng, M. H., Lu, Lu., Shieh, J. Y., & Cermak, S. A. (2014). Predictors of the health-related quality of life in preschool children with Autism spectrum disorders. *Research in Autism Spectrum Disorder, 8*(9), 1062–1070. https://doi.org/10.1016/j.rasd.2014.05.015

Clark, B. G., Magill-Evans, J. E., & Koning, C. J. (2015). Youth With Autism Spectrum Disorders: Self- and Proxy-Reported Quality of Life and Adaptive Functioning. *Focus on Autism and Other Developmental Disabilities, 30*(1), 57–64. https://doi.org/10.1177/1088357614522289

Coghill, D., Danckaerts, M., Sonuga-Barke, E., Sergeant, J., & The ADHD European Guidelines Group. (2009). Practitioner review: Quality of life in child mental health—conceptual challenges and practical choices. *Journal of Child Psychology and Psychiatry, 50*(5), 544–561. https://doi.org/10.1111/j.1469-7610.2009.02008.x

Colman, I., Kingsbury, M., Garad, Y., Zeng, Y., Naicker, K., Patten, S., & Thompson, A. H. (2016). Consistency in adult reporting of adverse childhood experiences. *Psychological Medicine, 46*(3), 543–549. https://doi.org/10.1017/S0033291715002032

Cribb, S., Kenny, L., & Pellicano, E. (2019). 'I definitely feel more in control of my life': The perspectives of young autistic people and their parents on emerging adulthood. *Autism, 23*(7), 1765–1781. https://doi.org/10.1177/1362361319830029

Dawson, M. & Fletcher-Watson, S. (2021). Commentary: What conflicts of interest tell us about autism intervention research—a commentary on Bottema-Beutel et al. (2020). *Journal of Child*

Psychology and Psychiatry, *62*(1), 16–18. https://doi.org/10.1111/jcpp.13315

de Vaus, D. (2011). Retrospective Study. In V. Jupp (dir.), *The SAGE Dictionary of Social Research Methods* (p. 269–270). London : SAGE Publications.

Delahaye, J., Kovacs, E., Sikora, D., Hall, T. A., Orlich, F., Clemons, T. E., & …Kuhlthau, K. . (2014). The relationship between Health-Related Quality of Life and sleep problems in children with Autism Spectrum Disorder. *Research in Autism Spectrum Disorder, 8*(3), 292–303. https://doi.org/10.1016/j.rasd.2013.12.015

DePape, A. M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities, 31*(1), 60–71. https://doi.org/10.1177/1088357615587504

Deserno, M. K., Borsboom, D., Begeer, S., Agelink van Rentergem, J. A., Mataw, K., & Geurts, H. M. (2019). Sleep determines quality of life in autistic adults: A longitudinal study. *Autism Research, 12*(5), 794–801. https://doi.org/10.1002/aur.2103

Deserno, M. K., Borsboom, D., Begeer, S., & Geurts, H. M. (2017). Multicausal systems ask for multicausal approaches: A network perspective on subjective well-being in individuals with autism spectrum disorder. *Autism, 21*(8), 960–971.

Egilson, S. T., Ólafsdóttir, L. B., Leósdóttir, T., & Saemundsen, E. (2017). Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: Self-and proxy-reports. *Autism, 2*(2), 133–141. https://doi.org/10.1177/1362361316630881

Eiser, C., & Jenney, M. (2007). Measuring quality of life. *Archives of Disease in Childhood, 92*(4), 348–350. https://doi.org/10.1136/adc.2005.086405

Epstein, A., Whitehouse, A., Williams, K., Murphy, N., Leonard, H., Davis, E., & Downs, J. . (2019). Parent-observed thematic data on quality of life in children with autism spectrum disorder. *Autism, 23*(1), 71–80. https://doi.org/10.1177/1362361317722764

Fekkes, M., Theunissen, N. C. M., Brugman, E., Veen, S., Verrips, E. G. H., Koopman, H. M., & …Verloove-Vanhorick, S.P. . (2000). Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1–5-year-old children. *Quality of Life Research, 9*(8), 961–972. https://doi.org/10.1023/a:1008981603178

Feldhaus, C., & von Ossietzky, C. (2015). Quality of life - development of an assessment for people with autism. *Psychology Research, 5*(5), 327–337.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., & …Pellicano, E. . (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Flor, J., Bellando, J., Lopez, M., & Shui, A. (2017). Developmental Functioning and Medical Co-morbidity Profile of Children with Complex and Essential. *Autism Research, 10*(8), 1344–1352. https://doi.org/10.1002/aur.1779

Franchini, M., Zöller, D., Gentaz, E., Glaser, B., Wood de Wilde, H. Kojovic, N., Schaer, M. (2018). Early adaptive functioning trajectories in preschoolers with autism spectrum disorders. *Journal of Pediatric Psychology, 43*(7), 800–813. https://doi.org/10.1093/jpepsy/jsy024

French, L., & Kennedy, E. M. M. (2018). Annual Research Review: Early intervention for infants and young children with, or at-risk of, autism spectrum disorder: a systematic review. *Journal of Child Psychology and Psychiatry, 59*(4), 444–456. https://doi.org/10.1111/jcpp.12828

Gasper, D. (2010). Understanding the diversity of conceptions of well-being and quality of life. *Journal of Behavioral and Experimental Economics, 39*(3), 351–360. https://doi.org/10.1016/j.socec.2009.11.006

Goris, J., Brass, M., Cambier, C., Delplanque, J., Wiersema, J. R., & Braem, S. (2019). The relation between preference for predictability and autistic traits. *Autism Research*. https://doi.org/10.1002/aur.2244

Green, S. A., Ben-Sasson, A., Soto, T. W., & Carter, A. S. (2012). Anxiety and sensory over-responsivity in toddlers with autism spectrum disorders: Bidirectional effects across time. *Journal of Autism and Developmental Disorders, 42*(6), 1112–1119. https://doi.org/10.1007/s10803-011-1361-3

Grove, R., Hoekstra, R. A., Wierda, M., & Begeer, S. (2018). Special Interests and Subjective Wellbeing in Autistic Adults. *Autism Research, 11*(5), 766–775. https://doi.org/10.1002/aur.1931

Grove, R., Roth, I., & Hoekstra, R. A. (2016). The motivation for special interests in individuals with autism and controls: Development and validation of the special interest motivation scale. *Autism Research, 9*(6), 677–688. https://doi.org/10.1002/aur.1560

Gulec-Aslan, Y., Ozbey, F., & Yassibas, U. (2013). "I have lived an autism experience. Autism is an interesting disease": The life story of a young man with autism. *International Education Studies, 6*(1), 74–84.

Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2014). Engaging young people with autism spectrum disorder in research interviews. *British Journal of Learning Disabilities, 42*, 153–161. https://doi.org/10.1111/bld.12037

Hassan, E. (2005). Recall bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology*. https://doi.org/10.5580/2732

Heasman, B., & Gillespie, A. (2019). Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism, 23*(4), 910–921. https://doi.org/10.1177/1362361318785172

Hong, J., Bishop-Fitzpatrick, L., Smith, L., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report vs. maternal reports. *Journal of Autism and Developmental Disorders, 46*(4), 1368–1378.

Ikeda, E., Hinckson, E., & Krägeloh, C. (2014). Assessment of quality of life in children and youth with autism spectrum disorder: a critical review. *Quality of Life Research, 23*(4), 1069–1085. https://doi.org/10.1007/s11136-013-0591-6

Ikeda, E., Krägeloh, C., Water, T., & Hinckson, E. A. (2016). An exploratory study of self-reported quality of life in children with autism spectrum disorder and intellectual disability. *Child Indicators Research, 9*(1), 133–153.

Jacques, C., Courchesne, V., Meilleur, A. A. S., Mineau, S., Ferguson, S., Cousineau, S., … Mottron, L. (2018). What interests young autisticchildren? An exploratory study of object exploration and repetitive behavior. *PLoS ONE*. https://doi.org/10.1371/journal.pone.0209251

Jahan, M. U., Karim, M. R., Rahman, A., & Akhter, S. (2015). Cognitive functions and health related quality of life of institutional autism spectrum disorder children in Dhaka city. *Bangladesh Medical Researsh Council Bulletin, 41*(3), 151–159.

Jivraj, S., Goodman, A., Ploubidis, G. B., & Oliveira, C. D. (2020). Testing comparability between retrospective life history data and prospective birth cohort study data. *Journals of Gerontology: Social Sciences, 75*(1), 207–217. https://doi.org/10.1093/geronb/gbx042

Jordan, C. J., & Caldwell-Harris, C. L. (2012). Understanding differences in neurotypical and autism spectrum special interests through internet forums. *Intellectual and Developmental*

Disabilities, 50(5), 391–402. https://doi.org/10.1352/1934-9556-50.5.391

Karkhaneh, M., Clark, B., Ospina, M. B., Seida, J. C., Smith, V., & Hartling, L. (2010). Social Stories^{TM} to improve social skills in children with autism spectrum disorder: A systematic review. *Autism, 14*, 641–662. https://doi.org/10.1177/1362361310373057

Kirby, A. V., Dickie, V. A., & Baranek, G. T. (2014). Sensory experiences of children with autism spectrum disorder: In their own words. *Autism, 19*(3), 316–326. https://doi.org/10.1177/1362361314520756

Knüppel, A., Telléus, G. K., Jakobsen, H., & Lauritsen, M. B. (2018). Quality of life in adolescents and adults with autism spectrum disorder: Results from a nationwide Danish survey using self-reports and parental proxy-reports. *Research in Developmental Disabilities, 83*, 247–259. https://doi.org/10.1016/j.ridd.2018.09.004

Kose, S., Erermis, S., Ozturk, O., & Aydin, C. (2013). Health Related Quality of Life in children with Autism Spectrum Disorders: The clinical and demographic related factors in Turkey. *Research in Autism Spectrum Disorder, 7*(2), 213–220. https://doi.org/10.1016/j.rasd.2012.09.009

Kuhlthau, K. A., McDonnell, E., Coury, D. L., Payakachat, N., & Macklin, E. (2018). Associations of quality of life with health-related characteristics among children with autism. *Autism, 22*(7), 804–813. https://doi.org/10.1177/1362361317704420

Kuhlthau, K., Orlich, F., Hall, T. A., Siroka, D., Kovacs, D., & J., & Clemons, T. E. . (2010). Health-Related Quality of Life in children with autism spectrum disorders: results from the autism treatment network. *Journal of Autism and Developmental Disorders, 40*(6), 721–729. https://doi.org/10.1007/s10803-009-0921-2

Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R. C., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism*. https://doi.org/10.1177/1362361320908107

Lindsay, D. S., Wade, K. A., Hunter, M. A., & Read, J. D. (2004). Adults' memories of childhood: Affect, knowing, and remembering. *Memory, 12*(1), 27–43.

MacPhail, C., Khoza, N., Abler, L., & Ranganathan, M. (2016). Process guidelines for establishing Intercoder Reliability in qualitative studies. *Qualitative Research, 16*(2), 198–212. https://doi.org/10.1177/1468794115577012

Marco, E. J., Hinkley, L. B. N., Hill, S. S., & Nagarajan, S. S. (2011). Sensory processing in autism: a review of neurophysiologic findings. *Pediatric Research*. https://doi.org/10.1203/PDR.0b013e3182130c54

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research, 11*(8), 1138–1147. https://doi.org/10.1002/aur.1965

Matza, L. S., Swensen, A. R., Flood, E. M., Secnik, K., & Leidy, N. K. (2004). Assessment of health-related quality of life in children: A review of conceptual, methodological, and regulatory issues. *Value in Health, 7*(1), 79–92.

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism, 18*(3), 223–232. https://doi.org/10.1177/1362361312474121

McConachie, H., Livingstone, N., Morris, C., Beresford, B., Le Couteur, A., Gringras, P., & Parr, J. R. . (2018). Parents suggest which indicators of progress and outcomes should be measured in young children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(4), 1041–1051. https://doi.org/10.1007/s10803-017-3282-2

McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental Disorders, 48*(5), 1596–1611. https://doi.org/10.1007/s10803-017-3402-z

McConachie, H., Parr, J. R., Glod, M., Hanratty, J., Livingstone, N., Oono, I. P., & Williams, K. . (2015). Systematic review of tools to measure outcomes for young children with autism spectrum disorder. *Health Technology Assessment, 19*(41), 1–538. https://doi.org/10.3310/hta19410

Meral, B. F., & Fidan, A. (2015). Measuring the impact of feeding covariates on health-related quality of life in children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 10*, 124–130. https://doi.org/10.1016/j.rasd.2014.11.009

Mercier, C., Mottron, L., & Belleville, S. (2000). A psychosocial study on restricted interests in high-functioning persons with pervasive developmental disorders. *Autism, 4*(4), 406–425.

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*(6), 1830–1837. https://doi.org/10.1007/s10803-017-3105-5

Mottron, L. (2019). Detrimental "Sensitivity" framework misses the positive performance role and autonomy of autistic perception.*Cognitive Neuroscience, 10*(3), 168–169. https://doi.org/10.1080/17588928.2019.1596073

Mottron, L., & Bzdok, D. (2020). Autism spectrum heterogeneity: fact or artifact? *Molecular Psychiatry, 25*, 3178—3185. https://doi.org/10.1038/s41380-020-0748-y

Nathan, P. C., Furlong, W., & Barr, R. D. (2004). Challenges to the measurement of health-related quality of life in children receiving cancer therapy. *Pediatric Blood and Cancer, 43*(3), 215–223.

National Institute for Health and Care Excellence (NICE) (2013). *Autism: the management and support of children and young people on the autism spectrum*. London, Great Britain: National Institute for Health and Care Excellence.

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for Reporting Qualitative Research: A Synthesis of Recommendations. *Academic Medicine, 89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

Oztürk, O., Erermis, S., Ercan, E. S., Gülen, F., Kabukçu Basai, B., & Basai, …Aydin, C. . (2016). Does the quality of life in autism spectrum disorder differ from other chronic disorders and healthy children? *Anadolu Psikiyatri Derg, 17*(5), 419–426. https://doi.org/10.5455/apd.185269

Pahnke, J., Lundgren, T., Hursti, T., & Hirvikoski, T. (2014). Outcomes of an acceptance and commitment therapy-based skills training group for students with high-functioning autism spectrum disorder: A quasi-experimental pilot study. *Autism, 18*(8), 953–964. https://doi.org/10.1177/1362361313501091

Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Norton, A., Thomas, E. E., & Guastella, A.J. . (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. *Autism, 23*(7), 1675–1686. https://doi.org/10.1177/1362361318823925

Pfeiffer, B., Piller, A., Giazzoni-Fialko, T., & Chainani, A. (2016). Meaningful outcomes for enhancing quality of life for individuals with autism spectrum disorder. *Journal of Intellectual & Developmental Disability, 42*(1), 90–100. https://doi.org/10.3109/13668250.2016.1197893

Plimley, L. A. (2007). A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities, 35*, 205–213. https://doi.org/10.1111/j.1468-3156.2007.00448.x

Porter, N. (2012). Promotion of pretend play for children with high-functioning autism through the use of circum- scribed interests. *Early Childhood Education Journal, 40*, 161–167.

Preece, D., & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. *British Journal of Learning Disabilities, 38*, 10–20. https://doi.org/10.1111/j.1468-3156.2009.00548.x

Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD009260.pub3

Ritchie, J., & Lewis, J. (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. SAGE Publications.

Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception, 44*(5), 569–586.

Robeyns, I. (2016). Conceptualising well-being for autistic persons. *Journal of Medical Ethics, 42*, 383–390. https://doi.org/10.1136/medethics-2016-103508

Rodary, C. (2000). Méthodologie d'étude de la qualité de vie chez l'enfant en recherche clinique [Methodology for studying the quality of life among children in clinical research]. *Archives De Pédiatrie, 7*(2), 230–232. https://doi.org/10.1016/S0929-693X(00)80049-4

Romelaer, P. (2005). L'entretien de recherche [Research interview]. In P. Roussel et F. Wacheux (dir.), *Management des ressources humaines* [Managing human resources] (p. 101–137). Paris, France : De Boeck Supérieur.

Sandbank, M., Bottema-Beutel, K., Crowley, S., Cassidy, M., Dunham, K., Feldman, J. I., & …Woynaroski, T. G. . (2020). Project AIM: Autism intervention meta-analysis for studies of young children. *Psychological Bulletin, 146*(1), 1–29. https://doi.org/10.1037/bul0000215

Sapey-Triomphe, L. A., Moulin, M., Sonie, S., & Schmitz, C. (2017). The glasgow sensory questionnaire: validation of a french language version and refinement of sensory profiles of people with high autism-spectrum quotient. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-017-3422-8

Sasson, N., Faso, D., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, D. P. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports*. https://doi.org/10.1038/srep40700

Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research, 48*, 203–216. https://doi.org/10.1111/j.1365-2788.2003.00558.x

Schalock, R. L., & Parmenter, T. (2000). Preface in quality of life: Its conceptualisation, measurement and application. In M. Rapley (Ed.), *Quality of Life research : A critical introduction* (pp. 11–16). Sage.

Schepers, S. A., van Oers, H. A., Maurice-Stam, H., Huisman, J., Verhaak, C. M., Grootenhuis, M. A., & Haverman, L. (2017). Health related quality of life in Dutch infants, toddlers, and young children. *Health and Quality of Life Outcomes*. https://doi.org/10.1186/s12955-017-0654-4

Sikora, D. M., Vora, P., Coury, D. L., & Rosenberg, D. (2012). Attention-deficit/hyperactivity disorder symptoms, adaptive functioning, and quality of life in children with autism spectrum disorder. *Pediatrics, 130*(2), 91–97. https://doi.org/10.1542/peds.2012-0900G

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Fisher, B. C., Wahler, R. G., & McAleavey, …Sabaawi, M. . (2006). Mindful Parenting Decreases Aggression, Noncompliance, and Self-Injury in Children With Autism. *Journal of Emotional and Behavioral Disorders, 14*(3), 169–177. https://doi.org/10.1177/10634266060140030401

Smith, R. S., & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome. *Journal of Autism and Developmental Disorders, 43*(4), 891–910. https://doi.org/10.1007/s10803-012-1633-6

Stafford, L. (2017). "What about my voice": Emancipating the voices of children with disabilities through participant-centred methods. *Children's Geographies, 15*, 600–613. https://doi.org/10.1080/14733285.2017.1295134

Stokes, M. A., Kornienko, L., Scheeren, A. M., Koot, H. M., & Begeer, S. (2016). A comparison of children and adolescent's self-report and parental report of the PedsQL among those with and without autism spectrum disorder. *Quality of Life Research, 26*(3), 611–624. https://doi.org/10.1007/s11136-016-1490-4

Tavernor, L., Barron, E., Rogers, J., & McConachie (2013). Finding out what matters: validity of quality of life measurement in young people with ASD. *Child: Care, Health and Development, 39*(4), 592–601. https://doi.org/10.1111/j.1365-2214.2012.01377.x

Taylor, J. L. (2017). When is a good outcome *actually* good? *Autism, 21*(8), 918–919. https://doi.org/10.1177/1362361317728821

Taylor, M. J., Gustafsson, P., Larsson, H., Gillberg, C., Lundstrom, S., & Lichstenstein, P. (2018). Examining the association between autistic traits and atypical sensory reactivity: A twin study. *Journal of the American Academy of Child and Adolescent Psychiatry, 57*(2), 96–102. https://doi.org/10.1016/j.jaac.2017.11.019

Teachman, G., & Gibson, B. E. (2013). Children and youth with disabilities: Innovative methods for single qualitative interviews. *Qualitative Health Research, 23*, 264–274. https://doi.org/10.1177/1049732312468063

Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Singh, L., Shikako-Thomas, K., & Elsabbagh, M. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism, 23*(8), 1882–1896. https://doi.org/10.1177/1362361319831487

Turner, R. R., Quittner, A. L., Parasuraman, B. M., Kallich, J. D., & Cleeland, C. S. (2007). Patient-reported outcomes: Instrument development and selection issues. *Value in Health, 10*(2), 86–93.

Turner-Brown, L. M., Lam, K. S., Holtzclaw, T. N., Dichter, G. S., & Bodfish, J. W. (2011). Phenomenology and measurement of circumscribed interests in autism spectrum disorders. *Autism, 15*(4), 437–456. https://doi.org/10.1177/1362361310386507

Ullman, M. T., & Pullman, M. Y. (2015). A compensatory role for declarative memory in neurodevelopmental disorders. *Neuroscience and Biobehavioral Reviews, 51*, 205–222. https://doi.org/10.1016/j.neubiorev.2015.01.008

Viera, A. J., & Garrett, J. M. (2005). Understanding interobserver agreement: the kappa statistic. *Family Medicine, 37*(5), 360–363.

Volkmar, F. R., & Cohen, D. J. (1985). The experience of infantile autism: A first-person account by Tony W. *Journal of Autism and Developmental Disorders, 15*, 47–54.

Wainer, A. L., Hepburn, S., & McMahon Griffith, E. (2017). Remembering parents in parent-mediated early intervention: An approach to examining impact on parents and families. *Autism, 21*(1), 5–17. https://doi.org/10.1177/1362361315622411

WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World HealthOrganization. *Social Science and Medicine, 41*(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

Winter-Messiers, M., Herr, C., Wood, C., Brooks, A., Gates, M., Houston, T., & Tingstad, K. (2007). How far can brian ride the daylight 4449 Express? A strength-based model of Asperger syndrome based on special interest areas. *Focus on Autism and Other Developmental Disabilities, 22*(2), 67–79.

Wood, R. (2019). Autism, intense interests and support in school: From wasted efforts to shared understandings. *Educational Review*, *73*(1), 34–54. https://doi.org/10.1080/00131911.2019.1566213

Zukauskas, P. R., Silton, N., & Baptista, F. (2009). Temporality and Asperger's syndrome. *Journal of Phenomenological Psychology, 40*(1), 85–106. https://doi.org/10.1163/156916209X427990