

Research Paper

The association of illness perceptions with depressive symptoms and general psychological distress in parents of an offspring with autism spectrum disorder

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Abstract

Background: Raising a child with an autism spectrum disorder (ASD) is a severe stressor and parents often present high levels of depression. Depression is associated with illness perceptions but this association has not been studied in parents of ASD offspring.

Objective: We aimed to assess the prevalence of psychological distress symptoms and their associations with illness perceptions in parents with an ASD offspring.

Methods: In 111 parents of ASD offspring we assessed depressive symptoms (PHQ-9), illness perceptions (B-IPQ) and general psychological distress (GHQ-28). Multiple linear and logistic regressions were used to assess their independent associations.

Results: The prevalence of parental clinically significant depressive symptoms was 34.2%, while 55% presented clinically significant levels of general psychological distress. Younger parents and those with lower financial resources had greater psychological distress and more severe depressive symptoms. Parents felt that the condition impacted their lives and believed it would be chronic. Their beliefs about the consequences and the chronicity of the disorder were significant independent correlates of their psychological distress and depressive symptoms severity.

Conclusions: These findings indicate that a remarkable proportion of parents with an ASD offspring present clinically significant depressive symptoms, which were associated with illness perceptions relevant to the consequences and the chronicity of the disorder. Our data encourage psychotherapeutic interventions aiming to support parents to deal with the consequences and chronicity of their offspring's disorder, in order to reduce parental psychological distress. © 2014 Elsevier Inc. All rights reserved.

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Autism spectrum disorders (ASDs) encompass a heterogeneous group of neurodevelopmental disorders that begin in infancy and continue throughout the lifespan. Their core features include disturbances in social interaction, impaired communication skills, and repetitive stereotypic behaviors.¹ A median prevalence of 62/10000 has been found across studies, indicating that these disorders are rather common in the general population.²

Raising a child with ASD may pose unique stressors related to the child's challenges in communicating and

behavioral difficulties,³ stigma⁴ and concerns about the development and the future of the child.⁵ In addition, Schieve et al reported that parenting a child with ASD is associated with high aggravation,⁶ especially for those parents whose child recently needed special services.³ Several studies reported higher levels of depression and other symptoms of psychological distress in parents of children with ASD as compared to parents of typically developing children^{7,8} or parents of children with other disabilities.^{8,9}

Several factors have been found associated with parental psychological distress. Evidence suggests that increased parental stress is associated with aspects of the child's behavior, especially with socially inappropriate and aggressive behaviors associated with ASD.¹⁰ Decreased parents' optimism and lower parental self efficacy have been also found to contribute to the development of parental

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depressive symptoms.^{10–12} Baker et al.¹¹ found that parents of preschool children with developmental delay who reported stronger beliefs about the chronic nature of the disorder had a more pessimistic perspective that could lead to depression. Parental gender and age also seem to play a part. Mothers reported more depressive symptoms than fathers,^{13–16} and maternal depressive symptoms have been found more often during the early years following diagnosis,¹⁷ while younger parents and those who received less education were found to be at greater risk for developing psychological distress.^{18–20} Parental beliefs about the long-term consequences of the disorder have also been found to held costs for the parents, including reinforcing the belief that they needed to regulate their own behavior.²¹ Finally, the high level of financial commitment often stemming from raising a child with ASD has been also found involved in parental stress and depression.^{18,22,23}

Parents' adjustment to this experience is therefore challenging and stressful. In their effort to attenuate the impact of the disorder on the child and on themselves, parents construct representations of ASD that may guide them to adjust (or prevent) their functioning, to interact with their child, and to take treatment decisions.²⁴ For example, parents' beliefs about their child's future and acceptance in the community as well as worries over limited family opportunities shape a characteristic parental stress profile^{4,13} that interferes with adaptation. Studies in other physical^{25–27} or mental²⁸ diseases have shown that perceptions about the controllability of a disease and its consequences are associated with depression, quality of life, coping and overall functioning.

Although, however, it is widely accepted that cognitive processes mediate people's adaptation to health threats, and that parents' attributions about the locus of cause, stability and controllability of a disease influence affective response and expectations about the future,²⁹ less attention has been paid to parental beliefs about autism, and few studies investigated the impact of cognitive representations upon the parents' reactions to ASD.²⁴ According to the attributional theory, if a parent views an event as uncontrollable then feelings of helplessness can emerge in the future.²⁹ Causal attributions have also been found associated with parental adjustment difficulties in parents of children with developmental disabilities,³⁰ and beliefs about the efficacy of intervention have been reported to predict parental stress levels.³¹

One of the most supported²⁴ theoretical framework of illness representations is the Self-Regulation Model (SRM) of Leventhal and colleagues.^{32,33} According to this model, the ways individuals perceive and respond to a health threat, such as an illness, depend on the ways the health threat is represented in their own minds.³² Their representations are processed in parallel through three stages: the patient first forms the representation of the health threat, next, he/she adopts behaviors to cope, and finally he/she appraises the efficacy of these behaviors. The model incorporates a continuous feedback loop in which the results of the appraisal process are fed back into the formation of the

illness representation and the adoption of coping responses. Illness representations, the subsequent coping procedures, and the criteria by which their effectiveness is judged are determined by common-sense beliefs and the social context in which the threat occurs.^{27,32,33}

The model proposes that patients' illness representations are based around distinct components. This means that patients and caregivers^{34,35} have their own ideas about the consequences, the identity (i.e., the amount of symptoms attributed to the disorder), the cause, and the timeline (i.e., how long the patient believes the illness will last) of the illness,³² as well as beliefs about the cure and controllability of the condition.³³ These illness perceptions influence health behavior, coping and outcome. Studies in mental illnesses indicate that the SRM explains considerable variance in important outcome measures for both patients and relatives.^{28,34} However, only one study investigated parental illness perceptions about their child's disorder in ASD.²⁴ This study found that parental perception of seriousness of the disease was associated with the use of educative methods, and higher sense of personal control was also associated with treatment decisions. This study concluded that components of representations of autism provided a reliable mean for exploring illness concept in parents of a child with ASD and may be useful for assessing potentially malleable beliefs with psycho-educational interventions.²⁴ These beliefs may also influence parents' psychological adaptation, as illness perceptions have been found significantly associated with depression in a number of studies in other physical and mental diseases.^{25–27}

To the best of our knowledge, however, no studies investigated the association between parental illness perceptions and depressive symptomatology in ASD. As illness perceptions seem amenable to modification,^{36,37} the relationship between illness perceptions and parental depressive symptomatology may enable mental health providers to target specific psychological dimensions associated with parents' psychological distress promoting therefore the parents' psychological adaptation to the condition. Therefore, this study aimed:

- 1) To assess the frequency of clinically significant depressive and psychological distress symptoms in parents of an offspring with ASD, and
- 2) To test the hypothesis that parents' illness perceptions about their offspring's condition are associated with parental psychological well-being, after adjusting for parental age, gender, education and the family's financial status, as these parameters are regarded significant correlates of parental psychological distress.^{13–23}

Methods

Setting

The education of children with ASD in Greece has progressed significantly over the last decades and this is

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