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Treatment choices in autism spectrum disorder: The role of parental illness perceptions

Nebal N. Al Anbar[a], Roland M. Dardennes[b,c,d,*], Arthur Prado-Netto[a], Kelley Kaye[c], Yves Contejean[c]

[a] Univ Paris Descartes, Faculty of Psychology, Graduate School 261, 71 Avenue Edouard Vaillant, 92774 Boulogne-Billancourt Cedex, France
[b] Faculty of Medicine Paris Descartes, 15 rue de l'école de médecine 75270 Paris Cedex 06, France
[c] Hosp Sainte Anne, 1 rue Cabanis, 75014 Paris, France
[d] INSERM, Center in Psychiatry and Neurosciences, UMR 894, 2 ter Rue d'Alésia, 75014 Paris, France

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ABSTRACT

A cross-sectional design was employed. Parents of a child with Autism Spectrum Disorder (ASD) were asked to complete a modified version of the Revised Illness-Perception Questionnaire (IPQ-RA) and answer questions about information-seeking activities and treatments used. Internal consistency, construct validity, and factor structure were assessed. Multivariate logistic regressions were performed. Eighty-nine parents having a child with ASD took part in the study. Five subscales of the IPQ-R were replicated. Causes were split into personal, external and hereditary factors. The most highly rated main cause was a genetic cause. Perception of seriousness of the disease was associated with the use of educative methods and unpredictable course of disorder associated with drug use. A higher sense of personal control was associated with reduced use of nutritional or pharmaceutical treatments. Attendance to training programs was associated with higher hereditary beliefs and lower perception of cyclical timeline. The IPQ-RA captures components of representations of autism and provides a reliable mean for exploring illness concept in parents of a child with ASD. Some illness dimensions may prevent parents from having the opportunity to modify their concept of autism. Such measure may be useful for assessing the modification of potentially malleable beliefs with psychoeducational interventions.

Raising a child with an autism spectrum disorder (ASD) is a stressful experience (Dumas, Wolf, Fisman, & Culligan, 1991). Parents must adjust to this chronic disorder experience and try to attenuate the impact of this disorder on the child and on themselves. They are also the cornerstone of many psychosocial interventions (Myers, Johnson, & The Council on Children With Disabilities, 2007). Meanwhile, they construct a representation of ASD that may guide them to adjust their functioning, to interact with their child, and to take treatment decisions. Besides recommended treatments (cf. Myers et al., 2007; see also Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996; Matson, Matson, & Rivet, 2007), vitamins and supplements, special diets, and other nontraditional treatments for ASD continue to grow in increasing popularity (Levy & Hyman, 2005).

The National Center for Complementary and Alternative Medicine (2007) defined complementary alternative medicine (CAM) as a "group of diverse medical and health care systems, practices, and products that are not presently considered to be

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[*] Corresponding author at: Clinique des maladies mentales et de l'encéphale, service du Pr. ROUILLON, 100 rue de la Santé, 75674 Paris Cedex 14, France. Tel.: +33 1 45 65 86 39; fax: +33 1 45 65 89 43.

E-mail addresses: nebalu2001@hotmail.com (N.N. Al Anbar), r.dardennes@gmail.com, r.dardennes@ch-sainte-anne.fr (R.M. Dardennes), saturno_68@hotmail.com (A. Prado-Netto), k.kaye@ch-sainte-anne.fr (K. Kaye), y.contejean@ch-sainte-anne.fr (Y. Contejean).

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part of conventional medicine". Recent chart reviews and surveys of parents of children with autism showed high percentages of the use of CAM (Green et al., 2006; Harrington, Rosen, Garnecho, & Patrick, 2006; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Wong & Smith, 2006), but controlled studies to date have found most CAM therapies to be ineffective (Levy & Hyman, 2005) and selected CAM therapies can lead to significant harm (Brown, Willis, Omalu, & Leiker, 2006; Cohen, Kemper, Stevens, Hashimoto, & Gilmour, 2005). Little information exists as to why parents make decisions regarding which treatment to implement with their children. Hanson et al. (2007) summarized the many reasons given to explain why parents appear to employ CAM more regularly for their children with autism: inefficacy of conventional treatments, poor access to rehabilitation programs, lack of agreement as to what treatment is the best, better comfort provided by CAM professionals, empowerment of families, preferences for less invasive and more "natural" remedies, and dissatisfaction with conventional care. Recommendations have been given for practitioners to recognize that many of their patients use nonstandard therapies (Committee on Children With Disabilities, 2001; Myers et al., 2007). Although it is widely accepted that cognitive processes mediate people's adaptation to their own health threats, less attention has been paid on parental beliefs about autism. To date, research looking at parents with a child affected by autism mainly consisted of empirical investigations (Elder, 1994; Gray, 1995). Cognitive models of parents' reactions to autism are very seldom. One of the most supported theoretical framework is the self-regulation model of illness behaviour elaborated by Leventhal, Meyer, and Nerentz (1980) and Leventhal, Leventhal, and Contrada (1998). This model is based on approaches to problem solving. The interpretation of symptoms and social messages relies on cognitive representations of illness which in turn determine the coping strategy.

It has been demonstrated that patients possess implicit common-sense beliefs in their illness and that representations of illness could be described according to the following five dimensions: identity, cause, consequences, timeline and control/cure (see Section 1). These beliefs have been shown to predict medication adherence (Brewer, Chapman, Brownlee, & Leventhal, 2002; Horne & Weinman, 2002), and have been associated with coping strategies, psychological well-being and level of functioning (Hagger & Orbell, 2003). As illness perceptions seem amenable to modification (Petrie, Cameron, Ellis, Buick, & Weinman, 2002), the relationship between illness perception and treatment choice might open the way to psychoeducational interventions to promote more evidence-based treatments and to enhance clinical outcome. Therefore, the aim of the present cross-sectional study was to demonstrate the association between illness perceptions and treatment choices.

In order to achieve this aim, we elaborated a modified version of the Revised Illness-Perception Questionnaire (IPQ-R, Moss-Morris et al., 2002) in order to make this scale directly applicable to parents of children with ASD. This paper also reports the modifications that were made, and the first psychometric properties of this measure. We also investigated the associations between parental illness perceptions and the sources of information used by the parents. To our knowledge, this is the first study to apply Leventhal's common-sense model of illness representations to ASD. Thus, we conducted exploratory analyses of putative causal factors and their relation to treatment choices.

1. Methods

1.1. Participants

Subjects were recruited by contacting parents who attended meetings held by different parent associations (such as Autisme-France and ARAPI), and through announcements on autism-focused websites and Internet special-interest groups. Only one questionnaire per family was included in the study. No limits with regard to child or parent age were established as the study sought to explore the variety of beliefs held. Questionnaires were given directly to parents or e-mailed, and they were returned either personally, electronically or by post. Eighty-nine questionnaires were obtained and the characteristics of the respondents are summarized in Table 1. The majority of respondents were married, middle-aged and well-educated mothers, professionally active and "well-off" financially. Most of their children were boys, with an average age of 13 years. A mean of 4 years elapsed between the first signs and the reported diagnosis of autism. Behaviour therapies were the most frequently used treatments. Most of the "other" treatments were speech therapy and psychomotor therapy.

1.2. Assessment of child's disorder

Questions were asked about the diagnosis of their child's disorder, age of their child at time of the diagnosis, and the kind of health professional who made the diagnosis. Assessment of ASD was performed with the *identity* subscale of the IPQ-RA where parents had to tick symptoms they observed with their child from a list of 14 symptoms directly inspired by the DSM-IV diagnostic criteria for autism disorder (American Psychiatric Association, 1994) – e.g. "does not show interest for others", "does not play make-believe". For each symptom, parents were asked to indicate if the symptom was observed in their child and if they thought the symptom belonged to the autism diagnosis. The sum of the symptoms attributed to the illness (yes-rated items) forms the identity score.

1.3. Measure of parental beliefs

The Revised Illness-Perception Questionnaire (Moss-Morris et al., 2002) modified for autism (IPQ-RA) was used in the study (available on The Illness-Perception Questionnaire website: www.uib.no/ipq/). In its original form, the questionnaire