



An ecological exploration of individual, family, and environmental contributions to parental quality of life in autism

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ABSTRACT

The aim of this study was to assess the respective weight of individual and environmental factors on quality of life (QoL) of parents of children with autism spectrum disorders (ASD). Few studies have investigated both individual and environmental predictors of QoL but to our knowledge, none of them has considered the child's and parents' characteristics, family context and services available in the same design. Participants were 115 parents (73 mothers and 42 fathers) of children with ASD aged from 3 to 10 years. Hierarchical regression analyses were conducted to investigate predictors of parental QoL among child-related, parent-related and environmental factors. Findings indicate that a higher QoL is associated with a good quality of interaction in marital and parent-grandparents dyads, no family medical history and access to psycho-educational interventions for the child, regardless of child's developmental quotient, comorbidity, parent sex and working time. This final model best fits the data and explains 31.5% of the variance of parents' QoL. This study highlights that it is crucial to consider both individual and environmental variables as potential protective factors of parental adjustment. An ecological approach seems to be relevant to understand which parenting resources should be targeted in support programs.

1. Introduction

Children with Autism Spectrum Disorders (ASD) have communication and social deficits that can impact parents' functioning and daily life. Caregivers have often costs and special needs in marital, financial, social and professional areas (Derguy et al., 2015; Fletcher et al., 2012). Mothers and fathers of children with ASD experience higher level of stress (Baker-Ericzen & Brookman-Frazee, 2005; Dabrowska & Pisula, 2010; Estes et al., 2009; Johnston et al., 2003; Seltzer et al., 2004). In the same way, they reported higher alteration of their QoL than parents of typically developing children (Allik et al., 2006; Khanna et al., 2010; Kheir et al., 2012; Lee, 2009; Pisula & Porębowicz-Dörsmann, 2017; Yamada et al., 2012) and those of children with other neurodevelopmental disorders (Lee, 2009; Mugno et al., 2007a).

While many studies have focused on identifying predictors of negative outcomes - particularly the parental stress - (e.g. Derguy et al., 2016) there are fewer and heterogenous data on what determines a good parental QoL (McStay et al., 2014). However, addressing this issue is particularly crucial in the case of ASD because it is a lifelong disorder

and it has no cure. Hence, a better understanding the predictors of QoL is an important challenge to improve parenting programs.

Most previous studies have focused on children related factors. Regarding demographic variables, there is no consensus about the impact of the child age: McStay et al. (2014) did not show any significant difference while others reported either a positive (Dardas & Ahmad, 2014b; Mugno et al., 2007a) or a negative correlation (Kousha et al., 2016) with parental QoL.

As regards to clinical variables, negative associations between parental QoL and autism severity have been shown (Baghdadli et al., 2014; Cappe et al., 2017; McKechnie et al., 2017). In the same way, high scores of challenging behavior and developmental delay are associated with low scores of parental QoL and well-being (Baghdadli et al., 2014; Nuske et al., 2017; Samadi & McConkey, 2012). Finally, children's comorbidities and communication problems are associated with a low QoL (Garrido et al., 2015; Zablotzky et al., 2013).

As far as parents' characteristics are concerned, some studies have reported differences between mothers and fathers on QoL, with mothers having lower scores (Dabrowska & Pisula, 2010; Ji et al., 2014; Kheir

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et al., 2012; Mugno et al., 2007a; Yamada et al., 2012), while others did not show any differences (L A Dardas & Ahmad, 2014a, 2014c; Hastings, 2003). Then, QoL is positively associated with several socio-economic factors such as family income, parents' education level and the working time (e.g. Hatton & Emerson, 2009; Parish et al., 2004; Yamada et al., 2012).

Finally, regarding environmental factors, previous study suggested that marital support was positively associated with QoL and well-being in mothers (Benson & Kersh, 2011; McStay et al., 2014). With regard to the social network, perceived social support is negatively associated with QoL in parents (Ji et al., 2014; Khanna et al., 2010). The parental QoL could be also impacted by services available for the child. Indeed, psychological well-being of mothers are more important when the child is schooled (Baghdadi et al., 2008). In addition, studies have failed to reach consensus on whether the diagnosis precocity have a positive or a negative impact on parental QoL. Indeed Ji et al. (2014) reported a better parental QoL with an early diagnosis while Kousha et al. (2016) showed the opposite. This difference in results may be due to the difference in children's age between studies and/or the diversity of caregivers interviewed in the first study (mothers, fathers, grandparents, aunts).

While there are a number of identified factors of parental QoL, some disagreements between studies remain and several limitations could be raised.

So far, very few studies have investigated both individual and environmental predictors of QoL (Kousha et al., 2015; e.g. McStay et al., 2014) but to our knowledge, none of them have considered the child's and parents' characteristics, family context and services available in the same design. However, Belsky's model (1984) emphasises that one's parenthood must be analysed "in context", taking into account various proximal and distal factors as the parent's personal characteristics (e.g. personality traits), the child's personal characteristics (e.g. sex, presence of a disability) and contextual characteristics (e.g. family and marital relationships, care services). This model justifies the relevance of adopting an ecological approach, which takes into account environmental factors as differences among countries' health policies. Actually, there are very few studies on quality of life predictors have been conducted among a sample of French parents. It is very important to fill this gap, especially since there are real differences in services context in France (Chamak & Bonniau, 2013). For example, the situation of schooling for children with ASD in France is still far below national and international targets (Convention on the Rights of Persons with Disabilities, 2006). In 2011, 65% of French teachers surveyed believe that the place of a child with autism is in a specialized institution (OpinionWay survey for "le Collectif Autisme" conducted March 17, 2011). This last point justifies the relevance of adopting an ecological approach, which takes into account environmental factors.

Moreover, previous studies do not often use the same measure of quality of life. Indeed, while QoL is a multidimensional concept many studies have evaluated only some of its aspects such as, Health-Related Quality of life (HRQoL) (e.g. Khanna et al., 2010) or Family Quality of life (FQoL) (e.g. Gardiner & Iarocci, 2015). Indeed, the first one is related to an individual's health or disease status, the second one refers to the QoL of members of the whole family (e.g. unmet needs, their life together). Therefore, QoL is an important measure of individual well-being and is not only health or family-related. QoL is defined as « individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns » (The WHOQOL Group, 1995 p.1405). Subjectivity and four dimensions characterize this concept: physical health, psychological health, social relationship and, environment. Studying parents' whole QoL could help us to better understand those aspects of life that extend beyond health such as for example education, marital relationships and the social environment.

Finally, the low rate of fathers' participation in previous studies is another important issue. Indeed, so far, very few studies on the specific

topic area of parents' quality of life have included fathers (e.g. Dardas & Ahmad, 2015; Mugno et al., 2007b). As a result, our understanding of the experience of fathers is limited and cannot be generalized from data on mothers (Johnson & Simpson, 2013).

To overcome the previously identified limitations, the present study adopt an ecological approach based on Belsky's model of parenting which has already shown its relevance to understand the experience of parents of children with an ASD (Derguy et al., 2016). Our main objective is to examine the joint impact of individual factors (children-related and parent-related factors) and environmental factors (family environment, services, working time) on both mothers' and fathers' QoL. According to the World Health Organization, we are interested in the quality of life of the parent as a multidimensional and subjective concept (The WHOQOL Group, 1995).

We hypothesized that:

- Both individual and environmental factors would be associated with parents' quality of life.
- The association of individual and environmental factors would better explain parental quality of life than the individual variables alone.

2. Methods

2.1. Participants and procedures

All study participants were recruited in diagnosis and treatment centers, parents' associations and schools. Education and health professionals sent out an information letter and a consent form to the participants. Then, parents received an email with a link to access to the questionnaires. The parents completed the "online" questionnaires on LimeSurvey software (LimeSurvey Project Team & Schmitz, 2012). When both the father and mother of the child participated, it was specified that they had to complete all the questionnaires individually and according to their own experience and feelings. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and consistent with the 1964 Helsinki Declaration and its later amendments, or comparable ethical standards. Moreover, an independent protection committee (Comité de Protection des Personnes Sud-Ouest et Outre Mer III) prospectively approved the research. Informed consent was obtained from all individual participants included in the study.

The sample included 115 parents of 78 children aged from 3 to 10 years. The mean age of the children was 6.3 years (SD = 2.3) and the sample included 63.5% of mothers ($N = 73$) and 36.5% of fathers ($N = 42$). In 64.4% of cases, both parents of the child participated (37 couples) and 94.7% of parents resided together in the family home. Regarding services available, ASD diagnosis was confirmed on average at 50.7 months. The child's diagnosis was made by a child psychiatrist using the Autism Diagnostic Interview - Revised (Le Couteur et al., 1989; Lord et al., 1994) or/and the Autism Diagnostic Observation Schedule (Lord et al., 1999). The child psychiatrist who made the diagnosis (ASD and comorbidities) was the one who told parents about the study and gave them the authors' contact. All of the children met the diagnostic criteria for ASD according to APA (American Psychiatric Association, 2003, 2013). Only 64% of children were enrolled in school and 70% had access to psychoeducational interventions. Finally, only 23% of parents received a formal support from a professional (in group or in individual session). Demographic data are presented in Tables 1 and 2.

2.2. Measures

2.2.1. Outcome measure

QoL was measured with the WHOQOL-BREF, a short version of the

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