



Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD)



Manuel Fernández-Alcántara^{a,*}, M^a Paz García-Caro^b, M^a Nieves Pérez-Marfil^a, Cesar Hueso-Montoro^b, Carolina Laynez-Rubio^c, Francisco Cruz-Quintana^a

^a Faculty of Psychology, Department of Personality, Assessment and Psychological Treatment, Brain, Mind and Behavior Research Center (CIMCYC), University of Granada, Spain

^b Faculty of Health Sciences, Department of Nursing, University of Granada, Spain

^c Unit of Monitoring and Early Assistance (UMEA), San Cecilio Clinical Hospital, Granada, Spain

ARTICLE INFO

Article history:

Received 17 December 2015

Received in revised form 24 April 2016

Accepted 9 May 2016

Keywords:

Grief

Autism

ASD

Parents

Qualitative

Disability

ABSTRACT

Background: Various authors have reported feelings of loss and grief in parents of children with autism spectrum disorder. However, no previous studies have investigated the structure of these feelings.

Aims: To analyze in depth the feelings of loss in parents of children diagnosed with autism spectrum disorder.

Method: A qualitative study was conducted based on grounded theory. Twenty parents participated through purposive sampling.

Procedure: Semi-structured interviews were conducted, asking about different emotional aspects of the upbringing of a child with autism spectrum disorder. Atlas.ti 6.2 program was used for open, axial, and selective coding.

Results: The core category that explained the feelings of these parents was unexpected child loss, associated with shock, negation, fear, guilt, anger, and/or sadness. Two processes were identified, one associated with the resolution of grief and the other with obstacles to overcoming it.

Implications: Feelings of loss play an important role in explaining the complex emotions experienced by these parents. Different intervention strategies are proposed.

© 2016 Elsevier Ltd. All rights reserved.

What this paper adds

- Analysis of the feelings of loss and grief of parents of children diagnosed with autism spectrum disorder (ASD) based on grounded theory, an inductive approach that permits generating a theory based on the discourse and direct experience of participants.
- According to the discursive structure of their feeling of loss, parents identified “Unexpected Child Loss” as their predominant feeling. The child they had been bringing up disappeared with the ASD diagnosis. This feeling was associated with emotions related to loss and two simultaneous processes: a resolution of these feelings and an encounter with obstacles found.

* Corresponding author at: Centro de Investigación Mente, Cerebro y Comportamiento (CIMCYC) Campus Cartuja, s/n 18071 Granada, Spain.
E-mail address: mfernandez@ugr.es (M. Fernández-Alcántara).

- It is crucial to identify the specific characteristics of these feelings of loss and grief in order to plan interventions with parents. Measures are required to improve communication of the diagnosis, considering the features and challenges of this disorder, and to dedicate adequate time for this purpose, emotionally accompanying the parents, resolving their doubts and facilitating access to different types of resource.
- Normalization of these feelings of loss facilitates acceptance by parents of the situation, and their assimilation of the diagnosis aids the development of positive emotions and learning related to the upbringing of the child, with whom they can create a different relationship.

1. Introduction

Autism Spectrum Disorders (ASDs) refer to numerous syndromes that appear at an early age and are characterized by difficulties in social interaction, communication, and flexibility, among others (Baron-Cohen, 2010; Wing, 1993). The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) places children with ASD in a continuum according to its severity and impact on their quality of life. There are two main classes of symptoms: (a) difficulties/deficits in social communication; and (b) restricted/repetitive behavior, interest, or activity patterns (APA, 2013; Hervás, Maristany, Salgado, & Sánchez-Santos, 2012). ASD manifestations vary widely and include sleeping problems, eating disorders, fears/phobias, and aggressive behaviors (Giovagnoli et al., 2015). ASD affects around 0.6% of the Spanish population (Hervás et al., 2012), with a higher prevalence among the siblings of autistic children (Alison McInnes, 2002).

The upbringing of a child diagnosed with ASD is complex and is associated with an important change in family dynamics (Altiere & Von Kluge, 2009; Cridland, Jones, Magee, & Caputi, 2014). Researchers have highlighted the emergence of physical and emotional health problems and high levels of overload in the parents of these children (Gatzoyia et al., 2014; Giovagnoli et al., 2015; Karp, Kuo, Sandler, & Suarez, 2015; O'Halloran, Sweeney, & Doody, 2013; Seguí, Ortiz-Tallo, & De Diego, 2008). Parental feelings of disbelief, distress, anxiety, or sadness are frequent during the diagnosis and the following months (Ludlow, Skelly, & Rohleder, 2012).

An important part of this emotional response is associated with feelings of loss or grief (Mulligan, MacCulloch, Good, & Nicholas, 2012; O'Brien, 2007). Thus, Ponte et al. (2012) observed emotional pain due to loss, the threat to parental expectations, shock, commotion, and/or impotence in family members after the diagnosis. Previous investigations proposed the idea of *ambiguous loss* to explain the dynamics experienced by these families (Boss, 1999; Boss, 2004). O'Brien (2007) relates this concept to various factors, including: uncertain diagnoses and prognoses, variable daily functioning, an apparent normal development of the child during the first few years, the manifestation of some symptoms but not others, and the difficulty of these children in recognizing and expressing their emotions. This approach assists understanding of the variety of diverse emotions experienced by parents, which include both hope and frustration, especially in early post-diagnosis stages, when pride and happiness can be mixed with sadness and guilt, among other feelings.

There are many similarities between the concept of *ambiguous loss* and *chronic sorrow*, which has been used to describe the feelings of loss in parents of children with other chronic health conditions, such as infantile cerebral palsy, neural tube defects, or diabetes (George, Vickers, Wilkes & Barton, 2006; Richardson, Cobham, Murray & McDermott, 2011). However, although this type of conceptual framework can be useful to explain the set of emotions and situations related to grief, it may provide an over-restrictive account of the experience of loss in these parents. Thus, a recent study of parents of children with cerebral palsy found that the intense sorrow or sadness associated with loss was related to the ending of parents' expectations and hopes for their "ideal" child (Fernández-Alcántara et al., 2015).

Qualitative studies on the parents of children with ASD have mainly used deductive analysis rather than an inductive approach (e.g., grounded theory), in which the development of theories is based on the discourse and direct experience of participants. To our best knowledge, no published studies have employed grounded theory to analyze feelings of grief and loss in parents of children diagnosed with ASD, a relevant issue given the importance of the emotional adaptation of parents (Cridland et al., 2014). These feelings have been related to reception of the diagnosis, hopes for the development of the child, perception of the positive aspects of his/her upbringing (Fernández-Alcántara et al., 2015), and different coping styles (Lutz, Patterson & Klein, 2012; Marshall & Long, 2010). Interventions to support these parents require knowledge of their emotional state in order to plan and implement programs adapted to their real needs.

The main objective of this qualitative study was to analyze the feelings of loss in parents of children diagnosed with ASD and to identify the key factors related to these emotions.

2. Method

2.1. Design

The design of this qualitative study was based on grounded theory, defined as a systematic process of obtaining and analyzing data in order to develop a theory directly based on the reported experience of participants (Strauss & Corbin, 2002).

Download English Version:

<https://daneshyari.com/en/article/371097>

Download Persian Version:

<https://daneshyari.com/article/371097>

[Daneshyari.com](https://daneshyari.com)