



HAL
open science

Couples' Experiences of Parenting a Child After an Autism Diagnosis: A Qualitative Study

Naomi Downes, Jérôme Lichtlé, Kristopher Lamore, Marie-Joëlle Orève,
Emilie Cappe

► **To cite this version:**

Naomi Downes, Jérôme Lichtlé, Kristopher Lamore, Marie-Joëlle Orève, Emilie Cappe. Couples' Experiences of Parenting a Child After an Autism Diagnosis: A Qualitative Study. *Journal of Autism and Developmental Disorders*, 2020, 51 (8), pp.2697-2710. 10.1007/s10803-020-04744-5 . hal-04572159

HAL Id: hal-04572159

<https://hal.science/hal-04572159v1>

Submitted on 19 Dec 2024

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution 4.0 International License

Couples' experiences of parenting a child after an autism diagnosis: a qualitative study

Naomi Downes¹, Jérôme Lichtlé¹, Kristopher Lamore¹, Marie-Joëlle Orêve², and Emilie Cappe¹

¹Université de Paris, LPPS, F-92100 Boulogne-Billancourt, France

²Service de Psychiatrie Infanto-Juvénile, Centre Hospitalier de Versailles, 78150 Le Chesnay, France

Correspondence concerning this article should be addressed to Emilie Cappe, Laboratoire de Psychopathologie et Processus de Santé EA4057, Institut de Psychologie, Université de Paris, 71 avenue Edouard Vaillant, 92100 Boulogne-Billancourt, France.

Email: emilie.cappe@u-paris.fr

Tel: +33 (0)1 76 53 30 80

Abstract

After a child is diagnosed with autism, parents' relationships are impacted as they reorganize their daily lives to support their child's specific needs. A better understanding of parenting couples' adaptation is needed to accompany them during this period. This qualitative study explored couples' experiences after their child's autism diagnosis. An inductive thematic analysis among ten couple interviews ($N=20$) revealed three key themes: emotional experiences, external support, and adaptation. Overall, the quality of couples' relationships before having a child influenced their relationship after the diagnosis. In general, parents presented complementary coparenting roles, while different opinions about how to raise the child strained their relationship. Helping parents adapt to a diagnosis together could prove to be important for future interventions and research.

Keywords: Parents, couples, coparenting, autism, diagnosis, qualitative analysis.

Couples' experiences of parenting a child after an autism diagnosis: a qualitative study

Autism is characterized by certain difficulties in social communication and interactions, as well as the presence of restricted, repetitive patterns of behaviors, interests, or activities (American Psychiatric Association (APA), 2013). An early diagnosis of autism is recommended to access interventions likely to have a positive impact on the child's development (Landa, 2018; Rabba et al., 2019; Rogé, 2019). Yet, the diagnosis process is often long and challenging for parents (McGrew & Keyes, 2014). They experience various emotions such as shock, despair, relief, and stress during this period (Boshoff et al., 2019). [This process, from the time between becoming aware of the first signs of autism and finally obtaining an official diagnosis, plays an important role in how parents progressively adapt to their child's autism \(Gentles et al., 2020\).](#) A UK survey conducted with 1,047 parents of children on the autism spectrum indicated that over half were dissatisfied with the diagnostic process (Crane et al., 2016). Factors associated with parents' satisfaction included: time waiting for a diagnosis; stress during the screening process; the child's age when diagnosed with autism; as well as post-diagnostic support (Crane et al., 2016). After a diagnosis, parents often struggle to find and manage qualified health care providers (Bonis, 2016). Their lives change to meet the specific needs of their child (Altiere & von Kluge, 2009; Karst & Van Hecke, 2012). This includes reorganizing their parenting responsibilities and roles, which can impact family life and the parent's relationship (Gau et al., 2012; Hock et al., 2012). Couples' relationships become highly focused on parenting with each partner being forced into a rigid parenting role, with mothers generally spending more time in childcare and fathers spending more time at work (Hartley et al., 2014; Hock et al., 2012).

Recent studies have explored how raising a child on the autism spectrum affects the parent's relationship. A meta-analysis showed that couples parenting a child on the autism

spectrum experienced less relationship satisfaction than parents of typically developing children (Sim et al., 2016). Other studies have highlighted how the child's autism can positively impact the couple's relationship (Saini et al., 2015). For example, the shared experience of managing stress to meet their child's needs can strengthen some couples' relationships (Altiere & Von Kluge, 2009; Bayat, 2007; Hutton & Caron, 2005). Hock and colleagues (2012) conducted retrospective interviews with couples suggesting parents' relationships may evolve at different rates over three different phases. The first phase was described as a time of "make or break" after a diagnosis when the child's autism tests the couple's relationship. Couples then entered a second phase of "tag team" where their relationship was mainly centered around parenting the child on the spectrum. Finally, some couples managed to pass to the last phase of deeper intimacy and commitment when they realized how important it was to focus on their relationship for themselves and their child. [These findings can be compared to mothers' reports in interviews conducted by Gentles et al. \(2019\), who showed that the initial process of coming to terms with their child's autism can motivate parents to be highly active in pursuing an intervention. This high level of engagement can be endured for months and sometimes years until parents realize that they cannot maintain investing so much time and energy in the long term. This leads to parents "easing off" to find more balance in their life.](#)

Parents raising a child on the autism spectrum generally consider their couple relationship as a primary source of support (Benson & Kersh, 2011; Hartley et al., 2011; Goedeke et al., 2019; Peperall et al., 2018). It is important to understand how couples can support each other after their child is diagnosed with autism as they experience accentuated levels of stress during this period (McGrew & Keyes, 2014). High levels of stress impact parenting, family functioning, and the parent's relationship (Bonis, 2016; Peterson & Hawley, 1998). For example, stress leads

1
2
3
4 to more conflict and affects parents' ability to support each other to manage their child's daily
5
6 care (Thullen & Bonsall, 2017; Bonis, 2016). Many studies have focused on individual coping
7
8 strategies for managing parents' stress (Bonis, 2016; Lai & Oei, 2014; Vernhet et al., 2019). Yet,
9
10 two intimate partners react to life stressors, such as an autism diagnosis, as an interpersonal unit
11
12 rather than as individuals (Bodenmann et al., 2019). Couples share their thoughts and feelings, as
13
14 well as working together to focus on resolving a common problem (Bodenmann et al., 2019).
15
16 This process of interaction corresponds to the concept of dyadic coping. Currently, only four
17
18 studies have explored dyadic coping among couples raising a child on the autism spectrum
19
20 (Brown et al., 2020; García-Lopez et al., 2016; Gouin et al., 2016; Sim et al., 2017). Positive and
21
22 supportive dyadic coping is associated with relationship satisfaction, as well as lower levels of
23
24 stress and physiological indicators that influence health outcomes among couples with a child on
25
26 the spectrum (Brown et al., 2020; García-Lopez et al., 2016; Gouin et al., 2016; Sim et al., 2017).
27
28 Dyadic coping is an additional source of support for these parents as it strengthens their
29
30 relationship by promoting a sense of togetherness (García-Lopez et al., 2016; Bodenmann,
31
32 2005).
33
34
35
36
37
38
39
40

41 However, few studies have assessed how couples adapt and support each other after their
42
43 child is diagnosed with autism. Among the wider population, couples who do not support each
44
45 other encounter difficulties in their coparenting relationships to work together to fulfill their
46
47 parental roles and responsibilities (McHale, 1995). Coparenting refers to how two individuals
48
49 support, coordinate, and cooperate when raising a child (Gable et al., 1995). To date, few studies
50
51 have assessed the coparenting relationship among parents of children on the spectrum
52
53 (Anonymous, 2020). A high-quality coparenting relationship has been shown to help parents of
54
55 children on the autism spectrum experience less stress (Anonymous, date). Individual interviews
56
57
58
59
60
61
62
63
64
65

with couples revealed the importance placed on making the coparenting relationship more efficient after a diagnosis of autism (May et al., 2017). It seems the unique demands of autism require parents to reorganize and rely on their coparenting relationship after a diagnosis (Anonymous, date).

Overall, couples seem to adapt and evolve differently, with some being more resilient than others (Saini et al., 2015; Sim et al., 2016). To date, fathers are not often recruited in research concerning children on the autism spectrum (Rankin et al., 2019). As a result, the mother's experiences are being generalized to represent the overall experiences of parenting a child on the autism spectrum. Further exploration of both mother's and father's individual and joint experiences is needed to understand variables related to positive outcomes among heterosexual as well as LGBTQ+ couples. Study samples have also included parents of differently aged children. For example, Hock et al.'s (2012) study recruited parents of children aged between 2 to 29 years. Yet, parents' relationships and resources can vary throughout their child's different developmental stages (Favez, 2017). Given the higher levels of stress, unique parenting demands of autism, and the effects on the couple's relationship, research exploring how parenting partners adapt and support each other during the stressful period following an autism diagnosis seems particularly relevant. This qualitative study uses couple interviews to explore and understand couples' experiences after their child has been recently diagnosed with autism by investigating how parenting couples use their relationship as a support system, communicate, and work as a team to fulfill their parenting responsibilities.

Method

Authors followed O'Brien and colleagues' (2014) checklist to write this article.

Participants

Twenty parents (11 mothers and 9 fathers), consisting of nine different-sex couples and one same-sex couple, were recruited through a screening center for autism in France. Couples were eligible if (1) they cohabitated and were in an intimate relationship since their child's birth; (2) their biological child received a diagnosis by a specialized autism screening center between the ages of 2 to 6 years and 11 months; (3) the diagnosis was given 1 to 36 months ago. The first criterion regarding couples' relationship length and living situation was to ensure relationship stability. In France, children are usually diagnosed up to the age of 6 and it is not recommended to diagnose a child with autism before the age of 2 (Baghdadli et al., 2006). The period of 1 to 36 months after a diagnosis was chosen to account for the evolution of parents' stress appraisal over time (McGrew, & Keyes, 2014). Parenting couples were excluded if they did not speak French or if they had another child with a disability.

In this study sample, participants had an average age of 38 years, which ranged from 30 to 47 years. Couples had been together 11.6 years on average, ranging from 4 to 22 years. At the time of the interview, their children were aged between 30 to 84 months with an average age of 50 months. Nine of the children on the spectrum were boys. The average time since diagnosis was 15 months and ranged between 1 to 36 months. In this sample, all children on the spectrum attended mainstream kindergarten on a part-time basis and half of them benefitted from between 1 to 5 hours of specialized care per week. A total of five couples had another child and two couples had two other children. Among two couples, three parents declared health issues. One couple worked full time, two couples worked part-time, four couples consisted of the father working full-time whereas the mother worked part-time, and there were three couples where one worked full-time as the other parent stayed at home. Monthly household income was diverse,

with five couples situated in the lower-class range and the other half in the middle-class range. Six parents had a high-school degree, and the rest had a higher-education degree. Regarding ethnicity, eleven parents were French, whilst nine parents had different origins. Even though couples were selected on a first-come-first-served basis, the sample is relatively heterogeneous. Participants' characteristics are presented in Table 2.

[place Table 2 about here]

Materials and design

This qualitative study used joint couple interviews to explore how couples: communicated about their child's autism diagnosis, used their relationship as a support system to deal with the diagnosis, and experienced the screening process. Couple interviews were conducted with both parenting partners present to explore couples' discussions about their joint experience of raising a child on the autism spectrum after a recent diagnosis. Joint couple interviews are interesting as they can provide rich data on what couples agree and disagree on, as partners can either corroborate or challenge each other's stories (Bjørnholt & Farstad, 2012). An interview schedule (table 1) of eleven questions was developed to guide the interviewer. Interviews began with a brief presentation of the current study as well as informing the parents about their ethical rights. The interviewer told couples to express themselves freely and follow any associations. They were also informed that all questions were addressed to both of them. To elicit detailed responses from each partner, the interviewer used general probes such as "What is your opinion about this?", "What are your thoughts about what your partner just said?", or "Can you give me an example".

[place Table 1 about here]

Procedure

This study is part of a larger research project using quantitative and qualitative data to explore how couples use their intimate and coparenting relationship to support each other in the three years following their child's autism diagnosis. This project received approval from the ethics Committee for the Protection of Persons (CPP) in France. Parents who completed questionnaires during the quantitative part of this project were asked if they were willing to participate in a couple's interview. The first couples interested in participating were contacted to convene a time and date. Overall, ten interviews were conducted until data saturation (Guest et al., 2020). Five interviews were conducted at the screening center and five by telephone as the parents resided at a distance. All interviews were conducted by the first author, a clinical psychologist, between May to September 2019. These semi-directive interviews were audio-recorded for later transcription and generally lasted for an hour.

Analysis

This study followed Braun and Clarke's (2006) guidelines to perform a thematic content analysis. An inductive approach was used to explore participants' experiences. Themes were analyzed in French at a semantic level using an essentialist method. Two authors (names have been omitted for double-blind reviewing) performed data analysis to ensure study strength and reliability (MacPhail et al., 2016). The first stage consisted of becoming familiar with the interviews by repeated readings. Initial codes were then produced by manual open coding. These codes were sorted into themes which were refined by analyzing themes in the data set. An initial coding guide of interview themes was generated and differences in findings were discussed until consensus among four authors was reached (names have been omitted for double-blind reviewing). Interviews were then manually recoded by (names have been omitted for double-

blind reviewing) using the updated coding guide. A second meeting between the four authors ensured the coding guide was coherent and clearly defined themes. This coding guide was then added to Nvivo and both authors (names were omitted for double-blind reviewing) independently recoded the interviews using this software. This analysis confirmed that the manually generated coding guide was satisfactory as the inter-rater agreement was $k = 0.79$. A value of k (Cohen's kappa coefficient) between 0.61 and 0.80 is considered significant according to Viera and Garrett (2005). The first author (name has been omitted for double-blind reviewing) who is a native English speaker then translated the selected interview extracts for this paper. We used pseudonyms to protect participants' identities. It is important to note that the frequency of occurrence of themes and sub-themes (i.e., among how many interviews a theme appears) is presented in the results from a descriptive point of view. This information does not intend to quantify results as the frequency of a theme does not equate to its importance within the dataset (Braun & Clark, 2006).

Results

A total of three themes and eight sub-themes describe couples' experiences after their child's autism diagnosis (see Table 3). The three key themes related to couples' emotional experiences, external support, and their adaptation. Any experience that is not shared by both partners is detailed within the sub-section.

[place Table 3 about here]

1. Theme 1: Emotional experiences

All couples reported various emotional responses at different time frames. Two subthemes emerged: emotional responses from the first signs of autism to the diagnosis; and daily emotional responses after the diagnosis.

1.1. Emotional responses from the first signs of autism to the diagnosis

All couples expressed emotions related to the period where they noticed the first signs of autism until the diagnosis at the screening center. Among five couples, both partners described this time as a progressive process that minimizes the shock of receiving their child's autism diagnosis. They stated that even though the diagnosis came as a slight shock, they mainly felt relief after so much time doubting and waiting for the diagnosis. As Emma and Mark mention "Emma: It was a relief as well because for one year we were between maybe yes maybe no and that was emotionally exhausting. [...] Mark: overall we had the feeling that we finally understood and could now move on". The opposite was described by two couples who experienced the diagnosis as being very difficult and a great shock. For Val and Alice: "Val: It was a shock even if we had doubts at the beginning. [...] Alice: It was complicated, very difficult to accept". Among three couples, partners experienced different emotional responses to the diagnosis. These mothers were not convinced by the autism diagnosis whereas the fathers expected and accepted the diagnosis. For example, Luke: "I quickly accepted it. My main issue was my wife's denial, she was in distress".

1.2. Daily emotional responses after the diagnosis

Couples identified a range of emotions they experience daily after the autism diagnosis. Seven couples described their daily life as complicated with numerous highs and lows. As Linda states "There are highs and lows, sometimes there are big lows and sometimes small moments of happiness". Or Mark: "Sometimes I'm happy and sometimes less happy, it's like that". One partner among five couples discussed sometimes feeling depressed or nearly breaking down. For Beth: "Even if I didn't show it physically or personally to people, I believe I was depressed". Or Peter: "Even in the ESDM [Early Start Denver Model] book, they talk about situations where

1
2
3
4 parents even think about suicide, and we haven't thought about suicide but sometimes we just
5
6 feel that we'll never be able to make it, it's not possible". Seven couples talked about often
7
8 feeling physically or mentally exhausted. As Mark explains "It's more a mental exhaustion" or
9
10 Peter "It's true that physically, we are so tired". Finally, seven couples experienced a regular
11
12 burden of stress and worry when organizing childcare as the administration and lack of services
13
14 demands constant preparation and anticipation. As Katie and Harry emphasize "Katie: We are
15
16 more worried about the organization... it's more how am I going to go back to work, how is this
17
18 going to work out, in the end, it's all about logistics and in the end, we don't even worry about
19
20 our child. Harry: Yes, we feel pretty confident he'll be fine".
21
22
23
24
25

26 ***2. Theme 2: External support***

27
28 All couples identified a need for support from external sources, which was not always
29
30 provided. This external support is divided into three sub-themes involving grandparents, service
31
32 providers, and their community.
33
34

35 ***2.1. Grandparents***

36
37 Eight couples highlighted the importance of grandparents for babysitting their children.
38
39 Three of these couples sent their child to stay with their grandparents during holidays but did not
40
41 feel they could ask grandparents to babysit at any other time. Four couples expressed distress
42
43 when grandparents lived at a distance as they could not provide babysitting. These couples did
44
45 not trust anybody else to babysit their child. Fiona said, "The fact that we don't have family here,
46
47 both our parents are in Algeria, I have a hard time trusting anyone else with my children, so we
48
49 only go out as a couple when we go to Algeria". Or David spoke about how he "would have
50
51 loved to have grandparents living close by, to relieve us a little from our child now and again".
52
53
54
55
56
57 Finally, grandparents were also considered unsupportive by five couples as they would judge or
58
59
60
61
62
63
64
65

pressurize parents. Andrea shared “Then there is also the grandma who is so worried she puts pressure on us” or as Peter stated “Their judging and everything, I’ve just had enough”.

2.2. Service providers

Support provided by service providers was separated into three sub-groupings. First, specialized care services offered support to eight couples through parent training programs. For Fiona, a psychologist provided parental guidance every month: “well it was really positive for me because I saw that it helped”. Richard said: “I admit that when we left the diagnostic center we had no idea. We had a very vague idea of what ABA [Applied Behavior Analysis] was and therefore the parent training helped because we really went in-depth and saw the results that had been achieved with other children on videos. And suddenly that gave us a frank idea of what progress could be achieved”. Five couples appreciated the support provided for parenting but thought they lacked time with a psychologist for emotional support. Emma and Mark were in therapy with a psychologist who only concentrated on their child “Emma: We never spoke about our relationship. And that was the space for that. I don’t know, it’s true that no professional has spoken to us about us as a couple. Mark: That’s true. [...] I would have found it reassuring. Emma: Yes, but would we have told her about the relationship difficulties we were experiencing at that time? I’m not sure. Mark: I’m sure we would have, but even if we didn’t it would have reminded us to think about our relationship”. Four couples felt “lucky” with their care service due to there being a lack of spaces in specialized care. As Richard said, “Yes, and I also found that we were very lucky to get everything we wanted in terms of help”. Second, seven couples felt unsupported by screening centers after the diagnosis as they lacked information on care service centers, helplines, and good practices. As Fiona and Luke explain: “Fiona: Inform parents about best practices for autism and what works. [...] Luke: It is necessary to find a way

1
2
3
4 to guide the parents after the diagnosis, if professionals find that they are in a condition to accept
5
6 or quickly assimilate the news, then why not give them the information directly? Otherwise,
7
8 leave the door open and send them addresses or a manual by mail to help guide them in the first
9
10 months so they don't waste time". Finally, parents require more support to deal with the
11
12 complicated administrative process of acquiring care services in France. Patricia and Peter
13
14 summarize "Patricia: We are told to apply to the MDPH [Departmental Office for Disabled
15
16 Persons] but we do not even know what it is, nor what they do. Despite two years of dealing with
17
18 them, I'm still learning about what they can offer parents. Peter: That's basically it in a nutshell".
19
20 The MDPH is a specific government office in France that parents must apply to every two years
21
22 via a complicated administrative process to access specialized childcare and financing (Chamack
23
24 & Bonniau, 2018).
25
26
27
28
29

30 **2.3. Community**

31
32 Overall, eight couples emphasized the importance of exchanging and networking with
33
34 other parents of children on the spectrum. First, this helped parents gain useful knowledge for
35
36 their child's care. For example, Elliot went on "Canadian forums and exchanged with parents
37
38 who are much more open. They are already much more advanced. We then decided to set the
39
40 things we discussed with them up at home". Second, simply talking and exchanging experiences
41
42 with other parents was also a source of support. Sophie and Richard enjoyed going to parental
43
44 support groups together: "Richard: What is good is that when both parents are there, it allows us
45
46 to see other parents and then to actually be able to speak in front of each other whilst in front of
47
48 other parents, sharing our experiences. [...] Sophie: It's true that yes it felt good to be able to talk
49
50 with other people who were going through the same thing as us".
51
52
53
54
55
56
57

58 **3. Theme 3: Adaptation**

59
60
61
62
63
64
65

All couples discussed how daily life changed and how they adapted to their child's autism diagnosis. These adaptations emerged among three sub-themes, as participants described (1) individual, (2) coparenting, and (3) couple adaptations.

3.1. Individual

Parents used individual strategies to adapt to the autism diagnosis. Among all couples, one partner sought information and solutions by reading about autism in books or on the internet. Patrick and Linda explained how “Linda: We always try to keep our heads high and move forward. It's our state of mind, that's why we didn't break down. We ask ourselves what we can do to help him, who are the people who can help him, in fact we are still the same now. [...] Patrick: we didn't wait for solutions, we went looking for them”. Among three of these couples, fathers sought information whereas mothers avoided reading as it was a source of distress. After the diagnosis, seven couples spoke about their different psychological processes to accept their child's autism. For Andrea and David: “Andrea: I have read a lot, met other parents. So I have a better understanding now about autism. I accept it. David: I also think that I accept it better now, I'm no longer looking for quick fixes that probably don't exist”. Parents also adapted by comparing themselves to other families in worse situations, which four couples called “putting it into perspective”. For example, Val and Alice: “Val: Put it into perspective, don't get overwhelmed, it's no use anyway, it will not help. Alice: We put it into perspective...It also could have been worse. He could have been sick, he could have passed away. His thing is that he is autistic”. Parents within four couples also expressed difficulty adapting to no longer having any time alone for respite since the diagnosis. For Katie and Harry: “Harry: We don't have any time, any time to just relax. [...] Katie: We run out of time, I don't have any time just on my own”.

3.2. Coparenting

Coparenting relationships changed after the diagnosis regarding childcare and shared parenting choices. First, seven couples revealed how important it was for them to agree on parenting strategies and autism methods. Different opinions on how to deal with the child's behavior was a source of conflict. As Linda and Patrick shared: "Linda: we don't have any issues concerning our child's care, you are always with me. You have to be on the same page for the child's care, that really helps, because if I had to fight with a partner who didn't have the same vision, that would be an obstacle. I don't think our relationship would last. Patrick: Yes. [...] To have the same point of view when we make a choice it's because we spoke about it and decided it was best for our child. You both have to go in the same direction". Four couples also changed their parenting priorities after the diagnosis. They accepted their child's differences instead of demanding the child to behave in a certain way. For example, Alice: "We ask less of him than we did before. So, he is less tense and we are less tense too. Since we're less annoyed, he's less annoyed too. Because we expect less from him, he reacts better and suddenly we all live better lives". Second, all couples changed the way they divided childcare after the diagnosis to accommodate the child's specialized care. They described their coparenting relationship as "complementary" with each parent having a specific role. The division of parenting roles happened naturally without any communication. Parents would spontaneously help each other in their specific role if they saw the other parent in difficulty. Robert and Beth summarize "Robert: We never discussed it officially, but what generally happens is that she takes more care of the house. Making the children's beds, cleaning tasks, all that. And often, I bath the children, I put them to bed, and we share it like that. Our routine is a bit like that, we each have our tasks. Beth: Yes, very natural, we just settled into that".

3.3. *Couple*

Couples spoke about how their relationships were affected by the diagnosis. The quality of couples' relationships before having children seemed to influence the way they adapted to the diagnosis. Four couples who described their relationship as always being solid developed an even closer relationship after the diagnosis. Fiona and Luke stated, "Fiona: Even before his autism, we were always a tightly knit couple, we have no problems and we get along very well, his autism has only strengthened our bond. Luke: Yes, I insist on communication and of course trust. He is the child of two partners, so it is natural and normal we both take care of him. Each person has their own way, we both do our best and we never criticize each other but instead try to understand the other person". Two high-quality couple relationships experienced conflict over different views about their child's first signs during numerous months. The diagnosis helped them become closer as they managed to find a common accord. However, for Beth and Robert who had relationship difficulties for many years, they maintained their different views after the diagnosis, which created even more tension between them: "Beth: I don't think it was our son's autism that distanced us, it has nothing to do with his autism, I think there was already a distance between us before he arrived, the autism just added to it. Robert: Our relationship was already a little distant, so it didn't help, it didn't bring us closer, it could have brought us closer but it didn't bring us closer. Because we didn't have the same vision at all, and we couldn't understand each other's perspectives, including that of our child's education.". Couples found it difficult to find time together, especially if the grandparents lived far away or the child had sleeping difficulties. For example, Sophie and Richard: "Sophie: For the moment our relationship has been put to the side. There is only us two, the grandparents live far away so it's complicated for the moment. Richard: It's true that we go out a lot less, we see a lot less people, I think all

1
2
3
4 parents generally have less time together. But it is true that managing the added specialized
5
6 childcare monopolizes a lot of our time in terms of organization”. Good communication between
7
8 partners was very important for seven couples. For Hayley and Elliot: “Elliot: We have always
9
10 spoken about it, and neither tried to tell the other what to do or that it’s not that bad. Straight
11
12 away we spoke about it and tried to be together to confront the autism. [...] Hayley: There is
13
14 solidarity, exchanges, we communicate, and when we do not communicate we feel and we take
15
16 initiatives. We really exchange a lot about our fears, doubts, difficulties”. Three couples avoided
17
18 talking about some of their worries to protect each other from negative feelings or because they
19
20 did not feel ready to talk. For Patrick: “It is true that when we are each in our own little bubble,
21
22 perhaps it’s a form of respect or we feel the need to leave each other a bit of space. We leave
23
24 each other space, wait for the storm to pass, and wait for a better moment to talk”.

31 Discussion

32
33 The present study used a qualitative framework to gain knowledge and understanding
34
35 about parenting couples’ daily lives after their child’s autism diagnosis. Ten couples discussed in
36
37 detail their experiences across three domains: their emotional response, a need for external
38
39 support, and the way they adapted to the diagnosis.
40
41

42
43 Couples responded differently to the diagnosis with some describing the final diagnosis
44
45 as a relief given the delays in the screening process, while others experienced it as a shock. The
46
47 emotional reaction to the diagnosis can be a part of a process that starts before the assessment
48
49 period at the screening center (Gentles et al., 2019; 2020; Mulligan et al., 2012). As found in this
50
51 study, the majority of parents already started a progressive process before the official diagnosis.
52
53 Hence, it is possible that some parents have already accepted and adapted to their child’s autism
54
55 before attending the screening process. Whereas other parents may struggle to adapt emotionally
56
57
58
59
60
61
62
63
64
65

1
2
3
4 during this process for multiple reasons, such as denial; accepting their child has an uncertain
5
6 future; navigating interventions alone; redefining their parental role and responsibilities; as well
7
8 as letting go of expectations they had for their child (Gentles et al., 2019). These parents will not
9
10 be as ready to engage in their child's care. This highlights the need to rethink about ways to
11
12 support parents, especially as most parental support is proposed after an official diagnosis.
13
14 However, in countries like France where parents can wait for up to three years for an official
15
16 diagnosis, it seems important to think of ways we can accompany parents as soon as they express
17
18 their first concerns (Haute Autorité de Santé, 2018). Overall, these findings emphasize the
19
20 necessity of adapting support to the specific needs of each parenting couple from the child's first
21
22 signs of autism. Especially as partners do not always experience the same emotional response,
23
24 which can strain a couple's relationship (Hock et al., 2012). In the current study, reactions varied
25
26 among couples. Some parenting partners presented opposite reactions (one parent responded
27
28 positively and another negatively) whereas other couples experienced the same positive or
29
30 negative response. Additionally, the lack of post-diagnostic support and information provided by
31
32 specialized autism screening centers was a major issue and source of stress for couples in this
33
34 study. Parents require information tailored to their needs as they struggle to obtain services and
35
36 support during this period (Crane et al., 2016, Carlsson et al., 2016). Navigating interventions is
37
38 an added burden that creates stress and diminishes parents' resources by reducing their finances,
39
40 time, and energy (Gentles et al., 2019). Parents would benefit from further consultations with
41
42 professionals after the diagnosis to accompany them with the administrative process of obtaining
43
44 care, as well as to provide emotional support to promote their well-being (Boshoff et al., 2019;
45
46 Gentles et al., 2019; Yi et al., 2019). In recent years, France has started proposing parental
47
48 guidance programs after a diagnosis, such as Beyond ASD, ETAP, and ABC programs (*Details*
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4 *omitted for double-blind reviewing, 2019*). Despite this progress, centers encounter certain
5
6 obstacles implementing these types of programs. A qualitative study showed that these programs
7
8 require more support and motivation from the professionals to recruit parents, find time and
9
10 space, as well as train practitioners (Anonymous, 2020). French centers need to include parental
11
12 guidance as an inherent part of their practice and standards to provide necessary resources for
13
14 implementation (Anonymous, 2020).
15
16
17

18
19 In the current study, couples highlighted how physically and mentally exhausted they
20
21 were daily. They found it difficult to find time for themselves individually or together, especially
22
23 when the child had sleeping difficulties. Indeed, Harper et al.'s study (2013) shows that more
24
25 respite is associated with higher marital quality and reduced stress among a hundred couples
26
27 raising a child on the spectrum. However, they did not explore whether parents' marital quality
28
29 was impacted differently if parents spent respite time together or alone. Participants in the
30
31 current study only trusted grandparents to babysit their child on the spectrum, which allowed
32
33 couples to spend time together and provided respite. They expressed how difficult daily life was
34
35 when grandparents did not babysit because they lived at a distance or were unsupportive.
36
37 Research has shown how a good quality relationship with grandparents can provide a better
38
39 quality of life and less stress (Derguy et al., 2017). Overall, grandparents are considered an
40
41 essential source of support for parenting couples (Hastings, 1997; Hillman et al., 2016).
42
43 However, grandparents experiencing difficulty accepting the diagnosis or interacting with their
44
45 grandchild are not as supportive (Anonymous, 2019). Professionals could indirectly support
46
47 parents by being attentive to grandparents' reactions after the diagnosis and offering guidance to
48
49 those struggling to adjust to their grandchild's autism.
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4 After the diagnosis, many couples changed their parenting priorities by changing their
5 expectations regarding their child. They no longer expected their child to behave a certain way,
6 but instead adapted to their child's individual needs and behaviors. Previous research suggests
7 that this may be linked to parents having a resolved reaction to the diagnosis (Poslawsky et al.,
8 2014; Wachtel & Carter, 2008). Resolution of the diagnosis occurs when parents come to terms
9 with their child's autism by accepting their new situation and its implications. Resolved parents
10 are more sensitive and support their child's needs by adapting routines as well as having a better
11 understanding of the child's behaviors (Poslawsky et al., 2014; Wachtel & Carter, 2008).
12
13

14 Resolution may be different between mothers and fathers at different times. For example, 36
15 months after a diagnosis, fathers' resolution levels remain stable whereas mothers' resolution
16 levels increase to become similar to fathers' levels (Yirmiya et al., 2015). Indeed, in the present
17 study, couples spoke about how they processed and accepted the diagnosis individually. Some
18 parents also used social downward comparisons to assimilate the diagnosis by comparing
19 themselves with worse situations (Hirsch & Paquin, 2019).
20
21

22 The coparenting relationship became a priority after the autism diagnosis as parents focused all
23 their efforts on reorganizing and sharing parenting roles to manage specialized childcare [that](#)
24 [became available after the official diagnosis](#). This corresponds to the "tag team" phase where
25 parents' relationships become focused on parenting to meet their child's needs and the couples'
26 intimate relationship is no longer considered a priority (Hock et al., 2012). Prioritizing the
27 coparenting relationship and sharing parenting tasks helps parents of children on the spectrum
28 become resilient and strengthens their parenting bond (Bayat, 2007; Hock et al., 2012; Marciano
29 et al. 2015). In the present study, all couples presented complementary coparenting relationships
30 as different tasks were shared between parents. They divided parenting responsibilities
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

1
2
3
4 spontaneously depending on partners' availability and natural affinity with each task. Even if one
5
6 partner spent more time at work, they were still involved with childcare for a certain percentage
7
8 of time and did not necessarily accomplish the same parenting tasks as the other partner. This is
9
10 an important finding for intervention, as work commitments leave the other parent with less time
11
12 to attend appointments and parent training programs at their child's specialized care center
13
14 (Bearss et al., 2015; Rivard et al., 2014). This parent misses out on professional guidance that
15
16 could help them develop certain techniques to interact with their child. Future research should
17
18 explore ways to involve both parents even if one parent cannot attend by developing alternative
19
20 programs and modes of delivery. For example, father involvement remains complicated, but
21
22 certain telemedicine programs are offering promising results (Arnaud et al., 2019; Heitzman-
23
24 Powell et al., 2014; Rankin et al., 2019). Exploring these options is important as parent-mediated
25
26 interventions among the general population have shown stronger effects on child and parenting
27
28 behaviors when both parents participate (Lundahl et al., 2008).
29
30
31
32
33
34

35
36 Adding to previous research, different opinions between parents about parenting styles
37
38 and methods were a source of tension for couples (Harper et al, 2013; Lickenbrock et al., 2011).
39
40 An interesting finding in the current study is that couples' relationship quality before having a
41
42 child influenced how couples reacted to child-rearing disagreements after the autism diagnosis.
43
44 *In this study, couples who described their relationship as solid before the diagnosis became*
45
46 *closer after the diagnosis, even when there was child-rearing disagreement.* However, the couple
47
48 with a history of relationship difficulties that existed before the child's birth became more distant
49
50 after the diagnosis. Among the wider population, a high level of relationship quality before birth
51
52 has been linked to more coparenting support after birth (Le et al., 2016; Van Egeren, 2004). A
53
54 specific factor that may be associated with this occurrence could be dyadic coping. Indeed,
55
56
57
58
59
60
61
62
63
64
65

dyadic coping can limit the negative consequences of stress on a couple's relationship and impact the coparenting relationship (Bodenmann et al. 2010; Zemp et al., 2017). For example, among mothers of neurotypical children, an increase in dyadic coping over a year predicts less coparenting conflict (Zemp et al., 2017). Another important element for parents was communication. However, some parents in this sample avoided talking about negative emotions. One theory is that this could be due to an avoidant attachment style among parents, as parents do not seek emotional support and just focus on the practicalities of raising their child on the autism spectrum (Kayser & Revenson, 2016; Mikulincer & Shaver, 2012).

Practice implications

This research contributes to the existing literature by adding new insights into couples' experiences when raising a young child on the autism spectrum and providing recommendations for clinical practice (see Box 1).

Firstly, the findings of this study corroborate suggestions provided by Gentles et al. (2020) of adapting the required amount of parental engagement or the information provided to each parent's level of understanding of autism and emotional experience. Some parents may need time and emotional support to adapt to their child's autism before they can engage in their child's intervention (Gentles et al., 2019, 2020). Indeed, for these parents, "insisting on high levels of engagement, such as by providing extensive verbal or written information at diagnosis, may have unintended psychological consequences and yield resistant or unmotivated responses" (Gentles et al., 2020, p. 480). Whereas, other parents may not require nor want psychological support as they have already adapted to their current situation. Instead, these parents wish for immediate information and help to navigate interventions. Our study adds further knowledge about the reaction to the diagnosis by showing that parenting partners are sometimes at different

1
2
3
4 stages of this process. This can be difficult for partners dealing with the other parent's denial or
5
6
7 grief. Overall, practitioners need to be sensitive to couples' profiles and individual internal
8
9
10 processes to be able to have a flexible approach for providing post-diagnostic information and
11
12 support. Any issues need to be addressed by practitioners at an early stage to prevent barriers to
13
14 the child's intervention. Especially as this can cause feelings of regret among parents at a later
15
16 date if they feel they are responsible for "wasting time" regarding their child's access to care
17
18 (Crane et al., 2018; Gentles et al. 2020). In this study, many parents felt unsupported by
19
20 screening centers for navigating intervention. The information provided needs to be tailored to
21
22 each family with follow-ups to check if parents have managed to access specific care services
23
24 and best practices. Specific to France, parents also need help to complete administrative
25
26 processes, such as the MDPH, which are very complicated and a cause of a lot of stress.
27
28
29
30

31 Regarding parents' relationships, practitioners should acknowledge that parents can have
32
33 complementary roles in childcare and may participate in the same or different parenting tasks at
34
35 various times. Practitioners should appraise couples' relationship quality as this could influence
36
37 how parenting partners transmit information about their child's care to each other. It is possible
38
39 that these parents experience difficulty sharing information or techniques provided by
40
41 professionals. It is also important to observe parents' level of child-rearing agreement, as any
42
43 disagreement can be a source of tension and may affect the child's care. Both parents could
44
45 benefit from consultations at care centers together or separately, as well as offering extra support
46
47 via couples or coparenting therapy. Given that some parents prioritize their child before
48
49 themselves and their relationship at certain stages of their clinical journey (Gentles et al., 2019,
50
51 2020; Hock et al., 2012; May et al., 2017), these parents may prefer to focus on childcare and
52
53 their coparenting relationship rather than their intimate relationship at that time. This study
54
55
56
57
58
59
60
61
62
63
64
65

suggests that parent groups may also be a good option for offering support and opportunities for communication between couples. Finally, the relationship with grandparents can play a major role in providing respite, as parents do not seem to trust anybody else to babysit when their child is young and non-verbal. Relationships with grandparents were a source of strain when parents perceived their reactions as negative and unsupportive. Practitioners need to be more attentive to the impact of grandparents' reactions on parents' daily lives and provide support when needed.

[place Box 1 about here]

Limitations and conclusion

First, couple interviews were chosen as the preferred interviewing method to explore couples' interactions and opinions about a joint experience. However, they can present certain limits as partners may not express themselves as freely as they would during individual interviews. Second, future studies would gain a better understanding of couples' experiences over time by applying longitudinal methods. It would also be interesting to further investigate the link found between prenatal relationship quality and couples' adaptation to an autism diagnosis. Third, even though this study sample is relatively heterogenous, it is important to explore in-depth cultural differences as well as various family structures (for example, more LGBTQ+ families) and situations (such as, different levels of education or household income). Furthermore, this study only focuses on parenting partners who are still in an intimate couple relationship. Future research also needs to explore ways to support separated or single parents. Finally, the majority of the sample were raising boys on the spectrum. As studies present conflicting findings, it is not clear whether parents' relationship satisfaction is impacted differently depending on if they are raising a boy or a girl on the spectrum (Ekas et al., 2015;

1
2
3
4 Kwok et al., 2014; Rodrigue et al., 1990; Weber, 2012). Given the inconclusive evidence, future
5
6 research should try to replicate this study with more families raising girls on the spectrum to
7
8 control for any possible differences.
9

10
11 Overall, this study illustrates the importance of adapting support to both parents and their
12
13 relationship. Depending on couples' relationship quality, they may be able to support each other,
14
15 or they may require external support. The knowledge gained by this study's findings should be
16
17 used to direct future research to develop practice guidelines. We provide preliminary
18
19 recommendations to optimize support for couples raising a child on the autism spectrum, which
20
21 will help practitioners support families to adapt together and become resilient after an autism
22
23 diagnosis.
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65

References

- Altieri, M. J. & Von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies*, *18*, 83-92.
doi:10.1007/s10826-008-9209-y
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorder* (5th ed.). Washington, DC: American Psychiatric Association.
- Arnaud, M., Baduel, S., Guillon, Q. & Rogé, B. (2019). Télésanté : les thérapies médiatisées par les parents [Telehealth: Technological therapies for parents]. *Enfance*, *1*(1), 99-118.
doi:10.3917/enf2.191.0099.
- Baghdadli, A., Beuzon, S., Bursztejn, C., Constant, J., Desguerre, I., Rogé, B., Squillante, M. Voisin, J., & Aussilloux, C. (2006). Recommandations pour la pratique clinique du dépistage et du diagnostic de l'autisme et des troubles envahissants du développement [Recommendations for clinical practice screening autism and pervasive developmental disorders]. *Archives de Pédiatrie*, *13*(4), 373-378.
<https://doi.org/10.1016/j.arcped.2005.12.011>
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*, 702-714. doi:[10.1111/j.1365-2788.2007.00960.x](https://doi.org/10.1111/j.1365-2788.2007.00960.x)
- Bearss, K. Burrell, T. L., Stewart, L. M. & Scahill, L. (2015). Parent Training in Autism Spectrum Disorder: What's in a Name? *Clinical Child and Family Psychology Review*, *18*(2), 170-182.
- Benson, P. R., & Kersh, J. (2011). Marital quality and psychological adjustment among mothers of children with ASD: cross-sectional and longitudinal adjustment. *Journal of Autism and Developmental Disorders*, *41*, 1675–1685.

Bjørnholt, M., & Farstad, G. R. (2012). 'Am I rambling?' on the advantages of interviewing couples together. *Qualitative Research*, 14(1), 3–19.

<https://doi.org/10.1177/1468794112459671>

Bodenmann, G. (2005). Dyadic Coping and Its Significance for Marital Functioning. In T.A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples Coping with Stress: Emerging Perspectives On Dyadic Coping* (33-50). Washington DC: American Psychological Association.

Bodenmann, G., Meuwly, N., Bradbury, T. N., Gmelch, S., & Ledermann, T. (2010). Stress, anger, and verbal aggression in intimate relationships: Moderating effects of individual and dyadic coping. *Journal of Social and Personal Relationships*, 27 (3), 408–424.
doi:10.1177/0265407510361616.

Bodenmann, G., Falconier, M. K., & Randall, A. K. (2019). *Dyadic Coping: A Collection of Recent Studies*. Frontiers Media SA. <https://doi.org/10.3389/978-2-88963-031-8>

Bonis, S. (2016). Stress and Parents of Children with Autism: A Review of Literature. *Issues in Mental Health Nursing*, 37(3), 153–163. <https://doi.org/10.3109/01612840.2015.1116030>

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2019). A Meta-synthesis of How Parents of Children with Autism Describe Their Experience of Advocating for Their Children during the Process of Diagnosis. *Health & Social Care in the Community*, 27(4), 143–157. <https://doi.org/10.1111/hsc.12691>

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

- 1
2
3
4 Brown, M., Whiting, J., Kahumoku-Fessler, E., Witting, A. B., & Jensen, J. (2020). A Dyadic
5
6 Model of Stress, Coping, and Marital Satisfaction Among Parents of Children With
7
8 Autism. *Family Relations*, 69(1), 138–150. <https://doi.org/10.1111/fare.12375>
9
- 10
11 Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). Negotiating knowledge: parents'
12
13 experience of the neuropsychiatric diagnostic process for children with autism.
14
15 *International journal of language & communication disorders*, 51(3), 328–338.
16
17 <https://doi.org/10.1111/1460-6984.12210>
18
19
- 20
21 Chamak, B., & Bonniau, B. (2018). « Mon fils, c'est ma petite entreprise ! » Les parcours des
22
23 enfants autistes entre carence de soins et inégalités sociales en Seine-Saint-Denis [“My
24
25 son is my own little business!” The trajectory of autistic children in Seine-Saint-Denis:
26
27 shortage of care and social inequality]. *Anthropologie & Santé*, 17.
28
29
- 30
31 Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism
32
33 diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, 20(2), 153–
34
35 162. <https://doi.org/10.1177/1362361315573636>
36
37
- 38 Author et al. (2018). *Details omitted for double-blind reviewing*.
39
- 40
41 Derguy C., Roux S., Portex M., & M'bailara K. (2017). An ecological exploration of individual,
42
43 family, and environmental contributions to parental quality of life in autism. *Psychiatry*
44
45 *Research*, 268, 87-93.
46
47
- 48 Ekas, N. V., Timmons, L., Pruitt, M., Ghilain, C., & Alessandri, M. (2015). The Power of
49
50 Positivity: Predictors of Relationship Satisfaction for Parents of Children with Autism
51
52 Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45(7), 1997–2007.
53
54 <https://doi.org/10.1007/s10803-015-2362-4>
55
56
57
58
59
60
61
62
63
64
65

Favez, N. (2017). *Psychologie de la coparentalité [Psychology of co-parenting]*. Malakoff: Dunod.

Gable, S., Crnic, K., & Belsky, J. (1994). Coparenting within the family system: Influences on children's development. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, 43(4), 380-386.

García-López, C., Sarriá, E., Pozo, P., & Recio, P. (2016). Supportive dyadic coping and psychological adaptation in couples parenting children with autism spectrum disorder: the role of relationship satisfaction. *Journal of Autism and Developmental Disorders*, 46(11), 3434-3447.

Gau, S. S.-F., Chou, M.-C., Chiang, H.-L., Lee, J.-C., Wong, C.-C., Chou, W.-J., & Wu, Y.-Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 263- 270.
<https://doi.org/10.1016/j.rasd.2011.05.007>

Gentles, S. J., Nicholas, D. B., Jack, S. M., McKibbin, K. A., & Szatmari, P. (2020). Coming to understand the child has autism: A process illustrating parents' evolving readiness for engaging in care. *Autism*, 24(2), 470-483.

Gentles, S. J., Nicholas, D. B., Jack, S. M., McKibbin, K. A., & Szatmari, P. (2019). Parent engagement in autism-related care: A qualitative grounded theory study. *Health Psychology and Behavioral Medicine*, 7(1), 1-18.

Goedeke, S., Shepherd, D., Landon, J., & Taylor, S. (2019). How perceived support relates to child autism symptoms and care-related stress in parents caring for a child with autism. *Research in Autism Spectrum Disorders*, 60, 36- 47.

- Gouin, J.-P., Scarcello, S., da Estrela, C., Paquin, C., & Barker, E. T. (2016). Dyadic coping and inflammation in the context of chronic stress. *Health Psychology, 35*(10), 1081–1084.
<https://doi.org/10.1037/hea0000395>
- Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLoS ONE 15*(5), e0232076.
<https://doi.org/10.1371/journal.pone.0232076>
- Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 43*(11), 2604–2616.
<https://doi.org/10.1007/s10803-013-1812-0>
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal on Intellectual and Developmental Disabilities, 116*(1), 81–95.
- Hartley, S. L., Mihaila, I., Otolara-Fadner, H. S., & Bussanich, P. M. (2014). Division of Labor in Families of Children and Adolescents with Autism Spectrum Disorder. *Family Relations, 63*, 627–638. <https://doi.org/10.1111/fare.12093>
- Hastings R.P. (1997). Grandparents of children with disabilities: A review. *International Journal of Disability, Development, and Education, 44*, 329–340.
- Haute Autorité de Santé. (2018, February 19th). *Autisme de l'enfant : accélérer les étapes jusqu'au diagnostic, agir sans attendre [Autism among children: speed up the steps until diagnosis, act now]* [Press release]. Retrieved from <https://www.has->

sante.fr/jcms/c_2829131/fr/autisme-de-l-enfant-accelerer-les-etapes-jusqu-au-diagnostic-agir-sans-attendre

Heitzman-Powell, L. S., Buzhardt, J., Rusinko, L. C., & Miller, T. M. (2014). Formative

evaluation of an ABA outreach training program for parents of children with autism in remote areas. *Focus on Autism and Other Developmental Disabilities, 29*(1), 23–38.

Hillman, J. L., Wentzel, M. C., & Anderson, C. M. (2017). Grandparents' Experience of Autism

Spectrum Disorder: Identifying Primary Themes and Needs. *Journal of Autism and Developmental Disorders, 47*(10), 2957–2968. [https://doi.org/10.1007/s10803-017-3211-](https://doi.org/10.1007/s10803-017-3211-4)

[4](https://doi.org/10.1007/s10803-017-3211-4)

Hirsch, K. H., & Paquin, J. D. (2019). “The Stress of the Situation has Changed us Both”: A

Grounded Theory Analysis of the Romantic Relationship of Parents Raising Children with Autism. *Journal of Child and Family Studies, 28*(10), 2673–2689.

<https://doi.org/10.1007/s10826-019-01448-y>

Hock, R. M., Timm, T. M., & Ramisch, J. L. (2012). Parenting Children with Autism Spectrum

Disorders: A Crucible for Couple Relationships. *Child & Family Social Work, 17*(4), 406–415. <https://doi.org/10.1111/J.1365-2206.2011.00794.X>

Hutton, A. M., & Caron, S. L. (2005). Experiences of Families with Children with Autism in

Rural New England. *Focus on Autism and Other Developmental Disabilities, 20*(3), 180–189. <https://doi.org/10.1177/10883576050200030601>

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders:

A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review, 15*(3), 247–277.

Kayser, K., & Revenson, T. A. (2016). Including the cultural context in dyadic coping:

Directions for future research and practice. In M. K. Falconier, A. K. Randall, & G. Bodenmann (Eds.), *Couples coping with stress: A cross-cultural perspective* (p. 285–299). Routledge/Taylor & Francis Group.

Kwok, S. Y. C. L., Leung, C. L. K., & Wong, D. F. K. (2014). Marital satisfaction of Chinese mothers of children with autism and intellectual disabilities in Hong Kong. *Journal of Disability Research*, 58(12), 1156–1171. <http://dx.doi.org/10.1111/jir.12116>.

Lai, W.W., Oei, T.P.S. (2014). Coping in Parents and Caregivers of Children with Autism Spectrum Disorders (ASD): a Review. *Review Journal of Autism and Developmental Disorders*, 1, 207–224. <https://doi-org.sirius.parisdescartes.fr/10.1007/s40489-014-0021-x>

Landa R. J. (2018). Efficacy of early interventions for infants and young children with, and at risk for, autism spectrum disorders. *International review of psychiatry*, 30(1), 25–39. <https://doi.org/10.1080/09540261.2018.1432574>

Le, Y., McDaniel, B. T., Leavitt, C. E., & Feinberg, M. E. (2016). Longitudinal associations between relationship quality and coparenting across the transition to parenthood: A dyadic perspective. *Journal of Family Psychology*, 30(8), 918–926. <https://doi.org/10.1037/fam0000217>

Lickenbrock, D. M., Ekas, N. V., & Whitman, T. L. (2011). Feeling good, feeling bad: Influences of maternal perceptions of the child and marital adjustment on well-being in mothers of children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 41(7), 848–858. <https://doi.org/10.1007/s10803-010-1105-9>

Lundahl, B. W., Tollefson, D., Risser, H., & Lovejoy, M. C. (2008). A meta-analysis of father involvement in parent training. *Research on Social Work Practice, 18*(2), 97–106.

<https://doi.org/10.1177/1049731507309828>

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>

Marciano, S. T., Drasgow, E., & Carlson, R. G. (2015). The marital experiences of couples who include a child with autism. *The Family Journal, 23*(2), 132–140. doi:10.1177/

1066480714564315.

May, C. D., St George, J. M., Fletcher, R. J., Dempsey, I., & Newman, L. K. (2017).

Coparenting Competence in Parents of Children with ASD: A Marker of Coparenting Quality. *Journal of Autism and Developmental Disorders, 47*(10), 2969–2980.

<https://doi.org/10.1007/s10803-017-3208-z>

McGrew, J. H., & Keyes, M. L. (2014). Caregiver stress during the first year after diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 8*, 1373–1385.

McHale, J. P. (1995). Coparenting and Triadic Interactions During Infancy: The Roles of Marital Distress and Child Gender. *Developmental Psychology, 31*(6), 985–996.

Mikulincer, M., & Shaver P. R. (2012). Adult attachment orientations and relationship processes. *Journal of Family Theory & Review, 4*(4), 259–274.

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, Hope, and Empowerment: A Model for Partnering with Parents of a Child with Autism Spectrum

Disorder at Diagnosis and Beyond. *Social Work in Mental Health, 10*(4), 311-330. DOI:

10.1080/15332985.2012.664487

- 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 recommendation. *Academic medicine*, 89(9), 1245-1251.
- Pepperell, T. A., Paynter, J., & Gilmore, L. (2018). Social support and coping strategies of parents raising a child with autism spectrum disorder. *Early Child Development and Care*, 188(10), 1392- 1404. <https://doi.org/10.1080/03004430.2016.1261338>
- Poslawsky, I. E., Naber, F. B., Van Daalen, E., & Van Engeland, H. (2014). Parental reaction to early diagnosis of their children's autism spectrum disorder: an exploratory study. *Child psychiatry and human development*, 45(3), 294–305. <https://doi.org/10.1007/s10578-013-0400-z>
- Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, 66, 101415. <https://doi.org/10.1016/j.rasd.2019.101415>
- Rankin, J. A., Paisley, C. A., Tomeny, T. S., & Eldred, S. W. (2019). Fathers of Youth with Autism Spectrum Disorder: A Systematic Review of the Impact of Fathers' Involvement on Youth, Families, and Intervention. *Clinical Child and Family Psychology Review*. <https://doi.org/10.1007/s10567-019-00294-0>
- Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 44(7), 1609–1620. <https://doi.org/10.1007/s10803-013-2028-z>
- Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19(4), 371–379. http://dx.doi.org/10.1207/s15374424jccp1904_9.

- 1
2
3
4 Rogé, B. (2019). Diagnostic et intervention précoce dans les TSA : des enjeux de société
5
6 [Diagnosis and early intervention in autism: society's challenges]. *Enfance*, 1(1), 5–12.
7
8 doi:10.3917/enf2.191.0005
9
- 10
11 Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., ... Zwaigenbaum, L.
12
13 (2015). Couple relationships among parents of children and adolescents with Autism
14
15 Spectrum Disorder: Findings from a scoping review of the literature. *Research in Autism*
16
17 *Spectrum Disorders*, 17, 142–157. <https://doi.org/10.1016/j.rasd.2015.06.014>
18
19
20
- 21 Author et al. (2018). *Details omitted for double-blind reviewing*.
22
- 23
24 Sim, A., Cordier, R., Vaz, S., & Falkmer, T. (2016). Relationship satisfaction in couples raising a
25
26 child with autism spectrum disorder: A systematic review of the literature. *Research in*
27
28 *Autism Spectrum Disorders*, 31, 30–52. <https://doi.org/10.1016/j.rasd.2016.07.004>
29
30
- 31 Sim, A., Cordier, R., Vaz, S., Parsons, R., & Falkmer, T. (2017). Relationship Satisfaction and
32
33 Dyadic Coping in Couples with a Child with Autism Spectrum Disorder. *Journal of*
34
35 *Autism and Developmental Disorders*, 47(11), 3562–3573.
36
37
- 38 Thullen, M., & Bonsall, A. (2017). Co-Parenting Quality, Parenting Stress, and Feeding
39
40 Challenges in Families with a Child Diagnosed with Autism Spectrum Disorder. *Journal*
41
42 *of Autism and Developmental Disorders*, 47(3), 878–886. [https://doi.org/10.1007/s10803-](https://doi.org/10.1007/s10803-016-2988-x)
43
44 [016-2988-x](https://doi.org/10.1007/s10803-016-2988-x)
45
46
47
- 48 Van Egeren, L. A. (2004). The development of the coparenting relationship over the transition to
49
50 parenthood. *Infant Mental Health Journal*, 25, 453-477. DOI: 10.1002/imhj.20019
51
52
- 53 Vernhet C, Dellapiazza F, Blanc N, Cousson-Gélie, F., Miot, S., Roeyers, H., & Baghdadli, A.
54
55 (2019). Coping strategies of parents of children with autism spectrum disorder: a
56
57
58
59
60
61
62
63
64
65

systematic review. *European Child and Adolescent Psychiatry*, 28(6), 747-758.

doi:10.1007/s00787-018-1183-3

Viera, A.J., & Garrett, J.M. (2005). Understanding Interobserver Agreement: The Kappa Statistic. *Family Medicine*, 37(5), 360-363.

Weber, P. H. (2012). *A comparison of parental stress and marital/couple satisfaction as reported by parents raising children diagnosed with Pervasive Developmental Disorder: An online mixed methods study*. (Doctoral dissertation). Available from Proquest. (3497863).

Yi, H., Siu, Q. K. Y., Ngan, O. M. Y., & Chan, D. F. Y. (2019). Parents' experiences of screening, diagnosis, and intervention for children with autism spectrum disorder. *American Journal of Orthopsychiatry* 90(3), 297-311. <https://doi.org/10.1037/ort0000433>

Yirmiya, N., Seidman, I., Koren-Karie, N., Oppenheim, D., & Dolev, S. (2015). Stability and change in resolution of diagnosis among parents of children with autism spectrum disorder: Child and parental contributions. *Development and Psychopathology*, 27(4), 1045–1057. <https://doi.org/10.1017/S095457941500067X>

Zemp, M., Milek, A., Cummings, E. M., & Bodenmann, G. (2017). Longitudinal Interrelations between Dyadic Coping and Coparenting Conflict in Couples. *Journal of Child and Family Studies*, 26(8), 2276–2290. <https://doi.org/10.1007/s10826-017-0742-4>

Tables

Table 1

Interview questions

Questions	Prompts
How did you experience the diagnosis?	
How did the two of you communicate with each other about the diagnosis?	
How did the two of you communicate with each other about what you felt when you received the diagnosis?	What about after the diagnosis?
What do you do when your partner shares their thoughts and feelings?	
What happened in your daily life during the weeks following the diagnosis?	How was it different to before?
How do you use your relationship to deal with the challenges of having a child on the autism spectrum?	Specifically, what did you do together to cope with the challenges of raising a child on the autism spectrum?
How do you protect your partner from the challenges linked to having a child on the autism spectrum?	
How do you protect your relationship from the challenges linked to having a child on the autism spectrum?	
How do you go about fulfilling your various parental tasks and responsibilities?	
In general, what support would be helpful for you to better manage your stress together?	In particular, how could professionals support you with this?
What advice would you give a couple in your situation during the weeks following the diagnosis?	With what you know now, what would you change?

Table 2

Sample characteristics

Couples' names (ages)	Length of relationship (years)	Employment status	Education	Monthly household income (in €)	Health issues	Children's gender (age)	Weekly amount of specialized intervention (hours)	Time since diagnosis (months)
Linda (40) Patrick (41)	22	Full-time Part-time	Master's Master's	5000	No No	Boy (10 years) Boy (66 months)*	6-10	36
Patricia (30) Peter (31)	10	At home Full-time	Master's 2 year degree	3372	No No	Girl (54 months)* Boy (2 years)	11-15	24
Sophie (40) Richard (47)	4	Part-time Full-time	High school Doctorate	3000	No No	Boy (36 months)* Boy (3 months)	1-5	5
Katie (39) Harry (39)	10	At home Full-time	Master's Master's	4000	No No	Boy (36 months)*	11-15	7
Beth (40) Robert (39)	8	Full-time Full-time	High school High school	2800	No No	Boy (60 months)* Boy (2 years) Boy (7 months)	11-15	25
Val (31) Alice (33)	10	At home Full-time	High school High school	2500	No No	Girl (10 years) Boy (36 months)* Girl (7 months)	1-5	4
Andrea (41) David (41)	7,5	Part-time Full-time	Bachelor's Master's	3500	No No	Boy (6 years) Boy (36 months)*	1-5	4
Fiona (37) Luke (44)	12	Part-time Full-time	Master's Doctorate	4500	No No	Boy (10 years) Boy (60 months)*	21-30	36
Hayley (39) Elliot (40)	18	Part-time Full-time	Master's 2 year degree	3000	No Yes	Boy (84 months)*	1-5	7
Emma (34) Mark (40)	14	Part-time Part-time	Bachelor's High school	2500	Yes Yes	Boy (30 months)*	1-5	1

Note: * Child on the autism spectrum

Table 3

Interview themes

Themes	Sub-themes
1. Theme 1: Emotional experiences	1.1. Emotional responses from the first signs of autism to the diagnosis 1.2. Daily emotional responses after the diagnosis
2. Theme 2: External support	2.1. Grandparents 2.2. Service providers 2.3. Community
3. Theme 3: Adaptation	3.1. Individual 3.2. Coparenting 3.3. Couple

Box 1.

Recommendations to optimize post-diagnostic support for couples

1. Emotional support
 - Provide psychological support for parents struggling to come to terms with the autism diagnosis
 - Be attentive to grandparents' reactions and provide necessary guidance
 - Help parents find sources of respite
2. Screening centers
 - Offer tailored information about childcare services
 - The option of giving information at a later date to parents who are not ready
 - Accompany parents with the administrative process of accessing childcare
3. Parents' relationships
 - Acknowledge that parents may have complementary roles and both may participate in childcare via different parenting tasks
 - Be attentive to couples' relationship quality as this will influence their capacity to share information and support each other
 - If couples experience difficulty coparenting facilitate access to childcare support for both parents
 - [Parent groups provide support and opportunities for communication between couples](#)
 - Be attentive to parents' level of child-rearing agreement
 - If needed, offer coparenting or couples therapy

Author Note

Author affiliations

Naomi Downes, Université de Paris, LPPS, F-92100 Boulogne-Billancourt, France

Jérôme Lichtlé, Université de Paris, LPPS, F-92100 Boulogne-Billancourt, France

Kristopher Lamore, Université de Paris, LPPS, F-92100 Boulogne-Billancourt, France

Marie-Joëlle Orève, Service de Psychiatrie Infanto-Juvenile, Centre Hospitalier de Versailles,
78150 Le Chesnay, France

Emilie Cappe, Université de Paris, LPPS, F-92100 Boulogne-Billancourt, France

No authors have changed affiliation subsequent to the time of the study.

Acknowledgments

We would like to thank all parents who participated in this research project. This study is part of a mixed-methods doctoral dissertation that received funding of 2500€ from the Fondation Mustela.

Author contributions

Naomi Downes, the principal investigator of the study, recruited participants, collected data participated in writing and proofreading the article. Jérôme Lichtlé and Kristopher Lamore participated in data processing and analysis. Marie-Joëlle Orève helped recruit participants. Emilie Cappe participated in the data analysis and proofreading the article.

Conflict of interest

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

Correspondence concerning this article should be addressed to Emilie Cappe, Laboratoire de Psychopathologie et Processus de Santé EA4057, Institut de Psychologie, Université de Paris, 71 avenue Edouard Vaillant, 92100 Boulogne-Billancourt, France.

Email: emilie.cappe@u-paris.fr

Tel: +33 (0)1 76 53 30 80