


Post-Traumatic Growth of Parents of Children with Autism Spectrum Disorder and Intellectual Disabilities: A Literature Review

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Abstract

This study intends to review the research on posttraumatic growth of parents of children with ASD and ID. A search for potentially eligible papers was undertaken across seven databases; PubMed, Medline, Web of Science, PsycINFO, CINAHL, PTSDpubs and EMBASE. The search time limit is from the establishment of the database to December 2023. The search terms include: post-traumatic growth, autism, intellectual disability, parent, father, mother, caregiver. Based on the search strategy, 68 relevant documents were initially retrieved, and 55 articles were obtained after eliminating 13 duplicate documents. By reading the titles and abstracts, 15 articles that were irrelevant to the topic were excluded, and 40 articles were initially included. After excluding 19 articles whose full texts could not be downloaded, 21 studies were finally included, including 11 studies on parents of children with autism, 5 studies on parents of children with ID, and 5 studies on parents of children with disabilities (including both parents of children with ASD and ID). Among them, there are 6 qualitative studies. The sample sizes of qualitative research are 10, 11 and 13 respectively, and the sample size of quantitative research ranges from 88 to 205.

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INTRODUCTION

Families of children with autism spectrum disorder(ASD) and intellectual disabilities(ID) need to bear more responsibilities and burdens than normally developing families. Parents of children with disabilities will encounter many difficulties when raising their children. Children with ASD and ID and their parents are particularly in need of special attention (Byraa & Ćwirynkało, 2020). Worldwide, the number of special children represented by ASD is increasing rapidly, which not only affects the healthy physical and mental development of children, but also brings huge mental pressure to parents (Eissa,2015,2016,2017,2018,2022; Mostafa, 2018). Due to the specific behaviors exhibited by ASD, communication between parents of children with ASD and their children is restricted, making parents prone to a series of problems (Qin et al., 2021).

Parents of children with ID face more challenges and require more efforts than parents of typically developing children (Luijckx et al., 2017), such as limited social support, low mood, stress, and anxiety (Marsh et al., 2018), for parents, acceptance of their child's diagnosis of ASD or ID and the various issues encountered in caregiving. It is undoubtedly a traumatic experience, but there is also post-traumatic growth (Smith-Young et al., 2020).

Post-Traumatic Growth (PTG) refers to individuals experiencing challenging situations. Positive psychological changes experienced after life crisis events (Smith-Young et al., 2020). This study intends to review the research on posttraumatic growth of parents of children with ASD and ID to provide inspiration for future related research.

METHODS

This systematic review was conducted and reported in this study. A search for potentially eligible papers was undertaken across seven databases; PubMed, Medline, Web of Science, PsycINFO, CINAHL, PTSDpubs and EMBASE. The search time limit is from the establishment of the database to December 2023. The search terms include: post-traumatic growth, autism, intellectual disability, parent, father, mother, caregiver.

LITERATURE INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria: 1) The research subjects are parents/fathers/mothers of children with ASD and/or ID; 2) The research content is post-traumatic growth; 3) Publicly published academic journal papers and master's and doctoral theses. Exclusion criteria: 1) Documents whose full text cannot be downloaded; 2) Duplicate or identical documents. 3) Review the literature.

LITERATURE SCREENING AND DATA EXTRACTION

Literature screening and data extraction were performed independently by the author. Firstly, the literature was initially screened by reading the title and abstract of the paper, and then secondary screening was carried out by reading the full text to finally decide which literature to include in this study. The content of data extraction mainly includes authors, research methods, research samples and important results. Based on the search strategy, 68 relevant documents were initially retrieved, and 55 articles were obtained after eliminating 13 duplicate documents. By reading the titles and abstracts, 15 articles that were irrelevant to the topic were excluded, and 40 articles were initially included. After excluding 20 articles whose full texts could not be downloaded, 20 studies were finally included, including 10 studies on parents of children with autism, 5 studies on parents of children with ID, and 5 studies on parents of children with disabilities (including both parents of children with ASD and ID). Among them, there are 6 qualitative studies. The sample sizes of qualitative research are 10, 11 and 13 respectively, and the sample size of quantitative research ranges from 88 to 205.

RESULTS

Different terms have been used in the literature to refer to positive outcomes of being a mother of a child with disability. The most frequently used include: posttraumatic growth (PTG) (CounselmanCarpenter, 2016), stress-related growth (Rubin and Schreiber-Divon, 2014), personal growth (Strecker et al., 2014), benefits or benefit-finding (McConnell et al., 2014), the positive impact of having a disabled child or positive impact(s) (Blacher and Baker, 2007), positive perceptions (Vilaseca et al., 2013), positive contributions (Hastings et al., 2005), transformations (Pelchat et al., 2009), positive aspects (Kenny and McGilloway, 2007), and positive experiences (Kimura and Yamazaki, 2013).

Research on PTG among mothers of children with developmental disabilities revealed the largest positive change with regard to appreciation of life, relations with others and personal strength, as well as minor change with regard to spirituality (Strecker et al., 2014). In their phenomenological study, Zhang et al. (2015) found positive change in the aftermath of a traumatic event in mothers of children with autism.

Qualitative research results show that the growth experience of parents of children with ASD is mainly reflected in four aspects: restarting the cycle of life, understanding the joys and sorrows of life, developing one's own potential, and increasing interpersonal benefits (Zhang, 2014). Results of another qualitative study indicated that a new philosophy of life, appreciation of life, relationships with others, personal strength, and spiritual changes were five areas of posttraumatic growth in mothers of children with ASD (Zhang et al., 2015). Empirical studies have found that the post-traumatic growth of parents/fathers/mothers of children with ASD is generally at a medium level (Zhang, 2014; Qin et al., 2021; Zhang et al., 2013).

Qualitative research found that parents of children with ID will experience five stages of post-traumatic growth, namely the pain time, the struggle time, the exhaustion time, the passive acceptance time, and the active growth time; their growth is mainly reflected in positive changes in personality, including self-esteem, adaptation, sense of responsibility, patience, and empathy (Cheng et al., 2022). Empirical studies have found that fathers or mothers of children with intellectual disabilities have higher levels of PTG and score highest in the following two areas: appreciation of life and positive changes in relationships with others (Byraa & Ćwirynkało, 2020; Kielb et al., 2019).

FACTORS INFLUENCING POST-TRAUMATIC GROWTH OF PARENTS OF AUTISTIC CHILDREN

Qualitative research has found that thinking about the meaning of events, adhering to attitude tendencies, social support, effective coping styles, peer role models and self-efficacy are the main factors promoting PTG in parents of autistic children (Zhang Wei, 2014; Zhang et al., 2015). Empirical research has found that social support, gender, quiet self characteristics, psychological resilience, family functioning, rumination, self-compassion and active coping are the main influencing factors of post-traumatic growth of parents of autistic children (Chan et al., 2020; Ebrahim & Alothman, 2021; Qin et al., 2021; Wayment et al., 2019; Zhang et al., 2013). Positive and effective coping styles can help parents of special children reduce their negative emotional experiences and encourage their self-expression, self-presentation and help-seeking. Although different coping styles will lead to different positive changes in them, they will ultimately promote their post-traumatic growth (Chan et al., 2020).

Results of Hong (2024) indicated that parents of children with ASD were above average in their post-traumatic growth; particularly those with children with milder symptoms and of higher family income levels. First-married parents had significantly higher post-traumatic growth than the Not first-married (i.e., remarried, divorced, widowed). Parents reporting with social support, quiet ego, and psychological capital had higher post-traumatic growth.

RISK AND PROTECTIVE FACTORS FOR POSTTRAUMATIC STRESS AND POSTTRAUMATIC GROWTH

As empirical studies indicated, Parenting trauma showed an adverse effect on developing PTS and a positive role in promoting PTG. Social support was protective in its correlation with lower levels of PTS and higher levels of PTG. Barriers to care were associated with increased PTS, but unrelated to PTG. Negative parenting showed a significant, but small, correlation with more severe PTS and was unrelated to PTG (Xiong et al., 2022).

Parents with high self-efficacy have more confidence, courage and ability to cope with difficulties. Specifically, grappling with difficulties helps parents develop a greater appreciation for what is important and valuable in life, while also helping to cope with the broader challenges associated with it. Raising a child with an intellectual disability forces parents to use as many resources as possible, develop potential, and make efforts that may not always be successful. In the face of severe traumatic events and life challenges, basic beliefs about the world play a decisive role in perceiving the difficulties encountered and one's own resources that may be available to deal with them (Byraa & Ćwirynkało, 2020; Kielb et al., 2019).

When facing traumatic events, adequate support can effectively help individuals reduce negative emotions, change their negative perceptions of events, increase problem-solving abilities, and experience more post-traumatic growth (Li & Hu, 2022). In the process of post-traumatic growth, highly educated parents are better able to understand and reconstruct their views of life and values in the face of difficulties, and are better able to truly understand the needs of their children, thereby making the greatest possible psychological, life and social changes. Parents with settled marriages have higher levels of post-traumatic growth than divorced parents because the former can receive more social support in raising and educating children with disabilities (Li & Hu, 2022).

INTERVENTION STUDIES

A study implemented a 6-week solution-focused group therapy and found that, in comparison to the control group, couples receiving SFBT improved in cohesion, consensus, and satisfaction, as measured with the Dyadic Adjustment Scale. It should be noted that affectional expression was not related to the independent variables. Participants also reported less intense arguments, blaming their partner, more affection and problem-solving, and greater focus on solutions and the use of tools (Zimmerman et al., 1997).

Bristol, Gallagher, and Holt (1993) found that mothers who participated in a psychoeducational treatment program, which informed them of their child's diagnosis, reported greater decreases in depressive symptoms in comparison to mothers without treatment. Similarly, Tonge et al. (2006) discovered that a 20-week parent education and skills training program for parents improved their mental health. Lastly, Acceptance and Commitment Therapy (ACT), was provided to parents raising a child with ASD in a 2-day, group workshop format (Blackledge & Hayes, 2006). Results from this study showed improvements on the Beck Depression Inventory, Brief Symptom Inventory, and the Global Severity Index.

DISCUSSION

There are obvious differences in the areas of growth between parents of children with ID and parents of children with ASD. The growth of parents of children with ID is mainly reflected in the dimension of appreciating life, while the growth of parents of children with ASD is mainly reflected in the dimension of personal strength. A possible reason for this difference lies in the fact that parents' efforts to cope with the difficulties posed by children with ID lead them to gain a greater appreciation for important and valuable things in life (Byraa & Ćwirynkało, 2020), thereby improving the "appreciation" achieve greater growth in life. The personal strength dimension has the highest

score, perhaps because parents of children with ASD receive insufficient support and therefore need to tap more of their own potential to cope with the pressure of caring for children (Zhang, 2014).

Little attention has been paid to the mechanisms influencing posttraumatic growth of parents of children with ASD and ID, and only 2 studies have been reported. The research by Byraa and Ćwirynkało (2020) found that general self-efficacy can significantly mediate the relationship between basic hope and post-traumatic growth total score and its various dimensions. Bak (2018) examined the role of adaptive cognitive emotion regulation strategies and disability acceptance attitudes in adult attachment and post-traumatic growth, but found no significant mediating effects.

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